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Guest Editorial

Is E-health Progressing Faster Than E-health Researchers?

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Related Article:

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Abstract

Formal Internet interventions exist in a broad context of diverse online health resources, which share elements in common like information, advice and peer support. However, most online health resources are not created by healthcare professionals. Internet interventions need to be designed to “compete” in that wider context. The democratization of production and distribution is central to the transformative effect of the Internet on society, yet potentially conflicts with healthcare’s need for an evidence base and safe practice. This is a core challenge for healthcare on the Internet.

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KEYWORDS

Internet interventions; Online treatment; Information services; Safety management; Research policy

E-health Consumers Are Ahead of E-health Researchers

In a paper in this issue of the *Journal of Medical Internet Research*, Ritterband and colleagues describe the directions being taken by the International Society for Research on Internet Interventions (ISRII) [1], offering a clearly signposted way ahead for research in this field. What they propose are things that clearly need to be done. Their privileging of randomized controlled trials as the gold standard methodology makes sense if Internet interventions are to continue to garner support from government agencies and healthcare bodies. Nonetheless, I argue here that their path is a narrow one. We should look further afield, both because that is our role as researchers but even more because patients and members of the public are racing ahead of us.

While evidence-based medicine (EBM) is an essential paradigm, we should not let the methodological tools of EBM railroad our

thinking: the desire to do systematic reviews and meta-analyses should not obscure issues of heterogeneity between interventions and between studies [2]. Equally, an artificial categorization of what constitutes an Internet intervention (or previous jargon like “interactive health communication applications”) should not blind us to systems involving similar processes.

The typical Internet interventions described by Ritterband et al use the Internet as a delivery system for computer-based treatments. However, such systems are only reaching a fraction of the audience using the Internet for health purposes. The ingredients of Internet interventions – information, advice, peer group support, one-to-one contact – are available through a huge variety of websites, online groups, blogs, wikis, BitTorrents and more. If we expand from health into related lifestyle issues like nutrition, fitness, sex and relationships and parenthood, the number of resources increases yet further. Tens of millions of people have joined online support groups in the US alone [3], while many more people are accessing health information. The

sites and groups concerned may have been set up by individual patients, charities, activist groups, commercial bodies (either selling a product or relying on advertising), or healthcare professionals. The overwhelming majority of all these resources are informal, untested and without clinical input, quite unlike the Internet interventions supported by the ISRII.

Competition

Faced with this diversity, health consumers are making choices about what resources to use. While clinicians value EBM quality criteria to support such choices, these are not used by the public [4]. Whether we like it or not, online health consumers are using untested, amateur resources or commercial sites with financial motivations. Moreover, they appear to be making greater use of such resources than 5 years ago [5]. Many of these amateur websites, online groups, blogs and all, seem valuable and safe, but is there enough ongoing research to demonstrate that?

The implication of this world of abundance of health-related information and peer support is that formal Internet interventions face competition, something not mentioned in the “directions” article [1]. The ISRII want to make Internet interventions available to “anyone, anywhere”: a laudable goal, but simply making them available will not be enough. The online consumer is not a passive recipient: they shop around, they try multiple sources, they review what they find and use others’ online reviews to guide their choices [6]. Online healthcare consumers are not assessing what they find against the EBM quality criteria on which formal Internet interventions score well, while some commercial sites have huge resources to spend on promotion and site design. This is the context that contributes to the low adherence that Ritterband and colleagues and others have described [1, 7]. We need Internet interventions that are not only good (effective and reliable), but which can compete for the online healthcare consumer’s attention and recognize that individuals will use multiple sites and in ways of their own choosing. Among other things, that means that Internet interventions should be free at the point of use, a tough economic model to achieve.

People want choice. Consider for example online support groups in cancer. There are online groups for very many types of cancer (far more than could ever exist as face-to-face groups), but the

variety does not stop there. For more common cancers, people fragment in different ways, so there are groups for specific varieties, stages and treatments and groups for different sorts of people by locale, age, religion and more (*e.g.* war veterans with prostate cancer, lesbians with breast cancer, even belly dancers with breast cancer). There are multiple groups with apparently the same coverage. Internet interventions need to be equally adaptable and diverse. I predict that there will be demand for a huge variety of Internet interventions tailored in all sorts of ways, just as people generally want personalized health information [5].

Democratization of Production

Away from healthcare, the Internet has been revolutionary and transformational because it has democratized production and distribution [6]. Traditional healthcare, given its safety critical context, utilises an evidence base and a process of risk management that generally involves some sort of governance. These are conflicting trends: the great value of the Internet is how easy it is to make material available, but the strictures of safety and proof of efficacy run counter to that. How do we garner the benefits of the Internet – the democratization of production and distribution that has produced so much content – while maintaining safe and good practice? The answer remains unclear, but it is a question the research community should address. Traditional Internet interventions, with content by healthcare professionals, prescribed to patients, can only be part of the answer. We should recognize the value and popularity of user-generated content in non-health contexts [6] and work out how to better integrate it into online healthcare resources.

The challenges of the online environment for healthcare have been considered before [8]. There are uncounted online resources, amateur as well as professional, that overlap with formal Internet interventions. ISRII might have to address the implications of this context more explicitly, as others have done [9, 10]. Beyond healthcare, there are many more innovations that draw on user-generated content and the Internet’s democratization of production and distribution. The “killer application” in e-health will perhaps be something that can marry the democratized nature of MySpace or Wikipedia with the safety critical nature of healthcare.

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Conflicts of Interest

None declared

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Abbreviations

EBM: Evidence-Based Medicine

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Short Paper

Responding Rapidly to FDA Drug Withdrawals: Design and Application of a New Approach for a Consumer Health Website

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Abstract

Background: Information about drug withdrawals may not reach patients in a timely manner, and this could result in adverse events. Increasingly, the public turns to consumer health websites for health information, but such sites may not update their content for days or weeks following important events like Food and Drug Administration (FDA) drug withdrawal actions. There is no recognized standard for how quickly consumer health websites should respond to such events, and reports addressing this issue are lacking.

Objective: The objective of this study was to develop and implement an approach to enhance the efficiency with which a consumer health website (NetWellness.org) responds to FDA drug withdrawal actions.

Methods: Evaluation of the current approach used by NetWellness staff to update content affected by FDA action revealed a slow process driven by the goal of performing thorough and comprehensive review and editing. To achieve our desired goal of accurately updating affected content within 24 hours of FDA action, we developed a strategy that included rapid updating of affected Web pages with warning boxes and hyperlinks to the information about the withdrawal. With the next FDA withdrawal event, that of valdecoxib (Bextra) on April 7, 2005, we applied this new approach, observed the time and resource requirements, and monitored the rate at which consumers viewed the updated information to gauge its potential impact.

Results: Application of the new approach allowed one person to modify the affected Web pages in less than 1 hour and within 18 hours of the FDA announcement. Using the old strategy, response to a similar event, the withdrawal of rofecoxib (Vioxx) 6 months earlier, had taken over 3 weeks and the efforts of several personnel. Updated valdecoxib content received 188 hits within the first month and 4285 hits within 1 year.

Conclusions: Rapid updating of a consumer health website's content in response to an FDA drug withdrawal event was easily accomplished by applying the approach described. This allowed consumers to view accurate information regarding the withdrawn drug much sooner than would otherwise have been the case. Given that consumers increasingly turn to websites for their health information, adoption of a rapid response standard for important health events like FDA drug withdrawals should be considered by the consumer health informatics community.

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KEYWORDS

Consumer health information; drug and narcotic control; cyclooxygenase inhibitors; adverse effects; time factors

Introduction

Despite the extensive evaluation process before a drug is approved for use by the US Food and Drug Administration (FDA), some drugs are occasionally found to have unanticipated significant adverse effects after their release. In such cases, drugs may be withdrawn from the market after having been in wide use, sometimes for years.

A high profile example involved rofecoxib (trade name Vioxx), which was withdrawn on September 30, 2004 [1]. This nonsteroidal anti-inflammatory drug (NSAID) is a member of the popular coxib class of drugs (selective cyclooxygenase-2 [COX-2] inhibitors). Post-marketing research data indicated that rofecoxib had unanticipated health effects, which led to its withdrawal from the market. At the time of its withdrawal, rofecoxib was in use by some 2 million people in the United States alone, making this the largest prescription drug withdrawal in US history [2].

Informing the public about drug withdrawals like this one often involves a combination of efforts by the FDA and the drug's manufacturer as well as pharmacy-level withdrawal of the drug to prevent further sales [1,3-5]. However, the timeliness and manner of informing health care personnel and patients of drug withdrawals varies [6-8]. There is evidence that patients continue to use medications for some time after withdrawal from the market, occasionally with adverse consequences [9,10]. Indeed, even brief prolongation of the use of drugs like rofecoxib may be detrimental to some users, further emphasizing the importance of informing the public of drug withdrawals as quickly as possible [11].

The World Wide Web (Web) is a major source of health information for millions of consumers [12,13]. While the quality of sites vary, some trusted resources provide credible evidence and serve as an important source of health information for many consumers [14]. One such trusted website is NetWellness (www.netwellness.org), a non-profit, consumer health information portal with ask-an-expert service. NetWellness provides anonymous access to all content, including over 29000 consumer-submitted questions and expert responses authored by over 380 volunteer health sciences faculty experts from NetWellness' three Ohio medical research university partners—University of Cincinnati, Case Western Reserve University, and The Ohio State University [15,16]. This content includes thousands of instances of drug-specific information. While it is the procedure of NetWellness to review and update content on at least an annual basis, events such as FDA drug withdrawals trigger more frequent updates. However, as described in greater detail below, the baseline process for performing such updates is often inefficient.

Given the public's growing use and reliance on such websites for their health information and the importance of rapidly informing consumers about significant drug events, the purpose of this project was to devise and implement an improved process that would allow for efficient and consistently effective updating of content in response to drug withdrawals. Our goal was to update all instances of the withdrawn drug name (generic and trade) in NetWellness within 24 hours of FDA action so that

visitors would have the benefit of full and accurate health information.

Methods

Baseline Approach to Drug Information Updates on NetWellness

An example of a drug update resulted from the withdrawal of rofecoxib from the world market on September 30, 2004. Interviews with NetWellness personnel revealed the following process. Upon learning of this withdrawal through media reports, NetWellness personnel performed a manual search of the NetWellness database using built-in search engines to identify Web pages containing the terms "rofecoxib" or "Vioxx." Once identified, Web pages containing those terms were archived, and authors were asked to evaluate the content and assess whether the page should be altered (and if so, how) or permanently archived. Finally, changes to the pages were made and revised pages were re-posted. The entire process took about 3 weeks to complete, owing mostly to delays in author responsiveness.

While the updating process was ultimately effective, it was quite time-consuming. As a result, information about the drug's withdrawal remained unavailable on NetWellness for weeks after it was withdrawn from the market. Furthermore, the process relied on the vigilance of NetWellness personnel to monitor relevant information sources, such as news items, in order to discover that such FDA actions had occurred, leaving open the possibility that such a process may not even be initiated for some time after an FDA action.

New Approach to Drug Information Updates on NetWellness

The first step toward achieving our objective was to determine a way to consistently and efficiently become aware of all instances of FDA drug withdrawal actions. Previously, NetWellness personnel learned about drug withdrawals through periodic review of reports in medical or popular media. For the new process, we considered several alternatives and opted to use the FDA's MedWatch E-list safety alert email reporting service. Key NetWellness personnel registered to receive and monitor the email alerts on a daily basis.

Next, we devised a new simplified method for updating the NetWellness database. As with the previous process, NetWellness personnel would query the database for all instances of the drug name (trade and generic). All instances identified would then be replaced with hyperlinked text using an automated find-and-replace function built into the NetWellness content management system. Updated pages would also contain a warning box at the foot of the page indicating the availability of important new information about the drug in question. Hyperlinked text items in the main body of the page or the footer would point to a new NetWellness page containing a warning about the FDA withdrawal and providing additional links to the FDA or drug manufacturer website for more information. Development and lab tests of this approach were completed in February 2005.

Results

On April 7, 2005, citing health concerns, the FDA issued an announcement that sales of another coxib medication, valdecoxib (trade name Bextra), were to cease immediately [17]. Designated NetWellness personnel received the notice via email from the MedWatch mailing list and immediately

activated the new updating procedure described above. All NetWellness Web pages mentioning the drug were updated with links to a newly created valdecoxib warning page. An example of a Web page before and after modification is shown in Figure 1. The valdecoxib warning page describing the withdrawal and providing a link to the relevant FDA Web page is shown in Figure 2.

Figure 1a. Example of a NetWellness content page before and after updates to reflect FDA withdrawal of valdecoxib (Bextra). (a) Before update

The screenshot shows the NetWellness website interface. At the top, there is a header with the NetWellness logo and text: "University of Cincinnati, The Ohio State University, Case Western Reserve University. NetWellness provides the highest quality health information and education services created and evaluated by faculty of our partner universities." The date "Friday, April 8, 2005" is displayed on the right. Below the header is a navigation bar with links: "Home", "HealthTopics", "Your Health", "Reference Library", and a search box labeled "Search this Topic". The main content area is titled "Arthritis and Rheumatoid Diseases" and "Any arthritis medication to reduce pain?". The date "04/08/2002 08:08AM" is shown. The "Question:" section contains a user's query about NSAIDs and Bextra. The "Answer:" section provides a response from a medical professional. The "Response by:" section identifies the responder as Larry Houk, M.D., with his title and affiliation.

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Friday, April 8, 2005

Home HealthTopics Your Health Reference Library Search this Topic

Arthritis and Rheumatoid Diseases

Any arthritis medication to reduce pain?

04/08/2002 08:08AM


Question:

Having severe OA,I've been on many NSAIDS. I may have relief for a short time only. With a sulpha allergy,I can't take Glucosamine or Celebrex. Vioxx and Mobic don't help. Is Bextra free of sulpha? My fingers are so swollen I drop things.My joints are stiff,so I do stretching before I can move. Any suggestions re medications?

Answer:

Bextra does not have a sulfa component but is no more effective than traditional NSAIDs. Finger joints can be injected with corticosteroids which is very effective for relieving pain. OA usually does not cause prolonged morning soreness and stiffness. Make sure you don't have Rheumatoid Arthritis superimposed on OA.

Response by:

 [Larry Houk, M.D.](#)
Professor of Clinical Medicine and Rheumatology
Division of Immunology and Allergy
[Department of Internal Medicine](#)
[College of Medicine](#)
[University of Cincinnati](#)


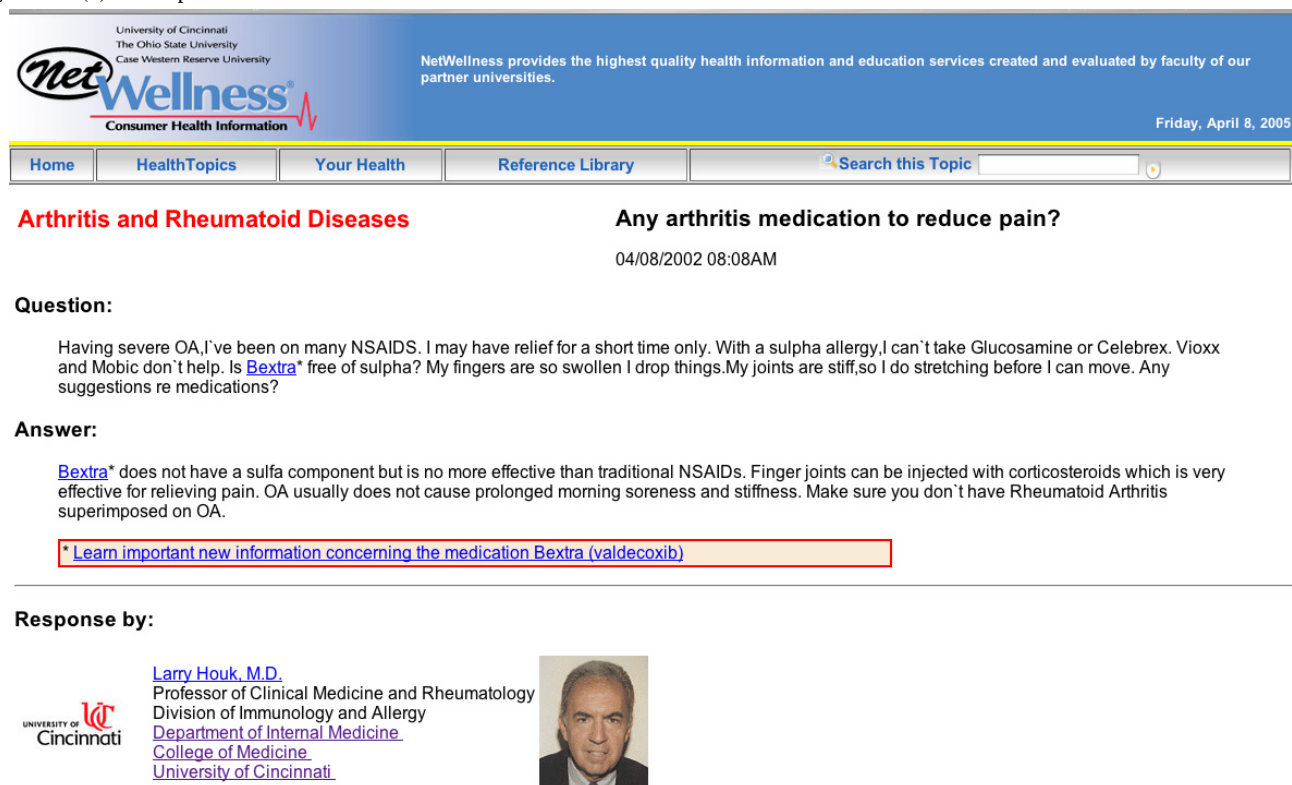


Figure 1b. (b) After update



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Friday, April 8, 2005

[Home](#) [HealthTopics](#) [Your Health](#) [Reference Library](#)

Arthritis and Rheumatoid Diseases **Any arthritis medication to reduce pain?**
04/08/2002 08:08AM

Question:


Having severe OA, I've been on many NSAIDs. I may have relief for a short time only. With a sulpha allergy, I can't take Glucosamine or Celebrex. Vioxx and Mobic don't help. Is [Bextra](#)* free of sulpha? My fingers are so swollen I drop things. My joints are stiff, so I do stretching before I can move. Any suggestions re medications?

Answer:

[Bextra](#)* does not have a sulfa component but is no more effective than traditional NSAIDs. Finger joints can be injected with corticosteroids which is very effective for relieving pain. OA usually does not cause prolonged morning soreness and stiffness. Make sure you don't have Rheumatoid Arthritis superimposed on OA.

* [Learn important new information concerning the medication Bextra \(valdecoxib\)](#)

Response by:

 [Larry Houk, M.D.](#)
Professor of Clinical Medicine and Rheumatology
Division of Immunology and Allergy
[Department of Internal Medicine](#)
[College of Medicine](#)
[University of Cincinnati](#)


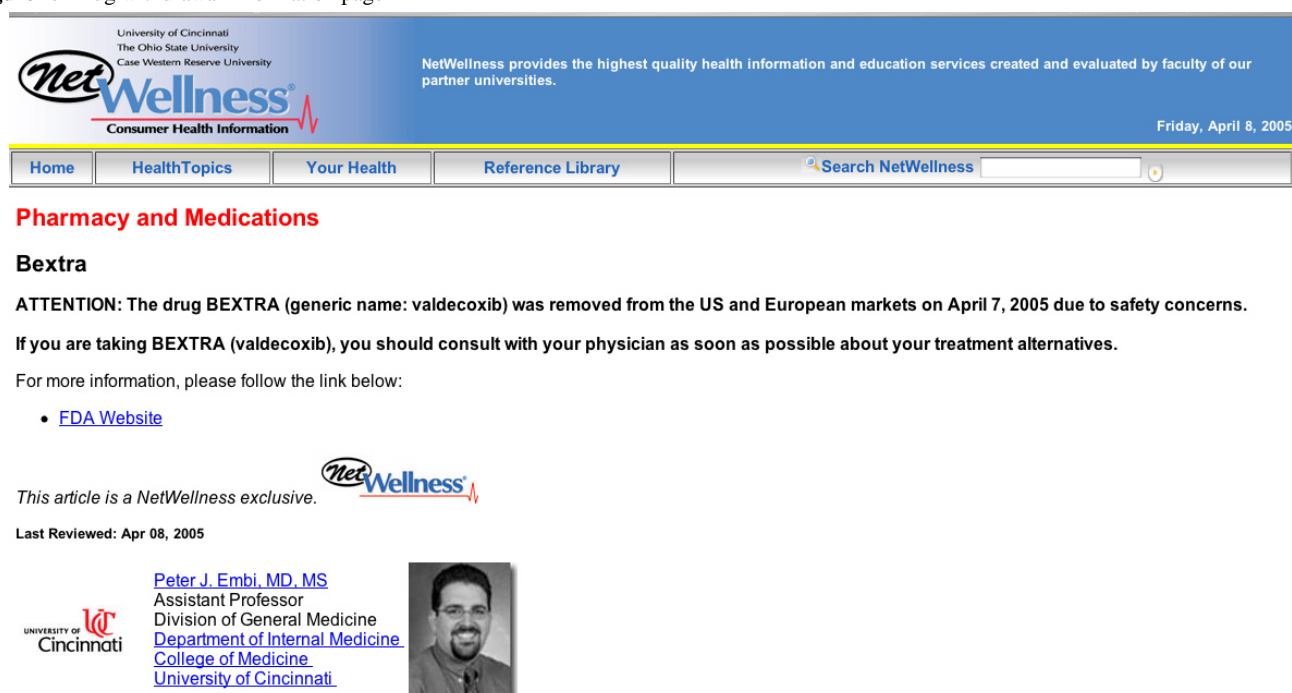


Figure 2. Drug withdrawal information page



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Friday, April 8, 2005

[Home](#) [HealthTopics](#) [Your Health](#) [Reference Library](#)

Pharmacy and Medications

Bextra


ATTENTION: The drug BEXTRA (generic name: valdecoxib) was removed from the US and European markets on April 7, 2005 due to safety concerns.

If you are taking BEXTRA (valdecoxib), you should consult with your physician as soon as possible about your treatment alternatives.


For more information, please follow the link below:


- [FDA Website](#)

This article is a NetWellness exclusive.



Last Reviewed: Apr 08, 2005

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[Department of Internal Medicine](#)
[College of Medicine](#)
[University of Cincinnati](#)



By following the procedure outlined above, updates to the system were completed within 18 hours of the FDA drug recall announcement. This represented a significant improvement over the weeks it had taken to fully respond to the previous FDA drug recall of rofecoxib six months earlier. Moreover, updates to the content were accomplished with a fraction of the resources previously required.

In the first month following the content update, NetWellness valdecoxib-related Web pages received 188 hits, with 156 (83%) following the links to the new warning page. As of April 8, 2006, 1 year after the withdrawal of valdecoxib, updated Web pages had received 4285 hits, with 1017 (24%) of those viewing the warning information page.

Discussion

Given the public's growing use of the Web for health information, it is important that Web-based consumer health content is kept up-to-date, particularly important content like that regarding withdrawal of a potentially harmful medication [18]. Unfortunately, many online health information providers do not respond rapidly enough to such important events, with most taking several days or longer to respond to the valdecoxib recall [19]. In the case of NetWellness, a paradigm shift was necessary in order to meet the challenge of a more rapid response time. The previous system of thorough review and revision of affected content throughout the website was replaced with a process that concentrated instead on rapid updating of affected content in a time- and resource-efficient manner.

Following our test event with valdecoxib, we observed many consumers reviewing the new health information and potentially benefiting from the rapid response. As might be expected, the proportion of those viewing the warning information was highest during the initial month after recall, although a substantial number of users also reviewed content many months later. This suggests that consumers' information needs regarding withdrawn drugs may persist long after the event, and it seems to support the importance of updating rather than simply permanently archiving such content.

This study has some limitations. The anonymous design of our website did not allow formal evaluation of the impact of the new update approach on NetWellness users, and we do not know to what extent users had already learned of the FDA action when they reviewed the updated content.

Future steps include evaluating this approach more rigorously and developing processes for responding to the far more frequent, if less extreme, drug warnings announced by the FDA. In order to respond even quicker in the future, we are working to automate as much of the updating process as possible. While human review is currently the best way to determine the significance of an FDA announcement and initiate an appropriate response, advancements in the structure and format of FDA-generated electronic information feeds may soon facilitate a fully automated response.

This paper demonstrates that a simple approach can allow for rapid updating of critical content on consumer health websites in response to a drug's withdrawal from the market. Given the importance of quickly performing such updates and the feasibility of doing so, we recommend that the consumer health informatics community adopt a 24-hour response standard for updating affected website content following a drug withdrawal event.

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Conflicts of Interest

Although the authors do not stand to gain financially from the material presented in this manuscript, several of the authors (MM, SM, DH) have as part of their job description the maintenance of the not-for-profit NetWellness consumer health information service.

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Abbreviations

COX-2: cyclooxygenase-2

FDA: Food and Drug Administration

NSAID: nonsteroidal anti-inflammatory drug

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Viewpoint

Directions for the International Society for Research on Internet Interventions (ISRII)

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Abstract

In 2004, the International Society for Research on Internet Interventions (ISRII) was formed to encourage eHealth researchers to collaborate in their efforts to further the science behind developing, testing, and disseminating Web-based treatment programs. The group held its second meeting (April 2006) to clarify the Society's direction and identify key issues that need addressing in the field. These issues are identified and examined in the current paper. Given the success of using the Internet to treat a range of medical and mental health problems, and the growing need for better dissemination of health care, Internet interventions will almost certainly play a prominent role in global health. ISRII plans to provide the necessary venue to ensure the science driving this field is strong, enabling researchers to conduct the highest quality research and permitting meaningful conclusions from completed studies.

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KEYWORDS

ISRII; Internet interventions; Online treatment

Introduction

The growth in Internet interventions for mental health and behavioral health programs has increased rapidly in the past decade (see [1]). Internet interventions are treatments, typically behaviorally based, that are operationalized and transformed for delivery via the Internet. Usually, they are highly structured; self-guided or partly self-guided; based on effective face-to-face interventions; personalized to the user; interactive; enhanced

by graphics, animations, audio, and video; and tailored to provide follow-up and feedback [2]. As of early 2006, there were over 25 randomized controlled trials of Internet-based mental health interventions (see reviews [3-6]), and, based on the 2006 meeting of the International Society for Research on Internet Interventions (ISRII) at the Karolinska Institute in Stockholm, Sweden, at least 10 additional Internet intervention trials are nearing completion or are being analyzed for publication (see www.isrii.org for a listing of presentations at the 2006 meeting).

While the *feasibility* (can the intervention be delivered) of Internet health interventions in general has been well validated, *efficacy* (is the intervention successful when delivered under controlled conditions [7]) of Internet applications has now also been established for a number of health problems, including anxiety (eg, panic [8-10], post-traumatic stress disorder [11-13], social anxiety disorder [14,15]), depression [16-18], eating disorders (eg, weight loss [19,20], binge eating and bulimia [21]), body image [22,23], insomnia [24], and more general medical areas such as headache [25,26], back pain [27], diabetes management [28], encopresis [29], tinnitus [30-32], and smoking cessation [33]. True *effectiveness* (is the intervention successful in actual clinical practice [7]) and cost-effectiveness trials are underway.

Clearly, there is an appreciation for this new form of treatment and its unique ability to be widely disseminated as millions of dollars have already been allocated by the National Institutes of Health in the United States and other government agencies and various industries around the world. The recommendation of computer-based interventions such as Fear Fighter [34,35] (for anxiety) and Beating the Blues [36,37] (for depression) by the United Kingdom's National Institute for Health and Clinical Excellence (NICE) introduces a new level of acceptance by government and medical insurers of the feasibility and value of such interventions [38]. This acceptance is an essential step in establishing this mode of treatment delivery (via computers and the Internet). This, along with investigating how Internet interventions compare with more traditional forms of treatment delivery (eg, bibliotherapy, individual and group face-to-face, telephone), will be important in clearly establishing Internet interventions as a viable and effective form of treatment, as well as demonstrating their ability to change behaviors and improve symptoms, cost-effectiveness, scalability, and acceptance in the community.

ISRII is an organization of researchers from around the world whose focus is on the development and testing of various Web-based health treatment programs. The primary aim of the Society is to promote the exchange of ideas and experiences among researchers involved in intervention research using the Internet. Among the many interests shared by the members are cognitive behavioral interventions using the Internet, technical solutions in Web applications, Web-based questionnaire assessments, and computer applications in clinical psychology and in psychiatry more broadly. At the April 2006 meeting, the organization confirmed its aims and identified a number of key issues for the future.

Key Aims and Directions

To continue to conduct the highest quality research and further establish the science of Internet interventions

The primary goal of ISRII is to continue high-quality research to determine the efficacy and effectiveness of health applications on the Internet, which is vital to the future of this mode of treatment. In particular, the Society aims to establish an evidence base for the usefulness of Internet applications across a range of disorders and diseases. This objective represented a major

drive for the first ISRII conference in 2004. At these meetings, experts convene to critically review and improve the quality of intervention research undertaken by Society members. By ensuring that programs are empirically validated, reliable, and appropriately generalizable, ISRII distinguishes them from other industry, commercial, or otherwise nonempirically based Web programs.

To facilitate collaboration among Internet intervention researchers

Internet applications are potentially global, and collaboration in research and dissemination is likely to improve the quality and scope of the research, reduce disease burden, and improve outcomes. In particular, there is recognition among the Society researchers of the importance of working strategically to develop and evaluate Internet applications. Scalable, interactive applications are costly and time-consuming to produce, especially if they are to be empirically validated. There is significant potential in strategically developing new websites to reduce duplication and to avoid "dead ends."

To better understand how behavior change and symptom improvement are produced through the use of Internet interventions

The chief goal of any Internet intervention is to produce cognitive and behavior change that leads to symptom improvement. Examining and testing this process using theories and models of behavior change is critical to furthering the understanding of how Internet interventions, and even treatments in general, work. Models specific to Internet interventions are needed as there are obvious differences in treatment delivery from traditional interventions. Evaluating the Internet as the platform for delivering treatments has some significant advantages over testing more traditional approaches. An advantage of conducting randomized controlled trials through the Internet is the ease of obtaining large sample sizes (no geographical limitations), making it possible to better examine mediators and moderators of treatment. In addition, deconstructing treatments is perfectly suited to Internet intervention research in that the programs are already operationalized and can be readily compartmentalized and studied separately. This may allow for a much better examination of the nonspecific variables of treatment than has been done in the past.

To implement and disseminate Internet applications to anyone, anywhere

A strength of the Society lies in the expertise of its members in delivering Internet applications at a community or population level. Models for the dissemination and implementation of scalable interventions are needed. A special function of the Society will be to organize translation of applications into languages other than the original development language in order to permit broader dissemination.

To develop an understanding of who will use Internet interventions and how to encourage adherence

Determining who wants to use and who is likely to use Internet interventions are important issues to consider for purposes of

dissemination. Examining characteristics of Internet intervention users will help not only improve the tailored nature of these programs, but also help better predict outcomes. Poor adherence is a significant issue for most health interventions, including Internet interventions. The World Health Report of 2002 declared that adherence was the primary determinant of the effectiveness of treatment [39]. This issue of adherence is a critical one for Internet intervention researchers and a key area of focus for the Society. Developing ways to reduce attrition, improve adherence, and maintain compliance is a major objective for members of the Society.

To use Internet research applications to collect minimum data sets

The inclusion of standard measures, such as the EuroQol (EQ-5D) [40] or the SF-12 [41], will allow comparisons across health care systems (eg, Internet communities, clinical groups, and formal health care services), across health problem samples (eg, applications for depression in comparison to diabetes), and within Internet applications (eg, pre- to post-symptom change due to a program for panic).

To examine and validate current tests and measures for Internet delivery

Before well-validated, paper-and-pencil measures should be delivered online, a process of validating these tests in this new mode should be made. While not a major area of focus for this Society, it is an important related issue which most Internet intervention researchers manage.

To examine and test the validity of a range of new online tests and assessments

Validating new online tests and assessments will lead to a library of useful and valid Internet assessments. For example, creating and testing shortened versions of various psychological scales would be relatively easily achieved by using online surveys to validate the items compared to longer versions. There are multiple reasons to develop and validate briefer tests, including the recognition that the Internet is used in short bursts. Data collection can be rapid on the Internet, especially on open-access sites. The Internet also offers the possibility to considerably reduce the length of questionnaires while maintaining reliability. These “adaptive testing techniques” have been shown to reduce the number of necessary items to almost a quarter of that needed in paper versions of questionnaires [42] without any loss of accuracy. This area extends to other psychological tests, such

as measures of information processing and neuropsychological testing via the Internet.

To provide a forum to examine models of commercialization

Given the time and resources invested in developing and testing Internet interventions, making these programs available to the public is often an important goal. Examining models of commercialization and dissemination to determine how best to make these programs available is critical. Given the research focus of the Society, these models might typically incorporate commercialization that allows continued research and evaluation. A range of business models are available to develop research prototypes into fully scaled applications. There may be joint business opportunities for groups of researchers. Discussions should lead to an understanding of how health structures and health system remuneration within countries influence methods of commercialization. Many researchers are interested in learning how their applications might be sustained when research funding ends. While commercializing is a potentially important area of focus, dissemination, however it may occur, is the goal.

To establish guidelines and parameters for the use of current and future interventions

Given the growth and consumer interest in Internet interventions, it is essential to establish and implement guidelines to identify and tag empirically validated, reliable, and effective applications. At a minimum, statements about minimal guidelines for quality and effectiveness are necessary. The Society also seeks to develop a classification scheme to differentiate intervention types (eg, information-only, interactive with information and decision support, interactive with additional human support) in order to enhance comparisons across applications, as well as improve consumer accessibility and understanding. This would likely also enrich future meta-analyses.

These 10 key issues constitute the main aims and directions of the ISRII. Given the wealth of experience, research, and dedication to the science of this discipline, ISRII expects to make significant and substantive contributions to the field of Internet interventions. The possibility of impacting countless lives with the ability to disseminate interventions anywhere in the world makes the mission of this Society a critical and rewarding endeavour.

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Conflicts of Interest

None declared.

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Abbreviations

ISRII: International Society for Research on Internet Interventions
NICE: National Institute for Health and Clinical Excellence

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Original Paper

Defining Participant Exposure Measures in Web-Based Health Behavior Change Programs

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Abstract

Background: Published research on the use of Web-based behavior change programs is growing rapidly. One of the observations characterized as problematic in these studies is that participants often make relatively few website visits and spend only a brief time accessing the program. Properly structured websites permit the unobtrusive measurement of the ways in which participants access (are exposed to) program content. Research on participant exposure to Web-based programs is not merely of interest to technologists, but represents an important opportunity to better understand the broader theme of program engagement and to guide the development of more effective interventions.

Objectives: The current paper seeks to provide working definitions and describe initial patterns of various measures of participant exposure to ChewFree.com, a large randomized controlled trial of a Web-based program for smokeless tobacco cessation.

Methods: We examined measures of participant exposure to either an Enhanced condition Web-based program (interactive, tailored, and rich-media program) or a Basic condition control website (static, text-based material). Specific measures focused on email prompting, participant visits (number, duration, and pattern of use over time), and Web page viewing (number of views, types of pages viewed, and Web forum postings).

Results: Participants in the ChewFree.com Enhanced condition made more visits and spent more time accessing their assigned website than did participants assigned to the Basic condition website. In addition, exposure data demonstrated that Basic condition users thoroughly accessed program content, indicating that the condition provided a meaningful, face-valid control to the Enhanced condition.

Conclusions: We recommend that researchers conducting evaluations of Web-based interventions consider the collection and analysis of exposure measures in the broader context of program engagement in order to assess whether participants obtain sufficient exposure to relevant program content.

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KEYWORDS

Health behavior; Internet; Web; behavioral research; participant exposure; engagement

Introduction

One of the common findings of research on Web-based behavior change programs is that participants spend only a relatively meager amount of time accessing their online intervention [1]. This implies minimal participant exposure to the critical behavior change ingredients of the program, which could potentially reduce program impact. In response to this finding, a number of published reports of Web-based interventions have

described website usage statistics, including number and duration of visits as well as the number and type of Web pages viewed [2-11]. Research on Web-viewing behavior is rapidly growing in other domains (eg, advertising [12] and technology [13]).

This paper describes participant exposure to a two-arm randomized controlled trial of Web-based programs designed to assist adults in quitting smokeless tobacco (either snuff or chewing tobacco). Following a brief program description, we

present a set of unobtrusive measures of website exposure [14] and the results of our exposure analyses. We believe that this level of detail will prove helpful to other researchers investigating the design of optimally effective Web-based behavior change programs.

Methods

ChewFree Program for Smokeless Tobacco Cessation

We designed the ChewFree trial to compare the efficacy of two smokeless tobacco cessation websites: Basic and Enhanced. The Basic condition, which represented a subset of the content presented in the Enhanced condition, offered a printable self-help smokeless tobacco cessation booklet, printable cessation resources (eg, describing the use of herbal snuff products, nicotine replacement products), and annotated links to other recommended websites for tobacco cessation. The Enhanced condition offered a tailored and interactive Web-based program that included text-based information (health and behavioral strategies focused on quitting and preventing relapse), video-based testimonials, printable resources, interactive activities, annotated links to other website resources, and two Web forums (a "Talk with Others" social support forum, and an "Ask an Expert" forum for submitting questions to project staff).

ChewFree.com intervention components were based largely on Bandura's Social Cognitive Theory [15-17] in which individuals are viewed as proactive agents who can exercise motivational

and self-regulatory skills to change their health habits. According to this theory, individuals choose their environments, seek out beneficial social networks, and engage in other self-management behaviors that allow them to achieve both initial change and long-term maintenance. Multi-component smoking cessation and relapse-prevention interventions have successfully incorporated these strategies [eg, 7,18-20], and adaptations of these same approaches have been found well suited to smokeless tobacco cessation programs [21-23].

The Basic and Enhanced Web-based programs offered smokeless tobacco cessation assistance using markedly different information architectures [24]. The Basic condition (Figure 1) presented text-based content using four navigational Web pages: Home, *Enough Snuff*—an adaptation of the smokeless tobacco cessation manual used in prior research [25], Resources, and Links. The Enhanced condition (Figure 2) used five navigational Web pages: Home, Personal Quitting Assistant, Resources, Forum, and Links. The Personal Quitting Assistant used a hybrid information architecture design [24] that guided participants in a step-wise manner through eight modules of the Planning to Quit content while offering optional content along the way. In addition, the information architecture prevented users from accessing content in the Staying Quit module until they returned to the website at a later date and reported that they had either quit using smokeless tobacco or had relapsed. Progress was self-paced in that participants in both the Enhanced and Basic conditions determined when they chose to visit the program and how much content they would cover during each visit.

Figure 1. Basic condition (excerpt of Enough Snuff guide)



Figure 2. Enhanced condition (excerpt showing video narration by a smokeless tobacco cessation expert to accompany the Personal Quitting Assistant, or PQA)



Content was presented using text, graphics, activities, and two types of videos: a video expert guide who narrated key portions of content that was also presented as text, and video testimonials of smokeless tobacco users whose presentations supported the recommendations of the program. The narration videos were automatically launched (ie, they did not require user selection) for users with high bandwidth connections, but they were not displayed automatically to participants with dial-up access [26]; all users could toggle them on or off as desired.

We designed the Enhanced condition to be attractive by offering a broad spectrum of content tailored to the interests and the smokeless tobacco use/abstinence status of each participant. For example, participants who were preparing to quit were encouraged to review program content focused on Planning to Quit, whereas those participants who indicated that they had quit using smokeless tobacco were encouraged to review content on Staying Quit. In addition, the intervention used multiple methods for delivering content along with engaging activities. Compared to the Basic condition, we predicted that the Enhanced condition would encourage participants to visit more often and for longer periods of time—especially during the first several weeks post-enrollment when attempts to quit and related lapse/relapse experiences would most likely occur.

Participants

Participants were recruited using a multifaceted marketing campaign that included (1) thematic promotional "releases" to print and broadcast media, (2) Google ads, (3) placement of a link on other websites, (4) limited purchase of paid advertising, (5) direct mailings to smokeless tobacco users, and (6) targeted mailings to health care and tobacco control professionals. This

campaign resulted in more than 23500 visits to the ChewFree.com recruitment website from distinct IP addresses over a 1-year period, which yielded 2523 eligible smokeless tobacco users who completed the registration process and enrolled in the ChewFree.com smokeless tobacco cessation research project [27,28]. Participants were randomly assigned either to the Enhanced condition ($n = 1260$) or the Basic condition ($n = 1263$).

Measures of Program Exposure

There is no single universally accepted measure for assessing participant exposure to a Web-based program. Computer-delivered content lends itself well to unobtrusive monitoring of usage patterns. As noted by Peterson [29], there are a number of potentially complementary sources of computer-based monitoring data, such as server log files, cookies, Web beacons, and session identifiers. Many commercial products are available that analyze Web server log files [eg, 30,31]. Cookies offer another powerful tool to tailor website content and monitor usage [32]. Web beacons can be inserted into Web pages to enhance the ability to obtain even more detailed tracking [33]. Because we used user authentication (obtaining username and password at the beginning of every session) with an appropriate scripting language (Macromedia ColdFusion) and SQL database to create the ChewFree websites, we were able to use the session identifier approach to measure exposure [29]. We believe that the session identifier approach offered more flexibility to focus on topics that were relevant to our research than did a commercial log analyzer product focused on issues of commercial importance such as pay-for-click

analyses, average revenue per order, top products, and customer segment analysis.

For the present paper, we examined data from participants as of January 10, 2006, which, for most participants, represented approximately 12 months after enrollment (mean = 367.1 days,

SD = 116.9; no significant differences between conditions). The minimum number of days since enrollment was 181 days and, in each case, the scheduled date of the 6-month follow-up assessment had elapsed. [Textbox 1](#) summarizes the measures we used, each of which is described below. Detailed measures are provided in the Multimedia Appendix.

Textbox 1. Measures of program exposure

Email prompts	Percentage of participants sent treatment-related email prompts
Participant visits	Number of visits
	Aggregate duration of visits
	Number of daily visits post-enrollment
	Number of days of program access post-enrollment
Web page views	Overall number of Web page views
	Specific Web page views (selected smokeless tobacco cessation content)
	Web forum postings

Treatment-Related Email Prompts

Participants in the Enhanced condition received a variety of email prompts during the study that were not related to assessments. These prompts fell into three categories:

1. Intervention: Participants were sent up to three email messages prior to their quit date, tailored to their chosen method of quitting (cold turkey, nicotine fading, brand switching, blending), and one message on their quit date.
2. Support: We sent three supportive emails timed at fixed intervals after the participant's self-reported quit date.
3. Re-engagement: Participants who failed to log in on a regular basis were typically sent multiple tailored email messages encouraging them to resume accessing the program.

Participant Visits

Typical measures of visit data include number of visits per participant per condition and both average and total visit duration. We programmed the ChewFree website to record the date/time stamp of the start and end of each participant visit (also referred to as a "session") and for each Web page the participant viewed during each visit. These date/time stamps allowed us to examine both the number of unique visits per participant and session duration.

Because participants were able to abruptly end their use of the program by closing their browser window, there were occasions when we did not capture the date/time data for the end of the session. To analyze these instances, we conservatively approximated the end of the visit by using the date/time of the last Web page that had been accessed before the abrupt end of the session. In addition, we followed the operational definition for visit expiration recommended by Peterson [29]; that is, any Web page viewed for 30 minutes or more was defined as having ended the visit using the ending date/time stamp of the Web page that immediately preceded the hiatus. Moreover, if, after

the hiatus, the participant resumed activity, it was considered to be a new visit for measurement purposes.

Participants in both conditions were required to complete an online baseline assessment prior to accessing the program. In addition, all participants received email reminders to complete online follow-up assessments at 6 weeks, 3 months, and 6 months. The email prompt contained a link that caused the log-in page of the Web-based program to appear, followed by presentation of the online assessment. At the end of each assessment, users were returned to their respective website, at which time they were free to explore the website and review its contents. When counting distinct visits that involved program content review, we excluded those visits associated with online assessments unless the participant also explored website content.

Website Visit Duration

We focused our analysis on aggregate duration (collapsed across visits) because we were concerned with the overall amount of participant exposure to the program. Although we did not choose to do so for purposes of this paper, we could also have examined the changing patterns in the duration of individual visits over time.

Visits Following Enrollment

We examined the time course for each participant visit by calculating the number of days in which a visit occurred since the date the participant completed the baseline assessment and formally began the study. It is important to note that at the end of the baseline assessment, each participant was automatically presented with the home page of the condition to which he/she was randomly assigned. If, following the end of the assessment, a participant continued to explore the Web-based content, then that event was counted as a unique visit and assigned a value of zero (since zero days had elapsed since the end of the baseline assessment). If a participant had multiple visits on any given day, then this analysis counted each of those visits in the total for that day (ie, participants could have multiple visits per day).

We limited our analysis to those visits in which Web-based program content pages were accessed.

In addition to measuring the number of visits per day, we used Kaplan-Meier survival analyses [34-36] to examine the pattern of reduced program participation, also known as *nonusage attrition* [1]. For purposes of this analysis, each participant's last visit that involved review of program content was designated as the date that program usage ended. Duration was defined as the number of days that elapsed since program enrollment (the start of the program) and the date of the last visit. More technically, the population survivor function represents time versus the probability that a randomly selected program participant will continue to access the program. Since all participants stopped using their assigned website in the analysis period (the defined terminal event), no cases were censored. In addition to examining the survival curve, we also report on the estimated median lifetime for each condition, which describes how much time passed before 50% of the sample stops accessing the Web-based program [34].

Viewing Smokeless Tobacco Cessation Content

Finer grained within-visit analyses focused on participants' viewing of Web pages that presented specific content designed to encourage smokeless tobacco cessation. Because we recorded the date/time of each Web page viewed during each visit, it was possible to calculate the percentage of participants who viewed specific types of Web pages (using the participant sample in each condition as the denominator). For example, we were able to measure the extent to which participants in either condition accessed a ChewFree.com Web page that provided links to other websites offering smokeless tobacco cessation information and assistance (eg, the National Cancer Institute, the National Spit Tobacco Education Program, and the Oral Health America Foundation).

In the Enhanced condition, we also measured participants' use of ChewFree.com Web pages that offered more interactive features, including whether they viewed pages that automatically played video testimonials, whether they accessed a Web page that offered a print feature (and triggered a print dialog box), and whether they listed the names of people whom they believed could offer useful support for smokeless tobacco cessation. And although this paper focuses on exposure rather than on outcome results, we also report on the extent to which participants in the Enhanced condition used the Web page designed to help them choose a quit date for stopping the use of smokeless tobacco.

Web Forum Data

Finally, we captured data on the extent to which participants in the Enhanced condition used the available peer Web forum ("Talk with Others") or expert forum ("Ask an Expert"). Forum use was logged into the database when participants posted messages, either by creating a new message or responding to an existing message. Unfortunately, we did not track passive

viewing of the forum messages, nor did we collect data that would allow us to calculate the amount of time spent viewing forum content.

Results

Treatment-Related Email Prompts

Analysis revealed that 63.3% of participants (760/1220) in the Enhanced condition set a quit date and were sent a program-generated series of tailored email prompts associated with preparing to quit. After having been sent at least one of these emails, 10.7% of these participants (81/760) requested to opt out of receiving further emails. A total of 40.7% of participants (488/1220) who reported having quit using smokeless tobacco during the course of the program were eligible to be sent a series of emails supportive of continued abstinence. However, the number of participants who were sent these supportive emails was reduced to 34.8% (425/1220) because 63 had opted out of receiving program-generated emails. Enhanced condition participants who had not exercised the opt-out option (90%; 1079/1200) were also scheduled to receive emails at 7, 30, and 60 days since last log-in, encouraging them to re-engage with the site. We plan to conduct future analyses to assess the relation between the automated email prompts, website usage, and outcome results.

Number and Duration of Unique Visits

Our initial analysis showed that 0.6% of participants (7/1260) in the Enhanced condition and 0.8% of participants (10/1263) in the Basic condition never visited their assigned website after completing the baseline assessment and becoming enrolled. An additional 3.7% of participants (47/1260) in the Enhanced condition and 5.9% of participants (74/1263) in the Basic condition returned following enrollment but did so only to complete online assessments. These individuals never viewed any Web pages that contained smokeless tobacco cessation content. Removing these participants from our analyses reduced the sample to 2375 participants (1200 in Enhanced condition; 1175 in Basic condition) for whom visit duration could be measured (Table 1).

Rather than being normally distributed, the observed patterns of website visit frequency and duration displayed a significantly positive- or right-skewed distribution, with most cases having occurred at lower values (more frequent and longer visits occurring soon after enrollment). We used the nonparametric Mann-Whitney *U* test to compare these results by condition. Participants in the Enhanced condition made significantly more visits than participants in the Basic condition ($z = -16.64$, $P < .001$, 2-tailed). We also calculated the length of each visit by summing the length of each page view within each visit. Participants in the Enhanced condition spent significantly more time viewing website content collapsed across all Web pages and visits ($z = -17.63$, $P < .001$, 2-tailed).

Table 1. Visit details by participant

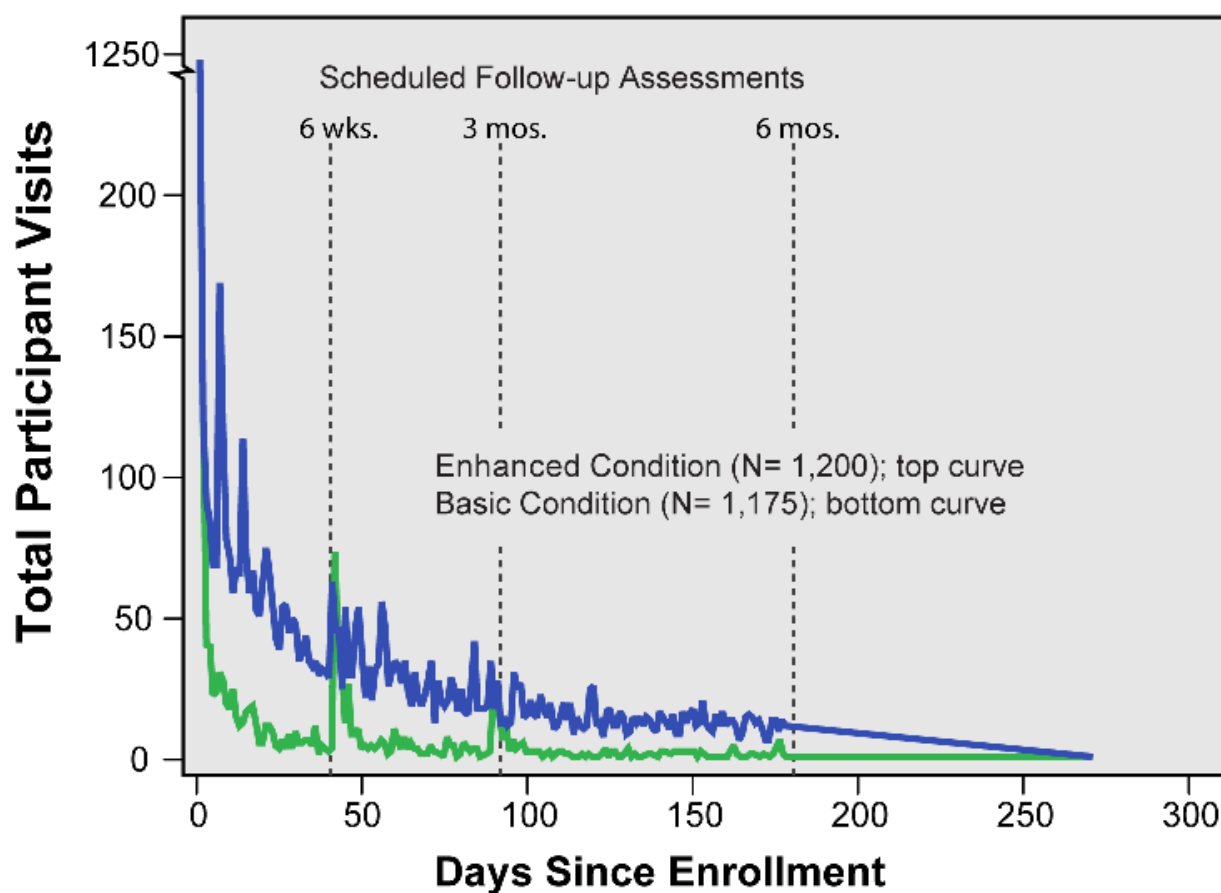
		Visits by Participant*		Overall Visit Duration by Participant* (min)	
Condition	N	Median	Interquartile Range	Median	Interquartile Range
Enhanced	1200	2.00	3 (1-4)	28.99	37.75 (13.60-51.35)
Basic	1175	1.00	1 (1-2)	12.50	15.83 (6.60-22.43)

*P < .001

Visits Following Enrollment

Visits by time course for those 2375 participants who viewed smokeless tobacco cessation content are depicted in Figure 3. Note that if a participant only viewed website content on the

day of his/her enrollment, then that individual would be listed in this analysis as having 0 days (zero days since the day of enrollment). In this analysis, a participant could have multiple visits in any given day.

Figure 3. Visits following enrollment

We observed 3783 visits for participants in the Enhanced condition and 2054 visits in the Basic condition. Consistent with usage patterns reported in other research of Web-based interventions [1], participants in our study visited their assigned website more frequently and in greater numbers immediately following enrollment. Thereafter, we observed a steady decrease in visits over time with rapid drops occurring soon after enrollment followed by a slower reduction in visits toward zero asymptote. Even though the analysis did not include all visits that focused only on online follow-up assessments, it nonetheless

appears that visits for program content were related to the timing of online assessments and their reminder emails (note vertical markers for the assessments at 6 weeks, 3 months, and 6 months) such that assessment dates appeared to reduce the rate (the steepness of the curve) of declining visits. It is important to note in this regard that upon completion of the online assessment, each participant was returned to the website home page, which would encourage them to review program content.

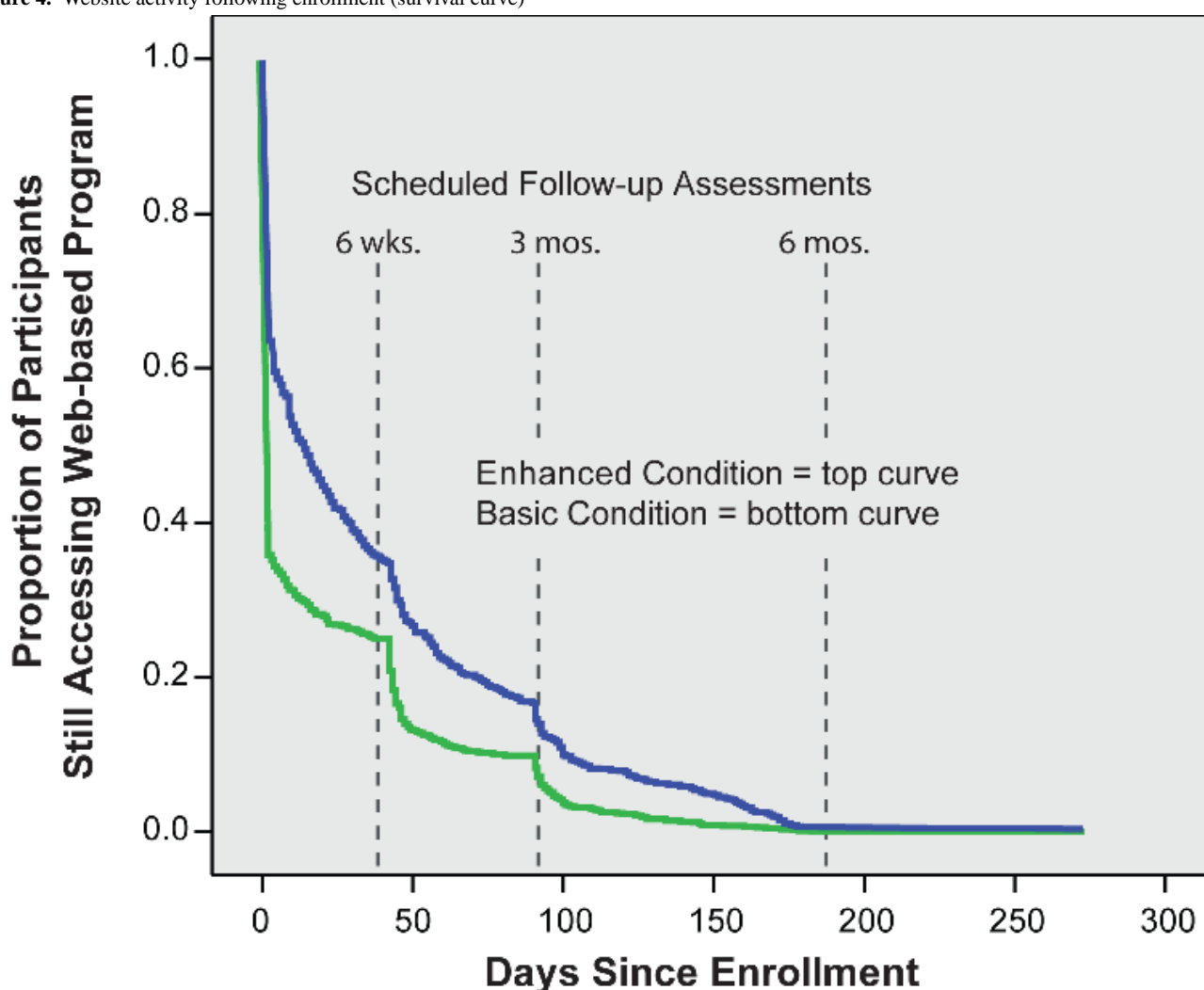
We also examined the number of days following enrollment that participants continued to access their assigned website for

program content (excluding visits to take online assessment only). For purposes of this survival analysis, the last content-accessing visit for each participant was designated as the final date of program usage. For example, 36.1% of participants (433/1200) in the Enhanced condition and 60.7% (713/1175) in the Basic condition stopped using the program on the day they enrolled in the program. Because Figure 4 depicts the percentage of participants who continued to use the program (the "survivors"), it shows that 63.9% of participants in the Enhanced condition and 39.3% of participants in the Basic condition continued to use the program after Day 0 (enrollment day).

We assumed that each participant, regardless of condition, would eventually stop using the Web-based program. Thus we examined the differential pattern of program use atrophy. As

depicted in Figure 4, website access essentially stopped by 6 months following program enrollment. The estimated median lifetime website usage (date when 50% of participants stopped using the program) was 11 days for the Enhanced condition and 0 days (ie, the enrollment day) for the Basic condition. A Kaplan-Meier survival analysis indicated that, following enrollment, participants in the Enhanced and Basic conditions exhibited significantly different patterns of continued access to the Web-based program. Both log-rank (Mantel-Cox) and Breslow (generalized Wilcoxon) tests were highly significant ($P < .001$), with the Enhanced condition showing a slower decay (less nonusage attrition) over time than the Basic condition. As noted in the analysis of total visits following enrollment (Figure 3), we observed that reduced program usage was related to the prompting effects of the follow-up assessments at 6 weeks, 3 months, and 6 months.

Figure 4. Website activity following enrollment (survival curve)



Viewing Web Pages With Smokeless Tobacco Cessation Advice

In addition to metrics of overall website exposure, we were interested in the extent to which participants accessed content that contained specific information most relevant to smokeless tobacco cessation and tobacco abstinence. Table 2 displays data on the viewing of selected Web pages that contained information

on smokeless tobacco cessation. It is interesting to note that when similar pages were available on both websites (those presenting outside links and the opportunity to print content), a higher percentage of participants in the Basic condition accessed that content than did participants in the Enhanced condition. Similarly, almost 88% of participants in the Basic condition compared with 12.2% of participants in the Enhanced condition viewed every page in an 11-page self-help smokeless

tobacco quitting guide. This guide, adapted from the *Enough Snuff* guide [37], was deeply embedded in the Enhanced condition website, thus making it somewhat more difficult to use.

Table 2. Web page viewing by participants who accessed at least one Web page containing smokeless tobacco cessation content

Condition	N	Outside Links (%)	Print Content (%)	Smokeless Tobacco Quitting Guide (%)	Video Testimonial (%)	List of Support People (%)	Set Quit Date (%)	Staying Quit Content After Quitting (%)
Enhanced	1200	18.2	78.3	12.2	68.2	24.7	63.3	32.8
Basic	1175	32.1	96.3	87.5				

Web Forum Usage

We found that 38.2% participants in the Enhanced condition (481/1260) posted content to the Web forum for peers, with 5.2% (65/1260) posting at least one message in the expert forum (Table 3). Each participant who posted a message to the "Ask an Expert" forum also posted at least one message to the peer forum. The distribution of forum postings was right- or positively-skewed, with most cases clustered at lower values

(fewer postings). The median number of postings was 2 in the peer forum and 1 in the expert forum. The interquartile range was 11 postings (1-11.50) for the peer forum and 1 posting (1-2) for the expert forum. Using the nonparametric Spearman rank correlation test, we found that forum postings were significantly correlated with visits ($p = .512$, $n = 481$, $P < .001$, 2-tailed) and Web page views ($p = .340$, $n = 481$, $P < .001$, 2-tailed) for participants in the Enhanced condition.

Table 3. Web forum activity in the Enhanced condition (n = 1260 users)

Forum Type	Users		Postings by User	
	n	%	Median	Interquartile Range
Peer	481	38.2	2	11 (1-11.50)
Expert	65	5.2	1	1 (1-2)

Discussion

It is important to acknowledge several limitations to the present study. First, we did not design the Enhanced intervention website to track passive Web forum viewing. This limitation prevented us from analyzing the duration of Web forum visits by participants who observed postings but did not post their own comment on the forum posts of others. In addition, although study inclusion criteria required all study participants to be able to access their personal email at least once per week, we did not collect data on participants' previous experience using the Internet or on their computer self-efficacy [38]. As a result, we cannot report directly on whether there were significant differences between the intervention and control conditions for these dimensions. We believe that random assignment and our large sample size (N = 2375) would tend to mitigate the likelihood of this effect.

It is thought that a key ingredient in determining the impact of any Web-based behavior change program is the extent to which participants are exposed to the program. This assumption is consistent with the finding that the efficacy and intensity of treatment programs tend to be positively related. For example, research on smoking cessation interventions—including self-help approaches—has illustrated the relationship between abstinence rates and program intensity, typically defined as contact time and number of sessions [4,39,40]. Williams et al [41] have coined the term program *thickness* to refer to the

"collective intensity, duration, delivery agent, and intervention modality" of an intervention. However, research has also shown that more is not always better when considering which ingredients to include in an intervention [42] or a website [19,43,44], perhaps because adding features increases the response cost of participation and reduces usage.

Some reviewers of this burgeoning field have recommended that fuller participation in Web-based interventions might be encouraged through the use of a "warm-up period" during which users can demonstrate their commitment by complying with precursor tasks while they become more familiar with what will be asked of them during the course of the program [1,45]. The use of intensive treatment approaches and preliminary litmus tests of commitment must be tempered by recognizing the continuum between clinic-based and public-health models for intervention. Specifically, it may be not be a practical goal to provide a highly intensive, population-wide intervention. Moreover, the use of preliminary barriers may help to reduce attrition in efficacy trials but reduce our ability to conduct effectiveness trials that have a broader reach and greater potential to achieve public health impact [46,47]. A challenging—and fruitful—line of research lies in identifying the proper program ingredients that provide a balance between sufficient exposure to relevant content and structure on the one hand while encouraging widespread user participation and engagement (both recruitment and follow-through).

We found that the estimated median lifetime website usage (date when 50% of participants stopped using the program) was 11 days for the Enhanced condition and 0 days (ie, the enrollment day) for the Basic condition. We anticipate that some measures of exposure and outcome will likely share a curvilinear (inverted U-shaped) relationship such that those individuals who are least ready to make a meaningful change may be more likely to visit the Web-based program for a short time, while participants who are most prepared to change their behavior may similarly choose to visit the Web-based program for a relatively short time. Those participants who are interested in quitting and decide to learn more about how to do so will spend relatively more time visiting the program. It remains for future research to differentiate characteristics that illuminate the pattern of this relationship among motivation, readiness to quit, and program usage.

Measures of participant exposure can help researchers and program developers determine the extent to which content is viewed. These data can point to needed changes in the information architecture and design features of the website. It is reasonable to assume that program content cannot be helpful if it is never viewed. Exposure measures may have utility in that they inform us about whether certain content—or clusters of content—is related to outcome and thus might be considered to be active ingredients in accomplishing the desired behavioral goals. They enable us to better understand idiosyncratic patterns of program use, highlighting ways we can adapt program structure and content to better accommodate (be tailored to) individual differences in participant interests, needs, and learning styles.

In this regard, we intend to examine a variety of relationships between and among measures of exposure and the smokeless tobacco and tobacco cessation outcome measures in the ChewFree.com research project. For example, we will test whether participants who set a quit date are more successful in quitting, as well as whether, after quitting, there is a relationship between accessing content from the Staying Quit module (number and duration of visits) and lasting abstinence. Similarly, we will examine whether those participants who spend more time reviewing program content after they have lapsed are better able to regain control over their behavior and regain abstinence.

We also plan to perform content and text analyses of Web forum postings [eg, 48] to explore whether smokeless tobacco cessation might be related to message types, whether cessation and maintenance strategies shared in postings are consistent with program recommendations, and the extent to which postings convey differing levels of confidence and self-efficacy across participants as well as within participants over time.

There is a significant risk of collecting so much detailed exposure and engagement data that the task of analyzing and interpreting results becomes difficult. We suggest that this task can become more manageable and, thus, more fruitful, by focusing its scope through the use of a rationale that incorporates both theory and pragmatism. Potentially relevant rationales are not difficult to identify. Consider, for example, a rationale that builds on the Web foraging model [49,50], which posits that Web users guide their review of online content by quickly identifying interesting *information scents* in website materials. This model suggests that websites should foreshadow content even when it is not immediately accessible in order to engage users. It also points to particular usage patterns—brief initial visits followed by later visits of more duration [49]. The Transtheoretical/Stages of Change model may also hold promise in focusing the analysis of exposure and engagement. Velicer et al [51] suggest that users in action stage will access a program relatively more than users characterized as being in early stages (precontemplation, contemplation) or the later maintenance stage. Similarly, it might be helpful to consider the behavioral self-management model [17,52,53], which suggests that users who become more confident and capable in their self-management skills would tend to access a program less over time.

We view exposure as representing one of a set of complementary measures of the broader theme of program engagement. Other engagement measures include participant comprehension of program content, practice of that content (especially in the participant's everyday routines outside of interacting with the Web-based program), self-reported satisfaction with the function and content of the website, and measures of self-efficacy. While exposure is obviously important (indeed, it is best viewed as a prerequisite), it represents only one piece of the puzzle in seeking to understand program effectiveness.

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Conflicts of Interest

None declared.

Appendix 1

Table 4. Table of detailed measures of program exposure

Email prompts	a) Percentage of participants receiving email prompts	Programmatic rules defined the timing of email prompts regarding completion of online assessments that were sent to participants in both conditions. Participants in the Enhanced condition also were sent "treatment-related" email prompts that contained tailored content related to quitting plan, quit date, and support of continued abstinence.
Participant visits	b) Number of visits	Visits by each participant to access smokeless tobacco cessation content on their assigned website were counted. All visits in which only online assessments were accessed were excluded.
	c) Aggregate duration of visits	Duration of each visit was defined as the sum of Web page durations during that visit. With one exception (noted next), Web page durations were defined as their logged end time minus start time. Because our program logic did not include a session-expiration feature that automatically logged out after a period of inactivity, we conservatively approximated the end of the visit by using the date/time of the last Web page that had been accessed before the abrupt end of the session. In addition, we followed the operational definition for visit expiration recommended by Peterson; that is, any Web page viewed for 30 minutes or more was defined as having ended the visit using the ending date/time stamp of the Web page that immediately preceded the hiatus. Moreover, if, after the hiatus, the participant resumed activity, it was considered to be a new visit for measurement purposes.
	d) Number of daily visits post-enrollment	The number of daily visits per participant was counted with "days" being defined in terms of their occurrence relative to the participant enrollment date. Participants could have more than one visit per day, and visits were defined using Peterson's recommendation (see above). Total visits per post-enrollment date aggregated these data across participants.
	e) Number of days of program access post-enrollment	The number of days of post-enrollment access to smokeless tobacco cessation content was defined for each participant as the last visit date minus the enrollment date.
	f) Plan to Quit	Participants in the Enhanced condition were given the opportunity to define a personal quitting plan and quit date. Although the program allowed participants to define their quitting plan and date multiple times, for purposes of the analyses in this report, we focused only on the first recorded date when a participant defined his/her quitting plan/date.
	g) Smokeless tobacco quit status	Participants in the Enhanced condition were able to indicate that they had quit using smokeless tobacco. This report enabled them to access "Staying Quit" content.
Web page views	h) Overall number of Web page views	The total number of Web pages viewed was logged.
	i) Specific page views (selected smokeless tobacco cessation content)	The total number of selected Web pages viewed related to smokeless tobacco cessation was logged, and a subset of these is described in this report.
	j) Web forum postings	Individual forum postings—in each of the two forums—were logged for each participant (Enhanced condition only).

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Original Paper

Characterizing Internet Searchers of Smoking Cessation Information

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Abstract

Background: The Internet is a viable channel to deliver evidence-based smoking cessation treatment that has the potential to make a large population impact on reducing smoking prevalence. There is high demand for smoking cessation information and support on the Internet. Approximately 7% (10.2 million) of adult American Internet users have searched for information on quitting smoking. Little is known about these individuals, their smoking status, what type of cessation services they are seeking on the Internet, or how frequently these searches for cessation information are conducted.

Objective: The primary goal of this study was to characterize individuals who search for smoking cessation information on the Internet to determine appropriate triage and treatment strategies. The secondary goal was to estimate the incidence of searches for cessation information using publicly available search engine data.

Methods: We recruited individuals who clicked on a link to a leading smoking cessation website (QuitNet) from within the results of a search engine query. Individuals were “intercepted” before seeing the QuitNet home page and were invited to participate in the study. Those accepting the invitation were routed to an online survey about demographics, smoking characteristics, preferences for specific cessation services, and Internet search patterns. To determine the generalizability of our sample, national datasets on search engine usage patterns, market share, and keyword rankings were examined. These datasets were then used to estimate the number of queries for smoking cessation information each year.

Results: During the 10-day study period, 2265 individuals were recruited and 29% (N = 655) responded. Of these, 59% were female and overall tended to be younger than the previously characterized general Internet population. Most (76%) respondents were current smokers; 17% had quit within the last 7 days, and 7% had quit more than 7 days ago. Slightly more than half of active smokers (53%) indicated that they were planning to quit in the next 30 days. Smokers were more likely to seek information on how to quit and on medications; former smokers were more interested in how to cope with withdrawal. All participants rated withdrawal information and individually tailored information as being more useful, while displaying little interest in telephone counseling, expert support, or peer support. Publicly available data from large search engines suggest that 4 million Americans search for resources on smoking cessation each year.

Conclusions: This study adds to the limited data available on individuals who search for smoking cessation information on the Internet, supports the prior estimates of the size of the population, and indicates that these individuals are in appropriate stages for both active cessation interventions and aggressive relapse prevention efforts. Continued development and evaluation of online interventions is warranted, and organizations seeking to promote cessation should carefully evaluate the Internet as a possible modality for treatment and as a gateway to other traditional programs.

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KEYWORDS

Smoking; cessation; Internet; search engine; query

Introduction

The Internet has become the first source of health information for many people, primarily due to the ease of finding information [1]. In particular, there appears to be great demand for online information and services related to smoking cessation. In a random-digit dial survey conducted in 2004, 7% of Internet users in the United States reported using the Web to search for information on “how to quit smoking” [2]; more women reported to have looked than men (10% vs 7%), and unlike other health-related information seekers, they tended to be younger. At the time, this represented approximately 10.2 million people who had ever turned to the Internet for smoking cessation-related information or services. Little is known about these individuals, including their basic demographic characteristics, smoking status (eg, current smokers seeking cessation treatment, recent quitters seeking support to maintain abstinence), readiness to quit, quitting history, and treatment preferences. With the proliferation of antismoking sentiments and restrictive smoking policies, a diverse group of individuals may be turning to the Internet for assistance. In order to provide individually tailored and effective cessation treatment services via the Internet, it is necessary to better understand the characteristics and needs of this population.

The Internet is a powerful delivery channel that has the potential to deliver behavior change interventions on a population-wide basis to help people modify risk factors such as smoking [3]. There are limited, but encouraging, data to indicate that Web-based cessation interventions are effective in controlled trials [4-6]. However, it is not known if these approaches are appealing to or appropriate for the broader population of Internet users seeking cessation assistance. For example, approximately 30% of visitors to a widely utilized smoking cessation website indicated that they had quit smoking within the past week [7]. These individuals would be excluded from most randomized clinical trials of smoking cessation treatment, but they may represent a sizable population in need of assistance to remain abstinent. Information and services may need to be specially tailored to address the unique needs of individuals searching for cessation information based on their smoking status, demographic characteristics, and quitting history.

The incidence of cessation-related Internet searches may provide an effective proxy for consumer demand for cessation services. To date, there is little information about the rate at which searches for smoking cessation information occur. Several different techniques have been used to estimate the frequency of general health-related Internet searches [8-10], with widely varying results. Analyzing the first 300 search terms of the Wordtracker Top 500 keyword list, Phillipov and Phillips found less than 1% to be health-related terms [10]. Eysenbach took repeated snapshots of current search terms used on a search engine over a 15-month period, analyzed a random subset of queries, and found that 3.6-5.3% could be classified as health related [8]. Fox found that 79% of surveyed individuals had ever searched for health or medical information, while 7% had searched for smoking cessation information [2].

The primary purpose of this study was to characterize individuals who search for smoking cessation information. Specifically, we sought to gather information about sociodemographic and smoking history variables, search patterns (eg, time of day, search terms used), and perceptions about specific types of cessation services. Additionally, we used publicly available data to estimate the incidence of these searches. This information will be critical to develop appropriate and effective online cessation treatment programs, to triage patients as part of a stepped-care treatment model, or to successfully recruit smokers into treatment via the Internet.

Methods

Recruitment and Eligibility

Our recruitment strategy leveraged the prominent position of QuitNet (www.quitnet.com) on three of the largest Internet search engines. QuitNet is an established smoking cessation website [7] that is highly utilized, with over 600000 visitors and 97000 new registrants in 2004 from the United States alone. During the period of this study, it was listed in the top results for queries using “quit smoking” or “stop smoking” on three large search engines: Google, Yahoo!, and MSN ([Appendix 1](#)). In 2003, approximately 210000 (globally) and 110000 US individuals looking for information on quitting smoking arrived at QuitNet via these search engines. It has been estimated that 80% or more of Web users seeking health information start from search engines [11,12]. Research shows that Internet users read search engine results linearly, pay the most attention to the top three to five results, and click on the first promising link they find in the results [11,13]. Therefore, individuals who click on the link to QuitNet from a search engine results page are likely to be a representative sample of those individuals looking for cessation information on the Internet.

We recruited individuals based on four inclusion criteria: (1) use of the terms “quit smoking,” “quitting smoking,” “stop smoking,” or “stopping smoking” in a search engine query; (2) use of one of three major search engines (Google, Yahoo!, or MSN) to conduct these queries; (3) no prior visit to the QuitNet website (defined as www.quitnet.com or www.quitnet.org) as determined by the absence of a persistent (long-term) tracking cookie; and (4) location within the United States as determined by reverse lookup of IP (Internet protocol) addresses. When eligible Internet users clicked on the QuitNet link in the results of a search engine query, they were “intercepted” and recruited to participate in the study. The recruitment screen contained links to the survey and to the QuitNet website ([Appendix 2](#)). Those who accepted the invitation were directed to the QuitNet website following completion of the survey. Those who declined the survey invitation went directly to the QuitNet website. Recruitment for the survey was conducted for a total of 10 days: it began December 30, 2003, was suspended January 1 through January 3 due to technical concerns, and was completed January 12, 2004.

Generalizability was established from the complete panel of respondents, while we restricted further analysis to the respondents that reported any history of smoking and were seeking assistance for themselves.

Measures

The survey consisted of 10 questions that included basic demographic information (age, gender), reasons for searching for cessation information, current smoking status, readiness to quit, quitting history (number of past quit attempts, length of quit, quit methods used), information desired, and ratings of perceived helpfulness of various online cessation features (eg, bulletin board, assistance in setting a quit date). The survey questions were administered on three separate screens, with no more than three questions per screen. Date and time of survey completion were automatically logged to the database.

Data on utilization of QuitNet after survey administration were extracted, including registration and total time online. Time online was defined as the time between the first page view after completion of the survey through the time of the last page view.

Statistical Analyses

To determine the generalizability of our final sample, we compared survey respondents to nonrespondents who went on to register and use the QuitNet website on the demographic, website utilization, and search pattern variables obtained from the QuitNet database. In addition, we sought to determine the generalizability of our sample to the broader population of individuals who search for online smoking cessation information throughout the year. To do this, we examined the percentage of participants referred from each search engine as well as the total volume of cessation search terms used in Internet search engine queries, using publicly available data from Nielsen/NetRatings

[14], Overture, and Wordtracker. Chi-square analyses were used to compare our sample to these national datasets.

For the 10-item survey, frequency tables were used to summarize the categorical data, and nonparametric tests were used to determine the statistical significance level. We used *t* tests for normally distributed continuous and ordinal variables.

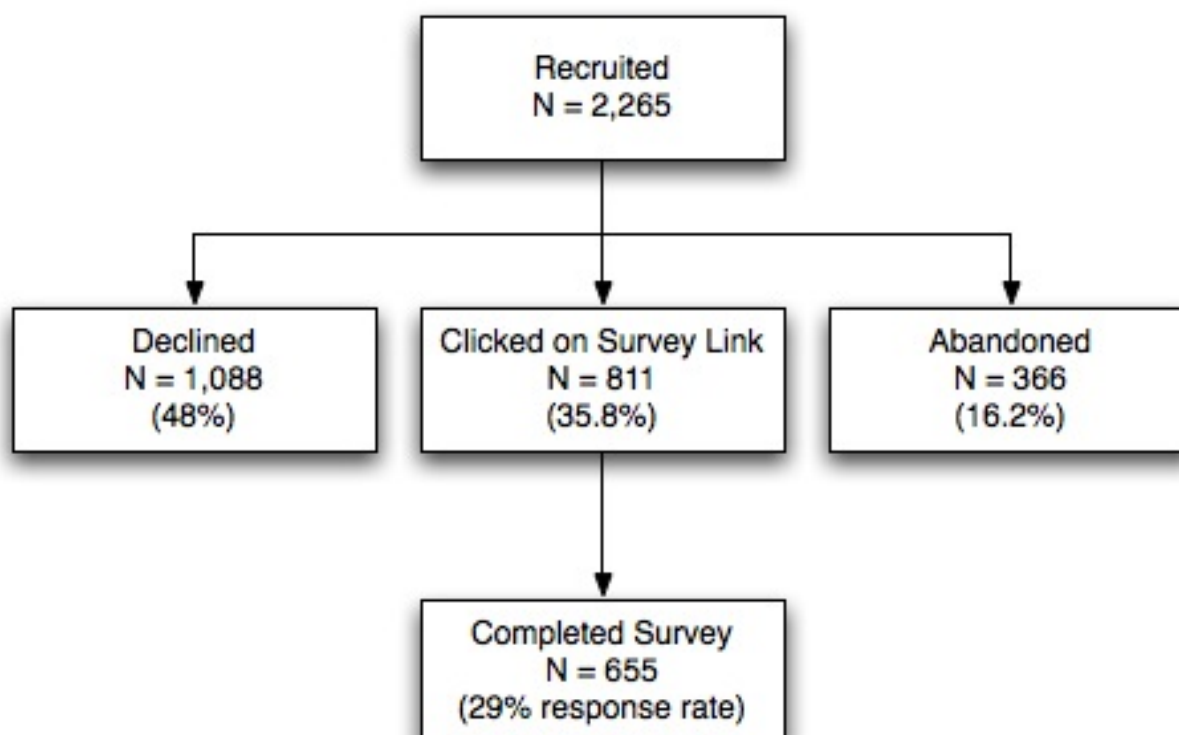
Finally, to estimate the incidence of cessation-related Internet searches each year, we replicated the technique used by Eysenbach and Kohler [8]. MetaSpy was queried several times per day over the course of 9 months and the active queries were logged. Duplicate results (defined as the same set of 10 search terms being returned in succession) were removed. Searches containing the key words “quit[ing] smoking” or “stop[ing] smoking” were classified as cessation related.

Results

Recruitment Outcomes

During the 10-day study period, 2265 eligible US residents were intercepted. Of those, 35.8% (*N* = 811) clicked on the “survey” link, 48% (*N* = 1088) clicked on the link to take them directly to the site (“declined”), and 16.2% (*N* = 366) did neither (“abandoned”). Of the 811 individuals who clicked through to the survey, 87.2% (*N* = 655) completed the full survey, yielding an overall response rate of 29% (Figure 1). Of the survey completers, 29 individuals reported having never smoked, leaving a final sample of 626 respondents.

Figure 1. Eligibility and Recruitment Results



Generalizability

To assess generalizability, we compared all survey participants ($N = 655$) with nonrespondents who proceeded to register with QuitNet ($N = 243$). Overall, nonrespondents ($N = 1454$, abandoned and declined) were significantly less likely than survey respondents to register on QuitNet (16.7 vs 51.4%, $X^2_2 = 303.7$, $P < .001$). Compared to survey respondents, nonrespondents spent less time on QuitNet (4.5 vs 12.0 minutes, $t = 13.4$, $P < .001$) and viewed fewer pages (5.9 vs 15.3 pages, $t = 16.0$, $P < .001$) on the website. Nonrespondents were more

likely to be female (59.4 vs 51.9%, $X^2_2 = 4.2$, $P = .02$) but did not differ by age, smoking status, time of survey invitation, or specific search engine used.

As shown in Table 1, the relative volume of participants referred from each search engine was consistent with national usage patterns ($X^2_2 = 1.06$, $P = .59$). In this study, 57% of participants were referred from Google, 29% from Yahoo!, and 14% from MSN. At the time of this study, 60% of all Internet search queries were estimated to be conducted using Google, 23% with Yahoo!, and 17% with MSN [14].

Table 1. Comparison of search engine usage to Nielsen/NetRatings statistics

Search Engine	Relative Reach of Search Engines	
	Survey Recruitment (%)	National Usage (%)
Google	57	60
Yahoo!	29	23
MSN	14	17
Total	100	100

The use of key search terms (“quit smoking,” “quitting smoking,” “stop smoking,” or “stopping smoking”) by survey respondents was also consistent with search patterns captured by Overture and Wordtracker. As shown in Table 2, the most commonly used search term was “quit smoking,” which

constituted 52.9% of study queries, 59.1% of Overture queries, and 47.8% of Wordtracker queries. “Stop smoking” was the second most frequently used search term, which constituted 24.9% of study queries, 31.1% of Overture queries, and 36.5% of Wordtracker queries.

Table 2. Frequency of smoking-related search terms in search engine queries

Search Term	Searches (%)	Survey Participants (%) ($X^2_4 = 3.35$, $P = .80$)	Overture (%) ($X^2_4 = 152$, $P < .001$)	Wordtracker (%) ($X^2_4 = 138$, $P < .001$)
quit smoking	52.9	55.4	59.1	47.8
stop smoking	24.9	23.9	31.1	36.5
quitting smoking	21.9	20.4	9.0	13.4
stopping smoking	0.3	0.4	0.6	1.8
giving up smoking	0.00	0.00	0.2	0.6

Participant Characteristics

As shown in Table 3, the majority of study participants were female (61.2%, $n = 383$) and between the ages of 26 and 44 years (62.7%, $n = 393$); 18.7% ($n = 117$) were aged 18-25 years, 17.1% ($n = 107$) were aged 45-64, and less than 1% were 65 or older ($n = 4$) or under age 18 ($n = 5$). Adjusted to local time of the participant, more than half (53.4%) of search engine queries for cessation information occurred during work hours (8 am-5 pm), 26.6% occurred between 5-9 pm, and 20% occurred at night (9 pm-6 am).

Participants were asked the reason they were searching for smoking cessation information. The majority of survey respondents (90.1%, $n = 590$) indicated that they were looking for help or support for themselves; 5.6% ($n = 37$) were looking for general information; 3.4% ($n = 22$) were looking for help for someone else; and 1% ($n = 6$) were health professionals or researchers looking for information. Further analyses were limited to individuals looking for cessation help or support for themselves or for general cessation information ($N = 626$). Among these individuals, 75.4% ($n = 472$) were current smokers, 17.4% ($n = 109$) had quit within 7 days (“recent quitters”), and 7.2% ($n = 45$) had quit more than 7 days ago (“longer-term quitters”).

Table 3. Demographic and smoking characteristics of study participants (N = 626)

Characteristic	Number of Participants (%)
Age	
< 18	5 (0.8)
18-25	117 (18.7)
26-34	232 (37.0)
35-44	161 (25.7)
45-54	87 (13.9)
55-64	20 (3.2)
65 or older	4 (0.6)
Gender	
Male	243 (38.8)
Female	383 (61.2)
Smoking Status	
Current smoker	472 (75.4)
Not thinking of quitting	1 (0.2)
Thinking of quitting in 6 months	222 (35.5)
Thinking of quitting in 30 days	249 (39.8)
Quit ≤ 1 week	109 (17.4)
Quit > 1 week, ≤ 1 month	43 (6.9)
Quit > 1 month	2 (0.3)

The majority of current smokers (52.8%, $n = 249$) planned to quit in the next 30 days, 47.0% ($n = 222$) planned to quit in the next 6 months, and one person (0.2%) was not thinking about quitting. Smokers had made an average of 5.1 quit attempts ($SD = 14.7$; median = 1) during the past year.

Information Preferences

As shown in Table 4, information preferences varied by smoking status. Current smokers were more likely than recent quitters

and longer-term quitters to be interested in information about how to quit smoking (88.1%, 54.1%, and 40.0%, respectively; $X^2_2 = 104.7$, $P < .001$) and medication usage (30.7%, 5.5%, and 4.4%, respectively; $X^2_2 = 41.0$, $P < .001$). Not surprisingly, both recent quitters and longer-term quitters were more interested than current smokers in information about withdrawal (77.1%, 66.7%, and 59.7%, respectively; $X^2_2 = 11.7$, $P = .003$).

Table 4. Information sought by smoking status (N = 626)

Information	Current Smoker (%) ($n = 474$)	Quit ≤ 1 Week (%) ($n = 109$)	Quit > 1 Week (%) ($n = 45$)	X^2_2	P value *
How to quit	88.1	54.1	40.0	104.7	< .001
Medications	30.7	5.5	4.4	41.0	< .001
Alternative methods	57.6	16.5	17.8	77.3	< .001
Withdrawal	59.7	77.1	66.7	11.7	.003

*Current smokers are the reference group.

Note: Multiple responses were allowed, so total percentages within smoking category exceed 100%.

Perceived Helpfulness of Cessation Services

Participants were also asked to rate the perceived helpfulness of various smoking cessation treatment interventions on a scale from 1 to 5, with 1 representing “very helpful” and 5 representing “not helpful at all.” As shown in Table 5, the three features that were rated most highly by all participants were (1) individually tailored information (mean = 1.90, $SD = 1.18$); (2) information on withdrawal (mean = 1.84, $SD = 1.15$); and (3)

a meter that keeps track of personal data (mean = 2.14, $SD = 1.37$). The three features rated the lowest by all participants were (1) support from a telephone counselor (mean = 3.21, $SD = 1.35$); (2) email support (mean = 2.95, $SD = 1.40$); and (3) support from others (mean = 2.90, $SD = 1.38$). Ratings of perceived helpfulness varied according to smoking status. Current smokers rated information about medications, assistance in setting a quit date, and assistance in choosing a medication as more helpful than did recent quitters and ex-smokers. Support

from others and information about withdrawal received higher ratings of perceived helpfulness from recent quitters and ex-smokers than from current smokers. As detailed in Table 6, information of withdrawal, individually tailored information,

and tracking meters were rated as “helpful” or “very helpful” by over half of the participants, while telephone counseling was thought to be helpful by less than 30% of participants.

Table 5. Perceived helpfulness of Internet features by smoking status

Feature	All Participants, Mean (SD) (N = 626)	Current Smokers, Mean (SD) (n = 472)	Quit ≤ 1 Week (n = 109)		Quit > 1 Week (n = 45)	
			Mean (SD)	P value*	Mean (SD)	P value*
Information on withdrawal	1.84 (1.15)	1.90 (1.17)	1.67 (1.08)	.06	1.51 (0.75)	.04
Individually tailored information	1.90 (1.18)	1.88 (1.18)	2.00 (1.25)	.36	1.79 (0.95)	.62
A meter that keeps track of personal data	2.14 (1.37)	2.14 (1.37)	2.14 (1.42)	1.0	2.15 (1.31)	.97
Information on medication side effects	2.59 (1.38)	2.55 (1.38)	2.79 (1.34)	.11	2.54 (1.43)	.97
Assistance in choosing a medication product	2.72 (1.37)	2.61 (1.36)	2.97 (1.38)	.02	3.24 (1.24)	.007
Information on medications	2.72 (1.36)	2.62 (1.36)	2.97 (1.37)	.02	3.23 (1.23)	.007
Online, personal help from a professional	2.81 (1.38)	2.79 (1.40)	2.86 (1.29)	.67	2.88 (1.39)	.70
Ability to find buddies	2.82 (1.37)	2.87 (1.39)	2.74 (1.29)	.40	2.59 (1.34)	.22
Assistance in setting a quit date	2.83 (1.39)	2.69 (1.37)	3.25 (1.32)	< .001	3.39 (1.37)	.003
Support via chat, forums, or email	2.90 (1.38)	2.98 (1.39)	2.67 (1.35)	.04	2.57 (1.30)	.07
Additional information that arrives by email	2.95 (1.40)	2.91 (1.43)	3.06 (1.30)	.34	3.08 (1.26)	.49
Talking by phone with a professional counselor	3.21 (1.35)	3.17 (1.39)	3.32 (1.22)	.32	3.46 (1.29)	.20

* P values compared to current smokers; P = ns for all comparisons between recent and long-term quitters.

Note: 1 = very helpful; 2 = helpful; 3 = somewhat helpful; 4 = not very helpful; 5 = not helpful at all

Table 6. Proportion of participants (N = 626) rating Internet cessation services as helpful or very helpful

Feature Offered	Helpful or Very Helpful	
	n	%
Information on withdrawal	460	73.5
Individually tailored information	450	71.9
A meter that keeps track of personal data	405	64.7
Information on medication side effects	303	48.4
Information on medications	275	43.9
Assistance in choosing a medication product	273	43.6
Online, personal help from a professional	265	42.3
Ability to find buddies	250	39.9
Assistance in setting a quit date	248	39.6
Support from others, via chat, forums, or email	233	37.2
Additional information that arrives by email	223	35.6
Talking by phone with a professional counselor	184	29.4

Estimating Incidence of Cessation Queries

Over the course of 9 months, 541685 searches were extracted from MetaSpy, of which a total of 38 were smoking cessation related. Assuming a total search engine volume of 52 billion searches per year [14], this ratio yields an estimate of 3.6 million (99% CI = 2.5-4.8 million) cessation-related searches per year in the United States alone.

Discussion

The Internet holds great potential to impact population smoking prevalence by delivering evidence-based treatments to greater numbers of smokers who may never receive treatment through other modalities. This is the first study to characterize the population of individuals looking for cessation information online. Results suggest that the Internet may be an effective way to reach smokers who are younger, who search for cessation services during work hours, and who have recently quit on their own.

The relatively large proportion (17.4%) of recent quitters (within 7 days) in this study who are actively seeking assistance is of particular importance. The majority of self-quitters relapse within 8 days [15]. Over 16 million Americans try to quit on their own each year, but less than 5% maintain abstinence for 3 months [16]. Thus, more than 15 million smokers relapse. Until recently [17], this segment of the population of smokers received little attention once formal cessation treatments ended. Given the reach and 24/7 availability of the Internet, effective relapse prevention interventions can and should be delivered to the thousands of smokers trying to maintain abstinence. An effective relapse prevention service for self-quitters with intensive support around the quit date could produce a significant impact on smoking prevalence and could be used in conjunction with any other cessation treatment.

New population-based strategies to identify and reach smokers with evidence-based cessation treatment are needed [3]. Currently, telephone quit lines are the primary public health delivery channel for low cost, effective tobacco treatment. Despite the obvious advantages of convenience and cost, uptake rates in states with quit lines have remained low despite aggressive promotion, with less than 2% of smokers participating [18]. Given that Internet searchers are more likely to prefer self-help treatment with lower efficacy rates, it is important to design interventions which capture initial interest that can successfully “up-sell” more intensive and effective treatment interventions such as telephone counseling and medication use. In this manner, the Internet may be able to provide a workable model for stepped care, where participants can be further triaged to receive telephone counseling; prescription medication; in-person, group, or individual counseling; or even inpatient treatment [19].

Limitations

Several limitations should be considered when interpreting results of this study. The relatively low response rate (29%) raises concern about the generalizability of findings. Survey respondents were more likely to go on to register with the site; this likely indicates that they were in a more advanced stage of

change than nonrespondents. It may, however, also indicate that the survey itself acted as an incentive to proceed to registration. Furthermore, we worked from the assumption that individuals who clicked on the link to QuitNet in search engine results were representative of the entire population of searchers. Although consistent with utilization patterns of search engines, this assumption has never been tested for searches on smoking cessation, or the QuitNet site in particular. It is possible that less motivated searchers may find the query results unappealing and not click on any link at all, thus biasing our results toward individuals closer to quitting.

A second potential limitation is the method we used to estimate the total number of people seeking smoking cessation information each year. This method does not take into account searches using other keywords or individuals using resources other than search engines to find information (eg, health Web portals, referrals from health professionals, direct-to-consumer advertising, or quit lines). In addition, individuals may search for information multiple times, making it difficult to estimate the actual number of unique individuals as opposed to the total number of searches. Finally, the dataset used to derive these estimates is of commercial nature and published online in a promotional context. It has not been peer-reviewed or made available in its raw form. The data for this study were collected from 2003-2004; it is possible that in the intervening time the demographics or search behavior of smokers has changed. However, given the limited changes in both search engine technology as well as the demographics of smokers in the United States, this seems unlikely. Despite these limitations, this study provides valuable information about people who search for smoking cessation information online, and it demonstrates a new methodology for validating this kind of survey data.

Conclusion

This study suggests that the potential public health impact that can be achieved through Internet-based smoking cessation programs is significant given the reach of the Internet—should these interventions be proven effective. Given that individuals may conduct multiple searches, our estimate of 3.6 million active searches per year for smoking cessation information is consistent with the 2004 data that showed 7% (about 10 million) of Internet users in the United States had searched for information on quitting smoking [2]. With 1.25 billion smokers throughout the world [20], there is enormous potential to globally impact smoking prevalence.

The public health community has invested heavily over the past 15 years in successfully de-normalizing smoking and encouraging cessation. However, low uptake rates seen in clinical programs and telephone quit lines call for new population-based approaches. Even if Internet-assisted tobacco interventions prove to have limited efficacy, the Web may still serve as a point of entry to multi-modality treatment programs. These programs may serve to simply link online searchers to more traditional treatment programs (such as telephone counseling or local group sessions), provide pharmaceutical products, or, in more sophisticated settings, use the Web as a platform to integrate voice counseling, local groups, mailed pharmaceutical products, and other proven modalities. We

anticipate that the consumer demand demonstrated in this report will ultimately drive increasing services that will reflect a mixture of these different evidence-based treatments.

Acknowledgments

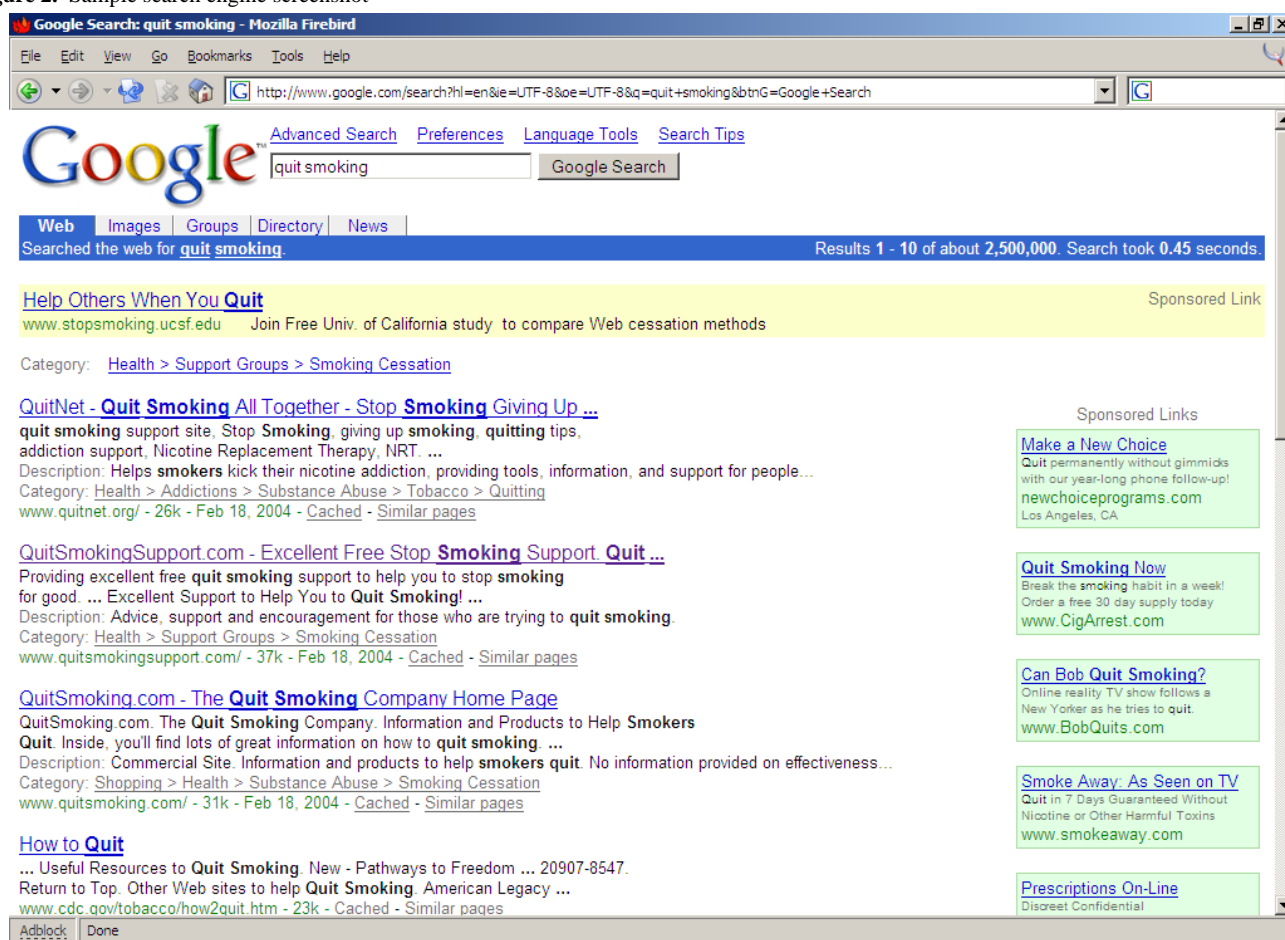
Survey deployment and data collection were performed at QuitNet Inc. by Dr. Cobb with support by the company. Drs. Graham and Cobb had complete access to all raw data, and performed all analysis and writing of the manuscript.

Conflicts of Interest

At the time of the survey design and data collection Dr. Cobb served as an executive of QuitNet Inc. as well as holding a financial interest in the company. Dr. Graham has served as a consultant to the company in the past. At the time of submission of the manuscript, neither author had an affiliation or financial involvement with QuitNet Inc.

Appendix 1

Figure 2. Sample search engine screenshot



Appendix 2

Figure 3. Survey invitation interception page



QUITNET
QUIT ALL TOGETHER

Welcome to QuitNet - the largest and oldest online resource for quitting smoking.

As part of our ongoing efforts to improve our service, we'd appreciate your time and help in answering a brief survey. It is short (8 questions) and will take about 2 minutes to complete. We value your privacy and assure you that your information will remain anonymous.

The results will be presented at an upcoming scientific conference and used to design new services. Your input, whether a smoker, ex-smoker or otherwise is critical to our success.

Thank you!

Nathan Cobb, MD
QuitNet Founder & Chief Medical Officer

[Take the Survey >>](#) or [Proceed Straight to QuitNet >>](#)

BOSTON UNIVERSITY Launched in 1995, QuitNet is the Web's original quit smoking site. QuitNet operates in association with Boston University School of Public Health.

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Original Paper

Are Physicians Ready for Patients With Internet-Based Health Information?

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Abstract

Background: An increasing number of patients bring Internet-based health information to medical consultations. However, little is known about how physicians experience, manage, and view these patients.

Objective: This study aimed to advance the understanding of the effects of incorporating Internet-based health information into routine medical consultations from physicians' perspectives, using a qualitative approach.

Methods: Six focus groups were conducted with 48 family physicians practising in Toronto. The data were analyzed using qualitative methods of content analysis and constant comparison, derived from grounded theory approach.

Results: Three overarching themes were identified: (1) perceived reactions of patients, (2) physician burden, and (3) physician interpretation and contextualization of information. Physicians in our study generally perceived Internet-based health information as problematic when introduced by patients during medical consultations. They believed that Internet information often generated patient misinformation, leading to confusion, distress, or an inclination towards detrimental self-diagnosis and/or self-treatment. Physicians felt these influences added a new interpretive role to their clinical responsibilities. Although most of the physicians felt obliged to carry out this new responsibility, the additional role was often unwelcome. Despite identifying various reactions of patients to Internet-based health information, physicians in our study were unprepared to handle these patients.

Conclusion: Effective initiatives at the level of the health care system are needed. The potential of Internet-based health information to lead to better physician-patient communication and patient outcomes could be facilitated by promoting physician acknowledgment of increasing use of the Internet among patients and by developing patient management guidelines and incentives for physicians.

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KEYWORDS

Internet; Health information; Consultation; Physician-patient communication; Qualitative; Focus group

Introduction

Internet access is rapidly changing the landscape of health information. In North America, 80% of the general population currently accesses health information on the Internet for

themselves, family, or friends [1,2]. Moreover, the number of patients bringing Internet-based health information to physicians is on the rise [3,4]. Patients report that use of Internet-based health information enhances their understanding and their ability to manage their health conditions [2,5,6]. Patients also report increased confidence in their interactions with physicians when

they are equipped with Internet information [5]. The revolution in health information is having a profound impact on how patients and physicians interact. How are physicians experiencing and managing this shift? What is their view of patients who bring Internet-based health information to the office?

Surveys of physicians have explored the impact of Internet-based health information on physician-patient relationships [7,8]. In a US study involving a nationally representative sample of 1050 physicians, Murray et al reported that 38% believed that the use of Internet information by patients has a beneficial effect on the physician-patient relationship, while 54% reported no effect [7]. A minority of physicians (8%) reported a worsening of the relationship due to physicians feeling “challenged” by patients. Likewise, an online survey by Potts et al with 800 Web-literate physicians concluded that benefits to patients from Internet use outweigh the harm, but that it presents more problems than benefits for doctors [8]. These studies demonstrate that some physicians experience difficulties with “Internet-informed” patients, but it is not clear why physicians feel challenged or report more problems [7]. Furthermore, we know little about how physicians view patients who take the initiative to introduce Internet-based health information into medical consultations. Thus, our goal was to use a qualitative approach to advance the understanding of the effects of incorporating Internet-based health information into routine medical consultations from physicians’ perspectives.

Methods

Focus Groups

A series of focus groups with family physicians was designed to explore physicians’ opinions of and experiences with patients who brought Internet-based health information to routine medical consultations. Focus groups allow for participant interaction, and, hence, they create a cueing phenomenon which leads to greater insight as to why certain beliefs and opinions are held. This unique feature of focus groups is not found in face-to-face interviews or questionnaires [9].

The focus groups were co-facilitated by a trained moderator and a member of the research team using standard moderation techniques [10] and an open-ended discussion guide that concentrated on the effect of Internet-based health information on physicians’ interactions with patients. Physicians were also encouraged to discuss the Internet-based health information as (1) enhancing effective use of consultation time, (2) an aid to

collaboration between patients and physicians and (3) a challenge to medical authority. All focus groups lasted approximately 2 hours.

Recruitment

Participants were recruited by telephone by a local recruitment firm whose database contains demographic information on more than 50000 persons in the greater Toronto area. This firm maintained a registry of health professionals volunteering for research. The study was approved by the Research Ethics Boards of St. Michael’s Hospital and York University. All participants provided written informed consent and were compensated with a modest sum for their time, in keeping with local standards for focus groups.

Analysis

The focus groups were tape-recorded and transcribed verbatim. The data were analyzed using qualitative methods of content analysis and constant comparison, derived from grounded theory approach [11]. This method aims to identify relevant themes and categories to summarize and systematize the content of the data. This method can effectively capture the range, diversity, and relative importance of certain ideas over others. The analytic process began inductively and was iterative, starting with the identification of key categories for individual questions. Categories were revised as new data and relationships emerged. Finally, categories were organized to reflect overarching messages or themes that spanned individual questions and focus groups [12]. Members of the research team met regularly to discuss the evolving categories and to establish consensus.

Results

Six focus groups were conducted with 48 family physicians, with an average of 10 participants per group (range 8-12), between April and October 2002. Participants, of whom 54% were male, had been practising for 6 to 27 years, and were encountering approximately 125-149 patients per week on average. All physicians had active practices in the greater Toronto area.

Three overarching and interrelated themes were identified: (1) perceived reactions of patients, (2) physician burden, and (3) physician interpretation and contextualization of information. Within the theme of interpretation and contextualization, the sub-themes of physician roles, resistance, and strategies were identified (Table 1).

Table 1. Physician perspectives on Internet-based health information introduced by patients

Theme	Description
Perceived reactions of patients	Physicians discussed various reactions of patients to the Internet health information brought to medical consultations. Some patients were perceived to have emotional reactions (confusion or distress) concerning the information they read. Others were perceived to have used the information for self-education or for self-diagnosis, with or without self-treatment; the latter group was perceived as challenging.
Physician burden	The introduction of Internet health information into the medical consultations was generally perceived as a burden, attributed to uncertainty about the website validity, limited Internet skills and/or access to up-to-date resources, lack of incentives, and time constraints.
Physician contextualization and interpretation	<p>i) New role</p> <p>Physicians perceived that a new interpretive role was added to their clinical responsibilities when patients introduced the Internet health information into the medical consultations. Although most of the physicians felt obliged to carry out this new responsibility, the additional role was often unwelcome based on the reasons described above. This was further compounded by perceived difficulties in interacting with challenging patients who made erroneous self-diagnoses and/or treatment plans based on Internet health information.</p> <p>ii) Resistance</p> <p>The new role was viewed as a particular burden for older physicians, compared to recent graduates.</p> <p>iii) Strategies</p> <p>Physicians discussed various strategies to cope with the new role. These approaches reflected a collaborative (eg, recommending reliable websites, asking for a follow-up visit) and defensive (eg, referring patients to specialists, suggesting extra charge for time) stance towards the new role.</p>

Dominant views as well as provocative dissenting views are presented below for each theme. Support for our interpretation is provided by including particular quotations from the data that most clearly illustrated the analytic points. From here onward, we refer to Internet-based health information as “Internet health information.” The abbreviations “FG 1,” “FG 2,” “FG 3,” and “FG 4” refer to the four focus groups, and “pg” indicates the page location of the quotes in the transcribed files.

Perceived Reactions of Patients

Physicians distinguished various patient reactions to the Internet health information brought to medical consultations. Broadly, some patients were perceived to have emotional reactions (confusion or distress) to the Internet health information, while others were perceived to have used the information for self-education on pre-established medical conditions or for self-diagnoses with or without self-treatment. The latter group was discussed as challenging despite its small size.

Patients with emotional reactions were perceived as being either “confused” or “distressed.” Physicians attributed patient confusion to their limited ability to evaluate, personalize, and interpret abundant Internet health information. Physicians identified these patients as needing clarification of the information brought to the visit:

Patients who do come with information, I find they are more confused than anything else and they come for clarification. [FG 3, pg 2]

They [patients] are getting full of rather stupid facts in many cases, which they do not know how to interpret, which are usually misinformation. [FG 2, pg 2]

In other instances, Internet health information resulted in patient distress, which was perceived by physicians as patient “anxiety,” “worry,” “nervousness,” panic,” or the patients feeling “overwhelmed” or “sicker.” For this cluster of patients,

physicians attributed their distress to such factors as the sheer volume of Internet health information, blind faith in or acceptance of Internet data (ie, believing everything one reads), and/or the inability to critically evaluate the personal relevance of the information:

They are bringing up sort of obscure articles and stuff about different conditions, and some of them are pretty scary.... They think everything is happening. [FG 4, pg 3]

It makes them sicker, because they get too worried about what their problems are. [FG 6, pg 11]

Physicians favorably perceived those patients who used Internet health information for educating themselves about their pre-established medical conditions. The self-educators were perceived to introduce the Internet information into the medical visits for confirmation, without challenging physicians’ expertise.

I think there’s one situation where the Internet is useful. If the person has the diagnosis, and they want to find out more, educate themselves..., I find that’s actually helpful in cases where...it’s not time-consuming for me. [FG 5, pg 4]

Patients were perceived as “challenging” when they used Internet information for self-diagnosis or self-treatment or to test the knowledge of physicians. The Internet was deemed simply another potential source of misunderstood health information for the challenging patients who were also described as adversarial, professional, difficult, or neurotic. Some physicians perceived these patients as lacking trust in their provider. Physicians often discussed having to defend their diagnosis or treatment plans, with feelings ranging from anger to frustration (for further details, see Physician Contextualization and Interpretation, below). However, a few physicians discussed how patients felt distressed and needed help after making self-misdiagnoses.

If they're, however, using it to diagnose, then I think that's where the problem lies.... [FG5, pg 10]

You may disagree with whatever disease that they've come in with all this research on.... I think it's like putting the cart before the horse.... They're ahead of you and not on the right track. [FG 4, pg 14]

I find that they are testing me on how up-to-date I manage to be. [FG 5, pg 9]

Part of the therapeutic relationship is the trust and the belief that the doctor will make you better. You don't have that, you have lost a great portion of your therapy. [FG 1, pg 5]

Physician Burden

Physicians discussed several difficulties arising from the introduction of Internet health information into the medical consultations. Expressions such as “awkward,” “tough spot,” “hard time,” “headache,” “nightmare,” “annoying,” “irritating,” and “frustrating” indicate the magnitude and nature of the difficulties and the accompanying sense of burden such information placed on physicians.

Concerns about the quality and quantity of health information on the Internet were common. Physicians linked their uncertainty about websites to their lack of information about recommended health sites and the instability of websites over time.

I can't answer for a lot of their questions about the validity of the sites that they've received information from.... [FG 1, pg 2]

I would like to be able to send them to a site that I know is, has reliable information. And I'm not at a point where I have that yellow page book for sites that are approved or somehow controlled. [FG 1, pg 3]

Time constraint was a major issue for these physicians. They discussed having limited time to deal with Internet-derived “volumes of pages” or “scrolls” of questions that patients bring to their visits. In only a few instances did physicians think Internet health information could actually be time-saving. “Big lists” of questions were particularly problematic and a cause for cynicism among some physicians:

As soon as that list comes out I panic...[because of] time constraints and everything else. [FG 5, pg 13]

I do not mind patients coming in with information, but it is very hard if they present you with a package of, you know, 60 sheets.... Time is really at a premium, so it makes it very difficult. [FG 1, pg 3]

Furthermore, some physicians acknowledged their limited Internet skills and attributed this to a lack of time to advance their computer skills. This was predominantly discussed among older physicians who seemed reluctant to spend time on learning this new technology:

One of the frustrations is, knowledge takes time, and it's fairly busy, in a busy practice, to just keep up and current in all areas. [FG 5, pg 8]

All the graduates [are] now using these technologies. So, it's not that it's too expensive for us as physicians. It's that we are caught in this transition in terms of “I do not feel comfortable, the time to learn it.” [FG 3, pg 10]

There were, however, a few instances of “rare conditions” and “travel medicine” when physicians thought that Internet information brought by patients into medical consultations had been helpful in making a diagnosis or identifying an appropriate referral.

We [family physicians] do not know everything. Then, it can't be challenges, actually “teach me” sometimes. [FG 6, pg 12]

I had a patient...I didn't know the diagnosis, something getting off a ship and having vertigo and some problems that ensued. The ENT doctor did not know...and in her search on the Web she found the diagnosis and found a single physician in Ontario. She ended up getting a referral by me.... [FG 1, pg 3]

Physician Contextualization and Interpretation

Many physicians viewed putting Internet health information in context for patients (ie, providing perspective on information in relation to a patient's unique history and health status) as part of their responsibility and role. Physicians generally believed they were in the best position to explain, synthesize, and contextualize information because of their training:

I think for many patients they don't have the wherewithal to assimilate this sort of information and come up with the appropriate response.... Part of our role is to explain that to them.... They don't have the background knowledge that we have in order to put it into proper perspective. [FG 6, pg 7]

The specific roles of physicians in relation to the contextualization and interpretation of Internet health information varied depending on the responses of patients to that information. For those patients perceived by physicians as self-educators, the work of the physician was generally limited and sometimes actually reduced.

However, for distressed or confused patients who took an uncritical stance toward the information, physicians discussed having the significant task of educating them by putting the information into its proper context. Physicians perceived this task as time-consuming, and, hence, a burden on their routine clinical responsibilities:

Similar experience where the patients are coming informed with information from the Internet, and sometimes from good sources and sometimes from more anecdotal, personal Web pages where the information may not be entirely correct. Then, you have to do lots of damage control and try to not disinform but try to undo and re-educate. [FG 5, pg 1]

For patients who used Internet for self-misdiagnosis or self-treatment, physicians described doing substantial work in

justifying and, at times, even defending their own diagnosis and treatment recommendations or in “debunking” incorrect information. In having their expertise challenged, some physicians felt they were at risk of “losing face” and/or being “put on the spot”:

Some of my patients come in with a diagnosis...convinced in their minds that this is what they have. Then you're almost put on the defensive sometimes as to why you think otherwise, or why maybe they should be looking elsewhere for what are their symptoms. So, it's more of a challenge. [FG 4, pg 3]

Resistance

Importantly, not all physicians embraced the role of interpreter, and there were indications of resistance from some to discussing Internet health information with any patient:

Most of them [patients] know it's annoying to me when they do it [bring in Internet downloads], so they don't. [FG 3, pg 1]

I just sort of stick with what I know and what I do and how I practice. [FG 3, pg 3]

The excerpt above highlights the fact that, in some instances, not only is the physician resistant to Internet health information, but his or her patients are aware of this resistance. Older physicians seemed more resistant:

A lot of people do not take new patients. So, we are going to grow old with our patients. And they're gonna get used to our ways and we're gonna [get] used to theirs. [FG 3, pg 11]

I think a lot of it is dependent on the age of the physician.... The older physicians are paternalistic and...do not feel comfortable when a patient comes in with an article.... [FG 5, pg 14]

Physician Strategies

Physicians discussed various strategies they had adopted in order to cope with Internet health information introduced by patients during medical consultations. These strategies included recommending reliable websites, asking for a follow-up visit, or expressing limited knowledge on specific details:

There is nothing wrong with saying, “You know what? I do not see a lot of this but I am going to find out for you.” (FG 1, pg 15)

They have huge time commitment and an emotional commitment to whatever it is they've brought in. So, I'll say, “Leave it with me for a couple weeks and let me think about it.” And I'll usually look it over, probably not while they're there, not that minute. (FG 4, pg 5)

Notably, some physicians discussed strategies of “firing” the patient, referring patients to specialists, or charging for extra time. These strategies have the potential to undermine the physician-patient relationship.

Well, frankly, we're paid for [the] visit. So, if your patient [is] having a \$15 visit, you're not going to sit

for 15 minutes going through all this, you're going to get them out of the office. [FG 4, pg 9]

If they come in and it's too much and it's too specialized...I let them slug it out with the specialist. They're paid very special money to do this kind of work. [FG 3, pg 4]

Maybe we can bill our patients privately for extra time to review research with them, if we can choose to do that or not do that. [FG 4, pg 13]

They're coming back [with Internet information]. It requires a little looking into. If you're tired, of course, you'll probably just fire them...if they're really belligerent. [FG 5, pg 7]

Discussion

Physicians in our study generally perceived Internet health information as problematic when brought by patients to medical consultations. They believed that Internet information generated patient misinformation, leading to confusion, distress, or an inclination towards detrimental self-diagnosis and/or self-treatment. Physicians felt these undesirable but common influences of Internet health information added a new interpretive role to their clinical responsibilities. Although most of the physicians felt obliged to carry out this new responsibility, the additional role was often unwelcome. Despite identifying various reactions of patients to Internet health information, physicians in our study were unprepared to handle these patients.

Despite the patient-perceived benefits of bringing Internet health information into medical consultations [2,5,6], physicians in our study viewed such consultations as too demanding. First, physicians viewed the task of contextualizing and interpreting the information as time-consuming. Misinformed, confused, and distressed patients needed not only an empathetic ear, but also supplementary education on how to assess the quality and relevance of Internet health information. In addition, intense involvement was deemed necessary for the challenging patients who used Internet information for self-diagnosis and/or treatment. Hence, physicians felt powerless when faced with the task of fulfilling their clinical responsibilities as well as answering a series of questions concerning Internet health information. Second, physicians experienced emotional difficulty in interacting with the challenging patients who made erroneous self-diagnoses and/or treatment plans based on Internet health information. Some physicians interpreted these situations as a threat to their medical expertise. The physicians' perception of threat also seemed to have a ripple effect to other patients who just needed clarification of the Internet health information but who encountered physician reservations.

Perceptions of consultations being too demanding were further compounded by physicians' uncertainty about website validity, lack of incentives to contextualize the Internet health information for patients, and limited access to up-to-date resources. The scepticism expressed by physicians about the quality of health information on the Internet is in accordance with existing empirical studies [13]. Nevertheless, the rising use of the Internet among patients to obtain health information [14] calls for concrete measures to facilitate physicians' access

to up-to-date technology and listings of reliable websites. In our study, the lack of tangible incentives appears to have been a fundamental barrier for physicians taking up the role of contextualizing and interpreting Internet health information. This led physicians to cope by making referrals to specialists—an expensive solution if increasingly adopted. Likewise, some physicians declined to continue caring for, or charged extra money to, patients who brought Internet health information to medical visits. These less than optimal strategies could undermine the continuity of the physician-patient relationship, which is a concern as continuity with the same health care provider is highly valued by patients [15] and primary care practitioners [16].

In our study, physicians' perceptions of difficulties in adopting their new role of contextualization and interpretation seemed to vary according to their perception of patients' reactions to Internet health information. This possible inter-relatedness should be examined in future research.

Implications

Many academic and nonacademic institutions have recently begun to train health care providers to critically evaluate Internet materials available to patients [17]. However, the un-preparedness of the physicians in our study to undertake the contextualization and interpretation of such information indicates the limited effectiveness of current efforts. In light of the study findings, we propose several possible avenues of improvement.

First, there is a need to increase the awareness of health care providers about the Internet-generated “reversed” information asymmetry [18]. Today, patients have easy access to medical information, and expert knowledge is no longer a “prohibited” zone for the general public. Such awareness would alleviate physician apprehension and the perceived threat to their medical expertise upon seeing a patient with Internet health information. Formal and informal educational initiatives for health care providers need to foster acknowledgment and, hence, acceptance of the emerging norm as increasing numbers of patients bring Internet health information to medical visits. Information management is a recognized task of physicians [19]. Internet health information is changing the dynamics through which this task is activated.

Second, training programs for health care providers need to enhance physicians' understanding of patients' perspectives on Internet information. For instance, patients with serious sickness are more likely to ask their physician about Internet health information [20]. Also, patients who feel overwhelmed by Internet information report difficulties in making an informed decision about their own care [21]. Physicians need to be prepared to address alternative sources that patients learn from, including the Internet. It may be useful for medical experts and health service administrators to establish patient management guidelines for physicians seeing patients with Internet health information. Such an approach has been applied to address issues around email communication between health professionals and patients [22]. The guidelines for management of patients with Internet health information should be sensitive to the diverse needs of patients. The guidelines should include

avenues for physicians to have ready access to up-to-date lists of recommended health websites, or the “yellow page” resource, described by our study participants. In addition, guidelines may incorporate a team approach to meet patient needs. For instance, nurse practitioners and diet counsellors routinely educate patients with respect to lifestyle modifications and self-management of chronic conditions. These existing human resources could be mobilized to address the patient misinformation, confusion, and distress generated by Internet health information.

Third, time-pressed physicians require tangible incentives to undertake the new role of contextualization and interpretation. Alongside monetary incentives, which require progressive structural changes in health care services, other incentives targeting professional “pride” should be considered. These include recognition in the form of certificates, award nominations, or credits for continuing medical education on information technology. The incentives should particularly target those health care providers who graduated before the inclusion of information technology in health care training programs.

Finally, patient-focused strategies related to Internet health information could complement physician-patient communication. Health care institutions could actively develop general patient guidelines on how to optimize the usefulness of Internet health information in physician-patient encounters. However, educating the public to apply evaluation criteria in a critical appraisal of the health information available on the World Wide Web, as proposed by others [23,24], is an overly optimistic approach. This approach ignores the existing digital divide among various strata of the population in accessing and understanding the Internet health information [25]. A cautious approach to health promotion via the Internet is recommended to avoid reproduction of existing social divisions [26-28]. Hence, too much emphasis on promoting the “responsible” use of the Internet among patients entails an inherent risk of ignoring less resourceful people.

Limitations

The study has some limitations. We used a convenience sample of urban physicians, which limits the generalizability. Physicians in our study seemed to have highly negative attitudes toward the influence of Internet health information on physician-patient relationships compared to prior physician surveys. Possible explanations include the cuing phenomenon of focus group methodology, use of prompts in the discussion guide, metropolitan sample of family physicians, and/or individual characteristics of the participants, such as number of years since graduation. Future research studies should examine physicians' perceptions by speciality, geographic location, and practice years. Nevertheless, our study findings represent the tip of the iceberg.

Conclusion

The dramatic increase in patient access to Internet health information of varying quality influences physician-patient relationships. We identified several factors that will need to be addressed in order for this information to be optimally

integrated. Effective initiatives at the level of the health care system are needed. The potential of Internet health information to lead to better physician-patient communication and patient outcomes could be facilitated by promoting physician

acknowledgement of an increasing use of Internet health information by patients and by developing patient management guidelines and incentives for physicians.

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Conflicts of Interest

None declared.

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Original Paper

Interest in an Online Smoking Cessation Program and Effective Recruitment Strategies: Results From Project Quit

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Abstract

Background: The Internet is a promising venue for delivering smoking cessation treatment, either as a stand-alone program or as an adjunct to pharmacotherapy. However, there is little data to indicate what percent of smokers are interested in receiving online smoking cessation services or how best to recruit smokers to Internet-based programs.

Objective: Using a defined recruitment sample, this study aimed to identify the percentage of smokers who expressed interest in or enrolled in Project Quit, a tailored, online, cognitive-behavioral support program offered with adjunctive nicotine replacement therapy patches. In addition, we examined the effectiveness of several individual-level versus population-level recruitment strategies.

Methods: Members from two large health care organizations in the United States were invited to participate in Project Quit. Recruitment efforts included proactive invitation letters mailed to 34533 likely smokers and reactive population-level study advertisements targeted to all health plan members (> 560000 adults, including an estimated 98000 smokers across both health care organizations).

Results: An estimated 1.6% and 2.5% of adult smokers from each health care organization enrolled in Project Quit. Among likely smokers who received proactive study invitations, 7% visited the Project Quit website (n = 2260) and 4% (n = 1273) were eligible and enrolled. Response rates were similar across sites, despite using different sources to assemble the invitation mailing list. Proactive individual-level recruitment was more effective than other forms of recruitment, accounting for 69% of website visitors and 68% of enrollees.

Conclusions: Smokers were interested in receiving online smoking cessation support, even though they had access to other forms of treatment through their health insurance. Uptake rates for this program were comparable to those seen when smokers are advised to quit and are referred to other forms of smoking cessation treatment. In this sample, proactive mailings were the best method for recruiting smokers to Project Quit.

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KEYWORDS

Internet; tobacco dependence; nicotine dependence; smoking cessation; recruitment activities

Introduction

In recent years there has been an explosive growth of Internet users around the world and a corresponding upsurge in interest

in using the Internet to deliver online public health interventions such as smoking cessation treatment. The potential advantages of Internet-based treatment are clear. From the users' perspective, online treatment programs are convenient; content

can be accessed 24 hours a day, 7 days a week, 365 days a year. They also offer a greater level of anonymity than in-person or phone-based counseling, which users may find appealing. From a delivery perspective, Internet programs allow rapid, broad, and economical treatment dissemination. Programs can be highly tailored to mimic the individualization of one-to-one counseling, and the Internet has the potential to reach audiences who might not seek services otherwise due to issues of cost, accessibility, or stigma.

Whether Internet-based smoking cessation programs will be as effective as person-to-person counseling remains to be proven. To date, very few randomized efficacy trials have been conducted [1], but some promising preliminary data [2-4] suggest that well-designed online cessation programs could be effective public health interventions, particularly when combined with pharmacotherapy [5].

The ultimate impact of any public health intervention, however, is dependent on its reach, as well as its efficacy [6]. Internet-based programs have the potential to reach millions of people, but potential reach is not actual reach. Actual reach requires access, acceptability, and utilization. While ongoing research seeks to establish the efficacy of online treatment, it is equally important to evaluate the acceptability and utilization of these programs in their target audiences. This assessment is hard to do because it requires a defined recruitment population and control over individuals' exposure to program advertisements, which is not possible in most research settings. No published studies to date, that we are aware of, have recruited smokers for Internet-based cessation treatment using a well-defined population that would allow accurate estimates of treatment uptake among smokers. Our best estimates come from surveys of Internet users. According to a recent Pew survey, 7% of adult US Internet users, approximately 8 million people, reported that they have searched online for information on how to quit smoking [7], but searching for information online is not the same as enrolling in an online cessation program. Joining a program requires a higher level of commitment and effort. This could partly explain why only 5-14% of smokers follow through with treatment referrals after being advised to quit [8-10] and less than 7% of smokers in the United States enroll in clinic-based cessation programs [11]. Research is needed that will allow us to better understand the acceptability and reach of Internet-based smoking cessation treatment. Moreover, it is important to understand how best to advertise these programs to smokers to maximize treatment uptake.

In this paper we report on smokers' interest in Project Quit, an online, individually tailored, cognitive-behavioral support program with adjunctive nicotine replacement therapy (NRT) patches. Participants were recruited from two large health care organizations in the United States using a combination of individual-level and population-level recruitment strategies. Working within the health care organizations provided a defined patient population, making it possible to estimate interest in this program among likely smokers who were invited to participate and to evaluate the effectiveness of our recruitment strategies.

Methods

Setting

Project Quit is a collaborative study between the University of Michigan (UM), Group Health Cooperative (GHC), and the Henry Ford Health System (HFHS). The primary purpose of Project Quit is to evaluate the "active ingredients" of an individually tailored, online smoking cessation program. A secondary aim is to evaluate smokers' interest in Web-based cessation treatment and evaluate optimal strategies for promoting this service among smokers. Project Quit is being conducted in two independent phases, each testing slightly different treatment content. This paper reports the recruitment outcomes for the first phase.

The Project Quit Internet program was primarily designed and maintained by the Center for Health Communications Research at UM. Study participants were recruited from the memberships of GHC and the Health Alliance Plan (HAP) of HFHS. Both GHC and HFHS are not-for-profit integrated health care delivery systems. At the time of this study, GHC served more than 540000 enrollees (adults and children) in Washington State and Idaho. An estimated 200000 adults and children in the greater Detroit, Michigan area were insured through HAP and received services through HFHS. Both GHC and HFHS/HAP provide behavioral counseling and pharmacotherapy for smoking cessation as covered insurance benefits, but at the time of this study neither offered an online cessation program.

All participants in this study received access to a tailored, cognitive-behavioral treatment program for smoking cessation that was delivered via the Internet. Treatment varied by the type and intensity of tailoring, but all participants received a personally tailored program and a 10-week supply of NRT patches. All treatment was provided free of charge. The study protocol was reviewed and approved by the Institutional Review Board (IRB) of each collaborating institution.

Recruitment

Participants were recruited through a combination of individual-level and population-level strategies. Each of the two health care organizations identified likely current smokers via either automated smoking status data collected during recent medical appointments (Organization 1) or documentation of smoking in electronic medical charts, use of an internal list of smokers collected during prior research, or lists of patients with smoking-related conditions who had previously been prescribed cessation medications (Organization 2). Thus, all invitees were known to have been recent smokers with a high probability of current smoking. Likely smokers were prescreened for minimal inclusion criteria (eg, age) and were mailed a study invitation letter. The letter content was comparable across both health care organizations, but not identical due to different IRB requirements. Both letters briefly described the Project Quit program and study eligibility criteria and invited smokers to visit the Project Quit website to learn more about the study and be screened for eligibility. Individuals could also inform study staff if they did not want to be contacted further about this research. Finally, each site allowed people to refer friends and family members to the program, as long as referred smokers

were members of one of the health care organizations. Information on how to refer a friend or family member was included in the invitation letter.

After approximately three months, we determined that we needed to boost our monthly enrollment rate to reach our recruitment goal during the study time frame. In an effort to expedite progress toward our overall recruitment goal, we amended the protocol to include a reminder mailing to likely smokers. Reminders were sent to all individuals who, at that point, had not yet visited the website or opted out of further contact regarding the study. From that point forward, reminder letters were sent to all persons who, four weeks after they received the initial invitation letter, had not visited the website or opted out of contact.

We also utilized several population-level enrollment strategies. The study was advertised in each health care organization's quarterly membership newsletter and was the focus of a feature article in one newsletter issue at Organization 2. Ads appeared in three to four issues total, depending on the site. Each site also advertised through a variety of supplemental strategies. Organization 1 highlighted the program in one issue of its staff newsletter and on the "Join a Study" page of the institution's website. Organization 2 advertised the study during a local promotion of the 2004 Great American Smokeout and allowed physician and nurse referrals, though the latter was not widely promoted among staff. Participants were actively recruited from September 2004 to July 2005.

Letters were proactively mailed to 34533 likely smokers at Organization 1 ($n = 18668$) and Organization 2 ($n = 15865$). Quarterly newsletters were mailed to the entire membership of each health care organization, including approximately 563200 adults with GHC or HAP insurance coverage. Based on smoking prevalence data from automated medical records at Organization 1 and regional smoking prevalence estimates for Organization 2 [12], approximately 63180 adults at Organization 1 and 34506 adults at Organization 2 were smokers. At Organization 1, the staff newsletter ad was distributed to approximately 10000 employees, of whom 1000 were estimated to have been smokers based on internal smoking prevalence data among staff. It is not possible to estimate how many smokers were exposed to the other referral sources (eg, friend and family referrals, website posting).

Each recruitment strategy was associated with a unique referral code. Potential participants used these codes to log in to the Project Quit website. It is possible that some participants were exposed to more than one recruitment strategy (eg, invitation letter and newsletter ad); however, by using the referral codes we were able to track which promotional strategy they were responding to when they enrolled and to which health care organization they belonged. After logging into the site, individuals were able to read an overview of the study, be screened for eligibility, and provide informed consent.

Participants

Individuals were eligible to participate if (1) they had smoked at least 100 cigarettes in their lifetime, currently smoked at least 10 cigarettes per day, and had smoked in the past 7 days; (2) were seriously considering quitting in the next 30 days; (3) were 21 to 70 years old; (4) were a member of GHC or HFHS/HAP; (5) had home or work access to the Internet and an email account that they used at least twice weekly; (6) were not currently enrolled in another formal smoking cessation program or currently using pharmacotherapy for smoking cessation; and (7) had no medical contraindications for NRT.

Results

Project Quit Recruitment Response

During the 11-month recruitment period for phase one of Project Quit, 3256 people from both health care organizations visited the website; 2651 were screened for eligibility (81% of website visitors); 2011 were eligible (62% of website visitors); and 1866 enrolled (57% of website visitors).

We examined the response to each recruitment strategy by evaluating the number of people who responded to each and either visited the website to learn about Project Quit or consented and enrolled in the study (Table 1). Because the total response rate to each of the supplemental strategies (eg, friend and family referrals, website posting, staff newsletter, physician referral) was low, these strategies are combined into a single category in Table 1. Nearly 9% of study participants ($n = 159$) were referred by friends or family, but response to each of the other supplemental referral sources ranged from 2 to 18 enrollees.

Table 1. Response to each recruitment strategy by health care organization

Organization	Visited Project Quit Website (N = 3256)			Enrolled in Study (N = 1866)		
	Letter n (%)	Newsletter n (%)	Other* n (%)	Letter n (%)	Newsletter n (%)	Other* n (%)
1	1224 (75)	260 (16)	136 (8)	730 (74)	171 (17)	85 (9)
2	1036 (63)	439 (27)	162 (10)	543 (62)	241 (27)	96 (11)
Both	2260 (69)	699 (21)	298 (9)	1273 (68)	412 (22)	181 (10)

*Includes friend and family referrals, web posting, staff newsletter, physician referral, and Great American Smokeout promotion.

The results suggest that the proactive invitation letters were superior to our other recruitment methods, accounting for 69% of people who visited the website and 68% of all enrollees. This finding was consistent across both health care organizations. A

greater percentage of the Organization 1 sample was recruited by letter, but the response rate to the proactive letters was nearly equal in both samples. At Organization 1, 6.6% of letter recipients visited the website and 3.9% enrolled. At Organization

2, 6.5% of letter recipients visited the website and 3.4% enrolled. Of those who enrolled, 870 did so after receiving their first invitation letter and 403 did so in response to the reminder letter.

Interest in Project Quit

The estimated percentage of adult smokers at each health care organization who enrolled in Project Quit was 1.6% and 2.5%, respectively, for Organization 1 and 2. Although newsletter advertisements were mailed to the entire membership of each health plan, there is no guarantee that smokers saw the population-level advertisements. Thus, a more valid estimate of smokers' interest in this program is based on the sample who received proactive invitation letters ($n = 34533$). Using this defined sample, we can better estimate the percentage of likely smokers who were interested in the online treatment program after learning about it: 7% of people who received a study invitation letter visited the Project Quit website ($n = 2260$), 6% of invitees were screened and eligible ($n = 2011$), and 4% of the total invitees ($n = 1273$), or 63% of those eligible, enrolled.

In total, 651 people were found to be ineligible for this study. The primary reasons for ineligibility were not smoking enough (26%), medical contraindications for NRT (23%), already being enrolled in another smoking cessation program (16%), lack of adequate Internet/email access (14%), not currently being

enrolled in a participating health plan (10%), and currently using pharmacotherapy to quit smoking (8%). Of those who were ineligible, 462 visited the website in response to an invitation letter. Compared to persons recruited through all other methods ($n = 189$), invitation letter recipients were less likely to be ineligible due to age (0.2% vs 2.6%, $P = .03$) or not being currently enrolled in a participating health plan (3.9% vs 25.9%, $P < .001$) and more likely to be ineligible due to current use of another smoking cessation program (11.7% vs 4.2%, $P = .003$) or a medical contraindication for NRT use (26.0% vs 15.3%, $P = .003$). These differences are consistent with our methods for identifying letter recipients.

Enrolled Participants

The demographic characteristics of enrolled participants are presented in Table 2. The sample is similar to smokers who enroll in phone counseling programs in that they were ready to quit and were middle-aged, moderate-to-heavy smokers with a history of numerous quit attempts [13-15]. The subsamples differed slightly by health care organization; Organization 2 participants were less likely to be married or living with a partner ($P < .001$), less educated ($P < .001$), less likely to be White ($P < .001$), less comfortable using the Internet ($P = .02$), and smoked slightly more cigarettes per day ($P < .001$).

Table 2. Characteristics of enrolled participants

	All (n = 1866)		Organization 1 (n = 986)		Organization 2 (n = 880)	
Characteristic	n	%	n	%	n	%
Female	1110	59.5	586	59.4	524	59.5
Married/living with partner	1278	68.5	682	69.1	595	67.6
Employed	1421	76.2	749	76.0	672	76.3
Education*						
High school/GED or less	451	24.2	204	20.6	246	28.0
Vocational/technical school	222	11.9	141	14.3	81	9.2
Some college	1050	56.3	564	57.0	486	55.2
Postgraduate degree	136	7.3	71	7.2	65	7.4
Caucasian*	1486	79.6	831	84.3	655	74.3
3 or more prior quit attempts [†]	1218	65.3	668	67.7	550	62.5
	Mean	SD	Mean	SD	Mean	SD
Age	46.3	10.7	46.5	11.1	46.1	10.2
Cigarettes per day*	21.8	9.3	21.0	8.6	22.7	9.9
Motivation to quit [‡]	8.3	1.7	8.3	1.7	8.3	1.8
Comfort using the Internet ^{†,‡}	6.8	3.7	7.0	3.7	6.6	3.7

*Significant difference between organizations, $P < .001$

[†]Significant difference between organizations, $P < .05$

[‡]Scores range from 1 to 10.

We also compared participants who were recruited by proactive invitation letter to those recruited by newsletter. Newsletter recruits were more likely to be female (64.1% vs 58.2%, $P =$

.03), Caucasian (88.6% vs 77.5%, $P = .06$), and older (47.0 vs 45.0 years, $P = .001$). There were no significant differences in

education, marital status, motivation to quit smoking, comfort using the Internet, or the number of cigarettes smoked per day.

Discussion

Principle Results

We found that smokers were interested in participating in Project Quit, a Web-based smoking cessation treatment program, even when they had access to other forms of comprehensive intervention through their health insurance. Of those who received a study letter and were invited to be screened for eligibility, 7% visited the website and 4% were eligible and enrolled. While these numbers may appear low, they are comparable to follow-through rates (5-14%) for referrals to other forms of cessation counseling [8-10]. Moreover, nearly two-thirds of those eligible (63%) agreed to enroll.

To our knowledge, this is the first study to document the level of interest in an online smoking cessation treatment program. We believe this is an important finding. Online cessation programs are becoming more prevalent on the Web. Whether or not they will be as efficacious as person-to-person counseling remains to be proven, yet no matter how efficacious an Internet cessation program is, its effectiveness will ultimately be dependent on its acceptability and utilization. These findings suggest that online cessation treatment can have comparable appeal to other forms of behavioral counseling, especially when part of a comprehensive intervention that combines cognitive behavioral counseling with pharmacotherapy, as is the best practice recommendation for tobacco dependence treatment [11].

While the uptake rate for Project Quit is comparable to that of other forms of therapy, these results may not generalize to other online cessation programs. Based on participants' self-report at follow-up, we know that a substantial portion of smokers were interested in receiving NRT. Online programs that do not offer the option of pharmacotherapy may be less appealing to smokers, at least to those with adequate health care coverage and other treatment options. Furthermore, our enrollment rate may have been limited by the eligibility criteria of our study. We selected adult smokers, with access to the Internet, who were ready to quit smoking and had no contraindications for NRT use. Higher enrollment may be seen for programs with less restrictive inclusion criteria. Finally, responses rates may differ in populations with different base rates of smoking. Our primary take rate (4%) is based on the percentage of likely smokers who received a proactive letter announcing the program. We selected people to receive these invitation letters based on internal data documenting their recent smoking. Unfortunately, population-level annual quit rates are fairly low in the United States. Each year, only about 2.5% of smokers successfully quit smoking permanently [16]. Thus, we have

reasonable confidence that the majority of individuals contacted were still smoking when they received the letters, but we cannot confirm the exact percentage who were smoking at contact. Less treatment interest may be found in future populations if the base rate of smoking is lower than in this study, and vice versa.

As a secondary outcome we examined the success of our various recruitment strategies and found that proactive, individual outreach was a more effective recruitment strategy than mass advertising. More study participants visited the website and enrolled in response to proactive invitation letters than to all other forms of recruitment. This finding may not be surprising. While our population-level advertisements had the potential to reach a greater number of people (> 560000 adults), there was no guarantee that they were actually seen by their intended audience of smokers (approximately 98000 adults). Consequently, we cannot directly compare the draw of the newsletter ads to our invitation letters or other referral strategies, but we can comment broadly on the effectiveness of each strategy as a means of outreach for this study. In addition, we cannot assume that people were not exposed to more than one recruitment strategy or that multiple exposures did not have some impact, but using our unique referral codes, we can state with confidence which promotional strategy participants were responding to when they visited the Project Quit website. Nearly 70% of all visitors responded to the invitation letters proactively mailed to likely smokers. This finding has implications for future research, as well as community-based treatment dissemination efforts. Proactive contact was possible in this trial because of our access to automated data and other internal indicators of smoking status, but a similar outreach strategy could be implemented in the community using commercially available mailing lists of smokers or mailing lists from state or national smoking quit lines of likely smokers. More widespread recruitment could be achieved via commercially available email address lists. Even if it were not possible to limit email distribution to likely smokers, the cost per recipient would be low enough to make this a cost-effective recruitment strategy.

Conclusion

The results of this study add to the small but growing literature on Internet-based smoking cessation treatment and suggest that online intervention can be as appealing to smokers as other forms of treatment, but utilization may be dependent on the overall program content and effective promotional outreach. Future research should continue to evaluate smokers' interest in using online services, among both insured and uninsured individuals. Additional methods for promoting utilization of online programs should also be explored. A greater understanding of these issues will be important for effectively delivering efficacious online cessation services in the future.

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Conflicts of Interest

Dr. Strecher is a shareholder in HealthMedia Inc, a company that builds and disseminates computer-tailored smoking cessation programs. He has also undertaken consultancy and research for, and received travel funds from, manufacturers of smoking cessation products, including GlaxoSmithKline.

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Abbreviations

GHC: Group Health Cooperative
HAP: Health Alliance Plan
HFHS: Henry Ford Health System
IRB: Institutional Review Board

NRT: nicotine replacement therapy

UM: University of Michigan

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Original Paper

Internet Interventions for Long-Term Conditions: Patient and Caregiver Quality Criteria

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Abstract

Background: Interactive health communication applications (IHCAs) that combine high-quality health information with interactive components, such as self-assessment tools, behavior change support, peer support, or decision support, are likely to benefit people with long-term conditions. IHCAs are now largely Web-based and are becoming known as "Internet interventions." Although there are numerous professionally generated criteria to assess health-related websites, to date there has been scant exploration of patient-generated assessment criteria even though patients and professionals use different criteria for assessing the quality of traditional sources of health information.

Objective: We aimed to determine patients' and caregivers' requirements of IHCAs for long-term conditions as well as their criteria for assessing the quality of different programs.

Methods: This was a qualitative study with focus groups. Patients and caregivers managing long-term conditions used three (predominantly Web-based) IHCAs relevant to their condition and subsequently discussed the strengths and weaknesses of the different IHCAs in focus groups. Participants in any one focus group all shared the same long-term condition and viewed the same three IHCAs. Patient and caregiver criteria for IHCAs emerged from the data.

Results: There were 40 patients and caregivers who participated in 10 focus groups. Participants welcomed the potential of Internet interventions but felt that many were not achieving their full potential. Participants generated detailed and specific quality criteria relating to information content, presentation, interactivity, and trustworthiness, which can be used by developers and purchasers of Internet interventions.

Conclusions: The user-generated quality criteria reported in this paper should help developers and purchasers provide Internet interventions that better meet user needs.

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KEYWORDS

Internet; patients; qualitative research; interactive health communication applications

Introduction

One aspect of eHealth is patients' use of new technologies to become better informed about their health and health care options [1].

In response to consumers' desire for information that enables them to play an active role in their health care, there has been a proliferation of health-related websites on the Internet. The interactive nature of the Internet, combined with the potential to store large volumes of information, provides a unique opportunity to offer high-quality interactive evidence-based

information. Interactive components such as self-assessment tools permit the provision of personalized tailored information to users and provide decision support, peer support, or behavior change support. This combination of health information and interactive components is known as an interactive health communication application (IHCA) [2]. Initially, IHCA were often developed on non-Web-based platforms such as CD-ROM. Recently, the emphasis has moved toward Web-based programs, which are becoming known as Internet interventions [3].

This combination of high-quality health information with interactive components is likely to benefit people with long-term conditions [4,5] who can be conceptualized as being on an "illness journey" [6]. As they progress through their journey, they experience changing needs [7], often becoming highly knowledgeable about their health problems and developing substantial expertise in self-management [8]. In a recent systematic review of IHCA for chronic conditions, IHCA were found to have largely positive effects, tending to improve user knowledge and perceived social support. The review also suggested that these positive effects of IHCA may extend to improved clinical outcomes [2]. However, there has also been anxiety about the potential harms caused by health-related Web-sites, particularly when the information provided is misleading or incorrect [9].

One response to these concerns has been the development of criteria to assess the quality of health-related websites. Numerous such criteria, mostly generated by professionals, have been proposed [10-12]. The criteria tend to reflect professional concerns, including accuracy, completeness, readability, disclosures, and references [11]. By contrast, little is known about the user perspective on health websites; however, we know that patients and professionals generate different criteria for assessing the quality of traditional non-Web-based information materials [13], suggesting that patients are likely to use different criteria than professionals for assessing the quality of health websites. In a qualitative study, Eysenbach observed healthy volunteers to determine how they found and appraised the quality of health websites [14]. The Pew Internet and American Life Project undertook a large questionnaire study of Internet users to determine how respondents appraised the quality of health websites [15]. However, people with long-term conditions have different information and health needs to healthy volunteers and hence may use different criteria for assessing the quality of interactive health websites.

A further limitation of most quality criteria and previous user perspective research is that they do not distinguish between sites which contain information only and interactive sites which combine information with decision support, behavior change support, or peer support. This distinction is important as information on its own is relatively ineffective in achieving behavior change or improving clinical outcomes [16]. While steps have been made to develop criteria to evaluate more interactive online health behavior change and disease management programs [17], these also neglect the user perspective.

We aimed to determine the criteria used by people with long-term conditions and their caregivers for assessing the quality of IHCA (or Internet interventions). As we were interested in user-generated criteria, we opted for a qualitative rather than a quantitative methodology (such as a questionnaire study that would have forced participants to choose between predefined criteria generated by the researcher).

Methods

Patients and caregivers managing long-term conditions used three IHCA relevant to their condition and subsequently discussed the strengths and weaknesses of the different programs in focus groups. Participants in any one focus group all shared the same long-term condition and viewed the same three IHCA. Patient and caregiver criteria for IHCA emerged from the data.

Sample

We selected a range of long-term conditions to cover: conditions that are highly prevalent in the UK population and account for substantial morbidity or mortality; conditions in which self-care is known to, or likely to, affect clinical status; and conditions that affect different age groups, including children, adults, and older adults. In addition, we aimed to include a highly stigmatized condition and one for which the scientific evidence base for treatment is changing rapidly (patients with such conditions may have particular need of an IHCA).

We recruited adult patients with diabetes mellitus, ischemic heart disease, or hepatitis C, parents of children with asthma or diabetes mellitus, and caregivers of people with Alzheimer's disease.

Recruitment Strategies

In order to recruit a maximally diverse sample, we used a range of recruitment strategies, including recruiting from both clinical and community settings in three UK areas with differing socioeconomic and ethnic profiles. These were inner London (urban, very mixed ethnically and socioeconomically); Nottingham (medium-sized city, mostly lower socioeconomic status, high proportion of South Asian residents); and Exeter (a small city set in a rural area, mostly indigenous English residents). People were invited to take part through advertisements in local newspapers and patient newsletters, posters in general practice (family practice) clinics, and flyers given out in patient self-help group meetings, exercise classes, and hospital outpatient clinics. Recruitment continued until we had sampled to the point of redundancy (ie, until no new data were emerging from the focus groups).

Intervention

Suitable IHCA were identified through authors of studies reporting on the development and/or evaluation of IHCA in the academic literature, Google Internet searches for each of the relevant long-term conditions, and by asking researchers, academics, and consumer representatives for interventions known to them personally. We excluded programs that only provided health information without any interactive components, as these do not meet the definition of an IHCA, and those that were aimed at more than one condition. We wanted to show

participants three programs that differed significantly, so we compiled a list of programs developed by different stakeholders (medical, academic, commercial, charitable, and self-help organizations) from different countries (although all using the English language). Table 1 provides details of the interventions

selected. Although we planned to use IHCA's on any available technological platform, all but one was Web-based, and hence we use the simpler more intuitive term of Internet interventions in reporting and discussing our results.

Table 1. Details of IHCA's shown to participants

Condition	IHCA	Details
Adult patients with diabetes	-My Diabetes	-Identified by Google Internet search
	-Freely available at www.mydiabetes.com	-Produced by US commercial stakeholder
	-Diabetes Insight	-Identified by Google Internet search
	-Freely available at www.diabetes-insight.info	-Produced by UK charitable stakeholder
	-Aida	-Identified via systematic review search of academic literature
Adult patients with heart disease	-Freely available at www.2aida.org	-Produced by European academic stakeholders
	-Heart center online	-Identified by Google Internet search
	-Freely available at www.heartcenteronline.com	-Produced by US commercial stakeholder
	-Your Heart	-Identified by Google Internet search
	-Freely available at www.yourheart.org.uk	-Produced by UK National Health Service (NHS) and academic stakeholders
Adult patients with hepatitis C	-Heart info	-Identified by Google Internet search
	-Freely available at www.heartinfo.org	-Produced by US charitable stakeholder
	-Hepatitis C forum	-Identified by consumer representative
	-Freely available at www.hepatitis-c.de	-Produced by German forum (stakeholder unclear)
	-Hep C vets	-Identified by consumer representative
Caregivers of people with Alzheimer's disease	-Freely available at www.hepcvets.com	-Produced by a US consumer representative stakeholder
	-Hep C UK	-Identified by consumer representative
	-Freely available at www.hepCuk.info	-Produced by UK charitable consumer representative stakeholder
	-Alzheimer's disease	-Identified by Google Internet search
	-Freely available at www.alzheimersdisease.com	-Produced by US commercial stakeholder
Parents of children with diabetes	-Alzheimer Society	-Identified by Google Internet search
	-Freely available at www.alzheimers.org.uk	-Produced by UK charitable consumer representative stakeholder
	-CHES AD	-Identified via systematic review search of academic literature
	-Web-based: permission, access passwords, and log-in provided by CHES project, University of Wisconsin	-Produced by US academic stakeholder
	-Juvenile diabetes research foundation	-Identified by Google Internet search
Parents of children with asthma	-Freely available at www.jdf.org	-Produced by US charitable stakeholder
	-American Diabetes Association	-Identified by Google Internet search
	-Freely available at www.diabetes.org/for-parents-and-kids.jsp	-Produced by US charitable stakeholder
	-Children with diabetes	-Identified by Google Internet search
	-Freely available at www.childrenwithdiabetes.com	-Produced by US commercial stakeholder
Parents of children with asthma	-National asthma campaign	Identified by Google Internet search
	-Freely available at www.asthma.org.uk	Produced by UK charitable stakeholder
	-CHES asthma	-Identified via systematic review search of academic literature
	-Web-based: permission, access passwords, and log-in provided by CHES project, University of Wisconsin	-Produced by US academic stakeholder
	-The Asthma Files	-Identified via systematic review search of academic literature
	-CD-ROM: permission provided by Dr Alan Smyth, Nottingham City Hospital	-Produced by UK medical stakeholders

Focus Groups

All the participants of any one focus group had the same long-term condition. Group size ranged from 2 to 8 participants. Groups were run at community information technology (IT) facilities to avoid a health service context. Participants initially accessed a networked personal computer (PC), pre-loaded with the three interventions. Individual participants used each Internet intervention for up to 30 minutes, spending up to 90 minutes at the PC. During this time, participants were free to explore each IHCA as they wished, to form an opinion of how useful it might be to them and be able to discuss this later. Facilitators assisted novice computer users, and participants were encouraged to make contemporaneous notes on the three IHCA's to serve as a memory aid for subsequent discussion.

After viewing the three IHCA's, participants re-convened for a 90-minute discussion facilitated by two experienced focus group facilitators. One facilitator led the discussion and the other served as an observer, making contemporaneous field notes. The discussions were tape-recorded.

Topic Guide

The topic guide was developed following a review of the literature and discussion with relevant researchers ([Multimedia Appendix](#)). Minor modifications were made following piloting with user representatives of hepatitis C and diabetes patients. Data emerging from some of the early groups influenced follow-up and probe questions with later groups, but without altering the topic areas. Areas covered in the topic guide included participants' overall reactions to the three IHCA's, preferences for and against particular IHCA's (and reasons for these), and information looked for but not found.

Analysis

Audiotapes of the discussions were transcribed verbatim. Each participant was given a unique anonymous identifier based on focus group location, disease condition, and chronological order of focus group. Hence, EHD refers to a participant from Exeter with heart disease, while LCD is a participant from London who cares for a child with diabetes. For clarity, each quote is also labeled with the focus group number and condition shared by participants. Analysis was conducted on un-edited transcripts, but for clarity, edited quotes are presented in the results section.

Analysis and data collection were conducted concurrently, starting as soon as the first audiotape had been transcribed. Thematic analysis of each transcript identified emerging

requirements and quality criteria. Analysis was organized into an expanding list of themes and subthemes, assisted by using QSR NUD*IST 6 software [18]. Analysis conducted initially by one researcher was checked for validity against observational research notes and discussed with the two focus group co-facilitators. The iterative process of data collection and analysis served to inform discussions in later groups. Follow-up and probe questions explored agreement or disagreement, with views expressed by earlier groups providing further detail and clarification of emerging themes. Focus groups with patients were conducted until the point of saturation, when no new themes were emerging. Focus groups with caregivers were curtailed by lack of caregiver participation.

The list of emerging themes was discussed with members of the multidisciplinary research team (representing clinical, health psychology, sociology, and consumer perspectives) before being summarized into a framework. All utterances expressing a judgment in the transcripts were then coded using this framework.

Respondent Validation

Once the initial analysis was complete, the resulting criteria were sent to focus group participants and those who had consented to participate in the study but had not been able to attend a focus group. Respondents were asked to rate each criterion on a scale of 1 (not at all important) to 5 (essential) and select the three criteria that they felt were most important. There was also space for respondents to add any criteria or topics that they felt were missing from the list.

Results

Sample

A total of 40 patients and caregivers participated in focus groups. An additional 40 people consented to participate in the study but were unable to attend focus groups or attended when no others did. Finding time to attend a focus group was particularly problematic for caregivers (including parents) who had other demands on their time. Focus group attendees consisted of roughly equal numbers of men and women. The sample was diverse in terms of age, ethnic background, previous computer literacy, and educational background ([Table 2](#)). Nearly one quarter of participants had left school at age 16 (the minimum allowable age in the United Kingdom), and nearly one third had either no, or only basic, previous computer experience.

Table 2. Self-reported characteristics of participants (N = 40)

		Number of Participants (%)
Gender	Male	22 (55)
	Female	18 (45)
Age	30-39	3 (7.5)
	40-49	7 (17.5)
	50-59	8 (20)
	60-69	16 (40)
	70-79	4 (10)
	Missing data	2 (5)
Employment	Employed	12 (30)
	Economically inactive	27 (67.5)
	Missing data	1 (2.5)
Education	School leaver	9 (22.5)
	A levels or vocational equivalent (A levels are advanced level examinations taken at age 18)	9 (22.5)
	University degree, Higher National Diploma, or similar	20 (50)
	Missing data	2 (5)
Ethnic group	White British	31 (77.5)
	White European (non-British origin)	6 (15)
	Asian or British Asian	2 (5)
	Black or Black British	1 (2.5)
English first language	Yes	34 (85)
	No	6 (15)
Computer experience	Novice	4 (10)
	Basic	8 (20)
	Experienced	28 (70)
Time since diagnosis	Less than 1 year	4 (10)
	Between 1 and 5 years	12 (30)
	More than 5 years	18 (45)
	Missing data	6 (15)

Focus Groups

We ran 10 focus groups, each attended by 2 to 8 participants. Focus groups were run for all conditions except for parents of children with asthma, who were not able to attend at the same time (Table 3).

Response to Internet Interventions

Overall, participants highly valued Internet interventions. They welcomed the existence of these programs, and were highly appreciative of their potential:

"Totally unbounded potential, the potential to step in and alleviate lots of conditions." [LAD20; G2, Diabetes]

However, it was clear that participants felt many of the interventions were not fulfilling their potential. Participants could see strengths and weaknesses of the various programs they explored, and they generated criteria that were generic across patient and caregiver groups that related to information content, presentation, interactive components, and trustworthiness.

Table 3. Summary of focus groups by condition

Condition	Number of Groups	Number of Participants	Locations
Adult patients with diabetes	4	13 (3 with comorbid heart disease)	London and Nottingham
Adult patients with heart disease	3	17 (2 with comorbid diabetes)	London and Exeter
Adult patients with hepatitis C	1	4	London
Caregivers of people with Alzheimer's	1	3	London
Parents of children with diabetes	1	3	London
Total	10	40	

Information Content

Participants tended to see the information content as the single most important feature of an Internet intervention and hence generated more criteria relating to information content than to presentation, trustworthiness, or interactive components. Information content criteria apply to all the information in the intervention, including that provided in the interactive components. Criteria relating to information content are presented in [Textbox 1](#).

Evolving Information Needs

Participants recognized that one of the potential strengths of Web-based information was the ability to provide an almost unlimited volume of information, and they wanted this reflected in the level of detail provided. Participants stated that information needs evolve as patients and caregivers become more experienced with managing their condition, and that a good Internet intervention should address the needs of both

newly diagnosed patients and people who are already knowledgeable about their condition. Internet interventions were frequently criticized for providing basic information only. More knowledgeable users wanted access to in-depth scientific information about the condition and specific treatments, with many wanting information about new research and promising future treatments. They wanted Internet interventions to contain detailed, specific, and practical information covering the wide range of topics in [Textbox 1](#).

"I think it's quite easy to find background information...it's the sort of reviewing things and revisiting and reassessing and keeping your eye on the ball...that's missing." [LCD07; G8, Parent of diabetic child]

"You actually accumulate quite a lot of information...on the way and so we're probably asking for more specific things and quite a lot of information." [LHD09; G6, Heart disease]

Textbox 1. Patients' and caregivers' quality criteria for Internet interventions relating to information content**Information content:**

- Content needs to be detailed, specific, and of practical use.
- Long-term use requires increasing depth of information as self-management experience grows, as well as new and up-to-date information.

A good Internet intervention will provide information about the following:

- What to expect of the condition and treatment (eg, usual course of the condition, possible complications, tests and treatments that may be offered).
- Medication (eg, indications for use and potential side effects).
- Available treatments in the United Kingdom and elsewhere.
- In-depth scientific information about the condition and treatments.
- The practicalities of day-to-day living (eg, going on holiday, traveling, planning what food to buy and eat).
- Practical information (eg, guidance on what relevant books and gadgets are available and where to buy them, information about legal issues and benefits available, including completed examples of relevant forms, letters, and templates).
- Local services and resources (eg, local health services, voluntary organizations, and self-help groups).
- New research and areas of scientific or medical uncertainty (eg, new research presented with an evaluation of the available evidence base and current practice).
- Conflicting expert or scientific views, with an explanation of what this uncertainty means for users (eg, new or emerging research or complementary therapies).
- Other people's experiences (eg, personal stories from other people with similar health problems, other people's questions and answers, facility to interact with other people).
- Information for family members, addressing the concerns and roles of those around them.

Other criteria particularly related to information content criteria:**Manage the quantity and depth of information available.**

- Allow the user to control how much information, and on what topic, they access at any one time.
- Users need to easily access understandable information on the correct topic and to easily find the correct level for them.

Ensure all information is accurate and up-to-date.

- This means dating entries, providing information about the frequency and means of updating, and referring to recent media stories and developments.

Scientific Uncertainty

Participants held a range of views on how Internet interventions should deal with scientific uncertainty. While some participants wanted to access all the latest research results and decide on their validity for themselves, others were concerned that unproven or uncertain information would undermine more generally accepted advice. Some participants favored setting a threshold of scientific acceptability before reporting new findings, but it was unclear how this threshold would be determined. Others felt that it would be sufficient to provide an evaluation of the strength of new evidence, highlighting areas of uncertainty and reasons for treating initial findings with caution.

"I'd rather know and know what the caveats are and what [the] sort of limitations of my access to it are.... I'd rather feel fully informed than not informed enough." [LHD07; G6, Heart disease]

"...confident that the research is sound, that it is peer reviewed...and...enough people have volunteered." [EHD05; G10, Heart disease]

Practical Information

Users wanted practical information to help with the activities of daily living, such as shopping, meal planning, and exercising, as well as help with potentially difficult situations such as going on holiday or traveling. Users looked for information that would help friends and family plan activities. Other people's experiences, provided through personal stories, question and answer forums, or chat room facilities, were considered a particularly good source of practical information.

"But it's actually the practical day-to-day living of it and your lifestyle management that you really need to be really clued up on." [LAD04; G4, Diabetes]

"Rather than reinventing the wheel, it's sharing with other people and there are hints and tips that you get from them that you just wouldn't get from a GP, just little practical things." [LHD07; G6, Heart disease]

Managing Access to Information

Users wanted to be able to control the amount and detail of information they accessed and not be forced to see potentially upsetting or overly complex information when they did not feel ready for it.

"We should have a choice of knowing...because all these websites presented you with information, whether you wanted to know it or not." [LHD05; G6, Heart disease]

Updating Information

Participants were highly critical of sites that were not regularly updated, and they wanted entries dated to help users assess how frequently sites were updated.

"The moment I saw the date 2000 it kind of shut me down, 'cos this is 2004.... I really wanna see end of 2003/2004." [LAD02; G4, Diabetes]

Presentation

Navigation

Participants stressed the need for easy navigation that allowed swift access to relevant information (Textbox 2). Sites that heavily relied on drop-down menus on the home page or contained the "back" button as the only way of exiting from a line of enquiry were criticized as being "frustrating" (LHD08; G6, Heart disease). Sites with multiple hyperlinks were praised as being "straightforward" (LAC04; G7, Alzheimer's caregiver), "idiot proof" (LHD10; G3, Heart disease), or "user friendly" (NAD02; G9, Diabetes).

Visual Appearance

The overall appearance of an Internet intervention contributed significantly to its appeal, for purely esthetic reasons, by enhancing usability, or by contributing to the tone of the information. Ideally, the site should strike a balance between being "too busy" (LCD09; G8, Parent of diabetic child) or too "tabloid" (LAD04; G4, Diabetes) on the one hand, and too "serious looking" (LCD09; G8, Parent of diabetic child) or too "bland" (LAD02; G4, Diabetes) on the other.

Patients and caregivers preferred sites where information was visually presented in various formats as "everybody learns differently" (LAD02; G4, Diabetes) and visual information

helps you "see what actually happened" (LHD08; G6, Heart disease).

Language and Tone

Language and tone were considered very important. Participants universally disliked the use of unexplained medical jargon or non-UK terminology. However, use of technical or medical terms was considered necessary to convey information accurately, and also to help users communicate with their health care professionals, as long as the terms were defined and explained. Language and appearance combined to set the tone of an Internet intervention. While the wrong tone could be off-putting, the correct tone reassured users. Participants did not like overly "worthy" sites (LAD20; G2, Diabetes), but preferred a site to be "no-nonsense" (LHC02; G5, Hepatitis C), "non-patronizing" (LAD04; G4, Diabetes), and "authoritarian but friendly" (LHC01; G5, Hepatitis C).

Two elements linked presentation to other concerns: logging in and links to other sites.

Logging In

Participants did not like sites that required users to log in. Novice users found it hard to do, while others found it time consuming. Participants were put off by having to provide personal information before accessing content, particularly if it meant providing personal details or a user name. Users were concerned about the trustworthiness of a site that required them to log in, as they were concerned about the security of personal information, or as one participant put it, "Who has the back door key for it?" (LAD20; G2, Diabetes).

Links to Other Sites

Participants preferred Internet interventions that provided comprehensive and consistent information, and that did not continually send users "off-site." Many users found it difficult to return to the home site after following a link to another site. Participants stated that they wanted clear notification of being taken "off-site" so they could judge the trustworthiness of any external site.

Textbox 2. Patients' and caregivers' quality criteria for Internet interventions relating to presentation**Presentation:**

- The presentation needs to facilitate easy and speedy access to relevant information content.
- It needs to be attractive, engaging, understandable, and visually varied.

A good Internet Intervention will have excellent Web design:

- Easy navigation, including rapid and easy return to the home page; easy to locate search engines that search within the confines of the site and show intelligence by responding meaningfully to searches conducted using simple terms; use of hyperlinks to link up various sections of information within a site and for easy navigation by novice users; site maps for easy navigation by more experienced users.
- An attractive appearance, using colors, graphics, videos, animations, photos, and text broken up into small sections.
- Use of plain English, with a straightforward, but not patronizing tone; medical terms and jargon should be explained, but not avoided.

Other criteria particularly related to presentation criteria:**Logging in**

- Not unnecessarily requiring users to log in or enter personal details before allowing access information.

Links to other sites

- Only for additional information and resources, with clear warnings about being taken off-site and summaries of information content and other relevant details of other sites.

Interactive Components

The interactive features discussed in focus groups included personalized online assessments with personalized advice, Ask the Expert facilities, and online peer support groups. Participants had a range of views about the interactive components of the websites. Almost all felt that some degree of interactivity was helpful as it made the site more appealing and easier to use.

"I enjoyed the fact it was more interactive.... I found it entertaining." [LAC01; G7, Alzheimer's caregiver]

Some valued the specificity and tailoring of advice and information that could follow completion of online self-assessment tools, stating that this was the best way of obtaining personalized advice (short of seeing a doctor). These users were also keen on facilities such as "Ask the Expert," which allow users to put questions to specialist advisors.

"Yes, it would appeal to you because you think Well they're looking at me specifically and they're guiding me.... So what is good for me, because I'll be different to you and to him." [LAD14; G2, Diabetes]

However, others were concerned that they might inadvertently enter incorrect information and hence receive inappropriate or unsafe advice.

Many participants favored online peer support and electronic discussion groups, seeing them as a nonjudgmental source of support from people facing similar issues and challenges, available 24 hours a day.

"I do think it's very helpful because 3 o'clock in the morning...I just felt like not wanting to go on any more. Where do I go to get help at 3 o'clock in the morning? There isn't anywhere, whereas if there's a website where you can go in and talk to somebody else that's going through the same, it might be helpful." [LHC03; G5, Hepatitis C]

"So you just write what you feel and hopefully somebody can give you something back without any risk of judgment." [LAC03; G7, Alzheimer's caregiver]

However, others said that they were well supported already and could not see the need for such online groups.

The divergent views of participants account for the criteria generated in that they felt Internet interventions need to provide multiple interactive components that are optional, allowing the user to choose which, if any, interactive features to use ([Textbox 3](#)).

Textbox 3. Patients' and caregivers' quality criteria for Internet interventions relating to interactive components**Interactive components:**

- These contribute to the tone of Internet interventions.
- They need to provide multiple, optional, interactive components and allow users to choose which, if any, to use.

A good Internet Intervention will include a range of interactive components:

- Personalized online assessments, advice, and monitoring of the condition
- Online facility for asking an expert questions about the condition or treatment
- A question and answer facility or online chat room for online questioning and discussion with other people with similar health problems

Trustworthiness

Trustworthiness was very important to participants, but they wanted to be able to evaluate a site's trustworthiness swiftly, based on what they already knew about the authors of the site. They did not want to have to look for credentials, disclaimers, or privacy policies of unfamiliar individuals or organizations. Some participants felt that a kite mark or quality seal from a recognized center would be helpful.

"I want to go to a site where there's a seal...a stamp, as long as I knew what the stamp was." [LAD20; G2, Diabetes]

The presence of adverts or commercial sponsors made users wary of the information provided.

"They [drug companies] lie. They've got to skew the facts in their direction, that's what they are there for. They've got to sell their product." [LACO4; G7, Alzheimer's caregiver]

Another feature that was important for developing and maintaining trust in a site was regular updating, demonstrated by dating information and having new information readily available (Textbox 4).

Textbox 4. Patients' and caregivers' quality criteria for Internet interventions relating to trustworthiness

Trustworthiness:

- The site needs to be deemed trustworthy, both immediately and on subsequent or return visits.
- Trust has to be maintained, and can be lost if the site is not updated regularly.

A good Internet Intervention will establish its trustworthiness by:

- Being accurate
- Having no commercial links
- Not displaying advertisements
- Being authored or sponsored by a known trustworthy organization (eg, the National Health Service, a local hospital, well-known university, charity, or patient organization)
- Being regularly updated

Respondent Validation

Of the 40 focus group participants, 37 (93% response rate) returned the postal survey ranking the criteria that emerged from the discussions. A further 20 of the 40 (response rate 50%) patients and caregivers who had consented to participate in the study but not been able to attend a focus group also returned the postal survey. Of these further 20, 8 were patients (1 had diabetes mellitus, 3 had heart disease, 2 had both heart disease and diabetes, 3 had hepatitis C) and 12 were caregivers (2 cared for people with Alzheimer's disease, 5 were parents of children with diabetes, 1 cared for both a person with Alzheimer's disease and a child with diabetes, and 4 were parents of children with asthma). Mean ratings for criteria were above 3 on a 5-point scale (from 1 = not at all important, to 5 = essential) for all but one criterion, suggesting that the analysis had identified criteria considered important by patients and caregivers. No new criteria emerged from the postal survey. The ratings and selection of the top three criteria emphasized the importance of providing useful, practical, and comprehensive information that is up-to-date, accurate, trustworthy, and easy to navigate. In line with the divergent views expressed in focus groups, many patients and caregivers rated interactive components as essential, while some rated them as unimportant.

Discussion

Main Findings

Participants welcomed the potential of Internet interventions but felt that many websites were not achieving their full

potential. Participants generated detailed and specific criteria relating to information content, presentation, interactivity, and trustworthiness, which can be used by developers and purchasers of Internet interventions.

Relationship With Previous Research

Professionally Generated Criteria

There have been a number of studies that have led to professionally generated criteria for health-related websites [11,12]. Our user-generated criteria complement and extend the professionally generated criteria, which have tended to focus on accuracy and completeness of information. Our participants expanded this focus to include control over what information is accessed, and when, as well as an emphasis on practical tips for assistance with activities of daily living. This latter type of information was not expected to be evidence based; rather, it should be based on personal experience of other users.

Moreover, although our participants' emphasis on ease of navigation is not unexpected, the emphasis on tone, visual appeal, language, and overall presentation provides practical guidance for those wishing to develop or improve a health information site.

Trustworthiness

Our data on how users assess trustworthiness concur with those of Eysenbach, who in an observational study of healthy volunteers in Germany found that, although users stated that the source of a website was an important feature in establishing credibility, few actually visited the "About us" section [14]. Our participants wanted instant recognition of the institution behind

a site rather than taking the time to search for information about the provider. Our data extends that of Eysenbach as our participants were patients or caregivers, rather than healthy volunteers. Moreover, our data suggest that users also appraise the presence or absence of commercial sponsorship or advertisements and the frequency of updating information when considering whether to trust a site or not. This result is congruent with that from the Pew online survey, which found that strong commercial presence, out of date information, or no clear referencing of information all caused users to turn away from a site [15].

Interactivity and Peer Support

Our data suggest that there is considerable divergence among users about the value of interactive components and online peer support in particular. Those that were in favor of having access to online peer support, either in the form of questions and answers or online chat rooms, voiced opinions compatible with previous research in this area [19]. However, a proportion of users were opposed to online peer support, underlining that different people will want their needs met in different ways. Researchers and policy makers need to ensure that online facilities are seen as one option and must recognize that many patients or caregivers will prefer alternative facilities. Similarly, Internet interventions that contain only one interactive facility are likely to appeal to only a proportion of potential users, while those that have multiple interactive facilities are more likely to appeal to a wider range of users.

Methodological Issues

The strengths of this study include the focus on patients and caregivers, that is, the people who are most likely to need and use Internet interventions for long-term conditions. Our sample was socioeconomically diverse and, perhaps more importantly,

included a range of educational achievement and computer literacy. The use of a multidisciplinary group for analysis is known to add reflexivity and rigor [20], and we undertook a process of participant validation of results in addition to having substantial consumer input into the design, implementation, and analysis of the study. The focus group methodology allowed participants to build on each other's experiences and insights and allowed for discussion among participants to clarify ideas or concepts.

There are some limitations to this study. Participants were self-selecting volunteers who, by being motivated to participate in this kind of study, may not represent typical patients or caregivers. Although the views of caregivers and people in the United Kingdom areas other than London were represented in this sample, they were the minority. Caregivers in particular were hard to involve, and we did not have the opportunity to sample to redundancy as we did for patients. While caregivers in the study voiced similar criteria to patients, we cannot be certain that further caregiver focus groups would not have generated other criteria. The study was also limited in the extent to which participants could evaluate some of the interactive components in the 30 minutes they had with each intervention. Full appreciation of the complexities and advantages of the interactive components may require repeated use over time.

Conclusions

Patients and caregivers welcomed the potential of Internet interventions to help users with long-term conditions take better care of their health. However, many of the currently available Internet interventions are not meeting this potential. The user-generated criteria reported in this paper should help developers and purchasers of Internet interventions provide websites that better meet users' needs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus Group Guide. [[DOC \(MS Word\) file, 28 KB - jmir_v8i3e13_app1.doc](#)]

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Letter

Internet Interventions or Patient Education Web sites?

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In the paper “Internet Interventions for Long-Term Conditions: Patient and Caregiver Quality Criteria,” [1] the authors raise a timely concern with Internet interventions – consumers’ perspectives on the quality of these interventions. Given that consumers will ultimately decide the fate of Internet interventions, it is critical that we, as Internet intervention developers and researchers, solicit their thoughts and perspective in creating these programs. However, we have two major concerns that we believe limit what can be drawn from this paper.

The authors attempt to put forward “quality criteria” for Internet interventions based on 10 focus groups with a total of 40 participants. They were given time to examine the sites and then provide feedback. However, it appears that the list of “Internet interventions” were mostly patient education web sites and not what most in the field of Internet intervention research would consider Internet interventions [2-5]. Internet interventions are typically behaviorally or cognitive-behaviorally-based treatments that have been operationalized and transformed for delivery via the Internet. Usually, they are highly structured; self or semi-self guided; based on effective face-to-face interventions; personalized to the user; interactive; enhanced by graphics, animations, audio, and possibly video; and tailored to provide follow-up and feedback [2].

Perhaps it is the term “Internet intervention” that is problematic, as one could regard an interactive patient education web site to be an intervention. “Internet intervention” could be considered an umbrella term that encompasses various types of web programs, including behaviorally-based and empirically validated web-based treatment programs as well as patient

education sites. However, currently, it is our belief that the term “Internet intervention” is not typically used as a generic phrase, but as the specific expression for what is described above. At present, the lack of formal terms to define these various web sites and web programs may be confusing to those not familiar with this area. However, with the significant use of the Internet for health purposes [6], it is important that standard terms be created and used to reduce confusion and to avoid the current practice of using these terms interchangeably.

Interestingly, in the introduction to the paper, the authors describe and cite Internet intervention research that fits the more specific definition above. In fact, two of the authors wrote a paper for the Cochrane review in 2005 evaluating this literature [7]. Near the end of the introduction, the authors even state that “A further limitation of most quality criteria and previous user perspective research is that they do not distinguish between sites which contain information only and interactive sites which combine information with decision support, behavior change support, or peer support.” The authors clearly set the stage to investigate such web-based programs (Internet interventions) but then fail to apply these criteria to the selection process of the interactive health communication applications (IHCAs) used in the current paper. In fact, only a couple of the web sites used in the focus groups for this paper even seem to come close to the criteria of what is typically considered true Internet interventions (i.e., the CHESS programs by David Gustafson’s group). Basically, the “results” in this paper are drawn from patient education sites (i.e., heartcenteronline.com and alzheimersdisease.com – and many more), and not from Internet interventions as they are described above. To conclude their

investigation by saying that participants "...felt that many [Internet interventions] were not achieving their full potential" is misleading given that most participants did not actually view or use true Internet interventions. It is also not surprising that participants believed these sites were not achieving their potential as patient education sites typically provide only a small component of what a true Internet intervention usually offers.

In this paper, the authors also inquired about and reported what "good Internet interventions" should contain or be (i.e., "A good Internet intervention will provide information about the following..."). These global statements are also flawed and misleading. First, they are again based on participants' viewing of patient education web sites (and not real Internet interventions). Second, it is unclear how the authors determined which criterion were important. Was there a threshold for determining that a criterion was worthy of follow-up examination in the respondent validation survey (e.g., 50% of participants mentioned it)? Third, it is difficult, and sometimes meaningless, to try to generalize across interventions/disorders. Interventions can (and should) be significantly different from program to program given the focused disorder. For example, we would not expect a program targeting diabetes to contain the same ingredients as a program targeting insomnia. Fourth,

to say "a good Internet intervention will provide information about 'medication' or 'available treatments in the UK and elsewhere'" is much too general a statement to be made. Instead, offering some of the bulleted items as issues for consideration would be more appropriate. Some useful, though-provoking information was obtained by the focus group members, and researchers, clinicians, and developers in the field of Internet interventions could learn from this contribution. However, the provision of the information as currently presented is at times misleading and the conclusions drawn are inaccurate.

This paper does raise the important point that there is a need for an authoritative body to provide information about, and possibly rate the quality of, Internet interventions. This should include not only patient and caregiver criteria, but empirically validated outcome studies demonstrating effectiveness. We hope the current paper and subsequent discussion will help provide the impetus to push this critical agenda forward. Similarly, there is an obvious need to better define what Internet interventions are and how to differentiate among various kinds of health-focused web sites. As we move forward in this young field, we must clarify how we communicate about these interventions to ensure productive exchanges and sound science behind our work.

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Letter

Internet Interventions or Patient Education Web Sites? – Author's Reply

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We agree with Ritterband and Thorndike that the terminology and definitions in this field are confusing, and should be clarified and standardized. We would be happy to work with them and others on such a project.

However, they are mistaken in their belief that the interventions used in our study were mostly patient education websites [1]. The interventions were carefully selected to fulfil the criteria for Interactive Health Communication Applications (IHCAs); namely that they were computer-based programs that combined health information with at least one interactive component, such as decision support, behavior change support or peer support. For example, heartcenteronline.com contains interactive self-assessment tools, as a support for behavior change, as well as online peer support, in the form of both personal stories and online chat groups. Similarly, alzheimersdisease.com contains interactive tools and online peer support, in the form of an e-mail "buddy" arrangement.

This definition of an IHCA was provided in the paper, as were the criteria for choice of IHCA used in this study. As IHCA is a somewhat clumsy term, we preferred to use the more intuitive term "Internet interventions" to refer to web-based IHCAs.

The other major point raised by Ritterband and Thorndike refers to our chosen methodology. It is the nature of qualitative

research to work in-depth with small samples. We believe the combination of a qualitative research design allowing participating patients and caregivers to generate and define criteria, followed by a further validation exercise allowing them to check we have identified important criteria, is a particular methodological strength [2-3]. We did not set out to produce a list of generic criteria and in our analysis we were alert to the likelihood that patients and caregivers managing different chronic conditions would have different quality criteria. Instead, however, it was striking how similar needs and quality criteria were across groups.

This is the basis for the generic quality criteria described in the paper and we question Ritterband and Thorndike's assertion that an intervention for people with diabetes would self-evidently be completely different to one for insomnia. Our work concentrates on people with long-term conditions. Lorig has proposed that people with long-term conditions face three tasks (medical management, emotional management and role management) irrespective of the type of condition. These tasks require specific skills, such as problem solving, decision-making, finding and utilizing resources, forming partnerships with health professionals and taking action. Lorig postulates that enhancing self-efficacy, (i.e. a person's belief in their capacity to carry out a specific action) is key to enhancing

self-care skills [4]. Based on this theory, interventions designed to enhance self-care skills in people with long-term conditions should target these skills and aim to enhance self-efficacy. The specific content of an intervention will differ according to the

condition targeted, but the theoretical basis, and hence the core components (e.g. tailored information, decision-support, action planning, emotional support) may well be similar.

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Letter

The Law of Attrition Revisited

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Eysenbach's Law of Attrition Revisited

Early last year, Eysenbach published a paper [1] urging the need for a science of attrition. Rather surprisingly, there has not been much debate about the issues raised in the paper (this judged by a Web of Science citation search), despite the clear observation that attrition is a major problem in the use and evaluation of ehealth sites. This letter is an attempt to stimulate more discussion about this important issue.

Eysenbach's paper gives us three major conceptual advances – the distinction between trial dropout and low/nonusage nondropouts; the proposition of “diffusion of innovation” effectively reversed as a model for the take-up of Internet interventions; and the concept of the “Run in and Withdrawal Design.” The diffusion of innovation reversed is essentially a structural one in that it suggests a number of “systems” features that influence dropout and usage including expectation management, ease of enrolment, ease of dropout, usability, adjunct personal contact, financial commitment, workload, competing events, and experience.

User Characteristics and Preferences are Important

A number of issues arise from Eysenbach's proposal. First, the structural or systems model factors in the model may need to be supplemented by consideration of user characteristics. For example, the use and uptake of Web sites in mental health are likely to be modulated by the severity of the user's mental health problem [2], the users need for anonymity (possibly arising from stigma), lack of alternative resources due to living in a

remote location, and the preferences an individual might have for certain sorts of help. The potential impact of these factors in contributing to site adherence is something that needs to be recognized and, more than that, actually studied! There are a number of methods, which although indirect, can provide possible clues for further analysis. These include techniques such as correlating or predicting user characteristics with usage patterns and outcome measures.

A second attribute of users that warrants incorporation in any model of nonusage is an understanding of the expectations that people bring to a Web site, and what they mean by their intention-to-use. For example, many young people do not recognize “lousy feelings” as depression or anxiety, but a brief visit to a Web site provides a “mini-diagnosis” and a label. For them, one module may well fulfill their needs: They have no expectation that they are lining up for a full set of modules. Recognizing these multiple paths and trajectories of web usage means that low usage and dropout do not necessarily coincide with “failure”. Dropouts may well be e-attainers [3].

The multiple uses made of Web sites by different users raises the distinct, but highly relevant issue of the suitability of the Internet to provide full treatment packages for different conditions. The Internet has the capacity to reach many individuals who may never seek formal treatment for mental health services. However, it may well be that the primary role of the Internet in disease prevention will be in the delivery of short positive health messages, rather than the delivery of ‘therapy’ that requires hours of online work. Web site adherence or “stickiness” may cease to be an issue for online sites like MoodGYM when shorter interventions can be demonstrated to

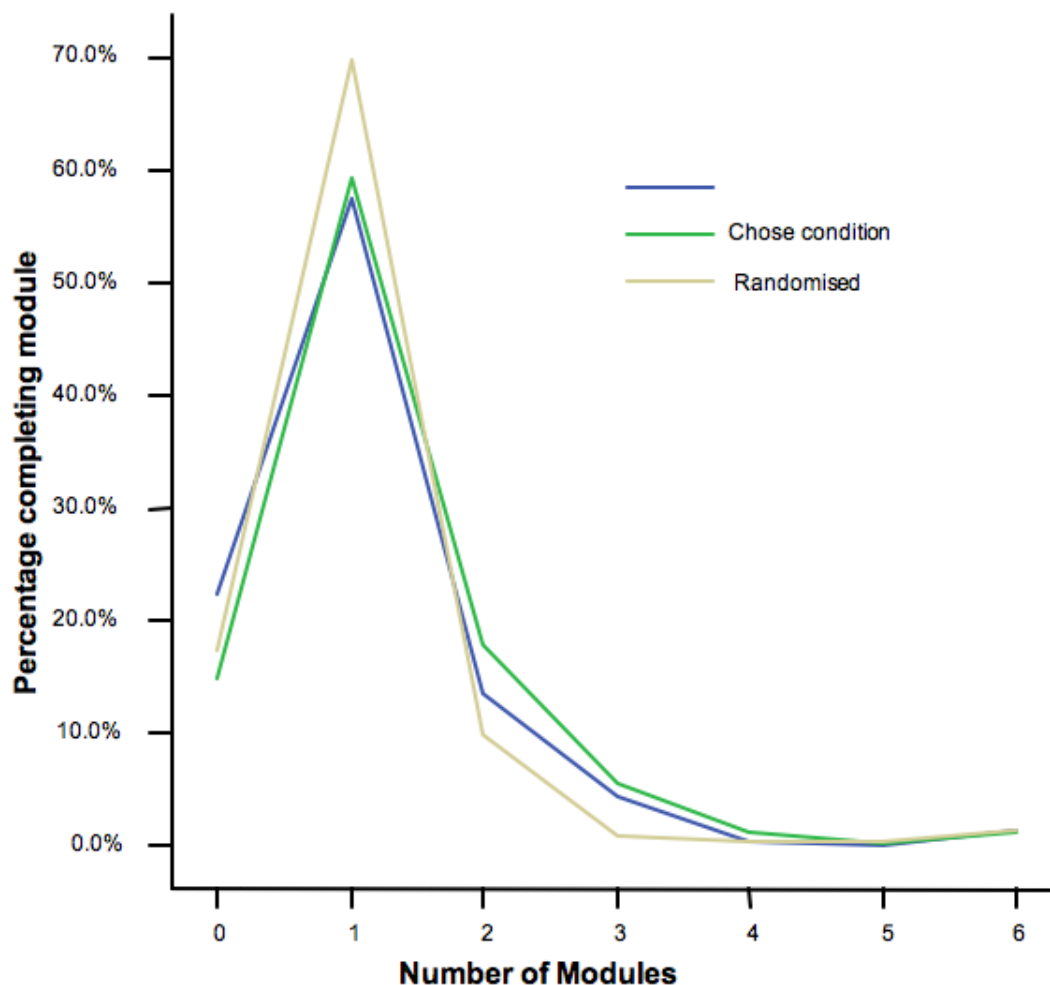
lead to similar health outcomes and brief bursts of information lead to increased help-seeking.

An Example

The following is an example of how attrition may be influenced by the personal characteristics or the preferences of the online users. We are currently conducting a trial of MoodGYM in which those intending to use the program: (a) report that they

have been asked to do the trial as a part of their clinician's treatment plan; (b) chose to do five modules when offered the opportunity to do only fewer than five in the early part of MoodGYM; or (c) are randomized to the MoodGYM condition as a function of an ongoing trial. Figure 1 shows the completion rates of modules as a function of group membership. It is emerging that those who commit to undertake five modules do have a higher likelihood continuing to use the site, although attrition after the third module is almost complete in all groups.

Figure 1. Completion rates of MoodGYM modules as a function of group membership



Similarities and Differences with Clinical Trials

We suggest that Eysenbach's argument asserting the differences between e-health and traditional clinical trials might be slightly overstated. Many researchers who have been involved with traditional randomized controlled trials (RCTs) of pharmacological treatments in psychiatry will recognize Eysenbach's characterization of attrition in such settings as extremely optimistic. The dropout of a third of recruited patients in such trials is common with rates exceeding 80% being observed in some long term trials aimed at relapse prevention. Determining whether patients have complied with medication regimes is difficult. In many respects, e-health is in a far stronger position than other studies to detail the low usage of the

interventions, given the tracking of length and number of visits to the application. Moreover, e-health interventions have high fidelity: the exact same intervention is potentially available to all the participants.

There are other minor points that need to be made. For example, Eysenbach makes a distinction between users lost to dropout and low usage nondropouts. This model suggests that people discontinue innovations because they are disenchanted or because they seek a better alternative to meet their needs. On reflection there are four theoretically possible usage curves: (i) dropout, low or no usage; (ii) nondropout, low or no usage; (iii) dropout, high usage; and (iv) nondropout, high usage. The dropout, high usage is a person who prefers not to engage with a Web site but undertakes the program under a new user name each visit (if the application is an open web-based one).

Emerging Statistical Techniques

Up until recently, interventions and clinical trials have been analyzed using classical analysis of variance methods. For these techniques, missing observations arising from participant dropout are a just nuisance factor which is addressed, *a priori*, by admonitions to minimize dropout [4] and, *post hoc*, by analysis of only those participants with complete data or by simplistic and often inappropriate methods of imputation. Mixed or random coefficient models are more recently developed methods that overcome problems due to missing data. These models operate under the assumption that the cause of dropout is measured as part of the available data rather than being contingent on the missing information itself (the missing at random assumption)[5]. These methods enable estimation of the effect of an intervention under the intention to treat model.

Mixed models themselves throw little light on the nature of attrition, its causes or consequences. However, more advanced techniques, based on latent variable modeling, may help us understand the complexity of the multiplicity of paths through and of out interventions. The complier average causal (CACE) model is specially aimed at estimating the effect of an intervention in the presence of noncompliance [6]. Related

techniques can be used to empirically delineate classes of response trajectories through and after an intervention [7]. These methods appear to be amenable to extension to accommodate attrition and to model causes of dropout.

Beyond Attrition

Developing a metric of the attrition attributable to an internet intervention site is an attractive initiative. It would parallel the notion of the acceptability or tolerability of conventional treatments. This concept, usually measured informally or only crudely, recognizes that some treatments, while efficacious, are possibly so odious as to be persevered with by only a few patients who might benefit from them. There are substantial hurdles to such measurements. It will prove difficult, if not impossible to disentangle attrition due to site effects from attrition due to the characteristics of users and the paths they take to a site. More important, to focus exclusive on attrition is to focus on the negative side of e-health interventions. E-health interventions have enormous potential to reach those warranting assistance and to address their needs. Recognizing the fact of high attrition, we need to respond with a science (and an art) of participation and encouragement.

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Letter

The Law of Attrition Revisited – Author's Reply

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Author's Reply

I agree with many of the points made by Christensen and Mackinnon in response to my “Law of Attrition” [1], which highlights the central role of adherence and exposure as important, but often underreported measures of eHealth interventions.

Recent articles in this journal, for example a paper by Danaher and colleagues on exposure measures in Web-based health behavior change programs [2], have picked up this discussion, and we are looking forward to receive more research explicating issues around sustained uptake of such interventions.

I do however not agree that focusing on attrition means focusing on the “negative” side of eHealth interventions. To formulate a “law of attrition” was partly motivated by the observation that many authors (the letter writer not included) are not very explicit about high dropout or nonusage rates in their study. Sometimes we have the impression that authors attempt to “hide” high attrition rates, perhaps fearing that reviewers and editors would deem a manuscript unpublishable if too many participants did not use an intervention or drop out from a trial. To explicate a “Law of Attrition” is an attempt to elucidate the fact that high dropout rates and nonusage seem common experiences for eHealth researchers and practitioners, and to encourage them to be forthcoming with such information, enabling them to cite a “law”. Attrition data should not be hidden or buried

somewhere in the manuscript, but explicitly stated (already in the abstract) and - even better - analyzed using multivariate models. Participant characteristics, intervention attributes, as well as external variables need to be incorporated in such models, to analyze and predict events such as dropouts or nonusage. We will not be learning about what works and what does not by concealing such data.

Attrition measures are particularly important for the interpretation of “negative” studies (studies which do not show an effect on outcomes), as can be illustrated by a recently published study on electronic links between an emergency room and primary care physicians, which did not result in a significant reduction in resource utilization [3]. That study is a perfect example for the current tendency to focus on reporting traditional outcome measures (in this case, resource utilization in the emergency department and family physician offices), while failing to report any detailed exposure, adoption, or usage data. Without proper reporting and analysis of such data we will – in an “intention-to-use” analysis - never know whether it is the intervention which is principally flawed, or whether it was simply not (or not to a sufficient degree) adopted by the user group [4]. Adoption and sustained use are obvious prerequisites for any information and communication technology to change outcomes, and little is gained by just reporting “negative” outcomes without exploring why and for whom the technology worked (or failed to work) in terms of engagement, adherence, and continued use.

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