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Editorial

The New Health-Related Top-Level Domains Are Coming: Will Cureforcancer.health Go to the Highest Bidder?

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Abstract

In 2012, the Internet Corporation for Assigned Names and Numbers (ICANN) opened a new round of applications for generic top-level domain (gTLD) names, receiving 1930 applications, of which at least 18 were related to health (eg, ".doctor", ".health", ".med"). The entry of new, commercial players applying to create health-related names reopens the debate on the role of international organizations, governments, non-governmental organizations, and other stakeholders regarding the safeguards and policies needed to protect consumers.

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KEYWORDS

top-level domains; global community health; health information sources; quality health information

The New Health-Related Generic Top-Level Domains

In 2012, the Internet Corporation for Assigned Names and Numbers (ICANN) opened a new round of applications for generic top-level domain (gTLD) names, receiving 1930 applications, of which at least 18 were related to health (eg, ".doctor", ".health", ".med"; see Textbox 1 for the full list). The potential creation of new health-related names by strictly commercial players reopens the debate on the role of international organizations, governments, non-governmental organizations, and other stakeholders regarding the safeguards and policies needed to protect consumers [1].

As the paper by Mackey and colleagues in this issue of Journal of Medical Internet Research (JMIR) shows [1], the global health community is in the process of losing an important battle: the sell-off of health-related gTLDs to the highest bidders, forfeiting a potential asset and unique opportunity to promote health. Despite multiple objections and concerns raised by different stakeholders, including the World Health Organization (WHO) [2], ICANN appears to forge ahead with its current plans to assign the administration of health-related gTLDs to operators whose business models are not necessarily aligned with public health objectives and without sufficient safeguards that are based on a community consensus. In fact, it appears that other top-level domain names like .bingo or .wtf receive more consumer protection and regulation than health-related top-level domains. For example, ICANN created additional safeguards for domains like .wtf or .sucks (asking top-level domain operators to define and implement policies against cyberbullying), but policies that ensure certain minimum standards for health information are lacking. ICANN has put generic safeguards in place for areas that are "highly regulated" but certain health-related domains like .health are on the auctioning block with only 3 minimal and generic safeguards such as removal of illegal content.

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Textbox 1. Some proposed new health-related top-level domain names (number of applications in brackets, if more than one).

- .health (4, one of which is withdrawn)
- .med (4, one of which is withdrawn)
- .doctor (3)
- .fit (2)
- .healthy (Chinese variant)
- .healthcare
- .medical
- .hospital
- .pharmacy
- .skin
- .surgery
- .heart (withdrawn)
- .hiv
- .clinic
- .dental
- .dentist
- .cialis (withdrawn)
- .fitness

Some potential operators of health-related gTLDs already promote their namespace as "trusted" (see Figure 1), and according to a JMIR poll, many users intuitively trust a health-related domain more than a .com domain (see Figure 2 and below). Hence, ICANN and gTLD operators have an ethical responsibility to implement appropriate safeguards and industry standards which go beyond the removal of illegal content, and to involve experts or organizations which have experience in assessing health information and in public health in the design of their processes and in their ongoing operations. Some gTLD applicants made a superficial attempt to balance commercial interests with public health objectives, and walk a difficult line between promising a "trustworthy" environment while trying to avoid expensive, time-consuming and potentially subjective examination of potential domain owners' source credibility. In an interview with JMIR, Andy Weissberg, CEO of DotHealth LLC, who is one of the remaining 3 contenders for the .health gTLD, explains that under their proposal, "harmful and illegal information will be removed" (as is expected for all gTLDs), but also states that "attempting to keep information off the .health gTLD in the name of 'quality' is a dangerous precedent that amounts to potential censorship of free speech at worst and favoritism at best". This perspective fails to acknowledge that quality assurance is not so much about censorship and "keeping information off" the Internet, but perhaps more about soliciting and providing *additional* information on prospective domain owners, for example conflicts of interest in the form of additional fields in WHOIS directories or standardized metadata [3,4]. No single body (let alone the domain registrar) should determine what is "correct" health information. It can not be the goal to "censor" content or the messages on .health websites. It will always remain up to the website owners to ensure "*message credibility*", and will always remain the responsibility of users to learn how to distinguish quality sites ("caveat lector") [5]. A gTLD can, if anything, only be a very indirect "quality label" for content, not least because when prospective applicants apply for the second level domain name, there is not necessarily any content to evaluate at that time, and withdrawing the address after content has been created would be a rather drastic and litigious measure unless there is blatantly illegal or harmful information. Thus, this debate should be less about *content* quality, rather, it should be about *source* quality. If the goal is to make the health-related domains a trusted space, then principles of source credibility must be implemented, and *transparency* should be the guiding principle to allow consumers to judge the *expertise* and *trustworthiness* of the source [4]. For dot-coms and other domains, it may be acceptable for the site owner to hide their identity and biases, but in health it simply is not [3-11]. It must be transparent at all times who the site owner is and what his potential biases are, and what the mechanisms are to maintain privacy, security, and confidentiality of medical and personal data, so that users can make their own judgments about the health information, products, or services provided by the site. These universal principles have been implemented in various ethical codes and health information quality initiatives on the Internet for over a decade [3-11], and should be operationalized at the registrar if they claim to operate a "trusted" namespace .

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Figure 1. Screenshot of DotHealth LLC.



Source credibility can be achieved in two ways: (1) an "upstream" evaluation by the registrar requiring certain credentials or criteria for the prospective second-level domain owner (for example ISO certification, professional licenses, educational degrees or other credentials), and/or (2) by a workflow where registrars take additional steps to ensure that site owners declare their financial interests and disclose their credentials and privacy protection mechanisms, making this information transparent (and machine-readable) so that users can judge for themselves if the source is trustworthy, and software can assist users in finding relevant and trustworthy information for their specific purpose. One approach to achieve this is through a simple but mandatory questionnaire to site owners when they apply for a second-level domain name. This metainformation should be viewable and searchable by consumers, and perhaps be mandated to be provided on the sites themselves as machine-processable meta-tags (metadata), which would make it possible for the site owner to change the metadata, or to have different metadata for different sections of the site, as suggested in the MedCERTAIN/MedCIRCLE projects [3,4,9]. In addition, this would allow domain registrars to automatically monitor the presence of disclosure statements, and allow search engines to further improve and filter search results.

Such considerations are currently not included in any of the applicants' documents. While DotHealth LLC is planning a "Request for Information" (RFI) process for selected second-level domain names which include, for example, disease names [12], it is unclear to what degree the information obtained will be publicly accessible, useful, or even machine-processable. Moreover, the proposed RFI process would only apply to a limited subset of second-level domain names under .health. Weissberg also stressed in an interview with JMIR that it would be "unacceptable if we were to in some way 'discriminate' the allocation of a reserved name or any .health name based on a prospective registrant's source credibility, financial interests or 'prescriptive' approaches to treating a disease/condition as being more favorable to over another registrant's non-commercial status or methods of treating a disease or condition." In other words, if a pharmaceutical company wanted to own mental.health to promote its psychotropic medications, it could do that, even if it were biased against non-pharmaceutical treatments such as psychotherapy, and there is nothing wrong with that, unless the consumer is not aware of the fact that the information offered is biased due to commercial interests. The RFI process is a step in the right direction, but the information obtained by the registrar should be public, and it also appears that questions critical for full transparency (eg, financial interests) are not asked or disclosed. If this level of transparency were present, then under the proposed framework above, consumers would at least still be able to identify the source and its potential biases. Apart from principles of transparency, there are other essential criteria for health information sources, such as privacy and confidentiality.

Are the proposed public interest commitments of the current applicants for health-related domains enough? Many in the global health community do not think so. The WHO received a mandate at the 9th plenary meeting of the World Health Assembly on May 27th, 2013, to "convey to the appropriate

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bodies, including the ICANN GAC and ICANN constituencies, the need for health-related global top-level domain names in all languages, including ".health", to be consistent with global public health objectives"[13]. It is currently unclear if the proposed public interest commitments of applicants are sufficient to meet this ambitious goal. No less than a dozen organizations have expressed reservations or objections, including the Cochrane Collaboration and the International Medical Informatics Association (IMIA) [14]. These objections were dismissed by a legal expert ruling on the objections, essentially implying that an organization that has "medical informatics" in its name is no more authorized to speak on behalf of the global health community than UFO enthusiasts speaking out against .astrophysics [14]. If concerns expressed by WHO and by international professional medical societies are not deemed representative for the health community, then who is authorized to speak for global health? And where are the consumers and patients in this debate?

Public Opinion: A Poll by JMIR

Where does the public stand on this issue and where are the voices of patient and consumer organizations? As the debate has not entered mainstream media, there has not been much (if any) debate. According to a poll conducted by JMIR Publications in February 2014 among Internet users from the US, over 80% of consumers have not heard about the new health-related gTLDs, and most are indifferent about the question who should administer health-related gTLDs (60.2% said they "don't care"), but among those who cared, a clear majority is against the idea that they should be managed by a private for-profit company (only 10.7% were comfortable with this idea), while most favored a non-profit organization to be in charge (20.2%) (Figure 2), and an additional 8.0% want an international organization (WHO) in charge.

Another poll conducted by JMIR Publications reveals that 43% of respondents are unsure if .health should be better regulated than .com or .org domains, but among those who have an opinion on this question, a slight majority thinks that this should be the case, with 33.3% of all respondents favoring more regulation and only 23.2% saying that this should not be the case (Figure 2).

A fourth JMIR poll confirms that gTLDs enjoy different levels of "credibility" among users (Figure 2), with the .org domain being the most trusted gTLD. This is consistent with earlier research published in this journal [15], but surprisingly, the yet-to-be-created and largely unknown gTLDs .med and .health enjoy at least the same, if not higher credibility than .com, with no statistically significant differences between them (Figure 2).

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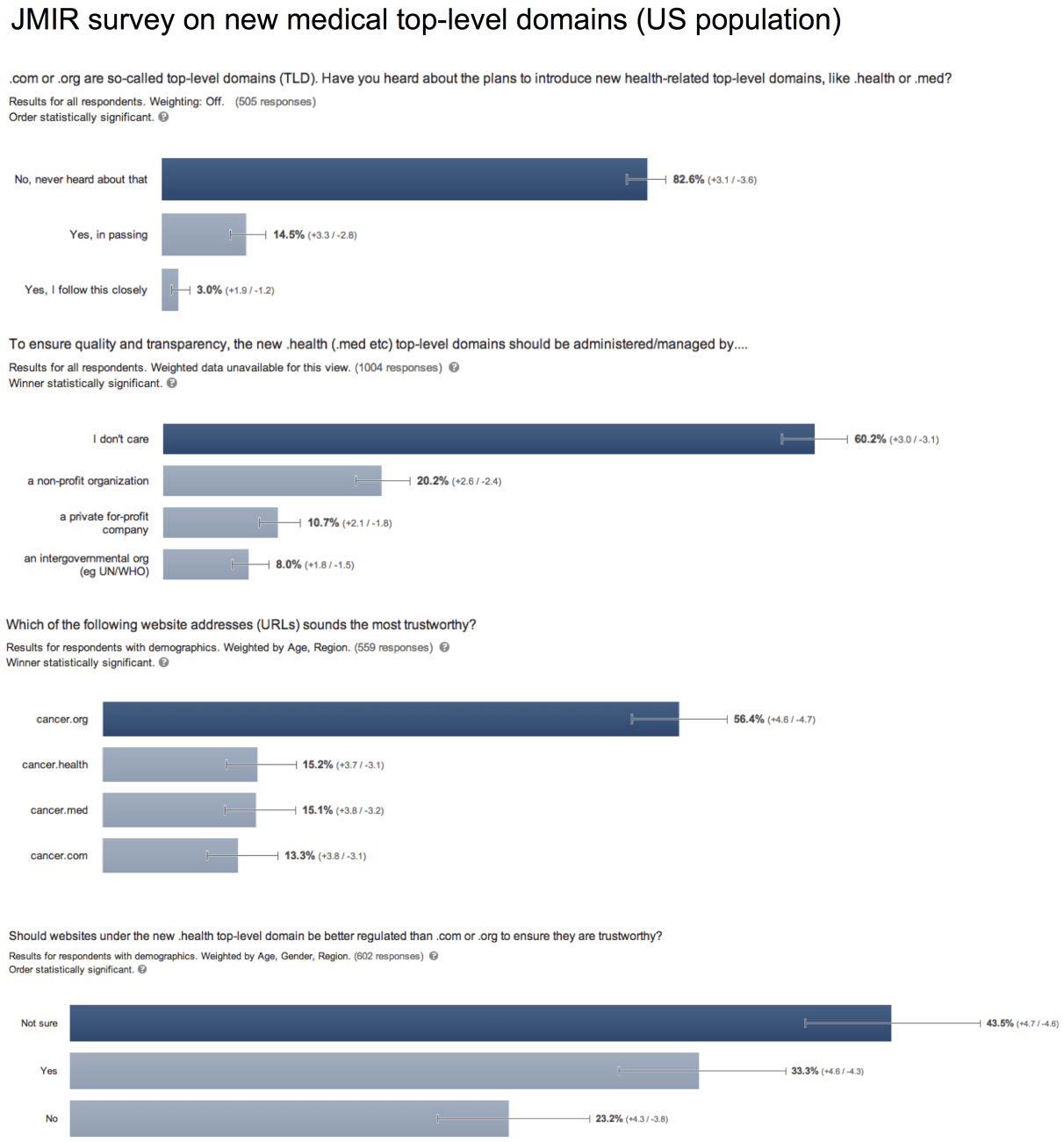
Figure 2. JMIR polling results among the US population regarding health-related top-level domains.



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Conclusions

Health related information and data occupy a crucial and unique status on the Internet. A domain name is associated with a site's brand, origin, content or quality. The sites that fall under .health are likely to be considered as the ultimate online source of information and advice on health, in particular by populations with less ehealth literacy. The marketing of .health as a trusted name, when it is not warranted, creates the likelihood of material detriment. The .health gTLD has been the 8th most contested name of the over 1900 gTLDs proposed—for good reason. It is time for ICANN to listen to the health community. The issue of how to define "quality health information" has been subject of much research and debate over the past decade, and contrary to what some applicants have implied, there is more consensus than disagreement over the criteria that should be taken into account when assessing health information quality and credibility [3-11]. What is lacking (and must be discussed in the context of gTLDs) is a consensus on *how these standards can and should be operationalized in the context of a domain registry*. We call for a delay in issuing the .health gTLD and other health-related gTLDs until adequate safeguards based on community consensus are in place.

However, given how readily the ICANN committees and their legal experts have brushed aside concerns from the health

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community, the most likely outcome is that a flood of new health-related gTLDs will enter the market late 2014 or 2015, marketing their gTLD as trustworthy to consumers. In this case, we urge any successful gTLD registries to seek collaboration with the health community and to reach out to individuals and organizations (including patient organizations) who have spent decades in conducting research on what quality health information means and how source credibility and technical criteria can be monitored. In the absence of that, perhaps it is time for the trusted players in the health community to apply for gTLD programs in a forthcoming round (for example, .who, .medcertain) that implement some of the suggestions related to transparency above, or to even go further by forming a large collaborative non-profit consortium which awards domain names under a new gTLDs based on the second-level domain applicants proposals and expertise, as opposed to their ability to pay. For consumers and patients, the adage “caveat lector” [5] remains crucial, and extends to having to learn about the different health-related top-level domains and the different levels of protection and “trustworthiness” they offer.

Acknowledgments

The author wishes to thank the participants of the Consultation On Maintaining Trust And Confidence in the Health Internet at the World Health Organization, 16-17 December 2013, Geneva, Switzerland, for the formative discussions that led to this editorial.

Conflicts of Interest

The author was involved in many health information quality initiatives, including the EU-funded MedCircle/MedCertain projects for trustworthy health information on the Web (as Principal Investigator), the e-Health code of ethics (e-Health Ethics Summit), and European Commission Quality Criteria for Health Websites. He is the editor of JMIR (and some of its sister journals like JMIR mHealth) and publisher at JMIR Publications, which assesses the quality of health information and Web-tools on a daily basis, and which may play a future role in assessing applicants for second-level domains under health-related top-level domains. The World Health Organization partially reimbursed travel costs for a trip to Geneva for a consultation about health-related top-level domains.

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Abbreviations

gTLD: generic top-level domain
ICANN: Internet Corporation for Assigned Names and Numbers
JMIR: Journal of Medical Internet Research
RFI: Request for Information
WHO: World Health Organization

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Viewpoint

Health Domains for Sale: The Need for Global Health Internet Governance

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Abstract

A debate on Internet governance for health, or “eHealth governance”, is emerging with the impending award of a new dot-health (.health) generic top-level domain name (gTLD) along with a host of other health-related domains. This development is critical as it will shape the future of the health Internet, allowing largely unrestricted use of .health second-level domain names by future registrants, raising concerns about the potential for privacy, use and marketing of health-related information, credibility of online health content, and potential for Internet fraud and abuse. Yet, prospective .health gTLD applicants do not provide adequate safeguards for use of .health or related domains and have few or no ties to the global health community. If approved, one of these for-profit corporate applicants would effectively control the future of the .health address on the Internet with arguably no active oversight from important international public health stakeholders. This would represent a lost opportunity for the public health, medical, and broader health community in establishing a trusted, transparent and reliable source for health on the Internet. Countries, medical associations, civil society, and consumer advocates have objected to these applications on grounds that they do not meet the public interest. We argue that there is an immediate need for action to postpone awarding of the .health gTLD and other health-related gTLDs to address these concerns and ensure the appropriate development of sound eHealth governance rules, principles, and use. This would support the crucial need of ensuring access to quality and evidence-based sources of health information online, as well as establishing a safe and reliable space on the Internet for health. We believe, if properly governed, .health and other domains could represent such a promise in the future.

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KEYWORDS

eHealth; global health governance; information technology; Internet; domain names

Background

A debate on Internet governance for health, or “eHealth governance”, is emerging with the impending award of a number of new health-related “generic top-level-domain names” (gTLDs; eg, similar to .edu for educational institutions) that could shape the future of online health information. The Internet, which consists of a hierarchical domain naming system of IP addresses of computers, services, and other digital resources, relies on domain names as an easily recognizable way for users

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to search and navigate online content. The Internet Corporation for Assigned Names and Numbers (ICANN), a nonprofit corporation founded in 1998 that controls this system, is currently undergoing the largest expansion of the Internet in history [1]. It is adding over a thousand new gTLDs, potentially including a new .health domain and close to 20 other gTLDs related to medicine and health, which are scheduled to become active as early as the beginning of 2014. Yet, ICANN's complex and highly political process of awarding health-related gTLDs could have a profound impact on information privacy, use, and sale; health marketing; and content quality that could influence future trust, security, and credibility of the health Internet. Hence, it is critical that applicants are carefully scrutinized to ensure that they are abiding by ethical principles, practices, and rules with respect to public health and the public interest.

Despite this need for careful consideration, it appears that current applicants for health-related gTLDs are highly varied, with few having strong ties to the global medical or public health community. Indeed, there are significant doubts of whether they will meet the needs of the broader public interest. Below, we describe the current debate surrounding the new .health domain as well as provide an overview of other health-related gTLDs within the context of the growing importance of the Internet on health behavior and information-seeking. We argue that there is a crucial need for better governance to enable evidence-based sources and to ensure .health and other domains represent a safe space on the Internet for health, rather than simply an unregulated space for health marketing.

Health Information and the Internet

Current controversy surrounding health domains is rooted in the Internet's growing importance as a health information source. In 2013, the International Telecommunication Union estimated that 38.8% (2.7 billion) of the world's population used the Internet [2]. Many of these users are seeking important health information online [2,3]. In the United States, surveys report 72% of online adults accessed the Internet to find health information primarily on the subjects of diseases and treatments [4]. Other regions, including the European Union and emerging markets, have also shown marked increases in online health information seeking and self-diagnosing behavior [3,5,6].

The promise of accurate and reliable health information online is its potential to empower patient participation and inform decision making. Yet there are risks beyond inaccurate information online, including consumer privacy issues, false, or misleading promotion directed towards health consumers/products, ensuring appropriate regulation of commercial health marketing, and cybersecurity-related health issues (such as health-related spam and financial fraud). These risks underlie the need to ensure a trusted online health environment that promotes consumer empowerment and public health [3]. But these risks are further exacerbated by a lack of global Internet governance. The result has been the proliferation of numerous types of health-related information sites without content quality assessment [3]. With more than 100,000 health-related websites estimated to be in existence, Internet users may have difficulty accessing evidence-based sources and often seek information through simple search engine (eg, Google, Yahoo, Bing) queries that may prioritize sites of lower quality, undisclosed commercially sponsored content, irrelevant information, and/or at worst, misinformation [3,7]. For example, illicit online pharmacies have been detected illegally marketing and selling pharmaceuticals without a prescription, misrepresenting crucial risk information, and not disclosing other risks of their often counterfeit and otherwise dangerous products [7-9].

In response, initiatives to direct users to medically dedicated online health information sources have been explored. This includes deployment of medical search engines (eg, Healthfinder), voluntary certification programs for online content (eg, HealthOntheNetFoundation Code/search toolbar), and websites backed by a well-known public or private health care delivery sources (eg, UK National Health Service). Yet, low user adoption, health literacy issues, and the growing popularity of alternative sources for health information (including social media) may pose ongoing challenges for future success of these efforts [3,7]. Hence, having convenient access to a safe and reliable source of health content online remains a critical concern for billions of global users increasingly relying on the Internet for health.

Expansion of the Internet

ICANN's New Naming Program

In June 2008, ICANN began the creation of a new program of expanding naming of the Internet from the original two limited rounds of applications for new top-level-domain (TLD) names conducted in 2000 (proof-of-concept round) and 2004. This new program opened up in 2011, allowing for the creation of numerous specific new gTLDs, expanding from the original list of 22 TLDs then in existence and aimed at vastly expanding the Internet name space. This expansion specifically included new unsponsored gTLDs (ie, operated under standard policies of ICANN's processes) that generally consist of three or more characters and are open for any purpose or use.

ICANN's new naming program allowed proposals for virtually any new domain name *suggested by applicants*, including those in different languages/characters, comprising numbers, and even using company brand names [10]. Acceptance of applications for new gTLDs began in January 2012 and has led to submission of nearly 2000 applications for a wide variety of gTLD strings [1]. Included were gTLDs that are geographic (eg, .paris, .Africa), general term domains (eg, .law, .money, .science, .sex), and those for specific entities (eg, .mit for Massachusetts Institute of Technology, .apple for Apple Inc, .bbc for the British Broadcasting Corporation, .McDonalds for McDonald's Corporation). ICANN anticipated the first group of new gTLDs passing through the application process to be operational in late 2013 [11]. However, final award of new gTLDs will undergo a complex evaluation process that could include considerable costly delays and also potentially end in award of gTLDs through an auction process (with the highest bidder being awarded a gTLD) when there are several contending applicants. This procedural complexity has led to intense lobbying pressure on ICANN to allow applications to proceed despite documented

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objections from countries, international organizations, consumer advocacy groups, independent watchdogs, and the broader public community. Further, this process would ostensibly favor richer and more well-connected applicants—a system that many observers find questionable and lacking credibility.

Importantly, included in this new program were a number of proposals by various entities for a new .health domain and other health-related gTLDs. Applications are predominantly from private corporate entities with most having little or no history in medicine nor public health, include large pharmaceutical manufacturers applying for gTLD proprietary/trademark names, and comprise only a handful from health organizations and associations. This uneven mix of applicants creates uncertainty for the future prospects of a trusted space for online health content, which we describe below.

.health Domain Applicants

The domain central in the current debate is the proposed ".health" gTLD [1]. Yet recognition of a need to create a dedicated Internet space for health is not new. More than a decade ago, the need for a trusted .health TLD with collaboration and oversight by the international community was explored [3,12]. In 2000, shortly after the creation of ICANN, the World Health Organization (WHO) and other stakeholders proposed formation of a .health TLD, but ultimately its proposal was not chosen as one of the seven proof-of-concept names for new TLDs during that round [12,13]. Subsequently, the new ICANN naming program announced in 2008 provided another opportunity to revisit the creation of .health (including possible resubmission of the original WHO proposal). Yet since this time, WHO and other public health-related stakeholders have been conspicuously absent in actively seeking the domain.

Instead, the current round of .health applicants consists exclusively of for-profit, private sector entities, all of which passed ICANN's initial assessment and remain unopposed (Table 1), meaning they have the potential to be awarded the gTLD through ICANN's evaluation process that will most likely end in an auction to the highest bidder. All are in single legal jurisdictions (eg, not represented by nor coordinating with any international/global health organization) and hence lack global geographic scope and representation. Indeed, simply on the basis of corporate law, none of the for-profit applicants are even publicly traded companies. This brings into question levels of transparency/disclosure, sufficiency of corporate governance (eg, those required under the US Sarbanes-Oxley Act and similar iterations in Australia, Canada, France, Germany, India, Japan, The Netherlands, South Africa, and other countries), ongoing financial viability, and accountability to the public.

Table 1. health gTLD applicants.

Applicant name	Application type, country, and status	Entity type	Affiliations	Proposed governance and criteria	Health sector support/ partnerships
DotHealth, LLC	Standard open gTLD USA Unchallenged; IO objection denied; award likely subject to auction.	Limited liability company	DotHealth, LLC (self)	Partnership with Neustar and Legitscript but no other formal governance structure. Purported use of policies, safeguards, and standard operating procedures to be actively monitored and enforced for inaccurate or misleading information (including illicit online pharmacies) in conjunction with partners. Also states that it will protect the name of the WHO's second-level domain names within health TLD (public interest commitments).	National Association of Boards of Pharmacy; Inter-American College of Physicians and Services (website not functional); Association of Black Cardiologists; World Federation of Chiropractic; Regulatory Harmonization Institute
Afilias Limited	Standard open gTLD Ireland Unchallenged; IO objection denied; award likely subject to auction.	Irish company limited by shares	Afilias Limited (self)	None specifically listed. Persons or entities licensed as a health care provider (public interest commitments).	None listed
Goose Fest, LLC	Standard open gTLD USA Unchallenged; IO objection denied; award likely subject to auction.	Limited liability company	Donuts Inc (parent applicant) Parent company: Covered TLD, LLC	None specifically listed. Generally open entry with certain security/abuse prevention mechanisms in place.	None listed; mentions on website that company has substantial funding from private equity and venture capital funds
dot Health Limited	Standard open gTLD Gibraltar Withdrawn	Limited liability company	CEO – Famous Four Media Limited Parent company: Domain Venture Partners PCC Limited	Establishment of Governance Council consisting of key sector stakeholders that self nominate to participate. Generally open entry with certain security/abuse prevention mechanisms in place. Will implement additional protections for IGOs for second-level domain names.	None listed

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Further, no applicants are familiar to the health field, but rather include companies such as various affiliates of Donuts Inc, which is attempting to obtain not just .health but has applied for more than 300 gTLDs under a number of different subsidiaries, most removed from health (eg, .apartments, .beauty, .casino, .dating, and even .wtf), suggesting the company is not focused on the prudent stewardship of patient-centered health information. Indeed, Donuts Inc is primarily backed by private equity/venture capital funds that has invested some $57 million in an attempt to secure gTLDs—a move that has raised concern among industry and Internet watchdogs [14]. Alarmingly, it has also been reported as being connected with other Internet companies that have provided services to spammers and cybersquatters, raising concerns about potential Internet fraud and abuse if Donuts is awarded its applied-for gTLDs [14].

Furthermore, of the current .health applicants, there are no developing countries, international/intergovernmental organizations, nonprofits, foundations, nor civil society groups as primary applicants. Only one applicant, DotHealth LLC, provides any support letters or specific inclusion from health-related stakeholders. However, DotHealth LLC supporters clearly do not constitute an adequate representation of the global health community. Indeed, all DotHealth LLC (only recently formed in 2011 based on its incorporation documents) supporters are US-focused, several are recently formed entities, one supporter's website is non-functional, and many have close ties to industry.

Absence of active participation by public health stakeholders may point to a lack of attention and priority setting in recognizing the potential importance of a .health domain. Further, public health actors may lack technical expertise and financial resources to submit a viable application, similar to concerns raised in the original WHO ICANN proposal [3,12]. ICANN's listed high entry and maintenance cost of gTLDs (including initial application fee of US $185,000 and annual fee of US $25,000) are not prohibitive for businesses generating profits but may be difficult to afford for the vast majority of global health organizations relying on unstable funding [1,3,10].

It is also unclear how current .health applicants would manage potential registrant quality and trustworthiness for .health use, or, in a related issue, possible categorization of restricted/reserved .health domain names. Since the applicants themselves are commercial, their ICANN .health applications indicate few if any restrictions on future .health registrants and would mostly offer registration and sale of .health use broadly. Only one of the applicants, Afilias Limited, indicates that under its revised criteria in response to public interest concerns, .health registrants would have to at least hold a health care provider license. Yet, it should be noted that requirement for licensure verification does not guarantee any level of protection for consumers, does not guarantee appropriate oversight, and is not sufficient in itself to safeguard the public interest.

Some hypothetical examples of .health gTLD second-level domain names that could be misused are provided in Table 2 and illustrate the immediate risk of unrestricted use proposed by the majority of current .health applicants. Indeed, in certain circumstances where there are multiple .health second-level domain registrants, award may be conducted by a third-party auction/broker system to the highest bidder, which would ostensibly favor for-profit or wealthier entities/individuals.

Table 2. Examples of potential misuse of .health second-level domain names.

Example	Possible applicants	Potential risks
tobacco.health	Tobacco manufacturers, industry marketing representatives, questionable corporate social responsibility platforms	Misinformation regarding health risks associated with tobacco use and products. Use of economic incentives and unregulated online marketing (eg, cigarette coupons) to induce demand for products.
vaccination.health	Anti-vaccination activists, vaccination adverse event plaintiff attorneys/solicitors, faith-based groups opposed to vaccinations on non-scientific grounds	Misinformation regarding the health risks associated with vaccination use could lead to public misperception and fear, resulting in lower vaccination rates and potential impact on maintaining population herd-immunity.
diet.health	Obesity-related food and beverage manufacturers, marketing companies of "health" products and related weight loss supplements without proven efficacy, direct-to-consumer advertising by pharmaceutical manufacturers.	Misinformation regarding health behavior and risks associated with obesity could result in unhealthy consumption behavior, promotion of unhealthy foods and beverages, use of unapproved/non-scientifically validated weight loss products, and possible overprescribing of obesity-related drugs through DTCA.
miraclecure.health	Telemarketers with unproven medical and health products, marketers of unapproved treatments (eg, unregulated stem cell clinics), marketing towards vulnerable patient populations (eg, rare diseases, diseases without treatment options)	The claim of this second-level domain name alone is cause for concern as it implies a "miracle" cure for a certain health-related condition. Whether such clearly risky descriptive domains will be restricted or reserved by current .health applicants is not clear.

.health Domain Controversy

Reflecting some of the above concerns, in January 2013, the International Medical Informatics Association (IMIA) filed an objection based on community opposition to the four .health gTLD applicants [15]. IMIA stated that all failed to demonstrate how their use of .health would be in the public interest, none had adequate consumer protections, and all were solely commercial in nature without any representation from the health community. Other stakeholders, including France, Mali, WHO, Save the Children, the HealthOntheNetFoundation, other nongovernmental organizations (NGOs), as well as the European Commission, voiced similar concerns [16,17].

In March 2013, following these objections, ICANN's Independent Objector (IO), an impartial party acting in the

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public interest, lodged formal objections to all four .health applicants [18]. Additionally, ICANN's At-Large Advisory Committee, which vets objections to gTLD applications, similarly voted to support an objection for three of the four applicants (except Afilias; the provider licensure provision may have been a differentiating factor) [19]. However, in a subsequent decision, the International Chamber of Commerce (ICC), an entity reviewing disputes filed by the IO, denied *all* limited public interest objections filed against current active .health applicants (ie, Donuts Inc, Affilias, DotHealth LLC) effectively clearing the way for future procedural decisions, favoring award of .health most likely through a bidding system [20,21]. Interestingly, objections filed by the IO for other health-related gTLDs (eg, .hospital, .med) described below and in Table 3 have been upheld. Yet ICANN has not explained how these gTLDs are more important than .health, thus creating a great deal of inconsistency in the objection process.

Another concerning development occurred in October 2013, when ICANN's New gTLD Program Committee issued a separate decision to re-categorize .health as being appropriate for open entry, effectively exempting it from certain "Safeguard Advice" (including requiring regulatory body oversight/licensure) that would limit its use [19]. In this decision, ICANN prioritized implementation of safeguards for "highly-regulated" gTLDs such as .sucks, .wtf, .poker, .lawyer, and .bank, over its limited safeguards proposed for .health [19].

Other Health-Related gTLD Applicants

Controversy regarding the three remaining applicants for .health has sparked global debate on eHealth governance and concerns from various public health stakeholders [1]. However, other important health-related gTLDs have not been adequately analyzed nor discussed that face similar concerns. In addition to reviewing current applicants for .health, other health-related gTLDs with key terms including .care, .clinic, .dental, .dentist, .diet, .doctor, .healthcare, .hospital, .medical, and .surgery are in play (Table 3). Alarmingly, Donuts Inc-related subsidiaries are named as applicants for all of the above health-related gTLD strings, and similarly will not require tangible restrictions or verification of licensure/credentials for future registrants. Only two other applicants for the .doctor gTLD have any verification systems, such as mandated medical licensure, prior to .doctor domain use.

Large multinational pharmaceutical companies are also active in gTLD applications. This includes applications by 6 pharmaceutical manufacturers including Pfizer, Eli Lilly and Company, Merck, Sanofi, Hisamitsu Pharmaceutical, and Teva Pharmaceutical Industries. Largely these corporations are registering for brand and trademark protection purposes and generally limit registrants to company affiliates or licensees/authorized partners, which may represent a legitimate use of a gTLD. One application for the proprietary name of erectile dysfunction drug Cialis by Eli Lilly was pursued but is no longer active. However, direct-to-consumer advertising of prescription products is not allowed in the vast majority of countries other than the United States and New Zealand, and it may be unlawful for pharmaceutical manufacturers to engage in multijurisdictional online advertising that could occur through future gTLDs [7,22].

In contrast to the .health gTLD applicants, the .med gTLD (abbreviation for medical) have included partnership with more reputable health care stakeholders and information technology providers and have processes for restricting future registrants. This included the Cleveland Clinic's engagement with Medistry LLC for its .med application requiring a request for proposal to vet qualifications of future registrants and Google Inc's own application (Charleston Road Registry Inc). However, despite the Cleveland Clinic affiliation representing a higher level of legitimacy compared to .health applicant counterparts, community objections to its .med applications were upheld by the ICC (along with objections to Google Inc's application), whereas similar objections raised by the IO for .health have been denied.

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Table 3. Other health-related gTLD applicants.

gTLD string	Description of gTLD	Applicant name	Application status and country	Applicant type	Specific restrictions
	Chinese characters for the term "healthy" (jiankang)	Stable Tone Limited	Passed ICANN Initial Assessment Hong Kong	Limited Company	Agrees to mitigate against sites that sell counterfeit pharmaceuticals or other violating products/services
.cancerresearch	gTLD string for Cancerresearch	Australian Cancer Research Foundation (ACRF)	Passed ICANN Initial Assessment Australia	Australian public company limited by guarantee, nonprofit company, charitable institution	Registration of .cancerresearch domain names will be restricted to entities affiliated with ACRF
.care	Descriptive term in health	Goose Cross (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.clinic	Health care location/site	Goose Park, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.diet	Health behavior associated with weight	dot Diet Limited	Passed ICANN Initial Assessment Gibraltar	Limited liability company	Governing Council as advisory board. Protection of Intergovernmental Organization names; no other specific restrictions
	Health behavior associated with weight	Uniregistry, Corp.	Passed ICANN Initial Assessment Cayman Islands	Exempted corporation	No specific restrictions
	Health behavior associated with weight	Pioneer Hill, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.dds	Abbreviation for dental profession licensure	Top Level Domain Holdings Limited	Passed ICANN Initial Assessment British Virgin Islands	Publicly traded corporation	Open to licensed dentist (Doctor of Dental Surgery degree recognized by accrediting body) only
	Abbreviation for dental profession licensure	Charleston Road Registry Inc	Passed ICANN Initial Assessment USA	Corporation (Google parent company)	Verification of dentist or dental practices through membership with American Dental Association
.dental	Descriptive term for oral health practice	Tin Birch, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.dentist	Descriptive term for dental health care professional	Outer Lake, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions

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gTLD string	Description of gTLD	Applicant name	Application status and country	Applicant type	Specific restrictions
.doctor	Descriptive term for physician health care professional	DotMedico TLD Inc	Passed ICANN Initial Assessment Republic of Seychelles	International business company	Registrants of .doctor will have to participate in a verification of their medical license as confirmed through data issued by the issuing authority of that license
		Brice Trail, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
		The Medical Registry Limited	Passed ICANN Initial Assessment USA	Corporation	All entities registering within the .doctor TLD being required to produce verifiable credentials linked to evidence of professional qualifications or affiliation
.healthcare	General descriptive term	Silver Glen, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.hiv	Descriptive term for human immunodeficiency virus infectious disease	dotHIV gemeinnuetziger e.V.	Passed ICANN Initial Assessment Germany	Gemeinnuetziger eingetragener Verein under German law (German charitable Incorporated nonprofit Association)	Open to all registrants. Aims to distribute at least 50% of all registration fees towards fundraising for HIV/AIDS.
.hospital	General term for health care facility	Ruby Pike, LLC (Donuts Inc)	Passed ICANN Initial Assessment; IO objection sustained USA	Limited liability company	No specific restrictions
.med	Abbreviated term for “medical”	Medistry LLC	Passed ICANN Initial Assessment; IO objection sustained USA	Limited liability company	Partnership to operate and maintain the gTLD with The Cleveland Clinic; will use request for proposals process to vet qualification of registrants
	Abbreviated term for “medical”	HEXAP SAS	Passed ICANN Initial Assessment France	SAS company	Eligibility restricted to a list of licensed practitioner and health care entities with re-verification upon domain name renewal
	Abbreviated term for “medical”	Charleston Road Registry Inc (Google Inc)	Passed ICANN Initial Assessment; IO objection sustained USA	Corporation	Limiting registration to only verified doctors
.medical	General descriptive health term	Steel Hill, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions
.pharmacy	General term for health care facility	National Association of Boards of Pharmacy	Passed ICANN Initial Assessment In Contracting USA	Nonprofit institution	Goal of forming .pharmacy gTLD as an international safe namespace for legitimate online pharmacies. Applicants will be vetted for applicable regulatory standards, pharmacy licensure, drug authenticity, and valid prescription requirements

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gTLD string	Description of gTLD	Applicant name	Application status and country	Applicant type	Specific restrictions
.rehab	General term for medical treatment	United TLD Holdco Ltd.	Passed ICANN Initial Assessment Cayman Islands	Corporation	No specific restrictions
.surgery	General term for health care procedure	Tin Avenue, LLC (Donuts Inc)	Passed ICANN Initial Assessment USA	Limited liability company	No specific restrictions

Similar to health care licensure verification requirements, the Australian Cancer Research Foundation (.cancerresearch) has policies requiring future registrants to be entities affiliated with the Foundation. The American Heart Association filed for two gTLDs (.heart and .stroke) but has subsequently withdrawn these applications (Table 4). In addition, the nonprofit German entity, dotHIV gemeinnuetziger e.V., applied for a .hiv gTLD to specifically leverage health communication and fund raising [23]. It has no restrictions on use and claims it will distribute at least 50% of future registration fees towards fundraising for the disease.

Some gTLD professional medical organization applicants have also initiated safeguards to protect public health, including the US National Association of Boards of Pharmacy (NABP) who is the sole applicant for .pharmacy and is currently in the award/contracting process. NABP's application includes the stated goal of addressing the growing problem of illicit online pharmacies. In its application, it commits to establishing a safe and reliable international online space for online pharmacies requiring vetting of applicants for applicable regulatory standards, licensure, drug authenticity, and valid prescription requirements.

Table 4. Examples of withdrawn applications.

gTLD string	Description of gTLD	Applicant name	Application status and country	Applicant type	Specific restrictions
.heart	General descriptive term/organ	American Heart Association, Inc	WithdrawnUSA	Not-profit institution	Various criteria as a restricted name space for registrants including specific requirements for hospitals, universities, individuals, and corporations.
.med	Abbreviated term for "medical"	DocCheck AG	WithdrawnGermany	Publicly traded corporation	Proof of formal or long-standing training and/or experience in any field of medicine. Target group for field of medicine very broad.
.stroke	General term for medical condition	American Heart Association, Inc	WithdrawnUSA	Not-profit institution	.STROKE will be a single registrant TLD and will have only registrations that are specific to and managed by AHA directly

Discussion

The review and delay of the .health gTLD and pending status of other health-related gTLDs provides the global community an opportunity to shape this important component of future eHealth governance. Clearly, use of the Internet for health information and its impact on health behavior is now a key issue in global health. In response, the global health community should recognize the importance of establishing a dedicated, safe, reliable, trustworthy, and accessible space for health information on the Internet to ensure that public health needs are met appropriately.

Establishing an evidence-based and appropriately validated .health gTLD can promote this goal and could be accomplished by international multistakeholder participation. Although WHO rightly expressed interest in a .health domain over a decade ago, a serious challenge to regain governance and oversight over .health has not occurred. This is despite the 66th World Health Assembly (WHA) calling for all health-related gTLDs to be used to promote public health. The WHA also urged its member states and the director-general to work within ICANN's Governmental Advisory Committee to ensure proper governance and operation of all health-related gTLDs—specifically .health [24]. However, at present, there is a lack of immediate and tangible action to intercede in the ongoing ICANN approval process, which is rapidly moving towards a final conclusion.

Global public health stakeholders should demand collective action by WHO, health-related United Nations organizations, multilateral/bilateral health agencies, national governments, NGOs, medical/patient professional societies, civil society, and other public health stakeholders. All should commit to securing a safe space for the health Internet that abides by ethical principles, practices, and rules that honor public health interests first and foremost. This community should call for ICANN to treat .health and other health-related gTLDs as protected, differentiating them from the other gTLD applications given their potential social and health impacts [1]. This should include reinforcing the universally agreed upon concept argued by the IO to the ICC that health is not just any commodity and that under international law, "health" is recognized as a fundamental human right, which includes the right to access accurate health

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information. Unfortunately, the ICC has rejected this position and the concerns of various public health stakeholders in its review of .health objections.

In response, concrete action should begin with calling for an immediate moratorium and suspension on ICANN decisions on .health and health-related gTLD applications to provide the global health community necessary time to explore an efficient, safe, and equitable governance structure that prioritizes stakeholder participation with the shared goal of ensuring adequate privacy, ethical use, and ensuring trust and protection of online health consumers. Indeed, WHO had specifically requested a postponement in a letter to ICANN in April 2012, though its actions and recent WHA resolution have been interpreted by the ICC as not definitive enough to support a call for protection of .health [19].

Future eHealth governance approaches to ensure the appropriate management of .health could be accomplished by requesting ICANN to re-categorize .health as a sponsored gTLD and proactively appoint WHO its sponsor [1]. By re-categorizing .health (similar to eligibility requirements in place since 2001 for .edu as a sponsored gTLD), WHO would develop policies to ensure accountability and transparency in gTLD operations that meet the best interests of the global health community and enforce eligibility rules regarding all future .health registrants [1].

However, in order to ensure a truly inclusionary and multistakeholder process necessary for the equitable management of .health, WHO's possible appointment as gTLD sponsor should be governed by a diverse and globally representative board of global health stakeholders in partnership with responsible Internet service providers. This governance mechanism can have representation and be organized into subject-specific advisory panels to review and recommend content to be included on for .health. It can also agree to standards of quality online health information and work towards developing globally accepted norms and standards for content (eg, evidenced-based information, public health agency information). This should also include health care providers appropriately vetted for content review, licensure, credentialing, and other quality indicia to ensure legal marketing of health-related products/services within appropriate jurisdictions.

At a minimum, the international community should demand a postponement of any imminent ICANN decisions on current .health applications and other health-related gTLDs reviewed above. This is particularly important for those health-related gTLDs that are currently being aggressively pursued by Donuts Inc as the sole applicant. Instead, multistakeholder groups with transparent and accountable governance mechanisms and a mandate to promote public health are key to ensuring the trust and credibility of health on the Internet.

Conclusion

The importance of establishing an inclusive yet reliable presence for health information online is critical to future global health outcomes given the growing importance of the health Internet. However, .health and many other health-related gTLDs are now on sale to private sector entities that largely permit open and unrestricted use. Yet, the globalized nature of the Internet, the public health need for privacy, security, and quality health information, and the rapid expansion of online health technologies demonstrate a critical need to ensure proper governance of future health domains. Focusing on the public good can be a first and crucial step to ensure an accurate, reliable, and evidence-based online presence for health for this generation and the next.

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Conflicts of Interest

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Abbreviations

ACRF: Australian Cancer Research Foundation
AHA: American Health Association
gTLD: generic top-level-domain
ICANN: The Internet Corporation for Assigned Names and Numbers
ICC: the International Chamber of Commerce
IGO: intergovernmental organization
IMIA: the International Medical Informatics Association
IO: Independent Objector
NAPB: National Association of Boards of Pharmacy
NGO: nongovernmental organization
TLD: top-level-domain
WHA: World Health Assembly
WHO: World Health Organization

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Viewpoint

Tailored and Integrated Web-Based Tools for Improving Psychosocial Outcomes of Cancer Patients: The DoTTI Development Framework

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Abstract

Background: Effective communication with cancer patients and their families about their disease, treatment options, and possible outcomes may improve psychosocial outcomes. However, traditional approaches to providing information to patients, including verbal information and written booklets, have a number of shortcomings centered on their limited ability to meet patient preferences and literacy levels. New-generation Web-based technologies offer an innovative and pragmatic solution for overcoming these limitations by providing a platform for interactive information seeking, information sharing, and user-centered tailoring.

Objective: The primary goal of this paper is to discuss the advantages of comprehensive and iterative Web-based technologies for health information provision and propose a four-phase framework for the development of Web-based information tools.

Methods: The proposed framework draws on our experience of constructing a Web-based information tool for hematological cancer patients and their families. The framework is based on principles for the development and evaluation of complex interventions and draws on the Agile methodology of software programming that emphasizes collaboration and iteration throughout the development process.

Results: The DoTTI framework provides a model for a comprehensive and iterative approach to the development of Web-based informational tools for patients. The process involves 4 phases of development: (1) Design and development, (2) Testing early iterations, (3) Testing for effectiveness, and (4) Integration and implementation. At each step, stakeholders (including researchers, clinicians, consumers, and programmers) are engaged in consultations to review progress, provide feedback on versions of the Web-based tool, and based on feedback, determine the appropriate next steps in development.

Conclusions: This 4-phase framework is evidence-informed and consumer-centered and could be applied widely to develop Web-based programs for a diverse range of diseases.

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KEYWORDS

Internet; consumer health information; health literacy; medical informatics; neoplasms; communication

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Introduction

Global Burden of Cancer and its Psychosocial Consequences

Cancer is one of the leading causes of death world-wide, accounting for 7.6 million deaths in 2008 [1]. A diagnosis of cancer can impose a significant psychological burden on patients and their families. Challenges include coping with uncertainty surrounding prognosis, making important treatment decisions, and learning how to manage often debilitating physical, psychological, and social effects of the disease. Cancer care is complex, involving a multidisciplinary team, including general practitioners, cancer doctors, nurses, and other allied health professionals, and patients often have to travel for treatment [2]. Between 32% and 48% of individuals diagnosed with cancer experience psychological distress, including anxiety and depression [3]. Failure to address these issues through the provision of appropriate information and psychosocial care may have a significant impact on clinical patient outcomes and the health care system, including higher frequency and intensity of physical symptoms [4], poorer adherence to treatment regimes [5], and increased utilization of medical services [6].

The Importance of Effective Communication in Reducing Psychosocial Burden

Effective communication and provision of information to cancer patients and their families about their disease, treatment options, and possible outcomes improve psychosocial outcomes [7,8]. Recognition of the importance of effective communication has been driven by increased consumer activism, as well as legal imperatives to ensure patients are well informed of their treatment options and are able to exercise control over their role in making decisions regarding their care [9]. In order to make an informed decision, for example, a patient must be provided with clear and sufficient information about the risks and benefits of available treatment options [10]. Failing to fully inform patients about their condition, treatment options, and potential consequences, as well as misrepresenting information, can lead to legal challenges and medical litigation [11]. This has led to a shift from paternalistic approaches to information provision and disclosure within the health care system to a model that emphasizes autonomy and patient-centered care [12], which are reflected in changes to legislation, bioethical guidelines, and accepted principles within the medical profession [12-15].

The philosophy of patient-centered care promotes self-management and patient empowerment by emphasizing patients as partners in decision making and offering tailored health care that is responsive to patient needs [16]. Effective patient-centered care is associated with improved health outcomes, enhanced patient and practitioner satisfaction, and decreased use of health care services [16]. The Institute of Medicine report, “Crossing the Quality Chasm”, promoted patient-centered care as an essential component of quality health care [12], a position that is passionately supported by consumer advocates. The involvement of consumers in health service reform and research is essential to ensuring patients’ needs, values, and preferences are represented [17]. The health consumer movement has strengthened in recent decades with the establishment of consumer advocacy groups, including MacMillan (United Kingdom) [18], Cancer Voices (Australia) [19], and LiveStrong (United States) [20]. Consumers are actively involved in campaigns to engender change in health care policy and practice, creating awareness of diseases and offering support to patients, and determining research priorities and distribution of funding [21]. The sense of autonomy and assertiveness promoted by the health consumer movement has led to an appeal by patients for active involvement in decision making in partnership with their health care provider [22].

Accounting for Individual Patient Variation in Communication

Ensuring patients are well informed and able to participate in making complex decisions about their care is complicated by several factors. As well as providing patients with information, there is a need to ensure that information is provided in a way that is understood and recalled. Health literacy refers to an individual’s ability to obtain, process, and understand health information to make appropriate decisions about their health care [23]. Around one in five adults in the United States has low health literacy [23]. Individuals with low health literacy often face challenges in acting as fully informed consumers. Consequently, they may lack a clear understanding about their condition, their options for and the potential consequences of treatment [24], and therefore find it difficult to be active in making decisions about their health care [23]. Given the increasingly complex treatment options available to cancer patients, health literacy must be an important consideration when providing information to patients [23].

Accounting for Clinician Variation and Patient Preferences in Communication

Patients often report that clinicians do not provide information about their diagnosis and treatment options in ways they can understand [23]. This mismatch between the information provided by clinicians and the patient’s level of health literacy hinders the ability of patients to recall and utilize the information [23]. There is also significant variation in patient preferences for involvement in medical decision making [25]. Degner and colleagues found that 22% of breast cancer patients preferred to make the decision about their treatment, 44% wanted a collaborative approach between themselves and their clinician, and 34% of women preferred their clinician having responsibility for treatment decisions [25]. Achieving the desired level of involvement in decision making may be further hindered by the ability of clinicians to accurately assess patient preferences. Several studies have revealed that clinician perceptions are incongruent with cancer patient preferences for involvement in medical decision making in approximately 58% of cases [25,26].

The Limitations of Traditional Approaches to Information Provision

There are a number of existing approaches to providing information to patients. These include patient-clinician interaction, written/printed leaflets and booklets, audio-visual materials, and more recently, websites accessed via the Internet.

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However, these approaches have a number of limitations. For example, patients consistently report being dissatisfied with the amount and quality of the information they receive directly from clinicians [27]. Health care professionals may not be aware of patients' needs and preferences for receiving information [26], and clinicians are known to have poor accuracy in tailoring information to match patient preferences [8,26]. Inadequate communication or withholding information by the health care provider can lead to poor recall or misunderstanding of information [27].

In addition, written information materials, including leaflets and booklets, often have a reading level that is higher than that of the majority of the population [8,28]. This discrepancy results in information materials that are not readily accessible to some consumers and have the potential to cause unnecessary confusion and anxiety. The most vulnerable consumers—those with low literacy and numeracy—are particularly likely to be affected by the challenges of written information. Varying learning styles and literacy levels may also make it difficult for patients to absorb and engage with written information [29]. Written information materials also depend on the consumer having adequate visual capabilities and therefore are not suitable for visually impaired groups. Currency of information is also important given ongoing developments in the health research literature. Regularly updating the content of printed materials to reflect current best evidence is often not cost-effective, resulting in out-of-date materials remaining in circulation [30]. Written and audio-visual information including videos, DVDs, and CD-ROMs also cannot be tailored to the individual needs of patients and are often very expensive to produce and update as new evidence becomes available [30].

The Unrealized Potential of Web-Based Information

Heralded as the future for providing patients with health information in the mid-1990s [30-32], the amount of health information on the Internet has grown exponentially. Surveys of cancer patients and their families have shown that 62-80% have an interest in obtaining information and support via the Internet [33,34]. Patients also frequently report the Internet as an important source of information about diagnosis and treatment [35,36]. The Internet shows great promise in reaching a large proportion of the community; 78% of citizens in the United States have Internet access [37], and new technologies including smartphones and tablet computers have led to a growth in accessing the Internet via mobile devices [38]. Mobile technology improves convenience for users and allows people to connect with Web-based services and information anywhere at any time, which is a feature reported by cancer patients as the main benefit of Web-based information [34]. This provides an ideal platform on which to develop information interventions for improving patient outcomes and health care delivery to a wide audience.

However, current Web-based information is not without limitations. While the Internet plays an important role in meeting the informational needs of many patients [35], the unmonitored provision of information, coupled with unstructured and unassisted use, has the potential to negatively impact psychological well-being and patient outcomes. There are growing concerns, for example, about the quality of health information available on the Internet [35,39]. Information is often provided without any regulation of credibility of authorship or accuracy of content. This has the potential for dangerous and negative consequences, particularly given that around half of all people who search for health information on the Internet do not discuss the information with their health care provider [40]. The reading level required for many cancer information websites is also far above that of the average population. Friedman and colleagues report that 64% of cancer websites are written at a level of grade 13 or higher [41], which suggests that a large proportion of information may not be accessible by less literate patients. Lack of specificity, complexity, and being too impersonal are also perceived as disadvantages by patients [34].

These findings highlight the need for more accurate, evidence-based information that is easily understood by consumers, developed in close co-operation with health care professionals, and integrated into clinical care in order to overcome the dangers of misinformation. There is an urgent need to develop a sustainable, systematic, and integrated approach to providing information in a way that addresses health literacy, increases patient involvement in decision making and their care, and operates independently of resource constraints and other barriers that deter the routine delivery of tailored information.

New-Generation, Integrated, and Tailored Web-Delivered Tools as a Solution for Effective Information Provision

Overview

In contrast to the passive dissemination of information via traditional Web-based approaches, new-generation Web-based technology offers an innovative and pragmatic solution to the shortcomings of general Web-based information by providing a platform for interactive information seeking, information sharing, and user-centered design.

Self-Tailored Content

Individual patient preferences for information vary. Some patients wish to obtain as much information as possible (monitors), while others prefer to avoid potentially threatening information (blunters) [42]. Tailoring information to match individual preferences improves psychosocial outcomes [12,43] by preventing unnecessary anxiety and increasing recall of information [44]. Web-based information tools have the potential to empower patients to determine when and how often they access information and the type and amount of information they would like, allowing them to become actively involved in their health care. This improves on traditional clinician-delivered information provision where patient preferences may not be considered.

There is also significant potential for Web-based tools to modify content to account for individual factors such as health literacy

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and cultural appropriateness. For example, upon login, the user may be asked to complete a brief screening questionnaire, indicating information such as their ethnicity, highest level of education, and preference for detailed versus brief descriptions. These data can be used to tailor the Web-tool content to suit the needs and preferences of the user, for example, by increasing the number of pictures and videos presented or including culturally relevant vocabulary and images. In addition, options can be made available to customize the language (eg, English, Japanese, Spanish) in which the information is presented or increase the size of the text to assist the visually impaired. The interactive nature of Web-based tools allows for real-time customization that is not offered by printed information materials.

Clinician-Tailored Content

Algorithms can be used to select the appropriate information to be presented in Web-based information tools based on data entered by the patient or their clinician. However, clinicians should also play a role in tailoring the information presented within a Web-based tool to ensure it is suited to the user's unique medical circumstances. For example, a Web-based tool can tailor the information presented based on data entered by the clinician regarding the patients' diagnosis and relevant treatment options. Customizing the content in this way may prevent the patient from feeling unnecessary distress or false hope over viewing treatment information that is not appropriate for their circumstances.

The involvement of clinicians in tailoring content is important for preventing potential harm caused by misinformation and ensuring the information is relevant to individual patients and their families. Cancer diagnoses can be very complex, and the resulting discussions about treatment options, side effects, and prognosis may require patients to absorb a large amount of complicated information within a short timeframe. The provision of a Web-based information tool that is tailored by the clinician to the unique circumstances of the individual can act as a reliable source of information, supplementary to the doctor-patient consultation. Web-based tools tailored in this way have the capacity to overcome issues such as misinformation [35,37-39], patient comprehension, and information recall [45].

Multiformat Presentation of Information

The ability to understand and recall medical information is important for ensuring adherence to recommendations for care [45]. Studies have reported that 40-80% of medical information is forgotten, and about half of the information provided to patients is remembered incorrectly [45]. Levels of anxiety can also negatively impact patient recall of information [45], which is particularly relevant for patients facing a life-threatening illness. A combination of written, spoken, and visual formats has been recommended for improving recall of information [45]. Web-based information tools have the potential to deal with issues surrounding patient memory for medical information and allow information to be presented in multiple formats (eg, diagrams, videos, text) to suit different learning styles [30] and literacy levels [45].

Connecting People and Information Sharing

New generation Web technology provides an effective way of connecting patients and families with information and support regardless of their location. For example, social networking sites, online discussion forums, and video-conferencing allow patients and carers, from various and remote locations, to be part of a virtual community, share their experiences and offer support to one another. The availability of this additional support network, which may be otherwise inaccessible, has the potential to improve socialization and reduce feelings of isolation often experienced by patients and their families dealing with a life-threatening illness such as cancer [46]. A survey of hematological cancer survivors found that the second highest ranked item of high-level unmet need was "finding someone to talk to who understands and has been through a similar experience" [47].

The availability of Web technology encourages the involvement of family and friends in information seeking. Family and friends are able to access information they may wish to know but are reluctant to seek from health care professionals for fear of upsetting the patient, such as information about prognosis, survival, or long-term complications. A Web-based information tool provides a discrete mechanism for accessing this information without the issues of information quality and accuracy often associated with Internet resources. This may allow loved ones to better plan for the future. The instantaneous nature of the Internet also allows for information to be easily shared between patients, their families, and friends. Users are able to access the same information at the same time, send information and links via email, share information and links using social networking sites, and discuss the information using video-conferencing software, such as Skype.

While Web-based tools allow for information to be shared quickly and easily, there are potential privacy issues that must be considered. In the United States, the Privacy Rule issued under the Health Insurance Portability and Accountability Act of 1996, governs the way in which health information can be shared in order to adequately protect the privacy of individuals while allowing the information flow necessary for the provision of high quality health care [48]. Similarly, a number of countries have legislation covering the recording, storage, and transmission of personal health information. Where Web-based tools require individuals' health information to be provided by their clinician and stored on a secure server in order to allow for sufficient tailoring of information, it is critical to design the system with a clear understanding of implications of the relevant legislation and in a manner that ensures that adequate privacy and data protections are in place to prevent unauthorized access or sharing of private health information. In addition, where Web-based tools are used to share information with friends and family as described above, it is essential that the tool allows for the patient, or an authorized proxy, to have control of what information is made available to others.

Inclusion of Decision Support Tools

The International Patient Decision Aids Standards (IPDAS) Collaboration [49] describes decision aids as evidence-based tools designed to prepare a person for making a decision about

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their health care options through deliberative exercises such as value weighting [50,51]. Web-based information tools offer a unique opportunity to seamlessly integrate decision aids with the provision of health care information. Web-based tools allow decision aids to be interactive and presented in multiple formats incorporating video, images, and animations, all of which are useful for presenting risk information to patients.

Integration With Clinical Care Rather Than Passive Patient-Directed Information Seeking

Web-based information tools may facilitate communication with health care providers. The use of a question prompt sheet within consultations has been shown to be effective in increasing patient participation and reducing unmet information needs [52]. The interactive nature of Web-based tools may enhance the generation and utilization of prompt sheets for patients by tailoring content to correspond with the areas of most interest to the patient. For example, a Web-based information tool has the capacity to generate a question prompt sheet based on the topics of information accessed by the user. The Internet also offers the additional advantage of allowing prompt sheets to be automatically emailed to the health care provider prior to the consultation. This may improve the relevance of the information provided to the patient within the consultation due to increased preparation by the health care provider.

Distribution, Maintenance, and Feedback

The ability to track and record how the website is used provides an accurate and detailed process measure for evaluating the intervention. Delivery and maintenance of Web-based information tools have the potential to be highly cost-effective [53] and can be easily updated in a timely manner to reflect current best evidence.

Framework for Developing an Integrated Web-Based Information Tool

Overview

Several reviews of the literature have examined the effectiveness of Web-based interventions for patient education, psychosocial care, and support [54-57]. While these reviews indicate some benefit of Web-based interventions on patient outcomes including knowledge, social support, health behaviors, and psychosocial well-being, findings are mixed and conclusions limited by the methodological weaknesses of the studies examined. Heterogeneity in the methods used to produce and deliver these interventions may contribute to inconclusive findings. There is often a lack of clear, explicit descriptions of the procedures for developing Web-based interventions in the literature, impeding replication and translation of effective interventions. While there are many useful resources available to guide the development of patient information materials in general [58-60], there is a need for a systematic process for the development of patient education and support interventions delivered specifically via the Internet.

We propose a framework for developing Web-based information tools that draws on our experience of constructing such a tool for hematological cancer patients and their families. The framework is based on principles proposed for the development and evaluation of complex interventions [61,62], which emphasize the importance of using a phased approach, starting with needs assessment, pilot work, and moving on to an exploratory and then definitive evaluation. The framework draws on the Agile methodology of software programming [63], which emphasizes collaboration and iteration throughout the development process. The Agile methodology allows for projects to evolve and be responsive to change, as programmers, researchers, and stakeholders are able to interact to shape the direction of the project through all phases of development.

Figure 1 illustrates the DoTTI framework for developing a Web-based information tool. The process involves four phases of development: (1) design and development, (2) testing early iterations, (3) testing for effectiveness, and (4) integration and implementation. At each step, stakeholders (including researchers, clinicians, consumers, and programmers) are engaged in consultations to review progress, provide feedback on versions of the Web-based tool, and based on feedback, determine the appropriate next steps in development. Stakeholder participation and iteration have been identified as being essential to the development of effective eHealth technologies [64]. The phases of development are not intended to represent what could be seen as a linear or waterfall approach [65] to the creation of the software underpinning the tool. Rather, the phases represent a staged and concurrently iterative process to the creation of the tool, noting that the development of the informational content and the implementing technology are entwined.

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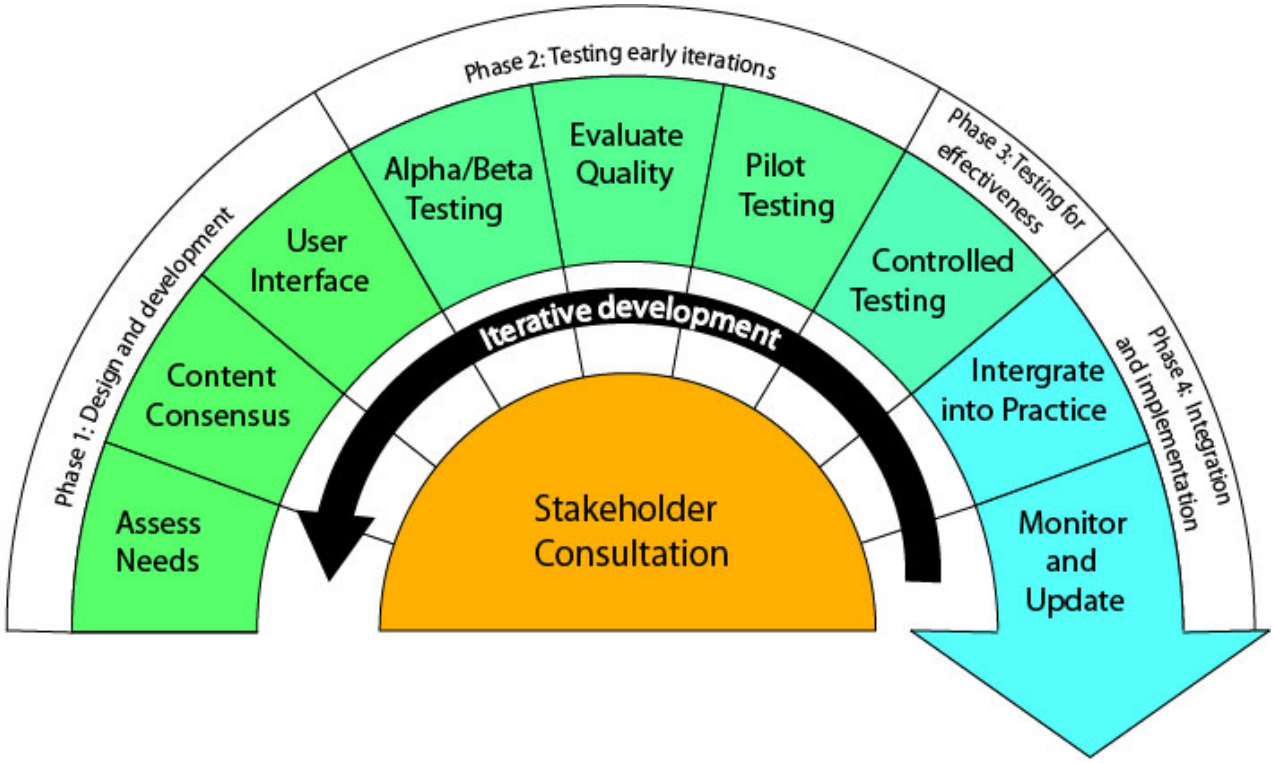
Figure 1. The DoTTI framework for the iterative and consultative development of a Web-based information tool.



Phase 1: Design and Development

Identify the Target Population and Conduct a Needs Assessment to Determine Patients' Information and Support Needs

Understanding the needs of the target population is the crucial first step for delivering high quality, patient-centered care [66]. Many existing needs assessment tools assess cancer patients' needs across a range of domains including physical, psychological, social, financial, and information [66]. While information needs vary, up to 97% of cancer patients report unmet information needs [67]. Common areas where cancer patients report needing additional information include being informed about self-care strategies and the benefits and side effects of treatment [67]. Furthermore, cancer patients tend to report greater unmet needs during the treatment phase [67]. Prior to developing a Web-based information tool, a needs assessment that identifies the informational and support needs of the target population should be undertaken.

Build on Existing Information Resources and Gain Consensus From Health Care Providers

Building a partnership with key patient support organizations within the field of interest is advantageous for sharing of resources and expertise. Many support organizations have an established set of information resources available for the target population, which may be used with permission to form the foundation of the Web program content.

Involving health care professionals in the production, implementation, dissemination, and evaluation of Web-based information tools may increase patients' use of the tool, adoption by health care organizations, and effectiveness and acceptability [39]. At least one advisory group should be established to provide guidance, advice, and feedback on the content of the intervention and to obtain consensus regarding this information. Expert advisory groups should comprise multidisciplinary health care providers as well as members of key support organizations, so that a wide range of views can be incorporated into the intervention. Building cooperative and respectful relationships with experts is essential for regularly updating the Web-based tool's content and successful dissemination of the intervention broadly.

We demonstrate the feasibility of gaining consensus from health professionals through our own experiences during the development of a Web-based information tool. Prior to the consensus meeting, convened in relation to a Web-based tool for hematological patients and their support persons, we allocated sections of content to members for review based on their areas of expertise. Using a rating scale, the quality of the content was scored out of ten in areas such as accuracy, completeness, level of detail, and communication style, allowing identification of areas where improvements were needed. The feedback was then collated and presented at the advisory group meeting. There are various well-established approaches to obtaining consensus, such as the Delphi method, which may be used to determine the content of the Web program [68].

The consensus meeting provided a valuable opportunity to openly discuss the sections of information that were considered to require significant revisions by reviewers or topics where conflicting feedback was provided. To ensure such meetings are productive and efficient, conflict resolution techniques, such as voting, should be employed when consensus cannot be reached. When consensus cannot be reached and there is high level evidence (for example, clinical practice guidelines or evidence from Cochrane reviews) providing support for one particular intervention over another, the result should be in favor

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of the evidence. Where such evidence is not available, or the evidence is conflicting, all options should be presented for users. A transparent approach should be employed for communicating information where there is poor or conflicting evidence and no consensus among clinicians. An approach similar to that recommended by Raine and colleagues [69] may be used for increasing the transparency of recommendations where there may be conflicting evidence. Such an approach involves making explicit the reasons for disagreement and the degree of consensus, to assist with decision making.

Other advantages to involving multidisciplinary health care providers and researchers in a consensus meeting during the development phase of the Web-based tool include the opportunity to (1) discuss the acceptability of the intervention from a health care provider perspective, (2) investigate the probability of health care providers endorsing the information tool and promoting it to patients, and (3) strengthen relationships with clinical colleagues and foster potential future research collaboration.

Ensure a Well-Constructed and User-Friendly Interface

To increase the likelihood of use and effectiveness of a Web-based information tool, it is essential that the tool allow the user to extract the desired information as easily as possible. Most literature on effective Web page design emphasizes at least some of Dieter Ram's design principles [70], namely that good design is innovative, useful, aesthetic, easily understood, unobtrusive, honest, durable, thorough, concerned with the environment, and has "as little design as possible". Achievement of innovation without being obtrusive or over designed is interesting in the Web context: the current Web 2 browsers support user-provided content and hence user interaction; Web 3 (the *semantic* Web) adds contextual personalization; and the proposed Web 4 (the *symbiotic* Web) will be highly intelligent and fully executing. Each new Web form brings with it increased portability, pervasiveness, interactivity, and better support for multimedia (eg, video, audio) [71]. It is important that the Web-based tool uses innovation as appropriate to enhance communication, avoiding unaesthetic, obtrusive glitz by embracing elegant simplicity.

Another consideration is observation of the patterns followed by users' eyes when reading Web pages [72]. Research shows that users typically read Web pages in an F-shaped pattern involving a pair of horizontal scans, the first across the top of the content, the second being lower and shorter, followed by a left-oriented vertical scan [72]. This has implications for Web page design as most users will not read all of a page's content. The first lines of a page should state the most important information in the page, and headings, subheadings, bullet points, and paragraphs should start with words that impart information because these represent the left-most content.

With regards to the content imparted by the Web-based information tool, its design and implementation must be logical and intuitive to support information seeking for diverse users, including those who are less technologically savvy. The Web pages should be structured in a way that is meaningful to the user and easy to use [73]. Compliance with standard Web design conventions, such as positioning the navigation bar at the top and the organization's logo in the top-left corner, allows users to easily understand the structure of the website based on their previous experience with other websites [73]. Incorporating various navigation aids, such as a search function, hyperlinks, tabbed menus, and sitemap, improves the ability of users to access desired information and offers navigation flexibility for browsing content [73,74]. Simplicity and consistency in design across all Web pages included in the intervention is essential for effective website navigation [73,74].

While content must be current, informative, and accurate, the visual design of the Web-based tool is important for capturing the user's attention. Careful inclusion of graphic features, such as colors, images, and icons, helps to highlight key points and serve to increase the comprehensibility of text-based information [73]. Visual design features such as white space, contrast, and typography are also important considerations for maximizing readability. Ensuring the user interface is attractive and easy to navigate is likely to improve consumers' use of and satisfaction with the Web-based information tool.

Phase 2: Testing Early Iterations

Conduct Alpha and Beta Testing of Early Versions of the Tool

As early iterations of the Web-based tool are developed, it is essential to follow a test strategy, including alpha and beta testing, to assess the functionality of the tool and ensure it meets the objectives of the project. Alpha testing is often carried out within the project team and typically involves checking for issues such as incorrect or broken links, misspelled words, and problems loading multimedia objects [75]. Following this, beta testing may be undertaken, where the tool is tested by a sample of the intended end-users for any additional defects [75]. At this stage, initial feedback regarding usability may also be sought. During the preliminary testing phase, it may also be beneficial to conduct a heuristic evaluation of the user interface of the Web-based tool leading to improved usability.

Evaluate the Quality of the Tool Against Established Guidelines

Checklists and guidelines for assessing the quality of health-related information on the Internet have been developed; however, many are not supported by empirical evidence [76,77]. Several quality criteria for assessing information for consumers of health services include those developed by the King's Fund, the United Kingdom National Health Service, and Coulter, Entwistle, and Gilbert [77]. These criteria emphasize the need for comprehensive and unbiased information that is presented in a way that is simple and easy to understand and can be integrated into clinical practice. Entwistle and colleagues advocate for additional dimensions of quality including relevance, accuracy, accessibility, comprehensibility, usability, and equity [78]. Other popular assessment tools include the DISCERN instrument [79] and IPDAS [49]. No gold standard quality criterion exists for assessing consumer health information, particularly when the intervention utilizes Internet technology. Evaluating a Web-based information tool against several criteria may provide the best measure of quality and serve to highlight areas where improvement is required.

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Pilot the Web-Based Tool With Patients, Clinicians, and Other Stakeholders

Obtaining feedback from patients, their families, and other key stakeholders regarding the usability and acceptability of the tool is crucial for maximizing the probability of use and adoption in cancer care settings. Stakeholders are those who have a vested interest in the outcome of the project or initiative and are able to influence the direction it takes [80]. Prior to evaluating the effectiveness of the Web-based information tool, the tool should be pilot-tested with intended users. This procedure allows valuable consumer feedback to be obtained where participants can reflect on their own experiences and offer suggestions about what would have been most helpful to them and their families. The piloting process also provides an opportunity to examine whether the intervention is able to improve health literacy. Feedback from stakeholders could be collected through a variety of sources including surveys, qualitative interviews, or focus groups. Feedback obtained from stakeholders should be evaluated and incorporated prior to assessing the intervention's effectiveness and included if recommended changes reflect the views of most consumers. Health care providers should again be consulted during this process to ensure the accuracy of amended information.

The involvement of clinicians throughout the previous development phase is advantageous in helping to ensure the Web-based information tool is acceptable to health care providers and readily integrated with current practice. It is, however, essential to conduct rigorous pilot testing of the acceptability and feasibility of the tool with clinicians who were not involved in Phase 1, given the role played by clinicians in tailoring the content of the tool. Similar techniques may be employed as for pilot testing with patients, such as surveys, qualitative interviews, or focus groups. Measurement of key strokes and eye movements can also be used to ensure that time demands are minimized and ease of use is maximized. This step is crucial for maximizing the probability that the tool will be integrated into clinical practice and adopted by clinicians in Phase 4.

Phase 3: Testing for Effectiveness

Test the Effectiveness of the Web-Based Tool in Controlled Studies

Before the Web-based information tool can be disseminated and adopted, the uptake and effectiveness of the tool for improving patient outcomes should be evaluated with an adequate sample of consumers. Key issues central to the evaluation of effectiveness include: Does the target sample access the intervention? Which patient outcomes are likely to be impacted by the Web-based information tool? and How can effectiveness best be measured? The CONSORT-EHEALTH guidelines should be considered when designing and reporting studies examining the effectiveness of Web-based interventions [81]. While the involvement of consumers in development, as well as rigorous pilot testing conducted in previous phases, is likely to improve the likelihood that the target sample will utilize the Web-based information tool, controlled testing may reveal that uptake is influenced by factors that were not previously considered. It may be necessary to revisit previous phases in order to ascertain the barriers to uptake and revise the tool accordingly. If the intervention is found to be effective in improving patient outcomes, then steps can be taken to broadly disseminate the information tool in a range of clinical settings. Optimal intervention delivery and uptake relies on effective integration into clinical practice. It is essential that health care providers find the information tool acceptable in order to ensure adoption into practice. Partnerships with patient support organizations will help to ensure that the information tool is viewed as credible by providers.

Phase 4: Integration and Implementation

Integrate the Tool Into Clinical Practice

Integration of a Web-based information tool is supported by its capacity to operate independently of health care provider and resource constraints. By automating and standardizing the provision of information, this approach minimizes the burden on physicians, reduces staffing costs, and increases patient convenience. While the burden on clinical staff is minimal, it is essential to provide education and training to ensure the innovative functions of the intervention are utilized to their potential. Educating clinical staff on the advantages of the information tool is likely to improve health care providers' endorsement and encourage patient uptake. Training clinical staff to tailor the tool's content to suit patients allows staff to maintain an active role in information provision without the added demands of traditional approaches.

Ensuring optimal intervention delivery and uptake is a complex issue faced by translational researchers and policy makers globally. The responsibility of educating and training clinical staff in the long term may be best managed by the medical college responsible for delivering care to the particular patient group. The application of evidence from Cochrane reviews [82-84] regarding effective methods of implementation into clinical practice is likely to be of significant benefit; however, this should be considered in conjunction with local protocols for health care delivery and information provision, which may differ between health care settings.

Monitor and Update the Web-Based Tool as New Evidence Becomes Available

Coulter, Entwistle, and Gilbert recommend that patient information be based on the best available evidence and be periodically reviewed and updated to reflect advancements [85]. Ensuring information is accurate and up-to-date is essential to informing patients of newly available treatment options and improved services. Partnership with patient support organizations may be extremely beneficial for assisting with this process, as they are likely to be in touch with the needs and preferences of consumers and aware of changing evidence within the field. Developers should also capitalize on the ability to track and record how the Web-based tool is used and obtain real-time feedback from consumers. This valuable data should be used as a means for evaluating and improving the Web-based tool regularly to address the information needs of consumers.

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Conclusions

New generation Web-based tools that are tailored and integrated into clinical care have the potential to overcome many of the limitations of general Web-based information, thus providing realizable benefits to patients and support persons. The proposed 4-phase DoTTI framework provides a model for a comprehensive approach to the development of Web-based informational tools for patients. The approach is evidence-informed, consumer-centered, flexible, and systematic. Implementation of the framework requires research at key phases including accessibility, acceptability, and effectiveness of each tool.

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Authors' Contributions

All authors were involved in the development of the Web tool for hematological cancer patients that informs the framework. RS and JB played a major role in concept development and manuscript preparation. RSF contributed to concept development and critical review of the manuscript. FT, CP, and WS assisted with preparation and critical review of the manuscript. FH provided expert knowledge of the software programming aspects of the framework and assisted with manuscript preparation.

Conflicts of Interest

None declared.

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Abbreviations

CD-ROM: compact disc, read-only-memory
CONSORT: Consolidated Standards of Reporting Trials
DoTTI: Design and develOpment, Testing early iterations, Testing for Effectiveness, Integration and implementation
DVD: digital versatile disc
IPDAS: International Patient Decision Aids Standards

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Original Paper

Comparison of Text and Video Computer-Tailored Interventions for Smoking Cessation: Randomized Controlled Trial

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Abstract

Background: A wide range of effective smoking cessation interventions have been developed to help smokers to quit. Smoking rates remain high, especially among people with a lower level of education. Multiple tailoring adapted to the individual's readiness to quit and the use of visual messaging may increase smoking cessation.

Objective: The results of video and text computer tailoring were compared with the results of a control condition. Main effects and differential effects for subgroups with different educational levels and different levels of readiness to quit were assessed.

Methods: During a blind randomized controlled trial, smokers willing to quit within 6 months were assigned to a video computer tailoring group with video messages (n=670), a text computer tailoring group with text messages (n=708), or to a control condition with short generic text advice (n=721). After 6 months, effects on 7-day point prevalence abstinence and prolonged abstinence were assessed using logistic regression analyses. Analyses were conducted in 2 samples: (1) respondents (as randomly assigned) who filled in the baseline questionnaire and completed the first session of the program, and (2) a subsample of sample 1, excluding respondents who did not adhere to at least one further intervention session. In primary analyses, we used a negative scenario in which respondents lost to follow-up were classified as smokers. Complete case analysis and multiple imputation analyses were considered as secondary analyses.

Results: In sample 1, the negative scenario analyses revealed that video computer tailoring was more effective in increasing 7-day point prevalence abstinence than the control condition (OR 1.45, 95% CI 1.09-1.94, *P*=.01). Video computer tailoring also resulted in significantly higher prolonged abstinence rates than controls among smokers with a low (ready to quit within 4-6 months) readiness to quit (OR 5.13, 95% CI 1.76-14.92, *P*=.003). Analyses of sample 2 showed similar results, although text computer tailoring was also more effective than control in realizing 7-day point prevalence abstinence. No differential effects were found for level of education. Complete case analyses and multiple imputation yielded similar results.

Conclusions: In all analyses, video computer tailoring was effective in realizing smoking cessation. Furthermore, video computer tailoring was especially successful for smokers with a low readiness to quit smoking. Text computer tailoring was only effective for sample 2. Results suggest that video-based messages with personalized feedback adapted to the smoker's motivation to quit might be effective in increasing abstinence rates for smokers with diverse educational levels.

Trial Registration: Netherlands Trial Register: NTR3102; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=3102 (Archived by WebCite at http://www.webcitation.org/6NS8xhzUV).

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KEYWORDS

smoking cessation; multiple computer tailoring; delivery strategy; educational level; text messages; video messages

Introduction

A wide range of different smoking cessation interventions have been developed and implemented. In spite of this, smoking rates remain high, especially among people with lower levels of education [1-4]. This illustrates the need to improve smoking cessation intervention strategies for this group. Computer-tailored smoking cessation interventions have already shown to be effective in increasing abstinence rates [5-7]. A main characteristic of computer-tailored smoking cessation interventions is that respondents are provided with personalized feedback on their smoking behavior and motivational characteristics, such as attitudes, social support, self-efficacy, intentions, and action planning [8]. Compared to nontailored information, tailored messages enhance the processing of the health information and are more likely to be read, remembered, and perceived as personally relevant. [9-11]. Additionally, past research has indicated that the effects of tailoring can be enhanced by providing multiple tailored feedback moments [7,12] and has suggested a dose-response relationship between the number of feedback moments and smoking abstinence [13].

The Internet has become a promising method of delivering smoking cessation interventions and has increased opportunities to reach large numbers of people [14,15]. Although Web-based computer-tailored smoking cessation interventions have been shown to be potentially effective [15,16], they often report problems in attracting, engaging, and retaining smokers and quitters [7,17-20]. Smokers with a lower levels of education often leave the program before completing all intervention elements and show a lower adherence toward these programs [21-23]. Because smokers with lower levels of education appear to be more addicted, show fewer quit attempts, and are often more vulnerable to relapse [4,18,24], they constitute an important target group for participation in these computer-tailored smoking cessation interventions.

To date, Web-based computer-tailored smoking cessation interventions delivered via the Internet often consist of simple text-based messages. However, this might be not attractive enough for Internet users, especially less-educated groups [25]. Internet users often scan a text for relevant information but do not read the whole text [26,27]. Websites increasingly make use of pictures, graphics, and videos, and are often interactive to increase attractiveness [28]. Additionally, previous studies have suggested that the use of rich media, such as videos, may improve the appeal of health interventions [29-32] and may attract and stimulate comprehension among low health literacy groups [25,33,34]. Because video-based information seems to require less mental effort and may help the person to concentrate on the core elements of the message [35], the use of videos might be a possible strategy to attract, engage, and retain less-educated respondents in Web-based computer-tailored smoking cessation interventions [25]. In contrast, people with higher levels of education might profit more from in-depth processing; therefore, they may be more attracted by text-based messages (Soetens, K, personal communication, 2013). Studies have already tested the effects of a combination of interactive components, such as graphics, audio clips, and video clips [27,36,37], but to our knowledge no previous study has assessed the specific effect of tailored video-based messages on behavioral change and, in particular, on smoking cessation among groups with different levels of education.

Another strategy to improve the success of computer-tailored smoking cessation interventions is by focusing on the smoker's motivation to quit smoking. Until now, most computer-tailored smoking cessation interventions have been developed for smokers with high motivation to quit [14,38], whereas less-educated smokers often show lower motivation to quit and might benefit from interventions which give them the possibility and time to reflect on their smoking behavior and intention to quit and to prepare successfully for their quit attempt. Consequently, Web-based computer-tailored smoking cessation interventions should be adapted to the needs of groups with different levels of education and should take the user's motivation to quit into account.

The study described in this paper was designed to investigate the effectiveness of 2 computer-tailored smoking cessation interventions after 6 months: (1) a text-based multiple computer-tailored intervention where smokers received tailored text-based messages during several feedback moments, and (2) a video-based multiple computer-tailored intervention where smokers received tailored video-based messages during several feedback moments. In both interventions, smokers with high or low readiness to quit were able to choose different routings and received tailored feedback adapted to their readiness to quit. The effectiveness of the 2 interventions was compared to a control condition (respondents received a generic short text advice).

We hypothesized video-based computer tailoring to be more effective for smokers with a lower level of education, whereas text-based computer tailoring was expected to be more effective in smokers with a higher level of education. Because the interventions included different routings tailored according to the smokers' readiness to quit, we expected less-motivated smokers to be equally successful in their quit attempts as more motivated smokers. Therefore, we explored whether the effects of the 2 interventions were different for individuals with a high or low readiness to quit. Moreover, we conducted our analyses in 2 different samples: (1) respondents who filled in baseline questionnaire and completed the first session of the program, and (2) a subsample of sample 1, excluding respondents who did not adhere to at least one further intervention session [7,13]. Finally, an overview of the program evaluation of respondents will be shown.

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Methods

Ethics Approval and Registration

The current study was submitted for approval to the Medical Research Ethics Committee (MREC) of Atrium Medical Centre Heerlen. The MREC decided that no MREC approval was necessary because respondents were not required to undertake any particular action. The study was registered at the Dutch Trial Register (NTR3102). The study was in-line with the ethical codes of conduct of the American Psychological Association (APA) [39].

Respondents and Recruitment

Respondents were recruited from December 2010 to June 2012 to participate in the Web-based multiple computer-tailored smoking cessation intervention. Respondents were eligible for participation if they were motivated to quit smoking within the next 6 months, were 18 years or older, and had access to the Internet.

Respondents were recruited by several channels. First, a random sample of approximately 150 general practitioners (GPs) was asked to refer smoking patients to the intervention website. The GP practices were provided with recruitment materials (flyers, business cards, etc) for this purpose. Second, respondents were also recruited to participate through advertising campaigns in local newspapers, newspaper websites, and Dutch health fund websites. Lastly, we used several national and international online social networking websites, such as Hyves and Facebook, to invite smokers to participate in our smoking cessation study. All advertisements provided a link to the intervention website that enabled people to find out more information about the intervention and participation.

Design and Procedure

The current study was a randomized controlled trial with 2 experimental conditions (text-based computer tailoring vs video-based computer tailoring) and a control condition in which respondents received only a single generic short text advice. Interested respondents could sign up via the intervention website [40]. On the intervention website, respondents were informed that they could be randomly allocated to 1 of the 3 conditions and that they would have the chance to win €100 if they completed all the assessments (before decision to participate, registration, and baseline measurement). After creating a personal log-in and account, respondents were randomized into 1 of the 3 conditions. Respondents were not told about the content of the other experimental condition.

After giving online informed consent, respondents were asked to fill out the baseline questionnaire. Respondents in the text-based and video-based condition received tailored feedback over 3 months (see Intervention and Figure 1 for details). At 6-month follow-up, all respondents were sent an email invitation with a link to the intervention website to fill out the 6-month follow-up measurement. Respondents who did not complete the follow-up measurement after 1 week were reminded by email to fill out the online questionnaire. A further reminder was sent after 2 weeks if necessary. Respondents who did not respond to the email invitation or the 2 reminders received another email, inviting them to briefly indicate their current smoking status. This email requested completion of a shortened version of the 6-month follow-up measurement, consisting of 10 (instead of 95) important smoking-related questions, which they could return by email. Lastly, if this abbreviated email assessment was still not completed, respondents were called for a short telephone interview, asking the same questions as in the shortened online questionnaire.

Intervention

The 2 Web-based multiple computer-tailored smoking cessation interventions (text-based vs video-based computer tailoring) varied only in their mode of delivery (see Figure 1). The intervention was based on 2 previously tested computer-tailored interventions which were found to be effective in smoking cessation [6,12]. The I-Change model, integrating various social cognitive theories [41-43], was used as a theoretical framework of the currently tested intervention. After completing the baseline assessment, respondents in the 2 experimental conditions first received tailored feedback on their smoking behavior, followed by feedback about their attitude (pros and cons of smoking and quitting), their perceived social influence (modeling and support), their perceived self-efficacy, and how to prepare to quit (eg, how to plan a quit date). Next, respondents were asked whether they wanted to quit within a month. Depending on this readiness to quit smoking within the following month, respondents received more personalized feedback during subsequent multiple computer-tailored sessions, defined in routing 1 or 2. These routings varied between those who already wanted to set a quit date within a month compared to those who did not plan a quit date in the forthcoming month (see Figure 1). Respondents in the 2 experimental conditions (text-based vs video-based computer tailoring) also received an overview of the tailored advice by email after each session.

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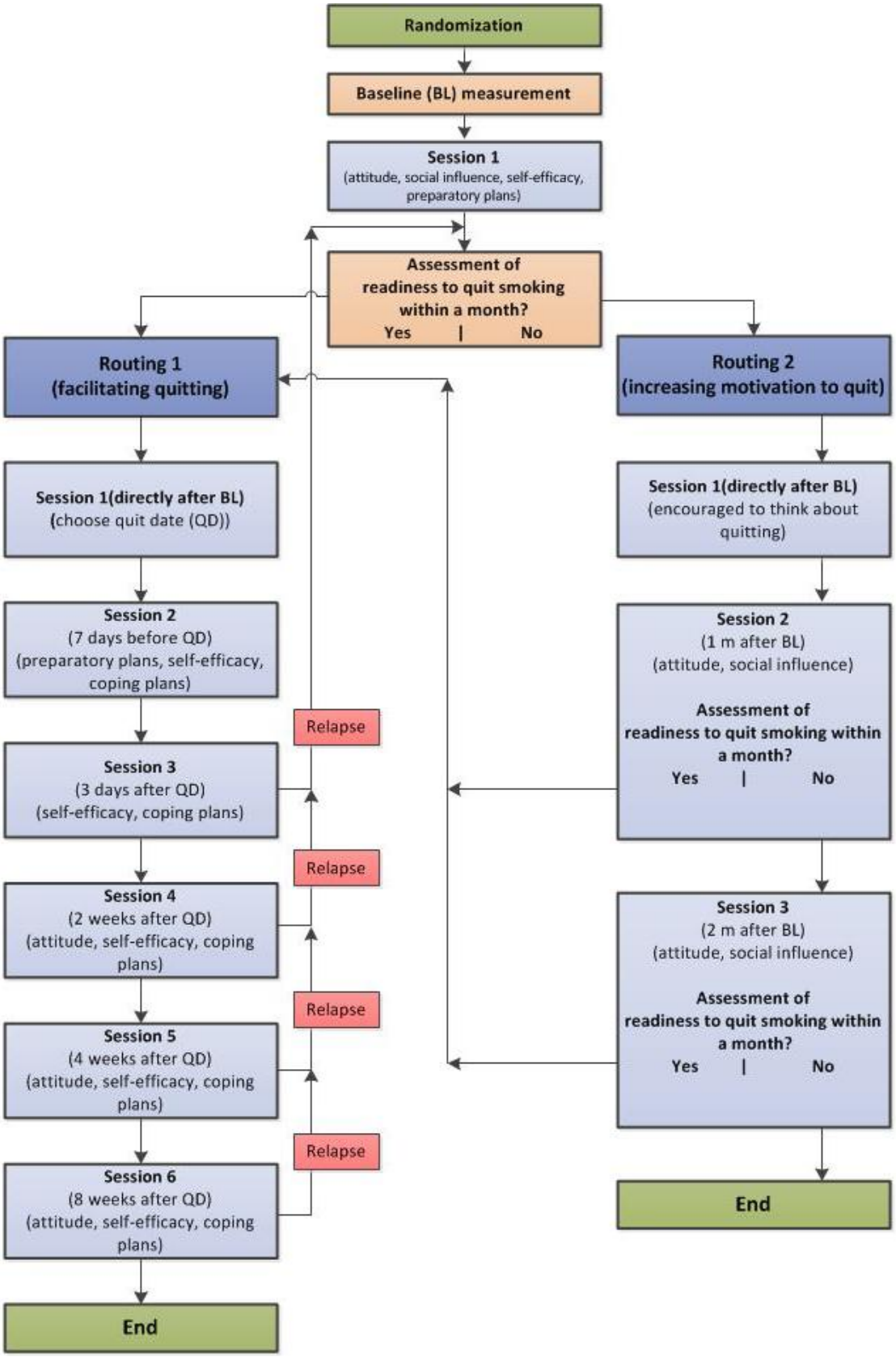
Figure 1. Intervention design of a video- and text-based computer-tailored intervention for smoking cessation following 2 routings.



Routing 1

Respondents who had set a goal to quit within 1 month were directed to routing 1.The goal of routing 1 was to help smokers translate their intention to quit into action by providing tailored feedback to increase self-efficacy and effective action planning. In the first session, after receiving feedback on their smoking behavior, attitude, social influences, and self-efficacy with respect to quitting, respondents were asked to choose a quit date (between 8 days and 1 month from the first session). At the end

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of this first session, respondents were informed that they would be invited to the next session 1 week before their quit date, to receive help with quitting. During the second session (1 week before their quit attempt), respondents received feedback on the extent to which they had already made concrete plans for their quit attempt because past research has revealed that preparing for quitting increases the likelihood of quitting [6]. In addition, they received feedback on their perceived self-efficacy, including tailored feedback on coping planning to help them to deal with difficult situations that may cause relapse. Different studies have found that ex-smokers often relapse shortly after their quit attempt; therefore, respondents were provided with different relapse prevention strategies as described previously [42,44,45]. During the third session, 3 days after their quit attempt, feedback was given on the quitter's perceived self-efficacy. Respondents also received personalized tips on how to deal with personal risk situations and were invited to formulate coping plans again to prevent potential relapse. During the fourth session, 2 weeks after their quit date, respondents received tailored feedback on their perceived self-efficacy, including feedback on how to deal with difficult situations and attitudes toward smoking and quitting (perceived pros and cons of smoking and quitting). In sessions 5 and 6 at 4 and 8 weeks, respectively, after their quit date, a similar strategy was used as for session 4. Respondents could choose to receive feedback on different items (eg, how to cope with negative moods with coping plans or self-efficacy items about how to deal with difficult risk situations). This option was provided because we expected respondents to encounter different problems throughout their quit attempt. During all sessions, respondents were invited to continue their quit attempt or, if they had relapsed, to indicate their readiness to quit smoking and plan a new quit date. Respondents could restart their quit attempt several times (no maximum) during the program, if they wanted.

Routing 2

Respondents who were not ready to quit within 1 month were directed to routing 2. The goal of routing 2 was to increase motivation by increasing perception of the pros of quitting and knowledge of how to obtain support for quitting. In session 1, directly after completion of the baseline assessment, smokers were encouraged to use the following month to reflect on their smoking behavior and motivation to quit. In session 2, 1 month after baseline, respondents were invited by email for the next session. Respondents received tailored feedback on their smoking behavior, their attitude (pros and cons of smoking and quitting), and their perceived social support. Next, they were invited to indicate their readiness to quit smoking. Respondents who indicated an intention to quit within 1 month were directed to routing 1 and were asked to set a quit date. Respondents who were not ready to quit received an invitation to take part in the next session (session 3); this session used a similar strategy that was used in session 2. Respondents ready to quit were directed to routing 1 and were asked to set a quit date. Respondents who indicated at the end of session 3 that they were not prepared to quit received a kind message indicating that the intervention program would respect the fact that they were not ready to quit smoking and that they would receive no further invitations.

Mode of Delivery

The content of the feedback messages was exactly the same in both the text- and video-based conditions. In the text-based condition, respondents received multiple sessions of text-based computer-tailored advice without any graphics or animations. In the video-based condition, the same tailored advice was presented by adults in a video message. Five different adult presenters (2 males, 3 females) were selected out of a screening test of 20 persons who delivered the tailored advice in a TV news program format. We used a mix of adults during the different sessions who presented the different pieces of tailored advice.

Measurements

Baseline Measurement

The following demographic variables were assessed: age, gender (0=male; 1=female), educational level (1=low corresponding to primary, basic vocational, lower general school, or no education; 2=intermediate corresponding to higher general secondary education, preparatory academic education, or medium vocational school; 3=high corresponding to higher vocational school or university level), and nationality (0=other nationality; 1=Dutch nationality).

Addiction level was measured by 6 items using the Fagerström Test for Nicotine Dependence (FTND), asking respondents how many cigarettes they smoked per day, at which time points, and whether they had difficulties not smoking in smoke-free places (0=not addicted; 10=highly addicted) [46].

Readiness to quit smoking was assessed with a single item asking respondents whether and when they intended to quit smoking, resulting in 3 categories (1=yes, within 4 to 6 months; 2=yes, within 1 to 3 months; 3=yes, within the following month) [43].

Smoking habit was assessed using an abbreviated version of Verplanken and Orbell's Self-Reported Habit Index of 6 items (eg, smoking is something which I do automatically) with which respondents could agree or disagree, resulting in a 5-point scale (1=I totally disagree; 5=I totally agree). A mean scale score was included in the analyses (Cronbach alpha=.78) [47].

Depressive symptoms were measured with the abbreviated 10-item Center for Epidemiologic Studies Depression scale (CES-D) that asked respondents whether they felt depressed during the past week, for example, resulting in a 4-point scale (1=rarely or none of the time; 4=most or all of the time) [48]. A sum score was included in the analyses (Cronbach alpha=.85).

Occurrence of smoking-related diseases was measured by 4 questions on a dichotomous scale, such as "Do you suffer from chronic obstructive pulmonary disease (COPD), cancer, diabetes, or cardiovascular disease?" (0=no; 1=yes).

Attitude was measured by 3 items assessing the pros and cons of quitting (quitting smoking would be reasonable, bad, or enjoyable), resulting in a 5-point scale (1=I totally disagree; 5=I totally agree). A mean scale score was included in the analyses (Cronbach alpha=.52). A higher score represents a positive attitude toward quitting.

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Social influence was measured by 2 scales: a social modeling and a social support scale. Social modeling was assessed by 2 items that measured whether other people in their environment smoked, such as partners (1=no, 2=yes, 9=not applicable), and in their social environment, such as family or friends (1=none, 2=a minority, 3=half, 4=a majority, 5=all, 9=not applicable). A total of 552 respondents for the partner question and 80 respondents for the social environment question filled in "not applicable" when they were asked whether their partner or their social environment smoked. Social support was measured with 2 items that asked whether smokers received social support (partners and social environment, respectively) in favor of quitting on a 4-point scale (1=no, 2=yes, a bit, 3=yes, moderate, 4=yes, a lot, 9=not applicable). A total of 787 respondents for the partner question and 229 for the social environment question filled in "not applicable" when they were asked whether they received support from their partner or their social environment. Not applicable was recoded into the lowest value (1=no support) for the social influence measure. The items were summed and formed an index that was included in the analyses.

Preparatory plans were assessed by 3 items that measured whether participants planned to execute different preparatory plans for their quit attempt (removing ashtrays, telling their environment to quit smoking, quitting without decreasing smoking first) on a 5-point scale (1=surely not; 5=surely yes). The items were summed and formed an index that was included in the analyses.

Coping plans were assessed by 4 items that measured whether participants had made specific plans to prevent relapse in difficult situations, such as plans how to cope with negative mood, plans how to cope when being at a party or drinking a cup of coffee, or being offered a cigarette (0=no; 1=yes). Difficult situations were selected and predefined based on previous studies [6,12,45]. The items were summed and formed an index that was included in the analyses.

Self-efficacy was measured by 3 items asking respondents whether they would be able to refrain from smoking in these difficult situations (Do you think you will manage not to smoke when you drink a cup of coffee, when you are in a negative mood, or when you visit a party?), resulting in a 5-point scale (1=definitely not; 5=yes, definitely). A mean scale score was included in the analyses (Cronbach alpha=.62).

The variables attitude, self-efficacy, preparatory plans, and coping plans were also used to determine the tailored advice during the first session of the intervention.

Follow-Up Measures

At the 6-month follow-up measurement, 7-day point prevalence abstinence was self-assessed by 1 item asking respondents whether they had refrained from smoking during the past 7 days (0=no; 1=yes) [49,50].

In addition, prolonged abstinence was self-assessed by 1 item asking respondents whether they had refrained from smoking since their last quit attempt allowing for a 2-week grace period during which the respondent could smoke 1 to 5 cigarettes (0=no;1=yes) [49,50]. In-line with the definition of prolonged abstinence, those who reported that they had quit less than 3 months before the follow-up measurements were not included as quitters in the prolonged abstinence measurement [50].

Evaluation of the Program

Process evaluation was conducted by measuring 5 concepts, each measured on a 5-point scale (1=totally disagree to 5=totally agree):

1. Attention to the tailored advice (eg, the advice was interesting) was measured by 3 items (Cronbach alpha=.94).
2. Comprehension of the advice (eg, the advice was clear to me) was measured by 3 items (Cronbach alpha=.78).
3. Adaptation toward the advice (eg, the advice was personally relevant for me) was measured by 3 items (Cronbach alpha=.79).
4. Appreciation of the advice (eg, I appreciated the advice) was measured by 3 items (Cronbach alpha=.93).
5. Processing of the advice (eg, the advice encouraged me to think more about smoking cessation) was measured by 8 items. For all process evaluation scales a mean scale score was included in the analyses (Cronbach alpha=.91).

Statistical Analysis

The inclusion of all randomly assigned respondents is a common approach to analyze the effects of an intervention [51,52]. Because not all respondents (video and text conditions) adhered to all intervention elements, the inclusion of these respondents in the effect analyses might distort the assessment of an intervention's effectiveness. It might be adequate to include only respondents in the analyses who actually followed the intervention for at least one session [7]. Therefore, we chose to analyze 2 different samples. The first sample included all randomly assigned respondents that filled in baseline questionnaire and session 1 (directly after baseline assessment, including setting a quit date). The second sample included only respondents in the experimental conditions who finished at least one further session of the 2 different routings of the intervention.

As a preliminary, descriptive analyses were conducted to check for baseline differences between the 3 conditions. Chi-square tests were used for categorical variables whereas analyses of variance (ANOVAs) were used for continuous variables. If the chi-square test showed a P value <.05, post hoc pairwise comparisons with Bonferroni correction (alpha=.05/3=.017) were used. If the overall F test showed a P value <.05, the Tukey honestly significant difference (HSD) method was used for post hoc pairwise comparisons. Second, logistic regression was used to analyze attrition, including baseline factors and condition as predictors. Baseline differences and significant predictors of dropout were included in all logistic regression effect analyses explained subsequently.

Third, logistic regression analyses were conducted to investigate the effectiveness of the intervention on the outcome measures assessed at the 6-month follow-up measurements. The analyses were performed adjusting for potential confounders, including demographic variables (eg, age, educational level, gender, and ethnicity) and possible moderators of the intervention effect (eg, addiction level, recruitment strategy, readiness to quit smoking, depression, smoking-related illnesses, self-efficacy, preparatory planning, and coping planning), baseline differences,

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dropout predictors and 2 interaction terms (readiness to quit smoking by condition and educational level by condition). Where significant interaction terms were found, stratified analyses were performed separately for each group.

In the effect analyses, a negative scenario was used in which every respondent missing at follow-up was regarded as a smoker. In addition, we also used multiple imputation [53] to fill in missing values. Missing values for outcome variables were imputed based on the regression of all relevant variables that were used in the main effect analyses. The number of imputations was set at 30. This was done according to the recommendation to create as many imputed datasets as the percentage of cases with missing data [54].

Lastly, we also conducted complete case analyses, in which we only took respondents into account who filled out the 6-month follow-up measurements (these results are presented in Multimedia Appendix 1). Data were analyzed using SPSS 19.0 (SPSS, Inc, Chicago, IL, USA).

Results

Sample Characteristics and Attrition Analysis

Figure 2 shows the flow of respondents for the 3 conditions. Of the 2551 potential respondents who were randomized to 1 of the 3 conditions, 49 (1.92%) declined to participate, 138 (5.41%) did not meet inclusion criteria, and 265 (10.39%) did not complete the baseline questionnaire or had no baseline quit date (within routing 1). As Figure 2 illustrates, eligibility was checked after randomization. The different tailored feedback sessions were organized around the quit date; therefore, respondents had to fill in their quit date (in the experimental conditions) otherwise they were excluded from the study. Finally, 2099 respondents were included in the video-based computer tailoring condition (n=670), the text-based computer tailoring condition (n=708), and the control condition (n=721).

Table 1 shows the characteristics of the total sample and the baseline differences between the 3 conditions in terms of demographic and smoking-related variables. Mean age of respondents was 45.7 years (SD 12.8). Of the 2099 respondents, 1278 (60.88%) were female and 705 (33.58%) had a low level of education. Furthermore respondents smoked on average approximately 19 (SD 8.6) cigarettes per day. Respondents in the 3 conditions differed significantly in terms of readiness to quit smoking. Respondents in the video-based and text-based computer tailoring conditions were less ready to quit smoking than respondents in the control condition. Moreover, there were also differences between the 3 conditions regarding preparatory planning and coping planning. Respondents in the 2 experimental conditions were more likely to have made preparatory and coping plans compared to respondents in the control condition. In sample 1, 238 of 670 (35.5%) were lost to follow-up in the video-based computer tailoring condition, versus 212 of 708 (29.9%) in the text-based computer tailoring condition and 196 of 721 (27.2%) in the control condition. Attrition analysis showed that respondents were significantly more likely to complete the follow-up assessment if they were in the text-based computer tailoring and control condition (OR 1.32, 95% CI 1.05-1.67, P=.02; OR 1.47, 95% CI 1.16-1.87, P=.001, respectively), if recruited by Internet or newspaper advertisements (OR 0.62, 95% CI 0.40-0.97, P=.04), if they were older (OR 1.02, 95% CI 1.01-1.03, P=.001), were of Dutch nationality (OR 1.63, 95% CI 1.06-2.52, P=.03), and had higher levels of self-efficacy (OR 1.12, 95% CI 1.06-1.33, P=.003). Baseline differences and significant predictors at dropout were included in all further analyses as potential confounders.

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Table 1. Baseline sample characteristics for the video-based computer tailoring (video), text-based computer tailoring (text), and control conditions (recruited between December 2010 and June 2012).

Variables	Overall sample (N=2099)	Video (n=670)	Text (n=708)	Control (n=721)	*P* [a]	Tukey HSD/ Bonferroni[b]
Gender (female), n (%)	1278 (60.9)	417 (62.2)	431 (60.9)	430 (59.6)	.61	
Age (years), mean (SD)	45.7 (12.8)	45.5 (13.0)	45.4 (12.8)	46.2 (12.5)	.46	
Educational level, n (%)					.41	
Low	705 (33.6)	225 (33.6)	231 (32.6)	249 (34.5)		
Medium	782 (37.3)	247 (36.9)	255 (36.0)	280 (38.8)		
High	612 (29.2)	198 (29.5)	222 (31.4)	192 (26.6)		
Dutch nationality, n (%)	1995 (95.2)	639 (95.5)	674 (95.2)	682 (94.9)	.85	
FTND[c] score (1-10), mean (SD)	4.9 (2.4)	5.0 (2.3)	4.9 (2.4)	4.9 (2.5)	.46	
Number of cigarettes smoked per day, mean (SD)	18.8 (8.6)	19.0 (8.1)	18.7 (8.4)	19.0 (9.2)	.75	
Readiness to quit, n (%)					.005	Video/text<control
Within 1 month	1093 (52.1)	368 (54.9)	384 (54.2)	341 (47.3)		
Within 1-3 months	636 (30.3)	205 (30.6)	203 (28.7)	228 (31.6)		
Within 4-6 months	370 (17.6)	97 (14.5)	121 (17.1)	152 (21.1)		
Diseases, n (%)						
With COPD diseases	290 (13.8)	97 (14.5)	99 (14.0)	94 (13.0)	.73	
With cancer	34 (1.6)	10 (1.5)	9 (1.3)	15 (2.1)	.46	
With diabetes	99 (4.7)	27 (4.0)	33 (4.7)	39 (5.4)	.48	
With cardiovascular diseases	210 (10.0)	63 (9.3)	60 (8.5)	87 (12.1)	.06	
With asthmatic diseases	171 (8.1)	63 (9.4)	57 (8.1)	51 (7.1)	.28	
Recruitment strategy, n (%)					.76	
General practitioner	166 (7.9)	56 (8.4)	57 (8.1)	53 (7.4)		
Newspaper/Internet	1631 (77.7)	511 (76.3)	551 (77.8)	569 (78.9)		
Family/friends	203 (9.7)	69 (10.3)	72 (10.2)	62 (8.6)		
Other strategies	99 (4.7)	34 (5.1)	28 (4.0)	37 (5.1)		
Depressive feelings	5.8 (2.4)	5.9 (2.5)	5.8 (2.4)	5.8 (2.4)	.42	
Habit	4.0 (0.6)	4.0 (0.6)	4.0 (0.6)	4.0 (0.7)	.50	
Social support	5.1 (1.8)	5.1 (1.7)	5.2 (1.8)	5.1 (1.9)	.41	
Social modeling	3.9 (1.2)	4.0 (1.2)	4.0 (1.3)	3.9 (1.2)	.15	
Attitude	4.2 (0.7)	4.2 (0.7)	4.1 (0.7)	4.2 (0.7)	.53	
Self-efficacy	3.2 (0.9)	3.2 (0.9)	3.1 (0.9)	3.1 (0.9)	.22	
Preparatory planning	11.0 (2.6)	11.2 (2.6)	11.0 (2.6)	10.8 (2.6)	.008	Video>control
Coping planning	1.2 (1.5)	1.5 (1.6)	1.3 (1.5)	0.96 (1.5)	<.001	Video/text>control

[a]Analyses of variance (ANOVAs, *F* test) were used for continuous variables; chi-square tests were used for categorical variables.

[b]Tukey honestly significant difference (HSD), alpha=.05; Bonferroni-corrected alpha=.05/3=.017.

[c]FTND: Fagerström Test for Nicotine Dependence.

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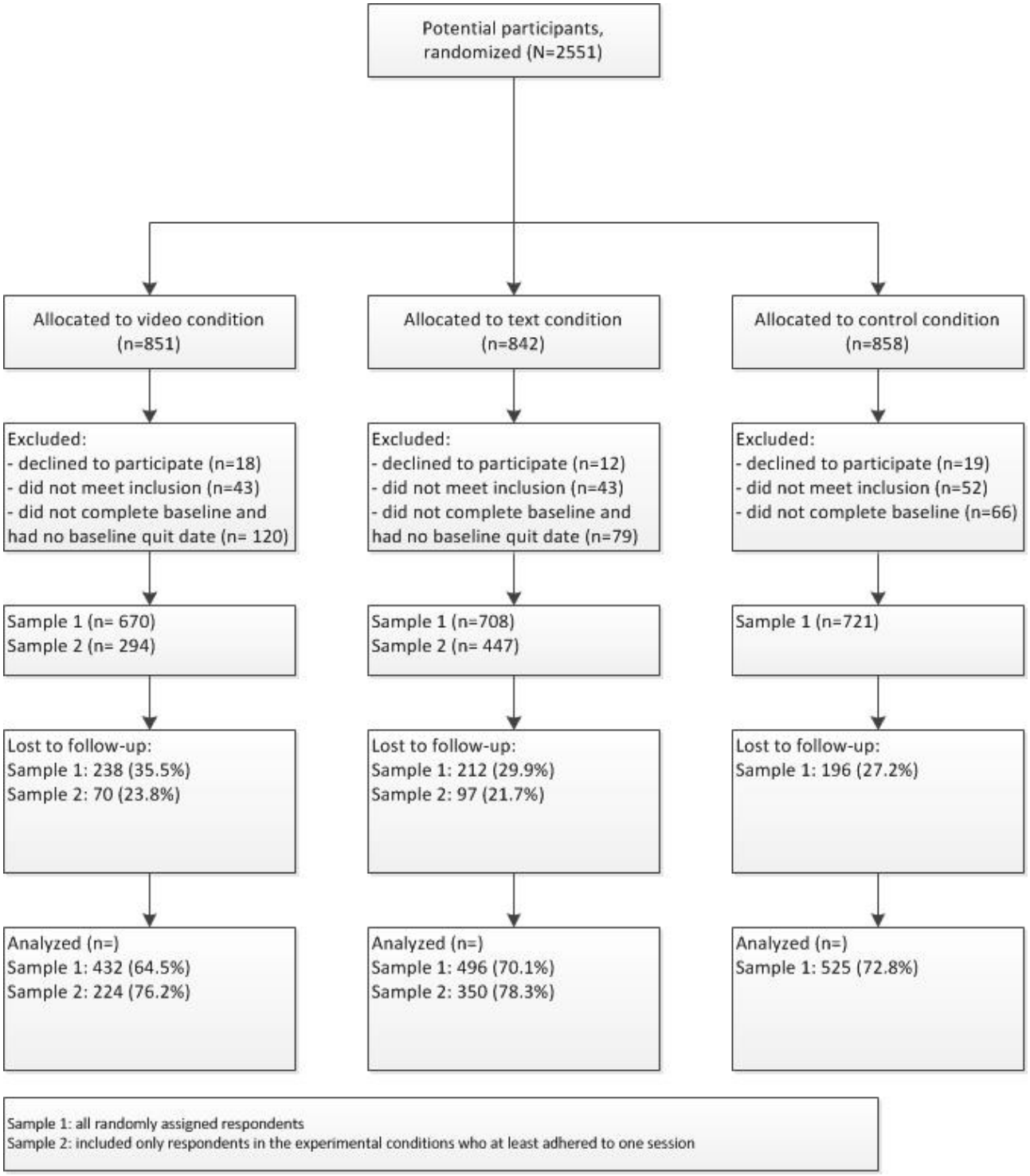
Figure 2. Flowchart of participant enrollment and inclusion. Sample 1: all randomly assigned respondents; sample 2: only respondents in the experimental conditions who adhered to at least one session.



Quit Rates at Six-Month Follow-Up

Table 2 shows the raw abstinence rates for sample 1 for the negative scenario. When respondents lost to follow-up were regarded as smokers (negative scenario), 7-day point prevalence abstinence rates in sample 1 were 20.9% in the video-based computer tailoring condition, 17.9% in the text-based computer tailoring condition, and 14.6% in the control condition. In sample 2, 7-day point prevalence abstinence rates were 30.6% in the video-based computer tailoring condition, 22.6% in text-based computer tailoring condition, and 14.6% in the control condition (see Multimedia Appendix 1). Prolonged abstinence rates are also presented stratified by readiness to quit smoking. In sample 1, prolonged abstinence rates in the video-based computer tailoring, text-based computer tailoring, and the control condition (for people with a lower readiness to quit over 4 to 6 months) were 14.4%, 8.3%, and 3.3%, respectively. Finally, sample 2 showed prolonged abstinence rates (for people with a lower readiness to quit within 4 to 6 months) of 23.1%, 9.5%, and 3.3%, respectively, in the video-based computer tailoring, text-based computer tailoring, and the control conditions (see Multimedia Appendix 1).

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Table 2. Six-month abstinence rates, including 7-day point prevalence abstinence (PPA) and prolonged abstinence (PA), for the video-based computer tailoring (video), text-based computer tailoring (text), and control conditions for sample 1 (negative scenario).

Negative scenario	Total, N	Condition, n (%)			*P* value
		Video	Text	Control	
7-Day PPA	2099	140 (20.9)	127 (17.9)	105 (14.6)	.008
PA	2099	98 (14.6)	99 (14.0)	87 (12.1)	.34
PA	2099				
Readiness to quit					
Within 1 month		62 (16.8)	71 (18.5)	52 (15.2)	.51
Within 1-3 months		22 (10.7)	18 (8.9)	30 (13.2)	.36
Within 4-6 months		14 (14.4)	10 (8.3)	5 (3.3)	.006

Differences in Point Prevalence Abstinence Between Conditions at Follow-Up

When respondents lost to follow-up were regarded as smokers in the analyses, no significant interaction was found between the type of condition and educational level (χ^2_4=6.3, *P*=.18) nor between condition and respondents' readiness to quit smoking (χ^2_4=3.1, *P*=.54) on 7-day point prevalence abstinence. Our analysis, however, revealed a main intervention effect on 7-day point prevalence abstinence. In sample 1 (including all respondents as randomly assigned), video-based computer tailoring was significantly more effective than the control condition (OR 1.45, 95% CI 1.09-1.94, *P*=.01). In sample 2 (with only those who followed at least one further session of the intervention), both experimental conditions were significantly more effective than the control condition (video-based computer tailoring: OR 2.29, 95% CI 1.64-3.20, *P*<.001; text-based computer tailoring: OR 1.57, 95% CI 1.15-2.15, *P*=.005) (see Multimedia Appendix 1). In sample 2, the video-based computer tailoring condition was significantly more effective than the text-based computer tailoring condition (OR 1.46, 95% CI 1.04-2.05, *P*=.03) Other predictors of 7-day point prevalence abstinence were a higher readiness to quit, a lower degree of depressive symptoms, making more preparatory plans, having a higher self-efficacy, and being recruited by GPs (see Table 3). The multiple imputation procedure revealed similar results. In samples 1 and 2, video-based computer tailoring was significantly more effective than the control condition (sample 1: OR 1.55, 95% CI 1.16-2.08, *P*=.003; sample 2: OR 1.93, 95% CI 1.38-2.70, *P*<.001). The text-based computer tailoring condition in sample 2 did not reach significance when compared to the control condition (text-based computer tailoring: OR 1.31, 95% CI 0.96-1.78, *P*=.09). Complete case analyses revealed comparable results (see Multimedia Appendix 2).

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Table 3. Factors associated with 7-day point prevalence abstinence in sample 1 (negative scenario) in the present study.

Negative scenario variables[a]	Sample 1 (N=2099)		
	OR	95% CI	*P* value
Video vs control	1.45	1.09-1.94	.01
Text vs control	1.22	0.92-1.63	.17
Gender (male)	0.90	0.70-1.14	.38
Age	1.01	1.00-1.02	.07
Dutch nationality	1.23	0.71-2.15	.46
Middle education level[b]	1.08	0.81-1.45	.58
High education level[b]	1.17	0.87-1.59	.30
Readiness to quit within 1 month[c]	1.71	1.16-2.50	.006
Readiness to quit within 1-3 months[c]	1.41	1.17-2.10	.09
FTND score	0.96	0.91-1.00	.07
CES-D score	0.94	0.89-.99	.03
With COPD[d]	1.03	0.71-1.50	.86
With cancer[d]	1.00	0.40-2.50	.99
With diabetes[d]	1.22	0.69-2.20	.51
With cardiovascular diseases[d]	1.18	0.78-1.78	.43
With asthma[d]	0.89	0.58-1.39	.61
Recruitment strategy, newspaper/Internet[e]	0.67	0.45-0.99	.04
Preparatory planning	1.07	1.02-1.12	.009
Coping planning	1.01	0.94-1.10	.72
Self-efficacy	1.15	1.01-1.33	.04

[a]Interaction terms are not included in the final model because they were not significant and ORs are adjusted for variables significant at baseline and dropout.

[b]Low education is the reference category.

[c]Willingness to quit within 4-6 months is the reference category.

[d]Not suffering from the disease is the reference category.

[e]General practitioner (GP) is the reference category.

Differences in Prolonged Abstinence Between Conditions at Follow-up

In the negative scenario, no significant interaction was found between condition and educational level on prolonged abstinence (χ^2_4=3.1, *P*=.54). However, analysis revealed a significant interaction effect between the type of intervention and respondents' readiness to stop smoking with regard to prolonged abstinence in sample 1 (χ^2_4=12.0, *P*=.02). Subsequent subgroup analysis showed that video-based computer tailoring was significantly more effective than the control condition in increasing prolonged abstinence rates among respondents who were less motivated to quit (ie, those who had stated they were ready to quit within 4 to 6 months; see subgroup analyses in Table 4). Similarly, in sample 2, a significant interaction was found between the type of intervention and respondents' readiness to quit smoking with regard to prolonged abstinence (χ^2_4=10.6, *P*=.03). Subsequent subgroup analysis showed that video-based computer tailoring was more effective in increasing prolonged abstinence rates among respondents with high (within 1 month) and low (within 4-6 months) readiness to quit (see Multimedia Appendix 1). The multiple imputation analyses yielded similar results. A significant interaction was shown, in which the video-based computer tailoring condition was still effective for smokers who were ready to quit within 4 to 6 months in both samples (sample 1: OR 2.75, 95% CI 0.94-8.10, *P*=.06; sample 2: OR 3.17, 95% CI 0.94-10.73, *P*=.06). The complete case analyses yielded similar results compared with the other analyses (see Multimedia Appendix 2).

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Table 4. Factors associated to prolonged abstinence in sample 1 (negative scenario) in the present study.

Negative scenario	Sample 1 (N=2099)		
	OR[a]	95% CI	*P* value
Variable			
Video vs control	5.13	1.76-14.92	.003
Text vs control	2.79	0.92-8.46	.07
Gender (male)	0.72	0.54-0.95	.02
Age	1.01	1.00-1.02	.05
Dutch nationality	1.31	0.69-2.44	.40
Middle education level[b]	1.16	0.84-1.61	.35
High education level[b]	1.01	0.72-1.43	.94
Readiness to quit within 1 month[c]	4.18	1.61-10.85	.003
Readiness to quit within 1-3 months[c]	4.11	1.55-10.95	.005
FTND score	0.95	0.89-1.00	.04
CES-D score	0.90	0.84-.96	.002
With COPD[d]	1.23	0.80-1.89	.34
With cancer[d]	0.66	0.26-1.66	.37
With diabetes[d]	1.04	0.55-1.96	.90
With cardiovascular diseases[d]	1.24	0.78-1.89	.37
With asthma	1.12	0.67-1.90	.66
Recruitment strategy, newspaper/Internet[e]	0.62	0.41-0.95	.03
Preparatory planning	1.08	1.02-1.14	.007
Coping planning	1.07	0.98-1.17	.14
Self-efficacy	1.18	1.01-1.38	.04
Interactions			
High readiness to quit × video	0.21	0.07-0.66	.007
High readiness to quit × text	0.45	0.12-1.45	.18
Middle readiness to quit × video	0.15	0.04-0.51	.002
Middle readiness to quit × text	0.23	0.06-0.81	.02
Subgroup analyses			
Readiness to quit within 1 month			
Video vs text	0.86	0.59-1.27	.46
Video vs control	1.07	0.71-1.62	.74
Text vs control	1.24	0.83-1.86	.29
Readiness to quit within 1-3 months			
Video vs text	1.23	0.63-2.40	.54
Video vs control	0.77	0.43-1.41	.40
Text vs control	0.63	0.34-1.18	.15
Readiness to quit 4-6 within months			
Video vs text	1.84	0.77-4.40	.17
Video vs control	5.13	1.76-14.92	.003
Text vs control	2.80	0.92-8.46	.07

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[a]ORs are adjusted for variables significant at baseline and dropout.

[b]Low education is the reference category.

[c]Willingness to quit within 4-6 months is the reference category.

[d]Not suffering from the disease is the reference category.

[e]General practitioner (GP) is the reference category.

Adherence to the Intervention

Table 5 presents the 7-day point prevalence abstinence rates for the 2 experimental conditions. Results showed significant higher abstinence rates for higher-educated smokers in the text condition. Table 5 also shows the 7-day point prevalence abstinence rates for those who did and who did not adhere to at least one further intervention element. Abstinence rates are presented separately for the 2 experimental conditions and are stratified by educational level. The results revealed significantly higher abstinence rates among those who adhered to the video-based computer tailoring condition across all educational groups. Additionally, in the text-based computer tailoring condition abstinence rates were significantly higher among smokers with a middle educational level who adhered to minimally one further session.

Table 5. Abstinence rates per educational level for the video-based and text-based computer tailoring interventions, stratified by adherence.

Condition	Abstinent n (%)	χ^2_2	*P* value
Per educational level			
Video condition (n=670)		0.0	.99
Low educational level	47 (20.9)		
Middle educational level	51 (20.6)		
High educational level	42 (21.2)		
Text condition (n=708)		8.0	.02
Low educational level	33 (14.3)		
Middle educational level	41 (16.1)		
High educational level	53 (23.9)		
Stratified by adherence			
Video condition (n=670)			
Low educational level		10.4	.001
Adherence=0 (n=128)	17 (13.3)		
Adherence>1 (n=97)	30 (30.9)		
Middle educational level		16.5	<.001
Adherence=0 (n=135)	15 (11.1)		
Adherence>1 (n=112)	36 (32.1)		
High educational level		29.9	.04
Adherence=0 (n=113)	18 (15.9)		
Adherence>1 (n=85)	24 (28.2)		
Text condition (n=708)			
Low educational level		3.5	.06
Adherence=0 (n=218)	8 (8.9)		
Adherence>1 (n=238)	25 (17.7)		
Middle educational level		10.1	.001
Adherence=0 (n=242)	8 (7.5)		
Adherence>1 (n=260)	33 (22.3)		
High educational level		3.4	.07
Adherence=0 (n=177)	10 (15.6)		
Adherence>1 (n=243)	43 (27.2)		

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Differences in Appreciation of the Program

Table 6 shows the program evaluation of sample 2. To test possible interaction effects between the conditions (video-based vs text-based computer tailoring) and educational level on process evaluation items, ANOVAs were conducted. There was no significant interaction between condition and educational level with respect to attention ($F_{1,327}$=0.17, P=.84), comprehension ($F_{1,327}$=1.59, P=.21), adaptation ($F_{1,327}$=1.24, P=.29), appreciation ($F_{1,326}$=0.07, P=.93), or processing ($F_{1,318}$=0.008, P=.99) of the feedback messages. As shown in Table 6, the video feedback messages seem to be slightly better evaluated than the text-based messages in terms of appreciation and processing, but the differences did not reach significance.

Table 6. Means and standard deviations (SD) for evaluation of different aspects of the video-based and text-based computer tailoring intervention programs at 6-month follow-up.

Evaluation items	Overall sample (N=333)	Video (n=142)	Text (n=191)	*P* value
Feedback was attractive (attendance), mean (SD)	3.40 (1.04)	3.49 (1.07)	3.37 (1.03)	.18
Feedback was understandable (comprehensibility), mean (SD)	3.63 (0.70)	3.69 (0.70)	3.58 (0.70)	.15
Feedback fit to own situation (adaptation), mean (SD)	3.31 (0.74)	3.35 (0.78)	3.28 (0.71)	.40
Feedback was useful (appreciation), mean (SD)	3.54 (0.96)	3.64 (1.02)	3.45 (0.90)	.07
Feedback helped to make quit attempt (processing), mean (SD)	3.27 (0.86)	3.37 (0.90)	3.20 (0.82)	.06
Overall grade of feedback (from 1-10), mean (SD)	6.45 (1.62)	6.60 (1.67)	6.34 (1.57)	.15

Discussion

Principal Findings

The aim of this study was to evaluate the effects and appreciation of 2 multiple computer-tailored smoking cessation interventions (video- vs text-based messages) delivered via the Internet, regarding 6-month smoking abstinence among different educational groups. To our knowledge, this study is one of the first studies to test the effects of mode of delivery in the context of smoking cessation. Low levels of adherence may lead to an underestimation of the effects; therefore, the effectiveness of the 2 computer-tailored interventions was assessed by analyzing 2 samples. The first sample included all randomly assigned respondents who filled in the baseline questionnaire and followed the first session of the intervention whereas the second sample was a subsample of sample 1 including only respondents (in the experimental conditions) who adhered at least to one further session of the intervention.

Our study revealed several important findings. In contrast to our expectations, the results of all analyses revealed no significant differences in quit rates between smokers with low and high educational levels in the 2 experimental conditions (video- vs text-based messages). However, in both samples, the video-based computer-tailored smoking cessation intervention was effective in increasing 7-day point prevalence abstinence. The text-based computer-tailored smoking cessation intervention, however, was only significantly effective in increasing 7-day point prevalence abstinence in people who adhered to at least one further session (after baseline and session 1). The video-based condition was also more effective compared to the text-based condition regarding 7-day point prevalence abstinence in sample 2.

Moreover, with regard to prolonged abstinence our study revealed a differential effect of the intervention between people with a low or high readiness to quit, consistent with our second expectation. In sample 1, the video-based computer-tailored intervention appeared to be especially successful in increasing prolonged abstinence rates among smokers with a lower readiness to quit (within 4-6 months), whereas in sample 2, the video-based computer-tailored intervention was also effective among smokers willing to quit within 1 month. The multiple imputation and the complete case analyses yielded comparable results, a finding that may be attributed to the fact that rates of missing data were not extremely high at 6-month follow-up (on average 30%).

Consistent with previous findings [33,34] in other behavioral domains, the results of our study indicate that tailored video-based messages might be more effective in supporting smokers to quit smoking regarding 7-day point prevalence abstinence compared to tailored text-based messages. Using video-based messages was equally effective in smokers of all educational levels. This is in-line with past research which found that Internet users appreciate the concept of tailored video interventions over text-based interventions [27]. Contrary to our first hypothesis, the video-based computer-tailored intervention was not more effective in less-educated groups than in highly educated groups. The delivery of information on the Internet is rapidly changing with the proportion of video content increasing [28]; therefore, it is possible that there is a general preference for receiving tailored information in a video format. In-line with this, our program evaluation also revealed a slightly better evaluation of the tailored video messages. Again, no differences were recognized between lower- and higher-educated respondents.

Our study revealed another interesting effect of the video-tailored intervention for people with a lower readiness to quit smoking. With different routings available in our smoking cessation intervention, we expected that both interventions would be effective for people with a lower motivation to quit at baseline. Partially consistent with our second hypothesis, the results revealed that only the video-tailored intervention appeared to be successful in smokers with a lower readiness to quit. The availability of different intervention routings provided

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these less-motivated smokers the possibility to reflect on their smoking behavior and their potential quit attempt; these less-motivated smokers may have benefited from this option in the video-based condition.

Consistent with our expectation, our study showed that abstinence rates were higher overall when respondents adhered to at least one further intervention element. In sample 2, adherence can be regarded as a determinant of the efficacy of the program. These findings are in-line with different previous research, which also found that the efficacy of a program increased when people adhered to the intervention [7,13].

Strengths and Limitations

To our knowledge, this is the first study to assess the effectiveness of a Web-based tailored video and text intervention aiming to promote smoking cessation in groups with varying levels of education and varying levels of readiness to quit. A strength of the study is that 2 different sensitivity analyses were performed to test the robustness of our results. However, our study is also subject to several limitations. First, a misreport may have occurred when respondents were asked to indicate their smoking status at the 6-month follow-up measurement. For financial reasons, we were not able to biochemically validate respondents' self-assessed smoking status. Although future Web-based intervention studies might be recommended to verify smoking status through the use of biochemical cotinine test as part of a more detailed follow-up assessment, it is also argued that this might be irrelevant (eg, if anonymity has been guaranteed) [55]. It may be that Web-based interventions are attractive because they enable people to participate anonymously. This topic requires further elaboration in future studies. Second, we assessed smoking status after 6 months; however, it might be valuable to replicate these findings and investigate whether these results persist over a longer follow-up period. Lastly, during our intervention, respondents were not able to choose a quit date within a week of baseline. Although there is value in taking advantage of current motivational readiness and not delaying an attempt, this could be seen as a weakness of our intervention [56].

Despite these limitations, the present study provides evidence that video-based messages are successful in stimulating quitting behavior. As past research has already indicated that Internet users prefer to receive content in the form of video-based messages [27] and our results confirmed this, the use of audiovisual content might increase the appeal of future health interventions and smoking cessation interventions in particular.

Conclusions

The current study provides important new evidence for the effectiveness of a video-based computer-tailored smoking cessation intervention. The results suggest that a video-based computer-tailored intervention with personalized feedback adapted to the smokers' motivation to quit might be effective in increasing abstinence rates for smokers with different educational levels. The results support the feasibility of using video messaging to affect smoking behavior. We measured smoking abstinence after 6 months; more research is needed to examine whether these results persist over longer follow-up periods.

Acknowledgments

The authors would like to thank all respondents for taking part in the study. This work was supported by ZonMw, the Netherlands Organisation for Health Research and Development (grant number: 20011007).

Conflicts of Interest

Hein de Vries is scientific director of Vision2-Health, a company that licenses evidence-based computer-tailored health communication tools.

Multimedia Appendix 1

Results of regression analysis on sample 2.

[PDF File (Adobe PDF File), 43KB - jmir_v16i3e69_app1.pdf]

Multimedia Appendix 2

Results of complete case regression analysis.

[PDF File (Adobe PDF File), 44KB - jmir_v16i3e69_app2.pdf]

Multimedia Appendix 3

CONSORT-EHEALTH checklist V1.6.2 [57].

[PDF File (Adobe PDF File), 981KB - jmir_v16i3e69_app3.pdf]

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Abbreviations

CES-D: Center for Epidemiologic Studies Depression scale
COPD: chronic obstructive pulmonary disease
FTND: Fagerström Test for Nicotine Dependence
GP: general practitioner
HSD: honestly significant difference
MREC: Medical Research Ethics Committee

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Original Paper

Supporting Self-Care for Families of Children With Eczema With a Web-Based Intervention Plus Health Care Professional Support: Pilot Randomized Controlled Trial

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Abstract

Background: Childhood eczema, or childhood atopic dermatitis, causes significant distress to children and their families through sleep disturbance and itch. The main cause of treatment failure is nonuse of prescribed treatments.

Objective: The objective of this study was to develop and test a Web-based intervention to support families of children with eczema, and to explore whether support from a health care professional (HCP) is necessary to engage participants with the intervention.

Methods: We followed the PRECEDE-PROCEED model: regular emollient use was the target behavior we were seeking to promote and we identified potential techniques to influence this. LifeGuide software was used to write the intervention website. Carers of children with eczema were invited through primary care mail-out and randomized to 3 groups: (1) website only, (2) website plus HCP support, or (3) usual care. Patient-Oriented Eczema Measure (POEM) scores were measured online by carer report at baseline and at 12 weeks. Qualitative interviews were carried out with 13 HCPs (primarily practice nurses) and 26 participants to explore their experiences of taking part in the study.

Results: A total of 143 carers were recruited through 31 practices. We found a decrease of ≥2 in follow-up compared with baseline POEM score in 23 of 42 (55%) participants in the website only group, 16 of 49 (33%) in the usual care group, and 18 of 47 (38%) in the website plus HCP group. Website use data showed that 75 of 93 (81%) participants allocated to the website groups completed the core modules, but less than half used other key components (videos: 35%; regular text reminders: 39%). There were no consistent differences in website use between the website only or the website plus HCP groups. Qualitative feedback showed that most HCPs had initial concerns about providing support for eczema self-care because this was not a condition that they felt expert in. However, HCPs reported productive consultations and that they found it helpful to use the website in consultations, while observing that some participants seemed to need more support than others. Qualitative interviews with participants suggested that HCP support was valued highly only by a minority, generally those who were less confident in their management of eczema or less confident using the Internet.

Conclusions: Our pilot trial demonstrated the potential for greater improvements in POEM scores in both website intervention groups and that a full-scale trial is feasible. Such a trial would quantify the effectiveness and cost-effectiveness of this intervention to determine whether it should be widely promoted to families of children with newly diagnosed eczema. In this study population, HCP support was not strongly valued by participants and did not lead to better outcomes or website use than use of the Web-based intervention alone.

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Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 98560867; http://www.controlled-trials.com/ISRCTN98560867 (Archived by WebCite at http://www.webcitation.org/6NcxvMtgN).

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KEYWORDS

child; primary care; randomized controlled trial; eczema; Internet; self-care

Introduction

Childhood eczema, or childhood atopic dermatitis, is very common, affecting more than 20% of children aged 5 years or younger at some point [1]. It can cause significant distress to the child and family because of sleep disturbance and itch [2]. The main cause of treatment failure is carers not using treatments correctly due to not understanding treatments, child refusal, or the therapy being too time-consuming [3]. Carers may need support in dealing with behavioral issues, such as scratching and sleep disturbance or children refusing topical treatments.

A Cochrane review found that most studies of parental education for childhood eczema have been small or of poor quality [4]. The National Institute for Health and Care Excellence (NICE) guideline on eczema in children [5] concluded that lack of education about therapy leads to poor adherence (ie, carers not using creams) and consequently to treatment failure.

Families of children with eczema express frustration that they do not receive enough support and information about how to manage the condition [6,7]. An Internet-delivered self-management intervention for carers offering information and support about childhood eczema to carers could address this gap. Web-based interventions have been shown to produce small but significant changes in health-related behaviors, particularly where intervention development is based on theory and multiple behavior techniques are incorporated [8]. In terms of patient outcomes, Web-based interventions for diabetes have shown small beneficial effects on blood glucose [9]. Among children and adults referred to secondary care for eczema, an eHealth package (including Internet-guided self-management and Web-based consultations) was found to be just as effective as usual face-to-face dermatology care, but was more cost-effective [10]. Internet-based self-management interventions have been found to lead to improved outcomes in other pediatric long-term illnesses, particularly asthma [11,12].

The effectiveness of computerized mental health interventions have been shown to be enhanced by health care professional (HCP) support or other social support [13]. A systematic review that included interventions aimed at lifestyle change, mental health, or chronic conditions suggested that increased human support is associated with increased adherence to interventions [14]. However, many of the interventions studied in chronic conditions involved clinic-based HCP support for conditions such as diabetes, arthritis, or chronic pain. It is not clear for which conditions and to what extent HCP support is necessary to engage users with Web-based interventions for chronic illness.

We developed a Web-based intervention aimed at improving management of childhood eczema by parents/carers. We sought to test the intervention in a pilot trial to investigate feasibility of intervention delivery and to gather preliminary information for a full-scale randomized controlled trial (RCT). We included 3 groups: (1) Web-based intervention plus usual care, (2) Web-based intervention plus HCP support plus usual care, and (3) usual care alone.

Methods

Development of Web-Based Intervention

The home page on the SPaCE (Supporting Parents and Carers of Children with Eczema) website had a link to allow users to access brief information about members of the research team (including University affiliations) and the medical experts who developed the website. Participants then followed 2 short compulsory modules (approximately 20 minutes) on “What is eczema?” and “Emollient moisturizers” before reaching a menu of modules reflecting common concerns of carers of children with eczema. These were identified through previous qualitative interviews and discussion with patient support groups.

We followed the PRECEDE-PROCEED model [15], using a team approach to identify relevant behaviors amenable to change and potential techniques for addressing these. Details of intervention development are presented in Textbox 1 and an overview of the intervention is given in Textbox 2.

The intervention included 20 of 26 theory-based behavior change techniques listed in a taxonomy developed to standardize definitions [18] (Table 1). See Figures 1 and 2 for illustrative screenshots of the website. More screenshots are shown in Multimedia Appendix 1.

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Textbox 1. Development of the Web-based intervention for childhood eczema.

- We followed the PRECEDE-PROCEED model to devise the intervention [15] (ie, state the quality of life aim, create an inventory of potential target behaviors that might influence this, and factors that affect these behaviors). Three sets of factors are identified that can affect behavior: predisposing, reinforcing, and enabling.
- Our aim was to improve quality of life for families of children with eczema through better control of eczema.
- Our target behavior was regular emollient use because this is relevant to all children with eczema, is thought to be amenable to change, and there is clinical consensus about the benefits of regular use.
- Factors that influence regular emollient use include predisposing factors (knowledge, beliefs and attitudes, perceived control over performing behaviors), reinforcing factors (eg, delayed improvement with emollient use potential barrier to reinforcement), and enabling factors (eg, demonstrating techniques to make emollient application easier).
- We used LifeGuide software to build the intervention.
- We drew on findings from qualitative interviews [16,17], evidence-based patient information leaflets (Nottingham Support Group for Carers of Children with Eczema), and expertise from patient support groups and clinicians to inform intervention design.
- We knew that lack of time was a barrier for carers of young children with eczema so did not incorporate tailoring at the start of the intervention. Instead, all users were tunneled through 2 core modules before reaching a menu of modules to allow them to tailor the intervention to their own priorities.
- We sought feedback through think-aloud interviews with 17 parents of children with eczema who were asked to say all their thoughts and impressions of the website out loud while they were using a draft version. We obtained feedback via email from 3 additional parents and 4 health professionals.
- Changes were made iteratively on the basis of feedback.

Textbox 2. Overview of Web-based intervention for childhood eczema.

- On their first visit to the website, users were tunneled through 2 core modules ("What is eczema?" and "Emollient moisturizers") before reaching a menu of 14 modules to allow them to tailor the intervention to their own priorities. The menu of modules reflected the concerns of carers of children with eczema, including diet and allergy, topical corticosteroids, involving your child in treatment, bath time, sleep problems, and managing scratching. A full list can be viewed in the illustrative screenshots.
- On subsequent visits to the website, users would go straight to the menu of modules. After completing a module, they would be asked whether they wished to mark it as a favorite. A tick would appear by this module if they had completed it and a star would appear if they had marked it as a favorite, which could be seen on subsequent visits.
- Some of the modules included short videos (approximately 4 minutes each) illustrating techniques such as applying emollients or bathing a child. Links to these videos were contained in the relevant modules, but there were also links to all the videos in a button on the menu screen. Similarly, print sheets (eg, tick charts for children, action plan to take to GP consultation, summary of eczema management for relatives, school, or nursery) appeared in the relevant modules, but there were also links to all these in a button on the menu screen.

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Table 1. Behavior change techniques [16] that are incorporated into the SPaCE Web-based intervention.

Technique	Definition	How is this addressed in SPaCE	Where technique is used in SPaCE
1. Provide information about behavior-health link	General information about behavioral risk (eg, susceptibility to poor health outcomes or mortality risk in relation to the behavior)	Information on role of emollients in controlling eczema and preventing flare-ups	Emollients module
2. Provide information on consequences	Information about the benefits and costs of action or inaction, focusing on what will happen if the person does or does not perform the behavior	Information on role of emollients in maintaining healthy skin and keeping child comfortable	Emollients module
3. Provide information about others' approval	Information about what others think about the person's behavior and whether others will approve or disapprove of any proposed behavior change	Telling other people's stories	Emollients module, topical steroids module
4. Prompt intention formation	Encouraging the person to decide to act or set a general goal (eg, to make a behavioral resolution such as "I will take more exercise next week")	Encourage participants to sign up to 2-week challenge where they can print out a chart and opt to receive daily email or SMS text reminders	Emollients module
5. Prompt barrier identification	Identify barriers to performing the behavior and plan ways of overcoming them	Acknowledge child resistance, telling other people's stories	Involving your child module
6. Provide general encouragement	Praising or rewarding the person for effort or performance without this being contingent on specified behaviors or standards of performance	Telling other people's stories of how regular emollient use has helped	Emollients module + throughout intervention
7. Set graded tasks	Set easy tasks and increase difficulty until target behavior is performed	—	
8. Provide instruction	Telling the person how to perform a behavior and/or preparatory behaviors	Videos demonstrating techniques for emollient application	Emollients module, bath time module
9. Model or demonstrate the behavior	An expert shows the person how to correctly perform a behavior (eg, in class or on video)	Videos demonstrating parent applying emollient to child	Emollients module, bath time module
10. Prompt specific goal setting	Involves detailed planning of what the person will do, including a definition of the behavior specifying frequency, intensity, or duration, and specification of at least 1 context (ie, where, when, how, or with whom)	Planning when/where/how to apply emollients during 2-week challenge	Emollients module
11. Prompt review of behavioral goals	Review and/or reconsideration of previously set goals or intentions	—	
12. Prompt self-monitoring of behavior	The person is asked to keep a record of specified behavior(s) (eg, in a diary)	Offering monitoring sheet for 2-week challenge	Emollients module
13. Provide feedback on performance	Providing data about recorded behavior or evaluating performance in relation to a set standard or others' performance (ie, the person received feedback on their behavior)	—	
14. Provide contingent rewards	Praise, encouragement, or material rewards that are explicitly linked to the achievement of specified behaviors	Completion of each module receives congratulations and an extra tick or star; provision of star chart	Main menu; printable star charts for carer or child to use
15. Teach to use prompts or cues	Teach the person to identify environmental cues that can be used to remind them to perform a behavior, including times of day or elements of contexts	Advise use after bath, at nappy (diaper) changes, other set times	Emollients module, bath time module
16. Agree on behavioral contract	Agreement (eg, signing) of a contract specifying behavior to be performed so that there is a written record of the person's resolution witnessed by another	—	
17. Prompt practice	Prompt the person to rehearse and repeat the behavior or preparatory behaviors	SMS text message at 6 pm every day during 2-week challenge	Emollients module
18. Use follow-up prompts	Contacting the person again after the main part of the intervention is complete	Participants received up to 4 reminder emails to log into SPaCE that contained prompts about how the website can help them	Emails
19. Provide opportunities for social comparison	Facilitate observation of nonexpert others' performance (eg, in a group class or using video or case study)	Telling other people's stories	

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Technique	Definition	How is this addressed in SPaCE	Where technique is used in SPaCE
20. Plan social support or social change	Prompting consideration of how others could change their behavior to offer the person help or (instrumental) social support, including buddy systems and/or providing social support	Provision of printouts for other family members and/or nursery to help them understand need for regular emollient use	Emollients module summary printout
21. Prompt identification as a role model	Indicating how the person may be an example to others and influence their behavior or provide an opportunity for the person to set a good example	—	
22. Prompt self-talk	Encourage use of self-instruction and self-encouragement (aloud or silently) to support action	Identify negative thoughts and encourage alternative thoughts	Avoiding stress module
23. Relapse prevention	Following initial change, help identify situations likely to result in readopting risk behaviors or failure to maintain new behaviors and help the person plan to avoid or manage these situations	Discussing methods to avoid child resistance	Involving your child module
24. Stress management	May involve a variety of specific techniques (eg, progressive relaxation) that do not target the behavior but seek to reduce anxiety and stress	Stress management techniques	Avoiding stress module
25. Motivational interviewing	Prompting the person to provide self-motivating statements and evaluations of their own behavior to minimize resistance to change	—	
26. Time management	Helping the person make time for the behavior (eg, to fit it into a daily schedule)	Tips for fitting emollients into everyday life were included both in core information and in quotes from other peoples' stories	Emollients module

Figure 1. Screenshot of SPaCE website welcome page.

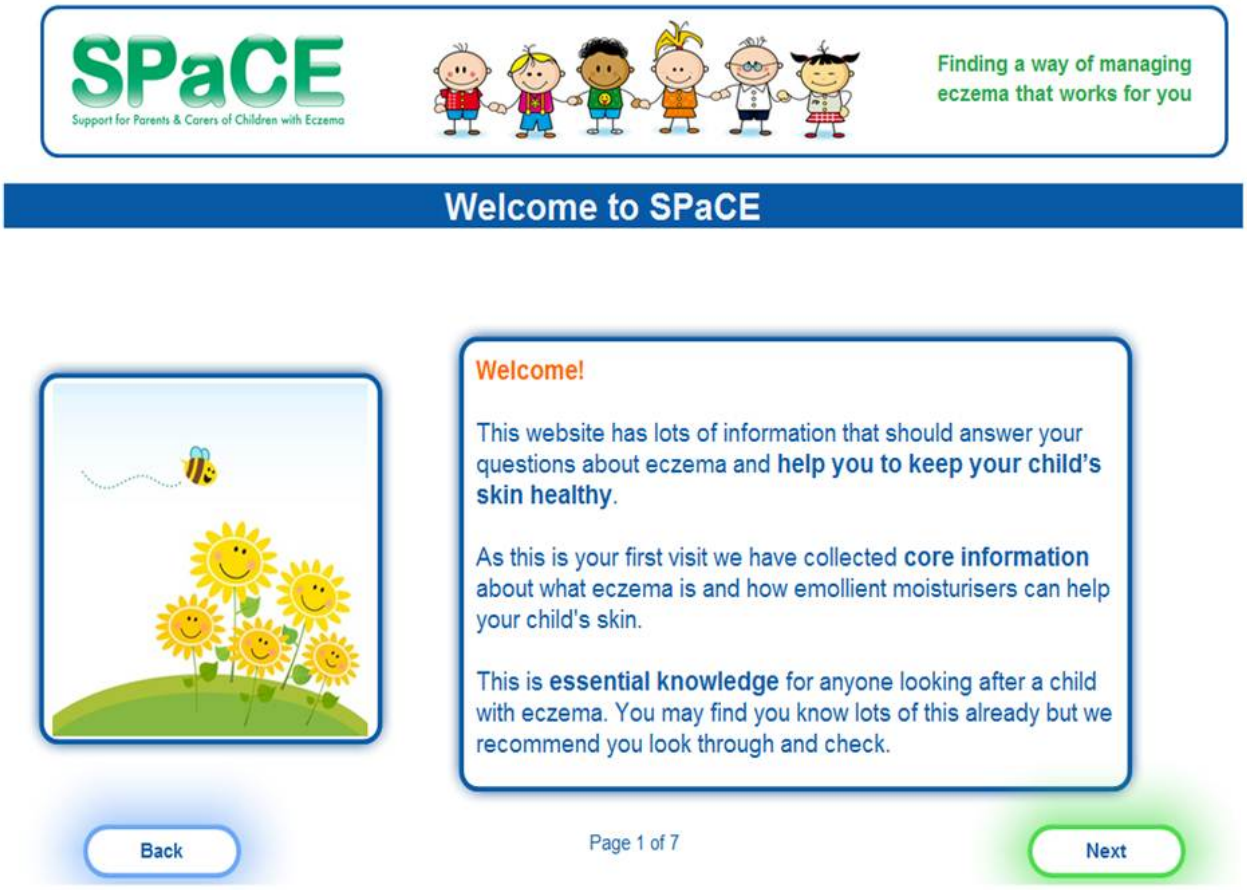

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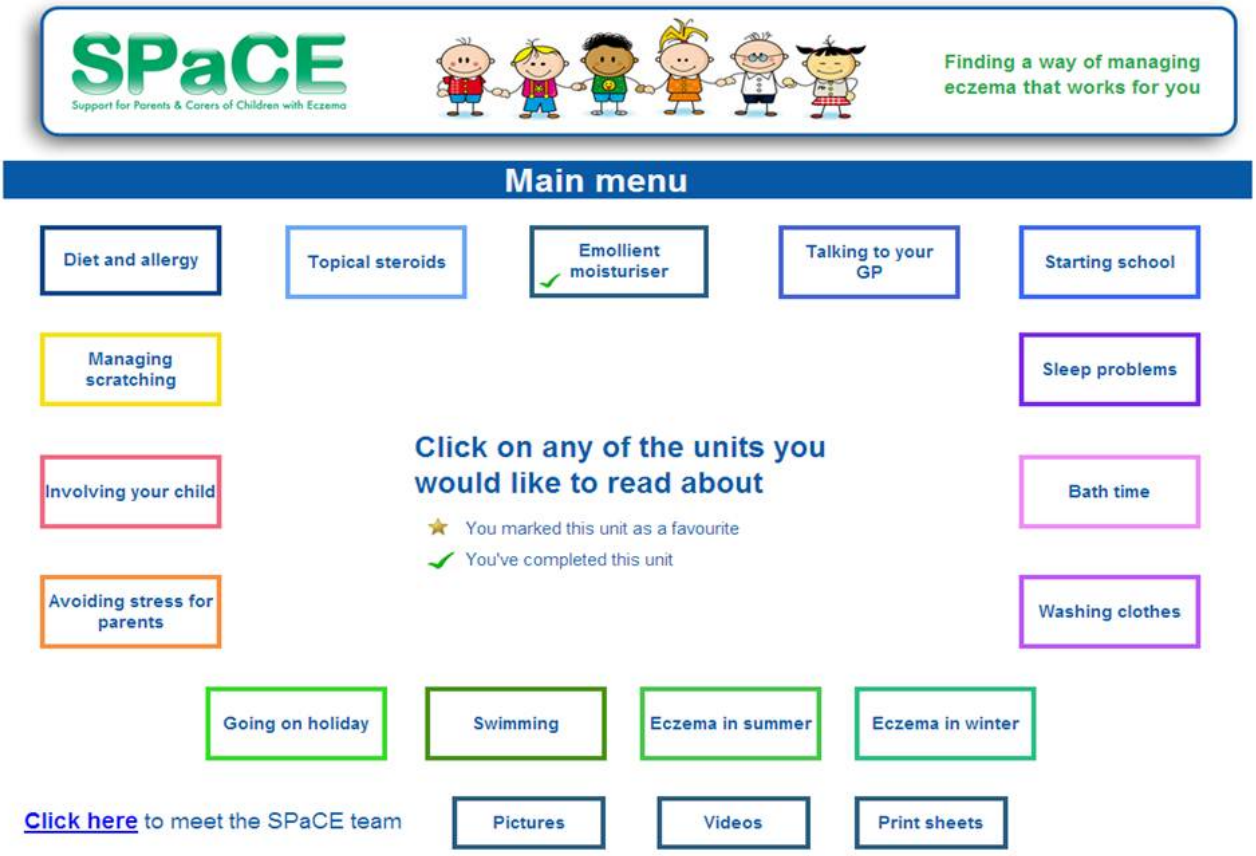
Figure 2. Screenshot of SPaCE menu of modules.



Study Population

Our intervention was aimed at carers of children with mild or moderate eczema; most of whom were managed in general practice in the United Kingdom. We recruited through a mail-out from 31 general practitioner (GP) practices in South West England, recruiting as many practices as possible from areas of social deprivation because this part of England is generally above average in terms of socioeconomic class. General practices posted invitations to parents/carers of children aged 5 years or younger with eczema. Carers were asked to post a reply to the research team if they wished to participate in the study.

Inclusion/Exclusion Criteria

Inclusion criteria included parent/carer of a child aged 5 years or younger with a GP diagnosis of eczema who had obtained a prescription for this in the past year. Exclusion criteria applied by GPs included child aged older than 5 years, known severe mental distress, recent bereavement, opposition to involvement in research, carer unable to give informed consent, or with insufficient English to use website or complete outcome measures. If carers did not wish to take part, they were invited to indicate on the reply slip why this was (see Figure 3). If a family had more than one child meeting eligibility criteria, they were asked to choose one child when answering questionnaire items about their child's eczema.

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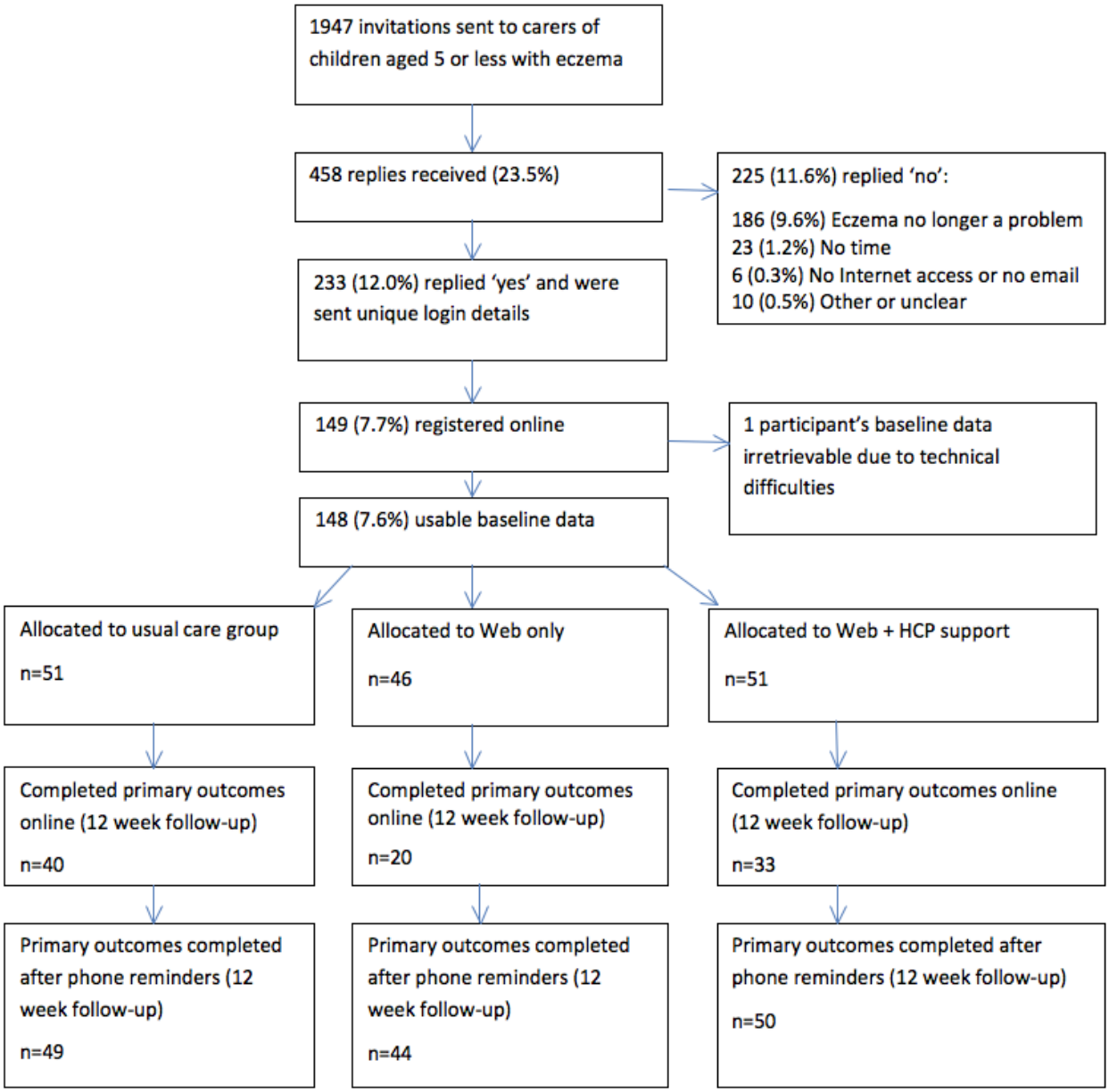
Figure 3. Flow of study participants through trial.



Pilot Randomized Controlled Trial

If carers replied that they were interested in participating, they were sent a unique log-in to complete online consent, baseline questionnaires, and randomization. Online randomization was carried out using LifeGuide software allocating participants to 1 of 3 equal groups: (1) usual care plus Web-based intervention, (2) usual care plus Web-based intervention plus HCP support, or (3) usual care.

Emails were sent 12 weeks later requesting online questionnaire follow-up with 2 email reminders and subsequent phone follow-up for nonresponders requesting responses for core outcome measures.

Health care professional support was a single appointment aimed at engaging carers with the intervention, rather than teaching them about eczema. In 11 practices this was carried out by a practice nurse, but 1 practice assigned the role to a health care assistant and 1 to a GP. Only one of the practice nurses had specific dermatology training. Health care professionals were asked to spend up to 1 hour familiarizing themselves with the intervention. Participating HCPs were then asked to phone participants to arrange a 20-minute appointment at a convenient time in the first few weeks after randomization. The HCPs were informed that their role was not to deliver eczema care, but to encourage participants to use the website as a resource to help them manage their child's eczema. They were asked to have the website open during the appointment and to go through the core modules with the participants if they had not already completed them, and to discuss the 2-week challenge if they had not already done this. If they had completed these, the HCPs were asked to allow the participant to choose other modules to go through together.

Usual care consisted of carers continuing to attend services in the usual way. For most participants this meant making an appointment with their GP when they felt it necessary. A

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minority were under regular secondary care review by a dermatologist or dermatology nurse.

Outcome Measures

Our primary outcome was the Patient-Oriented Eczema Measure (POEM) [19] questionnaire completed online by carers at 12 weeks. This includes 7 questions about eczema symptoms over the previous week which are summed to give a score from 0 (no eczema) to 28 (worst possible eczema). POEM is a patient-reported outcome that can be used by proxy (carer report), is recommended by NICE, and demonstrates good validity, repeatability, and responsiveness to change [20]. Disease-specific quality of life was measured by the Dermatitis Family Impact (DFI) questionnaire, Infants Dermatitis Quality of Life (IDQoL) index, and Children's Dermatology Life Quality Index (CDLQI). The DFI [21] is a widely used validated instrument that measures the impact of eczema on the family's quality of life. The IDQoL [22] and CDLQI [2] are validated measures in children aged 4 years or younger and 5 years or older, respectively.

To explore the effectiveness of the intervention, the pilot study also included questionnaire items to measure adherence (self-reported emollient use) and attitudes that should predict adherence (instrumental and affective attitudes, perceived attitudes of others, and perceived control over adherence). We included the Problematic Experiences of Therapy Scale (PETS), used in previous studies to explore adherence to interventions [23,24]. The PETS asks participants to what extent they have been prevented from carrying out the intervention by socially acceptable reasons for noncompliance (eg, uncertainty about how to carry out treatment, lack of time) before asking about adherence to the intervention and to treatment (emollient use). We also asked participants to complete the Patient Enablement Instrument, which assesses whether they feel they can understand and manage treatment better [25].

Quantitative Analysis

A change in POEM score of 3 or more is thought to be clinically significant in a secondary care setting [26]. However, baseline POEM scores in primary care are lower because many children experience mild eczema; therefore, we determined a score change of 2 would likely to be a clinically significant difference. We wished to be able to detect a small difference because the intervention is relatively inexpensive and even small effect sizes are likely to be cost-effective for such a common condition. Differences between groups were examined using chi-square tests. Analyses were carried out on an intention-to-treat basis. Analyses were carried out using SPSS version 21 (IBM Corp, Armonk, NY, USA).

Qualitative Interviews With Health Care Professionals

Qualitative interviews were carried out with 13 of 14 HCPs who provided support sessions, but one could not be contacted after repeated attempts. Interviews were carried out by phone by a researcher who was not otherwise involved in the study. The interview guide included general questions about their experiences of participating in the study and detailed questions about the conduct and content of appointments they had had with carers, including what parts of the website they had looked at, problems encountered at any stage, and their impressions of usefulness of the appointment for carers. Interviews were recorded, transcribed, and analyzed thematically.

Qualitative Interviews With Participants

Of the 143 parents/carers who took part in the pilot study, 82 agreed to be contacted for a feedback interview. We approached 45 of these after they had completed their follow-up questionnaire, purposively sampling those who had been in the website only or website plus HCP groups, including those who had not attended appointments. We also purposively sampled participants from lower socioeconomic class areas. Of the 45 we approached, 14 were uncontactable after 6 attempts, 4 declined to be interviewed, 1 gave email feedback, and 26 were interviewed. We offered a choice of telephone or face-to-face interview; 10 interviews were carried out by phone, 15 were carried out in participants' homes, and 1 at a participant's workplace. Interviews lasted from 20 to 60 minutes and were audio-recorded, transcribed, and analyzed thematically.

Qualitative Analysis

Thematic analysis was used to analyze the data [27]. Transcripts were read and reread to allow familiarization with the data. Initial coding was applied by MS then developed iteratively until all important information within the dataset was coded. Coding schedules and themes were further refined through discussion (MS, IM, and LY for HCP interviews; MS, HS, and LY for participant interviews). Coding was applied using NVivo 10 software to facilitate data handling. Pseudonyms have been assigned in reporting the findings.

Ethics Approval

Ethical approval for this study was given by the Berkshire Research Ethics Committee (MREC: 10/H0505/56) as a registered randomized controlled trial (ISRCTN 98560867).

Results

Recruitment and Participant Characteristics

A total of 1947 invitation letters were sent from 31 GP practices to parents or carers of children with eczema. We received replies from 458 households (23.52%), with 233 of 1947 (11.97%) replying that they wished to take part in the study. The main reason for not wishing to take part was that their child's eczema was no longer a problem (186/1947, 9.55%). In all, 149 of 1947 (7.65%) people registered online and were randomized into the trial, but 1 participant did not have usable data because of technical problems and was not included in the analysis. At follow-up, 88 of 143 (61.5%) completed the questionnaire online, 50 (35.0%) completed key questions by phone (POEM, DFI, and questions about adherence to emollient therapy), and 5 (3.5%) were uncontactable. Follow-up questions not asked by phone received response rates below 60%; therefore, they will not be presented here. Figure 3 shows the flow of participants through the study and Table 2 shows participant characteristics.

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Table 2. Participant characteristics.

Participant characteristic	Website (n=46)	Website plus HCP (n=51)	Usual care (n=51)	Total (N=148)
Gender of carer, n (%)				
Female	44 (96)	50 (98)	50 (98)	144 (97)
Male	2 (4)	1 (2)	1 (2)	4 (3)
Age of carer (years), n (%)				
≤25	1 (2)	3 (6)	3 (6)	7 (5)
26-30	7 (15)	7 (14)	6 (12)	20 (14)
31-35	12 (26)	17 (33)	18 (35)	47 (32)
36-40	15 (33)	13 (25)	19 (37)	47 (32)
41-45	10 (22)	10 (20)	2 (4)	22 (15)
≥46	1 (2)	1 (2)	3 (6)	5 (3)
Age of child (years), n (%)				
0	1 (2)	3 (6)	9 (18)	13 (9)
1	9 (20)	11 (22)	11 (22)	31 (21)
2	9 (20)	6 (12)	8 (16)	23 (16)
3	11 (24)	14 (27)	13 (25)	38 (26)
4	8 (17)	5 (10)	8 (16)	21 (14)
5	8 (17)	12 (24)	2 (4)	22 (15)
Age carer left education (years), n (%)				
15-16	7 (15)	8 (16)	6 (12)	21 (14)
17-18	11 (24)	9 (18)	8 (16)	28 (19)
19-21	12 (26)	19 (37)	18 (35)	49 (33)
≥22	16 (35)	15 (29)	19 (37)	50 (34)

Intervention Use

Total time spent on the website ranged from 8 to 253 minutes with a median of 40 minutes (IQR 23-59). Of the 93 participants in the website groups, 75 (81%) completed the core modules. This was completed with relatively few visits, with only 45 of 93 (48%) participants in the website groups visiting 3 times or more. Key components of the intervention were thought to be watching videos and signing up to the 2-week challenge (see Table 1), but only 35% of website users watched 1 or more videos and only 39% signed up for short message service (SMS) text message alerts for the 2-week challenge. There were no consistent differences in website use between the website only and the website plus HCP groups (Table 3).

Uptake of HCP support for the intervention was lower than expected. Only 23 of 50 (46%) participants who were allocated to the website plus HCP support group actually attended their appointments (12 declined the appointment, 9 participants could not be contacted to arrange an appointment, 6 made an appointment but did not attend).

Table 3. Intervention use.

Measures of website use	Website only (n=44)	Website plus HCP (n=49)	Website groups combined (n=93)
Total time spent on website (minutes), median (IQR)	34 (20-50)	45 (26-70)	40 (23-59)
Core modules completed, n (%)	38 (86)	37 (76)	75 (81)
3 or more visits to website, n (%)	16 (36)	29 (59)	45 (48)
Watched 1 or more videos, n (%)	16 (36)	17 (35)	33 (35)
2-week challenge SMS text alerts, n (%)	18 (41)	18 (37)	36 (39)

Primary Outcome

Baseline POEM scores were relatively low (mean 9.0, SD 6.6), with POEM scores of 0-2=clear/almost clear, 3-7=mild, 8-16=moderate, 17-24=severe, and 25-28=very severe [28]. All groups showed improvement by 12 weeks (mean 7.8, SD 6.6) (see Table 4). This improvement was greater in the website groups: there was a decrease of 2 or greater in follow-up

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compared with baseline POEM score in 23 of 42 (55%) participants in the website only group, 16 of 49 (33%) in the usual care group, and 18 of 47 (38%) in the website plus HCP group (*P*=.09). The mean change in POEM score between baseline and follow-up was 1.56 in the combined website groups and 0.41 in the usual care group (ie, a difference between groups of 1.15, 95% CI –0.81 to 2.3).

To assess whether the intervention was more effective in those with higher baseline eczema severity, we restricted the analysis to the 96 participants with a baseline POEM score of 5 or more, but found a similar relationship: POEM score decreased by 2 or more in 21 of 30 (70%) participants in the website group, 17 of 35 (49%) in the website plus HCP group, and 13 of 31 (42%) in the usual care group (*P*=.07).

We also wished to look at whether duration of eczema diagnosis influenced effectiveness of the intervention, but only 14 of 130 (10.8%) participants who answered this question reported that their child had had eczema for 6 months or less. This subgroup was too small to allow reliable comparisons to be made.

Table 4. Patient-Oriented Eczema Measure (POEM) and Dermatitis Family Impact (DFI) scores at baseline and at 3-month follow-up.

Outcome measure	Usual care n=49	Website n=44	Website plus HCP n=50	Total n=143
POEM [a] score, mean (SD)				
At baseline	7.47 (6.2)	10.3 (7.0)	9.4 (6.2)	9.01 (6.6)
At follow-up	7.1 (6.6)	7.6 (6.1)	8.7 (7.0)	7.8 (6.6)
DFI [b] score, mean (SD)				
At baseline	5.2 (5.9)	5.3 (5.3)	6.4 (5.6)	5.5 (5.6)
At follow-up	4.4 (5.5)	4.0 (4.2)	5.9 (5.3)	5.0 (5.1)

[a]POEM includes 7 items scoring 0, 1, 2, 3, and 4 to give a total score out of 28, where 28 is most severe.

[b]DFI includes 10 items scoring 0, 1, 2, and 3 to give a total score out of 30, where 30 is most severe.

Secondary Outcomes

The DFI showed even lower baseline scores than POEM. The mean baseline score in this study was 5.7 (SD 5.6), and mean follow-up DFI was 4.8 (SD 5.1). This score is too low to demonstrate differences between groups because of floor effects.

Health Care Provider Feedback

Qualitative interviews were carried out with 13 HCPs, 11 practice nurses, 1 GP, and 1 health care assistant. All were women except for the GP. Our findings centered around the following themes: HCP apprehensions about taking part in the study, HCPs and the self-care support role, and HCP perceptions of the usefulness (or not) of the appointments. HCPs said they were pleased to be involved in a study that gave them the opportunity to provide a self-care support role. However, they did report feeling apprehensive initially about supporting self-care for a condition in which they did not view themselves as expert. Training was viewed as very minimal and some concerns remained after training. After seeing participants, HCPs thought consultations had gone well and felt supported by the website, saying that they liked having it open during consultations and felt this worked well. HCPs observed that some parents seemed to find the HCP session more useful than others and felt their support to be unnecessary in some cases:

> *I think my only concern really was that they were going to expect me to know a tremendous amount about eczema, and that I wouldn't sort of meet their expectations...but that didn't really happen to be honest, because obviously all of the answers were on the website so they were in front of me as well as them.* [Geena]

> *I thought it was good they could point at, for instance use of steroids, and...discuss it in further detail. So they were able to pick an aspect that was from a third party, which is the website, and then bounce ideas or bounce queries off of me. And I think looking to the future, if people have that knowledge already, that might be something that they would be able to use more effectively in a consultation.* [William]

> *The one lady definitely liked the support, the other lady was sort of a bit like, well I've done it, why do I need to come in and talk to you about it?* [Qadira]

Participant Feedback

Two men and 24 women, ages ranging from 24 to 44 years, were interviewed. Five were full-time carers and the remainder were working full-time or part-time in a wide range of occupations. Most parents interviewed were managing mild eczema. They had all been managing their child's eczema for at least 6 months, but most had been managing it for some years.

Most people found the website helpful, easy to use, and easy to understand. The benefits they ascribed to website use are shown in Table 5.

Five of the 26 interviewees said they did not find the website helpful, either because it would have been helpful in the past but that they were confident in managing their child's eczema now or because their child's eczema was so mild that it did not feel relevant. However, there were others managing mild or longstanding eczema who still found the website helpful. So, although confidence in self-management appeared to be related to how useful they found SPaCE, duration of diagnosis and severity were not necessarily important.

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Table 5. Qualitative findings from participant interviews about experiences of using SPaCE website.

Theme	Summary	Illustrative quote
Confidence in eczema management	Approximately one-third of participants said using SPaCE had made them more confident in managing eczema, more able to control it, or more confident that they would be able to manage future flare-ups	*The website was very useful and then from that, it's kind of changed some of our approaches to-to how we treat the eczema of our youngest daughter. It's made us more confident actually, I'd say.* [David]
Getting into the habit of using emollients	Approximately half of interviewees said they had increased emollient use since using the website, mainly related to the 2-week challenge. 3 interviewees mentioned the (optional) daily text reminders and had really liked this. Benefits ascribed to the 2-week challenge included demonstrating that emollient helped; demonstrating that emollient did not help, leading family to try a new emollient; establishing habit of regular emollient use; helping child to accept regular emollient use	*We printed out the 2-week trial tick sheet. He thought it was good, cos it involved him [because] he got to have a tick if he put his cream on which I think helped him with it. Because sometimes he doesn't like it because the creams can be quite thick, so that helped, having a reward chart.* [Jo]
Increased awareness of treatments available or confidence in treatments available	Some carers said that the website had made them aware that there were different treatments available for eczema, for instance number of different types of emollient and that it may be worth trying different ones. Some said that the website had allayed their fears about using topical corticosteroids on their child's skin	*We've only ever had Diprobase and hydrocortisone cream, but apparently there are lots more emollients that you can use, which I didn't realize. So I was wondering-I'll keep going with the Diprobase for a bit but actually if we are still not getting any improvement, perhaps go and speak to the doctor and get another one.* [Annie]
Views about consulting the GP	Some carers said that using the website had made them feel more confident to re-consult if the eczema was not improving. Others said that they felt the website would help them to consult less as they could use the website for reference if they had questions about eczema care in the future	*I thought the creams weren't working, I just sort of thought, "Oh, creams aren't any good for this sort of thing." But it made me realize that I could actually just keep going back to the doctor and not feeling like I was just being an overprotective mother and sort of like complaining about things. So it gave me confidence to actually sort of approach the doctor with my concerns about my son.* [Hayley]
Videos	Videos led to increased awareness of techniques for applying emollients, particularly using larger volumes	*What I actually found useful was the videos because, to be honest, I just used to put on the cream and I obviously wasn't putting on enough on and just going through those little videos, it showed me I needed to step up on the amount I was putting on.* [Bee]
"It's nice to know you're not alone"	Carers valued increased awareness that they were not alone in finding eczema management challenging and that their child was not alone in resisting the application of creams	*I just think it is really helpful: again, it just reminds you that there are other people going through the same sorts of things. Because it can, you know, it's one of these things where it's not the worst thing in the world, some children have terrible illnesses, but in the middle of the night when your child is absolutely crying in agony because her skin hurts so much and they're bleeding through the pajamas, you just think, "Oh, this is just really difficult." But knowing that there are going to be other people in a similar situation...it's kind of reassuring.* [Emily]

Feelings About Being Offered Health Care Provider Support

In the website plus HCP group, 15 of 26 were interviewed, of whom 10 had attended appointments and 1 had discussed her daughter's eczema by phone with the practice nurse. Of the remaining 4, 1 forgot to attend, 1 did not think she had been contacted by the practice, 1 said that the times offered by the nurse were unsuitable for her, and 1 declined the appointment. Sophie was offered a HCP appointment but did not attend:

> *I might have done if he was younger and I was still in the state of, "I don't know what I'm doing and am I doing it right," but I think, because I feel like I know how it's going that I didn't really need any more help really. I think the website being there put me at ease, where if I'd have had no website and the nurse had rung, I would probably have gone to see her, if you see what I mean, because it was nice to have reassurance.* [Sophie]

Kim had a nurse appointment that she forgot to attend:

> *I wanted to go and see her and tell her that I want to help the study, but like I didn't, it sounds really conceited, but I didn't think I would be told anything I didn't know. Maybe I would have done, like I did in the modules, but I wasn't really thinking it was going to be any great difference in what I already know.* [Kim]

The 11 interviewees in the website only group were mainly happy with their group allocation, saying that the website was enough or fit with everyday life better than attending a nurse appointment. Only 2 of 11 interviewees said that they would

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have liked to have been offered an appointment: one offered no reason and the other said it might have made her more enthusiastic about using the website more.

Experiences of Participants Who Attended Health Care Provider Support Session

Parents' views regarding the value of the HCP support varied widely. Of the 10 who attended HCP appointments, 4 said they found the appointment useful (although one of these discussed food allergies rather than eczema), 3 said they did not find it useful, and the remainder were noncommittal about whether they found it useful or not. Reasons parents gave for not valuing the HCP appointment included not really feeling they needed help with eczema management (eg, parents felt confident in managing it) or that they felt confident in obtaining information through the Internet:

> *We did go and see a nurse during the trial but she didn't say anything different to what I already knew anyway, so when we made the appointment and went up to see her I must admit, I did think, "Why am I here?"* [Charlotte]

Among the few carers who found the HCP appointment useful, they reported that this had encouraged them to revisit the website or directed them to part of website they had not looked at before (eg, videos) or helped them to feel more confident about consulting in the future (although other participants ascribed this to the website rather than the nurse appointment). One participant had enjoyed her appointment, but had chosen to discuss health problems other than eczema and another valued her appointment because she was provided with emollient samples (although this was not part of the intervention):

> *I met with the nurse practitioner at my GP surgery and she went through a couple of things on the website with me and we discussed some things together. So actually it brought me closer to the medical team within my own GP surgery as well, so the website was a bit of a connection...and, you know, it's kind of-very much a long-term situation with eczema but at least I feel like I know who I can speak to if I need to get advice.* [Emily]

Nicole is unusual in our sample in that she did not feel comfortable with the Internet and, therefore, really valued the nurse input:

> *To be honest I'm not a massive kind of computer person, I don't work with computers...So it's probably more to do with that I'm not really used to using them, I don't really use computers in my daily life. So I think just going and speaking to the nurse was more helpful to me personally.* [Nicole]

Discussion

Principal Results

This pilot RCT showed a greater improvement in carer-reported eczema scores in both the website only and website plus HCP groups compared with a usual care group. Although the study was not powered, potentially important changes in outcomes were observed in the hypothesized direction and, although not significant at the 5% level, they were significant at the 10% level. Completion of core modules was good in both the website only and the website plus HCP groups, although uptake of some of the intervention components was low.

This study showed the feasibility of HCPs using a website to support self-care for eczema within the consultation and that initial concerns about providing support for a condition they were not expert in dissipated after they had tried it. However, among this group of carers it seems that many did not particularly value the HCP support, as evidenced by the low take-up of support session appointments and the qualitative findings.

Limitations

Our initial mail-out received a low response rate; therefore, those using the intervention could be unrepresentative of families of children with eczema, possibly with higher health literacy or higher motivation than other families. Our intervention, if shown to be beneficial, is designed for dissemination to families of children newly diagnosed with eczema in primary care. Ideally, we would have carried out opportunistic recruitment of newly diagnosed families, but this would not be feasible in primary care so we recruited by mail-out instead, with the consequence that the intervention was less relevant to some families, probably contributing to the low response rate.

The relatively low use of some components of the intervention (videos and 2-week challenge) suggests that we need to refine the intervention before further evaluation. Although the intervention was developed carefully and adapted on the basis of initial feedback, complex interventions and trials to examine their efficacy frequently need further iterative development [29].

We are unable to comment on adherence to the target behavior (emollient use) for this intervention because these findings are extremely difficult to interpret. If eczema is in remission, then twice-daily emollient is adequate, but if there is a flare up, then more frequent application is required. Therefore, increased use of emollient can either be related to better adherence or worse eczema, and decreased use of emollient could mean worse adherence or better eczema. For instance, if a child was no longer bathing in soapy water as a result of the intervention, this could lead to an improvement in eczema and effective self-care could mean that emollient use stays the same or even decreases.

Comparison With Prior Work

Other studies have found that human support is important in engaging users with online interventions [14,30], but we did not find that in this study. Unsupported use of Web-based interventions requires a fairly high degree of critical health literacy and motivation (ie, due to high symptom distress) [31]. Qualitative interviewees in our study were predominantly comfortable obtaining information online and often referred to the mildness or severity of eczema as being important in how motivated they were to engage with the website. It may be that there are particular features of the population under study that

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means they are less likely to value health professional support, such as that they were adults aged 20 to 40 years (so relatively computer literate), that eczema is a condition in which a high degree of self-care is expected [7], and many were looking after relatively mild eczema. It is also possible that participants would have welcomed the support more if they had initiated contact with the HCP themselves, rather than the reverse.

Conclusions

We conclude that a full-scale RCT of this Web-based intervention is feasible. The findings presented here suggest that HCP support for this study population might not be necessary; therefore, this will not be included in the RCT. These findings also support keeping the invitation to participate quite broad because some parents caring for mild or longstanding eczema still valued having access to the website (even though it was targeted at the newly diagnosed). The website will be further refined before the next stage of evaluation.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Illustrative screenshots.

[PPTX File, 2MB - jmir_v16i3e70_app1.pptx]

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Abbreviations

CDLQI: Children's Dermatology Life Quality Index
DFI: Dermatitis Family Impact
GP: general practitioner
HCP: health care professional
IDQoL: Infants Dermatitis Quality of Life
PETS: Problematic Experiences of Therapy Scale
POEM: Patient-Oriented Eczema Measure
RCT: randomized controlled trial
SMS: short message service
SPaCE: Supporting Parents and Carers of children with Eczema

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Review

Effectiveness of eHealth Interventions and Information Needs in Palliative Care: A Systematic Literature Review

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Abstract

Background: One of the key components in palliative care is communication. eHealth technologies can be an effective way to support communications among participants in the process of palliative care. However, it is unclear to what extent information technology has been established in this field.

Objective: Our goal was to systematically identify studies and analyze the effectiveness of eHealth interventions in palliative care and the information needs of people involved in the palliative care process.

Methods: We conducted a systematic literature search using PubMed, Embase, and LILACS according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. We collected and analyzed quantitative and qualitative data regarding effectiveness of eHealth interventions and users' information needs in palliative care.

Results: Our search returned a total of 240 articles, 17 of which met our inclusion criteria. We found no randomized controlled trial studying the effects of eHealth interventions in palliative care. Studies tended to be observational, noncontrolled studies, and a few quasi-experimental studies. Overall there was great heterogeneity in the types of interventions and outcome assessments; some studies reported some improvement on quality of care, documentation effort, cost, and communications. The most frequently reported information need concerned pain management.

Conclusions: There is limited evidence around the effectiveness of eHealth interventions for palliative care patients, caregivers, and health care professionals. Focused research on information needs and high-quality clinical trials to assess their effectiveness are needed.

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KEYWORDS

palliative Care; eHealth; systematic review

Introduction

Background

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering" [1]. Further, WHO clearly states that implementing "a support system to help patients live as actively as possible until death" [1] is one of the responsibilities of palliative care. In the WHO's

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definition, the aforementioned support system does not necessarily refer to a technical system, but to all the infrastructure and supporting services that are needed to help patients in palliative care, which may include information technologies (IT).

As the world population grows older, chronic noncommunicable conditions have emerged as the main causes of mortality worldwide. It is estimated that there are 600 million people older than 60 years, and of the 58 million deaths that occur each year, 60% can be attributed to progressive conditions such as cancer and cardiovascular diseases [2]. These progressive conditions determine an increasing demand for palliative care. Considering this large and ever-growing demand, as well as the scarcity of trained specialists in palliative care to meet those needs, both in developed and developing countries, it is critical to identify methods to augment available resources. Given the scalability of tools and interventions based on information technologies, we believe that there is a high potential for IT tools and applications in palliative care.

eHealth

eHealth has been defined as "health services and information delivered or enhanced through the Internet and related technologies" [3], and it has been progressively incorporated into the options available to deliver health care. In other domains of health care, eHealth has been successfully used to support patients and clinicians during the routine tasks involved in clinical care. Among many examples, we can find a study conducted by Clarke et al [4] that demonstrated that patients allocated to receive an Internet self-help intervention had a greater reduction in depressive symptoms than the control group. Similarly, another study tested the use of SMS text messaging (short message service) to monitor low back pain in primary care patients [5].

Considering the key role of information and communication in palliative care, these positive effects might also be true for patients, family members, and clinicians in the domain of palliative care. To validate this assumption, we identified two broad questions to guide this research:

(1) What eHealth interventions with proven efficacy exist for use in palliative care? It is unclear whether the advances eHealth made in recent years are already available in the area of palliative care. Further, the efficacy of such measures remains uncertain.

(2) What is known about the information needs of the participants in the palliative care process? To be efficient and successful, an existing or planned eHealth system needs to fulfill these specific information needs.

eHealth for Palliative Care

Several attempts have been made to extend the coverage of currently available resources in palliative care. A traditional communication technology frequently used with this purpose in palliative care is the telephone. Several studies have reported on the usefulness of phone services to support palliative care patients and caregivers. However, since telephone communications require the synchronous interaction between the communicating parties, it is expensive to scale them up since they require proportional availability of human resources. Today, with the advances of information and communication technologies (the Internet, mobile phones, and smartphone applications), there may be additional evidence about the effectiveness of nonsynchronous communications.

To our knowledge, no systematic review of the research conducted in this field has been published. The goal of this study was to conduct a systematic literature review with the following two objectives: (1) identify studies on eHealth interventions in palliative care that assessed the efficacy of the intervention, and (2) identify studies reporting on the information needs of patients, caregivers, and health professionals in palliative care.

The identified studies will be used to identify current knowledge gaps and to highlight the areas where more research is needed regarding the use of IT to support palliative care. Once the information needs are known, it will be possible to develop eHealth systems adequately tailored to meet those needs.

Methods

Eligibility Criteria

Inclusion Criteria

For this systematic literature review, we followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines [6]. To assess the effectiveness of eHealth interventions, we included experimental or observational studies published in English, German, or Spanish that assessed the effectiveness of eHealth interventions for patients in palliative care or those involved in their care such as caregivers or health care providers. We defined eHealth interventions as any information and communication technology designed to conduct measurements, enhance communications, or deliver relevant information for patients, caregivers, or health care providers. We excluded communication technologies that relied exclusively on synchronous communication (eg, telephone or video consultations), given the limited scalability of such systems (ie, a health professional can answer only one call at a time). If the number of patients rises, callers may have to wait in a queue or the number of health professionals must be increased to take calls in parallel. We did include systems based on mobile phones when they consisted of asynchronous communications such as SMS text messaging (short message service) or smartphone applications.

To understand users' information needs, we included experimental or observational studies published in English, German, or Spanish that explicitly assessed the information needs related to eHealth applications of patients in palliative care or those involved in their care, such as caregivers or health care providers. We defined eHealth interventions as any information and communication technology designed to conduct measurements, enhance communications, or deliver relevant information for patients, caregivers, or health care providers, including synchronous communication like telephone or video consultations. We accepted reports on systems based on synchronous communication for the search on users' needs

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because these studies might provide important information for the future development of an asynchronous eHealth system as defined above.

Exclusion Criteria

Reports that met the following criteria were excluded from this study: articles not assessing the effectiveness of eHealth applications or participant's information needs; articles reporting on interventions with synchronous communication; articles not involving palliative care patients, caregivers, or health care providers; letters, editorials, white papers, and conference abstracts; and articles written in languages other than English, German, or Spanish.

Search Strategy

To identify relevant studies, we conducted electronic searches in June 2012 using PubMed, Embase, and LILACS (Literature in the Health Sciences in Latin America and the Caribbean). We constructed a search strategy using the following terms, adapted to each of the databases used, using standard terminology when available: (smartphone OR "Short Message Service" OR "SMS" OR "text messaging" OR "text message" OR "Cellular Phone" OR "Electronic Medical Record" OR "Patient Health Record" OR "Telemedicine" OR "mhealth" OR "m-health" OR "ehealth" OR "e-health" OR "mobile health" OR "electronic health") AND ("Palliative Care").

Study Selection and Data Extraction

To assess whether they met our inclusion and exclusion criteria, 2 researchers independently reviewed the titles and abstracts of all retrieved articles. Disagreement was resolved by consensus. If the title and abstract were insufficient to decide the inclusion, we reviewed the article's full text to decide on final inclusion or exclusion. In addition to the electronic search, we manually reviewed citations of relevant publications identified through the electronic search. Once a final list of articles was available, we obtained the full text of all articles for complete data extraction.

Relevant data were extracted from all included articles using an online data capture form. To increase the consistency of data extraction, three researchers conducted an initial parallel data extraction of a subset of articles. The results were reviewed and disagreements resolved. The process was further repeated until consistent data extraction was obtained. Two researchers extracted the data of the remaining articles independently. Some additional articles were excluded during the data extraction stage if the abstract presented misleading information about the scope of the study.

Results

Summary

The flowchart depicting the results of the literature selection process is shown in Figure 1. Our database queries resulted in 237 records. Two of these results were systematic literature reviews [7,8] from which we decided to manually review their citations. They included 11 additional research papers not included in the original database search. These papers were added to our review process. After screening titles and abstracts, we excluded 187 papers from our data pool. Assessment of the remaining papers' full texts resulted in the exclusion of another 36 papers since they did not meet our inclusion criteria. The respective reasons for exclusion are reported in Multimedia Appendix 1. All resulting papers were written in English. In the end, 16 publications were identified through the database search [9-24], and one additional article was identified by manually reviewing citations from relevant publications [25].

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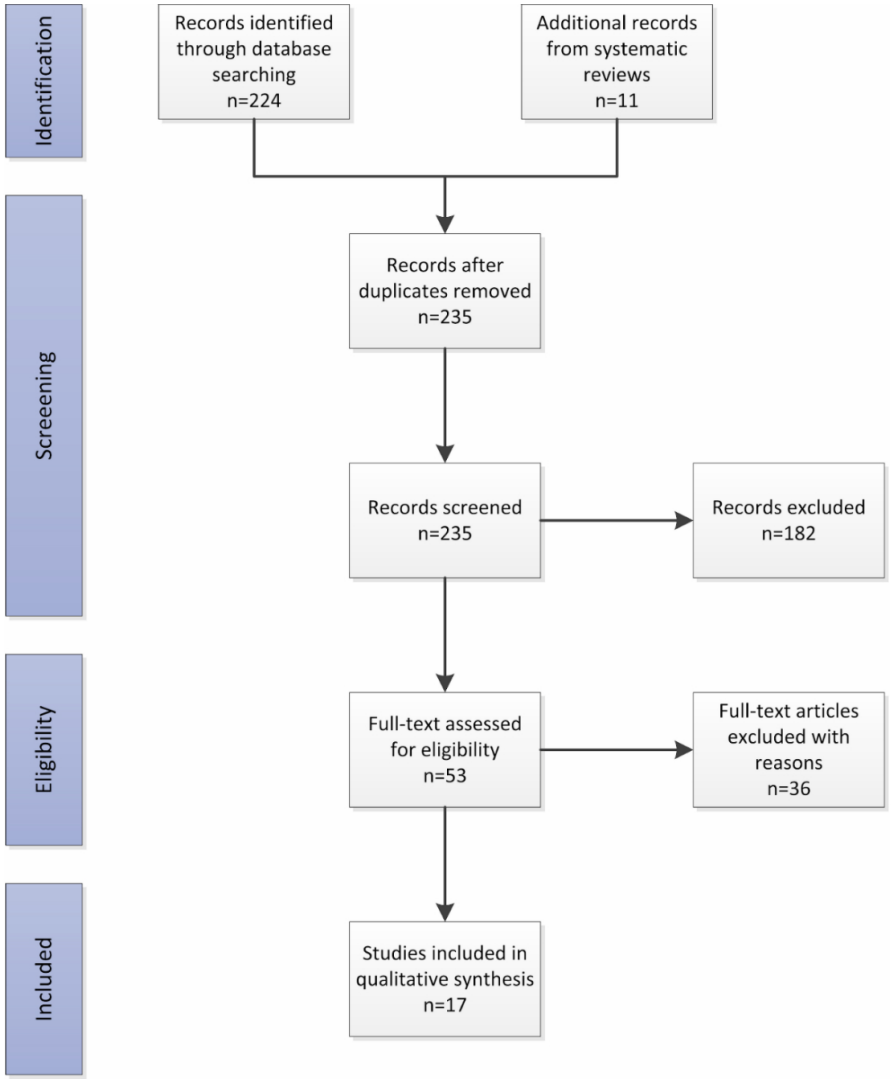
Figure 1. PRISMA flowchart of the systematic review.



Key Feature of Selected Studies

Table 1 shows an overview of the 17 included papers. In terms of location and resources available, all but 1 study were conducted in high-income countries, using the World Bank classification [26]; 7 studies were conducted in Europe, 6 in North America, 3 in Australia, and only 1 study was done in Africa. The 7 studies included participants from rural settings, 2 from urban settings, and the rest did not provide specific information in that regard. With respect to the types of the studies, 11 were observational studies, 3 quasi-experimental, 1 was a hypothesis-generating study, and 1 was a narrative case study. There was wide variability on information about units of analysis and sample sizes. For example, some studies measured individual visits or patient numbers; others considered single consultations or phone calls. The follow-up time of the studies could be extracted only from 3 papers and ranged between 2 weeks and 1229 hours.

As far as our study questions are concerned, two of the papers cover both of our questions. Users' information needs in palliative care were described in nine publications, while six publications assessed only the efficacy of eHealth systems for palliative care.

Table 2 summarizes the types of interventions assessed by the included studies. The most frequent intervention was the implementation of telephone-based support infrastructures. Other interventions aimed to simplify various aspects of documentation, for example, by introducing digital pens or by simplifying the use of questionnaires with eHealth methods (eg, [27]). The wide variations in study methods, interventions, and outcomes assessed prevented any attempt to pool results.

Table 3 summarizes the participants of the studies and the number of occurrences in the studies included. A study could have participants of more than one type.

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Table 1. Overview of the studies included in the systematic review.

Author, year	Intervention	Location	Type of study	Sample size	Follow-up
Coleman 2005 [25]	Study about the effects of a frequently asked questions module added to an Internet chat room on pancreatic cancer	USA (Internet users)	Quasi-experimental (nonrandomized controlled trials, time series, before-after)	600 posts	N/A
Grant 2011 [9]	Qualitative assessment of 3 palliative care programs in extremely underserved areas; qualitative findings included the utility of mobile phones to communicate with the palliative care team	Uganda (rural), Kenya (rural), Malawi (peri-urban)	Observational: Cross-sectional	3 programs	N/A
Kallen 2012 [10]	Improve patient symptom status reporting and symptom management with novel software	Texas, United States (setting unclear)	Observational: Cross-sectional	27	N/A
Koczwara 2010 [11]	An education program for rural health providers incorporating information on palliative cancer treatments and supportive care, as well as strategies on how to provide effective multidisciplinary care in rural settings	Australia (rural)	Observational: Cross-sectional	90	1229 hours
Lind 2004 [12]	Development and assessment of system to monitor patient symptoms using digital pens	Linköping, Sweden (setting unclear)	Observational: Cross-sectional	12	N/A
Lind 2008 [13]	Qualitative study assessing the impact of a digital pen–based system to monitor symptoms	Linköping, Sweden (setting unclear)	Observational: Cross-sectional	12	2 weeks
Linklater 2009 [14]	Evaluation of a specialist palliative care helpline for general practitioners	Grampian, United Kingdom (rural)	Observational: Cross-sectional	1146 calls	N/A
Maudlin 2006 [15]	Pilot study for using specialized teams and technology to enhance care and support veteran patients and their families	Florida/Puerto Rico, United States	Quasi-experimental (nonrandomized controlled trials, time series, before-after)	100	N/A
McCall 2008 [16]	Study testing the feasibility of using mobile phone–based technology to monitor and manage symptoms reported by patients being cared for at home in the advanced stages of their illness	Scotland, United Kingdom (rural)	Observational: Cross-sectional	21 patients, 9 HC professionals	30 days
Van Heest 2009 [17]	Analysis of surveys conducted after palliative care consultations between GPs and palliative care specialists	The Netherlands (rural)	Observational: Cross-sectional	415 consultations	N/A
Paré 2009 [18]	Evaluation of effects of a provider-focused telehomecare intervention implemented in an oncology and palliative care unit	Quebec, Canada (urban)	Quasi-experimental (nonrandomized controlled trials, time series, before-after)	7	N/A
Phillips 2008 [19]	Qualitative assessment of a telephone consultation service.	New South Wales, Australia (rural)	Other hypothesis- generating studies (eg, qualitative inquiry)	8 caregivers, unclear number of health care professionals	N/A
Ridley 2008 [20]	Study examines a 24-hr telephone hotline available to physicians, nurses, and pharmacists across the province.	British Columbia, Canada (rural and urban)	Other hypothesis- generating studies (eg, qualitative inquiry)	692 calls	N/A
Roberts 2007 [21]	Feature on telephone support for palliative care patients and their carers	Canada (setting unclear)	Report	254	N/A
Teunissen 2007 [22]	Descriptive assessment of a telephone consultation system	Utrecht, Netherlands (setting unclear)	Observational: Cross-sectional	2089 consultations	N/A
Walker 2006 [23]	Evaluation of an electronic tool that can be used on PDAs for assessment of patient-reported outcomes (patient's symptoms)	St. Gallen, Switzerland (setting unclear)	Observational: Cross-sectional	54 patients	N/A
Wilkes 2004 [24]	Descriptive evaluation using an audit of telephone logbook, text analysis of reflective journals, questionnaire, and interviews	Grafton, New South Wales, Australia (rural)	Observational: Cross-sectional	69	N/A

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Table 2. Summary of interventions described in included papers.

Category of intervention	Number of articles	Reference
Education	1	[11]
Other	3	[9,17,25]
Digital pen	2	[12,13]
Phone support	6	[14,19-22,24]
Process software	2	[10,18]
Questionnaire, phone	1	[16]
Questionnaire, other	2	[15,23]

Table 3. Types of participants covered by the studies.

Participants	Number of studies
Patients	11
Caregivers (family, friends)	7
Nurses	12
Physicians	9
Others	4

Primary Outcome: Effectiveness of eHealth Interventions in Palliative Care

The results for the first study question—efficacy of eHealth system for palliative care—are shown in Table 4. The eight studies describing the effects of eHealth interventions reported being effective with regards to the following aspects of palliative care: improvement of quality of care, improved communication, reduction of documentation effort, and reduction of costs.

A high level of user satisfaction was reported (eg, [10,15,18]). The only article reporting quantitative effects of an eHealth intervention was a nonexperimental study published by Maudlin et al. This was a time-series study in which the authors compared health care utilization before and after implementing the system, which consisted of a combination of text messaging and videophones. According to [15], the number of hospital admissions decreased by 66%, the number of emergency room visits by 19%, and the number of bed days by 77% after introducing the text messaging and videophone devices.

Table 4. Results describing efficacy of eHealth system for palliative care.

Author, year	Results
Kallen 2012 [10]	Improved contact with caregivers; better quality of care
Koczwara 2010 [11]	Curriculum influences practice of health professionals
Lind 2004 [12]	Improved contact with caregivers; better quality of care
Lind 2008 [13]	Improved contact with caregivers; better quality of care
Maudlin 2006 [15]	Lower number of hospitalizations, emergency room visits, and bed days; reduced costs
McCall 2008 [16]	Helpful for patients; useful or detecting symptoms earlier
Paré 2009 [18]	Reduction of documentation efforts; more time for direct care
Walker 2006 [23]	28 patients prefer PDA (personal digital assistant) questionnaires; 10 patients prefer paper; 16 had no preference.

Secondary Outcome: Information Needs in Palliative Care

Table 5 shows the information needs of participants in the palliative care process as reported in the included papers. The most prevalent information need that we identified was information related to pain management, such as recommended drug combinations and dosages. Further questions dealt with the management of other palliative symptoms and care in general. Figure 2 shows how the patient, caregiver, nurse physician, and other roles are represented in the included studies. As shown in Table 5, some studies covered multiple roles. Despite their key role in palliative care, informal caregivers were infrequently included in these studies. Some studies reported that users of the respective system (mostly telephone-based interventions) needed reassurance on the treatment they intended to perform or medication dosage.

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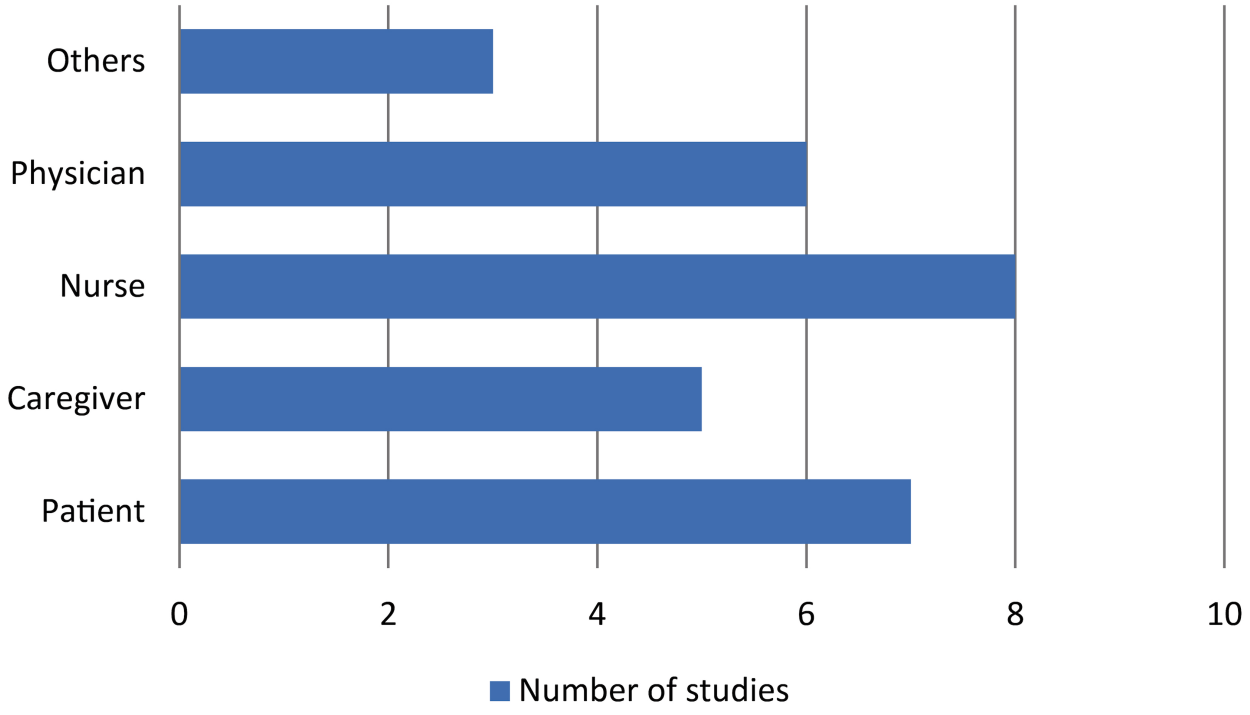
Table 5. Results for users' needs.

Author, year	User needs	Participants
Coleman 2005 [25]	Information on medical, experimental, and alternative treatments; information on cancer-related symptoms, prognosis, and end-of-life care	Patients, informal caregivers
Grant 2011 [9]	Information on diseases and care management	Patients
Linklater 2009 [14]	Support with pain management, support with other symptoms	Physicians, family physicians/general practitioners, nurses, patients, and caregivers
Maudlin 2006 [15]	Patients need to feel connected to themselves and others	Patients, informal caregivers, nurses
McCall 2008 [16]	Patients want to express their feelings and reception of their status, patients feel looked after because someone is reading their questionnaire	Patients, nurses, physicians
van Heest 2009 [17]	Consultation on sedation or euthanasia, validation of proposed clinical actions	Physicians, nurses, pharmacists, and specialists
Phillips 2008 [19]	Reassurance on medication usage, support with symptom management, anxiety, death	Patients, informal caregivers, nurses, physicians
Ridley 2008 [20]	Assistance in pain management, support with gastrointestinal concerns, psychosocial, and ethical questions	Nurses, physicians, pharmacists
Roberts 2007 [21]	Support with questions related to care, access to health records	Patients, informal caregivers
Teunissen 2007 [22]	Information about pain, delirium, nausea, and other symptoms	Nurses, physicians, pharmacologist
Wilkes 2004 [24]	Reassurance with specific care questions	Nurses, physicians

Figure 2. Palliative care roles covered in 11 studies included for information needs.



Discussion

Principal Findings

The literature review resulted in the inclusion of 17 primary studies. The fact that none of these studies were randomized controlled trials and they did not describe patient-relevant clinical outcomes highlights the current need to formally evaluate the effectiveness of these technologies. As far as efficacy of the interventions is concerned, some studies reported positive results in terms of quality of care, communication, and cost development, but since they were all observational or quasi-experimental studies, risk of bias is significant. In addition, IT was used in rather conservative ways throughout the studies.

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Often, IT was used to mimic analog processes, like filling in questionnaires or simplifying documentation tasks [13,16,18]. The digitalization of analog procedures is probably beneficial for participants in palliative care. However, it seems likely that the application of more advanced information and communication technology developments might lead to better results. For example, communication-centered technologies based on the Web, such as social networking sites, may give patients and caregivers an increased feeling of connectedness; applications that provide interactive learning experiences may help empower patients and caregivers. The proliferation of smartphones and ubiquitous sensors, on the other hand, could help address a broader population with eHealth interventions both in terms of usability and Internet coverage.

To further specify possible fields where knowledge gaps might exist, it is helpful to consider the results of our secondary research question regarding information needs in palliative care. Of the 11 studies that addressed that question, only three reported on an eHealth intervention. Most of the studies were based on synchronous communication over the phone—an approach with limited scalability since it requires the concurrent participation of individuals at an elevated cost [28]. Despite this, the results of these studies are valuable sources to determine the information needs of the roles participating in the palliative care process.

In terms of user needs, the most frequent issue was knowledge about pain management. This need was prevalent not only with patients and informal caregivers, but also health care professionals not specialized in palliative care. Although this finding is not surprising, it provides valuable information on how other technology-based interventions, such as pain monitoring using mobile devices or infusion pumps for analgesics, could be used in the future. There is also evidence that communication itself was an important factor for many users of phone support systems. However, as the results of [16] suggest, verbal communication was not necessarily essential to induce a feeling of connectedness in users of an eHealth system. The possibility to communicate about one's feelings and problems and the knowledge that someone might read it can be beneficial by itself.

As shown in Figure 2, a great majority of studies are covering information needs reported on health care professionals and patients. Only five studies provided data on the information need of informal caregivers involved in the palliative care process. Considering the high burden experienced by informal caregivers and the high responsibility role they play in many societies, this seems to be a noteworthy shortcoming in current literature.

This systematic review also highlights the lack of information about the use of eHealth for palliative care in developing countries. With all but one study being conducted in high-income countries, information to understand the efficacy of these systems in different economic settings is lacking. This is particularly urgent given the great and accelerating penetration of information technologies, especially mobile phone and Internet connections in developing countries, which is creating large numbers of potential users that could benefit from well-designed systems to support health in general and palliative care in particular. The availability of effective ways to communicate with patients and caregivers, along with effective eHealth interventions or applications, might significantly improve the availability of palliative care especially in underserved populations.

Limitations of the Review

The studies considered for this research were peer-reviewed publications identified from three scientific databases. The inclusion of additional data sources might have returned additional publications including gray literature, especially concerning the question on information needs. Furthermore, the database queries were narrowed down to eHealth applications. As a consequence, information needs were returned only if they were reported in the context of such applications. Although we included reports on systems based on synchronous communication, there still might be publications covering information needs in different contexts of care or in studies not involving eHealth interventions.

Future Research Priorities

Future research in the domain of eHealth for palliative care should first concentrate on studying information needs of the diverse roles involved in palliative care. Special focus should be given to informal caregivers, since they carry a major burden of delivering care but are often neglected when new eHealth applications are designed. Research on information needs should lead to data that have a finer granularity, for example, compared to the rather coarse need for information on pain management that we identified. To avoid bias in these investigations, the number of individuals contributing their information needs should be appropriately large.

The information needs should be the basis for developing new eHealth systems targeting the different roles. To validate the approach, this domain needs high-quality randomized controlled trials to formally establish the effectiveness of these interventions.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Excluded studies.

[PDF File (Adobe PDF File), 216KB - jmir_v16i3e72_app1.pdf]

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Abbreviations

IT: information technology
LILACS: Literature in the Health Sciences in Latin America and the Caribbean
PDA: personal digital assistant
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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Original Paper

An Internet- and Mobile-Based Tailored Intervention to Enhance Maintenance of Physical Activity After Cardiac Rehabilitation: Short-Term Results of a Randomized Controlled Trial

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Abstract

Background: An increase in physical activity for secondary prevention of cardiovascular disease and cardiac rehabilitation has multiple therapeutic benefits, including decreased mortality. Internet- and mobile-based interventions for physical activity have shown promising results in helping users increase or maintain their level of physical activity in general and specifically in secondary prevention of cardiovascular diseases and cardiac rehabilitation. One component related to the efficacy of these interventions is tailoring of the content to the individual.

Objective: Our trial assessed the effect of a longitudinally tailored Internet- and mobile-based intervention for physical activity as an extension of a face-to-face cardiac rehabilitation stay. We hypothesized that users of the tailored intervention would maintain their physical activity level better than users of the nontailored version.

Methods: The study population included adult participants of a cardiac rehabilitation program in Norway with home Internet access and a mobile phone. The participants were randomized in monthly clusters to a tailored or nontailored (control) intervention group. All participants had access to a website with information regarding cardiac rehabilitation, an online discussion forum, and an online activity calendar. Those using the tailored intervention received tailored content based on models of health behavior via the website and mobile fully automated text messages. The main outcome was self-reported level of physical activity, which was obtained using an online international physical activity questionnaire at baseline, at discharge, and at 1 month and 3 months after discharge from the cardiac rehabilitation program.

Results: Included in the study were 69 participants. One month after discharge, the tailored intervention group (n=10) had a higher median level of overall physical activity (median 2737.5, IQR 4200.2) than the control group (n=14, median 1650.0, IQR 2443.5), but the difference was not significant (Kolmogorov-Smirnov Z=0.823, P=.38, r=.17). At 3 months after discharge, the tailored intervention group (n=7) had a significantly higher median level of overall physical activity (median 5613.0, IQR 2828.0) than the control group (n=12, median 1356.0, IQR 2937.0; Kolmogorov-Smirnov Z=1.397, P=.02, r=.33). The median adherence was 45.0 (95% CI 0.0-169.8) days for the tailored group and 111.0 (95% CI 45.1-176.9) days for the control group; however, the difference was not significant (P=.39). There were no statistically significant differences between the 2 groups in stage of change, self-efficacy, social support, perceived tailoring, anxiety, or depression.

Conclusions: Because of the small sample size and the high attrition rate at the follow-up visits, we cannot make conclusions regarding the efficacy of our approach, but the results indicate that the tailored version of the intervention may have contributed to the long-term higher physical activity maintained after cardiac rehabilitation by participants receiving the tailored intervention compared with those receiving the nontailored intervention.

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Trial Registration: ClinicalTrials.gov: NCT01223170; http://clinicaltrials.gov/show/NCT01223170 (Archived by WebCite at http://www.webcitation.org/6Nch4ldcL).

(J Med Internet Res 2014;16(3):e77) doi:10.2196/jmir.3132

KEYWORDS

rehabilitation; cardiovascular diseases; exercise therapy; eHealth; telemedicine; Internet; cellular phone; self-management; physical activity; persuasive communication; health behavior

Introduction

The burden of disease because of cardiovascular diseases (CVDs) has increased over the past several decades, currently ranking as the most common cause of death in Western Europe [1]. There is solid evidence that secondary prevention and cardiac rehabilitation programs can decrease the mortality risk and increase health among patients with CVD [2,3], and an important element of such interventions is engagement in physical activity [4,5]. There are different models for the delivery of secondary prevention and cardiac rehabilitation interventions, but Internet- and mobile-based platforms are very promising [6].

Internet- and mobile-based health interventions are easily accessible to many people and have the potential to influence the physical activity level of those people [7-9]. Reviews in the literature have indicated that under certain conditions such interventions can be useful tools in supporting self-management [7,10-15] and health behavior [16,17]. The effectiveness of these health interventions depends on the adoption of the appropriate theoretical framework [7,18-21], whereas the viability of these interventions is associated with strong user involvement in their design [22]. In addition, many successful interventions have utilized tailored content [9,16,22]. A tailored intervention is an intervention that is adapted to the characteristics of an individual, typically based on an individual's responses to a questionnaire [23]. Tailored health information is generally perceived as more interesting and personally relevant, better liked, more thoroughly read and discussed, and better remembered than nontailored educational material [16,20,24-27].

We can roughly separate the technology-based cardiac rehabilitation interventions for physical activity into 2 categories. The first category aims to replace the traditional cardiac rehabilitation programs and increase the physical activity of the participants in comparison with the baseline physical activity. The second category is complementary to the traditional cardiac rehabilitation program and aims to help the users maintain their baseline level of physical activity for a longer period of time. In 2 studies that have tested the effects of such interventions by using telephone follow-up, the results have been inconsistent [28,29].

The recommended physical activity for patients in cardiac rehabilitation varies according to their risk profile, their exercise capacity, and whether the exercise training is supervised or not [2]. The general recommendation is a minimum of 2.5 hours per week of moderate aerobic activity, in multiple bouts lasting more than 10 minutes, and evenly spread throughout the week. This should be combined with the suggestion for submaximal endurance training and weight/resistance training twice a week [4]. There is evidence that aerobic interval training in short high-intensity bouts is beneficial for patients with CVD [30] and safe [31,32]. Home-based unsupervised high-intensity training was as effective and safe as supervised hospital-based training [32], but it had lower adherence. After leaving cardiac rehabilitation, patients are expected to maintain at least the recommended level of physical activity. In Northern Norway, patients are only followed up by their family doctor after discharge and there is no formal follow-up procedure by the rehabilitation center or other specialist care structure. An intervention that would support patients in maintaining their level of physical activity after their rehabilitation stay and would assist the contact and follow-up by the specialists from the rehabilitation center has the potential to facilitate the compliance with the current guidelines for cardiac rehabilitation.

The aim of our study was to assess the effect of a tailored Internet- and mobile-based intervention on the maintenance of physical activity levels after a cardiac rehabilitation stay. Our main hypothesis was that the users of the tailored intervention would maintain their level of physical activity better than the users of the nontailored intervention (control group). In our cluster randomized controlled trial (RCT), we compared a tailored version of the intervention to a nontailored version. The study design, described previously [33], allowed us to isolate the effect of tailoring and understand how and for whom the intervention worked in a real-world setting. We developed the intervention using a methodological approach that combined user input from a focus group and health behavioral theory that we have described in detail previously [34].

Methods

Design

The study used a 2-group cluster RCT design. The clusters were randomly assigned to either the control group, which was given access to a generic version of the website and an online forum, or the tailored group, which received the tailored intervention in addition to access to the generic content and the online forum. We used parallel groups cluster randomization based on a true random number online service. The investigators and outcome assessors were blinded to the group assignments; however, for quality assurance related to technical issues, they had to uncover the assignments early during the statistical analysis process. The participants were instructed by the personnel of the rehabilitation center to use a specific number (code) that would automatically allocate them to their monthly cluster and they were not informed of their assignment condition.

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The data were collected from January 2012 until October 2013. The study measurements were made using questionnaires delivered online when the participants logged on to the Internet site while at the rehabilitation center (baseline), a short time after the planned discharge (1-3 days) from the rehabilitation center, 1 month after discharge, and 3 months after discharge (Multimedia Appendix 1). Both email and short message service (SMS) text message reminders were sent to the participants for 3 days each time they had to fill in the online questionnaire, but no further retention efforts were made. The first time the users visited the website after having received reminders about a questionnaire, they were redirected to the questionnaire. Any inconsistencies because of this were corrected to the closer follow-up time. Specifically, we analyzed at a later time point 1 response from baseline, 7 from discharge, and 4 from 1 month. Three responses from 3 months were excluded because they were closer to 1 year after discharge.

The main outcome measure was self-reported overall physical activity measured with the International Physical Activity Questionnaire (IPAQ) at 1 month and 3 months after discharge. The secondary outcome measures were self-efficacy, social support, anxiety, and depression. The process measures were the stage of change, perceived tailoring, use of the intervention, and user evaluation of the intervention.

Participants

The participants included 69 Norwegians between the ages of 33 and 75 years recruited from Skibotn Rehabilitation Center. The inclusion criteria were (1) older than 18 years, (2) history of cardiovascular disease, (3) admission to Skibotn Rehabilitation Center, (4) access to the Internet after their stay at the rehabilitation center, and (5) possession of a personal mobile phone. The study protocol was approved by the Regional Ethics Committee for health region NORD (REK-NORD), and all participants signed a consent form before being included in the study. All participants received a present of symbolic value (a water bottle with the Web address of the intervention, NOK 50-60) if they filled in the questionnaire at 1 month after discharge. The present was offered as an incentive to use the intervention and participate in the study, but also as a token of appreciation for being part of the study. The majority of the participants were referred to the cardiac rehabilitation program by their general practitioner approximately 6 months after a hospitalization for CVD, usually after myocardial infarction.

The Intervention

All the participants of the cardiac rehabilitation program were informed in a meeting about the study during their 4-week rehabilitation stay. Those who were interested met later to receive additional information, complete the consent form on paper, and receive training in the use of the intervention. During the training, the users registered and answered the baseline questionnaire online. The time of registration varied for the clusters. Then, the participants completed the normal rehabilitation stay, receiving no differential treatment while at the rehabilitation center. There were computers at the rehabilitation center where the participants could start using the intervention before their discharge. However, the usage was not prompted by the intervention, and the tailored component of the intervention for the tailored group was activated after discharge. Detailed description of the intervention, the tailoring algorithm, and the functionality of the intervention have been published in previous papers [33,34].

We used the free, open-source content management framework Drupal to implement all the necessary functionalities of the intervention. The intervention was provided free-of-charge to the users. The content of the website was created by the personnel of the rehabilitation center and the authors. The website was administered by one member of staff of the rehabilitation center, but most of the functionality, including the tailoring, was fully automated. We had minor changes and bug fixes to the intervention and some of the website content was updated, but because both groups used the same website, the changes affected both groups in the same way.

Control Group

All the participants were given access to the basic Internet-based intervention “ikkegideg.no” (Norwegian for “Don’t give up”), which contained general information about CVD and self-management, including information about diet, physical activity, smoking, and medication, as well as access to an online discussion forum (Figure 1). In the discussion forum, there were 2 levels of access. The closed group level allowed the users to create and take part in discussions that could only be accessed by those who were members of the same monthly group. In the second, open level of access, all the users were able to create, read, and take part in discussions that were visible by all the registered users of the website. The participants of the control group were also able to plan training activities (Figure 2), but they were not prompted to do it and they received no feedback.

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Figure 1. Screenshot of the discussion forum.

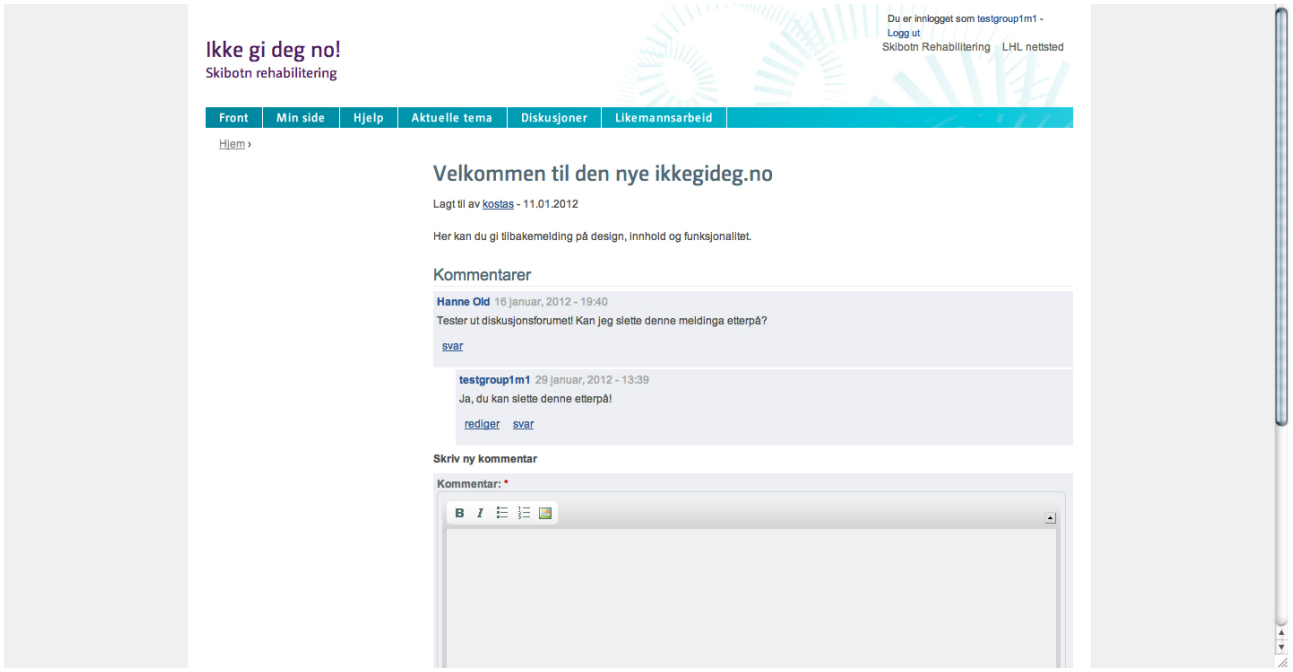
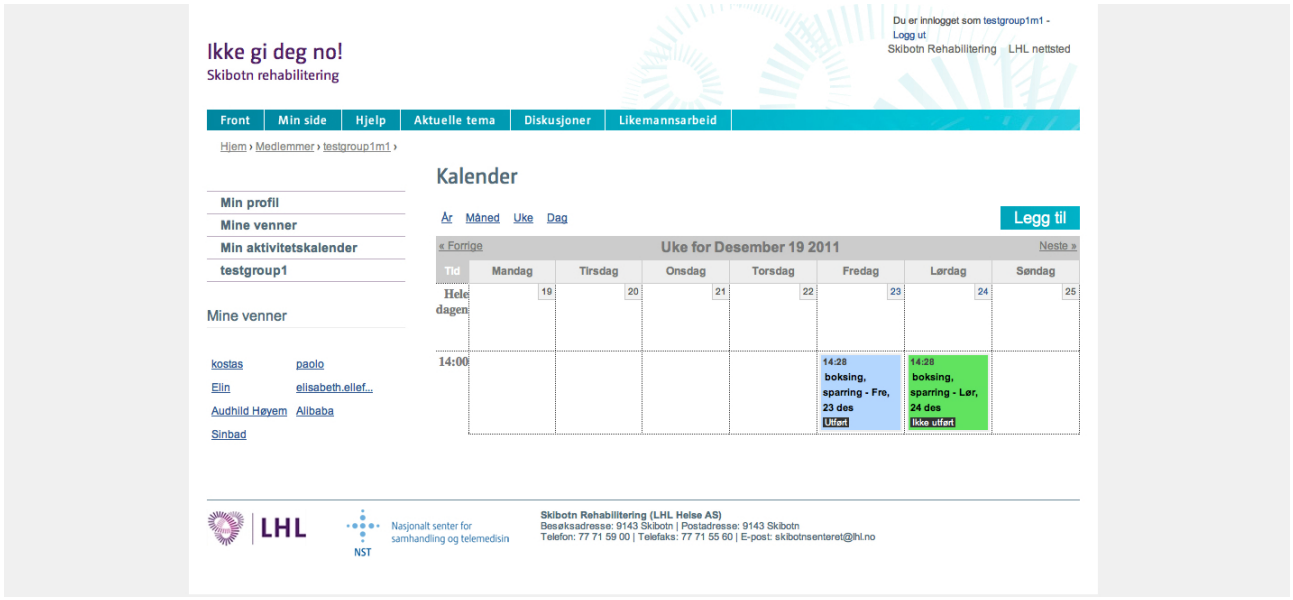


Figure 2. Weekly overview of the planned activities in the activity calendar. The usernames in the screenshot are of test users and not of real cases.



Tailored Group

The participants of the tailored group had access to the same functionality as the control group as well as access to tailored content. The participants in the tailored group were required to answer more online questions than the control group, usually every 2 weeks, and they were reminded to log in through email and SMS text messages and answer the questionnaires. Based on the tailoring questionnaires, they received tailored messages via the website and SMS text messages (Figure 3). Depending on their stage of change, the participants were asked to plan training activities or set weekly goals. They then received feedback in the form of a simple graph on the website regarding the achievement of their goals (Figure 4). If the participants planned an activity, they received an SMS text message reminder shortly before the start of the planned activity. At the end of the planned activity, they received another SMS text message asking them to confirm that the activity was completed (Figure 3). The adaptive tailoring of this intervention was based on integrative models that combined sociocognitive determinants of health behavior with a process view, such as the Health Action Process Approach (HAPA, Multimedia Appendix 2) [35]. As we have described previously [34], we tailored to the stage of change first [36], which determined if and when the other concepts were used for further tailoring (eg, self-efficacies [35,37,38] and regulatory focus [39,40]).

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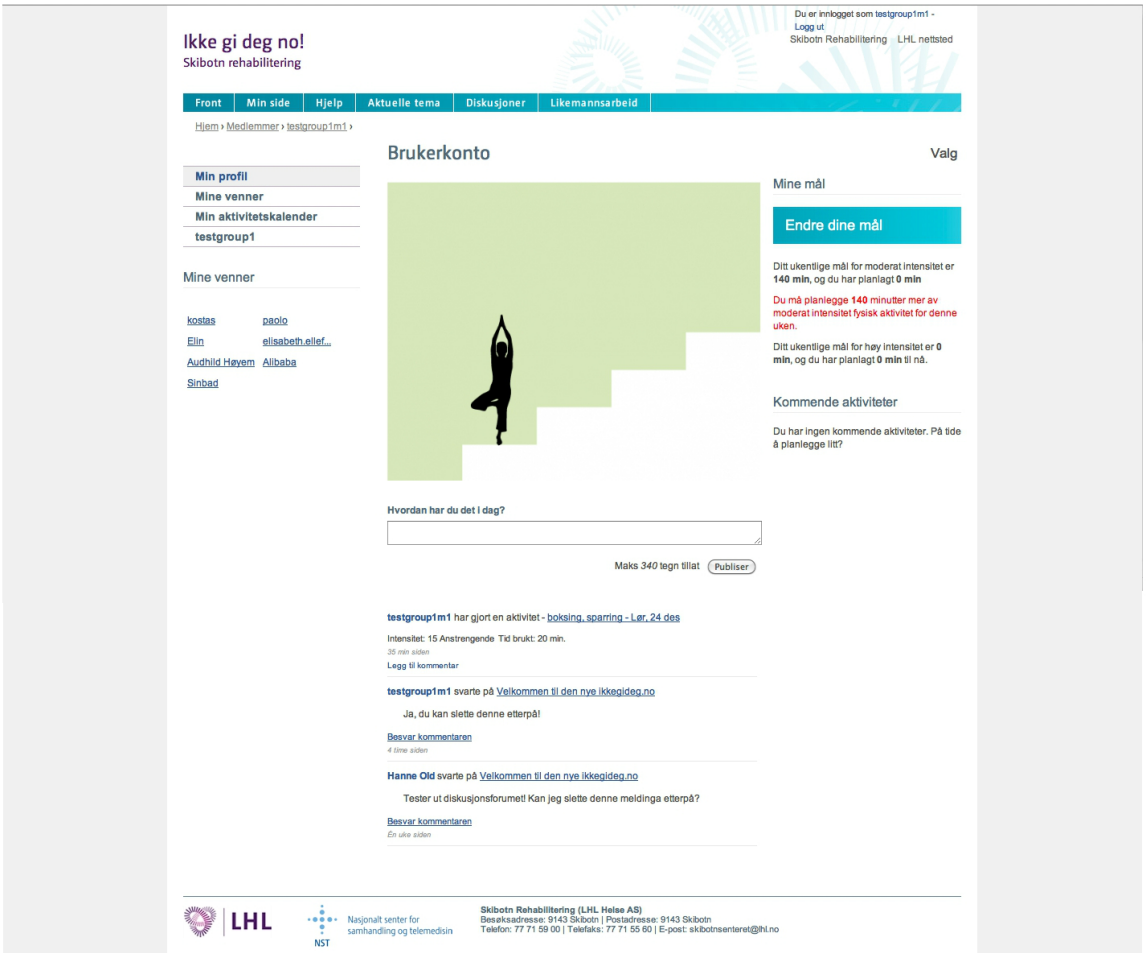
Figure 3. Sample SMS text message translations. Motivational (top): Don't give up! Both young and old benefit from physical activity. Therefore, it is never too late to start. Before planned activity (middle): Remember ball game, football/handball at 17:50. After planned activity (bottom): Did you do the activity ball game, football/handball? If so, you can confirm it by following the link.



Figure 4. Screenshot of profile page (My Page) with a graph representing the user's level of achievement of their weekly physical activity goals. The usernames in the screenshot are of test users and not of real cases.



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Measures

The background information collected included age, gender, highest level of education, weight, and height. Physical activity was measured using the IPAQ [41,42]. Adverse events and cardiovascular outcomes were not measured. The data on use were gathered through Web logging. Our intent was to measure the number of log-ins, time spent logged in, and what elements were used most for each participant. Because of a technical issue, the time spent logged in data that we collected were not reliable. Instead, we used the time between the first and last log-in as the duration of the website use. We suspect there may have been issues with the number of log-ins per user as well, but in this case, the problem affected only a small portion of the users for a limited period of time.

The stage of change was assessed using the URICA-E2 scale [43], which gives a more comprehensive assessment of the stage than simply time before or after initiation of an action. Cronbach alpha of the 4 items that represent each stage, varied from .66 to .84. Self-efficacy was measured using the perceived competence for regular physical exercise (PC-EX) scale [44]. Responses were reported using a scale from 0 (not at all) to 6 (to a great extent). Social support was assessed using an adaptation of the scale from Barrera et al (Cronbach alpha=.93) [45].

Anxiety and depression was assessed using the Hospital Anxiety and Depression Scale (HADS), which is widely and successfully used for the postdischarge period and demonstrates satisfying diagnostic usefulness for screening depression symptoms and measuring anxiety in CVD patients [46]. There are 7 items associated with anxiety that had Cronbach alpha=.88 and 7 items for depression with Cronbach alpha=.81. The perceived tailoring was assessed using 4 items from Dijkstra [47] (Cronbach alpha=.86).

The user evaluation was assessed based on whether they would recommend the site to a friend and whether they found each of the components useful. The participants were also asked to choose the component that they found most useful and the component they found least useful from a list of the components.

Statistical Analyses

We calculated the a priori sample size estimation with an equivalence test for 2 proportions in a cluster randomized design to detect 15% vs 5% differences in the proportion of meeting self-management behavior goals. For a .05 alpha level and 0.80 power, the required sample size was 16 clusters with 15 participants in each [33]. This sample size would be able to detect differences of 2608.1 metabolic equivalent of task (MET) min/week in the total IPAQ continuous score, a difference according to recent recommendations can result in up to 8% higher reduction in all-cause death or hospitalizations [2]. We used a standard deviation of 6095.9 MET-min/week [48], 0.015 intracluster correlation coefficient [49], and the program PASS version 12 (NCSS, Kaysville, Utah, USA). In practice, we recruited 18 clusters, but the interest of the participants within the groups was much lower than expected, resulting in an average recruitment of 3.8 participants per cluster. Because of the small size of the clusters and the variance in their size, in the following analyses we did not take into account the clusters but analyzed the population in 2 groups (tailored and control).

We tested the normality of the distribution with the Shapiro-Wilk test because the sample size was reduced to less than 50 after baseline. We found that we could not assume a normal distribution for the majority of the variables at most time points. Therefore, we report the median and the interquartile range (IQR) for the variables in each group, and we have used nonparametric methods to compare the 2 groups. Also, because of the small sample size, for the main outcome and for other continuous variables, we used the Kolmogorov-Smirnov (K-S) *Z* test with an exact calculation of the significance to compare the intervention with the control group. As an indicator of the effect size of the Kolmogorov-Smirnov *Z* comparisons, we calculated the strength of association, *r*. For the analysis of the categorical data, we used a chi-square test with an exact calculation of the significance and present the effect of the size with the phi coefficient (ϕ). To maximize the use of our data, we included all cases with valid data per time point and per variable.

For the analysis of adherence to the website, we used Kaplan-Meier survival curves. We used the days between the first and the last log-in and we defined “quit event” as not having used the website for the past month before the data retrieval. A Kaplan-Meier analysis can calculate the time-to-event in the presence of censored cases, such as users who are still using the website or recently recruited users. We compared the adherence curves of the tailored and control groups with the generalized Wilcoxon (Breslow) test because we expected and experienced considerably higher dropout rates at the beginning compared to the rest of the period, and the censoring patterns were similar between the groups. In contrast, when comparing the difference in adherence for gender, we used the log-rank test because we only had censored cases for the male participants.

The statistical analyses were conducted using SPSS Statistics for Mac, version 21.0 (IBM Corp, Armonk, NY, USA).

Results

Summary

The characteristics of the study participants are described in Table 1. The 2 groups were similar with respect to age, body mass index (BMI), years of education, overall physical activity (IPAQ continuous score), social support, self-efficacy, anxiety, depression, or stage of change. The flow of the participants through the study is presented in Figure 5.

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Figure 5. Flow diagram of the study.

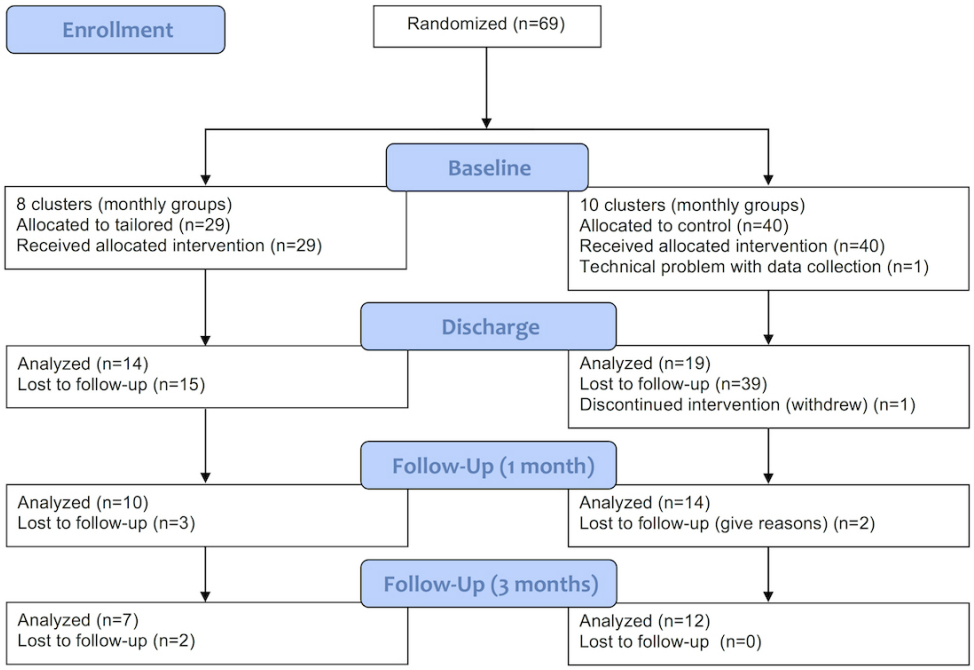

Table 1. Baseline characteristics of the participants in the tailored and control groups.

Baseline variables	Tailored group, n=29	Control group, n=38
Age (years), mean (95% CI)	59.5 (56.3-62.8)	58.8 (55.8-61.7)
Women, n (%)	7 (24)	8 (21)
BMI, mean (95% CI)	30.4 (28.8-32.0)	29.0 (27.3-30.4)
Educational attainment (years), mean (95% CI)	13.4 (11.9-14.9)	12.4 (11.4-13.4)
Social support scale, mean (95% CI)	4.2 (3.8-4.6)	4.2 (3,8-4.6)
Self-efficacy, median (IQR)	6.0 (2.0)	5.0 (2.0)
Baseline IPAQ scores (MET-minutes/week), median (IQR)		
Continuous score for walking	1386.0 (742.5)	792.00 (841.5)
Continuous score for moderate activity	1440.0 (2400.0)	930.0 (1320.0)
Continuous score for vigorous activity	3240.0 (4260.0)	2400.0 (2802.0)
Continuous score for overall activity	4266.0 (6999.0)	3810.0 (3649.1)
Hospital Anxiety and Depression Scale, median (IQR)		
Anxiety	4.0 (4.0)	5.0 (5.0)
Depression	2.0 (3.5)	3.0 (4.0)
Stage of change, n (%)		
Precontemplation	2 (7)	3 (8)
Contemplation	14 (48)	17 (45)
Preparation	1 (3)	1 (3)
Action	6 (21)	8 (21)
Maintenance	6 (21)	9 (24)

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Physical Activity

The changes in total physical activity for each group are shown in Figure 6, and the medians and comparisons for total physical activity at each time point after baseline are shown in Table 2. One month after discharge, the overall physical activity score of the tailored group (median 2737.5, IQR 4200.2) was higher than the overall physical activity of the control group (median 1650.0, IQR 2443.5). This trend continued at 3 months after discharge with the tailored group having a significantly higher median physical activity than the control group at this time point (tailored: median 5613.0, IQR 2828.0; control: median 1356.0, IQR 2937.0).

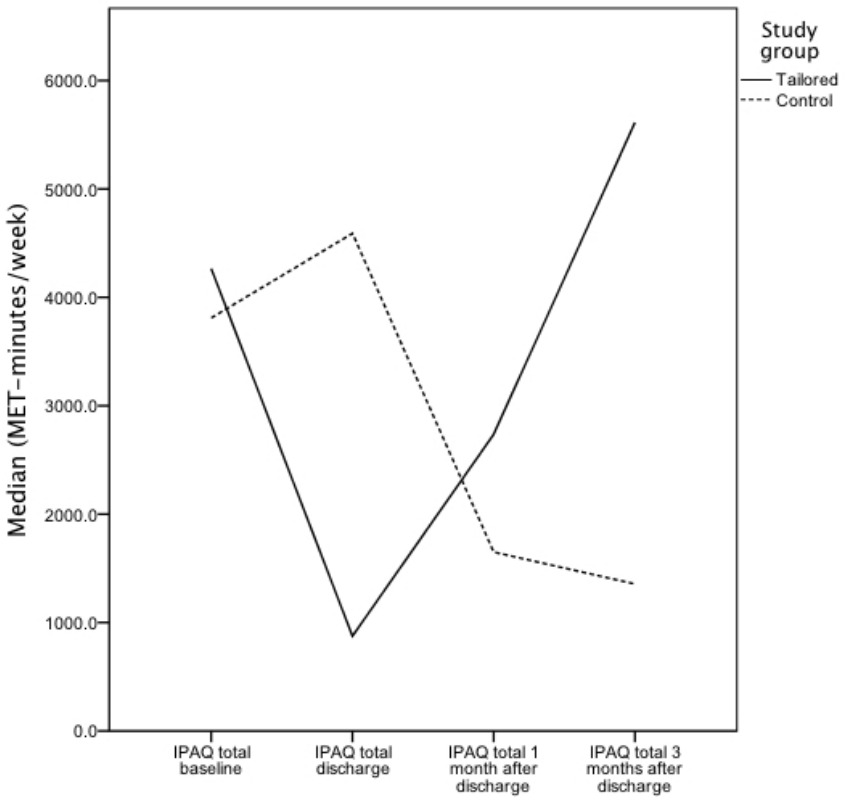
If we look at the physical activity at different intensities, we find similar patterns Multimedia Appendix 3. Typically, the control group showed a decrease in all forms of activity at 3 months after discharge compared with the baseline value, whereas the participants in the tailored group showed an initial drop in physical activity before returning to approximately baseline levels at 3 months postdischarge (Figure 6). Three months after discharge, the tailored group had significantly higher level of walking than the control group (tailored: median 940.5, IQR 891.0; control: median 486.7, IQR 742.5), whereas the differences between the 2 groups for moderate (tailored: median 1440.0, IQR 2000.0; control: median 480.0, IQR 1080.0) and vigorous activity (tailored: median 2300.0, IQR 1824.0; control: median 0, IQR 1920.0) were not statistically significant.

For the minutes per day spent sitting, we found that at 1 month after discharge, the sitting time was higher for the control group (median 300.0, IQR 300.0) than the tailored group (median 150.0, IQR 315.0) but the difference was not significant (K-S Z=0.572, P=.61, r=.14). At 3 months after discharge, the tailored group showed a greater increase in sitting time than the control group, reducing the difference between the sitting times of the 2 groups (tailored: median 280.0, IQR 155.0; control: median 360.0, IQR 180.0; K-S Z=0.816, P=.43, r=.23).

Table 2. International Physical Activity Questionnaire (IPAQ) scores for total activity for the tailored and control group.

IPAQ total	Study group				Comparison test		
	Tailored		Control		K-S Z	P	r
	n	Median (IQR)	n	Median (IQR)			
At discharge	14	875.2 (5959.5)	19	4590.0 (3978.0)	1.473	.02	.26
At 1 month after discharge	10	2737.5 (4200.2)	13	1650.0 (2443.5)	0.823	.38	.17
At 3 months after discharge	7	5613.0 (2828.0)	11	1356.0 (2937.0)	1.397	.02	.33

Figure 6. Change in International Physical Activity Questionnaire (IPAQ) total physical activity median score for each group over time.



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Secondary Outcomes

Self-efficacy at 1 month after discharge was the same for the tailored and the control group (tailored: median 5.0, IQR 2.0; control: median 5.0, IQR 1.0). At 3 months after discharge, the tailored group self-efficacy remained unchanged (median 5.0, IQR 2.0), but the self-efficacy of the control group increased slightly (median 5.5, IQR 2.0). The differences between the 2 groups were not statistically significant at 1 month (K-S Z=0.709, P=.27, r=.16) or 3 months after discharge (K-S Z=0.667, P=.36, r=.15).

Social support scores at 1 month after discharge, was the same for the tailored group (median 4.2, IQR 1.8) as for the control group (median 4.2, IQR 2.7). Three months after discharge, the social support of the tailored group increased (median 4.8, IQR 2.3), but it decreased in the control group (median 3.9, IQR 1.8). The difference between the groups was not significant at 1 month (K-S Z=0.522, P=.88, r=.12) or 3 months after discharge (K-S Z=0.775, P=.46, r=.19).

At 1 month after discharge, the control group experienced more anxiety than the tailored group (control: median 3.0, IQR 3.5; tailored: median 2.5, IQR 4.2). Three months after discharge, anxiety had increased for both groups, but was still higher in the control group (control: median 4.5, IQR 4.7; tailored: median 4.0, IQR 4.0). The difference in anxiety level between the groups was not statistically significant at 1 month (K-S Z=0.276, P=.98, r=.06) or 3 months after discharge (K-S Z=0.701, P=.44, r=.16).

At 1 month after discharge, depression in the control group was the same as in the tailored group (control: median 1.0, IQR 3.2; tailored: median 1.0, IQR 4.0). Three months after discharge, depression increased in both groups (control: median 1.5, IQR 2.0; tailored: median 2.0, IQR 2.0). The difference in the level of depression between the groups was not statistically significant at 1 month (K-S Z=0.311, P=.98, r=.06) and 3 months after discharge (K-S Z=0.576, P=.58, r=.13).

Process Measures

At 1 month after discharge, 3 of 7 (43%) of the tailored group and 4 of 8 (50%) of the control group were in the action stage. Three months after discharge, 5 of 11 (45%) of the control group participants were in the action stage and 3 of 11 (27%) were in the maintenance stage, whereas 3 of 6 (50%) of the members of the tailored group were in the action stage and the other 3 (50%) were in maintenance. Overall, the participants in both groups progressed forward through the stages of change over the course of the study (Multimedia Appendix 4). There were no significant differences between the 2 groups at 1 month (χ^2_4=2.1, P=.99, ϕ=0.37) or 3 months after discharge (χ^2_3=2.2, P=.77, ϕ=0.36).

Perceived tailoring measured at 1 month after discharge was the same in the tailored (n=6, median 3.2, IQR 1.4) and the control group (n=8, median 3.2, IQR 1.6). At 3 months after discharge, the level of perceived tailoring had increased in the tailored group (n=6, median 3.6, IQR 1.4) and remained the same for the control group (n=11, median 3.2, IQR 1.7). We did not find the difference between the 2 groups statistically significant at 1 month (K-S Z=0.694, P=.60, r=.19) or 3 months after discharge (K-S Z=0.716, P=.39, r=.17).

The adherence curve was L-shaped reaching a stable use plateau at approximately 30% (Figure 7). At 1 year from baseline, the adherence rate was 25.6% for the tailored group and 24.0% for the controls. The median for adherence time for the tailored group was 45.0 (95% CI 0.0-169.8) days and 111.0 (95% CI 45.1-176.9) days for the control group; these findings were not significantly different (Breslow χ^2_1=0.7, P=.39). The median adherence time for men was 122.0 (95% CI 14.8-229.2) days and 75.0 (95% CI 0.0-153.3) days for women; these values were significantly different (log-rank χ^2_1=4.2, P=.04).

In terms of total page views, 1 month after discharge, the tailored group had visited the website more often (median 733.0, IQR 606.0) than the control group (median 392.5, IQR 464.0). However, the difference was not statistically significant (K-S Z=1.249, P=.06, r=.27). By 3 months after discharge, the tailored group had still visited the website more often than the control group (tailored: median 1312.0, IQR 1171.0; control: median 712.0, IQR 669.0), but the difference between the 2 groups was not significant (K-S Z=0.851, P=.38, r=.19).

The user evaluation was measured at 1 month after discharge. In the tailored group, 68% (6/9) of participants would recommend the website to a friend and 69% (9/13) of the control group would do likewise, although this difference was not significant (χ^2_1=0.02, P=.99). We also asked whether the participants found the different functionality elements useful. The percentages of the participants in each group that found the various functionalities useful are presented in Table 3. The most popular general functionality was goal setting (approved by 100%, 11/11 of the participants in both groups), followed by the activity calendar (approved by 100%, 6/6 of the tailored group and 90%, 9/10 of the control group), general information (approved by 83%, 5/6 of the tailored group and 80%, 8/10 of the control group) and the discussion forum (approved by 86%, 6/7 of the tailored and 73%, 8/11 of the control group). None of these differences between groups was statistically significant.

The tailored group considered the email and SMS text message reminders and messages to be the least useful functionality elements (selected by 29%, 2/7 of participants for each). The control group considered the SMS text message reminders and messages to be the least useful (selected by 20%, 2/10 of the control group participants); for the control group, these were only the reminders to complete the study questionnaires. The activity calendar was chosen as the most useful functionality by the highest proportion of users in both the tailored group (43%, 3/7) and the control group (70%, 7/10). For both the least and the most useful functionality of the intervention, the users were presented with the same list functionalities listed in Table 3.

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Table 3. Usefulness of intervention elements.

Intervention elements	Study group, n (%)	
	Tailored	Control
General information		
Yes	5 (83)	8 (80)
No	1 (17)	2 (20)
Discussion forum		
Yes	6 (86)	8 (73)
No	1 (14)	3 (27)
Activity calendar		
Yes	6 (100)	9 (90)
No	0 (0)	1 (10)
SMS text messages and reminders		
Yes	4 (67)	5 (50)
No	2 (33)	5 (50)
Email messages and reminders		
Yes	4 (67)	7 (70)
No	2 (33)	3 (30)
Challenge others		
Yes	5 (83)	7 (70)
No	1 (17)	3 (30)
Challenged by others		
Yes	5 (83)	7 (77.8)
No	1 (17)	2 (22.2)
My page		
Yes	5 (100)	9 (100)
No	0 (0)	0 (0)
Visit other profiles		
Yes	3 (60)	5 (56)
No	2 (40)	4 (44)
Group page		
Yes	3 (60)	5 (56)
No	2 (40)	4 (44)
Questionnaires		
Yes	4 (80)	7 (78)
No	1 (20)	2 (22)
My goals		
Yes	3 (100)	8 (100)
No	0 (0)	0 (0)

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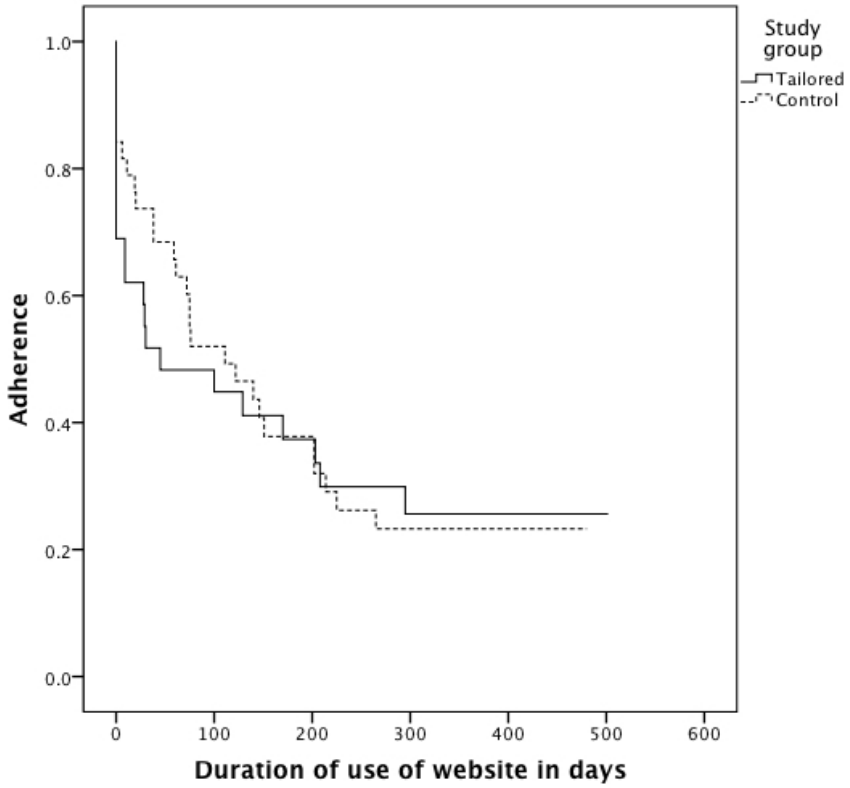
Figure 7. Adherence to the website.



Discussion

Principal Findings

The intervention had high attrition rates. At the beginning of the intervention, there was a higher dropout rate in the tailored group than in the control group. The difference in average time until dropout for the 2 groups was not statistically significant. Overall, the remaining participants in our intervention moved forward through the stages of change following their rehabilitation stay; at discharge, approximately half of the participants were in the contemplation stage, whereas 3 months after discharge, half of the participants were in the action stage. Despite the fact that half of the participants received a version of the intervention that was tailored to their stage of change, there were no differences between the groups with respect to their stage progressions. There was, however, a clinically meaningful and statistically significant difference between the groups in how well they were able to maintain their total physical activity. After discharge, the tailored group began increasing their physical activity after an initial drop, whereas the control group's physical activity decreased. This trend continued at 3 months after discharge; the physical activity of the tailored group continued to increase, whereas the physical activity of the control group continued to decline.

As the stage of change results suggest, this intervention might not have worked through the hypothesized mechanisms. The participants in the tailored group did not perceive their intervention as more personally relevant than the participants in the control group perceived theirs, and they did not consider the tailored messages received by email and SMS text message or the tailored questionnaires as particularly useful. Furthermore, the participants in the tailored group reported slightly lower self-efficacy than the control group did and approximately the same level of perceived social support as the control group.

The number of responders at 3 months was 19 of the 69 recruited at baseline (27%). This participation rate is low, but it is an expected rate for an eHealth [50] Internet-based [51] physical activity [52] intervention. There were no statistically significant differences between the 2 groups. Despite the nonsignificant difference, at the beginning of the intervention, the attrition was higher for the tailored group. A possible explanation is the increased workload of answering more questions that was required by the participants of the tailored group. The fact that the difference was not significant might be a positive sign because other studies have reported significantly higher attrition for the intervention group [53]. The dropout rate of both groups was higher at the beginning of the intervention, leading to an L-shaped adherence curve indicating that the intervention did not manage to address the needs of many users [50]. The lack of a "curiosity plateau" in the beginning, the period in which the users stay in a trial out of curiosity, might be explained by the timing of the recruitment and by the characteristics of the study population. Most of the participants of the study, especially during the beginning of their rehabilitation stay, might have been eager to employ as many methods as they could to change and maintain behavior, something that might have eased after discharge. Also, women who were interested in participating dropped out very early, significantly earlier than men. There is a known problem with cardiac rehabilitation interventions failing to address women's needs [54-56].

Another reason for the users to stop using the intervention is that they might have achieved a satisfactory (for them) level of

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activity and, therefore, did not need the help of the intervention. A similar effect has been reported in smoking cessation, where nonresponders were more likely to quit than responders [57]. In an online weight management intervention, those doing light exercise were more likely to respond at 12 months than those doing moderate or vigorous exercise [58]. For the tailored group of our intervention, the algorithm would detect that the user was in the stage of maintenance, making the intervention less intensive, but for stage detection the user would have to answer some questions. If the user had already achieved a behavior, given the least effort principle, they might not see the point in spending time answering the questions. In addition, it has been found that frequency of interaction with the system might have negative impact on adherence [22]. For the nontailored group, the lack of tailoring could have made it less appealing. We can assume that because the intervention was starting immediately after discharge from the cardiac rehabilitation program, some users would already fall into the category of having an adequate level of physical activity.

A member of staff from the collaborating rehabilitation center was the website administrator, but there were no regular planned interactions by protocol. A Delphi-type study that tried to identify issues relevant to the development of an Internet-based cardiac rehabilitation intervention among specialists, found that one of the issues that scored high in relevance and consensus was the role of the cardiac case manager [59]. The frequency of interaction with a counselor was found to be a significant predictor of adherence in Web-based interventions [22]. Also, “push” factors related to researchers’ practices to keep participants in the study also have the potential to decrease dropout attrition [50], and this might be the reason that RCTs have been found to have higher adherence than larger real-life studies [22]. In our trial, we sent an SMS text message and an email reminder daily for 3 days for the research questionnaires, but we did not have any additional follow-up phone calls or actions after a dropout. Because most of the functionalities of the intervention were automated, they required little contribution from health personnel after registration, resembling a real-world sustainable scenario for such an intervention. In this way, the nonusage attrition rate of our study is an accurate estimate of the nonusage attrition rate the intervention would have if it was implemented as a routine service. Nevertheless, it is expected that increased intervention-related interaction with health professionals will improve adherence.

Problems related to user experiences might have been a reason for low adherence [50]. Even if we developed the intervention based on user needs, some elements of the intervention would not satisfy some of the users. An example is the feedback we received from some users that they would like to be able to stop receiving SMS text messages for a defined period of time, such as if they are on holiday or sick. This affects user acceptance negatively and might lead to higher attrition. A combination of methodological, economical, and technical reasons did not allow for these changes to happen. It can also be considered as more methodologically consistent to not change an important functionality of the intervention while the trial was running. However, we found that the participants, in general, were satisfied with the intervention.

The higher level of physical activity observed in the tailored group at 3 months can be primarily attributed to an increase in walking (MET-minutes/week). This difference may be due to several factors. The motivational messages that were sent to the users based on the tailoring algorithm promoted the implementation of small everyday life changes to increase physical activity, using the strategy that the participants expressed preference for in a formative focus group [34]. In addition, it may be easier for older individuals to increase their walking rather than moderate and vigorous activity [60], and individuals in Norway might prefer walking tours over other activities either on their own or in a group because of the open-air activity culture of Scandinavia [61].

Regarding the clinical relevance of our findings, the lowest group median for overall activity was observed in the tailored group at discharge (875.2 MET-min/week) and the second lowest was observed in the control group at 3 months after discharge (1356.0 MET-min/week). Thus, all the measured activity levels in our study were close to or greater than the recommended minimum limits of energy expenditure of 500-1000 MET-min/week [62]. The same guidelines, however, emphasize the importance of moderate and vigorous activity. Walking is typically categorized as a low-to-moderate activity [2,63], although its intensity can be perceived differently for different age groups [63]. Ideally, we would also like to see differences in moderate and vigorous activity to achieve levels that can predict improvements in cardiorespiratory fitness [2,4], but this does not mean that we cannot expect a benefit from the observed improvement.

To the best of our knowledge, this is the first report of an Internet- or mobile-based computer-tailored intervention targeting physical activity in cardiac rehabilitation patients. There are, however, many relevant studies of Internet-based physical activity interventions in other populations. A review of general Internet- and/or mobile-based interventions for physical activity has found consistent evidence that such programs are effective in increasing physical activity, and the most effective interventions provided tailored guidance and ongoing support [9]. Another review of Internet-based tailored health behavioral interventions that included 23 studies targeting physical activity also suggested that there is evidence for the overall efficacy of such interventions [16]. Mobile phone-based interventions to increase physical activity have been demonstrated to have a beneficial impact on influence physical activity behavior as well, especially if they are theoretically grounded [7,64].

Strengths and Limitations

Our sample was small; therefore, our comparisons do not have enough power to confidently detect the effect of the intervention. Despite our efforts, the recruitment of participants was not at the desired levels, primarily because of the age of the participants at the cardiac rehabilitation program we recruited from. The mean age of the participants at the rehabilitation center was older than expected; therefore, interest was lower because they were less familiar with the technology we were using. In addition to the small sample size, our study was characterized by high attrition. Our study protocol did not

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include additional contact with the participants other than automated SMS text message and email reminders in the event of a dropout or nonusage, reflecting our choice to conduct a real-world trial of an automated system.

Furthermore, our control group received a nontailored version of the intervention, whereas the control group in other studies received usual care. This makes a difference between the groups even more difficult to detect, adding to the low statistical power problem. Although the design of our study might have decreased the statistical power, it helps us estimate if the tailored program is helpful and, if so, how it works and for whom. Our design was an effectiveness study design with the goal of isolating the effect of the tailoring rather than determining the effect of an intervention compared with a no-treatment control group.

Our approach, like that of many others [54-56], was not successful in addressing the needs of women; therefore, our results cannot be generalized to both genders. There were only a small number of women who were interested in the study and we had higher attrition rates among the women participants, contributing to the high attrition problem. Reasons that may contribute to the low adherence of women to rehabilitation programs include the tendency to minimize or play down the impact of their health situation to avoid burdening their social contacts, lower functional capacity after ischemic heart disease, and a lack of time due to family or social commitments [54]. Comorbidities, such as arthritis, osteoporosis, and urinary incontinence, can also make it harder for women to exercise [54]. At the focus group during the design phase of the intervention, women expressed their need for a service that would appeal to them too [34], but we did not receive enough information to determine what that meant and we assumed that the tailoring algorithm would address their individual needs. To increase the participation and adherence of women, we should have investigated more thoroughly any gender-specific barriers and needs.

The inclusion criteria of our study were very broad, allowing for the recruitment of participants within a wide age range with a variety of comorbidities. This makes it more difficult to demonstrate the effect of the intervention because it is more difficult to affect the health behavior of patients with more complicated cases or older people, and it is more difficult to isolate the effect of the intervention than in a carefully selected population. However, this makes our study a real-world trial that will help us understand if and how the intervention helps the population that needs it.

Future Research

One of the major issues identified in the intervention is the high attrition. Our future research should focus more on studying attrition, and include different elements that can reduce it. Frequent interaction between a cardiac case manager and the participants seems to have great potential in improving adherence [22,59].

The addition of at least one focus group of users who used the intervention would be interesting and would complement the study. Such an approach would offer a qualitative insight into several of the quantitative findings, especially the problem of high attrition. The intervention should be developed further to include and address the needs of women, and because women are already underrepresented at the face-to-face rehabilitation program, a different approach should be used. In this case, a focus group should be organized for CVD patients after their discharge from hospital and without having participation in a cardiac rehabilitation program as a precondition.

An interesting direction for future research would be to study the effect of such an intervention before participation in a cardiac rehabilitation program. Specifically in the case of North Norway, there is a long interval between discharge from hospital and cardiac rehabilitation; therefore, an intervention such as this can be offered during this interval. This has the potential to increase recruitment to the cardiac rehabilitation program [65] because this seems to be more problematic than long-term maintenance of physical activity [66].

Conclusion

Our main hypothesis was that participants who received a tailored intervention would maintain higher levels of physical activity over time compared to the control group. We also expected the tailored group to have better adherence to the intervention and to achieve better self-efficacy for maintenance of physical activity than the control group. The small sample size and the high attrition rate at follow-up visits in this study did not allow us to draw clear conclusions; however, the trends from our findings indicate that a tailored intervention holds promise for supporting the maintenance of long-term physical activity after cardiac rehabilitation.

Acknowledgments

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Conflicts of Interest

The authors participated in the design of the interventions described in the manuscript.

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Multimedia Appendix 1

Timing of the trial.

[JPG File, 182KB - jmir_v16i3e77_app1.jpg]

Multimedia Appendix 2

Video presenting an example of the tailoring algorithm.

[MOV File, 7MB - jmir_v16i3e77_app2.mov]

Multimedia Appendix 3

Intensity-specific IPAQ scores for the all the time points of the trial.

[PDF File (Adobe PDF File), 5KB - jmir_v16i3e77_app3.pdf]

Multimedia Appendix 4

Stage of change from discharge until 3 months after discharge.

[PDF File (Adobe PDF File), 4KB - jmir_v16i3e77_app4.pdf]

Multimedia Appendix 5

CONSORT-EHEALTH checklist V1.6.2 [67].

[PDF File (Adobe PDF File), 993KB - jmir_v16i3e77_app5.pdf]

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Abbreviations

BMI: body mass index
CVD: cardiovascular disease
HADS: Hospital Anxiety and Depression Scale
HAPA: Health Action Process Approach
IPAQ: International Physical Activity Questionnaire
MET: metabolic equivalent of task
RCT: randomized controlled trial
SMS: short message service

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Original Paper

Do Email and Mobile Phone Prompts Stimulate Primary School Children to Reuse an Internet-Delivered Smoking Prevention Intervention?

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Abstract

Background: Improving the use (eg, initial visit and revisits) of Internet-delivered interventions to promote healthy lifestyles such as non-smoking is one of the largest challenges in the field of eHealth. Prompts have shown to be effective in stimulating reuse of Internet-delivered interventions among adults and adolescents. However, evidence concerning effectiveness of prompts to promote reuse of a website among children is still scarce.

Objective: The aim of this study is to investigate (1) whether prompts are effective in promoting reuse of an intervention website containing information on smoking prevention for children, (2) whether the content of the prompt is associated with its effect in terms of reuse, and (3) whether there are differences between children who do or do not respond to prompts.

Methods: The sample of this cluster-randomized study consisted of 1124 children (aged 10-11 years) from 108 Dutch primary schools, who were assigned to the experimental group of an Internet-delivered smoking prevention intervention study. All participants completed a Web-based questionnaire on factors related to (non-)smoking. Schools were randomized to a no-prompt group (n=50) or a prompt group (n=58). All children could revisit the intervention website, but only the children in the prompt group received email and SMS prompts to revisit the website. Those prompt messages functioned as a teaser to stimulate reuse of the intervention website. Reuse of the website was objectively tracked by means of a server registration system. Repeated measures analysis of variance and linear regression analysis were performed to assess the effects of prompts on website reuse and to identify individual characteristics of participants who reuse the intervention website.

Results: Children in the prompt group reused the intervention website significantly more often compared to children in the no-prompt group (B=1.56, P<.001). Prompts announcing new animated videos ($F_{1,1122}$=9.33, P=.002) and games about (non-)smoking on the website ($F_{1,1122}$=8.28, P=.004) resulted in most reuse of the website. Within the prompt group, children with a low socioeconomic status (SES) reused the intervention website more often (B=2.19, P<.001) than children of high SES (B=0.93, P=.005).

Conclusions: Prompts can stimulate children to reuse an intervention website aimed at smoking prevention. Prompts showed, furthermore, to stimulate children of a low SES slightly more to reuse an intervention website, which is often a difficult target group in terms of stimulating participation. However, the number of revisits was quite low, which requires further study into how prompts can be optimized in terms of content and frequency to improve the number of revisits.

Trial Registration: Netherlands Trial Register Number: NTR3116; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=3116 (Archived by WebCite at http://www.webcitation.org/6O0wQYuPI).

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KEYWORDS

Internet; Internet-delivered intervention; prompts; primary school children; computer-tailoring

Introduction

Smoking prevalence rates among Dutch primary school children increase rapidly when they make the transition to secondary school [1]; therefore, it is important to prevent the uptake of smoking before positive attitudes and beliefs toward smoking are formed [2]. Internet-delivered computer-tailored interventions have the potential to be effective in promoting healthy lifestyle behaviors among adults, adolescents [3-7], and children [8,9]. Internet-delivered interventions also hold the promise of reaching large numbers of people; however, achieving that reach is a problem for all these target groups, including children. Although large numbers of children can be reached when health promotion interventions, such as smoking prevention interventions, are implemented in the school setting [10,11], dropout of children in those interventions is high [12]. Optimal use and reuse of programs is a prerequisite for achieving optimal program impact [13]. To improve use and reuse of healthy lifestyle-promoting Internet-delivered interventions and to prevent premature dropout from such programs, new strategies are required to stimulate reuse of such interventions [14,15] and to remind participants of their involvement in an intervention.

Prior studies have shown that frequent use of an Internet-delivered intervention resulted in higher smoking cessation rates among adults and adolescents [16-19]; it is to be expected that sustained use of an Internet-delivered intervention will also have a positive effect on the smoking behavior of children. However, no research concerning a dose-response relationship in smoking prevention in children is available yet. To stimulate reuse of an Internet-delivered intervention, periodic prompts may be a valuable tool [20]. Previous studies among adults [20-23] and adolescents [24,25] have demonstrated that the provision of prompts had a positive effect on reuse of an intervention website, for example on the number of log-ins. Evidence on how children respond to prompt messages when they are involved in an Internet-delivered intervention is scarce. Therefore, it is important to study the effects of prompts in primary school children to increase the potential reuse of effective interventions.

Reuse of Internet-delivered interventions is dependent on both the intervention characteristics (eg, updates of the intervention website or email contact) and the individual characteristics of the participants [23,26,27]. Furthermore, there is evidence that prompt content may be of importance for intervention use and reuse, even though no conclusive evidence has been found as to what type of content is most effective in stimulating curiosity among participants to reuse an Internet-delivered intervention. Prior research among adults has indicated that participants were more willing to log in to an intervention website if they received prompt messages containing a preview of new information compared to standard prompt messages (a message that reminded people of their previous visit and invited them to reuse the website without addressing new content added to the intervention website) [28]. Furthermore, it is plausible that individual characteristics of participants, such as age, gender, or socioeconomic status (SES), are associated with whether or not they reuse an Internet-delivered intervention [21,26,27].

Prompts can be sent in various ways and the most efficient and low-cost options may be using current technologies [ie, email and short message service (SMS)]. These can be low in cost when compared to conventional postal mail or telephone calls and are relatively easy to implement in Internet-delivered computer-tailored interventions [23,29-31]. Furthermore, the use of multimedia such as the Internet or mobile phones among Dutch children (aged 10-11 years) is relatively high (93% of these children use email and 60-69% have their own mobile phone) [32-35].

The objectives of the present study are to examine (1) whether prompts will stimulate primary school children to reuse a smoking prevention website, (2) whether the prompt content is related to its effect in terms of reuse, and (3) which individual characteristics of children are associated with a higher likelihood to respond to prompts and reuse an intervention website.

Methods

Study Design, Participants, and Procedure

The study was conducted as a cluster-randomized controlled trial in which 108 primary schools in the Netherlands were randomized to either a prompt (n=58) or no-prompt group (n=50) of a larger smoking prevention intervention study called “Fun without Smokes” [36]. Both groups had access to the Fun without Smokes website and one group received prompts reminding them to revisit the website (prompt group), while the other group did not receive prompts. Participants in the present study were children in grade 7 (aged 10-11 years). Primary schools were recruited by Municipal Health Promotion Organizations and Maastricht University for participation in the smoking prevention intervention study. Children in grade 7 of all participating schools were included in the intervention study, unless they or their parents refused to be involved (passive informed consent procedure). This study was approved by the Medical Ethics Committee of the Atrium-Orbis-Zuyd Hospital (NL32093.096.11/MEC 11-T-25).

In October 2011, all children received personalized log-in codes (username and password) to access the Fun without Smokes website (Figure 1) and were asked to fill out a Web-based questionnaire at their primary school concerning their smoking status and other factors related to smoking. After completion, children in both the prompt and no-prompt group received personalized computer-tailored feedback letters in their own email box and at the Fun without Smokes website. Those feedback letters were not only tailored to children’s personal characteristics, but also to sociocognitive variables (eg, attitude, social influences, and self-efficacy expectations) toward

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(non-)smoking. The children in the prompt group received 6 prompt messages to stimulate them to reuse the Fun without Smokes website, where they could read new information concerning (non-)smoking, play games, or watch animated videos with non-smoking content. After children completed the questionnaire at school, they were able to use the Web-based intervention at home.

Use and reuse of the website was monitored by means of server registrations. Data gathered during the first year of the intervention study (October 2011-September 2012) was used in the analyses. Since prompts were sent via email and SMS, inclusion criteria for the present study were that children had entered a complete and verifiable email address or mobile phone number and that they had indicated they actually use this email address or mobile phone number.

Figure 1. 'Fun without Smokes' website.



Intervention Website

The Fun without Smokes website was accessible to the children in both the prompt and no-prompt groups during the intervention period. Core elements of the Fun without Smokes website were the Web-based questionnaire and the computer-tailored feedback letters. Furthermore, the website provided information on non-smoking through facts concerning non-smoking, anti-smoking games, and short animated videos with non-smoking content. Furthermore, children had the opportunity to ask questions concerning (non-)smoking. To create a website that was most attractive and appreciated, children from the target group were involved in the development process [36]. It was expected that higher reuse of the website would also increase exposure to the tailored content. For that reason, children were also able to complete the Web-based questionnaire as often as they wanted and receive renewed computer-tailored feedback.

Email and SMS Prompts

In the computer-tailored feedback letters, it was indicated that participants in both the prompt and no-prompt groups were able to reuse the website during the intervention period. Children who had entered an email and/or mobile phone number in the prompt group received 6 prompt messages within 9 months to stimulate them to reuse the Fun without Smokes website. The prompts were sent via email and/or as SMS messages, depending on whether the child had provided an email account and/or mobile phone number and had indicated to use this device. Children received an email and SMS message if they provided both (ie, email address and phone number), otherwise they received only an email or SMS. Children without email or mobile phone did not receive the prompts.

All prompt messages varied in content and were sent at different time periods. The first 3 prompts were sent 1, 2, and 3 months

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after the baseline questionnaire was completed. The last 3 prompts were sent 5, 7, and 9 months after baseline. In accordance with the prompts, some of the content of the intervention website was refreshed to address a new topic relevant for smoking prevention. The prompts functioned as a teaser to increase curiosity among the children to view the new content at the Fun without Smokes website (eg, "Hi, now there is a funny game on the Fun without Smokes website. Check it out today and play this game!"). The content of the first and second prompt indicated that new facts on (non-)smoking were posted on the website (Table 1), the third prompt announced that new animated videos, including non-smoking messages, were posted on the website, the fourth prompt reported that a game was available about (non-)smoking, the fifth prompt mentioned new facts about (non-)smoking, and the last prompt announced a new game of non-smoking. Every prompt also included the personal log-in codes of the Fun without Smokes website, to make sure that the children could access the website immediately.

Participants in the no-prompt group also had access to the new information, games, and videos. However, reuse of the Fun without Smokes website was dependent on their own initiative since they did not receive any of the 6 prompt messages. They received their personal log-in codes at the baseline measurement of Fun without Smokes and were asked to save those codes. If they lost the codes, they were able to request them at the Fun without Smokes website.

Table 1. Period and content of prompts posted on the website.

Prompt	Prompt period	Prompt content
Prompt 1	1 month after baseline	Facts about (non-)smoking
Prompt 2	2 months after baseline	New facts about (non-)smoking
Prompt 3	3 months after baseline	New animated videos
Prompt 4	5 months after baseline	Game on (non-)smoking
Prompt 5	7 months after baseline	New facts about (non-)smoking
Prompt 6	9 months after baseline	New game on (non-)smoking

Measurements

Overview

Primary outcome measure of the present study is reuse of the Fun without Smokes website. Use and reuse of the website was assessed objectively by means of a server registration system. Reuse was measured as a continuous variable, based on the number of clicks (ranging from 0 to 95). Characteristics of the user and reuser such as age, gender ethnicity, and SES were derived from the baseline questionnaire that the children completed in the classroom on the Fun without Smokes website.

Assessment of Website Use and Reuse

Data on website visits was retrieved from a specific server registration system, which made it possible to register website access for each individual child. Using the personal usernames of all participating children, we tracked how often and when (date and time) they reused the Fun without Smokes website.

Reuse of the website was calculated by summing all clicks in the different website components from the first till the last prompt. The clicks in the first month of the intervention period were not included in the calculation since children of both the prompt and no-prompt groups had to complete the Web-based questionnaire at their primary school and no prompt messages were sent in this period. By using this approach, reuse of the intervention website indicates how intensively the website was reused after the prompts were sent.

Self-Reported Data Retrieved From the Baseline Questionnaire

Availability of email addresses for the participating children was measured in the Web-based questionnaire. Children were able to fill out their email address (scored as "1") or indicate if they had no email address or had forgotten their email address (scored as "0"). Children could also indicate whether they actually used their email address (coded 1) or not (coded 0).

Availability of mobile phone numbers for the participants was also measured in the questionnaire. Children having a mobile phone number were scored with a "1", whereas children without a mobile phone number or if they had forgotten their mobile phone number were scored with a "0". Children could also indicate whether they actually used their mobile phone (coded 1) or not (coded 0).

In the questionnaire, the following background variables were measured: age (in years), gender (1=boy; 2=girl), ethnicity, and SES of the participants. Ethnicity indicated whether a child had a Western or non-Western background. A child was considered to be of Western ethnic background (coded 1) if he or she and both parents had been born in the Netherlands, another European country, North America, Oceania, Indonesia (a former colony of the Netherlands), or Japan. Otherwise the child was considered to be of non-Western ethnic background (coded 2) [37]. SES was based on their postal code, which the children had provided in the questionnaire. The Netherlands Institute for Social Research (Dutch government agency that conducts research into the social aspects of all areas of government policy) calculated the SES in every 4-digit postal code area based on income, occupation, and education of Dutch inhabitants in 2010 [38]. In this study, low SES was coded with a "0" and a high SES was coded with a "1".

The data from the server registration system and the data from the baseline questionnaire could be linked by means of the personal usernames, making it possible to unobtrusively observe

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if a participant reused the intervention website after a prompt message was sent and to combine usage information with individual data of the users.

Statistical Analyses

General descriptives were carried out to describe the sample under study. Differences at baseline between characteristics of children (ie, age, gender, ethnicity, SES, having/using their email address, and having/using their mobile phone) in the no-prompt and prompt group were analyzed with chi-square and *t* test analyses.

A multiple linear regression analysis was conducted to identify whether there was a difference in website reuse between the prompt and the no-prompt groups. In this analysis, reuse of the intervention website was the dependent variable, and group and demographic characteristics were the independent variables. To identify whether there were differential effects of the prompt condition based on demographic characteristics, a linear regression analysis was done that included group*demographic variable interaction terms (ie, age, gender, ethnicity, or SES). If interaction effects were present, separate analyses were performed for two subgroups of a variable.

To indicate which prompt(s) motivated children most to reuse the Fun without Smokes website, a repeated-measures analysis of variance (ANOVA) was carried out. In this analysis, the number of clicks in the separate prompt periods were analyzed between the prompt and no-prompt group. All analyses were performed in SPSS 20.0. *P* values were said to be significant if they were equal to or lower than .05. Interaction effects were considered to be significant if the *P* value was equal to or lower than .10 to reduce potential type I errors [39].

Results

Basic Characteristics

A total of 1124 children met the inclusion criteria and were included in the analyses (13.87%, 181/1305, were excluded). As shown in Table 2, in the total sample, more girls (55.43%, 623/1124) and more children of a Western ethnic background were included (85.50%, 961/1124). Furthermore, fewer children were of high SES (43.06%, 484/1124). None of the differences between the prompt and the no-prompt groups were statistically significant. Most children had an email address and made use of this email address (98.49%, 1107/1124). A minority of the children had and used a mobile phone (15.04%, 169/1124).

Effect of Prompts on Reusing the Intervention Website

Mean reuse of the intervention website was 2.14 times (SD 7.53) in the prompt group and 0.47 times (SD 2.30) in the no-prompt group and this difference was significant (*B*=1.56, *P*<.001).

Association between Child Characteristics and Reuse of the Intervention Website

Mean reuse of the intervention website in the prompt group among children of low SES was 3.03 times (SD 9.84) and among high SES children 1.37 times (SD 4.62). Moreover, Table 3 shows that only the “group by SES” interaction term was significant (*B*=−1.22, *P*=.06). Analyses stratified for high and low SES revealed that children of low SES in the prompt group used the website more often (*B*=2.19, *P*<.001) than high SES children in the prompt group (*B*=0.93, *P*=.005). There was no significant difference observed of SES in the no-prompt group.

Table 2. Basic characteristics.

Characteristic	Total sample (n=1124)	Prompt (n=586)	No prompt (n=538)	*t*	X^2	df	*P*
Age in years, mean (SD)	10.35 (0.57)	10.32 (0.56)	10.38 (0.57)	1.62	-	1098	.11
Gender, n (%) girl	623 (55.43)	336 (57.34)	287 (53.35)	-	1.81	1	.18
Ethnicity, n (%) Western	961 (85.50)	500 (85.32)	461 (85.69)	-	0.03	1	.86
SES[a], n (%) high SES	484 (43.06)	245 (41.81)	239 (44.42)	-	0.13	1	.72
Email address, n (%) yes	1120 (99.64)	585 (99.83)	535 (99.44)	-	1.18	1	.28
Email address use, n (%) yes	1107 (98.49)	577 (98.46)	530 (98.51)	-	0.46	1	.50
Mobile phone, n (%) yes	175 (15.57)	84 (14.33)	91 (16.91)	-	0.14	1	.71
Mobile phone use, n (%) yes)	169 (15.04)	83 (14.16)	86 (15.99)	-	2.44	1	.12

[a]SES: socioeconomic status

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Table 3. Interaction effects between subgroups and group on reuse of the intervention website[a].

Group/subgroup	*B*	95% CI	*P*
Age	−1.65	−4.58 to 1.28	.27
Gender (1=male; 2=female)	0.82	−2.50 to 4.13	.63
Ethnicity (1=Western; 2=non-Western)	−0.43	−5.11 to 4.26	.86
SES[b] (0=low SES; 1=high SES)	2.26	−1.03 to 5.55	.18
Group (0=no prompt; 1=prompt)	−5.76	−17.95 to 6.44	.36
Age*Group	0.77	−0.37 to 1.92	.19
Gender*Group	−0.17	−1.46 to 1.13	.80
Ethnicity*Group	0.16	−1.68 to 1.99	.87
SES*Group	−1.22	−2.50 to 0.07	.06

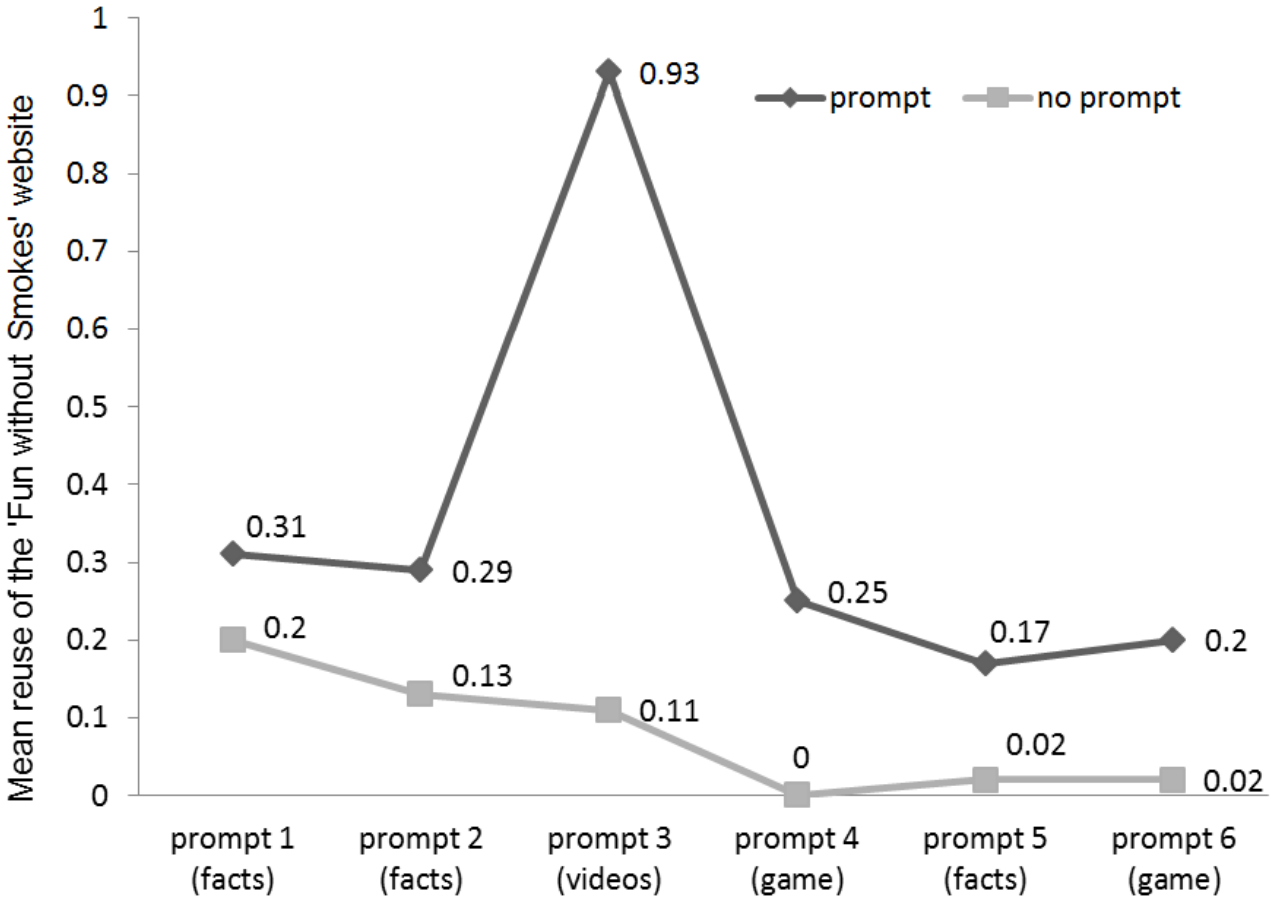
[a]R^2=.037

[b]SES: socioeconomic status

Content of the Prompts

In Figure 2, the mean reuse of the website at all 6 time points is plotted for the prompt and no-prompt groups. Reuse of the website is higher in the prompt group as compared to the no-prompt group after every prompt ($F_{1,1122}$=3.66, P=.04), with larger differences between the second and third ($F_{1,1122}$=9.33, P=.002) and between the third and fourth prompt periods ($F_{1,1122}$=8.28, P=.004). The third prompt announced that new animated videos were available at the website and the fourth prompt announced a game on non-smoking.

Figure 2. Means of reuse of the "Fun without Smokes" website between prompt and no-prompt group. X-axis time points: prompt 1= 1 month; prompt 2= 2 months; prompt 3= 3 months; prompt 4= 5 months; prompt 5= 7 months; prompt 6= 9 months.



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Discussion

Principal Findings

The aims of the present study were to investigate whether prompt messages (via email and SMS) were effective in stimulating primary school children to reuse an intervention website containing information on non-smoking, to assess whether the prompt content was associated with the reuse of the intervention website, and whether there were differences in characteristics between children who responded or did not respond to the prompt messages. Results indicated that prompts had a positive effect on reuse of the intervention website; in particular, prompts that announced new animated movies or games increased reuse more than prompts that announced new information on the website. Additionally, children with a low SES seemed to be even more responsive to the prompts than children with a high SES.

This was the first study on the effects of prompts via email and SMS on reuse of a smoking prevention website among children. Even though the prompt messages seemed to improve website reuse, the total website reuse was still very low, though comparable with what has been found for adults and adolescents [21-23,40]. This low reuse may be explained by the topic (smoking prevention) of the current study. Smoking prevalence rates among Dutch children are low (0% is a daily smoker at age 12) [1] and attitudes of children toward smoking are generally negative [41]. Other explanations may be that children were not interested or thought they had no reason to reuse the intervention website. Besides the topic of the present intervention study, there is, however, room for improvement regarding how to use prompts. One of the solutions may be found in optimizing the frequency of the prompt messages. In this study, we used 6 prompt messages that were sent at different time intervals (1 month or 2 months). Until now, it has only been known that Internet-delivered interventions benefit most from relatively short prompt timing (eg, 2 weeks) [28]; however, it was not known which time periods are most effective. Our goal was to regularly prompt children to reuse the intervention website, but not to overload them with prompt messages. In the development process of the current study, children indicated 1 or 2 months being most appreciated to receive prompt messages. The prompt messages improved reuse of the intervention website, even after the sixth prompt, which was sent almost 1 year after the initial exposure to the intervention. This may demonstrate that prompting children to reuse a website can be effective even over a longer period with changing time intervals. However, it is recommended that future studies put effort in studying the desired frequency of prompt messages by the target group, to maximize the effectiveness of prompts and reuse of the Web-based intervention. Perhaps participants would also be more motivated to respond to prompts if those prompt messages were not imposed on them but instead based on their personal preferences (ie, what kind of prompt messages they prefer to receive and when they prefer to receive them). Another solution to increase website reuse may lie in the content of the prompts. Until now, the evidence toward optimal prompt content has still been lacking [28]. According to the Elaboration Likelihood Model [42], people who are less involved in an intervention are less likely to process information. By tailoring arguments in a persuasive message (ie, prompts), peripheral cues are able to stimulate people to respond to those messages. Armstrong and colleagues [43] showed that prompts were effective in improving adherence when prompt messages contained information that was interesting to the participants, made them curious, or was customized to their personal preferences. Furthermore, interest of participants has shown to be valuable in explaining intervention use [44], since participants with increased interest spent more time reading information on a specific topic [45]. Findings of the present study show that prompt messages containing information on new animated movies and new games stimulated children most to reuse the intervention website, which indicates those messages being most effective. This might be explained since Dutch primary school children are known to be interested in playing online games (68%) or watching short movies on YouTube (95%) [34]. However, it remains unclear whether the presence of new games or animated videos stimulated the children to reuse the intervention website or whether it was the variety in prompt content. This topic should be further investigated in coming studies.

The effects of prompts appeared promising for low SES children. This is especially relevant for them since they suffer more often from health problems than high SES groups [46], are more difficult to reach to participate in Web-based interventions [27,47], and, if they are included in the intervention, they more often refrain from continued use [21,40]. The reason that low SES children seemed to respond a little bit more to the prompts may be that they are more interested in playing online games and watching online videos, whereas high SES children use the Internet more often to search for general information or for school purposes [48]. Another possibility is that low SES children are more curious about smoking, since they engage more often in smoking than high SES children when they make the transition to secondary school [1]. This possibility is also supported by a study of Crutzen et al [49], where adolescents with higher smoking and alcohol drinking intentions were more willing to use an Internet-delivered lifestyle intervention. However, according to our findings, differences concerning reuse between low SES and high SES children are small.

Strengths and Limitations

A major strength of the present study is the large and diverse sample, since a representative sample of grade 7 children from all regions in the Netherlands was included. The majority of previous studies conducted observational research or lab studies [25] in which no firm conclusions could be given regarding the effectiveness of intervention characteristics or their impact in real life. A further strength was the aggregation of both the data from a Web-based questionnaire with the data regarding use of an intervention website. By using this unique approach, it was possible to associate the individual characteristics of the participants (ie, age, gender, ethnicity, and SES) with the objectively tracked data of the intervention website and, thus, gain more insight into effects of prompts. Despite these strengths, this study was also subject to some limitations. First, it is to be expected that the results presented in this study are

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less generalizable to countries with less access to technologies such as mobile phones and the Internet. For children in more developed countries, however, these results seem to be promising. Based on national reports [35], it was expected that 60-69% of Dutch primary school children own a mobile phone. However, in the present study, only 15.57% indicated having a mobile phone and even fewer children reported actually using this device. Reasons for these low numbers may be that the children were too young to carry a mobile phone and received one just before they made the transition to secondary school. One advantage of the present study is that prompts were also sent via email, therefore children were still able to receive the prompt messages. Further, we only analyzed if children reused the intervention website but we did not verify whether they visited the website components the prompt message referred to. Our main goal was to test whether prompt messages motivated children to reuse the intervention website, so that they could be exposed to any form of smoking prevention information that was provided on the website. Another limitation might be that we did not verify the email addresses and mobile phone numbers of the children. Too many actions would have had to be taken by the children if verification of the email addresses and mobile phone numbers were mandatory and that may be a reason that they discontinued their participation in the smoking prevention intervention study. However, a tool was developed to correct misspellings in the email addresses or mobile phone numbers, which increased the likelihood that prompts were received correctly by the participating children. A final limitation is that we were not able to objectively assess whether the prompt messages were read by the participating children or if children provided social desirable answers concerning the use of their email or mobile phone. Yet the current study found effects on the number of clicks on the intervention website, which may assure that participants opened and read the prompt messages. However, it remains advisable for future research to put effort in assessing the extent to which prompt messages are actually read and used by the participants to increase reliability of the data.

Conclusions

Prompt messages via email and SMS can improve reuse of an intervention website with information on smoking prevention among children. Specifically, prompt messages that announced animated videos and games concerning non-smoking stimulated children most to reuse the website. Furthermore, prompt messages seemed to stimulate children of low SES slightly more than high SES children to reuse the intervention website.

Acknowledgments

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Conflicts of Interest

Hein de Vries is scientific director of Vision2Health, a company that licenses evidence-based innovative computer-tailored health communication tools. The other authors declare that they have no competing interests.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [50].

[PDF File (Adobe PDF File), 988KB - jmir_v16i3e86_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
SES: socioeconomic status
SMS: short message service

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Original Paper

Efficacy of a Web-Based Computer-Tailored Smoking Prevention Intervention for Dutch Adolescents: Randomized Controlled Trial

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Abstract

Background: Preventing smoking initiation among adolescents is crucial to reducing tobacco-caused death and disease. This study focuses on the effectiveness of a Web-based computer-tailored smoking prevention intervention aimed at adolescents.

Objective: The intent of the study was to describe the intervention characteristics and to show the effectiveness and results of a randomized controlled trial. We hypothesized that the intervention would prevent smoking initiation among Dutch secondary school students aged 10-20 years and would have the largest smoking prevention effect among the age cohort of 14-16 years, as smoking uptake in that period is highest.

Methods: The intervention consisted of a questionnaire and fully automated computer-tailored feedback on intention to start smoking and motivational determinants. A total of 89 secondary schools were recruited via postal mail and randomized into either the computer-tailored intervention condition or the control condition. Participants had to complete a Web-based questionnaire at baseline and at 6-month follow-up. Data on smoking initiation were collected from 897 students from these schools. To identify intervention effects, multilevel logistic regression analyses were conducted using multiple imputation.

Results: Smoking initiation among students aged 10-20 years was borderline significantly lower in the experimental condition as compared to the control condition 6 months after baseline (OR 0.25, 95% CI 0.05-1.21, *P*=.09). Additional analyses of the data for the 14-16 year age group showed a significant effect, with 11.5% (24/209) of the students in the control condition reporting initiation compared to 5.7% (10/176) in the experimental condition (OR 0.22, 95% CI 0.05-1.02, *P*=.05). No moderation effects were found regarding gender and educational level.

Conclusions: The findings of this study suggest that computer-tailored smoking prevention programs are a promising way of preventing smoking initiation among adolescents for at least 6 months, in particular among the age cohort of 14-16 years. Further research is needed to focus on long-term effects.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 77864351; http://www.controlled-trials.com/ISRCTN77864351 (Archived by WebCite at http://www.webcitation.org/6BSLKSTm5).

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KEYWORDS

computer tailoring; Web-based intervention; Internet; smoking prevention; smoking initiation; adolescents; randomized controlled trial

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Introduction

Background

Of every three young smokers, one will die as a result of their tobacco use [1]. The overwhelming majority of smokers first begin to smoke during adolescence, the period in which youngsters are most vulnerable to social influences, tobacco product marketing, and risky behavior [2,3]. In fact, 88% of all first use occurred by age 18 and 99% of all adult smokers started smoking by the age of 26 [1,4].

In adolescents, nicotine dependence develops rapidly during experimentation, often before adolescents start smoking on a daily basis [5]. Early onset of tobacco use is associated with subsequent heavier smoking and contributes to greater rates of addiction [4,5]. Moreover, the younger children start smoking and persist in the habit as adults, the greater the risk of getting lung cancer and other smoking-related diseases [2,4]. To end the tobacco epidemic, it is therefore critical to prevent smoking onset among youngsters [1].

Several effective, mostly school-based, adolescent smoking prevention programs have been developed [6,7], including in the Netherlands [8-10], with positive program effects on smoking behavior sometimes lasting for up to 15 years [11]. However, doubts exist concerning sustained effects in the years following program delivery [6,12]. School-based programs encounter several challenges in implementation, including limited time and inadequate training for teachers [13-15]. By providing easily accessible and standardized information, computer-based interactive interventions have the potential to overcome these implementation challenges [16]. Moreover, computer-based interventions can also be used to reach youngsters in an out-of-school setting [17,18]. They appear an attractive method to engage young people in smoking prevention and cessation [19,20]. Focus group results, conducted among 15-17 year old Dutch students, demonstrated that the Internet is the most desired medium for education about smoking. Adolescents preferred clear, interactive, and personal information regarding this topic [21]. Web-based computer-tailored interventions fit this need.

Computer-tailored interventions provide feedback adapted to the user's individual characteristics and needs [22]. By increasing personal relevance, tailored messages are more likely to be read, thoughtfully considered, and influence beliefs and behaviors [22-26]. Computer-tailored interventions can reach large groups of people in a cost-effective way [25,27,28], and users can take part in the intervention in private at any preferred time [29]. An additional advantage of computer-tailored interventions for schools is that, due to a semiprivate computer environment, students can be more willing to disclose personal information and smoking status [30]. Web-based computer-tailoring has proven to be successful in influencing health behaviors like nutrition and physical activity, among both adults [27,29,31] and adolescents [32,33]. Additionally, multiple studies have demonstrated the effectiveness of Web-based computer-tailored interventions for the promotion of adult smoking cessation [24,34,35].

Few studies have focused on computer-based tailored programs addressing adolescent smoking prevention. Both Prokhorov and colleagues [16,30] and Buller and colleagues [18] evaluated computer-based tailored smoking prevention programs for adolescents, consisting of multiple sessions delivered over 6 weeks. Although the results suggest that these tailored programs may be beneficial for the prevention of smoking, the researchers reported problems with recruitment and retention of adolescents. They stress the need for shorter interventions [18] that are theory-based, technologically advanced, and tailored to the needs of adolescents [30].

This paper focuses on a Web-based smoking prevention and cessation program aimed at Dutch adolescents, called "Smoke Alert", which consisted of a Web-based questionnaire and fully automated, computer-tailored feedback. Smokers were provided feedback messages about how to stop smoking and non-smokers could learn how to refrain from smoking. The Smoke Alert program addressed both smoking cessation and prevention, as adolescents in schools for this age category can be both smokers and non-smokers. The intervention presented in this study was an improved version of the Smoke Alert program that was described in an earlier study and had shown positive effects on smoking cessation [36]. This paper addresses the effectiveness of the intervention for the prevention of smoking.

Objectives

The main aim of this paper is to describe the intervention characteristics and to show the results of the randomized controlled trial on its effectiveness for the prevention of smoking among Dutch adolescents. This trial was conducted among students ranging from 10-20 years of age in order to detect whether implementation could be recommended for different age groups, since usage statistics showed that a wide age range of students participated in the previous version of the Smoke Alert program. We hypothesized that smoking initiation rates would be lower in the experimental condition at 6-month follow-up, as compared to the control condition (hypothesis 1). By targeting social influences and providing skills for refusing cigarettes, we expected the smoking prevention program to be most effective for adolescents in a context in which some of their peers already smoke [18]. Smoking initiation in the Netherlands is highest between the ages of 14 and 16, with uptake levels ranging from 7% at age 14 to 23% at age 16 respectively [37]. Consequently, we expected the program to have significant effect in particular in this specific at-risk age group (hypothesis 2). Finally, we explored whether gender and baseline education level of adolescents were potential moderators in the present study.

Methods

Design

Intervention effectiveness was studied by means of a cluster randomized controlled trial and encompassed the implementation of Smoke Alert in the experimental condition (at school). The intervention was being tested against a no-intervention control condition. Allocation ratio was 1:1 and respondents from both conditions filled out a Web-based questionnaire at baseline and at 6-month follow-up, assessing

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smoking behavior, intention to start smoking, age, gender, and educational level. The trial is registered in the ISRCTN Register (ISRCTN77864351).

Participants and Procedure

Participants in the present study were students from secondary schools in the Netherlands. The eligibility criteria for participants were: age between 10 and 20 years; having computer/Internet literacy; having sufficient command of Dutch; no previous exposure to the earlier version of Smoke Alert [36]; and being a non-smoker or former smoker. During the spring of 2011, 1380 secondary schools throughout the country were approached by sending a letter to their principals. The principals were asked to hand out the attached flyers to their teachers, inviting them to make use of a free computer-tailored smoking intervention in their classrooms, as part of an effectiveness trial. Local health departments assisted in recruiting schools through announcements on websites and in newsletters. Teachers were invited to digitally sign up for participation to the Smoke Alert intervention. After subscription, teachers received a letter with more extensive information about the purpose, design, and planning of the effectiveness study. Furthermore, a letter to inform the students' parents was attached. Teachers were requested to schedule 30 minutes, between 9 May and 10 June 2011, for the students to complete the Web-based questionnaire in the classroom. In contrast to the baseline assessment, which took place at school, the students were invited by email for the 6-month follow-up measurement. Students who did not supply a valid email address at baseline were excluded from participation in the follow-up measurement. To stimulate response, students were told that they could win an iPod or cinema voucher by participating in the follow-up assessment. Respondents in the control condition were given the opportunity to obtain computer-tailored advice after they filled out the follow-up questionnaire.

Intervention

The Smoke Alert program was based on the I-Change Model, or the Integrated Model for exploring motivational and behavioral change [38,39]. According to the I-Change Model, behavior (eg, smoking behavior) is influenced by awareness factors (knowledge, risk perceptions, and cues to action), motivational factors (attitudes, social influence beliefs, and self-efficacy), and action factors (action plans and goal actions) (Figure 1).

The previous version of Smoke Alert [36] was revised on the basis of focus group discussions with adolescents suggesting improvements such as the use of avatars, different Web design, and less extensive feedback messages. In order to increase recruitment and retention of adolescents, the revised version contained a combination of textual information with other (content-related) elements like graphics and animated videos [40-42].

The questionnaire and content of the feedback messages of Smoke Alert were updated versions of previously used questionnaires and feedback, derived from evidence-based interventions on smoking prevention and cessation [9,10,17,43]. Pilot tests revealed that the questionnaire should not be too long, resulting in a questionnaire that focused on assessing sociodemographics (age, gender, and education level), intention to start smoking, and motivational determinants.

To measure intention to start smoking, students were asked to select a statement that best described their situation, with options ranging from "I know for sure I won't ever start smoking" to "I think I will start smoking within 1 month". Three social cognitive concepts were measured according to the I-Change Model: namely, attitude towards smoking, perceived social influence, and self-efficacy not to smoke. Attitudes were assessed by 9 items that measured the pros and cons of smoking, for instance: "If I smoked, I would feel more confident", "If I smoked, it would cost me a lot of money", etc. Perceived influences from the social environment were measured by 2 items that assessed social modeling. Self-efficacy was measured with 6 items via which students could indicate how sure they were that they could remain a non-smoker in certain situations. These situations can be divided into 2 types: stressful situations (eg, feeling nervous) and social situations (eg, at a party, when friends smoke) [38]. Finally, non-smokers were asked to indicate to what extent they planned on using certain strategies when someone would offer a cigarette, for instance, using a clear "no" statement, stating the reason for refusing the cigarette, walking away, etc.

The respondents used their unique log-in information, provided by their teachers, to access the intervention website at school. Students in the experimental condition received their feedback on the computer screen immediately after filling out the questionnaire. The advice consisted of a home page, containing an introduction and a 30-second animated video, as well as several subpages, each providing feedback on a specific determinant (for a screenshot of the home page, see Multimedia Appendix 1). Facts and figures were depicted on the right and left sides of the pages, also tailored to the answers of the students. The introduction consisted of a personal greeting that contained the name of the student, followed by a confirmation of their smoke-free status and intention to start smoking. Students were praised for being a non-smoker. The animated video presented a male or female avatar and focused on reasons to refuse a cigarette (eg, "Why would I take the cigarette? My girlfriend/boyfriend would never want to kiss me anymore"). The video content was based on principles of social cognitive theory [44], also used in a previous booklet-based version in the Netherlands and Romania [8,43], and focused on social influences. The subpages of the advice addressed the psychosocial determinants.

The first subpage was dedicated to beliefs about smoking (ie, attitude). The students' beliefs were considered as a balance indicating whether he or she perceived more or less advantages than disadvantages of smoking. The students' opinion of each belief was stated and commented on. These messages had the general intention of countering beliefs about the positive effects of smoking (eg, smoking will make me feel relaxed, smoking will make me popular) and to strengthen beliefs about the negative effects (eg, smoking will cost me a lot of money). The second subpage addressed the perceived social influence. Based on students' answers, they were informed about the negative influence of smokers in their environment. When the student

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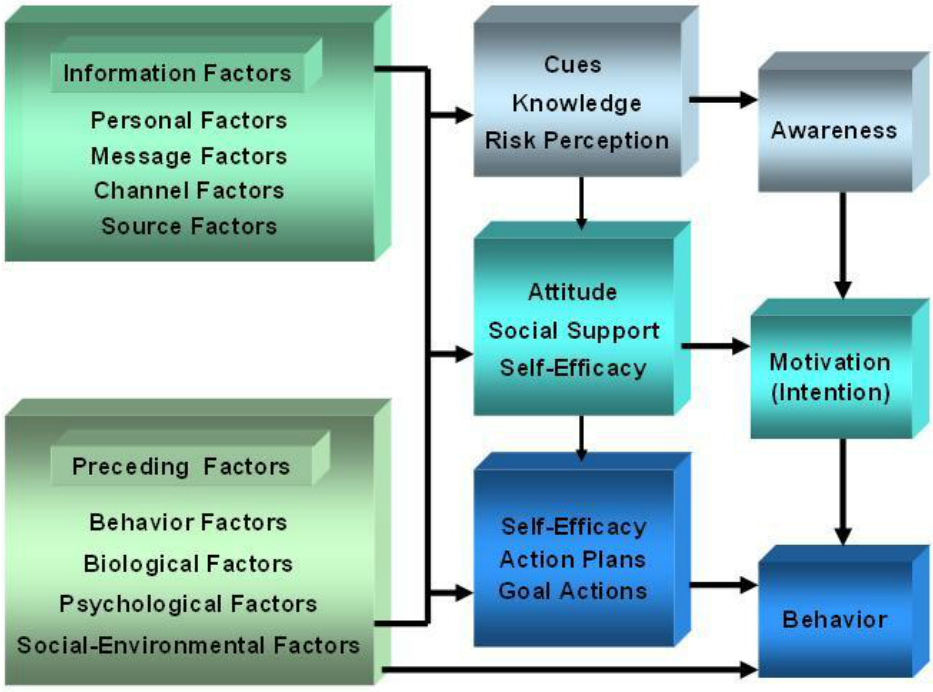
indicated having a lot of smokers in their environment, the idea of smoking as a "normal activity" was counteracted by stating that the majority of people in the Netherlands do not smoke. When most people in the environment of the student were non-smokers, the feedback confirmed that smoking is not the norm in the Netherlands. The third subpage was dedicated to self-efficacy. For situations where the student expected difficulties in remaining a non-smoker, strategies were offered to help the student to get through these situations without initiating smoking (eg, thinking about the reasons for being a non-smoker). The final subpage focused on action plans. The feedback reflected on every action plan the student had indicated he or she would use in situations where someone would offer a cigarette. Examples of action plans were provided when a student was not planning to use a certain action plan. The main message regarding action plans was: by preparing yourself for the situation when someone offers you a cigarette, you will be more confident and it will be easier to refuse the cigarette.

Examples of the computer-tailored feedback messages are provided in Table 1. A copy of the advice (a PDF file) was sent when an email address was voluntarily provided. This way, the students could re-read or print their advice at home.

Table 1. Examples of feedback messages [36].

Feedback type	Message
Intention feedback	*You don't smoke. That's great! But...do you really want to try a cigarette in the future? That would be a pity. In this advice, you'll discover what you really think about smoking.*
Attitude feedback	*Your answers show that you see a lot of advantages of smoking. That can make it difficult to remain a non-smoker. Let's have a look at your answers.*
Social influence feedback	*Almost none of your friends smoke. However, you mentioned about half of the people around you smoke. Maybe you feel like smoking is normal. But that's not true. Most people in the Netherlands do not smoke. Did you know that almost three-quarters of Dutch citizens do not smoke? So only 1 out of 4 people is a smoker.*
Self-efficacy feedback	*You find it difficult not to smoke when you're at a party. Why would you start smoking? Think about your reasons for being a non-smoker. Smoking with others at a party doesn't make you better company for your friends. That has nothing to do with cigarettes. Your friends like you for who you are. They probably think it's good that you don't smoke.*
Action plans feedback	*There's one thing you'll do when someone offers you a cigarette. You'll just say no and explain why you don't want it. Very good. For some youngsters, it's hard to say no. It's also good that you'll explain why you don't want to smoke. This way, they won't offer you a cigarette again. Think in advance what you would do when they keep pushing you. That can make you feel more confident.*

Figure 1. The I-Change Model [38,39].



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Measures

Outcome Measurements

The primary outcome measure was smoking behavior defined as smoking at least occasionally. Respondents were asked to pick a statement that best described them out of 9 smoking-related statements [9,17,36,45]. They were categorized as non-smokers if they selected one of the following statements: (1) “I have never smoked a puff”, (2) “I have tried smoking but I do not do this anymore”, (3) “I have stopped smoking. I used to smoke less than once a week”, or (4) “I have stopped smoking. I used to smoke more than once a week”. Respondents were categorized as smokers if they selected one of the following statements: (5) “I try smoking sometimes”, (6) “I smoke less than once a month”, (7) “I smoke at least once a month, but not weekly”, (8) “I smoke at least once a week, but not daily”, or (9) “I smoke daily”. To quantify the intervention effects on smoking initiation, we assessed the percentage of baseline non-smokers that indicated to smoke at follow-up.

Baseline Measurements

Intention to start smoking was measured by asking students to select a statement that best described their situation, with the following response options: (1) “I know for sure I won’t ever start smoking”, (2) “I think I won’t ever start smoking”, (3) “I think I will start smoking in the future”, (4) “I think I will start smoking within 5 years”, (5) “I think I will start smoking within 1 year”, (6) “I think I will start smoking within 6 months”, and (7) “I think I will start smoking within 1 month”. Adolescents were also asked to report their age (in years), gender (1=“male”, 0=“female”) and educational level: high (senior general secondary education / pre-university education=1) or low (practical education / lower secondary professional education=0).

Sample Size

Power analysis was based on the assumption that 2% of the experimental condition would initiate smoking 6 months after baseline, whereas among the control condition the national prevalence rate of ever smoking was expected to increase by 7% at the age of 15, the expected mean age at follow-up. To be able to detect this difference with a power of .80 at 5% significance level (two-sided testing), assuming that 95% of the schools in the control condition have uptake rates between 0.8% and 56%, corresponding with an intraclass correlation (ICC) of .34 on the logit scale, 54 schools and 702 non-smokers should be included in the study. Accounting for the efficiency loss due to unequal amounts of students per school, the number of schools was raised by 10% [46], resulting in 60 schools and 780 non-smokers. After adjusting for a potential 50% dropout at student level at 6 months [36], at least 1560 non-smokers had to be included in this study. In 2011, the national prevalence rate of ever smoking among Dutch adolescents aged 10-19 years was 37% [37]. Of these ever smokers, 47% had already stopped smoking, resulting in an expected smoking prevalence rate of 20%. To include at least 1560 non-smokers in the study, a total of 1950 students was required.

Randomization

The schools were randomly assigned to the experimental or control condition. Randomization was performed automatically by computer software that was developed specifically for the execution of Web-based computer-tailored programs [47]. The teachers were informed by email about their allocation to either the experimental or control condition, with unique log-in information for each student attached. The teachers who were allocated to the control condition were told that their students could take part in the intervention 6 months later, after filling out the baseline and follow-up questionnaire. This way, all teachers who signed up could be offered the Smoke Alert program.

Statistical Methods

All analyses were done using MLwiN (multilevel modelling for Windows), since adolescents were nested within schools. Ignoring this nesting structure may inflate type I errors and lead to too narrow confidence intervals for treatment effects [48]. Previous Dutch studies on smoking prevention at primary schools [17] and smoking cessation at secondary schools [36] also used this type of analysis. To check whether the randomization was successful, both conditions were compared on age, gender, educational level, and intention to start smoking. Dropout was checked using multilevel logistic regression analysis with attrition at post-test as outcome, and baseline demographic variables and intention to start smoking as predictors. Interaction terms of predictors with treatment condition were included in the model to analyze whether predictors for dropout differed by condition. Differences between the conditions on smoking initiation were analyzed by multilevel logistic regression analysis. Demographic variables and significant baseline differences were entered as covariates. Interactions of these covariates with treatment condition were also included to examine inequalities in the effects of the intervention on smoking initiation. Interactions with a P value higher than .05 were deleted stepwise. Effects of covariates and the intervention were considered significant if $P \leq .05$. To accommodate missing values in the effect analyses, the multiple imputation procedure in MLwiN was employed, the results being based on 50 imputed datasets. This procedure saves cases for the analysis and can be considered an intention-to-treat analysis. Analysis under multiple imputation is valid when the data are missing at random [49], that is, when the missingness only depends on variables included in the analysis. In this case, it is considered to be the best method available for imputing missing values [49].

Ethics

Students’ participation in both conditions was voluntary, respondents were guaranteed anonymity, and it was explained that they could withdraw participation at any time. This study was part of a larger study on the effectiveness of the Smoke Alert study for which ethical clearance was obtained [36].

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Results

Study Recruitment and Sample Characteristics

In total, 89 schools signed up for participation, resulting in a total of 10,500 students. At baseline, 83 out of 89 schools responded to the questionnaire, 4 schools indicated that they no longer had time to participate, and 2 schools did not explain their non-response to the baseline questionnaire. A total of 6078 students completed the baseline questionnaire, 1099 did not meet the inclusion criteria, resulting in a total of 4979 non-smokers that remained for participation in the follow-up measurement.

Mean age of the respondents at baseline was approximately 14 years (SD 1.1), with age ranging between 10 and 20 years (Table 2). Of the 4979 participants, 2518 (50.57%) were male and 2744 (55.11%) were students at a lower level of education. At baseline, no significant differences between the experimental and control condition were observed (P>.05).

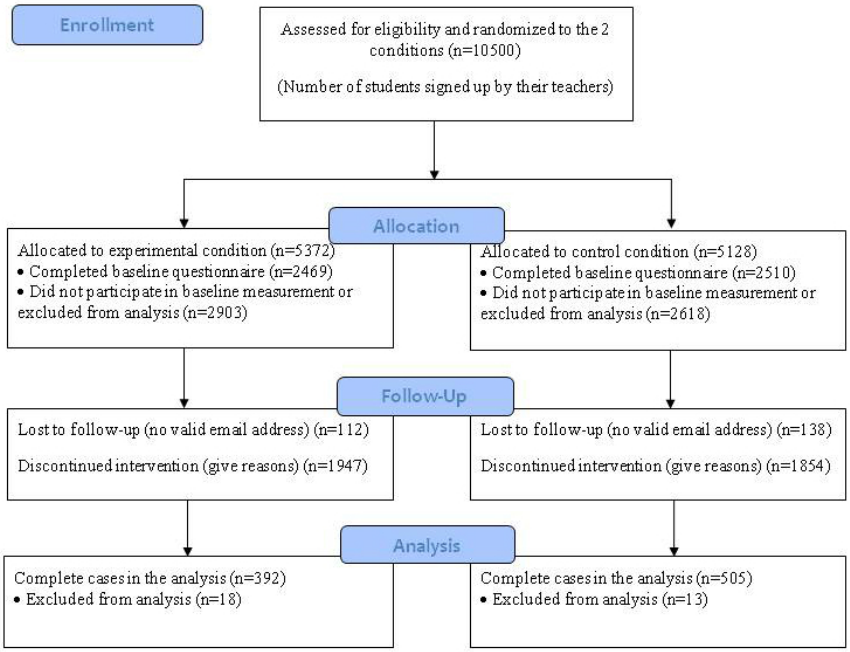
The CONSORT flowchart (Figure 2) shows the flow of respondents from enrollment in the study to allocation to the experimental (E) and control (C) condition, and whether they were included in the analysis. Of the 4979 participants that completed the baseline questionnaire (E: n=2469; C: n=2510), 4729 respondents supplied a valid email address and were invited by email to participate in the follow-up survey. After 2 email reminders, 712 participants completed the follow-up questionnaires. Non-responding students received an invitation by email to briefly indicate their current smoking status by selecting a statement that best described their behavior. This strategy resulted in a final sample size of 897 adolescents with complete data (E: n=392; C: n=505) from 64 schools at 6-month follow-up (ie, response rate 18%).

Attrition analysis showed that lower educated students were significantly more likely to drop out compared to higher educated students (OR 0.37, 95% CI 0.19-0.70, P=.002), and male students were more likely to drop out than female students (OR 1.77, 95% CI 1.11-2.82, P=.02). Furthermore, dropout was higher among respondents with a higher intention to start smoking (OR 1.37, 95% CI 1.03-1.82, P=.03). There were no significant differences (P>.05) regarding dropout between the experimental and control condition nor any significant interaction effects (P>.05) between covariates and the intervention factor.

Table 2. Baseline sample characteristics of non-smoking adolescents (n=4979), recruited in 2011.

Characteristic		Total (n=4979)	Experimental condition (E) (n=2469)	Control condition (C) (n=2510)
Age in years, mean (SD)		13.7 (1.1)	13.7 (1.0)	13.7 (1.1)
Male, n (%)		2518 (50.57%)	1220 (49.41%)	1298 (51.71%)
Educational level, n (%)				
	Low	2744 (55.11%)	1374 (55.65%)	1370 (54.58%)
	High	2235 (44.89%)	1095 (44.35%)	1140 (45.42%)
Intention to start smoking, mean (SD)		1.55 (0.7)	1.58 (0.7)	1.52 (0.7)

Figure 2. Participant flow chart.



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Effects on Smoking Initiation at 6-Month Follow-Up in the Overall Population

Of the 392 students with complete data in the experimental condition, 15 (3.8%) initiated smoking 6 months after baseline. Of the 505 complete cases in the control condition, 28 (5.5%) initiated smoking. Table 3 shows the results of the regression model predicting smoking initiation at 6-month follow-up, employing multiple imputation. After adjusting for demographic variables and intention to start smoking, the experimental condition predicted smoking initiation close to significance (OR 0.25, 95% CI 0.05-1.21, *P*=.09) with students in the control condition reporting higher initiation, yielding borderline significant support for the first hypothesis. Another significant predictor of smoking initiation was intention to start smoking, with students with a higher intention being at higher risk. The ICC, reflecting the proportion of unexplained outcome variance that was accounted for by the schools, was .73 (*P*<.001), as obtained with the regression model in Table 3.

Interactions were added to this model to analyze whether the effect of the program was gender, education, and age dependent. No significant interactions were found regarding these covariates (*P*>.05).

Table 3. Predictors of smoking initiation at 6-month follow-up.

Predictor	OR	95% CI	*P* value
Intervention (1=yes, no=0)	0.25	0.05-1.21	.09
Gender (male=1, female=0)	1.21	0.63-2.32	.56
High educational level (1=yes, no=0)	0.53	0.20-1.37	.19
Age	0.16	0.94-1.42	.17
Intention to start smoking (never=1, within 1 month=7)	2.51	1.62-3.89	<.001

Effects on Smoking Initiation at 6-Month Follow-Up Among 14-16 Year Olds

Next, in order to test our second hypothesis, an analysis was done for the age cohort of 14-16 years. There were 385 complete cases (E: n=176; C: n=209), with 24 students (11.5%) in the control condition reporting initiation compared to 10 students (5.7%) in the experimental condition. Table 4 shows the results of the analyses based on multiple imputation. After adjusting for demographic variables and intention to start smoking, condition predicted smoking initiation significantly (OR 0.22, 95% CI 0.05-1.02, *P*=.05). Similar to the analysis for the overall population, intention to start smoking was a significant predictor of smoking initiation (students with a higher intention being at higher risk). The ICC was .43 (*P*=.07).

Table 4. Predictors of smoking initiation at 6-month follow-up for students aged 14-16 years.

Predictor	OR	95% CI	*P* value
Intervention (1=yes, no=0)	0.22	0.05-1.02	.05
Gender (male=1, female=0)	1.69	0.75-3.84	.21
High educational level (1=yes, no=0)	0.43	0.11-1.63	.21
Age	2.09	1.11-3.94	.02
Intention to start smoking (never=1, within 1 month=7)	2.96	1.83-4.78	<.001

Discussion

Principal Findings

This paper describes a cluster randomized controlled trial examining the effectiveness of a computer-tailored intervention on smoking prevention, called Smoke Alert, aimed at adolescents. This trial was conducted among students aged 10-20 years in order to detect whether implementation could be recommended for a wide age range of students. We hypothesized that smoking initiation rates would be lower in the experimental condition at 6-month follow-up, as compared to the control condition. The results offered some support for our first hypothesis revealing that students in the control condition reported higher smoking initiation at 6-month follow-up. The results provided significant support for our second hypothesis, as the data for the 14-16 year age group showed a significant effect with lower smoking initiation rates in the experimental condition.

The results of this study support earlier findings that Web-based computer-tailored programs can be an effective tool in the prevention of smoking among youth [16-18]. Moreover, the results for the 14-16 year age group confirm the hypothesis of Buller and colleagues [18] that tailored smoking prevention programs targeting social influences and providing skills for refusing cigarettes will be most effective for adolescents in a context in which some of their peers already smoke. A similar conclusion was drawn from a recent Dutch smoking prevention program for 9-11 year-olds that did not reveal any effects, most likely because smoking has become less accepted leading to later onset rates among Dutch youth [50]. Based on our results, implementation of the Smoke Alert program is recommended, in particular, for students aged 14-16 years, when smoking uptake in the Netherlands is highest [37].

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Smoking initiation was lower in the experimental condition among both higher and lower educated students. This is encouraging, since educational level is one of the strongest predictors of smoking behavior [51,52]. Also, in the Netherlands, smoking is more prevalent among secondary school students with a lower educational level [37]. Effective smoking prevention programs for lower educated students could reduce the gap in smoking prevalence between lower and higher educated students.

Schools serve as an important access point to reach many adolescents. Hence, it is recommended to incorporate the intervention within the regular curriculum at school. This way, even the least motivated adolescents will participate and complete the intervention. As has been noted previously, implementation challenges at school contribute to the decay of prevention program effects over time [13]. By providing easily accessible, standardized information in a semiprivate computer environment, we expect the Smoke Alert program to overcome these implementation challenges. Further research is needed to focus on effects of the Smoke Alert program in the years following program delivery.

Limitations

There are several important limitations to consider in interpreting the results of this study. First, all measurements were self-reports. Biochemical validation may not be necessary or advisable in studies like the current study using Internet data collection without face-to-face contact [53]. In their review of tobacco cessation interventions for young people, Grimshaw and Stanton [54] noted that biochemical validation can affect recruitment and retention, and may not be a very sensitive measure of change in smoking behavior for irregular smokers. For these reasons, logistical constraints, and the fact that we promised anonymity, we did not perform biochemical verification. When confidentiality and anonymity are assured, adolescent self-reported smoking will lead to similar results as obtained by biochemical validation [55,56]. Hence, in the present study, the respondents were guaranteed confidentiality and were informed of the exclusion of their names and email addresses from the remaining answers [57].

Second, of the 1380 schools approached, only 89 agreed to participate, which may reveal an overall negative climate toward smoking prevention in the Netherlands and/or to participating in experimental studies. Most often, however, reasons for non-participation mentioned were lack of time and lack of interest, which is often the case in many schools in the Netherlands, since health promotion is not integrated into the Dutch school curriculum [10,58,59]. This clearly implies a need for health promoting policies to outline the need for adoption of evidence-based smoking prevention programs.

Third, we experienced high but equal loss to follow-up in both the experimental and control condition. The attrition at student level was 82% and outnumbered the expected dropout rate of 50%. High attrition is a well-known feature of many studies of eHealth interventions [60,61] and may be a threat to internal validity. In the current study, attrition risk may have been elevated because participants had to complete the follow-up questionnaire in their spare time, as compared to it being an activity at school [62]. Attrition analyses showed that dropout was selective. Dropout was higher among lower educated and older students and adolescents with a higher intention to start smoking. Since intention is an immediate antecedent of behavior [63], caution is warranted in generalizing the findings. Also, even though the effect analysis corrected for several covariates, the number of covariates was rather limited, implying that unobserved confounding may have occurred, thus biasing the results on the treatment's effectiveness.

Handling dropout was performed using multiple imputation, thus preserving as many cases for analysis on the intervention effects as possible. Multiple imputation is considered the best method for imputing missing values [49], provided the missing values are missing at random. The current study did not allow time for qualitative assessment of missingness due to dropout, as we promised anonymity. The most likely explanation for non-participation, as voiced by their teachers, is that the students had a lack of interest in participating in a study, rather than reasons relating to their smoking behavior. It is important to gain insight into predictors of dropout and examine strategies to enhance engagement with Web-based interventions over time and reduce the excessive rates of attrition. Web 2.0 features, like allowing adolescents to manage, display, and share their data with peers, could be incorporated in order to attract, retain, and engage adolescents [62,64], although these hypotheses require additional research.

Conclusions

Web-based computer-tailored interventions are a promising way of preventing smoking initiation among adolescents for at least 6 months, in particular among the age cohort of 14-16 years. The findings of the present study illustrate the need for smoking prevention programs beyond the 12-14 year age group that is traditionally targeted by these programs. Long-term assessment is needed to determine if the preventive effect of Web-based computer-tailored interventions is sustained in the years following program delivery.

Acknowledgments

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Conflicts of Interest

Hein de Vries is scientific director of Vision2Health, a company that licenses evidence-based innovative computer-tailored health communication tools.

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Multimedia Appendix 1

Home page showing computer-tailored feedback with animated video.

[JPG File, 114KB - jmir_v16i3e82_app1.JPG]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [65].

[PDF File (Adobe PDF File), 989KB - jmir_v16i3e82_app2.pdf]

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Review

Characterizing Periodic Messaging Interventions Across Health Behaviors and Media: Systematic Review

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Abstract

Background: Periodic prompts serve as tools for health behavior interventions to encourage and maintain behavior changes. Past literature reviews have examined periodic messages targeting specific behaviors (smoking, physical activity, diet, etc) or media (telephone, email, face-to-face, newsletter, etc) and have found them to be effective in impacting health behavior in the short term.

Objective: Our goal was to review the literature related to periodic messaging and prompts in order to explore typical characteristics, assess the role of prompt timing, identify common theoretical models used, and identify characteristics associated with the effectiveness of periodic prompts.

Methods: Electronic searches of PubMed, PsycINFO, CINAHL, and Web of Science were conducted in October 2012 and May 2013. Database search terms included variant terms for periods, prompts, interventions, media, and health behaviors.

Results: Forty-two of the 55 included research articles found that prompts resulted in significant positive behavioral outcomes for participants. Prompts were delivered via text messages, email, mailed communications, and in a few instances via phone. Generally, the provision of feedback and specific strategies to accomplish behavior change appears to be important for the success of periodic prompts. Rationale for prompt timing was rarely provided, although some studies did organize message content around days of the week or times perceived to be high risk for particular behaviors. Smoking cessation interventions tended to be organized around quit date. Among studies using theoretical models to inform their interventions, the transtheoretical model was most common.

Conclusions: Periodic messaging interventions yield positive results for short-term health behavior changes. Interventions including feedback and prompts that included strategies were more likely to report significantly positive outcomes. Work remains to better understand elements that make periodic prompts successful and whether they are effective in producing long-term outcomes.

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KEYWORDS

prompts; periodic messaging; health behavior; review, systematic

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Introduction

Technology has facilitated the delivery of periodic health messages as a low-cost alternative to repeat clinic visits or counseling in an effort to promote health behavior change. Periodic prompts have been delivered through a variety of platforms, including mobile devices. As the use of periodic messages becomes more pervasive in the health intervention literature, it is valuable to examine the characteristics that are associated with the success or failure of periodic prompts.

In 2009, Fry and Neff published a systematic review of periodic prompts in health promotion and health behavior interventions [1]. Fry and Neff focused on literature related to weight loss, physical activity, and diet. They found that periodic messaging had a positive effect, but the effect without personal counseling appeared to wane over time. This result was unclear, however, due to the heterogeneous methods used in the articles reviewed. They also found that when personal feedback was not a part of the intervention, the medium used to communicate prompts did not affect results.

Other literature reviews have also noted the value of periodic messaging. Williams et al, in a review of interventions to increase walking behavior, concluded that non−face-to-face delivery methods may be optimal for walking promotion interventions [2]. Whittaker et al's systematic review of mobile phone smoking cessation interventions found these interventions are effective at helping people quit smoking in the short term [3]. Cole-Lewis and Kershaw's review of text-messaging interventions for disease prevention and management found evidence of the short-term effect of these interventions [4]. Text messaging interventions (short message service, SMS) were reported to exhibit good acceptance and short-term efficacy in Wei et al's review on text messaging for clinical and health behavior interventions [5]. Wei et al agreed with previous reviews that more evidence was needed regarding long-term outcomes.

Recent reviews specific to Web-based interventions have pointed to the importance of better understanding the impact of an intervention's persuasive features on adherence [6,7]. In a 2012 review, Kelders et al found that significant predictors of improved adherence to Web-based interventions included increased interaction, more frequent updates, dialogue support (including praise, reminders, and suggestions) and participating in the intervention as intended by researchers [7]. Given that prompt characteristics are fundamental elements of periodic messaging interventions, additional investigation is warranted to further identify specific best practices in intervention design.

This review considers literature related to periodic messaging up until May 2013. Whereas previous reviews focused on specific health behaviors or specific media, this review expands upon this body of work by including studies that address a range of health behaviors and employ a variety of media. This review aims to (1) identify prompt characteristics that are associated with intervention effectiveness, highlighting key studies where these elements are closely examined and where lessons can be gleaned, (2) assess whether or not interventions provide rationale for the timing of prompts, and (3) identify common theoretical models used to inform message content.

Methods

In October 2012, electronic searches were conducted in PubMed, PsycINFO, CINAHL, and Web of Science. This search was not bound by dates. Keywords were customized to optimally search each database and included variant terms for periods (daily, weekly, monthly, periodic, etc), prompts (message, prompt, reminder, notice, etc), intervention (or campaign), medium (telephone, email, face-to-face, newsletter, etc), and health behavior (smoking, drinking, physical activity, diet, etc). Search results were exported into a reference manager where duplicates were eliminated.

Articles that focused on mass media campaigns, websites, knowledge, and/or awareness without addressing a behavioral outcome were excluded. Articles that used periodic messaging as a form of instruction, treatment, and/or therapy (including telehealth) were also excluded as the periodic receipt of the intervention was coincidental and did not provide insight into features used in periodic messaging interventions. Additionally, articles of high intensity interventions perceived to be difficult to replicate on a large scale due to a lack of automaticity in prompting mediums were not considered for inclusion in the final review. Articles were included in this final review if periodic prompts were used as a standalone intervention or as part of a larger program as long as periodic messaging was tied to a primary behavioral outcome, if a biological or behavioral outcome measure was used, and if ongoing health promotion behaviors were targeted. Prompts were considered periodic if they were administered more than twice.

Unique search results underwent a title review to assess relevance. Potentially relevant or ambiguous titles underwent abstract review. Abstracts clearly discussing an intervention including more than two prompts and/or containing specific behavioral outcomes were promoted to "full review". Abstracts where periodicity was unclear were also promoted at this stage.

Articles that clearly adhered to our inclusion criteria at this stage were included in the final synthesis. In cases where interventions had multiple trials, all trials with different populations were included. In the case of two articles discussing the same trial, the later trial was included. Included articles were assessed using a rating system to quantitatively represent the quality of evidence for each article. Fry and Neff adapted a rating system from a review conducted by Revere and Dunbar [1,8]. Fry and Neff's [1] adapted rating system is applied here (Table 1).

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Table 1. Rating system as adapted by Fry and Neff.

Factor	Description	Possible points
Randomization	Assignment to different intervention by chance	2
Control group	Comparison made to group of subjects not given the health behavior intervention	2
Sampling		
	Sampling method described	3
	Sample composition clearly described	
	Sample of adequate size	
	Number and ratio of withdrawals described	
Analysis of main effect variables		
	Clear definitions for each variable	1
	Clear description of methods and results	
	Numeric table presented for each effect variable	
Follow-up	Follow-up data collection measure effects beyond immediate findings	1
Content		
	Intervention clearly described and replicable	1
	Discussion of withdrawals	
	Discussion of study limitations	

Results

Summary

Searches of the selected databases yielded 1597 search results; of these, 1297 were unique articles. At the conclusion of the review of these titles, 440 were perceived as potentially relevant and underwent abstract review. Of the 440 abstracts reviewed, 108 articles were promoted for full review. Each of the 108 articles was acquired and reviewed with the exception of 5 articles for which full text was unavailable. A final set of 48 articles was included at this stage. In May 2013, an additional 119 titles were identified, 58 abstracts reviewed, and 21 articles were fully reviewed. Of these, 7 articles were included in the final review for a total of 55 articles. An additional 5 reviews on related topics, including Fry and Neff [1], were identified for comparison purposes. Figure 1 depicts the process of inclusion and exclusion for this review.

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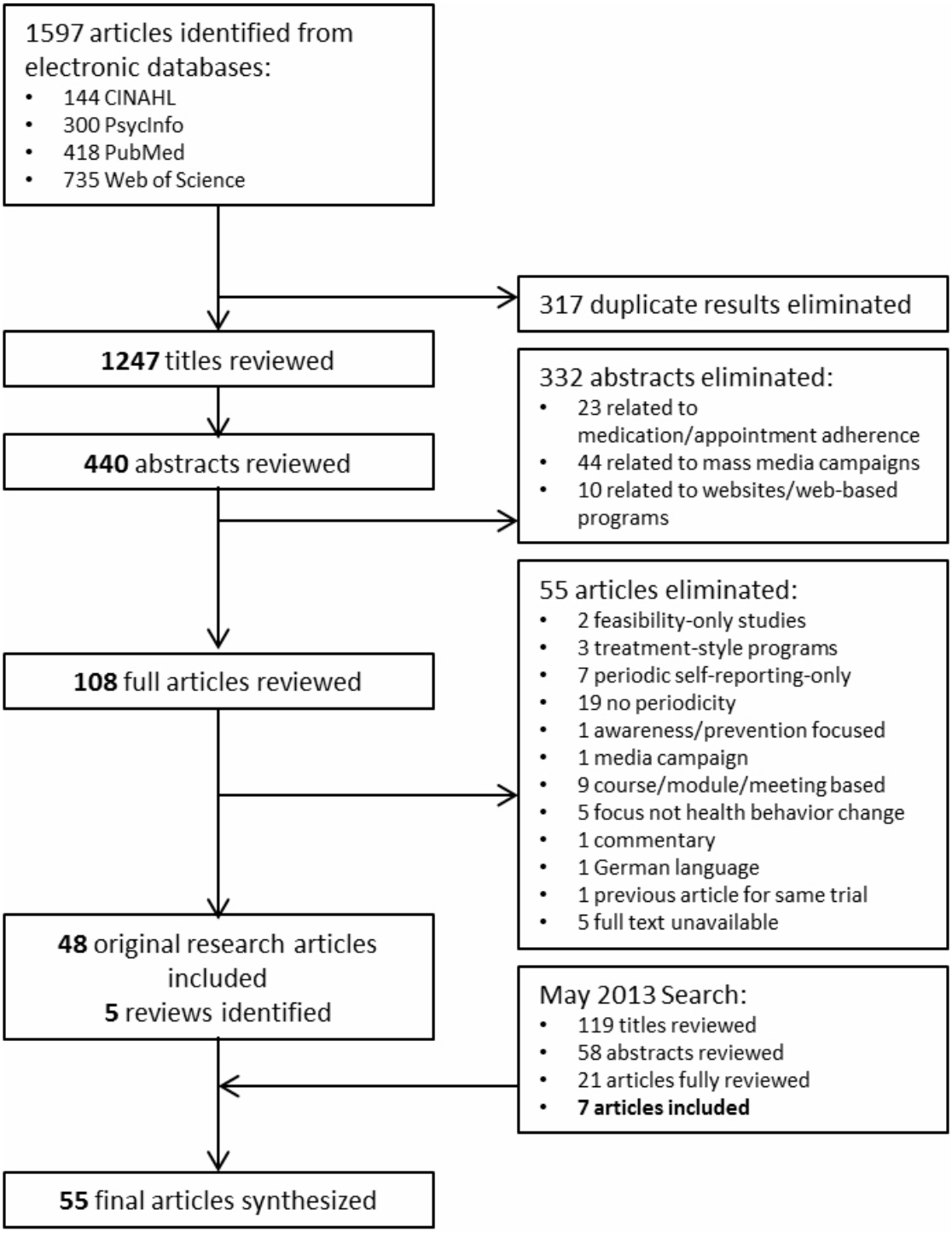
Figure 1. Inclusion and exclusion process.



Behaviors

A variety of different health behaviors have been targeted using periodic messaging including breast self-examinations [9,10], diabetes management [11-13], diet [14-30], physical activity [15-18,20,21,23-26,28,31-42], smoking cessation [43-56], methamphetamine use [57], sexual health [57,58], mammography adherence [59], and sun protection [60,61] (Multimedia Appendix 1). Of the 55 original research articles using periodic messaging identified by this review, 42 reported significant differences in behavior-related outcomes between intervention and comparison groups across all behaviors, with the exception of sun protection [60,61] and the dietary behavior of iodine consumption [22].

It should be noted that these positive findings only suggest short-term effectiveness due to the limited number of studies with long-term follow-up. Only 5 studies included in this review conducted follow-up beyond 1 month post-intervention [26,29,31,41,56]. Only 12 studies engaged in follow-up beyond the conclusion of their interventions (3 weeks-9 months). Results are mixed for whether these interventions influence long-term behavior change.

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Study Design

Out of 55 studies, 37 included process outcomes as part of their study. A total of 44 studies used a comparison group, where a group either did not receive the intervention or received one of lower intensity, such as a "usual care" intervention, and 30 studies provided participants with feedback regarding their progress.

Multimedia Appendix 2 displays each article's sample size, health behavior, duration, and design, as well as whether or not studies used controls, performed follow-up, or had additional intervention components. Study design indicates pre-test and post-test when studies involved a statistical comparison between baseline and post-intervention/follow-up measures. Multimedia Appendix 1 presents a condensed version of Multimedia Appendix 2, displaying behavior, purpose of the periodic messaging, tailoring, feedback, medium, and findings.

The purpose of using periodic messages was not consistent across all studies, primarily differing by whether the intervention was intended to deliver educational content, serve as a reminder, or both. In some contexts, prompts were part of a larger intervention, whereas in others prompts were standalone interventions. Of the 13 studies that did not report significant results, 4 provided only health education content via prompts without supplementing this information with strategies and/or counseling. These 4 studies did not provide participants with feedback, such as information about participants' progress toward health behavior goals, often in relation to milestones set by participants or the intervention. In comparison, of the 42 studies that did report significant results, only 5 delivered education-only prompts without additional tips, strategies, or other forms of guidance, with 2 of these 5 studies including feedback for participants. Thus, the effect of informational content delivery via prompts appears to be enhanced when specific strategies and/or feedback are also provided.

Generally, the provision of feedback appears to be implicated in the success of periodic messaging interventions. Of the 13 studies that did not report significant differences between intervention and comparison groups, 8 did not provide feedback to participants. Conversely, a smaller proportion that did report significant results (17 of 42 studies) did not provide feedback.

Tailoring

Tailoring prompts was a popular technique used in 34 of the 55 studies. Common tailoring strategies included tailoring using participant name, by baseline characteristics, and for interventions using the transtheoretical model, by stage of change. Only a few studies were designed to assess the effect of tailoring, comparing tailored to untailored prompts [14,17,19,36]. Hageman, Noble, and Pullen were unable to identify a significant difference in physical activity for older women who received tailored newsletters versus those who received a standard newsletter. Heimendinger et al did not find any enhanced effect on fruit and vegetable consumption by tailoring materials when participants received only one mailing, but it was advantageous when participants received four mailings, with tailored materials "more likely to be remembered, read, and appreciated" [19]. Like Heimendinger et al, Allicock et al found that the more content read from tailored newsletters and the more personally applicable readers felt the information was, the more they increased fruit and vegetable consumption [14]. De Vries et al also identified that participants receiving tailored mailings read more of the information provided than participants who received generic letters [17].

Medium

Prompts were delivered via different media across interventions, with the majority delivered via mobile messaging [11,12,20-24,35,37,42,43,45-47,49,50,52-58,62], followed by print communications [9,10,14,17,19,20,24,25,27,29,30,32,33,36,39,40,42,48,59,63], email [15,18,26,28,31,34,38,44-47,51,58,60], telephone [10,13,14,24,32, 33,39,41,45,46], and even newspaper articles [16]. The medium did not appear to impact the success of an intervention in eliciting behavior change.

Frequency

Frequencies for prompts included multiple prompts per day, daily, several times a week, weekly, monthly, bi-monthly, and even yearly (Multimedia Appendix 2). Some interventions varied their periodicity depending on progress through the intervention. This pattern was particularly dominant in smoking cessation interventions that often used quit date or stage of change to moderate the intensity of prompts [43-47,49,51-53,55,56,62]. Frequency of messages tended to be of higher intensity before and immediately following the quit date.

Interventions with both very high frequency of prompts as well as interventions of low or irregular frequency yielded positive results. With regard to low frequency, 3 studies with a monthly frequency did not report significant results, none of which provided feedback. Ten studies of monthly frequency did report significant results, 4 of which provided participant feedback. The vast majority of studies using monthly or less frequent prompts were print-based interventions.

Of the 55 studies included in this review, only Haug et al considered variation in frequency by examining whether or not frequency of text messages (1 versus 3 weekly) could impact smoking cessation [50]. No difference was identified between these two conditions.

Timing

None of the studies included in this review provided an explicit rationale for the pattern of messaging in their interventions. In most of the few studies that described the pattern and/or timing of messaging, the decision-making process of why a particular approach was taken was not discussed. Studies that described their pattern for prompt delivery are discussed further here.

Patrick et al's text messaging intervention for improved diet and increased physical activity [24] identified through their formative research that preferred number of messages per day varied across participants. During implementation, researchers chose to provide flexibility in the number and daily timing of messages. If a user did not respond to a message, the number of messages requesting replies was reduced in an effort to minimize annoyance. Overall, the intervention consisted of

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weekly topics, where messages related to the topic were sent on Mondays, Wednesdays, and Saturdays. Tips or questions were sent on Tuesdays, Fridays, and Sundays. The latter messages were tailored by eating behaviors.

Arora et al similarly used days of the week to dictate the information sent via text messages in a proof-of-concept intervention for inner city patients with poorly controlled diabetes [11]. Messages were sent three times daily, and prompts were organized by time of day as well. Prompts sent at 9 a.m. took several forms: (1) medication reminders were sent Mondays and Wednesdays, (2) healthy living challenges were sent Tuesdays and Saturdays, (3) trivia messages were sent Thursdays, and (4) a phone number for free diabetes management gifts were sent on Sundays. At all other times (noon and 6 p.m. daily), messages sent were meant to educate/motivate participants.

In an intervention targeting waist circumference and blood pressure, Park and Kim sent prompts via text messages three times weekly [23]. Monday messages were meant to "greet the new week"; messages delivered Wednesdays encouraged lifestyle modification. The third message of the week was sent on Fridays, and researchers used participant self-monitoring data to offer personalized recommendations for diet and exercise. For Reback et al's intervention to reduce methamphetamine use and high-risk sexual behaviors among men who have sex with men, study staff responded to participant text messages during hours that were identified in a formative stage as time when high-risk activity would occur [57]. It was unclear whether or not prompts were also sent during these high-risk times.

Other interventions chose to send prompts at the end of the week in order to counter potentially heightened risk during the weekend. Lim et al's sexual health intervention sent text messages to participants every 3-4 weeks, and although messages were sent at "various times and on different days", the majority of their text messages were sent on Friday and Saturday evenings while monthly emails about different safe sex or sexually transmitted infection (STI) topics were sent during the work week [58]. Dixon et al's sun protection intervention emailed UV forecasts to participants at the end of the working week to prompt sun protection behaviors over the weekend [60].

In Gierisch et al's mammography adherence intervention, reminders were delivered 2-3 months prior to participants' mammography due dates [59].

Theoretical Underpinnings

Kim and Glanz argued that health communications interventions are most effective when grounded in behavioral theory [37]. Several studies utilized theoretical models for behavior change to inform the content of prompts and/or to tailor prompts for individuals. The transtheoretical model (TTM), was the most popular foundation for the interventions identified [17,19,26,30,32-34,39,41,48,50,51,53]. Other theoretical models employed include social cognitive theory (SCT) [17,19,21,26,27,29,32,33,39,57], the theory of planned behavior (TPB) [17,26,33,48,59], the health belief model (HBM) [17,19,57,59], self-determination theory (SDT) [27], precaution adoption model (PAM) [17,30], goal setting theories [13,15,17,19,21,30,32,34,35,39,43,59], the elaboration likelihood model [59], and behavioral self-regulation [52,53]. Some studies chose several different models and/or theories to draw upon. For example, de Vries developed the I-change model, which integrates TPB, SCT, HBM, TTM, PAM, and goal-setting [17].

Two interventions directly compared theoretical models to inform the tailoring of prompts. Resnicow et al compared SCT to SDT, which "differentiates between autonomous and controlled behavioral regulation" as the building blocks for tailoring newsletters designed to increase fruit and vegetable consumption [27]. Participants who received newsletters tailored using the SDT and motivational interviewing principles/strategies perceived their newsletters as marginally more relevant than participants who were provided SCT-based newsletters. However, no between-group differences in fruit and vegetable intake at 3 months were found; each group showed similar improvement.

With regard to support theories, Gabriele et al tested the effects of nondirective and directive e-coach support on weight loss [18]. Researchers hypothesized that individuals in the nondirective support condition ("cooperation and accepting the support recipient's thoughts and choices") would show greater changes in diet and physical activity than those in the directive support condition ("prescriptive and guided by rules"). However, Gabriele et al found greatest loss of weight and waist circumference for directive support participants.

Participant Feedback

Information regarding participant experience was solicited in 28 of the included 55 studies. Multimedia Appendix 2 summarizes information regarding participant feedback for all studies where this information was available. Overall, participants expressed that prompts were helpful and reported high satisfaction with the interventions for which this information was available [11,14,15,20,24,36,39,44,45,48,52-54,58]. Participants reported reading emails with less frequency than text messages [43]. In another intervention, email was preferred over paper or website [26]. Tailored material was perceived by participants to be personally meaningful and/or helpful [14,15,17,19,42,63]. Participants in Faridi et al's text messaging diabetes management intervention reported that low adherence was likely due to an interface that was not user-friendly or was due to inexperience with mobile phone use [12]. Fjeldsoe et al suggested that assessment burden was a possible reason for attrition in their text messaging exercise intervention [35].

Discussion

Principal Findings

Periodic prompts have been used extensively in health behavior interventions over the past decade. This review identified 55 original research articles related to a variety of behaviors, with 42 bearing evidence of short-term behavioral changes, and 3 studies additionally suggesting long-term behavioral changes.

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Given that the included interventions varied by many factors, including behavior, prompt, use of feedback, goal-setting, and theoretical models, it is difficult to form a conclusive judgment regarding which combination of elements is most effective. What is clear, however, is that periodic messaging has positive short-term effects across a number of health behaviors and across media and frequency. Unfortunately, the sustainability of these outcomes remains a concern due to the small number of studies that conducted follow-up beyond the conclusion of their interventions.

Only a small subset of studies compared the use of specific features, thus little is known regarding best practices to appropriately leverage tailoring, frequency, timing, and the use of theoretical models in periodic prompting interventions. For those looking to structure periodic messaging interventions, participants tend to read more of the information provided in tailored materials versus untailored materials [17,19]. It also appears that the effect of tailoring is more evident upon the receipt of more than one tailored message [14,19]. Generally, participants show preference for tailored messages/materials over untailored content [14,15,17,19,42,63]. Directive support appeared to be more beneficial in impacting weight and waist circumference than nondirective support [18]. Participants appear to prefer text messages over emails [43] and emails over paper materials or websites [26]. Additionally, this review has identified feedback as an important factor in determining prompt intervention success. Studies with significant results tended to provide participants with feedback regarding progress in making a given health behavior change. Interventions with prompts delivered on a monthly basis did better if they included feedback. Enhancing prompt content with specific strategies also appeared to be associated with intervention success.

All media, including printed/mailed materials, were successful in encouraging health behavior changes, though text messaging allowed for the greatest number of prompts to be delivered on a daily basis. Unfortunately, information regarding whether particular patterns of messaging are most effective for specific behaviors and media is unclear. Authors of the included trials offer sparse rationale for decisions regarding the timing and frequency of their interventions. Only Haug et al compared prompt frequency (1 vs 3 text messages weekly) and found no differences between the two frequency conditions [50]. This missing information would be incredibly valuable as prompt frequency and days of prompt delivery may be most impactful for participants. For smoking cessation, periodic messaging interventions tend to use quit day to dictate the crescendo of prompt frequency, and still other interventions targeted times when they felt participants would be most at risk for engaging in negative behaviors. Other interventions may also benefit from targeting specific days and/or time of the week where prompts would be most likely to be acknowledged.

Although we characterize the use of comparison groups, process evaluation, follow-up, feedback, tailoring, and other characteristics of these interventions, the espousing of specific facets as “best practice” is a challenge and a limitation of this review. Typical attrition for these interventions was also difficult to assess due to the automated nature of many of these prompts (ie, participants may not have formally withdrawn from the study but may stop acknowledging the majority of messages sent). As is the nature of all reviews, the reach of articles reviewed is another limitation, reflecting the search terms used in the databases utilized. It is also possible that our inclusion/exclusion criteria may have excluded articles that could have also characterized the nature of periodic messaging.

This review sought to identify the behaviors that have been targeted by periodic prompts, the outcomes of these interventions, and the variety of approaches that have been used, in order better understand how to best use periodic prompts for health behavior change. Our review is robust due to our systematic approach; we were able to ensure that we were inclusive with regard to both prompt medium and targeted health behaviors. Additionally, each study was rated in such a way that allows for between-study comparisons despite the diversity in study design.

Conclusions

In light of this review, it is suggested that future periodic messaging interventions be conducted purposefully in order to better examine what elements make these interventions successful. Although this review identified cases that compared frequency of contact, prompt medium, and theoretical frameworks, work remains to be done to identify best practices for these interventions. Additionally, future studies should communicate the rationale behind decisions regarding the pattern and content of messages to identify whether or not there are optimal times and situations when these messages should be administered for particular populations. Finally, future periodic messaging interventions should consider the long-term benefits of the intervention by observing a substantial follow-up period post intervention. Despite the breadth of literature demonstrating the use of periodic messaging for several health behaviors, much work remains to be completed that provides evidence for the frequency and timing of the messages and sustainability of outcomes for these interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary table of purpose, features, and medium for included periodic messaging interventions.

[PDF File (Adobe PDF File), 40KB - jmir_v16i3e93_app1.pdf]

Multimedia Appendix 2

Features of included periodic messaging health interventions.

[XLSX File (Microsoft Excel File), 80KB - jmir_v16i3e93_app2.xlsx]

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Abbreviations

HBM: health belief model
PAM: precaution adoption model
SCT: social cognitive theory
SDT: self-determination theory
SMS: short message service
STI: sexually transmitted infection
TPB: theory of planned behavior
TTM: transtheoretical model

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Original Paper

Does Brief Telephone Support Improve Engagement With a Web-Based Weight Management Intervention? Randomized Controlled Trial

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Abstract

Background: Recent reviews suggest Web-based interventions are promising approaches for weight management but they identify difficulties with suboptimal usage. The literature suggests that offering some degree of human support to website users may boost usage and outcomes.

Objective: We disseminated the POWeR ("Positive Online Weight Reduction") Web-based weight management intervention in a community setting. POWeR consisted of weekly online sessions that emphasized self-monitoring, goal-setting, and cognitive/behavioral strategies. Our primary outcome was intervention usage and we investigated whether this was enhanced by the addition of brief telephone coaching. We also explored group differences in short-term self-reported weight loss.

Methods: Participants were recruited using a range of methods including targeted mailouts, advertisements in the local press, notices on organizational websites, and social media. A total of 786 adults were randomized at an individual level through an online procedure to (1) POWeR only (n=264), (2) POWeR plus coaching (n=247), or (3) a waiting list control group (n=275). Those in the POWeR plus coaching arm were contacted at approximately 7 and 28 days after randomization for short coaching telephone calls aimed at promoting continued usage of the website. Website usage was tracked automatically. Weight was assessed by online self-report.

Results: Of the 511 participants allocated to the two intervention groups, the median number of POWeR sessions completed was just one (IQR 0-2 for POWeR only, IQR 0-3 for POWeR plus coach). Nonetheless, a substantial minority completed at least the core three sessions of POWeR: 47 participants (17.8%, 47/264) in the POWeR-only arm and 64 participants (25.9%, 64/247) in the POWeR plus coaching arm. Participants in the POWeR plus coaching group persisted with the intervention for longer and were 1.61 times more likely to complete the core three sessions than the POWeR-only group (χ^2_1=4.93; OR 1.61, 95% CI 1.06-2.47; n=511). An intention-to-treat analysis showed between-group differences in weight loss ($F_{2,782}$=12.421, P<.001). Both intervention groups reported more weight loss than the waiting list control group. Weight loss was slightly, but not significantly, greater in the POWeR plus coaching group. A large proportion of participants assigned to POWeR plus coaching refused phone calls or were not contactable (57.9%, 143/247). Exploratory analyses identified health and sociodemographic differences between those who did and did not engage in coaching when it was made available to them. Users who engaged with coaching used the intervention more and lost more weight than those who did not.

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Conclusions: In common with most Web-based intervention studies, usage of POWeR was suboptimal overall. However, our findings suggest that supplementing Web-based weight management with brief human support could improve usage and outcomes in those who take it up.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 98176068; http://www.controlled-trials.com/ISRCTN98176068 (Archived by WebCite at http://www.webcitation.org/6OKRjM2oy).

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KEYWORDS

weight loss; obesity; Internet; adherence; behavioral; randomized controlled trial

Introduction

Background

Internationally, obesity is one of the biggest public health concerns [1]. Interventions that promote changes in diet and physical activity and include behavior modification techniques such as goal setting and self-monitoring are considered the gold standard of treatment [2]. However, high cost and low access limit the reach of such programs when delivered face-to-face by health professionals [3,4]. The Internet has emerged as a promising way to reach greater numbers of individuals at low cost and, in recent years, various Web-based weight loss programs have been developed and evaluated [4-10].

Despite holding promise as potentially cost-effective interventions, recent reviews of Web-based weight loss interventions have found that effect sizes for weight loss tend to be fairly modest, with substantial heterogeneity in outcomes, and many online programs suffer from suboptimal engagement [11-13]. Such findings are not limited to Web-based weight loss interventions but are common across different types of eHealth interventions.

One possible explanation for variations in the efficacy of and engagement with Web-based interventions is the variation in the human contact participants have to support them as they participate in the Web-based program. Human support may be in various formats including face-to-face individual or group meetings, telephone calls, text messages, emails, or online chat. It may be from health professionals, researchers, or technicians and may serve various purposes ranging from answering technical queries, to encouraging prolonged use, to providing substantial therapeutic input. Taken as a whole, the eHealth literature suggests that engagement and behavioral or health outcomes for Web-based interventions tend to be better when usage is accompanied by some form of human contact [14,15]. For example, within the Web-based mental health literature, meta-analyses show larger effect sizes for interventions that also include some contact with a therapist than interventions that are wholly Web-based [16,17], and qualitative studies suggest some participants perceive a need for human contact and support [18,19]. In the field of physical health and weight management, reviews have identified contact, counselling, and support from a health professional as key elements responsible for high engagement and effectiveness of Web-based interventions [20,21]. Interestingly though, the few randomized controlled trials (RCTs) of weight management programs that have directly compared different types or intensities of human support have not always found evidence that higher support versions have superior engagement or weight-related outcomes [4-6]. Yet, in these trials, even participants in the ostensible minimally-supported website arms actually received considerable human contact and support, including initial orientation to the website and contact with the research team throughout the trial [4,5] and counsellor-facilitated online chatrooms [6]. Therefore, these trials cannot provide clear comparisons between Web-based interventions provided with and without human support. Furthermore, recent reviews have drawn attention to how the mixture of modalities and features in Web-based interventions complicates the task of teasing out the impact of any specific component within and across research studies [22].

Overall, there has been insufficient research focused on how to use human contact to boost engagement with Web interventions. This is an important research topic since extensive reach and low marginal cost per additional user are among the key proposed benefits of Web-based interventions [13]. Despite this, many Web-based weight management interventions evaluated to date have featured face-to-face orientation sessions plus various forms of telephone, email, Web chat, or face-to-face contact with a health care professional or researcher during the intervention period [4-8]. By adding human support, the cost and reach benefits may be undermined because costs increase when staff are required, particularly if support is provided by highly trained professionals. Gaining a better understanding of what types of human contact boost engagement with Web interventions, and investigating brief and low-cost formats for such support, is therefore of great importance. It is equally important to understand how human contact/support might influence engagement with and effectiveness of Web interventions. A clear framework for this has been absent until recent theoretical work on “Supportive Accountability”’ [14], which proposes that human support can enhance adherence to eHealth interventions through accountability to another person. Accountability is the expectation that an individual may be called upon to explain his or her actions to another person. The model hypothesizes that successfully fostering “Supportive Accountability” involves some human presence, either face-to-face, or remotely. The model considers progress monitoring to be central to fostering accountability and proposes ways in which to conduct this in an effective and acceptable way. A recent trial using telephone coaching based upon this model showed that this form of human support increased adherence to a Web-based depression intervention [23].

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Current Study Context and Aims

In the current study, we disseminated "POWeR" (Positive Online Weight Reduction), a completely automated Web-based weight management intervention (described in detail below). Other RCTs (ISRCTN31685626 and ISRCTN21244703) are examining the efficacy of POWeR for weight loss in a primary care setting with nurse support. In contrast, the current study sought to investigate engagement with this intervention in a high-reach, low-cost public health context. Unlike previous Web-based weight management trials, our research procedures were handled automatically by our intervention software, which meant that the trial took place without participants having contact with the researchers at registration, baseline, and follow-up. We examined engagement with the intervention and self-reported weight change in this more remote context and tested whether the provision of brief human support influenced this.

Our primary aim was to assess whether human support in the form of brief telephone coaching, based around the Supportive Accountability framework [14], improved engagement with our Web-based weight intervention, as measured by session usage. Secondary analyses examined the self-reported weight loss that participants experienced when following the coached and uncoached version of the intervention. We also explored the uptake of telephone coaching, whether this was associated with user characteristics and outcomes, and whether accountability to a coach might be a mechanism through which coaching boosts engagement with the website and weight loss.

Methods

Recruitment

Ethics and research governance approvals were granted by the University of Southampton and the trial was registered (ISRCTN98176068). A variety of methods were used to recruit participants from community settings in the North East of the United Kingdom between June 2012 and January 2013. We mailed out written invitations to 15,000 homes, which resulted in 287 registrations—a 1.91% response rate. Other recruitment methods included local press releases, posters in community settings, and information on local government and NHS (National Health Service) public health websites and intranet, as well as paid advertising on Facebook and posts/tweets on organizational social media.

Recruitment materials invited members of the public to try a new online weight management program as part of a research trial. Recruitment materials and participant information sheets carried the organization name and logo of the local NHS public health organization and also emphasized the involvement of academics and clinicians from the University of Southampton in the development of the intervention. Participation was free and no financial incentives were provided.

Eligibility, Screening, Consent, and Registration

All recruitment procedures including study information, eligibility screening, obtaining informed consent, baseline data collection, and randomization were conducted online using automated procedures. To proceed through the registration process, participants had to report being UK-resident adults with a body mass index (BMI) of ≥23 and having regular Internet access. Users were cautioned to consult a health professional prior to using POWeR if they reported having a condition that might make changing diet and exercise inappropriate.

The first author's email address was provided for asking questions prior to signing up (no questions were received). A "POWeR" email address was provided once participants were in the trial. Brief email contact between participants and the first author took place if participants needed to report technical problems or request withdrawal or cancellation of automatic email prompts or reminders. With the exception of coach phone calls and emails received by the POWeR plus coaching participants, there was no other human contact with participants while they were in the trial.

Randomization and Blinding

Randomization was at the individual level and stratified by BMI (lower BMI <27.5 vs higher BMI ≥27.5) to ensure that the arms were reasonably balanced in terms of overweight, obese, and morbidly obese participants. Participants were allocated with a balanced ratio to one of three arms. The "POWeR only" arm was granted immediate access to the POWeR intervention. The "POWeR plus coaching" arm was granted immediate access to the intervention plus telephone coaching (described below). The waiting list "Control" arm was blocked from using POWeR for 8 weeks. They were not given specific instructions to abstain from weight management or avoid using other interventions during this time. At the end of the 8 weeks, they were provided with access to POWeR (without coaching). It was impossible to blind participants or coaches to trial arm assignment. Researchers were not blinded but did not interact with or collect data from participants directly, as usage was tracked automatically and self-report data was collected via online questionnaires.

Sample Size

The sample size was calculated a priori using GPOWER v3.1 [24]. We powered the study to compare the POWeR only and the POWeR plus coaching arm on our primary outcome variable (intervention usage). We calculated that we would need 253 participants in each arm to detect a small effect size (d=.25) with .80 power (alpha=.05, 2-tailed test). Therefore, we aimed to randomize a total of 759 participants (2 intervention arms and 1 control arm). Because our primary outcome was automatically logged by our website software for all participants, we did not deliberately over-recruit in order to allow for losing participants to follow-up.

The Web-Based Intervention

POWeR is a fully automated, tailored, Web-based weight management intervention constructed using the LifeGuide open access intervention authoring software [25]. The intervention aims to empower users to become their own personal health trainer through the development of new self-regulation skills. POWeR draws on various theoretical models and incorporates multiple behavior change techniques. The intervention planning and considerable iterative qualitative work undertaken during

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development stages are described in detail elsewhere [26]. POWeR is structured as a series of online sessions. In the first session, users choose an eating plan, explore their personal motivations for weight loss, and set personalized eating goals to follow in the subsequent week. Further sessions all begin with a weight and goal review (ie, self-monitoring and goal-setting with tailored feedback) and then progress to new content that includes information and tools to help develop cognitive and behavioral self-regulatory weight management skills, each with an explicit scientific rationale. There are interactive activities for participants to complete, user stories/testimonials, and optional links to more detailed information, including reputable external websites. The second session theme is social support and the third focuses on physical activity. The first three sessions are "core" sessions that each user is funneled through; then from the fourth session onward, after initially working through the weight and goal review, users have a choice of whether to also access Web pages about specific topics that interest them (eg, emotional eating, fitting healthy behavior into busy lives) or whether to end the session at that point. A demonstration version of POWeR can be accessed at [27]. See Multimedia Appendix 1 for screenshots.

Intended use of POWeR is the completion of one session per week. Each time a session is completed the subsequent session becomes available 7 days later and remains available until the user next logs in. Participants received automatic email reminders to advise them that their new session is ready, provide a description of what will be covered, and invite them to log in to use it. They also received one automatic email reminder one week later if they had not logged on. A total of 12 different sessions are available and users can continue to complete sessions for as long as they are finding it useful and log in to complete weekly weight and goal reviews even after all sessions have been completed. In the current trial, we followed up with participants and examined their engagement with the intervention and weight loss 8 weeks after randomization.

During the trial, the intervention content was "frozen" and no changes or bug fixes were made to the POWeR website.

Coaching

The coaching calls aimed to promote continued usage of the POWeR website and adherence to the recommendations within the website. Coaches were postgraduate students and research assistants affiliated with the health psychology research center at the University of Southampton who had been provided with training in the coaching procedures and a brief introduction to the POWeR website. Coaching procedures were developed based on the Supportive Accountability model [14]. Coaches could access a coaching portal of POWeR where they were able to review the usage patterns of participants, a graph showing weight change, and the participant's current eating and physical activity goals and plans. Coaching sessions were focused on promoting on-going use of the Web intervention by monitoring usage and giving feedback on progress, and offering support and encouragement for use of the website. The calls were scheduled for one week and four weeks after participants were granted access to POWeR. Each coaching call was intended to last for approximately 10 minutes. Coaches followed detailed protocols that set out ways to proceed with the two phone calls depending on whether the user was engaging with POWeR as intended (summarized in Table 1). Multimedia Appendix 2 contains detailed coaching protocols, plus further details on scheduling of coaching sessions, attempts made to contact participants, and the coaches' background, training, and supervision.

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Table 1. Summary of content of coaching telephone calls.

Call	Content
Coaching call 1 (week 1)	
	Welcome participant to POWeR
	Build a friendly relationship
	Explain what the role of the coach is/is not
	Explain how progress monitoring will be conducted and reassure that it will be done in a supportive and encouraging way
	Review POWeR use so far (with reference to data available in the coach portal)
	Praise/encourage any POWeR use (or gently explore reasons for non-use and encourage future use)
	Ask about questions and concerns and point in direction of POWeR tools/future sessions
	Ask about eating goals and plans (with reference to data available in the coach portal) and offer encouragement
	Remind about on-going monitoring and another phone call in week 4
Coaching call 2 (week 4)	
	Build a friendly relationship
	Remind about reason for today's call
	Review POWeR use (with reference to data available in the coach portal)
	Praise/encourage any POWeR use (or gently explore reasons for non-use and encourage future use).
	If relevant, congratulate on weight loss (with reference to data available in the coach portal)
	Ask about questions and concerns and point in direction of POWeR tools/future sessions
	Ask about eating and physical activity goals and plans (with reference to data available in the coach portal) and offer encouragement
	Mention coaching is ending and suggest considering support from elsewhere

Measures and Data Collection

The primary outcome variable (usage of the Web-based intervention) was automatically logged by the intervention software. The LifeGuide software logs all usage data including which pages were viewed, in what order, when, and for how long. For the current analyses, we analyzed the number of POWeR sessions each participant had completed by 8-week follow-up.

All self-report data were collected using Web-based questionnaires. To ensure we had complete data on our participants at baseline, all baseline questionnaires were mandatory (ie, the participant could not progress without submitting a response). The follow-up point was 8 weeks post-randomization. Automatically generated emails requested participants to complete a brief follow-up questionnaire and included a hyperlink to Web-based questionnaires. Up to three reminder emails were automatically issued after 5, 10, and 15 days of non-response.

At baseline, we collected demographic data including: age, gender, marital status, ethnicity, highest education level, employment status, postcode (from which we derived an Index of Multiple Deprivation [IMD]), health literacy (a single-item measure) [28], and estimated weekly hours of Internet usage. Participants self-reported height (in cm or feet/inches) and weight (as measured on home scales). Participants also reported whether a health professional had ever advised weight loss or referred them to weight management programs, and whether they had asthma, diabetes, heart disease, hypertension, or a stroke.

At follow-up, participants in all treatment arms were asked to enter their current weight and whether they had followed any other weight loss programs over the last 8 weeks. Participants in both of the active treatment arms were also administered the Supportive Accountability Questionnaire [29], which assesses the user's perceptions that they are held accountable to somebody else for their adherence to the intervention. Participants indicated on a 7-point Likert scale the extent to which they agreed with six statements. For coach arm participants, the items referred to a coach (eg, "I believe my POWeR coach is aware of and notices when I use the website") and for Web only participants, questions referred instead to "the POWeR team". Higher scores indicated higher perceived accountability (Cronbach alpha=.70). Uptake of the two available coaching sessions was recorded by the coaches.

Analysis

Overview

All analyses were conducted in SPSS version 20. Means and standard deviations were computed for continuous variables, and "n" and percentage were computed for categorical variables. We used an alpha level of .05 for all statistical tests.

Primary Outcome: Intervention Usage and Between-Arm Differences

For the primary analysis, we planned to conduct independent *t* tests to examine between-arm differences in mean number of

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sessions completed. However, due to highly skewed data, such analysis was inappropriate. Instead, and as recommended by Glasgow et al [5], we computed a meaningful "threshold" usage dichotomous variable that indicated whether or not the participant had completed the core three POWeR sessions. Between-arm differences were then analyzed using a chi-square test.

Secondary Outcome: Self-Reported Weight Loss and Between-Arm Differences

To examine our between-arm differences in self-reported weight loss, we used ANCOVA (analysis of covariance), with follow-up weight as a dependent variable, baseline weight as a covariate, and trial arm as the independent variable. We performed an intention-to-treat (ITT) analysis. Where weight at follow-up was missing, this was imputed using the "Multiple Imputation" procedure in SPSS. We performed 100 imputations using baseline variables and any available weight measurements as predictors. ANCOVA was performed and the pooled results from the multiple imputation reported. We also conducted a completers analysis by repeating another ANCOVA on the sample of participants who had completed follow-up measures. We also categorized participants according to whether or not they had lost at least 3 kg at 8-week follow-up. Such weight loss would correspond to approximately 0.4 kg (just under 1 lb) weight loss per week and would indicate a rate of weight loss in line with the POWeR program recommendations, which emphasize building healthy habits rather than rapid weight loss. We reported the percentage of participants in each arm meeting this criterion.

We produced descriptive statistics to summarize coaching uptake and used *t* tests or chi-square tests to explore whether coach participants who had the full dose of coaching (ie, both sessions) differed from those who did not on baseline variables, sessions completed, weight loss, and Supportive Accountability.

Results

Participants

Figure 1 shows flow of participants through the study. Between June 2012 and January 2013, 1131 users completed the initial step in the registration process. Of these, 786 (69.50%) subsequently returned to the website, completed the baseline questionnaires, and were randomized. A total of 275 participants (35.0%) were randomized to the control arm, 264 to POWeR only (33.6%), and 247 (31.4%) to POWeR plus coaching.

The primary outcome, website usage, was successfully tracked for 100% of randomized participants. However, loss to follow-up was very high for the self-report measures. Full or partial self-report follow-up data at 8 weeks was provided by only 58.9% (162/275) of control, 15.2% (40/264) of POWeR only, and 21.5% (53/247) of POWeR plus coach participants. A total of 246 participants provided weight data at follow-up; 540 did not. Chi-square tests showed that missingness of weight data at 8 weeks was related to trial arm, with control participants more likely to provide data than participants in the two intervention arms. Looking within the two intervention arms, missingness was also related to website usage, with those having used POWeR the most (≥3 sessions) being more likely to provide follow-up data than those with lower usage (<3 sessions). Most baseline demographic, health, or weight-related variables were unrelated to missingness but participants who were older, less deprived, and university educated were more likely to provide follow-up data. All baseline variables, including those that were significantly associated with failure to provide follow-up data, were included as predictors in the multiple imputation model.

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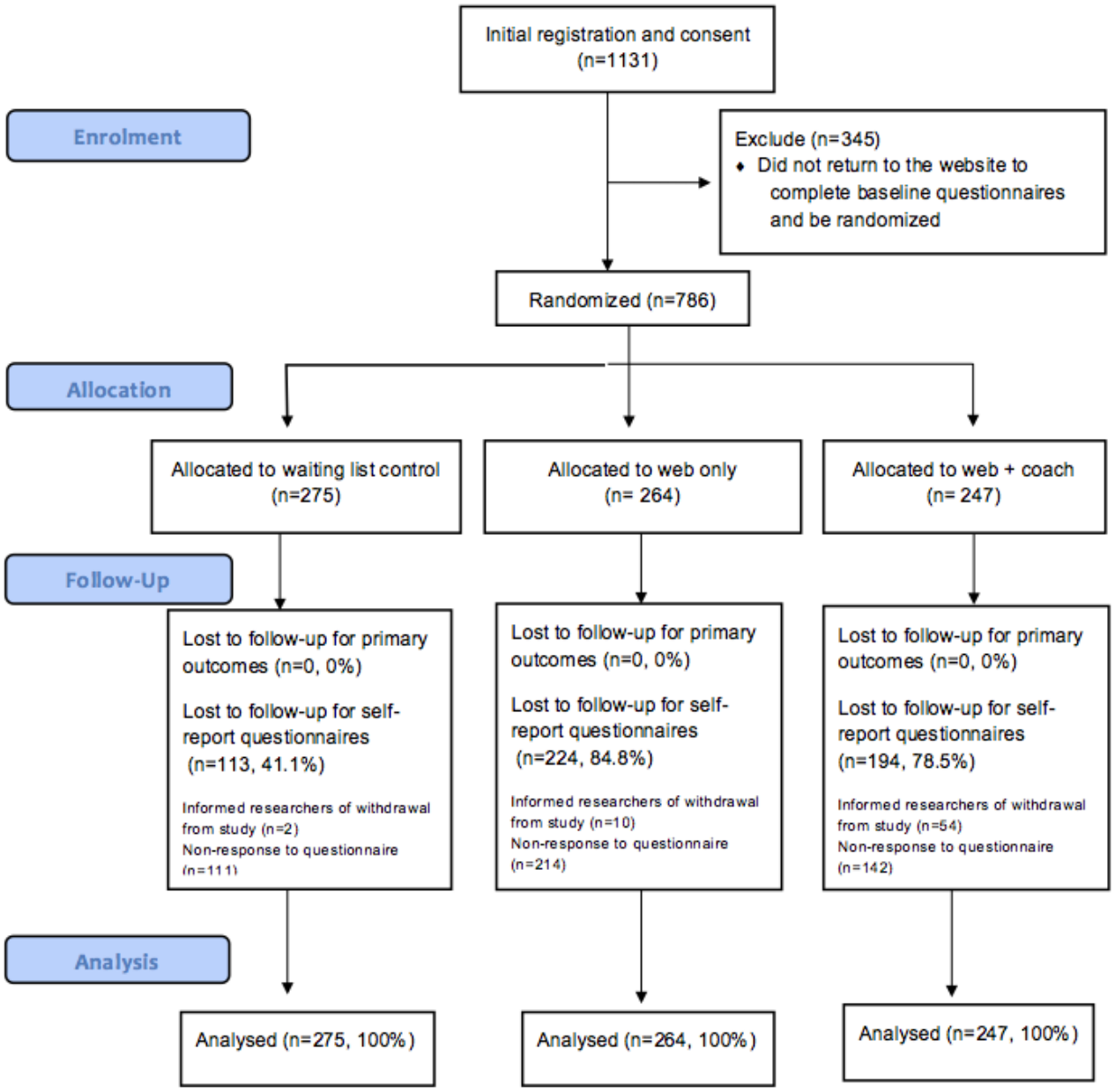
Figure 1. Flow of participants through the trial.



Participant Characteristics

Table 2 shows demographic and health characteristics of the sample. Participants were predominantly female, white British, and around half (444/786, 56.5%) were married. The age range of users was wide, with a mean of 44 years (SD 12.7). Overall, participants tended to live in fairly non-deprived areas, although scores ranged from deprived to fairly affluent. Few participants had problems with health literacy. Participants were mostly overweight and obese, with 15.0% (118/786) meeting criteria as morbidly obese and a minority (48/786, 6.1%) falling into the top end of the normal/healthy weight category. One-third (276/786, 35.1%) reported obesity-related health conditions (hypertension, diabetes, asthma, heart disease, or stroke). Roughly half (417/786, 53.1%) reported ever having been advised to lose weight by a health professional, around one-fifth (163/786, 20.7%) had ever been referred to a weight management program by a health professional, and just under half (383/786, 48.7%) said that they were currently or recently engaged in weight management attempts. One-way ANOVA (analysis of variance) and chi-square tests revealed no significant differences between groups at baseline on any of the sociodemographic, health, or weight-related variables.

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Table 2. Participant characteristics.

Characteristic	Full sample (n=786)	Control (n=275)	POWeR only (n=264)	POWeR plus coaching (n=247)
Age in years, mean (SD)	44.0 (12.7)	44.2 (13.0)	43.3 (12.5)	44.4 (12.6)
Female gender, n (%)	628 (79.9%)	216 (78.5%)	217 (82.5%)	195 (78.9%)
White British ethnicity, n (%)	760 (96.7%)	265 (96.4%)	253 (95.8%)	242 (98.0%)
Marital status, n (%)				
Married	444 (56.5%)	154 (56.0%)	147 (55.7%)	143 (57.9%)
Living with partner	120 (15.3%)	41 (14.9%)	37 (14.0%)	42 (17.0%)
Single	123 (15.6%)	44 (16.0%)	44 (16.7%)	35 (14.2%)
Divorced or separated	78 (9.9%)	32 (11.7%)	22 (8.4%)	24 (9.7%)
Widowed	15 (1.9%)	2 (0.7%)	10 (3.8%)	3 (1.2%)
Highest education, n (%)				
No formal	42 (5.3%)	16 (5.8%)	11 (4.2%)	15 (6.1%)
GCSE[a] or equivalent	178 (22.6%)	60 (21.8%)	62 (23.5%)	56 (22.7%)
A levels or equivalent	110 (14.0%)	35 (12.7%)	39 (14.8%)	36 (14.6%)
University (undergraduate or postgraduate)	253 (32.2%)	98 (35.7%)	86 (32.6%)	69 (27.9%)
Diploma / professional / vocational qualification	197 (25.1%)	64 (23.6%)	63 (23.8%)	69 (27.9%)
Employment status, n (%)				
Full or part time employment / self-employment	555 (70.6%)	189 (68.6%)	184 (69.8%)	182 (73.6%)
Not working due to sickness or disability	22 (2.8%)	6 (2.2%)	7 (2.7%)	9 (3.6%)
Unemployed	20 (2.5%)	7 (2.5%)	7 (2.7%)	6 (2.4%)
Homemaker	31 (3.9%)	14 (5.1%)	11 (4.2%)	6 (2.4%)
Student	65 (8.3%)	21 (7.6%)	26 (8.9%)	18 (7.3%)
Retired	75 (9.5%)	33 (12.0%)	21 (8.0%)	21 (8.5%)
IMD[b] score (higher is more deprived), mean (SD)	25.9 (15.3)	25.2 (14.5)	26.4 (15.5)	26.0 (16.0)
Health literacy (1-5, higher is poorer literacy), mean (SD)	1.1 (0.4)	1.1 (0.4)	1.1 (0.4)	1.1 (0.4)
Internet usage (typical hours per week), mean (SD)	13.0 (12.0)	13.6 (13.6)	13.0 (10.7)	12.4 (11.5)
BMI[c], mean (SD)	33.0 (7.0)	32.9 (6.8)	33.1 (6.4)	33.1 (7.8)
BMI category, n (%)				
Upper part of normal / healthy range (23-24.9)	48 (6.1%)	18 (6.5%)	17 (6.4%)	13 (5.3%)
Overweight (25-29.9)	267 (34.0%)	100 (36.4%)	80 (30.3%)	87 (35.2%)
Obese (30-39.9)	353 (44.9%)	111 (40.4%)	128 (48.5%)	114 (46.2%)
Morbidly obese (40+)	118 (15.0%)	46 (16.7%)	39 (14.8%)	33 (13.4%)
Has one or more of the following health conditions (hypertension, diabetes, heart disease, asthma, stroke)	276 (35.1%)	96 (35.3%)	85 (33.2%)	95 (39.4%)
Ever advised to lose weight by a health professional	417 (53.1%)	150 (55.1%)	141 (54.2%)	126 (52.1%)
Ever referred to a weight management service / program by a health professional	163 (20.7%)	61 (22.3%)	53 (20.5%)	49 (20.6%)
Current / recent attempt to manage weight	383 (48.7%)	128 (46.5%)	136 (51.5%)	119 (48.2%)

[a]GCSE: General Certificate of Secondary Education

[b]IMD: Index of Mass Deprivation score

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[c]BMI: Body Mass Index

Primary Outcome: Intervention Usage and Between-Arm Differences

Website usage patterns were analyzed in the 511 participants allocated to the two active intervention arms. Overall, the number of POWeR sessions completed was low. The median number of sessions completed was 1 in both the POWeR only and the POWeR plus coaching arm (IQR 0-2 for POWeR only, IQR 0-3 for POWeR plus coaching). The data were positively skewed because around one-third of participants (94/264, 35.6% of POWeR only; 80/247, 32.4% of POWeR plus coaching) never completed a session and many participants completed only one or two sessions. Nonetheless, a substantial minority completed at least the core three sessions of POWeR (ie, the meaningful usage threshold) (Table 3). Those in the POWeR plus coaching arm were 1.61 times (95% CI 1.06-2.47) more likely to have continued to use POWeR until at least the end of the core three sessions (χ^2_1=4.93; *P*=.026; n=511).

Table 3. Usage of POWeR sessions.

Usage	POWeR only (n=264), n (%)	POWeR plus coaching (n=247), n (%)
Did not reach the meaningful usage threshold (<3 sessions)	217 (82.2%)	183 (74.1%)
Reached the meaningful usage threshold (≥3 sessions)	47 (17.8%)	64 (25.9%)

Secondary Outcome: Self-Reported Weight Loss and Between-Arm Differences

Table 4 shows weight data for the entire sample with follow-up weight imputed for those participants who did not provide data at 8 weeks. Overall, weight loss was highest in the coaching arm and lowest in the control arm. Between-arm differences were significant ($F_{2,782}$=34.02, *P*<.001). Post-hoc pairwise comparisons indicated that those in the coaching arm lost more weight than those in the control arm (mean difference 1.97 kg, *P*<.001, *d*=−.63, 95% CI −1.40 to 2.49). Those in the POWeR only arm also lost more weight than those in the control arm (mean difference 1.70 kg, *P*<.001, *d*=−.54, 95% CI 1.15-2.22). The difference between the POWeR plus coaching and the POWeR only arms was not significant (mean difference=0.27 kg, *P*=.676, *d*=−.08, 95% CI −0.29 to 0.81). The proportion of participants losing 3 kg or more was highest in the POWeR plus coaching arm and lowest in the control arm (Figure 2).

Weight data for the 246 follow-up completers is shown in (Table 5). Between-arm differences in weight loss were significant ($F_{2,242}$=20.73, *P*<.001). Post-hoc pairwise comparisons indicated that differences were between the control and each of the active treatment arms (mean difference between POWeR only and control 2.49, *P*<.001, *d*=−.82, 95% CI −1.18 to −0.46 and between POWeR plus coaching and control 2.69, *P*<.001, *d*=−.89, 95% CI −1.22 to −0.5567), but not between the POWeR plus coaching and the POWeR only arms (mean difference 0.20 kg, *P*=.755, *d*=−.07, 95% CI −0.49 to 0.35). The proportion of completers losing 3 kg or more was highest in the POWeR plus coaching arm and lowest in the control arm (Figure 2). In order to ensure that the ANCOVA results were not an artefact of an incorrect assumption about the normality of the data, we also conducted a non-parametric analysis using quantile regression and controlling for baseline weight. The results of this approach echoed those of the parametric analysis with a significantly lower median weight in the intervention groups than the control group (*P*=.019 for the POWeR only group and *P*<.001 for the POWeR + coach group) but no statistically significant difference between intervention groups (*P*=.207)

Table 4. Weight change by treatment arm (ITT analysis).

Weight	Control (n=275)	POWeR only (n=264)	POWeR plus coaching (n=247)
Weight at baseline (kg), mean (SD)	91.64 (20.31)	92.02 (20.09)	91.86 (20.96)
Weight at follow-up (kg), mean (SD)	91.34 (20.15)	90.00 (19.89)	89.59 (20.65)
Weight change (kg), mean (SD)	−0.30 (2.82)	−2.01 (3.45)	−2.27 (3.41)

Table 5. Weight change by treatment arm (follow-up responders only).

Weight	Control (n=158)	POWeR only (n=39)	POWeR plus coaching (n=49)
Weight at baseline (kg), mean (SD)	91.85 (20.42)	90.53 (16.86)	94.80 (23.64)
Weight at follow-up (kg), mean (SD)	91.38 (20.47)	87.67 (16.10)	91.63 (23.17)
Weight change (kg), mean (SD)	−0.41 (2.43)	−2.86 (4.42)	−3.17 (3.61)

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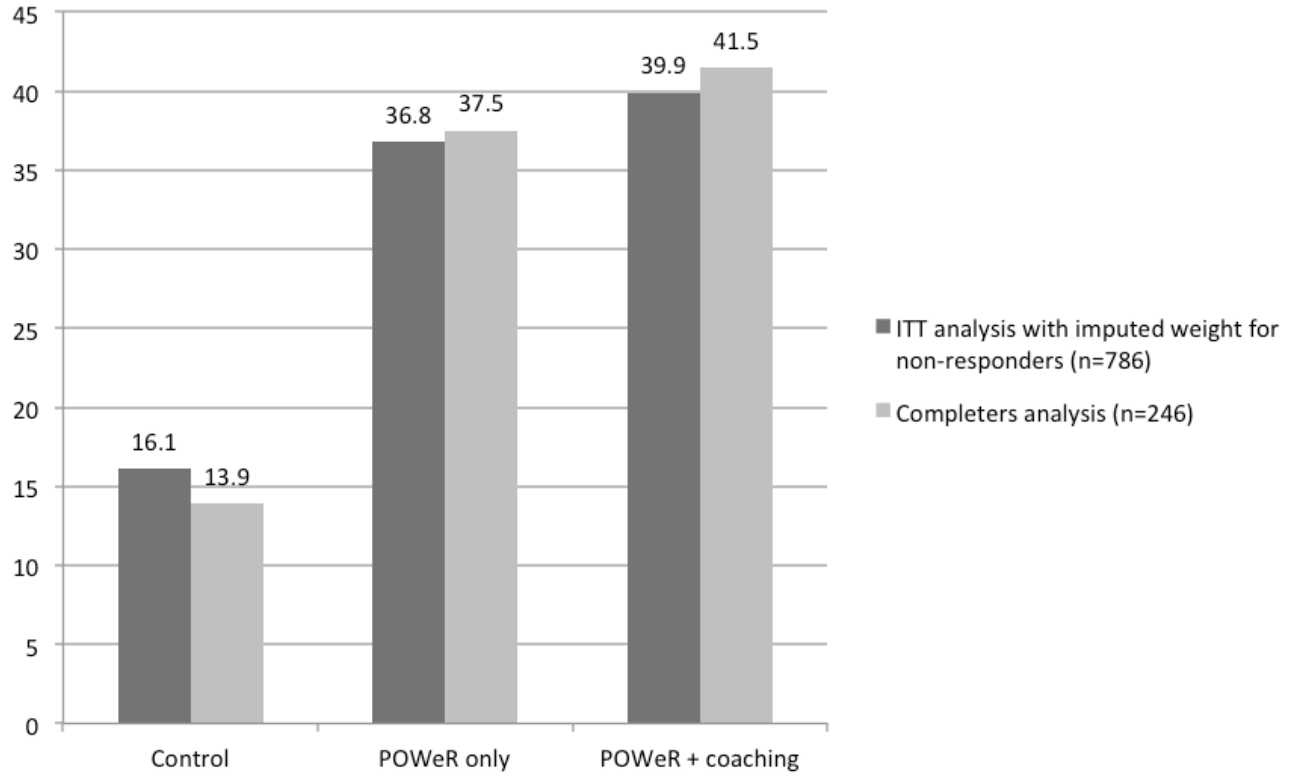
Figure 2. Percentage of participants self-reporting a weight loss of ≥3 kg at 8-week follow-up by treatment arm.



Exploring Coaching Uptake

Overall, uptake of coaching calls was low. More than half (57.9%, 143/247) of those in the POWeR plus coaching arm actually received no coaching calls. Of the 104 participants that had coaching, most (n=58, 55.8%) had just one call. Only 46 participants (18.6%, 46/247) received both calls (ie, a full dose of coaching as per protocol). When coaching calls occurred, they tended to last for roughly 7.5 minutes each. The low rate of coaching calls can be partially explained by participant withdrawal, as 54 (21.9%, 54/247) POWeR plus coaching arm participants withdrew during the 8-week study period (see Figure 1), but the remainder of those who did not receive coaching calls simply did not answer the phone calls.

Compared to POWeR plus coaching participants who did not receive full coaching, participants that had the full "dose" of coaching (ie, both calls) tended to be older (t_{245}=−4.03, P<.001, d=−.66) and have higher baseline BMI (t_{245}=−2.13, P=.038, d=.35). They were 2.16 times more likely to have hypertension (χ^2_1=4.38; P=.036; n=241) and 2.79 times more likely to have been referred to a weight loss scheme by a health professional (χ^2_1=8.22; P=.004; n=238). Table 6 shows that overall, participants allocated to POWeR plus coaching who did not receive full coaching had usage and weight outcomes similar to (or slightly worse than) participants allocated to the Web-only arm. Compared to participants allocated to POWeR plus coaching who did not receive full coaching, those that did receive full coaching completed significantly more POWeR sessions ($t_{55.186}$=−5.78, P<.001, d=.94) and were 6.73 times more likely to have completed the core sessions (χ^2_1=31.65 (n=247), P<.001). Their mean weight loss was 2.79 kg compared to 0.77 kg ($t_{50.459}$=3.82, P<.001, d=.623) and they were 5.12 times more likely to have lost 3 kg or more (χ^2_1=19.75 (n=247), P<.001). Supportive Accountability scores were slightly, but not significantly higher between full coaching receivers/non-receivers (t_{50}=−1.38, P=.17, d=.38) and between all participants allocated to the coach arm and those in the Web arm (t_{90}=−1.14, P=.256, d=.24).

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Table 6. Differences in usage, weight outcomes, and supportive accountability in the active treatment arms depending on whether full coaching was received.

	POWeR only n=264	POWeR plus coaching n=247	
		Did not receive full coaching n=201	Received full coaching n=46
Number of weekly POWeR sessions completed, median (IQR)	1 (0-2)	1 (0-2)	4 (2-6)
Number of participants completing the 3 core POWeR sessions, n (%)	47 (17.8%)	37 (18.4%)	27 (58.7%)
Weight change (kg), mean (SD)	−0.80 (2.22)	−0.77 (1.78)	−2.79 (3.48)
Participants achieving recommended amount of weight loss, ie, 3 kg or more,n (%)	27 (10.2%)	19 (9.5%)	16 (34.8%)
Supportive Accountability, mean (SD)[a]	3.63 (1.30)	3.72 (1.08)	4.11 (0.94)

[a]Data based on responders to follow-up from both active treatment arms (n=40 in Web only, n=25 who received full coaching, and n=27 who did not receive full coaching).

Discussion

Engagement With the POWeR Intervention and Differences Between Groups

In common with most studies of Web-based interventions [9,30], participants overall made suboptimal use of the intervention. However, usage was indeed improved, as predicted, by supplementing the website with brief phone calls focused on improving engagement. Despite the majority of the eHealth literature suggesting that human support is important for boosting engagement and outcomes [16-21], several previous Web-based weight loss trials have found that providing more intense support did not make a significant difference to usage or outcomes [4-6]. One explanation for why our study did identify website usage differences between website plus coaching and website-only participants might be that our website-only condition was (in contrast to previous studies) a completely stand-alone intervention that was registered for and used without any contact with the research team or health professionals. Therefore, we were truly comparing a supported and an unsupported version. Another explanation is that, by explicitly basing our coaching around a theoretical framework that specifically seeks to delineate how to boost adherence and engagement with Web-based interventions, the human support we offered may have been more successful than that in previous studies.

Self-Reported Weight Loss and Differences Between Groups

Despite the overall pattern of light usage, in our secondary analyses of weight loss we showed that both of our intervention arms reported losing more weight than the control arm. Furthermore, a substantial minority of participants in the POWeR only and the POWeR plus coaching arm had high engagement with website sessions and reported losing clinically important amounts of weight (≥3 kg) at short-term follow-up. Hence, even though the effect sizes of the interventions were small overall, the impact at public health level could be considerable, given the low costs associated with entirely automated (POWeR only) or minimally-supported (POWeR plus coaching) Web-based interventions.

Encouragingly, our exploratory analyses tentatively indicated that the higher engagement seen in the POWeR plus coaching arm may have been associated with improved effectiveness of the Web-based intervention. Differences in weight loss between the POWeR only and the POWeR plus coaching arm were not significant overall, but substantial effect sizes were observed when comparing participants in the coaching arm who actually received both coaching phone calls to those who did not.

Uptake of Telephone Coaching

The impact of coaching on both usage and weight loss outcomes is likely to have been reduced by low uptake, as less than one in five participants in the coaching arm actually received both phone calls. The reasons for low uptake of coaching are not entirely clear. Some participants might have welcomed the opportunity for coaching but were unreachable by telephone when the calls were attempted—even though coaches made several attempts to contact participants and tried to accommodate their preferred contact times. However, some participants may have found the prospect of coaching off-putting. Indeed, the higher rate of withdrawal from the study observed in the coach arm compared to the website-only arm (n=54 vs n=10) might be taken as an indication that some participants disliked the prospect of coaching. Although most participants did not provide a reason for their withdrawal (typically they simply emailed “please withdraw me from the POWeR study”), we noted that most withdrawals happened shortly after allocation to the coach arm, or around the time participants were expecting the first coaching call. This raises the possibility that offering coaching may have multiple impacts: for some, it may boost usage but for others it might actually increase the likelihood of attrition. Whether certain groups of Web intervention users would be more comfortable with and responsive to human support if it was provided through different channels is an interesting question, requiring further study. It may be that there are groups of users who would cease using the intervention, whatever support was provided, and some who actually prefer to have no human contact and see the privacy

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and independence associated with Web-based interventions as a benefit.

A positive finding was that uptake of coaching calls was greatest among users who seemed particularly suitable candidates for weight management interventions (ie, more overweight, more likely to have hypertension, and to have been referred to a weight management program by a health professional). Future studies could build on this work to investigate further the users who are most likely to use and benefit from human support for Web interventions and how best to overcome barriers to uptake.

While the current study focused on a telephone-based form of human support, different approaches to boosting engagement have either capitalized on more recent technology or have emphasized peer support as an alternative to a health professional or coach. For example, Web-based health interventions have made use of email contact [10], SMS [10,31], online chatrooms or forums [6,10], and link-ups to online social networking sites [32]. Although some studies suggest these approaches may be promising in boosting usage, engagement, and outcomes, others suggest low uptake and lack of interest from users. Furthermore, these studies were not designed to isolate the influence of these supposed supportive features. We therefore do not yet have a substantial body of systematic research comparing interventions delivered with and without these supportive features and consequently have limited insight into likely uptake, effectiveness, and cost-effectiveness.

Supportive Accountability as a Mechanism for Boosting Engagement

One of our study objectives was to explore whether coaching, based around the Supportive Accountability model [14], increased participants' perceived accountability for using the intervention. Although we did not detect a statistically significant between-group difference, this analysis may be underpowered due to high loss to follow-up. Indeed, effect sizes were consistent with a trend toward greater levels of perceived accountability in those who received coaching. Another explanation for not observing substantial between-group differences in accountability is that there may have been a ceiling effect, since perceptions of accountability were moderately high in both the coached and uncoached participants who responded to this questionnaire. The POWeR website itself and/or the context of participating in research may have instilled a certain level of accountability regardless of whether there was any coaching available. POWeR involves weekly self-monitoring and tailored feedback and has many interactive features and a human tone that may have been successful in promoting perceptions of accountability. Although recent eHealth research and reviews have highlighted contact with a human as important for boosting engagement and effectiveness [14,20,21], some people may find it sufficient to use Web-based programs that effectively mimic some of the important aspects of human support, whether that be accountability, being treated as an individual, or feeling that somebody cares. Further research could seek to identify mechanisms through which human support offers additional benefits and explore whether well-designed and engaging website features can successfully simulate some of these features and processes.

Strengths and Limitations

A strength of this research is that our coaching protocols were well-documented, specific in their aims, and based on a theoretical model of engagement with digital interventions. Such explicit explanation of the aims and nature of human contact is rare in the reporting of Web-based interventions. Furthermore, the coach contact was brief (around 15 minutes for participants receiving the full dose) and delivered by providers with minimal training. This type of additional human support should be replicable in future studies and might prove feasible to implement and cost-effective for improving engagement and boosting intervention effectiveness even if effect sizes are modest.

The current study benefited from having primary outcome data available from all participants (by automatically tracking website usage), allowing this analysis to include all randomized participants. However, our pragmatic research design, which included minimal contact between researchers and participants and which probably attracted participants who were curious but not committed to following an online weight management program, may have contributed to the very high loss to follow-up for the secondary outcome data collected via self-reported questionnaires. Low follow-up rates are common in Web-based intervention trials, especially when research methodologies are more in line with a pragmatic trial than an efficacy trial. However, the large amount of missing data at follow-up limited statistical power and reduced our ability to draw firm conclusions about change and group differences in the self-reported follow-up data. Therefore, our secondary and exploratory analyses based on these measures need to be interpreted with caution.

Due to the large number and wide geographical dispersion of participants, only self-reported weight data could be obtained. Most Web-based weight loss trials have obtained objective weight data at face-to-face baseline and follow-up assessments [6-10]. Although in one respect self-reported weight data is a limitation of this study, on the other hand the absence of face-to-face assessment in this study allowed us to obtain website usage data in a context where there is no contact with a researcher. We believe that weight loss, website usage, and retention for follow-up in many existing Web weight loss trials may be influenced to some degree by the contact with researchers, the expectation of being weighed by the research team at a later date, and the perceptions of accountability and pressure this creates. In the current pragmatically-oriented study, we may have obtained a more representative view of users, usage patterns, and weight loss in contexts similar to what could be practical and affordable for a public health intervention. Furthermore, a recent study suggests that online self-reported weight tends to be reasonably accurate [33]. Nonetheless, we cannot rule out the possibility that contact with the coach in the coaching arm may have influenced participants' self-reporting of weight in some way, potentially leading to biased (possibly inflated) self-reports of weight loss at follow-up. However, given that testing the efficacy of POWeR for weight loss was not our main research question in this trial, we believe the self-report data remains a useful initial indicator of weight loss outcomes from using POWeR with and without coaching.

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This study chose to use the number of sessions completed as the indicator of participant engagement with the intervention. This has several advantages, including that it allowed us to obtain objective data unobtrusively for every participant and gave a reliable indication of the "dose" of the intervention that participants had been exposed to and which aspects they had seen. It is, however, not the only way to usefully investigate participant engagement and only gives a rudimentary picture of the extent to which participants were absorbing, understanding, and applying material presented on the Web pages. Future research may wish to use alternative ways of operationalizing engagement in order to investigate how deeply participants are engaging with intervention content. The challenge facing researchers, however, is how to measure engagement without relying on self-report follow-up data, which in many Web-based trials is unlikely to be provided by the majority of users.

Conclusions

In common with most Web-based intervention studies, usage of POWeR was suboptimal overall. Our findings suggest that supplementing Web-based weight management with brief human support might have a modest effect on persistence with the Web-based sessions, might improve weight loss outcomes, and could prove cost-effective. However, uptake of telephone support may be low overall, with particular types of users more likely to engage with it. Further research is needed to understand and optimize strategies to keep users engaged with Web-based weight interventions.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots from POWeR.

[PDF File (Adobe PDF File), 229KB - jmir_v16i3e95_app1.pdf]

Multimedia Appendix 2

Coaching protocol.

[PDF File (Adobe PDF File), 39KB - jmir_v16i3e95_app2.pdf]

Multimedia Appendix 3

CONSORT-EHEALTH checklist V1.6.2 [34].

[PDF File (Adobe PDF File), 1MB - jmir_v16i3e95_app3.pdf]

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Abbreviations

ANCOVA: analysis of covariance
BMI: body mass index
IMD: Index of Multiple of Deprivation
ITT: intention to treat
NHS: National Health Service
POWeR: Positive Online Weight Reduction intervention
RCT: randomized controlled trial

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Original Paper

Internet-Based Motivation Program for Women With Eating Disorders: Eating Disorder Pathology and Depressive Mood Predict Dropout

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Abstract

Background: One of the main problems of Internet-delivered interventions for a range of disorders is the high dropout rate, yet little is known about the factors associated with this. We recently developed and tested a Web-based 6-session program to enhance motivation to change for women with anorexia nervosa, bulimia nervosa, or related subthreshold eating pathology.

Objective: The aim of the present study was to identify predictors of dropout from this Web program.

Methods: A total of 179 women took part in the study. We used survival analyses (Cox regression) to investigate the predictive effect of eating disorder pathology (assessed by the Eating Disorders Examination-Questionnaire; EDE-Q), depressive mood (Hopkins Symptom Checklist), motivation to change (University of Rhode Island Change Assessment Scale; URICA), and participants' age at dropout. To identify predictors, we used the least absolute shrinkage and selection operator (LASSO) method.

Results: The dropout rate was 50.8% (91/179) and was equally distributed across the 6 treatment sessions. The LASSO analysis revealed that higher scores on the Shape Concerns subscale of the EDE-Q, a higher frequency of binge eating episodes and vomiting, as well as higher depression scores significantly increased the probability of dropout. However, we did not find any effect of the URICA or age on dropout.

Conclusions: Women with more severe eating disorder pathology and depressive mood had a higher likelihood of dropping out from a Web-based motivational enhancement program. Interventions such as ours need to address the specific needs of women with more severe eating disorder pathology and depressive mood and offer them additional support to prevent them from prematurely discontinuing treatment.

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KEYWORDS

attrition; Web-based treatment; eHealth, eating disorders; motivation to change; anorexia nervosa; bulimia nervosa; bootstrapping; survival analysis

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Introduction

Internet-based interventions have proven to be effective treatments for a variety of psychological disorders [1]. These interventions provide easy access to help for individuals who would otherwise delay seeking treatment and, hence, risk developing a more chronic course [2,3]. The advantages of Web-based interventions seem to be especially valuable in individuals with eating disorders, who are known to seek face-to-face treatment relatively late [4] because of feelings of shame and fear of stigma [5]. Therefore, Web-based interventions for individuals with eating disorders [6-10], their caregivers [11], and individuals at risk for eating disorders [12] have been developed. These interventions yield moderate to large treatment effects [6-14]. Whereas most of these studies investigated Web-based programs for women with bulimic symptoms, online interventions for patients with anorexia nervosa are rare [15].

However, the limitation of such accessible interventions is that they allow participants to easily terminate (ie, with a mouse click) online treatment prematurely [16]. Accordingly, dropout rates for online interventions can be high, ranging from 3% to 81% across trials [17]. The high variance in dropout rates seems to be at least partially because of differences in the intensity and nature of the personal contact offered [18-20]. For example, patients who receive telephone contact instead of only email contact with the therapist have a higher likelihood of staying in online treatment [21].

Beyond the generally elevated dropout rates of Internet interventions, disorder-specific differences also need to be considered. Specifically, individuals with eating disorders may be at particular risk of dropping out from online treatments given their elevated dropout rates from face-to-face treatments [22,23]. Dropout from face-to-face interventions for eating disorders generally ranges from 20% to 40% [22,23]. Research conducted in these settings has identified a number of predictors of treatment dropout for eating disorders. Several studies indicated that patients with higher levels of psychopathology (ie, low self-esteem [24], more severe eating disorder symptoms [25-27], and binge eating/purging subtype of anorexia nervosa [26-28]) at the beginning of treatment are more likely to terminate treatment prematurely. The results concerning comorbid depressive symptoms are mixed. Although the majority of studies have found a higher risk of dropout for patients with higher depression scores [29,30], this effect did not reach significance in a meta-analysis [23]. Additionally, age has been identified as a predictor of staying in treatment in bulimia nervosa because older patients tend to persist longer with face-to-face treatment than younger patients [23]. However, 2 recent meta-analyses found that psychopathology, symptom severity, and age are not stable predictors of dropout from face-to-face therapies for women with eating disorders [22,23].

Another potential predictor of treatment dropout is motivation to change (for a review see [28]) because it has been shown that participants with initially low levels of motivation to change their eating disorder symptoms [31,32] or low cooperativeness scores [27] are more likely to drop out of treatment. Therefore, interventions to enhance motivation to change in women with eating disorders have been implemented and have been shown to reduce dropout as well as enhance motivation to change and reduce eating pathology in some studies [33].

In spite of the growing interest in Internet-delivered interventions for women with eating disorders, there is a dearth of research in this regard, with only 8 studies having investigated predictors of treatment dropout from Internet programs aimed at women with anorexia nervosa, bulimia nervosa, or subthreshold eating disorders [6,8,15,34-38]. Most studies explored dropout by comparing demographic variables and symptom severity in dropouts (women who terminated treatment prematurely) and completers (women who completed treatment). Such a group comparison approach neglects information about the time course of attrition; that is, it does not allow the comparison of different attrition curves according to possible predictors of dropout. Instead, survival analysis seems to be much more suitable for describing and testing whether and when participants drop out [39]. An exception to this can be found in a study by Fernández-Aranda and colleagues [35] who used survival analysis to predict dropout from an Internet-based program for women with bulimia nervosa. The authors found that higher anxiety and lower reward dependence, lower hyperactivity, and lower minimum body mass index (BMI) were predictive of dropout from Internet-delivered cognitive behavioral therapy for bulimia nervosa.

In summary, most studies reporting on dropout from Web-based programs for eating disorders did not find a significant impact of participants' age on dropout [6,38], although one study found that older patients were less likely to drop out [15]. Symptom severity at the beginning of treatment, including eating disorder pathology [15] and body dissatisfaction [6], has been shown to be positively related to dropout in some studies. However, other researchers found no differences between completers and dropouts concerning eating disorder symptoms [34,38]. A higher level of general psychopathology has been found to increase the likelihood of premature termination of Internet treatment in some studies [6,35]. One study found an effect of depressive and anxious symptoms on dropout [6], whereas 2 other studies found no such effect [37,38].

Taken together, it seems that demographic variables are not reliable predictors of treatment dropout, either in face-to-face or in online settings. In contrast, symptom severity may be a more robust predictor of online treatments, but it has yielded inconclusive results in face-to-face settings [22,23]. Depression has been demonstrated to be a predictor in face-to-face settings, but not in Web-based interventions. Motivation to change is an important predictor of dropout in face-to-face settings, but it has not been studied in online interventions to date.

The aim of the present study was to bridge this gap and to investigate factors leading to dropout from an anonymous Internet-delivered program to enhance motivation to change in individuals with eating disorders [13]. We investigated age, depressive mood, symptom severity, and motivation to change as predictors of dropout from this program. Given the ease of access to and termination of this program, we expected the dropout rate to be relatively high. Based on the studies described

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previously, we expected participants with higher depression scores, more severe eating pathology, and lower motivation to change to be more likely to terminate treatment early. We did not expect to find any effect of participants' age. We used survival analysis (ie, Cox regression) to test possible predictors of dropout from the program. Because the number of participants who dropped out was high and, accordingly, the number of events per variable was relatively low, we used the least absolute shrinkage and selection operator (LASSO) method to identify predictors.

Methods

Participants

Participants were recruited between March 2011 and March 2012 through newspaper, magazine, and radio announcements as well as via social networks and reports on websites for people with eating disorders. Potential participants completed a self-report screening battery before treatment. The inclusion criteria included female gender and at least one of the following eating disorder symptoms once or more per week within the past 4 weeks (assessed with the Short Evaluation of Eating Disorders [40]): purging, dieting, or excessive exercise. Additionally, a self-reported BMI greater than 15 kg/m^2 and less than 30 kg/m^2 was required. Participants who indicated no weight control behaviors at least once per week within the past 4 weeks and participants who reported binge eating only with the absence of any compensatory behaviors were excluded. Furthermore, those with severe depression (a score of 35 or more on the Center for Epidemiologic Studies Depression Scale, CES-D [41]), risk of suicide (assessed with items designed by the authors [13]), severe self-harming behavior (assessed with items designed by the authors [13]), psychotic disorders (a score of 13 or more on the Dutch Screening Device for Psychotic Disorder [42]), dissociative symptoms (a score greater than 8 on the Somatoform Dissociation Questionnaire [43]), substance abuse (a score of 10 or more on the Alcohol Use Disorders Identification Test [44] or the Drug Use Disorders Identification Test [45]), or in current psychotherapy treatment were excluded from the study (for more information on the inclusion and exclusion criteria, see [13]). The final sample consisted of 179 participants who commenced the online program (ie, completed the baseline assessment and received an invitation for the first session).

Intervention

The online program ESS-KIMO ("Klärendes Internetprogramm zur Steigerung der Veränderungsmotivation bei Essstörungen" or "Internet program to enhance motivation to change in eating disorders") aims to enhance motivation to change in women with symptoms of anorexia nervosa or bulimia nervosa. The methods and results of the ESS-KIMO have been published elsewhere [13]; this is a secondary analysis of the program. It is based on the transtheoretical model of behavior change [46] and uses the principles of motivational interviewing [47]. It contains 6 weekly online sessions comprising evidence-based interventions to enhance motivation to change [48,49], which are often used in conjunction with motivational interviewing. All aspects of the program and the study took place online and participants remained completely anonymous apart from providing an email address at which they could be contacted. The ESS-KIMO was designed based on the results of previous research [1]. It consisted of individual sessions, a closed website with screening for inclusion and exclusion criteria, and individualized feedback (from RvB or KH) for the required writing tasks in each session. In this feedback, the authors used methods and principles of motivational interviewing, such as selectively reflecting participants' change or confidence talk and trying to enhance participants' perception of discrepancies between their current (eating-disordered) behavior and their long-term values and goals.

In general, all sessions dealt with the participants' ambivalence regarding behavior change. The session content included (1) the typical reasons for and against change in women with eating disorders (eg, participants were asked to make a list of pros and cons); (2) physical and psychological consequences of eating disorders and the eating disorder's congruity or incongruity with life goals; (3) the eating disorder's impact on the person's daily life; (4) self-esteem and its link to the eating disorder; (5) a summary of the aspects that were considered important by the participant regarding behavior change; and (6) information regarding treatment. The content of each session (eg, information given) and the therapeutic tasks were standardized and were the same for each participant. All participants received an invitation to the next session via email 1 week after completing the previous session. During this time, an author (RvB or KH) wrote individualized feedback for the participant's answer to the writing task. If participants did not log into the program during the 2 days following their invitation, a reminder email was sent on the third day. Up to 3 reminders were sent, each after 3 days. The effectiveness of the program was evaluated in a randomized controlled trial, in which the ESS-KIMO showed promising results for the completers of the program in terms of an improvement in motivation to change and eating disorder symptomology as well as an enhancement of self-esteem [13].

Ethical approval for the study was obtained by the German Psychological Society (Deutsche Gesellschaft für Psychologie, DGPs). Individuals interested in participating received information about the study and were informed that they could withdraw from the study at any time. Participants also received an email address so that they could contact one of the authors (RvB or KH) if they needed additional support. Participants were also given the telephone numbers of emergency contacts in Germany, such as the crisis helpline.

Measures

Overview

In addition to reporting their age, participants completed measures regarding psychopathology and motivation to change at baseline and posttreatment.

Eating Disorder Pathology: Eating Disorder Examination-Questionnaire

Eating disorder pathology was assessed with the German version of the Eating Disorder Examination-Questionnaire (EDE-Q) [50,51]. The EDE-Q entails 22 items asking about eating

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disorder symptoms occurring within the last 28 days, with responses ranging from 0=none to 6=every day. It consists of 4 subscales: Dietary Restraint, Eating Concerns, Weight Concerns, and Shape Concerns. Furthermore, the EDE-Q asks about eating disorder core behaviors (eg, binge eating and purging) and their frequency during the past 28 days. The EDE-Q also allows the calculation of the patient's self-reported BMI. Similar to the original English-language questionnaire, the German version shows very good internal consistency (Cronbach alpha=.85-.93) and a 3-month test-retest reliability between r_{tt}=.68 and r_{tt}=.74 [51,52].

Motivation to Change: University of Rhode Island Change Assessment Scale

The University of Rhode Island Change Assessment Scale (URICA) [53] assesses participants' global motivation to change. It consists of 4 subscales representing the precontemplation, contemplation, action, and maintenance stage of change according to the transtheoretical model [46]. Items are rated on a 5-point Likert scale ranging from 1=disagree strongly to 5=agree strongly. Reliability in women with eating disorders is satisfactory, with internal consistencies between alpha=.58 and alpha=.95 and test-retest reliabilities between r_{tt}=.58 and r_{tt}=.73 [54].

Depressive Mood: Depression Subscale of the Hopkins Symptom Checklist-25

Depressive mood was assessed with the depression subscale of the German version of the Hopkins Symptom Checklist (HSCL-25) [55-57]. Participants were asked to indicate how strongly they experienced typical depressive symptoms within the past month. The scale has a 4-point Likert format ranging from 1=not at all to 5=very. Reliability in inpatient and outpatient samples is good, with an internal consistency of alpha=.91 and a test-retest reliability of r_{tt}=.79 to r_{tt}=.90.

Participants also gave information on a range of different baseline measures including previous treatment, housing situation, marital status, educational level, and experience with the Internet and computers (all assessed with the Biographical Information Questionnaire [58]). They also filled in an assessment of ambivalence (the German Pros and Cons of Eating Disorders Scale [59]), a symptom-specific motivation questionnaire for eating disorders (Stages of Change Questionnaire for Eating Disorders [60]), the Rosenberg Self-Esteem Scale [61], and the Self-Efficacy Scale [62]. These questionnaires were hypothesized as outcome variables in the primary analysis of the ESS-KIMO trial. For the analysis of this study, we based our selection of variables on the literature concerning dropout from face-to-face therapies and Internet programs for women with eating disorders as well as on the restrictions because of the sample size.

Definition of Dropout

Several authors have pointed out the importance of clearly defining dropout [16,22]. Because we were interested in the predictors of treatment adherence in women with eating disorders, we only investigated dropout from treatment (*treatment dropout*) and not from the study (*study dropout*). That is, we only included participants who had completed all baseline measurements before treatment. Each dropout was patient-initiated; we did not recommend withdrawal from the program at any time. We defined dropout for a particular participant in a particular session when this participant completed the prior session but did not finish the current session during a 4-week time period. We then deleted the participant's account because of our data privacy protection policy.

Data Analysis

The present study aimed to test 14 variables as potential predictors of dropping out of the program. These were the EDE-Q scales Dietary Restraint, Eating Concerns, Weight Concerns, and Shape Concerns; participants' BMI; the frequency of the core eating disorder behaviors binge eating, purging, and excessive exercise; the 4 URICA scales precontemplation, contemplation, action, and maintenance; depressed mood assessed with the HSCL-25; and participants' age. As recommended [39], we used survival analysis (ie, Cox regression) to test the predictors. Because 91 participants dropped out, the number of events per predictor variable (EPV) was much lower than the recommended 10 EPV [63]. Therefore, we used the LASSO to identify relevant predictors [64] because this method yields reliable estimates in such scenarios [65]. Because this method is not invariant to linear scaling, we standardized the individual variables before the analysis. The variability of the LASSO estimates is typically assessed using a simple bootstrapping approach [66]. Specifically, we drew (with replacement) 1000 pseudosamples from our full sample and calculated the LASSO. For each pseudosample, the optimal lambda was calculated by using a crossvalidation procedure with 50 folds. The smallest lambda was then chosen to calculate the LASSO estimates, and the resulting estimates were recorded. Descriptive statistics (mean, SD, 95% CI) were used to inspect these estimates. The software R was used for data analysis [67].

Results

Baseline Characteristics

The core demographic characteristics of participants at the beginning of the program are shown in Table 1. The maximum BMI reported (30.47 kg/m^2) is based on participants' responses to the EDE-Q directly before the beginning of the intervention, whereas eligibility for the study (ie, a maximum BMI of 30) was determined based on participants' earlier responses to the screening battery. Some participants differed in their answers between the screening and preassessment time points given the time lag between these assessments (eg, participants in the waiting-list condition waited 8 weeks until the beginning of the program).

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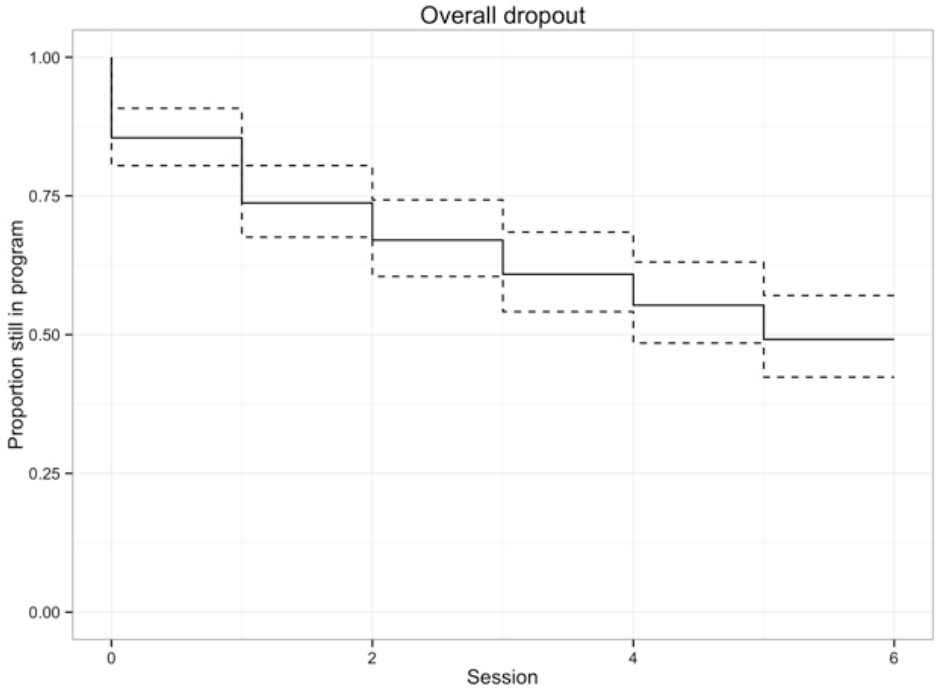
Table 1. Participants' characteristics at baseline.

Variable	Mean (SD)	Minimum	Maximum
Age	27.54 (8.02)	18.00	59.00
Body mass index (kg/m^2)	20.56 (3.49)	15.06	30.47
Eating Disorder Examination-Questionnaire (EDE-Q)			
Eating Concerns	2.93 (1.30)	0.20	5.60
Dietary Restraint	3.76 (1.35)	0.20	6.00
Shape Concerns	4.17 (1.29)	0.50	6.00
Weight Concerns	3.75 (1.37)	0.40	6.00
Binge eating episodes (past 28 days)	9.91 (8.74)	0.00	28.00
Vomiting frequency (past 28 days)	8.43 (10.28)	0.00	28.00
Excessive exercise	6.28 (8.14)	0.00	28.00
University of Rhode Island Change Assessment Scale (URICA)			
Precontemplation	1.61 (0.57)	1.00	4.50
Contemplation	4.20 (0.53)	1.25	5.00
Action	3.74 (0.60)	1.50	5.00
Maintenance	3.35 (0.76)	1.25	5.00
Hopkins Symptom Checklist (HSCL-25)			
Depression	2.40 (0.63)	1.17	3.83

Overall Dropout

Of the 179 participants who completed the first session, 91 (50.8%) dropped out at some point during the program. On average, the participants completed mean 4.92 (SD 2.4) out of the 6 sessions. The dropout was equally distributed across the sessions (Figure 1), with approximately 10% of the participants dropping out after each session.

Figure 1. Overall dropout of participants during the course of the program (broken lines represent 95% CI).



Predictors of Dropout

As shown in Table 2, the LASSO method identified the EDE-Q subscale Shape Concerns, frequency of vomiting within the past 28 days, frequency of binge eating within the past 28 days, and the HSCL-25 depression score with Cox regression as relevant predictors of dropout within the full sample. Results indicated that participants with high levels of Shape Concerns and

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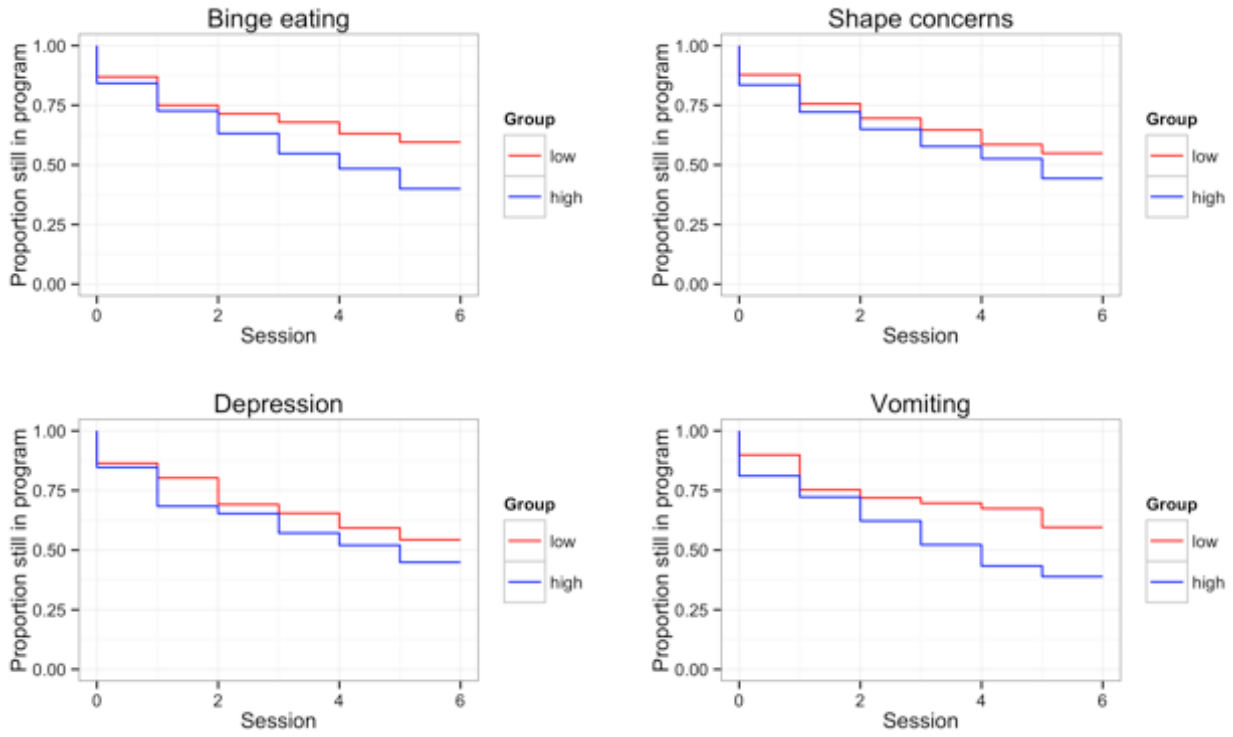
depression as well as frequent binge eating episodes and vomiting were more likely to drop out of the program (see Figure 2). All other variables, including age, the URICA scores, BMI, and the EDE-Q scales Restraint, Eating Concerns, and Weight Concerns were not significantly related to dropout.

Table 2. Model parameters.

Variable	Full sample	Bootstrapping results		
	LASSO estimate	Mean (SD)	95% CI	*P*
EDE-Q Shape Concerns	.07	.07 (.10)	.06, .08	<.001
Vomiting	.03	.07 (.09)	.06, .07	<.001
HSCL-25 depression	.05	.06 (.08)	.05, .06	<.001
Binge eating	.14	.10 (.09)	.09, .10	<.001

Figure 2. Dropout stratified by high vs low levels of the relevant variables based on median split.



Bootstrapping LASSO

By using bootstrapping to estimate the variability of these results, we found that the 4 variables identified as predictors in the full sample were also the only variables that were identified in more than 50% of the bootstrapping samples (see Figure 3). Across samples, the frequency of binge eating, the frequency of vomiting, the EDE-Q subscale Shape Concern, and depressive mood were identified as predictors of participants remaining in the program. Importantly, the bootstrapped confidence intervals of these estimates did not include zero, indicating that these are larger than expected by chance effects alone.

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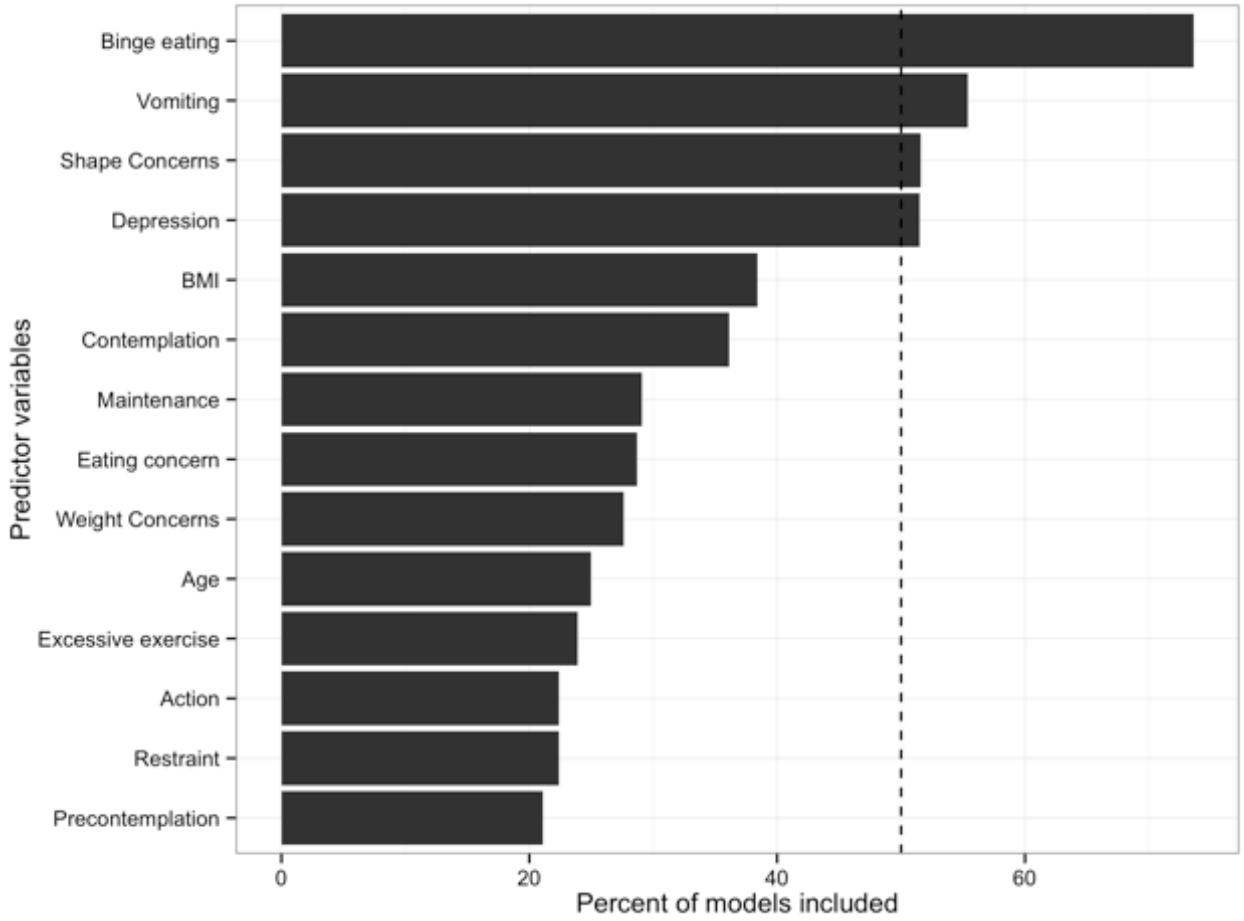
Figure 3. Number of pseudosamples for which the LASSO identified the variables as relevant.



Discussion

Principal Findings

The primary aim of the present study was to identify predictors of dropping out of an online program for women with eating disorders. We found that 50.8% (91/179) of the participants terminated their participation in the program prematurely. Our analysis identified 4 indexes of symptom severity that predicted dropout, namely the EDE-Q Shape Concerns subscale, frequency of vomiting within the previous 28 days, frequency of binge eating within the previous 28 days, and the HSCL-25 depression subscale. Neither motivation to change nor age predicted dropout.

The overall level of symptom severity in the present sample was high when comparing the scores of the present sample with the published norms of the EDE-Q [51]. This shows that a large proportion of participants suffered from significant eating disorder pathology, although diagnoses were not made by means of structured clinical interviews. Therefore, the sample seems to be suitable for drawing assumptions about women with eating disorders in general.

Similarly, the overall level of the dropout rate is comparable to that from other Web-based programs in general [17]. The current program was completely anonymous, which might have made it easier for participants to prematurely terminate their participation. Future research should evaluate the importance of anonymity in Web-based interventions for individuals with eating disorders and determine its role in dropout.

The dropout rate was equally distributed across the 6 sessions. However, it remains unclear whether the reasons for early versus late dropout are identical [22,39]. It is possible that early dropout is primarily because of participants' dissatisfaction with the program, whereas late dropout may also be because of progress withdrawal (ie, participants feeling that they have already benefited enough) [22,39,68]. Speculative reasons for program withdrawal in the study may have included feeling dissatisfied with the motivational content and the absence of practical advice and strategies for overcoming the eating disorder, feeling overwhelmed by negative emotions when dealing with one's own reasons for and against the eating disorder, or having resolved motivational issues faster than in 6 sessions [22]. Because dropout was distributed evenly across the 6 sessions, the specific content of any particular session can be discarded as a cause of dropout.

Although the high dropout rate is fairly typical for Web-based interventions [19], a high dropout rate is related to poorer outcome [16], meaning that it is important to understand the factors predicting early termination. Concerning the predictors of dropout, various indexes of symptom severity (ie, the EDE-Q Shape Concerns subscale as well as the frequency of binge eating and vomiting) predicted premature discontinuation of the Internet program. The finding regarding Shape Concerns is

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consistent with results from research in women with eating disorders in face-to-face settings [25,26] as well as previous Web-based interventions [6], which also showed that higher body dissatisfaction makes treatment dropout more likely. The finding that the higher the frequency of binge eating and vomiting, the more likely participants were to terminate treatment early is also in-line with previous findings. Accordingly, Kahn and Pike [26] and Woodside and colleagues [28] found that patients with the binge eating/purging type of anorexia nervosa were also more likely to drop out of face-to-face treatments. The commonly high levels of impulsivity in this patient group may also facilitate treatment dropout [28]. Because higher symptom severity is associated with longer duration of illness, it may reflect that these patients are also more reluctant to confront their maladaptive behavior [25]. The relationship between higher eating disorder pathology and premature termination of the online treatment program observed in the present study suggests that the online modality may be insufficient for those with more severe eating disorders.

We also found that participants with higher levels of depressive mood were more likely to drop out of our program. This finding is in accordance with previous findings from face-to-face settings for eating disorders [29,30] and a study on a Web-based treatment program for women with eating disorders [6]. However, other studies have reported a lack of association between depression and dropout from Web-based programs for women with eating disorders [37,38]. It seems plausible that an impact of depression which emerges in conventional therapies could also be relevant in Web-based treatment because the contents of the Web-based treatments were the same as the contents of face-to face therapies (ie, mostly consisting of cognitive behavioral therapy and motivational interviewing; eg, [5,36]). Participants in the present study showed high depression scores, whereas the participants of other Web-based interventions for eating disorders reported only moderate depressive symptoms [37,38]. Thus, it is possible that the effect of depression on treatment dropout only emerges for participants with relatively severe depressive symptomatology, for whom programs such as ours may be inadequate because they fail to target depressive features [13]. It is important to note that although we excluded participants with severely elevated depressive symptoms, our cutoff point of 35 on the CES-D is still relatively high [69], meaning that participants with elevated depressive symptoms were included in the study. Moreover, the fact that depressive mood was predictive of treatment termination although participants with extreme scores were a priori excluded from the study underscores that even moderate levels of depression may constitute a contraindication to engaging in such programs.

It is also noteworthy that several of the tested variables were not significant predictors of treatment dropout. In accordance with previous studies [6,38], we did not find any effect of age on dropout although the age range in our study was relatively wide, which should have facilitated the detection of any existing age effect. Furthermore, we did not find any effect of motivation to change as assessed by the URICA on treatment retention, despite the fact that motivation to change seems to be a stable predictor in face-to-face therapies [31,32,70]. Given that our program dealt exclusively with participants' motivation to change and aimed specifically at enhancing motivation, it may have been helpful to negate the impact of low motivation on treatment adherence. It is plausible that motivation to change is a more robust predictor of treatment adherence in interventions without a motivational focus, such as conventional cognitive behavioral therapy [71]. In contrast, in most studies, motivation to change was not investigated as a predictor of treatment retention in face-to-face programs aimed at enhancing motivation to change [72,73]. An exception to this is the study by Allen and colleagues [74] who directly investigated the role of motivation to change in predicting treatment dropout from a motivational program. They did not find any effect on most of the measures, with the exception that higher scores on the precontemplation scale were predictive of dropout. To sum up, motivation to change seems to be a more robust predictor of treatment retention in interventions targeting change rather than motivation to change. This may be because motivational programs help to increase participants' motivation; hence, eliminating the adverse effects of low motivation on dropout. Furthermore, the limited variance in motivation to change in this study may have made it more difficult to detect any effect of motivation. The limited variance in the URICA scores in our study is comparable to those from other studies on motivational enhancement programs [75,76], with the highest scores on the contemplation scale. It is perhaps not surprising that participants were primarily ambivalent about change given that participants would have needed a minimum amount of motivation to register for the program and they believed that they could benefit from a motivational program.

Limitations

Several limitations should be kept in mind when interpreting the results of the present study. The complete anonymity and lack of direct contact made it impossible to obtain clinical diagnoses. Although the high scores on the EDE-Q indicate a clinical level of symptom severity, because we were unable to distinguish between people with different eating disorder diagnoses, we were also unable to test for diagnosis as a predictor of dropout. Furthermore, we used a global measure of motivation to change, which has been criticized in the context of eating disorders [77] because a patient's motivation to change her eating disorder may vary between different symptoms. For example, motivation to change binge eating is usually higher than motivation to change dietary restriction [78]. Therefore, some authors argue that it is not adequate to assess a patient's motivation to change globally for the eating disorders as a whole [79]. It is possible that we were unable to detect an effect of motivation to change because of the global assessment of the construct.

Nevertheless, this is the first study investigating a wide range of predictors of dropout from a Web-based program using adequate methodology in a large sample of women suffering from a wide range of eating disorder pathology.

Conclusions

This study identifies symptom severity and depressive symptoms as predictors of dropout from a Web-based program targeting motivation to change in women with symptoms of an eating

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disorder. In contrast, retention in the program was not dependent on age or initial motivation. These findings have the potential to guide further development of Web-based treatment programs in terms of tailoring online-delivered therapies to the specific needs of patients. For example, women who indicate high levels of depression could be offered an additional module that addresses affective disturbance. Furthermore, women who suffer from more severe eating disorder pathology might need more therapeutic guidance or additional contact via telephone or in a face-to-face setting to help them to continue the program. Although high dropout rates remain problematic in online treatments, there is still a large proportion of patients (particularly those with less severe eating disorders and depressive symptoms) who complete this easily accessible means of delivering therapeutic interventions.

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Authors' Contributions

RvB, KH, and SV developed the ESS-KIMO program and RvB and KH wrote participants' feedback.

Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
CES-D: Center for Epidemiologic Studies Depression Scale
EDE-Q: Eating Disorders Examination-Questionnaire
EPV: events per predictor variable
HSCL-25: Hopkins Symptom Checklist
LASSO: least absolute shrinkage and selection operator
URICA: University of Rhode Island Change Assessment Scale

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Original Paper

An Innovative Smartphone-Based Otorhinoendoscope and Its Application in Mobile Health and Teleotolaryngology

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Abstract

Background: The traditional otorhinoendoscope is widely used in the diagnosis of a variety of ear and nose diseases, but only one doctor can use it at a time. It is also very difficult to share observations from one doctor with another doctor. With advances in electronic health technology, the extended potential application of smartphones to support medical practice or mobile health has grown steadily.

Objective: The first phase of the study discussed how smartphones may be used for otorhinoscopic imaging and image management via an innovative adaptor. The second phase of the study was to evaluate the diagnostic capability of the smartphone-based otorhinoendoscope, as compared to the traditional otorhinoendoscope, and its application in mobile health and teleotolaryngology.

Methods: We designed a unique adaptor to connect the otorhinoendoscope and smartphone in order to perform smartphone-based otorhinoendoscopy. The main aim was to transform the smartphone into an otorhinoendoscope. We devised a method that would allow us to use the smartphone's camera to capture otorhinoscopic images. Using a freely available Web-based real-time communication application platform and the 3G (or WIFI) network, the smartphone-based otorhinoendoscope could synchronize the smartphone-based otorhinoscopic image with smartphones, tablet PCs, computer notebooks, or personal computers.

Results: We investigated the feasibility of telemedicine using a smartphone, tablet PC, and computer notebook. Six types of clinical otorhinoscopic images were acquired via the smartphone-based otorhinoendoscope from six patients, which were examined in this study. Three teleconsultants (doctors A, B, and C) reviewed the six types of clinical otorhinoscopic images and made a telediagnosis. When compared to the face-to-face diagnosis, which was made in-person via a traditional otorhinoendoscope, the three teleconsultants obtained scores of a correct primary telediagnosis 83% (5/6), 100% (6/6), and 100% (6/6) of the time, respectively. When the clinical data were provided, the three teleconsultants obtained a correct secondary telediagnosis score of 100% (6/6), 100% (6/6), and 100% (6/6) of the time, respectively.

Conclusions: The use of previously available technologies in the absence of any additional expensive devices could significantly increase the quality of diagnostics while lowering extraneous costs. Furthermore, this could also increase the connectivity between most isolated family doctors and remote referral centers.

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KEYWORDS

otorhinoendoscope; smartphone; mobile health; teleotolaryngology; telediagnosis

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Introduction

Electronic health is defined as the use of information and communication technologies in support of health and health-related fields, including health care services, health surveillance, health literature, and health education, knowledge, and research [1]. Mobile health is a term used for the practice of medicine and public health and is supported by mobile devices, such as mobile phones, smartphones, tablet computers, and PDAs (personal digital assistants). Mobile health has emerged as a subsegment of electronic health [2]. Mobile health is now pushing the limits of how we acquire, transport, store, process, and secure raw and processed data to deliver meaningful results. Mobile health also supports health care workers who perform clinician-like duties where there are no doctors and can help to keep track of patients, which may not have been possible in the past [1,2]. There have been considerable advances in the field of mobile phone technology within the past few years. It is predicted that by 2017 there will be more mobile phones than people in the world. Currently, three-quarters of the world's population have access to a mobile phone [3,4]. With nearly 5 billion mobile phone users worldwide, researchers are now realizing the great potential of using mobile health technology, such as smartphones, for electronic health services. Mobile health can also support the daily practice of health care workers via the dissemination of clinical updates, learning materials, and reminders [5], particularly in underserved rural locations, as well as in low-income and middle-income countries. With the development of smartphone technology, mobile health can support daily practice in the field of telemedicine.

Telemedicine is a technique that enables virtual online communication in real time among health care providers who are located in distant places and for patients in rural areas. There are several ways in which to perform telemedicine. In its most basic form, telemedicine is similar to a videophone, consisting of a camera, a monitor, and a microphone to transmit video and audio from one location to specialists in another location [6]. This enables the primary care doctor who is located in a rural area to discuss patients in detail with a specialist at another remote site in order to provide diagnostic and therapeutic advice. According to a World Health Organization (WHO) report, telemedicine is particularly useful in rural areas or in developing countries where access is limited to specialists and subspecialists. According to Vera-Domínguez J et al (2010), the use of telemedicine by a trained technician at the site where the patient is can provide information to the physician who specializes in this problem—this may be a referral hospital in another distant location [6]. Teleotolaryngology is defined as telemedicine in the specialty of otolaryngology and head and neck surgery. With advances in technology, the use of telemedicine to treat diseases has grown significantly. Diseases of the ear, throat, and nose are among the most common diseases, which can be diagnosed and treated via teleotolaryngology.

According to a WHO global report on chronic disease prevention, chronic otitis media is one of the major chronic diseases in low-income and middle-income countries [7]. When categorized by cause, global and regional projections of mortality and burden of disease for the years 2000, 2010, and 2030 indicated that hearing loss is projected to be among the top ten causes of burden of disease in high-income and middle-income countries according to the WHO report [8]. To address the widespread demand for raising awareness regarding ear and hearing diseases in global health, and thereby support international health policy and priority setting, we have devised an innovative device to help diagnose chronic ear disease in the field of telemedicine.

Our study was motivated by several reports on health care technology published by Rubisky et al (2008) and the WHO [9-11]. According to WHO reports, the majority of the world's population does not have access to health care technologies [10,11]. For example, traditional otorhinoendoscopes (Figure 1) are widely used in the diagnosis of a variety of ear and nose diseases, but can be used by only one doctor at a time. In addition, it is also notably difficult for a doctor to share his or her observations with another doctor during an examination. This difficulty is particularly true for a junior primary care doctor, where it is highly difficult to precisely describe the eardrum and external auditory canal condition to someone during an examination. A traditional otolaryngological video endoscope system can be used as an alternative tool in the field of teaching and telemedicine. However, an affordable and reliable otolaryngological video endoscope system is also lacking in many developing countries due to its high cost, maintenance difficulty, and weight. Moreover, despite the availability of an otolaryngological video endoscope system, these systems were often of an inadequate type, non-functional, or handled incorrectly due to the lack of well-trained doctors. According to WHO reports, more than 50% of medical equipment is not being used in the developing world because it is too sophisticated or is in disrepair, or due to the lack of trained health workers and maintenance. On the other hand, the lower cost of mobile phones (smartphones) and their great mobility has attracted more people who can afford and make use of mobile technology, even in developing countries [12]. With advances in electronic health technology, the extended application of the smartphone in medicine has evolved over time. This article introduces an innovative device and discusses how smartphones can be used for otorhinoscopic imaging and image management, as well as its application in mobile health and teleotolaryngology.

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Figure 1. A traditional commercial otorhinoendoscope is widely used to help diagnose a variety of ear and nose diseases, but it can only be used by one doctor at a time.



Methods

Designing a Specific Adapter Device

The key concept of the smartphone-based otorhinoendoscope is to make a connection between the smartphone's camera and the otorhinoendoscope. The process sounds simple, but several challenges had to be overcome. The aim was to transform a smartphone into an otorhinoendoscope. In developing our mobile health technology, the technical part of this study was challenging due to the lack of a commercial adapter to connect the smartphone and otorhinoendoscope. The challenge of our study was the need to create a specific adapter and portable light source. First, we designed an adapter to align the optical access of the otorhinoendoscope with the camera of the smartphone, which was employed to capture the otorhinoscopic images. For the smartphone-based otorhinoendoscopy, we designed a unique adapter (Figure 2) to connect the otorhinoendoscope to the smartphone. Figure 3 shows the connection of the otorhinoendoscope and specific adapter, which we refer to as the smartphone-based otorhinoendoscope. However, the smartphone-based otorhinoendoscope will not work without a portable light source. As a result, we designed a portable light source, which was modified from a commercial electric Light-Emitting Diode (LED) flashlight. The external LED light source of the device was powered by rechargeable batteries. The complete unit was extremely portable and easy to manipulate. No additional power supply unit or electrical sockets were required.

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Figure 2. Self-designed specific adapter with portable light source.



Figure 3. Prototype of a self-designed smartphone-based otorhinoendoscope.



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Evaluation of Diagnostic Quality and Application in Telemedicine

Six patients (#1, 2, 3, 4, 5, and 6) were tested during a humanity mission in the mountainous area of Taiwan. Only patients who agreed to be evaluated using the traditional otorhinoendoscope and smartphone-based otorhinoendoscope were enrolled in this study. Written informed consent for participation in the project was obtained from the parents of all infants, and all procedures were approved by the Research Ethics Committee of the Kaohsiung Veterans General Hospital. Three teleconsultants who were professional otolaryngologists from a tertiary medical center in Taiwan participated. In this study, all otorhinoscopic images (Figures 4 and 5) were captured using a smartphone (Samsung, Galaxy Note II) with a built-in 8-megapixel camera with autofocus, macro mode, and zoom functions. A freely available Web-based real-time communication application platform (Google Plus Hangouts) was used to transmit the otorhinoscopic images via a third-generation network. An Internet connection was made available for the three teleconsultants. Two of the teleconsultants used a computer notebook with a 14-inch LCD monitor (Sony, VAIO and Acer, V5 Ultrabook) and the other teleconsultant used a tablet PC with a 10-inch LCD monitor (Apple, third-generation iPad).

Six types of clinical otorhinoscopic images were acquired from the six patients (#1, 2, 3, 4, 5, and 6) at the Kaohsiung Veterans General Hospital. The same otolaryngologist performed the face-to-face diagnosis, using a traditional otorhinoendoscope. After the face-to-face diagnosis was performed at a remote site, the raw data without details about the related clinical conditions were transmitted through the 3G network to a teleconsultant for a primary telediagnosis. Three teleconsultants—doctors A, B, and C—first reviewed the clinical images and reported their primary telediagnoses. All teleconsultants reviewed the cases independently from each other and directly responded with their primary telediagnoses using the real-time communication platform.

After the first telediagnosis was made, the patient's clinical conditions were provided to each of the teleconsultants. Subsequently, a second telediagnosis was made. The three teleconsultants were asked to provide a specific telediagnosis (eg, acute otitis media, eardrum perforation) for each case in the primary and second telediagnoses, and only one telediagnosis was accepted. The telediagnoses were compared to the face-to-face diagnoses. The face-to-face diagnosis was assumed to be the correct diagnosis. Diagnostic agreement was defined as the concurrence between the telediagnoses and face-to-face diagnoses. The three teleconsultants were also asked to judge the quality of each image using the following scale: poor, fair, and good. The image quality was judged by the three teleconsultants subjectively. One of the limitations of this study worth noting is that the sample size was not large enough. In order to effectively develop this tool for clinical use, additional studies performed on a larger series of cases are required to confirm the effect of image quality on mobile health telediagnoses. Further larger series studies will be performed in the near future.

Figure 4. Using a smartphone-based otorhinoendoscope to evaluate an ear condition in a young male patient.

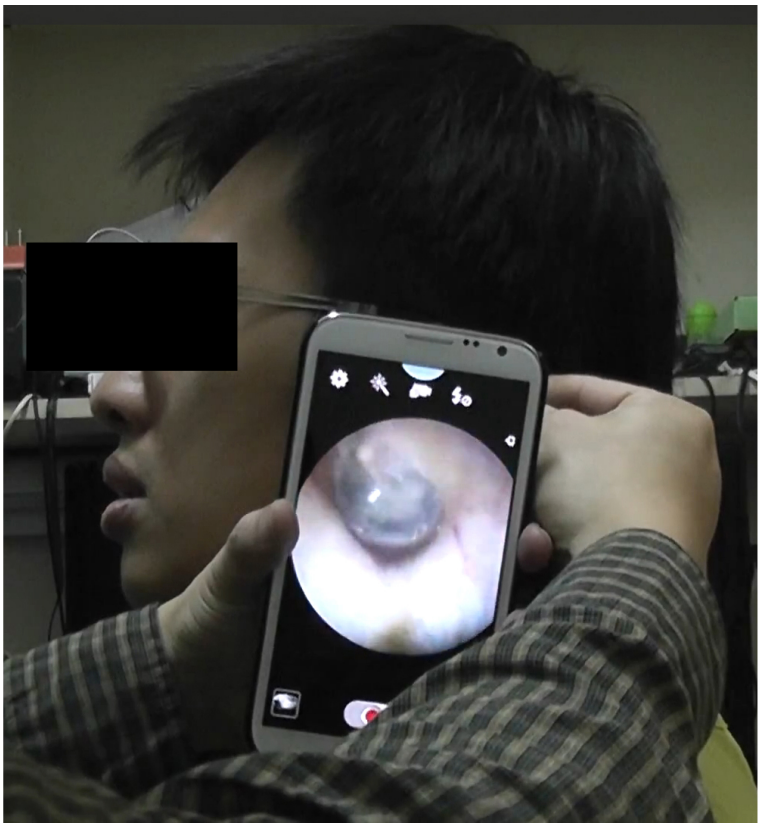

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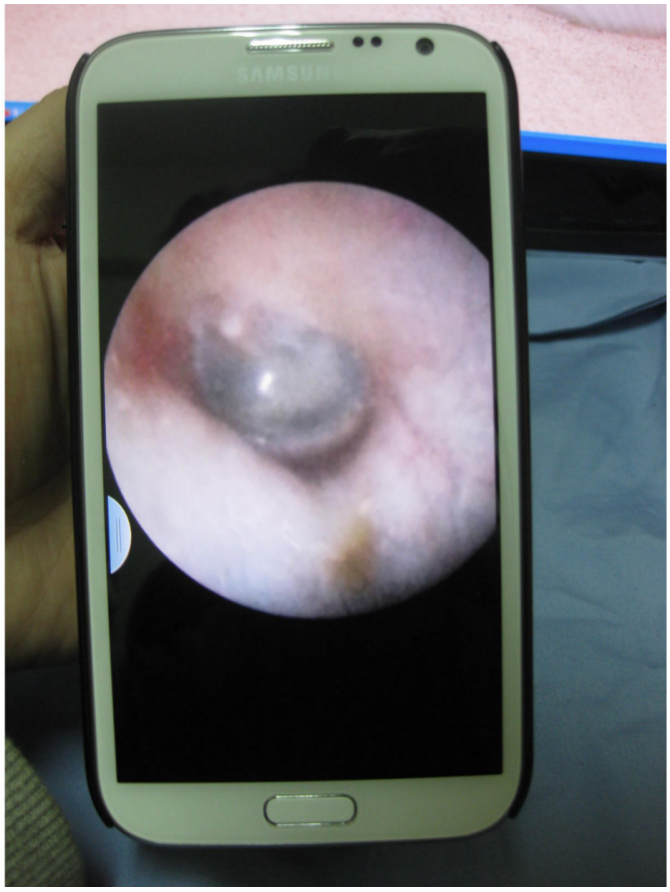
Figure 5. Clinical picture captured using a smartphone-based otorhinoendoscope.



Results

The clinical otorhinoscopic images acquired under the six conditions using the smartphone-based otorhinoendoscope were examined in this study (Table 1). Three teleconsultants reviewed the six conditions and performed the telediagnoses. The same otolaryngologist determined the face-to-face diagnosis for each case using the traditional otorhinoendoscope. The face-to-face diagnosis was assumed to be the correct diagnosis. Compared with the face-to-face diagnoses, the primary telediagnoses made by the three teleconsultants were 83% (5/6), 100% (6/6), and 100% (6/6) correct. After the patient's clinical information was provided, the second telediagnoses made by the three teleconsultants became 100% (6/6), 100% (6/6), and 100% (6/6) correct. In one case, an atrophic scar of the tympanic membrane was overdiagnosed as an eardrum perforation due to poor image quality. Poor image quality was defined as severe loss of sharpness or color accuracy and with artifacts (distortion). Fair image quality was defined as mild loss of sharpness or color accuracy and without artifacts. Good image quality was defined as no loss of sharpness or color accuracy and without artifacts. Sharpness is affected by the lens of the smartphone (manufacturing quality, focal length). In this study, loss of sharpness was affected by camera shake due to the device being too light to hold steadily. It is worth noting that digital images from many smartphone cameras will sometimes lose the accuracy in color saturation due to the basic physical limitation of the lens. Further, a smartphone's digital camera lens converts light into electricity and then that electricity is converted into pixels. The ability of the smartphone's sensor chips to handle these conversions is not as good as a traditional digital camera. As such, the digital noise is higher in smartphones compared to traditional digital cameras. In our study, the quality of the images was judged as poor for 1 case (17%), fair for 2 cases (33%), and good for 4 cases (50%).

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Table 1. Face-to-face diagnosis and telediagnosis of teleconsultants A, B, and C.

Patient	Face-to-face diagnosis	Primary telediagnosis[f]			Secondary telediagnosis[g]			Image quality of pictures		
		A[a]	B[b]	C[c]	A[a]	B[b]	C[c]	A[a]	B[b]	C[c]
#1	Allergic rhinitis	1[d]	1	1	1	1	1	Good	Good	Good
#2	Nasal polyp	1	1	1	1	1	1	Good	Good	Good
#3	Nasopharynx tumor	1	1	1	1	1	1	Fair	Fair	Fair
#4	Atrophic scar of the tympanic membrane	0[e]	1	1	1	1	1	Poor	Poor	Poor
#5	Acute otitis media	1	1	1	1	1	1	Fair	Fair	Fair
#6	Eardrum perforation	1	1	1	1	1	1	Good	Good	Good
Diagnostic agreement, n/n (%)		5/6 (83%)	6/6 (100%)	6/6 (100%)	6/6 (100%)	6/6 (100%)	6/6 (100%)			

[a]A: teleconsultant A

[b]B: teleconsultant B

[c]C: teleconsultant C

[d]1: agreement with face-to-face diagnosis

[e]0: disagreement with face-to-face diagnosis

[f]Primary telediagnosis: telediagnosis without clinical information

[g]Secondary telediagnosis: telediagnosis with clinical information

Discussion

Principal Findings

Our study examined the feasibility of the use of teleconsultation for ear and nose lesions using a smartphone-based otorhinoendoscope. The clinical pictures that were captured by using the newest generation of smartphones were excellent. In fact, the high resolution of the built-in autofocus camera in the new generation of smartphones resolves the problems of image quality found in previous reports [13,14]. These devices produced a *full* 1080 pixel *HD video image.* However, the images captured using the smartphone were not perfect—approximately 17% of the images were judged as being of poor quality by our teleconsultants. Poor image quality was defined as low sharpness, out-of-focus, inaccurate color, and with artifacts. It is important to remember that smartphones are phones first, then computers and also cameras. Unlike cameras, smartphones don't have good anti-shake features. Also, the weight of device is light, making it difficult to hold steady. Although the image quality was not perfect, the three teleconsultants still obtained a 100% correct telediagnosis after the patient's clinical information was provided. However, further studies performed on a larger series of cases are required to confirm the effect of image quality on mobile health telediagnoses.

It must be emphasized that the clinical information was not initially provided to the teleconsultants. To test the device's real capability to formulate a telediagnosis, only the clinical images were initially provided. One of our patients had an atrophic scar of the eardrum. She had a history of traumatic eardrum perforation. An atrophic scar of the eardrum can be easily diagnosed using a pneumatic otoscope and clinical information. Without the most important clinical information and related history, one of our teleconsultants overdiagnosed at the primary telediagnosis. This result may be explained by the fact that in some cases, using the image alone is not sufficient to achieve a correct diagnosis. The correction rate of the telediagnosis was not attributed to a single factor. The quality of the telediagnosis was determined using the quality of the clinical image, the accompanying clinical information, and the experience of the teleconsultant.

A number of common treatable diseases account for the vast majority of ear and nose disease burdens in developing countries, such as chronic otitis media, allergic rhinitis, acute otitis media, and hearing impairment. There is a high demand for otolaryngologists in these developing countries. Most of these ear and nose diseases are readily treatable with the consultation of an otolaryngology specialist. With the help of mobile health technology, most otolaryngological diseases can be managed at a local health unit after a telediagnosis has been made by the teleconsultants. According to Haegen TW's report (2004), teleotolaryngology resulted in the avoidance of 22.7% of consults. Only 13.0% of patients required traditional face-to-face otolaryngology consultation. These studies demonstrated the ability of teleotolaryngology to function in a general otolaryngological setting. For teleotolaryngology, suitable equipment is required to properly transmit audio-visual data so that otolaryngologist specialists and audiologists can benefit from the data in their examination and treatment of the patient. In addition, the application of teleotolaryngology can help patients to minimize their treatment expenses and to evaluate their treatment in a more efficient manner [15,16]. The possible contributions of mobile health can result in a significant health gain for both the individuals and communities in developing countries.

New acute otitis media treatment guidelines emphasize awareness. The American Academy of Pediatrics has released

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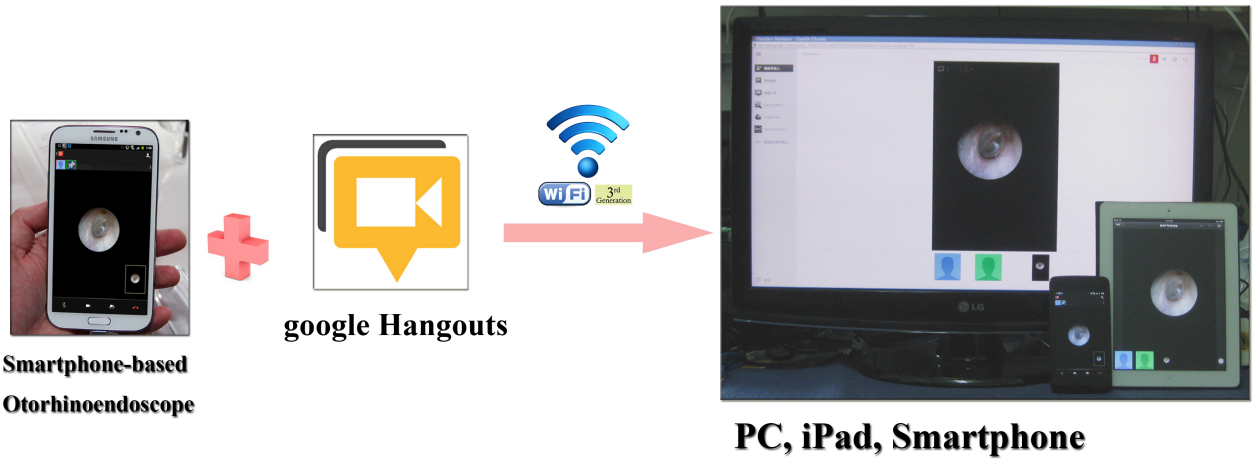
the new 2013 guidelines for the management of acute otitis media, which provide more strict criteria to limit unnecessary antibiotic prescriptions, and advice against prophylactic antibiotic treatment for children with recurrent infections [17]. Approximately 70% of children who present with ear infections get better on their own within three days and 80% are better within a week according to the new guidelines [17]. Overtreatment of ear infections with antibiotics in preschoolers may cause antibiotic resistance and has caused millions of unnecessary visits and prescriptions for antibiotics in the United States. Currently, physicians diagnose ear infections using otorhinoendoscopes to examine the eardrum. With advances in mobile health technology, primary care would able to take pictures via the smartphone-based otorhinoendoscope, and telediagnosis could be made by sending the pictures digitally to a remote otolaryngologist. The smartphone-based otorhinoendoscope is very easy to operate. Even parents could potentially record a clinical image without a doctor's help. It is impossible for a patient to go to the outpatient clinic for an otological examination by an otolaryngologist daily to see if their eardrum condition has improved. However, it is possible for parents to take clinical images using these devices at home daily. The smartphone-based otorhinoendoscope has the potential to change the doctor's practice patterns of overutilizing antibiotics for ear infections. Currently, otolaryngologists can wait to see if a child's infection improves or if antibiotic treatment is warranted after the series of clinical images are obtained from parents.

Technologies designed for developed countries are often incompatible with a developing country's infrastructure, habits, and culture. Thus, local users must develop their own electronic health technology [4,5]. The development of a smartphone-based otorhinoendoscope may solve this problem. The complete unit of our smartphone-based otorhinoendoscope is extremely portable and easy to maneuver. No additional power supply unit or electrical sockets are needed, which is very convenient in developing countries where a power supply may be lacking. The device can be taken to the patient for use instead of bringing the patient to the device for their examination. One of the most impressive elements of the device was that it could be used for medical applications in the field of telemedicine. Using a network connection, the device could serve as a good diagnostic tool for doctors in remote areas around the globe. The device delivers a higher level of magnification as compared with traditional otorhinoendoscopes, making it easier to visualize the auditory canal and tympanic membrane. The device also has a significant advantage in transmitting images to another smartphone, notebook, tablet PC, or personal computer (Figure 6) via a freely available Web-based real-time communication application platform (FaceTime in iOS system or Google Plus Hangouts in the Android system), providing an improved perspective for enhanced learning and decision-making. It can be used in a daily outpatient office practice to demonstrate the clinical signs of ear and nose diseases to the patient or even to teach students and younger residents. Even patients or parents themselves could monitor changes in the ear condition and capture an image of the lesion using these devices and send the images digitally. The use of current widely available mobile technologies [18], in the absence of any additional otolaryngological video endoscope system, could significantly increase quality diagnostics and lower extra costs.

The cost of our specific adapter device was less than US$350. In our research, we used a refurbished smartphone, which was about US$300. A portable light source, which was modified from a commercial electric LED flashlight, was roughly US$40 and the adapter case cost about US$10. With little additional equipment required, the proposed device is a cost-effective smartphone-based otorhinoendoscope.

Figure 6. The smartphone-based otorhinoendoscope has a significant advantage in transmitting images to a smartphone, notebook, tablet PC, or personal computer via a freely available Web-based real-time communication application platform (Google Plus Hangouts in the Android system).



Conclusions

Medical facilities in developing countries and rural regions are lacking. Advanced diagnostic tools are quite rare and very often there are no subspecialists providing services to these remote areas. In a surprising twist on technology, mobile phone use in developing countries has surpassed that of developed areas according to a recent World Bank report. There is also increasing connectivity between most isolated doctors and distant referral centers or hospitals. Thus, a smartphone-based otorhinoendoscope has the potential to become an easily applicable tool for everyone and a new approach to enhanced

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self-monitoring of ear and nose diseases, particularly in developing countries.

The present work is the first study on mobile health in the field of telemedicine using smartphones in the otolaryngological field. More prospective, randomized clinical studies are needed to test the application of the smartphone-based otorhinoendoscope in the field of mobile health and teleotolaryngology.

Conflicts of Interest

None declared.

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Abbreviations

LED: Light-Emitting Diode
PDA: personal digital assistants
WHO: World Health Organization

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Original Paper

Web-Based Apps for Reflection: A Longitudinal Study With Hospital Staff

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Abstract

Background: Reflection is an important cognitive process in workplace learning; however, it occurs only rarely on its own and therefore needs additional support.

Objective: In this study, we investigated the effect of software applications (apps) that aim to support reflection on hospital staff's actual reflection behavior. In doing so, we also analyzed the relationship between reflection and the job satisfaction of health care professionals.

Methods: Reflective learning was introduced in the ward of a neurological hospital by providing apps that aimed to foster particular aspects of individual and collaborative reflection. Data were collected repeatedly: once before the introduction of the apps and again 2 years after the initial measure. We used a questionnaire with subjective ratings of reflection and job satisfaction. Response rates were 34.4% (167/485) for the first and 40.6% (210/517) for the second measure.

Results: Collaborative reflection was increased (P=.047) after the provision of the apps (2010: mean 2.84, SD 0.72; 2012: mean 3.06, SD 0.63) in contrast to a control group of other wards of the same hospital (2010: mean 2.68, SD 0.67; 2012: mean 2.63, SD 0.68). In addition, we revealed a positive correlation between collaborative reflection and job satisfaction (r=.61, P<.001).

Conclusions: The findings provide evidence for an effect of the apps on hospital employees' reflection behavior. Apps that foster reflective learning can increase health care professionals' reflection about work experiences and support them in discussing experiences in teams or with their supervisors. The relationship between collaborative reflection and job satisfaction suggests that opportunities for joint reflection on work experiences in a hospital have further impact over and above fostering reflective learning per se. We discuss the limitations of our study and provide suggestions for both future research and the development of Web-based apps.

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KEYWORDS

computer applications software; mobile applications; learning; education, continuing; job satisfaction; hospitals; longitudinal studies; self report

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Introduction

Background

Learning and the continuing development of employees are important issues in hospitals. Confronted with complex problems and stressful situations, nurses and physicians always need to keep their skills up to date and develop them further [1-3]. This happens not only through formal training but also informally in the daily routine of health care professionals [4-6]. Hospital management needs not only skilled and competent employees but also contented employees, since dissatisfied nurses and physicians are more likely to resign [7,8]. Job satisfaction of health care staff is related to patient satisfaction [8] and patient care (for an overview see [7]) and therefore plays an important role when it comes to the quality of medical care.

The aim of the present study is to examine an easy and efficient way of supporting reflective learning in hospital staff. For this purpose, we tested the suitability of application software (apps) that support reflection. Our aim was also to examine the relationship between reflection and job satisfaction of hospital staff.

We present theoretical and empirical considerations of reflection processes in the workplace and of job satisfaction, with each presentation leading to a concrete hypothesis. Then we describe the methods of this longitudinal study and its results. Concluding, we discuss our findings with respect to their practical implications and suggestions for future research in medical informatics.

Reflection

One informal way of learning at work is through reflecting on work situations that employees themselves or colleagues have experienced [9,10]. Reflection is a process “in which people recapture their experience, think about it, mull it over and evaluate it” [11]. Reflection is considered to be an important process in organizations, for example, for innovation [12] or for organizational learning [13,14]. Although reflection is quite a natural process [9], people often do not use it consciously or intentionally as a skill to improve learning and performance [15]. Moreover, there are several other preconditions for the successful application of reflection in the workplace. On the part of the individual, not only a lack of awareness of the benefits of reflection, but also an absence of motivation for reflective thinking, as well as a lack of metacognitive skills like self-monitoring and self-evaluating might hinder reflective learning [16]. On the part of the organization, there are also certain conditions necessary to foster reflective thinking. An organization that wants employees to engage in reflection needs to give them opportunities to participate in shaping their work environment, at least in some areas. If an organization is characterized by strong hierarchies and employees are not involved in decision-making processes, the potential for change through reflective thinking is quite limited [16]. In sum, reflection, whether carried out individually or in teams, does not tend to occur by itself [12], rather, it needs support [13].

One area where reflection and reflective thinking are broadly researched topics is in the health care sector [3,17-20]. A special focus of previous research has been on the education of nurses [17-21] and physicians [1,22-26]. In hospitals, reflection helps the staff combine theory and practice [3,20] and enables them to turn experiences into learning opportunities [27]. In this way, reflection and reflective work behavior foster continuing professional development [28]. Research findings in this field suggest, however, that reflectivity is indeed not an easily applied skill. Instead, guidance and support are needed to achieve higher levels of reflection [21].

Since reflection is rare, but important and valuable for health care professionals, research needs to find approaches that can support this process [23]. One option that is relevant from a medical informatics perspective is the development of Web-based or mobile apps [29-31] to assist individuals and teams in their reflection processes in hospitals. These apps are supposed to support staff in exercising different aspects of reflection. Apps can remind people to reflect on their experiences and therefore compensate for low awareness or motivation. They can also extend the range of situations and experiences a single person faces, for example, by making additional experiences possible through virtual worlds or computer simulations. Moreover, apps can support collaborative reflection. Through collaborative reflection, people can learn from others and benefit from their experiences [32]. Since memories of experiences can become imprecise over time, it is important to capture them in such a way that they can be used for further reflection [33]. Apps can foster reflection in different ways, by providing experiences (eg, in virtual settings), documenting experiences, triggering reflection about experiences, and supporting communication and cooperation in collaborative reflection. So the first hypothesis of the current study is that (1) apps designed to foster reflection of health care professionals have a positive impact on the reflection activity of hospital staff.

Job Satisfaction

One reason why people learn for their job is that the tasks of the job require it. But this is not the only motive. People also learn because it helps them in their career and because they have certain personal goals [6]. These goals comprise, among others, a need for personal achievement and development, and a feeling of autonomy [6]. Job satisfaction can be interpreted as the sum of the job expectations employees have that are met [34]. This means not only monetary expectations but also the wish to reach personal goals of development and achievement.

Consequently, we expect that job satisfaction is increased by good learning conditions. Some empirical evidence already exists for the potential influence of learning on job satisfaction. In different studies, significant correlations between organizational learning and job satisfaction [35], as well as between workplace learning and job satisfaction [36-38] have been found. Other authors have identified organizational learning culture as a predictor for general job satisfaction [39,40]. There is also support for the assumption of a relationship between learning and job satisfaction in the health sector. A strong correlation has been identified between professional growth and job satisfaction among nurse practitioners [41].

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Because reflective learning is one type of informal learning that enables employees to develop and shape their working environment to a certain degree, we hypothesize that fostering reflection leads to an increase in job satisfaction. So the second hypothesis to be tested in this study is that (2) reflection is positively related to the job satisfaction of hospital staff.

Methods

Study Design and Setting

A longitudinal study was designed with the staff of a neurological hospital as participants. The study represented a 2 × 2 factorial design with reflection apps and time of measurement as between-subject factors. Due to privacy protection regulations, it was not possible to connect the data of the two measurement points on an individual level. Therefore, time of measurement could not be treated as a within-subject factor. Accordingly, we cannot completely rule out that the samples at the two points of measurement included slightly different individuals. But there was a low turnover rate in this hospital (around 3%); during the study, only two members left the unit that served as the experimental group. Reflection and job satisfaction were measured both before (2010) and after the introduction of the apps (2012).

The staff in one ward of the hospital participated as the experimental group. Participants in this group had the opportunity to use the apps. The staff in all the other wards of the hospital served as the control group. Participants in this group were not acquainted with the apps. The experimental group were ward personnel caring for patients suffering from acute strokes and other neurological emergencies ("Stroke Unit"). The staff of this ward consisted mainly of nurses and physicians. Participants of the control group were staff either of a ward treating all different kinds of neurological injuries, of a neurological intensive care unit, of a rehabilitation unit, or interdivisional staff.

Procedure and Material

In the period between the two data collections, participants were involved in user studies and workshops in order to examine the reflection behavior and needs of hospital staff. Those findings were accounted for in the development of the apps. After the development stage, participants in the experimental group tested the apps in workshops and used them during their everyday work. The developing and testing phases together covered the entire time span between the two points of measurement. During this time, several 1-day workshops as well as two user studies were conducted in order to give the entire staff the chance to participate. The participants were provided with devices to make sure everyone could use the apps and nobody was prevented from participation. The apps addressed the different aspects of reflection as described above.

DocTrain is an app for mobile phones as well as a Web application. It was developed to support physicians during their specialist training. It reminds its users to reflect upon their experiences and helps them document their tasks and capture and share with their mentor their progress in training elements. The app provides a list of tasks, and the users can connect them via the barcode of a patient case with a particular patient. Users can also add personal notes. Data can then be used to reflect about a case individually or with a mentor [42].

CLinIC-The Virtual Tutor is a serious game. It was created to help nursing staff and physicians reflect on and prepare for difficult situations with patients. With the help of the game, users are provided with virtual experiences in handling difficult conversations with patients in order to be better prepared for corresponding situations in real life. A virtual tutor provides feedback and advice. Users can also take notes to reflect on them later. The set of tasks in the game is complemented by so-called mini games. These mini games are integrated into the branching stories of the game as a whole. They allow users to practice skills that are required in the health sector, such as recognizing emotional facial expressions and reflecting on them [43,44].

Finally, the Talk Reflection App allows users to reflect collaboratively on difficult situations with patients and relatives [45]. It consists of a forum where users can contribute experiences with difficult conversations and reflect on them asynchronously together with colleagues. Users can document problematic experiences, share them with others, and add their own thoughts about the situations privately or publicly. Others can then contribute to this topic. In addition, users can document their reflection outcomes [46]. So the app facilitates reflection by capturing data and provides support for coordination and communication in collaborative reflection.

Data Collection

A survey with the hospital staff was conducted twice during the study. The first data collection took place in November and December 2010. The second measurement point was October/November 2012. The response rate was 34.4% in 2010 and 40.6% in 2012.

Participants

In 2010, 167 employees of the hospital participated in the survey: 21 individuals worked in the Stroke Unit, 132 individuals in other wards of the hospital, and 14 did not indicate their ward affiliation. In 2012, 210 employees answered the questionnaire: 17 members of the Stroke Unit, 164 staff members of other wards, and 29 participants did not indicate their ward. The difference in group sizes between the experimental and the control group is due to the fact that the participants of the Stroke Unit were compared to the staff of all the other wards of the hospital; however, response rates did not differ between conditions (all Ps>.05). Staff consisted of nurses, different kinds of therapists, physicians, and administration staff. Participants not indicating their ward were excluded from further analyses, so 334 individuals were considered for the investigation.

Instruments

A 10-item questionnaire was used to measure reflection. Items were created during the research project MIRROR [47] on the basis of those aspects of reflection specified in the literature that were relevant to this study. Particularly relevant are the needs to reflect and to develop through reflection [48]. These

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aspects concern the motivational side of reflection, since motivation is considered an important precondition for the occurrence of reflection [10]. Another important requirement is the absence of barriers such as time pressure [4,10]. The positive consequences of collaborative reflection in terms of sharing and discussing experiences and different perspectives are described by several authors (eg, [4,9,10,13,49]). Collaborative reflection includes team reasoning, that is, the collective analysis of problems [9,12,50]. Collaborative reflection also includes support by a person with greater experience, such as a mentor or a supervisor [9]. To make sure that the items were comprehensible to the participants, their content was discussed with various hospital representatives beforehand, and some revisions were made [47]. The items that resulted from this procedure are listed in Table 1. Participants rated these items on 4-point Likert scales from 1=totally disagree to 4=totally agree.

In addition, participants were also asked 8 questions regarding general job satisfaction (Table 2). Participants rated these items also on 4-point Likert scales from 1=totally disagree to 4=totally agree. Moreover, they were asked to indicate their occupation group and the ward they worked in.

Table 1. Reflection items.

No.	Item
1	I often have the need to think about my work experiences.
2	I am provided with enough time to reflect upon my experiences at work.
3	It helps me for my development to think about my work experiences.
4	We discuss on a regular basis if we work successfully together as a team.
5	If things do not work out as they should, we try as a team to find the reason.
6	We as a team think about how we can learn from past experiences.
7	When I think I did not do a good job, I discuss with colleagues how I could improve.
8	When I think I did not do a good job, I discuss with my supervisor how I could improve.
9	I often think about how we can improve things in our organization.
10	In our organization we are encouraged to reflect upon our experiences at work.

Table 2. Job satisfaction items.

No.	Item
	In general, I am satisfied with...
1	…my work situation.
2	…the advanced and professional training.
3	…the work climate.
4	…the communication.
5	…the operational procedures.
6	…the quality of care.
7	…the leadership of my supervisor.
8	…the neurological hospital as employer.

Statistical Analysis

To assess the internal consistencies of the scales, we calculated Cronbach alpha values and conducted an exploratory factor analysis for the reflection scale. For testing hypothesis 1, we conducted a contrast analysis [51]. The second time of measurement (2012) in the Stroke Unit ward was tested against the three other conditions (Stroke Unit 2010; other wards 2010 and 2012). For conducting the contrast analysis, we treated the 2 (2010 vs 2012) × 2 (Stroke Unit vs other wards) factors as a 1 × 4 design. The hypothesis that there was a higher level of reflection in the Stroke Unit in 2012 than in all other conditions (A>B=C=D) is represented in the focal contrast with the coefficients 3 -1 -1 -1. We also conducted an analysis of single items using *t* tests. For testing hypothesis 2, we calculated Pearson product-moment correlations for both the complete scales and for single items. Statistical analyses were conducted using IBM SPSS Statistics 20.

Ethical Considerations

Data collection was approved by the hospital's works council and the data protection officer. Participants signed a consent form that was also approved by the works council and the data protection officer.

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Results

Internal Consistency and Factor Analysis

The complete reflection scale had an internal consistency of alpha=.84. To further explore the structure of the scale, a factor analysis was conducted extracting two factors, using a Varimax rotation. The two factors explained 56% of the variance that emerged (factor 1: 37%, factor 2: 19%). After rotation, all items had factor loadings of at least .50 on one of the two factors and not more than .40 on the respective other factor. The first factor was labeled *collaborative reflection* and the second factor labeled *individual reflection*. The collaborative reflection subscale consisted of 7 items (items 2, 4-8, and 10 in Table 1) and had an internal consistency of alpha=.85. The corrected item-total correlations of these items are presented in Table 3. The individual reflection subscale consisted of 3 items (items 1, 3, and 9 in Table 1) and had only an internal consistency of alpha=.59. Therefore, we had to exclude this subscale from further analyses. The internal consistency of the job satisfaction scale was alpha=.89.

Table 3. Corrected item-total correlations of the collaborative reflection items.

Item	Corrected item-total correlations
I am provided with enough time to reflect upon my experiences at work.	.38
We discuss on a regular basis if we work successfully together as a team.	.66
If things do not work out as they should, we try as a team to find the reason.	.68
We as a team think about how we can learn from past experiences.	.75
When I think I did not do a good job, I discuss with colleagues how I could improve myself.	.59
When I think I did not do a good job, I discuss with my supervisor how I could improve myself.	.64
In our organization we are encouraged to reflect upon our experiences at work.	.62

Reflection

To test whether there was more reflection in the Stroke Unit in 2012 compared to 2010 and to the other wards (hypothesis 1), we conducted a contrast analysis with collaborative reflection as a dependent variable. To check whether there was systematic variance besides the variance of the focal contrast, we computed additional orthogonal contrasts. If the hypothesis of the focal contrast was correct, only the focal contrast but not the residual contrasts should be significant.

Regarding collaborative reflection, the hypothesis was supported by the data. There was a significant effect of the focal contrast: $F_{(1, 327)}$=3.97, P=.047, eta squared=.01. But there was no effect of the associated orthogonal effects: $F_{(1, 327)}$=1.90, P=.17. So the contrast analysis shows that collaborative reflection increased in the Stroke Unit from 2010 (mean 2.84, SD 0.72) to 2012 (mean 3.06, SD 0.63) but not in the other wards (2010: mean 2.68, SD 0.67; 2012: mean 2.63, SD 0.68).

In order to provide more information regarding their construct validity [52], we also considered the particular items of the scale and compared the data of the Stroke Unit in 2012 with the combined other conditions on item level. Results are presented in Table 4. For five of the seven collaborative reflection items, we found significantly higher means for the Stroke Unit in 2012 compared to the other conditions.

Table 4. Collaborative reflection items: means, standard deviations, *t*, and *P* values.

Item	Stroke Unit 2012, mean (SD)	Other conditions, mean (SD)	*t* (df)	*P* (one-tailed)
I am provided with enough time to reflect upon my experiences at work.	2.81 (0.91)	2.38 (0.79)	2.14 (323)	.02
We discuss on a regular basis if we work successfully together as a team.	3.35 (0.70)	2.53 (0.99)	4.59 (19.65)	<.001
If things do not work out as they should, we try as a team to find the reason.	3.41 (0.71)	2.96 (0.93)	2.00 (328)	.02
We as a team think about how we can learn from past experiences.	3.35 (0.61)	2.90 (0.91)	2.00 (329)	.02
When I think I did not do a good job, I discuss with colleagues how I could improve myself.	3.00 (0.87)	2.98 (0.93)	0.08 (326)	.47
When I think I did not do a good job, I discuss with my supervisor how I could improve myself.	2.88 (1.17)	2.37 (1.03)	1.98 (326)	.03
In our organization we are encouraged to reflect upon our experiences at work.	2.65 (1.00)	2.50 (0.91)	0.67 (322)	.25

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Job Satisfaction

In order to test hypothesis 2, we computed a Pearson product-moment correlation to analyze the relationship between collaborative reflection and job satisfaction measurements. As expected, the collaborative reflection scale was positively correlated to the job satisfaction scale (r=.61, P<.001).

Analogous to the presentation of the reflection results, we considered the single items of the collaborative reflection scale in order to provide more information regarding their construct validity. For this purpose, we computed Pearson product-moment correlations for job satisfaction with the individual items of the collaborative reflection scale. As shown in Table 5, all items of the collaborative reflection scale were positively correlated to job satisfaction (all Ps<.001).

Table 5. Significant correlations of the collaborative reflection items with job satisfaction.

Item	*r*
I am provided with enough time to reflect upon my experiences at work.	.43
We discuss on a regular basis if we work successfully together as a team.	.38
If things do not work out as they should, we try as a team to find the reason.	.49
We as a team think about how we can learn from past experiences.	.45
When I think I did not do a good job, I discuss with colleagues how I could improve.	.37
When I think I did not do a good job, I discuss with my supervisor how I could improve.	.42
In our organization we are encouraged to reflect upon our experiences at work.	.58

Discussion

Main Findings

The first goal of this study was to test whether the introduction of apps that support reflection would affect hospital staff's actual reflection behavior at the workplace. We found an increase in collaborative reflection for those hospital employees who had the opportunity to use the apps. With regard to the contents of the reflection items, our findings illustrate which aspects of reflection the apps were particularly able to support. The apps facilitated the conjoint aspects of reflection. In 2012, participants in the Stroke Unit indicated to a higher degree that they discuss on a regular basis their work as a team. They also stated an increased effort to collaboratively learn from past experiences and to find reasons if something did not work out as it was intended. App users also indicated they increased communication with their supervisors. These are aspects that were explicitly addressed by the apps, since they aimed directly at collaborative reflection. The Talk Reflection app, for instance, was designed with the ambition of fostering collaborative reflection. DocTrain was not only designed for individual reflection but also for reflecting with a mentor. Finally, CLinIC simulated colleagues in the game and allowed for collaborative reflection as an opportunity to improve performance.

As expected, there was a positive relationship between reflection behavior and job satisfaction, indicating that higher levels of collaborative reflection processes go along with enhanced job satisfaction among participants in the hospital. This further supports the findings of other authors regarding a relationship between informal learning and job satisfaction as introduced above. The content of our collaborative reflection scale suggests that being provided with sufficient time to reflect, reflecting collaboratively in a team, and discussing work with a supervisor go along with a higher level of job satisfaction.

Limitations and Future Work

A limitation of this study is that there were three different reflection apps. Thus, it is not possible to say whether it was the co-actions of all the apps or only a particular app with certain features that led to the increase in reflection. The DocTrain app, for instance, mainly captures data for reflection. CLinIC provides users with additional experiences in a virtual world where they can test different reactions to a situation without doing any harm. But even a single app might itself foster reflection in diverse ways. In the case of the Talk Reflection app, for example, it could be that just writing down their problems helps users to think about them in a different way. But it could also be that the comments of their colleagues help them to acquire new insights. Future studies with single specific reflection apps should be designed to shed light on these questions.

Another issue is the topic of collaborative reflection. All apps aimed at fostering collaborative reflection. And in fact, participants in the experimental condition indicated that there was more reflection in the team after the introduction of the apps. However, it remains unclear whether this increase in reflective activity was directly affected by the apps, or whether it just happened that people started to talk about the experiences they had using the apps, or a combination of both. Our data do not ultimately indicate how often and in which way participants used the apps during their everyday work. Future studies should be designed in a way that allows capturing pertinent data about usage. In addition, we did not entirely evaluate the extent to which each individual item of the collaborative reflection scale represented typical reflection behavior from the perspective of the participants. Further research using qualitative methods should assess the representativeness of these items with respect to collaborative reflection.

Another limitation of the study is the character of the analysis of the relationship between reflection and job satisfaction. As the relationship could only be shown here correlatively, future

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research should study this relationship in more detail in order to find out under which conditions reflection apps increase general job satisfaction. Finally, it might be worthwhile for future research to examine the connection between app-induced reflection and other socio-emotional experiences of health care professionals over and above job satisfaction.

Conclusions

The current study shows that collaborative technology is relevant for health care professionals [53] and that apps that support reflection have an impact on the collaborative reflection behavior of hospital staff. App designers should therefore have a special eye on the issue of collaborative reflection. Developers should also keep in mind that apps might preferably be used by the whole team of a hospital unit. In order to accommodate this preference, developers should consider the different occupation groups in their app design in order to facilitate multidisciplinary collaboration. Reflection apps should provide opportunities for simple and self-evident interactions with colleagues.

We also found that collaborative reflection is related to the job satisfaction of hospital staff, further indicating the high relevance of reflection for health care professionals. This provides an additional reason for designers of medical apps to look into this topic. Reflection apps seem to have strong potential in various respects. They may not only facilitate users' cognitive processes, such as improving their ways of learning and working. Apps that foster reflection also seem to have the potential to support health care professionals on a socio-emotional level.

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Conflicts of Interest

None declared.

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Original Paper

Smartphone Apps for Cardiopulmonary Resuscitation Training and Real Incident Support: A Mixed-Methods Evaluation Study

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Abstract

Background: No systematic evaluation of smartphone/mobile apps for resuscitation training and real incident support is available to date. To provide medical, usability, and additional quality criteria for the development of apps, we conducted a mixed-methods sequential evaluation combining the perspective of medical experts and end-users.

Objective: The study aims to assess the quality of current mobile apps for cardiopulmonary resuscitation (CPR) training and real incident support from expert as well as end-user perspective.

Methods: Two independent medical experts evaluated the medical content of CPR apps from the Google Play store and the Apple App store. The evaluation was based on pre-defined minimum medical content requirements according to current Basic Life Support (BLS) guidelines. In a second phase, non-medical end-users tested usability and appeal of the apps that had at least met the minimum requirements. Usability was assessed with the System Usability Scale (SUS); appeal was measured with the self-developed ReactionDeck toolkit.

Results: Out of 61 apps, 46 were included in the experts' evaluation. A consolidated list of 13 apps resulted for the following layperson evaluation. The interrater reliability was substantial (kappa=.61). Layperson end-users (n=14) had a high interrater reliability (intraclass correlation 1 [ICC1]=.83, P<.001, 95% CI 0.75-0.882 and ICC2=.79, P<.001, 95% CI 0.695-0.869). Their evaluation resulted in a list of 5 recommendable apps.

Conclusions: Although several apps for resuscitation training and real incident support are available, very few are designed according to current BLS guidelines and offer an acceptable level of usability and hedonic quality for laypersons. The results of this study are intended to optimize the development of CPR mobile apps. The app ranking supports the informed selection of mobile apps for training situations and CPR campaigns as well as for real incident support.

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KEYWORDS

basic life support (BLS); cardiopulmonary resuscitation (CPR); external chest compression (ECC); smartphone apps; mobile phone; mobile health

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Introduction

The pervasive use of mobile phones has motivated several initiatives to integrate them into the chain-of-survival for cardiac arrest [1]. While the phone has naturally been used to support bystanders remotely with dispatcher instructions, recently several initiatives have made use of the advanced capabilities of smartphones [2,3]. For a variety of reasons, the rate of bystander cardiopulmonary resuscitation (CPR) is low. In Germany, for example, the bystander CPR rate is approximately 20% [4]. Reasons often mentioned are a lack of knowledge and the fear to perform mouth-to-mouth ventilation [5,6]. This is one reason for the introduction of "compression-only CPR" in Basic Life Support (BLS) guidelines from the European Resuscitation Council (ERC)/American Heart Association (AHA). This easy-to-learn approach ("push hard and fast in the middle of the chest") without ventilation is intended to alleviate fear and motivate more of the public to perform CPR. Smartphones have the great advantage of providing situational support and easily accessible information (ie, apps) and therefore have become more and more valuable for CPR training and real incident support.

A recent systematic review has shown that a variety of mobile health apps for medical professionals and patients is available [7]. Due to the high number of available apps, some authors even speak about a phenomenon of "app overload" [8]. Since there is no quality control on the content and usability of a mobile app, quality and conformity with guidelines cannot be guaranteed. The term "usability" has been defined as the ease of use and learnability of a human-made object, and usability design guidelines have been defined by the International Standardization Organization in the standard ISO/TR 16982:2002 [9]. Holzinger mentions five criteria—learnability, efficiency, memorability, low error rate, and satisfaction—as essential characteristics of usability [10].

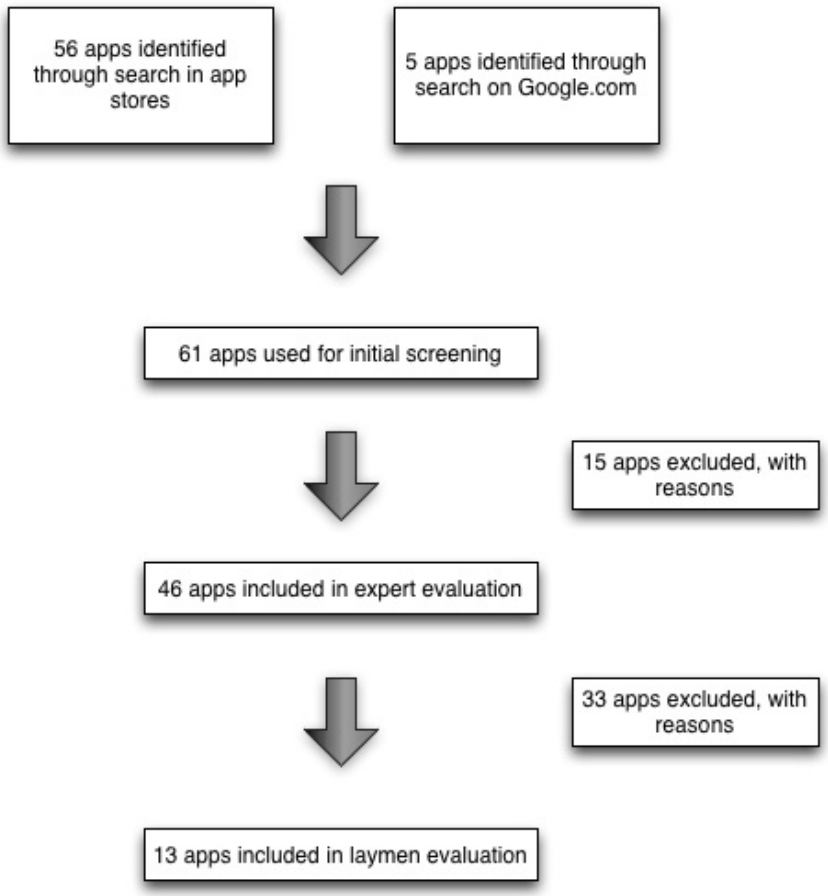
How many and, in particular, which apps might be helpful in supporting cardiopulmonary resuscitation (CPR) training as well as in a real incident of cardiac arrest is unknown. A helpful app should include correct and current medical content and deliver this content with high usability. In this context, our study provides an overview of the quality of available mobile apps. We report results of a mixed-methods evaluation study of mobile training and real incident support apps for cardiopulmonary resuscitation. This study is part of the European project "EMuRgency - New approaches for resuscitation support and training" [11].

Methods

Design

In this study, we applied a mixed-methods sequential design (Figure 1). Initially, an identification of apps and expert evaluation was conducted. As a second step, layperson users were involved to evaluate the usability and the appeal ("hedonic quality") of the preselected apps. In the study, we followed guidelines for agreement studies [12].

Figure 1. App selection procedure.



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Participants

Six board-certified emergency physicians from Germany agreed on minimum medical content requirements for apps to be included in the evaluation phase. Two of them screened and evaluated the apps and 14 layperson volunteers were recruited from the staff of the Open University of the Netherlands for the second phase of the evaluation. The recruitment of the volunteers was organized via a news item on the intranet of the Open University.

Materials

Overview

The material for the study consisted of mobile phones and mobile apps. Materials used in the expert evaluation were two smartphones (iPhone 4S & HTC Desire) equipped with the apps to be reviewed. In the second evaluation phase, three phones (iPhone 3S, iPhone 4S, and HTC Desire) were used in combination with an iPad and a computer to fill out the questionnaires. The identification and selection of mobile apps to be included in the study is reported based on PRISMA guidelines [13].

Identification of Apps

In May 2012, we conducted a search on the two largest online stores for mobile applications (Google Play Store and Apple App Store). Search terms were “CPR” and “resuscitation”. In addition, we conducted a Google search using search words “CPR apps” and “resuscitation apps”.

Screening

CPR apps containing Basic Life Support (BLS) and/or Advanced Life Support (ALS) material were considered eligible. At this stage, apps were screened and classified according to their different features, namely:

- type of content (video instructions, video chest compression simulation, animations, graphics, audio instructions, audio chest compression rhythm simulation, text instructions)
- aim of the app (training or real incident support)
- only CPR or several first aid features
- mobile sensors used in the app (GPS or accelerometer)
- underlying guidelines (most notably American Heart Association and/or European Resuscitation Council), date of guidelines (2010 or older)
- correct reproduction of guidelines’ recommendations
- targeted patient (adult, children, infant, animal)
- language (English, German, Spanish, or others)
- cost of the app
- mobile operating system (iOS or Android)
- company or provider of the app on the market

Eligibility/Inclusion

To our knowledge, no quality and/or content criteria for CPR apps have been defined to date. Due to broad approval within the resuscitation research group, the features shown in the first category in Table 1 were set as mandatory for inclusion in further evaluation steps with non-medical end-users. The feature in the second category was considered as important. The third category contains desirable special features. Hence, two board-certified emergency physicians screened the apps for requirements on these three quality levels.

Table 1. Requirements catalogue for mobile app screening by experts.

Mandatory features	Important feature	Special features
Training feature	Direct access to emergency call (112, 911, 999)	Focus on compression-only CPR
Conformity to ERC/AHA 2010 BLS Guidelines		Use of accelerometer
Emergency support for real incidents		

Instruments

After identifying and screening the apps, experts’ opinions were sought in a first evaluation. Raters were prompted to take the following items into account:

- estimated benefit for users compared to conventional teaching material
- estimated usability (ease of use regarding the user interface and logic of handling the different parts of the app)
- feature quality (video/graphic/picture/animation/audio/text instructions, graphic/animation/audio/video beat rhythm)
- application possibilities (training, real scenario support, accelerometer, location GPS, direct access to emergency call number, includes compression only CPR)
- CPR focus
- consideration of current guidelines (American Heart Association, European Resuscitation Council)

Independently, two experts rated each app on an ordinal scale (0 to 10=unsatisfactory to perfect). Testing and rating time for each app was adapted to rater’s needs. In total, each expert completed eight test sessions. Each session lasted 2-4 hours. An interrater reliability analysis using Cohen’s kappa (weighted) was performed to determine consistency among both raters. The first phase of the evaluation focused on ensuring sufficient content quality, instructional value, conformity with current guidelines, and availability of a minimal set of features as listed above.

The second phase of the evaluation focused on usability and hedonic quality of the mobile apps.

For the usability evaluation, we used the System Usability Scale (SUS) [14]. This tool is a simple but reliable method to evaluate the usability of a diverse set of technologies [15,16]. The SUS scale consists of 10 questions with a 5-point Likert scale, where item directions are changed with each question. Results of the SUS questionnaire were recoded and normalized. A specific

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value of usability was calculated for each app. Based on current literature, a SUS score above 68 (SD 12.5) is rated as a usability value above average. To benchmark these results against other results, we followed recommendations by Sauro and converted raw SUS scores to percentile ranks [17]. This conversion maps the raw SUS results to results from 446 studies including over 5000 individual SUS responses. While a raw SUS score can theoretically be 100, the distribution of available SUS scores is negatively skewed and therefore the conversion in percentile ranks results in more meaningful results. A raw SUS score of 73 results in a percentile rank of 66.5%. This means that the object of evaluation can be considered more usable than 66.5% of all products evaluated with the SUS instrument.

We have calculated an intraclass correlation coefficient (ICC) for uneven and even questions (ICC1 and ICC2). The SUS scale has been used earlier to evaluate the usability of medical devices and mobile devices in a hospital context [18].

Hassenzahl has criticized that the current approaches to test usability have taken into account only the user's recognition of design objectives represented by the ergonomic quality but not the subjective experience in terms of user satisfaction. To take the non-task-related quality dimensions like originality or innovativeness into account, he proposes the concept of "hedonic quality", which represents the appeal of a user-interface [19]. Other authors have stressed the importance of appeal for the design of user interfaces and the potential negative consequences if technology is designed based only on a functional definition of usability [20].

To evaluate the hedonic quality, we employed the ReactionDeck toolkit (Figure 2). This toolkit is based on the desirability toolkit developed by Benedek and Miner at Microsoft Research to assess aspects like "desire" and "fun" of products [21]. These product reaction cards have been transferred to digital format by the Open University of the Netherlands and published as ReactionDeck toolkit [22]. Thus, participants were asked to select six product reaction cards that best describe the emotional appeal of the mobile applications.

Between December 2012 and February 2013, 14 evaluation sessions took place with volunteers. Each evaluation session lasted approximately 60 minutes and was conducted in a standardized evaluation laboratory setting.

Demographic details and experiences with resuscitation and mobile apps were collected with a pre-questionnaire. Apps were randomly assigned to participants. Participants were asked to use the respective mobile apps for learning basic cardiopulmonary resuscitation knowledge and skills and were thus assigned to them via one of the three study smartphones (iPhone 3GS, iPhone 4S, and HTC Desire). Participants were asked to complete an electronic version of the SUS (available in Dutch and English) on an iPad and to select six cards from the ReactionDeck toolkit, available on computer, to describe the hedonic quality of the app.

Figure 2. ReactionDeck toolkit.



Results

Results of the Expert Evaluation

The first search process resulted in a full list of 61 apps. In the eligibility testing phase, 15 apps were excluded because they were specifically focused on pediatric/newborn life support, on CPR for animals, or were listed but not downloadable. The remaining 46 apps were evaluated by experts.

While all 46 evaluated apps offered training features, only 75% (35/46) included emergency (real incident) support and 35% (16/46) followed current ERC/AHA guidelines [5,6]. In total, 28% (13/46) of available CPR apps fulfilled the three minimum criteria: training feature, conformity with ERC/AHA 2010 BLS Guidelines, and emergency (real incident) support (Table 2).

Of the 46 apps from the experts' evaluation, 15% (n=7) offered direct access to an emergency call as well. The only app that offered an accelerometer for real-time feedback during compressions is Pocket CPR; FDNY Lifesaver Beta V1.0 offered GPS location.

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Table 2. CPR apps and features for layperson evaluation.

App name	Mandatory features	Important feature	Special features
CPR & Choking, by University of Washington and King County EMS	yes	yes	compression-only CPR
CPR Steps (now available as Free CPR), Evolving Monkeys, LLC	yes	yes	no
Emergency First Aid &Treatment Guide, by Phoneflips	yes	no	compression-only CPR
FDNY Lifesaver Beta V1.0, by the New York City Fire Department/Bavelle Technologies	yes	no	compression-only CPR
First Aid White Cross, by Bruno Mandolesi	yes	yes	no
Hands-Only CPR, by the American Heart Association/Jive Media Inc.	yes	yes	compression-only CPR
Leben retten, by the German Heart Foundation/Fuse GmbH	yes	yes	compression-only CPR
Pocket CPR, by Bio-Detek, Inc.	yes	yes	focus on compression-only CPR use of accelerometer
Pocket First Aid & CPR, by the American Heart Association/Jive Media Inc.	yes	no	compression-only CPR
Reanimatie, by the Dutch Heart Foundation	yes	yes	no
SCDF Choking CPR AED, by The Singapore Civil Defence Force (SCDF)	yes	no	no
SOS American Red Cross	yes	yes	compression-only CPR
St John Ambulance First Aid, by St. John Ambulance	yes	no	compression-only CPR

Results of Layperson Evaluation of Usability and Hedonic Quality

Demographics

The 13 apps providing the minimum criteria were included in this second phase.

A total of 14 volunteers were recruited (5 female); 7 participants had little experience with mobile apps, while the others had moderate or much experience. Of the 14 participants, 9 had no experience with CPR, 2 had taken a first aid course once, and 3 had dedicated CPR training. Two participants were in the age range 20-29 years, 3 in the age range 30-39 years, 2 between 40-49 years, and 7 participants were above 50 years of age. All participants had good English language skills, all but one were Dutch native speakers, and most participants could understand German well.

Usability Evaluation

To test agreement for the usability evaluation, the ICC was calculated for the two directions of the SUS scale. This analysis has resulted in strong to perfect agreement: ICC1=.83, $P<.001$, 95% CI 0.75-0.882 and ICC2=.79, $P<.001$, 95% CI 0.695-0.869. Table 3 shows the results of the usability evaluation. For the five ratings per app, mean values were calculated. Items 4 and 10 were taken as a subscale for learnability, while the rest of the items contribute to the construct usability. The study shows that only five apps have a usability score above average (SUS>68) and fall into the percentile rank of above 50%.

We furthermore analyzed results with regard to subscales “learnability” and “usability”. Results of this analysis are presented in Figure 3.

This additional perspective on the data shows that most apps with high usability also have high learnability. Only for the Hands-Only CPR app was the learnability evaluated with one of the highest values while the usability subscale delivers resulted below average.

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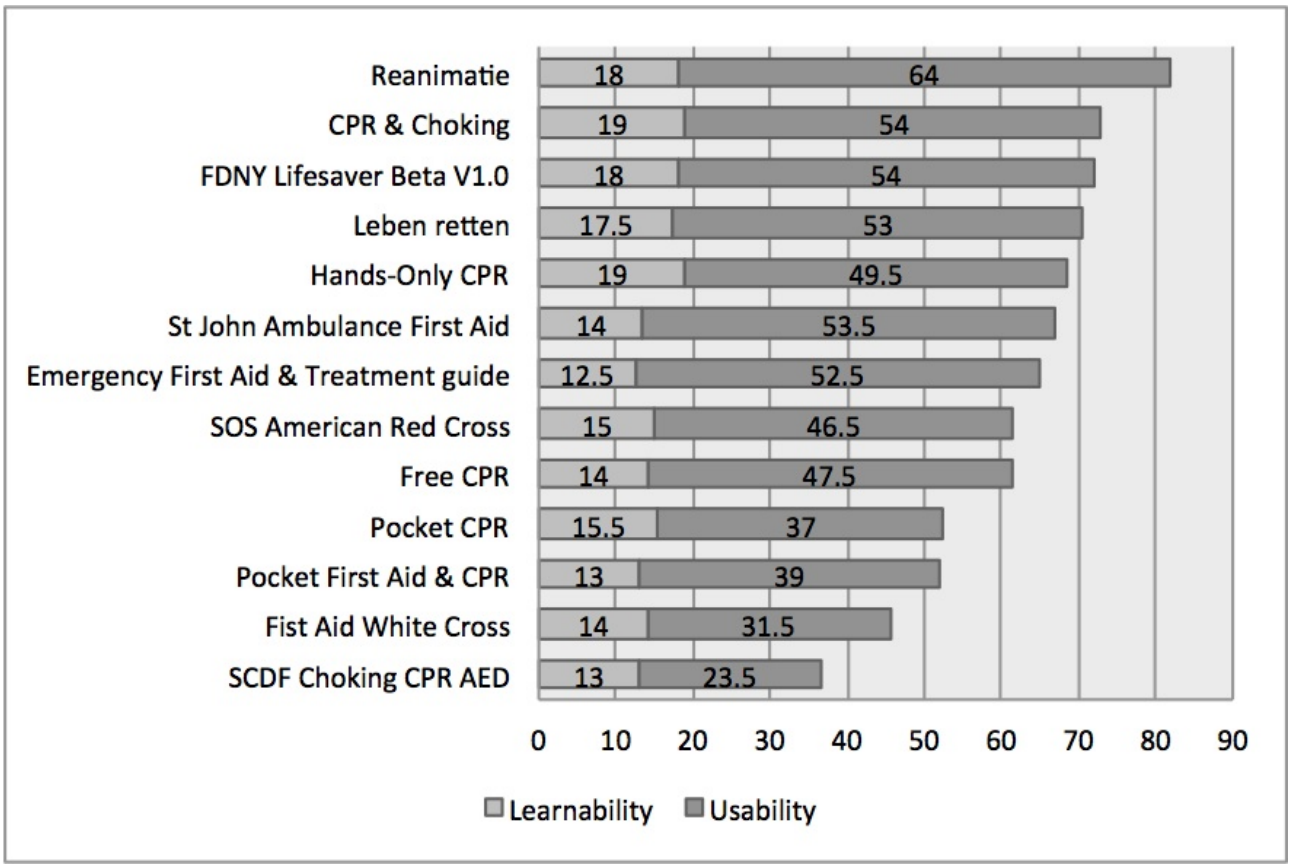
Table 3. Mean System Usability Scale (SUS) score and standard deviation.

App name (language)	Mean SUS score	SD	Percentile rank, %
Reanimatie (Dutch)	82.00	14.40	92.6
CPR & Choking (English)	73.00	11.91	66.5
FDNY Lifesaver Beta V1.0 (English)	72.00	14.51	63.1
Leben retten (German)	70.50	19.48	58.1
Hands-Only CPR (English)	68.50	15.17	51.6
St. John Ambulance First Aid (English)	67.00	23.48	46.9
Emergency First Aid & Treatment Guide (English)	61.90	8.50	33.1
Free CPR (aka CPR Steps) (English)	61.50	14.43	32.1
SOS American Red Cross (English)	61.50	16.55	32.1
PocketCPR (English)	53.80	21.70	17.8
Pocket First Aid & CPR (English)	52.00	25.46	15.4
First Aid White Cross (English)	45.50	21.97	9.1
SCDF Choking CPR AED (English)	36.50	11.67	4.3

Figure 3. Usability evaluation results with subscales learnability and usability.



Results of Hedonic Quality Evaluation

For hedonic quality evaluation, Table 4 presents adjectives selected more than once.

The hedonic quality evaluation delivers mixed results: one app (Reanimatie, Figure 4) ranked high in the usability evaluation and received very positive results for hedonic quality as well. Other top-ranked apps received positive adjectives in most instances but also some relevant negative adjectives (see Table 3) (eg, CPR & Choking shown in Figure 5 and FDNY Lifesaver Beta V1.0). The two other top-ranked apps from the usability evaluation (Hands-Only CPR shown in Figure 6 and Leben retten in Figure 7) received mainly negative hedonic adjectives. Other apps received mixed results in this part of the evaluation.

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Table 4. Hedonic quality results with adjective occurrences >1.

App name	Hedonic quality adjectives
Reanimatie	Professional, effective, easy to use, inviting, stable
CPR & Choking	Simplistic, ordinary, understandable, ineffective, easy to use, dull, usable
FDNY Lifesaver Beta V1.0	Helpful, usable, relevant, useful, dull, poor quality
Leben retten	Understandable, dull, simplistic, ineffective
Hands-Only CPR	Unattractive, easy to use, simplistic, poor quality
St. John Ambulance First Aid	Slow, useful
Emergency First Aid & Treatment Guide	Understandable, reliable
Free CPR (aka CPR Steps)	Relevant, dull, simplistic, ineffective, easy to use
SOS American Red Cross	Understandable, usable
PocketCPR	Frustrating, difficult, confusing, hard to use
Pocket First Aid & CPR	Ineffective, intuitive, helpful, professional, usable
First Aid White Cross	Annoying, ineffective, frustrating, dull, hard to use, slow, poor quality
SCDF Choking CPR AED	Hard to use, undesirable, slow, complex, annoying, helpful, ineffective, unattractive

Figure 4. Screenshot Reanimatie app by the Dutch Heart Foundation.



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Figure 5. Screenshot CPR and choking by University of Washington and King County EMS.

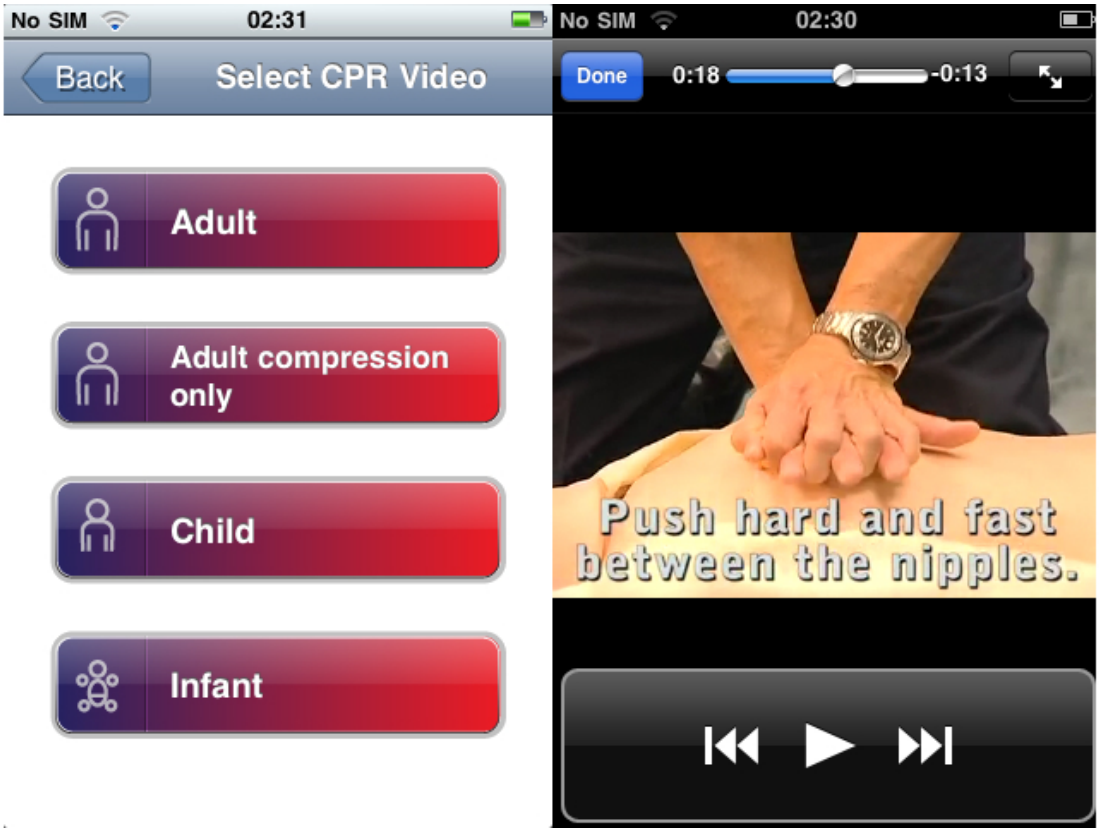

Figure 6. Screenshot Hands-only CPR by the American Heart Association/Jive Media Inc..

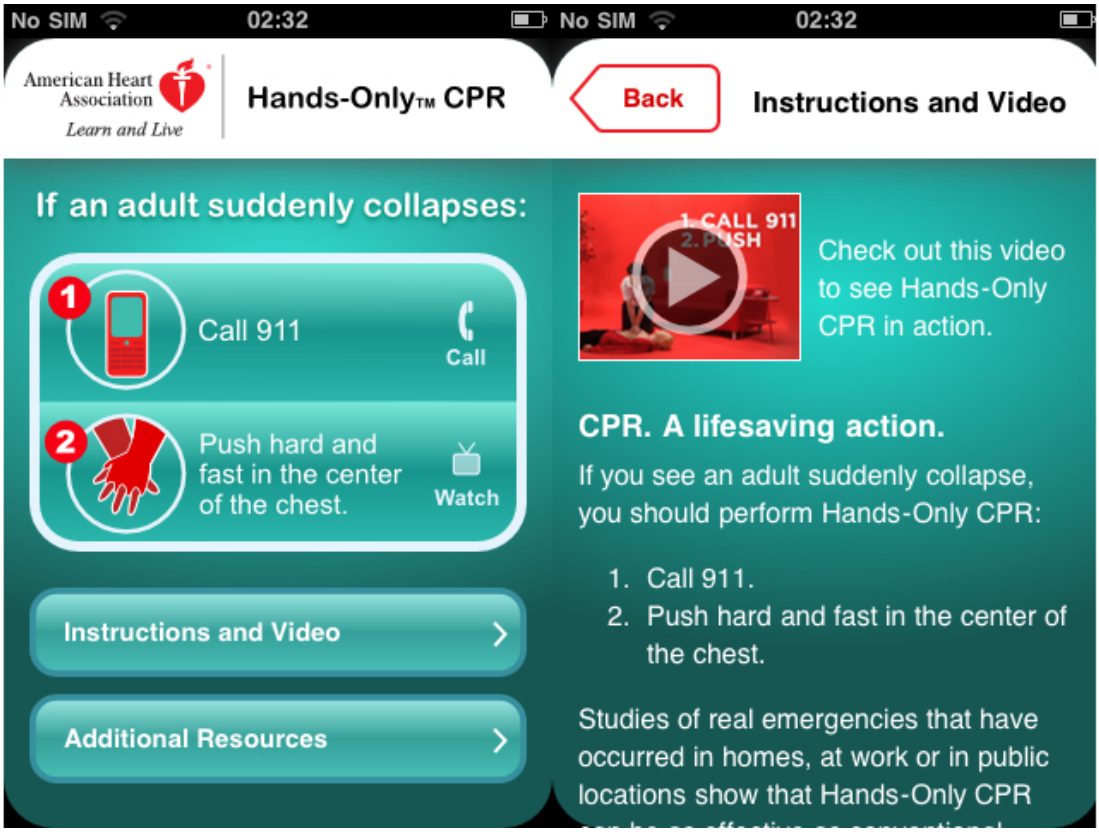

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Figure 7. Screenshot Leben retten app by the German Heart Foundation/Fuse GmbH.



Discussion

Principal Results

This study emphasizes that several apps are available for resuscitation training and real incident support on the two largest app markets. However, very few are designed according to current CPR guidelines and offer acceptable usability as well as hedonic quality for laypeople. At the time of this study, only about five apps could be recommended in terms of guidelines and usability. In the 2010 AHA/ERC guidelines, depth and rate of chest compressions were raised. The chance of survival after a cardiac arrest is inevitably linked to high-quality chest compressions. Therefore, it is extremely important to comply with current guidelines [5,6]. Many available apps do not meet these basic requirements and, in the worst case, an app might inhibit optimal chest compressions.

In a recent systematic review, Mosa et al analyzed effects of health care applications for smartphones [7]. While this review delivered interesting findings and a good overview of existing studies, only 83 mobile applications were included in their review out of the approximately 20,000 mobile applications in the medicine category and 44,000 apps in the “Medicine” and “Health and Fitness” categories on the Apple App Store. This large number of available mobile apps has motivated van Velsen et al to address the problem of “app overload” [8]. While the authors propose to centralize the development of mobile apps for health and medicine, we think that quality assurance mechanisms are the more appropriate solution to address the large number of mobile apps. This approach is in line with earlier proposals to deal with quality management of medical information on the Internet [23] and also recent guidance by the US Food and Drug Administration about the regulation of mobile medical applications [24].

The mixed-methods evaluation conducted in this study and its results are a first step to optimize the development and evaluation of mobile apps for resuscitation training and real incident support. Particular focus is on content as well as usability and hedonic quality. Furthermore, it supports the informed selection of mobile apps for training situations and/or real incident support.

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During the initial screening phase, several CPR-related apps that did not fulfill the inclusion criteria of this study attracted our attention because of very promising approaches. PulsePoint, for example, uses the Global Positioning System (GPS) to locate potential responders in the vicinity of an emergency and directs them to the place of action. Fatal no-flow time in a cardiac arrest might be reduced [25].

Low et al as well as Semeraro et al showed increased CPR performance by health care professionals and layperson end-users, respectively, in simulated medical emergency cases. Feasibility in and relevance for real emergency cases is not proven yet and should be of interest for further investigations [25,26].

Limitations

Our study has several limitations. CPR apps were first screened for inclusion criteria by only two board-certified emergency physicians. Thus, one could argue that some apps may have been misjudged, but two out of three mandatory criteria directly reflect the enquiry (potential support for training and real incidents). The third criterion, current ERC/AHA BLS guidelines, represents generally accepted European and American standards and this appraisal is quite easy for an expert physician. As the "important" and "desirable special features" constitute a more subjective expert view, these did not lead to an exclusion from the evaluation. Furthermore, we calculated the interrater reliability (substantial for the experts) to ensure that decision making by two experts delivers adequate agreement. We therefore consider this approach as a valid way to include and categorize apps for this study. In future studies or when setting up more detailed quality standards, it is probably reasonable to include more experts.

A limitation resulting from the apps is that three out of five recommended apps are available only in English (CPR & Choking, FDNY Lifesaver Beta V1.0, and Hands-Only CPR), one only in German (Leben retten), and one (Reanimatie) only in Dutch. Since we evaluated the apps at a Dutch University, there might have been a language bias that led to the very high usability value of the "Reanimatie" app.

Adherence to current CPR guidelines and usability for the public was the main focus in this study. Hence, conclusions for developing and selecting apps can be drawn. However, we cannot make conclusions about the efficacy of each single app in a real emergency situation. The use of the ReactionDeck toolkit served the purpose of collecting input from study participants about the hedonic quality of the mobile apps. However, this method has not been further evaluated regarding its reliability and validity for analyzing hedonic aspects of software.

In the digital age, especially when working on mobile applications, timeliness of data is a general problem. The number and quality of apps are constantly changing. In addition, lists of apps are likely to be incomplete due to varying availability of apps in different stores (operator-related as well as country-related), varying search methods, or apps published after the market search for this study. Therefore, it remains unclear which apps are "the best ones" for CPR support and training at the time of publication. We must highlight the enormous number of apps that are not useful or have substantial deficits as a key finding. The smartphones themselves also have an impact on the appearance and usability of an app and therefore may have affected the participants' experiences.

Further Research

Smartphones and easy-to-learn approaches like "compression-only CPR" seem to match well: situational support and easily accessible information (ie, apps) can be provided in all situations. Often-mentioned reasons for low rates of bystander CPR (eg, fear and lack of knowledge) might be alleviated by these supporting devices resulting in more laypeople being motivated to perform CPR. In contrast, teaching obsolete guidelines or giving too detailed information could deter the public from performing CPR or lead to worse CPR quality.

Recently, You et al proposed the use of quick response (QR) codes displayed in public places and on personal belongings like key rings, wallets, and necklaces of patients with cardiovascular risk to provide access to critical video instructions required during resuscitation [27].

The top-ranked apps of this study, as well as apps released after the evaluation period (eg, Lifesaver Mobile, Viva! CPR, Staying Alive 3D), characterize the evolution from simple teaching materials to multifunctional programs with feedback devices (eg, metronome) and game-based learning modules for virtual scenarios and/or real incidents. Future research will need to focus on analyzing more closely which features motivate end-users to use these apps for training, refreshment of knowledge, and real incident support and which features are most effective. While recently published apps invest more and more in professional media production or 3D environments, it is questionable whether these huge investments also have an impact on increasing knowledge, skills, or the willingness to help in a real cardiac arrest situation.

Conclusions

To our knowledge, our study is the first to give a general overview of existing apps for resuscitation training and real incident support. All apps were examined under consideration of current CPR guidelines as well as usability and hedonic quality for layperson end-users. This study has shown availability of a multitude of mobile apps for CPR training and real incident support in the largest mobile app markets. Unfortunately, only a few follow recent guidelines, are designed with acceptable usability, and are easy to learn for non-expert users. While mobile phones are increasingly integrated into the chain-of-survival, the wide usage of mobile apps for resuscitation training and real incident support cannot be recommended without caution at this point of time. More interdisciplinary studies and joint development of mobile apps for resuscitation training and support are needed. Besides correct guidelines and good usability, testing should include efficacy in real incident scenarios wherever possible. The method used in this study has the potential to be applied to other evaluation studies where a focus on both regulation and end-users is

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required for quality assurance of mobile apps in the health context.

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Authors' Contributions

All authors listed made substantial contributions to (1) the conception and design of the study, acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, and (3) final approval of the version to be submitted.

Conflicts of Interest

None declared.

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Abbreviations

AHA: American Heart Association
BLS: Basic Life Support
CPR: cardiopulmonary resuscitation
ECC: external chest compression
ERC: European Resuscitation Council
ICC: intraclass correlation coefficient
ISO: International Organization for Standardization
SUS: System Usability Scale

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Review

The Use of Social Networking Sites for Public Health Practice and Research: A Systematic Review

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Abstract

Background: Social networking sites (SNSs) have the potential to increase the reach and efficiency of essential public health services, such as surveillance, research, and communication.

Objective: The objective of this study was to conduct a systematic literature review to identify the use of SNSs for public health research and practice and to identify existing knowledge gaps.

Methods: We performed a systematic literature review of articles related to public health and SNSs using PubMed, EMBASE, and CINAHL to search for peer-reviewed publications describing the use of SNSs for public health research and practice. We also conducted manual searches of relevant publications. Each publication was independently reviewed by 2 researchers for inclusion and extracted relevant study data.

Results: A total of 73 articles met our inclusion criteria. Most articles (n=50) were published in the final 2 years covered by our search. In all, 58 articles were in the domain of public health research and 15 were in public health practice. Only 1 study was conducted in a low-income country. Most articles (63/73, 86%) described observational studies involving users or usages of SNSs; only 5 studies involved randomized controlled trials. A large proportion (43/73, 59%) of the identified studies included populations considered hard to reach, such as young individuals, adolescents, and individuals at risk of sexually transmitted diseases or alcohol and substance abuse. Few articles (2/73, 3%) described using the multidirectional communication potential of SNSs to engage study populations.

Conclusions: The number of publications about public health uses for SNSs has been steadily increasing in the past 5 years. With few exceptions, the literature largely consists of observational studies describing users and usages of SNSs regarding topics of public health interest. More studies that fully exploit the communication tools embedded in SNSs and study their potential to produce significant effects in the overall population's health are needed.

(J Med Internet Res 2014;16(3):e79) doi:10.2196/jmir.2679

KEYWORDS

public health informatics; public health; social network; health communication

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Introduction

Overview

Public health has achieved great advances in improving population health over the past century through education, communication, policy development, and risk management. Public health practitioners and researchers have been exploring new information technologies to more effectively and efficiently communicate with, engage, and educate the public. Today, social media offers a range of possibilities for establishing multidirectional communication and interaction, as well as quickly monitoring public sentiment and activity. These new tools have the potential to help public health meet many of its modern challenges and mandates regarding communicating with, educating, engaging, and monitoring a diverse public [1]. We conducted a systematic review of the use of social networking sites (SNSs) in public health practice and research to better understand the use of these technologies for public health purposes.

Background

An expanding number of people use the Internet in their daily lives, including for accessing health information [2]. Recently, the growth of interactive and dynamic Web applications has allowed the growth of SNSs, such as Facebook and Twitter. In 2011, 65% of Internet users in the United States reported using SNSs; 61% of Americans aged 18 to 30 years reported using an SNS every day and daily usage by Americans aged 50 to 64 years rose from 20% in 2010 to 32% the following year [3]. Facebook is currently the most popular SNS in the world, topping 1 billion active users, with 580 million who engage with the site daily [4]. Twitter, with 500 million users worldwide [5], has gained a reputation as a way to detect and predict events and sentiments by observing users' posts (tweets) in real time [6]. In addition to these very large SNSs, innumerable smaller SNSs exist serving a range of interests and needs, from LinkedIn for professional networking to PatientsLikeMe, where patients of similar diseases connect to share treatment resources and support. These sites allow users to engage with and shape their Internet content, from creating a network of connections with other users, to posting their own content, and to reacting and adding to content posted by other users. SNSs are a subset of social media. Social media is a broader concept that encompasses sites that allow users to generate and share content, such as blogs, wikis, and content communities, such as YouTube. SNSs are also characterized by user-generated content, but their defining characteristic is the ability to generate direct communication and 2-way interaction between users, thus generating networks of users [7].

Although the increasing popularity of SNSs is clear, there is no single canonical definition for an SNS. A social networking tool or site is generally distinguished by the creation of individual public profiles and multidirectional communication and collaboration, allowing users to connect to one another within the site [8,9]. Public health researchers and practitioners are interested in the use of SNSs because of the quick and inexpensive access to a broad or specific population that they afford and the possibilities for multidirectional communication that they offer [9].

These qualities give SNSs the potential to expand and enhance core public health functions. For instance, research, surveillance, health education, and linking people with health resources are essential public health services [1]. These tasks are traditionally resource-heavy, requiring in-person participant recruitment and sometimes resulting in lag times in detecting or notifying the public of health threats [10,11]. Furthermore, the public health community often has difficulty reaching certain vulnerable populations who may have the greatest need for services [12]. The large user population and immediate nature of SNSs have the potential to increase the reach and efficiency of these core public health services. Some traditionally hard-to-reach populations, such as adolescents, Hispanics, and low-income Americans, use SNSs at a rate higher than the general population [13] providing a new opportunity for inexpensive public health communication to key demographics. The Centers for Disease Control and Prevention (CDC) provides tools for public health departments to use SNSs to extend the reach of their campaigns [14]. Previous publications have examined the use of SNSs for sexual health promotion, dissemination of health information, and recruitment of difficult-to-reach populations, such as individuals who seek sex online [15-17]. Thus, SNSs may provide new opportunities to effectively achieve the aims of public health.

Given the increasing popularity of SNSs, and the range of possibilities that they offer for public health practice and research, we conducted a systematic review to assess the current uses of SNSs for public health practice and research. This review will serve to inform public health practitioners and informatics researchers of the state of knowledge in the field and identify gaps where more research is needed.

Methods

Literature Search

We conducted a database search that included PubMed, EMBASE, and CINAHL Plus using a query consisting of an extensive list of names of specific SNSs, as well as the terms "social networking," "social network site," and "public health." Given the constant evolution of SNSs—with new sites being added while others disappear—we utilized a list of 199 specific SNS names from the corresponding Wikipedia entry [18] current up to the search date. We eliminated all SNS titles that did not generate results. This process yielded the following PubMed search query:

> *("social networking"[All Fields] OR "social network site"[All Fields] OR twitter[All Fields] OR facebook[All Fields] OR patientslikeme[All Fields] OR myspace[All Fields] OR renren[All Fields] OR kaixin[All Fields] OR whyville[All Fields]) AND ("public health"[All Fields] OR "public health"[MeSH terms]) NOT "behavior, animal"* [MeSH terms]

The query was modified to fit specific requirements of each of the databases searched. We included articles published up until

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March 31, 2012. We also conducted a manual search through the references of the articles retrieved through the electronic search.

Article Selection

Two researchers reviewed every article to determine if inclusion criteria were met. Discrepancies were resolved through discussion. We included articles that met the following inclusion criteria:

1. Published in peer-reviewed journals,
2. Featured SNSs as the primary subject of study or a main component of the study methodology, and
3. Focused on a topic of public health practice or research or a disease of public health importance. We used the CDC's 10 Essential Public Health Services [1] and the Information Access for the Public Health Workforce's list of public health disease processes as criteria to determine public health relevance [19].

We excluded narrative reviews and articles that did not constitute original research communications, such as letters to the editor, whitepapers, and comments.

Data Extraction

After selecting the articles for inclusion, authors extracted data using an online form specifically designed for this purpose. The extracted data included publication year, location (defined by the location on the study population), study design, sample size, purpose of the study, specific SNS involved (ie, Facebook, Twitter), how the SNS was used (ie, recruiting study participants, promoting public health messaging), target population, and public health topic. We also categorized each article according to whether the study described the use of SNSs for activities currently performed by public health practitioners (we labeled this *practice*) or whether it described novel uses related to public health (we labeled this *research*). Because some studies analyzed individual posts on an SNS as opposed to including individuals or SNS page profiles corresponding to a single person, we also captured the unit of analysis. Data was entered into a specially constructed spreadsheet generated for analysis.

During this step, every article was randomly assigned to 2 researchers to assess intercoder reliability and discrepancies were resolved through discussion with other members of the team.

Results

We ran our search in July 2012. The literature review retrieved 429 individual articles that were screened for eligibility. A total of 20 duplicates were excluded. After reviewing title and abstract, 318 articles did not meet our inclusion criteria. We reviewed 91 articles in full. Another 18 articles were removed after reviewing the full text because they did not meet our inclusion criteria. Therefore, our final review included 73 unique articles. See Figure 1 for the detailed description of the search process. Table 1 includes a complete description of the included articles.

Figure 1. Prisma flow diagram describing the different literature search and selection stages.

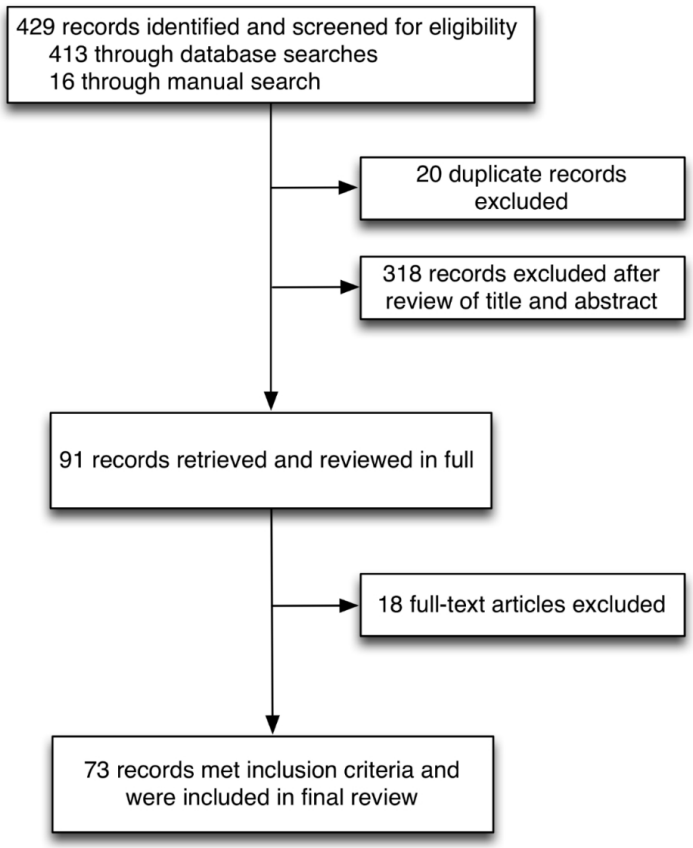

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Table 1. Brief description of all included articles about social networking sites (SNSs).

Author/year	Description/general purpose	Social networking site
Moreno 2007 [20]	Determine the prevalence of personal health risk behavior descriptions and identifiable information on MySpace	MySpace
Ybarra 2008 [21]	Determine the use of SNS for unwanted sexual solicitation or Internet harassment of youth	Unrestricted
Blackwell 2009 [22]	Assess the frequency of men who have sex with men (MSM) requesting safer sex when soliciting sex on SNS	SNS targeting MSM
Chou 2009 [23]	Identify the sociodemographic and health-related factors associated with current adult social media users in the US	Unrestricted
Jenssen 2009 [24]	Determine exposure of adolescents to tobacco advertisements on the Internet	Facebook
Moreno 2009 [25]	Determine adolescents' interpretations of alcohol references displayed on SNS	Unrestricted
Moreno 2009 [26]	Determine the prevalence of and associations among displayed sexual, substance use, and violent risk behavior on teen MySpace profiles	MySpace
Moreno 2009 [27]	Determine whether an online intervention reduces references to sex and substance use on teen SNS profiles	MySpace
Rogers 2009 [28]	Compare differences in emotional self-disclosure between young adults who prefer face-to-face therapy to those who prefer Internet therapy	Facebook
Silenzio 2009 [29]	Explore SNS as a venue for suicide prevention among lesbian, gay, and bisexual young people	MySpace
Yoshimitsu 2009 [30]	Describe the use of a SNS by depressive patients	SNS targeting depressive patients
Bull 2010 [31]	Explore ethics issues with research when using SNS to contact youth	Facebook
Chew 2010 [32]	Evaluate the use of Twitter as an "infodemiology" method during the 2009 H1N1 outbreak	Twitter
Freeman 2010 [33]	Explore whether employees of tobacco companies are promoting tobacco products on Facebook	Facebook
Griffiths 2010 [34]	Examine how young people in New Zealand engage with alcohol and reproduce alcohol marketing messages and alcohol-related branding on Bebo	Bebo
Huang 2010 [35]	Describe the uses of SNS during the natural disaster in Taiwan	Twitter, Plurk
Keelan 2010 [36]	Determine the reaction of the public to the HPV vaccine on social media	MySpace
Kontos 2010 [37]	Describe inequalities in SNS use	Unrestricted
Mitchell 2010 [38]	Describe the variety of ways SNSs are used to facilitate the sexual exploitation of youth, as well as identify victim, offender, and case differences between arrests, with and without a SNS nexus	Unrestricted
Moreno 2010 [20]	Analyze older adolescents' displayed alcohol references on MySpace	MySpace
Scanfeld 2010 [16]	Categorize tweets mentioning antibiotics and to explore cases of misunderstandings and misuse of antibiotics	Twitter
Stephenson 2010 [39]	Examine the use of an online survey to collect data on the experience and perpetration of intimate partner violence among self-identifying gay and bisexual men in the United States	MySpace
Stulhofer 2010 [40]	Provide a better understanding of the likely mechanisms underlying regular condom use	Multiple
Baptist 2011 [41]	Describe asthma patients' use of social media and SNS	Unrestricted
Centola 2011 [42]	Analyze how homophily—the tendency of social contacts to be similar to one another—can affect health behavior change in the context of a SNS	Self-created SNS
Chilvers 2011 [43]	Case study of how school nurses began a Facebook page to connect young people with services, schedule appointments, and provide health promotion	Facebook
Dowdell 2011 [44]	Evaluate online social networking patterns among adolescents, young adults, and sexual offenders to provide information to better focus online youth protection education and prevention efforts for nurses and other health care providers	Unrestricted
Feldacker 2011 [45]	Measure the degree to which SNS can increase recruitment for HIV testing	Multiple
Frost 2011 [46]	Describe patient-reported outcomes as a source of evidence in off-label use of drugs within an online community	PatientsLikeMe

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Author/year	Description/general purpose	Social networking site
Gamage 2011 [47]	Describe effectiveness of Facebook to advertise STI health services and recruit rural young people	Facebook
Gold 2011 [15]	Examine the extent to which SNS are currently being used for sexual health promotion and describe the breadth of these activities	Unrestricted
Grosskopf 2011 [48]	Understand the characteristics, beliefs regarding the risk of HIV infection, and sex-related behaviors of MSM who use SNS to seek sex partners	SNS targeting MSM
Heaivilin 2011 [49]	Analyze tweets to characterize content related to tooth pain	Twitter
Khosropour 2011 [17]	Examine the demographic and behavioral characteristics of MSM enrolled in an online study to determine the factors that predicted retention of participants in an online, prospective follow-up study of MSM	MySpace
Levine 2011 [50]	Describe the process of conducting formative research on MySpace in an effort to involve youth of color in the design of an Internet intervention	MySpace
Liang 2011 [51]	Assess the prevalence of leading pharmaceutical company presence and drug product marketing in online interactive social media technologies	Multiple
Lord 2011 [52]	Facebook survey to gain a better understanding of the beliefs and attitudes that college students have about prescription drug misuse	Facebook
Moreno 2011 [53]	Evaluate depression disclosures by college students on Facebook	Facebook
O'Dea 2011 [54]	Explore SNS as a source of peer mental health support in rural areas	Unrestricted
Pemu 2011 [55]	Determine acceptability and efficacy for diabetes self-management behavior change, and success factors for use of e-HealthyStrides, a SNS designed specifically for diabetes patients	e-healthyStrides
Pletneva 2011 [56]	Present attitudes toward Internet use for health purposes among health care consumers and professionals	Facebook, Twitter
Ridout 2011 [57]	Investigate the presentation of alcohol-identity on SNS	Facebook
Rosselli 2011 [58]	Evaluate an innovative model, "@Prevention," designed to enhance the culture of prevention among health care professionals and to improve health literacy among the population through information and social marketing	Facebook
Shaw 2011 [59]	Understand the online health information-seeking behaviors of people with diabetes	Unrestricted
Signorini 2011 [60]	Examine the use of Twitter to monitor H1N1 disease activity and public concern	Twitter
Stephenson 2011 [61]	Use Facebook to recruit participants for a study examining reporting of intimate partner violence among MSM in South Africa and associations between intimate partner violence and sexual risk taking	Facebook
Su 2011 [62]	Apply machine intelligence for improving retrieval of health information from Twitter	Twitter
Sullivan 2011 [63]	Determine bias in survey recruitment on MySpace	MySpace
Weitzman 2011 [64]	Test the willingness of an online diabetes community to share data for public health research	TuDiabetes network
Young 2011 [65]	Study the correlation between use of SNS and risky sexual health behavior	Unrestricted
Egan 2011 [66]	Assess the extent to which adolescents display alcohol consumption behaviors on SNS	Facebook
Egan 2011 [67]	Assess the extent to which college students display stress-related emotions on SNS	Facebook
Litt 2011 [68]	Study the role that the social norms displayed on SNS, in the form of profile, play on alcohol-related cognitions in adolescents	Facebook
Selkie 2011 [69]	Understand participants' willingness to use SNS to obtain information regarding sexual health education	Unrestricted
Chunara 2012 [70]	Assess correlation of volume among cholera-related HealthMap news media reports, Twitter postings, and government cholera cases reported in the first 100 days of the 2010 Haitian cholera outbreak	Twitter and HealthMap
D'Alessandro 2012 [71]	Investigate how college students can be social support catalysts for organ donation and how social and attitudinal dimensions impact organ donor registration, in order to design a SNS organ donation registration campaign	Facebook and YouTube
Gowen 2012 [72]	Examine the ways that young adults with mental illnesses currently use social networking and how they would like to use a social networking site tailored to them	Unrestricted

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Author/year	Description/general purpose	Social networking site
Jones 2012 [73]	Describe the use of Facebook in the re-recruitment and tracking of adolescent girls in a follow-up study on physical activity	Facebook
Krakower 2012 [74]	Recruit participants from SNS to assess the awareness of, interest in, and experience with pre-exposure prophylaxis (PrEP) among MSM before and after a trial demonstrating PrEP's effectiveness	SNS targeting MSM
Leighton 2012 [75]	Investigate consumers' understanding of direct-to-consumer genetic test results using a Facebook survey	Facebook
Lowe 2012 [76]	Investigate social factors, including SNS, that help women who quit smoking because of pregnancy from returning to smoking after giving birth	Unrestricted
Margolis 2012 [77]	Assess HIV testing among adult male members of an MSM sexual networking website, analyze factors associated with "never testing," and describe reasons for not testing	SNS targeting MSM
Moreno 2012 [78]	Examine association between alcohol use/drinking references on Facebook and reported problem drinking	Facebook
Moreno 2012 [79]	Examine the associations between displayed alcohol use and intoxication/problem drinking references on Facebook and self-reported problem drinking using a clinical scale	Facebook
Norman 2012 [80]	Describe how SNS, interactive blogging, and social media and multimedia platforms have been used to engage youth around issues of health and social action	Unrestricted
Oh 2012 [81]	Test in what ways Korean diabetes patients' exchanges of computer-mediated social support (CMSS) in diabetes online communities influence their sense of empowerment and intention to actively communicate with their doctor	SNS for diabetes patients
Pantic 2012 [82]	Investigate the relationship between SNS use and depression indicators in adolescents	Unrestricted
Rice 2012 [83]	Use social network analysis to examine the acceptability of a youth-led, hybrid face-to-face and online social networking HIV prevention program for homeless youth	Multiple
Robertson 2012 [84]	Describe the role of SNS and text messaging as sources of contagion and obstacles to recognition in an adolescent suicide cluster	Bebo
Sullivan 2012 [85]	Analyze the online content of concussion-related tweets on Twitter to determine the concept and context of mild traumatic brain injury communication online	Twitter
Thackeray 2012 [86]	Assess the extent to which state health departments are using social media to engage audiences	Unrestricted
Wagenaar 2012 [87]	Compare factors associated with low HIV/AIDS knowledge among Internet-using MSM in South Africa to those in the United States	Facebook
Ramo 2012 [88]	Recruit patients for a tobacco and substance abuse study using an SNS	Facebook

Despite the emergence of Internet SNSs in the late 1990s, the topic did not become prominent in the public health literature until the late 2000s. Since then, the number of publications describing the use of SNSs for public health research and practice has been steadily increasing. In 2007, there was only 1 publication, increasing to 9 in 2009, 12 in 2010, 31 in 2011, and 19 in the first 3 months of 2012. Regarding the location of the study, 43 of the 73 articles (60%) were conducted in the United States. Using the World Bank classification of countries, 14 were conducted in other high-income countries and 1 was conducted in a middle-high income country (South Africa). Only 1 study was conducted exclusively in a low- or low-middle income country (Haiti), but 13 articles explicitly included SNSs and their users without any reference to a particular region or country.

Facebook was the most commonly used SNS (27%). In all, 10 of 73 studies (14%) used MySpace, 6 (8%) used Twitter, and 12 (17%) used other SNS, including Bebo, Friendster, LinkedIn, and PatientsLikeMe. There were 25 (34%) that studied multiple SNSs or did not limit by any specific site (Figure 2). Figure 2 shows the changes over time, with MySpace being most frequently used in the early years, and the later appearance of Facebook, Twitter, and other SNSs.

Most studies (63/73, 86%) were cross-sectional observational studies providing descriptions of SNS usage or SNS users. Examples of cross-sectional studies include a study by Jenssen et al [24] analyzing adolescents' exposure to tobacco advertisements on SNS and a study by Kontos et al [37] in which the authors studied inequalities in SNS usage and its implications for public health communications. Only 5 studies used an experimental design to test a specific intervention, and all 4 were randomized controlled trials. For instance, Centola [42] randomized participants to different user groups on an SNS to study the effect of homophily (similar social contacts) on health behavior change. We found 1 systematic review of non-randomized controlled trials published by Gold et al [15], in which the authors explored the use of SNSs for sexual health promotion.

Articles describing the use of SNSs for public health practice (n=15) focused primarily on hard-to-reach populations. Five articles used SNSs to reach youth and adolescents, or individuals

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at risk for sexually transmitted diseases (STDs) and human immunodeficiency virus (HIV), to connect them with available services. In an article by Feldacker et al [45], the authors describe their positive experience using SNSs to contact students at high risk for HIV and offer them HIV testing. Another significant use of SNSs for public health practice was to promote healthy behaviors. For example, Pemu et al [55] designed a diabetes management and education SNS and evaluated it with diabetes patients. Other activities routinely conducted by local health departments for which SNSs are being used included disease surveillance and communications during natural disasters [34,59]. See Table 2 for the frequency of SNSs in public health research publications.

Table 2. Frequency of uses for social networking sites (SNSs) in public health research publications (n=58).

Use	n (%)
Description of users or usage	39 (67)
Participant recruitment	14 (24)
Outcome assessment	3 (5)
Other	2 (3)

With respect to target population, 32 of 73 studies (44%) focused on young users, such as teenagers, adolescents, or college students. The second largest group of studies targeted the general population without specific restrictions (15/73, 20%). In all, 6 of 73 studies (8%) focused on individuals with specific diseases. Articles focused on a wide array of public health issues; 21 studies (29%) focused on sexual and reproductive health, 17 (23%) on general health promotion strategies, 14 (19%) on noncommunicable diseases, 13 (18%) on alcohol, tobacco, and substance abuse, and 8 (11%) on mental health (see Table 3).

Table 3. Frequency of population targeted and public health issue covered in all 73 included articles.

Target population and public health issue	n (%)
Target population	
Youth and young adults	32 (44)
General population	15 (21)
Patients with specific chronic noncommunicable diseases	6 (8)
Patients at high risk for sexual or relationship health diseases	11 (15)
Other	9 (12)
Public health issue	
Sexual, reproductive health	21 (29)
General health promotion	17 (23)
Chronic noncommunicable diseases	14 (19)
Alcohol, tobacco and substance abuse	13 (18)
Mental health	8 (11)

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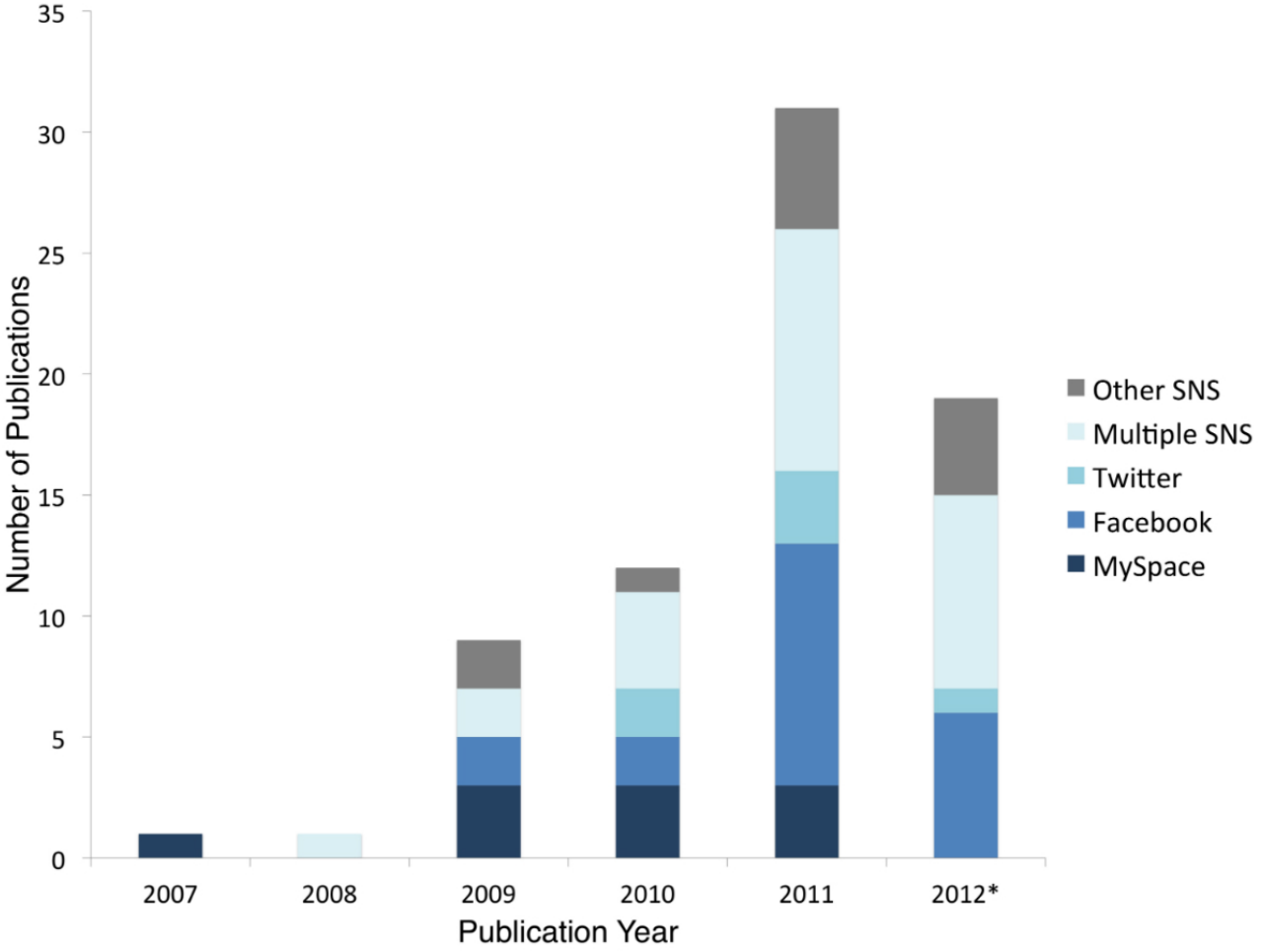
Figure 2. Number of publications and type of social networking sites (SNSs) per year describing the use of SNSs for public health research or practice. *2012 only includes publications through March 31.



Discussion

Principal Findings

With over 1 billion active users worldwide on Facebook alone [4], SNSs have become a place where individuals express themselves and interact with one another. Multidirectional communication tools—a hallmark of these sites—allow for rapid and collaborative dissemination of information. This scenario opens up great opportunities for assessing a population's risk factors and monitoring their health. Thus, SNSs represent a new avenue of action for public health researchers and practitioners. This systematic review provides an overview of the literature concerning the current use of SNSs in public health.

Our results suggest that the application of SNSs to public health research and practice is still maturing. Most articles in this review describe relatively passive approaches to SNSs, rather than harnessing the full potential of SNSs in terms of multidirectional communication and networking. For example, most studies that used SNSs for recruiting study participants simply posted a recruitment ad or survey on the SNS, much as they could on a regular website. In contrast, 2 studies utilized SNSs not only to recruit study participants, but also to maintain contact with participants; thus, improving long-term participation [17,73]. These findings are consistent with the gaps identified in a recently published systematic review. Although different in scope—that review explored the use of social media for health communication—the authors also identified a lack of studies evaluating the impact of such novel technologies [7]. However, examples of more complex uses of SNSs are starting to emerge. Norman and Yip [89] utilized a wide range of SNS capabilities to first recruit young adults to create their own SNS content and then use this content to recruit and communicate with additional young adults around a host of health promotion issues.

Because the popularity of SNSs is a recent phenomenon, we are confident that these formative studies are the required foundation that will provide key knowledge to inform more interactive and experimental studies in the future. The formative study design of these initial SNS studies is suggestive of a developing domain. Most studies utilized a cross-sectional observational design; only 4 were experimental studies and 1 was a systematic review. This preponderance of nonexperimental designs is consistent with what is seen in other nascent domains, such as in the use of information technologies to help treat noncommunicable conditions [90]. It is likely that in coming years we will see an increase in the number of experimental studies using SNSs. For example, one of the studies included in this systematic review was recently followed by a randomized controlled trial that tested the effectiveness of Facebook messages to decrease risky sexual behaviors [91]. In

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the field of public health research and practice, SNSs may be an attractive low-cost tool to explore and test public health interventions with a large number of diverse participants—interventions that historically have been difficult to conduct using more traditional methods.

One critical—and maybe limiting—issue to be considered when designing randomized trials involving SNSs is their rapid change to potential obsolescence. We were able to show an important number of studies were conducted using MySpace initially, a situation that changed after 2010 in parallel with a decline in the number of MySpace users [92]. These rapid changes in SNS utilization might not be entirely compatible with the time it takes to obtain funding for a randomized trial.

In addition to the types of studies, our findings suggest that although SNSs offer an opportunity to reach a wide range of the population at lower costs when compared to traditional communication methods [93], most published studies have been conducted in high-income countries—predominantly in the United States. Only one study was conducted in South Africa, a higher middle-income country. The cause of this phenomenon is unclear. With the accelerated adoption of mobile broadband and smartphones in both developed and developing countries [94], we will probably begin to see a broader use of SNSs for public health research and practice in low- and middle-income countries in the future.

SNSs provide unique research and practice benefits beyond their low cost, high-reach, multidirectional communication. SNSs appear to be especially well-suited to research and practice on “taboo” public health topics, with nearly half (44%) of the studies included in our review addressing sexual and reproductive health and/or alcohol, tobacco, or substance use. Multiple aspects of SNSs make them suitable for such topics: SNSs afford a high level of anonymity; people display stigmatized behavior more freely online (visiting SNSs for sex, posting about their depression, etc) [95] and youth and young adults, a population largely affected by these issues, has the highest rate of SNS usage of any age group [3]. Not only do SNSs allow easier exploration of traditionally hard-to-discuss topics, they can also facilitate identification of and outreach to certain traditionally hard-to-reach populations, such as men who have sex with men (MSM) with risky sexual behavior [47,76,86], homeless youth [64,82], and young people suffering from mental illness [52,71]. Finally, SNSs allow for the exploration of public health issues associated with the increasing use of SNSs, such as promotions for drugs and tobacco on SNSs [31,50], online harassment and sexual solicitation of youth [20], and depression associated with SNS use [81].

Study Limitations

The main limitations of this systematic review arise from our search strategy, which included articles only published in scholarly journals, thus excluding communications published in the grey literature. In addition, some articles might have been missed because of limitations of our search terms. We tried to minimize this by including a broad list of SNS keywords in our list of terms.

Conclusions

An increasing number of studies involving the use of SNSs within the domain of public health have been published and the frequency and complexity of such studies parallels the growing popularity of SNSs in general. Most of the published studies are descriptive and take a limited approach to using SNSs. When the multiple possibilities that emerge from low cost are considered (eg, high visibility, multidirectional communications), it is obvious that there is a gap in range of possible study areas in public health and SNSs. As the field matures and our knowledge concerning the most effective ways to use these technologies to support public health research and practice matures, we expect to see additional innovative uses of SNSs to engage diverse and broad populations with the goal of better understanding and improving health.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
HIV: human immunodeficiency virus
MSM: men who have sex with men
SNS: social networking sites
STD: sexually transmitted diseases

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Review

Do Online Mental Health Services Improve Help-Seeking for Young People? A Systematic Review

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Abstract

Background: Young people regularly use online services to seek help and look for information about mental health problems. Yet little is known about the effects that online services have on mental health and whether these services facilitate help-seeking in young people.

Objective: This systematic review investigates the effectiveness of online services in facilitating mental health help-seeking in young people.

Methods: Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, literature searches were conducted in PubMed, PsycINFO, and the Cochrane library. Out of 608 publications identified, 18 studies fulfilled the inclusion criteria of investigating online mental health services and help-seeking in young people aged 14-25 years.

Results: Two qualitative, 12 cross-sectional, one quasi-experimental, and three randomized controlled trials (RCTs) were reviewed. There was no change in help-seeking behavior found in the RCTs, while the quasi-experimental study found a slight but significant increase in help-seeking. The cross-sectional studies reported that online services facilitated seeking help from a professional source for an average of 35% of users. The majority of the studies included small sample sizes and a high proportion of young women. Help-seeking was often a secondary outcome, with only 22% (4/18) of studies using adequate measures of help-seeking. The majority of studies identified in this review were of low quality and likely to be biased. Across all studies, young people regularly used and were generally satisfied with online mental health resources. Facilitators and barriers to help-seeking were also identified.

Conclusions: Few studies examine the effects of online services on mental health help-seeking. Further research is needed to determine whether online mental health services effectively facilitate help-seeking for young people.

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KEYWORDS

adolescent; young adult; Internet; medical informatics; mental health; mental disorders; systematic review; information seeking behavior

Introduction

Mental health problems affect adolescents more than any other age group [1]. Help-seeking is an important first step in improving mental health and accessing appropriate avenues of care [2]. Defined as “the process of actively seeking out and utilizing social relationships, either formal or informal, to help with personal problems” (p. 8) [2], help-seeking is a complex process involving awareness and appraisal of the problem, the ability to express the problem and need for support, relying on accessible and available sources of help, and a willingness to seek out and disclose relevant information [2]. In the last decade,

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the Internet has become a predominant source of health information [3,4] particularly for young people [5,6]. Various online services are readily available for young people including self-directed, low intensity Web-based mental health support (eg, ReachOut), national online counseling services (eg, eheadspace), repositories for information and resources concerning mental health (eg, Somazone), and structured self-directed online therapy (eg, MoodGym [7]). Online mental health services may conceivably assist in all elements of the help-seeking process.

Despite large investments in mental health reforms, face-to-face services are unable to support the large number of young people experiencing mental health problems [8,9]. In addition, existing face-to-face services pose significant barriers for young people [10-16] largely due to access, availability, and high costs of these services [17], as well as the reluctance of young people to seek professional help due to stigma and embarrassment [18-20]. Wilson and colleagues [21] identified that young people have a strong desire for autonomy, believing they should solve problems for themselves. In terms of these barriers, Internet services have several advantages: no geographical boundaries, services are generally free to the user, and the Internet is largely anonymous and private, which is likely to reduce the stigma and embarrassment associated with seeking help [22]. The interactive nature of the Internet allows for the provision of online therapies in various forms such as games or eLearning websites [23,24]. Online mental health services can provide interactive solutions to engage young people in a self-directed and anonymous way, thus assisting and supporting overburdened face-to-face services. Understanding young people's readiness for care is a key factor in supporting young people in reaching services appropriate to their needs [16]. Web-based technology can deliver stepped care services [25], providing non-intrusive treatments for those with mild problems and increasing with intensity as required.

It is important to ensure that young people are aware of local face-to-face services as well as online options, particularly for young people with severe mental health problems who require intensive treatment or medication. Online directories can facilitate pathways to face-to-face services as well as online care [24,26], allowing young people who need intensive services to readily access them while also supporting the large number of young people with mild or moderate mental health concerns.

Routinely, investigations into health and mental health websites has involved evaluation of (1) the quality of the information [3,27-30], (2) the scope and reach of the website [31-33], and (3) consumer satisfaction [34,35]. There is also considerable research demonstrating that structured online therapy programs (eg, MoodGym) effectively improve mental health outcomes [36-40] and that mobile self-monitoring is a useful tool [41-43]. Online mental health websites have also been shown to increase the use of services for adults [44]; however, the effect of online information services and other regularly used unstructured websites on help-seeking in young people is rarely explored [45].

As improving help-seeking is integral to accessing care and improving mental health, this systematic review investigates the effectiveness of current online mental health services in facilitating the help-seeking process in young people. The aims of this review are to explore past literature that investigate whether online mental health services facilitate the help-seeking process in young people, specifically focusing on help-seeking behaviors, the barriers and facilitators influencing online help-seeking, and the experiences of young people who use these services.

Methods

Literature Search

This review was conducted in accordance with PRISMA guidelines [46] and registered on PROSPERO (Prospero Registration Number: CRD42013003904)[47]. Peer-reviewed English citations up to February 27, 2013, on the databases PsycINFO, PubMed, and the Cochrane Library, were searched using search terms representing three concepts: Web-based technology, mental health, and help-seeking (details described in Multimedia Appendix 1). All controlled and uncontrolled studies were eligible for inclusion including qualitative studies. The reference lists of all relevant studies, reviews, and meta-analyses identified in this search were also manually searched for inclusion into the review.

Selection of Studies

The first author examined all titles and abstracts extracted for relevance and read the full text for any potentially eligible article. Table 1 describes the exclusion criteria. The second author confirmed that all selected articles were eligible for inclusion.

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Table 1. Exclusion criteria.

Criteria	Description
Over 25 years of age	Depending on how age was described in the study, studies were excluded when over 25% of participants in the study were not young people between the ages of 14 and 25 years (per Gulliver [13]); the average age of participants was >30 years; or no age was mentioned and the article referred to adults.
Not mental health	The outcome addressed was a health outcome other than mental health (eg, diabetes, heart disease).
Not Web-based	There was no technological component discussed such as online mental health services.
Unrelated technology	The online program did not specifically explore mental health (eg, the effects of popular computer games or social networking sites on mental health outcomes). Online forums were excluded except when they were specifically dealing with mental health issues (eg, forums specifically for young people with depression).
Electronic medical records	The program was an electronic system to keep medical records.
No evaluation	The paper described the program but did not evaluate help-seeking behavior, attitudes, or intentions.
Not a study	The paper was not a study (ie, a review paper or discussion piece). Any relevant studies in reference lists were included.
Third-party program	The study focused on a third party seeking help for the young person (eg, parent or teacher).

Coding of Studies

The first author extracted data from the studies using the form described in Table 2, which was confirmed by the second author. Risk of bias within each study was assessed using a version (Multimedia Appendix 2) of the Quality Rating Scale (QRS) [48] adapted to include qualitative and uncontrolled studies. The first two authors used the QRS independently. Interrater reliability was assessed by Cohen's absolute weighted kappa statistic in Stata Version 12.0. Weighted kappa allows for different levels of agreement in ordered data, and the absolute function allows for all numbers including those unassigned by either rater.

The country, research group, and year published were also examined to determine whether there were biases across studies in terms of the country of research, research group, or years in which the research was conducted. All studies were included irrespective of their design, quality, and biases. As suggested by Linde and colleagues [49], this review included uncontrolled trials and qualitative studies to obtain an overview of the topic and inform future research. No statistical analyses were conducted due to the heterogeneity of study designs permitted in the inclusion criteria. Instead, a broad qualitative overview of the data was conducted and statistical analyses from the studies were reported.

Table 2. The pre-determined form used to code the selected studies.

Reference	Authors' names, research group (including the department, organization, and country), and the year published
Sample	Number of participants, age of participants (either mean and standard deviation, range, or percentage of young people), percentage of female participants, population targeted (ie, mental health status or risk profile)
Study design	Qualitative or quantitative (cross-sectional, quasi-experimental, longitudinal, RCT)
Program	Type of online mental health services examined (eg, information website, discussion forums, screening tool, online therapy)
Outcome	Outcomes studied (ie, mental health or help-seeking outcomes, user satisfaction, economic evaluation), the measures used to assess the outcome, and summary statistics reported

Results

Summary

A total of 487 articles were identified through the literature search. All relevant review and research papers [37,41,50-70] were then manually searched, which uncovered a further 121 potential studies. Of these 608 papers, 405 were excluded based on their abstracts and a further 149 excluded after the full article was examined, leaving a total of 18 studies to review. Figure 1 depicts the PRISMA flow diagram for inclusion.

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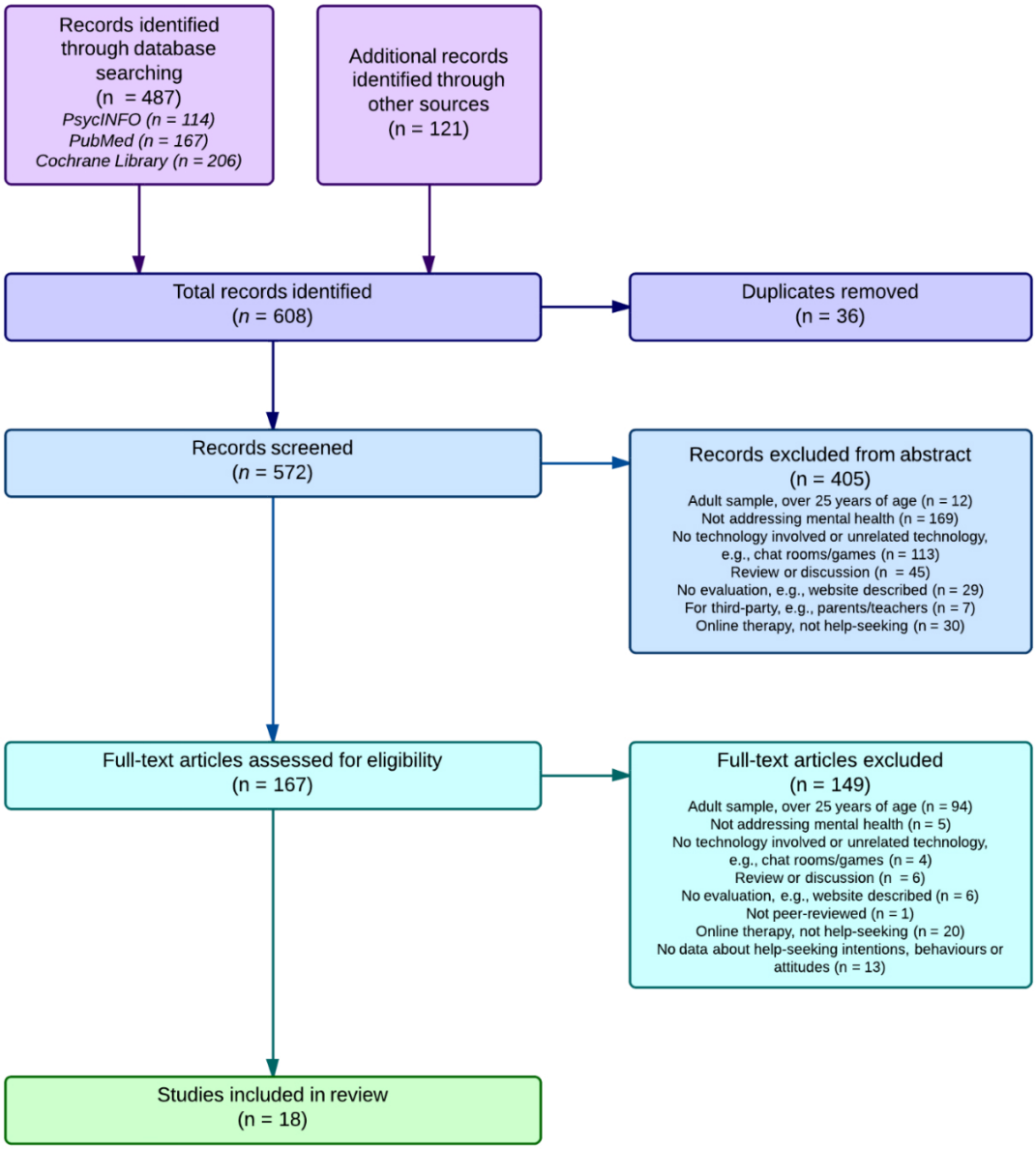
Figure 1. PRISMA flow diagram for inclusion into the review.



Study Characteristics

Eighteen publications met the inclusion criteria including two qualitative [51,55], 12 cross-sectional [53,56,60,63,64,71-77], one quasi-experimental [68], and three randomized controlled trials (RCTs) [52,78,79]. The sample sizes ranged from 9 to 2700: median 420, mean 762.3 (SD 838.10). There were a high proportion of females in the studies, ranging from 50% to 80%: median 68%, mean 67.1% (SD 9.73%). The characteristics of each study are presented in Table 3.

The majority of participants were students at a university [55,56,60,63,74,76] or high school [73]. Other studies involved users of online services [53,68,72,75,77]. Within these settings, 10 studies targeted young people with mild to moderate mental health problems [52,53,55,63,64,68,72,75-77], one study focused on young athletes at risk of mental health problems [79], and seven studies involved all young people regardless of mental health status [51,56,60,71,73,74,78].

The types of programs investigated were varied as outlined in Table 3. Most commonly, the use of several programs and websites [56,60,71,73,74,76] were investigated, such as online information sites, chat groups, self-directed online therapy, and forums. Other studies investigated a specific information site [53,64,77-79], a self-directed online therapy [51,52,55], a discussion forum about mental health problems [72,75], a Web-based mental health educational game [68], and a screening tool [63].

Figure 2 shows the age ranges and means for each study. Most studies (11/18) were inclusive of the target age range; 55% (10/18) of studies focused on participants who were 18 years of age or older. The mean age of participants for the studies ranged from 16.5-26.2 years of age.

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Table 3. Study type, target group, service evaluated, sample, study design, and findings related to help-seeking of the included studies.

Study	Target group / online service	Sample / design[a]	Help-seeking findings
Discussion forums			
Eichenberg [72]	Message board posts were examined from adolescents who used the forum "Selbstmord" and users completed a survey	N=164 50% female CS	38/164 (23%) answered "yes" to the question "did you use the forum in order to obtain information about professional help?"
Kummervold et al [75]	Users of the forums Doktor Online & SOL Helse completed a survey	N=492 78% female CS	19/165 (6%) answered "yes" to the question "did participating in the forum increase your use of traditional services?"
Web-based mental health educational game			
Shandley et al [68]	Young Australians who registered to play ReachOut Central	N=266 66% female QUASI	A significant increase in willingness to seek help was found from pre-test (male mean 4.01 [SD 2.98]; female mean 4.17 [SD 2.69]) to post test (male mean 4.39 [SD 3.13], female mean 5.04 [SD 2.99]); $F_{1,264}$=18.04, P<.001.
Internet-based self-help program			
Bradley et al [51]	Pilot study with 15-18 year olds with no previous mental illness scoring below severe on the Depression, Anxiety and Stress Scale completed the Feeling Better Program	N=13 69% female QUAL	Participants qualitatively expressed that they thought the online mental health service improved accessibility to help
Clarke et al [52]	Depressed and non-depressed 18-24 year olds were recruited and randomized into an online self-help program or treatment as usual	N=160 80% female RCT	The chi-square test revealed no significant difference for mental health visits between the intervention (mean 1.3 [SD 3.1]) and the control group (mean 0.9 [SD 2.7]).
Davis-McCabe & Winthrop [55]	Pilot study of university students who used the Computer Aided Lifestyle Management program	N=9[a] QUAL	Participants "saw the program as a useful tool that aids further self-help" (p. 51)
Gulliver et al [79]	Elite athletes were randomized into three versions of an online self-help program: mental health literacy and de-stigmatism, a feedback condition about symptoms, or a minimal content condition involving a list of help-seeking resources or a waitlist control group	N=59 72% female RCT	No difference in help-seeking behavior was found between any of the intervention groups and the control group over time (mental health literacy/destigmatization OR 57.38, 95% CI 0.85-3868.09, P=.06; feedback OR 5.15, 95% CI 0.04-637.04, P=.51; help-seeking list OR 57.38, 95% CI 0.15-1263.93, P=.25).
Collin et al [53]	Young people who used ReachOut.com completed a survey	N=2291 76% female CS	546/1552 (35.2%) of participants said "yes" to "Did ReachOut.com help you ask a professional for help?"
Costin et al [78]	Random representative sample of 19-24 year olds recruited through a postal mail-out randomized to (1) receiving brief, (2) advanced or (3) non-related depression health e-cards	N=348 75% female RCT	No increase was found in help-seeking on the AHSQ for formal (OR 1.17, χ^2_1=0.14, P=.70) or informal (OR 0.86, χ^2_1=0.18, P=.67) sources.
Klein et al [64]	Drug and alcohol users who accessed at least 1 of 14 drug and alcohol websites completed a survey	N=1214 66% female CS	336/994 (38.8%) of participants indicated a preference for websites with email support from a therapist
Nicholas [77]	Young people who used ReachOut.com completed a survey	N=1016[b] CS	386/1016 (38%) of participants said yes to "Are you more likely to talk to a mental health professional after visiting ReachOut.com?"
Online screening tool			
Kim et al [63]	University students used a Web-based self-screening and referral system and completed a survey	N=2700 68% female CS	43/57 (75.4%) of participants said "yes" to "Did the screening tool help you make your decision to see a mental health care professional?"
Multiple online services			

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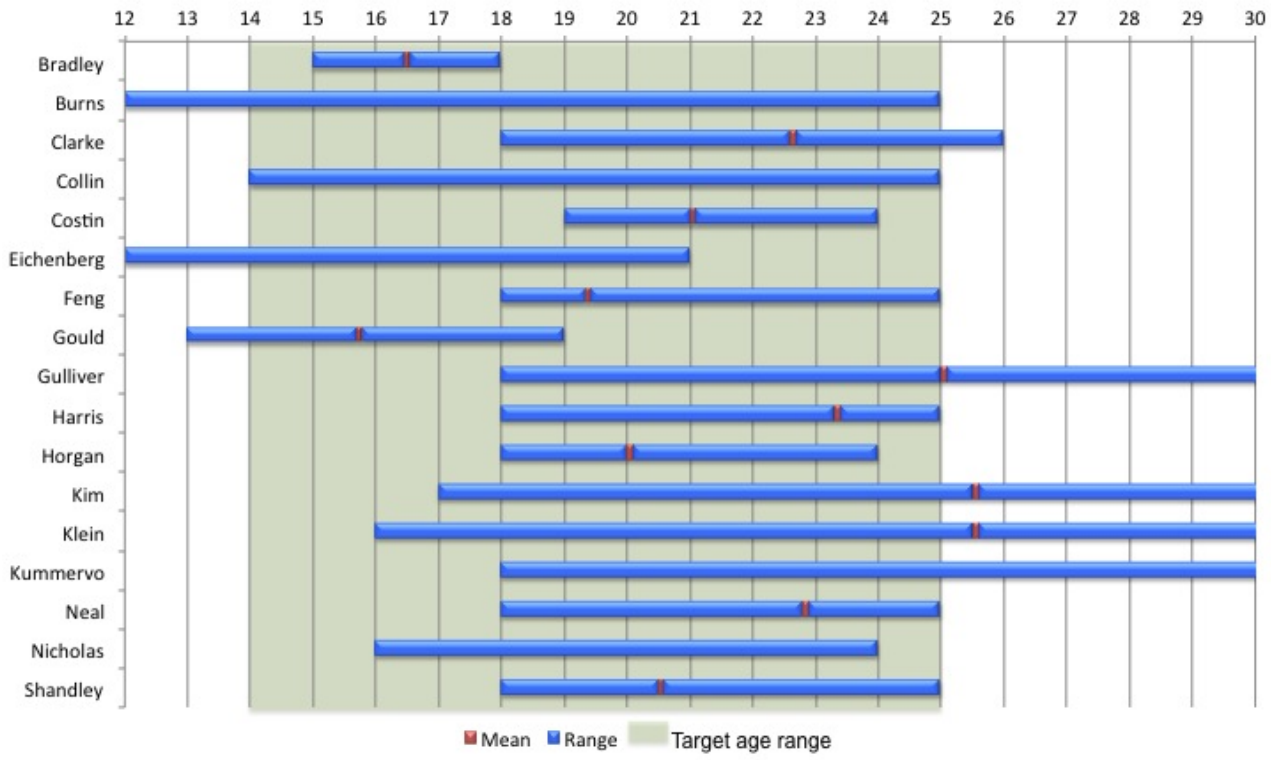
Study	Target group / online service	Sample / design[a]	Help-seeking findings
Burns et al [71]	Random representative sample of 12-15 year olds via telephone were asked their opinions about online mental health services	N=2000 50% female CS	70/227 (30.8%) of participants said "yes" to "Have you ever used the Internet to find information for a mental health, alcohol, or other substance use problem?"
Feng & Campbell [56]	University students were asked their opinions about online mental health services	N=176 68% female CS	77/176 (44%) of participants said "yes" to "Have you used the Internet in the past to learn about personal feelings, anxiety, sadness, or confusion?"
Gould et al [73]	High school students were asked their opinions about online mental health services	N=519 50% female CS	94/519 (18%) of participants said "yes" to "In the past 12 months, did you use the Internet to seek help when you felt very upset, sad, stressed or angry?"
Harris et al [60]	University students were asked about the online mental health services used to seek help for suicidal ideation	N=64 75% female CS	24/64 (37.5%) of participants said "yes" to "How likely would you be to use a help-site?"
Horgan & Sweeney [74]	University students completed a survey about their opinions about online mental health services	N=922 62% female CS	267/867 (30.8%) of participants said "yes" to "Have you used the Internet for mental health information?"
Neal et al [76]	University students were asked their opinions about online tools	N=1308 68% female CS	698/1308 (53%) of participants said "yes" to "Have you used the Internet in the past for information on mental health when sad, anxious or confused?"

[a]CS=cross-sectional; QUAL=qualitative study; QUASI=quasi-experimental.

[b]Percentage of females not provided.

Figure 2. Age range and means for each study, with target age range indicated (mean age was not reported for some studies; end age range exceeded 30 years for the Klein study [70 years]).



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Primary Outcomes

Overview

Help-seeking behavior or service utilization was the primary outcome in four studies [53,63,78,79]. The primary outcomes for the remaining studies were the characteristics of young people who sought help online [56,60,72-77], mental health [52,55,68], and process evaluation of online services [51,64,71]. These are summarized below.

Help-Seeking

Studies were included in this review only if they explored help-seeking, yet only four studies included help-seeking as their primary aim, two of which were RCTs [52,78,79] and two were cross-sectional studies [53,63]. Costin et al [78] hypothesized that young people who received the intervention (depression information eHealth cards) would be more likely to seek professional health care than those who received the attention-control condition (non-depression information eHealth card). This hypothesis was not supported as no difference between the groups was found. Gulliver et al [79] investigated the effects of three conditions of an Internet-based self-help program on help-seeking attitudes, intentions, and behavior and found no difference in help-seeking between groups. Kim et al [63] conducted a cross-sectional study to examine the ability of an online screening tool to help students assess their mental health and encourage them to seek treatment. The majority of students (75.4%) indicated that screening enhanced their decision to see a professional. Collin et al [53] examined young people's engagement with an online mental health service and how the service facilitated help-seeking in a cross-sectional study and found that a minority of users (35.2%) thought the service helped them ask a professional for help.

Overall, no increase in help-seeking or health utilization was found in the three RCTs for the intervention groups compared to control groups (these statistics are found in Table 3). The lack of change in these studies may have been due to small sample sizes, an active comparison group [52], mild mental health problems rather than severe symptoms [79], or the fact that participants had previously sought help or were currently in treatment [78]. In the quasi-experimental study [68], participants rated on a 10-point scale: "if you felt sad, down, or miserable for >2 weeks, how likely is it that you would get help from a counsellor, psychologist, or psychiatrist?" There was a statistically significant increase in willingness to seek help (as listed in Table 3); however, the post-test mean was 5.01 for females and 4.39 for males, suggesting a low to medium score on the 10-point scale.

Of the cross-sectional studies, two general types of questions were asked: questions about Internet help-seeking behaviors (eg, "have you ever used the Internet for mental health information?") [56,60,71,73,74,76] and questions about the use of the Internet to seek professional help (eg, "did the service help you make your decision about seeing a professional?") [53,63,72,75,77]. The mean percentage of young people answering "yes" to these questions across studies was low, 38.4% (range 18% to 53%) and 34.9% (range 6% to 75.8%) respectively.

Descriptive Characteristics

Feng et al [56] explored the relationship between personality types and online help-seeking and found no association, all participants were equally likely to engage in online help-seeking. Eichenberg [72] assessed whether online message forums for people to discuss suicidality were harmful and found that users primarily used the site for constructive reasons. Three type of users participated in the suicide forums: those with destructive motives who participated for constructive reasons (21%, 23/108), those without a clear motivation for visiting (31%, 33/108), and those with constructive motives (48%, 52/108). Gould et al [73] investigated demographic characteristics, hopelessness, and functional impairment with the use of online services and found that at-risk young people were using online help-seeking in combination with other services, rather than substituting online services for other resources. Horgan and Sweeney [74] asked young people about their views and usage of Internet help-seeking and found that 267 out of 867 (30.8%) used the Internet to search for mental health information, 593 out of 872 (68%) indicated they would use the Internet if they needed to, and 689 out of 868 (79.4%) said they would prefer face-to-face support. Neal et al [76] also explored young people's opinions of online mental health help and how well the program engaged young adults' attention. Most young adults used Google to find mental health information and were unaware of potential websites that may assist them. Nicholas [77] investigated the perceived effects of the ReachOut site on its users and found that 37% (376/1016) of users visited the site more than once a week, 83% (832/1016) reported learning more about mental health issues, and 77% (872/1016) reported learning where to get help. Harris et al [60] investigated young people's intentions to use online sources and found that previous phone helpline usage, a suppressive problem-solving approach, and not seeking face-to-face professional services were associated with an increase in seeking help online (R^2=.32, $F_{3,60}$=9.44, P<.001). Kummervold and colleagues [75] examined who used mental health forums, why they used them, and the implications of forum use and found that women were the predominant users of forums (78%, 384/492), 75% (306/408) found it easier to discuss problems online compared to face-to-face, and 62% (195/317) used the forums as a supplement to mental health services. Professionals were welcome to participate and pseudonyms were important to 68% (334/492) of users.

Mental Health

The qualitative study by Davis-McCabe and Winthrop [55] investigated the potential of an online self-help program at a university and found that students reported positive changes and experiences from the program. Clarke and colleagues [52] compared an online program with treatment-as-usual and found that young adults with depressive symptoms had a modest yet significant reduction in symptoms post test (N=160, d=0.20, 95% CI 0.00-0.50) with a moderate effect for women (n=128, d=0.42, 95% CI 0.09-0.77). Shandley et al [68] evaluated the benefits of an online game designed to help young people with mental health problems and found slight but significant improvements in problem-solving (post test: $F_{1,264}$=4.42, P=.04;

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follow-up: $F_{1,264}$=4.92, P=.03), seeking support (follow-up: $F_{1,264}$=7.70, P=.01), avoidance (post test: $F_{1,264}$=4.10, P=.04; follow-up: $F_{1,264}$=3.94, P=.04), psychological distress (post test: $F_{1,264}$=11.89, P<.001; follow-up: $F_{1,264}$=9.04, P<.001), resilience (post test: $F_{1,264}$=5.87, P=.02; follow-up: $F_{1,264}$=10.86, P<.001), and satisfaction with life (post test: $F_{1,264}$=4.68, P=.03; follow-up: $F_{1,264}$=4.70, P=.03).

Process Evaluation

Burns [71] explored young people's Internet use for mental health resources and found that the Internet was used by 76.9% (1464/1905) of young people to connect with peers and by 38.8% (735/1894) of young people to seek information about mental health. Bradley et al [51] investigated what young people wanted in an Internet program for psychological distress and using thematic analysis found that usefulness, credibility, privacy, convenience, and accessibility were important to young people as well as being aware of the program and having the motivation to use the program. Klein et al [64] explored individual preferences for content and functionality on alcohol and other drug websites and found that interactive functionality (being asked a question: $\chi^2_{10=}$36.1, P<.001; consumer hub: $\chi^2_{10=}$34.6, P<.001) and social networking features (chat room access: χ^2_{10} =28.9, P<.001; blogging feature: $\chi^2_{10=}$53.3, P<.001) were valued by younger adults compared to older adults.

Barriers and Facilitators to Online Help-Seeking

A range of barriers and facilitators of help-seeking were mentioned in the articles, although these were rarely measured empirically. Barriers to help-seeking included lack of awareness [51,56,76], being male [68,71,73], a preference for face-to-face services [73,74], lack of motivation [51], uncertainty about confidentiality [74], and unfavorable content [64,76]. Facilitators to help-seeking included accessibility to online resources [51,53,55,71,74], the ease of sharing personal information compared to face-to-face services [74-76], anonymity [51,71,74,75], trust and credibility [53], reduction of stigma [55,68,79], high distress [55,73], and an increase in mental health literacy [53,68,74-79]. Table 4 describes these facilitators and barriers in detail.

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Table 4. Barriers and facilitators of online mental health resources.

Theme (n)	Findings
Barriers to online mental health services	
Lack of awareness (3)	Young people reported a lack of awareness of the online mental health services available [51,56,76].
	"Many participants commented that they would not have thought to look for online distress-management programs" (Bradley et al [51], p. 30).
	Young people most commonly used text-based search engines and information sites and were either not aware of other online mental health resources [56,76] or did not believe that they would help [76].
Online mental health services are not everyone's preferred source (2)	Young people were more likely to seek help from informal sources such as friends and parents when compared to Internet resources [73].
	Some young people preferred face-to-face services to Internet services [74].
Males don't seek help online (3)	Young men were less likely to seek help using online mental health services than young women (χ^2=8.6, P<.01) [71].
	After playing ReachOut Central [68], young women were marginally more willing to seek help than young men.
	Gould et al [73] showed no gender differences in frequency of online help-seeking behavior.
Lack of motivation (1)	Some distressed young people would not be motivated to seek help on or offline. "You have to want to help yourself" [51] p 30.
Not confidential / impersonal (1)	Online mental health services were reported by some participants [74] as unreliable (15.1%), untrustworthy (5%), lacking in privacy (2.5%), impersonal (7.5%), and as providing insufficient support (3.9%).
Content unfavorable (2)	Information websites can to be too technical to understand [76], forums contain inaccurate information, with people complaining and unhelpful [76], and finding the desired information on alcohol websites can be difficult [64].
Facilitators to online help-seeking	
Accessibility of online mental health resources (5)	67.3% of users agreed that ReachOut was "there when they need it" [53]. Horgan and Sweeney [74] reported that participants used the Internet for mental health support because of the vast amounts of information valuable online (21.8%), the Internet is easily accessed 24 hours (10.1%), it is easy to find information (11%), fast (8.3%), cheap (2.7%), convenient (1.7%), and a good place to start and find out where to go for further assistance (4.7%). One of the useful features of online mental health services is accessibility as they are available when required in crisis situations when other support cannot be reached, particularly flexible programs that allow users to come and go [55].
	In the qualitative study by Bradley et al [51], participants expressed that they thought online mental health services improved accessibility to help; "anyone, anywhere, anytime" (p. 29).
	Late night Internet usage is another benefit to online mental health services [71], with Internet use after 11 p.m. the only predictor for young men to use the Internet as a mental health resource (OR 2.1, CI 1.1-4.3).
Anonymity (4)	In one study [74], 22.3% of participants preferred online mental health services to face-to-face services because they are anonymous, private, and confidential.
	In another study [75], 64% of participants valued the anonymity that the program allowed and indicated that they would not have used the service if they had to give their real name.
	Bradley et al [51] reported that participants felt that online mental health services were the most private way to seek help; however, Burns et al [71] found that young people did not consider anonymity helpful.
Trust/credibility (1)	Only one study [53] examined how trustworthy young people found online mental health services to be and found that the majority of visitors agreed that ReachOut.com was relevant, credible, and trustworthy (74.3%). Participants preferred online mental health services to face-to-face services because they believed they would not be judged (7.3%).
Reduction of stigma (3)	The results from Gulliver et al [79] demonstrated a significant interaction between the type of program and time in depression stigma ($F_{667.51}$=3.99, P=.002) and anxiety stigma ($F_{662.22}$=3.20, P=.008). Further investigation showed that the mental health literacy/destigmatization condition had a greater decrease in stigma than the other two conditions. There was no difference in stigma from pre-test to follow-up in the evaluation of ReachOut Central [68].
	One study [55] qualitatively found that online services were associated with less stigma than face-to-face services.

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Theme (n)	Findings
Sharing personal information (5)	Two benefits of discussion forums were mentioned: (1) reading and posting on discussion forums demonstrated to young people that there are other people going through similar problems and that they were not alone [76], and (2) 75% of young people said it was easier to discuss personal problems using online mental health services than face-to-face services and that they would discuss things they would not offline [75].
	Some of the reasons for using the Internet for mental health support in Horgan and Sweeney's study [74] included ease of communicating with other young people (3.7%), more inclined to open up on the Internet (1.7%), believed it would be easier to express themselves online (1.1%), and discussing personal problems online is less embarrassing than talking to a professional, friend, or family member (2.9%).
	Interestingly, two studies indicate an association between distress and help-seeking online [55,73].
High distress (2)	Participants in Davis-McCabe and Winthrop's study [55] reported that they were more likely to use online mental health services when distressed.
	Similarly, young people who were functionally impaired (ie, scoring >16 on the CIS) were more likely than unimpaired to seek information online (34% versus 20.6%; χ^2=7.4, P<.01) as were young people scoring nine or above on the Beck Hopelessness Scale when compared to those with low scores (16.1 versus 9.1%; χ^2=3.8, P>.05) [73].
Increase of mental health literacy (8)	Eight studies explored mental health literacy. Participation in the mental health literacy/destigmatization condition in Gulliver et al's study [79] demonstrated a greater increase in depression literacy; $F_{669.41}$=2.47, P=.03) and anxiety literacy; $F_{667.51}$= 3.99, P=.002, compared to the other conditions.
	Users reported that ReachOut.com contributed to their knowledge about mental health issues: 43.3% learned skills, knowledge, and confidence to seek help if they needed it [53], 57% gained an understanding about mental health issues [53], and 77% said they learned where to get help [77].
	Neal et al [76] reported that several participants indicated in their qualitative responses that information websites helped learn about their feelings. Those who had previously sought online help rated all online mental health services higher than those who had not previously sought help [76]. A small proportion of participants (4.7%) said that they used online mental health services because they believed it would be a good place to get initial information about mental health [74].
	Forum users believed the forum increased their knowledge and understanding of mental problems, health care services, their rights, and what they could expect from health services [75]. In addition, being part of the forum made them feel more pro-active, prepared, and goal-oriented with seeking help [75].
	ReachOut Central, however, was not associated with an increase in mental health literacy for males or females [68]. No difference was found in help-seeking knowledge, ability to recognize depression, or intentions to seek help between different information eHealth cards, although an increase in beliefs about efficacy of formal help-seeking from pre-test to post test [78] was found.

User Experience

Young people's experiences with online services were investigated in 50% (9/18) of the studies. Generally, participants were asked to rate how helpful the service was [56,63,71,73,76,78], how easy it was to use [63,68], whether they would use it again [63,68], whether they would recommend it to others [53,68,71,73], or if they were satisfied with the service [63,71,73]. There was high variability in the measures used, and therefore the results are difficult to compare between studies. All of these studies used from one to six questions, which were constructed by the authors. No standard measures were used. User experience is summarized in Table 5.

Overall, experiences of the online services were positive. Of the nine studies that evaluated these experiences, 90% of participants were satisfied with the service, 86% would continue to use the service or use it again in the future, and 72% would recommend it to a friend. However, approximately half of participants received the information they were looking for, and only 65% found the programs helpful.

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Table 5. User experience of online services.

Theme (n)	Overall percentage (n/N)	Individual studies percentage (n/N)
Somewhat to very helpful (6)	65.50% (1156/1765)	85.96% (98/114) [78]
		78.11% (571/731) [71]
		55.35% (383/692) [76]
		50.88% (29/57) [63]
		45.74% (43/94) [73]
		41.56% (32/77) [56]
Somewhat to very satisfied (3)	90.35% (796/881)	93.57% (684/731) [71]
		71.28% (67/94) [73]
		80.36% (45/56) [63]
Would recommend to a friend (4)	71.94% (1838/2555)	88.20% (157/178) [68]
		84.95% (621/731) [71]
		65.98% (1024/1552) [53]
		38.90% (36/94) [73]
Received the information they wanted (2)	52.18% (1595/3057)	49.11% (359/731) [71]
		50.68% (596/1176) and 55.65% (640/1150) found it within 5 to 15 minutes [64]
Ease of use (2)	91.91% (216/235)	98.25% (56/57) [63]
		89.89% (160/178) [68]
Would continue to use (2)	86.38% (279/323)	89.29% (50/56) [63]
		86.09% (229/266) [68]

Assessment of Bias

The adapted QRS ranged from 6 to 37 for both raters and had similar means (Rater 1 mean 19.5 [SD 7.45]; Rater 2 mean 20.2 [SD 8.66]). The qualitative and cross-sectional studies scored low, between 6 and 24 for both raters. The quasi-experimental study [68] scored 20 by rater 1 and 29 by rater 2, and the RCTs scored high from 31 to 37 by both raters. Interrater agreement was higher (89.8%) than the expected agreement (76.1%) with an acceptable kappa score (κ=.57, CI 0.32-0.82, P<.001). All studies were published between 2002 and 2012 (median 2010), with 15 studies occurring in the last 5 years (2009-2012). Seven studies [52,53,55,63,77-79] developed the intervention that they were evaluating, which may have led to a bias towards more favorable reporting.

There was a bias towards affiliations with four organizations, with nine studies conducted within Australia compared to three in the United States, two in Canada, and one each in Germany, Ireland, Norway, and United Kingdom. Three studies were from the Inspire Foundation, Sydney [53,71,77], two from the National eTherapy Centre at Swinburne University in Melbourne [64,68], two from the Centre for Mental Health Research at Australian National University in Canberra [78,79], and two from the Faculty of Health Sciences at the University of Sydney [56,76]. The remaining nine were not affiliated with the other studies included in this review. Table 6 lists the study, research group, year of publication, country where the research was conducted, and QRS.

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Table 6. Assessment of bias for each study.

Study	Research group	Year published	Quality[a]
Bradley et al [51]	IWK Health Centre, Canada	2012	11.5
Burns et al [71]	Inspire Foundation Australia	2010	19
Clarke et al [52]	Kaiser Permanente Center for Health Research, United States	2009	34
Collin et al [53]	Inspire Foundation Australia	2011	19.5
Costin et al [78]	Centre for Mental Health Research, Australian National University, Australia	2009	34
Davis-McCabe & Winthrop [55]	Counselling Psychology, Teeside University, United Kingdom	2010	6
Eichenberg [72]	Institute of Clinical Psychology and Psychotherapy, University of Cologne, Germany	2008	16
Feng & Campbell [56]	Department of Health Science, University of Sydney, Australia	2011	21.5
Gould et al [73]	Columbia University, United States	2002	19.5
Gulliver et al [79]	Centre for Mental Health Research, Australian National University, Australia	2012	34
Harris et al [60]	School of Psychology, University of Queensland, Australia	2009	17.5
Horgan & Sweeney [74]	Brookfield Health Science Complex, University College Cork, Ireland	2010	20
Kim et al [63]	Department of BioEngineering, University of Washington, United States	2011	19
Klein et al [64]	National eTherapy Centre, Swinburne University, Australia	2010	17
Kummervold et al [75]	Norwegian Centre for Telemedicine, University Hospital of North Norway	2002	16
Neal et al [76]	Faculty to Information and Media Studies, University of Western Ontario, Canada	2011	17
Nicholas [77]	Inspire Foundation Australia	2010	11
Shandley et al [68]	National eTherapy Centre, Swinburne University, Australia	2010	24.5

[a]Average score on the Quality Rating Scale between the two raters.

Limitations of the Studies

The majority of studies included a comprehensive list of limitations: small sample size [51,52,55,60,68,78,79], resulting in insufficient power to detect a change [52,68,78,79]; a self-selected sample, not representative and possibly biased [56,60,63,68,73,77-79]; majority of participants were female [51,56,60,64,68,79]; a lack of longitudinal tracking in the study [53,71,77]; only one online mental health service was investigated [51]; only one behavior change theory was investigated [51]; limited outcome measures [52,60,64,73]; insufficient length of follow-up time points [78]; no quantitative analysis [55]; non-validated and possibly biased measures [56,64,74,77]; and lack of qualitative information to provide depth about attitudes [77].

Discussion

Principal Findings

There is a plethora of online services available with the aim of facilitating help-seeking for young people with mental health problems [80], yet only 18 studies were identified in this review that evaluated whether these services increased help-seeking in young people. Overall, these studies did not indicate that online services facilitate mental health help-seeking in young people. No change in help-seeking was found in the three RCTs [52,78,79]. The quasi-experimental study found a slight but significant increase in help-seeking [52,68,78,79]. The cross-sectional studies found that only 35% of participants indicated the services helped them seek help from a professional. Only 52% of participant also reported that they received the information they wanted, and only 65% found the services helpful.

Despite these unfavorable results, the results show that young people regularly used these services, would generally recommend the services to friends, would use them again, and generally found the services easy to use and satisfactory. Furthermore, young people suggested that these services were accessible and available [51,53,55,71,74], anonymous [51,71,74,75], allowed personal stories to be shared with others [55,73-76], were less stigmatizing than phonelines and face-to-face services [68,79], and trustworthy [53]. This finding suggests that online services fulfil a need, although perhaps do not increase help-seeking. Further exploration into what young people use these services for is warranted.

As with face-to-face services, some barriers to online services remain such as lack of awareness of online resources [51,56,76], young men seeking online help less often than females [68,71,73], some young people's preference for face-to-face services [73,74], lack of motivation to seek help online [51], the lack of trust of websites [74], and unfavorable content [64,76].

Interestingly, young women were overrepresented in online mental health services in much the same way as in traditional face-to-face care [81]. This could be due to young women using online services, or participating in research, more often than young men. A recent study indicated that young men were

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generally high use Internet users [82] with 55% seeking help online. Utilizing the advantages of technology by specifically tailoring services for young men may increase rates of young men seeking help online as well as face-to-face [82]. Using the Internet may also assist with young people who prefer face-to-face services by directing young people to appropriate face-to-face services in local areas in the form of online directory services.

Furthermore, online services often include information about mental health literacy [83], providing young people with information about mental illness, where to get help, and what to expect at services. This type of information may increase readiness for care and motivation to seek help.

Another interesting finding was that online services appeared to increase mental health literacy [53,74-77,79], although two studies found no change in mental health literacy [68,78]. Improvements in mental health literacy are likely to assist young people in recognition and management of mental health and may also reduce the self-stigma associated with mental illness [84]. Mental health literacy is associated with seeking help from appropriate treatment and professional services [85]. A recent meta-analysis demonstrated that interventions with a focus on mental health literacy significantly improved help-seeking intentions, although no effect was found for help-seeking behaviors [86]. Ensuring that websites maintain young people's confidentiality and anonymity appears to be critical to increasing usage of online services.

This systematic review highlights the need for rigorous evaluation methods of online help-seeking programs. The methodology was generally poor across the studies with a high risk of bias. Samples were generally small, the studies often included short-term, if any, follow-up, and non-validated measures of help-seeking behavior and intentions were often used, in some cases with just one question to assess the complex concept of help-seeking. Help-seeking was not the primary outcome for most studies. It is also important to note that help-seeking was not the primary purpose of some of the services, such as discussion forums and self-help programs, where the primary purpose may have been self-help rather than assisting young people to seek help from other services. These methodological issues may account for the lack of change in help-seeking. Also, despite the general satisfaction with online services reported, evaluation of satisfaction was poor. No standard measures of satisfaction were used in the studies limiting the ability to compare user experiences across studies. Short user satisfaction measures are available such as the validated Client Satisfaction Questionnaire (CSQ-3 or 8) [87], which summed together gives an understanding of client's satisfaction of the service.

Structured online treatment programs, though effective at reducing adolescent depression and anxiety [36-40,88], have poor uptake [89], high dropout rates, and the reduction of mental health symptomatology is not maintained long term [90]. In contrast, unstructured mental health websites have high uptake [77], allowing users to explore the contents, select links that appeal to them, and disregard information that is not relevant or interesting. The primary aim of these services is to give young people information about mental health as well as facilitate help-seeking and pathways to mental health care; however, these aims are rarely evaluated [45]. It is time now to focus on whether these sites facilitate help-seeking and improve well-being to ensure that the online services we provide to young people assist their help-seeking journey and lead to better outcomes and better access to care.

High-quality randomized control trials are needed before the implementation of new services as well as ongoing longitudinal trials to ensure the efficacy of existing services. These trials should include large representative samples, long-term follow-up measures of at least 6-12 months, the use of appropriate, validated measures of help-seeking behavior, help-seeking intentions, beliefs about help-seeking, and client satisfaction. Analyses should also be appropriate and indicate an effect size for future inclusion into meta-analyses.

Strengths and Limitations

This review is timely and highlights the need to properly evaluate websites aiming to assist young people with their mental health problems and seek help. Including uncontrolled studies in this review allowed for a broad overview of research in this area to date, and as only three RCTs were found, a meta-analysis was not possible. Some studies included were primarily self-help websites, therefore one would hope that further help-seeking was reduced rather than increased. Nevertheless, as the studies themselves included help-seeking as a primary or secondary aim, it can be assumed that help-seeking was considered a goal of these studies. One of the strengths of this review was the focus on both help-seeking behaviors and intentions, as intentions do not always translate into behavior. Further research is needed to explore the mechanisms that facilitate and hinder this process.

Conclusions

At present, there is a paucity of research exploring the relationship between online services and help-seeking behavior. This is not to say that there is no benefit in online services, rather, that this field has yet to be properly evaluated. Only 35% of young people experiencing mental health problems seek professional face-to-face help [91,92]. Online mental health services may conceivably assist in all elements of the help-seeking process; however, further research into the effectiveness of online services, how they interact with face-to-face services, and whether online services can overcome barriers to mental health care, facilitate readiness for care, and increase help-seeking behavior is needed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Terms used for the literature search.

[PDF File (Adobe PDF File), 145KB - jmir_v16i3e66_app1.pdf]

Multimedia Appendix 2

The adapted Quality Rating Scale.

[PDF File (Adobe PDF File), 44KB - jmir_v16i3e66_app2.pdf]

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Abbreviations

AHSQ: Actual Help Seeking Questionnaire
CIS: Columbia Impairment Scale
QRS: quality rating scale
RCT: randomized controlled trial

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Original Paper

Web-Based Intervention in Mindfulness Meditation for Reducing Residual Depressive Symptoms and Relapse Prophylaxis: A Qualitative Study

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Abstract

Background: Mindful Mood Balance (MMB) is a Web-based intervention designed to treat residual depressive symptoms and prevent relapse. MMB was designed to deliver the core concepts of mindfulness-based cognitive therapy (MBCT), a group treatment, which, despite its strong evidence base, faces a number of dissemination challenges.

Objective: The present study is a qualitative investigation of participants' experiences with MMB.

Methods: Qualitative content analysis was conducted via 38 exit interviews with MMB participants. Study inclusion required a current PHQ-9 (Patient Health Questionnaire) score ≤12 and lifetime history ≥1 major depressive episode. Feedback was obtained on specific website components, program content, and administration as well as skills learned.

Results: Codes were assigned to interview responses and organized into four main themes: MBCT Web content, MBCT Web-based group process, home practice, and evidence of concept comprehension. Within these four areas, participants highlighted the advantages and obstacles of translating and delivering MBCT in a Web-based format. Adding increased support was suggested for troubleshooting session content as well as managing time challenges for completing home mindfulness practice. Participants endorsed developing affect regulation skills and identified several advantages to Web-based delivery including flexibility, reduced cost, and time commitment.

Conclusions: These findings support the viability of providing MBCT online and are consistent with prior qualitative accounts derived from in-person MBCT groups. While there is certainly room for innovation in the domains of program support and engagement, the high levels of participant satisfaction indicated that MMB can significantly increase access to evidence-based psychological treatments for sub-threshold symptoms of unipolar affective disorder.

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KEYWORDS

mindfulness-based cognitive therapy; online depression; Web-based depression; Internet-based depression; depression relapse prevention; residual depression symptoms; online psychological treatment; qualitative methods

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Introduction

Mindfulness-based cognitive therapy (MBCT) is an empirically supported intervention designed to teach participants emotion-regulation skills for reducing residual depressive symptoms and avoiding relapse triggers that contribute to a chronic illness course [1-3]. A recent meta-analysis indicated that MBCT conferred a 43% reduction in relative risk for relapse among participants as compared to controls [4]. Despite MBCT's efficacy, it faces challenges to dissemination that are common to psychotherapeutic treatments, including: (1) service costs, waiting lists, and distance to access care [5], (2) scheduling and coordinating challenges inherent to delivery of an 8-session, 2-hour course with groups of 8 to 12 participants, and (3) a shortage of trained therapists who have competence in the delivery of CBT (cognitive behavioral therapy) and mindfulness meditation.

Web-based psychological interventions offer one solution to many of the aforementioned challenges [6-8]. They eliminate both travel and treatment waiting times, are cost effective with respect to clinician resources, increase treatment accessibility and flexibility, and empower participants to utilize self-help options [9,10]. The Web-based delivery of CBT for depression has been associated with large effect sizes in systematic reviews (d=.60) [8,11] and high user acceptability and satisfaction [12-14], particularly when combined with the use of reminders or live support [15,16]. A Web-based CBT program designed for partially remitted depressed patients showed lower relapse rates compared to controls when measured at 6 and 24 months post treatment [17,18]. Moreover, a Web-based program combining elements of Mindfulness-Based Stress Reduction and MBCT recently showed significant improvements, which were comparable to in-person group outcomes, on self-reported indices of perceived stress, anxiety, and depression [19].

The present study is a qualitative investigation of participants' experiences with Mindful Mood Balance (MMB), the first 8-week Web-based treatment that features the core elements of the MBCT group program. Qualitative examination of other Web-based interventions has yielded valuable insights [14,20], particularly with respect to what is gained or lost in the translation from in-person formats. As a natural starting point, qualitative studies of MBCT groups provide an important perspective for examining the user experience of MMB [21,22]. Mason and Hargreaves (2001) [21], using both in-depth interviews and grounded theory methods, identified core themes among MBCT participants, including: relaxation, mindfulness skills, accepting attitude, discovery/surprise, group support and identification, knowledge of worsening mental state, and applying skills to everyday living. Allen et al (2009) [22] also conducted a qualitative study of MBCT and identified overlapping themes.

The present study's primary objective was to learn about participants' subjective experiences of the core intervention components, suggestions for improvement of program content, format, and delivery, and the experience of implementing mindfulness skills in their daily lives.

Methods

Mindful Mood Balance

MBCT integrates mindfulness meditation with the tools of CBT to teach participants skills for recognizing responses to dysphoric moods that can perpetuate and trigger more chronic mood symptoms. Although the mindfulness meditation and CBT content is delivered in an integrated manner across the 8 sessions, the first 4 sessions focus heavily on establishing a foundation of mindfulness practice and bringing awareness to daily activities, the body, and the breath. In Sessions 5 through 8, CBT principles figure more prominently as the focus becomes more squarely on depression. Home practice is assigned in each session and includes formal mindfulness practices (eg, sitting meditation, body scan meditation), informal mindfulness practices (eg, performing everyday activities mindfully), and CBT practices (writing a relapse prevention plan). MMB closely follows these concepts in the translation of MBCT to a Web-based platform.

MMB used a variety of Web-based learning modalities within 60-90 minute sessions (Figure 1). First, group leaders functioned as hosts, welcoming participants to each session and guiding them through didactic content and experiential practices. Second, a substantial portion of each session was allocated to practicing mindfulness meditation (Figure 2) and engaging in a reflective process, following the practice through targeted questions that participants respond to in writing (Figure 3). Third, in order to mirror the group process component of MBCT, videos of selected portions of an in-person MBCT group were provided (Figure 4). Examples of video topics included: challenging moments during meditation, making time to actually do the practices between sessions, and reflections on implementing new ways of reacting to stressful situations. Connection with the larger group of MMB users was facilitated by an "ask a question" function, allowing all participants to anonymously post questions that were answered by MMB developers (ZVS and SD) within one week. These questions and answers were compiled across time such that participants enrolled later in the study had the advantage of viewing more content. Fourth, interactive exercises were included in the program to facilitate experiential learning of key points relevant both to mindfulness mediation practice and CBT skills. Fifth, all participants had access to a master's level support person via phone or email (JNF), who contacted all participants within 48 hours of enrollment to introduce herself and orient them to the website and study procedures. Participants were provided with her phone number and email address and were encouraged to contact her with any questions, concerns, or challenges. Thereafter, some participants did not contact her again, while others reached out frequently via email or phone. She did not provide therapeutic intervention, but assisted with questions relating to log-in difficulties and troubleshooting both technical and situational barriers to program engagement. She also provided reminders to participants who did not log in for more than a week to help maintain engagement with the program and offer support if they were having trouble. Sixth, participants were provided with PDF and audio guides for home practice exercises, where they were asked to complete and record daily home practice using

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online logs. Participants were able to record several days at one time and if participants did not record home practice at least weekly, the support person provided phone or email reminders.

Figure 1. Mindful Mood Balance home page.

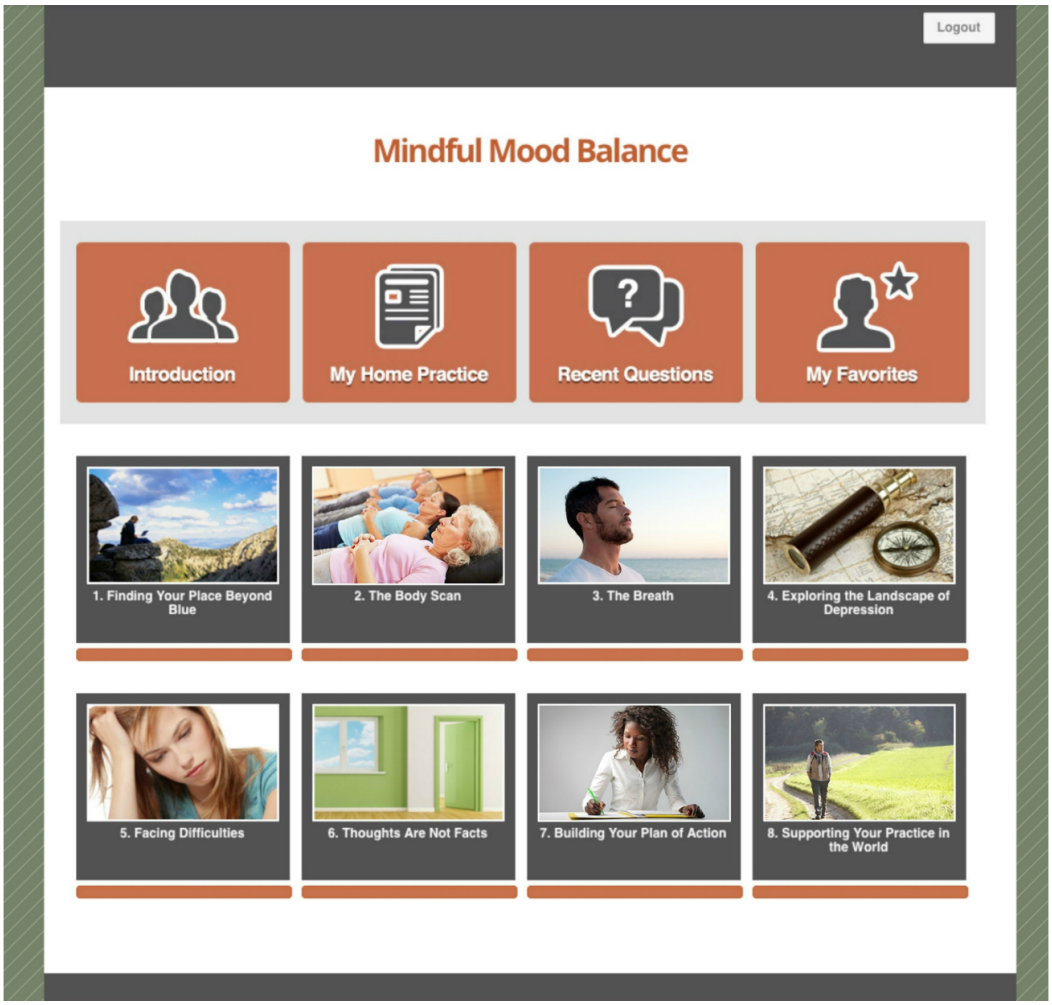

Figure 2. Three-minute coping breathing space completed during an MMB session with audio download available.

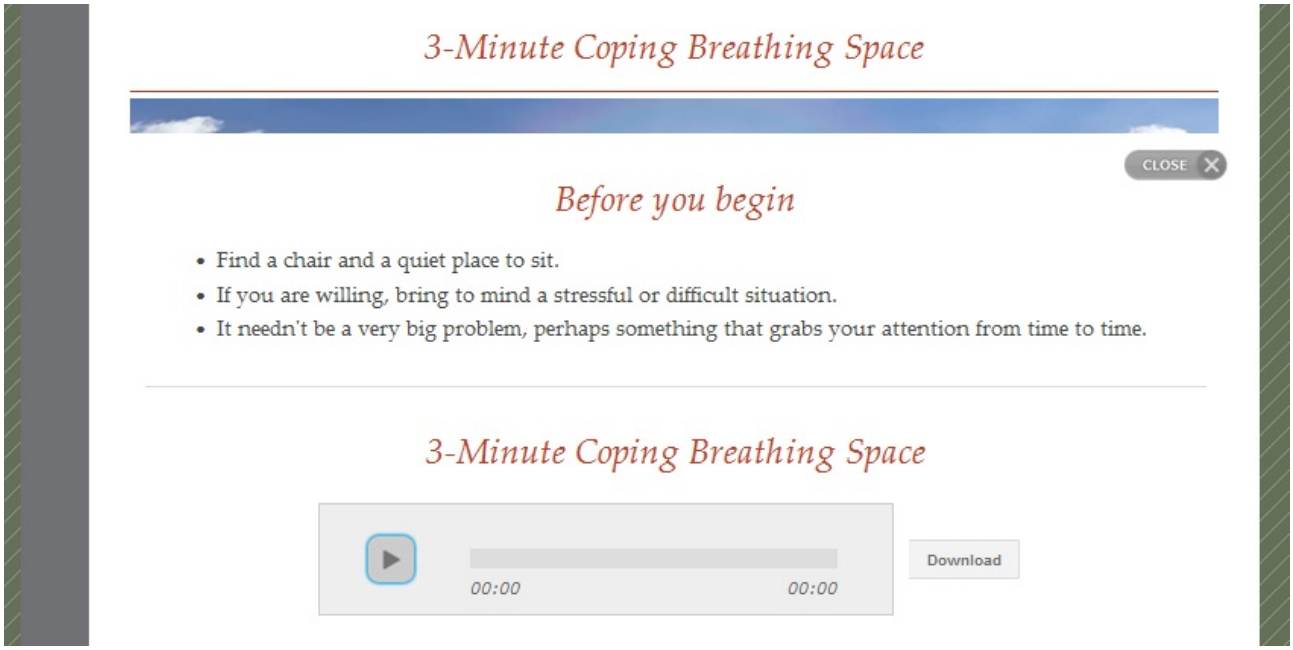

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Figure 3. Interactive exercises - Thoughts are not facts.

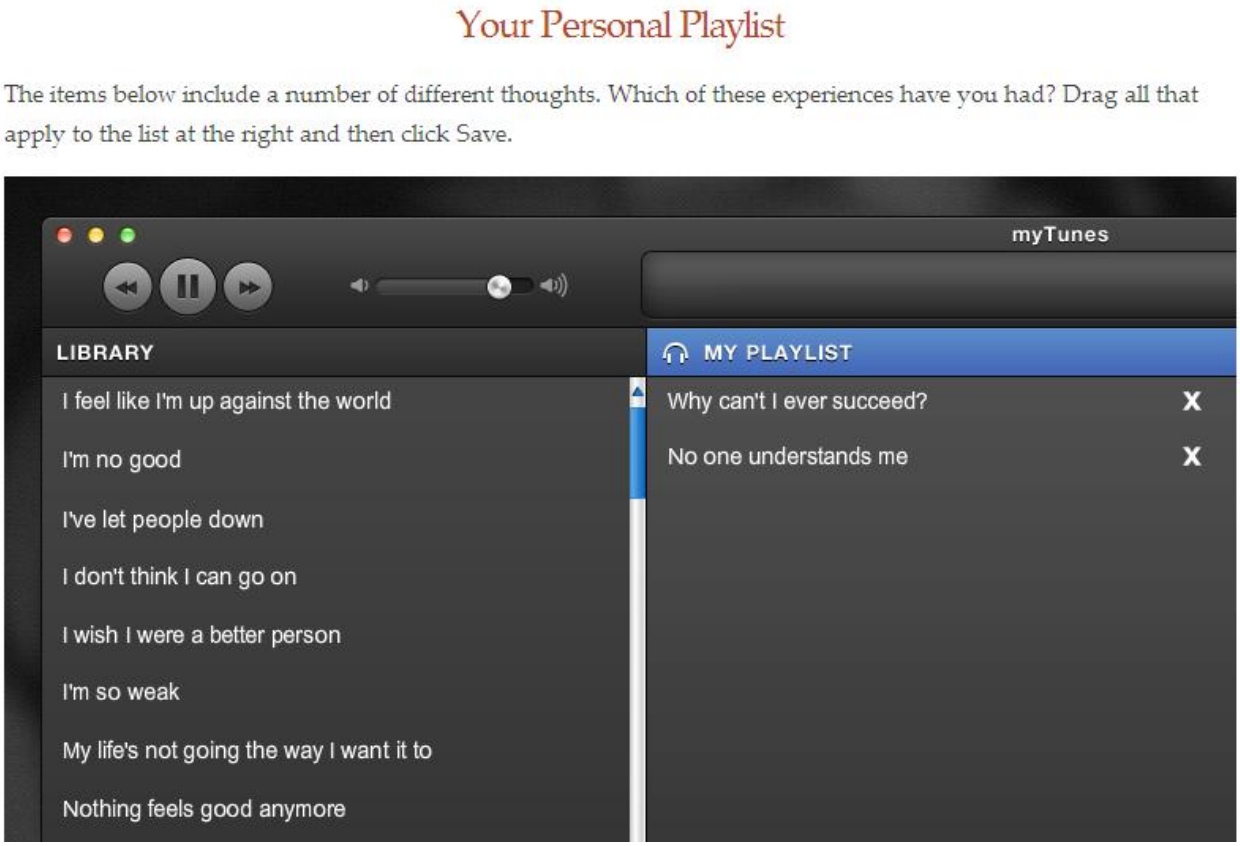
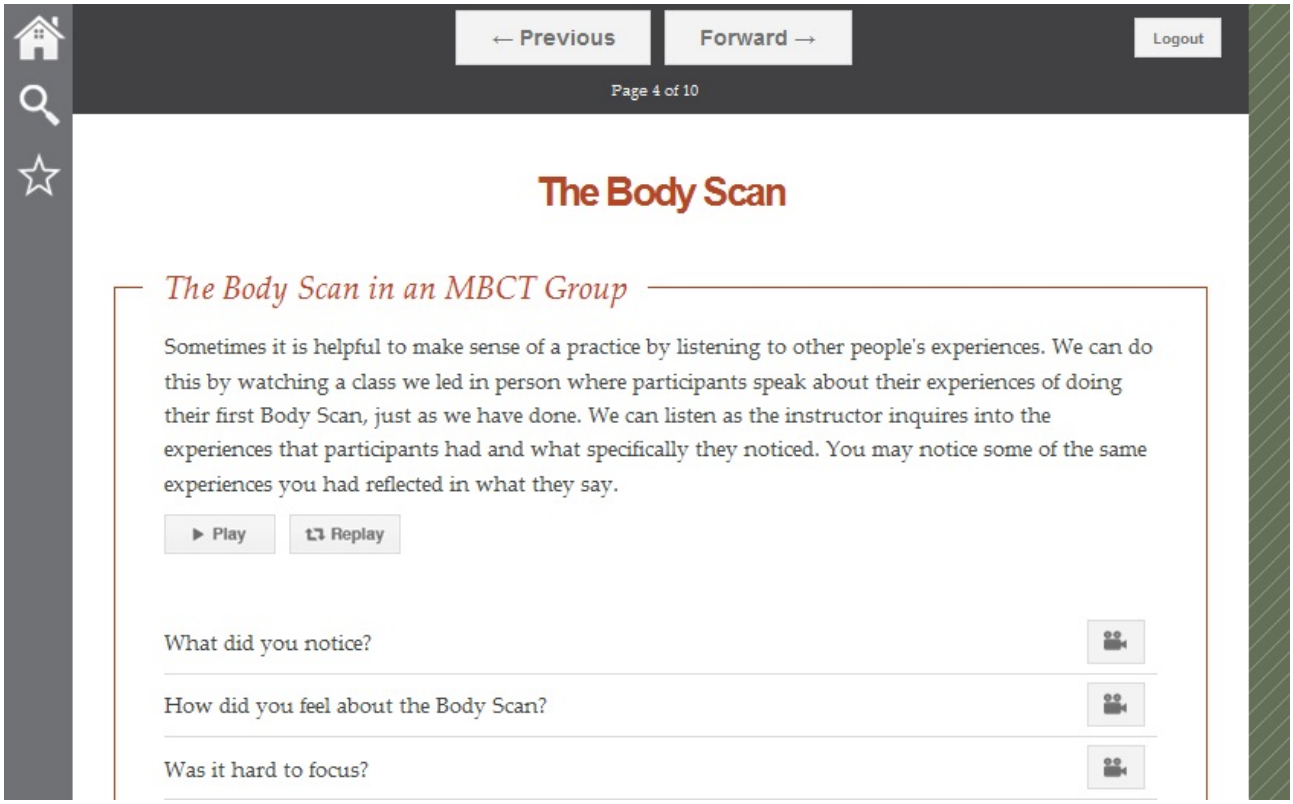


Figure 4. Video clips of MBCT group discussing the body scan and pertinent questions from community on this topic.



Participants

All participants were Kaiser Permanente Colorado members over age 18 who provided informed consent to participate in an open trial efficacy study of MMB (N=100). This qualitative study was embedded within a larger quantitative assessment of patient outcomes for the MMB program (quantitative results to be published elsewhere). Participants were recruited from

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primary care and behavioral health medical settings via an invitation letter, flyer posted in medical office, or referral from provider. We enrolled 100 participants in the Mindful Mood Balance open trial and exit interviews were conducted with 38 participants, 37 of whom completed all 8 MMB sessions. Characteristics of all 100 participants are presented in Table 1, comparing those who were and were not interviewed.

Table 1. Demographic and clinical characteristics (N=100).

Characteristic		Interviewed (n=38) mean (SD) or n (%)	Not interviewed (n=62) mean (SD) or n (%)
Age, mean (SD)		46.89 (12.38)	47.71(10.90)
Gender			
	Male	11 (28.9%)	16 (25.8%)
	Female	27 (71.1%)	46 (74.2%)
Race			
	Asian	1 (2.6%)	1 (1.6%)
	Black/African American	1 (2.6%)	3 (4.8%)
	White	34 (89.5%)	53 (85.5%)
	Other	2 (5.3%)	5 (8.1%)
Ethnicity			
	Hispanic or Latino	1 (2.6%)	5 (8.1%)
	Not Hispanic or Latino	37 (97.4%)	57 (91.9%)
Marital status			
	Single	4 (10.5%)	11 (17.7%)
	Married or living with significant other	28 (73.7%)	41 (66.2%)
	Separated/Divorced	6 (15.8%)	10 (16.1%)
Employment status			
	Unemployed, homemaker, or retired	6 (15.8%)	17 (27.4%)
	Full-time	22 (57.9%)	36 (58.1%)
	Part-time	8 (21.1%)	6 (9.7%)
	Student	2 (5.3%)	3 (4.8%)
No. of prior depressive episodes			
	One	1 (2.6%)	11 (17.7%)
	Two	11 (28.9%)	9 (14.5%)
	Three or more	26 (68.4%)	42 (67.7%)
Antidepressant use in last year		31 (82%)	54 (87.1%)
At least 1 psychotherapy visit in last year		14 (37%)	23 (37.1%)
Past psychiatric hospitalization (past 5 years)		4 (10.5%)	5 (8.1%)

Enrollment Criteria and Procedures

Inclusion criteria were: (1) English speaking, (2) access to the Internet, and (3) lifetime history of at least one major depressive episode, confirmed via Structured Clinical Diagnostic Interview (SCID) [23], and score of ≤12 on the PHQ-9 (Patient Health Questionnaire) [24]. The study was reviewed and approved by the Kaiser Permanente Institutional Review Boards (IRB) directly and by institutional agreement with the University of Toronto and the University of Colorado Boulder.

Qualitative Study Design

All participants in the MMB study were invited to participate in an exit interview upon completion of the 8-session MMB open trial or upon early termination. A master's level support person (JNF) conducted all interviews via telephone. Interviews averaged 35 minutes (ranging from 30-60 minutes). Consistent with grounded theory, an iterative process was used where the interviewer made notes after each interview, consulted periodically with the study team, and clarified key concepts in subsequent interviews.

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Interview questions focused on the following areas: components of the MMB website (animations, group videos, leader videos, text, reflection questions, etc); ways MMB facilitated or hindered their ability to complete home practice; organization, clarity, quality, and quantity of information provided; and skills learned, personal insights, or information from their experience in MMB (full interview guide is available in Multimedia Appendix 1).

Data Analysis

Interviews were de-identified, transcribed, and loaded into Atlas.ti (qualitative software analysis program) to assist with content analysis using both inductive and deductive approaches. The inductive approach applied several key concepts consistent with grounded theory including: first cycle coding, memo writing throughout data collection and analysis, categorization of codes into larger themes in order to develop a theory of the data presented, and explicitly defined saturation [25]. The first author (JMB) conducted content analysis with code review performed by CAM. Initially, all interviews were read and document summary memos were created for each transcript [26]. Thematic memos were created as themes emerged throughout summarizing and subsequent coding. The document and thematic memos were used to create a data driven code book. Next, a first cycle coding process was conducted using this code book. Throughout coding, new codes were added and clarification of code definitions was periodically performed with the members of the research team (JNF, ZVS, SD, AB) using peer debriefing sessions. These procedures yielded 54 codes with an average of 19.8 quotations per code (ranging from 5-61 quotations). Ten codes had less than 5 associated quotations and these were considered to not meet adequate saturation, due to their limited presence and lack of applicability to larger concepts under study here. A reliability check was conducted by CAM, who reviewed a sample of 5 quotations for each of the remaining 54 codes in order to evaluate the fit of each quotation to the code definition. Discrepancies of fit were discussed by CAM and JMB, some quotations were re-categorized into different codes or eliminated from the code book, and a few code definitions were re-worded to more accurately capture the quotations. When all coding was complete, the 54 process codes were organized into large categories [27]. The code book was created after extensive memo writing of the interview data, which resulted in thorough code definitions. This catalyzed the development of large categories and theories without the need for second cycle coding. Network modeling in Atlas.ti was used to create the large categories, which assists with building visual representations of code schemes. Categories included: participant feedback on MBCT Web-based content, participant feedback on MBCT Web-based group process, and participant feedback on home practice.

A separate analysis was undertaken for a code with the largest number of quotations (186) called “evidence of concept comprehension”. This analysis used evaluation coding or a priori code definitions from Allen et al (2009) who reported participant experiences with in-person MBCT using thematic analysis. The purpose of this evaluation coding was to assess the presence or absence of learned behaviors and strategies previously described for in-person MBCT groups.

Results

Evidence of Concept Comprehension

The “evidence of concept comprehension” theme captured participants’ descriptions of the key concepts of MBCT and is based on 186 quotations coded in response to questions about skills and insights learned from the program.

Nearly every participant mentioned the impact of newly learned activities and tools on managing distressing thoughts and feelings associated with symptoms of depression. Many participants reported positive impacts of completing some form of daily mindfulness practice including: increased awareness of rushing through life on “autopilot” and recognition of the benefit of “slowing down”, reducing stress and anxious feelings, re-framing negative thoughts about activities they do not enjoy such as “doing diapers”, and increased awareness of emotions and their impact on behavior as shown here, “I think looking at patterns of thinking, black and white thinking and catastrophizing—to catch myself on those, rather than just reacting.” One participant described the experience of doing the home practice as follows:

> *A little tricky at first because it’s hard to slow things down. I was very impatient in the beginning, like, when is this going to be over? I’m not sure why, but the further I got into it, the more I started to realize it is not about rushing through, it’s more about helping me not be on autopilot anymore.*

Many participants found that applying the combination of mindfulness meditation and CBT skills increased their sense of control and confidence in preventing the return of future depressive symptoms. Some participants expressed an intention to use the tools regularly as a prevention strategy, even in the absence of any signs of depression, and others indicated they would apply these tools when they felt the “creeping signs of depression”. Related to this was “knowing my triggers”, which was characterized by increased awareness and recognition of thoughts, emotions, or behaviors that signal relapse. Participants reported that mindfulness meditation practices taught them to “stay focused on the present moment”, and as described by one participant, helped to recognize early warning signs: “I always think I’m over it and then it sneaks up on me. I think this—staying focused on the present moment—would help me recognize sooner what was going on.”

The CBT portion of the program and its emphasis on teaching “thoughts are not facts” was often mentioned in regard to observing, questioning, and objectifying depressive thoughts and emotions (ie, viewing these thoughts and emotions as characteristics of depression, not as representative of the self or “truth”), thereby reducing their impact. One participant expressed the concept of “thoughts are not facts” this way:

> *One of my triggers or clues that I’m going to possibly start having problems is having images of horrible things happening—that’s always been one of my big things—thoughts that come out of nowhere, and so*

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> *because of that I'm able to say, 'That's not real. That's a thought.' And that's been really helpful, rather than, 'Why am I thinking that!' So it's sort of just accepting it and moving on.*

Some participants reported changing their focus from negative to positive during the MMB program by engaging in such positive activities as exercise, enjoying the outdoors, socializing, being more self-compassionate, or focusing daily on a positive experience. The positive impact of the MMB experience is described below:

> *I think it gives me a sort of foundation of experience and after committing to it and doing my best with it, I can remember back—I was a happier more grounded person when I was doing that (MMB). So I always know there's a tool that I can use to make life a little more enjoyable.*

Participant Feedback on MBCT Web-Based Content

Almost all participants thought that the text was clear and concise and that it conveyed key concepts effectively. Approximately half the participants chose to have the text on webpages read aloud and even those who did not use this audio feature believed that having this option was important. The audio to text option created a different way of interacting with the Web-based program that is described well by this participant:

> *I thought that [audio to text] was very helpful. By the end, I was choosing to do that instead of reading. I found that listening probably put the emphasis on the words in places it was meant to be rather than my interpretation of the words. Perhaps they didn't always match. I'm a really literal person, so sometimes I lose things. It was a deeper understanding for me to listen to it. And if there was something I missed or didn't think I understood, I could go back and read it, but I think having both is useful.*

The videos of the group leaders speaking as hosts of the program for participants were received very positively and some participants believed this was a good alternative to written text for conveying information, although some preferred to read text. The videos included motivational content about accepting and being gentle with oneself in the learning process and also addressed common challenges associated with learning to practice mindfulness meditation. Specific topics included self-criticism, impatience, or feelings of inadequacy and guilt. Some participants expressed neutral responses to the group leader videos, commenting that they were "fine" or "good" or "just transitional". Others found more value in the videos and reported that the group leaders were highly qualified and trustworthy. "I could tell they were both very empathic and very invested and believed in it. They felt very authentic and felt like they were really practitioners. I liked both of them a lot."

Participants strongly supported the PDF worksheet downloads for home practice and the MP3 audio downloads of meditation practices. Several commented that this provided them with specific tools to retain after the program ended that could support ongoing practice. "I think having downloaded some of the PDFs will be a good resource too, so if I feel I might be heading toward a relapse, I will have something active to do." Others felt the printed PDF increased accountability by providing a daily reminder. Some downloaded the MP3 files to their smartphone, so they could access the meditation practices at any time. There were suggestions for improvements to the PDFs and downloads including availability on iTunes, smartphones, integrated calendar reminders, adding visuals to the worksheets, and a "take-home kit" or list of all PDFs and MP3s in one place at the end of the program (in addition to weekly sessions).

Interactive exercises and animations were included to convey key concepts and metaphors, such as watching thoughts as if they were "leaves" floating down a river. Interactive exercises included developing a "playlist" of negative automatic thoughts that individuals frequently struggled with when depressed. Most people reported that they did not remember the animations during the exit interviews or find these to be especially powerful as a learning device. When reminded of examples, some still had trouble recalling them and comments were mostly neutral (eg, "they were fine") or negative (eg, "superfluous").

Participant Feedback on Web-Based MBCT Group Process

Converting an in-person group program to a Web-based format, where the experience is inherently individual, presents an interesting challenge. Benefits of the Web-based format were noted as: the flexibility of completing weekly sessions on one's own schedule, the ability to temporarily pause the sequence of sessions for travel and other reasons, freedom from pressure to drive to classes or find child care, and feeling less self-conscious doing the program from home.

Participants identified live interactivity as a key difference between these two formats. For a number of participants who had previously participated in a mindfulness group, the Web-based approach lacked some advantages of the in-person format. Chief among these were the absence of an instructor and the opportunity to learn together as a group. "It really wasn't as satisfying as an in-person group, like questions on this sort of thing aren't normally linear, but you fumble along and the leader answers and there is back and forth."

The embedded videos of an in-person group, a central feature of MMB, were well received and participants indicated that they felt a connection to the group members. Participants appreciated that the same group was featured in every session, so that they got to know the individuals and develop a sense of belonging. A key advantage identified from the group videos was the knowledge that they were not the only ones who found the material and mindfulness practices challenging. "What I liked about them (the group videos) is that I went through the exercises and if I wasn't sure what it meant or what I felt about it, I watched the group and it made more sense." Others indicated that the group members' adaptations of home practice to fit with the demands of their lives provided important insights. Not all reactions to the group videos, however, were positive. Some participants thought that there were too many videos, that it took too long to watch all of them, and that they should watch every single clip. However, others were more flexible and were

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selective in watching only those videos that were relevant to their experience. Additionally, a small subset of participants indicated they were not "group learners" and did not find the group videos to be an important aspect of their learning. One participant commented, "If I ever needed counseling or therapy of some sort, the last thing I would do is go to a group." Another expressed, "I really didn't watch a lot of them…I tend to look at my depression as more of an individual situation. I just could not relate to them and what they were doing and what they were feeling."

When asked about ways to improve MMB, many participants described the desire for actual interaction with other MMB participants or a therapist. "I think this would be a lot better if there was a Web-based group…I felt alone out here. I would have been engaged more." Some described needing more support as they went through the program, "I needed my hand held a little more." Others described a desire for feedback from a professional therapist in person and some suggested professional feedback could be provided to reflection question inputs. Some saw the "Ask a Question" function as a good way to have some interaction beyond the website and enjoyed posting or just reading materials in this section posted by other users. Suggestions were provided for adding a community component such as: Web-based message boards with other users, hold a few in person meetings (although the logistical scheduling barriers to this approach were recognized), or create opportunities for telephone and/or video chat meetings.

Interestingly, all participants saw the value of having a support person available who was only a phone call or email away. Some participants mentioned more frequent interactions with the support person and even those who did not use the support reported that it was an important asset of the program. The benefit of reminders and follow-up contacts also was mentioned: "I think it's nice to have someone available, whether someone wants it or not. It was nice that you were like, 'you haven't logged on in a while'…it's hard to stay on track."

Participant Feedback on Home Practice

Participants described distinct preferences regarding the home practice component of MMB. While there was broad endorsement of the 3-minute Breathing Space, reactions to the Body Scan was more mixed. Positive responses noted that it was an effective relaxation technique, particularly for helping to "wind down" at the end of the day, whereas others reported that they felt uncomfortable with it.

Overall, there was a very well-saturated theme of time and commitment challenges for home practice. Most preferred the shorter practices for several reasons, including: scheduling time, attention or focus drifting with longer practices, impatience or trouble slowing down the mind or sitting still, or difficulty finding time alone for practice. One suggestion to address home practice challenges was a slower "ramp-up" to the longer practices. For example, it was suggested that the program should start with a 15-minute meditation, not a 30-minute meditation. However, some participants reported that they preferred the longer practices because they allowed time for the mind to slow down and focus. Additionally, some believed that the expectation for time commitment was unreasonable and felt guilty or resentful that they could not meet it. For example, in response to a question about her experience with home practice, this participant describes the self-criticism she experienced as well as some benefit from the practice: "[I felt] a little critical of self, felt like I couldn't do it all, and it was my fault somehow, and this is too much to ask with your daily life, and resentful. But I tried my best to do it all, gave it a pretty good effort, and got stuff out of it."

Others saw the value in completing the home practice and understood that the time investment is important to learn a new skill. The balance of positive and negative feedback was articulated by one participant:

> *It was difficult in that you had to carve out the time really consistently, but it was also really valuable. I don't think the program would be as effective if you weren't being asked to do it daily. What I understand is you're trying to develop a habit. My only suggestion would be to give the option to do 15-20 minute practices and stress that any time they can do the 30 minutes, they should.*

Discussion

Evidence of Concept Comprehension: Comparison to In-Person Delivery

We found a high degree of endorsement in the evaluation coding for themes previously identified by others describing learned behaviors and strategies associated with in-person delivery of MBCT [21,22]. Specifically, we found participants had increased awareness for personal warning signs of impending relapse and that they utilized meditation practices and/or cognitive behavioral strategies like "thoughts are not facts" to counteract these symptoms. We also observed that some participants used the meditation practices regularly to assist them daily with residual depressive symptoms. Furthermore, we observed that participants felt an increased sense of personal agency to handle depression and also reported increased engagement in positive activities. Contrary to prior work, we found little evidence of themes indicating improved relationships, increased self-value, or decreased feelings of isolation. One explanation for this might be the absence of synchronous group interaction in MMB compared to in-person delivery.

While MMB attempts to provide an experiential learning experience through videos of an in-person group presented in each session, it is to be expected that there will be some loss of the interpersonal learning dynamic in a Web-based program. It is possible that enhancing Web-based opportunities to engage with other MMB learners may improve the saturation of interpersonal learning in this program. The addition of a community of participants learning MMB, either synchronously or asynchronously, may help foster skills relevant to valuing self, feeling closeness with others, and it may also help participants feel less isolated.

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Enhancing the Support Function and Re-Purposing Content for Delivery Online

A noted limitation of the Web-based program was the loss of direct contact with instructors compared to in-person groups and the reduced accountability for completing sessions and home practice. These are important issues to address for any Web-based program [28], but especially so for MMB, as the likelihood of clinical benefits are linked to the frequency of practice [29]. Although we were unable to collect non-completer exit interviews, we know that the most frequently cited reasons for dropout were time/scheduling issues. It will be important to enhance and clarify MMB's messaging at the outset, regarding time expectations for session and home practice completion in order to improve participant satisfaction and increase retention. Participants offered a number of constructive suggestions for addressing this concern: a slower ramp-up each week of the time commitment for home practice exercises, options for short or long home practice exercises each week, addition of a community function with other users or a therapist to maintain engagement, keeping the live support person, better integration of program content with personal technologies (calendar reminders, iTunes accessibility, ability to view MMB on iPad or smartphone), and outlining expectations for degree of session participation (eg, you don't have to watch every video).

Considering that participants perceived a lack of support, it is not surprising that there were suggestions to curtail the frequency or duration of home practice—something reported in traditional MBCT groups as well. Prior studies of Web-based interventions suggest that reminders and administrative or therapist support are associated with higher retention rates and satisfaction with Web-based depression treatments as compared to unsupported delivery formats [15,16,30]. There was strong endorsement for the live administrative support and reminders in MMB. While participants were informed of the home practice time commitment during the consent process, perhaps there is a misconception that an online program implies a lesser time commitment. It will be important for future iterations of MMB to refine the support function, potentially by adding an online community, and also to clarify the importance and expectations for home practice at the outset. Other Web-based depression treatment programs have offered therapist support, although the use of professional therapists may be cost prohibitive when planning for more widespread dissemination of these programs [13,14].

Balancing Flexibility and Fidelity

Our results indicated differing and sometimes contradictory preferences, such as the desire by some for increased group interaction versus a lack of interest in the group dynamic. Other differences were a matter of preference, such as reading text to understand the content versus listening to audio or watching a video. These differences highlight the importance of offering flexibility in order to appeal to a large audience of users, while still holding true to the MBCT model. The experiences of the "non-group learners" merit consideration as they demonstrate that completing MBCT online could be different, but still potentially beneficial. Other issues of fidelity include balancing participants' desire to reduce the amount of home meditation practice, in light of the empirical support for a link between degree of home practice and improved clinical outcomes [29]. These are but two of a number of issues that are likely to arise when adapting the online version of MBCT to a wider and more diverse population.

Integration With Personal and Mobile Technologies

The PDF downloads of home practice exercises and MP3 downloads of meditation practices were among the most popular features of MMB. Enhancements of these features were suggested including a compilation of downloads so participants would have a tangible take-home tool kit as a reference in case they sensed depression returning in the future. Additionally, participants wanted better integration with their iTunes accounts for MP3 meditation practice downloads, integrated calendar reminders, and also suggested access to the entire program from smartphones or iPads.

The strong desire to have an organized home tool kit and more seamless integration with current personal use technologies illustrates participants' preferences for continued support structures that would help to sustain recovery. Specifically, participants desired better integration of program content with daily habits to promote mindfulness practice after program completion. This feedback is valuable for future website modifications to MMB and may also be pertinent to others developing online psychological treatments.

Limitations

This qualitative investigation has several limitations that should be considered. Although we sought feedback from both completers and non-completers, we were successful only in gaining one interview from a non-completer. Therefore, the feedback presented represents a population of engaged participants; non-completers may have expressed more negative reactions to MMB, which are not represented here. Additionally, interviews were collected shortly after program completion and, therefore, we do not know if the concepts discussed would reflect participants' appraisals of MMB and their use of learned skills over a longer time period. Our sample was relatively homogenous with regard to race and ethnicity and it included a number of individuals with prior experiences and interest in mindfulness practices. This may limit the generalizability of the viewpoints expressed to more diverse populations. The potential for subjective bias was possible with one primary coder (JMB) who was closely involved in project management and recruitment for the MMB trial; however, the coding review by CAM provided alternative perspectives that were included in the final code book. It is also possible that social desirability biased some responses given that the research assistant (JF) who conducted the interviews was associated with the MMB program through her role as the administrative support member; however, it is possible that her relationship with participants and familiarity with the MMB program facilitated more detailed disclosure. Since this is the first evaluation of online provision of MBCT, our findings should be considered tentative until qualitative analyses of new cohorts are available.

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Conclusions

The current study describes participant experiences with MMB, including challenges, positive elements, and suggestions for programmatic changes to increase engagement and effectiveness. Some of the feedback presented here may inform future studies with similar types of Web-based depression intervention programs, particularly the need to define participation expectations, include options for different levels of time commitment and to respond to desires for increased group support and integration with personal use devices. The close alignment between participants' reports of skills learned in MMB and those that are central to the in-person MBCT program also may provide encouragement for the translation of other in-person psychological treatments to a Web-based platform. As identified here, balancing fidelity to the traditional MBCT model with participants' desire for flexible modes of learning will need to be carefully negotiated. We foresee this challenge as vital for any future studies in this area. As a brief Web-based program, MMB may offer a scalable, cost-effective alternative to in-person MBCT that may be effective in reducing residual depressive symptoms and preventing depressive relapse.

Acknowledgments

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Conflicts of Interest

Mindful Mood Balance is being developed for commercialization by MindfulNoggin as a therapist training tool. While at the time of publication no formal agreements are in place, ZS and SD may receive royalties or other compensation in the future.

Multimedia Appendix 1

Interview guide.

[PDF File (Adobe PDF File), 10KB - jmir_v16i3e87_app1.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
MBCT: mindfulness-based cognitive therapy
MMB: Mindful Mood Balance
PHQ-9: Patient Health Questionnaire

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Original Paper

Acceptability of Online Self-Help to People With Depression: Users' Views of MoodGYM Versus Informational Websites

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Abstract

Background: Little is known about the factors that influence acceptability of and adherence to online psychological interventions. Evidence is needed to guide further development of promising programs.

Objective: Our goal was to investigate users' views of two online approaches to self-help for depression: computerized cognitive behavior therapy (cCBT) and informational websites, in a workplace context. Computerized CBT offers an inexpensive and accessible alternative to face-to-face therapy, and employers have an interest in reducing the working time lost to depression or stress. Yet little is known about how employees, who have actual experience of using online approaches, judge the intervention as a process.

Methods: The qualitative data reported here were collected within an online randomized controlled trial whose participants had diagnosable depression. The experimental intervention was a 5-week cCBT program called MoodGYM, and the control condition was five informational websites about mental health. Data were collected via online questionnaires. There was no evidence of the superiority of either in terms of treatment outcomes. In parallel, using brief rating scales and open-ended questions designed for this purpose, we examined the relative acceptability of each approach over time, including perceptions of cCBT compared to seeing a health care professional.

Results: At least 60% of participants held online therapy to be at least as acceptable as seeing a professional about mental health issues, and they were more likely to retain this opinion over time if they used the interactive program, MoodGYM, rather than informational websites alone. Barriers to cCBT use fell into four categories: intrinsic, intrapersonal problems; extrinsic technical problems; generic issues mostly pertaining to perceptions of cCBT; and specific issues about the intervention or control condition. These indicate strategies for improving engagement.

Conclusions: As first-aid for mild to moderate mental health problems, evidence-based computerized approaches have broad acceptability. This could be increased by attending to the barriers noted here and by proactively managing users' expectations at individual and organizational levels. The findings have implications for occupational health providers and others addressing the needs of working-age adults with depression. They also raise methodological issues for online research.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 24529487; http://www.controlled-trials.com/ISRCTN24529487 (Archived by Webcite at http://www.webcitation.org/6O8cCL4mh).

(J Med Internet Res 2014;16(3):e90) doi:10.2196/jmir.2871

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KEYWORDS

computers, cognitive therapy; method acceptability; depression; workplace; qualitative evaluation

Introduction

The demand for cognitive behavioral therapy (CBT) is such that the supply of therapists for face-to-face counseling is insufficient. Thus, the attraction of computerized approaches lies in low cost, ease of access, broad acceptability [1], and the possibility that online provision is relatively free of the stigma attached to formal mental health services and their users [2]. The evidence for effectiveness is growing rapidly in relation to a handful of interventions designed to address common mental disorders [3-6]. This demand is driven partly by employers' awareness of the impact on productivity of depression in the workplace [7].

Maxwell proposed six indicators of service quality: acceptability, efficacy, safety, equity, efficiency, and accessibility. Acceptability was defined as responses to the following questions: What do service users think of a service? How would they feel if the service was the most costly? Are there any issues of privacy or confidentiality? [8] As Kaltenthaler et al assert, the acceptability of an intervention is crucial to appraising its effect. If trial participants are reluctant to engage fully with an intervention, or if they drop out in disproportionate numbers, the internal or external validity of the results may be compromised [4]. Acceptability is also vital to the implementation of evidence-based treatment in practice, since low take-up will impair efficacy. People with depression may face particular difficulty in complying with treatment due to their low mood [9]. Contextual factors, subjective beliefs, and technical problems may also affect engagement with an intervention [10]. Therefore, in evaluating novel approaches, explicit questions need to be asked about user expectations, experience, and satisfaction: this is what is meant by acceptability. While it is crucial to understand the underlying reasons for (un)acceptability of computerized treatments of depression, there is still limited information in this regard.

The aim of this paper is to examine the acceptability of one form of computerized cognitive behavioral therapy (cCBT)—online self-help for depression—in the context of a workplace trial where the data were largely collected online. It reports on a study that explored two different dimensions: acceptability (data presented here), and effectiveness of computerized treatments (data presented by Phillips et al, 2013) [11]. One problem with online data collection is retaining subjects in the trial; the present study is no exception, with a relatively high dropout rate (45% at 6 weeks). However, those people who completed are a group whose opinions may suggest improvements, both to the interventions tested and to the method of data collection.

MoodGYM was chosen for this study because it is freely available on the Internet [12]. Its website describes MoodGYM as "A free self-help program to teach cognitive behavior therapy skills to people vulnerable to depression and anxiety". There is evidence of effectiveness from a community-based trial, in which users were supported by weekly phone calls [13,14]. In that study, 79% completed the intervention. Although the dropout was greater from MoodGYM than from the control group, the effect of MoodGYM endured longer than the other intervention, self-help. One recent UK study indicates that MoodGYM is effective in promoting general mental well-being in a non-clinical population [15].

This paper addresses the participants' views about the process of online interventions, in order to guide the design of future developments and their evaluation. The present study indicated that both the participants who received the interactive online intervention and those who received passive information provision improved equally over time. Although the interactive online self-help did not display superior effectiveness, the two approaches may still differ in terms of acceptability. In any case, it is important to explore acceptability of computer methods in comparison with face-to-face interventions. Considering the large numbers of people affected by common mental health problems, online self-help, in either interactive or passive forms, may be one means to reduce the demand for face-to-face therapy and cut costs.

Methods

Overview

A workplace setting was chosen because of the prevalence and impact on productivity of mild to moderate depression [16] and early evidence of the benefits of cCBT [4,5,13]. A phase III, two-arm, parallel randomized controlled trial (RCT) whose main outcome was total score on the Work and Social Adjustment Scale (WSAS) was implemented using an online questionnaire. A list was produced by the Nottingham Clinical Trials Unit to allow simple (unrestricted) randomization. Statistical analysis shows improvement in both arms but no difference between the experimental and attentional control groups [11]. Acceptability of the intervention was investigated qualitatively by incorporating five Likert-style questions, an open-ended question about likes and dislikes, and four comparative questions designed for the study and described below.

Ethical approval was granted by Australia National University ethics committee and a favorable opinion was given by the Derby local research ethics committee.

Recruitment

The study was promoted in three large UK employers: two private enterprises (telecommunications and transport) and one public sector employer (health) between September 2009 and May 2011. The first employer to join the trial actively promoted the opportunity to staff through internal communications and ultimately recruited 396 participants. The second provided it mainly but not exclusively through their occupational health department personnel, who identified people likely to qualify for it and recruited 100. The third employer had a hands-off approach, simply publicizing it on an intranet, and recruited 141 participants. The numbers do not reflect the effectiveness

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of the different approaches to recruitment because the workforces also differed in size. Assurances were given that participation was voluntary and that the study was independent of the employers, so that respondents' identities and data would be confidential.

Inclusion Criteria

Online screening of potential participants offered the option of joining the trial if they were over age 18 and met the following criterion of likely depression: on Patient Health Questionnaire-9 (PHQ-9) [17], the employee scored 2 or more on 5 of the 9 items, including 2 or more on item 1 (little interest in doing things) or item 2 (feeling hopeless). To be eligible, the employee also had to confirm that at least one of the items identified as a problem for them made it difficult to work, take care of things at home, or get along with other people. People who did not meet the PHQ threshold, or whose functioning at work or home was not impaired, or who were unwilling to give consent and be contacted by telephone were excluded from the trial.

Procedures

Participants in both the MoodGYM and the control groups received six weekly telephone calls from clinical studies officers (CSOs) of the UK Mental Health Research Network, to screen for risk of self-harm, deal with technical problems, and gather data about service use (not presented here). Participants input the rest of their own data through a research portal, which in effect screened them for eligibility, took consent, delivered the interventions, and administered baseline and follow-up measures. Participants were kept "blind" to their status as intervention or control group members, by referring to the trial's focus as "self-help for stress", which describes both conditions.

The MoodGYM intervention is a modularized course developed at Australia National University. It is designed to last 5 weeks with assessments in the sixth week, although participants proceed at their own pace. The websites selected for the "attentional control" group were judged to be reliable sources of information about mental health problems. They were known to the chief investigator from a previous review of self-help in mental health, had been identified for teaching purposes as suitable materials to inform UK health and social care professionals, and included the British Broadcasting Corporation (the BBC), National Health Service (NHS) Direct, and Royal College of Psychiatrists information pages. A different website was recommended each week by automated emails. Sample screenshots of the intervention and control group are presented in Figures 1 and 2.

Figure 1. Example page from experimental website.

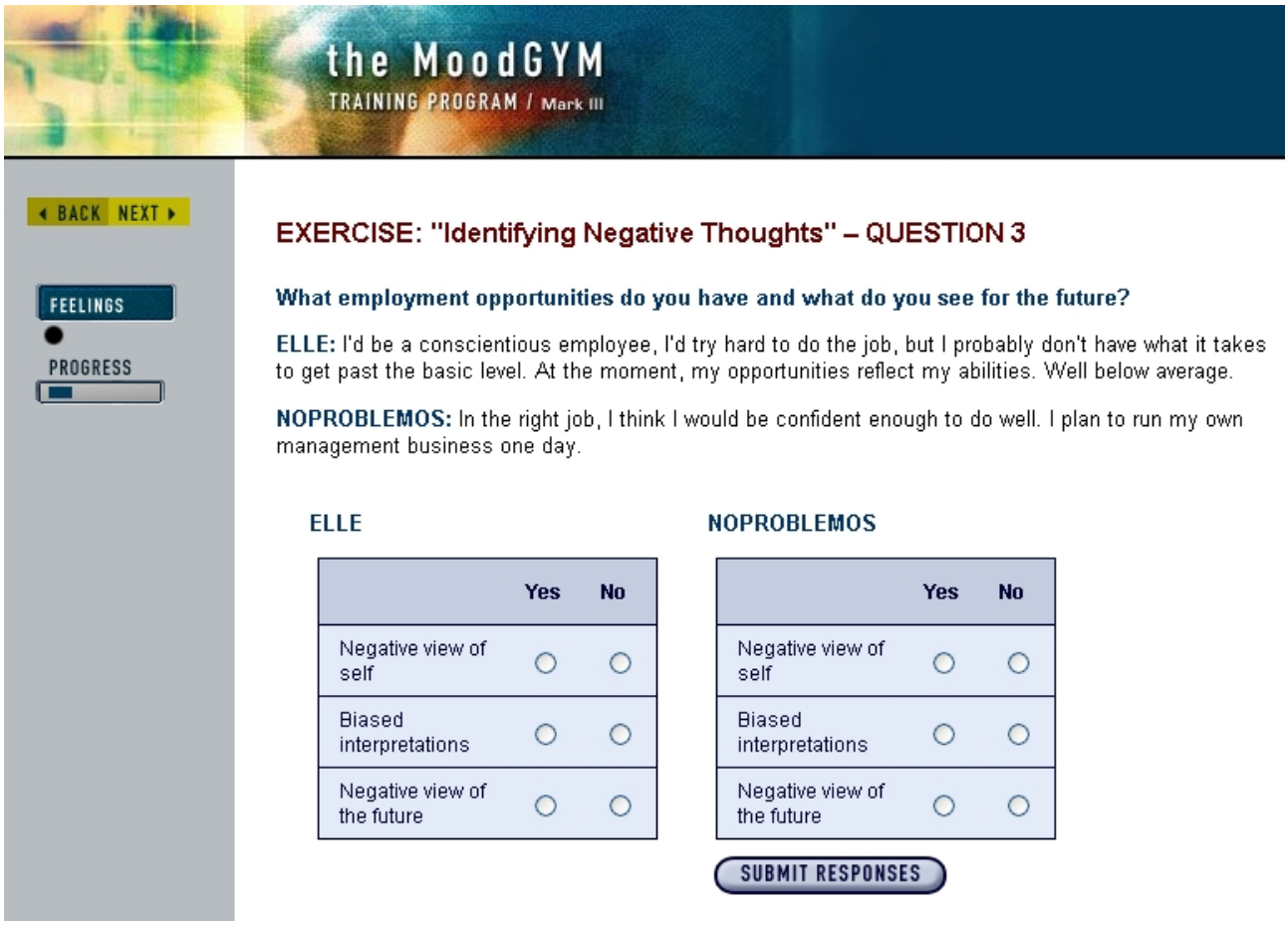

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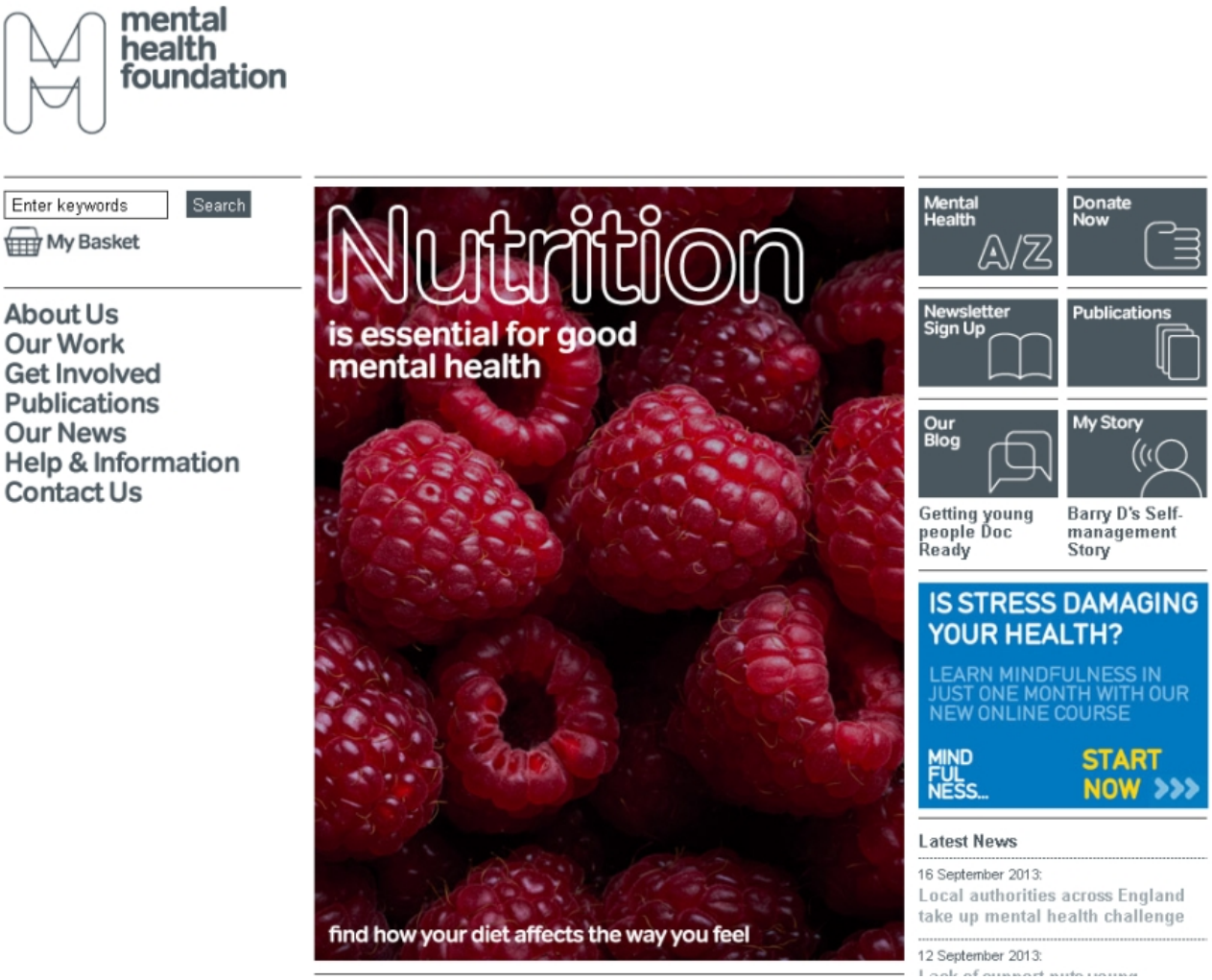
Figure 2. Example page from one control-arm website.



Measures of Acceptability

"Acceptability" is used here to convey the users' appraisal of online self-help. Lacking much prior work in this area and bearing in mind the self-selected nature of the sample, we explored three perspectives on what we broadly call acceptability using questions devised by the study team. These three tools were piloted along with the rest of our instruments. First, participants were asked in the online questionnaire to judge the importance of five statements that might be taken to reflect aspects of acceptability (not important, important, very important). They were also given an open-ended statement that invited further comments on reasons to like or dislike help via the Internet. Finally, we sought to investigate the relative acceptability of online self-help by asking participants to compare it with their perceptions of personal consultations with a range of health care professionals: general practitioner (GP), counselor, psychologist, and psychiatrist (see Figure 3). We did not ask whether respondents had prior experience of such services for their mental health.

In our analysis, in order to differentiate between anticipated or imagined preferences and actual impressions of the online approaches, baseline results were taken to reflect users' *expectations* of the process, as compared to 6- and 12-week results, when people reported their actual *experiences* of using the online resources.

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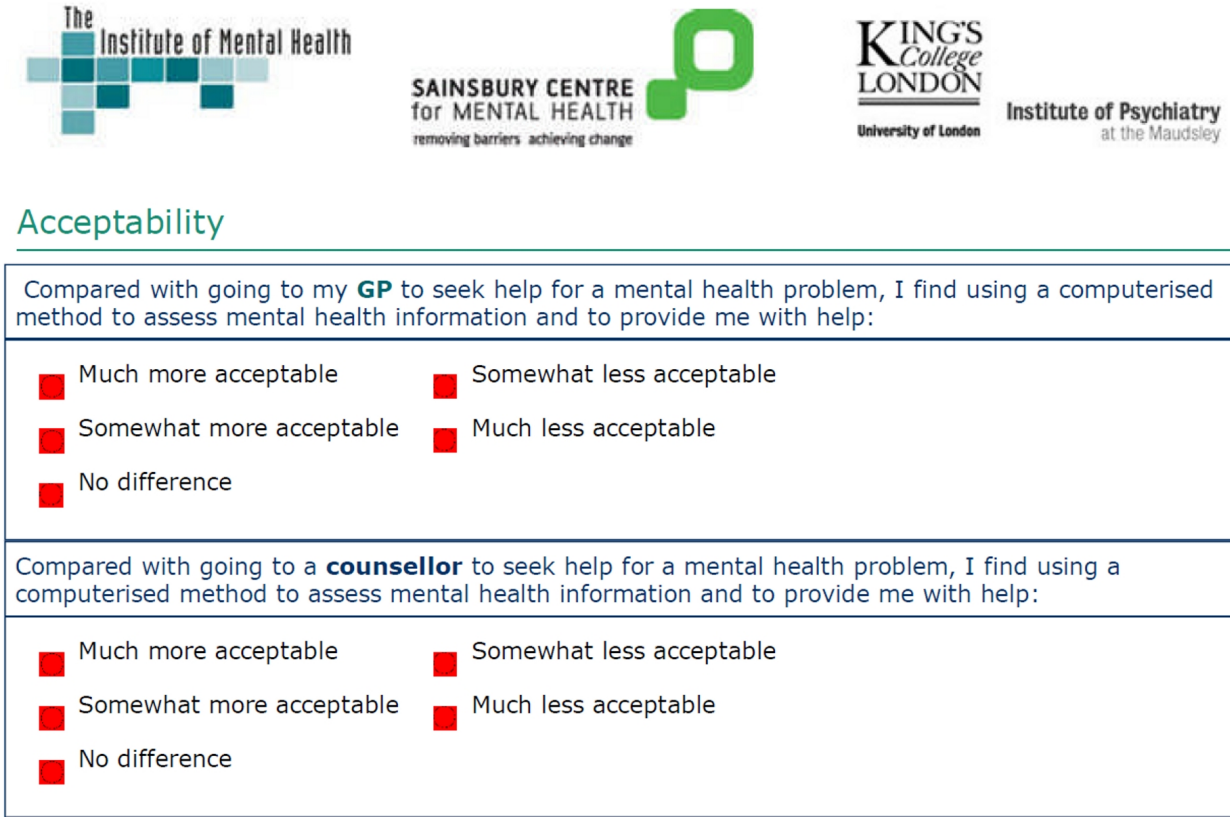
Figure 3. Questionnaire screenshot.



Quantitative Analysis

Agreement with structured statements about acceptability and comparisons with professional help were analyzed using descriptive statistics. Change in individual ratings over time was explored using paired *t* tests. *T* tests of independent means were used order to investigate (1) differences between intervention and control groups and (2) differences between those people who started out with positive or negative expectations of the online approach. Probability of completing the structured questions about acceptability at 6 and 12 weeks was investigated by study arm using chi-square tests.

Qualitative Analysis

Responses to open-ended questions were imported into MS Excel, sorted, and coded using a grounded theory approach [18]. The categories were not pre-set but evolved from the data, which were iteratively reviewed and reclassified to reduce the findings to concise, meaningful, and mutually exclusive topics. Once categories emerged in this way, the respondents' comments were allocated and counted. In some categories, they were also coded as broadly negative, positive, or neither.

Results

Summary

There were 9305 visits to the website: 1715 went on to give informed consent and complete the screening for eligibility, 1111 were eligible because of their level of depression, and 637 complied with the requirements to proceed, which included giving a contact telephone number and completing the baseline questionnaire. Of these participants in the trial, 56% (359/637) responded to the structured questions 6 weeks later and 36% (231/637) responded to them at 12 weeks. See Multimedia Appendix 1 for a flow diagram.

Sample Profile

The study sample is described in Table 1. There were no major differences; subjects had similar mean age, years in school, occupations, and levels of alcohol consumption compared across both arms. More males were randomized to control than MoodGYM (50.2%, 160/319 vs 42.8%, 136/318), and more females were randomized to MoodGYM than control (55.3%, 176/318 vs 47.6%, 152/319). More single people were randomized to control than MoodGYM (25.7%, 82/319 vs 21.1%, 67/318), and more of the married/cohabiting group were randomized to MoodGYM than control (68.5%, 218/318 to 61.4%, 196/319). Comparison with workforce profiles of the employing organizations confirmed that the opportunistic approach to recruitment to the trial resulted in a sample that was not representative of the wider workforces. The major discrepancy is that people who do not work in offices are underrepresented.

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Table 1. Characteristics of subjects according to trial allocation.

Characteristics		Control (n=319)		MoodGYM (n=318)	
		n	%	n	%
Gender					
	Male	160	50.2%	136	42.8%
	Female	152	47.6%	176	55.3%
	Missing	7	2.2%	6	1.9%
Age in years, mean, SD		42.7	9.6	42.2	9.6
Marital status					
	Single	82	25.7%	67	21.1%
	Married/cohabiting	196	61.4%	218	68.5%
	Widowed/separated	34	10.6%	27	8.5%
	Missing	7	2.2%	6	1.9%
Employer					
	Telecommunications	195	61.1%	198	62.3%
	Transport	51	15.9%	49	15.4%
	Health	73	22.9%	71	22.3%
Occupation					
	Manager or senior official	92	28.8%	91	28.6%
	Professional	66	20.7%	63	19.8%
	Assoc. prof. or technical	33	10.3%	32	10.1%
	Admin. & secretarial	34	10.6%	52	16.3%
	Skilled trade	14	4.4%	5	1.6%
	Personal services	0	0.0%	2	0.6%
	Sales and customer service	60	18.8%	61	19.2%
	Plant & machine operative	1	0.3%	1	0.3%
	Other	19	5.9%	10	3.1%
	Missing	0	0.0%	1	0.3%
Education post-16 yrs, median, range		3	0-39	3	0-39
Interquartile range			5		5
Alcohol consumption units, median, range		5	0-140	4	0-70
Interquartile range			14		11

Acceptability

The levels of agreement that aspects of online self-help are "important" or "very important" are summarized in Table 2. There was strong agreement with all of these assertions at baseline. At 6 weeks this remained true, but there was a significant reduction in the number of people who thought that accessing help "at any time" was an advantage t_{359}=3.396, P=.001). At 12 weeks, compared to baseline, when the intervention had been completed at least one month earlier, there was a statistically significant drop in the importance given to all but one statement ("I can use the computer at my own pace"), yet a majority of respondents still regarded all five features as important. Responses to these questions were highly intercorrelated.

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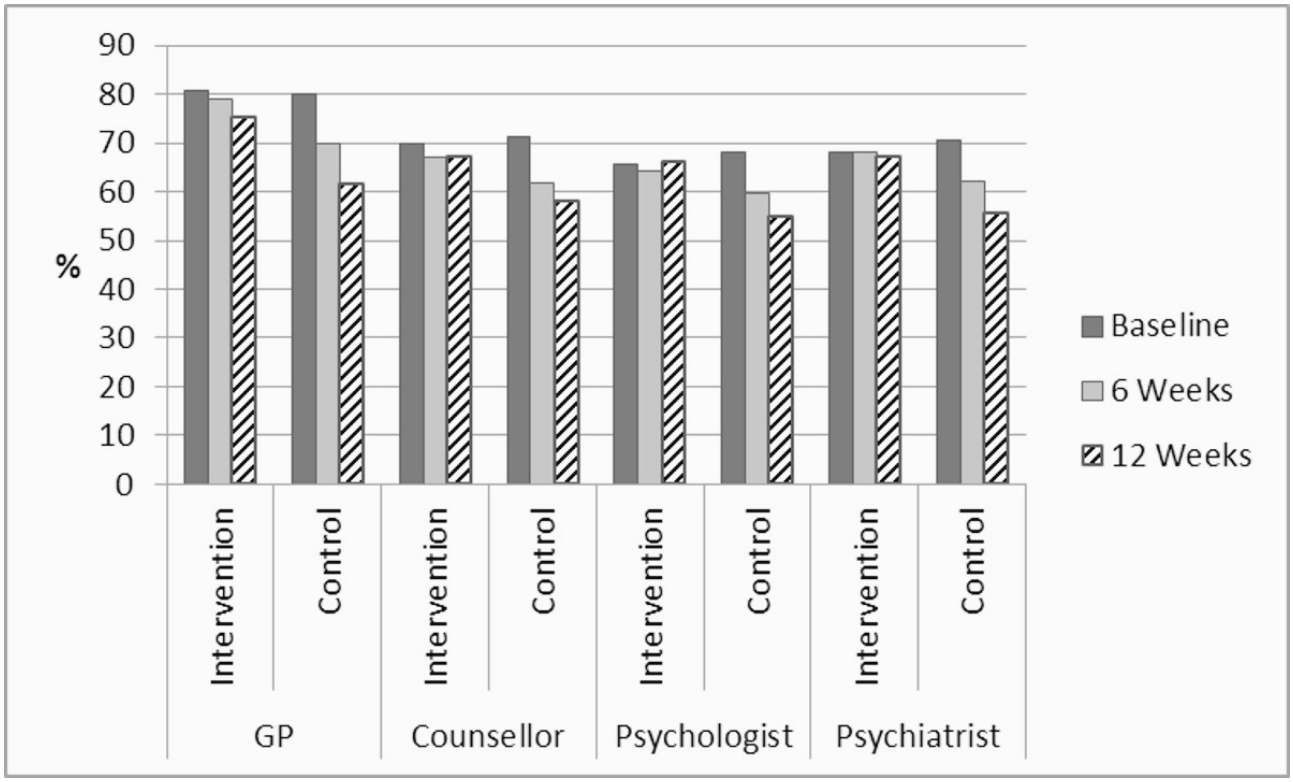
Table 2. Percentage of participants rating features "important" or "very important".

Statement	Baseline n=654	6 weeks n=360	12 weeks n=219
I can use the computer at my own pace.	89.9%	90.8%	87.7%
Using a computer is anonymous, I don't need to tell people about my problems.	74.8%	73.6%	73.1%
It is convenient for me to access help via the Internet and not to have to go to a health centre or clinic.	83.0%	82.2%	76.7%
I can access help at any time that suits me.	94.0%	90.0%	87.2%
The computer will not criticize me.	63.2%	58.9%	65.6%

Comparisons

Figure 3 shows how the comparisons with professional inputs were measured, and Figure 4 shows how they differed between control and intervention group. At the outset, a majority of respondents regarded online self-help to be equally or more acceptable than seeing health care professionals face to face. This held true at 6 weeks and 12 weeks across both study arms. However, unlike the intervention group, the control group's ratings decreased significantly at 6 weeks in relation to three of the four alternatives: GP (t_{189}=2.472, P=.014), counsellor (t_{189}=2.206, P=.029), psychologist (t_{189}=1.527, P=.129), and psychiatrist (t_{189}=2.267, P=.025). The 12-week data showed that the difference between the ratings of intervention and control participants was sustained over time. Again, responses were highly intercorrelated at all points in time.

Figure 4. Comparisons between online self-help and face-to-face professional help.



Expectations and Experience

The open-ended comments in response to "Any other reasons to like or dislike help via the Internet: please give brief details" provide insight to interpret respondents' views; 284 participants (78%) responded to the open question (142 of them from each arm). At 6 weeks, 98 participants (51 from the control condition) commented again (30% of those retained in the study), and 28 at 12 weeks (20 from the control condition), which was 12% of the number who responded at this time point. Edited slightly to protect anonymity, representative comments by study arm at baseline are given below, distinguishing between comments from people in the control ("C") and experimental ("E") arms of the trial.

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Table 3. Representative comments from control and intervention group members.

Group	Comments
Control group	
	Dislike psychoanalysis by computer because it is impersonal, and human conditions do not readily fit computer program algorithms so accurate or appropriate diagnosis is a hit and miss process.
	I can print things off and read them at my own pace—as well as ensuring that I understand what is going on. The only issue is still feeling very alone because the computer is not a person.
	I feel that if you think you have a slight problem, then this is a good first step. If you feel like there is more treatment needed then other avenues can be looked at. This is a non-committed [sic] way of dealing with a problem.
	In theory I like help via the Internet, but to be honest I have found this program completely useless. It was not what I expected at all. All it did was provide me access to websites which are the sort of thing I can find easily on the Internet anyway.
Intervention group	
	I have struggled to find the time / prioritize with a very high workload. I should have done more modules and prioritized this higher.
	Just the fact it's there when you need it, although does not suggest to get help if trend is getting worse. The questions didn't ask about any traumatic/stressful events during the week…
	The Internet is a useful way of accessing information and help, but there will always be occasions when it could not replace talking to a person face to face.
	There were a number of the personal logs that were unclear and needed to be discussed with someone before completion. This meant that I didn't necessarily get the best out of the program.

At baseline, 40 people (14%) felt that they could not yet comment or made statements that were neither positive nor negative, and dropout at 12 weeks was high (63%, 406/637); therefore, the 98 comments given at 6 weeks are the best indicator of experience of using the websites. Negative comments outnumbered positive across the study by about 2.5 to 1, with intervention and control participants generating a similar ratio of negative to positive statements, while the reasons given for dissatisfaction vary widely, some reflect the different arms of the trial: "This 'course' which I was on was no help to me at all. There was no interaction with the program and I feel let down by it" [C] and "I have struggled to find the time / prioritize with a very high workload. I should have done more modules and prioritized this higher". [E]

Completion of online sessions for the control group was not monitored, but for the intervention group the mean number of sessions completed out of a possible 20 was 8.35 (SD 6.76). This did not differ significantly between the three workforces.

Participants' Views of the Process

Participants came from a wide range of occupational backgrounds and ranged from those who rejected the use of the term "mental health problem", for example, "I consider myself to be stressed due to excessive work load—I am 100% sane and still in control—albeit struggle with corporate bullying at work. Mental health problem reminds me of Film One Flew Over the Cuckoo's Nest" [E], to those who had extensive experience of mental health services: "Materials viewed over the past few weeks have all been fairly basic, and having coped with depression for the last 30 years some of it was not new info." [C]

Altogether, 400 comments of all kinds were submitted at all three time points. These fell into four broad categories: (1) intrinsic, or individual barriers that people faced to participating fully in the trial, (2) extrinsic issues concerning the structure or content of the websites or the context of their use, (3) generic judgments or generalizations about online self-help with only indirect reference to the respondents' experience in the trial, and (4) specific opinions about MoodGYM or the control condition.

Intrinsic Barriers

Regardless of which study arm they followed, a number of respondents were negative towards computer use from the start: "I use the computer almost 100% of the time at work. Using it to reduce my stress and depression hasn't been helpful, in fact I found it stressful." [C]

By contrast, doing things online was seen as familiar, convenient, and "relaxing" by others: "[I]t gives you a sense that you're not really having a real mental health issue when using your PC online at home, as its very relaxed etc, whereas visiting a health center would probably bring home the notion that you are actually having a real problem." [E]

Other intrinsic barriers included lack of time and distractions. In addition, depression brings its own obstacles to self-help, for example, low self-esteem, apathy, and difficulty concentrating. Several people in both arms acknowledged that their motivation to complete the program was low: "Can be too tired to bother with and when feeling low what's the point?" [C] and "It can be impersonal and it is too easy to 'slack off' some of the exercise". [E]

There were indications that that the ease of access of online resources could help to overcome some of the inertia of depression: "My GP recommended seeking CBT support through the NHS, which just seems too difficult to coordinate and organize right now, while trying to stay functional at work. Online access to support means I can do something to take a step in the right direction…" [E]

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Yet participation was seldom entirely easy and straightforward. The following comment reminds us that the control condition consisted of informational websites, in contrast to the intervention, which offered a more interactive package: "When you are pressured at work and it's all getting too much, the last thing you have time for or want to do is go on the computer and search websites." [C] At the same time, this response illustrates the interaction between workload, stress, and the inertia often associated with depression.

Extrinsic Barriers

Practical obstacles to access are treated here as "extrinsic" barriers. Some dissatisfaction with the online self-help approach was due to avoidable technical issues, as a small proportion of people mentioned that they encountered recurrent difficulties, for example, the "page kept expiring". Several people made suggestions about how the experimental interface could be improved to promote accessibility and their own engagement with the process. For example, "The interaction between myself and the online system is not great. The questions are not likely to change on the strength of the answers I give so a predetermined path will be followed regardless. There are occasions where assistance could be given." [E]

The comment that "the questions are not likely to change" seems to be a criticism of the extent to which any program can be tailored to individuals, or is presented as being adaptable, thus personalization of the online materials could be an area for development.

An issue affecting the delivery of online interventions was raised by a couple of respondents who had dyslexia: one mentioned that screen reader software (a text-to-speech application) could have improved the trial's accessibility for people with this kind of problem.

As a means of overcoming some intrinsic barriers, people suggested adaptations such as auto-links embedded in emails to prompt them to log on or to complete exercises, making it harder for people to "forget" to use the program. Most extrinsic barriers would be amenable to improvements.

Generic Judgments

The largest single category of critical comments (93/404, 23% of all comments at baseline, 6 or 12 weeks) concerned the impersonal nature of the online approach, such as, "I dislike using the Internet intensely as most issues relating to anxiety, depression, and stress at work are relational in nature and therefore best dealt with in relation to at least one other person instead of a piece of machinery!!" [E] and "Computer is impersonal, asks a predefined set of questions that may not be relevant to me." [C]

However, 50 people (12.5%) actively preferred an indirect approach, due to embarrassment, shyness, fear of being judged, or of repeating painful encounters: For example, "No eye contact, less chance of me crying" [E] and "Previously, talking about my situation person-to-person had made me very emotional. Answering questions on the Internet does not elicit the same response." [C]

While recognizing the drawbacks, such participants felt that on balance, the computerized approach suited them in their particular circumstances. To this group may be added a smaller number (15, 4%) who stated that the anonymity of the approach was an advantage: "When you are in a high profile job, a computer doesn't care who you are." [C] and "My main fear if I were to seek help face to face would be the impact this would have on my self-esteem." [C]

Positive opinions were also expressed about the ease of access, range of information, and structure offered by the online approaches by 32 people (8% of all comments at baseline, 6 or 12 weeks). In total, over all data collection points, there were 24% (97/404) of people who expressed positive opinions, compared to 23% (93/404) who found it unacceptably impersonal.

Specific Responses

People in the intervention arm were more likely to express satisfaction with particular aspects, although with reservations in some cases: "I like the fact that I have a written record and can look back on the information. The tips and relaxing techniques give me a little bit of control in working towards a feeling of well-being." [E]

A few specific issues were raised concerning the content of the intervention: "I did not find this tool helpful. The wording (perhaps translation) was poor, sounded pat…" [E] and "Not all results explained well. Some of written exercises quite laborious too." [E]

Nonetheless, positive responses were more frequent: "It is a fantastic idea and the only thing that has really helped me" [E] and "I found the introduction of concepts I didn't know about and they were useful apply to my own thinking." [E]

As noted, some people in the control arm were clearly dissatisfied with the websites they were offered, for example "can't find a user-friendly website" and "I have found this program completely useless", although there were also more moderate views such as "a good first step" or "you can gather comparative information from different sources" and one citing the scope and flexibility of online resources. "Sadly, this course of 'self-help' did not give me any HELP, only access to information which I already knew how to access. I felt it was a waste of my time, although I kept it up in the hope that next week may show an improvement in satisfying my needs." [C]

Discussion

Principal Results

The main finding of this analysis is that employees with diagnosable depression who chose to use online self-help were broadly positive about the experience when asked to rate it, although they identified a number of areas for improvement. Despite the fact that negative comments outnumbered positive by 2.5 to 1, more than 60% of people who were willing to try the online approach considered it to be at least as acceptable as seeing a professional about mental health issues. It is important to note that they were more likely to retain this opinion over

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time if they used the interactive program, rather than informational websites alone.

The respondents commented on barriers to engagement with the online resources, which included psychological and emotional impediments together with imperfections in the technical aspects of the websites and the barriers to their use faced by people with dyslexia. This provides background information about the perceived advantages and disadvantages of cCBT, over which our respondents were fairly equally divided. While some found the Internet non-threatening, convenient, and anonymous, a similar number felt that what they needed most was someone to talk to. These results echo previous studies, including a systematic review of the drivers of adherence to Internet trials [19-21]. In particular, the findings show that many participants were facing logistical, psychological, and emotional barriers to seeking help in person from conventional professional sources. This indicates a reservoir of need that cCBT could potentially meet more effectively than standard treatment approaches.

From a methodological perspective, the views of such a substantial number of users are a valuable resource in developing online interventions to make them more user-friendly, accessible, acceptable, and hopefully more effective. The findings also have relevance for researchers seeking to gather data online, indicating, for example that while some topics are more amenable to face-to-face interviewing, there are people who are willing to engage with online approaches.

Limitations

Participants were self-selected; people who find online self-help unacceptable would never have considered taking part in this trial. The dropout rate from this study (45% at 6 weeks) was high, meaning that the inferences drawn here about the acceptability or effectiveness of online interventions come mainly from people who were motivated to complete the course. It might have been preferable to include interactive materials as the attentional control, making this more similar to MoodGYM. Some dissatisfaction reported here clearly relates to the discontinuity between the informational websites provided to the control group. While it is regrettable that the content of the control condition caused frustration, this should not reflect badly on the experimental intervention. The materials offered in each arm inevitably suited some people better than others, and the potential range of resources that people can access online is bound to be larger than that available to clients of a single counselor, especially those on time-limited courses of treatment. This suggests that expert appraisal and selection of resources for a range of purposes would be helpful. From a methodological perspective, these findings underline the importance of having a carefully designed active control group in RCTs of this kind.

Implications

It is possible that dropout indicates dissatisfaction. Retaining people in online interventions for longer is one means to increase their exposure to the therapeutic effects, and therefore to the potential benefits [20]. Yet, since costs of delivering online programs are generally low by comparison with face-to-face counseling, the diversion of any consumers from the latter to the former represents a potential saving. A middle path appears to be online therapy supported by some professional input. We used clinical studies officers simply to monitor and troubleshoot adherence to the intervention, while Warmerdam et al [22] utilized a life coach with a similar function, and Mohr et al in a feasibility study, provided manualized telephone and email support provided by “PhD-level licensed psychologists” [23].

The comments presented here confirm that online self-help does not suit everyone, but as one participant said “it certainly has its place”. At the point of delivery, careful management of users’ expectations is needed to ensure that online self-help is not seen disparagingly as a less costly and inferior alternative to interpersonal therapy. Online interventions are continually evolving; adapting them to meet individual need seems to be the key to success. More knowledge is needed about the characteristics of people who are best suited to online self-help in order to predict who is likely to benefit [24].

We suggest that the acceptability of online self-help could be improved in three ways. First, at the individual level, effective engagement could be promoted by investigating the intended consumers’ expectations and concerns and then exploring how their particular needs can be met. For instance, offering back-up advice by telephone might be one way to encourage those who are reluctant users. This could be delivered by different levels of staff according to the users’ needs. Networks of peers who have used the same online approaches could be developed to offer the longer-term support that some people seek to respond to the evident need for more human contact. Second, it is reasonable to expect that adaptations for sensory impairment and dyslexia should be incorporated into existing and new online packages. Finally, at the systemic level, expectations of cCBT could be actively shaped by public health initiatives and social marketing with reference to the wider evidence base.

There is further research to be done to ascertain whether approaches combining face-to-face with online interventions can satisfy the need expressed for person-to-person encounters to overcome their mental health problems—and if so, how much personal contact is enough in combination with online CBT.

Conclusions

The following comments sum up the views of the respondents: “It’s a little TOO impersonal but it’s an excellent complementary way to handle emotional/psychological issues and to provide self-help techniques. I don’t think this can replace the more usual means of obtaining help but it certainly has its place” [C] and “Help via the Internet is far more accessible than having to wait on a GP referral to a counselor. Some emotional problems can certainly be helped by following a CBT program on the Internet.” [E]

Our conclusion is that online, self-help resources for depression will help some people but not all. Clearly they cannot replace face-to-face therapy but may be a useful adjunct in certain circumstances. Many providers already include structured self-help as an integral part of treatment pathways of care for common mental disorders, and the findings of this study support that strategy. Barriers to use of online self-help resources may relate to individual perceptions and expectations, public opinion,

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or to the nature of the online resources. Attention to the detailed findings presented here could help reduce the typically high dropout rates from online interventions in general.

To the extent that people who might otherwise have been on waiting lists for face-to-face services found the use of online resources helpful, they offer potential benefits. Not everyone believes they need face-to-face counseling. An important conclusion from this study is that some people in employment with depression simply prefer a "faceless" approach. With the caveat that screening for immediate risk should be provided, the broad acceptability of online interventions makes them a promising option for many working adults who experience depression.

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Conflicts of Interest

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Multimedia Appendix 1

Consort diagram.

[PDF File (Adobe PDF File), 12KB - jmir_v16i3e90_app1.pdf]

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Abbreviations

CBT: cognitive behavior therapy
cCBT: computerized cognitive behavior therapy
CSO: Clinical Studies Officer
GP: general practitioner
NHS: National Health Service
PHQ: Patient Health Questionnaire
RCT: randomized controlled trial
WSAS: Work and Social Adjustment Scale

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Original Paper

Stroke Experiences in Weblogs: A Feasibility Study of Sex Differences

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Abstract

Background: Research on cerebral stroke symptoms using hospital records has reported that women experience more nontraditional symptoms of stroke (eg, mental status change, pain) than men do. This is an important issue because nontraditional symptoms may delay the decision to get medical assistance and increase the difficulty of correct diagnosis. In the present study, we investigate sex differences in the stroke experience as described in stories on weblogs.

Objective: The goal of this study was to investigate the feasibility of using the Internet as a source of data for basic research on stroke experiences.

Methods: Stroke experiences described in blogs were identified by using StoryUpgrade, a program that searches blog posts using a fictional prototype story. In this study, the prototype story was a description of a stroke experience. Retrieved stories coded by the researchers as relevant were used to update the search query and retrieve more stories using relevance feedback. Stories were coded for first- or third-person narrator, traditional and nontraditional patient symptoms, type of stroke, patient sex and age, delay before seeking medical assistance, and delay at hospital and in treatment.

Results: There were 191 relevant stroke stories of which 174 stories reported symptoms (52.3% female and 47.7% male patients). There were no sex differences for each traditional or nontraditional stroke symptom by chi-square analysis (all *P*s>.05). Type of narrator, however, affected report of traditional and nontraditional symptoms. Female first-person narrators (ie, the patient) were more likely to report mental status change (56.3%, 27/48) than male first-person narrators (36.4%, 16/44), a marginally significant effect by logistic regression (*P*=.056), whereas reports of third-person narrators did not differ for women (27.9%, 12/43) and men (28.2%, 11/39) patients. There were more reports of at least 1 nontraditional symptom in the 92 first-person reports (44.6%, 41/92) than in the 82 third-person reports (25.6%, 21/82, *P*=.006). Ischemic or hemorrhagic stroke was reported in 67 and 29 stories, respectively. Nontraditional symptoms varied with stroke type with 1 or more nontraditional symptoms reported for 79.3% (23/29) of hemorrhagic stroke patients and 53.7% (36/67) of ischemic stroke patients (*P*=.001).

Conclusions: The results replicate previous findings based on hospital interview data supporting the reliability of findings from weblogs. New findings include the effect of first- versus third-person narrator on sex differences in the report of nontraditional symptoms. This result suggests that narrator is an important variable to be examined in future studies. A fragmentary data problem limits some conclusions because important information, such as age, was not consistently reported. Age trends strengthen the feasibility of using the Internet for stroke research because older adults have significantly increased their Internet use in recent years.

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KEYWORDS

cerebral stroke; signs and symptoms; sex differences; Internet; blogging

Introduction

Background

The Internet has become a valuable tool in clinical medicine, both as a source of health information and by providing online interventions designed to improve health [1]. Moreover, the Internet also offers a research opportunity through the wealth of information available from search queries or social network posts. For example, the type and frequency of search queries concerning infectious disease have been associated with outbreaks of these diseases [2,3] and analysis of weblog stories has revealed young adults' mental health concerns [4]. Following this infodemiology approach [5], the present research investigates the feasibility of analyzing weblog posts about cerebral stroke experiences as a source of evidence to test a hypothesis in basic medical research: whether or not there are sex differences in cerebral stroke symptoms.

Our interest in variation between men and women in stroke experiences derives from reports based on hospital records of a variety of sex differences ranging from experience of symptoms to treatment, and from the possibility that these differences may influence stroke outcome. There is evidence that women experience delays from the onset of symptoms to diagnosis and treatment of stroke compared to men [6,7], although this difference is not consistently reported [8]. Such delays are a concern because they may obviate certain treatments that require rapid administration after onset of symptoms. Indeed, women are less likely than men to receive thrombolytic treatment, which may be because women are more likely to experience delay after the onset of symptoms that is beyond the 3-hour treatment window [6,9]. Women receive fewer diagnostic tests than men do, even when controlling for age, ethnicity, insurance status, and risk factors [10]. Moreover, outcomes of stroke are poorer for women compared to men [7,11-14]. Women's older age at the time of stroke is a likely factor, but delays in treatment and the type of treatment may also be a factor as well [15].

In sum, there are several factors that may contribute to sex differences in type and delay of treatment. We focus on one of them: There are reports that women experience more nontraditional symptoms of stroke than men and this may make correct diagnosis more difficult for women [9,15,16].

Sex Differences in Stroke Symptoms

Stroke is the fourth leading cause of death in the United States, [17] with more women than men dying of stroke each year [14,17]. Traditional symptoms of stroke include hemibody numbness and paresis, language disorders in comprehension and/or production, dysarthria, diplopia and other visual disturbances, facial weakness, ataxia, vertigo, and imbalance. Nontraditional symptoms of stroke include pain, mental status change (disorientation, confusion, or loss of consciousness), headache, lightheadedness, other general neurological symptoms (nausea, hiccups, and nonfocal weakness), and some nonneurological symptoms (chest pain, palpitations, and shortness of breath) [15,18,19]. Although headache has been reported as a symptom of ischemic and hemorrhagic strokes [20,21], headache has been considered a nontraditional symptom because it is not a focal neurological sign and it is common in a number of health problems [18].

Mental status change is the nontraditional stroke symptom most consistently reported as occurring more frequently in women than men [11,13,15,18,22,23]. Other nontraditional symptoms that have been reported as more frequent in women than men, although with less consistency, are pain other than headache [15]; (see [8] for a marginally significant difference), difficulty swallowing [11,24], headache [20], visual disturbances [24], and generalized weakness [23]. In contrast, women were significantly less likely than men to report traditional symptoms of dizziness or problems with walking or balance [15,16,23,25]. Indeed, in one study, women were less likely than men to experience any traditional stroke symptoms or to suspect stroke [8].

The Present Study

In this study, we investigate the feasibility of using stroke experiences described in weblogs as a source of data on sex differences in traditional and nontraditional symptoms. We used newly developed software that identified personal stories on the blogosphere that were relevant to a prototype story. We then analyzed symptoms described in the blogs by a stroke survivor or a third-person narrator. This follows hospital studies of stroke patients that included symptom reports by patients or third parties [16,18,23]. We predict that the identity of the narrator will be significant in reports of mental status change, a symptom often reported as more common in women patients. Mental change may have no effect observable to a third party unlike traditional symptoms, such as hemibody weakness, speech impairment, or loss of balance. Moreover, a patient's communication of internal mental states to a third party may be constrained by speech impairments associated with stroke. Thus, we will test for the first time whether or not changes in mental status are more likely to be reported as a symptom by a first-person than a third-person narrator, and whether there are sex differences in these reports.

We anticipated that descriptions of stroke experiences would vary widely in the information supplied because of the absence of a prescribed format for blogs, but that salient aspects of the experience, such as symptoms, the identity of the narrator, and delay in treatment, would be included in most descriptions. We also anticipated that the patient population would over- and underrepresent certain demographic groups in the population of stroke patients inasmuch as younger adults use blogs more than older adults and women bloggers make up the majority of this younger age group, whereas men bloggers make up the majority in the older age group [26]. These constraints will be

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considered in evaluating the feasibility of analysis of weblog data in testing hypotheses concerning sex differences in stroke symptoms.

Methods

Sampling Blogs

Stroke experiences described in weblogs were identified using a program called StoryUpgrade [27]. StoryUpgrade is a system we developed to aid in the retrieval of stories that describe classes of activities or events that we wish to analyze (eg, stories about protest rallies, car crashes, or stroke experiences). The system is supplied with a constant stream of stories pulled from the Web. Each day, the system downloads 1.5 million English-language weblog posts. The system then applies supervised machine learning techniques to classify these posts as personal stories. This classifier has a precision of 0.66 and recall of 0.5, meaning that it detects approximately half of all English-language personal stories, but one-third of posts it considers stories are actually not [28]. These posts are then indexed by using an off-the-shelf information retrieval platform, enabling them to be searched quickly. Figure 1 shows an example set of search results from the StoryUpgrade system. For the present study, the system was backed by 17.4 million personal stories posted to weblogs in 2010 and 2011.

In addition to enabling search queries, the StoryUpgrade system allows a user to provide feedback about the relevance of the retrieved stories to the user's information need. A user can mark a story as relevant, irrelevant, or the user can simply skip the story. This feedback is then incorporated into the search system, allowing it to retrieve increasingly relevant stories. To accomplish this, the StoryUpgrade system uses the Rocchio algorithm [29]. This technique incorporates the user's relevance feedback, encoding the information about story relevance provided by the user directly into the query. Words from stories the user considers relevant are weighed heavily, and words from stories the user considers irrelevant are weighed less heavily. This process modifies the original query to be more similar to relevant stories and less similar to irrelevant stories. The skip category allows a user to remove a story from the queue of stories to be judged without it impacting the weights of words in the query [30].

For this study, we wrote a fictional prototype story to be used as a query to the StoryUpgrade system. This prototype story was written in a colloquial style typical of blogs. It described a stroke experience including keywords for traditional and nontraditional symptoms (eg, "my speech did not make sense and was slurred," "could not pick up my arm or leg on one side," "I felt confused"), as well as "911," "emergency room," "paramedics," and "diagnosed with stroke." These keywords were selected based on symptoms and events that appear in hospital admission interviews or medical records of stroke patients [8,15,23]. The prototype story is presented in Multimedia Appendix 1.

The technique of writing a prototype story is one that has worked well with the StoryUpgrade system in other contexts. It is effective because it seeds the system with a vocabulary similar to what an actual blogger might use when writing a relevant story. An important concern of this technique is how it may bias the search results toward stories that feature details and phrasing included in the prototype story. Although this bias must be taken under consideration when analyzing the stories retrieved by StoryUpgrade, the bias is mitigated by the relevance feedback system previously described. As a StoryUpgrade user marks stories as relevant, the vocabulary from these stories is incorporated into the search query, casting a wider net for relevant stories. For instance, an initially retrieved story may describe the author experiencing slurred speech, a symptom described in the prototype story. This same story may describe vertigo, a symptom not included in the prototype story, or the author may say she "couldn't think clearly," describing confusion in a way that was not done in the prototype story. Although the initially retrieved stories may be biased toward the initial query, this bias is reduced as the user marks stories as relevant.

In this study, all stories retrieved by StoryUpgrade were read by 2 of the authors and marked as relevant if they contained information about a stroke experience in either a first- or third-person account, and marked as irrelevant if the story was not about a stroke. Irrelevant stories were dropped from further analysis. Stories that did not identify the sex of the stroke patient or were in blogs that denied access, such as expired pages or blogs requiring a subscription or permission, were ignored by being placed in the skip category (281 stories in this study). Using this procedure, we identified 191 relevant stories and 244 irrelevant stories.

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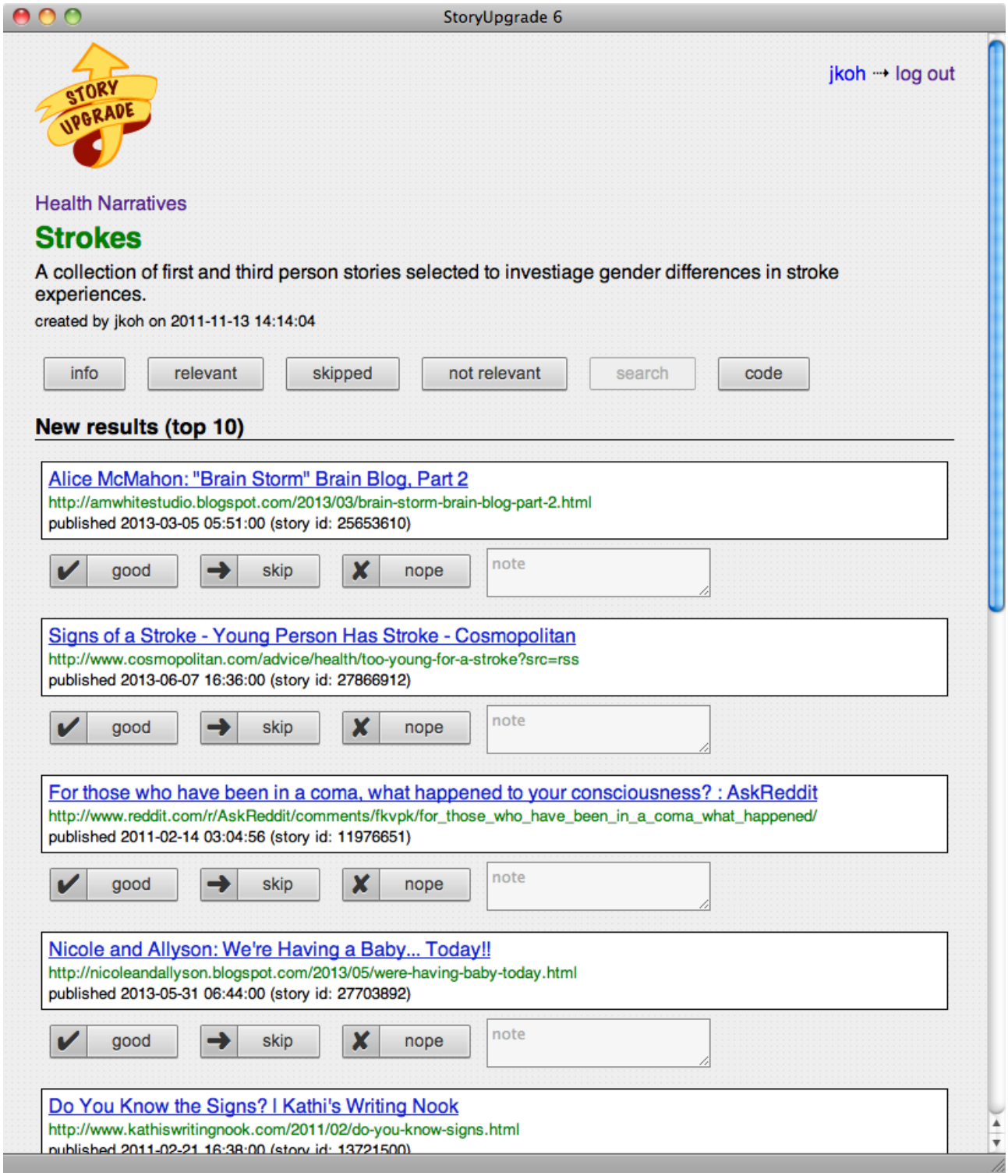
Figure 1. Screenshot of StoryUpgrade showing search results for stroke narratives.



Coding

We developed codes for first- or third-person narrator, whether or not a third-person narrator witnessed the event, the relation of the third-person narrator to the patient, patient sex and age, patient symptoms, assistance to obtain medical attention (eg, 911) , delay before seeking assistance, delay at hospital, treatment, and stroke outcome. If the specific age of the patient was not available, age range was coded if explicit information was available.

Classification of symptoms as traditional or nontraditional was based on the American Stroke Association's stroke warning signs [31] as well as symptom classifications used in previous research on sex differences [15,18,19]. Traditional symptoms were hemiparesis/hemiplegia (for body, for face, or both body and face), impaired speech or comprehension, visual disturbance, ataxia/discoordination, vertigo, and difficulty with balance. Nontraditional symptoms were pain (excluding headache), mental status change (disorientation, confusion, loss of consciousness), headache, lightheadedness, other neurologic

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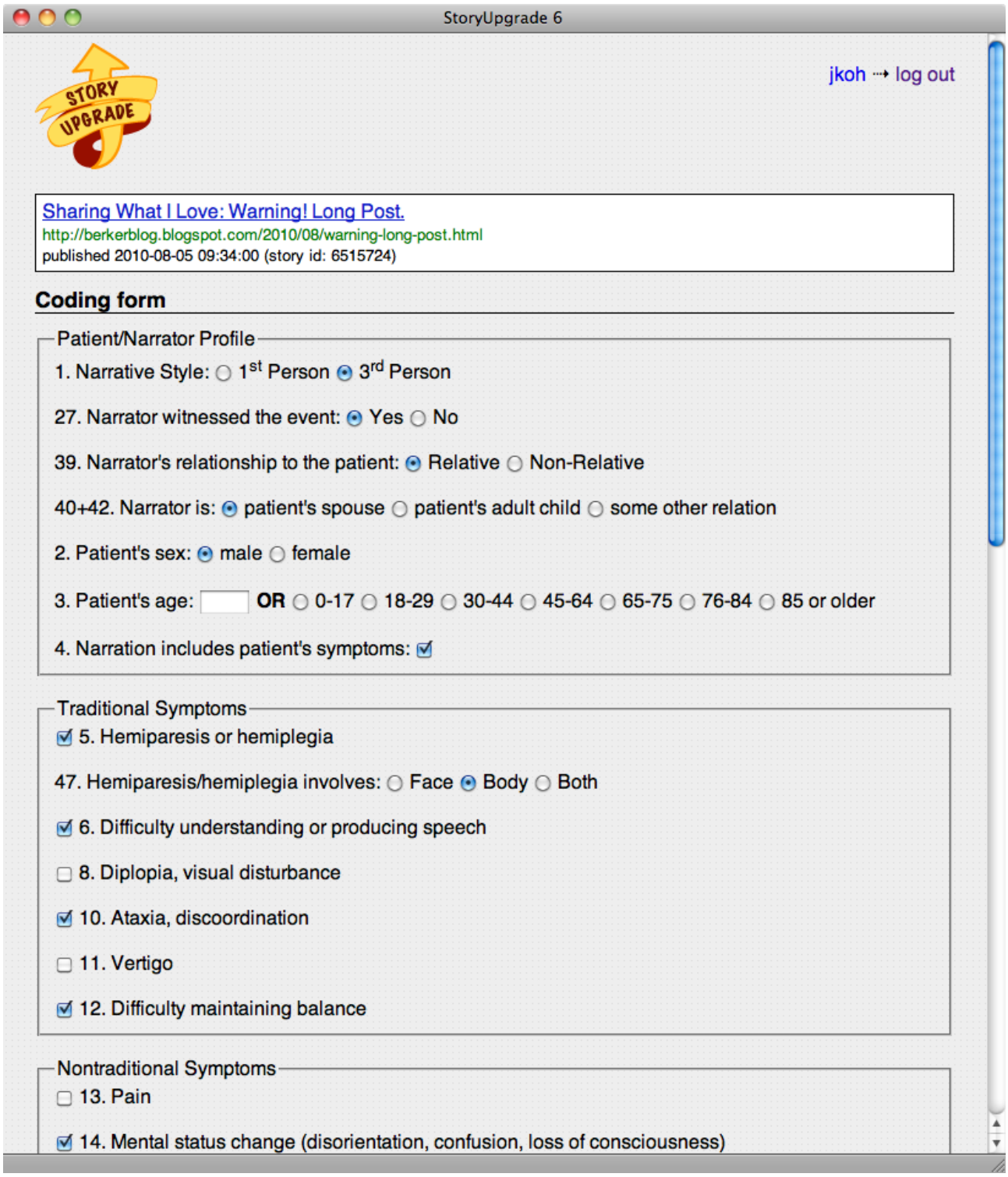
symptoms (nausea, hiccups, nonfocal weakness), and nonneurologic symptoms (chest pain, palpitations, shortness of breath). Although the American Stroke Association identifies confusion as a symptom, we categorized it as nontraditional consistent with previous research on sex differences. Each traditional and nontraditional symptom was coded for each patient as a dichotomous variable (reported or not reported). Symptoms were coded that occurred in the interval from the onset of the stroke experience until medical assistance was secured. Two of the authors coded all stories. An example of the form used to code each story is shown in Figure 2. Initial agreement in codes across the 2 coders was 83% and discrepancies in codes were discussed and resolved.

Figure 2. Screenshot of StoryUpgrade annotation tool for coding stroke narratives.



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Statistical Analysis

Each relevant story was assigned to a category for patient sex, stroke type, and type of narrator, with third-person narrators also categorized by whether or not they witnessed the stroke and their relation to the patient. The frequency of occurrence of each traditional and nontraditional symptom was compared between men and women and between ischemic and hemorrhagic stroke types using chi-square tests. Logistic regression was used to compare nontraditional symptoms as a group, and mental status change, in particular, by narrator type and sex.

Results

We obtained data from 191 stroke stories that met the inclusion criteria, with 52.4% (100/191) about female stroke patients and 47.6% (91/191) about male stroke patients. Of these stories, 174 reported symptoms (52.3%, 91/174 for women patients; 47.7%, 83/174 for men patients). Of the 174 stories reporting symptoms, 85 (48.9%) stories included age. Table 1 presents the age distribution by sex. Given the age distribution of bloggers [26], our sample overrepresented younger adults, yielding proportionately more reports about patients aged 45 to 64 years than 65 years and older. This contrasts with the monotonic increase in risk of stroke that occurs with age during adulthood [17,19]. However, 89 stories (51.1%) did not include age and it is unknown if the patients in these stories had an age distribution similar to Table 1.

Of the 191 stories, 50.8% (97/191) were narrated by the patient and 49.2% (94/191) were narrated by a third person. These percentages did not differ by sex of the patient, as shown by chi-square analysis (Table 2). When a third person was the narrator, he or she was a witness to the stroke for 39.6% (19/48) of women and 45.7% (21/46) of men, a nonsignificant sex difference. Most (83%, 78/94) third-person narrators were a relative of the patient and the type of relative varied for men and women patients in the chi-square analysis (P=.008). The narrators for women patients were more likely to be their adult child (60.0%, 24/40) or other relative (25.0%, 10/40) than for men patients (39.5%, 15/38 and 13.2%, 5/38, respectively). Men patients were more likely to have their spouse as narrator (47.4%, 18/38) than women patients were (15.0%, 6/40).

Table 1. Age distribution for women (n=40) and men (n=45) patients reporting age.

Age (years)	Patients, n (%)	
	Women	Men
0-17	2 (5)	1 (2)
18-29	9 (23)	5 (11)
30-44	16 (40)	8 (18)
45-64	8 (20)	19 (42)
65-75	3 (8)	8 (18)
76-84	0 (0)	3 (7)
85+	2 (5)	1 (2)

Table 2. Profiles of narrators for women (n=100) and men (n=91) patients.

Narrator characteristics	Patients, n (%)		P
	Women	Men	
Narrator			.72
First-person	52 (52.0)	45 (49.5)	
Third-person	48 (48.0)	46 (51.5)	
Third-person witness to stroke			.55
Yes	19 (39.6)	21 (45.7)	
No	29 (60.4)	25 (54.3)	
Third-person relationship-relative			.008
Adult child	24 (60.0)	15 (39.5)	
Other	10 (25.0)	5 (13.2)	
Spouse	6 (15.0)	18 (47.4)	
Third-person relationship-nonrelative			n/a
Friend	2 (25.0)	3 (37.5)	
Stranger	6 (75.0)	5 (62.5)	

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Chi-square analyses of the number of men and women experiencing specific stroke symptoms showed no significant sex differences for traditional or nontraditional symptoms, as seen in Table 3. The largest sex differences were for mental status change and visual disturbances, with women reporting more of these symptoms, although neither difference reached statistical significance. In a further analysis, we evaluated sex differences in mental status change separately for first- and third-person narrators (the small number of reports of visual disturbances precluded a similar analysis of this symptom). The narrators for the 91 women and 83 men patients included in the symptom analysis were 53% (92/174) first person and 47% (82/174) third person across sex. First-person narrators reported more mental status change than third-person narrators (*P*=.01). When mental status change was analyzed by patient sex (see Table 4), first-person narrators were more likely to report mental status change when the narrator was a woman patient (56%, 27/48) than a man patient (36%, 16/44), although this effect narrowly missed statistical significance (*P*=.056). However, third-person narrators showed no difference in their reports of mental status change for women (28%, 12/43) and men patients (28%, 11/39).

Table 3. Stroke symptoms reported for women (n=91) and men (n=83) patients.

Symptom type	Patients, n (%)		*P*
	Women	Men	
Traditional symptoms			
Hemiparesis/hemiplegia	68 (74.7)	63 (75.9)	.86
Body	30 (44.1)	33 (52.4)	.33
Face	2 (2.9)	4 (6.3)	
Both body and face	36 (52.9)	26 (41.3)	
Impaired speech or comprehension	59 (64.8)	47 (56.6)	.27
Visual disturbance	11 (12.1)	5 (6.0)	.17
Ataxia, discoordination	16 (17.6)	11 (13.3)	.43
Vertigo	13 (14.3)	13 (15.7)	.80
Difficulty with balance	7 (7.7)	8 (9.6)	.65
Nontraditional symptoms			
Pain (excluding headache)	5 (5.5)	5 (6.0)	.88
Mental status change	39 (42.9)	27 (32.5)	.16
Headache	16 (17.6)	11 (13.3)	.62
Lightheadedness	5 (5.5)	3 (3.6)	.55
Other neurologic symptoms	13 (14.3)	9 (10.8)	.67
Nonneurologic symptoms	4 (4.4)	5 (6.0)	.63

Table 4. Reports of mental status change for women (n=91) and men (n=83) patients by narrator.

Mental status change	Patients, n (%)		*P* value
	Women	Men	
First-person narrator			.056
Yes	27 (56.3)	16 (36.4)	
No	21 (43.7)	28 (63.6)	
Third-person narrator			.97
Yes	12 (27.9)	11 (28.2)	
No	31 (72.1)	28 (71.8)	

We tested whether this same pattern of effects for patient sex and type of narrator was found for all other nontraditional symptoms combined, excluding mental status change. With 174 male and female patients combined, more of the 92 first-person narrators (44.6%, 41/92) reported at least 1 nontraditional symptom than the 82 third-person narrators (25.6%, 21/82, *P*=.006). As shown in Table 5, this same pattern was seen for each sex separately with no significant differences between male and female patients in the narrator effect. This pattern of more nontraditional symptoms reported by first- versus third-person narrators was not because third-person narrators reported fewer symptoms in general: 90% or more of both first-

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and third-person narrators reported traditional symptoms for both men and women patients.

Table 5. Reports of nontraditional symptoms (excluding mental status change) for women (n=91) and men (n=82) patients by narrator.

Number of nontraditional symptoms	Patients, n (%)		*P*
	Women	Men	
First-person narrator			.80
≥1	22 (45.8)	19 (43.2)	
None	26 (54.2)	25 (56.8)	
Third-person narrator			.62
≥1	12 (27.9)	9 (23.1)	
None	31 (72.1)	30 (76.9)	

Of the stories describing symptoms, 96 reported a medical diagnosis of an ischemic (n=67) or hemorrhagic (n=29) stroke. We compared the number of reports of each traditional and nontraditional symptom by ischemic and hemorrhagic stroke patients (see Table 6). Chi-square analysis showed differences between the 2 stroke types for 2 specific symptoms: ischemic stroke patients were significantly more likely to experience vertigo (*P*=.008), whereas hemorrhagic stroke victims were significantly more likely to experience headaches (*P*=.002). Categorizing stroke symptoms as traditional or nontraditional symptoms, 79% (23/29) of hemorrhagic stroke patients experienced nontraditional symptoms whereas only 54% (36/67) of ischemic stroke patients did (*P*=.001). Looking at percentage of patients in Table 6, symptoms of general pain, mental status change, and headache seemed to contribute most to this effect of stroke type on nontraditional symptoms.

Table 6. Reports of stroke symptoms by ischemic (n=67) and hemorrhagic (n=29) stroke.

Symptom type	Stroke type, n (%)		*P*
	Ischemic	Hemorrhage	
Traditional symptoms			
Hemiparesis/hemiplegia	56 (84)	20 (69)	.11
Body	19 (34)	9 (45)	.30
Face	5 (9)	0 (0)	
Both body and face	32 (57)	11 (55)	
Impaired speech or comprehension	42 (63)	19 (66)	.79
Visual disturbance	8 (12)	3 (10)	.82
Ataxia, discoordination	13 (19)	2 (7)	.12
Vertigo	18 (27)	1 (3)	.01
Difficulty with balance	5 (7)	2 (7)	.92
Nontraditional symptoms			
Pain (excluding headache)	3 (4)	4 (14)	.11
Mental status change	21 (31)	14 (48)	.11
Headache	7 (10)	11 (38)	.002
Lightheadedness	5 (7)	0 (0)	.13
Other neurologic symptoms	10 (15)	5 (17)	.77
Nonneurologic symptoms	5 (7)	2 (7)	.92

Virtually all stroke patients sought medical assistance (96%-97%) regardless of sex, although 44% (35/80) of women patients delayed getting assistance and 32% (24/76) of men patients delayed, a difference that did not reach statistical significance (*P*=.12). There was no sex difference in time to get treatment in the hospital; 90% to 91% of both women and men patients received treatment immediately upon arrival.

Discussion

Principal Findings

The results demonstrate that weblogs are a useful source of stories of stroke experiences and that most stories describe symptoms. The reliability of the description of experiences in the weblog stories is supported by their replication of several

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previous findings in studies based on hospital interview data: the more frequent reports of traditional than nontraditional symptoms [15], evidence that women patients experience mental status change (here in the analysis by narrator) as a symptom more than men [11,13,15,18,22,23], the greater frequency of ischemic than hemorrhagic strokes [8,11,15], and the greater frequency of headaches and other nontraditional symptoms in hemorrhagic strokes [25,32].

The results also offer some new findings involving variables that affect symptom reports and sex differences, but that have been relatively unexplored in previous studies. As hypothesized, mental status change was reported more by first- than third-person narrators. The most obvious explanation is that this symptom is a change in an internal state that the patient is aware of but may not be visible to a third-person observer, unlike other symptoms that involve observable effects (eg, hemiplegia, impaired speech). Moreover, the frequency of report of mental status change showed no sex difference with third-person narrators, but was greater for women than men patients with first-person narrators, although this missed statistical significance (P=.056). Further research is needed to follow up this finding with a study including a greater number of patients that will allow control of variables confounded with sex in the present study, most importantly age. The age distribution suggests that the sample of women patients was younger than the sample of men patients, although narrators did not consistently supply information on patient age. Nonetheless, the narrator effect is consistent with the hypothesis that mental status change may be more available to the patient than to third-person narrators because it is an internal state.

Another significant effect of narrator was on reports of nontraditional symptoms. First-person narrators produced more nontraditional symptoms than third-person narrators, excluding the symptom of mental status change. This difference may be because other nontraditional symptoms involve internal states and are difficult for a third party to observe (eg, headache, pain). Thus, the results suggest that a first- or third-person narrator significantly affects the type of symptom reported and also whether or not sex differences are observed for symptoms, such as mental status change.

Third-person narrators are frequently called upon to describe symptoms to first responders or hospital personnel. Indeed, first- and third-person narrators are common in studies of stroke symptoms based on hospital interviews or records (eg, [11,15,16,18,23]). The present study, however, is the first to suggest that type of narrator is an influential variable and to demonstrate its significant association with specific symptoms. Previous studies have not evaluated effects of type of narrator. The present results suggest that type of narrator is an important variable to include in analysis of symptoms in hospital stroke studies, especially in the analysis of sex differences.

Limitations

The results also demonstrate the limitations of using weblogs as a source of data. Important information about the patient, especially age, was often not reported. The stories were from public blogs and written by people who were not given specific instructions about which details to include. This creates a fragmentary data problem that is inherent in this type of research. Additionally, the StoryUpgrade system does not provide a complete picture of all stroke experiences narrated on the Web. The system does not find all stories posted to weblogs, and as new technologies emerge for sharing personal experiences (eg, platforms such as Twitter and Facebook), additional techniques will be required to capture these stories. With respect to patient age, the distribution of ages that were included in stories showed overrepresentation of younger adult patients and very few patients older than 76 years. This contrasts with the monotonic increase in risk of stroke that occurs with age during adulthood [17,19]. The atypical representation of relatively young adult patients in weblogs may reflect, in part, the surprise and shock when a relatively young adult suffers a stroke, an illness associated with old age. Such an emotional response may motivate a blog. The most important factor for the observed age distribution in this study, however, is likely that younger adults use weblogs more than older adults [26] and adults aged 65 years and older use the Internet substantially less than younger adults.

Conclusions

Our results demonstrate that our method of using weblogs as a source of data on stroke experiences can produce interesting new findings that have important implications for understanding sex differences and that generate hypotheses to test in future research. Older adults' rapidly increasing use of the Internet [33] suggests that their representation in future Internet research will only grow, reducing a limitation of the present research. Using weblogs to collect data for medical research has the advantage of being relatively fast and inexpensive because it greatly reduces the time and cost of gathering data, relative to hospital studies. The price for this, however, is that data are fragmentary without a standard format for generating data.

Finally, the description of symptoms in blogs is important in terms of testing sex differences, but also for the insight it provides into the nature of stroke symptoms communicated to people who frequent weblogs or search the Internet to obtain information about strokes. That is, the Internet has become a key destination for people seeking information about disease [34]; thus, stories in blogs are likely to influence how people conceptualize stroke symptoms.

Overall, we see an important place for techniques such as these in medical research. They provide health scientists with a useful effective tool to explore medical issues. Very quickly, a health researcher can examine the experiences of people confronted with a medical issue of interest. Although these experiences will be colored by biases introduced by the query process and the population of bloggers, the information gleaned may be useful to formulate new questions and hypotheses that warrant additional investigation. Without the time and expense required for a full-scale traditional hospital study, health professionals can leverage the experiences of Web users to formulate promising avenues for future research.

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Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Prototype story used for initial search query of blogs.

[PDF File (Adobe PDF File), 24KB - jmir_v16i3e84_app1.pdf]

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Original Paper

Determinants of Follow-Up Participation in the Internet-Based European Influenza Surveillance Platform Influenzanet

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Abstract

Background: "Influenzanet" is a network of Internet-based platforms aimed at collecting real-time data for influenza surveillance in several European countries. More than 30,000 European volunteers participate every year in the study, representing one of the largest existing Internet-based multicenter cohorts. Each week during the influenza season, participants are asked to report their symptoms (if any) along with a set of additional questions.

Objective: Focusing on the first influenza season of 2011-12, when the Influenzanet system was completely harmonized within a common framework in Sweden, the United Kingdom, the Netherlands, Belgium, France, Italy, and Portugal, we investigated the propensity of users to regularly come back to the platform to provide information about their health status. Our purpose was to investigate demographic and behavioral factors associated with participation in follow-up.

Methods: By means of a multilevel analysis, we evaluated the association between regular participation during the season and sociodemographic and behavioral characteristics as measured by a background questionnaire completed by participants on registration.

Results: We found that lower participation in follow-up was associated with lower educational status (odds ratio [OR] 0.80, 95% CI 0.75-0.85), smoking (OR 0.64, 95% CI 0.59-0.70), younger age (OR ranging from 0.30, 95% CI 0.26-0.33 to 0.70, 95% CI 0.64-0.77), not being vaccinated against seasonal influenza (OR 0.77, 95% CI 0.72-0.84), and living in a household with children (OR 0.69, 95% CI 0.65-0.74). Most of these results hold when single countries are analyzed separately.

Conclusions: Given the opportunistic enrollment of self-selected volunteers in the Influenzanet study, we have investigated how sociodemographic and behavioral characteristics may be associated with follow-up participation in the Influenzanet cohort. The study described in this paper shows that, overall, the most important determinants of participation are related to education

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and lifestyle: smoking, lower education level, younger age, people living with children, and people who have not been vaccinated against seasonal influenza tend to have a lower participation in follow-up. Despite the cross-country variation, the main findings are similar in the different national cohorts, and indeed the results are found to be valid also when performing a single-country analysis. Differences between countries do not seem to play a crucial role in determining the factors associated with participation in follow-up.

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KEYWORDS

participatory surveillance; Internet; influenza

Introduction

The Internet is an increasingly used tool in epidemiological data collection, especially for recruitment and follow-up of large cohorts. Successful examples of this approach include the Millennium Cohort Study [1], the Nurses and Midwives e-Cohort Study [2], the Internet-based Pregnancy Planning Study ("SnartGravid") [3], the participatory nutritional study Nutrinet [4], and the newborn cohort NINFEA [5]. Some studies have systematically examined the advantages of the Internet-based approach [6,7], mostly in terms of the reduction of costs and time required for the data collection. Moreover, an unknown proportion of individuals with symptoms do not seek health care, and this proportion may vary with age, sex, or other social groups. Health care-seeking behavior also varies between countries and may change over the course of an epidemic. There is currently no method for systematically assessing health care usage. The use of the Internet-based cohorts can help to overcome this issue. Here we focus on Internet-based community surveillance of influenza-like-illness (ILI) as a means of gathering epidemiological data from the general population in a participatory fashion. In particular, we will study how the characteristics of individuals who register for the surveillance system are related to their involvement over the course of a surveillance season.

Influenza-like illness in Europe is monitored by means of nationwide networks of sentinel General Practitioners (GPs) detecting only medically attended ILI cases. Internet-based community surveillance of influenza can help to determine the disease burden [8], time trends and seasonality, and to characterize care-seeking and treatment behavior [9] and patterns of absenteeism [10]. Internet-based systems can thus enhance traditional GP-based surveillance and support the interpretation of recorded data, both for pandemic and seasonal influenza [8,9].

Collection of data related to influenza-like symptoms using an Internet platform is ongoing in several European countries: since 2003 in the Netherlands and Belgium [11], since 2005 in Portugal [12], 2008 in Italy, and 2009 in the United Kingdom [8,9]. Starting during the influenza season of 2011-2012, for the first time a network of Internet-based surveillance systems, called Influenzanet [13], has been active in seven European countries (the Netherlands, Belgium, Portugal, Italy, the United Kingdom, Sweden, and France), each using the same platform with the aim of gathering data across different countries in a standardized way, to monitor ILI in the community in real-time, track vaccine effectiveness [10,14], and to estimate risk factors for ILI.

In the seven countries, epidemiological data are collected with the participation of a self-selected cohort of volunteers followed over the influenza season. The success of the data collection strongly depends on the regular participation of the volunteers. Here, we investigate the determinants of participation in follow-up of volunteers enrolled in the Influenzanet platforms during the influenza season of 2011-2012.

Methods

Any resident of a country where Influenzanet is implemented can be involved in the influenza data collection by registering through the national Web page [15-20]. In each country, identical questionnaires are implemented with questions about respiratory symptoms, access and utilization of care and self-medication, uptake of vaccines, attitudes to influenza vaccines, and absenteeism. For the sake of clarity in the following, the term "users" will indicate all the individuals who have registered with the platform and possess a username and a password, regardless of their subsequent activity during the influenza season.

Upon registration, users are invited to complete a background questionnaire containing various sociodemographic, medical, geographic, and behavioral questions. In particular, the background questionnaire covers age, gender, household size and composition, location of home and workplace, education level, occupation, vaccination status for the previous and present influenza season, the presence of a chronic disease, possible pregnancy, and other issues (see the complete list of questions in Multimedia Appendix 1). Users are reminded weekly, via an email newsletter, to report their health status through a brief symptoms questionnaire, whether or not they experienced any symptoms since the last time they visited the platform. Users who report the presence of symptoms are asked some follow-up questions about the symptoms' onset date, about their health care-seeking behavior, medications taken for that particular episode of illness, and time off work/school. The weekly newsletter contains also a summary of the latest influenza facts and news to maintain users' interest in the questionnaire. Users can also create accounts on behalf of other members of their family/household, thus enabling, for instance, parents to record data for their children.

To study the determinants of participation in follow-up, we analyzed the behavior of users over the course of an influenza season, focusing on their propensity to return to the platform

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and provide information about their health status. Information collected in the background questionnaire allows us to study how the sociodemographic characteristics of participants are related to participation in follow-up. The study sample here consisted of all the Influenzanet volunteers in the seven European countries who contributed at least one symptoms questionnaire during the 2011-2012 influenza season and who inserted their own data. Since users can also create accounts on behalf of other people of their family/household, we discarded users whose information was reported to have been provided by someone else (eg, a husband whose questionnaires are filled in by his wife). Likewise, we did not consider subjects less than 15 or more than 70 years old, on the assumption that a different participant may have managed their account. In fact, more than 400 children younger than 15 years old and more than 200 individuals older than 70 years have their own account (ie, their own username and password to access the platform). This is a legacy from previous seasons when some of the platforms had the requirement that each individual have his/her own account even if it was managed by someone else. Therefore, we did impose the additional constraint on the volunteer's age in an attempt to ensure, as far as possible, that we were considering volunteers who manage their own accounts.

From the study sample, we considered as "enrolled participants", those participants eligible to be included in the analysis presented here, those who completed their first symptoms questionnaire at least 60 days before the end of the monitoring season, and completed at least one additional symptoms questionnaire within 15 days of the first symptoms questionnaire. From enrolled participants, we considered as "participants in follow–up" or "respondent participants" (either terms will be used in the following), those individuals who filled in at least two symptoms questionnaires during the time window of 30 to 60 days after their first symptoms questionnaire. Otherwise, the enrolled participants were considered to have a lower participation in the follow-up (see Figure 1).

In order to properly follow the unfolding of the seasonal epidemic and collect data that can be compared with the sentinel-based surveillance (which aggregates data on a weekly basis), users were asked to fill in a symptoms questionnaire each week. However, although completing the symptoms questionnaire only took a couple of minutes each week, there were numerous missing reports. Nevertheless, many individuals who missed a week did not drop out of the study; instead, they updated their health status more infrequently but they continued to provide useful information. On the other hand, some individuals registered on the website just to explore the website and its functionalities and never updated their health status; these individuals are not considered to be enrolled in the study. The definitions used for enrolled participants and participants involved in the follow-up, though by necessity somewhat arbitrary, were chosen to capture behavior that would generate a flow of useful information throughout the season.

By means of a multilevel analysis, we evaluated the association between participation in follow-up during the season and sociodemographic and behavioral characteristics collected in the background questionnaire. A multilevel analysis is generally used when the set of values of a categorical predictor variable are seen not as the complete set but rather as a random sample of all values, in order to allow inferences over a wider population than is possible with regression or other general linear model methods. In this case, we considered the follow-up participation as a dichotomous outcome, the sociodemographic and behavioral characteristics as independent variables, and the country variability as a random effect. We used as independent variables: gender, age, education level, household composition, smoking, presence of a chronic condition, and vaccination status. For each variable, we used the levels shown in Textbox 1.

Textbox 1. Levels used on the independent variables for the multilevel analysis.

- gender: male, female
- age (years): 15-30, 31-40, 41-50, 51-60, 61-70
- smoking: yes (smoking occasionally or daily), no (never smoked or quit smoking)
- education level: no formal qualification (final stage of compulsory education not completed), secondary/high school education (highest level completed was the final stage of compulsory education or the high school diploma), university degree (Bachelor's or a higher degree), and still in education (this was not a mutually exclusive category per se, as users were asked, if still in education, to select also the highest level of education achieved; we thus performed a sensitivity analysis considering this category as a missing value and obtaining very similar results)
- presence of a chronic condition/disease: yes (regularly taking medications for asthma, diabetes, lung disorder, heart disorder, kidney disorder, or an immune-compromising condition), no
- vaccination against seasonal influenza for 2011/12 season: yes, no
- household with children (≤18 years old): yes, no

In the multilevel analysis, each variable was adjusted against all the others as potential confounders for the outcome. Since some subject records for the various independent variables were missing, we used a complete-subject analysis to deal with such missing records; thus, the multilevel regression was performed only on those enrolled individuals who provided information for all the considered variables. The education level was asked only to participants above 15 years old, and therefore those with 15 years old are excluded from the multivariate analysis. The reference age group was chosen to be the one with more participants in the total population (51-60 years old) in order to reduce the estimates of confidence intervals. Given the relatively small number of clusters (ie, countries), we verified that a logistic regression where the countries are considered as dummy variables led to results comparable with those obtained with the multilevel regression in terms of strength of association (ie,

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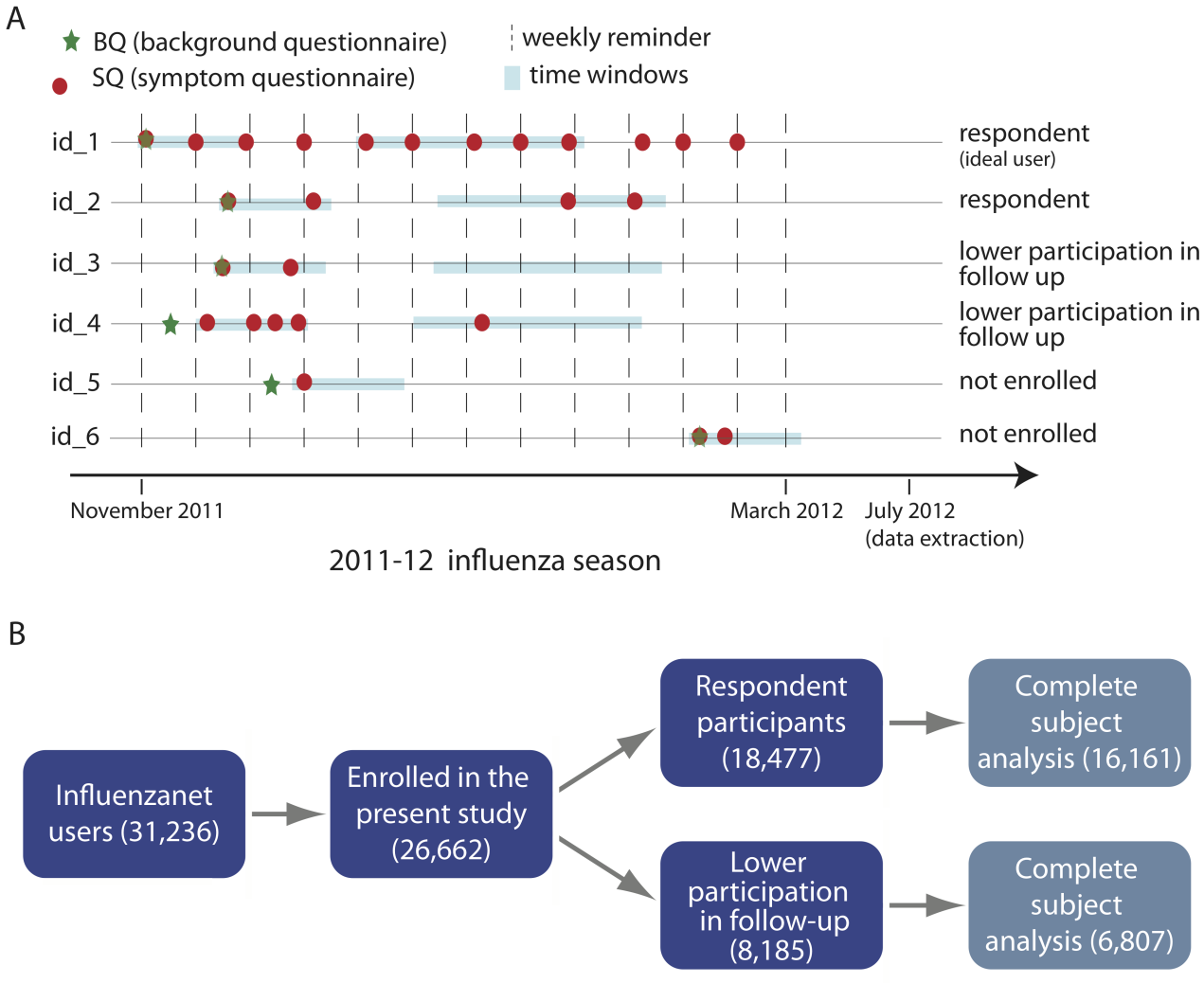
odds ratios) and significance (*P* value). Data were analyzed using Stata software, version 11.0.

In the United Kingdom, the Flusurvey study was approved by the London School of Hygiene and Tropical Medicine Ethics Committee (Application number 5530). In Sweden, the Influensakoll study was approved by the Stockholm Regional Ethical Review Board (Dnr. 2011/387-31/4). In France, the Grippenet study has been approved by the Comité consultatif sur le traitement de l'information en matière de recherche (CCTIRS, Advisory committee on information processing for research, authorization 11.565), and by the Commission Nationale de l'Informatique et des Libertés (CNIL, French Data Protection Authority, authorization DR-2012-024).

In all the participating countries, the study was conducted in agreement with national regulations on privacy and data collection and treatment. Informed consent was obtained from individuals who participated in the study described in this article that the information collected through their data may be used for scientific purposes and published.

Figure 1. Panel A: Illustration of study definitions for enrollment and follow-up participation. Definition for enrollment: first symptoms questionnaire (SQ) at least 60 days before end of monitoring season and at least one more SQ within 15 days from first SQ; Definition for follow-up participation: at least two SQs during time window of 30 to 60 days after first SQ. Panel B: The numbers of Influenzanet users and enrolled participants, obtained applying the enrollment definition given in Panel A, are shown. The final sample on which the multilevel regression was performed, after the complete-subject exclusion of individuals with missing records, was of 22,968 enrolled individuals who provided information for all the variables. Among these, after applying the definition for follow-up participation given in Panel A, 16,161 were respondent participants and 6,807 had a lower participation in the follow-up.



Results

Overall, 31,236 individuals registered and completed at least one symptoms questionnaire during the influenza season of 2011-2012, of whom 28,644 were aged between 15 and 70 years old, thereby comprising the sample in this study. Among these, there was a total of 26,662 enrolled participants, according to the definition above. The sociodemographic characteristics of enrolled participants are shown in Figure 2 (gender, age, education level, household composition, smoking, presence of a chronic condition, and vaccination status).

For each country, the numbers of enrolled participants and follow-up respondents are shown in Table 1. After the complete-subject exclusion of individuals with missing records,

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the final sample on which the multilevel regression was performed was 22,968 enrolled individuals who provided information for all the variables (86.15% of all enrolled participants, 22,968/26,662).

The proportion of respondent participants varies between 43% and 79% across the national platforms. The Dutch cohort represents almost half of the entire Influenzanet cohort (46.97%, 12,524/26,662), while the sample sizes of the others studies range between 1152 (Portugal) and 3834 (Belgium) individuals.

For comparison, we report in Table 2 the information regarding Internet access in each country (ie, the fraction of Internet users with respect to the general population).

A *P* value of <.001 associated with the likelihood-ratio test allows us to reject the null hypothesis that the between-cluster (ie, between country) variance is 0, thus confirming that a multilevel analysis is required. The results of the multilevel analysis are shown in Table 3.

The multilevel results show that men and women do not differ significantly in terms of follow- up participation. Holding a university degree, non-smoking behavior, having received an influenza vaccination, and increased age are associated with a higher participation in follow-up. Presence of a chronic health condition and living with children are associated with lower participation in follow-up.

We performed a separate analysis for each country by calculating both the crude and adjusted odds ratio for being a follow-up participant using the same variables that were used for the random effects multilevel analysis. Results are shown in Figure 3.

The adjusted results in Figure 3 (and Table 4 in Multimedia Appendix 2) indicate that for all the "n" countries where a significant association was obtained, participation at follow-up was positively associated with being: non-smoker (n=7 countries), older than 60 years (n=5), vaccinated against seasonal influenza (n=4), not having a chronic condition (n=3), having a university degree (vs secondary/high school, n=3; or vs having no formal education, n=2), and being female in the United Kingdom, while being male in France.

To assess the suitability of our definitions of enrollment and participation in follow-up, and to test the possible sensitivity of the results to the details of the definitions, we tested a slightly stricter definition for enrollment and follow-up participation, requiring one additional symptoms questionnaire for "enrollment", and shifting the time window for "follow-up participation" to 45 to 75 days (instead of 30 to 60 days) after the first symptoms questionnaire. Similar conclusions were obtained for the determinants of follow-up participation when using the stricter definition for enrollment and follow-up participation (results not shown).

Table 1. Cohort size and participation in the seven countries considering two different enrollment definitions.

Country	Enrolled participants	Respondent participants, n (%)	Participants not involved in follow-up, n (%)
Sweden	2097	904 (43.11)	1193 (56.89)
United Kingdom	2171	1180 (54.35)	991 (45.65)
Netherlands	12,524	9679 (77.28)	2835 (22.64)
Belgium	3834	3042 (79.34)	792 (20.66)
France	3540	2227 (62.91)	1313 (37.09)
Italy	1354	657 (48.52)	697 (51.48)
Portugal	1152	788 (68.40)	364 (31.60)
Total	26,662	18,477 (69.30)	8185 (30.70)

Table 2. General population and fraction of Internet users for each country in the cohort.

Country	Population (2012 est.)	Internet users (30 June 2013)	Penetration (% population)
Sweden	9,103,788	8,441,718	92.73 %
United Kingdom	63,047,162	52,731,209	83.64%
Netherlands	16,730,632	15,549,787	92.94 %
Belgium	10,438,353	8,489,901	81.33 %
France	65,630,692	52,228,905	79.58 %
Italy	61,261,254	35,800,000	58.44 %
Portugal	10,781,459	5,950,449	55.19 %

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Table 3. Random effect multilevel logistic regression performed on the set of enrolled individuals.

Variable		Reference group	Adjusted OR	95% CI	*P* value
Gender					
	Female	Male	1.01	0.95-1.08	.775
Age					
	15 - 30	51-60	0.30	0.26-0.33	<.001
	31-40	51-60	0.47	0.43-0.52	<.001
	41-50	51-60	0.70	0.64-0.77	<.001
	61 -70	51-60	1.42	1.28-1.59	<.001
Smoking					
	Yes	No	0.64	0.59-0.7	<.001
Education					
	No formal qualification	University degree	0.70	0.55-0.88	.002
	Secondary/high school education	University degree	0.80	0.75-0.85	<.001
	Still in education	University degree	0.71	0.53-0.95	.023
Chronic condition/disease					
	Yes	No	0.80	0.74-0.87	<.001
Vaccination against seasonal influenza for 2011/12					
	No	Yes	0.77	0.72-0.84	<.001
Household with children					
	Yes	No	0.69	0.65-0.74	<.001

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Figure 2. Country-specific distribution of independent variables of enrolled participants: gender, age, education level, household composition, smoking, presence of a chronic condition, and vaccination status (SE = Sweden, UK = United Kingdom, NL = the Netherlands, BE = Belgium, FR = France, IT = Italy, PT = Portugal).

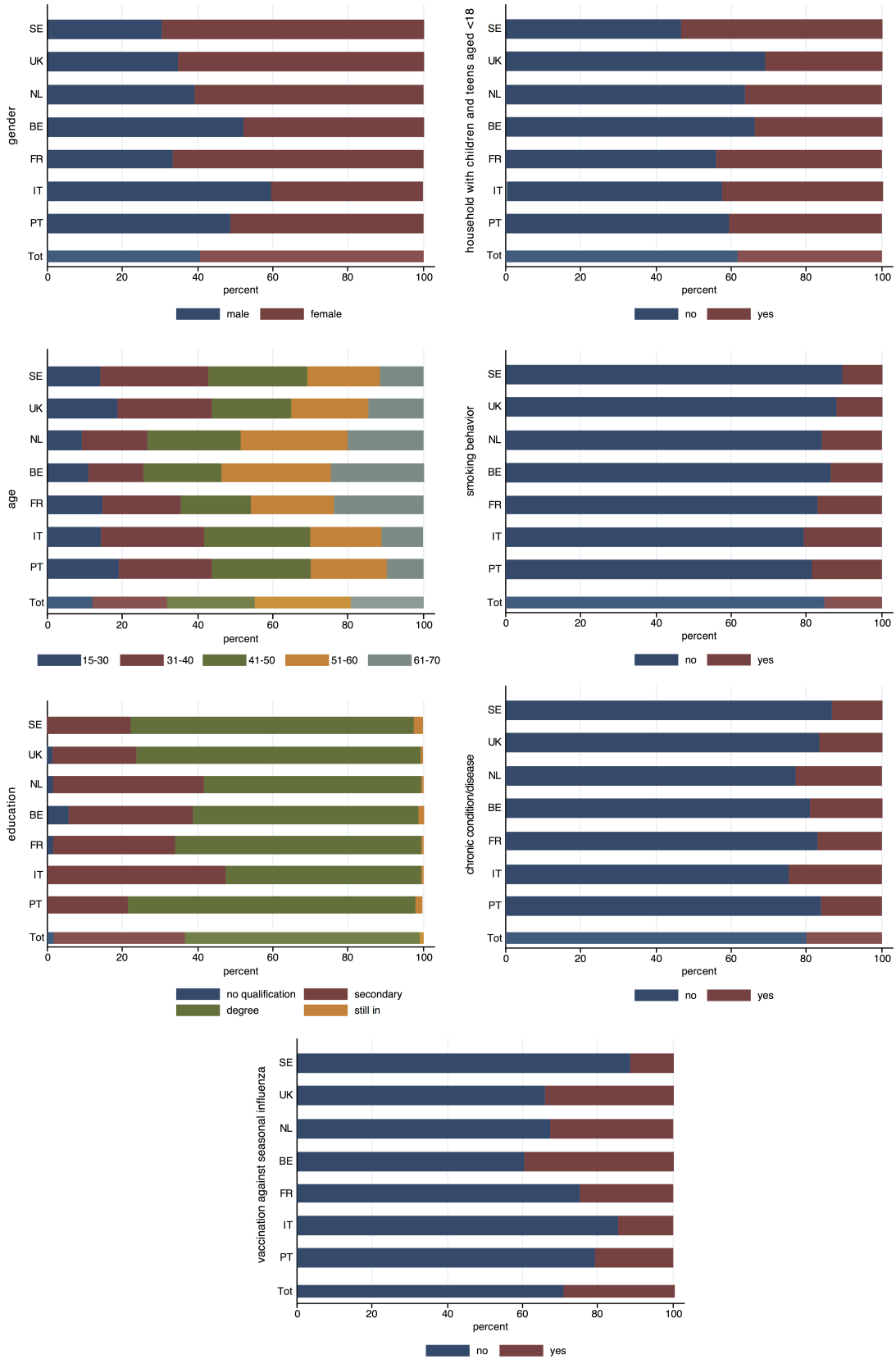

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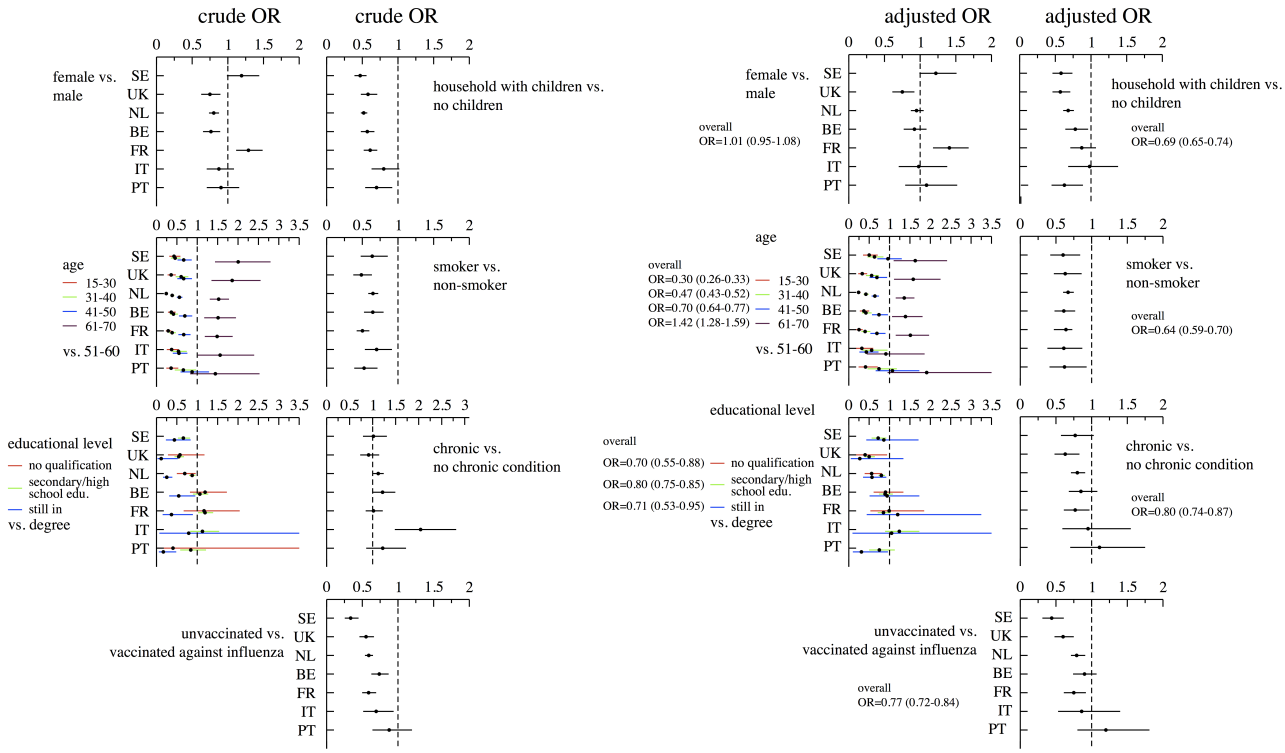
Figure 3. Crude (left panels) and adjusted (right panels) odds ratio by country. An odds ratio greater than 1 is associated with higher likelihood of participation in follow-up ((SE = Sweden, UK = United Kingdom, NL = the Netherlands, BE = Belgium, FR = France, IT = Italy, PT = Portugal).



Discussion

Principal Findings

The first year of Influenzanet data collection took place in seven European countries and saw the participation of tens of thousands of individuals among the general population. Given the opportunistic enrollment of self-selected volunteers in the Influenzanet study, it is important to investigate how sociodemographic and behavioral characteristics may be associated with follow-up participation in the Influenzanet cohort.

The study described in this paper shows that, overall, the most important determinants of participation are related to education and lifestyle: smoking (odds ratio [OR] 0.64, 95% CI 0.59-0.70), lower education level (OR ranging from 0.70 to 0.80 depending on the educational level compared with people holding a university degree), and younger age (OR ranging from 0.30 to 0.70 with an increasing trend in participation with older age) are associated with a lower rate of follow-up participation. People living with children participate in follow-up less than people living alone or in a household consisting only of adults (OR 0.66, 95% CI 0.65-0.74); people who have not been vaccinated against seasonal influenza tend to have a lower participation in follow-up with an associated (OR 0.77, 95% CI 0.72-0.84). We speculate that even though individuals living with children are at greater risk of being infected with ILI and so might be expected to be more motivated to report their health status, the demands of parental care mean that voluntary participation in follow-up could be affected by lack of time. The fact that individuals who chose to be vaccinated are more likely to be follow-up respondents could be because individuals who get the vaccine might also be individuals more concerned about their personal health and thus more likely to be involved in follow-up throughout the influenza season. Finally, males and females do not have significantly different follow-up participation behavior (OR 1.01, 95% CI 0.95-1.08).

Despite the cross-country variation, the main findings are similar in the different national cohorts, and indeed the results are found to be valid also when performing a single-country analysis. Differences between countries do not seem to play a crucial role in determining the factors associated with involvement in follow-up. The results of the multilevel analysis performed on the Influenzanet cohort as a whole indicates, as expected, that the results regarding smoking, education, and age are similar to what can be found in the literature for traditional non−Internet-based epidemiological studies [21-23] (ie, people who smoke, who are younger, and who have a lower educational level are more likely to have a lower participation in follow-up). This suggests that the self-selection of volunteers through an Internet-based system does not introduce different motivations or determinants for follow-up participation in a study with respect to traditional non−Internet-based epidemiological studies.

The overall percentage of follow-up responders for the different countries varies between 43% and 79%. The platforms running longer (the Netherlands, Belgium, and Portugal) tend to have higher proportions of follow-up responders, suggesting that the participation behavior of Influenzanet users may change over the years as they are more likely to become regular respondents the longer they are involved in the project. It is also worth mentioning that longer-standing systems may well be better able to keep people engaged, due to lessons learned about what works and what does not. Moreover, participants who continue to participate over several years are also more motivated to

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participate than those who drop out. In our sample, we did not distinguish between users who registered during the 2011-12 season and users from previous seasons but future work could investigate whether this explains the differences between countries. These differences could be also due to different levels of Internet penetration. The large differences in the proportion of Internet users among the general population, as shown in Table 2, can be an index of different cultural attitudes in the various countries leading to differing attitudes to participation. Further analysis might also consider the level of engagement, defining the outcome as the proportion of symptoms questionnaires completed out of the maximum possible number of questionnaires that could have been completed since registration, instead of the dichotomous definition of follow-up participation explored in the present analysis. Future work could also investigate whether the determinants associated with participation over several seasons are the same as the determinants identified in the present study.

Conclusions

Previous studies compared the self-selected sample of Influenzanet users in a single country with the general population [8,11] and it was found that individuals recruited by the platforms are neither demographically nor geographically representative [8]. In this work, we focused on the cohort of enrolled participants from the seven countries during the 2011-12 season as a whole but we did not attempt to make comparisons with the general population. Rather, this is one of the first attempts to describe the determinants of follow-up participation in an Internet-based multi-country cohort study assessing the impact of demographic and behavioral characteristics on follow-up participation.

This study has thus provided information that will help investigators improve the planning of studies for future Internet-based surveillance and to guide enrollment and retention strategies aimed not only at enlarging the samples with motivated participants but also to enhance control over potential biases introduced by differences in follow-up behavior among participants. Our findings can additionally be used to inform the design of engagement campaigns strategically targeted at less self-motivated people to promote their participation and thereby further enhance these surveillance systems by minimizing the selection bias.

Acknowledgments

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Authors' Contributions

All the authors were involved in the management, design, and editing of the Influenzanet national websites. Paolo Bajardi and Daniela Paolotti conceived the study, analyzed the data, and prepared the manuscript. Ken TD Eames, Clément Turbelin, Marion Debin, Vittoria Colizza, Ana O Franco, Annasara Carnahan, and Moa Rehn also contributed to improve previous versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Influenzanet questionnaires for 2011-2012.

[PDF File (Adobe PDF File), 466KB - jmir_v16i3e78_app1.PDF]

Multimedia Appendix 2

Factors associated with participation in the single country Influenzanet cohorts. Participation rate, crude, and adjusted odds ratios and confidence intervals are shown for different strata.

[PDF File (Adobe PDF File), 160KB - jmir_v16i3e78_app2.pdf]

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Abbreviations

GP: General Practitioners
ILI: influenza-like-illness
OR: odds ratio

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Original Paper

Considerations for Conducting Web-Based Survey Research With People Living With Human Immunodeficiency Virus Using a Community-Based Participatory Approach

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Abstract

Background: Web or Internet-based surveys are increasingly popular in health survey research. However, the strengths and challenges of Web-based surveys with people living with human immunodeficiency virus (HIV) are unclear.

Objective: The aim of this article is to describe our experience piloting a cross-sectional, Web-based, self-administered survey with adults living with HIV using a community-based participatory research approach.

Methods: We piloted a Web-based survey that investigated disability and rehabilitation services use with a sample of adults living with HIV in Canada. Community organizations in five provinces emailed invitations to clients, followed by a thank you/reminder one week later. We obtained survey feedback in a structured phone interview with respondents. Participant responses were transcribed verbatim and analyzed using directed content analysis.

Results: Of 30 people living with HIV who accessed the survey link, 24/30 (80%) initiated and 16/30 (53%) completed the survey instrument. A total of 17 respondents participated in post-survey interviews. Participants described the survey instrument as comprehensive, suggesting content validity. The majority (13/17, 76%) felt instruction and item wording were clear and easy to understand, and found the software easy to navigate. Participants felt having a pop-up reminder directing them to missed items would be useful.

Conclusions: Strengths of implementing the Web-based survey included: our community-based participatory approach, ease of software use, ability for respondents to complete the questionnaire on one's own time at one's own pace, opportunity to obtain geographic variation, and potential for respondent anonymity. Considerations for future survey implementation included: respondent burden and fatigue, the potentially sensitive nature of HIV Web-based research, data management and storage, challenges verifying informed consent, varying computer skills among respondents, and the burden on community organizations. Overall, results provide considerations for researchers conducting community-based participatory Web-based survey research with people living with HIV.

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KEYWORDS

HIV infections; Internet; self-report; health surveys; questionnaires; community-based participatory research

Introduction

Web or Internet-based surveys are increasingly popular in health survey research, enabling researchers to obtain a large amount of information in a cost-effective manner [1,2]. Strengths include the ability for individuals to anonymously complete a questionnaire on their own time at their own pace [3,4]. Nevertheless, Web-based surveys are complex to design and administer for a variety of reasons, including issues surrounding informed consent, risk, anonymity, data storage and security, and sampling [1,5,6]. Response rates with Web-based surveys may be lower compared with paper-based questionnaires further highlighting the importance of carefully considering survey design in relation to the target population [7]. Methodological considerations of Web-based survey research have been considered in other chronic illness populations such as cancer [8], cardiovascular disease [9], Parkinson's disease [10], and diabetes [11]. Issues conducting Web-based surveys have also been described with men who have sex with men [12,13], and in the context of human immunodeficiency virus (HIV) testing and prevention [14-16]. However, the strengths and challenges of Web-based surveys directly related to people living with HIV are unclear [17].

Community-based participatory research is a "collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings" [18]. Community engagement is a principle of community-based participatory research that collaboratively involves community members, organizational representatives, and researchers in varying degrees of partnership [19,20]. Community engagement in survey research can help to ensure questionnaires are contextually relevant, sensitive, and applicable to the population of interest [21]. In particular, engaging community through a participatory research approach can help to establish strategies to address complexities related to neurocognitive health, fatigue, disclosure, and varying socioeconomic status that may exist for people living with HIV. Internet tools have been used to build capacity for conducting community-based participatory research [22], and guidelines and principles exist for community-based participatory HIV research [19,20,23,24]. However, little is known about the role of HIV community members in guiding Web-based survey research.

In this article, we describe our experience piloting a cross-sectional, Web-based survey with people living with HIV in Canada, using a community-based participatory approach. Specifically, we present feedback from participants living with HIV on our survey implementation, and discuss strengths and considerations for conducting Web-based survey research with people living with HIV.

Methods

The Context: Assessing Disability and Rehabilitation Services Use

HIV is increasingly considered a chronic illness in developed countries. More individuals are living longer and aging with the health challenges of HIV, comorbidities, and the side effects of treatment [25-28]. As a result, an increasing number of individuals are now aging with a range of health-related challenges known as disability. Disability is defined as symptoms and impairments (eg, fatigue, weakness, pain), difficulties with day-to-day activities (eg, household chores), challenges to social inclusion (eg, ability to work), and uncertainty or worrying about future health [29]. To provide optimal care for people living with HIV, clinicians and researchers need to understand the range and prevalence of health-related challenges (or disability) experienced by this population [29,30]. We broadly define "rehabilitation"' as any service or provider who seeks to prevent or address disability experienced by people living with HIV [31]. Rehabilitation can help manage forms of disability such as fatigue, pain, cognitive problems, challenges participating in the labor force, and has the potential to improve health and quality of life outcomes for people living with HIV [32]. Researchers have explored disability and rehabilitation service provision among HIV and health providers and found that despite a high prevalence of disability experienced among people living with HIV, few rehabilitation professionals work in HIV care. However, these concepts have not yet been investigated from the HIV perspective nationally [33-35]. Hence, we developed a survey to establish a profile of disability and rehabilitation services use from the perspective of people living with HIV.

We conducted a pilot study of a cross-sectional, electronic survey with a sample of adults living with HIV across Canada using a community-based participatory research approach. Community partner organizations invited individuals to complete the Web-based survey questionnaire followed by a one-on-one structured telephone interview to provide feedback on the survey process (Figure 1).

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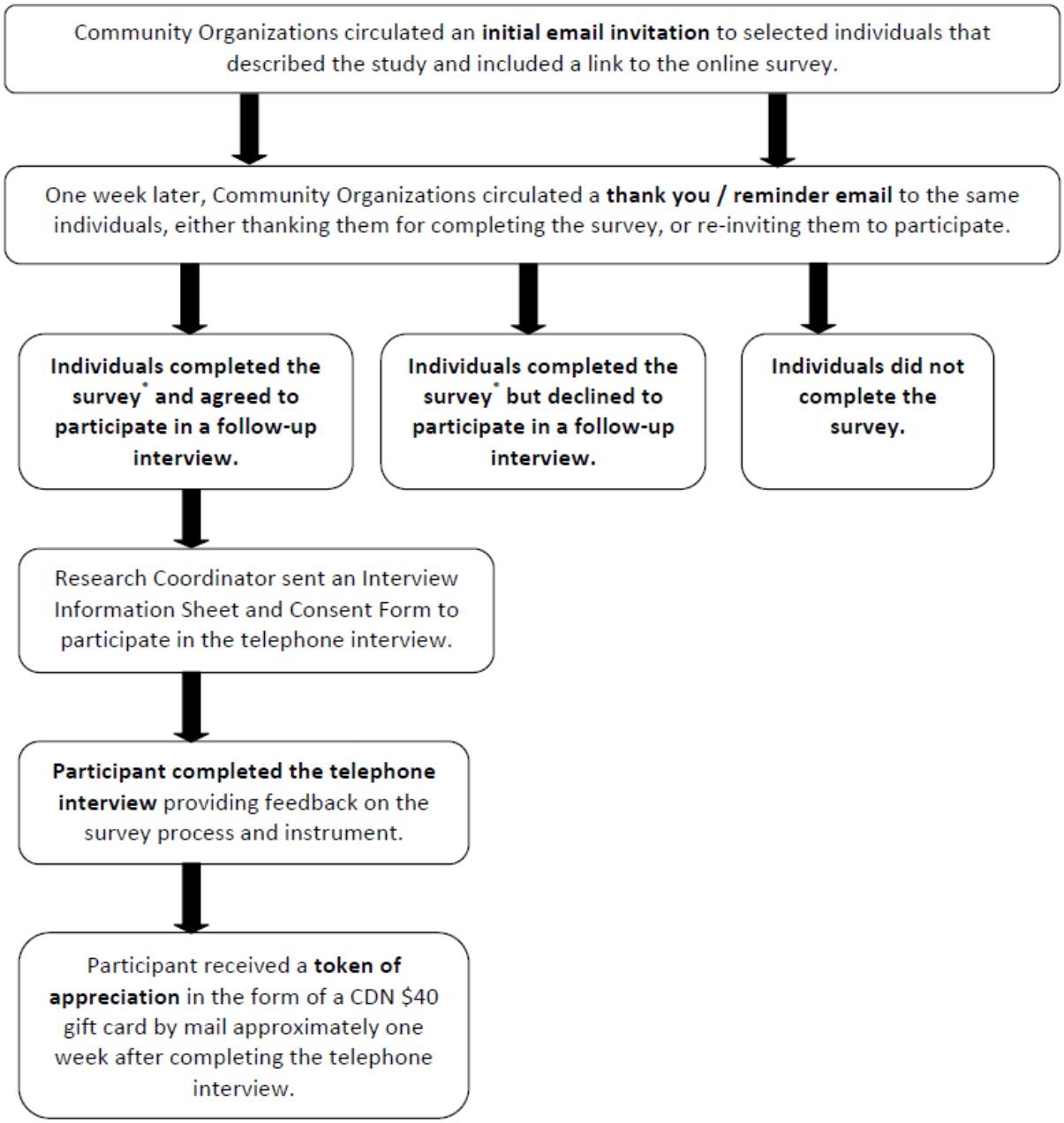
Figure 1. Overview of pilot survey procedure.



* The last screen of the survey asked participants to contact the Research Coordinator by email or phone to schedule a follow-up telephone interview.

HIV Community Partnerships

This research was a community-academic-clinical partnership among academic researchers, people living with HIV, and community-based and health provider organizations. Our team was comprised of eight researchers, five adults living with HIV, one clinician, and seven representatives from community and health provider organizations (categories were not mutually exclusive). Community members provided advice and guidance throughout all phases of this research to ensure successful development and implementation of the survey instrument with the HIV community. The Canadian Working Group on HIV and Rehabilitation (CWGHR) was the principal knowledge user in this research, providing community leadership in all aspects of this work. Our team has a longstanding history of working together in HIV and rehabilitation research. Researchers and community members worked in equal partnership, collectively involved in the conceptualization of the research objectives, application for funding, development of the survey instrument, and implementation and interpretation of the pilot findings. This research was approved by research ethics boards at McMaster University, University of Victoria, and Dalhousie University.

Survey Instrument Development

Our team of researchers and community members developed a survey instrument called the *HIV, Health and Rehabilitation Survey*, which aimed to describe disability, use of rehabilitation services, and other wellness living strategies used by people

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living with HIV to manage their health challenges. We developed the instrument collectively as a team, building upon existing frameworks and questionnaires to capture the key constructs of interest. The survey instrument was reviewed, revised, and pre-tested three times by our entire team. Pre-testing involved all team members independently reviewing the questionnaire for content, clarity, and format. Members of the team living with HIV completed the questionnaire as potential participants. We then met for a one-day face-to-face meeting to review the content, wording, format, and administration of the survey instrument and finalize our recruitment process prior to implementation. The final survey instrument was comprised of six components: (1) disability, (2) rehabilitation services use (occupational therapy, physical therapy, speech-language pathology, physiatry, complementary and alternative medicine therapies and providers, AIDS service organizations, and community-based service organizations), (3) comorbidities, (4) living strategies adopted by people living with HIV to deal with HIV and disability, (5) demographic and disease characteristics, and (6) stigma and social support. The survey questionnaire spanned 31 survey screens, four of which were conditional on type of rehabilitation services use. The instrument also included a welcome, eligibility/consent, and instruction page at the beginning and a thank you page at the end. We used LimeSurvey software to administer the survey [36].

Survey Implementation

We administered the survey instrument electronically via five community organizations using a modified Dillman Tailored Design Method [37] between December 2011 and February 2012. Eligible participants included adults (18 years of age or older) living with HIV in Canada who were able to read and understand English and who had access to the Internet and email. Community organizations (each represented by a community member on our team) circulated an initial email invitation to approximately 7-15 clients who they considered may be eligible for the study. Approximately one week after the initial email was sent out, organizations circulated a thank you/reminder email to the same clients.

As pilot testing aims to gather information from a wide range of potential study participants, recruitment included a combination of formal (email), informal (in-person), and snowball sampling. Sampling was selective, whereby members of organizations specifically approached individuals who they felt would be interested and willing to participate. The primary mechanism of recruitment was email; however, organizations also informally recruited individuals in person at the organization.

Telephone Interview

At the end of the survey, respondents were invited to take part in a 30-minute structured telephone interview to provide feedback on the survey process and instrument. Interested participants were emailed an information sheet and consent form. During the interview, participants were asked about how well the survey captured their disability, the health services utilized, and the living strategies they used to address the challenges of living with HIV. Participants also were asked about ease of use and readability of the survey instrument and their overall experience with the survey process. Responses were documented verbatim and later analyzed using directed content analysis [38]. Participants were offered a CDN $40 gift card as a token of appreciation for their participation.

Results

Recruitment and Participation

At least 56 adults living with HIV were invited to participate in the *HIV, Health and Rehabilitation Survey* pilot, of whom 30 accessed the survey link. Of the 30 who accessed the survey link and introductory page (53% view rate), 24/30 (80%) initiated the survey (participation rate) and 16/30 (53%) completed the survey (completion rate).

Among the 24 adults living with HIV who initiated the survey, 20 (83%) were notified about the survey from one of the five community organizations and 4 (17%) reported that they were forwarded the link from a friend (snowball sampling).

Demographic Characteristics of Pilot Survey Participants

The median age of survey participants was 52 years (range: 34-63 years) and the majority were men (17/24, 71%) living in a metropolitan geographic area (21/24, 88%). The majority of participants were diagnosed prior to the advent of antiretroviral therapy in the mid-1990s (16/24, 67%), and all were taking antiretroviral medications. Respondents lived in British Columbia, Manitoba, Alberta, Ontario, or Nova Scotia. A total of 22 participants (92%) reported living with at least one concurrent health condition, the most frequent including mental health conditions (14/24, 58%), joint pain (11/24, 46%), muscle pain (10/24, 42%), or addiction (7/24, 29%).

Given our aim was to pilot the *HIV, Health and Rehabilitation Survey*, results focus on the feedback received from participants on the survey instrument and implementation, followed by considerations for conducting community-engaged Web-based survey research with people living with HIV. Results from the full survey implementation will be published in a separate manuscript.

Pilot Survey Interviews

A total of 17 respondents expressed their willingness to participate in an interview, all of whom provided feedback on the Web-based pilot survey: 16 by telephone interview and one by email. Of these 17 participants, three did not complete the survey questionnaire but followed up with the research coordinator to express his or her interest in participating in the interview. See Table 1 for characteristics of the interview participants.

Table 2 summarizes the perspectives from the pilot participants across six themes: length of time to complete the survey questionnaire, overall thoughts on the Web-based survey, ease of usage and format, software, clarity of questionnaire, and token of appreciation (Table 2).

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Table 1. Characteristics of interview participants (n=16).

Characteristic		n (%)
Gender [a]		
	Man	12 (70%)
	Woman	2 (12%)
	Other	3 (18%)
Median age (range)		52 years (34-60 years)
Geographical location (province [a] **)**		
	British Columbia	11 (65%)
	Manitoba	3 (17%)
	Alberta, Ontario, or Nova Scotia	3 (17%)
Median year of HIV diagnosis (range)		1993 (1985-2005)
Number diagnosed prior to the advent of combination antiretroviral therapy (defined as diagnosis before 1996)		10 (59%)
Number taking antiretroviral therapy		16 (100%)
Number born in Canada		14 (88%)
Ever accessed rehabilitation services for HIV or another health condition		10 (62%)

[a]n=17; all other variables out of n=16.

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Table 2. Participants' perspectives on the survey instrument and process[a].

Theme	Pilot survey results
Length of time to complete the survey questionnaire	
	Majority of participants (10/15, 67%) completed the Web-based survey questionnaire in approximately 30-45 minutes (range: 10-70 minutes).
	Length of time to complete the questionnaire appeared to be linked with participants' familiarity with computers.
	Although 7 participants felt 30-45 minutes was an appropriate length of time to complete the survey, overall participants were divided on the appropriate length of time it should take to complete the survey questionnaire.
Overall thoughts on the Web-based survey questionnaire	
	Participants described the *HIV, Health and Rehabilitation Survey* questionnaire as "comprehensive", "detailed", "straightforward", which supported content validity in each section.
	Some participants found the instrument "too or very long", but were unable to suggest items to remove from the instrument, stating all was relevant and important.
	While some participants felt it was burdensome, others wanted more items to further explain their experiences.
Ease of usage and format	
	Majority of participants (13/17, 76%) felt instructions and item wording were clear and easy to understand.
	Some participants with English as a second language found challenges with the survey terminology.
	Participants were divided on whether they preferred a questionnaire that could be completed in one sitting versus having a save and return option.
	Some felt if participants were completing the survey in a public space (eg, community organization or library), an anonymous survey that could be completed in one sitting would be essential.
	Others expressed concerns about providing personal information required to save and return later, which could make them less willing to participate in the survey.
Software	
	LimeSurvey software was an ideal mechanism in which to administer the survey.
	The majority of participants (13/15, 87%) had no technological difficulties and found the software "straightforward", "easy to work through, go back and forth", and "easy to navigate".
	Some identified potential barriers such as the ability to access a computer and the ability for community organizations to have dedicated computers and space to complete the survey.
	Others raised potential barriers for those not familiar with computers.
	Participants appreciated having no timeout factor, which enabled them to complete the survey at their own pace on their own time. Eight participants used the option to move forward and back during the survey.
	Participants who navigated backwards did so when they realized they had missed certain items, wished to review answers, or wanted to add to an earlier answer when triggered by a later question.
	Participants appreciated having the completion proportion rate (%) at the top of the survey to monitor their progress.
	Eleven participants reported they did not intentionally skip questions in the survey. The majority of participants (12/16, 75%) favored having a pop-up reminder of missed items so that they could choose to go back to complete or confirm that they choose to refuse to answer.
Clarity of instructions and question wording	
	Majority of participants (13/16, 81%) felt that the instructions and questions were clear and there was flow to the sequence of items.
	Others found instructions and questions "wordy", response options "too much" or "a little bit hard to understand", and after a while reported: "I was just watching the completion bar".
Token of appreciation	
	Participants had varying preferences for the type of token of appreciation for their participation in the research, but felt it should not be less than CDN $20.
	Many liked the choice of an electronic gift card and preferred receiving an honorarium compared with having their name entered in a draw for a larger prize.

[a]Note the denominator may change based on the number of participants who responded to the interview question.

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Discussion

Overview of Findings

The Web-based *HIV, Health and Rehabilitation Survey* pilot highlighted important considerations for conducting Web-based surveys with people living with HIV. Despite existing reflections on Web-based surveys specific to men who have sex with men [12,13], and in the context of HIV testing and prevention [14-16], to our knowledge, this is the first article to present considerations for implementing a Web-based survey among people living with HIV using a community-based participatory approach. Our aim in conducting this pilot was to evaluate our recruitment and data collection methods, test the software, and refine our survey instrument [39]. Results will directly inform the full implementation of the *HIV, Health and Rehabilitation Survey* with adults living with HIV conducted in partnership with community-based organizations across Canada. Below we provide an overview of the strengths of our approach, and articulate considerations for conducting future community Web-based surveys with people living with HIV. Lessons learned from this pilot study may be more broadly applicable to others conducting community Web-based survey research in other chronic illnesses.

Strengths of HIV Community Web-Based Survey Research

Strengths of implementing our Web-based self-administered survey included the ease of software use, the ability for participants to complete the questionnaire on their own time at their own pace, and the ability to offer anonymity [3,4]. Well-constructed Web-based surveys may be appealing to respondents, which can increase representativeness of a population. These provide the ability to collect a large amount of data quickly across large geographical areas at a low cost, which is ideal for a national survey that aims to obtain both rural and urban perspectives [3]. Furthermore, evidence suggests response rates and reliability and validity of Web-based health status questionnaires are similar to questionnaires administered with pen and paper, with fewer recruitment efforts among people with chronic disease [40]. Allowing backward and forward navigation and including a pop-up reminder to prompt participants to complete missing responses may help to maximize future survey completion rates.

Our community-based participatory approach to this Web-based survey meant community members and organizations were integrally involved in all aspects of the survey process including development, pre-test, and piloting of the survey instrument. Developing the survey instrument and sampling strategy with community members helped to increase the relevance of the questionnaire to people living with HIV. Community organizations were essential to the recruitment of participants. Team members from the HIV community felt that receiving personal email communications from local community-based organizations may have helped to increase response rates [3]. With community organizations inviting over 50 individuals to participate, we were able to achieve our targeted sample of 30 individuals who accessed the survey link. Although fewer participated in an interview (n=17), we were able to obtain insightful feedback on the survey process and instrument that will enhance the next phase of implementation. Overall, our community-based participatory approach will help to ensure the survey is comprehensive, feasible, and contextually relevant to people living with HIV, while promoting integrated capacity-building and knowledge translation throughout [19].

Although the role of community was initially in an advisory capacity, the nature and extent of engagement increased over the course of this research. Through ongoing team meetings and individual consultations, community members became increasingly experienced and engaged in this work, and invested in the potential impact on their community. This ultimately led to an enhanced partnership and a strengthened and sustainable community-academic research team.

Considerations for HIV Community Web-Based Survey Research

Our experience illuminated key considerations for conducting Web-based survey research with people living with HIV using a community-based participatory approach.

While it has been suggested that no association exists between survey length and response rate [41], respondent burden and fatigue can increase attrition and missing responses, potentially reducing the validity of HIV Web-based survey research. Computer skills varied among participants resulting in disparities in the length of time to complete the survey and opinions on a feasible timeframe in which to complete the questionnaire. Although no standard length of time is recommended for Web-based surveys [14], researchers are challenged to develop a survey instrument that comprehensively captures the construct of interest while remaining feasible for participants with fewer computer skills in order to maximize response rate and limit sampling bias. Researchers should collaborate with the community to establish the appropriate length of survey instrument for a particular construct.

Completing a Web-based survey may trigger emotional responses, of which the researcher is unaware and unable to offer immediate support [42]. For some participants, completing items about disability and rehabilitation reminded them of the rehabilitation services they had available, evoking feelings of thankfulness, hope, and optimism. Alternatively, completing a questionnaire about disability could evoke feelings of anxiety or uncertainty. Web-based surveys can be useful when asking respondents about sensitive topics that may be difficult to discuss in person [4,5], enabling participants to respond more honestly, and reducing social desirability bias [6,12]. Researchers should consider the sensitive nature of HIV Web-based research and the potential to evoke emotional responses among participants. Removing the term “HIV” in email or e-blast subject headings may help to enhance privacy for those accessing computers in public spaces for whom disclosure is of concern. Providing participants with contact information for the research team and resources to offer support may help to minimize any adverse events [4].

Secure data management and storage to ensure respondent anonymity are essential for Web-based survey research with people living with HIV. Researchers should retain data on a

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secure server that is inaccessible to other parties and that is approved by their research ethics boards. Information regarding anonymity and data storage should be clearly articulated to participants in the introductory email and survey page so that individuals can make an informed decision about participation. Maintaining anonymity can be challenging when researchers aim to provide a token of appreciation to respondents [12]. Constructing a separate "token of appreciation" survey where respondents are invited to enter an email address to receive an electronic gift card, separate from the survey, may help to ensure anonymity of survey responses, but may still identify respondents as participants in the research. Furthermore, offering incentives in the context of an anonymized survey could lead to respondents duplicating or falsifying survey responses in order to take advantage of study incentives. Further research examining how to provide study incentives that do not encourage multiple survey submissions is needed [13].

Web-based research makes it difficult to verify informed consent. Volunteers independently interpret the purpose, risks, and benefits of participating in the research (often stated in the email invitation or introductory page of the instrument) and consent is implied based on the completion of consent items and the questionnaire. No opportunity exists for dialogue between the researcher and the participant to determine capacity to consent and complete the survey. In our study, we were unable to determine whether respondents truly understood the research and the questions asked, and we were limited in our ability to provide opportunities for clarification [4,12,42]. This has further implications for people living with HIV who may have varying neurocognitive ability. All components of the consent process including declaration of the study purpose, institutions behind the study, risks and benefits, and how privacy will be maintained should be made available online for the respondent [43,44]. Having clear questions that review eligibility criteria and asking participants to confirm their understanding of what is involved in participating may help confirm they have read the information and agree to participate in the study. Providing contact details of the research team also can help participants clarify details of informed consent [5].

Lack of computer and Internet access, and variability in computer skills may pose barriers for people living with HIV who wish to participate in Web-based surveys, resulting in potential selection bias and reduced generalizability [43]. Variation in Internet speed and devices such as desktop, laptop, or tablet, may pose implications for font size and further influence the ability to navigate Web-based surveys [37,45]. While resource intensive, researchers should consider having Internet-accessible computers and research or peer personnel support available within community-based organizations to maximize participation.

Finally, our community-based participatory research approach may be burdensome for community organizations with little time or mandate to engage in research beyond the scope of their current programs and services. Timelines of the email distribution varied depending on the workload across the five community organizations and it was difficult to ascertain the number of people who received the invitation email. Ongoing tailored communication with each organization is important for strategizing ways to maximize their ability to engage in HIV Web-based survey research with minimal burden.

Limitations

Our study is not without limitations. Respondents primarily included men over 50 years old living with HIV, recruited from AIDS Service Organizations, who were more likely to self-select to participate in the research. Hence, while our completion rate was slightly higher than 40% reported in a meta-analysis of 68 electronic surveys [3], respondents may not be representative of the broader HIV population. Estimates suggest that approximately only one-third of adults living with HIV in Ontario access an AIDS Service Organization [46,47]. These respondents may be linked with AIDS Service Organizations to access social support and services, suggesting they may have increased severity of self-identified health-related challenges compared with the broader HIV population. Moreover, Web-based surveys may not translate into higher response rates compared to other methods such as mailed surveys [48]. Increasing the number of email communications to three, ensuring email communication is personalized, along with pre-notification of the survey may help to increase response rate [3]. Finally, while concerns of multiple responses by the same person in Web-based surveys exist [4,43,49], we did not feel this was an issue in our pilot study, given the personalized nature of recruitment and length of reported time it took to complete the questionnaire. Researchers may consider monitoring IP addresses and assigning a unique identifier to every questionnaire viewer to determine participation rates and filter multiple responses [43]. However, this may not be feasible if surveys are completed by different respondents on the same computer at collaborating organizations.

Conclusions

Our experience piloting the *HIV, Health and Rehabilitation Survey* highlighted important considerations for the implementation of Web-based surveys with people living with HIV. Strengths included our community-based participatory approach, ease of software use, ability to complete the questionnaire on one's own time at one's own pace, opportunity to obtain geographic variation, and ability for anonymity. Considerations include respondent burden and fatigue, the potentially sensitive nature of HIV Web-based research and inability for researchers to provide immediate support, data management and storage, challenges verifying informed consent, varying computer skills among respondents, and the burden on community organizations. Results provide strategies for enhancing community participatory Web-based survey research in the field of HIV.

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Authors' Contributions

KKO led the conceptual design of the study, acquisition of funding, survey development and implementation, and drafted the manuscript. KKO, PS, CW, FIC, and SN were researchers and LB, RBT, GR, and EZ were community members who collectively participated in the conceptual design of the study, acquisition of funding, development and refinement of the survey instrument, implementation, and interpretation of the pilot findings. EZ was the principal knowledge user on the team who provided community leadership via the Canadian Working Group on HIV and Rehabilitation. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Original Paper

Multimodal Guided Self-Help Exercise Program to Prevent Speech, Swallowing, and Shoulder Problems Among Head and Neck Cancer Patients: A Feasibility Study

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Abstract

Background: During a 6-week course of (chemo)radiation many head and neck cancer patients have to endure radiotherapy-induced toxicity, negatively affecting patients' quality of life. Pretreatment counseling combined with self-help exercises could be provided to inform patients and possibly prevent them from having speech, swallowing, and shoulder problems during and after treatment.

Objective: Our goal was to investigate the feasibility of a multimodal guided self-help exercise program entitled Head Matters during (chemo)radiation in head and neck cancer patients.

Methods: Head and neck cancer patients treated with primary (chemo)radiation or after surgery were asked to perform Head Matters at home. This prophylactic exercise program, offered in three different formats, aims to reduce the risk of developing speech, swallowing, shoulder problems, and a stiff neck. Weekly coaching was provided by a speech and swallowing therapist. Patients filled out a diary to keep track of their exercise activity. To gain insight into possible barriers and facilitators to exercise adherence, reports of weekly coaching sessions were analyzed by 2 coders independently.

Results: Of 41 eligible patients, 34 patients were willing to participate (83% uptake). Of participating patients, 21 patients completed the program (64% adherence rate). The majority of participants (58%) had a moderate to high level of exercise performance. Exercise performance level was not significantly associated with age (P=.50), gender (P=.42), tumor subsite (P=1.00) or tumor stage (P=.20), treatment modality (P=.72), or Head Matters format (Web-based or paper) (P=1.00). Based on patients' diaries and weekly coaching sessions, patients' perceived barriers to exercise were a decreased physical condition, treatment-related barriers, emotional problems, lack of motivation, social barriers, and technical problems. Patients' perceived facilitators included an increased physical condition, feeling motivated, and social and technical facilitators.

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Conclusions: Head Matters, a multimodal guided self-help exercise program is feasible for head and neck cancer patients undergoing (chemo)radiation. Several barriers (decreased physical condition, treatment-related barriers) and facilitators (increased physical condition, feeling motivated) were identified providing directions for future studies. The next step is conducting a study investigating the (cost-)effectiveness of Head Matters on speech, swallowing, shoulder function, and quality of life.

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KEYWORDS

eHealth; self-care; head and neck cancer; exercise; speech; swallowing; shoulder; surgery; radiotherapy; chemotherapy

Introduction

Head and neck cancers (HNC) in the oral cavity, nasopharynx, oropharynx, hypopharynx, and the larynx represent 5% of all cancers. About 2800 new cases are reported in the Netherlands each year. Treatment intensification using multimodality approaches, such as accelerated radiotherapy (RT), concomitant chemotherapy, and surgery with adjuvant radiotherapy with or without chemotherapy result in a significant improvement in loco-regional control and overall survival [1-3]. During a 6-week course of RT, many patients have to endure radiotherapy-induced toxicity such as oral mucositis, pain, salivary changes, dry mouth, skin toxicity, hoarseness, swallowing problems, trismus, fibrosis in the orofacial region, throat, neck and shoulders, and stiffness and pain in the neck and shoulders [4-15]. These acute side effects of radiation result in a significant symptom burden and interfere with normal physiologic functions and daily activities, such as chewing, swallowing and speech, and related social withdrawal and psychological distress, negatively affecting patients' quality of life [16,17]. Swallowing problems are among the most cited functional impairments after chemoradiotherapy [18-20] with an estimated prevalence of 43% to 64% [21,22]. These results emphasize the importance of prevention, monitoring, and management of swallowing dysfunction as an integral part of treatment protocols [23].

It is expected that fewer speech and swallowing problems persist when these acute side effects of radiation are prevented and/or managed in an early stage [24,25]. Pretreatment counseling by a speech and swallowing therapist (ST) could be provided to inform the patient and family on possible speech and swallowing problems that may occur during and after treatment [26]. Patients should, for example, be informed about the importance of continuing to swallow throughout their courses of (chemo)radiation ([C]RT), because inactivity of the swallowing muscles may lead to disuse atrophy, and then lead to future, temporary inability to consume food orally and long-term feeding tube dependency [19,27,28]. In order to possibly prevent atrophy of the head and neck muscles, to maintain speech and swallowing function, and to improve functional swallowing outcome and swallowing-specific quality of life following (C)RT, counseling combined with exercise prescription should be provided prior to (C)RT [29-34].

Research is, however, still in an early stage and much is unknown [35,36]. As a result, not all patients with HNC undergoing (C)RT are prescribed a standardized exercise program as a preventive measure [37]. Given the burdensome period of (C)RT for HNC patients, there is an urgent need for an easily accessible prophylactic education and exercise program, countering the radiation fibrosis, and safeguarding patients against additional consults with health care professionals during (C)RT. A multimodal self-help program is expected to enhance reach by overcoming logistical and financial barriers both on the part of health care providers and patients [38,39]. To our knowledge, there are no self-help programs offered with remote coaching, targeting prevention of deterioration of speech, swallowing, and shoulder function.

Therefore we developed Head Matters (HM), a multimodal guided self-help exercise program for HNC patients during (C)RT. The aims of the present feasibility study were (1) to explore uptake, adherence, and exercise performance (by exercise levels and exercise categories) of the guided self-help exercise program HM in HNC patients, (2) to explore predictors of exercise performance, and (3) to gain insight into barriers and facilitators to exercise adherence.

Methods

Description of the Self-Help Exercise Program Head Matters (HM)

HM was developed by a team of health care professionals consisting of speech and swallowing therapists, otolaryngologists, head and neck surgeons, radiation oncologists, and a physiotherapist. HM comprises one face-to-face pretreatment counseling session, on the first day of (C)RT, to inform the patient of possible speech, swallowing, and shoulder problems during treatment and to encourage patients to maintain speech, swallowing, and shoulder function during treatment. HM consists of a 15-minute per day program with four categories of prophylactic exercises: (1) exercises to maintain mobility of the head, neck, and shoulders, (2) exercises to optimize and maintain swallowing function, (3) exercises to optimize and maintain vocal health and vocal function, and (4) exercises to optimize and maintain speech function and functional communication. Coaching is offered in weekly 10-minute coaching sessions by an experienced ST by phone or email.

Because the target group (HNC patients) does not have equal access to the Internet, HM is available in three different formats. Both the online format and booklet format offer general information about HNC and its treatment, with written descriptions of the exercises, and with photo and video examples of the exercises either offered online [40] or by means of a 15-minute instructional DVD. The third format consists of a 2-paged A4 leaflet that offers only a written description of the exercises. Multimedia Appendix 1 shows an overview of

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exercise categories and the three formats of HM. Examples of screenshots of the online format are shown in Figures 1 and 2.

Figure 1. Screenshot of Head Matters: general information about head and neck cancer.

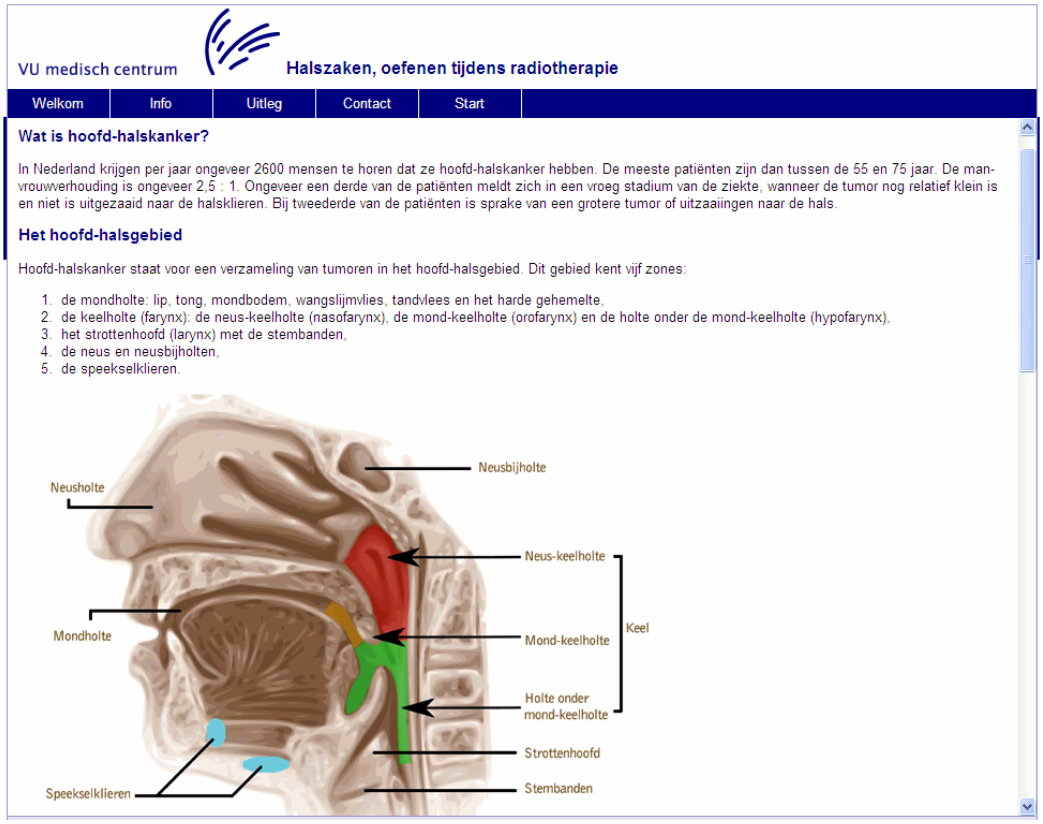

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Figure 2. Screenshot of Head Matters. Exercise 1: Move your shoulders up and down.



Study Sample and Procedure

HNC patients treated at the VU University Medical Center Amsterdam, the Netherlands, had to fulfil the following criteria to be included in this feasibility study: (1) age ≥18 years, (2) HNC originating in the oral cavity, oropharynx, hypopharynx, or larynx, (3) stage I-IV cancer, according to the Union for International Cancer Control (UICC) TNM-classification system, (4) no distant metastases, (5) radiation, (C)RT or postoperative (C)RT, and (6) absence of any psychological, familial, sociological, or geographical condition potentially hampering compliance with the study protocol. Three radiation oncologists introduced the study to eligible patients who met the inclusion criteria based on medical chart reviews, and based on the conversation with the patient during a regular consultation. If a patient expressed interest in participation, he or she was approached by the researcher for further details about the study. The patient's written informed consent form was obtained.

Patients were invited to perform HM at home, at least once a day. If a patient was willing to perform the exercises, a 15-minute face-to-face instruction session by an ST was planned on the first day of (C)RT. Safety was ensured by demonstrating each exercise appropriately, by giving the participants adequate instructions on each exercise, and by providing an instruction leaflet, an instruction booklet (with DVD), or a log-in code to activate an account for the website [40]. Postoperative participants were offered the HM program on a leaflet. Patients with Internet access and treated with (C)RT were offered the HM online format and the HM instruction booklet with general information about HNC, written instructions, and photo demonstration. Patients without Internet access and treated with (C)RT were offered the HM instruction booklet with general information about HNC, written instructions, and photo and video demonstration (on DVD).

Patients were asked to fill out a diary on paper or online for 6 weeks. In their diaries, patients noted which exercises they performed (of the four categories), and the frequency of exercising (1, 2, or 3 times per day.)

During 6 weeks of exercising with (C)RT, subjects participated in weekly 10-minute coaching sessions by an ST by phone or email to maintain motivation and to help them to achieve adherence to the HM protocol. During these coaching sessions, open-ended questions about general well-being were asked ("How are you?") and questions about exercise performance ("Could you tell me something about your exercise frequency this week?", and "Could you name any reasons (not) to exercise?"). The ST took a supportive role, while actively asking the participants for further explanations of their answers when necessary. During these weekly coaching sessions, notes were taken.

The study was conducted according to regular procedures of the local ethical committee of the VU University Medical Center, Amsterdam.

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Measures

Demographic (ie, gender, age) and clinical (ie, tumor subsite and stage, treatment modality) information of participating patients was extracted from the hospital information system.

Uptake

Uptake of HM addressed how many patients were willing to start HM during (C)RT (uptake percentage).

Adherence

Adherence concerned the degree to which HNC patients followed HM at least once a day during 6 weeks of (C)RT and was assessed in two ways: (1) patient-completed diaries, and (2) percentage of patients who started and kept up exercising for 6 weeks.

Exercise Performance Level

Patient-completed diaries were used to identify exercise performance levels. A low level of exercise performance consisted of an exercise performance of all exercise categories during 6 weeks at most once a day on average (range 0-168). A moderate level consisted of an exercise performance of all categories during 6 weeks between once and twice a day on average (range 169-336). A high level of exercise performance was defined as an exercise performance of all exercise categories during 6 weeks at least twice a day on average (range 337-504).

To gain insight into which exercises were performed most often, the diaries were analyzed in more detail regarding the frequency of exercising (1-3 times) and type of exercise (four categories). Exercise performance by exercise format was defined as how well the prescribed exercise regimen was followed by patients, following a specific format (online exercising or exercising by leaflet or booklet).

Feasibility

HM is defined to be feasible in case of an uptake percentage >50%, adherence rate >50%, and when >50% of the patients perform at least the minimum number of exercises (168) during 6 weeks (moderate or high performance level). This definition of feasibility is based on adherence rates reported in previous research [32,37]. In a retrospective study, adherence to unsupervised, home-based swallowing exercises is quite low, ranging from 13% for full adherence to 32% for partial adherence [37]. Van der Molen [32] retrospectively assessed adherence via two self-report items estimating duration of adherence in days and familiarity with exercises 10 weeks after treatment. They found that 14% of the total sample reported doing exercises every day during the entire radiation treatment and follow-up period and that 57% stopped their exercises after an average of 3.5 weeks.

Barriers and Facilitators to Exercise

Reports of the coaching sessions were used to identify patients' perceived barriers and facilitators to perform HM during (C)RT.

Data Analysis

Quantative data were analyzed using IBM SPSS Statistics for Windows, version 20. Descriptive statistics were used to summarize the sociodemographics and clinical characteristics of the study participants and the data on uptake, adherence, and performance level of HM.

Patients were categorized regarding exercise performance level (low, moderate, high), and age (≤60 years vs ≥61 years, based on median split), tumor subsite (oral cavity, oropharynx, hypopharynx, larynx, other), tumor stage (I, II, III, IV), treatment (RT, chemoradiation [CRT], surgery, and [C]RT), and format of HM (leaflet, booklet, online). Fisher's Exact tests were used to determine differences in exercise performance level (performance level low vs moderate/high) regarding age, gender, tumor subsite (oral cavity/oropharynx vs hypopharynx/larynx), tumor stage (stage I/II vs III/IV), treatment modality ([C]RT vs postoperative [C]RT), and format of HM (online vs leaflet vs booklet). For all analyses, $P \leq .05$ was considered statistically significant.

Reports of the weekly coaching sessions were analyzed by 2 independent observers (IC and CvU). Both coders separately read all reports of the weekly coaching sessions several times to familiarize themselves with the data. Barriers and facilitators for exercising were selected and coded independently into categories. Subsequently, the coders met to discuss their findings and resolve differences with the aim of reaching consensus, after which categories were refined, and subcategories were identified. The coders met regularly with a third coder (IV) to resolve disagreements in coding.

Results

Uptake and Participants' Characteristics

In total, 41 eligible patients were referred to the study. Due to shortage of time, 7 of the 41 patients refused to participate; 34 patients agreed to participate and were enrolled in the study (83% uptake). One patient agreed to participate but died 1 week after giving written informed consent. Eleven postoperative patients (33%) received HM on a 2-paged leaflet, 11 patients (33%) chose to receive HM in a 28-page booklet format with photos and video examples on a DVD, and another group of 11 patients (33%) chose to receive HM online.

The mean age of the participants was 60 years (range 21-77). Of the 33 patients (76% male, and 24% female), one third of the patients was treated with RT (33%), one third of the patients was treated with CRT (33%), and one third with surgery (33%). After surgery, 7 patients received postoperative RT, and 4 patients received postoperative CRT (Multimedia Appendix 2).

In the planned face-to-face instruction session, 26 of the 33 patients (79%) received exercise instructions on day one of (C)RT. The other 7 patients (21%) received their exercise instructions 3-11 days earlier and started exercising before (C)RT started. In total, 33 patients filled out a diary.

Adherence and Exercise Performance Level

Of the 33 patients who were interested in performing exercises, 21 patients started and kept up exercising for 6 weeks (64% adherence rate). Of the 33 patients, 14 patients (42%) were performing the exercises at a low level (exercise frequency range of 4-167 during 6 weeks), 10 patients (30%) were exercising at a moderate level (exercise frequency range of

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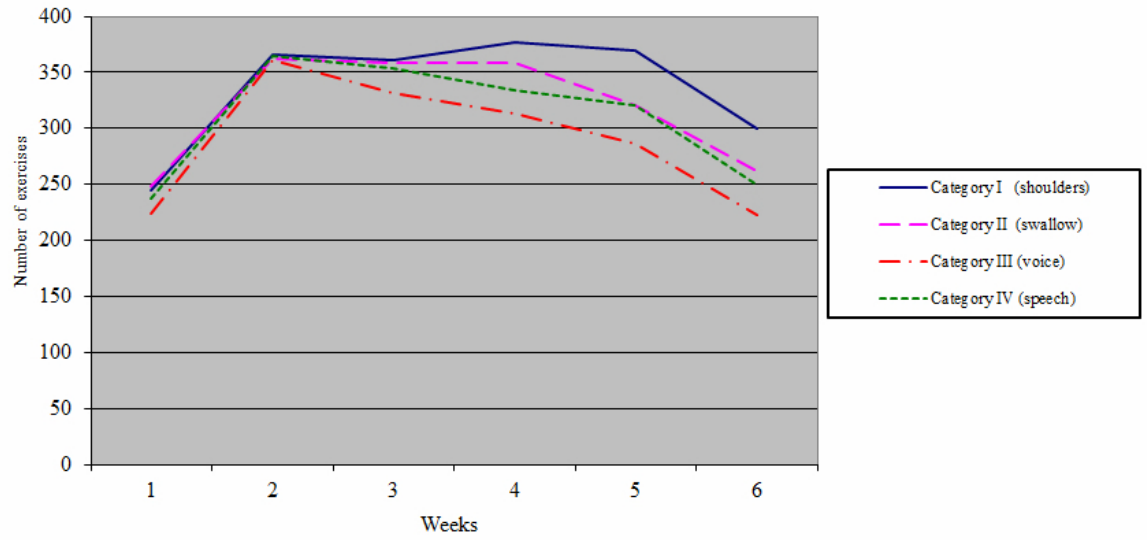
196-332), and 9 patients (27%) were exercising at a high level (exercise frequency range of 372-495) (Multimedia Appendix 3).

Exercise Performance by Exercise Category

Figure 3 presents an overview of all 33 patients regarding the course of exercise through the 6 weeks of (C)RT. Patients most often performed the exercises to maintain mobility of the head, neck, and shoulders. The exercises least performed by patients were to optimize vocal health and maintain vocal function. During the first 2 weeks, exercise performance of all 33 patients increased from 224 to 366 exercises, on average. After the second week, a decline in exercise performance of all participants in all exercise categories was observed. During the sixth week of (C)RT, patients were still performing HM exercises, with an average of 259 times.

Based on these results, HM appears to be feasible in general, with an uptake percentage >50% (in the present study 83%), with an adherence rate >50% (in the present study 64%), and with a moderate to high performance level >50% of the patients performing exercises in all categories at least once a day on average (in the present study, 58% of the participants).

Figure 3. Weekly exercise performance by exercise category.



Predictors of Exercise Performance

Exercise performance level was not significantly related to age (P=.50), gender (P=.42), tumor subsite (P=1.00), tumor stage (P=.20), or treatment modality (P=.72). Exercise performance level was also not significantly different regarding HM format (P=1.00).

Barriers to Exercise

Overview

From the analysis of reports of weekly coaching sessions, several barriers to perform HM emerged: a decreased physical condition, treatment-related barriers, emotional problems, lack of motivation, social barriers, and technical problems (Multimedia Appendix 4).

Decreased Physical Condition

During coaching sessions, participants commented that they did not perform the exercises because of oral complications and throat problems (eg, swallowing, speech and voice problems, limited mouth opening, skin and oral wounds, oral infections, saliva problems, swelling, taste problems, having a poor appetite, and dental extractions), as well as stiffness in the neck and shoulders. In addition, participants mentioned more general physical symptoms resulting from cancer or cancer treatment, such as pain, nausea, weight loss, and fatigue, which prevented them from performing the exercises.

Treatment-Related Barriers

Some participants indicated that daily travelling to the outpatient clinic for (C)RT or just the (C)RT itself was too time-consuming to perform exercises. Others mentioned feeling embarrassed having to perform (voice) exercises in a hospital ward during hospitalization for chemotherapy.

Emotional Problems

Some participants noted that they found it difficult to focus on and pay attention to HM due to emotional problems (eg, anxiety, worrying, having panic attacks, feeling scared).

Lack of Motivation

Some participants indicated that they did not feel motivated to exercise because of not experiencing any complaints. Others mentioned that they were not convinced that the exercises would help. Some did not feel motivated to perform the exercises at home and preferred face-to-face contact with an ST. Others commented that the exercise program would distract them from their daily routine or reported a lack of motivation because of a “perceived information overload” during treatment.

Social Barriers

Some participants reported problems combining HM at home and work situations. Especially informal caregivers and participants with job responsibilities could not find the time to exercise and felt not able to concentrate on the exercise program.

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Technical Problems

With regard to technical issues, patients reported installation problems and were not able to see the demonstration videos on the computer. One participant indicated that the exercise repetitions on DVD took too much time, leading to boredom. Four participants mentioned that they lost their log-in password or forgot the website address and therefore could not see the exercise demonstrations on video.

Facilitators to Exercise

Overview

Besides barriers, facilitators to perform HM during (C)RT emerged: an increased physical condition, a general sense of psychological well-being, feeling motivated, and social and technical facilitators (Multimedia Appendix 4).

Increased Physical Condition

Some participants mentioned that a regained vocal function, an improved appetite, and a decreased size of their tumor enabled them to perform HM. Others mentioned that an increased general physical condition (eg, regained energy) facilitated exercise performance.

General Sense of Psychological Well-Being

Some participants stated that a general sense of psychological well-being, expressed as feeling good and being good-humored, encouraged them to perform the exercises.

Feeling Motivated

Participants reported enhanced motivation to perform the exercises because the exercises were simple and easy to follow. A motivational facilitator for some of the participants was that they knew the exercises by heart and could therefore perform the exercises while taking a shower or while on their way to the hospital (in a taxi). Some reported that they enjoyed the exercises because they experienced them as relaxing. They indicated liking the swallowing strategies at breakfast, lunch, or dinner. Others stated feeling motivated because, by adhering to the exercise program, they felt able to contribute to their own recovery process. Some stated that they adapted the exercises to their own ability and decided to perform the exercises more carefully and slower than demonstrated, and in shorter sessions throughout the day.

Participants stated that they enjoyed the design of HM. They especially mentioned the face-to-face introduction of the exercises and weekly coaching sessions as motivational.

Social Facilitators

Participants indicated social support in the home situation to be an important facilitator. Some felt encouraged to exercise because they performed the exercises together with their partner and/or family. Others felt motivated because their partner and/or family reported improvement due to exercising, such as a better speech function. One participant reported performing (more of) the exercises while being off duty, while another performed (more of) the exercises during working hours.

Technical Facilitators

Online or DVD exercise demonstrations were indicated by participants as an enabler to perform the exercises (in the right way and at the same place) as instructed.

Discussion

Principal Findings

Results from this feasibility study indicated that the guided self-help exercise program HM is feasible among HNC patients undergoing primary or postoperative (C)RT with high uptake and reasonable adherence rates. The majority of the included patients performed at least the minimum number of exercises during 6 weeks (moderate or high performance level).

The majority of HNC patients in our study (34/41, 83%) responded positively to the offer of pretreatment counseling on exercises to maintain speech, swallowing, and shoulder function while undergoing (C)RT. While the efficacy of our guided self-help exercise program is yet to be demonstrated, the high uptake of HM suggests that this program may have addressed specific needs among the target population.

To understand the true benefits of an exercise program, the adherence rates of patients involved in such programs is one of the key issues [31]. In the present study, adherence rate to the home-based HM program was 64%. Adherence to similar prophylactic exercise programs targeting HNC patients varied between 14% (a home-based program) [32] and 68% (twice a week supervised hospital-based exercises, combined with home-based exercises) [32-34]. Results are, however, not fully comparable because HM, unlike the other interventions, is a self-help program. Self-help programs, especially those administered online, often suffer from non-adherence [41,42]. The adequate adherence rate found in our study suggests that an exercise program such as HM can be offered in a home-based self-help format, with the use of self-regulating strategies, including diary keeping, possibly enhancing motivation, and adherence.

We explored predictors of exercise performance in HNC patients willing to use a guided self-help exercise program during (C)RT with minimal therapist guidance, offered in three exercise formats. Initially, we developed a leaflet format, followed in a later stage by an online and booklet format of HM, including photo and video demonstration of the exercises. Although we expected the later formats would possibly lead to a higher exercise performance level, in the present study no relation between exercise performance level and exercise format (exercising online or exercising by leaflet or booklet) were found. The small sample size of this feasibility study, lack of randomization, and lack of statistical power limited the comparability of findings and may explain why exercise performance levels and exercise format were not related significantly. Furthermore, exercise performance levels were based on patient-completed diaries and may not truly reflect the user's experience and dose. In the upcoming study on (cost-)effectiveness of HM, we will maintain the online and booklet formats. The use of Web-based diaries enables health care providers to send reminders to participants and may provide

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interactive Internet feedback tailored to each patient, improving adherence. Despite the high prevalence of Internet access in the Netherlands and advantages of eHealth interventions, including multimedia presentation, easy updating of the information provided and tailoring, we think a booklet format is still required [43]. Within a specific part of the population of HNC patients (with higher age and lower socioeconomic status) the percentage of patients for whom an online intervention is not eligible is deemed high, because of low eHealth literacy skills, concerns about Internet privacy, and/or preferences for using a booklet [44,45]. Furthermore, online exercise videos and exercise demonstrations on DVD help HNC patients to safely and properly perform the exercises. Although the adherence rate in the present study was adequate (64%), efforts to increase adherence rate are needed. Low or non-adherence has been proposed as a risk and a reason for a possible limited impact of self-help programs [46].

To understand and possibly intervene in the process of non-adherence, our third objective was to study patients' perceived barriers and facilitators to adhere to HM. Barriers to adhere to HM are comparable to results of other studies on prophylactic education and exercise programs, either home-based and/or institution-based, targeting patients who are about to undergo (C)RT for HNC [32,34]. Physical barriers to perform self-help exercises as identified in our study are in accordance with the findings of Kotz [34], who reported that 69% of HNC patients were unable to perform the swallowing exercises throughout the entire course of (C)RT because of oral pain, throat discomfort, and overall fatigue. Van der Molen [32] reported that 37% of HNC patients stopped training because of pain in the mouth, nausea, and fatigue. Additionally, Lagorio and Carnaby-Mann [47] reported that adherence of the preventative swallowing exercises was significantly associated with presence of depression and fatigue. Overall, it is important to realize that HNC patients often struggle to cope with the challenges of treatment while attempting to manage the other aspects of their lives such as work responsibilities, family issues, and social relationships [48]. HNC patients in our study reported time constraints, time consuming treatment protocols, being a caregiver, and distraction of daily routine as barriers to adhere to the HM exercises. These reports are consistent with previous qualitative studies [49,50]. During coaching sessions, exercise acceptance and adherence may be improved by paying attention to psychosocial factors [42,47], for example by providing e-counseling [51-53]. These counseling interventions deserve attention and may be uniquely beneficial as they spare patients the cost and burden of traveling to a hospital for psychosocial care [54]. However, the effects of such (psychosocial) interventions are yet unclear [55]. Future research is needed to assess the impact of (combined) coaching strategies (face-to-face, email, and/or telephone contact).

In the present study, several adherence facilitators related to the multimodal design of HM were identified, such as simple and easy-to-follow exercises, online or DVD demonstrations, the face-to-face introduction of HM, and the weekly coaching sessions. Efforts to enhance exercise adherence in HNC patients should focus on optimizing enjoyment while managing symptoms, providing education in overcoming treatment-related barriers, helpful types of support, self-monitoring, reminders, and telephone follow-up [56-58]. Other researchers suggest the use of a hook (a message or program design to build curiosity) to engage participants who are starting the intervention [49].

Results of earlier studies demonstrated the importance of the introduction session of a self-help program, to be able to achieve a successful dissemination. For health-related interventions, it is deemed crucial that the introduction is provided by a care professional who is a credible source for patients and who is committed to the program [59]. HM has the advantage that health care professionals have been involved in the development of the intervention, which increases commitment to the intervention and hereby the chance of optimal dissemination [60].

Limitations

The outcome of our feasibility study provided support that a guided self-help exercise program during (C)RT is feasible. However, some limitations should be mentioned. The results were based on a relatively small sample size from a single center setting, which may have hampered the generalizability. Furthermore, no information was obtained from patients who refused to participate. Information from a non-participating group of patients would give a more balanced view of the perceived barriers to the HM program and to the feasibility of the program.

Another limitation was that exercise adherence and performance levels were reported on the basis of patients' self-reported data (diaries). Use of paper diaries to capture patient experiences are favored due to familiarity, ease of use, low cost, and allowing locus-of-control by the patient. However, intentionally or not, many individuals may have difficulty keeping faithful records. Furthermore, the data may have been influenced by social desirability effects [61,62] and may not truly reflect the user's experience and dose. Ideally, self-reports should be supplemented using alternative objective sources of data, such as usage statistics (number of log-ins, frequency, duration, activities completed, time spent online, pages opened), combined with qualitative measures, such as semistructured telephone interviews [63,64].

Though strengths of the present study include high uptake, the position of both the researcher and participant need to be considered. As typical of evaluative research, the interaction between an evaluator and participant may have produced an understanding that portrayed the feasibility in an excessively positive light. Hence, future research will focus on consistency of the barriers and facilitators perceived by participants with findings from quantitative analysis of adherence and the impact of different HM formats [65].

Finally, we explored barriers and facilitators to adherence. The qualitative nature of these data in this study did not enable us to identify the barriers and facilitators that would make the largest contribution to the adherence with and compliance to the self-help program. Further quantitative research is therefore needed.

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Conclusions

This feasibility study demonstrated that a multimodal guided self-help exercise program HM is feasible for HNC patients undergoing (C)RT. Feasibility of the exercise program in HNC patients is supported by high uptake (83%) and a reasonable adherence (64%). Several barriers (decreased physical condition, treatment-related barriers) and facilitators (increased physical condition, feeling motivated) were identified providing directions for future studies. Because HM is feasible, a study will be carried out investigating the (cost-)effectiveness of self-help exercises among HNC patients to prevent speech, swallowing, and shoulder problems after treatment.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Overview of Head Matters: exercise categories and formats.

[PDF File (Adobe PDF File), 23KB - jmir_v16i3e74_app1.pdf]

Multimedia Appendix 2

Patient characteristics.

[PDF File (Adobe PDF File), 22KB - jmir_v16i3e74_app2.pdf]

Multimedia Appendix 3

Exercise performance levels.

[PDF File (Adobe PDF File), 25KB - jmir_v16i3e74_app3.pdf]

Multimedia Appendix 4

Patients' perceived barriers and facilitators to perform Head Matters.

[PDF File (Adobe PDF File), 24KB - jmir_v16i3e74_app4.pdf]

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Abbreviations

(C)RT: (chemo)radiation
CRT: chemoradiation
HM: Head Matters
HNC: head and neck cancer
RT: radiotherapy
ST: speech and swallowing therapist
TNM: classification of Tumor size, lymph Nodes, and Metastasis
UICC: Union for International Cancer Control

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Original Paper

Animated Randomness, Avatars, Movement, and Personalization in Risk Graphics

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Abstract

Background: Risk communication involves conveying two inherently difficult concepts about the nature of risk: the underlying random distribution of outcomes and how a population-based proportion applies to an individual.

Objective: The objective of this study was to test whether 4 design factors in icon arrays—animated random dispersal of risk events, avatars to represent an individual, personalization (operationalized as choosing the avatar's color), and a moving avatar—might help convey randomness and how a given risk applies to an individual, thereby better aligning risk perceptions with risk estimates.

Methods: A diverse sample of 3630 adults with no previous heart disease or stroke completed an online nested factorial experiment in which they entered personal health data into a risk calculator that estimated 10-year risk of cardiovascular disease based on a robust and validated model. We randomly assigned them to view their results in 1 of 10 risk graphics that used different combinations of the 4 design factors. We measured participants' risk perceptions as our primary outcome, as well as behavioral intentions and recall of the risk estimate. We also assessed subjective numeracy, whether or not participants knew anyone who had died of cardiovascular causes, and whether or not they knew their blood pressure and cholesterol as potential moderators.

Results: Animated randomness was associated with better alignment between risk estimates and risk perceptions ($F_{1,3576}$=6.12, P=.01); however, it also led to lower scores on healthy lifestyle intentions ($F_{1,3572}$=11.1, P<.001). Using an avatar increased risk perceptions overall ($F_{1,3576}$=4.61, P=.03) and most significantly increased risk perceptions among those who did not know a

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particular person who had experienced the grave outcomes of cardiovascular disease ($F_{1,3576}$=5.88, P=.02). Using an avatar also better aligned actual risk estimates with intentions to see a doctor ($F_{1,3556}$=6.38, P=.01). No design factors had main effects on recall, but animated randomness was associated with better recall for those at lower risk and worse recall for those at higher risk ($F_{1,3544}$=7.06, P=.01).

Conclusions: Animated randomness may help people better understand the random nature of risk. However, in the context of cardiovascular risk, such understanding may result in lower healthy lifestyle intentions. Therefore, whether or not to display randomness may depend on whether one's goal is to persuade or to inform. Avatars show promise for helping people grasp how population-based statistics map to an individual case.

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KEYWORDS

risk graphics; health communication; cardiovascular disease; animation; avatar; pictograph; icon array

Introduction

Health risk communication is an inherently challenging proposition. People's risk perceptions are shaped by powerful cognitive and affective biases [1,2] and often align poorly with their actual risk [3-5], even when they are provided with accurate risk estimates [6]. In other words, people at low risk may feel at considerable risk, whereas people at high risk may not perceive themselves as such.

Lack of alignment between actual and perceived risk may be partly due to barriers to comprehension, such as low health literacy or, in the case of communication about numbers, low numeracy [7,8]. Across levels of education and expertise, many people, particularly those with poor numeracy, have trouble interpreting numbers in health risk communications [9,10] and demonstrate biased interpretations of proportions [11,12].

Icon arrays (or pictographs) are graphical displays, often with 100 or 1000 icons arranged in rows and columns and in which each icon represents one unit in the population of interest. They have been shown to help people overcome natural tendencies toward misinterpretation [13] and, for people with low numeracy, maximize comprehension compared to other graphic types and text or numbers alone [14-18]. However, despite their advantages, they can still fall short of facilitating full comprehension [19].

One of the key challenges to such comprehension is adequately conveying the inherent uncertainty of risk statistics. In this study, we aimed to address the issue of aleatory or first-order uncertainty, which has been highlighted as an entrenched conceptual problem and a key challenge when communicating risk. First-order uncertainty arises from the "fundamental indeterminacy" of future events [20]. We operationalized the communication of such indeterminacy as consisting of 2 related challenges: conveying the randomness of events and helping people grasp how population-based statistics map onto individual circumstances.

Randomness is conceptually challenging, especially for people with little training in statistics. For example, many people believe that their iPod's shuffle feature does not actually choose songs randomly because the algorithm may play several songs from the same album in a row, or the user may not hear a new song within their expected time frame. These perceptions persist even though such behaviors on the part of the algorithm are perfectly reasonable within a random ordering [21]. In health communication, previous work suggests that using randomly dispersed events in pictographs may help to better convey the randomness inherent in population-based risk estimates; however, this work also suggests that people may find such graphics confusing, may find the estimate less certain, and may have a more difficult time interpreting the magnitude of the risk when it is scattered randomly in the display [22-28]. Our research group previously tested methods of simultaneous animated randomness in the context of 2 side-by-side icon arrays and found, similarly, that many methods of displaying randomness resulted in confusion, but that at least one method had promise [29].

In addition to the challenge of interpreting the meaning of background randomness, it is difficult for people to map population-based statistics, which are often proportions, onto individual circumstances, which are often whole numbers. No matter how average they might be, a family cannot, after all, actually have 2.3 children [30]. When it comes to health risks, it can be conceptually difficult to apply the information that a side effect occurs 16% of the time and is randomly distributed within a population to an individual's binary experience of either having the side effect or not. Although less work in health risk communication has focused on this issue than on randomness, a gamified design—in which participants clicked concealed icons in an array to reveal whether or not the event occurred for each individual in the population—showed promise, with a positive trend toward helping people understand the risks [31].

In this study, we considered another potential approach for helping people understand what population-based statistics mean for individual risk: the use of avatars. People understand avatars to represent individuals and react to them accordingly; for example, by putting more trust in more relatable avatars [32] or those with a more professional appearance [33]. Further, people perceive their avatar as representing them [34-36] and have been shown to identify strongly with their avatars in a variety of online applications [37-39]. The phenomenon of integrating one's avatar into one's identity, dubbed the Proteus Effect, is demonstrated in the way that social gaming players exhibit gender role behavior that aligns more strongly with the gender of their avatar than with their actual gender identity [40] and in experimental studies where people who are assigned a taller or more attractive avatar in a simulation subsequently

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show more confident or more intimate behavior in a face-to-face interaction [41].

In this study, we evaluated 4 specific risk graphic design factors dealing with the display of randomness and the use of avatars that, in principle, might better convey these challenging concepts—the randomness of events and how population-based statistics apply to an individual—with the goal of helping people better understand the nature of a health risk.

In addition to these experimental factors, we also examined the potential moderating effects of 3 planned individual factors: (1) an individual's actual level of risk, (2) his or her numeracy, and (3) whether or not she or he has known someone who has experienced the negative health event in question. Each of these may influence how people respond to different risk graphics by moderating the personal salience of the risk information or the way people understand risk numbers.

Regarding the first moderator, to our knowledge, no literature exists concerning the different responses to the same risk graphic formats at different levels of risk. However, it seems plausible that someone receiving a low risk estimate might respond to a particular risk presentation format differently than someone receiving a high risk estimate. Regarding the second moderator, different risk graphic formats have been shown to generate different responses in people at different levels of numeracy [15]. Most importantly, a previous study by our group that set the stage for this study demonstrated, among other findings, that interactive elements were associated with lower understanding among people with higher numeracy, but not among those with lower numeracy [29]. Regarding the third moderator, we speculated that personal familiarity with the negative health outcomes being presented (eg, knowing someone who has experienced grave outcomes) might provide a concrete personal example of how a statistical probability can map onto individual circumstances and, thus, make the risk more salient. People are more sensitive to risks associated with events that they can more easily call to mind [42] or that have stronger emotions associated with them [43] (eg, due to personal loss).

We further investigated the effects of 2 additional potential moderators whose importance emerged from our observed data: whether or not people know their (1) blood pressure and (2) cholesterol and are thus able to choose from a drop-down menu of potential ranges for such values. Although this information was not required in order for participants to receive a risk estimate, having entered more information relevant to one's own individual health may well increase the salience of the risk information.

Ultimately, our aim is to improve understanding of risk estimates, which we operationalized in this study as alignment between subjective risk perception and an objective risk estimate along with accurate recall of the risk estimate. Therefore, we investigated the following specific research questions: (1) which design factors might help to increase alignment between perceptions of risk and actual risk, (2) which design factors might help to encourage intentions toward actions associated with healthy living, and (3) do any of the design factors affect recall of risk numbers? The first and third of these specifically addressed our primary goal of improving comprehension; the second addressed questions around the applicability of these design factors to different purposes.

Methods

Recruitment

We invited a random sample of US adults aged 35 to 74 years from a panel of Internet users administered by Survey Sampling International (SSI), stratified by gender, age, and race to ensure demographic diversity in similar proportions to the US population, to participate in an online survey. The number of email invitations sent to each stratum was dynamically adjusted to maintain demographic balance despite varying response rates. Participants who completed this experiment as well as another unrelated cross-randomized study contained within the same survey were entered into both an instant-win contest and a monthly drawing administered by SSI for modest prizes. The study was deemed exempt by the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board as anonymous survey research. All participants viewed a consent page before clicking to begin the study in which they were informed that the survey would involve learning about their personal risk of heart disease and stroke, and that if they did not want to learn about their risk, they should not participate in the study. At the conclusion of the survey, participants were provided with a list of resources for learning more about cardiovascular health and ways to prevent cardiovascular disease.

Design of Experiment

To explore our research questions, we chose the clinical context of general cardiovascular disease because of the availability of a robust simple model [44] that estimates an individual's risk of general cardiovascular disease within the next 10 years based largely on information that laypeople would be likely to know. Namely, it allows for the input of height and weight if blood lipids results are not known. It is widely applicable and returns a large range of risk numbers, thus providing a fruitful context for investigating risk communication methods. The model was originally developed for clinical use and uses blood pressure as one of the predictors. In our study, because we were deploying the model in a survey of laypeople, we allowed for the fact that people may not know their blood pressure. When people indicated this was the case, we made conservative assumptions. If these participants responded that they were not taking any medication to treat high blood pressure, we assigned the lowest possible number of model points (ie, lowest risk) using average blood pressure for the person's age. If they responded that they were taking medication to treat high blood pressure, we allotted 2 model points from the potential ranges of 0 to 5 for men and -1 to 7 for women (higher points mean higher risk). This corresponds to a treated systolic blood pressure between 120 and 129 mm Hg.

Estimates returned by the model range from a risk of less than 1% to a risk greater than 30%. Risk estimates between the lower and upper limits are returned as integer percent values. In other words, the vast majority of risk estimates were numbers such as 4% or 21%, but results at the upper and lower ends of the range were not simple integers. For the risk graphics, we

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described these less specific values in the legend and introductory text as being "less than 1%" and "more than 30%," and used 1 and 31 event rectangles, respectively, in the array of 100. Similarly, in our analyses, we used the values .999 and 31 as conservative estimates of these cases, respectively. Throughout the experiment, rather than the term, "general cardiovascular disease," we used the more familiar terminology "heart disease and stroke."

The model applies only to people who have not already experienced general cardiovascular disease, so we screened out those who had a history of cardiovascular disease (448/4124, 11%). Remaining participants were asked to enter their information to calculate their personal risk estimate, which they subsequently viewed in an animated risk graphic randomly assigned from 10 possible versions created from the 4 risk graphic design factors (see Design of Risk Graphics section). We only presented absolute numbers and did not provide any context of expected levels of risk. In other words, we did not give participants any indication of whether their risk was higher or lower than might be expected for their age and gender before we assessed their risk perceptions.

Design of Risk Graphics

For all designs, we used a 10×10 matrix of rectangle icons and animated the construction of the icon array (as previously tested [29]) to visually introduce each event rectangle one at a time. This animation served to signal several concepts to people viewing the risk graphic. First, it highlighted the discrete and, hence, countable nature of events within the population of 100. This is a strength of both natural frequency and icon array formats. Second, it served as a temporal signal about the size of an individual's risk. A person given the risk estimate "1 in 100" had only to wait briefly for the 1 event rectangle representing a risk event to appear before moving on. By contrast, someone whose risk was "30 in 100" had to wait 30 times longer for the animation to add all the event rectangles. Signaling is frequently used in multimedia to draw attention to important ideas and elements [45,46].

In keeping with our goal of conveying 2 key concepts (ie, the underlying randomness of events and the mapping of population-based statistics onto individuals), we used 2 main experimental design factors in our graphics. The first of these was animated randomness, a factor that showed promise when previously explored in combination with a different set of design factors [29]. Participants randomized to graphics with the random design factor observed the event rectangles appear one at a time as in the standard condition, but in a random spatial position throughout the array. Once all event rectangles appeared, the animation concluded with all the randomly dispersed event rectangles settling into a standard grouped display. The goal of this settling was to avoid the comprehension problems observed in previous research on randomly dispersed events in icon arrays [22-29].

The second main design factor was the use of an avatar. We designed this factor to give more explicit signals about how such risks apply to a single individual. Graphics that included a standard avatar had a generic avatar shape animated to drop into the icon array and disappear, then emerge with a question mark at the conclusion of the animation. The disappearance and re-emergence with a question mark were intended to convey that we do not know which event out of the 100 will apply to a single individual. Within the avatar design factor, we also had 2 other nested factors. The first of these (avatar moves) specified that after the avatar was dropped into the array, it would move within the array, randomly landing on either event rectangles or nonevent rectangles to further emphasize how the randomness inherent in the risk statistic applies to a single individual. The second nested factor (color choice), designed to help participants identify with the avatar, offered participants the chance to choose a different color from a palette of Web colors, instead of the default color, which was standard Web black (#000000).

These factors created a 2×2 factorial design nested within another 2×2 factorial design. See Figure 1 for a chart illustrating the experimental design, and Figure 2 for a still image of a sample graphic. See Multimedia Appendix 1 to view a video (.mp4 version) of a graphic with the random factor and a nonmoving default color avatar (see Multimedia Appendix 2 for the same video in .avi format).

Figure 1. Randomization and graphics factors.

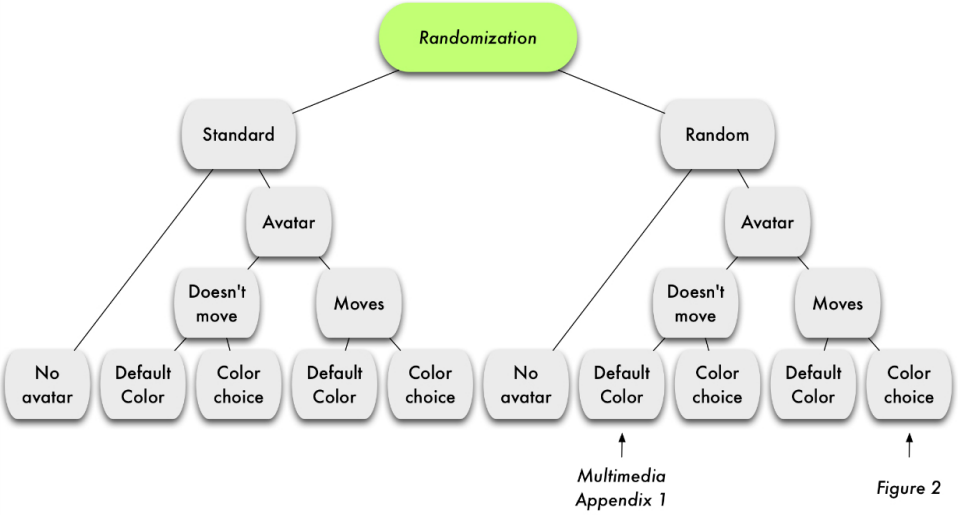

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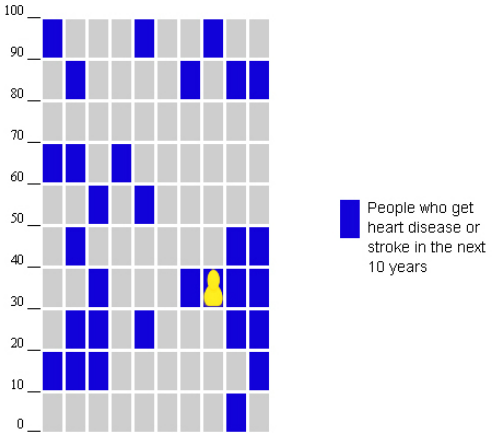
Figure 2. Sample risk graphic (random, avatar moves, color choice).



Technologies

We programmed the risk graphics and an avatar color-chooser in ActionScript 3.0 and integrated them into a custom survey system programmed in Ruby on Rails. The number of event rectangles in the icon array were set dynamically via JavaScript, using participants' risk numbers as calculated by the model algorithm implemented in the survey system.

Measures

Independent Variables

There were 4 independent dichotomous variables. The random variable describes whether or not the event rectangles were dispersed randomly in the pictograph (random condition) or whether they are grouped together at the bottom of the page (standard condition). The avatar variable describes whether or not an avatar was used in the risk graphic. The avatar moves variable indicates whether or not the avatar moved around randomly within the pictograph, randomly landing on event rectangles or not, as the animation proceeded. The color choice variable refers to whether or not participants were asked to select a color for the avatar that they felt best represented themselves.

Primary Outcome

The primary outcome variable for this study, risk perception, was created from 3 questions, all asked together on the same page immediately after viewing the risk graphic. These questions were intended to capture people's immediate reactions to the risk number and graphic presentation. We first asked participants to answer the question, "How big or small does this risk feel to you?" on a 10-point Likert scale with anchors "extremely small" on the left and "extremely big" on the right. We then asked people to indicate, "How worried do you feel about your chance of getting heart disease or stroke in the next 10 years?" on a 10-point Likert scale anchored by "not at all worried" on the left and "extremely worried" on the right. Values for 10-point Likert scales were assigned as 0-9 but survey responses were not labeled numerically, meaning that participants did not see any numbers, only a horizontal visual array of equally-spaced radio buttons. Finally, we asked them, "How likely does it feel to you that you will actually get heart disease or stroke in the next 10 years?" which we assessed on a horizontal slider. The slider recorded integer values between 0 (label "extremely unlikely") and 100 (label "extremely likely"). Participants saw only the visual position of the slider, not the numeric values representing their response. Because we wanted to capture participants' subjective risk sense, we used this measure rather than asking for a numeric estimate of their risk. We surmised that if we asked for a numeric estimate, many participants would simply return the risk estimate they had been given. We further suspected that this would be most likely to occur among participants with higher numeracy; thus, this measure could bias the potential effects of numeracy on the subjective feeling of being at risk. To combine these 3 measures with equal weight accorded to each, we rescaled the likelihood question by multiplying values by 9/100. We then averaged responses to the 3 questions (Cronbach alpha=.88) to calculate risk perception.

Secondary Outcomes

We considered 3 secondary outcome variables in this study: 2 behavioral intention measures and a recall task.

Behavioral intentions were all collected together on 1 page. Participants were given the text, "There are ways to improve your heart health and reduce your risk of heart disease and stroke. How likely are you to do the following things in the next 30 days?" This was followed by a list of 4 or 5 potential actions: quit smoking (presented only to participants who indicated in the risk calculator they had smoked in the last month); exercise 30 to 60 minutes a day, at least 5 days a week; eat a diet that is low in salt, low in fat, and has at least 5 to 10 servings of fruits and vegetables each day; start a weight loss program; and make an appointment to see a doctor about your heart health. Responses were collected for each action on a 10-point Likert scale with anchors "not at all likely" on the left and "extremely likely" on the right. Again, responses were not labeled with their numeric value, meaning that participants did not see any numbers, only a horizontal visual array of equally-spaced radio buttons. Participants were not provided with details about these behaviors beyond their verbal label, nor were they given any information about the extent to which engaging in such behaviors might lower their risk. At the conclusion of the survey, after the study was complete, participants were provided with links to webpages by reputable sources about healthy lifestyles for reducing cardiovascular risk. (See also Multimedia Appendix 3 for results of a small secondary study that was conducted within this study about the effects of a "heart age" message on behavioral intentions.)

The first 4 behavioral statements (3 for nonsmokers) are typical behavioral outcomes in interventions addressing cardiovascular health. We averaged them to form the lifestyle intentions scale (nonsmokers: Cronbach alpha=.68; smokers: Cronbach alpha=.70). We added the final variable, see a doctor, because we postulated that intentions to see a doctor for personalized counsel would be a more appropriate measure of the effects of a brief online risk calculator. In other words, an increased understanding of one's risk may not be sufficient to provoke behavior change, but it may prompt people to seek more information via a medical consultation.

Recall was collected on the last page of the survey (participants had been presented with 14 to 22 pages since receiving their risk estimate) by asking participants, "Please answer the

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following question based on your memory of the numbers you were given by the risk calculator earlier in this study. If you are unsure, please take your best guess. Please do not go back to check your answers. If there were 100 people exactly like you, how many of them would have heart disease or stroke in the next 10 years?" Participants entered their recalled value in a text box. To analyze the effects of experimental and moderating factors on recall, we defined the dependent variable recall as the absolute difference between the recalled estimate and the correct value. However, to maximize clarity for readers when tabulating descriptive results about recall in this paper, we define correct recall as a recalled risk within 5 percentage points in either direction of the risk estimate.

Moderators

We planned for the inclusion of 3 attributes in our model that might moderate participants' responses. First, we considered the impact of the participant's actual estimated 10-year risk of cardiovascular disease as presented to them (actual risk). We used the original quasi-continuous variable in our analyses, but to facilitate readers' interpretation of descriptive statistics in this paper, we present data according to whether a participant's risk was below the median risk (8%) or not. We further distinguish participants at either end of the spectrum of risk estimates for whom the model provided a less precise numeric risk estimate. Thus, the levels for reporting are very low risk (<1%), lower risk (1%-7%), higher risk (8-30%), and very high risk (>30%). We emphasize that these labels were not shown to study participants nor were they used for analysis; they are simply for readers' comprehension. We further note that because so few participants were in the very low risk group (n=7; see Table 1), in the Results sections of this paper, we report mean values only for the latter 3 risk levels: lower risk, higher risk, and very high risk.

We collected 2 self-report individual difference measures, selected because of their potential moderating effect on individuals' responses to different ways of presenting risk numbers and graphics about cardiovascular disease. Participants completed a validated measure of numeracy, the Subjective Numeracy Scale, which asks people how confident they feel with numbers and how much they prefer information be presented numerically [47,48]. We also asked participants an ad hoc question, "Have you ever known anyone who died of heart problems or stroke?" to assess their personal familiarity with the potential impact of cardiovascular disease. We hypothesized that familiarity would provide a concrete personal example of how a statistical probability can map onto individual circumstances.

In addition to these planned moderators, we noted in our data that a sizeable proportion of participants indicated that they did not know their blood pressure and/or cholesterol. Given that the input of such personal information might affect the salience of the risk, we also included 2 additional variables, blood pressure known and cholesterol known, in our analyses. For the latter, we classified participants who knew either 1 or both of their total or high-density lipoprotein (HDL) cholesterol as knowing their cholesterol.

Statistical Analyses

The effects of risk graphic factors and individual difference measures on outcomes were examined via nested factorial ANOVA. All main effects were analyzed, as were all possible interactions. For the primary outcome, we used an alpha level of .05. For the 3 secondary outcomes, to control for Type I error, we applied a Bonferroni correction, yielding an alpha level of .017. All tests were 2-tailed. To present results, we give *F* statistics and *P* values, as well as mean values to provide a sense of the size of differences observed. Exploratory correlations were calculated as Pearson's correlations. Data were entered and analyzed in R, version 2.15.2 [49] with use of the package psy, version 1.1 [50], to calculate Cronbach alpha scores, and the package car, version 2.0-18 [51] for conducting Levene's test of homogeneity of variances. Because participants whose actual risk was less than 1% or greater than 30% were not given an exact number in the text (although they were given an exact number of event rectangles in the graphic), we conducted analyses on all outcomes both with and without those participants to explore the impact of the upper and lower limits of the underlying risk model on our findings.

Results

Study Participants

Of the 4859 people who received an invitation email and clicked the link to the survey, 4124 (85%) completed the survey. Of these, 3676 (89%) were eligible for this study, meaning that they were between ages 35 and 74 years and had neither been diagnosed with heart disease nor had a stroke. For analysis, we included participants who completed the full survey, which included this study, a second unrelated study, demographic questions, and other measures of individual differences. The median time to complete the full survey was 16 minutes and the interquartile range (IQR) was 11 minutes. We excluded participants who completed the full survey in less than 6 minutes from analysis because this speed suggested that they may not have been paying attention to the content. Thus, the final sample for analysis comprised responses from 3630 people (99% of eligible respondents).

Participants were diverse in terms of gender, age, ethnicity, race, and level of education. The median 10-year risk of general cardiovascular disease was 8% (IQR 11%). See Table 1 for details of study participant characteristics. None of these characteristics varied significantly between the different graphics (all *P*>.05).

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Table 1. Study participant characteristics (N=3630).

Characteristic	Statistic
Age (years), mean (SD)	53 (10)
Gender, n (%)	
Female	2000 (55)
Male	1630 (45)
Ethnicity, n (%)	
Hispanic	404 (11)
Middle Eastern	44 (1)
Race, n (%)	
White or Caucasian	2827 (78)
Black or African American	514 (14)
American Indian or Alaska Native	48 (1)
Asian or Asian-American	145 (4)
Pacific Islander or Native Hawaiian	10 (<1)
Other	124 (3)
Highest education level reached, n (%)	
None	1 (<1)
Elementary school	3 (<1)
Some high school, but no diploma	73 (2)
High school (diploma or GED)	681 (19)
Trade school	216 (6)
Some college, but no degree	975 (27)
Associate's degree (eg, AA, AS)	384 (11)
Bachelor's degree (eg, BS, BA)	871 (24)
Master's degree (eg, MA, MPH)	335 (9)
Doctoral/professional degree (eg, PhD, MD)	88 (2)
General cardiovascular disease 10-year risk, median (IQR)	8 (11)
General cardiovascular disease 10-year risk, n (%)	
Very low risk (<1%)	7 (0.2)
Lower risk (<median risk or 1-7%)	1714 (47)
Higher risk (≥median risk or 8-30%)	1630 (45)
Very high risk (>30%)	279 (8)
Risk estimate factors [a]	
HDL ("good") cholesterol (mg/dL), n (%)	
<35	160 (4)
35-44	304 (8)
45-49	218 (6)
50-59	231 (6)
≥60	321 (9)
I don't know	2396 (66)
Total cholesterol (mg/dL), n (%)	
<160	566 (16)
160-199	622 (17)

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Characteristic	Statistic
200-239	368 (10)
240-279	70 (2)
≥280	24 (1)
I don’t know	1980 (55)
Systolic blood pressure (mm Hg), n (%)	
<120	989 (27)
120-129	1095 (30)
130-139	478 (13)
140-149	186 (5)
150-159	59 (2)
≥160	36 (1)
I don’t know	789 (22)
Currently taking medication to treat high blood pressure, n (%)	1182 (33)
Has diabetes, n (%)	469 (13)
Has smoked in the past month, n (%)	974 (27)
Body mass index (BMI), n (%)	
<18 (underweight)	30 (1)
18-24.9 (normal weight)	690 (19)
25-29.9 (overweight)	794 (22)
≥30 (obese)	932 (26)
Height and/or weight not given[b]	1184 (33)
Other individual difference measures	
Subjective numeracy (out of possible 6-48), median (IQR)	35 (10)
Knows someone who died because of heart problems, n (%)	2702 (75)

[a]HDL: high-density lipoprotein.

[b]Height and weight were only asked of participants who did not know their cholesterol counts.

Primary Outcome: Risk Perception

We first explored relationships between actual risk and risk perception via Pearson correlations, stratifying by all possible combinations of design factors as shown in Table 2. We observed that correlation values appear to be larger overall in the random condition than in the standard condition, and that nonmoving avatars also appeared to possibly increase correlations.

Testing the risk graphic factors and moderators for their effects on risk perception, we observed an interaction between the actual risk and the random variables in their association with risk perception. Adding the element of randomness resulted in lower risk feeling smaller, higher risk feeling slightly larger, and very high risk feeling larger (see details in Table 3).

Table 2. Correlations between actual risk and risk perception by study arm.

Type of Avatar	Standard		Random	
	r	*P*	*r*	*P*
No avatar	.13	.02	.25	<.001
Avatar moves: no; color choice: no	.25	<.001	.30	<.001
Avatar moves: no; color choice: yes	.23	<.001	.18	<.001
Avatar moves: yes; color choice: no	.13	.01	.28	<.001
Avatar moves: yes; color choice: yes	.11	.03	.21	<.001

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Table 3. Summary of findings for primary outcome risk perception.

Effects	Mean values[a] (SD)	$F_{1,3576}$	P
Effects of experimental design factors			
Interaction between actual risk and random		6.12	.01[b]
Lower risk			
Standard	3.2 (2.1)		
Random	3.0 (2.2)		
Higher risk			
Standard	3.7 (2.0)		
Random	3.8 (2.1)		
Very high risk			
Standard	4.1 (2.1)		
Random	4.6 (1.9)		
Main effect of avatar		4.61	0.03[b]
No avatar	3.3 (2.1)		
Avatar	3.5 (2.2)		
Interaction between avatar and familiarity		5.88	.02
No familiarity			
No avatar	2.7 (2.0)		
Avatar	3.2 (2.1)		
Familiarity			
No avatar	3.5 (2.1)		
Avatar	3.6 (2.1)		
Interaction between avatar, color choice, and blood pressure known		4.57	.03
Blood pressure unknown			
No avatar	3.5 (2.2)		
Generic avatar	3.3 (2.2)		
Avatar with color choice	3.6 (2.2)		
Blood pressure known			
No avatar	3.3 (2.1)		
Generic avatar	3.6 (2.1)		
Avatar with color choice	3.5 (2.1)		
Effects of moderating variables			
Main effect of actual risk		166	<.001
Lower risk	3.1 (2.2)		
Higher risk	3.7 (2.1)		
Very high risk	4.4 (2.0)		
Main effect of numeracy		86.2	<.001
Low numeracy	3.8 (2.1)		
High numeracy	3.2 (2.1)		
Main effect of familiarity		28.3	<.001
No familiarity	3.1 (2.1)		
Familiarity	3.6 (2.1)		

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Effects	Mean values[a] (SD)	$F_{1,3576}$	P
Interaction between actual risk and blood pressure known		7.56	.006
Lower risk			
Blood pressure unknown	3.3 (2.2)		
Blood pressure known	3.0 (2.1)		
Higher risk			
Blood pressure unknown	3.5 (2.1)		
Blood pressure known	3.8 (2.0)		
Very high risk			
Blood pressure unknown	4.3 (2.0)		
Blood pressure known	4.4 (2.0)		
Interaction between numeracy and blood pressure known		4.36	.04
Lower numeracy			
Blood pressure unknown	3.6 (2.1)		
Blood pressure known	3.8 (2.1)		
Higher numeracy			
Blood pressure unknown	3.2 (2.3)		
Blood pressure known	3.2 (2.1)		

[a]Assessed on scale of 0 (lowest risk perception) to 9 (highest risk perception).

[b]No longer significant when participants at very low or very high risk were removed from the sample.

We observed a main effect for the design factor avatar, with slightly higher overall risk perceptions when an avatar was used, as well as another interaction between avatar and familiarity on this outcome. This interaction suggested that for people who knew someone who had died of cardiovascular problems, the use of an avatar was associated with a minimal increase in risk perceptions, but for people who lacked such familiarity, an avatar significantly increased their risk perceptions.

As expected, all 3 planned moderators had significant main effects, with risk perception increasing with actual risk and decreasing with increasing numeracy. People who knew someone who had died of cardiovascular problems (familiarity) perceived their risk as larger. Neither additional moderator (blood pressure known and cholesterol known) had a significant main effect on risk perception. There was, however, a significant interaction between blood pressure known and actual risk on this outcome. Among participants at lower risk, knowing one's blood pressure was associated with lower risk perception whereas the reverse was true for participants at higher risk and, to a certain extent, those at very high risk. We also observed an interaction between blood pressure known and numeracy. For participants with higher numeracy, knowing one's blood pressure did not appear to affect risk perception whereas for those with lower numeracy, knowing one's blood pressure was associated with somewhat higher risk perception.

Finally, we observed an interaction between blood pressure known, avatar, and color choice in their association with this outcome. Among people who knew their blood pressure, the presence of a generic avatar was associated with somewhat higher risk perception but no additional increase was observed for a personalized avatar. However, among people who did not know their blood pressure, a generic avatar was associated with a small decrease in risk perception whereas a personalized avatar was associated with a small increase.

When we explored these analyses on the middle 2 subsets of participants, removing all participants with risk estimates less than 1% or greater than 30%. Findings remained similar overall; however, the observed interaction between actual risk and random was no longer significant ($F_{1,3291}$=2.58, P=.10) nor was the observed main effect of avatar ($F_{1,3291}$=3.62, P=.06).

Secondary Outcomes

Lifestyle Intentions

Examining the effects of different variables on lifestyle intentions, we observed that the factor random had a main effect: participants who received randomly dispersed events were less likely to indicate intentions toward healthy behaviors in the next 30 days (see details in Table 4).

In addition, nearly all moderating variables had significant main effects. Greater intentions toward healthy lifestyles were observed among participants with lower actual risk, those with higher numeracy, and those who knew their blood pressure and cholesterol.

No significant interactions were observed on this outcome. When we explored these analyses within the subgroup of participants that remained after removing all participants with risk estimates less than 1% or greater than 30%, all findings remained similar.

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Table 4. Summary of findings for secondary outcome lifestyle intentions.

Effects	Mean values[a] (SD)	$F_{1,3572}$	P
Effects of experimental design factors			
Main effect of random		11.1	<.001
Standard	5.2 (2.2)		
Random	4.9 (2.2)		
Effects of moderating variables			
Main effect of actual risk		17.4	<.001
Lower risk	5.2 (2.2)		
Higher risk	5.0 (2.3)		
Very high risk	4.7 (2.1)		
Main effect of numeracy		25.4	<.001
Lower numeracy	4.9 (2.2)		
Higher numeracy	5.2 (2.2)		
Main effect of blood pressure known		30.8	<.001
Blood pressure unknown	4.7 (2.4)		
Blood pressure known	5.2 (2.2)		
Main effect of cholesterol known		34.9	<.001
Cholesterol unknown	4.8 (2.3)		
Cholesterol known	5.4 (2.1)		

[a]Assessed on scale of 0 (lowest intentions) to 9 (highest intentions).

Intentions to See a Doctor

We observed a significant interaction between actual risk and avatar in which the use of an avatar appeared to increase the spread, making those at lower risk less likely to plan to see a doctor, and those at higher risk more likely (see details in Table 5).

The 3 moderating variables having to do with medical data all had significant main effects in expected directions on participants' intentions to see a doctor in the next 30 days. Participants with higher actual risk indicated stronger intentions, as did those who knew their blood pressure and cholesterol.

We observed another interaction between numeracy, avatar, and color choice. Among those with higher numeracy, personalization via color choice was associated with somewhat increased intentions to see a doctor, whereas this difference was not observed for those with lower numeracy.

When we explored these analyses within the subgroup of participants that remained after removing all participants with risk estimates <1% or >30%, all findings described previously remained similar; however, an interaction that did not reach significance in the analysis of the full dataset (P=.06) was significant in the restricted dataset. Specifically, within the restricted set, we observed an interaction between actual risk and blood pressure known ($F_{1,3273}$=6.73, P=.01). Among those who did not know their blood pressure, intentions to see a doctor were similar across levels of risk, whereas for those who knew their blood pressure, increased risk was associated with increased intentions (blood pressure unknown: mean 4.2 (SD 3.0) for lower risk vs mean 4.1 (SD 3.2) for higher risk; blood pressure known: mean 4.5 for lower risk (SD 3.0) vs mean 5.4 (SD 2.9) for higher risk).

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Table 5. Summary of findings for secondary outcome see a doctor.

Effects	Mean values[a] (SD)	$F_{1,3556}$	P
Effects of experimental design factors			
Interaction between avatar and actual risk		6.38	.01
Lower risk			
No avatar	4.7 (3.0)		
Avatar	4.4 (3.0)		
Higher risk			
No avatar	4.8 (2.9)		
Avatar	5.2 (3.0)		
Very high risk			
No avatar	4.9 (3.4)		
Avatar	5.8 (2.6)		
Interaction between numeracy, avatar, and color choice		10.1	.001
Lower numeracy			
No avatar	4.8 (2.9)		
Generic avatar	4.9 (3.0)		
Avatar with color choice	4.8 (3.0)		
Higher numeracy			
No avatar	4.7 (3.0)		
Generic avatar	4.8 (3.0)		
Avatar with color choice	5.1 (3.1)		
Effects of moderating variables			
Main effect of actual risk		81.6	<.001
Lower risk	4.5 (3.0)		
Higher risk	5.1 (3.0)		
Very high risk	5.7 (2.8)		
Main effect of blood pressure known		44.5	<.001
Blood pressure unknown	4.2 (3.1)		
Blood pressure known	5.0 (3.0)		
Main effect of cholesterol known		63.0	<.001
Cholesterol unknown	4.4 (3.1)		
Cholesterol known	5.4 (2.9)		

[a]Assessed on scale of 0 (lowest intentions) to 9 (highest intentions).

Recall

We observed an interaction between random and actual risk in their association with recall. Participants at lower risk demonstrated a slight increase in correct recall in the random condition, those at higher risk showed a slight decrease, and those at very high risk had a larger decrease (see details in Table 6).

Differences in numeracy were also associated with differences in recall. Participants with lower numeracy had more trouble accurately recalling their risk estimate. We also observed a similar main effect for blood pressure known. Participants who knew their blood pressure were also more able to recall their risk estimate.

Rerunning these analyses after removing the participants who had received a less precise estimate in the text (ie, those who received an estimate of “less than 1%” or “more than 30%” but who nonetheless received a risk graphic with a discrete number of event rectangles), we found that the main effects of moderating variables remained similar, but the interaction between random and actual risk was no longer significant ($F_{1,3260}$=4.73, P=.03). There was also a complex interaction between random, avatar, and avatar moves that did not reach significance in the larger dataset ($F_{1,3544}$=5.16, P=.02) but did

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so in the restricted set ($F_{1,3260}$=6.27, P=.01). In this interaction, we observed that in the standard condition, presence of an avatar was associated with a decrease in correct recall, more so with a moving avatar (correct recall: 85% without avatar, 82% with nonmoving avatar, 78% with moving avatar). On the other hand, in the random condition, correct recall was somewhat lower to begin with and remained relatively consistent, regardless of the presence or absence of an avatar and whether or not it moved randomly within the graphic (correct recall: 80% without avatar, 80% with nonmoving avatar, 79% with moving avatar). Table 7 presents participants' recall by study arm.

Table 6. Summary of findings for secondary outcome recall.

Effects	Participants with correct recall[a]	$F_{1,3544}$	P
Effects of experimental design factors			
Interaction between random and actual risk		7.06	.008[b]
Lower risk			
Standard	83%		
Random	85%		
Higher risk			
Standard	79%		
Random	76%		
Very high risk			
Standard	76%		
Random	64%		
Effects of moderating variables			
Main effect of numeracy		75.7	<.001
Lower numeracy	74%		
Higher numeracy	86%		
Main effect of blood pressure known		10.6	.001
Blood pressure unknown	74%		
Blood pressure known	82%		

[a]Analysis used quasi-continuous difference between recalled value and actual risk. Correct recall for reporting purposes defined as within 5 percentage points.

[b]No longer significant when participants at very low or very high risk were removed from the sample.

Table 7. Percent correct recall[a] by study arm.

Type of Avatar	All data included (n=3597)		<1 and >30 removed (n=3312)	
	Standard	Random	Standard	Random
No avatar	85%	80%	85%	82%
Avatar moves: no, color choice: no	86%	82%	86%	82%
Avatar moves: no, color choice: yes	78%	77%	78%	78%
Avatar moves: yes, color choice: no	78%	83%	79%	84%
Avatar moves: yes, color choice: yes	77%	75%	78%	78%

[a]Correct recall for reporting purposes defined as recall within 5 percentage points of given estimate.

Discussion

Principal Results

Our results demonstrate several key findings. First, consistent with our earlier work [29], by animating event rectangles in an icon array to appear one at a time scattered randomly throughout the array and then having them settle at the bottom of the array, we were able to convey the randomness of events without sacrificing overall indications of comprehension of the risk estimate. Further, this design factor helped to increase the concordance between actual risk and risk perceptions, with people at lower risk perceiving themselves to be at lower risk, and people at higher risk perceiving themselves at higher risk. This suggests that animated randomness of this sort may help people better understand their individual risk. It may be that

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random dispersion of the colored rectangles may reinforce the rareness of small risks and also the magnitude of large ones (eg, "There are colored blocks everywhere!") This finding is especially notable given that we did not provide participants with any indication of whether their risk was low or high.

The observed effect of animated randomness was driven by the strength of the effect for the 8% of participants who were at very high risk and whose risk estimate was presented in text as "more than 30%." These participants had to wait as 31 event rectangles appeared randomly in the graphic one by one, never quite knowing where the next one would appear or when the process would stop. The combined uncertainty of the text statement, random positioning of the event rectangles, and uncertainty around how many event rectangles would appear may well compound each other and lead to a heightened sense of being at risk. Because it is common for models of health risk to be mathematically convergent only within certain boundary conditions and/or to generate ranges of risk estimates rather than point estimates, this design technique of animated randomness combined with the temporal signaling of one event appearing at a time may be broadly applicable. Nonetheless, further research will be needed to determine its effectiveness—or lack thereof—across a range of situations.

We further note that although there was no main effect of animated randomness on recall, those at higher risk demonstrated a small decrease in their ability to precisely recall the risk estimate they were given whereas those at lower risk demonstrated a small increase. As with the interaction discussed previously, this relationship was driven by the strength of effect in those at very high risk, who were not given a precise numerical risk estimate in text and thus had the more challenging task of recalling the number of event rectangles in their risk graphic. This additional difficulty may have contributed to the lower recall in this group. We further speculate that people who are reassured by a risk estimate may find it somewhat easier to remember the number whereas those who are alarmed may be less likely to remember an exact number because of distracting emotions, such as fear.

Despite the overall welcome finding that animated randomness may help better align risk perceptions with actual risk, we note that in the study context of lifestyle-preventable disease, emphasizing the haphazard and random distribution of negative outcomes led to lower intentions of behavior that might prevent such events. Visually depicting randomness may cause people to focus on the role of chance in health outcomes, drawing their attention to the fact that one's behavior does not completely determine one's health outcomes. We note that we did not present visual depictions of the potential for health behaviors to change the risk estimate. Doing so might possibly have reduced the negative effects of animated randomness on healthy behavior intentions. Further research will be necessary to fully understand this aspect of our findings. Such research should explore the role of potential moderators of health behavior, such as beliefs about the efficacy of lifestyle changes as well as self-efficacy and fatalism in health.

Ultimately, these findings suggest that the value of explicitly showing randomness may depend on whether one's goal is to persuade or inform. Helping people understand randomness may be less useful in persuasive contexts such as promoting lifestyle change. However, it may be more useful in cases in which the primary objective is to inform; for example, in preference-sensitive decisions or when informing people about the risk of a side effect. Importantly, aiming to fully inform people is arguably more ethical than aiming to persuade them. This design factor will need to be tested in other contexts and may also require some unpacking to determine the effects of design choices that did not vary across experimental conditions, such as the fact that higher risks took a longer time to appear.

Second, using an avatar increased overall risk perceptions, and showed promise particularly for people who did not personally know anyone who had experienced grave outcomes in this context. Thus, avatars may be especially useful for drawing attention to risks related to rare or hidden conditions. This interaction, combined with the fact that the main effects of familiarity were similar to the effects of an avatar in the absence of familiarity, suggests that the avatar achieved our design goal of helping people better grasp how population-based statistics can apply to an individual. This conclusion is bolstered by the fact that use of an avatar significantly shifted intentions to see a physician in sensible directions, with people at lower and higher risk indicating, respectively, lower and higher intentions to see a doctor in the next 30 days.

However, other design factors related to the presentation of the avatar showed mixed results. Having the avatar move around randomly in the risk graphic appeared to simply confuse most participants. Allowing people to choose the color of their avatar may have increased identification with the avatar among those with higher numeracy, as they were more likely to indicate intentions to see a doctor when they were encouraged to choose the color. We speculate that those with higher numeracy may be better equipped to understand the risk graphic and thus, adding an extra element that draws their attention can be helpful. By contrast, the extra factor may have added a level of confusion or overwhelm for those with lower numeracy. Allowing people to choose the color of their avatar also appeared to make up for the loss of personal salience among participants who did not know their blood pressure and thus, slightly encouraged intentions to engage in health lifestyle behaviors and see a doctor. However, for those who knew their blood pressure, it tended to have the opposite effect. Taken together, these results suggest that when risk salience may be low, using a personalized avatar may help people feel like the risk applies to them, individually. However, these effects were small; moreover, if risk salience is higher, such basic attempts at personalization may backfire. Therefore, using color choice as a method of personalization, although efficient and quick, appears to be insufficient to allow all people to identify with their avatar and may even lead to undesirable results. Further research will be required to investigate the effects of different forms of personalization.

Third, we note that all 3 planned moderating factors had significant effects. For example, people at higher risk perceived their risk as higher and indicated stronger intentions to see a doctor in the next 30 days; people scoring lower on numeracy indicated higher overall risk perceptions, lower intentions toward

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healthy behaviors, and lower recall, and participants who knew someone who had died of cardiovascular causes had higher risk perceptions. We also observed that people at higher risk tended to indicate lower intentions toward healthy behavior. This latter finding—that people at higher risk have lower intentions to do such things as quit smoking, exercise, and eat well in the next 30 days—may reflect that those at lower risk may already be engaging in those behaviors and thus can easily indicate higher intentions toward such behaviors in the next 30 days. It also aligns with findings about how negative feedback can discourage people, whereas positive feedback can motivate people in a success breeds success cycle [52]. These findings support the need for extra attention when considering how to design better risk communication for those at higher risk, lower numeracy, and with more or less personal familiarity with the condition. We highlight that the fact that many of the observed interactions with actual risk were driven by the participants at the highest level of risk suggests that risk communication methods should be tested across the full range of possible risk values to ensure that studies capture relevant findings.

Analyses of participants who did or did not know their blood pressure and/or cholesterol suggested that these were important moderators, particularly the former. People who knew their blood pressure had greater alignment between their actual and perceived risk, overall higher intentions toward healthy lifestyle actions and seeing a doctor, and more accurately recalled their risk estimate. It may be that this latter finding is reflective of an underlying ability to recall numbers; however, in such a case, we would expect to see an interaction with numeracy, which was not present. Numeracy did interact with knowledge of one's blood pressure when it came to risk perceptions and behavioral intentions. For people with higher numeracy, risk perception was consistent whether they knew their blood pressure or not, whereas for those with lower numeracy, their overall higher risk perceptions were further increased with knowledge of their blood pressure. In addition, for those with lower numeracy, knowing one's blood pressure was more influential in increasing behavioral intentions than it was for those with higher numeracy. We speculate that people with lower numeracy may accord more importance to their blood pressure number. Similar to the results for blood pressure, people who knew their cholesterol were more likely to indicate intentions to engage in healthy behaviors and see a doctor in the next 30 days. These findings support the idea that risk estimates are likely to be more impactful when they are more individually tailored.

Limitations

This study was limited by the fact that we used an Internet survey panel to recruit participants. Although this recruitment choice allows us to ensure a more diverse sample, it necessarily introduces selection bias in that participants are those who registered on a panel to take surveys; thus, they may not be representative of the broader population.

In addition, we observed small effects. This is expected in a study with outcomes such as risk perceptions and behavioral intentions because such outcomes have significant variation in individual responses. Even the actual risk estimate was associated with only a 1.4-point difference on a 10-point scale of risk perception between those at high and very low risk, suggesting that there is little room on the scale within which to work. This limits the overall utility of these design factors, as it may not be worth the additional design complexity and development time to make small gains. Such small gains, however, may be worth pursuing when one considers cumulative effects within a population.

The underlying risk model also limited this study in 2 ways. First, because the risk estimate for cardiovascular disease uses age as an important predictor, we were not able to isolate the effects of age on participants' reactions to the different risk communication designs. It is possible, for example, that older adults might have different reactions to randomization or avatars. Further research will be needed to explore the effects of these kinds of design factors in older versus younger adults. Second, because the model does not provide numerical risk estimates below 1% or above 30%, approximately 8% of the sample population in this study did not receive a precise numerical text estimate. Instead, these participants received a risk estimate of "less than 1%" (7 participants) or "more than 30%" (279 participants) along with 1 or 31 event rectangles in their risk graphic, respectively. This additional ambiguity in the textual risk estimate appeared to amplify findings regarding randomization in the risk graphic. As discussed previously, this is a realistic portrait of many risk calculators, as many risk analysis models are mathematically convergent only within certain boundary conditions. However, the observed interaction between risk level and animated randomness may not translate to calculators that yield precise estimates across a full range of potential risk.

Finally, it is important to note that because this study was conducted in the United States before the introduction of the Affordable Care Act ("ObamaCare"), findings about participants who did not know their blood pressure or cholesterol and findings concerning intentions to see a doctor may reflect an underlying issue of lack of access to medical care rather than effects that would translate to other settings.

Comparison With Prior Work

Previous work has suggested that randomly displaying events in an icon array can increase understanding of the random nature of such events, but at the expense of comprehension of the numerical risk estimate [22-27]. Our study, along with our previous work [29], demonstrated that animating the randomly distributed events to ultimately settle into a standard display can convey randomness without such a sacrifice.

A previous study by Ancker and colleagues [31] tested a somewhat similar interface in which participants were shown 1 of 4 risk graphics to display a risk of heart disease and also a risk of infectious disease: a static standard icon array, a static random icon array, an interactive display in which participants switched back and forth between the static standard and static random array, and an interactive display in which participants began with all icons covered and clicked to uncover a static random display. The third of these, which the authors dubbed "switch," had the most similarities with our random condition in that it alternated between random and standard displays of risk. The key differences between our design of randomness

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and the switch design were in our use of animation to signal quantity by adding one event rectangle at a time and having the rectangles dynamically settle into a standard display at the conclusion of the animation automatically, unlike the interactive nature of Ancker and colleagues' design [31].

Another study conducted by Han and colleagues [28] examined different methods for representing randomness by experimentally varying the presentation of a hypothetical risk of colon cancer. After introducing participants to the National Cancer Institute Colorectal Cancer Risk Assessment Tool, they tested 5 representation formats for risk; namely, a static standard icon array, a static random icon array, a dynamic random icon array in which the event rectangles changed location randomly (and did not settle into a standard display at the conclusion of the animation), and text with and without cues about randomness.

In comparing our study to previous work, we note that the studies by both Ancker et al [31] and Han et al [28] used hypothetical contexts and assigned risks that did not vary by participant, a common practice in the field of risk communication research when the goal is to evaluate the utility of a given communication format. In contrast, our study had participants enter their personal information into a risk calculator and receive their actual risk estimate. Both previous studies found no differences in risk perceptions by graphic format. We observed a similar lack of main effect of randomness; however, because our study used varying levels of risk, we were able to observe an interaction in which randomness was associated with lower risk perception at lower levels of risk, and higher risk perception at higher levels of risk, suggesting that randomness helps align risk perceptions with actual risk. We note that both of these previous studies included a measure or method of assessing perceived uncertainty in the risk estimate. We did not measure such an outcome; therefore, we are unable to compare our findings to theirs on that construct.

To the best of our knowledge, ours is the first study to test the effects of including an avatar as a design factor in risk communication graphics. Previous work in other contexts has suggested that people identify strongly with their avatar [34-41]. Our results, which suggest that including an avatar helped increase realization of personal risk, are in line with these findings. More research is needed to study the use of avatars and other embodied agents in health risk communication.

More recent research has also suggested that graphical displays may not always outperform simple percentages or absolute frequencies in risk communication [53] and that their utility may depend on graphical literacy, with people who score low on graphical literacy performing better with numbers alone [54]. Because the data for our study were collected before publication of the graphical literacy scale, we did not measure graphical literacy and were unable to examine this issue. Graphical literacy will be an important moderating factor to include in future research, and the question of whether or not to use graphics when communicating risk remains open.

The present study continues a program of research by our group in which we previously noted that 2 animated displays side by side were problematic [29]. In this study, we deliberately used one signal at a time and did not observe the same deleterious effects of animation and randomness on performance. Our findings about the generally negative effects of a moving avatar, however, continue to encourage careful design when including animation and motion in risk graphics.

Conclusions

An animated display of risk that adds events one at a time in a randomly dispersed icon array and where they settle at the bottom of the display at the conclusion of the animation may help align risk perceptions with actual risk estimates without sacrificing number sense. This method shows promise for helping people better understand the random nature of risk. Such understanding may come at a cost of discouraging behavioral intentions, suggesting that the use of this method may depend on whether the goal of the risk communication is to persuade or to inform.

The use of an avatar in a risk graphic also shows promise for helping people to grasp how population-based statistics can apply to an individual, particularly in cases when the person does not know anyone who has experienced the outcome under consideration. An avatar that is animated to move randomly within the graphic does not appear to be helpful. Personalization via color choice shows mixed effects, suggesting that personalization of an avatar may be an interesting avenue for further study, but that this particular method of personalization does not appear to be optimal.

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Authors' Contributions

All authors contributed to the conception and design of the study. HOW, AFF, MD, NE, VK, and BJZ-F contributed to technical design and HCW contributed clinical insight about use of the model and wording. MD programmed the application and survey.

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HOW, MD, LH, NE, and BJZ-F were involved in data acquisition. HOW analyzed and interpreted data with insight from HCW and BJZ-F. HOW wrote the first draft of the article; all authors revised it critically for important intellectual content, saw, and approved the final version submitted.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Video of risk graphic (.mp4 version).

[MP4 File (MP4 Video), 307KB - jmir_v16i3e80_app1.mp4]

Multimedia Appendix 2

Video of risk graphic (.avi version).

[AVI File, 462KB - jmir_v16i3e80_app2.avi]

Multimedia Appendix 3

Secondary study: effects of heart age message.

[PDF File (Adobe PDF File), 119KB - jmir_v16i3e80_app3.pdf]

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Abbreviations

AA: Associate of Arts
AS: Associate of Science
BA: Bachelor of Arts

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BS: Bachelor of Science
GED: General Educational Development
HDL: high-density lipoprotein
MA: Master of Arts
MD: Doctor of Medicine
MPH: Master of Public Health
PhD: Doctor of Philosophy
SD: sample standard deviation
SSI: Survey Sampling International

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Original Paper

Confirmation Bias in Web-Based Search: A Randomized Online Study on the Effects of Expert Information and Social Tags on Information Search and Evaluation

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Abstract

Background: The public typically believes psychotherapy to be more effective than pharmacotherapy for depression treatments. This is not consistent with current scientific evidence, which shows that both types of treatment are about equally effective.

Objective: The study investigates whether this bias towards psychotherapy guides online information search and whether the bias can be reduced by explicitly providing expert information (in a blog entry) and by providing tag clouds that implicitly reveal experts' evaluations.

Methods: A total of 174 participants completed a fully automated Web-based study after we invited them via mailing lists. First, participants read two blog posts by experts that either challenged or supported the bias towards psychotherapy. Subsequently, participants searched for information about depression treatment in an online environment that provided more experts' blog posts about the effectiveness of treatments based on alleged research findings. These blogs were organized in a tag cloud; both psychotherapy tags and pharmacotherapy tags were popular. We measured tag and blog post selection, efficacy ratings of the presented treatments, and participants' treatment recommendation after information search.

Results: Participants demonstrated a clear bias towards psychotherapy (mean 4.53, SD 1.99) compared to pharmacotherapy (mean 2.73, SD 2.41; t_{173}=7.67, P<.001, d=0.81) when rating treatment efficacy prior to the experiment. Accordingly, participants exhibited biased information search and evaluation. This bias was significantly reduced, however, when participants were exposed to tag clouds with challenging popular tags. Participants facing popular tags challenging their bias (n=61) showed significantly less biased tag selection ($F_{2,168}$=10.61, P<.001, partial eta squared=0.112), blog post selection ($F_{2,168}$=6.55, P=.002, partial eta squared=0.072), and treatment efficacy ratings ($F_{2,168}$=8.48, P<.001, partial eta squared=0.092), compared to bias-supporting tag clouds (n=56) and balanced tag clouds (n=57). Challenging (n=93) explicit expert information as presented in blog posts, compared to supporting expert information (n=81), decreased the bias in information search with regard to blog post selection ($F_{1,168}$=4.32, P=.04, partial eta squared=0.025). No significant effects were found for treatment recommendation (Ps>.33).

Conclusions: We conclude that the psychotherapy bias is most effectively attenuated—and even eliminated—when popular tags implicitly point to blog posts that challenge the widespread view. Explicit expert information (in a blog entry) was less successful in reducing biased information search and evaluation. Since tag clouds have the potential to counter biased information processing, we recommend their insertion.

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KEYWORDS

Web-based systems; prejudice; folksonomy; taxonomy; collaborative tagging; human information processing; psychotherapy; pharmacotherapy

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Introduction

Background

In the last decade, patients' preferences have increasingly been taken into account when choosing a treatment for depression [1], which conforms to American Psychiatric Association guidelines [2]. Previous research has demonstrated, however, that laypeople hold beliefs about depression treatment that are partly inconsistent with scientific evidence. They believe, for instance, that psychotherapy is a more effective treatment for depression than pharmacotherapy [3,4]. In contrast to this, current scientific evidence demonstrates that pharmacotherapy and psychotherapy are nearly equally effective [5,6]. Consequently, the layperson's beliefs are biased.

This paper investigates how biases like this one can be reduced. For our study, we chose the domain of depression treatment and made use of the psychotherapy bias. Specifically, we expected that laypeople's bias towards psychotherapy leads to a confirmation bias in information search and evaluation. The confirmation bias refers to the robust findings that individuals tend to process information in a manner that confirms their pre-existing beliefs. Therefore, a confirmation bias in searching for information is not only of interest for depression treatment or the comparison of psychotherapy and pharmacotherapy, but for health-related information search in general. Individual convictions lead to one-sided information processing. When these convictions are not justified by scientific evidence, people run the risk of being misinformed.

Therefore, we investigated two factors that might reduce one-sided information processing. One of the most reliable and objective information sources on the Web is expert information. We tested whether facing explicit expert information would reduce the bias. Moreover, we were interested if aggregated expert information presented in tag clouds would reduce the bias as well.

Blogs and Social Tagging

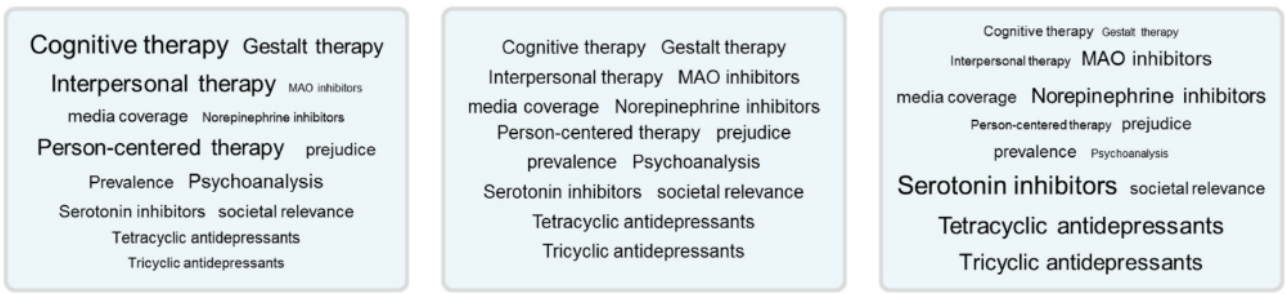
In the last decade, the Internet has become one of the most important sources for health-related information [7]. This phenomenon created the need to investigate the communication between experts and laypeople [8]. Blogs have been among the most effective applications for disseminating and discussing health-related topics by experts and a general audience. Blogs are authored by and targeted at laypeople as well as health professionals (eg, New York Times Well Blog [9], Harvard Health Blog [10]), and blogs often report current scientific studies, as well as the author's personal opinion, which can be discussed by the public in the comments section. Moreover, blogs are among the crucial starting points for health-related online information search [11].

In order to provide an overview of the relevant content of a blog and to organize related blog posts, popular blogging sites such as Technorati, WordPress, or Counselling Resource [12-14] include tag clouds or tag lists [15]. We focus on tag clouds (Figure 1) because tag clouds provide implicit information on the popularity of topics. Tag clouds display different tags in varying font sizes, according to tag popularity. In broad folksonomies (eg, del.icio.us), which allow not only creators, but also recipients to tag digital artifacts, many people search for the same tags or provide the same tag for numerous blog posts. These co-occurring tags can be displayed in a tag cloud with varying font size, according to the number of co-occurrences.

Tags have two important functions. First, tags organize content. When people provide the same tag for different blog posts, blog posts with a common topic are quickly found via a common tag (eg, the topic with the tag "health" on WordPress [13]). Second, the font size of a tag reflects the popularity of the underlying concept. For example, Figure 1 demonstrates the three versions of a tag cloud with the same content, but different popularity of treatments for depressive disorders, used in the current study. Popular tags that represent treatments can be seen at a single glance [16,17].

Previous research on the perception of tag clouds has demonstrated that the popularity of tags (presented as tag size) influences information search and information evaluation [18,19]. Popular tags in a tag cloud, for instance, are more frequently selected and their resources more often consulted [20]. Popular tags not only guide navigation behavior but also information evaluation. Concepts represented by popular tags are rated as more typical of a domain [18]. Moreover, people align their cognitive concepts to the concepts represented by popular tags. After navigating with tags, people remember more popular concepts compared to less popular concepts [20,21].

Figure 1. Tag cloud versions used in the study.



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Confirmation Bias in Online Information Search

In order to investigate the confirmation bias in health-related information search, we chose the topic of depression treatment with pharmacotherapy or psychotherapy because previous research has demonstrated a discrepancy between laypeople's beliefs and scientific evidence. As mentioned, psychotherapy is viewed to be more effective [3,4], whereas scientific evidence points to a comparable efficacy of both treatments [5,6]. We refer to this misconception as psychotherapy bias. Bias in our conception thus differs from personal preference in that it represents a systematic deviation from scientific knowledge and it describes subjective weightings of information. We expected that users' information search is influenced by their belief that psychotherapy is more effective. Research from the confirmation bias has shown that people confirm their pre-existing beliefs by selecting information that supports those beliefs [22-26] (for an overview, see [27]).

The confirmation bias describes people's need to confirm their beliefs and attitudes when engaged in search for online information [22,25]. Regarding the psychotherapy bias of laypeople, we expected that when people search for information, they would prefer information about the efficacy of psychotherapy over information about the efficacy of pharmacotherapy. This preference in turn strengthens their prior belief that psychotherapy is effective in treating depression.

Accordingly, our first hypothesis is that the psychotherapy bias—the conviction that psychotherapy is more effective than pharmacotherapy—leads to a confirmation bias in online information search where people prefer to select psychotherapy-related tags and content (H1).

If this confirmation bias determines information search, the question arises as to how the bias can be reduced. Research has shown that people perceive expert information as credible [27,28], and this leads people to align subsequent information search behavior. Therefore, we hypothesized that prior expert information that challenges pre-existing efficacy evaluations, compared to prior expert information that supports pre-existing evaluations, decreases biased information search (ie, tag selection and blog post selection; H2). Likewise, biased information search was expected to decrease with the provision of tag clouds that challenge pre-existent efficacy evaluations. That is, being exposed to tag clouds that have antidepressants as popular tags should decrease the predominant selection of psychotherapy-related tags and blog posts, in comparison to balanced tag clouds and tag clouds with psychotherapy as popular tags (H3). The same bias-reducing effects of challenging (vs supporting) prior expert information (H4) and challenging (vs balanced or supporting) tag clouds (H5) were expected with regard to the evaluation of information. Furthermore, we expected challenging (vs supporting) prior expert information (H6) and challenging (vs balanced or supporting) tag clouds (H7) to lead to a more frequent recommendation of pharmacotherapy.

Methods

Recruitment

Participants were recruited via two mailing lists, to which mostly university students from a broad range of disciplines had voluntarily enrolled. They were provided with a link that led them to a fully automated online survey. We reminded all participants twice via email to take part in the study. We did not use cookies or an IP (Internet protocol) check to detect or prevent multiple participation. However, all the provided email addresses were unique. There were no specific eligibility criteria with the exception of computer literacy as an implicit criterion. In order to have an 80% chance to detect a moderate effect (f=0.25), we would require 26 participants per group (a priori analysis of variance [ANOVA] power analysis conducted with G*Power 3.1.5; parameters set to f=0.25, 1-beta=.80, alpha=.05, numerator degrees of freedom=2, 6 groups; [29]). The study was conducted within a period of 10 weeks from December 2012 until March 2013 and was stopped after planned sample size was reached in all conditions.

We outlined in the invitation mail that we were conducting a study on the treatment of depression, with the main task of rating short blog posts about different treatment options. We emphasized that participation would be voluntary, could be withdrawn at any point, and that the study would not cause harm of any kind. We also assured anonymity and the option to withdraw the data at the end of the study without providing reasons. Participants were informed about the duration of the study and the possibility to win €25 or €50 Amazon gift certificates. They were informed that by clicking the next button, they would provide informed consent. Moreover, they were asked to contact the experimenter (email was provided) in case of questions or considerations of any sort. There was no institutional affiliation presented in the invitation mail, but during the online study (see upper left part of Figure 2). Ethical approval was provided by the Ethical Committee of the Knowledge Media Research Center (LEK 2012/023).

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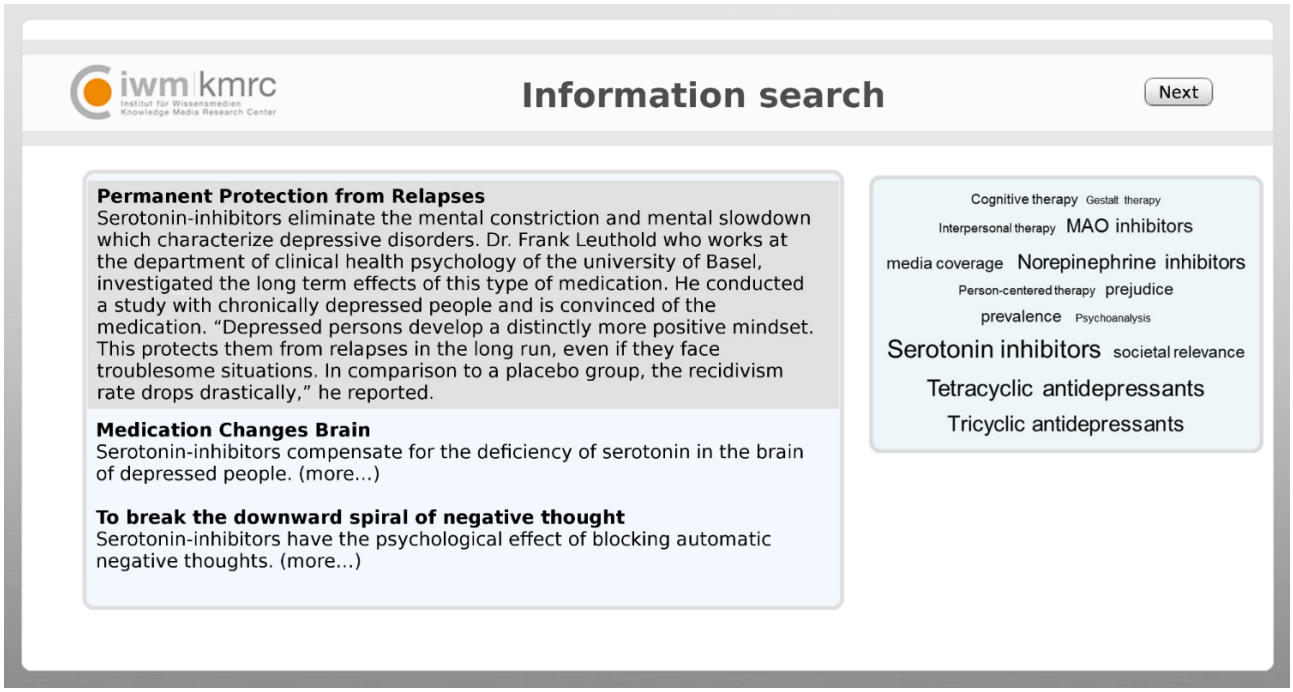
Figure 2. Screenshot of information search environment.



Design and Procedure

The study comprised a 2 (prior expert information: supporting, challenging) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) between-subjects design. Participants were randomly assigned the following simple randomization procedures (computerized random numbers) to the different treatment groups, with the only restriction that a maximum of 35 individuals (who completed the study) were allowed per condition. We manipulated *prior expert information* by the content of the blogs that participants read before navigating in the tagging environment. Participants read either two blog posts highlighting the efficacy of psychotherapeutic treatment (supporting) of depressive disorders, or two blog posts highlighting the efficacy of pharmacotherapy (challenging).

As a second factor, we manipulated *tag popularity* by the font size of tags in the tagging environment. In the case of tag popularity, it is not a single resource that explicitly provides a statement regarding the efficacy of a treatment. Rather, the size of the tags implicitly provides insight into the popularity of treatments, as it is seen by experts. Either psychotherapy tags were displayed with a larger font size compared to pharmacotherapy tags, or pharmacotherapy tags were larger, or tags of both types of treatment had the same size (Figure 1, middle panel). Importantly, the tag-related blog posts presented during information search were the same across all conditions.

After the first two pages where participants were informed about the study and provided informed consent, the algorithm randomly assigned participants to one of the six conditions and a series of online forms followed. Participants filled out demographic data, followed by questionnaires (eg, prior beliefs about treatment efficacy, cf. measures section).

In the first phase of the experiment, participants read two blog entries. Participants were randomly assigned to read either two blog posts emphasizing the efficacy of psychotherapy (supporting the bias, n=93) or to read two blog posts emphasizing the efficacy of pharmacotherapy (challenging the bias, n=81) in the treatment of depressive disorders. The first blog entry reported that a large global network of “neurologists and psychologists” (expert information) agree on the efficacy of either pharmacotherapy or psychotherapy in the treatment of depression. The second blog entry presented the positive results of a neuroimaging evaluation study, arguing for the respective interpretation. Prior information was held constant, so the reasoning in both conditions was exactly the same; we interchanged only the terms antidepressants and psychotherapy. Note that no comparison to other types of treatment was provided in the blog posts. After each blog post, participants rated its persuasiveness.

After the first phase, participants were informed about the nature of tags and tag clouds. It was stated that tags describe and categorize online content, and an example of a tag cloud was shown. Participants were told that experts provided the tags in the following task. The more often a certain tag had been provided by these experts, the larger the tag in the cloud appeared. Therefore, participants were aware that large tags described popular topics among experts.

In the second phase of the experiment, participants searched for treatment-related information. The task for participants was to find useful information to provide information to a hypothetical friend who suffered from major depressive disorder. After the instructions, the information search environment appeared. Participants were randomly assigned to one of the three versions of a tag cloud (Figure 1). The tag cloud either supported psychotherapy bias (psychotherapeutic treatments popular, n=56), or it was neutral with respect to treatment popularity (all treatments equally popular, n=57), or it challenged psychotherapy bias (pharmacological treatments popular, n=61). Participants navigated with the static tag cloud to search information for psychotherapy and pharmacotherapy treatments.

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When participants clicked on a tag, three short related blog posts appeared to the left of the tag cloud. Blog posts were constant across all experimental conditions. Therefore, all participants had access to the same information. A pilot study (n=32) had assured that blog posts did not differ in persuasiveness, in order to rule out material effects. Tags in the cloud represented different types of treatment, and tag-related blog posts described the efficacy of the respective treatment. After 5 minutes, a stop button appeared at the upper right part of the screen. From this moment, participants could freely choose when to end the information search task. The timer was implemented in order to assure sufficient amount of navigational data.

At the end of the study, all participants were thoroughly debriefed and informed about the fact that the presented materials were not genuine materials and that tag clouds thus did not reflect actual scientific knowledge but had been experimentally designed.

Materials

Content of Prior Expert Information

The two blog posts in the two different conditions of expert information contained matched main arguments for the efficacy of psychotherapy versus pharmacotherapy. Therefore, all blog posts in this study were fictitious. The first blog post in both conditions described the establishment of a database with scientific studies by an extensive and worldwide network of researchers. The second blog post in both conditions described the successful remediation of neuronal brain activity and brain structures, after treatment with either psychotherapy (supporting prior expert information) or pharmacotherapy (challenging prior expert information). Text length ranged from 98 to 118 words.

Tagging Environment

The tagging environment for information search consisted of two main sections (Figure 2). At the right side of the screen, 14 tags were presented. Five tags indicated psychotherapy, five tags indicated pharmacotherapy, and four tags were neutral with respect to treatment (media coverage, prejudice, prevalence, societal relevance; Figure 1). We varied tag popularity. In the *psychotherapy tags popular* condition, all psychotherapy tags were larger compared to pharmacotherapy tags. In the *pharmacotherapy tags popular* condition, all pharmacotherapy tags were larger compared to psychotherapy tags. In the *balanced tag popularity* condition, all tags had the same size.

At the left side of the screen in the tagging environment, for each tag, related blog posts were presented (Figure 2). Three blog posts were related to each tag. The content of the blog posts for pharmacotherapy (15 posts) and psychotherapy (15 posts) was held constant. We composed pairs of psychotherapy and pharmacotherapy blog posts, with the same main arguments and length (mean 76.8 words, SD 6.1) but different wording. Each post described a common symptom of depressive disorders (eg, psychomotor impairment) and scientific studies reported by an expert. The alleged experts concluded that the studies showed the efficacy of treatment by successfully reporting a remediation of the symptoms. All reported studies referred only to the efficacy of the respective treatment. There was no information available on the comparability of efficacy between pharmacotherapy and psychotherapy. A pilot study (n=32) assured that the blog posts had equal readability and that the persuasiveness and quality of all arguments did not differ within the pairs of blog posts about pharmacotherapy and psychotherapy. Initially, only the headline and the first sentence of each blog post were presented. In order to read the full blog post, participants had to click on the first sentence to expand the blog post.

The tagging environment displayed in the Web browser (programmed with Adobe Flash Builder) was developed by software developers at the Knowledge Media Research Center. The tagging environment was used for the first time; there were no changes of functionality during the period of data collection. Personal information (email address, demographic data) was stored separate from the survey data on a local server.

Measures

Overview

Items of all the questionnaires were in fixed order; up to 7 items were displayed per screen. We implemented a completeness check so no items could be skipped by participants. Participants could not use a back button of the browser or within the survey. The measures are described in the order they appear in the experiment.

Prior Knowledge

Prior knowledge about depressive disorders was examined by 24 items regarding general knowledge (eg, false: “Women suffer from depressive disorders as often as men do”; true: “People suffering from diabetes are more likely to suffer also from depressive disorders compared to the general population”) and symptoms of depressive disorders according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM IV) and the International Classification of Diseases (ICD) 10 (eg, true: “Depressive disorders are often characterized by heightened or lowered appetite”; false: “People with a depressive disorder show an obsessive need for cleanliness and order”). The answer format had the three categories: true/false/I don’t know (Cronbach alpha=.72).

Evaluation

Efficacy ratings were inquired for all the treatments that were presented prior to and after the experimental manipulations (see pre- and posttest, Figure 3). Five pharmacotherapy treatments and five psychotherapy treatments were rated on a 7-point scale ranging from 1 (not effective) to 7 (highly effective). Prior to the experimental manipulation, we also provided an additional category “I don’t know”, in case participants were not knowledgeable about the treatment in question (which was coded as 4 on the 7-point scale). A rating bias score was derived by subtracting the sum score of pharmacotherapy from psychotherapy efficacy ratings. If participants did not click on a tag, the respective treatment rating was excluded. The tagging environment produced log files that coded every click in the environment and the respective time. For the posttest ratings, we analyzed only treatments that were viewed by participants for at least 10 seconds according to the log files.

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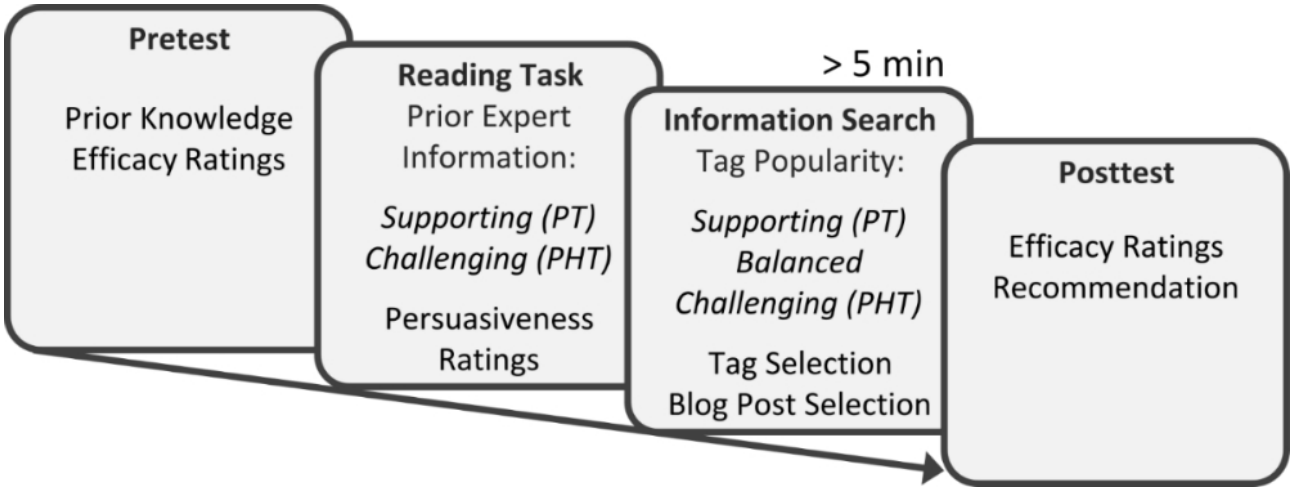
Figure 3. Study procedure.



Persuasiveness Ratings of Blog Posts

After reading each of the two prior blog posts, participants rated the degree to which each blog post stated the efficacy of the presented treatment (either psychotherapy or pharmacotherapy) on a 7-point Likert scale (1=I agree not at all, 7=I completely agree). This rating served to ensure that the texts in both prior expert information conditions were equally convincing.

Information Search

In order to analyze the psychotherapy bias in information search, the number of selected pharmacotherapy tags was subtracted from the psychotherapy tags. Thus a positive value represented a searching bias towards psychotherapy. The same procedure was applied to the number of blog posts that participants read.

Recommendation

After the experimental manipulations, participants were asked to provide a treatment recommendation for a hypothetical friend. They were instructed to give reasons for the recommendation in about five sentences. Recommendations were coded from 1-5 (5: recommendation for psychotherapy only, 4: psychotherapy preferred, 3: combination therapy, 2: pharmacotherapy preferred, 1: pharmacotherapy only).

At the end of the study, participants had the opportunity to provide qualitative feedback through a feedback form.

Statistical Methods

In order to test our main hypotheses, we conducted a 2 (prior expert information: supporting, challenging) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) ANOVA with planned contrasts for the factor tag popularity. With additional *t* tests, we examined whether participants in the challenging *tag popularity* condition demonstrated any bias in information search at all.

Results

Participants and Dropout Analysis

Initially, 440 individuals followed our invitation and started the online experiment. As can be seen in Figure 4, 33.6% (148/440) participants dropped out after the welcome page, and 24.3% (107/440) dropped out during the actual survey. The dropout during the survey is comparable to other online surveys [30]. In addition to these dropouts, we excluded a small number of participants 2.5% (11/440) due to excessive navigation times (see Figure 4). This was done in order to assure that the subsequent analysis of information search was not distorted by outliers. Excessive navigation times were detected using the conservative outlier labeling rule [31]. In order to make sure that our results were not specific for the complete cases, we analyzed tag selection and blog post selection for all participants who had participated up to this point and regardless of their navigation duration (50.9%, 224/440). The pattern of results was identical, which argues for the robustness of our findings. Our subsequent report will be based on those participants who completed the study and did not exhibit excessive navigation times (39.5%, 174/440).

Table 1 details the demographics and baseline characteristics of participants. Ages ranged from 16-62 years (mean 23.8, SD 3.8); 74.7% (130/174) were women. Regarding familiarity with the applications under investigation, 44.8% (78/174) stated that they were familiar with social tags, 26.4% (46/174) had knowingly assigned social tags on the Web, 67.2% (117/174) were reading blogs, and 13.8% (24/174) had authored a blog. Most of them were students (74.7%, 130/174) of a non–health care related subject (72.4%, 126/174). A minor proportion had health care related background knowledge due to their field of study (21.3%, 37/174): psychology, medicine, pharmacy, nursing care, molecular medicine, and neuroscience. It is noteworthy that we reran all analyses without participants from health care related subjects in order to test whether our results hold for laypeople, but the pattern of results was identical.

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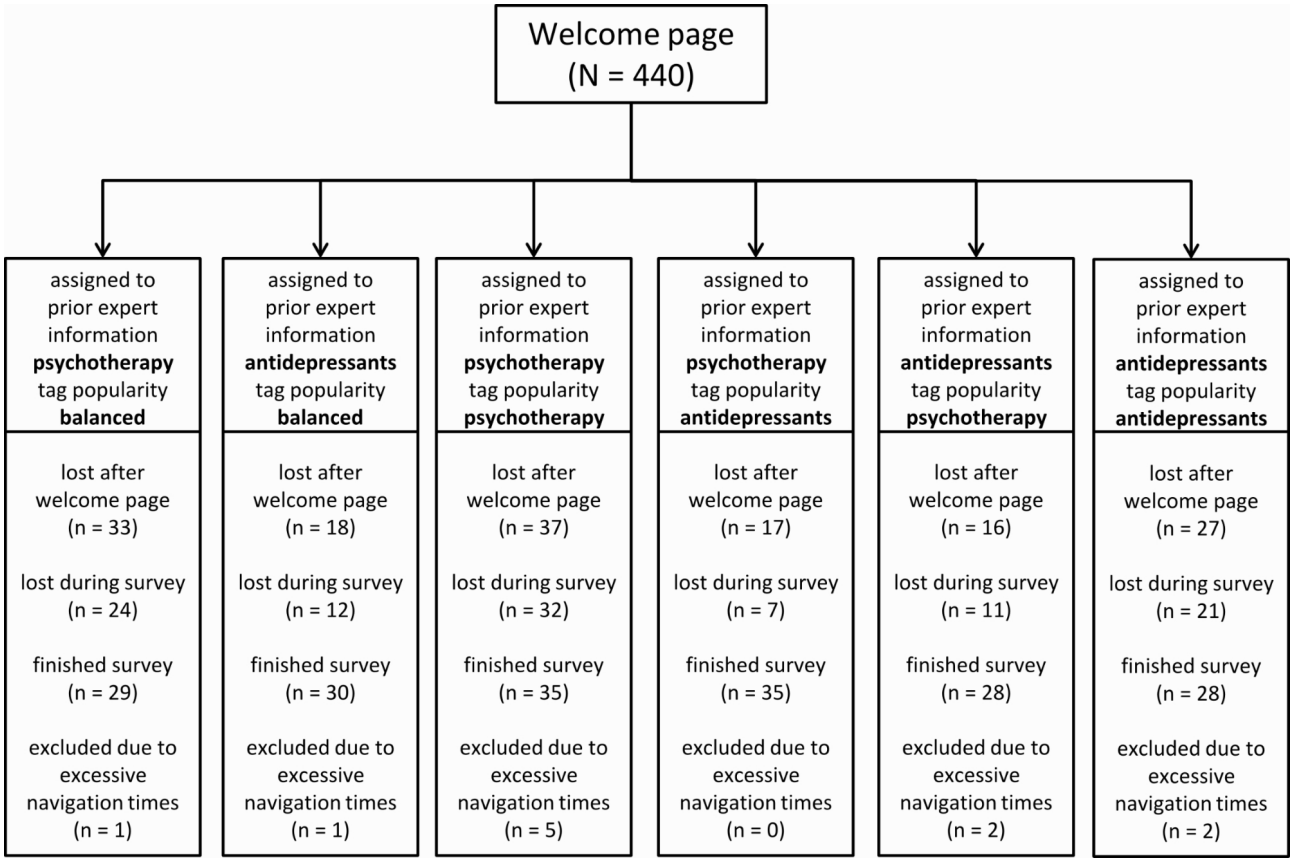
Table 1. Sample characteristics (N=174).

Characteristics		n	%
Education			
	Not yet graduated	130	74.7
	Graduated	43	24.7
	No higher education	1	0.6
Field of study			
	Health care related subject	37	21.3
	Non–health care related subject	126	72.4
	Not specified	11	6.3
Age			
	15-19	26	14.9
	20-24	97	55.7
	25-29	36	20.7
	30-39	10	5.7
	40-49	4	2.3
	62	1	0.6
Total		174	100

Figure 4. Participant flow diagram.



Assuring Equivalence of Groups

First, we checked the equivalence of groups regarding participants' *prior knowledge*. A 2 (prior expert information: supporting, challenging) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) ANOVA showed no main effect of tag popularity ($F_{2,168}$=2.32, P=.102, partial eta squared=0.027), and no significant effect of prior expert information ($F_{1,168}$=3.63 P=.06, partial eta squared=0.021). Prior knowledge was not significantly related to any of the

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dependent variables (tag selection: r=–.04, P=.62; blog post selection: r=–.03, P=.66, efficacy rating: r=.03, P=.66, recommendation: r=.06, P=.47), nor was it a significant covariate, nor did prior knowledge as a covariate change the pattern of significance for each dependent variable in separate ANCOVAs. Therefore, we did not include prior knowledge as a covariate in the following analyses.

In order to assure equivalent *treatment intensity of prior expert information*, participants rated persuasiveness of both blog posts on a 7-point scale (1=I don't agree, 7=I completely agree). There was no difference of the persuasiveness ratings between the prior pharmacotherapy expert information group (mean 5.86, SD 1.03) and the prior psychotherapy expert information group (mean 5.91, SD 1.11; t_{173}=0.27, P=.79, d=0.08).

Psychotherapy Bias

In the following analyses, we investigated whether participants showed a psychotherapy bias regarding pre-existent beliefs. To this end, we analyzed efficacy ratings of psychotherapy and pharmacotherapy that had been assessed prior to the information search. Efficacy ratings on a scale ranging from 1-7 showed that participants expressed strong superiority of psychotherapy (mean 4.53, SD 1.99) over pharmacotherapy (mean 2.73, SD 2.41; t_{173}=7.67, P<.001, d=0.81) with regard to the treatment of depression. Thus the participants of our study clearly demonstrated a psychotherapy bias [3,4]. In the following sections, we will show how the bias influenced information processing and what factors affected the bias.

Information Search

We first tested whether the psychotherapy bias emerges in information search (H1). This hypothesis was confirmed, since participants generally selected more psychotherapy tags (mean 4.66, SD 2.28) compared to pharmacotherapy tags (mean 3.87, SD 3.35; t_{173}=2.83, P=.005, d=0.25). Further support was provided by the fact that participants selected more psychotherapy blog posts (mean 7.02, SD 4.47) compared to pharmacotherapy blog posts (mean 4.21, SD 3.97; t_{173}=6.47, P<.001, d=0.66).

Beyond demonstrating the biased information search behavior, we hypothesized that the psychotherapy bias is reduced by providing prior expert information (H2) and popular tags (H3) that challenge the psychotherapy bias. We will report two separate 2 (prior expert information: supporting, challenging) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) ANOVAs for tag selection on one hand, and blog post selection on the other. With regard to *tag selection*, the analysis did not yield a significant main effect of *prior expert information* ($F_{1,168}$=.32, P=.57, partial eta squared=0.002). There was no tendency of participants to prefer either pharmacotherapy or psychotherapy tags when prior expert information challenged or supported psychotherapy bias (Figure 5, left panel). There was, however, a significant main effect of *tag popularity* ($F_{2,168}$=10.61, P<.001, partial eta squared=0.112). A polynomial contrast analysis showed that there was a linear trend of selection bias across the tag popularity conditions (P<.001; Figure 5, left panel). Psychotherapy tag selection was higher in the condition with psychotherapy tags being popular compared to the balanced condition (Cohen's d=0.49) and the pharmacotherapy popular condition (Cohen's d=0.85). The interaction between prior expert information and tag popularity ($F_{2,168}$=.02, P=.98, partial eta squared<0.001) was not significant.

With regard to the second dependent measure of information search, *blog post selection*, a separate 2 x 3 ANOVA revealed a significant effect of *prior expert information* ($F_{1,168}$=4.32, P=.04, partial eta squared=0.025). Reading a prior blog post that challenged the psychotherapy bias led participants to read more pharmacotherapy blog posts during their navigation in the tag cloud (Cohen's d=0.30; Figure 5, right panel). The ANOVA also showed a main effect of *tag popularity* on biased *blog post selection* ($F_{2,168}$=6.55, P=.002, partial eta squared=0.072). A polynomial contrast analysis showed that there was a linear trend of selection bias across the tag popularity conditions (P<.001; Figure 5, right panel). Psychotherapy blog post selection was higher in the psychotherapy tags popular condition compared to the balanced condition (Cohen's d=0.38) and the pharmacotherapy popular condition (Cohen's d=0.61). The interaction of prior expert information and tag popularity was not significant ($F_{2,168}$=.02, P=.98, partial eta squared<0.001).

In an additional analysis, we exploratively examined whether participants in the challenging *tag popularity* condition exhibited any bias in information search at all. As indicated by t tests, this was not the case. Neither *tag selection* nor *blog post selection* were significantly biased: Ps>14.

Taken together, we found evidence for a confirmation bias with participants selecting significantly more resources that were consistent with their previously held beliefs that psychotherapy is more effective. Our results also demonstrate, however, that this biased information selection can be significantly reduced. Whereas prior expert information reduced the biased selection of blog posts (but not of tags), tag popularity affected both measures of information search. Being exposed to a tag cloud that contained pharmacotherapy tags as the most popular ones did not only significantly decrease the biased search, but eventually eliminated the confirmation bias in that participants selected as many tags and resources of both treatment types. Hence, challenging tag clouds led to a balanced (ie, unbiased) information search.

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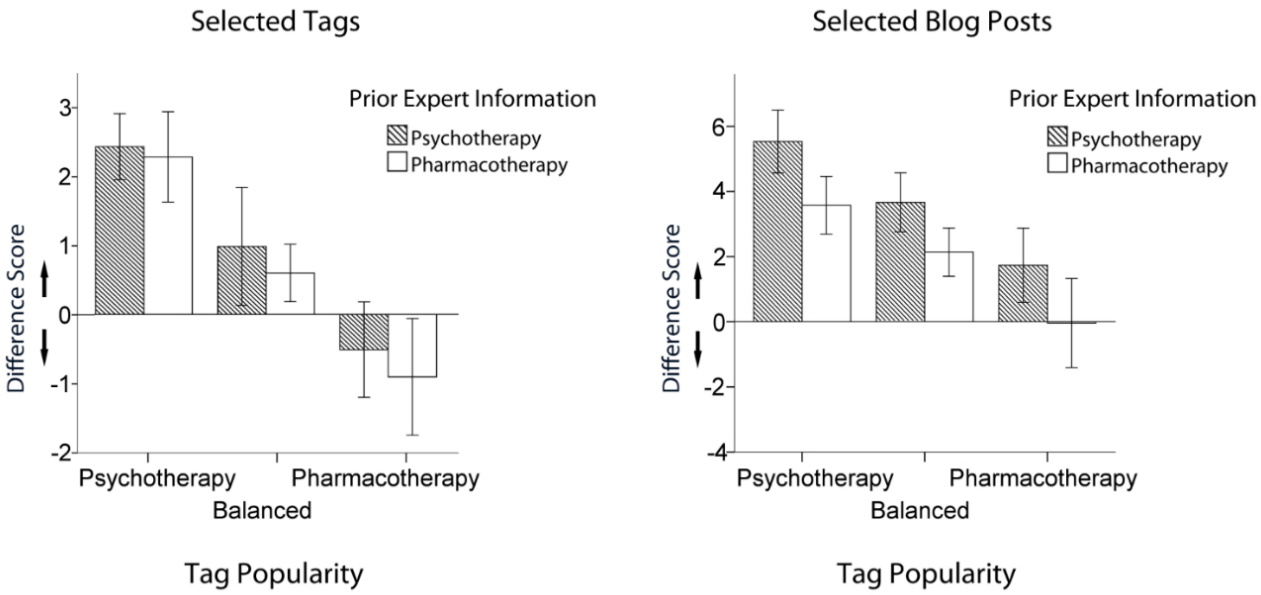
Figure 5. Information search bias (pharmacotherapy scores subtracted from psychotherapy scores; positive scores indicate a preference for psychotherapy over pharmacotherapy; negative scores indicate a preference of pharmacotherapy over psychotherapy).



Evaluation of Information

With regard to information evaluation, we hypothesized that prior expert information (H4) that challenges the psychotherapy bias decreases biased evaluation of information, compared to prior expert information, which confirms psychotherapy bias. We also expected popular tags (H5) that challenge psychotherapy bias to reduce biased evaluation of information, compared to balanced tag popularity and even more compared to popular tags that support the bias. In order to analyze both hypotheses, we conducted a 2 (prior expert information: supporting, challenging) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) ANOVA, with efficacy ratings as the dependent measure. The main effect of *prior expert information* (H4) on biased *efficacy rating* failed to reach conventional significance levels ($F_{1,168}$=2.93, P=.09, partial eta squared=0.017). Prior expert information that challenged psychotherapy bias failed to significantly decrease biased information evaluation compared to prior expert information that confirms the bias.

Popularity of tags challenging psychotherapy bias, in contrast, decreased biased information evaluation as indicated by a significant main effect of *tag popularity* on *evaluation of information* ($F_{2,168}$=8.48, P<.001, partial eta squared=0.092). A polynomial contrast analysis showed that there was a linear trend of evaluation bias across the tag popularity conditions (P<.001; Figure 6). Psychotherapy bias in treatment evaluation was higher in the psychotherapy tags popular condition compared to the balanced condition (Cohen's d=0.35) and the pharmacotherapy popular condition (Cohen's d=0.77). The interaction of prior expert information and tag popularity was not significant ($F_{2,168}$=.18, P=.84, partial eta squared=0.002).

Further explorative analyses supported what can be derived from Figure 6 already. Efficacy ratings after the information search task were no longer biased in the challenging *tag popularity* condition (t_{33}=0.37, P=.72 in the supporting *prior expert information* condition and t_{25}=0.55, P=.59 in the challenging *prior expert information* condition).

In sum, our interventions were differentially successful in reducing the confirmation bias with regard to the evaluation of information. Whereas prior expert information failed to exert a significant influence, tag clouds with tags that challenged the psychotherapy bias not only reduced biased information evaluation, but eventually eliminated any bias. Efficacy ratings in this condition were thus eventually in line with scientific evidence.

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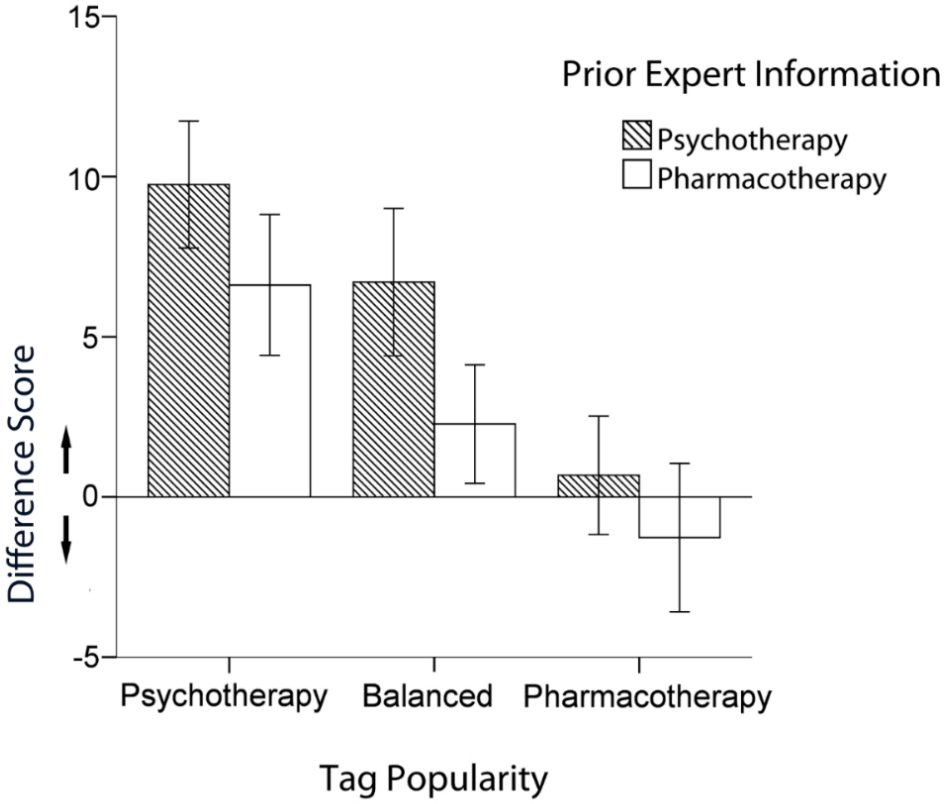
Figure 6. Efficacy ratings of blog posts (pharmacotherapy scores subtracted from psychotherapy scores; positive scores indicate a preference for psychotherapy over pharmacotherapy; negative scores indicate a preference of pharmacotherapy over psychotherapy).



Recommendation

Beyond information selection and evaluation, we expected that *prior expert information* (H6), as well as *tag popularity* (H7) that challenges the psychotherapy bias, to decrease biased treatment recommendation for a hypothetical friend. We conducted an additional 2 (prior expert information: challenging, supporting) x 3 (tag popularity: psychotherapy, balanced, pharmacotherapy) ANOVA with treatment recommendation as the dependent variable. The results showed neither a significant main effect of tag popularity ($F_{2,168}$=.22, P=.81, partial eta squared=0.003) nor a significant main effect of prior expert information ($F_{1,168}$=.97, P=.33, partial eta squared=0.006). The interaction was also not significant ($F_{1,168}$=.08, P=.92, partial eta squared=0.001). Overall, prior expert information and tag popularity had no effect on recommendation. Figure 7 shows that most of the participants recommended psychotherapy.

We conducted an exploratory qualitative analysis of the reasons for the treatment recommendation. Most of the participants did not provide any reasons but among those who did, the most frequently mentioned aspects regarded etiology or negative consequences of antidepressants. Specifically, 16.7% (29/174) participants argued for psychotherapy because they were convinced that biographical and social causes are crucial for the causation and treatment of depression. Another 10.3% (18/174) participants mentioned side effects, and 6.3% (11/174) reasoned that antidepressants are addictive. Finally, 4.6% (8/174) revealed that they believed that overcoming depression is an act of will or a personal responsibility.

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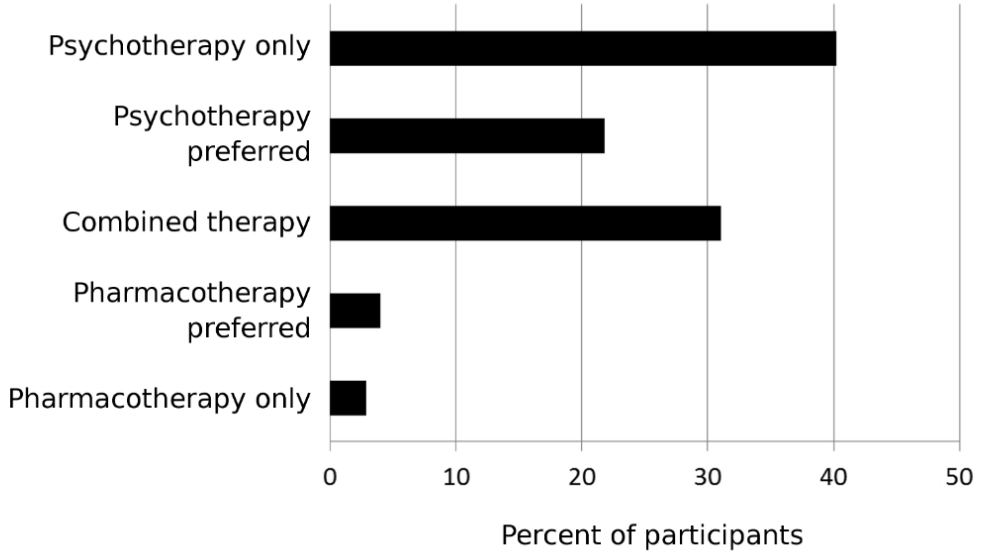
Figure 7. Treatment recommendation after experiment.



Discussion

Principal Findings

This study investigated potential measures to decrease biased beliefs and their influence on information selection and information evaluation. To this end, we made use of laypeople's (erroneous) convictions that psychotherapy is more effective in treating depression and examined whether this conviction guides online information search. In line with prior findings, participants did believe in the superiority of psychotherapeutic treatment and thus exhibited a psychotherapy bias. When searching for information online about the treatment of depressive disorders, participants showed a general bias towards selecting psychotherapy treatments compared to pharmacotherapy treatments.

We took two measures to reduce biased information processing. First, we exposed participants to expert information explicitly challenging the superiority of psychotherapy, by demonstrating the effectiveness of pharmacotherapy. This manipulation led participants to select fewer blog posts that were related to psychotherapy compared to the presentation of expert information supporting the effectiveness of psychotherapy. It did not affect, however, tag selection, and there was only a trend for it to exert an influence upon subsequent efficacy ratings. Hence, explicit expert information was only partially successful in reducing biased information processing.

Second, we attempted to decrease biased information processing by presenting participants with tag clouds in which the most popular tags referred to pharmacotherapy (vs psychotherapy). Consistent with our hypotheses, participants in the pharmacotherapy condition selected these popular pharmacotherapy tags more frequently and read more of the underlying blog posts. Moreover, treatment efficacy ratings were affected. In contrast to our expectations, however, we did not find any effects on treatment recommendations.

Although both manipulations had an impact upon search behavior and efficacy evaluation, the manipulations did not exert an impact on providing recommendations to other people. The gap between the efficacy ratings and treatment recommendations might be due to other beliefs people have with regard to both therapies, such as side effects [32,33]. Participants might be convinced that pharmacotherapy is effective, but they might still have feared detrimental side effects. The reasoning of participants supported this notion, as they frequently referred to side effects and even addictiveness of antidepressants when justifying their recommendation. This might indicate that even if a part of the beliefs changed (ie, the efficacy beliefs), other beliefs (eg, about side effects) still have a strong impact on the overall evaluation of a treatment. This is likely to be based on multiple aspects with efficacy being only one of them. Nevertheless, because our primary aim was to reduce laypeople's misconceptions and to counter their biased information processing, we had primarily focused on treatment efficacy. After all, their beliefs had been shown to stand in contrast to scientific evidence. And it was due to this focus that all of our materials concerned treatment efficacy only. With regard to this misconception, however, our findings clearly argue for a success. Tag clouds with challenging popular tags were able to not only reduce biased information search and evaluation, but eventually led to an unbiased search and evaluation. That is, we were able to completely eliminate laypeople's bias regarding treatment efficacy.

Theoretical Implications

Previous research on confirmation bias has shown that people's prior beliefs influence their information search in a way that they seek to confirm their beliefs [22,27]. The present study showed that implicit presentation of expertise is even more effective than the explicit one. Earlier research [21] showed that tag semantics and popularity determine individual information processing behavior. Likewise, previous studies successfully showed that social tags influence information selection, evaluation, incidental learning [18,19], and conceptual memory

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representations [20,21]. The findings of the current study extend existing evidence by showing that expert information exerts an even larger influence on users' beliefs, if it is presented implicitly such as in tag clouds compared to explicit presentations as in blog posts alone. This finding has some practical implications.

Practical Implications

In order to make people more aware of expert information and to overcome their individual biases, it seems to be useful to provide them with tag clouds. If these tag clouds challenge their subjective beliefs, users are motivated to select more popular tags (that are inconsistent with their own beliefs) and to read more information challenging their own views. This leads to a reduced confirmation bias, not just with regard to information search, but also with regard to evaluation.

A "correction" of subjective biases can only be achieved, however, if the information provided is not also biased. Thus, whether the effect that tag clouds have is really positive depends on the quality of tags and resources: does tag popularity really represent the scientific knowledge about a topic? In order to ensure that, it is important that people with high expertise provide the resources and tags. The provision of such expert information could be fostered if experts were encouraged to publish scientific studies in a style suitable for a broad audience, as this is already sufficient to reduce biased attitudes.

Limitations

In the current study, we carefully balanced the quality of arguments for both types of treatment. We therefore provided information only about the efficacy of treatments, not about other aspects such as side effects, which would be specific for each treatment. For future studies, it may be desirable to test this in more depth by including diagnostic information with respect to relative efficacy of both treatment types (eg, information on treatments that are less effective compared to others or placebo), as well as providing information on side effects or other treatment-specific information.

Second, it must be pointed out that the present sample consisted mainly of university students or persons with a degree in higher education. Some of our participants had a health care related background. Our analyses showed, however, that the pattern of results was identical when these more knowledgeable participants were excluded. Hence, our findings should be valid with regard to laypeople. Nevertheless, future studies should also include participants without a higher education, as well as older persons.

Conclusions

Our major aim in this study was to investigate whether people exhibit a biased online information search behavior that is guided by biased beliefs. We examined the biased perception of laypersons that psychotherapy is more effective than pharmacotherapy, when it comes to the treatment of depression [3,4]. We do not believe that our results are limited to the topic of depression or the pharmacological or psychological treatments. Rather, we would suggest that for any health-related issue involving different accounts or treatments, information challenging users' prior knowledge and attitudes may increase their understanding of the topic in question [34,35].

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [36].

[PDF File (Adobe PDF File), 999KB - jmir_v16i3e94_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
DSM IV: Diagnostic and Statistical Manual of Mental Disorders, 4th edition
ICD-10: International Classification of Diseases

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Original Paper

Who Uses Physician-Rating Websites? Differences in Sociodemographic Variables, Psychographic Variables, and Health Status of Users and Nonusers of Physician-Rating Websites

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Abstract

Background: The number of physician-rating websites (PRWs) is rising rapidly, but usage is still poor. So far, there has been little discussion about what kind of variables influence usage of PRWs.

Objective: We focused on sociodemographic variables, psychographic variables, and health status of PRW users and nonusers.

Methods: An online survey of 1006 randomly selected German patients was conducted in September 2012. We analyzed the patients' knowledge and use of online PRWs. We also analyzed the impact of sociodemographic variables (gender, age, and education), psychographic variables (eg, feelings toward the Internet, digital literacy), and health status on use or nonuse as well as the judgment of and behavior intentions toward PRWs. The survey instrument was based on existing literature and was guided by several research questions.

Results: A total of 29.3% (289/986) of the sample knew of a PRW and 26.1% (257/986) had already used a PRW. Younger people were more prone than older ones to use PRWs (t_{967}=2.27, P=.02). Women used them more than men (χ^2_1=9.4, P=.002), the more highly educated more than less educated people (χ^2_4=19.7, P=.001), and people with chronic diseases more than people without (χ^2_1=5.6, P=.02). No differences were found between users and nonusers in their daily private Internet use and in their use of the Internet for health-related information. Users had more positive feelings about the Internet and other Web-based applications in general (t_{489}=3.07, P=.002) than nonusers, and they had higher digital literacy (t_{520}=4.20, P<.001). Users ascribed higher usefulness to PRWs than nonusers (t_{612}=11.61, P<.001) and users trusted information on PRWs to a greater degree than nonusers (t_{559}=11.48, P<.001). Users were also more likely to rate a physician on a PRW in the future (t_{367}=7.63, P<.001) and to use a PRW in the future (t_{619}=15.01, P<.001). The results of 2 binary logistic regression analyses demonstrated that sociodemographic variables (gender, age, education) and health status alone did not predict whether persons were prone to use PRWs or not. Adding psychographic variables and information-seeking behavior variables to the binary logistic regression analyses led to a satisfying fit of the model and revealed that higher education, poorer health status, higher digital literacy (at the 10% level of significance), lower importance of family and pharmacist for health-related information, higher trust in information on PRWs, and higher appraisal of usefulness of PRWs served as significant predictors for usage of PRWs.

Conclusions: Sociodemographic variables alone do not sufficiently predict use or nonuse of PRWs; specific psychographic variables and health status need to be taken into account. The results can help designers of PRWs to better tailor their product to specific target groups, which may increase use of PRWs in the future.

(J Med Internet Res 2014;16(3):e97) doi:10.2196/jmir.3145

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KEYWORDS

physician-rating websites; sociodemographic variables; psychographic variables; digital literacy

Introduction

Development of Physician-Rating Websites

In recent years, there has been increasing interest in online rating websites, which have become part of life for many of us [1]. Web 2.0 has supported the enormous growth of online rating websites [2] and online reviews tend to shift the balance of authority in the doctor-patient relationship [3]. Physician-rating websites (PRWs) are structured in a similar way to other existing rating sites (eg, travel-, hotel-, or restaurant-rating sites). Patients can rate and discuss the quality of their physicians online [4]. Rating sites for professional services or restaurants and hotels are already widespread and well known, but this is a relatively new Web-based tool in the area of medicine. For instance, PRWs provide information about a physician's address, business hours, and certifications. However, the most important goal of a PRW is to rate and discuss a physician's quality [5].

Examples of PRWs are RateMDs [6], Vitals [7], ZocDoc [8], and jameda [3,9,10-13]. Some sites are free (eg, RateMDs), whereas other sites provide some free information with more detailed information provided for a fee (eg, Healthgrades [14]) [15,16]. By now, 1 in 6 physicians have already been rated, with 90% of all ratings being positive [10].

Experts' opinions differ on whether the standard of care in the future will improve or not [3]. Since 2001, the Bertelsmann Health Care Monitor, a periodically conducted survey financed by the German Bertelsmann foundation, has been collecting data from a representative sample of the German population aged between 18 and 79 years on diverse aspects of health care. According to the 2009 Bertelsmann Health Care Monitor [17], there has been an emerging trend to use the Internet for searching for a general practitioner (GP), for example. In 2007, 5% of 1464 representative selected respondents in the German population had used the Internet to search for a GP, and that percentage had risen to 9% in 2009 [18]. The percentage had increased even higher for searching for a medical specialist (8% in 2007 to 13% in 2009). According to a recent study conducted by Gesellschaft für Konsumforschung (GfK) HealthCare, a leading survey research company in Nuremberg, Germany, almost 23% of German Internet users trust PRWs when looking for a physician online [19]. Emmert et al [20] conducted a study in Germany in January 2013 that showed that 32% of an online panel were aware of PRWs, 25% of respondents had used a PRW in the past when searching for a physician, and 11% had rated a physician on a PRW at least once. Another important result of this study was that 65% of those who received information from a PRW consulted a physician based on the provided rating, whereas 17% had not consulted a particular physician because of the results found on a PRW [20]. In 2012, Galizzi et al [21] investigated the awareness and use of PRWs in a borough of London, United Kingdom. They calculated that 15% of the respondents (a convenience sample of the general population) were aware of the existence of PRWs [19]. In the United States, usage of PRWs is also still poor [4].

The PRWs seem to offer many advantages for patients. They may provide them with important information, help patients to find physicians with a particular style, help them in their decision-making process, and make them better prepared for their future visits to doctors. PRWs may even improve standards of care and promote trustful doctor-patient relationships [22]. Patients are more likely to rely on PRWs if the information they find is specific to their needs [23]. Some disadvantages are also obvious: physicians fear that PRWs encourage negative reviews. However, an analysis of health care providers' online ratings showed that online ratings were largely positive [24]. Additionally, too few ratings on a site raise concerns—especially from physicians and health organizations—over the representativeness of judgments and scientific validity [3,4]. In general, physicians tend to be skeptical about the quality of health information on the Internet, which is in-line with existing empirical studies assessing the quality of health information on the Internet [25]. If patients are looking for structural information (eg, services offered, opening hours, office location) rather than process or outcome measures, PRWs are successful [5]. PRWs are able to deliver information, but PRWs also cause misinformation and present risks for the rated person in terms of outcome measures [11].

One important question raised is whether patients are able to evaluate the medical expertise and capabilities of a doctor [26]. It should also be considered that, for instance, an analysis of German PRWs demonstrates that the average number of ratings per physician available on PRWs is still poor. For the ratings website jameda [9], which has the largest number of total ratings, an average of 4 evaluations per physician could be found [5]. A recent study in Great Britain found an average of 2 ratings per practice over a 15-month period for a PRW funded by the government [27]. Gao et al [28] reported that only 1 in 6 physicians included in their comprehensive analysis of national ratings in the United States between 2005 and 2010 had been rated on a PRW. In Germany in 2011, a new PRW was created called "Weisse Liste." More than 30 million Germans insured by AOK, BARMER GEK, and other statutory health insurance funds were invited to rate their physicians [29]. In contrast to other PRWs, this Internet portal is noncommercial and free of ads, insured individuals are invited to participate, and a secure registration and authentication procedure prevents misuse of data [29]. Therefore, this site is one of the first to meet most of the demands of quality criteria for PRWs [30,31]. According to Emmert et al [5], further relevance of PRWs can be assumed for other reasons, such as an increasing number of websites [18] and the rapid spread of Web 2.0 services [32].

Health Information Search

Health is one of the most searched topics online [17]. In 2011, 4 out of 5 adult Internet users in the United States searched for health information on the Internet [17,18]. Some demographic groups are more likely to look online for health information than others. Adults between the ages of 18-49 years, for example, are more likely to seek health information online than older people. Less than half of the adults in the United States

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aged 65 years and older use the Internet to look for health information [33]. With regard to gender, women are more likely to look online for health-related information than men [33-36]. Almost 90% of people with a college degree use the Internet to gather information online, compared to 62% of those with a high school education [33,35]. People with a chronic disease or disability are more interested in online health information than people without a chronic disease or disability [37]. Approximately one-quarter of all Internet users in the United States who use the Internet for health- and medical-related information look at PRWs [23,37], and 30% of adult American patients compare physicians online before making a selection. Regarding data obtained from the RateMDs website, 16% of national physicians were rated online in the United States [10,13]. Almost 18% of patients with a chronic disease have looked for physician rankings or reviews online and 6% of patients with a chronic disease have already posted a review [37]. A recent US study showed that online reviewers of social care review sites tend to be younger, healthier, and more affluent than health care users overall [3].

However, little is known about variables that influence usage of PRWs. The question arises how the previously mentioned variables analyzed in the health information literature along with additional psychographic variables can be related to the use of PRWs. The objectives of this research are to:

1. Analyze patients' knowledge and use of PRWs,
2. Describe users and nonusers in terms of sociodemographic variables, psychographic variables, and health status, and
3. Assert whether these variables can also serve as predictors of usage and nonusage of PRWs.

Results of this paper will be useful for the improvement of PRWs as they help to tailor PRWs more closely to the needs of users. In addition to sociodemographic variables (gender, age, education), this paper also takes psychographic variables (eg, feelings toward the Internet, digital literacy) and health status into account.

Methods

Participant Recruitment

An online survey of 1006 German patients was conducted in September 2012. The term "patients" in this paper refers to individuals that have visited a physician at least once in the previous 3 months. The sample was drawn from an e-panel maintained by GfK HealthCare, a leading survey research company in Nuremberg, Germany. It was based on a randomly generated set of users who had visited a GP at least once during the 3 months before the beginning of the survey. Originally, 1561 individuals were contacted; 555 persons could not participate because they did not fulfill this criterion. The recruitment rate was 64.45% (1006/1561) [38]. In all, 20 participants were excluded from the analysis because of an extremely short answer time and/or inconsistent answer patterns (eg, flatliners, contradictions) resulting in 986 usable respondents. Small monetary incentives were offered for survey completion.

Questionnaire

The survey was designed by the researchers based on the existing literature and was guided by the research questions. All items apart from categorical variables were measured with 7-point rating scales (see Multimedia Appendix 1). All items had a "no answer" category as an alternative. Existing scales from the literature were used where applicable. Data were analyzed using SPSS version 20 (IBM Corp, Armonk, NY, USA).

Measurement of Physician-Rating Website Items

Knowledge of Physician-Rating Websites

To assess whether respondents knew about PRWs, they were explicitly asked if they knew any online physician-rating platforms with the following question: "Do you know websites on which patients have the opportunity to rate their physicians?" (1=yes; 2=no). To ensure that the respondents understood the term "PRW," an example of a rating platform was given as an introductory phrase before asking the actual question.

Usage of Physician-Rating Websites

Respondents were asked if they had gathered information at least once on a PRW with the question: "Have you ever gathered information on a physician from a PRW?" (1=yes; 2=no). Additionally, they were asked whether they had rated a physician on an online rating platform like this before (1=yes; 2=no). All respondents with a negative response to this question were asked additionally whether they could imagine rating on an online physician-rating platform (1=cannot imagine this at all; 7=can imagine this very well) and how probable it is that they would use online physician-rating platforms in the future (1=not at all probable; 7=very probable).

Usefulness of Physician-Rating Websites

The usefulness of online physician-rating platforms was judged in comparison to other recommendation sources, such as physicians, family, and friends with the following question: "How useful are PRWs in comparison to other recommendation sources (eg, other physicians, family, friends) from your point of view?" (1=not at all useful; 7=very useful).

Trust in Physician-Rating Websites

To examine respondents' trust in PRWs, we asked whether they trusted the information on online physician-rating platforms with the following question: "How much do you trust the information on PRWs?" (1=no trust at all; 7=very high trust).

Measurement of Sociodemographic and Psychographic Variables

Sociodemographic Variables

Age was measured through the inquiry about the participant's year of birth and education through the highest completed level of education. The respondents were asked whether they had a chronic disease or not (1=yes; 2=no; 3=no answer).

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Feelings About the Internet and Other Web-Based Applications

Feelings about the Internet and other Web-based applications in general were measured with the following question: "What kind of feelings do you have toward the Internet and other Web-based applications (eg, apps on smartphones or tablets) in general?" (1=very negative; 7=very positive; 8=no answer).

Digital Literacy

Digital literacy is the ability to effectively and critically use a range of digital technologies. Literate individuals are able to make responsible choices and to access information and ideas in the digital world and to share information with others. High levels of digital literacy are seen as an important prerequisite in today's digital world [39]. Digital literacy was measured with an item based on Norman and Skinner [40]. The respondents were asked the following: "How would you rate your own Internet skills?" (1=not literate at all; 7=very literate).

Daily Internet Use

Concerning daily Internet use, respondents were asked how many hours on average on a daily, weekly, or monthly basis they spend on the Internet for private purposes (total private use) and searching for health-related information (total private use for health-related information). Respondents should choose 1 of 3 options (daily, weekly, monthly). We then calculated the total private use of Internet and the total private use of Internet for health-related information for each respondent on a daily basis.

Importance of Different Sources for Health-Related Information

Respondents were asked to state the importance of the following single sources for health-related information search on a 7-point scale (1=not important at all; 7=very important; 8=no answer): family, friends, physician, pharmacist, insurance agent, Internet, books/journals, and other sources.

Results

Definition of Users and Nonusers

To compare the sociodemographic variables of users and nonusers of PRWs, the respondents were split into 2 groups: those who did have experience with PRWs (users) and those who did not (nonusers). With regard to knowledge about PRWs, 29.3% (289/986) of respondents answered that they knew of PRWs, 68.1% (671/986) of respondents did not know of PRWs, and 2.6% (26/986) of respondents chose the alternative response (no answer). To identify usage of PRWs, respondents were asked whether they had used PRWs for an information search at least once. In all, 26.1% (257/986) of respondents said yes (named users of PRWs), 72.2% (712/986) of respondents said no (named nonusers of PRWs), and 1.7% (17/986) of respondents chose the alternative response (no answer) and were excluded from the analyses.

Differences Between Users and Nonusers

Table 1 presents the results from the descriptive analysis of chi-square test for users and nonusers of PRWs regarding gender, education, and health status and of *t* test for age.

As shown in Table 1, there are significant differences between men and women in their experience with PRWs. More women than men had used them in the past (χ^2_1=9.4, *P*=.002). More respondents with a higher education entrance qualification (eg, people with a high school diploma or people who have graduated from university) had experience with PRWs (χ^2_4=19.7, *P*=.001) and younger respondents had experience with gathering information through PRWs (t_{967}=2.27, *P*=.02). Finally, significantly more participants with chronic disease(s) had used information from a PRW than those without chronic disease(s) (χ^2_1=5.6, *P*=.02).

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Table 1. Differences between users and nonusers of physician-rating websites (PRWs) in reference to sociodemographic variables and health status.

Variables	Users n=257	Nonusers n=712	Total N=969	χ^2 (*df*)	*t* (*df*)	*P*
Age (years), mean (SD)	42.28 (12.92)	44.42 (12.99)	43.85 (13.00)		2.27 (967)	.02
Gender, n (%)				9.4 (1)		.002
Male	118 (22.5)	406 (77.5)	524 (100)			
Female	139 (31.2)	306 (68.8)	445 (100)			
Education, [a] n (%)				19.7 (4)		.001
Without school qualification	2 (50.0)	2 (50.0)	4 (100)			
Secondary general school	2 (16.7)	10 (83.3)	12 (100)			
Polytechnic secondary school	14 (11.7)	106 (88.3)	120 (100)			
Intermediate secondary school	71 (25.4)	208 (74.6)	279 (100)			
Matura examination or higher	166 (30.4)	380 (69.6)	546 (100)			
Health status, [b] n (%)				5.6 (1)		.02
No chronic disease	122 (23.6)	396 (76.4)	518 (100)			
Chronic disease	131 (30.4)	300 (69.6)	431 (100)			

[a]Users: n=255; nonusers: n=706; total: n=961.

[b]Users: n=253; nonusers: n=696; total: n=949.

Differences Between Users and Nonusers: Psychographic Variables

Table 2 provides the corresponding results of unrelated *t* tests for the psychographic variables and information-seeking behavior variables. As can be seen from the data, there was a significant difference between the 2 groups in their feelings toward the Internet and other Web-based applications in general (t_{489}=3.07, *P*=.002) and their digital literacy (t_{520}=4.20, *P*<.001). Users had more positive feelings about the Internet and other Web-based applications than nonusers and had higher competence in digital literacy. When the participants were asked to evaluate the importance of different sources for health-related information, users of PRWs rated the Internet higher than nonusers of PRWs and they rated books or journals and other sources (not specified in the questionnaire) lower than nonusers (see Table 2 for details). The 2 groups did not differ in their daily Internet use measured by the daily hours spent online for private use and, in particular, for using the Internet for health-related information.

Further unrelated *t* tests were used to analyze variables concerning PRWs: usefulness and trust in PRWs and future behavior intentions of the 2 groups. In terms of judging the usefulness of PRWs compared with other recommendation sources, the 2 groups differed as expected (t_{612}=11.61, *P*<.001) with users ascribing higher usefulness. It can be seen from the data in Table 3 that users trusted information on PRW sites to a greater extent than nonusers (t_{559}=11.48, *P*<.001) and were more prone to rate a physician online in the future (t_{367}=7.63, *P*<.001) as well as use PRWs in the future (t_{619}=15.01, *P*<.001).

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Table 2. Differences of users and nonusers of physician-rating websites (PRWs) in reference to psychographic variables and information-seeking behavior variables.

Variables	Users (n=257)		Nonusers (n=712)		Total (N=969)		*t* (*df*)	*P*
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)		
Feelings about the Internet and other Web-based applications in general (1=very negative, 7=very positive)	254	5.96 (1.02)	702	5.72 (1.12)	956	5.78 (1.10)	3.07 (489)	.002
Digital literacy (1=not literate at all, 7=very literate)	257	6.08 (0.95)	712	5.78 (1.10)	969	5.86 (1.06)	4.20 (520)	<.001
Daily Internet use (hours)								
Total private use	257	3.17 (2.04)	712	3.04 (2.34)	969	3.07 (2.27)	0.78 (967)	.43
Total private use for health-related information	257	0.55 (1.82)	712	0.39 (1.45)	969	0.43 (1.56)	1.47 (967)	.14
Importance of different sources for health-related information (1=not important at all, 7=very important)								
Family	256	4.77 (1.70)	703	4.87 (1.73)	959	4.84 (1.73)	–0.81 (957)	.41
Friends	252	4.27 (1.70)	703	4.13 (1.75)	955	4.17 (1.74)	1.13 (953)	.26
Physician	256	6.40 (0.88)	709	6.42 (0.99)	965	6.42 (0.96)	–0.35 (963)	.73
Pharmacist	248	4.93 (1.56)	699	5.05 (1.58)	947	5.02 (1.57)	–0.98 (945)	.33
Insurance agent	236	1.82 (1.46)	664	1.73 (1.27)	900	1.75 (1.32)	0.95 (898)	.34
Internet	256	5.08 (1.19)	707	4.38 (1.50)	963	4.57 (1.46)	7.47 (569)	<.001
Books/journals	248	4.64 (1.62)	684	4.10 (1.69)	932	4.24 (1.69)	4.32 (930)	<.001
Other sources	161	3.26 (1.89)	480	2.75 (1.75)	641	2.88 (1.80)	3.16 (639)	.002

Table 3. Differences of users and nonusers of physician-rating websites (PRWs) in reference to variables concerning PRWs.

Variables	Users (n=257)		Nonusers (n=712)		Total (N=969)		*t* (df)	*P*
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)		
Usefulness of PRWs (1=not at all useful, 7=very useful)	254	5.24 (1.45)	692	3.88 (1.98)	946	4.24 (1.95)	11.61 (612)	<.001
Trust of information on PRWs (1=no trust at all, 7=very high trust)	252	4.45 (1.30)	692	3.26 (1.65)	944	3.58 (1.65)	11.48 (559)	<.001
Willingness to rate a physician on a PRW (1=not willing at all, 7=very willing)	193	5.27 (1.74)	678	4.13 (2.11)	871	4.38 (2.09)	7.63 (367)	<.001
Probability of using a PRW in the future (1=not probable at all, 7=very probable)	255	5.46 (1.44)	701	3.69 (1.99)	956	4.17 (2.02)	15.01 (619)	<.001

Causal Relationship Between the Variables: Binary Logistic Regression

Table 4 shows the results of 2 binary logistic regressions. In a first step, a binary logistic regression (n=942) with the user and nonuser distinction (usage=1; nonusage=0) as criterion and the variables gender, age, education, and health status was carried out. All the remaining variables were entered into the regression in their original form, which means that gender and health status were scaled nominally, education ordinally, and age was scaled metrically. However, our model did not reveal significant fit. Nagelkerke R^2 was quite low (Nagelkerke R^2=.052) and –2 log-likelihood was too high (–2 log-likelihood=1059.625). The analysis showed that the sociodemographic variables and health status alone did not satisfactorily predict whether persons were prone to use PRWs or not. An additional binary logistic regression (n=815) was calculated with the user and nonuser distinction as criterion and the variables gender, age, education, health status, feelings about the Internet, digital literacy, total daily Internet use in general, total daily Internet use for health-related information, importance of different sources for health-related information, appraisal of usefulness of PRWs, and trust of information on PRWs as predictors. The regression coefficients for gender and age were no longer significant. The regression coefficients were significant for the following variables: education (beta=.237, *P*=.005) implicating that a higher level of education predicted usage of PRWs, health status (beta=–.621, *P*=.001) demonstrating that a chronic disease predicted usage of PRWs, importance of family and pharmacist for health-related information demonstrating that lower importance of the 2 sources for health-related information had a significant impact on usage (family: beta=–.166, *P*=.02; pharmacist: beta=–.124, *P*=.046), trust in information on PRWs (beta=.329, *P*=.001), and the appraisal of usefulness of PRWs

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(beta=.216, *P*=.01) showing that higher trust and higher appraisal fostered usage of PRWs. Digital literacy (beta=.209, *P*=.05) and importance of the Internet for health-related information (beta=.141, *P*=.08) were also predictors, revealing that higher digital literacy and higher importance of the Internet were predictors for usage of PRWs. Nagelkerke R^2 was satisfying (Nagelkerke R^2=.248) with –2 log-likelihood=796.464.

Table 4. Binary logistic regressions for the user versus nonuser distinction.

Stepwise binary logistic regressions for different variables	Statistical fit	Standardized regression coefficients (beta)	*P*
Step 1 (n=942)			
–2 Log-likelihood	1059.625		
Pseudo R^2 (Nagelkerke)	0.052		
Predictors			
Constant (–1.561; *P*=.01)			
Gender		.370	.02
Age		–.012	.047
Education		.271	<.001
Health status		–.511	.001
Step 2 (n=815)			
–2 Log-likelihood	796.464		
Pseudo R^2 (Nagelkerke)	0.248		
Predictors			
Constant (–4.100; *P*<.001)			
Gender		.293	.11
Age		–.012	.11
Education		.237	.005
Health status		–.621	.001
Feelings about the Internet and other Web-based applications in general		–.053	.60
Digital literacy		.209	.05
Total private daily Internet use		–.069	.12
Total private daily Internet use for health-related information		.021	.70
Importance of family for health-related information		–.166	.02
Importance of friends for health-related information		.069	.32
Importance of physician for health-related information		.071	.49
Importance of pharmacist for health-related information		–.124	.046
Importance of insurance agent for health-related information		–.024	.73
Importance of Internet for health-related information		.141	.08
Importance of books/journals for health-related information		.000	.99
Usefulness of PRWs		.216	.01
Trust of information on PRWs		.329	.001

Discussion

Principal Findings

One of the most significant findings to emerge from this study is that users and nonusers of PRWs differ according to several sociodemographic and psychographic variables and health status. Approximately one-quarter of respondents in our survey had used a PRW before. This is similar to the percentage described in the online study conducted by Emmert et al [20] in Germany in 2013 (25.3%) and it is higher than the percentage from a telephone survey of respondents in Germany in 2011 (10%) [41]. We agree with Emmert et al [20], who ascribed the difference between the 2 results to the survey method (telephone vs online panel). Our study revealed that younger people have more experience with PRWs. Further, more women than men,

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more highly educated people, and more persons with a chronic disease use PRWs. The findings of the current study are consistent with those of previous studies that suggested some sociodemographic groups are more likely to look online for health information than others [37]. The study by Emmert et al showed that women were more aware of German PRWs than men were. The same was true for people with higher health care utilization. Another finding of that study was that more women than men and more people with higher health care utilization had searched for physicians by using a German PRW [20]. Age was a significant (negative) predictor of PRW awareness in the study led by Galizzi et al in the United Kingdom [21].

However, the findings of the current paper go beyond those of the existing studies. The results of this investigation show that there are no significant differences between users and nonusers of PRWs in their daily Internet use, but users express more positive feelings toward the Internet and are more digitally literate than nonusers. Users and nonusers do not even differ in their daily Internet use for health-related information. The difference between users and nonusers may not lie in the quantity, but in the quality and content of Internet consumption because users see themselves as more digitally literate and have more positive feelings toward the Internet. It may be assumed that users search more efficiently for health-related information and use other sources and content of the Internet than nonusers of PRWs. This can be accentuated by the fact that the Internet is a more important source of health-related information for users than nonusers of PRWs. As expected, the usefulness of information and trustworthiness of PRWs is judged to be higher by users than nonusers. The 2 groups differ significantly in their future intentions concerning PRWs: Users are more prone to use a PRW in the future and to rate a physician online in the future.

This study has demonstrated that sociodemographic variables alone do not produce a satisfying model to predict usage or nonusage of PRWs. Instead, it is necessary to integrate additional psychographic variables and participants' health status to predict usage or nonusage of PRWs to a more satisfying extent.

According to a causal perspective, higher education, a chronic disease, higher digital literacy, less importance on family and pharmacist for health-related information, higher importance on the Internet for health-related information, higher trust in information on PRWs, and a higher appraisal of the usefulness of PRWs are positive predictors of usage of PRWs. Other variables are not predictors of usage and nonusage (eg, gender and age), which is consistent with findings by Galizzi et al [21] who also found in their logistic regressions that gender and age had no effect on the intention to use PRWs. In our study, having a chronic disease lead to a higher probability of using PRWs. This is in-line with French and Italian studies demonstrating that respondents perceiving themselves as less healthy are more prone to use eHealth [20,42]. However, other studies (eg, Emmert et al [20]) did not find a significant impact of health status on awareness of searching on PRWs or the use of the Internet for health-related information [43,44]. Additional research is necessary to gain more insight into these divergent findings in the literature. In our study, a higher importance of family and pharmacist as an information source for health-related information predicted lower usage of PRWs. One explanation might be that there is a trade-off between the family and the pharmacist and PRWs as sources for health-related information. Respondents preferring the personal relationship of others as a source of health-related information are less prone to use PRWs. On the other hand, if someone ascribes high importance to the Internet (instead of personal relationships, for example) as a source of health-related information, he/she is also more prone to use PRWs. The latter is in-line with the results of Galizzi et al [21], who argued that the willingness to use PRWs is higher for individuals judging websites of hospital statistics as important sources of information.

The results suggest that the level of usage of PRWs is different in different population segments. It seems that current users of PRWs are younger, better educated, female, as well as individuals with a chronic disease. These segments may be innovators in the area of PRW usage, which could be a valuable insight for those interested in increasing PRW usage.

Limitations

There are some limitations to this study. There is the possibility of selection bias among respondents, although random selection out of the database was held to minimize its likelihood and the recruitment rate was 64% for this online panel sample. Participants of an online sample may be more familiar with Internet-related topics [20], such as PRWs; therefore, it can be assumed that they have a higher awareness of PRWs than the average population. A demographic comparison of our sample showed that there were more respondents with a higher education than in the general population. An additional large randomized sample of the average population would certainly be desirable. But, as far as we know, no study has investigated psychographic differences in addition to the sociodemographic ones between users and nonusers of PRWs from the patients' point of view. So, the results shed new light on the possibilities of boosting usage of existing PRWs or on the development of new PRWs.

Practical Implications

Based on our results, communication concepts of PRWs should be tailored to the requirements of their users. The website design, the usability, and the accessibility of the PRWs and user-generated content should meet the users' requirements for further usage of PRWs (eg, clear design of the PRWs, simple handling of the search functions when looking for a physician, introducing links to the websites of the physicians) [45,46]. Consideration should be given to using the innovators (female, better-educated, younger individuals that have experience with PRWs) as a personal communication source for others to spread the usage of PRWs. One might think about the kind of social media that are used by these user segments and tailor communication concepts for PRWs through social media according to the consumer habits of these segments. Reimann and Strech [12] argued that the use of PRWs will increase in the near future when the generation socialized with social media (eg, Facebook) reaches the age in which health questions and doctors become more important.

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It should be kept in mind that all users who are satisfied with their experience with PRWs could function as promoters to diffuse their experience to new user segments, which can be seen as followers in this innovative area.

Results could also be interesting for physicians. Instead of rejecting PRWs, physicians should regard PRWs as an important source of recommendation. If physicians know about the sociodemographic and psychographic profiles of PRW users, they could invite specific patients belonging to these segments who are more likely to use PRWs, to rate them on PRWs, and to pass on their experiences to other patients on PRWs. Also, creators of PRWs should convince physicians of the advantages of PRWs, for example, that good ratings would enhance the possibility of winning new patients and broaden their patient base. Physicians could also use PRWs as a marketing instrument. In this vein, usage of PRWs could also be pushed from the physician side.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire PRWs.

[PDF File (Adobe PDF File), 91KB - jmir_v16i3e97_app1.pdf]

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Abbreviations

GfK: Gesellschaft für Konsumforschung
GP: general practitioner
PRW: physician-rating website

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Original Paper

Economic Evaluation of a Web-Based Tailored Lifestyle Intervention for Adults: Findings Regarding Cost-Effectiveness and Cost-Utility From a Randomized Controlled Trial

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Abstract

Background: Different studies have reported the effectiveness of Web-based computer-tailored lifestyle interventions, but economic evaluations of these interventions are scarce.

Objective: The objective was to assess the cost-effectiveness and cost-utility of a sequential and a simultaneous Web-based computer-tailored lifestyle intervention for adults compared to a control group.

Methods: The economic evaluation, conducted from a societal perspective, was part of a 2-year randomized controlled trial including 3 study groups. All groups received personalized health risk appraisals based on the guidelines for physical activity, fruit intake, vegetable intake, alcohol consumption, and smoking. Additionally, respondents in the sequential condition received personal advice about one lifestyle behavior in the first year and a second behavior in the second year; respondents in the simultaneous condition received personal advice about all unhealthy behaviors in both years. During a period of 24 months, health care use, medication use, absenteeism from work, and quality of life (EQ-5D-3L) were assessed every 3 months using Web-based questionnaires. Demographics were assessed at baseline, and lifestyle behaviors were assessed at both baseline and after 24 months. Cost-effectiveness and cost-utility analyses were performed based on the outcome measures lifestyle factor (the number of guidelines respondents adhered to) and quality of life, respectively. We accounted for uncertainty by using bootstrapping techniques and sensitivity analyses.

Results: A total of 1733 respondents were included in the analyses. From a willingness to pay of €4594 per additional guideline met, the sequential intervention (n=552) was likely to be the most cost-effective, whereas from a willingness to pay of €10,850, the simultaneous intervention (n=517) was likely to be most cost-effective. The control condition (n=664) appeared to be preferred with regard to quality of life.

Conclusions: Both the sequential and the simultaneous lifestyle interventions were likely to be cost-effective when it concerned the lifestyle factor, whereas the control condition was when it concerned quality of life. However, there is no accepted cutoff point for the willingness to pay per gain in lifestyle behaviors, making it impossible to draw firm conclusions. Further economic evaluations of lifestyle interventions are needed.

Trial Registration: Dutch Trial Register NTR2168; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2168 (Archived by WebCite at http://www.webcitation.org/6MbUqttYB).

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(J Med Internet Res 2014;16(3):e91) doi:10.2196/jmir.3159

KEYWORDS

randomized controlled trial; economic evaluation; cost-effectiveness; cost-utility; lifestyle behaviors; Internet interventions; Web-based; computer-tailoring

Introduction

Noncommunicable chronic diseases are associated with various modifiable health risk behaviors, such as physical inactivity, bad nutrition, excessive drinking, and smoking [1]. An unhealthy lifestyle and the consequences involved are related to a reduced quality of life [2] as well as substantial health care costs [3,4]. Stimulating a healthy lifestyle is important to improve health and prevent illness and to also reduce health care costs, especially with current budget cuts in the Netherlands and other countries [5,6].

Computer tailoring can be used successfully as an intervention to promote behaviors associated with a healthy lifestyle [7]. When applying computer tailoring, personalized feedback is generated by a computer program based on an individual assessment [8]. Earlier studies have demonstrated that tailored information is perceived as more relevant than nontailored information [9]. Moreover, computer-tailored interventions have proven to be effective in stimulating a healthier lifestyle, such as smoking cessation [10], preventing smoking relapse [11], encouraging healthy nutrition [12], lowering alcohol intake [13], and increasing physical activity [14]. Previous research has also indicated that changing multiple lifestyle-related behaviors is likely to be more effective than changing only a single behavior [15]. A recent study has shown that tailored interventions that aim to reduce multiple health risk behaviors are not only successful in reducing unhealthy behaviors but also in simultaneously enhancing the overall well-being of the individual [16]. The delivery of computer-tailored interventions targeting multiple health risk behaviors through the Internet has various benefits: These programs can be applied in privacy and at a time and place the respondent finds convenient, many people can be reached at relatively low intervention cost because more than 90% of the Dutch population has Internet access nowadays [17], and because the system is computerized it can be easily combined with and/or integrated in other programs or interventions.

Some economic evaluations of Web-based and/or computer-tailored programs have been conducted to date (eg, [18-23]). In general, these studies have given a first indication that these interventions—most were single behavior change interventions—can indeed be cost-effective. To our knowledge, however, no economic evaluation of a Web-based computer-tailored intervention targeting multiple health risk behaviors has been conducted so far.

Web-based computer-tailored lifestyle interventions are an interesting and promising option to make the health care system more sustainable because of their proven clinical effectiveness and their potential cost-effectiveness due to relatively low intervention costs and wide reach. Thus, information regarding the cost-effectiveness of Web-based computer-tailored intervention programs is crucial for health care decision makers and the government in making evidence-based decisions regarding large-scale implementation of such programs [24]. The aim of the present study, therefore, is to assess from a societal perspective the cost-effectiveness and cost-utility of 2 different versions (sequential and simultaneous) of a Web-based computer-tailored lifestyle intervention for adults compared to a control group that received only a minimal intervention.

Methods

Study Design and Participants

The economic evaluation was embedded in a 2-year single-blind randomized controlled trial including 3 study groups. The study was approved by the Medical Ethics Committee of Maastricht University and the University Hospital Maastricht (MEC 09-3-016/NL27235.068.09) and registered by the Dutch Trial Register (NTR2168).

In October 2009, the Dutch Regional Health Authorities of North-Brabant and Zeeland conducted the quadrennial Adult Health Monitor 2009 among inhabitants of these 2 provinces. This questionnaire could be completed on paper or online via the Internet. Respondents who completed the online version of the questionnaire were invited to take part in the present study. The Adult Health Monitor was interconnected with and integrated into our Web-based lifestyle intervention. The study website was also open to the general public; therefore, it was also possible to register for participation in the trial directly on the study website without having completed the Adult Health Monitor.

The inclusion period for this study was from November 2009 up to and including July 2010. The following inclusion criteria were used: aged between 18 and 65 years, having a computer with Internet access and basic Internet literacy, and having a valid email address. Participants were randomized into 1 of 2 experimental groups (sequential condition or simultaneous condition) or into the control condition, with an equal probability of being assigned to any of the 3 groups. Randomization took place at the individual level by means of a computer software randomization system. Figure 1 shows the Consolidated Standards of Reporting Trials (CONSORT) flow diagram.

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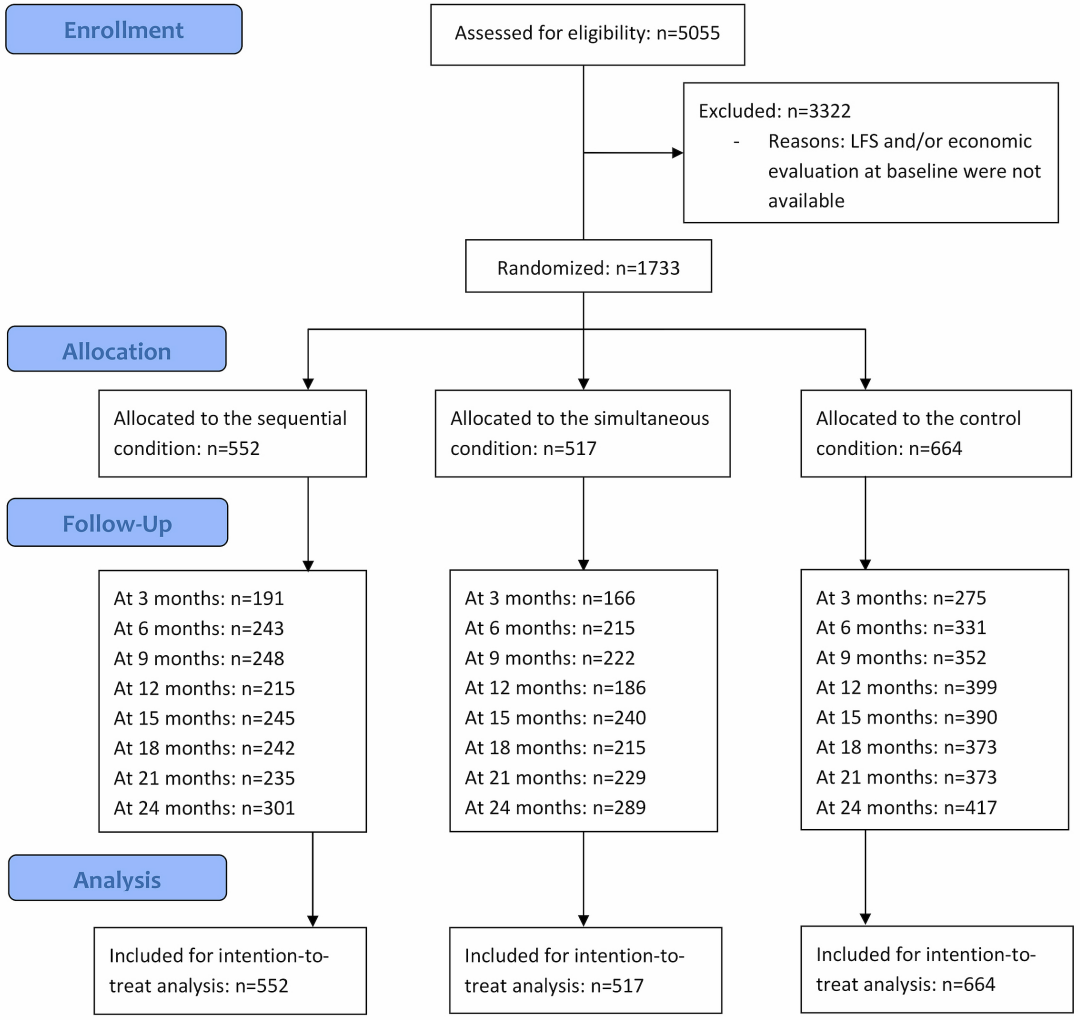
Figure 1. Flow diagram of the economic study.



Intervention

The intervention was a Web-based computer-tailored multisession program targeting adults. The primary aim of this lifestyle intervention was to motivate participants to be sufficiently physically active, to eat enough fruit and vegetables, to drink less alcohol, and to quit smoking. The intervention was based on the I-Change model, an integration of social cognitive models [25,26] and previously developed programs that have proven to be effective in increasing the level of physical activity [27], promoting the intake of fruit and vegetables [28], reducing the consumption of alcohol [29], and smoking cessation [30]. The respondents received feedback texts on their computer screens, which were aimed to motivate them to adopt the recommended health behaviors. All respondents received a health risk appraisal (HRA) indicating whether they adhered to the following public health guidelines: being moderately physically active for 30 minutes at least 5 days a week [31], eating 200 grams of vegetables per day [32], eating 2 pieces of fruit per day [32], not drinking more than 1 (for women) or 2 (for men) glasses of alcohol a day [32], and not smoking [33]. For all health risk behaviors, they received a traffic light image indicating whether they met (green), almost met (orange), or failed to meet (red) the guideline.

The experimental groups subsequently received personalized advice provided in 4 steps based on questions about different psychosocial determinants of the I-Change model [25,26]: (1) attitude, (2) social influence, (3) preparatory planning, and (4) self-efficacy and coping planning. At the end of every step, personal advice was given to participants. At baseline, respondents in the sequential condition could select a module concerning one of the lifestyle behaviors for which they did not meet the public health guidelines (ie, received a red or orange traffic light in their HRA); on completing this module, they received personalized feedback regarding this particular behavior. After 12 months, a second assessment took place and respondents had the opportunity to choose a second module and to receive feedback on a second lifestyle behavior for which they did not meet the public health guidelines. At baseline and after 12 months, respondents in the simultaneous condition received feedback on all the behaviors they did not meet the public health guideline for at one time. In both conditions, an overview of all received pieces of advice was available (via a link which was also sent by email) for the respondent at the end of the sessions. The control group received the HRA at baseline and after 24 months, but did not receive any additional personal advice. Figure 2 presents the design of the study, including all parts of the intervention. A detailed description of the study protocol has been published elsewhere [34].

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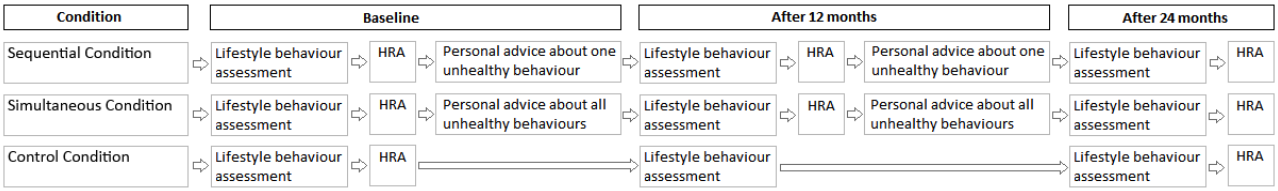
Figure 2. Design of the study. HRA: health risk appraisal.



Identification, Measurement, and Valuation of Costs and Effects

Overview

The economic evaluation was conducted from a societal perspective; therefore, all relevant costs (ie, intervention costs, health care costs, and respondent costs) and effects, such as quality-adjusted life years (QALYs) and lifestyle factor score (LFS), were taken into account [35].

Costs

Intervention costs consisted of hosting costs for the website, including costs for technical assistance and required updates. Costs for the development of the intervention program and research-specific costs were excluded because these are once-only costs that are not necessary again when implementing the program. The intervention costs were the same for all study groups because all groups received tailored advice that was integrated in the study website.

Health care costs included use of medication, medical consultations, inpatient and outpatient specialist care, hospital admissions, and other care (eg, professional home care). Health care costs were assessed using a 3-month retrospective questionnaire consisting of multiple choice and open-ended questions. This online questionnaire was taken quarterly during the 24 months. The updated Dutch Manual for Cost Analysis in Health Care was used to valuate costs [36]. If cost prices were not available, other sources were used. For instance, the website of the Healthcare Insurance Board [37] was used to calculate medication costs. The costs of medications were calculated based on the dose described by the respondent. Hence, costs per tablet, gram, or milliliter were used to calculate total medication costs for each respondent. Costs for health care services that could not be found in the Dutch Manual for Cost Analysis in Health Care were looked up on the Internet (eg, via the websites of health care services). If possible, 3 costs for each health care service were looked up to ultimately calculate a mean cost price for this service. Cost price details can be found in Multimedia Appendix 1.

Productivity costs included costs because of sickness absenteeism from work. They were calculated by the human capital method using mean costs for the Dutch population corrected for gender and age [36].

Respondent costs (also known as patient and family costs) included the time respondents spent on the website for participation and costs for traveling to health care services. For the time spent on the website, we used the mean time that was necessary to complete the program within the 3 study groups. The time lost due to participation in the Adult Health Monitor was also taken into account, but we only added the time people needed to fill out the parts of the Adult Health Monitor regarding the 5 lifestyle behaviors. We made this decision for 2 reasons: Firstly, it was not necessary to combine the interventions and the entire Monitor of the Regional Health Authorities; secondly, respondents who participated in the Adult Health Monitor skipped these parts on our website, whereas people who did not take part in the Adult Health Monitor completed these questions on our website (ie, in the end, all respondents completed the same number of questions). Ultimately, we used an average time of 70 minutes for the sequential condition, 100 minutes for the simultaneous condition, and 20 minutes for the control condition. To determine the cost of time spent on the website, we valued the time by applying the labor time using the mean costs of the Dutch population corrected for gender and age [36]. Costs for traveling to health care services were also valued in monetary terms. These costs were assessed based on average travel distances to health care services in the Netherlands [38] and the mean costs per kilometer [36].

Effects

For the cost-effectiveness analysis, the primary outcome measure was the total LFS. The following questionnaires were used to assess the 5 lifestyle behaviors: the Short Questionnaire to Assess Health-enhancing physical activity (SQUASH) [39,40], a 4-item Food Frequency Questionnaire (FFQ) assessing weekly fruit and fruit juice intake [39], a 4-item FFQ assessing the weekly consumption of boiled or baked vegetables as well as salads or raw vegetables [39], the 5-item Dutch Quantity-Frequency-Variability (QFV) questionnaire to assess alcohol intake [39,41], and questions asking participants if they smoked, what they smoked (cigarettes, cigars, or pipe tobacco), and how much they smoked per day (cigarettes) or per week (cigars or pipe tobacco) [39]. Based on the guidelines for physical activity, fruit intake, vegetable intake, alcohol consumption, and smoking, we calculated this LFS by summing all healthy behaviors (ie, complying with the guideline in question)—a similar method (Prudence score) was applied by Parekh et al [42]—at baseline and after 24 months; thus, the value of the LFS could range from 0 (adhering to no guidelines) to 5 (adhering to all guidelines). Moreover, a lifestyle factor change index (LFCI) was calculated by subtracting the LFS at baseline from the LFS at 24 months [43]. The value for this index could range from -5 to +5 on a continuous 10-point scale; positive scores indicated an increase, whereas negative scores indicated a decrease in the number of healthy behaviors.

For the cost-utility analysis, the primary outcome measure was utilities based on a health-related quality of life instrument. The Euro-Qol EQ-5D-3L questionnaire [44] was used to assess health-related quality of life and was completed by respondents every 3 months. The EQ-5D-3L consists of the following 5

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health dimensions: mobility, self-care, daily activity, pain/discomfort, and anxiety/depression. On a 3-point Likert scale, respondents had to indicate their own state of health (no complaints=1; some complaints=2; many complaints=3). A utility score was calculated for each measurement point using the Dutch tariff [45]. This score could range from -0.33 (death) to 1 (perfect health). This utility score, in turn, was used to calculate the QALYs gained or lost during the 2-year study period by making use of the area under the curve method. The area under the curve stands for the duration of the health state (x-axis, 24 months) multiplied by the quality weight for the health state (y-axis, utility score).

Indexing and Discounting

The price year of this study was 2013. All cost prices were indexed to the year 2013 by using the consumer price indexes of 105.38 for the year 2009, 106.72 for the year 2010, 109.22 for the year 2011, 111.90 for the year 2012, and 115.00 for the year 2013 [46]. Because of the long-term follow-up of 2 years, costs made in the second year were discounted by 4%, and effects regarding the LFS assessed after 24 months and effects in QALYs measured in the second year of the study were discounted by 1.5% [36,47].

Statistical Analyses

Respondents were included in the analyses when their LFS at baseline was available and when the economic evaluation measurement was completed at least at baseline.

To examine whether randomization was successful and whether the 3 groups were comparable in terms of demographics, baseline LFS, quality of life, and health care costs over the previous 3 months, analyses of variance (ANOVA) were used for continuous variables and chi-square tests for dichotomous or categorical variables. To investigate whether selective dropout had occurred, logistic regression analyses were used to compare (1) those who took part in the intervention but did not complete the questionnaires needed for the economic evaluation with those who did complete these questionnaires and were included in this study, and (2) of those included in this study, those who filled out at least 1 follow-up questionnaire regarding the economic evaluation with those who did not fill out any of the follow-up questionnaires.

Intention-to-treat analyses were performed. Mean imputation was used to fill in missing values regarding medication use, health care services, absenteeism from work, EQ-5D-3L items, and lifestyle items. When applying mean imputation, the mean of the previous and next value for the same variable was calculated. If mean imputation was impossible because of missing values on multiple measurement points, the last observation carried forward (LOCF) method was used to fill in missing values [48]. The next observation carried backward method was used when the value was not available on the baseline questionnaire. Unrealistic/impossible values (eg, more than 90 days absent from work in a period of 90 days) were recoded as the highest possible value. In case of unclear answers to the open-ended question regarding medication use (eg, private, too much, I do not know anymore), mean prices of the study group for this question were imputed.

To compare the 3 study groups regarding their biennial costs (ie, health care costs and respondent costs over a period of 2 years), nonparametric bootstrapping (5000 times) with 95% confidence intervals in percentiles was used. ANOVAs were performed to compare the groups regarding the LFS assessed after 24 months and the QALYs measured over the study period of 2 years.

Incremental costs (in Euros) and effects were calculated for all 3 study groups as well as a net monetary benefit by valuing the effectiveness and utility outcomes in monetary values using a threshold for society's willingness to pay (WTP) per gain in the LFS (ie, per additional guideline met) and per QALY gained [49]. The probability of the highest net monetary benefit was presented from a WTP of €0 to €80,000 [50]. Additionally, we explicitly reported the probabilities when using a WTP of €18,000 because this is an accepted Dutch cutoff point per QALY gained as a result of preventive interventions [50].

Uncertainty Analyses

For the cost-effectiveness and cost-utility analyses, bootstrapping resampling techniques (with 1000 times replacement) were carried out to deal with uncertainty around the estimates of cost-effectiveness and cost-utility. The results were presented in cost-effectiveness and cost-utility acceptability curves. Seven different sensitivity analyses were performed to deal with the uncertainty of parameter estimates from the primary analysis: (1) we executed the analyses from a health care perspective by excluding the productivity costs and the respondent costs (these might be reflected in participants' reported quality of life anyway) [36]; (2) we excluded costs due to absenteeism from work because these costs differed significantly between the 3 study groups before the intervention; (3) we excluded respondents with less than 4 follow-up measurement points because of the large number of missing values (>50%); (4) we used a LFS change index as outcome variable to correct for the LFS before the intervention (cost-effectiveness analysis) and corrected the QALY for baseline utility (cost-utility analysis) [51]; (5) we excluded respondents with the highest costs based on the 95th percentile; (6) we did not discount costs and effect outcomes [36,47]; and (7) we discounted both the costs and effect outcomes by 4.0% instead of discounting only costs by 4.0% and effects by 1.5% [47].

Bootstrap analyses were done using Microsoft Office Excel 2010; all other analyses were done using SPSS version 20.0 (IBM Corp, Armonk, NY, USA).

Results

Sample Characteristics

A total of 1733 respondents were included in the analyses. Table 1 presents the baseline characteristics of the 3 study groups. One baseline difference was found between the groups: the sequential condition had significantly higher costs because of absenteeism from work compared to the control group.

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Table 1. Comparability of the 3 study groups regarding demographics, health status, lifestyle behavior, and health care and travel costs over the past 3 months before baseline (N=1733)

Variable	Sequential (n=552)	Simultaneous (n=517)	Control (n=664)	*F* (*df*)	χ^2 (*df*)	*P*
Age, mean (SD)	47.31 (11.62)	48.15 (11.96)	48.88 (12.19)	2.61 (2, 1730)		.07
Gender, n (%)						
Men	279 (50.5)	264 (51.1)	366 (55.1)			
Women	273 (49.5)	253 (48.9)	298 (44.9)		3.1 (2)	.21
Educational level, n (%)						
Low	53 (9.9)	64 (12.9)	90 (13.7)			
Medium	274 (51.3)	222 (44.7)	319 (48.7)			
High	207 (38.8)	211 (42.5)	246 (37.6)		7.9 (4)	.10
Income per month (€), [a] n (%)						
< 1,750	123 (22.9)	123 (24.7)	161 (24.5)			
1750 - 3050	265 (49.3)	249 (50.0)	341 (52.0)			
> 3050	150 (27.9)	126 (25.3)	154 (23.5)		3.2 (4)	.52
Employment situation, n (%)						
Job (paid)	389 (72.2)	350 (70.3)	443 (67.4)			
No job	150 (27.8)	148 (29.7)	214 (32.6)		3.2 (2)	.20
Marital status, n (%)						
Relationship	423 (78.9)	402 (80.2)	507 (77.4)			
Single	113 (21.1)	99 (19.8)	148 (22.6)		1.4 (2)	.50
Persons in household, mean (SD)	2.83 (1.65)	2.69 (1.24)	2.71 (1.37)	1.54 (2, 1695)		.21
Native country, n (%)						
The Netherlands	511 (95.0)	480 (96.0)	627 (95.3)			
Other	27 (5.0)	20 (4.0)	31 (4.7)		0.6 (2)	.73
BMI, mean (SD)	25.70 (4.18)	25.38 (3.91)	25.80 (5.71)	1.56 (2, 1714)		.21
Psychological distress, mean (SD)	44.46 (6.40)	45.00 (5.84)	44.74 (6.10)	1.00 (2, 1687)		.37
Diseases, [b] n (%)						
Diabetes	25 (4.7)	20 (4.0)	23 (3.5)		1.0 (2)	.61
Brain hemorrhage, TIA	2 (0.4)	4 (0.8)	7 (1.1)		1.9 (2)	.38
Heart attack	8 (1.5)	5 (1.0)	5 (0.8)		1.5 (2)	.48
Other serious heart disease	4 (0.7)	12 (2.4)	15 (2.3)		5.2 (2)	.07
Cancer	12 (2.2)	7 (1.4)	11 (1.7)		1.1 (2)	.58
High blood pressure	67 (12.5)	67 (13.4)	112 (17.2)		6.0 (2)	.05
Asthma, COPD	36 (6.7)	34 (6.8)	43 (6.6)		0.01 (2)	.99
Lifestyle factor, mean (SD)	3.26 (1.04)	3.32 (1.07)	3.27 (1.06)	0.52 (2, 1730)		.59
Euroqol/utility (EQ-5D-3L), mean (SD)	0.89 (0.17)	0.89 (0.15)	0.90 (0.15)	0.40 (2, 1617)		.67
Health care costs (€), [c] mean (SD)						
Medication use	44.62 (256.77)	39.14 (313.81)	31.68 (204.78)	0.39 (2, 1725)		.68
Health care service	119.12 (401.90)	114.42 (201.50)	99.16 (184.52)	0.88 (2, 1729)		.42
Admissions	32.95 (231.26)	31.98 (222.70)	62.85 (422.57)	1.88 (2, 1728)		.15
Other care	34.04 (220.28)	21.28 (157.88)	40.41 (265.29)	1.08 (2, 1728)		.34

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Variable	Sequential (n=552)	Simultaneous (n=517)	Control (n=664)	*F* (*df*)	χ^2 (*df*)	*P*
Absenteeism from work	676.68 (3135.31)	405.10 (2076.48)	328.19 (1413.07)	3.63 (2, 1674)		.03
Travel costs (€), mean (SD)	3.20 (10.42)	3.46 (6.41)	2.97 (5.63)	0.54 (2, 1579)		.59

[a]Respondents who did not want to report their income (n=257) were classified in the category €1751-€3050.

[b]TIA: transient ischemic attack; COPD: chronic obstructive pulmonary disease.

[c]Costs for prior 3 months.

Dropout Analyses

Results from the logistic regression analysis showed that respondents who were excluded from the analyses of the present study (ie, those who took part in the intervention, but did not complete the questionnaires needed for the economic evaluation, n=3322) were significantly younger (beta=.03; *P*<.001), had a lower LFS (beta=–.12; *P*<.001), reported less diseases such as brain hemorrhage and transient ischemic attack (TIA) (beta=1.14; *P*=.04), and more of them did not have a paid job (beta=.40; *P*<.001) than respondents included in our analyses.

Each of the 8 retrospective questionnaires for the previous 3 months required for the economic evaluation was completed by at least 36.47% (632/1733) and not more than 57.76% (1001/1733) of the respondents, whereas 506 of 1733 respondents (29.20%) did not complete any of these questionnaires. The latter were younger (beta=.02; *P*=.002) and reported an unhealthier lifestyle (beta=–.12; *P*=.02) than those who completed at least 1 questionnaire.

After imputing missing values, total cost data was available for 1662 of 1733 respondents (95.90%), and effect data was available for all 1733 respondents (100%) for the LFS and for 1690 of 1733 respondents (97.52%) for QALYs.

Costs and Effects

Table 2 shows that the simultaneous condition reported statistically significantly higher costs for health care services during the 2-year period than the control condition did. However, no differences were found regarding the total biennial health care costs. The travel costs were also statistically significantly higher for the simultaneous condition than the control condition. Because the simultaneous condition was the most time-intensive condition, followed by the sequential condition and then the control condition, total respondent costs were also higher among the simultaneous condition compared with the sequential and control conditions, and higher among the sequential condition compared to the control condition. Table 3 demonstrates that there were no differences found between the 3 study groups regarding effects on the LFS or on QALYs. Detailed information regarding the lifestyle scores at the different time points and effects of the intervention on the 5 behaviors are presented elsewhere [52].

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Table 2. Mean biennial costs per participant per study group based on 5000 bootstrap replications.

Cost type	Costs per study group (€), mean (SD)			95% CI		
	Sequential	Simultaneous	Control	Sequential-Simultaneous	Control-Simultaneous	Sequential-Control
Intervention costs						
Fixed hosting costs	0.54	0.54	0.54			
Health care costs						
Medication use (n=1733)	193 (57)	200 (74)	162 (31)	-208.73, 166.37	-222.27, 91.00	-81.95, 175.03
Health care service (n=1733)	719 (124)	861 (73)	641 (42)	-385.33, 169.11	-386.86, -56.07	-131.59, 368.62
Admissions (n=1732)	396 (89)	303 (78)	461 (97)	-141.58, 325.48	-87.86, 401.07	-327.51, 200.20
Other care (n=1732)	222 (67)	178 (40)	247 (67)	-97.69, 204.61	-76.51, 230.00	-211.27, 161.91
Total health care costs (n=1714)	1521 (195)	1534 (162)	1502 (151)	-508.11, 504.92	-461.19, 399.62	-453.30, 493.35
Productivity costs						
Absenteeism (n=1714)	3489 (652)	3563 (666)	2600 (538)	-1889.89, 1751.48	-2642.42, 673.86	-724.22, 2586.62
Respondent costs						
Travel costs (n=1678)	25 (3)	30 (3)	24 (2)	-13.26, 3.42	-12.55, -0.41	-5.40, 9.10
Fixed time costs (n=1733)	41 (0)	59 (1)	12 (0)	-18.65, -16.27	-47.71, -45.71	28.53, 29.95
Total respondent costs (n=1678)	64 (3)	87 (3)	35 (2)	-30.66, -13.28	-57.81, -45.39	22.25, 37.19

Table 3. Mean biennial effect on the lifestyle factor score (LFS) and quality-adjusted life year (QALY) score per participant per study group.

Effect	Mean (SD) per study group			*F* (*df*)	*P*
	Sequential	Simultaneous	Control		
LFS[a] (n=1733)	3.37 (1.08)	3.42 (1.06)	3.34 (1.05)	0.92 (2, 1730)	.40
QALY (EQ-5D-3L) (n=1690)	1.80 (0.30)	1.78 (0.31)	1.82 (0.27)	1.79 (2, 1687)	.17

[a]This factor could range from 0 (adherence to all guidelines) to 5 (adherence to no guideline at all), plus discounting effect.

Cost-Effectiveness Analyses

Table 4 shows that the costs in the control condition were less than the costs in the sequential and the simultaneous conditions, but that the effects in the 2 experimental conditions were higher. From a WTP of €4594 or more, the sequential condition appeared more likely to be cost-effective than the control condition. From a WTP of €10,850 or more, the simultaneous condition seemed more likely to be cost-effective than the control condition. When comparing the cost-effectiveness of the 2 experimental conditions, the simultaneous condition seemed more likely to be cost-effective than the sequential condition from a WTP of €17,106.

The probability that the sequential condition was cost-effective at a WTP of €0 per gain in lifestyle score was 42%. For the simultaneous condition, the probability was 10% and for the control condition, the probability was 48% (see Table 5 and Figure 3). With a WTP of €18,000 per gain in lifestyle score, the simultaneous intervention would probably (ie, 45%) be the most cost-effective, followed by the sequential intervention (ie, 39%). The 2 sensitivity analyses performed with different discounts confirmed this finding. Results based on the other sensitivity analyses were slightly different. The sensitivity analysis using a LFCI as outcome variable (ie, correcting for the baseline lifestyle score) showed that the sequential condition might be most likely to be most cost-effective independent of the WTP. According to the sensitivity analysis performed from a health care perspective, the sensitivity analysis from which costs because of work absenteeism were excluded and the sensitivity analysis from which respondents with extremely high costs were excluded, both experimental conditions were found to be more likely to be cost-effective than the control condition regardless of the WTP. Based on the sensitivity analysis with inclusion of respondents who filled out the follow-up questionnaires at least 4 times (50%), the sequential condition was shown to be less likely to be cost-effective than the simultaneous and control condition for a WTP up to €9000.

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Table 4. Incremental costs and effects per gain in lifestyle factor score (LFS) and per quality-adjusted life year (QALY) gained for the study groups with a willingness-to-pay threshold of €18,000.

Intervention	Incremental costs (€)[a]	Incremental effect[b]	Incremental costs per LFS/QALY (€)
Lifestyle factor			
Sequential vs control	183.76	.04	4594.00
Simultaneous vs control	868.00	.08	10,850.00
Sequential vs simultaneous	–684.24	–.04	17,106.00
QALY (EQ-5D-3L)			
Sequential vs control	183.76	–.01	Dominated[c]
Simultaneous vs control	868.00	–.03	Dominated[c]
Sequential vs simultaneous	–684.24	.02	Dominated[c]

[a]Costs per participant (€): sequential=4324.76; simultaneous=5009.00; control=4141.00.

[b]Lifestyle factor effects per participant: sequential=3.38, simultaneous=3.42, control=3.34; QALYs effects per participant: sequential=1.80, simultaneous=1.78, control=1.81.

[c]In one group, the costs are higher and the effects are lower compared to the other group.

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Table 5. Results from cost-effectiveness and cost-utility analyses based on 1000 bootstrap replications for the sequential (seq), simultaneous (sim), and control (con) conditions.

Type of analysis	Study group (n)			Probability of highest net monetary benefit (%)								
	Seq	Sim	Con	WTP=€0			WTP=€18,000			WTP=€80,000		
				Seq	Sim	Con	Seq	Sim	Con	Seq	Sim	Con
Primary analysis												
LFS	552	517	664	42	10	48	39	45	16	26	68	6
QALY (EQ-5D-3L)	535	501	654	39	12	49	21	4	76	7	1	92
Sensitivity analyses LFS												
Only health care costs included	552	517	664	38	27	35	24	70	6	24	71	6
Productivity costs Excluded	552	517	664	59	20	21	22	71	7	20	73	7
≥ 50% of follow-up questionnaires completed	100	104	195	3	29	68	14	83	2	20	80	0
LFCI to correct for baseline scores	552	517	664	45	11	45	65	15	20	63	27	10
Respondents with outliers on total costs excluded[a]	525	488	637	81	11	8	25	69	6	22	72	6
Without discounting costs and effects	552	517	664	41	11	48	37	45	18	26	66	8
Discounting costs and effects 2nd year with 4.0%	552	517	664	43	11	46	39	45	16	27	66	7
Sensitivity analyses QALY (EQ-5D-3L)												
Only health care costs included	535	501	654	31	32	38	10	3	87	7	1	92
Productivity costs excluded	535	501	654	56	19	25	14	2	84	7	1	93
≥ 50% of follow-up questionnaires completed	100	104	195	6	25	70	5	21	74	7	21	73
QALY corrected for baseline as outcome variable	513	482	621	38	18	43	36	13	51	29	8	63
Respondents with outliers on total costs excluded[a]	509	475	627	80	9	11	25	3	73	13	2	85
Without discounting costs and effects	535	501	654	38	12	50	22	4	75	8	1	91
Discounting costs and effects 2nd year with 4.0%	535	501	654	40	12	48	22	4	75	7	1	92

[a]Based on the 95th percentile: €18,567.64.

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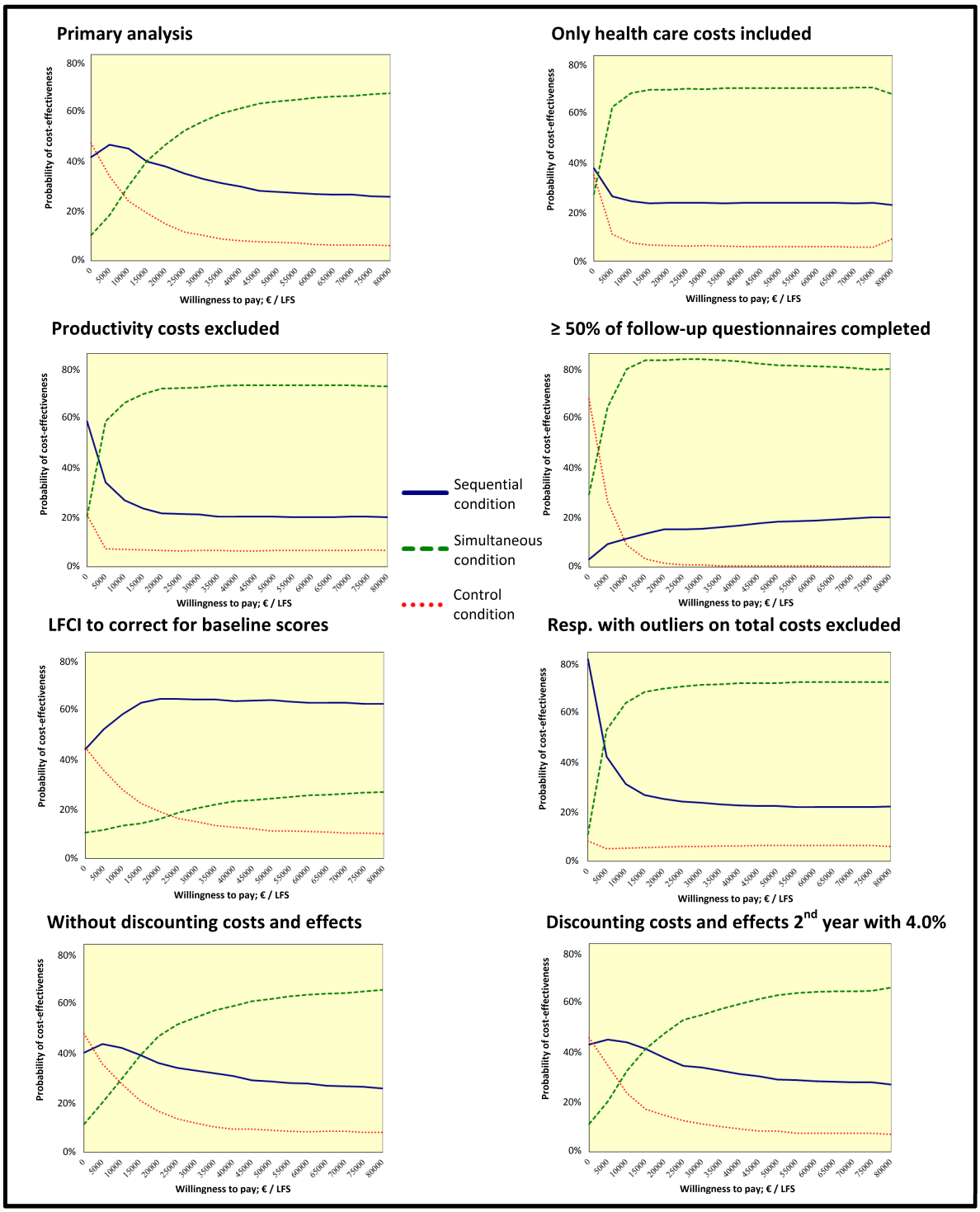
Figure 3. Cost-effectiveness acceptability curve for the study groups based on primary and sensitivity analyses.



Cost-Utility Analyses

With regard to cost-utility, Table 4 shows that both the sequential and the simultaneous condition were dominated by the control condition. This means that the costs of the control condition were lower and the effects with regard to QALYs gained were higher in this group. When comparing the sequential condition with the simultaneous condition, costs were lower and effects on QALYs were larger in the sequential condition. Thus, the simultaneous condition was dominated by the sequential condition.

The probability that the sequential condition was most efficient at a WTP of €0 per QALY gained was 39%. For the simultaneous condition, the probability was 12% and for the control condition, the probability was 49% (see Table 5 and Figure 4). With a WTP of €18,000 per QALY gained, the cost-utility analysis showed that the control condition would probably (ie, 76%) be the most efficient condition. Indeed, Figure 4 shows that the control condition was most likely to be efficient, irrespective of the WTP. All but 3 sensitivity analyses confirmed these results. The sensitivity analysis in which costs due to work absenteeism were excluded and the sensitivity analysis in which respondents with extremely high costs were

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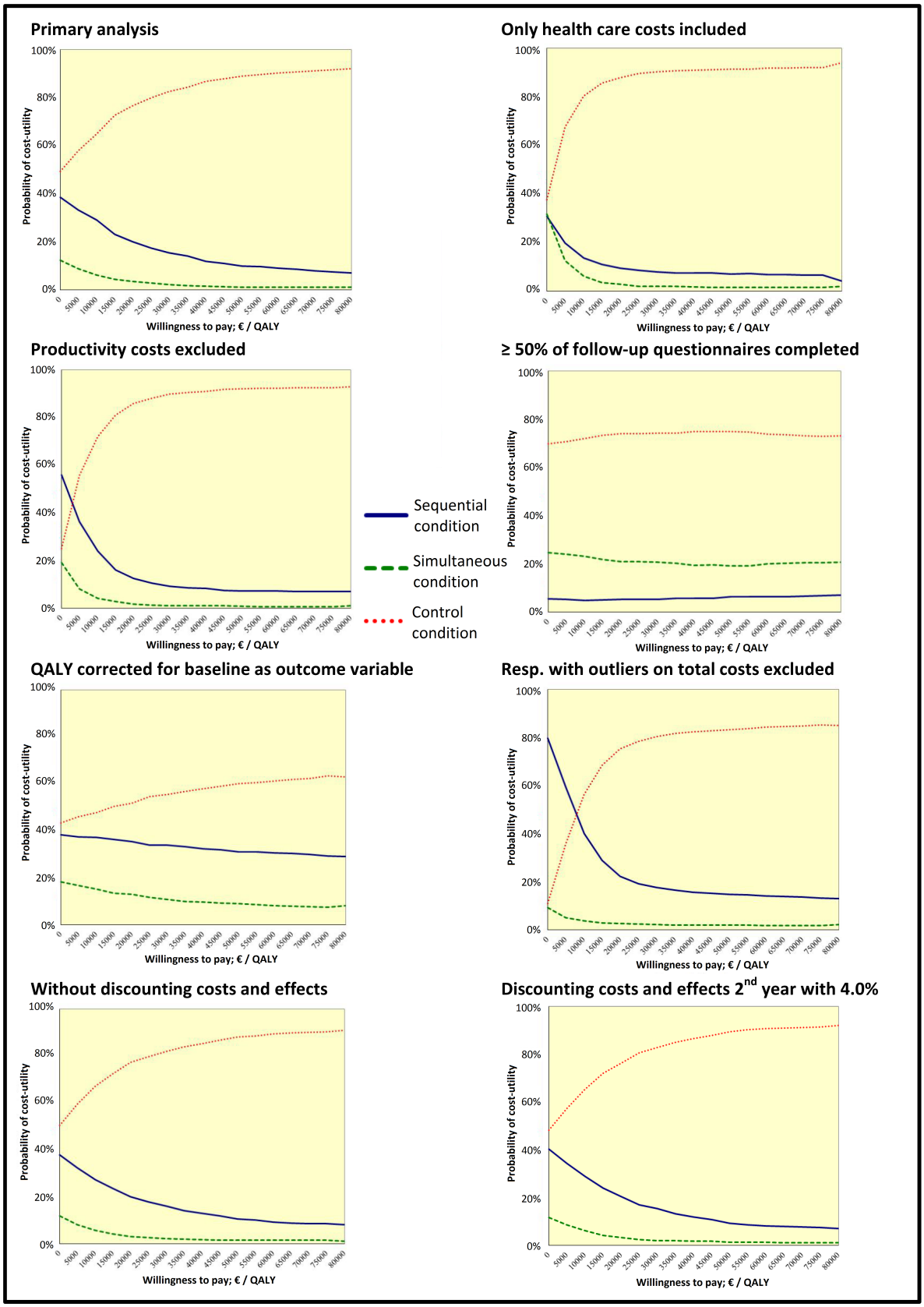
excluded showed that with a WTP up to €2980 and €7900, respectively, the sequential condition would probably be the most efficient (ie, >45% and >48% chance, respectively). The sensitivity analysis that included only those respondents who filled out the follow-up questionnaires at least 4 times (50% of all questionnaires) showed that the simultaneous condition was likely to be more efficient than the sequential condition, independent of the WTP. In all other analyses, this was the other way around.

Figure 4. Cost-utility acceptability curves for the study groups based on primary and sensitivity analyses.



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Discussion

Principal Findings

An economic evaluation of 2 different versions of a Web-based computer-tailored multiple lifestyle intervention was performed. Despite some variations in the different sensitivity analyses outcomes, the results of this study give an indication that the 2 tailored intervention programs are likely to be more cost-effective when looking at lifestyles as a primary outcome than that of a control group, in which respondents received a short tailored overview. In general, the simultaneous intervention was likely to be most cost-effective, followed by the sequential intervention. However, the results were sensitive to baseline scores. When correcting for lifestyle behavior at baseline, the sequential intervention was probably most cost-effective. Regarding cost-utilities, the intervention received by the control group might be most preferable when compared to both lifestyle interventions (sequential and simultaneous).

With incremental costs of €4594 per gain in lifestyle score by meeting additional public health guidelines, the sequential condition is most likely to be cost-effective. With incremental costs of €17,106 or higher, the simultaneous version of the Web-based intervention is even more likely to be cost-effective than the sequential version. The incremental costs of our intervention seemed to be less favorable than the costs of €160 per guideline met in the study by Van Keulen et al [22]. However, the studies are hard to compare because the intervention tested by Van Keulen and colleagues [22] only considered 3 lifestyle behaviors (ie, physical activity, fruit intake, and vegetable intake) and tailored print communication was used instead of Web-based communication. Their study population consisted of older adults (aged 45-70 years). Most importantly, their control group received no intervention at all, whereas in our study the control group received a minimal intervention. Information regarding one's lifestyle behavior may be sufficient to facilitate change and improve health risk behaviors [42]. Although the effects might be modest, in the present study the difference in effects between the control group who received the minimal intervention and the experimental conditions who received the sequential and simultaneous versions of the Web-based interventions might have become smaller. In a single behavior change intervention aimed at smoking cessation, Smit et al [21] reported incremental costs of €5100 per abstinent participant. This amount is comparable to our findings regarding gains in lifestyle behaviors, including smoking cessation. However, both studies [21,22] used shorter study periods (1.5 years and 1 year, respectively). This means that the cost-effectiveness regarding outcomes measured at the last follow-up in this study, which was after 2 years, cannot truly be compared with the cost-effectiveness results found in those studies.

Our finding that the control group might be most preferable regarding cost-utilities is comparable to the results reported by Smit et al [21] who found that the usual care their control group received was probably the most preferable intervention when compared with a Web-based computer-tailoring intervention and a combination of the Web-based intervention and face-to-face counseling by a practice nurse. A likely explanation for this finding may be that the follow-up period of 2 years was too short to find effects on quality of life. Although the intervention leads to lifestyle improvements that may prevent or postpone the incidence of a variety of lifestyle-related diseases, health gains from prevention programs often only become noticeable many years after the costs are made [53]. Moreover, baseline scores on the EQ-5D-3L were already high at the beginning of the study (mean 0.90, SD 0.15), which might be related to a restriction of this measurement tool (ie, the ceiling effect: the tool does not differentiate between high scores of the healthy utility range [54]). Consequently, the finding that our study population consisted of people reporting high scores on the EQ-5D-3L may be an explanation for not finding any statistically significant differences in QALYs gained between the groups. For public health interventions, it might be better to use other outcomes related to quality of life (eg, nonhealth outcomes, such as empowerment or satisfaction), which are more sensitive to changes in the short term because these quality of life measures tend to underestimate the relative benefits of this kind of intervention [55]. However, 2 cost-effectiveness acceptability curves (sensitivity analyses in which productivity costs were excluded and in which respondents with extremely high total costs were excluded) showed that the sequential condition might be preferable up to a WTP of €2700 and €8600, respectively, which is opposite to the findings by Van Keulen et al [22], whose control group was probably the most cost-effective intervention for ratios lower than €2851 per QALY gained.

In the literature, a WTP of €18,000 is the accepted cutoff point per QALY gained [50]. However, there is no such cutoff point regarding lifestyle changes as used in our study. This makes the interpretation of the results regarding cost-effectiveness complicated. Lifestyle interventions usually aim at preventing different kinds of diseases with different burdens. This makes it difficult to determine such a cutoff point, something that has also been pointed out for increases in smoking abstinence rates [21] or for each kilogram of body weight lost [56], for example. As suggested by Tate et al [24], for future research it would be good to transform the unit changes of different outcome measures into metrics that can be compared across different kinds of interventions (regardless of the target behavior). Thus, future research should aim to define a WTP cutoff point for different lifestyle behaviors or metrics that can be used for different lifestyle behaviors.

Furthermore, there has been discussion about the rates of discounting effects (eg, [36,57,58]), especially in the field of prevention. Effect outcomes should be discounted because the value of QALYs or health increases with time [59,60] and this value change is not taken into account in economic evaluations [61]. It has been argued that the same value of discounting should be used for costs and effects to be consistent [62], whereas it has been recommended that effects should be discounted at lower rates to correct for the increasing monetary value of health over time [36,47,53]. In our study, we reported the results without discounting, with 1.5% discounting, and with 4.0% discounting based on the guidelines for

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pharmacoeconomic research [47]. The similarity of the findings provides evidence for the robustness of our results.

The results revealed that respondents in the simultaneous condition reported higher costs because of health care service use during the 2-year study period than did respondents in the control condition. The travel costs in this group were also higher. These costs might be related to the number of visits to caregivers. The advice may have served as a kind of prompt among the respondents to ask caregivers for help in improving their lifestyle (eg, for smoking cessation guidance) [21]. However, it remains unclear why these costs were higher among respondents in the simultaneous intervention. It is conceivable that the marginal differences between the groups occurred because of measurement errors.

Strengths and Limitations

To our knowledge, this was the first study assessing cost-effectiveness and cost-utility of 2 versions of a Web-based tailored lifestyle intervention aiming at multiple behavior change. Two outcome measures (ie, a LFS and QALYs) were used to evaluate costs and intervention effects over a relatively long period of 2 years. Seven different sensitivity analyses based on different views of economic evaluations found in the literature [36,51,57,62] were performed to test the robustness of the results. This is a further strong point of this study, although some analyses showed slightly different results.

There are some limitations that should be kept in mind when interpreting the results. First, we compared our intervention groups to a control group that also received a small amount of tailored information (ie, a personalized HRA). Because this HRA was integrated in the study website, the intervention costs were the same for all study groups. This strategy may have inflated the results and it may be that the cost-effectiveness would have been better if a different control group—who received either general information or no information at all—was used. Second, although we used a large sample (N=1733), the study suffered from high dropout rates, a common phenomenon in Web-based intervention studies (eg, [63-65]); therefore, many missing values for the follow-up assessments had to be imputed. Consequently, the imputation procedure may have distorted the reliability of the findings to some extent. That is, when using the conservative LOCF method to fill in the missing data for a large part of the sample, finding any intervention effects becomes more unlikely. The high dropout rates might have been caused by the need to assess health care costs and quality of life on a relatively large number of occasions. Although it might be good to measure health care use, medication use, absenteeism from work, and quality of life every 3 months to counteract recall bias [66], this may also be too time-consuming for some participants. This may have resulted in most of the respondents not completing all questionnaires and others dropping out of the intervention. Thus, future studies should aim to prevent loss to follow-up by sending tailored reminder emails [67], for example.

As presented in the dropout analysis, selective dropout occurred. Sensitivity analyses were performed to provide a more complete picture of the results among this selective group. Despite randomization of respondents to 1 of 3 study groups, statistically significant differences were found with regard to productivity costs, and some differences almost reached statistical significance (ie, age, high blood pressure, and serious heart diseases). These differences may have influenced the results. Also, we assessed absenteeism from work, but not "presenteeism" [68]. Finally, we used self-reported questionnaires that are subject to bias. Additional objective measures, such as medication registration at pharmacies and data from insurance companies, and cost diaries [69] could be included in future studies.

Conclusions

Computer-tailored advice on lifestyle behaviors was likely to be cost-effective after 24 months when looking at lifestyles as a primary outcome. The Web-based tailored lifestyle intervention using a simultaneous approach is promising as the most cost-effective intervention in improving someone's lifestyle, followed by the intervention using a sequential approach. However, with regard to improving quality of life, the control condition seemed to be preferable. Future studies should aim to compare different computer-tailoring conditions to a control group that does not receive any personalized advice, and to identify a cutoff point for the WTP for lifestyle changes.

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Conflicts of Interest

Hein de Vries is scientific director of Vision2Health, a company that licenses evidence-based innovative computer-tailored health communication tools. No other authors reported any conflicts of interest.

Multimedia Appendix 1

Cost prices for the different types of health care costs and absenteeism from work.

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[PDF File (Adobe PDF File), 8KB - jmir_v16i3e91_app1.pdf]

Multimedia Appendix 2

CONSORT-EHEALTH checklist [70].

[PDF File (Adobe PDF File), 996KB - jmir_v16i3e91_app2.pdf]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
FFQ: Food Frequency Questionnaire
HRA: health risk appraisal
LFCI: lifestyle factor change index
LFS: lifestyle factor score
LOCF: last observation carried forward
QALY: quality-adjusted life year
QFV: Quantity-Frequency-Variability
TIA: transient ischemic attack
WTP: willingness to pay

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Original Paper

Evaluating User Experiences of the Secure Messaging Tool on the Veterans Affairs' Patient Portal System

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Abstract

Background: The United States Department of Veterans Affairs has implemented an electronic asynchronous "Secure Messaging" tool within a Web-based patient portal (ie, My Health*e*Vet) to support patient-provider communication. This electronic resource promotes continuous and coordinated patient-centered care, but to date little research has evaluated patients' experiences and preferences for using Secure Messaging.

Objective: The objectives of this mixed-methods study were to (1) characterize veterans' experiences using Secure Messaging in the My Health*e*Vet portal over a 3-month period, including system usability, (2) identify barriers to and facilitators of use, and (3) describe strategies to support veterans' use of Secure Messaging.

Methods: We recruited 33 veterans who had access to and had previously used the portal's Secure Messaging tool. We used a combination of in-depth interviews, face-to-face user-testing, review of transmitted secure messages between veterans and staff, and telephone interviews three months following initial contact. We assessed participants' computer and health literacy during initial and follow-up interviews. We used a content-analysis approach to identify dominant themes in the qualitative data. We compared inferences from each of the data sources (interviews, user-testing, and message review) to identify convergent and divergent data trends.

Results: The majority of veterans (27/33, 82%) reported being satisfied with Secure Messaging at initial interview; satisfaction ratings increased to 97% (31/32, 1 missing) during follow-up interviews. Veterans noted Secure Messaging to be useful for communicating with their primary care team to manage health care needs (eg, health-related questions, test requests and results, medication refills and questions, managing appointments). Four domains emerged from interviews: (1) perceived benefits of using Secure Messaging, (2) barriers to using Secure Messaging, (3) facilitators for using Secure Messaging, and (4) suggestions

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for improving Secure Messaging. Veterans identified and demonstrated impediments to successful system usage that can be addressed with education, skill building, and system modifications. Analysis of secure message content data provided insights to reasons for use that were not disclosed by participants during interviews, specifically sensitive health topics such as erectile dysfunction and sexually transmitted disease inquiries.

Conclusions: Veterans perceive Secure Messaging in the My Health*e*Vet patient portal as a useful tool for communicating with health care teams. However, to maximize sustained utilization of Secure Messaging, marketing, education, skill building, and system modifications are needed. Data from this study can inform a large-scale quantitative assessment of Secure Messaging users' experiences in a representative sample to validate qualitative findings.

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KEYWORDS

veterans; secure messaging; patient-provider communication; Department of Veterans Affairs; usability testing; mixed methods; patient-centered care

Introduction

The Institute of Medicine (IOM) has identified patient-provider communication as a central component to improving quality of care and patient outcomes [1]. My Health*e*Vet is the Department of Veterans Affairs' (VA) online patient portal and personal health record designed for veterans, active duty service members, and their dependents and caregivers. My Health*e*Vet provides veterans with tools (eg, Blue Button, VA immunization records, laboratory test results, prescription refills, VA appointments) to make informed decisions and manage their health care. "Secure Messaging" is an email-like electronic resource within My Health*e*Vet designed to promote continuity of patient-provider communication [2-4]. As VA further implements Patient Aligned Care Teams (PACT) as a model of the patient-centered medical home, secure messaging is emerging as a key mechanism of communication between veterans and their health care team members. Successful implementation of secure messaging is therefore a priority not only for VA but also for other health care systems in the United States that strive to adopt principles of the patient-centered medical home. Moreover, outside VA, providers are being incentivized via Stage 2 Meaningful Use requirements (Medicare Electronic Health Records (EHR) Incentive Program) to use secure messaging among at least 5% of their patients to communicate relevant health information [5].

Previous work has demonstrated the utility and value of providing patients access to their electronic health record [6-8]. Patients also value secure messaging to communicate electronically with their providers [2-4]. Effective use of secure messaging can improve patient self-care management, patient engagement, and utilization of health services. In addition to allowing an option for self-care management, this electronic tool holds potential for supporting clinical tasks including medication reconciliation [9]. Secure messaging supports system utilization benefits in addition to perceived benefits by patient and clinical team users. A recent study showed a 7-10% decrease in outpatient visits and a 14% reduction in telephone contacts as a result of secure messaging [10,11]. Houston et al reported that 95% of respondents felt email was a more efficient means of communication with their physicians than the telephone, and 77% noted being able to communicate adequately via email without a face-to-face appointment [4]. Patient use of secure messaging has been associated with improved outcomes for chronic conditions [10,12]. Zhou et al reported in a recent study that within a two-month period there were improvements in care as measured by the Healthcare Effectiveness Data and Information Set (HEDIS) [10]. Patients with diabetes using secure messaging improved on all measures recommended for testing and control of glucose, cholesterol, and blood pressure levels by an average of 2.4-6.5% compared with patients not using secure messaging. In the same study, rates of received health services improved in the secure messaging group compared to the control group [10]. These findings suggest that successful implementation of secure messaging may provide a viable cost-efficient means of patient-provider communication.

Implementing health information technology, such as secure messaging, requires systematic inquiry grounded in implementation science to identify barriers to and facilitators of user adoption and utilization. The Technology Acceptance Model (TAM) [13] and the Theory of Planned Behavior (TPB) [14] have been found to be useful in predicting adoption of technology. While secure messaging has been shown to promote continuous and coordinated patient-centered care, little research has evaluated patients' experiences with and preferences for using secure messaging. In order to maximize sustained utilization of secure messaging, marketing, education, skill building, and minor system modifications may be needed. Evaluation of secure messaging users' experiences using the TAM and TPB frameworks can increase our understanding of issues related to access, continuity, and coordination of care for veterans that will support adoption and long-term utilization of Secure Messaging in My Health*e*Vet.

Findings from the Secure Messaging evaluation research will inform efforts to transform care delivery both within and beyond the VA system. Thus, the aims of this study were to (1) characterize veterans' beliefs, attitudes, and perceptions toward using the Secure Messaging tool, (2) describe the patterns of veterans' use of Secure Messaging, (3) identify the barriers to and facilitators of using Secure Messaging, and (4) describe strategies for promoting facilitators and overcoming barriers to using Secure Messaging.

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Methods

Study Design

This prospective descriptive qualitative study used mixed-methods to describe veterans' experiences using Secure Messaging in the My Health*e*Vet portal. As an implementation study, the underlying objective was to understand veterans' needs to promote increased access to and sustained utilization of the Secure Messaging tool. A combination of in-depth interviews, user-testing, a 3-month review of transmitted secure messages between veterans and staff, and 3-month follow-up phone interviews was used to characterize veteran Secure Messaging utilization. Demographic data as well as computer and health literacy measurements were collected through survey and in-depth interviews at baseline and 3-month follow-up.

Setting and Participants

The two-site study was conducted at two large VA Medical Centers (VAMCs): the James A. Haley Veterans' Hospital (Tampa, Florida) and the Veterans Affairs Boston Healthcare System (Boston, Massachusetts). We used administrative data to identify veterans at both VAMCs who had registered for My Health*e*Vet, completed the in-person process of authenticating their identity, and accessed the system to "opt-in" to use Secure Messaging. This approach identified 3926 potential participants at Tampa and 924 at Boston. Next, randomization was used to create contact lists of 120 potential participants from each site list. All 240 potential participants were contacted and screened to be purposively sampled based on their self-reported previous use of Secure Messaging. Participants were recruited for study participation until domain and theme saturation was reached.

Inclusion criteria included veterans who were independent Secure Messaging users, without cognitive impairment that prevented use of a personal computer or the ability to provide informed consent. Based on qualitative sampling methods [15,16], saturation was anticipated to occur between 12 to 15 interviews; an over-recruitment strategy was used at each site to allow for attrition, resulting in 33 total participants. One participant was lost to follow-up for unknown reasons, resulting in a complete dataset of 32 participants. Veterans received up to US$50 for their participation: US$20 for participation in the initial interview and user-testing and an additional US$30 for allowing the researchers unrestricted access to review the content of their secure messages and participation in the 3-month follow-up telephone interview. Participants provided informed consent upon their arrival for the initial face-to-face interview and user-testing. This study was approved and regulated by the VA Central Institutional Review Board.

Data Collection Instruments

Overview

Data were collected using demographic and health literacy surveys, in-depth face-to-face interviews, Secure Messaging usability testing, prospective collection of the content of secure messages, and 3-month follow-up telephone interviews. All data, with exception of the Secure Messaging data, were collected at two time points: during a baseline in-person meeting and during a 3-month follow-up phone interview. Prospective Secure Messaging data were collected between the baseline and 3-month follow-up time points.

Participant Surveys and Assessments

During the initial research visit, veterans completed a 13-item demographic survey to ascertain age, gender, race/ethnicity, education level, income level, marital status, computer use, Internet use, My Health*e*Vet use, and Secure Messaging use. Health literacy was assessed using two validated instruments: (1) the Brief Health Literacy Screening Tool (BRIEF), and (2) the Rapid Estimate of Adult Literacy in Medicine (REALM) survey. The BRIEF is a 4-item self-report screening tool to assess health literacy skills [17]. The REALM assesses health literacy by having respondents verbally articulate three columns of 22 health-related terms [18].

Electronic health literacy was also assessed using two instruments: (1) the eHealth Literacy Scale (eHEALS), and (2) the Computer-Email-Web (CEW) Fluency Scale. The eHEALS is a 10-item measure of eHealth literacy developed to measure consumers' knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems [19]. The CEW Fluency Scale is a 21-item measure of common computer skills [20].

Interviews

Face-to-face semi-structured interviews with participants were conducted by an experienced interviewer trained in the social sciences. Interviews focused on participants' experiences using Secure Messaging. The interview guide was created following the Theory of Planned Behavior (TPB) framework to elicit beliefs and attitudes, subjective norms, perceived behavioral control, and behavioral intention toward Secure Messaging use. Other interview questions were developed based on the Technology Acceptance Model (TAM) and addressed usefulness and ease of use of Secure Messaging. Interviews followed the guide but were open-ended in nature, allowing the interviewer flexibility to ask probing questions and to follow up on interesting topics and user experiences related to Secure Messaging.

Based on the initial interviews, a brief phone interview guide was developed to address Secure Messaging use during the 3-month period after the first interview. These interviews were conducted to assess recent Secure Messaging use: usefulness, expectations, barriers and facilitators, satisfaction, and suggestions for improvement.

Secure Messaging User-Testing

In-person Secure Messaging user-testing was conducted to prompt participants to complete a series of tasks they would normally encounter while using Secure Messaging. User tasks included navigating to the My Health*e*Vet site, logging in to Secure Messaging, setting user preferences, checking the Inbox, opening a secure message, opening and reading an attachment, and sending a secure message. Task completion, obstacles, and facilitators were recorded using a checklist, which directly corresponded to the user-testing tasks. Usability testing with each participant was conducted using Morae software [21,22], and allowed for the live, remote observation and video-recording

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of the user being tested (eg, recording of clicks, keystrokes, and other events) [23]. Participants were asked to "think aloud" and vocalize their thoughts, experiences, feelings, and opinions while interacting with the program as they used the Secure Messaging feature [24,25].

Secure Messaging Content

Secure messages were collected, both outgoing and incoming secure messages were collected for each participant over a 3-month period following their provision of informed consent. Data included sender and recipient identification, date and time of delivery, subject header, category of message subject (eg, test, appointment, medication, general), and verbatim content of the secure message text. We examined the quantity of messages, message content, exchange patterns, and timing of inbound and outbound messages between participants and their health care teams. This approach allowed for analysis of authentic user content and patterns to further inform research findings.

Data Management and Analysis

All data, including interviews and paper-based surveys gathered in this study were stored on a secure VA network. Audio recordings of all interviews were transcribed and subsequently analyzed using ATLAS.ti [26], qualitative data analysis software. Descriptive statistics from veteran surveys were managed using the statistical software suite SPSS version 21 (SPSS IBM, New York, USA). Data from Secure Messaging usability testing were captured using Morae recording software.

We used content analysis methods to analyze all interview data to identify domains and taxonomies related to participants' experiences using Secure Messaging [15]. We used the semi-structured interview guide to organize and code interview text to develop thematic categories. Categories were grouped into taxonomic relationships and then compared and contrasted across coded categories. Coding schemas were developed by two research team members to create domains and taxonomies and evaluated for inter-rater reliability and credibility. Data were then categorized and interpreted, and barriers and facilitators were identified. Quantitative data were summarized with descriptive statistics to describe sample characteristics. Frequency counts and proportions provided a descriptive overview of the user-testing findings.

Results

Participants

A total of 33 participants were recruited, of whom 32 provided complete data. One participant provided initial interview, user-testing, and secure message content data, but could not be reached for the follow-up phone interview.

Survey and Assessment Findings

The majority of participants were older white males (26/33, 79%) and ranged in age from 27 to 77 years, mean age 59.5 (SD 11.9). All participants had at least a high school education, and 64% (21/33) had an annual income of US$35,001 or more. Demographic characteristics are reported in Table 1.

Though skills varied, the majority of participants had adequate health literacy and eHealth competency skills. Study participants had higher levels of health literacy than the general veteran population [27]. Though comparative studies are not available for this population using these tools, the electronic health literacy scores on the eHEALS and the CEW produced similar findings. Instrument range, sample range, mean, and SDs are illustrated in Table 2.

At baseline, all participants (n=33, 100%) reported using a computer and the Internet more than once a week. Most participants (22/33, 67%) reported using Secure Messaging for at least the past six months (10/33, 30%) or longer (12/33, 36%), while the remaining participants reported using Secure Messaging for less than six months (11/33, 33%). The majority of participants (28/33, 85%) reported using Secure Messaging "at least once a month" (12/33, 36%) or "a few times a year" (16/33, 49%). Most veterans (27/33, 82%) reported being satisfied with Secure Messaging.

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Table 1. Demographic characteristics of study participants (n=33).

Characteristic		n (%)
Gender		
	Male	26 (79)
	Female	7 (21)
Education		
	High School	4 (12)
	Some College/Vocational	6 (18)
	Associate Degree	6 (18)
	College Degree	8 (24)
	Graduate Degree	9 (27)
Ethnicity		
	Caucasian/White	22 (67)
	African American/Black	5 (15)
	Hispanic/Latino	2 (6)
	American Indian/Alaskan Native	1 (3)
	Unknown/Missing	3 (9)
Annual income (US$)		
	$5,000 - $10,000	1 (3)
	$10,001 - $15,000	3 (9)
	$15,001 - $25,000	4 (12)
	$25,001 - $35,000	2 (6)
	$35,001 - $45,000	5 (15)
	More than $45,000	16 (48)
	Missing	2 (6)

Table 2. Instrument range, sample range, mean, and standard deviation.

Instrument	Possible range	Sample range	Sample mean	SD
BRIEF[a]	4-20	10-20	17.7	2.5
REALM[b]	0-66	55-66	63.3	2.8
eHEALS[c]	10-50	29-50	42.7	5.7
CEW[d]	18-90	54-90	82.8	10.4

[a]BRIEF: Brief Health Literacy Screening Tool

[b]REALM: Rapid Estimate of Adult Literacy in Medicine Survey

[c]eHEALS: eHealth Literacy Scale

[d]CEW: Computer-Email-Web (CEW) Fluency Scale

Interview Findings

Overview

Qualitative analysis of interviews revealed that veterans valued Secure Messaging based on time saving, data security, and the ease and efficiency of communicating with their health care team. Veterans asserted that Secure Messaging was an excellent alternative to calling the hospital, allowing them to communicate with their primary care team at their convenience (eg, late at night). Veterans reported the top reasons they used Secure Messaging included: (1) general questions, (2) medication refills, (3) appointments, and (4) test results. Veterans also expressed satisfaction with the timely manner of Secure Messaging communication, generally receiving a response from their primary care team within 48 hours. Veterans reported no problems understanding secure message responses from their primary care team members, and few veterans noted being uncomfortable sharing private health information through Secure Messaging. Interview themes emerged in four major domains:

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(1) perceived benefits of using Secure Messaging, (2) barriers to using Secure Messaging, (3) facilitators of using Secure Messaging, and (4) suggestions for improving Secure Messaging.

Perceived Benefits of Using Secure Messaging

This domain focused on benefits related to resource and communication efficiency between veterans and their primary care team, as seen in Table 3. Veterans highlighted the fact that Secure Messaging saved them time and resources by providing them "24/7" access to their primary care team. Veterans noted that, through Secure Messaging, appointments could be made, referrals provided, and prescriptions filled, thus avoiding the frustration of spending hours on the phone or driving long distances to accomplish these tasks face-to-face. Veterans also reported that having 24-hour access to Secure Messaging increased their ability to communicate effectively with their primary care team and that this increased access gave them the ability to send a secure message late at night, instead of waiting to call during business hours. Similarly, veterans indicated that Secure Messaging afforded them the ability and confidence to draft a question to their provider in their own time and without the pressure of having to relay the same question over the phone or in person. Having a written record of Secure Messaging conversations also helped veterans effectively communicate their questions and concerns to their provider.

Table 3. Exemplar quotes of perceived benefits of using Secure Messaging.

Theme	Exemplar quotes
Resource efficiency	*It's [Secure Messaging] immediate and hands-on—you don't have to wait 6 months for an appointment, you don't have to go through acute care, you don't have to go through all this stuff just to get a referral to your primary [care physician]…so it's contacting the primary immediately, which is great…I think it saves money, 'cause every time you go to acute care that costs money. So I think it saves money and a lot of time, a lot of wasted time, you know.*
	That direct communication without having to stop what I was doing to go see [my primary] and try to make an appointment or get in. I can talk bluntly [on Secure Messaging] you know, just like we were face-to-face. I love that, because there were some really personal things going on, you know, with me and my body and I was like, give me some advice on this, and she would just email right away…
Communication efficiency	*I like to do most of my studying at night and if I happen to think that I got to re-order this prescription, I just get on [Secure Messaging] and do it. It's 24/7 you know, and the next thing I know I got it [prescription] within a week…It doesn't tie up personnel at the VA. It just makes life easier.*
	In Secure Messaging, you can narrate [your message] very, very precisely and have it understood by the clinical team that reads your message and it's a lot better than someone just answering the telephone and then try to decide how your call should be routed.

Perceived Barriers to Using Secure Messaging

This domain encompassed issues related to initiation and knowledge barriers, privacy and security issues, prohibited personal expression, and clinician resistance. These themes included not knowing how to register and initiate the authentication process required to use Secure Messaging, not being able to locate the link within My HealtheVet to access the Secure Messaging feature, and not fully understanding the circumstances and situations in which they should use the Secure Messaging tool. These reported barriers are presented in Table 4.

Other barriers included confusion regarding who, among the primary care team, receives their secure messages. For example, some participants reported "learning" that their messages were not going directly to their primary care physician, and felt uncomfortable with the fact that multiple members of their primary care team had access to their secure messages. As a result, these veterans reported being disappointed and indicated that having multiple team members reading their messages would affect the type of health information they would include in future secure messages. Others reported learning that their primary care team discouraged them from sending personal non-health-related information.

Surprisingly, veterans noted VA staff resistance to Secure Messaging use as a barrier to their use of the tool. Several veterans cited having initiated contact with a specialty clinic, pharmacy, or primary care provider through Secure Messaging only to have the clinic attempt to respond to the veteran by telephone, rather than replying via Secure Messaging. Other veterans reported that when they asked their specialist if they could contact them through Secure Messaging, they were told to call the clinic instead. These veterans perceived that staff members were avoiding Secure Messaging in favor of traditional methods of communication.

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Table 4. Exemplar quotes of barriers to using Secure Messaging.

Theme	Exemplar quotes
Initiation and knowledge barriers	*The authentication process to use [Secure Messaging] is too cumbersome. I feel like if I can come in and see a doctor without having to do all this and the doctor knows it's me. I mean, this seems like it ought to be something that could be done in your doctor's office and not some other way. There has to be an easier way to do it.*
	I would say [Secure Messaging] is a good idea. I'm not 100% sure what you're supposed to use it for. The site doesn't tell you so I'm never sure if I'm supposed to ask medical questions or just, hey, can I make an appointment, or hey, can I get a refill. I don't know how in-depth you're supposed to get with your provider.
Privacy and security issues (personal health information)	*I think Secure Messaging has great potential but it just has to be explained…they have to stop letting you think you're talking to your doctor somehow, it has to be a little clearer…it's misleading to say you're sending a message directly to your primary care provider.*
	I would say it's an indirect way of getting in touch with your doctor, and it's open to who knows how many people in the system. I get responses from a lot of people, sometimes the call center even. It's disconcerting…when I first started using Secure Messaging, it would go directly to [my primary physician] although everybody in the clinic gets them for some reason.
Prohibited personal expression	*I've just made my messages more brief. Instead of sending a clinical message and then tagging on a personal message, I don't tag on a personal message anymore.*
Clinician resistance	*There's another specialty clinic I went to not long ago and the [specialist] told me at this point in your treatment I want you to call me and tell me this. He said, 'I probably won't answer the phone, so leave a message.' I said, 'Can I just use Secure Messaging?' And he said, 'No, no, I don't use that, I don't want to have an inbox with a thousand messages'.*

Facilitators of Using Secure Messaging

This domain included two major categories of facilitators including convenience and Secure Messaging user-friendly features. Participants reported conveniently communicating with their primary care team and getting responses and results. Other facilitators of using Secure Messaging included user-friendly features such as message notification (ie, getting a message via a non-VA email account indicating that there was a new message to be viewed in the Secure Messaging Inbox), dropdown menus, and folders for organizing received and sent messages. Veterans expressed the ways in which these features enhanced their ability to use and manage their secure messages effectively. These reported facilitators are illustrated in Table 5.

Table 5. Exemplar quotes of facilitators of using Secure Messaging.

Theme	Exemplar quotes
Convenience	*I was taking nicotine patches, nicotine gum, and they expire quickly, and, if I look at my med history, I'll see that it's expired and that I'm not scheduled to see [my primary] to order more. So I would send a secure message stating that I've ran out of my nicotine gum…and they came in the mail. And I just love that! I love that, whereas you can use Secure Messaging like that instead of getting on the phone and trying to describe it and telling them your last four of your Social Security Number.*
	The great thing is, when you get a response from your [primary care] team, you also get a notification in your private email letting you know you have a new Secure Message. So at least I know somebody replied back and that's a feature that I believe is, is working great, because you know somebody answered you. That way you know, you got to go back and log on and get into your Secure Messaging.
Secure Messaging user-friendly features	*One feature that I use is you can create more folders, that you can save and divide your messages from your primary doctors, or create another one for your nurse, or your team, or by illness. I have some friends that divided their [secure messages] by illness, because sometimes you're requesting information about a prescription and you can keep all that in a folder…I try to keep my Inbox clean.*
	To be able to [use] the dropdown box where I can see my primary doctor, and when I click in her email address and then I can put my message in the area where I'm supposed to type it in and hit send. It's very simple, you know, it's very simple. Then I go back and check it in the Inbox I'll have a message and, uh, just read it…

Suggestions for Improving Secure Messaging

Suggestions for improving Secure Messaging encompassed a broad array of system characteristics and approaches to engaging veterans. Veterans suggested the need for enhancements in the following areas: ease of navigation and use; available features; user interface and visual appearance of the on-screen content; ease of access and log-in; and awareness, education, and marketing (see Table 6). To improve ease of use, participants stated the need for a clearer navigation path to get from the main My Health*e*Vet site to the Secure Messaging feature. Currently, veterans have the option to activate a setting to provide non-VA email notification of Secure Messaging activity; veterans suggested setting the default preference setting for this notification to occur, thereby requiring veterans to change settings to deactivate it. Many veterans reported being unaware of the availability of the message notification feature, yet found it extremely useful once they learned about it and changed their

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setting preferences to enable it. In addition to simplifying the message notification feature, standard email features were commonly requested by veterans including a print option, spell check, formatting tools, and a message receipt system (ie, an automated reply message stating that their message was received by the intended recipient). Other ease-of-use suggestions included improvements for individuals with visual impairment, such as incorporating larger print/font and icons or images, rather than text, to guide the user; changing the amount of information presented per screen, or otherwise adjusting the display characteristics, to eliminate the need for scrolling; and ensuring key elements such as tabs and icons are clearly visible without magnification. Another suggested improvement was for the veterans' primary care team members to identify themselves when responding to secure messages. Suggested identifiers included health team members' names, photos, clinical role, and credentials. This improvement would help to eliminate confusion regarding which individual member among their primary care team was responding to their secure messages.

To increase usefulness, Secure Messaging respondents most commonly reported a strong desire to access specialty clinics via Secure Messaging, especially clinics where they are current patients. Veterans expressed frustration about not having access to some specialists and having to revert to traditional methods of communication. Others cited redundancy in having to ask their primary care physician to facilitate communication with their specialist.

Other suggestions for innovation and improvement included voice/image options (eg, Web cam, live chat), a Secure Messaging application for mobile devices (ie, a smartphone app), separate Secure Messaging log-out from My Health*e*Vet log-out, and the ability to import/attach information from Blue Button (a single electronic file that contains all available personal health information) and other My Health*e*Vet features (eg, test results) into their secure messages when communicating with their VA health care team.

In addition to suggestions to improve ease of use and usefulness, participants reported a need for increasing awareness, education, and instruction about Secure Messaging and My Health*e*Vet. Participant comments also highlighted a need for promotional strategies to facilitate veteran awareness and adoption of Secure Messaging, as represented in Table 6.

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Table 6. Exemplar quotes of suggestions to improve Secure Messaging.

Theme	Exemplar quotes
Improve ease of navigation and use	*It's not so easy to get that [Secure Messaging] page where you first start doing it 'cause it seems like every time I do it I have to, I don't know, like I end up "Googling" My HealtheVet and then I have to look and try and find it and then I have click here and then I have to…I don't know [laughter].*
	So it's hard to find what I'm looking for because as a patient what I'm looking for is, you know, a priority. You gotta figure most patients are like me and they would want appointments and, uh, appointments, medications, and possibly talk to the doctor, but you got all this other stuff, uh, that is competing for your attention.
	As it is built right now, I think it keeps me from using it and so it would have to streamline, you know, for me to [use]…have to make it user customized…
Features	*What I would like to see in the near future, would like to see that Secure Messaging, going probably in some kind of an application in the cell phone, like they've been doing, like with the PTSD program. They have some kind of application…but will be great, you know, using the cell phone and having application that can connect you directly. That will be great.*
	A Web cam, you know what I mean. You could probably do it with that if you could adjust it… you could click on it and see what it looks like and either gives me a decision of what it or, you know, a picture or whatever.
Screen visualization	*Uh, the Secure Messaging [button] is way up in the right hand corner off the screen and I think it should be more in a more recognizable place, 'cause if you didn't know it was there you wouldn't know it's there, so I would think to place the button in a more visual place on the, uh, screen, on the window.*
Access to specialty clinics	*Being able to secure message other clinics that I receive care in if there's other doctors that I see. I see doctors in the stroke clinic, I see doctors in the MOVE clinic, the weight management clinic, um, so I think it would be nice if I could communicate with weight management clinic and the stroke clinic.*
Awareness, education, marketing	*I think that they should have some kind of tutorial, to show every veteran [Secure Messaging] uses so at least everybody would be knowledgeable. Once you see the home page of My HealtheVet, you think it's too cumbersome or too much to get involved…people don't want to go any further than refills. I think there should be a way on the main page to give them a tutorial on how to use [Secure Messaging] to make it useful to each and every vet.*
	You don't get any notification on your email. For instance, like, my email is Hotmail so I don't get any notification telling me that 'hey, you've got a message on your Secure Messaging, VA has sent you a secure message' so I don't get any of that feedback because I'm only on the SM when I need to be…
	I don't see any problems with [Secure Messaging] so I wouldn't change anything. It's just getting the information out to the veterans to let them know that there is a convenient and secure way to communicate with your primary.
	For me, I honestly, I probably wouldn't drive all the way to the hospital to go to an education class on [Secure Messaging], but if they would put the same education video on the website, I might watch it so I don't have to learn through trial and error.
	I especially like to read, so if they would just provide information on the website as far as a short piece about how [Secure Messaging] works, what are the benefits, and how to use it, I would definitely read it. I'm not a big fan of paper so I would definitely be happy with something that was online.

Follow-Up Interview Findings

All 32 veterans who completed the follow-up interview reported using a computer/Internet more than once a week. Most veterans (84%, 27/32) reported using Secure Messaging "at least once a month", compared with 36% (12/33) upon initial survey. Almost all veterans (97%, 31/32, 1 missing) reported being satisfied with Secure Messaging. In general, follow-up data mirrored responses to initial (baseline) assessment. The BRIEF (r=.51, P<.003), CEW (r=.61, P<.001), and eHEALS (r=.58, P<.001) were significantly correlated from baseline to 3-month follow-up. Changes in Secure Messaging use in 3-month reports included higher utilization since initial assessment. Those who reported not using the system generally indicated that they had no need to contact their health care team via Secure Messaging during the 3-month time period.

Follow-up interview themes addressed participants' increased Secure Messaging utilization, learning about Secure Messaging through interviews, and self-care management. A minority of participants cited learning more about Secure Messaging during their initial interview, particularly about reasons for using Secure Messaging and different features such as the folders and the option to receive notification via personal (non-VA) email when a secure message is received. Veterans also mentioned engaging in Secure Messaging more often as a result of having participated in the study, citing greater confidence and understanding of the Secure Messaging interface. A few veterans even indicated that they increased their motivation to improve how they manage their own health care as a result of learning more about Secure Messaging through participating in the study. These comments are reflected in Table 7.

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Table 7. Exemplar quotes from follow-up interviews.

Theme	Exemplar quotes
Increased Secure Messaging utilization	*I used to use [Secure Messaging] in the past and, uh, it wasn't as frequently as I do now, based on the fact that I know it's there and so that's my first course of action. When I'm thinking about trying to get anything or get answers from my physician, I go through Secure Messaging first thing right off the bat.*
	Yeah, because I really hadn't used it much prior to our meeting and, you know, I've made a conscious effort of using it versus calling, yes.
Learning about Secure Messaging through interviews	*I'm impressed. It does make it easier to be notified of a message, uh, especially to be notified of appointments that have been scheduled…and as I mentioned I hadn't gone that deep into preference, but I know now that I can do this at home with my preferences.*
	I didn't know about the draft feature before the interview. Now I can save a draft.
	Really, I've never thought about user preferences, I just never thought that, if I had an ongoing communication with my primary…I think I would change my user [preferences] whereas right now it's not set.
	I didn't even know [user preferences] was there. When I go home, I'll look.
	I really hadn't looked at these dropdown boxes, which make it simple, you know.
Self-care management	*Yes, and I'm finding that this is a good tool. I'm beginning to recognize that, in the long term, this is going to be beneficial to me especially…now I'm getting old and if I can't speak, my wife's gonna have to speak for me with all this information in front and we'll be able to do that.*
	I think that it's helped me become more involved in my health care. Just knowing that I have that opportunity to ask a question and I don't have to schedule an appointment to ask it. If I do have that question, I'm gonna ask versus not asking it so I can be a little more proactive in my health care versus [waiting] until something happens and then going in and trying to figure out what's wrong at that point.

User-Testing Findings

Though participants were able to complete most tasks necessary to use Secure Messaging, user-testing findings indicated potential opportunities for improving usability, including navigation of the My Health*e*Vet website, setting user preferences, categorizing message subject headings (Secure Messaging users can access a dropdown menu to populate the subject line of their messages with one of four predefined categories, ie, general, appointment, medication, test result inquiry, to indicate the purpose of the message). For example, it currently takes four steps to access Secure Messaging; participants suggested that fewer steps or a separate log-in for Secure Messaging (distinct from the My Health*e*Vet portal), would support easier navigation access to the messaging tool (see Figure 1). Additionally, several features were not easily accessible and sometimes unknown to participants, including setting user preferences and categorizing message subject (see Figure 2). However, opening folders and navigating through folders did not pose issues for participants during the user-testing (see Figure 2). User-testing findings are illustrated in Table 8.

Table 8. User-testing findings (n=33).

Task	Able to complete task n (%)	Completed task with difficulty n (%)	Did not complete task n (%)
Navigate to site	21 (64)	10 (31)	2 (6)
Log in to site	30 (91)	2 (6)	1 (3)
Set "User Preferences" option	23 (70)	8 (25)	2 (6)
Check Inbox	33 (100)	0 (0)	0 (0)
Use links within Secure Messaging	33 (100)	0 (0)	0 (0)
Open secure message	33 (100)	0 (0)	0 (0)
Open attachment	33 (100)	0 (0)	0 (0)
Send secure message	30 (94)	3 (9)	0 (0)
Choose recipients for secure message	32 (97)	0 (0)	1 (3)
Categorize message subject	9 (28)	0 (0)	24 (73)
Formulate subject header	18 (55)	0 (0)	15 (47)
Formulate a secure message	33 (100)	0 (0)	0 (0)

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Figure 1. Four-step process for logging in to Secure Messaging.

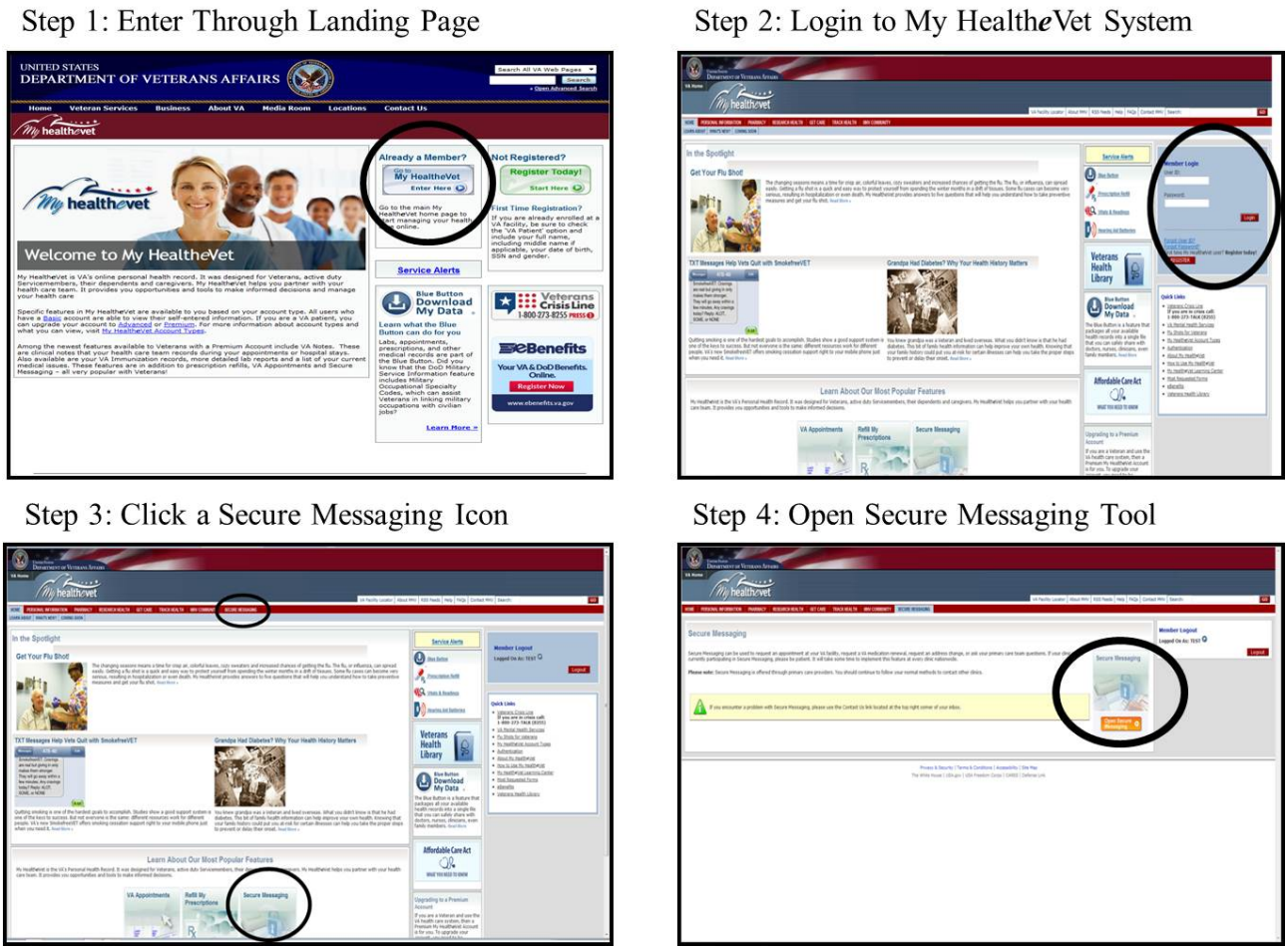

Figure 2. Folder, subject categorization, and preferences features in Secure Messaging.



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Secure Messaging Data Content Findings

Data were collected for 33 participants during the 3-month review period, of whom 18 (55%) sent a total of 66 secure message threads (series of messages from one original message). Three of the 18 participants' messages were simply to test the system and did not include any substantive content, and 15 participants (45%) did not use Secure Messaging during the 3-month timeframe, other than when conducting the user-testing on the test account. Nearly all of the message threads (62/66, 94%) were categorized in one of four categories (ie, general, appointment, medication, test) by senders to indicate the message topic. Though the message content matched the selected category in messages sent by secure message senders, due to the generic nature of the categories, "general" was over-used to address all topics, including those represented by the other three categories (ie, appointment, medication, test). Secure message content topics are illustrated by veteran-selected category in Table 9.

A total of 50 (76%) of the 66 veteran-initiated secure messages received responses from their health care team members. Several messages sent by veterans did not result in a response from the health care team; however, some messages revealed that a clinical response had occurred through other mechanisms (eg, veteran sent secure messages thanking team members for a call). For those messages that did receive a reply, response times from VA team members ranged from 8 minutes to 136 hours (>5 days). The expectation for response time, based on VA guidelines, is 3 federal business days after the original secure message is sent.

Table 9. Secure Messaging content topic by veteran-selected category.

Category	n	Secure Messaging content topic
General	36	condition management/report, specialty/procedure request, correspondence request, medication refill request, test results, appointment requests, treatment/appointment follow-up (2 messages sent to check if previous messages were received; 1 to report of being removed from team on the secure messaging recipient list)
Appointment	15	confirmations, cancellations, specialty appointment requests
Medication	10	refill requests, medication inquiries
Test	1	test request

Discussion

Principal Findings

We conducted a multi-method study of veterans' use of Secure Messaging, an email-like communication tool embedded in the Department of Veterans Affairs' online personal health record and patient portal, My Health*e*Vet. We found that the majority of veterans who participated in this study were satisfied with Secure Messaging, reported it to be a useful tool for managing their health care, and generally demonstrated facility using its features. Perceived benefits of Secure Messaging most commonly related to the convenience of communicating with their primary care team. The ability to avoid telephone triage, to send messages at a time of their choosing, and to edit messages before sending them to their primary care teams were strong motivators for continued Secure Messaging use. Similar findings were reported in another study that found patients preferred secure messaging over phone calls to communicate their health care needs [28].

Using TAM and TPB, we prompted participants to identify ways to improve ease of use and make system changes to promote their sustained utilization. Although participants were generally able to complete most of the user-testing tasks with ease, they reported some barriers to use, specifically opportunities for improved usability related to navigating the My Health*e*Vet site, setting user preferences, categorizing messages, and formulating subject headers. Veterans suggested improvements to the system to overcome barriers to use, such as changing the default settings of preferences so that veterans would automatically receive regular email notification when they received a secure message on My Health*e*Vet, and adding more dropdown menus to guide veterans with a set of options populating the subject line of their messages. Our study highlighted a need for promotional strategies, instructional interventions, and aligning expectations for use to support Secure Messaging and My Health*e*Vet utilization across the VA [29].

Though participants reported several benefits and intention to continue Secure Messaging use, barriers to use were also reported. Participants reported perceived resistance from their clinical team members as a barrier to continued use. These results echo a similar study that found physicians consistently preferred traditional methods of communication with patients including face-to-face, telephone, and written communication [30].

Sample characteristics, including educational and income levels as well as eHealth and health literacy levels, were not typical of the general veteran population; however, these findings are consistent with existing literature, which suggests that eHealth users tend to have higher levels of eHealth and health literacy, as well as educational and socioeconomic status, than the general population. As a result, this sample is representative of those more likely to be eHealth users [31-34].

The "learning effect" (eg, learning about features), reported by veterans during face-to-face interviews, indicates the need for the provision of user training. A considerable number of veterans articulated the misperception that only their primary care physician would receive and view their secure messages. Moreover, veterans expressed some degree of betrayal and dissatisfaction when they learned, whether through our study or otherwise, that other members of their health care team could review and respond to their messages. These observations

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indicate a need to address veterans' misperceptions and a possible role for enhanced education of and disclosure to veterans about how their clinical team receives and responds to the veterans' messages. Our findings reveal a need for improved instruction when veterans begin using Secure Messaging to improve uptake, utilization, and sustained use.

Though our results from questionnaires, interviews, user-testing, and review of message content were generally convergent and internally consistent, some data sources indicated discrepancy between veterans' reports and objective data collection. For instance, more than 80% (27/33) of participants reported using Secure Messaging at least once in the past 3 months, but Secure Messaging content analysis indicated only 55% (18/33) of veteran participants sent messages during that time window. This discrepancy may be result of recall bias or social desirability bias. Another possible explanation for this discrepancy is participants' confusion between the My Health*e*Vet portal and Secure Messaging tool, such that veterans may have used My Health*e*Vet but not Secure Messaging. Veterans who did not use the system had not perceived a need to communicate at all with their health care team during that time period. This reason for non-use has been provided by participants in previous research [29]. Similarly, the majority of veterans reported receiving Secure Messaging responses within 24-48 hours; however, review of the Secure Messaging content suggested that response times ranged anywhere between 8 minutes to 136 hours (>5 days). Analysis of secure message content data also revealed that veterans sent messages to inquire about sensitive topics, such as sexually transmitted diseases (STDs) and erectile dysfunction (ED), and that these topics were not revealed in interviews. These observations underscore the value of using mixed methods to characterize the uses of Secure Messaging that could not be gleaned from veterans' self-reports alone. Similarly, face-to-face interviews provided in-depth perspective into how veterans perceive and experience Secure Messaging, while observational data from usability testing revealed how veterans actually interact with the Secure Messaging platform in a "real-world" setting. Multiple datasets also allowed the research team to compare and contrast veterans' reports with objective Secure Messaging data sources, providing a more thorough and textured understanding of veterans' experiences when using Secure Messaging.

As health care evolves from a reactive, episodic disease-based paradigm to a preventative continuous health model, large health care systems such as VA will require the integration of electronic health resources to promote continuity and increase communication and workflow efficiency. Consumer adoption and sustained utilization are necessary to leverage these tools and their benefits to capacity. The science of marketing, implementing, disseminating, and sustaining Secure Messaging and other patient-facing eHealth technologies has not yet been perfected. Understanding consumer needs is central to intervening and remediating any barriers to adoption and sustained use of Secure Messaging. Both qualitative and quantitative methods to understand veterans' and clinicians' experiences and perceptions of Secure Messaging use are needed to overcome barriers and promote facilitators. This study's exploratory findings provide a comprehensive framework for future evaluation of Secure Messaging use in a large-scale representative veteran sample.

Limitations

The mixed methods used in this study with users and non-users of Secure Messaging provided a rich dataset that resulted in a comprehensive perspective of veterans' experiences using Secure Messaging. Though this study yielded valuable data to inform marketing, education, and system-based changes to improve awareness, adoption, and sustained utilization of Secure Messaging, limitations should be noted when interpreting findings. First, although our sample size was comparable to other qualitative mixed-methods studies [35], these results may not be generalizable to the general veteran patient population. This limitation is particularly salient in this study due to the relatively high levels of education and health literacy among study participants. However, this sample was purposively recruited to represent the perspective of veterans with Secure Messaging access and theoretical saturation was reached. Second, although our sample included veterans who did not use Secure Messaging during the 3-month data collection period, we limited our sample to include those who had previously accessed to the system. While our sampling procedure provided insight to veterans' experiences using Secure Messaging, collecting data with those who did not register for access to use the Secure Messaging system would provide useful information about reasons for non-adoption. Third, this study included veterans without prejudice to their personal health history or absence thereof. Future research should explore Secure Messaging utilization, among those who may stand to benefit most, such as veterans with mental health problems or chronic health conditions. Fourth, this study did not capture the perspectives of staff or clinicians; these perspectives will be important to ascertain in future research, because study participants indicated that clinician resistance can impact patient use of Secure Messaging. This study and previous research [30] indicate that resistance on the part of clinicians can affect patient utilization. Understanding how clinicians' perceptions of Secure Messaging influence patients' adoption and use of this technology remains of interest for future study. Yet, previous work has also indicated clinicians' perceived value of Secure Messaging, especially when becoming familiar with how it worked [7,28]. Fifth, we recognize that study participants may have altered how they use Secure Messaging after providing prospective informed consent for researchers to review their messages for the succeeding 3-month time period. Future studies may benefit from collecting retrospective message data, rather than prospective data, to ensure messages are not censored by users. In addition, though the content review was conducted for a 3-month timeframe, due to long periods of time when people do not routinely interact with their health care team, future studies should collect message data for a longer timeframe (eg, six months to one year).

Conclusions

VA is invested in leveraging electronic health resources to facilitate patient-centered care for veterans and their families. Secure Messaging provides a patient-driven method of communication that can empower patients to effectively engage

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in continuous health relationships with their health care teams through meaningful use of this technology-based resource. As VA continues to promote Secure Messaging as a viable communication tool, results of this study can be used to improve and expand veterans' use of Secure Messaging for better access to health care.

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Conflicts of Interest

None declared.

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Abbreviations

BRIEF: Brief Health Literacy Screening Tool
CEW: Computer-Email-Web Fluency Scale
eHEALS: eHealth Literacy Scale
PACT: Patient Aligned Care Teams
REALM: Rapid Estimate of Adult Literacy in Medicine Survey
TAM: Technology Acceptance Model
TPB: Theory of Planned Behavior
VA: Veterans Affairs
VAMC: VA Medical Center

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Original Paper

Implementing a Virtual Community of Practice for Family Physician Training: A Mixed-Methods Case Study

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Abstract

Background: GP training in Australia can be professionally isolating, with trainees spread across large geographic areas, leading to problems with rural workforce retention. Virtual communities of practice (VCoPs) may provide a way of improving knowledge sharing and thus reducing professional isolation.

Objective: The goal of our study was to review the usefulness of a 7-step framework for implementing a VCoP for general practitioner (GP) training and then evaluated the usefulness of the resulting VCoP in facilitating knowledge sharing and reducing professional isolation.

Methods: The case was set in an Australian general practice training region involving 55 first-term trainees (GPT1s), from January to July 2012. ConnectGPR was a secure, online community site that included standard community options such as discussion forums, blogs, newsletter broadcasts, webchats, and photo sharing. A mixed-methods case study methodology was used. Results are presented and interpreted for each step of the VCoP 7-step framework and then in terms of the outcomes of knowledge sharing and overcoming isolation.

Results: Step 1, Facilitation: Regular, personal facilitation by a group of GP trainers with a co-ordinating facilitator was an important factor in the success of ConnectGPR. Step 2, Champion and Support: Leadership and stakeholder engagement were vital. Further benefits are possible if the site is recognized as contributing to training time. Step 3, Clear Goals: Clear goals of facilitating knowledge sharing and improving connectedness helped to keep the site discussions focused. Step 4, A Broad Church: The ConnectGPR community was too narrow, focusing only on first-term trainees (GPT1s). Ideally there should be more involvement of senior trainees, trainers, and specialists. Step 5, A Supportive Environment: Facilitators maintained community standards and encouraged participation. Step 6, Measurement Benchmarking and Feedback: Site activity was primarily driven by centrally generated newsletter feedback. Viewing comments by other participants helped users benchmark their own knowledge,

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particularly around applying guidelines. Step 7, Technology and Community: All the community tools were useful, but chat was limited and users suggested webinars in future. A larger user base and more training may also be helpful. Time is a common barrier. Trust can be built online, which may have benefit for trainees that cannot attend face-to-face workshops. Knowledge sharing and isolation outcomes: 28/34 (82%) of the eligible GPT1s enrolled on ConnectGPR. Trainees shared knowledge through online chat, forums, and shared photos. In terms of knowledge needs, GPT1s rated their need for cardiovascular knowledge more highly than supervisors. Isolation was a common theme among interview respondents, and ConnectGPR users felt more supported in their general practice (13/14, 92.9%).

Conclusions: The 7-step framework for implementation of an online community was useful. Overcoming isolation and improving connectedness through an online knowledge sharing community shows promise in GP training. Time and technology are barriers that may be overcome by training, technology, and valuable content. In a VCoP, trust can be built online. This has implications for course delivery, particularly in regional areas. VCoPs may also have a specific role assisting overseas trained doctors to interpret their medical knowledge in a new context.

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KEYWORDS

community of practice; virtual community of practice; general practice; family physician; training; medical graduate; education; social media

Introduction

General practice, or family physician, training in Australia can be isolating [1]. Trainees, or registrars, enrol in a regional training scheme, which can cover a region of over 150,000 square kilometres. Training begins with a 12-month post-internship hospital placement, usually in a large urban environment with open wards and teams looking after patients. Trainees then move through 18-24 months of placements in at least two practices, with at least 6 months in a rural area. In these busy general practices, trainees see patients on their own, supervised by a senior general practitioner.

The changes in training from hospital to general practice can contribute to the development of three types of isolation [1] that in turn lead to decreased knowledge sharing [2], lowered intention to work in rural areas [1], and a change of career choice [3]. Social isolation, which can be described as a kind of loneliness [4], occurs more commonly during rural terms [1,5]. Structural isolation results from a single doctor consulting with a single patient in a closed room, with appointments often not in synchrony with other doctors, leading to lack of interaction with colleagues, and can occur in both urban and rural placements [1]. Finally, professional isolation is associated with barriers to knowledge sharing, including access to networking and training events [1]. Since rural health workforce retention remains a challenge in Australia [6] and elsewhere, and as isolation can lead to lower intention to work in rural areas, measures to overcome perceived isolation are important.

Communities of Practice theory is an appropriate model for explaining medical knowledge sharing and for overcoming one type of isolation, that is, professional isolation. Communities of practice (COP) have been described as “groups of people who share a concern or a passion for something they do and learning how to do it better as they interact regularly” [7]. The three elements of a COP are domain, community, and practice [7]. In general practitioner (GP) training, these are a shared domain of medical knowledge, a defined community of practitioners with differing levels of expertise, and a shared practice of medicine to which the knowledge will be applied [8]. However, geographic and structural isolation form barriers to the natural knowledge sharing in a COP. Thus virtual communities of practice (VCoPs) have been proposed as a strategy for reducing isolation by overcoming barriers to knowledge sharing within a COP by augmenting face-to-face communication and facilitating collaboration online, particularly through social media technologies [9-11].

Studies have shown that GP trainees have the interest, ability, and necessary online access to trial a VCoP designed to enhance GP training, while acknowledging potential barriers of time, privacy, and technology [12,13]. A framework for the implementation of health-focused VCoPs has been developed based on a successful business CoP implementation model [14,15]. The steps in this framework are (1) organizing facilitation, (2) finding a champion and supporters, (3) establishing goals, (4) having a “broad church” of users, (5) ensuring a supportive environment, (6) providing benchmarking and feedback, and (7) considering technology and community factors that promote usage. This case study examines the value of the framework in implementing a VCoP, and the usefulness of that VCoP in overcoming knowledge sharing barriers and improving support for GP trainees, and thereby reducing professional isolation.

Methods

Summary

A mixed-methods case study methodology was used to describe and examine the implementation and impact of the online community, Coastcitycountry Online Network for an Educational Community of Training for GP Registrars (ConnectGPR). Results are presented and interpreted for each step of the VCoP 7-step framework. The description of the implementation in the Methods section is brief as implementation is addressed in each of the 7 steps within the Results section. When using a case study format, only a selection of the overall results can be presented from the array of available data. For completeness, a full description of the methods for

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survey and interview data collection follows, then a discussion of the case itself.

Surveys were developed to collect data from general practice trainees, term 1 (GPT1s), and supervisors before and after the intervention. Respondents were categorized into three subgroups: (1) supervisors, (2) GPT1s who did not participate in the online trial (the non-implementation group), and (3) GPT1s who participated in the trial (the implementation group). Instrument development was informed by both the literature review and previous stages of the project. Included in the questions was the UCLA (University of California, Los Angeles) Loneliness Scale (Russell, Peplau & Ferguson, 1978). Six items were taken from the measure by Russell, Peplau, and Ferguson (1978). The remaining seven were modified to include questions on isolation within Coast City Country GP Training and within the GP practice where respondents were based. Responses were measured on a 7-point Likert scale ranging from *Strongly Disagree* (1) to *Strongly Agree* (7). Knowledge questions were based on stems "GPT1s need help KNOWING…" or "GPT1s need help IMPLEMENTING…" finishing with a range of topics such as asthma. These topics were drawn from the GPT1 first 6 months support guide, GP-Start. Preference questions included "I would prefer the network to be led by…".

The surveys were formatted to use online with SurveyMonkey [16]. An email containing a participant information sheet and a link to the survey was sent to all GPT1s and their supervisors using the contact details supplied by Coast City Country General Practice Training (CCCGPT), and usage questions were self-reported use of the network. Table 1 presents a sample of question types, groups receiving them, and response rates. Due to the complexity, length of the survey, and its use of skip logic (which is designed for online delivery), the survey itself is not included in the Multimedia Appendices, but the authors will supply survey questions on request.

Data were checked for missing values or data entry errors. Participants with missing demographic data were excluded from the study. Participants who did not complete the majority of the survey were excluded from the survey. The data were analyzed using SPSS version 17. Frequencies and descriptive analysis were used to produce summary statistics on the data as shown in the results section.

Paired-samples *t* tests were used to compare means of scale data such as need for knowledge support compared with implementation support within a group, and independent sample *t* tests were used to compare means of scale data between groups such as knowledge support in GPT1s compared with supervisors. All statistical comparisons were two-tailed and statistical significance was set at $P<.05$.

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Table 1. Survey response rates and question types.

When	Participant	Responses and response rate, n (%)	Knowledge questions	Preferences for online network questions	UCLA scale isolation questions	Usage questions
Pre pilot						
	GPT1 survey 1	Total=43 Usable=40 Rate=40/55 (72.7%)	Yes	Yes		
	GPT1 survey 2	Total=38 Usable=37 Rate=37/55 (67.3%)			Yes	
	Trainer	Total=23 Usable=21 Rate=21/50 (42.0%)	Yes		Yes	
Post pilot						
	GPT1 control	Total=11 Usable=11 Rate=11/23 (47.8%)		Yes	Yes	
	GPT1 intervention	Total=25 Usable=14 Rate=14/32 (43.8%)	Yes	Yes	Yes	Yes
	Trainer	Total=22 Usable=14 Rate=14/50 (28.0%)	Yes		Yes	

Telephone Interviews

Data and Sample Selection

At the end of the intervention, the 28 GPT1 members of the online community were stratified into non-users (5), passive users who log in but do not post (6), intermittent users (10), and regularly active users (7). A random selection from each group was invited for semistructured telephone interviews. There were 11 interviews, comprising active users (5), intermittent (3), non-user (1), medical educator (1), and topic expert (1). There were 3 male and 8 female participants. The average length of interview was 35 minutes.

Measures

The semistructured interviews were designed to explore the themes of the Health Framework for Implementation of Virtual Communities of Practice [14], along with themes of professional isolation. The interviews were performed, recorded, and transcribed by research assistants. After an initial review of the interview transcripts by SB, major themes and analysis approaches were discussed by the authors and a coding structure agreed upon. SB then followed this approach, coding interviews against the 7 steps from the Health VCoP Framework, with the additional themes of isolation/connectedness and knowledge sharing.

The Case

The case was set in Coast City Country General Practice Training (CCCGPT), from January to July 2012. CCCGPT is a regional GP training provider in southern NSW, Australia, covering a region of 160,000 square kilometres. It includes rural and regional areas, incorporating the urban centres of Wollongong and Canberra (see Multimedia Appendix 1).

During the case study period, CCCGPT had 135 trainees in its program, with 55 in their first term, or GPT1, divided among three regional local training groups (LTGs). Previous studies in CCCGPT identified that, while there was general support for an online network for GP training, the highest interest came from the most junior training stage (GPT1). This GPT1 group is also the most vulnerable group, as they leave the support of a large hospital and are thrust into more independent practice in the community setting for the first time. The 34 GPT1s in two of the three LTGs were invited to participate in the Coast City Country Online Network of an Educational Community of Training for GP registrars (trainees)—ConnectGPR. These two LTGs were chosen for practical reasons as two of the

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authors (TC, SB) were GP trainers in these regions and had good relationships with the training provider, trainees, and online communities. The 21 GPT1s in the third LTG were included as a passive group to provide further survey data and provided some between-group comparisons in the "post" survey. Due to low numbers in the LTGs, this comparison was within the context of a case study, rather than as a case-control study.

ConnectGPR was a secure, online community site, using Ning online social software. Ning was chosen for several reasons. In a previous survey of this study group (unpublished data), respondents had ranked the most important features as the ability to document share and use forums, within a private network. Ning was able to supply forums and document sharing within a private network and was therefore chosen as a technology that was simple to set up and administer. The Davis Technology Acceptance Model [17] also describes that perceived usefulness and ease of use are two main drivers for technology uptake. After a trial of the Ning platform, the authors (SB, TC) decided it would be easy to use.

Configuration and technical support was provided by the University of Wollongong educational technology team. ConnectGPR included standard community options such as discussion forums, blogs, newsletter broadcasts, webchats, and photo sharing. The process of running the site included, ideally, posting a case on the forum on a Sunday night, adding some resources or photos to the site, running a webchat mid-week, and answering questions on the forum during the week. One of the authors (SB) maintained the role of central facilitator, co-ordinating the roster, sending out the weekly newsletter, and acting as support for other facilitators. This role required an average of 3 hours per week.

Access was via password, and users were identified by their full name. Data included website usage using Google analytics, Ning reporting, and manual counts of total posts and manual review of website posts by the authors (SB, TC).

Consent was obtained in keeping with the ethics approval granted by the University of Wollongong human research ethics committee.

Results

Overview

Over the 26 weeks from January to July 2012, 82% (28/34) of GPT1s enrolled in the VCoP. The case study results are presented in two sections. The first section describes the implementation of a VCoP for GP training, while the second section discusses its usefulness for GP training. In addition, the response rates of the surveys with their differing question types are presented in Table 1.

Implementation Using the Health VCoP Framework

Step 1: Facilitation

"Facilitators promote engagement and maintain community standards" [14]. In October 2011, following several studies demonstrating the ability, interest, and access required to trial an online community for GP training, CCCGPT agreed to fund an implementation trial.

The literature indicated that facilitation needs to be ongoing and ideally done by a group that understands the participants [18]. As GP trainers, the lead authors (SB and TC) were the main facilitators; however, to avoid facilitator fatigue, a further group of three GP trainers was engaged. Facilitators had several planning meetings to develop a process and roster to support ConnectGPR.

The use of active, clinically relevant facilitators was key to the success of the site as indicated by both pre- and post-intervention feedback. In the pre-intervention survey, all GPT1s agreed that it was important that the network had formal facilitation (40/40, mean 3.88 on a 5-point scale, SD 0.91).

The majority of post-intervention interviewees acknowledged the value of facilitation. There were a number of comments on facilitators being helpful and supportive, particularly by being personal in their responses and being organized and useful:

> *I was really impressed…(the facilitators were) highlighting new points and always replying to questions that were asked, or acknowledging when people put new stuff up and that sort of thing. And then saying—replying but not just replying, personally replying but actually being really useful with professional guidelines and that sort of thing to guide you in the right direction.* [GPT11]

Another participant indicated that it was good to have a facilitator who was senior, so that there was feedback to prevent "chaos in the system…There should be an authority otherwise there is unlimited fighting" [GPT1]. Regular, personal facilitation by a group of GP trainers, with a lead facilitator to co-ordinate the other facilitators, was an important factor in the success of ConnectGPR.

Step 2: Champion and Support

"The network needs to have an initial stakeholder champion, with stakeholder support" [14]. The development of ConnectGPR demonstrated the need for champions and stakeholder support. The initial studies resulted from a CCCGPT funding round that supported the exploratory studies on VCoPs to enhance GP training. As a result of these initial positive studies, the "champion" (SB) was funded by CCCGPT for the intervention trial. While the authors' (SB, TC) enthusiasm was important, stakeholder engagement was indispensable. In addition to funding, the support of the training organization allowed access to the study population. The training organization prioritized the study leading to good uptake among GPT1s, provided promotional opportunities during normal GP training workshops, and provided administrative support for email addresses and enrolment. By identifying the project as an official CCCGPT project, rather than simply a private offering, it also encouraged participation of facilitators.

The importance of CCCGPT's involvement was also supported by GPT1s. In the pre-intervention survey, on a 5-point Likert item, GPT1s agreed that it was important that the network was formally sponsored by CCCGPT (40/40, mean 4.15, SD 1.00).

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In the interviews, one GPT1 commented that having CCCGPT engaged was important, as without its endorsement, GPT1s may not give projects serious consideration. In fact, this GPT1 was supportive of further integration, an opinion supported by the facilitator group at the end of the study. While receiving formal support from CCCGPT, the program was not a required component of the training program. Thus, it was seen as a good, but an optional educational activity. Further benefit may have been obtained if ConnectGPR had been officially recognized as contributing to training time. Leadership and stakeholder engagement were vital in this project.

Step 3: Objectives and Goals

"Clear objectives provide members with responsibilities and motivate them to contribute more actively" [14]. In the pre-intervention survey, GPT1s were asked to indicate their goals for participation in an online community. Participants ranked highly the goals of knowledge and professional support including help with exams, putting guidelines into practice, being more supported, and becoming more confident (Table 2).

Table 2. GPT1 rating of importance of outcomes from participation in an online community (5-point Likert scale, with 5 being very important; N=40).

Item	Minimum	Maximum	Mean	Standard deviation
Help trainees pass exams	3.00	5.00	4.48	0.60
Feel more confident in medical skills	1.00	5.00	4.28	0.91
Learn from colleagues how to put guidelines into practice	1.00	5.00	4.08	1.00
Feel more supported in general practice	1.00	5.00	4.18	0.91
Develop a broader network of colleagues	2.00	5.00	4.05	0.71
Develop links with experts	2.00	5.00	4.18	0.75

At the GPT1 orientation workshop, facilitators gave a short presentation on ConnectGPR, in which the goals of the site were outlined. The case study authors (SB and TC) summarized the focus of the site for trainees, which was to improve connectedness, overcome isolation, and provide support by improving knowledge sharing.

During the first 6 months of GP training in CCCGPT, GTP1s worked through a curriculum of 15 topics. These include practical topics such as billing, administration, and consultation management, along with clinical topics such as cardiovascular medicine. These topics formed the basis of the knowledge sharing topics. A roster of topics was developed, running through the 15 topics over 26 weeks, divided between the 5 facilitators.

The ConnectGPR project established clear goals around knowledge sharing and improving connectedness. These goals were reflective of the goals expressed by GPT1s. A clear focus on these goals and on the curriculum made planning the roster simpler and helped to keep the site discussions focused.

Step 4: A Broad Church

"Consider involving different, overlapping but not competing, professional groups, different organizations and external experts. However make sure the church is not too broad..." [14]. The ConnectGPR case study focused on GPT1s on the grounds that this group needed the most help in the transition from hospital to community practice. In previous studies, junior trainees also seemed more receptive to an online community [12]. However, as all members were at the same training stage, their knowledge base was similar, which conflicts with the COP ideal of having a range of knowledge levels to promote knowledge sharing. At the end of the intervention, only 8 of the 14 (57.1%) intervention GPT1 respondents felt that the VCoP had a sufficiently broad user base to maintain their interest. GPT1s considered it most important to include supervisors in the online platform, followed by medical specialists, GPs, and university academics.

During the post-intervention interviews, GPT1s commented on potential benefits and areas of concern in having a broader community. For example, one GPT1 said that a broad community, including more urban-based subspecialties, would be useful when working in a rural area, particularly in guiding appropriate referrals and pre-referral "workups": "down here in [rural town] it is mostly general surgery so anything more complicated, it's a bit hard to decide what to do and where to send" [GPT19]. Two other GPT1s were keen to have speciality colleagues online, but one had some concerns about allied health, citing lack of relevance, and "because of the breadth of information—it could get a bit out of control and overwhelm everything" [GPT11].

A "broad church" of users is desirable for an online GP training community. In the ConnectGPR study, the community was too narrow, focusing only on GPT1s. Involvement of more senior trainees, trainers, and specialists would have been good, but not so broad as to be overwhelming. Some GPT1s said that including allied health might make the site too broad.

Step 5: A Supportive Environment

"Health VCOPs should promote a supportive and positive culture that is both safe for members, and encouraging of participation" [14]. The facilitators generated the majority of the content and provided most of the responses to the questions posted by participants. As a result of this level of facilitator involvement, participants were encouraged to post questions and comments or to respond again once a facilitator had replied. The tone of the site remained supportive and respectful throughout, with constructive and respectful engagements between GPT1s and between GPT1s and facilitators.

In the post-intervention survey, GPT1s in the intervention group responded that facilitators were helpful in maintaining

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community standards (12/14, 85.7%) and in encouraging participation (10/14, 71.4%). Facilitators were also seen as being an important factor in encouraging ongoing use of the site (5/14, 35.7%) but were less important than the value of the content (8/14, 57.1%). The majority of GPT1s (11/14, 78.6%) also agreed that the culture of ConnectGPR was supportive.

ConnectGPR provided a supportive environment, with facilitators maintaining community standards and encouraging participation. GPT1s were also supportive of each other, maintaining a respectful tone throughout the study. While this encouraged participation, the value of the content was the primary motivator.

Step 6: Measurement Benchmarking and Feedback

"Health VCoPs should consider measurement as a factor in their design, including benchmarking and feedback" [14]. Regular feedback to the participants from the main facilitator was vital in encouraging site usage. This feedback primarily consisted of a weekly newsletter with activity on the site, site usage, useful comments, cases, and upcoming webchats. The majority of usage was centrally driven, by facilitators and the newsletter, with site usage data demonstrating a peak of logins each week on the day of the webchat and newsletter, with limited activity in between (as shown in Figure 1).

Three GPT1s on the ConnectGPR forum posted that getting feedback through knowledge sharing with their colleagues and educators was important; in essence, the feedback effectively benchmarked their approach with that of their colleagues. One interviewee said: "It allows us to know what other trainees are doing, so that we learn from each other and from our educators" [GP9].

In the post-intervention survey, the majority of users (8/13, 62%) stated that the network had helped them to benchmark their knowledge against their peers. In the interviews, one overseas-trained GPT1 described how valuable feedback can be in guiding learning, particularly in the absence of a specific guideline for a local situation. In such situations, sharing knowledge and receiving feedback can assist the learner to determine whether they are on the right track. "It looks like you are sitting in an isolated place…Once you can share your knowledge then you can understand why you are in the right track because ConnectGPR, this thing we use to discuss cases and topics all the time" [GPT1].

Another user noted that participating in a forum, or even reading other people's forum discussions, can be like speaking with a senior doctor and could help when it is hard to attend a face-to-face workshop. "If you can participate in the forum, it's almost like you are talking to a senior. And if you can't do that, still you can see the archive readings…it can be a good way of communicating, other than physically attending a workshop" [GPT8].

Finally, one expert facilitator commented that it would be good to have more feedback on the material they had supplied for the site to make sure that the materials provided were adequate.

ConnectGPR activity was primarily driven by a centrally generated newsletter that summarized activity on the site, with links to resources and feedback on usage of parts of the site. Viewing comments by other participants was a way for users to benchmark their own knowledge, particularly around applying that knowledge in a clinical situation.

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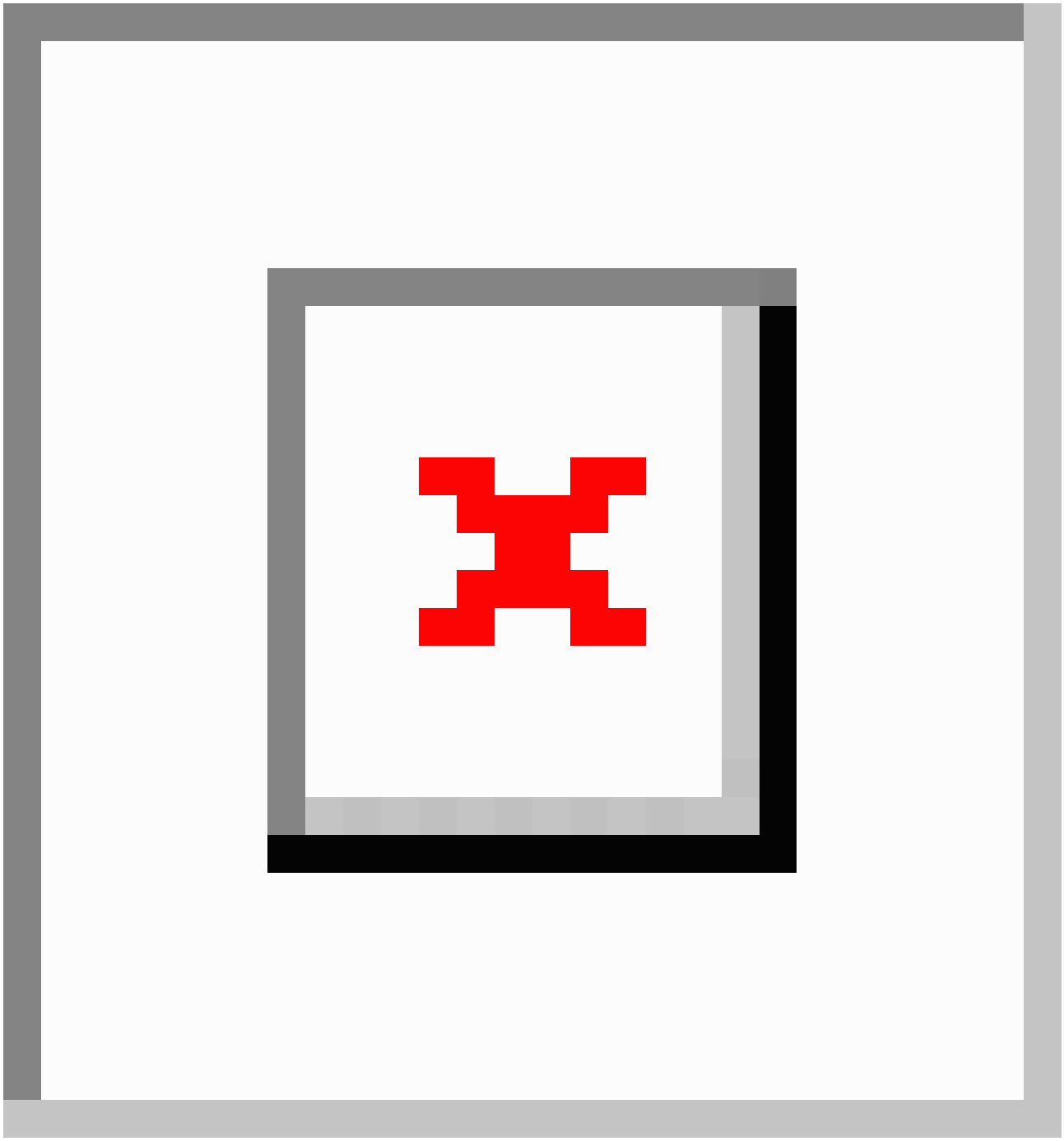
Figure 1. Google analytics results for ConnectGPR logins over 26 weeks.



Step 7: Technology and Community

"Online CoPs should ensure ease of use and access, along with asynchronous communication. Other options including chat and meetings can also be considered, along with the need for training. Communities are more likely to share knowledge when there is a mixture of online and face-to-face meetings, members self-select, and both passive and active users are encouraged" [14].

While all GPT1s were offered enrolment, enrolment was voluntary, thereby allowing self-selection. The initial launch and some follow-up occurred face-to face, but the remainder of the interactions were online.

In the pre-intervention survey, there was no significant difference in GPT1s' mean responses in terms of preferring to build trust online or through face-to-face interactions (sig=0.46). However, in the post-intervention survey, participants on ConnectGPR indicated they primarily built their trust through online interactions (see Table 3).

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Table 3. ConnectGPR GPT1 preferences for building trust with other users.

	Disagree, n (%)	Neither, n (%)	Agree, n (%)
Online interactions with members	0 (0)	4 (28.6)	10 (71.4)
Through prior knowledge of the members	2 (14.3)	3 (21.4)	9 (64.3)
Face-to-face meetings	1 (7.1)	5 (35.7)	8 (57.1)

In terms of the Web tools that were offered, GPT1s found document sharing (11/13, 84.6%) and discussions (10/13, 76.9%) the most useful; however, the majority of participants found all items useful.

Finally, GPT1s mostly felt that adequate training was provided (10/13, 76.9%) and that the site was easy to use (11/13, 84.6%).

In the interviews, GPT1s rated forums, resource sharing, and photos of skin lesions the most useful. One GPT1 believed that GPT1s needed more training on skin lesions thus the photo section helped provide insights, while another found the forum format helpful "because you're getting first-hand information from the very experienced medical supervisor, medical educators" [GPT8].

While a small group used the webchats regularly, "I attend every week" (GPT1), most users commented that the webchat had barriers related to data entry and typing speed. However, participants found that email links in newsletter reminders were a useful reminder and easy to use: "it comes to my personal email and it's easy to click" [GPT18].

GPT1s interacted differently during the course of the study. Some used the live webchat or posted on the forum, while others found benefit from passive interaction as well, even if they did not have time to take part in the interaction. One GPT1 commented that she did not always have time during the day, but "but when I would go back and read all the things that had been discussed, it was very helpful" [GPT19]. This flexible approach with a range of options was important in engaging a range of users. The majority of GPT1s also placed a high value on the day release workshops, reinforcing that while online tools are useful, they work with, rather than replace, face-to-face opportunities.

A number of barriers mentioned by interviewees included comments about technology, most often about the webchat facility, which was seen as slow and reliant on fast typing. Participants indicated that additional training may have helped some of the presenters who were unfamiliar with the technology and of what was expected of them.

However, the barrier mentioned by almost all participants was time. This included allocating time, as well as finding a time slot that suited everyone, as it competed with personal time, "I've got to use that hour for myself" [GPT3] and patient contact time, "If you make it the evening, by 6 o'clock we have to go to the hospital and see the patient" [GPT18].

Several GPT1s and a medical educator commented that more users would make the community more useful. This included the comment that with few active participants, there is less activity:

> *I think there we're only a fixed number of people, active participants (on ConnectGPR). I don't know if it's again lack of time or lack of interest. With the nature of the programs it's very useful, but unless someone shows an interest and participates then that person can't get a real taste of it because to start with there are less participants there.* [GPT8]

One educator also questioned the value of expending educator effort on a webchat if only a small number of GPT1s participated. One suggestion for improving the uptake was by having webinars to overcome the webchat barriers:

> *I think it would need to grow numbers-wise and I think the format needs to change…a webinar would be ideal because you've got the option to speak as well as type and then you've got the option for some visual capacity there as well* [GP Educator]

GPT1s found a range of social media tools on the site useful but suggested that webinars rather than chat would be desirable in future studies. Time is a common barrier to usage, but a larger user base and more training may help uptake. Finally, while theoretically trust is built better with a mixture of online and face-to-face meetings, trust can be built primarily online, which may have benefit for GPT1s that cannot attend face-to-face workshops.

Usefulness of a VCoP for GP Training

Overview

ConnectGPR was set up using the 7-step framework for VCoPs. The previous section described the usefulness of the framework in implementing a VCoP. The following section discusses the usefulness of the VCoP for GP training. It focuses on ConnectGPR's two goals of knowledge sharing and overcoming professional isolation.

Goal 1: Knowledge Sharing

ConnectGPR had 28 enrolments (28/34, 82%). During the 26-week study period, knowledge was shared via webchats, forums, photo postings, videos, and shared resources. The site averaged 38 unique visitors each week. Visitors were measured by a login from a unique computer or device IDs rather than by a unique user login, so actual users per week was likely lower. There was an average of 4.4 page views per visit and a total of 4377 page views. Page views were recorded as a single view of that page by a user, but a single user could generate multiple views by revisiting the page.

Discussions took place around the clinical and practical topics in the GPT1 curriculum, including discussions related to interpretation of guidelines and the cultural context of medical care. This review of the cultural context of medical care occurred

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particularly with overseas-trained doctors during the webchats, giving these trainees the opportunity to discuss how their medical knowledge can be applied in the Australian setting.

There were 18 webchats over the 26-week intervention (see Table 4). Full text logs of these were produced from the webchat software and posted onto the forums. There were between 1 and 5 GPT1 attendees per week (mean 3), and 1 and 4 moderators (mean 2).

Table 4. Use of different aspects of ConnectGPR.

	Number	Replies		Views	
	n	n	mean (range)	n	mean (range)
Forums: 16 categories	58	79	1.4 (0-12)	1085	18.4 (4-67)
Content resources	19			177	9.8
Videos (humorous)	4			58	13
Photos	8			123	13.7
Webchats	18				

A number of GPT1s benefited from discussions via webchat. In the webchat logs, one GPT1 started the diabetes lifestyle modification discussion with: “This is my daily nightmare” but finished with “I will try this” [GPT10]. Another GPT1 noted the usefulness of webchats, despite the challenge of finding time, by saying, “Time is a question (always), but what better option have we than this (the webchats)?” [GPT1].

Photos of skin conditions were a popular trigger for using the site, gaining high views and multiple comments. The most popular item was a photo of erythema multiforme, with 68 views and 2 comments. Another topic with significant interactivity was a pediatrician hosting “Ask an Expert” with 67 views and 12 comments.

One of the forum topics on the site asked for feedback on the value of the site itself and whether it should continue. The posts were all positive, with the most comprehensive one providing good insight into the value of an online community in improving knowledge sharing, overcoming isolation, and providing support:

> *I think it should continue. It allows us to know what other trainees are doing, so that we learn from each other and from our educators. It makes me feel connected to my peers, not isolated in one practice. The links are very useful. It makes me feel supported if I have any questions or difficult cases, I know I will always get a reply from someone.* [GPT9]

In the post-implementation survey, intervention GPT1s responded that they interacted with ConnectGPR, including reading the newsletter, most commonly once or twice a week, followed by twice a month, and less than monthly (see Figure 2). Site usage statistics at the end of the implementation were similar, showing that of the 28 GPT1s, 6 (21.4%) had logged in during the last week, 5 within the past 2 weeks (17.9%), 3 within the past month (10.7%), 6 within the past 2 months (21.4%), 3 within the past 3 months (10.7%), and 5 had not logged for more than 3 months.

In the post-implementation interviews, most participants commented on the benefits of knowledge sharing using ConnectGPR. These included comments on the benefit of sharing knowledge and getting feedback from colleagues, supervisors, and experts. One GPT1 commented that if they had any difficult cases, “We usually put [it] in (ConnectGPR) and then usually the educators give us the feedback answer” [GPT8]. Another noted that feedback was important as “When you get the feedback, you’ll improve your knowledge and skill so in that sense I found ConnectGPR one of the interesting websites” [GPT1].

One interviewee did not use the site but instead described a functioning community of practice, with a range of learners providing views on a topic, within his own practice “[There is a] range of people in the practice so I do get different viewpoints about issues” [GPT3]. Another GPT1 also had excellent in-practice support but acknowledged the benefits of other avenues of support, including other GPT1s and “also through the website (ConnectGPR)” [GPT11].

To investigate which topics were perceived to be most important and whether “knowing” and “implementing” were perceived as different, supervisors and GPT1s were asked in the pre-implementation survey about their perceptions of how much GPT1s needed help knowing, or implementing, the 15 GP-Start medical topics (Multimedia Appendix 2). There was no difference between GPT1s and supervisors in their mean scores for “need for knowledge” or “need for implementation” across 15 topics. There was only one significant difference in ranking between the groups for specific topics. GPT1s rated the need for cardiovascular knowledge more highly than supervisors ($t_{35.4}$=2.054, sig 0.047, mean difference 0.523, CI 0.0064-1.04). Of the five highest ranked topics for both groups, four contained significant “practice” as opposed to pure “knowledge” components, namely work injury consultations, administration, consultation management, and fitness to drive.

There was also no significant difference between the mean score for all “knowledge” questions pre- and post implementation for registrars.

GPT1s found ConnectGPR useful for knowledge sharing, but there was no measurable difference on total knowledge scores. Photos, forums, and webchats all provided benefit and the knowledge that someone would respond to a query was important. Support around practical rather than pure medical topics was identified as a learning need for trainees.

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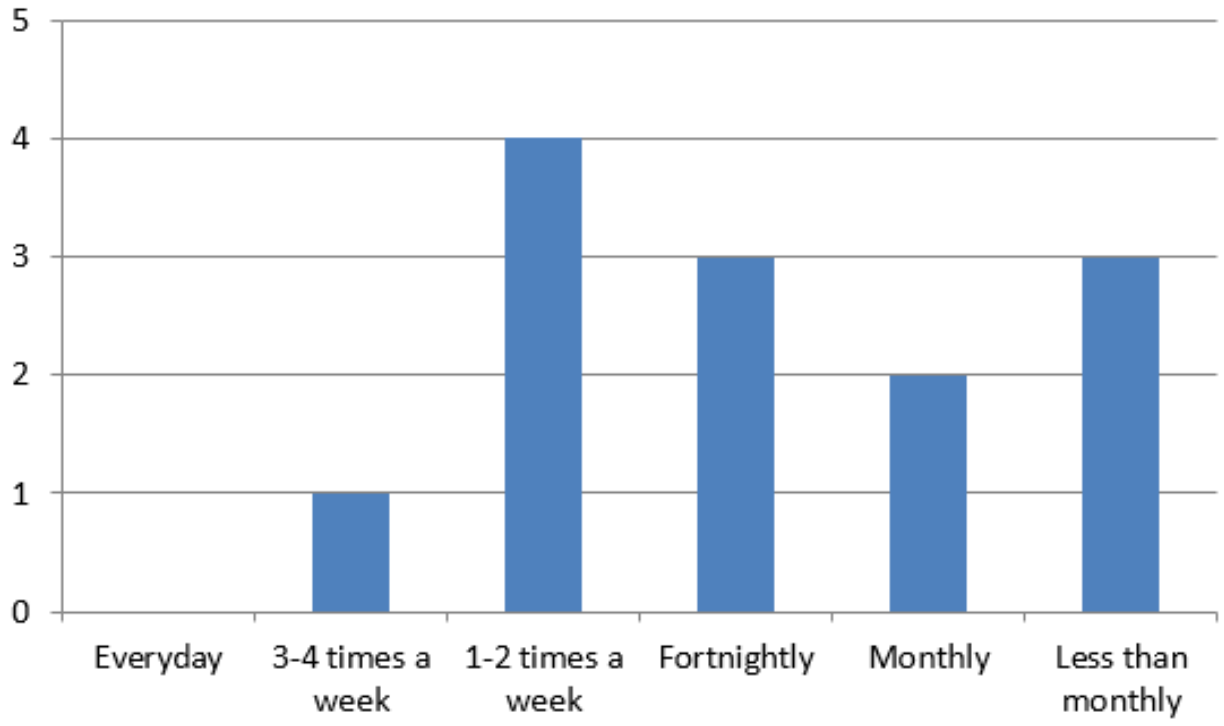
Figure 2. Frequency of use of ConnectGPR.



Goal 2: Overcoming Isolation/Providing Support

To assess the need for support, GPT1s were asked about isolation pre-implementation and post-implementation. On the modified UCLA Loneliness scale [19], there were no differences pre- or post-implementation within or between the implementation and non-implementation GPT1 groups. However, when asked about the practical outcomes for them of using ConnectGPR, nearly all respondents reported that they felt more supported in their general practice (13/14, 92.9%)—an indication that professional isolation may have been reduced through ConnectGPR (see Table 5).

Table 5. Practical outcomes of ConnectGPR for post-pilot intervention GPT1s.

Outcome	Disagree, n (%)	Neither, n (%)	Agree, n (%)
Feel more supported in general practice	0 (0)	1 (7.1)	13 (92.9)
Learn from colleagues how to put guidelines into practice	0 (0)	3 (21.4)	11 (78.6)
Develop a broader network of colleagues	0 (0)	3 (21.4)	11 (78.6)
Feel more connected with my colleagues	0 (0)	3 (21.4)	11 (78.6)
More confident in medical skills	0 (0)	5 (35.7)	9 (64.3)

In the post-implementation interviews, a number of GPT1s mentioned isolation, though not all experienced it. Structural, social, and professional isolation were all mentioned during the interviews. Structural isolation was noted: “being a GP is a lot more isolating I guess than working in the hospital system and that was something I really realized” [GPT11]. Structural isolation is due to the nature of general practice, for example, “The fact that you’re not on a team” [GPT11]. In general practice, practitioners often work asynchronously, with a single patient in front of them and when they exit their room they often find that their colleague’s door is closed. One GPT1 commented on this as a trigger for loneliness: “When you start in general practice you’re quite isolated, even from the people in your own practice because you can get quite busy and you can get almost, sometimes I almost feel like you feel lonely because you’ve got to see the next patient and the next patient” [GPT3].

Social isolation can be described as a kind of loneliness [4] and in the case of this GPT1, the isolation was overcome not by having more professional support, but by finding opportunities to socialize. “(You need to) get out and talk to your colleagues or have lunch with a friend because it can feel pretty insular at the end of the day” [GPT3]. Another felt that, despite an excellent clinical rural experience, it was socially isolating because “There’s no kind of more middle class around my age so that was a bit different…” [GPT11].

Professional isolation is also associated with a lack of professional networking and knowledge sharing opportunities. Although it is more commonly associated with rural terms, it

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can be found in any practice in which the interaction with colleagues is limited. One doctor was more isolated in her second term, which was urban, than her country term. “If I started my training in this particular practice I would probably hate the GP role. Because today it’s only me in the whole building” [GPT9].

In terms of protective factors for isolation, several GPT1s noted that while GP training is isolating at times, the online network provided support. One GPT1 found the weekly chat particularly supportive and felt that it helped him overcome any isolation. “I found this ConnectGPR every Wednesday (and) GP training professionally is a bit challenging because you are totally isolated. If you have this facility like weekly chat or weekly seminar, communication, so you can overcome that isolation” [GPT1].

Several GPT1s commented on the benefits of sharing knowledge in overcoming isolation and building connectedness. One GPT1 described seeing a photo that another GPT1 had posted, seeing the same thing and using the lessons learned online to assist in a consultation, which in turn reduced isolation. “They would post some pictures and you might see something similar 2 days later and you say, ‘OK we talked, other people suggested we do this about those things, maybe I should do those things’. In that way it was good to connect and you don’t feel as isolated in your rooms” [GPT19]. Another GPT1 noted that in such a big training region, it is harder to physically meet on a regular basis, but the Internet can facilitate regular communication. “(Regarding ConnectGPR)…physically we are quite isolated from each other because CCCGPT covers such a big area so we can’t really see each other every day, but I think we can communicate still if we want on the Internet” [GPT12].

Trainees commonly described aspects of isolation during their training. ConnectGPR helped trainees feel more connected by using technology to overcome some of the barriers to knowledge sharing.

Discussion

Principal Findings

Overall, ConnectGPR was judged to be useful by those who tried it. We also found that the 7-step framework for implementation of an online community [14] was appropriate and facilitated the implementation and evaluation of the intervention. Data from the survey and the discussion forum indicated that ConnectGPR was useful for knowledge sharing and providing support to GPT1s who used it. However, there was no difference between the implementation and non-implementation groups on the modified UCLA Loneliness scale [19]. Given the positive feedback from interviews, usage, and the survey, it is possible that the modified UCLA Loneliness scale [19] was not an appropriate tool. In particular, the words loneliness and isolation may be pejorative; thus future surveys should consider focusing more on the concepts of connectedness and support. This contradiction of findings was most obvious in the interview data in which several GPT1s denied any isolation or loneliness initially but then went on to describe the isolation that they had experienced. Another explanation of these results is that while there was a group of users that found ConnectGPR useful, the group was over-represented in the interviews and the impact on the overall group may have been limited. Only 50% of participants on ConnectGPR used the site more than monthly, and it could be argued that higher usage should correlate with higher connectedness. Yet one of the interviewees who was an intermittent user was one of the most supportive of the site. Larger studies need to examine any actual effect sizes.

The isolation experienced by a number of intervention GPT1s supports previous findings about structural, social, and geographic isolation. The isolation may be transitory or mild in some cases, but in other cases it can affect decisions about rural versus urban work [1]. This was described well by one GPT1 who, despite an excellent rural clinical term, felt much happier and more confident once she returned to her urban environment. In other cases, despite good clinical and social structures, GPT1s still experienced the structural isolation that comes with the general practice environment of closed consultations with a single patient and doctor. These findings suggest that more needs to be done to understand the severity and prevalence of these experiences, and how they can be addressed for both trainees and general practitioners, as a happier and more connected workforce is more likely to attract and retain graduates, especially in rural areas.

Limitations

There are several limitations to this study. Concerning the technology choice and educational outcomes, Ning was a simple and easy-to-use online community platform; however, this simplicity had a number of limitations in terms of evaluating the learning impact. These included limited reporting, no built-in educational tools such as pre- and post-assessment, and limited learner engagement tools such as page prediction. Further intervention studies could engage more rigorous learning evaluation tools into their communities. In addition, while some knowledge sharing took place, actual changes in competency were not assessed. Larger experimental trials are needed to demonstrate this. Another limitation is that, as noted, active users were over-represented in the interview section, which could over-represent positive responses. Although one passive user was interviewed, there was no response to requests for interviews from other passive users. In addition, while some outcome data were collected, such as isolation and knowledge scores pre- and post-implementation, none of the changes were significant. This may be due to survey design limitations or small numbers, or problems with the implementation itself. Larger experimental trials are needed. Other limitations that may affect the external validity are that this is a single case study of an implementation or a VCoP in regional Australia and that two of the authors were facilitators of the study.

Conclusions

Overcoming isolation and improving connectedness through an online knowledge sharing community shows promise in GP training [12,13]. Intervention GPT1s described a good experience with forums, document and photo sharing, newsletters, and chats. However, there were barriers to usage. First, a number of participants described problems with using

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chats as a method of communication. Despite this, the users of chats rated the overall experience positively, and the feedback about the site as a whole was that it was easy to use. In response to this, it is suggested that webinars would be a more appropriate tool in the future.

The second barrier to usage was time. This is in keeping with the feedback from exploratory studies on intention to use [12,13] and in keeping with other studies on information technology usage [20]. Previous studies have described users overcoming barriers if perceived usefulness was high; a number of participants in this case study demonstrated this by using the site despite having concerns [11,20]. This reinforces the importance of the value of the content and experience delivered in a VCoP.

Another positive feature of the online community was the trust that was built among participants. Previous studies and the responses of the control GPT1 group supported the concept that trust can be built through a mixture of face-to-face and online training [14,15]. In this study, the face-to-face workshops were highly valued in their own right. However, the trust between participants was largely built online. This provides some evidence that while face-to-face workshops are a valuable experience, online knowledge sharing and trust building can occur regardless of whether participants are connecting face-to-face. This has implications for the delivery of course material, particularly in regional areas, and supports improved virtual workshop interaction, for example by webinars.

Knowledge sharing is also most effective where there is a knowledge gradient among a range of users. This case study noted that the user base could be broader, including more trainees, supervisors, specialists, and even allied health professionals, along with a larger number of participants overall. Two further aspects of knowledge sharing were noted in this case study, which together have implications for training delivery. First, there was a mismatch between GPT1 and trainer perceptions of knowledge topics, for example, cardiovascular medicine, in which supervisors underrated the support that GPT1s felt they needed. However, there was agreement between the groups that more “practice-based” topics, such as administration and work-injury management, needed more attention during the training program. Second, while medical knowledge sharing was the goal of the site, at least one overseas trained doctor commented on the value of the cultural interpretation that came through during discussions. Taken together, these results show a need for greater alignment of expectation and curriculum between GPT1s and supervisors. These findings also support the notion of “masters and apprentices” sharing the practice of medicine, which is the premise of a CoP, whereby apprentices are helped to understand the finer details inherent in the administrative side of medicine in a busy clinical practice. Last, these VCoPs may have specific advantages for assisting overseas-trained doctors as they interpret their medical knowledge in an Australian context.

Acknowledgments

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Conflicts of Interest

Dr Stephen Barnett is the Medical Director of an online community for Australian doctors (eHealthspace).

Multimedia Appendix 1

GP training region map.

[PDF File (Adobe PDF File), 309KB - jmir_v16i3e83_app1.pdf]

Multimedia Appendix 2

Knowledge and implementation needs of GPT1s, ranked by GPT1s and supervisors.

[PDF File (Adobe PDF File), 36KB - jmir_v16i3e83_app2.pdf]

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Abbreviations

ConnectGPR: Coastcitycountry Online Network for an Educational Community of Training for GP Registrars
COP: community of practice
GP: general practitioner
GPT1: general practice trainee, term 1
VCoP: virtual community of practice

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Original Paper

Internet-Based Cognitive Behavioral Therapy for Patients With Chronic Somatic Conditions: A Meta-Analytic Review

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Abstract

Background: Patients with chronic somatic conditions face unique challenges accessing mental health care outside of their homes due to symptoms and physical limitations. Internet-based cognitive behavioral therapy (ICBT) has shown to be effective for various psychological conditions. The increasing number of recent trials need to be systematically evaluated and quantitatively analyzed to determine whether ICBT is also effective for chronic somatic conditions and to gain insight into the types of problems that could be targeted.

Objective: Our goal was to describe and evaluate the effectiveness of guided ICBT interventions for chronic somatic conditions on general psychological outcomes, disease-related physical outcomes, and disease-related impact on daily life outcomes. The role of treatment length was also examined.

Methods: PubMed, PsycINFO, and Embase were searched from inception until February 2012, by combining search terms indicative of effect studies, Internet, and cognitive behavioral therapy. Studies were included if they fulfilled the following six criteria: (1) randomized controlled trial, (2) Internet-based interventions, (3) based on cognitive behavioral therapy, (4) therapist-guided, (5) adult (≥18 years old) patients with an existing chronic somatic condition, and (6) published in English. 23 randomized controlled trials of guided ICBT were selected by 2 independent raters after reviewing 4848 abstracts. Demographic, clinical, and methodological variables were extracted. Standardized mean differences were calculated between intervention and control conditions for each outcome and pooled using random effects models when appropriate.

Results: Guided ICBT was shown to improve all outcome categories with small effect sizes for generic psychological outcomes (effect size range 0.17-0.21) and occasionally larger effects for disease-specific physical outcomes (effect size range 0.07 to 1.19) and disease-related impact outcomes (effect size range 0.17-1.11). Interventions with a longer treatment duration (>6 weeks) led to more consistent effects on depression.

Conclusions: Guided ICBT appears to be a promising and effective treatment for chronic somatic conditions to improve psychological and physical functioning and disease-related impact. The most consistent improvements were found for disease-specific outcomes, which supports the possible relevance of tailoring interventions to specific patient groups. Explorative analyses revealed that longer treatment length holds the promise of larger treatment effects for the specific outcome of depression. While the current meta-analysis focused on several chronic somatic conditions, future meta-analyses for separate chronic somatic conditions can further consolidate these results, also in terms of cost-effectiveness.

(J Med Internet Res 2014;16(3):e88) doi:10.2196/jmir.2777

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KEYWORDS

eHealth; internet; intervention; self-management; cognitive behavior therapy; meta-analysis

Introduction

Cognitive behavioral therapy (CBT) focuses on challenging cognitive distortions and dysfunctional underlying beliefs, and on teaching coping and problem solving skills [1]. A variety of techniques are combined to achieve this, including cognitive restructuring, relaxation, problem solving, and stress management. The central idea of CBT is that the way people make sense of their environment affects their feelings and behavior. CBT is an extensively researched and widely used form of treatment for a variety of psychological conditions [1] and is increasingly used to help a growing number of patients suffering from chronic somatic conditions cope with the consequences of their condition [1-5]. CBT models can, for instance, be applied to improve patients' adjustment to receiving a diagnosis of a chronic somatic condition and coping with it, to improve comorbid mood problems such as anxiety and depression, to alter disease-specific beliefs and attitudes, and to teach pain/symptom management strategies [6,7].

Although studies indicate that CBT may be an effective treatment for chronic somatic conditions, it has not been implemented on a large scale, partly due to the lack of CBT therapists specializing in patients with chronic somatic conditions. Furthermore, chronically ill patients may have physical limitations that make it difficult to travel to a clinic for face-to-face CBT. A possible solution is to offer CBT online: Internet-based cognitive behavioral therapy (ICBT). Generally, ICBT takes the form of an online self-help program, guided by a therapist who gives feedback and answers questions [8]. Advantages of ICBT over offline computerized CBT and over bibliotherapy include the possibility of the patient connecting with a therapist or with peers who cope with similar problems, and the ability to log on and use the intervention anytime and anywhere they would like. ICBT may be beneficial to both patients and therapists: it is more convenient, flexible, and reduces traveling time, costs, and waiting lists, enabling more patients to be reached and treated [9]. In addition, providing CBT online may reduce the stigma of needing psychological help. Recently, first indications have been reported for the cost-effectiveness of ICBT [10-12].

Internet interventions are generally found to be effective for a variety of psychological conditions [13-16]. Preliminary evidence is also emerging for its effect on psychological and physical outcomes in various health problems [17-21] and in promoting health behavior change [22,23]. In order to determine whether ICBT is effective for chronic somatic conditions, the results of the increasing number of recent randomized controlled trials (RCTs) need to be systematically evaluated and quantitatively analyzed. Moreover, knowledge of which types of outcomes are specifically improved by ICBT will provide insight into the types of problems that could be targeted with ICBT.

An additional focus on which elements of interventions are effective for which patients at what disease stage will aid development of effective tailored interventions. Scarce evidence suggests that the amount of therapist contact is related to effectiveness [16]. An aspect of ICBT that has not been examined is whether the duration of ICBT influences treatment outcomes. For traditional face-to-face CBT for chronic somatic conditions, an average treatment of 12-16 sessions given once a week is suggested [24]. Although there are indications in patients with depressive symptoms that a longer ICBT treatment duration yields better outcomes [25], the role of treatment duration has not yet been examined for chronic somatic conditions.

The current review aims to describe and evaluate the effectiveness of guided ICBT interventions in randomized controlled trials, for three specific outcome categories—general psychological outcomes, disease-related physical outcomes, and disease-related impact outcomes—and to explore the role of treatment duration. The review focused on guided ICBT interventions, in order to optimize comparability with face-to-face CBT and decrease heterogeneity, as it is known that guided ICBT interventions generally lead to different (larger) effects than non-guided self-help interventions [16]. This review has a broad focus, including a large population of chronic somatic conditions. Because the literature on ICBT in different chronic somatic conditions is rather limited at this time, it is not yet possible to meaningfully summarize the evidence for efficacy of ICBT for these separate categories of chronic somatic conditions. Because the main elements of CBT are generic in scope and can be applied to a large variety of problems, combining these different chronic somatic conditions in this meta-analysis provides a first overall indication of the efficacy of ICBT interventions in the large population of chronic somatic conditions. In addition, the separate outcomes for different somatic conditions can also be deduced from the paper.

Methods

Search Strategy and Inclusion Criteria

PubMed, PsycINFO, and Embase were searched from inception until February 2012, by combining index terms indicative of effect studies, Internet, and cognitive behavior therapy, and including the following Medical Subject Heading (MeSH) terms: Internet, electronic mail, behavior therapy, psychotherapy, rehabilitation, counseling, and self-care (see Multimedia Appendix 1 for search strategies). Only studies investigating guided ICBT, which is comparable to face-to-face CBT, were included. All retrieved references were loaded into Endnote, and 2 raters (SvB, MSc Psychology, HvM, PhD Psychology) independently screened titles and abstracts without blinding to authorship or journal. The full text of potentially relevant studies was examined. Discrepancies between reviewers were resolved by discussion. The kappa statistic was calculated to determine consistency among raters. Inclusion criteria were (1) RCT or equivalence trial, (2) therapy provided with the Internet (not face-to-face, telephone, onsite computerized therapy, videoconferencing, or personal digital assistants) as the main

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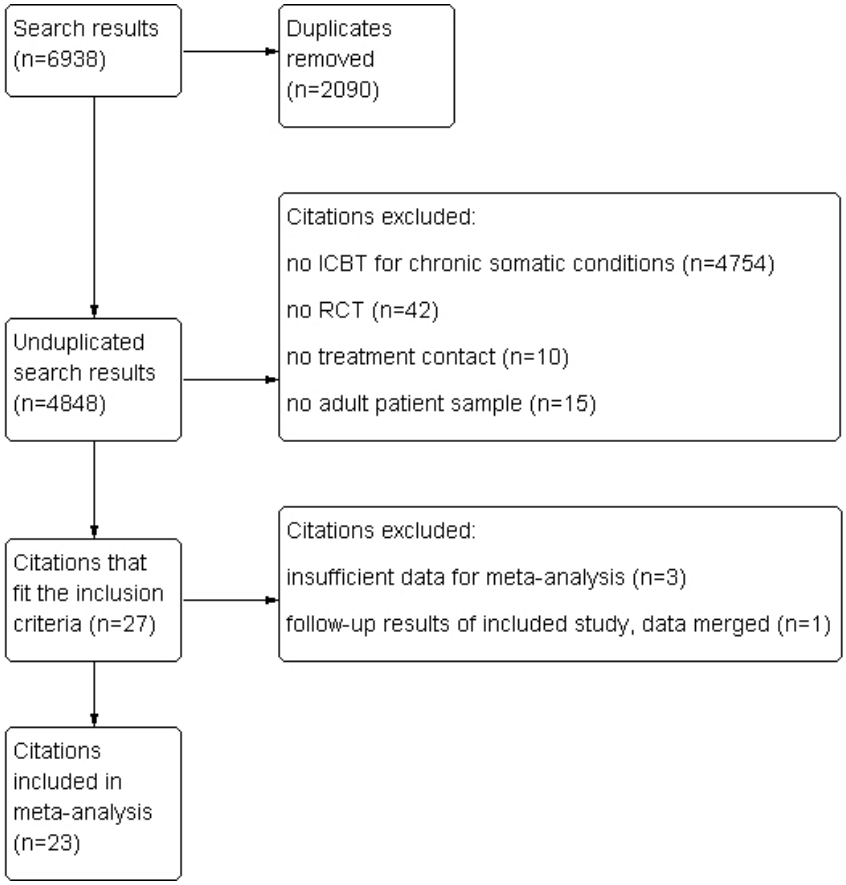
way of communication (eg, patient spends >50% of total intervention time spent on an Internet-based intervention), (3) therapy based on CBT principles (in which at least some forms of cognitive and behavioral techniques are used), (4) therapy guided by contact with a therapist, with at least one episode of personalized patient contact (either through asynchronous messages, telephone, or another mode of contact), and (5) adult study sample (age ≥18 years) with an existing chronic somatic condition (ie, a condition expected to last a year or longer, limit what a patient can do, and/or may require ongoing medical care) [26]. Etiology was not an inclusion criterion; both functional and structural disorders were included. Conditions that may have physical consequences but do not have physical illness as its primary feature, such as eating disorders, insomnia, addiction problems, fertility problems, and sexual dysfunction, were also excluded. Papers not published in English were also excluded. Studies were excluded when the main focus of the intervention was focused on lifestyle change, such as increasing levels of exercise or improving diet. Publications of the same intervention were included if each study was based on a new patient sample. Papers were excluded based on a hierarchical approach, in which articles were not further assessed for remaining reasons if they were excluded based on a previous reason. The hierarchy of reasons for exclusion were that (1) the study does not examine ICBT for chronic somatic conditions, (2) the study is not an RCT, (3) the ICBT intervention is not guided by a therapist, and (4) the study does not examine adult patient populations (see Figure 1).

Figure 1. PRISMA flow diagram of study selection.



Data Extraction

The following information was gathered per study: publication year, chronic somatic condition, country of data collection, number of patients included, completers, dropouts, dropout reasons, age, gender, type of CBT intervention, therapist contact, control condition, outcome measures, intervention length, completer or intent-to-treat analyses, post-treatment results, and follow-up results. A large variety of outcome measures were reported across studies. To enable general conclusions, these were grouped together into three main outcome categories that are of relevance to patients with chronic somatic conditions: (1) general psychological outcomes of depression, anxiety, and distress, (2) disease-related physical outcomes related to symptom severity, such as pain, fatigue, and headache, and (3) disease-related outcomes concerning the impact of a chronic somatic condition on daily life (ie, disease-specific distress and disease-specific quality of life) (see Multimedia Appendix 2). To improve homogeneity and narrow the scope of the review, outcome measures that did not fit these categories (eg, coping or behavior) or that were not suitable for pooling in meta-analysis (ie, because of being assessed infrequently (eg, general quality of life) or by means of different measures (eg, disability) were excluded. When more than one outcome was used to measure the same construct, results for the outcome that was most generic (eg, total scale score versus subscale scores), most validated (eg, Beck Depression Inventory (BDI [27]) versus Modified Beck Depression Inventory (mBDI [28]), or most comparable to other studies (eg, visual analogue scale [VAS] of distress versus therapist-rated distress) was used, to

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prevent separate studies having too much influence on the analysis.

Assessment of Risk of Bias in Included Studies

Two independent authors (SvB, MSc Psychology, MF, MSc Psychology) assessed each study using the Cochrane risk of bias tool, including selection bias (randomization process), performance bias (blinding of subjects and personnel), detection bias (blinding of outcome assessment), reporting bias (handling of missing data), and attrition bias (reasons for withdrawal in all conditions) [29]. A third rater (MR, professor of evidence-based surgery) was consulted to reach consensus when 2 raters were in disagreement. Risk of bias was assessed based on the information of original publications and on trial registrations on the ClinicalTrials website.

Reporting Study Results

Only between-group results were taken into account to examine the effect of ICBT as compared to a passive control condition. Passive control conditions were defined as conditions in which participants do not receive a therapeutic program and instead are placed on a waiting list, or receive only treatment as usual or treatment that is theorized to not lead to changes in therapeutic outcomes (eg, patient education) (see Multimedia Appendix 2). For equivalence trials, in which patients receive an intervention that is theorized to lead to clinically relevant changes in outcomes as an active comparison condition, and for studies with a three-arm design, both between-group effects and main effects are reported (see Multimedia Appendices 3 and 4). Intent-to-treat analyses (ITT), in which all randomized patients are analyzed regardless of adherence to study protocol [30], were used wherever possible. When two active ICBT interventions were compared to a passive control condition in a three-arm RCT design, both comparisons are reported. Two types of dropout rates were calculated: (1) intervention dropouts by dividing the number of patients reported to have stopped the intervention (or did not return post-intervention questionnaires) by the number randomized to the intervention group, and (2) measurement dropouts by dividing the number of patients from both the intervention and control groups who did not return post-intervention questionnaires by the total number of patients randomized. As between-group follow-up results were not consistently and uniformly reported across studies, pooling was not feasible. Therefore, only post-intervention study results are reported and the number of studies that included follow-up results are briefly summarized.

Data Analyses and Synthesis

Standardized mean difference of effect sizes (SMDs) were calculated by subtracting the difference in means in the ICBT group from the difference in means in the control group and dividing the outcome by their pooled standard deviation [31]. Effect sizes of 0.2, 0.5, and 0.8 can be considered as small, moderate, and large, respectively [32]. When a study contained multiple eligible ICBT treatment groups, these were combined in a single pairwise comparison, according to recommendations and calculation methods from the Cochrane handbook [29]. If mean values and SDs were not reported, authors were contacted to obtain original trial data. When not provided, alternative methods were used (ie, using reported mean change scores and associated SDs). To decide whether meta-analytic pooling of data was justified, we computed I^2, which describes the percentage of total variation between studies due to heterogeneity rather than chance [33]. An $I^2$of 25%, 50%, and 75% can tentatively be considered as low, moderate, and high heterogeneity, respectively [33]. High heterogeneity indicates that the effects are not the same for all studies and that there may be other variables that explain this heterogeneity. As significant heterogeneity is to be expected, SMDs were calculated in random effects models, using Cochrane Collaboration software Review Manager, version 5.1. These models assume that there is no one “true effect size”, but rather the effect sizes are sampled from a population of varying effect sizes [34]. Subgroup differences in intervention duration were analyzed using the chi-square test, with $P<.05$ indicating statistically significant differences.

Results

Search Results and Study Characteristics

The literature search identified 4848 unique studies, 23 of which met the inclusion criteria (see Figure 1) [35-57]. Interrater reliability of study selection was kappa=.805. The included studies involved 4340 subjects (2299 ICBT and 2041 control); 59% of subjects participated in three large studies by Lorig and colleagues [52-54].

In 74% (17/23) of studies, subjects were randomized to one of two conditions, 15 of which compared ICBT with a passive control condition: waiting-list (12 studies), care-as-usual (2 studies), and information-based psycho-education (1 study) (Multimedia Appendix 2). Three studies compared ICBT with an active CBT control condition: face-to-face group therapy, online stress management without CBT, and ICBT with added telephone contact (Multimedia Appendix 3). Five studies used a three-arm design, two of which reported results of the two joint intervention groups compared to a passive control condition (Multimedia Appendix 2), and three compared each of the three conditions (Multimedia Appendix 4).

A total of 70% (16/23) of studies were published between 2008 and 2011, and 52% (12/23) were carried out in Sweden. Eleven studies (48%) used intent-to-treat (ITT) analyses. The majority of these studies (6/11) used the last observation carried forward (LOCF) method, in which a participant’s missing values after dropout are replaced with the last available measurement [58]. Four of the 11 studies used mixed models approaches [59], and 1 used multiple imputation by chained equations [60]. 74% (17/23) included some form of follow-up assessment ranging from 1-18 months: 10 (43%) used a between-group follow-up and 7 (30%) included a within-group or completers-only follow-up, ranging from 2 months to 1 year. Dropout rates differed widely but were overall relatively high (median 18%, range 2-57%), particularly in the intervention groups (median 29%, range 1-72%) (Multimedia Appendix 2). Of the 5 studies that reported reasons for dropout, the most common reason mentioned was lack of time.

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Patient Populations

Patient populations included chronic pain (5/23 studies, 21%), headache or migraine (4/23 studies, 17%), tinnitus (4/23 studies, 17%), irritable bowel syndrome (IBS, 4/23 studies, 17%), diabetes (2/23 studies, 8%), breast cancer (1/23 studies, 4%), epilepsy (1/23 studies, 4%), fatigue in patients with chronic neurological disorders (1/23 studies, 4%), and a heterogeneous patient population (1/23 studies, 4%) (Multimedia Appendix 2). Twenty studies of 23 (87%) involved community-based samples. The mean age range of subjects within studies varied between 34 and 66 years; most studies included more female than male subjects.

Intervention Content and Duration

Interventions consisted of a variety of generic CBT-based techniques, often supplemented with specific approaches appropriate for the chronic condition under study. Interventions focusing on relaxation and psycho-education were included only when combined with other CBT techniques, that is, some form of cognitive reappraisal or restructuring [61]. Treatment content was categorized into well-known CBT elements such as cognitive therapy, behavioral therapy, applied relaxation, and psycho-education (see Multimedia Appendix 2). The vast majority of studies described the interventions as self-help programs with structured modules, which were typically completed in a rate of one module per week, with minimal therapist guidance. Interventions consisted of a variety of generic CBT-based techniques, often supplemented with specific approaches appropriate for the chronic condition under study. The most commonly mentioned intervention components were cognitive therapy techniques, (applied) relaxation, psycho-education, and improving coping skills. These components were mentioned in 74-100% of interventions. Stress management and behavioral therapy techniques were also mentioned in over half of included interventions. Other therapy components, incorporated in 26-35% of interventions, were problem solving techniques, mindfulness-based techniques, exposure, and physical exercise. The majority of interventions were labeled as CBT and/or self-management interventions, while some interventions were based on acceptance and commitment therapy (ACT) [46], exposure-based treatment in combination with mindfulness techniques [49-51], or mindfulness-based cognitive therapy (MBCT) [56].

Interventions were generally broad and multifaceted, targeting various aspects of chronic somatic conditions within one intervention (eg, comorbid mental health problems, coping with the chronic somatic condition, and reducing physical symptoms). Incidentally, studies indicated that there was a specific primary aim, for example, to reduce depressive symptoms [56-57], distress associated with the condition [35,37], or severity of the chronic somatic condition [41,43,50]. However, also in the interventions with a more specific aim, components were generally included to fit other aims as well. Therefore, it was not possible to meaningfully categorize interventions according to the intervention aim (eg, physical, mental, prevention). When analyzing the results, the SMDs in each meta-analysis did not meaningfully differ from one another, indicating that there are no differences in SMDs according to intervention aim.

Therapist Contact and Peer Contact

All studies incorporated treatment-related contact options, usually in the form of (weekly) email contact with (psychology master students supervised by) licensed clinical psychologists. One study was based solely on therapist-patient contact via email without additional treatment components. Most studies did not report, or not in detail, the average time therapists spent on patients. The main mode of therapist contact was through asynchronous (email) messages, but in 3 of 23 studies (13%) telephone was the main contact option. Five studies (22%) used online group formats. A total of 43% (10/23) of studies included a bulletin board that enabled patients to interact with each other, as an addition to individual treatment tools.

Risk of Bias in Included Studies

The authors' judgments about risk of bias for each included study and presented as percentages across all included studies can be found in Figures 2 and 3. While the majority of studies (14/23, 61%) reported adequate methods of randomization, 35% (8/23) of studies did not report randomization methods, and 4% (1/23) reported inadequate methods. The study with inadequate methods (eg, randomization based on order of enrollment [47]) was excluded from primary analyses, as a randomized design was one of the inclusion criteria for this study. To be complete, we also report the results including this study, in a secondary analysis. In 8 studies of the 23 (35%), allocation of participants was adequately concealed, while allocation concealment remained unclear in 10 of 23 studies (43%) and was at risk for inadequate concealment in 22% (5/23); for example, tossing a coin, picking a piece of paper, or throwing dice. None of the included studies reported blinding of participants, personnel, and outcome assessments, which led to an unclear risk of bias in 43% of studies (10/23; no information on blinding) or a high risk of bias in 57% of studies (13/23; information indicating that blinding did not take place). Over half of all studies had incomplete outcome data that led to a high risk of bias, which was mainly due to a lack of intent-to-treat analyses in 48% (11/23) of studies. The risk of selective reporting bias remained largely unclear, mainly because only 26% (6/23) were registered with the ClinicalTrials site and registration often took place after study completion.

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Figure 2. Risk of bias graph.

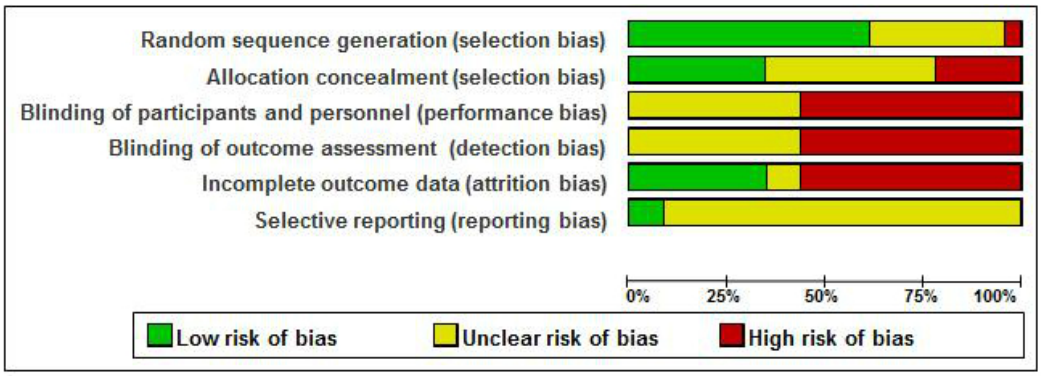
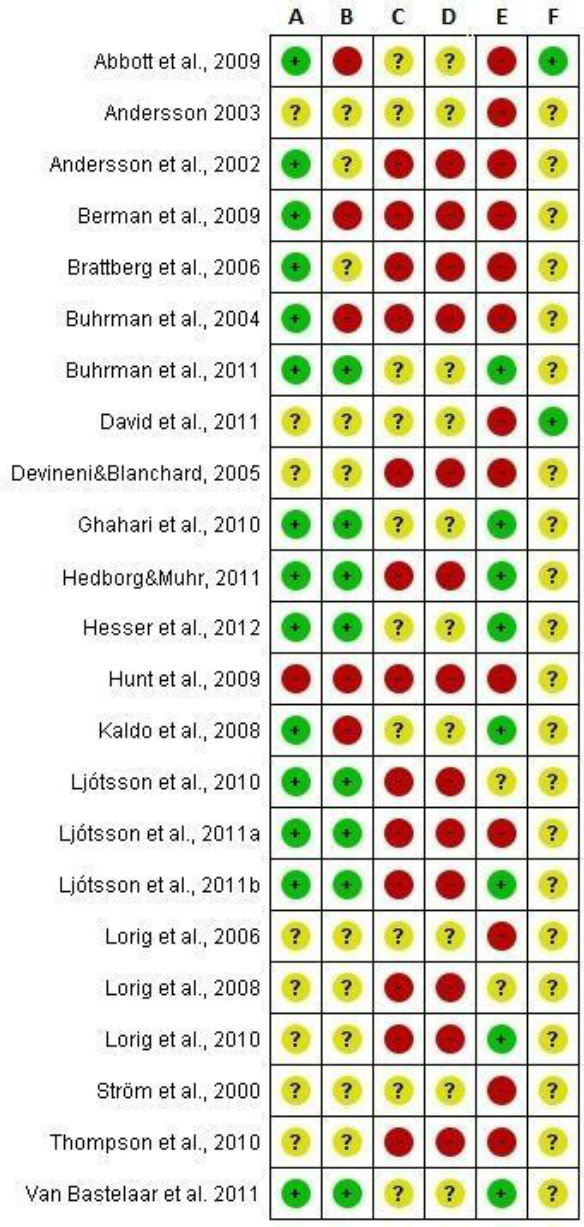


Figure 3. Risk of bias summary: review authors' judgements for each included study about each risk of bias item. A=Random sequence generation (selection bias); B=Allocation concealment (selection bias); C=Blinding of participants and personnel (performance bias); D=Blinding of outcome assessment (detection bias); E=Incomplete outcome data (attrition bias); F=Selective reporting (reporting bias).



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Effectiveness of ICBT Interventions

SMDs for the included outcomes are reported in Multimedia Appendix 2 for the 17 studies with a passive control condition, Multimedia Appendix 3 for the 3 studies with an active control condition, and Multimedia Appendix 4 for the 3 studies with a three-arm design. Pooled SMDs for the three outcome categories can be found in Table 1.

Table 1. Pooled SMDs for ICBT versus passive control conditions.

Outcome category	*k* [a]	SMD[b]	95% CI	*z*	*P*	I^2(%)
General psychological outcomes						
Depressive symptoms	15	0.21	0.08-0.34	3.18	.001	29
Anxious symptoms	10	0.17	0.01-0.32	2.14	.03	0
General distress	6	0.21	0.00-0.41	1.98	.05	0
Disease-related physical outcomes						
Irritable bowel syndrome (IBS) symptoms	2	1.19	0.82-1.57	6.25	<.001	0
Headache	3	0.49	0.21-0.77	3.41	<.001	0
Sleep quality	3	0.25	-0.02 to 0.53	1.80	.07	0
Pain	6	0.18	0.08-0.28	3.61	<.001	0
Fatigue	2	0.15	0.05-0.26	2.87	<.01	0
Tinnitus loudness	2	-0.04	-0.40 to 0.32	0.24	.81	0
Glycemic control	2	0.07	-0.17 to 0.30	0.54	.59	62
Disease-related impact outcomes						
Disease-specific quality of life	3	1.11	0.79-1.44	6.73	<.001	0
Disease-specific distress	6	0.17	0.03-0.31	2.41	.02	57

[a]*k*=number of comparisons.

[b]SMD=standardized mean difference.

General Psychological Outcomes

Sixteen of 17 studies comparing ICBT with a passive control condition included general psychological outcomes, 5 of which (31%) found greater improvements in the ICBT condition on at least one outcome (see Multimedia Appendices 2 and 4). ICBT had similar effects as active treatment control conditions (see Multimedia Appendices 3 and 4). Pooled SMDs for depressive symptoms, anxious symptoms, and general distress yielded small but generally statistically significant effects (see Table 1 and Figures 4 to 6). For depressive symptoms, results of a sensitivity analysis excluding one outlier with a very large effect on depression (SMD 4.34, [56]) are reported; if included, the SMD would be 0.32 (*k*=16, 95% CI 0.09-0.55, *P*=.005, I^2=78%).

Figure 4. Forest plot of standardized mean differences of the effect on depression of Internet-based cognitive behavioral therapy compared with a passive control condition.

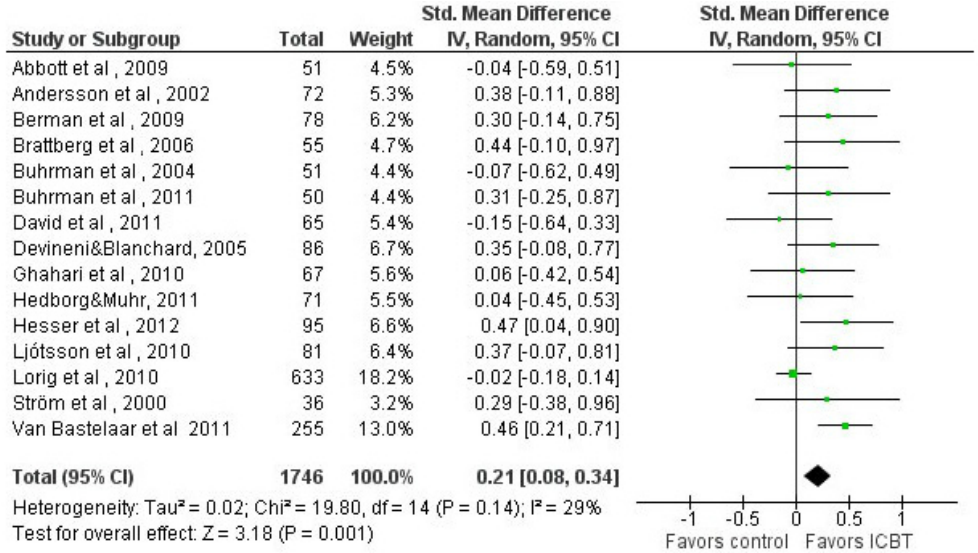

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Figure 5. Forest plot of standardized mean differences of the effect on anxiety of Internet-based cognitive behavioral therapy compared with a passive control condition.

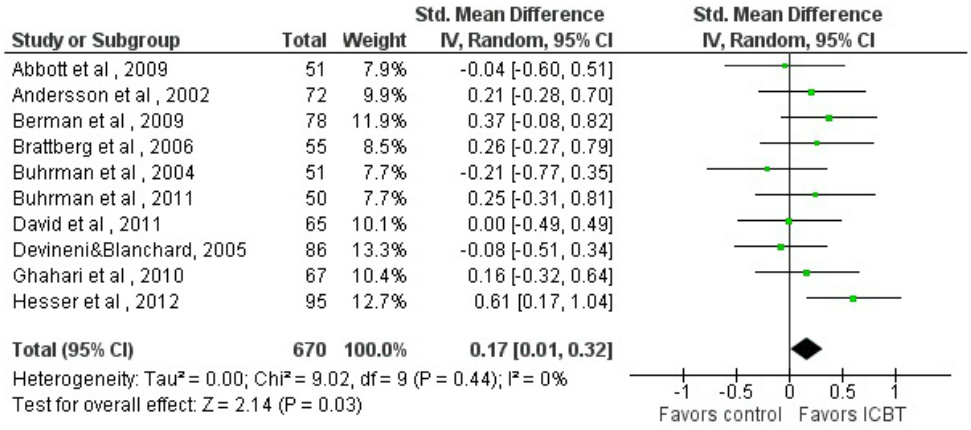
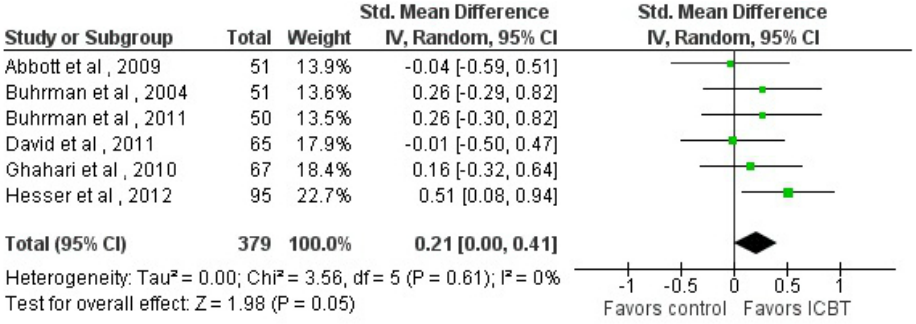


Figure 6. Forest plot of standardized mean differences of the effect on general distress of Internet-based cognitive behavioral therapy compared with a passive control condition.



Disease-Related Physical Outcomes

Seventeen studies comparing ICBT with a passive control condition included disease-related physical outcomes, with 59% (10/17) finding effects in favor of the ICBT condition on at least one outcome (see Multimedia Appendices 2 and 4). Pooled SMDs for physical outcomes yielded varying results. Large effects were found for IBS symptoms, moderate effects for headache, small effects for pain and fatigue, and non-significant effects were found for tinnitus loudness, sleep quality, and glycemic control (see Table 1). In the case of IBS symptoms, one study was excluded based on inadequate randomization procedures. A secondary sensitivity analysis including this study led to very similar results as the primary analysis (pooled SMD 1.14, 95% CI 0.81-1.48, P<.001, I^2=0%, k=3). Studies with an active control condition were not pooled due to a limited number of studies and comparable outcomes (see Multimedia Appendices 3 and 4 for the results of individual studies).

Disease-Related Impact on Daily Life

Nine studies with a passive control condition included measures of disease-related distress or quality of life, of which 7 (78%) found effects in favor of the ICBT condition on at least one outcome (see Multimedia Appendices 2 and 4). Small but significant effects were found on disease-related distress, and large effects were found on disease-specific quality of life (see Table 1 and Figures 7 and 8). In the case of disease-specific quality of life, one study was excluded based on inadequate randomization procedures. A secondary sensitivity analysis including this study led to very similar results as the primary analysis (pooled SMD 1.09, 95% CI 0.80-1.39, P<.001, I^2=0%, k=4). Results from studies with an active control condition were not pooled due to a limited number of studies and outcomes. Individual study results can be found in Multimedia Appendices 3 and 4.

Figure 7. Forest plot of standardized mean differences of the effect on disease-specific quality of life of Internet-based cognitive behavioral therapy compared with a passive control condition.

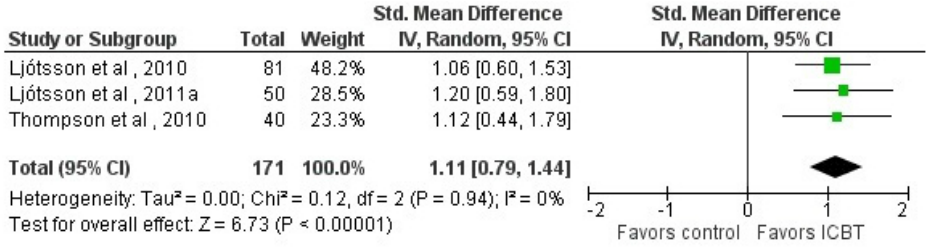


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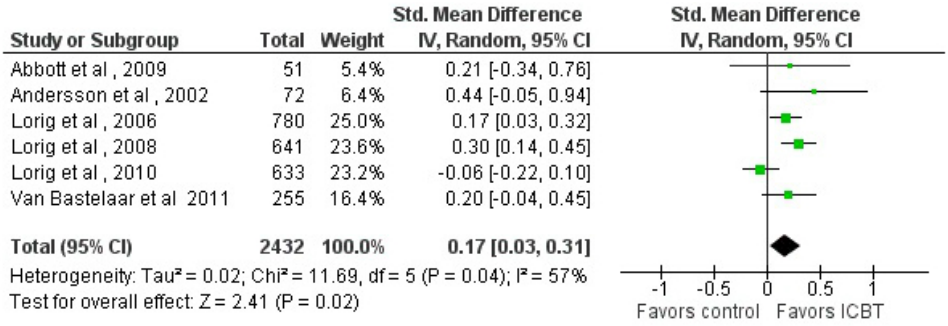
Figure 8. Forest plot of standardized mean differences of the effect on disease-specific distress of Internet-based cognitive behavioral therapy compared with a passive control condition.



Role of Treatment Duration on Intervention Effectiveness

Most interventions were relatively short, with little variability in treatment duration: 4% (1/23) of the interventions lasted 4 weeks, 48% (11/23) lasted 6 weeks, and 48% (11/23) lasted 7-24 weeks (see Multimedia Appendix 2). Consequently, outcomes of the studies in which the intervention lasted ≤6 weeks and >6 weeks were compared. Of the 5 studies finding a between-group effect on depression, 4 (80%) had an intervention duration of >6 weeks. Effect sizes of the longer interventions (n=8; SMD 0.29; 95% CI 0.13-0.46) were larger than those in the shorter interventions, with marginal statistical significance (n=7; SMD 0.08; 95% CI -0.05 to 0.22) (χ^2_1=3.91, *P*=.05). Intervention duration did not influence effectiveness for other outcomes.

Discussion

Principal Findings

Our meta-analysis indicates that ICBT is effective for chronic somatic conditions regarding both general psychological outcomes and disease-specific outcomes. Effect sizes were generally small to moderate, with larger effect sizes occasionally found for disease-related outcomes, such as self-reported headache and IBS symptoms, and for disease-specific quality of life. These findings of larger effects on disease-specific outcomes may on the one hand reflect the larger sensitivity to change of these measures [62,63] and on the other hand support the idea of tailoring interventions to the needs of specific patient groups, as disease-specific measures are likely the measures that respond well to more tailored, disease-specific approaches [64-67].

The three included studies that compared ICBT with an active treatment condition showed that ICBT can be as effective as group-based face-to-face CBT, for example. However, two studies also found that ICBT and an informational website without CBT content were similarly effective. These results indicate a need for studies in which the effect of specific components of ICBT are more closely investigated. The role of one such component of ICBT was examined in this meta-analysis—intervention length—suggesting that interventions lasting longer than 6 weeks result in greater improvements in depression.

Overall, results of this review extend previous reviews and meta-analyses, which concluded that ICBT may be a promising adjuvant treatment for psychological outcomes [13-16] and for patients with health problems [17-23]. Meta-analyses have typically reported small [18] to moderate [14,16] pooled effect sizes for Internet-based psychotherapeutic interventions. The results are also comparable to meta-analyses of face-to-face CBT, which typically find small to moderate effect sizes on a variety of outcomes [1,68-70], with sometimes larger disease-specific than more general mood-related effects [69]. Our review adds to previous findings by including all available studies in chronic somatic populations and by identifying differences in effectiveness for specific categories of outcome. With this approach, it was shown for the first time that guided ICBT is effective for various psychological and physical outcomes, with most promising results for disease-related outcomes and that intervention duration might be a determinant of the effectiveness of ICBT for depression. These results underline the potential benefit of ICBT for patients with chronic somatic conditions in helping them cope with the consequences of their condition.

Limitations

Some potential limitations should be discussed. First, there are still a limited number of studies on ICBT in chronic somatic conditions, and sometimes only one study was available for a specific condition, which precludes drawing reliable conclusions about specific patient groups and generalizing across conditions. Over half of the studies were performed in Sweden by the same authors, but post-hoc analyses did not find differences in outcomes between the Swedish and other studies (data not shown). Women constituted a large proportion of most study populations, reflecting the often unequal gender distribution of different chronic somatic conditions. Second, studies were found to be of variable methodological quality, which may influence both individual study results and overall outcomes in meta-analysis. Although all studies had unclear or high risk of blinding bias, this is often unfeasible or very difficult to achieve in non-pharmacological behavioral interventions and thus may not be a valid indicator of study quality [71]. In many studies, inadequate descriptions resulted in unclear risk of bias. This may be resolved by using guidelines for reporting RCTs [72]. Third, the appropriateness of pooling studies of ICBT for various patient populations can be discussed, as pooling is intended for more or less homogeneous populations and outcomes. The current review included a relatively diverse range of chronic

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somatic conditions, and outcomes were often assessed with various different questionnaires. However, similar effects and low heterogeneity were found for most outcomes, supporting the idea that the included studies were comparable regarding their outcomes. Including these various studies in this meta-analytic overview provides the reader with a first indication of the overall effectiveness of ICBT for chronic somatic conditions and increases the generalizability of findings [73,74]. As more trials become available in the future, meta-analyses should be performed for separate chronic somatic conditions. Fourth, long-term between-group follow-ups were often lacking, precluding a reliable long-term estimate. Fifth, there was substantial variation in description of treatment content, therapist contact, and dropout. For instance, not all therapist contact was with a trained therapist but could also include "expert" patients, nurses, physicians, occupational therapists, or research assistants. Dropout rates were not always adequately described and generally high, which is a common problem with Internet interventions [75]. Sixth, publication bias cannot be precluded. The current review was limited to published studies, as it was unfeasible to obtain a complete and unbiased overview of all unpublished grey literature on this subject. This may have led to an overestimation of effectiveness, as published studies are generally more likely to include statistically significant results [76]. However, several studies that did not find an effect were included in the current review, indicating that not only studies with significant results are published on this topic.

Finally, we used the pooled standard deviation based on pre- and post-intervention measurements in our meta-analysis. When using change scores in meta-analysis, the most appropriate measure would have been the standard deviation of changes. However, the included studies did not report sufficient information to calculate these standard deviations [29], which has been recognised as a common problem when using change scores. Our approach can, however, be considered as a conservative approach since the calculated standard deviations will be slightly larger than the standard deviations of changes would have been. Another alternative would have been to perform the meta-analysis based on post-intervention measurements, but such an approach does not take into account possible differences in baseline measurements. Nevertheless, we also performed a meta-analysis based on post-intervention measurements results. The results of this meta-analysis were very similar to the change score results reported in our study (data not shown), and would have led to similar conclusions.

Future Research

Results from this review suggest several areas for future research, related to study methodology and intervention design. More studies with adequate sample sizes focusing on a wider range of chronic somatic conditions with between-group long-term follow-up are needed. Only one study involved older patients [38], yet older patients are often affected by chronic conditions. As dropout is common with ICBT, ways to promote engagement and improve adherence should be investigated. Preliminary research suggests that tailoring interventions may be an effective strategy to promote engagement and adherence [77-79]. Strategies found to be predictive for adherence include increased therapist contact, more frequent website updates, and more frequent intended usage [80]. Also, future research is needed to examine the effects of ICBT on outcomes such as work-related outcomes, health behaviors, and cost-effectiveness, which were not evaluated in this meta-analysis in order to narrow its scope. Last, the "active ingredients" of interventions need to be identified, in order to develop effective interventions for specific problems. Additional control conditions including "sham" treatment websites should be included to assess the specific value of ICBT [81]. Analyses on computer-generated data about how subjects access the website may also be a worthwhile approach to examine engagement, usability, and active ingredients [82].

Conclusions

The current review indicates that ICBT interventions improve both psychological and disease-related physical outcomes in patients with chronic somatic conditions, with small-to-medium effect sizes. Larger improvements are occasionally found for disease-specific outcomes related to daily-life impact of the illness, which underlines the importance of tailoring interventions to specific (patient) groups. Our results also indicate that interventions of longer duration may be more effective on psychological outcomes such as depression, which implies that tailoring the duration of interventions to specific problems may be appropriate.

Acknowledgments

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Authors' Contributions

S van Beugen and M Ferwerda were responsible for the risk of bias assessment and were advised by M Rovers when in disagreement. S van Beugen and H van Middendorp were responsible for the systematic literature search. AWM Evers, S van Beugen, and (partly) H van Middendorp were responsible for the concept, structure, and methodology of this meta-analytic review. All authors made substantial contributions to writing the paper.

Conflicts of Interest

None declared.

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Multimedia Appendix 1

Search strategies for PubMed, PsycINFO, and Embase.

[PDF File (Adobe PDF File), 16KB - jmir_v16i3e88_app1.pdf]

Multimedia Appendix 2

Study characteristics and post-intervention effects of ICBT for chronic somatic conditions: two-armed studies with a passive control condition.

[PDF File (Adobe PDF File), 392KB - jmir_v16i3e88_app2.pdf]

Multimedia Appendix 3

Study characteristics and post-intervention effects of ICBT for chronic somatic conditions: two-armed studies with an active comparison condition.

[PDF File (Adobe PDF File), 427KB - jmir_v16i3e88_app3.pdf]

Multimedia Appendix 4

Study characteristics and between-group post-intervention effects of ICBT for chronic somatic conditions: three-armed studies with two active treatment conditions and one passive control condition.

[PDF File (Adobe PDF File), 328KB - jmir_v16i3e88_app4.pdf]

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Abbreviations

ACT: acceptance and commitment therapy

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CBT: cognitive behavioral therapy
CI: confidence interval
IBS: irritable bowel syndrome
ICBT: Internet-based cognitive behavioral therapy
ITT: intent to treat
LOCF: last observation carried forward
MBCT: mindfulness-based cognitive therapy
MeSH: medical subject heading
RCT: randomized controlled trial
SD: standard deviation
SMD: standardized mean difference

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