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Contents

Reviews

Original Papers

Corrigenda and Addenda

Review

Clinical Decision Support Systems for Drug Allergy Checking: Systematic Review

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Abstract

Background: Worldwide, the burden of allergies—in particular, drug allergies—is growing. In the process of prescribing, dispensing, or administering a drug, a medication error may occur and can have adverse consequences; for example, a drug may be given to a patient with a documented allergy to that particular drug. Computerized physician order entry (CPOE) systems with built-in clinical decision support systems (CDSS) have the potential to prevent such medication errors and adverse events.

Objective: The aim of this review is to provide a comprehensive overview regarding all aspects of CDSS for drug allergy, including documenting, coding, rule bases, alerts and alert fatigue, and outcome evaluation.

Methods: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed as much as possible and searches were conducted in 5 databases using CPOE, CDSS, alerts, and allergic or allergy as keywords. Bias could not be evaluated according to PRISMA guidelines due to the heterogeneity of study types included in the review.

Results: Of the 3160 articles considered, 60 met the inclusion criteria. A further 9 articles were added based on expert opinion, resulting in a total of 69 articles. An interrater agreement of 90.9% with a reliability K=.787 (95% CI 0.686-0.888) was reached. Large heterogeneity across study objectives, study designs, study populations, and reported results was found. Several key findings were identified. Evidence of the usefulness of clinical decision support for drug allergies has been documented. Nevertheless, there are some important problems associated with their use. Accurate and structured documenting of information on drug allergies in electronic health records (EHRs) is difficult, as it is often not clear to healthcare providers how and where to document drug allergies. Besides the underreporting of drug allergies, outdated or inaccurate drug allergy information in EHRs poses an important problem. Research on the use of coding terminologies for documenting drug allergies is sparse. There is no generally accepted standard terminology for structured documentation of allergy information. The final key finding is the consistently reported low specificity of drug allergy alerts. Current systems have high alert override rates of up to 90%, leading to alert fatigue. Important challenges remain for increasing the specificity of drug allergy alerts. We found only one study specifically reporting outcomes related to CDSS for drug allergies. It showed that adverse drug events resulting from overridden drug allergy alerts do not occur frequently.

Conclusions: Accurate and comprehensive recording of drug allergies is required for good use of CDSS for drug allergy screening. We found considerable variation in the way drug allergy are recorded in EHRs. It remains difficult to reduce drug allergy alert overload while maintaining patient safety as the highest priority. Future research should focus on improving alert specificity, thereby reducing override rates and alert fatigue. Also, the effect on patient outcomes and cost-effectiveness should be evaluated.

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KEYWORDS

alert; clinical decision support systems; computerized physician order entry; drug allergy; patient safety

Introduction

Worldwide, the burden of allergies is growing—in particular, drug allergies (DAs) are becoming increasingly common [1]. DAs can be categorized as abnormal immunoglobulin E-mediated reactions (eg, anaphylaxis) or delayed, nonimmunoglobulin E-mediated reactions, which are generally less severe (eg, intolerances) [2].

DAs are perceived as an important problem. In a study conducted by the European Network on Drug Allergy and the EAACI Drug Allergy Interest group, 10% of parents reported that their child was allergic to a drug [3]. A study in a tertiary care academic medical center in Chicago reported a DA prevalence of 25% in the general adult population [4]. Looking at the clinical investigations of suspected reactions, the results demonstrate that these numbers are overvalued [3]. In a general hospital in Singapore, the estimated incidence of DAs was 4.20 per 1000 hospitalizations (95% CI 2.93-5.46) and the estimated mortality attributable to DA was 0.09 per 1000 hospitalizations (95% CI 0.06-0.12) [5]. A study in a university hospital in Korea reported an estimated incidence of drug hypersensitivity reactions of 1.8 per 1000 hospital admissions [6].

In the process of prescribing, dispensing, or administering a drug, a medication error can occur and may have adverse consequences, for example, when a drug is given to a patient with a documented DA to this particular drug [7]. Only a minority (0.25%) of these medication errors result in an adverse drug event (ADE), but allergic reactions represent an important cause of preventable ADEs caused by medication errors [8,9]. It was estimated that 12.1% of all medication errors with the potential for an ADE arise from incomplete or incorrect allergy documentation [10].

Bates et al [11] and Classen et al [12] estimated that each ADE resulted in a prolonged length of hospital stay of 2.2 and 1.7 days, respectively. Looking more specifically at penicillin allergy, Macy et al [13] demonstrated that in the Kaiser Foundation Hospitals in Southern California, 0.59 additional hospital days (95% CI 0.47-0.71) per hospitalization resulted in an extra cost of US $1252.90 in 2012.

CPOE systems with built-in CDS have the potential to prevent such medication errors and consequent ADEs [14-16]. When a prescription poses a threat to the patient, the clinical decision support system (CDSS) warns the user by providing an alert message. However, it is well known that current CDSS for DA checking are impaired by alert fatigue caused by low alert specificity [17-19].

Several systematic reviews have been conducted to evaluate CPOE and CDSS in general or in specific domains of clinical care such as pediatrics [14-16,19-28]. To the best of our knowledge, no systematic review has been conducted focusing specifically on CDSS for DA. In this systematic review, we aimed to provide a comprehensive overview of all aspects of CDSS for DA including documenting, coding, rule bases, alerts and alert fatigue, and outcome evaluation.

Methods

Search Strategy

A systematic literature review was performed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews and meta-analyses [29] as much as possible. Bias could not be evaluated according to the PRISMA guidelines due to the heterogeneity of study types included in the review. Here, we focused on searching for articles related to CDSS and associated alerts in the domain of DAs. We performed searches in the bibliographic libraries of Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, Embase, Ovid, and PubMed from database inception up to February 2016. The search strategy for the 5 databases is provided in Multimedia Appendix 1. Because the aim of the review was to provide a broad overview of all aspects of DA-related CDSS, reviews and conference proceedings were also included. Only English language papers were included. Additional publications of interest that included information relevant to this review were included based on expert opinion. Our search strategy is presented in Figure 1. The terms "Computerized Physician Order Entry" (CPOE) and "Clinical Decision Support System" (CDSS) were combined with the term "alert." These terms were combined with the term "allergic" or "allergy" to limit the scope to the allergy field.

Study Selection

The titles and abstracts of identified articles were independently screened by two researchers (LL and SVL) to assess inclusion in the full review (Figure 2). If one or both reviewers selected the paper for further evaluation, we included the article for full assessment. Articles were included for analysis if the study involved at least one of the following: (1) prevalence of allergy alerts; (2) coding or documenting of DA information; (3) implementation of a CDSS for DA; (4) perceptions of care providers on CDS for DAs; or (5) alert acceptance and interface design in the domain of allergies. Disagreements were discussed with a third reviewer (PC) until consensus was reached.

Data Extraction

From each article included, the two researchers (LL and SVL) extracted predefined information including the author names, year of publication, main topic of the paper, aim of the study, study design, number of subjects (care providers, alerts, etc), and key findings. The third reviewer (PC) evaluated the extracted data, and disagreements were resolved by consensus.

Figure 1. Search strategy used for navigating the 5 libraries (Cumulative Index to Nursing and Allied Health Literature, Cochrane, Embase, Ovid, and MEDLINE). The matching search terms are listed in the lower part of the figure. CDSS: clinical decision support system; CPOE: Computerized Physician Order Entry.

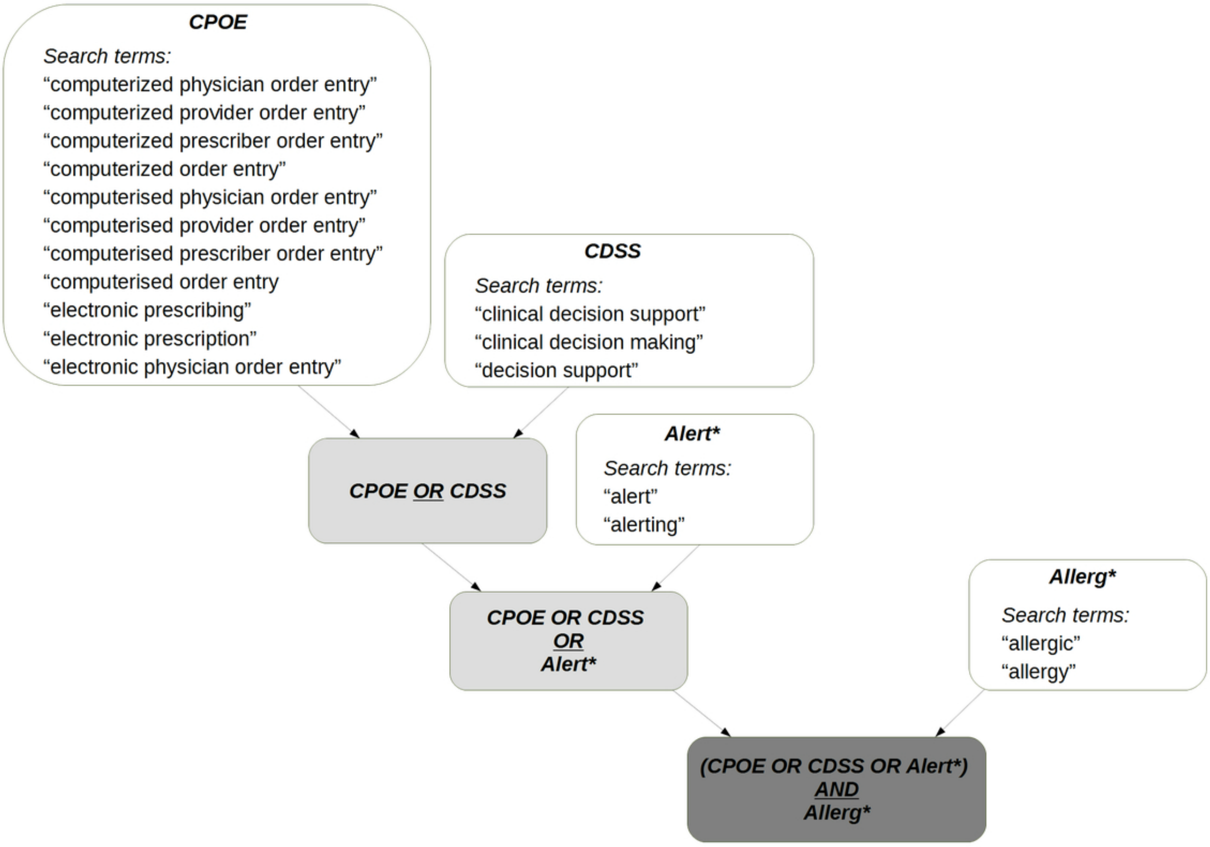
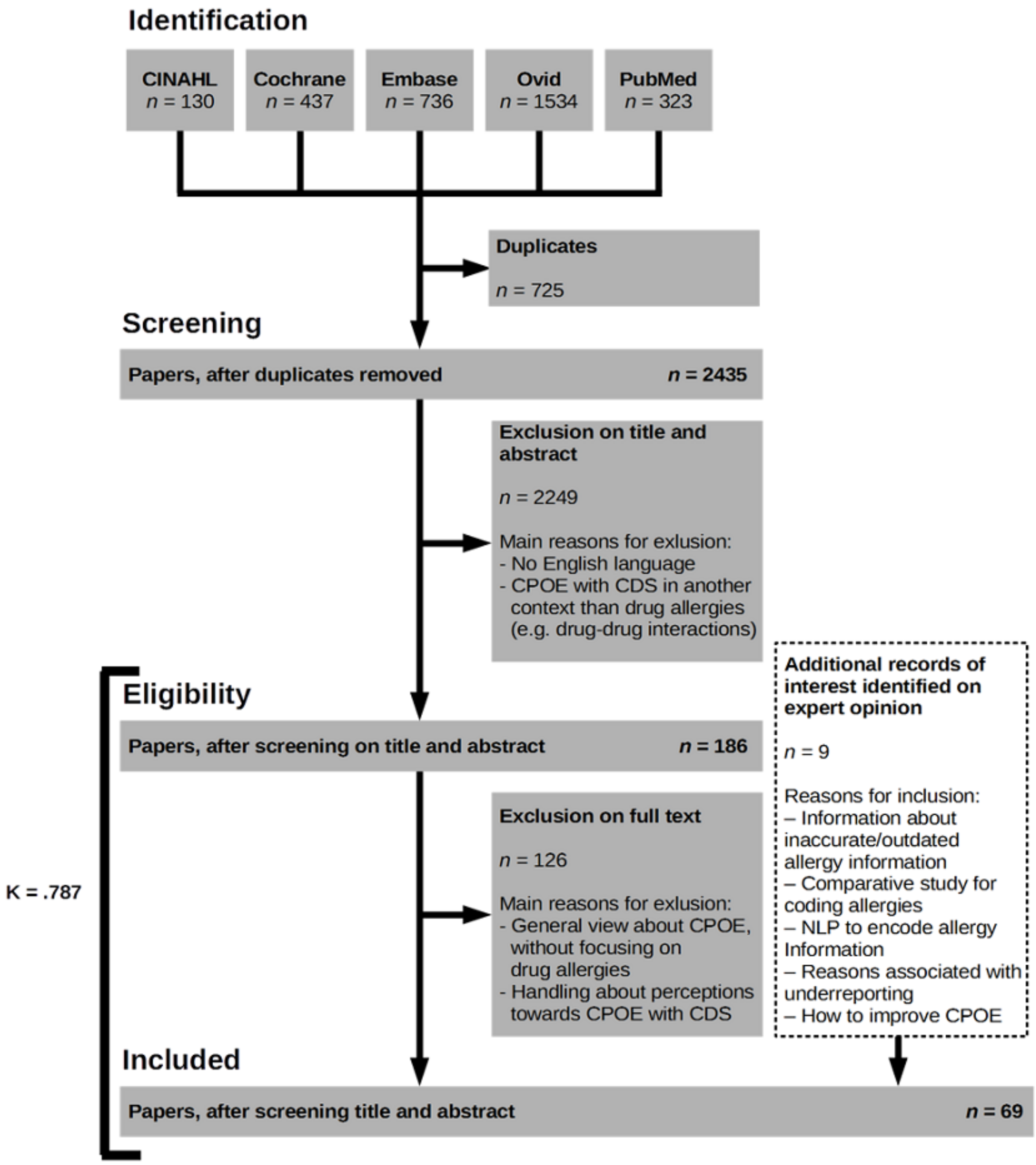


Figure 2. Search strategy (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), with reasons for exclusion and inclusion of articles added based on expert opinion. CDS: clinical decision support; CINAHL: Cumulative Index to Nursing and Allied Health Literature; CPOE: computerized physician order entry systems; NLP: natural language processing.



Assessment of risk of bias was not conducted because the heterogeneity in the quantitative and qualitative study designs, reviews, and reports did not allow for a comprehensive and consistent evaluation of bias.

Results

Study Selection and Reviewer Agreement

We started the study with 3160 articles from 5 different literary sources (Figure 2). After the removal of duplicates (725 duplicates), 2435 articles remained for title and abstract review. Eventually, 186 articles were included for full text review, of which 60 were included in this review. The interrater reliability between LL and SVL was calculated using Cohen's kappa. An interrater agreement of 90.9% with a reliability of K=.787 (95% CI 0.686-0.888) was reached between the two reviewers. Additionally, 9 articles were added based on expert opinion, resulting in a total selection of 69 articles. Although these 9 articles were not retrieved by the search query, they reported on aspects relevant for this review, including information related to the coding of allergy information, reporting of DAs, and strategies for improving CPOE alerts. These articles were identified by PC from automatic weekly updates on PubMed (My NCBI). These weekly updates were based on separate queries with individual key words including "Computerized Physician Order Entry," "Clinical Decision Support," "Medication error," and "Drug allergy." PC collected and indexed relevant articles from this weekly list using reference manager software over the years. Articles included in the library of the reference software that dealt with relevant topics but were not discovered via the search queries were included.

Study Characteristics

The names of the authors, year of publication, study design, aim of the study, and key findings are shown in Multimedia Appendix 2. Papers in Multimedia Appendix 2 are organized by topic [1,14,16-19,22,30-91]. Papers belonging to different topics are categorized in all corresponding topics. In Multimedia Appendix 3, a table with the number of subjects included in the study can be found. Most studies (56/69, 81%) were published after 2005. The 69 studies consisted of 28 observational studies (23 retrospective studies, 2 cross-sectional studies, 1 prospective time series analysis, 1 prospective study with interviews, and 1 cohort study), 13 review articles, 8 practice experiences, 6 before-after studies, 3 surveys, 3 controlled trials (1 randomized controlled trial, 1 randomized crossover study, and 1 nonrandomized controlled trial), 2 economic evaluations, 2 focus group studies, 1 scenario-based simulation study, 1 study describing a draft for an algorithm to classify information automatically, 1 study discussing a workshop, and 1 study describing a comparative study on standards in the DA field.

Documenting the Presence or Absence of an Allergy

For a functional CDSS, accurate and consistent documentation of patient allergy information is necessary. Currently, there is no agreement about what needs to be recorded and how to do so [30]. In 1964, Mills addressed the importance of capturing information on allergies and drugs, proposing a new checklist that served as a guideline in hospitals [31]. A similar initiative was taken more recently by Burrell et al [32], who introduced a pharmacist-driven protocol in a hospital to improve the completeness of DA or intolerance documentation. A review of medical notes in a general district hospital demonstrated poor documentation practices where 97.4% (114/117) of drug allergy boxes were only partially completed and 2.6% (3/117) had nothing documented [33]. In another analysis comparing two oncology wards, one ward showed 100% consistency, while the other ward demonstrated drug charts with allergy entries in 82.4% of cases, of which only 68.8% corresponded to information in the medical notes [34]. Failure to accurately document DAs may lead to prescribing and administering medications that could be harmful to the patient. Besides accurate documentation, correct patient identification with linking of medication information with patient DA information, for example wristband barcoding, is required for real-time CDS [35].

Lopez-Gonzalez et al [38] reviewed factors for not reporting ADRs and found that the most prominent factor associated with underreporting was ignorance based on the fact that physicians often think that only severe ADRs need to be reported. Secondary factors, such as the hierarchical nature of hospital culture combined with stressful working conditions, also contributed to prescribing errors [41]. Moreover, at the time of documenting, there is often no clear distinction between a real allergy-related ADR and other minor reactions [37].

Inaccurate or outdated DA information can also be a factor that influences the functioning of a CPOE system with CDS. Rimawi et al [40] observed a small use case (150 patients) that was documented as intolerant to penicillin even though a negative penicillin skin test was observed. Of these, 36% (20/55) patients who revisited the medical center within the year were redocumented as having a penicillin allergy without proper indication.

Porter et al [39] demonstrated that without healthcare personnel re-asking and validating information, there is a significant risk of error at the decision step of ordering or prescribing medications. Additionally, side effects related to the drug's primary pharmacological effect are sometimes misinterpreted and documented as DAs, resulting in inaccurate DA information.

The more complete and accurate DAs recorded in patients' EHRs, the greater the potential of CPOE systems with CDS to improve patient safety and reduce medication-related costs [14].

Coding

Information on how allergy data are structured or coded in EHRs is scarce. Slight et al [52] recently stated that the US government has not yet specified what standard terminologies should be used to structure allergy information.

A first approach is to enter information concerning DAs in free text. In order to use free text information for CDSS, natural language processing is applied taking the context into consideration [47]. Currently, this technique is not widely used because of the difficult nature of natural language processing.

A review of the available literature indicates that different coding systems are used for documenting DA information in EHRs, including International Classification of Diseases (ICD) [44,51], Systematized Nomenclature of Medicine, Clinical Terms (SNOMED CT) [49], RxNorm, and National Drug File-Reference Terminology (NDF-RT) [50]. Sometimes mapped coding schemes are used to add functionality. Benkhaial et al [44] used the Anatomical Therapeutic Chemical classification for mapping all drugs belonging to a specific ICD group. However, mapping might not always be this simple. Bernstein [45] recently indicated in a Danish use case that there is not yet a clear consensus regarding the alert information concept (eg, drug alerts) and how drug allergy or other allergy subtypes are linked to that concept.

Goss et al [48] performed a comparative study of the SNOMED CT, NDF-RT, Medication Dictionary for Regulatory Activities, unique ingredient identifier, and RxNorm standards for encoding allergy information. The qualitative part of their study demonstrated that SNOMED CT had the most desirable characteristics, including concept coverage, subset capabilities, and vocabulary structure. The quantitative part showed that RxNorm had the highest concept coverage to represent drug allergens, followed by unique ingredient identifier, SNOMED CT, NDF-RT, and Medication Dictionary for Regulatory Activities. SNOMED CT was the only coding system capable of representing unique concepts to encode ignorance of allergies.

The option to have an entry to indicate the ignorance of allergies is important for patient care because not documenting any DA information does not necessarily mean that there are no known DAs. Abookire et al [43] stated that "every hospitalized patient should have DAs entered by the admitting physician (this is a forced entry; 'no allergies' may be entered)."

Rule Bases

In the literature, we observed underreporting of the rule bases used to support CDSS. Most CDSS for DA screening are knowledge-based systems supported by evidence-based rule databases. Some organizations use internally developed rule bases [54], while others use vendor-supplied rule bases [56].

We observed two types of CDSS in the literature: basic and complex. Basic CDSS provide alerts when a prescribed drug is listed in the patient's DA list. In these systems, rules are implemented to screen for cross-reactivity within and between drug classes [55]. More complex CDSS use an inference mechanism to generate recommendations specific to a patient by integrating contextual information from the patient's EHR (eg, previously tolerated administrations of the drug and results from DA tests) [55].

As reported by Kuperman et al [14], healthcare provider organizations ideally use a combination of vendor-supplied rule sets, which are developed by other organizations, and internally developed rules, which are derived from the literature and national and local consensus on what constitutes best practice. In any system, as medicine evolves and clinical knowledge grows, a timely review of the rule bases is warranted, for example using a Delphi approach to analyze what rules are useful [53].

Alerts and Alert Fatigue

Alert fatigue has been defined as "declining physician responsiveness to a particular type of alert as the physician is repeatedly exposed to that alert over a period of time, gradually becoming 'fatigued' or desensitized to it" [60]. Alert fatigue caused by one type of alert may also lead to declined responsiveness to other types of CDS alerts (eg, drug-drug interaction, DDI, alerts). The state of the art in CDS for DA is such that alerts are not specific enough, resulting in high override rates [17,18]. Current systems, which generate an alert at the moment of prescribing, have very high override rates of over 90% [1,17]. The first concern regarding increasing DA alerting rates and overrides was raised by Abookire et al [43]. This problem has since been investigated in several other studies. Bryant et al [59] retrospectively analyzed physician responses to DDI and DA interaction alerts in two university hospitals and reported high override rates in all categories, ie, 92.87% (2280/2455 alerts) in general and 90.86% (1183/1302 alerts) for DAs. No significant difference in override rates was observed between hospitals or between physicians-in-training and residents. Topaz et al [80] demonstrated a significant increase in DA alert overrides from 83.3% in 2004 to 87.6% (P<.001) in 2013 in a retrospective longitudinal study of two large academic medical centers. Similarly, Lin et al [71] demonstrated an increase in drug allergy override rates from 72 overrides out of 105 alerts (68.6%) in 2001 to 341 overrides out of 420 alerts (81.2%) in 2006.

In a recent observational study, Slight et al [1] evaluated DA alerts generated over a 3-year period in a tertiary care teaching hospital and 36 primary care practices and found that in total, 81.10% (128,157/158,023) DA alerts in both settings were overridden. In a retrospective 5-month chart review study conducted by Genco et al [63], a similar override rate of 87.4% (153/175) DA alerts was observed and the overall override rate for all types of alerts was 93.51% (12,829/13,719).

When an alert is overridden, analyzing the override reasons can help to understand the specific context. Several studies have reported the reasons frequently given for DA alert nonadherence, including (1) "medication was previously tolerated"; (2) "known DA for which only monitoring is needed"; (3) "the benefit outweighs the risk"; and (4) "alert considered not clinically important" [66,67,79].

Besides evaluating override reasons, the underlying causes of high override rates should be investigated. Hsieh et al [37] cited two important causes. The first cause is highly inclusive drug class and drug cross-reactivity mapping, which generates a large number of DA alerts for drugs with only minor potential to cause an allergic reaction. Alert acceptance is more likely when the warning is infrequently encountered [68] and when the physician encounters an exact drug match instead of a drug class warning [77]. The second cause is difficulty maintaining accurate allergy lists because there may not be a clear distinction between immune-meditated allergies and nonimmune-mediated sensitivities, and there is no general consensus on whether both should be included in allergy lists [37]. The likelihood that alerts will be ignored is related to the low predictive value for allergic drug reactions and inaccurate alerts because of inconsistent information in medical records [37,69].

Strategies for improving alert specificity and acceptance have been proposed. Horsky et al [65] stated that the specificity and contextual relevance of alerts can be increased by periodically reviewing trigger rules, a thorough analysis of performance logs, and maintenance of accurate allergy, problem, and medication lists in EHRs. Additionally, Brodowy et al [58] demonstrated a reduction in DA alerts by simply eliminating alerts resulting from inactive ingredients.

The possibility of customizing CDSS to increase alert specificity and alert acceptance has also been reported [61]. CDSS, where the severity levels for drug or disease interactions can be modified by the physician to exclude alerts at a level considered not relevant, or the use of an on-demand approach that provides decision support only when a physician considers it relevant, could improve alert acceptance [78]. This may be related to the caregiver status of the person using CDSS. Knight et al [68] demonstrated, for example, that nurses are nearly twice as likely to accept an alert compared with a resident (odds ratio [OR] 1.92, 95% CI 1.44-2.57). The usability of the alerts can also be improved by applying human factors design principles [65,75]. For example, a tabular format for presenting multiple alerts and the grouping of similar information aid in making prescribing decisions [75]. Designing a workflow with minimum disruptions by only showing critical to high-severity alerts, as suggested by Shah et al [76], could also be effective.

Outcomes

In the literature, we found limited results related to the outcomes of CDSS for DA. We did find studies that investigated the number of prescribing errors (PEs) and studies discussing patient outcomes for different types of ADEs, including ADEs originating from DAs.

CPOE systems can help in making fewer PEs, although not all studies quantify this improvement. Benkhaial et al [44] did not find a significant difference in the risk of being prescribed a drug potentially inducing an allergy using electronic recording of the allergy via ICD-10 codes compared with paper records. Oliven et al [89] compared the number of PEs between a department using handwritten drug orders with that of a department using CPOE systems and found a reduced number of PEs in the department using CPOE. No significant difference was found between the two departments for DAs. On the contrary, Evans et al [54] demonstrated a reduction from 2.46% (28/1136) patients to 0.07% (4/545) patients with adverse events caused by anti-infective agents due to the introduction of a computerized anti-infective management program. Likewise Mahoney et al [56] demonstrated a reduction in PE rates related to DAs from 833 in the preimplementation phase to 109 in the postimplementation phase (OR 0.14, 95% CI 0.11-0.17).

When looking at the outcomes for ADEs, Bates et al [83] demonstrated a reduction of 55%, from 10.7 events per 1000 patient-days to 4.86 events per 1000 patient-days for nonintercepted serious medication errors, defined as those either resulting in or with the potential to result in ADEs. In a follow-up study [84], this rate decreased to 1.1 events per 1000 patient-days after additional refinements of the system. This objective was reached by including a dose selection menu, simple DA and DDI checking, and the requirement that clinicians indicate the route and frequency of drug administration. Hsieh et al [37] found that ADEs resulting from overridden DA alerts do not occur frequently (19/320, 5.9%). In this study, none of the ADEs were considered preventable because the overrides were deemed clinically justifiable. There is limited evidence that systems, mostly electronic systems combining CPOE with CDS, for preventing represcription after the occurrence of an ADE (including DAs) are effective [90].

The implementation of CDSS can also influence economic outcomes, eg, by decreasing costs related to medication errors [86,88]. However, information on cost-effectiveness, specifically of CDS for DAs, was not found.

Discussion

Principal Findings

To the best of our knowledge, this is the first systematic review focusing on CDSS in the field of DA. We included 69 articles in our review. The main findings are the problem of incomplete and inaccurate recording of patients' DA information, the absence of an appropriate standard terminology that guides the rule bases within a CDSS, problems with rule bases, and the low specificity of DA alerts resulting in alert fatigue.

The first key finding was the incomplete or inaccurate documenting of patients' DA information in medical records. Accurate and comprehensive recording of DA information in EHRs is essential for the proper functioning of CDSS for DA screening. A recurrent problem described in the literature is the absence of documented information on patients' allergies, which can be interpreted in two ways: (1) the patient has no known allergies or (2) the patient has an allergy to a certain substance that has not yet been documented in the patient record [92]. Therefore, the absence of any known DA should also be documented in EHR. Besides underreporting of DAs, outdated or inaccurate DA information in EHRs also poses an important problem.

The second key finding was the absence of a generally accepted standard terminology for the structured documentation of allergy information. The use of Anatomical Therapeutic Chemical, ICD, NDF-RT, RxNorm, and SNOMED CT was described in the literature, but limited information was provided about the exact manner of implementation or integration of these coding systems. An evaluation of terminologies by Goss et al [48] showed that currently, a combination of RxNorm and SNOMED CT satisfies most criteria for encoding allergies. The use of free text for documenting DA information in EHRs should be discouraged because of the difficulties for CDS. The use of a standard terminology is required for coded exchange of DA information between institutions on a national and international level and for creating exchangeable decision rules based on standard terminologies. Governments have an important role in providing standardized terminologies in the official national languages. Policies and regulations may be required to support the effective use of coding standards in clinical practice.

The third key finding was that all reported CDSS for DA screening were knowledge-based systems requiring timely review of the rule bases to keep CDSS up to date. Ideally, end users and program developers should work together to regularly review the alerts logs and decision rules to reduce the risk of alert fatigue [67]. This is a continuous process and not a "one and done" step. Both in-house curated knowledge bases and vendor-based rule bases were reported in the literature, and both have their advantages and disadvantages. In an in-house curated knowledge base, flexibility is guaranteed, leading to potentially higher alert specificity, but it requires substantial effort to develop and maintain the rules base. A vendor-based rule base is easily purchased, but it has less flexibility when it comes to changing decision rules. The end user is dependent on the vendor for updates, but the maintenance burden lies with the vendor. A third possibility is the implementation of a hybrid system combining a commercial rule base with internally defined content refinements or decision rules.

The last key finding is the consistently low specificity of DA alerts. This remains an important problem as it causes high override rates, resulting in alert fatigue. Researchers have tried to tackle the problem of alert fatigue by providing on-demand decision support or customizable computer-triggered decision support. Another option is to turn off certain alerts, for example, by looking at the personal preferences of the healthcare provider who can decide to no longer receive a particular type of warning [93]. It remains difficult to find a good balance between reducing alert overload and keeping patient safety at a high level. A fixed rule base may therefore not always be appropriate; rather, an adaptive CDSS supported by a predictive risk model may be more useful [70]. Taking contextual factors into consideration as part of the CDS rules may help in increasing the specificity of DA alerts and lowering the rate of alert overrides. This strategy has been successfully applied for increasing the specificity of DDI alerts. Duke et al [94,95] and Cornu et al [96] have developed context-aware DDI alerts based on relevant patient-specific information, resulting in improved alert acceptance.

Recommendations for Policy, Practice, and Future Research

Future policies should focus on the implementation of standard terminologies to allow standardized coded exchange of DA information on a national and international level and to create exchangeable decision rules.

Information on the effect of CDSS for DAs on patient outcomes was very limited. Thus, future research should focus on evaluating patient outcomes. Hsieh et al [37] demonstrated that after overriding DA alerts, none of the resulting ADEs were preventable. However, in their study, only overridden DA alerts were evaluated. It would be interesting to know the number of ADEs that was effectively prevented by CDSS.

It is assumed that implementing DA checking in a CPOE system also has a beneficial financial impact. We did not find any studies specifically related to the economic outcomes of CDS for DAs, but general conclusions about the economic benefits of implementing CPOE systems for the hospitals were documented. At the start, the implementation of a CPOE system requires a large investment, but soon the costs are outweighed by the benefits and result in savings [97]. However, the cost-effectiveness of CDSS for DA should be further investigated.

Current systems often warn about all possible cross-reactions, although the substance-specific risk should be estimated and the severity of the alert may change as a function of the possibility of cross-reaction (eg, likely, possible, or unlikely). Future research should explore strategies for optimizing cross-reactivity rules and enhancing alert specificity.

Study Limitations

This study has several limitations. First, because of the heterogeneity across the study objectives, study designs, study populations, and reported results, a meta-analysis could not be performed. Second, different study designs require a different methodological framework for assessing bias. The heterogeneity in quantitative and qualitative study designs, reviews, and reports did not allow for a comprehensive and consistent evaluation of bias. This may limit the generalization of the results, but it allowed us to take a broader view of all relevant research in the field of CDS for DAs. Third, we excluded non-English papers, which may constitute selection bias. Additionally, 9 papers were added based on expert opinion because they included information relevant to this review. These extra articles were not retrieved with the query because they included keywords other than those included in the search query. Adjusting the query was not feasible because the keywords were often too general (eg, medication safety), which would result in a high number of irrelevant articles. Finally, publication bias cannot be excluded. We observed a high number of studies published in the US setting, which may lower the international relevance of the results. However, we believe that the findings of our review are relevant in an international context.

Conclusions

This review shows that CPOE systems with CDS for DA screening are perceived as useful in clinical practice. Nevertheless, there are some important problems associated with their use. First, it is not yet clear how and where to document DA information in patients' EHRs. Second, there is a lack of proper coding terminology for documenting allergies. A major problem with current systems is that alerts are not specific enough, resulting in high override rates and consecutive alert fatigue. Future research should focus on strategies to improve alert specificity and evaluating patient and economic outcomes.

Acknowledgments

LL, SVL, and PC participated in the design of the study. LL and SVL conducted the search. LL, SVL, and PC were responsible for critical evaluation of the search results. LL, SVL, and PC drafted the manuscript. MN, SS, AGD, and PC provided expert opinion on the topic. All authors critically evaluated the article and gave their final approval before submission.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

[PDF File (Adobe PDF File), 55KB - jmir_v20i9e258_app1.pdf]

Multimedia Appendix 2

Table with author names, year of publication, study design, aim of the study, and key findings of articles included in the review.

[PDF File (Adobe PDF File), 334KB - jmir_v20i9e258_app2.pdf]

Multimedia Appendix 3

Table with the number of subjects included in the review.

[PDF File (Adobe PDF File), 138KB - jmir_v20i9e258_app3.pdf]

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Abbreviations

ADE: adverse drug event
ADR: adverse drug reaction
CDS: clinical decision support
CDSS: clinical decision support system(s)
CINAHL: Cumulative Index to Nursing and Allied Health Literature
CPOE: Computerized Physician Order Entry
DA: drug allergy
DDI: drug-drug interaction
EHR: electronic health record
ICD: International Classification of Diseases
NDF-RT: National Drug File-Reference Terminology
NLP: natural language processing
PE: prescribing error
OR: odds ratio
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SNOMED CT: Systematized Nomenclature of Medicine, Clinical Terms
UNII: unique ingredient identifier

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Original Paper

Patient Experiences of Web-Based Cognitive Behavioral Therapy for Heart Failure and Depression: Qualitative Study

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Abstract

Background: Web-based cognitive behavioral therapy (wCBT) has been proposed as a possible treatment for patients with heart failure and depressive symptoms. Depressive symptoms are common in patients with heart failure and such symptoms are known to significantly worsen their health. Although there are promising results on the effect of wCBT, there is a knowledge gap regarding how persons with chronic heart failure and depressive symptoms experience wCBT.

Objective: The aim of this study was to explore and describe the experiences of participating and receiving health care through a wCBT intervention among persons with heart failure and depressive symptoms.

Methods: In this qualitative, inductive, exploratory, and descriptive study, participants with experiences of a wCBT program were interviewed. The participants were included through purposeful sampling among participants previously included in a quantitative study on wCBT. Overall, 13 participants consented to take part in this study and were interviewed via telephone using an interview guide. Verbatim transcripts from the interviews were qualitatively analyzed following the recommendations discussed by Patton in *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*. After coding each interview, codes were formed into categories.

Results: Overall, six categories were identified during the analysis process. They were as follows: "Something other than usual health care," "Relevance and recognition," "Flexible, understandable, and safe," "Technical problems," "Improvements by real-time contact," and "Managing my life better." One central and common pattern in the findings was that participants experienced the wCBT program as something they did themselves and many participants described the program as a form of self-care.

Conclusions: Persons with heart failure and depressive symptoms described wCBT as challenging. This was due to participants balancing the urge for real-time contact with perceived anonymity and not postponing the work with the program. wCBT appears to be a valuable tool for managing depressive symptoms.

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KEYWORDS

cognitive therapy; content analysis; depression; heart failure; internet; patient experience; telehealth

Introduction

Approximately 20% of the heart failure population suffers from depressive symptoms [1,2]. Depressive symptoms in heart failure are associated with a poorer health-related quality of life [3,4], morbidity [5,6], and increased mortality [1,2,7]. Depression is also associated with impaired self-care ability [8-11]. Self-care can be complex for persons with heart failure and requires knowledge (about heart failure), decision making, and practical skills [12]. The complexity of self-care may contribute to the poor prognosis and outcomes among persons living with heart failure [13,14]. Additionally, when depressive symptoms coexist with heart failure, the situation may be even more problematic because depression can impede learning ability, decision making, and task performance [15,16].

Guidelines on heart failure from the European Society of Cardiology (ESC) [17] and the American College of Cardiology/American Heart Association (ACC/AHA) [18] point out depression as a common comorbidity in heart failure resulting in poorer prognosis and reduced health-related quality of life. The ACC/AHA guidelines state that the current evidence is too weak to give recommendations on treatment of comorbid depression [18]. According to ESC guidelines, routine screening for depression in heart failure is good practice, and psychosocial and pharmacological interventions are regarded to be helpful [17]. However, no clear recommendation regarding the management or treatment of depression in heart failure is provided [17,18]. Generally, depression is effectively treated with pharmacological and psychotherapeutic interventions [19]. However, treatment of depression in patients with heart failure is challenging. Tricyclic antidepressants should be avoided because of their negative effects on the heart [17] and selective serotonin reuptake inhibitors have not shown greater effect on depressive symptoms than placebo [20]. Another challenge is that psychotherapeutic competence in the health care system is lacking [21]. To sum up, a large group of individuals do not receive adequate treatment while living with heart failure and depressive symptoms owing to lack of clear recommendations and psychotherapeutic competence. Cognitive behavioral therapy (CBT) for depressive symptoms in persons with heart failure has shown promising results in reducing depressive symptoms in a few studies [22,23] and in secondary prevention in persons with coronary heart disease [24]. The effect of CBT on self-care was similar compared with controls without feedback [25] or usual care [22]. Face-to face CBT is resource demanding because it requires health care personnel allocated to support individual patients for approximately 1-2 hours per week over 10-20 weeks [26]. Thus, owing to a lack of trained CBT therapists and time in the health care system, other ways to provide CBT have been suggested [21]. One such form of CBT is Web-based CBT (wCBT). wCBT is an effective treatment for mild to moderate depression; wCBT has thus been suggested as a treatment option for depressive symptoms in patients with chronic somatic diseases, such as heart failure [27]. wCBT programs need to be adapted to fit the context of the specific somatic disease [28-30], and such programs for depressive symptoms in persons with heart failure are still rather new and unexplored [31].

At a conceptual level, wCBT can be described as a form of telehealth, that is, a system that enables patients to access health education and support for self-care usually through the internet [32]. In line with Colucci et al [33], wCBT can be seen as a form of telepraxis with applications of interventions, support, and education to the patient by a health care professional. Though there is no consensus definition of telehealth or telemedicine, most definitions include or acknowledge a physical distance between the health care provider and the person receiving health care [34]. In heart failure care, a number of telehealth applications that can be defined as those used for monitoring patients have been evaluated and shown to reduce mortality and heart failure-related hospital admissions compared with usual care. Telehealth applications employing telephone-delivered support have also demonstrated a positive effect in heart failure care [35]. However, the use of telehealth applications for cardiovascular care with asynchronous or text-based communication (similar to most wCBT interventions) appears less common [36,37]. There are a limited number of studies investigating patients' experiences of wCBT [38]. Previous qualitative studies on wCBT have explored issues related to reducing dropout [39], describing how treatment effect can be sustained over time [40], and investigating the experience of smartphone-based interventions [41]. In heart failure care, evaluations of telehealth applications have mostly focused on applications that are used for monitoring patients [42]. Despite the lack of knowledge regarding how wCBT and other telehealth interventions are experienced by persons receiving health care, there is a drive to implement telehealth applications for the care of persons with chronic somatic disorders [43].

Our research group has recently developed and pilot-tested a 9-week guided wCBT program (Table 1) aimed at decreasing depressive symptoms in persons with heart failure [44]. The length, structure, and way of providing our wCBT program are similar to those of other wCBT programs for depression [45]. The program was developed based on Beck's description of models of depression [46] and is described in more detail in a proof-of-concept study [47]. However, because previous research has indicated the importance of context adaption of wCBT for persons with chronic somatic diseases [28,29], we chose to adapt the program to fit persons living with heart failure [47]. The results of the study conducted by Lundgren et al [44] were promising because it reported a decrease in depressive symptoms and improvement in health-related quality of life. The study also showed an association between patient activity in the treatment program, age, and sex with the treatment outcome [44]. However, the quantitative design of that study could not provide answers to what aspects were important for activity in the program or how the participants experienced the intervention, underpinning the need for qualitative studies on wCBT. Thus, there is a gap in knowledge regarding how persons with chronic heart failure and depressive symptoms experience wCBT. Exploring the perspective of persons receiving telehealth interventions is important to further develop and improve health care interventions, such as wCBT programs [48,49]. Therefore, the aim of this qualitative study was to explore and describe experiences of participating and receiving health care through a wCBT intervention among persons with heart failure and depressive symptoms.

Methods

Design

This was a qualitative, inductive, exploratory, and descriptive interview study [50] using data obtained from participants in a wCBT program.

Setting

The participants were persons with heart failure and depressive symptoms who were recruited after their participation in a wCBT program for depressive symptoms, hereafter called the wCBT program [44]. The wCBT program consists of 7 modules (Table 1), including text and assignments that the participants work with in their everyday setting. Written feedback was provided on all assignments. The participants could also ask questions through a secure message system. The program did not entail face-to-face or direct interaction (except technical telephone support if needed). A detailed description of the wCBT program is published elsewhere [47].

Participants: Sampling and Recruitment

To ensure that participants had experience of wCBT, purposive sampling was used [50]. All participants (n=27) that had been active in the wCBT modules during or after the active study were invited via mail to participate in a qualitative research interview. Of those contacted, 13 (9 men and 4 women, aged 41-80 years with median 69, living in Sweden; Table 2) consented to participate and were included in this study. In alignment with the inclusion criteria for the wCBT program, all participants had, at the start of the wCBT program, at least mild depressive symptoms, had been diagnosed with heart failure for more than 6 months, and had not been admitted to hospital for at least one month.

Data Collection

Semistructured telephone interviews [51,52] using an interview guide (Table 3) were performed between 1-12 months after the program had ended. The participants choose the time and place for the interview.

Table 1. Description of the Web-based cognitive behavioral therapy program.

Module and homework assignment	Description of homework assignment given to participants
Introduction	
Expectations and goal for the program	Describe their expectations and goal for the program
Living with heart failure	
My symptoms of heart failure	Describe their symptoms of heart failure, how much and when these symptoms affected them, as well as what they thought they could do to reduce their problems
Knowledge about heart failure	Answer multiple-choice questions about heart failure and treatment of heart failure
How does heart failure affect me?	Identify situations when they were affected by heart failure and suggest changes that might ease the burden of heart failure
Depression and heart failure	
My symptoms of depression	Describe symptoms of depression, how much and when these symptoms affected them, as well as what they thought they could do to reduce their problems
Knowledge about depression	Answer multiple-choice questions about depression and treatment of depression
Worries and fears	Identify situations where they felt worries or fear in relation to heart failure, elaborate on what they thought could reduce these feelings, and discuss these issues with a significant other
Behavior activation 1: To enable change	
Activity plan 1	Make an activity plan for one week and assess each activity as positive or negative
Desirable activities	Make a list of desirable activities
Increase the likelihood of performing desirable activities	Describe situations that would make it likely that they performed the desirable activities
Activity plan 2	Implement one or more desirable activities in their activity plan
Behavioral activation 2: To implement change	
Activity plan 3	Review negative activities in their activity plan and reduce the number of negative activities
Problem solving: A tool for dealing with problems	
Practical problem solving	Identify problems in their everyday life, list a number of possible solutions for each problem, test one solution and evaluate the chosen solution
Consummation	
To create an action plan	Review and summarize the program and identify what they have learned to be used in an action plan

Table 2. Characteristics of the sample (N=13).

Sociodemographics	n (%)
Gender	
Men	9 (69)
Women	4 (31)
Family situation	
Married or cohabiting	9 (69)
Living alone (single, widowed, or divorced)	4 (31)
Place of residence (type)[a]	
Town with >100,000 inhabitants	4 (31)
Urban area with 20,000-49,999 inhabitants	3 (23)
Urban area with 1000-19,999 inhabitants	3 (23)
Health- and illness-related factors	
Mild depressive symptoms at beginning of wCBT[b,c]	7 (54)
Moderate depressive symptoms at beginning of wCBT	3 (23)
Moderately severe to severe depressive symptoms at beginning of wCBT	3 (23)
Completion of the wCBT program[d]	
1-3 modules	3 (23)
4-6 modules	6 (46)
7 modules	4 (31)

[a]Town and urban areas are defined as having at least 200 inhabitants with a maximum distance between the houses of 200 meters information; not available for 3 participants.

[b]wCBT: Web-based cognitive behavioral therapy.

[c]Depressive symptoms assessed with Patient Health Questionnaire-9. The following cut-off scores were used: 5-9 mild depressive symptoms; 10-14 moderate depressive symptoms; ≥15 moderately severe to severe depressive symptoms.

[d]The wCBT program consisted of a total of 7 modules designed to be used during a 9-week period.

The interviews lasted between 36-72 minutes (median 50 minutes) and were performed by JL (9 interviews) and AKK (4 interviews). Both interviewers were registered nurses. JL performed the interviews in his role as a PhD student and AKK in her role as a lecturer. Both had a good contextual understanding of the program. JL had some previous experience and AKK had extensive experience of qualitative interviewing. JL had previous contact (emails and writing feedback) with the participants during the program. All 13 interviews were digitally recorded and transcribed verbatim, 7 by a professional secretary with experience and 6 by JL.

Data Analysis

First, all transcripts were checked for accuracy against the recordings. Second, all transcripts were read as a whole to become familiar with the data. Third, a coding scheme was developed by JL and AKK. JL and AKK read and independently coded one interview. Anonymized parts of 3 transcripts were then used to generate tentative codes during a data workshop with PhD students from the disciplines of nursing and occupational therapy. The tentative codes generated by JL, AKK, and the workshop participants were then discussed by JL and AKK and a refined coding scheme was developed. Based on the developed coding scheme, JL then systematically coded all transcripts. At the end of the coding process, one more transcript was selected and coded by both JL and AKK to ensure a fair and neutral application of the coding scheme [50]. Fourth, codes were sorted into inductively emerging patterns to form subcategories and categories. After all of the codes were preliminarily categorized, the categories were examined to assess whether themes could be constructed [50]. The construction of subcategories, categories, and themes was documented in a memo that also was checked by AKK for clarity and understanding; if necessary, preliminary categories were revised in accordance with the consensual understanding of JL and AKK. Lastly, preliminary categories were either reformulated as final categories or incorporated with other categories with similar content into final categories. The final categories were checked for confirmability [50] by PJ. Figure 1 shows an example of the analysis process.

Ethics

All participants were informed about the study and gave informed consent. To protect their confidentiality, published data were scrutinized to prevent the identification of the participants. The study conformed to the principles for medical research, as described in the World Medical Association's Declaration of Helsinki [53], and was approved by the regional ethical review board in Linköping, Sweden (dnr 2011/166-31).

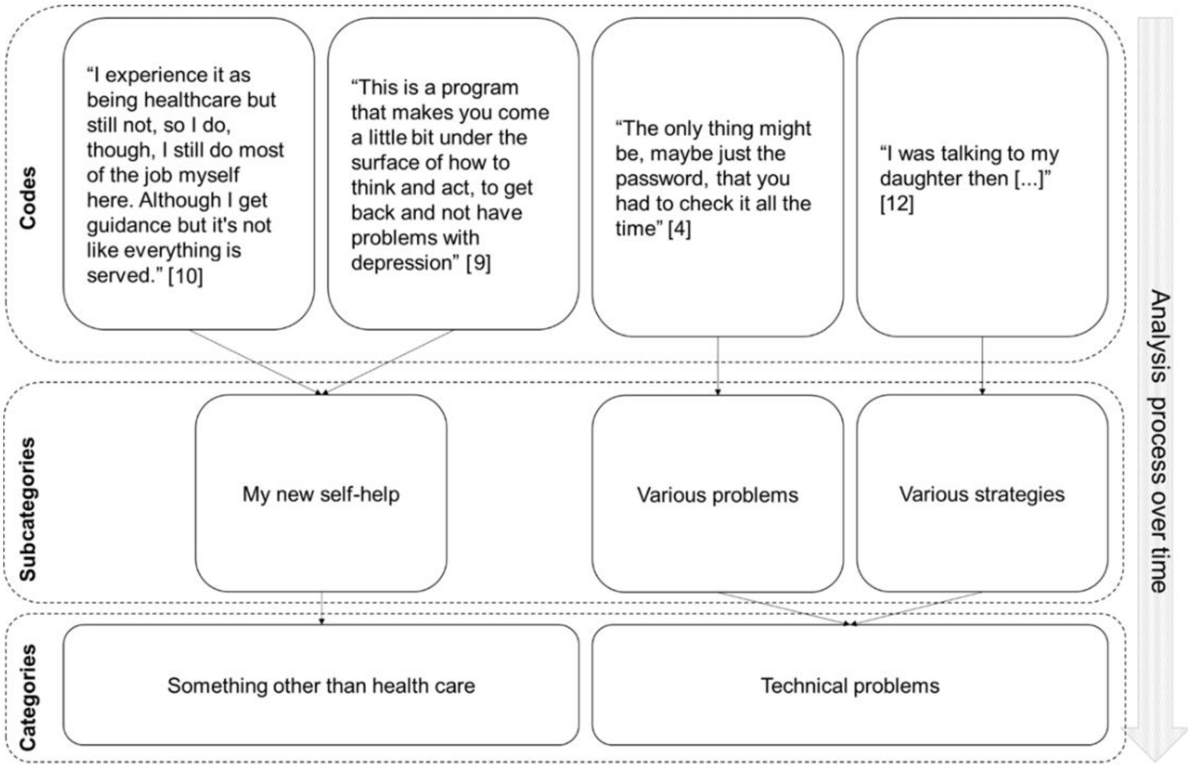
Table 3. Interview guide.

Opening question	You have (recently) participated in a Web-based cognitive behavioral therapy program (targeting depressive symptoms in people with heart failure). Can you please tell me about this?

If not spontaneously addressed, ask about the following topics or areas:	• Advantages and disadvantages of the treatment program
	  • Hindrances and barriers and problems due to the fact that the treatment was given through the internet? How did you cope with this?
	  • Positive aspects of treatment through the internet?
	• How would you describe what the program was or is?
	• Contact with the feedback provider
	• Experience of the feedback
	• Use of the internet for any other type of health care?
	• What do you think about the health care system using the internet more for information and interventions?
	• In your experience, what is the difference between health care provided face-to-face compared with health care provided through the internet? What are the advantages and disadvantages?
	• Integrity and health care through the internet.

Probing questions to be used during the interview	• Can you tell me more about...? • Can you explain or clarify what you mean...? • Earlier you said...? • Can you give an example...?
Ending	• Is there anything more you would like to tell me? • Is there anything we have not talked about?

Figure 1. Example of the data analysis process from code to categories. Codes consist of text chunks from the transcripts. Codes with similar meaning were sorted into categories and subcategories. Participant ID shown in brackets.



Results

Main Findings

Overall, 6 categories were identified during the analysis process. The categories, as well as the included subcategories, are listed in Table 4. One central and common pattern in the findings was that the participants experienced the wCBT program as something they did themselves and many described the program as a form of self-care.

Something Other Than Usual Health Care

The participants described wCBT as a multifaceted experience. A common pattern was the experience of actively doing something to feel better or gain health. wCBT was described as a good way to treat depressive symptoms. Most participants described their experiences of wCBT in relation to other types of health care interventions they had encountered. Two subcategories were identified.

My new self-help meant that wCBT assisted with self-help or self-care that helped participants to actively learn new ways to take responsibility for their health. Some participants stressed that wCBT was about learning and described the program as a course. Other participants said that wCBT could be similar to health care because professional health care personnel were accessible through the program but that wCBT was different from what they generally thought of as health care. However, most participants were hesitant about using words such as "health care." This was due to their experience of having to be very active. wCBT was experienced as something one did in contrast to health care, which was seen as something one received.

> *Yes, it is, kind of, a good reason to make, or maybe get help to make these changes that...And maybe I can get some advice that I hadn't thought of myself...Kind of like someone taking one's hand and saying: Let's do it this way.* [Participant 10]

Helping other people meant that the program was experienced as a research project with the purpose of helping people with heart failure. Codes in this subcategory often came from participants describing the wCBT program as a treatment that was not mainly focused on them as individuals but an experience of contributing to other people's well-being was conveyed.

> *I think that it's the right thing to do to give one's support. If I can contribute in any way to research then I'll do so willingly.* [Participant 3]

Relevance and Recognition

Most participants experienced the program as relevant and useful, at least to some degree. However, a few participants experienced no benefits from the program. An important factor related to finding the program useful was to recognize oneself in the program.

Mainly useful meant that some participants experienced the program as highly relevant. A few participants described no experience of any shortcomings in the content of the program. However, most participants generally described the content of the program as helpful but with some disadvantages, such as describing the behavioral activation as hard to grasp or experiencing that the content of the program did not address areas and topics that they thought important for their health, such as management of health problems other than heart failure and stress management.

> *Then I thought that it [the program] would probably contain a little bit more when it came to tools for stress too [...] There was a little but it didn't give me those...I would have really liked a pure exercise program [to handle stress] there.* [Participant 9]

In contrast to *Mainly useful*, in *No use*, a few participants reported that the program had not been of any benefit for them.

> *No, I don't really think I got anything that I considered a cure if I can put it like this. [...] No, I might as well say that it was not of any benefit.* [Participant 7]

Table 4. Overview of findings.

Categories	Subcategories
Something other than usual health care	• My new self-help • Helping other people
Relevance and recognition	• Mainly useful • No use • Different levels of recognition
Flexible, understandable, and safe	• Working at home • When I want and have time • Adapting the content • Challenging format and medium • Everyday life affecting the treatment • Integrity is protected • Written format • Anonymous and honest
Technical problems	• Various problems • Various strategies
Improvements by live contact	• Depending on the circumstances • Preferred situations
Managing my life better	• Feedback is confirming and motivating • Reflecting and new understanding

Different levels of recognition meant that experiences of recognition in and relevance of the program were commonly described by the participants. Examples and problems addressed were found to be realistic and similar to their everyday life. Furthermore, if participants described CBT components in the program as helpful, this contributed to their experiences of the program being recognizable and relevant.

> *That's the way it is, and I'm the one who is most positive about the program because it's worked for me from start to finish.* [Participant 8]

However, in contrast, some participants did not recognize themselves in the program. The reasons for this were described as feeling too well or too ill compared with the presented examples. Another reason was described as having health problems not addressed in the program.

> *That is to say some of the examples that you gave there [in the program] didn't seem relevant to me.* [Participant 7]

Flexible, Understandable and Safe

The participants experienced working through the internet as positive and flexible. There were also challenges and some barriers connected to the use of the internet; 8 different subcategories were identified in this category.

Working at home meant that most participants positively described working with the program at home because the home environment was peaceful and quiet. Working at home reduced the barriers to participating in a treatment program because one did not have to travel. This was important because getting started with different activities was experienced as difficult when suffering from depressive symptoms.

> *Let's put it this way, it was really nice to be able to be at home and do it in peace and quiet.* [Participant 4]

When I want and have time meant that the format and medium of the program provided a positive opportunity to work when the participants wanted to. Feeling motivated was described as important when choosing when to work with the program. In addition, the ability to increase or decrease the work tempo and repeat parts of the program were experienced as positive aspects. Contributing to the flexibility was the opportunity to make adjustments to when and where to work with the program, for example, if participants made a trip.

> *If I wanted to sit down and do it at two in the night or five in the morning or in the middle of the day then this was fine I could choose when to carry out my exercises [...] it is an advantage to be able to do it at a time of my choice.* [Participant 6]

Adapting the content meant that participants described choosing to focus on the parts of the program that they experienced as meaningful and putting less effort into parts experienced as less important. The parts of the wCBT program that participants chose not to work with concerned things they already knew or did.

> *I located and picked those small components, now what were they called? Little gems, [...] Oh, they were part of the internet program and they worked for me and were great.* [Participant 8]

Challenging format and medium meant that the format and medium made it easy to postpone the work on the program. Some participants therefore thought of setting fixed times to work on the program despite it reducing the flexibility. The experience of the program requiring self-discipline was common. The work was often experienced as lonely, especially if participants encountered problems with the program. The participants experienced a need to be active and take the initiative to solve some problems by themselves to gain a positive effect from the program.

> *I'm a bit like, I'll do this later and this bit I'll postpone. And this is exactly what happens, and then things get difficult [...] It was not always a good thing that it was Internet-based and things got postponed.* [Participant 4]

Other challenges described were that the program required a lot of time and that there was a lot of text and assignments that needed to be completed during the program, which was experienced as stressful. In contrast, some participants described the program as timesaving owing to the medium and format. This was because the wCBT program gave the participants the opportunity to focus on the parts they felt important and because they did not have to travel to receive health care.

The participants also said that they were not used to working with treatment through the internet, but they did not clearly assess the medium as negative or positive—rather, most participants described it as unusual. Another aspect experienced as valuable was the possibility to read the content of the program in printouts or on screen. Commonly, participants said that they were not used to reading long texts on the screen. Being presented with a number of different choices on how to perform the tasks in the program was sometimes experienced as hard, especially if the participants were not used to working with information technology and computers. Participants also said that the medium and format made them feel tied to the computer and vulnerable if the technology did not work. In contrast to the challenges experienced above, some participants mentioned no challenges with the medium and format.

Everyday life affecting the treatment meant that factors or events not directly related to the program, heart failure, or depressive symptoms were important for how wCBT was experienced. These factors sometimes made it harder to work with the program, for example, if there was a demanding situation at work or if they had to handle other health problems.

> *Just when one starts to establish a routine, things crop up which get a higher priority, and then these objectives and reviews get put on the back burner.* [Participant 9]

Integrity is protected meant that no experiences were identified of integrity being insufficiently protected in the program. The security system used in the program made them feel safe in regard to how information about them was handled. The organization behind the program was also important for creating experiences of safety. Universities and other public institutions were described as more reliable compared with private companies. Some participants experienced that integrity generally received too much attention when information technology systems were discussed.

> *Look here, I'm 75 and have a number of medical problems and I don't give a damn about confidentiality just as long as I receive decent health care.* [Participant 2]

However, among all the participants there was a limit to how, where, and by whom the information should be accessed; for example, some participants said that they would not be comfortable if such information was spread through social media. The participants said a number of times that it was important that health-related information was accessible for health care personnel, even if this came at the price of unauthorized persons being able to access the information. Close relatives such as spouses were also described as persons one may want to protect personal information from, something that was described as complicated when working at home with the program.

> *...it is worse if one is writing something that one doesn't want the family to see...it can be a negative aspect of such a course of treatment if one has an inquisitive partner, indeed then things can get quite difficult.* [Participant 8]

In *Written format,* the experiences differed in that the program mainly consisted of written information and depended on written communication. Some described the texts and feedback as well thought out and easy to read and understand. Furthermore, it was experienced to be easier to write about some types of health problems compared with talking about them. The written format was described as facilitating and clarifying what the participants were expected to do when working with the program. In contrast, some experiences suggested that the written format was a barrier to communication, and descriptions revealed that oral communication between participant and feedback provider was preferred.

> *Exactly, one gets a question which one starts to answer [...] one understands exactly what they're after [...] it's the way I am [...] it can be difficult to express oneself [verbally].* [Participant 4]

Anonymous and honest meant that working through the internet created conditions for a positive experience of anonymity. The participants thought that they could write exactly what they thought about things and be more honest in their communication. They were also positive about not feeling observed or analyzed. A requisite for this was that the communication took place without personal encounters. Furthermore, written delayed communication led to experiences of the feedback provider as a neutral medium or an unknown person. Both perceived anonymity and written delayed communication contributed to the experience of being protected or doing something behind a screen.

> *Yes, this I would recommend, namely that one can be completely open there is no need to feel observed or analyzed or monitored in any way–instead it all takes place behind a screen, so to speak.* [Participant 6]

Technical Problems

A number of technical problems were reported during participants' work with the program. However, not everyone described such problems, and most participants experienced that they had been able to manage the problems they came across.

Various problems were encountered and experienced in 4 different ways. First, problems were associated with participants' computer equipment, such as old computers and problems with viruses. Second, the technique used in the program was demanding and complicated. Third, the interface of the program was sometimes confusing, creating insecurity regarding how to perform different tasks; for example, there was lack of automated feedback to know if assignments had been submitted.

> *[...] when one had submitted something then one was uncertain as to whether it had arrived.* [Participant 12]

Fourth, technical problems during the log-in and authorization process were described. The log-in process could be complicated and some stated that they would have preferred to be able to set a less complicated password. *Various strategies* meant that technical problems were managed in different ways. One strategy was to postpone the work if a technical problem was encountered, assuming that the problem would have been solved the next time one tried doing a task. Support was sought from relatives, friends, or the feedback provider. One participant said that she chose to get a new computer of the same model as a relative to get support that way. Another strategy was to read the instructions and test different solutions on one´s own.

> *Yes, I had to wait, repeat and try again. Yes, now and then I contacted [name of feedback provider] for assistance. [...] I sat there and explored the software by myself.* [Participant 10]

Improvements by Real-Time Contact

Most participants were less used to indirect contact with health care personnel. This was sometimes experienced as challenging and demanding. Participants described this as having to learn a new way of communicating with health care personnel. Several participants stated that they would have preferred more real-time contact, that is, direct verbal communication via telephone or video-telephony. Real-time communication through sound and picture (not necessarily only face-to-face) was described to make communication more dynamic and was thought to facilitate relationship building better than indirect communication. These experiences were described regardless of whether participants described the feedback in the program as positive and supportive or not.

Depending on the circumstances meant that the experiences of the need for real-time communication were described as more important in some situations and less important in other situations. The purpose of an intervention or interaction was crucial for how important real-time communication was; for example, real-time communication was important for feeling cared for. Some participants said that delayed and indirect contact made them feel anonymous or reduced to a number. In contrast, when the experience of the program was described to be about learning, which was common, the delayed and indirect contact was experienced as suitable and sufficient.

> *Oh yes, the obvious way is a face-to-face meeting with a person. But the thing with CBT and the like, and learning generally...Obviously things go really well with the Internet perhaps it is even an advantage.* [Participant 11]

Preferred situations meant that more real-time contact would have been preferred to allow for check-ups of the progress in the work and how the participant was doing. The use of real-time communication as a back-up if something did not work was also stressed.

> *For example suppose that you gave feedback via phone in a different way. Then one can explain a bit more and other things too.* [Participant 5]

Managing My Life Better

The participants described that they had generally become better at managing their lives. This was expressed in different ways among the participants. Some participants had learned to stop activities perceived as negative and had started to do things that balanced their activities in daily life. Others said that they had started to take the initiative to perform more positive activities and that they had begun to appreciate life again.

The participants experienced that problems could be solved and tasks could be performed differently compared with before they participated in the program. A prominent pattern was the experience of the program as stimulating them to take a greater responsibility for their health, for example, by seeking information about health problems and discussing health problems with their close relatives. This behavior change made them feel safer, reduced their feelings of hopelessness, and helped them to gain greater acceptance of their own health problems. The following 2 subcategories were identified: *Feedback is confirming and motivating* and *Reflection and new understanding*.

Feedback is confirming and motivating meant that the feedback participants received from the feedback provider was important because it facilitated the work process. One divergent finding was that a few participants described the feedback as not powerful enough to create a change in behavior. However, the feedback mostly was described as good and sometimes as prompt.

> *But no, I think it would give a little more I mean you need some pressure, you need a carrot and stick you know.* [Participant 2]

The feedback was described as answering questions and providing new perspectives on the health problems that the participants worked with. Participants said that the feedback helped them to continue working in the program even if it felt cumbersome at times. Adding to this, the following 3 different experiences of good feedback were identified: confirmatory, coaching, and motivating.

> *And receive an answer, an answer of concern to me alone. One doesn't get standard answers.* [Participant 2]

Reflection and new understanding meant that the program gave rise to increased reflection, leading to new understanding and perspectives on their health and life situation. Descriptions showed that it could be painful to accept that heart failure comes with a poor long-term prognosis. On the other hand, experiences of being more prepared to manage worsening in heart failure were expressed. Participants described it as important that they had understood that depressive symptoms could be associated with heart failure and that it was common among patients with heart failure to experience depressive symptoms. Furthermore, participants said that the program had contributed to the experience of having gained new tools to manage problems and it had thereby affected their situation and well-being. They had learned to think in new ways and the program gave them new perspectives on everyday life. A common pattern was that participants started to challenge their old inward thinking. New thoughts were mostly positively expressed, including metaphors such as “the program was an eye opener” or “I see things from new angles.” However, one participant said that the program made him identify his health problems but that he could not take advantage of the program. Instead, he had sought other types of health care.

> *However, I noted the following: well, I never, that was interesting. One hadn't seen the connection and context of the two things, but when one got these two questions the penny dropped and one started to think in new ways.* [Participant 1]

Discussion

Principal Findings

The main finding of this study was that persons with depressive symptoms and heart failure described wCBT as a form of self-care for their health problems. Overall, the program was experienced as a new way to create self-care by active reflection on relevant and recognizable situations and support from a trustworthy person that was confirmative and motivating. The program was described as safe without any major challenges to integrity, except from their partners.

The primary target of the wCBT intervention was to decrease depressive symptoms. However, the participants' narratives most often referred to the program as something they experienced to help them take care of their own health problems, including both physical and psychological health problems. We interpret this as a holistic perspective on health among the participants. It is important to realize that the findings of this study are what the participants experienced and described and not primarily a qualitative evaluation of the wCBT program's effect on depressive symptoms.

Participants experienced that wCBT required them to be active participants in the treatment process and that the program helped them to focus on what they could do to improve their health.

This is consistent with meta-analyses reporting data in studies of cancer survivors [54] and in the field of depression and anxiety [30]. If patients' and health care professionals' expectations differ with regard to patients' active participation, this may be a substantial barrier for telehealth interventions [48]. Consistent expectations regarding the roles and activity between patient and health care provider are an important factor affecting adherence to treatment and patients´ perceived quality of care [55]. Our finding that the participants experienced wCBT as self-care is important and may contribute to a common and good starting point for this type of intervention. The experience of wCBT as requiring the patient to be active and perform self-care with the description of wCBT as a learning process indicates that this type of intervention may not be suitable for all patients. Self-care ability can be negatively affected by learning problems [56]; thus, some patients may need other types of support with their health problems, such as face-to-face interventions. In our findings, the participants described wCBT as a good way of addressing depressive symptoms. This is important because participants' attitudes to psychological Web-based interventions have been found to be an important factor for response to treatment, as demonstrated by Lutz et al [57]. From a professional perspective, it is important to make a comprehensive assessment of self-care and learning ability as well as the attitudes to Web-based interventions of patients before considering what type of intervention to offer to individual patients.

The above-mentioned findings can be said to have general implications for health care interventions, regardless of how they are delivered. In our findings, there are also some aspects specifically related to wCBT as a telehealth intervention.

Telehealth interventions are often seen as a practical and cost-effective way to face increased demands on a health care system [58]. A wide variety of telehealth applications have been developed, ranging from monitoring health status to the provision of health education and psychological support [59]. A common feature of telehealth interventions is that they change the context in which health care is provided, generally from within health care facilities to the home of the health care recipient. This transition raises questions about personal integrity. The experiences regarding protection of personal integrity were somewhat surprising in our study. Based on the contemporary discourse regarding personal integrity in the context of telehealth (cf. Hall and McGraw [60] or Sabin and Skimming [61]), it was assumed that parts of the interviews addressing this topic would focus on areas such as protection from hackers, nonauthorized third party access, and other more general information technology security topics. Instead, participants described other aspects of integrity as important, such as the need to protect information from close relatives. Moving health care from a traditional face-to-face context to a telehealth context will also move the responsibility for protection and safeguarding of integrity from the health care professional to the patient. Technical solutions, such as passwords, used by the patient can be useful to some extent [62], but these methods may cause other types of problems; for example, passwords on computers, which are often shared among family members, and changing or hiding passwords may be perceived as deception and cause feelings of suspicion, distrust, and dishonesty in the family [63,64].This may have a negative impact on the health process and family function. Therefore, the introduction of telehealth calls for the development of new methods for health care personnel to safeguard their patients' integrity.

The findings described in the subcategories *Anonymous and honest* and *Written format* with the category *Improvements by real-time contact* reveal a complex relationship between the possibility of being anonymous and a wish to have real-time contact. Anonymity is experienced as an easy way to address sensitive topics and to be honest but at the same time, it also led to an experience of being reduced to a number. Moreover, both positive and negative experiences regarding the use of written material and feedback and the need for more real-time communication were described in our findings. The contradicting findings regarding the written format and real-time communication can be seen as illustrating a dialectic relationship, similar to that described by Knowles et al [30], with participants acknowledging and appreciating the benefits of perceived anonymity and written format but at the same time, longing for the benefits of real-time contact. Acknowledging that this relationship exists in telehealth interventions, such as wCBT, raises a number of questions related to the way health care personnel can act to establish stable and caring relationships and to determine the right amount of personal contact between patients and health care personnel to facilitate optimal care in telehealth interventions. As pointed out by Nagel et al [65], the nursing profession is facing philosophical and transformative challenges as health care increases its use of telehealth. The answers to these questions are beyond the scope of this study; however, this study may contribute to future research that aims to investigate how a caring relationship can be established in a telehealth context. Such research is needed to prepare the present and future generations of health care professionals to deliver high-quality health care when using telehealth applications.

Methodological Limitations and Considerations of the Study

There are several limitations to this study. The authors' involvement in designing the program may have affected their preunderstanding in regard to the analysis and presentation of findings [50]. Because the findings represent a construction made by the authors, it is most likely that the findings would be different if the data were analyzed by other researchers. In addition, another sample would most likely render a different finding. In qualitative content analysis, this is a phenomenon that the reader must be aware of [50]. The fact that different findings can be constructed from the same data does not mean that one of these findings is more or less true compared with another construction; instead, they give different perspectives of the phenomenon studied. To enable the reader to assess the trustworthiness of our findings, we have described the setting (Table 1). To further increase trustworthiness, we have provided a detailed and transparent description of the analysis process [66]. To create a credible construction of the findings [50], multiple analysts' triangulations were used. We also considered member checking [50]. However, it has been proposed that this may lead to confusion about the findings rather than confirmation [67]. Reflexivity and dependability were facilitated by memo writing and by reporting deviating findings of the particularities of the analyzed cases that have been brought out [50].

The use of 2 different interviewers was important to counterbalance the risk of informant or researcher bias. No considerable differences were detected between the interviews conducted by JL and those conducted by AKK.

We performed 13 interviews, which may be considered a small number. However, there are no clear guidelines for an appropriate sample size in qualitative descriptive studies [68]. Because no new codes were identified in the coding of the last transcripts, we believe that the data in this study give a broad description of the participants' experiences of wCBT. Regarding the heterogeneity of the sample [68], the sample may be considered rather homogeneous, which may limit the contexts to which the findings may be transferred. However, because all participants had similar health problems and participated in the same program, the sample gives a rather exhaustive description of the group's experiences of the program. Regarding transferability, the participants in the sample in this study are younger than the average person living with heart failure. This may limit the transferability of the findings to the general heart failure population.

Interviews conducted via telephone may have rendered less rich data than those conducted face-to-face. However, face-to-face interviews were assessed as less beneficial because they required restrictions in the sampling process given the geographical spread of the participants. The median interview time was 50 minutes, which is similar to that often seen in other qualitative studies using face-to-face interviews [69]. Despite these limitations, we believe that this study contributes important insights into the novel area of patients' experiences of participating in a wCBT program.

Conclusion

Persons with heart failure and depressive symptoms experienced the wCBT intervention as challenging. This was because of participants balancing the urge for real-time contact with perceived anonymity, not postponing the work with the program, and learning a new way of communicating with health care personnel. Important advantages of the program were learning by reflection to gain new understanding of health problems and managing self-care to improve health. Being able to choose the time and place for the work was another advantage. wCBT appears to be experienced by persons with heart failure as a valuable tool to manage depressive symptoms. However, more research is needed to identify the circumstances in which anonymity is beneficial for the patients and how wCBT programs should be designed to balance the challenges experienced by persons receiving health care through wCBT.

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Conflicts of Interest

None declared.

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Abbreviations

ACC/AHA: American College of Cardiology/American Heart Association
CBT: cognitive behavioral therapy
ESC: European Society of Cardiology
wCBT: Web-based cognitive behavioral therapy

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Original Paper

Mindfulness-Based Resilience Training in the Workplace: Pilot Study of the Internet-Based Resilience@Work (RAW) Mindfulness Program

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Abstract

Background: The impact of mental illness on society is far reaching and has been identified as the leading cause of sickness absence and work disability in most developed countries. By developing evidence-based solutions that are practical, affordable, and accessible, there is potential to deliver substantial economic benefits while improving the lives of individual workers. Academic and industry groups are now responding to this public health issue. A key focus is on developing practical solutions that enhance the mental health and psychological resilience of workers. A growing body of research suggests resilience training may play a pivotal role in the realm of public health and prevention, particularly with regards to protecting the long-term well-being of workers.

Objective: Our aim is to examine whether a mindfulness-based resilience-training program delivered via the internet is feasible and engaging to a group of high-risk workers. Additionally, we aim to measure the effect of the Resilience@Work Resilience@Work Mindfulness program on measures of resilience and related skills.

Methods: The current pilot study recruited 29 full-time firefighters. Participants were enrolled in the 6-session internet-based resilience-training program and were administered questionnaires prior to training and directly after the program ended. Measurements examined program feasibility, psychological resilience, experiential avoidance, and thought entanglement.

Results: Participants reported greater levels of resilience after Resilience@Work training compared to baseline, with a mean increase in their overall resilience score of 1.5 (95% CI -0.25 to 3.18, t_{14}=1.84, *P*=.09). Compared to baseline, participants also reported lower levels of psychological inflexibility and experiential avoidance following training, with a mean decrease of -1.8 (95% CI -3.78 to 0.20, t_{13}=-1.94, *P*=.07). With regards to cognitive fusion (thought entanglement), paired-samples *t* tests revealed a trend towards reduction in mean scores post training (*P*=.12).

Conclusions: This pilot study of the Resilience@Work program suggests that a mindfulness-based resilience program delivered via the Internet is feasible in a high-risk workplace setting. In addition, the firefighters using the program showed a trend toward increased resilience and psychological flexibility. Despite a number of limitations, the results of this pilot study provide some valuable insights into what form of resilience training may be viable in occupational settings particularly among those considered high risk, such as emergency workers. To the best of our knowledge, this is the first time a mindfulness-based resilience-training program delivered wholly via the internet has been tested in the workplace.

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KEYWORDS

resilience training; workplace mental health; occupational health; wellbeing; online intervention; employee resilience; health and safety; psychological health

Introduction

Improving workplace mental health is an opportunity of immense scale and profound importance [1-3]. By developing evidence-based solutions that are practical, affordable, and accessible, there is potential to deliver substantial economic benefits, while improving the lives of individual workers [4,5]. The impact of mental illness on society is far reaching and has been identified as the leading cause of sickness absence and work disability in most developed countries [6-11]. Poor mental health also produces large productivity losses due to absenteeism as well as presenteeism, with affected workers attending work, yet performing at a diminished capacity [12,13]. As a result, common mental health conditions such as depression and anxiety have a significant and direct impact on the overall economic welfare of a nation [14,15]. However, the impact of mental illness in the working population goes well beyond macroeconomics. Once an individual worker develops a mental health condition, they often suffer personal financial losses, career disruption, and reduced well-being.

Academic and industry groups are now responding to this public health issue. A key focus is on developing practical solutions that enhance the mental health and psychological resilience of workers [16]. There is no simple universal solution to workplace mental health. Best practice frameworks highlight the importance of a multifaceted approach that addresses individual, team, and organizational level factors. These factors include work design, organizational culture, good management, promoting and facilitating early help-seeking and early intervention, as well as supporting return-to-work programs and recovery [16,17]. These frameworks also make specific reference to the importance of employee resilience training. This type of individual training can form part of broader programs of workplace health promotion [18].

Indeed, a growing body of research suggests resilience training may play a pivotal role in the realm of public health and prevention, particularly with regards to protecting the long-term well-being of workers [17,19,20]. While definitions of resilience are diverse and plentiful, there is growing consensus that resilience is a malleable construct, wherein an individual's ability to adapt effectively during challenging circumstances can be enhanced over time. Leading researchers in the field, along with the American Psychological Society, describe resilience as a process of "bouncing back" from difficult experiences and "adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress" [21,22].

In terms of enhancing resilience, numerous studies have described positive outcomes from various types of resilience training programs among groups including medical specialists, youth workers, nurses, factory workers, and public servants [23-28]. In addition, research among emergency workers (ie, firefighters, police, paramedics) and military personnel highlights the benefits of resilience training among individuals who frequently experience high-stress situations as an inherent aspect of their work [29-31]. Conversely, a number of larger trials with US Army Personnel and more recently with London Ambulance in the United Kingdom reported limited improvements following resilience training [32,33]. Establishing what types of resilience training programs are beneficial to high-risk groups such as emergency workers is particularly important for several reasons. First, these workers play an essential role in delivering and maintaining critical services in our communities. Second, given the nature of their work, emergency workers are at greater risk of developing common mental health conditions such as depression, anxiety, and alcohol misuse as well as posttraumatic stress disorder (PTSD) [34-37]. Finally, resilience programs that are evaluated and found to be useful among emergency service personnel may provide valuable insight on how to best support the mental health of workers in other high-stress occupations (eg, health care, journalism).

Despite the growing body of research supporting resilience training, considerable measurement variation exists in terms of how researchers evaluate the effectiveness of these programs. For example, some researchers specifically focus on changes observed on reliable and validated measures of psychological resilience following times of intense stress and adversity. Windle et al [38] offer a review of resilience measures. Other researchers have primarily examined the overall impact of resilience training on measures of general well-being and mental health symptomology. While research continues to highlight a positive relationship between resilience and psychological well-being, the latter approach may provide limited insight into whether a resilience intervention can truly facilitate change in an individual's overall ability to bounce back from adversity. A program may improve mental health symptoms, yet not enhance a person's overall psychological resilience or vice versa [39,40]. The use of reliable and validated measures of psychological resilience is central to examining the efficacy of any intervention aimed at enhancing psychological resilience [38], particularly in groups where people identify as "mentally healthy."

Resilience training programs can differ considerably in terms of content, delivery, and length. In their systematic review of resilience interventions, Leppin et al unsurprisingly concluded "no single accepted theoretical framework or consensus statement exists to guide the development or application of these programs" [19]. This may explain why resilience researchers are now drawing on evidence-based therapies such as Acceptance and Commitment Therapy (ACT), Cognitive Behavioral Therapy, Mindfulness-Based Cognitive Therapy, and Mindfulness-Based Stress Reduction (used in the treatment of common mental health conditions) to inform program development [23,24,27,41-45]. These resilience programs tend to include a combination of cognitive strategies, mindfulness training, psycho-educational material, and goal setting. They typically focus on enhancing a person's capacity to manage stressful situations and adverse circumstances more effectively and with greater emotional insight. These skills and strategies require time to practice and gain proficiency. As such, the majority of resilience studies to date describe interventions involving multiple face-to-face training sessions [19,20]. This is a particular challenge for many employers, where taking workers away from the workplace to attend training creates considerable disruption to business and critical services. In addition, the associated costs for replacement staff during this time can be significant. The expense inherent in face-to-face training can pose a hindrance, as can the availability of trainers and programs in remote areas. Moreover, stigma associated with mental health remains prevalent and may prevent a subset of workers from choosing to engage openly in group-training sessions that focus on psychological topics [46]. A universal approach where all employees complete the training may go some way towards reducing this stigma [47].

To address these barriers, we developed an interactive e-learning program called The Resilience@Work (RAW) Mindfulness Program. This self-paced intervention aims to enhance psychological resilience among workers. It consists of 6 internet-based training sessions, each taking about 20-25 minutes to complete on a tablet or computer (see Figure 1).

The RAW program involves mindfulness training, psycho-education, and a range of skills and strategies drawn from evidence-based therapies including ACT, Mindfulness-Based Stress Reduction, and Compassion-Focused Therapy. A large body of literature highlights the positive benefits of mindfulness practice on mental health outcomes [48-53] while a growing number of studies also describe the positive impact of mindfulness training on psychological resilience [23,24,41,54].

The RAW program also teaches a number of core cognitive strategies, which may further enhance a learner's ability to manage stress and cope with adverse circumstances more effectively. These core strategies, drawn from ACT, aim to enhance psychological flexibility by applying mindfulness, acceptance-based emotion regulation strategies, and cognitive skills, while also emphasizing behavioral change that reflects personal values. Psychological flexibility is "the ability to be in the present moment with full awareness and openness to our experience, and to take action guided by our values" [55]. Psychological flexibility is associated with lower levels of depression, anxiety, and distress in clinical and nonclinical populations [56-58]. More recently, it has been found to protect against depression and PTSD among returned service personnel [59].

Figure 1. Resilience@Work Mindfulness Program homepage.

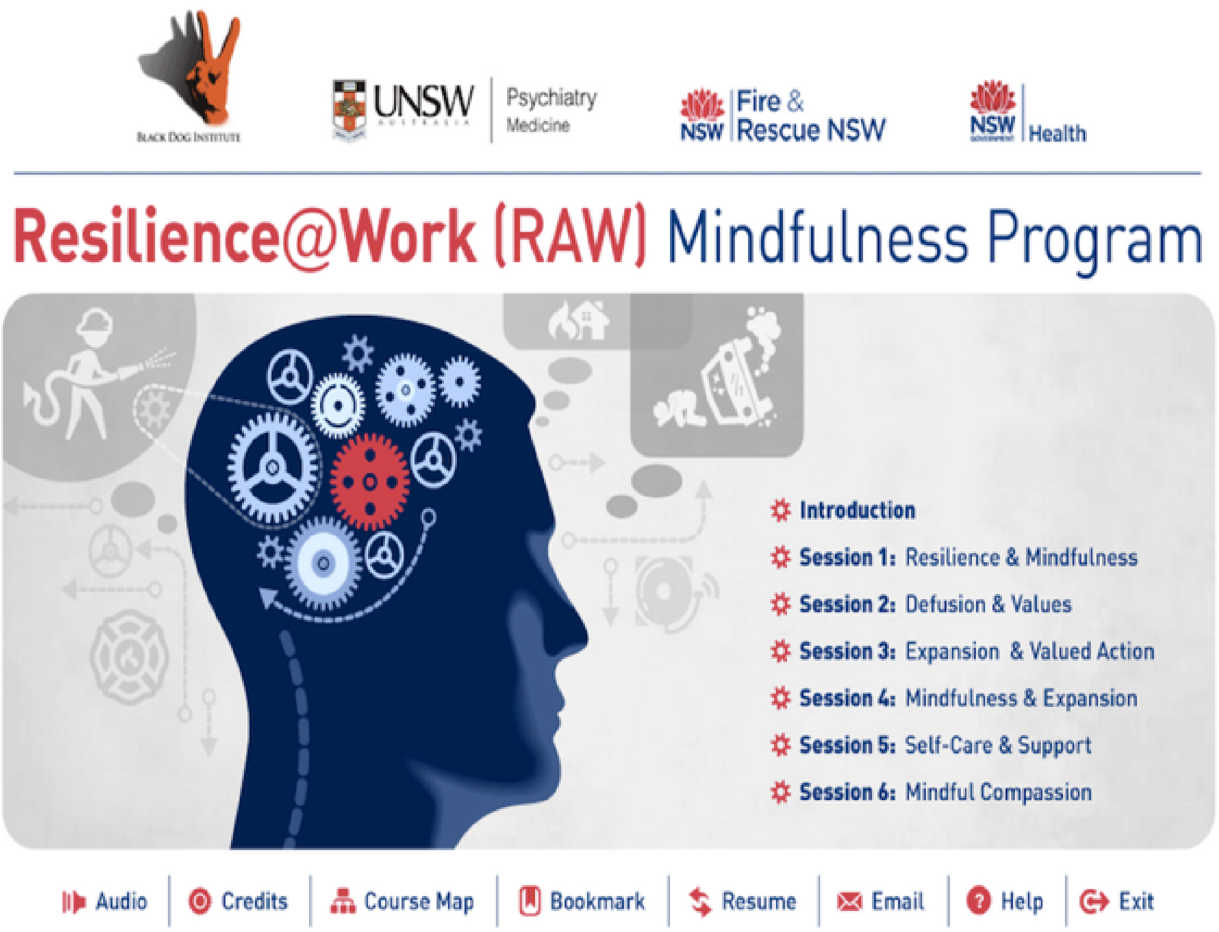

Table 1. Overview of skills and topics covered in the Resilience@Work Mindfulness Program.

Session	Resilience topic and skills focus	Mindfulness tracks
1	Introduction to mindfulness, resilience and psychological well-being	1. Drop Anchor 2. Take 10 3. Leaves on a Stream
2	Mindfulness skills, Understanding your reactive mind versus wise mind, Recognizing unhelpful mind chatter and managing uncomfortable and unhelpful thoughts (cognitive defusion); Recognizing your values exercise	1. Mindful Breathing 2. Defusion Technique; Notice it, Name it, Let it Go (I'm having the thought that…) 3. Defusion Technique 2: Thank you Mind
3	Revision of cognitive defusion, Introduction to mindfulness with emotions, The reactive mind and avoidance, Understanding how values are linked to emotions; Valued action check	1. Creating Space (mindfulness with emotions) 2. Mindful Body Scan 3. The Golden Room
4	The problem with avoidance, Recognizing avoidance strategies versus adaptive strategies	1. Creating Space 2. A Mindful Break (mindfulness with words) 3. Surfing Waves
5	Self-care and support, The compassion myth, barriers to accessing compassion, compassion fatigue, self-compassion actions & resilience; Identifying mindful support (compassionate, nonjudgmental and mindful); Valued action check	1. A Kind and Gentle Hand (loving-kindness practice) 2. A Safe Place (compassion-focused mindfulness) 3. A Bird's Eye View
6	Compassion-focused mindfulness; Gratitude practice, optimism and resilience, identify and celebrate the milestones; Creating a personalized action plan to practice skills	1. Breathing in the Present Moment 2. A Golden Moment exercise 3. Being Kind to your old wounds

Table 1 provides an overview of the resilience topics, core strategies, and mindfulness skills covered in each session. Several reviews and meta-analyses have found medium to large effect sizes for ACT-based interventions across a range of clinical and nonclinical settings including anxiety, depression, substance abuse, worksite stress, and burnout [60-64]. Moreover, a number of studies have found that ACT can improve mental health in the workplace [64,65], highlighting its potential as an intervention that may promote psychological resilience in occupational settings.

A recent review and meta-analysis found that digital mental health interventions in the workplace can improve psychological well-being and work effectiveness among employees [66]. Despite the apparent advantages of online resilience training, there has been very limited research examining the acceptability and efficacy of this approach. A few trials have examined either a blended approach (ie, programs that combine internet-based and face-to-face resilience training) [24,41] or an online approach with an emphasis on stress reduction and/or enhancing resilience-related factors [67,68]. As with the main resilience literature to date, these studies vary greatly in their approach to measuring program efficacy and thus limited conclusions can be drawn. In addition, while the research evidence for online mindfulness interventions continues to grow [48,69], to date there have been no published trials examining the efficacy of a mindfulness-based resilience training program delivered solely online.

The primary aim of our pilot study is to examine whether a mindfulness-based resilience-training program delivered via the internet is feasible and engaging to a high-risk group of workers, that is, firefighters. A secondary aim is to capture changes in measures of resilience and psychological skills among firefighters undertaking the training program. To the best of our knowledge, this is the first pilot study of a self-paced mindfulness-based resilience training program delivered completely in an online format.

Methods

Resilience@Work Mindfulness Program

The RAW program is a mindfulness-based intervention, which also draws on ACT and has significant emphasis on self-compassion and acceptance skills. The intervention involves completing 6 internet-based training sessions. Each session takes about 20-25 minutes to complete on a tablet or computer. It was anticipated that an engaging and interactive program would help address the issue of adherence; a challenge that employers frequently encounter when offering resilience training and support to their workers. Rather than having to read through lengthy paragraphs on a website, the RAW program engages workers in the process of learning by utilizing a combination of interactive exercises, audio, and animation (see Figure 2).

Participants were able to download mindfulness tracks to their own device for continued practice. Participants also had the opportunity to sign up for text-message reminders and/or reminder emails. A podcast accompanied each RAW session with additional mindfulness tracks to encourage skills development. Podcasts were not a mandatory part of the training but were available via a website for those participants who chose to use them.

Figure 2. Screenshots of training material from the Resilience@Work Mindfulness Program

To ensure program engagement, workers from target industries were invited to provide detailed insight into the specific work-related challenges they encountered on a regular basis. Examples were provided by workers to the research team via email, phone, and in person during a workplace well-being seminar. This information was collated and incorporated throughout the RAW program as "real-world" examples when introducing new resilience strategies and techniques.

Each session teaches a new strategy to cultivate psychological resilience and involves a combination of psycho-education and mindfulness training. The program also interweaves simple quotes and messages from the eastern philosophies of Buddhism and Yogic teaching traditions from which mindfulness has its origins [70-74].

Participants

Participants for this pilot study were drawn from Fire and Rescue New South Wales (FRNSW) in Australia. FRNSW is the seventh largest urban fire service in the world and responds to firefighting, rescue, and hazardous material emergencies in Sydney, Australia, and surrounding regional areas. Given the nature of their work, employees are known to have elevated risk of depression, anxiety, and PTSD [36].

Potential participants were informed about the study during a standard well-being talk facilitated by members of the FRNSW Peer Support Team. Firefighters were provided with a participant information sheet and consent form to read and review along with the study questionnaire. Participation was voluntary. Firefighters who opted to participate in the study signed the consent form and provided a valid email address in order to register into the training program. Prepaid envelopes were provided to mail consent forms and completed questionnaires to the research team. Overall, 29 firefighters were recruited (see Table 2). Any potential participants who were currently engaged in any regular individual psychological therapy sessions with a psychologist and/or psychiatrist were excluded from this study. Ethics approval was obtained via the Human Research Ethics Committee at the University of New South Wales, Australia.

Measures

The current pilot study sought to (1) examine the initial feasibility of the RAW Mindfulness Program in a workplace setting and (2) determine whether it would lead to measurable changes in resilience and key process variables, specifically cognitive fusion and experiential avoidance.

Measure of Feasibility

Engagement and feasibility of the RAW Mindfulness Program were recorded by storing the total number of sessions completed by each participant and the number of training hours completed.

Measure of Resilience

Psychological resilience was measured using the validated short form 10-item version of the Connor-Davidson Resilience Scale (CD-RISC 10) [75]. Participants respond to each item on a 5-point scale, ranging from 0 (not true at all) to 4 (true nearly all of the time). The total score ranges from 0-40 with a higher score indicative of higher psychological resilience. Previous studies have found the CD-RISC 10 to be a reliable and valid measure with Cronbach alpha ranging from .81-.88 [76,77] and test-retest reliability of 0.9 at 6 weeks [77,78].

Measure of Process

The RAW Mindfulness Program was designed to utilize a variety of mindfulness and ACT techniques, the most prominent of which were cognitive defusion and psychological flexibility. In order to measure the impact of the intervention program on these processes, the Cognitive Fusion Questionnaire (CFQ) and the Acceptance and Action Questionnaire version 2 (AAQ-II) were administered to participants.

Cognitive Fusion Questionnaire

The CFQ is a measure of cognitive fusion and defusion, a core component of the ACT model [79]. The CFQ contains 7 items rated on a 7-point scale from 1 (never true) to 7 (always true) with a total score range of 7-49. A higher score reflects greater cognitive fusion and thought entanglement. A sample item is “I get so caught up in my thoughts that I am unable to do the things that I most want to do.” Previous studies have found the CFQ to be a reliable and valid measure with Cronbach alpha ranging from .89-.93 [79,80].

Table 2. Demographics of participants in Resilience@Work pilot study (N=29).

Characteristics	Value
Age, mean (SD); range	43.7 (8.7) 24-59
Sex, n (%)	
Male	28 (97)
Female	1 (3)
Highest education, n (%)	
High school	8 (27.6)
Technical and Further Education (TAFE)	15 (51.7)
Graduate degree	5 (17.2)
Postgraduate degree	1 (3.4)
Years with Fire and Rescue New South Wales , n (%)	
1-5	3 (10.7)
6-10	4 (14.3)
11-15	5 (17.9)
16-20	3 (10.7)
20+	13 (46.4)

Acceptance and Action Questionnaire-II

The AAQ-II is a 7-item self-reported measure of experiential avoidance and psychological inflexibility. Participants rate each question on a 7-point Likert scale from 1 (never true) to 7 (always true) with a total score range of 7-49. A higher score reflects greater avoidance behavior and less psychological flexibility. Previous research has found the AAQ-II to be a reliable and valid measure with a Cronbach alpha of .84 and test-retest reliability of 0.81 at 3-month follow-up [56].

Data Analysis Plan

Analyses were conducted using SPSS statistical analysis program. Prior to analysis, frequency distributions and plots for each of the outcome and process variables were examined for unusual data points and to ensure the assumption of normality was not violated, using the Shapiro-Wilk's test. Paired-samples *t* tests were used to determine any differences between each measure at baseline and immediately after the intervention. The main measure of the efficacy of the intervention was the level of psychological resilience as measured by the CD-RISC 10. We proposed that an effect size of 0.5 would be considered a meaningful and clinically important effect. Based on such figures, we aimed to recruit at least 26 participants to this pilot study, which would achieve 0.8 power of detecting an effect size of 0.5 in terms of the CD-RISC 10 with an alpha of 0.1 (two-sided). This approach is similar to other pilot studies of this kind [81]. The total number of modules completed by each participant was also recorded to examine program engagement. In addition, univariate analysis using chi-square tests and Student *t* tests were used to examine which baseline measures predicted completion of at least 50% of the RAW program. Baseline factors considered were age, gender, level of education, years working as a firefighter, and baseline resilience.

Results

Overview

A total of 29 firefighters were recruited for the pilot study. Of the participants, 72% (21/29) had completed some form of post-high school education and the majority (16/29, 55%) had been employed by FRNSW for more than 15 years. In line with most first responder agencies, the vast majority of participants were male. Baseline resilience scores on the CD-RISC 10 were similar to normative data from first responders [69].

Program Engagement

Table 3 outlines the number of RAW program sessions completed by participants. The majority of participants (16/29, 55%) completed more than half the program (mean number of sessions completed was 3.6 out of a possible 6, SD 2.2) equating to 60-75 minutes of training. Eleven participants (11/29, 38%) completed all 6 sessions (a total of at least 2 hours training).

Analysis examining for baseline predictors of completion found no evidence that age, gender, level of education, years working as a firefighter, or baseline resilience were able to predict which participants were more likely to complete at least half of the RAW program (P>.05 for all).

Resilience, Cognitive Fusion, and Psychological Inflexibility/Experiential Avoidance

Participants reported greater levels of resilience after RAW training compared to baseline, with a mean increase in their CD-RISC 10 score of 1.5 (95% CI -0.25 to 3.18, t_{14}=1.84, P=.09), equating to a moderate effect size of 0.5. Table 4 displays the baseline and post-training measurements of resilience and measures of process.

Table 3. The number of Resilience@Work sessions completed by pilot study participants.

Minimum number of sessions completed	n (%)
1	29 (100)
2+	21 (72)
3+	16 (55)
4+	14 (48)
5+	14 (48)
6	11 (38)

Table 4. Baseline and post-training scores for measures of resilience and process variables.

Measure	Baseline, mean (SD)	Post Resilience@Work training, mean (SD)	*P* value
Resilience, CD-RISC 10[a] (n=15)	26.0 (5.5)	27.5 (4.9)	.09
Cognitive fusion, CFQ[b] (n=13)	20.7 (8.9)	18.4 (7.5)	.12
Psychological inflexibility, AAQ-II[c] (n=14)	18.5 (6.7)	16.7 (5.7)	.07

[a]CD-RISC 10: 10-item version of the Connor-Davidson Resilience Scale.

[b]CFQ: Cognitive Fusion Questionnaire.

[c]AAQ-II: Acceptance and Action Questionnaire version 2.

Compared to baseline, participants reported lower levels of psychological inflexibility and experiential avoidance following training, with a mean decrease of -1.8 (95% CI -3.78 to 0.20, t_{13}=-1.94, *P*=.07). With regards to cognitive fusion (thought entanglement), paired-samples *t* test revealed a trend towards reduction in mean scores post training (*P*=.12).

Discussion

Principal Findings

This pilot study of the RAW Mindfulness Program suggests that an internet-based resilience-training program is feasible in a workplace setting. In addition, those using the RAW program showed a trend toward increased resilience and psychological flexibility. To the best of our knowledge, this is the first time a wholly online mindfulness-based resilience-training program and its feasibility have been tested in the workplace.

While it is difficult to directly compare effect sizes from pre-post studies compared to control trials, it is worth noting that the moderate effect sizes demonstrated in this pilot study are similar to those described in a recent meta-analysis examining the effectiveness of online mindfulness interventions aimed at reducing stress [48]. In addition, the observed trends in both of the predicted process factors, cognitive fusion (thought entanglement), and psychological inflexibility/experiential avoidance, suggest the desired skills and techniques can be taught via an internet-based format.

Limitations

There were some important limitations to this pilot study, most notably the lack of a control group, the small sample size, and the absence of longer-term follow-up. The use of self-reported measures of resilience and process measures is also a limitation, although all scales used were well validated and the resilience measure chosen is known to be associated with a range of mental health outcomes among working populations [82]. Recruitment was facilitated by peer supporters and occurred while a proportion of firefighters were either responding to emergency calls or off duty. It is therefore unknown what proportion of firefighters were informed of the program and subsequently signed up for resilience training. Thus, limited insight was gained into overall acceptability of the program. It is important to note that our sample of emergency workers was a uniformed, male-dominated, high-risk group. Therefore, it remains unclear as to whether this form of resilience training is feasible among gender-balanced, low-risk workforces.

While most participants completed half of the program, there was a notable drop in completion after the second session. This may be due to a new cognitive skill being taught in this session that focused on how to manage difficult and uncomfortable thoughts. This may have been particularly confronting or challenging for some learners. Dropout analysis found that level of baseline resilience, age, gender, education level, and years on the job did not predict who would go on to complete more than 50% of the program. It is worth noting that this analysis is hindered by an overall lack of power and that other factors such as intrinsic motivation may have influenced completion rates. That said, most participants completed at least half of the RAW program and of these most went on to complete the entire program (ie, all 6 sessions).

Conclusion

Despite these limitations, the results of this pilot study provide some valuable insights into what form of resilience training may be viable in occupational settings. More specifically, it suggests that internet-based resilience training is a feasible approach in workplaces, particularly among those considered high risk, such as first responders, and those with specific inherent challenges for training, such as shift work, frequent travel on the road, and limited access to face-to-face training.

In spite of these promising results, the effectiveness of the RAW Mindfulness Program needs to be tested via a larger randomized controlled trial, ideally with both short-term and longer-term follow up. Additional secondary outcome measures, such as levels of psychological symptoms, perceived stress, and well-being are also needed to establish whether programs such as the RAW program can create meaningful changes beyond short-term gains in self-reported resilience.

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Authors' Contributions

SJ and SBH devised the study. SJ developed the RAW Mindfulness Program, the internet-based format, and collected, scored, and entered the data. TJL assisted with data collection. SJ and SBH analyzed and interpreted the data, and SJ wrote the first draft of the manuscript. All authors read and contributed to subsequent versions and approved the final manuscript.

Conflicts of Interest

SJ and SBH are associated with a company that offers resilience training (RAW Mind Coach). SBH and FS work for the Black Dog Institute, a not-for-profit organization that provides mental health and resilience training to various other organizations.

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Abbreviations

AAQ-II: Acceptance and Action Questionnaire version 2
ACT: acceptance and commitment therapy
CD-RISC 10: 10-item version of the Connor-Davidson Resilience Scale
CFQ: Cognitive Fusion Questionnaire
FRNSW: Fire and Rescue New South Wales
NSW: New South Wales
PTSD: posttraumatic stress disorder
RAW: Resilience@Work

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Original Paper

Using Partially-Observed Facebook Networks to Develop a Peer-Based HIV Prevention Intervention: Case Study

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Abstract

Background: This is a case study from an HIV prevention project among young black men who have sex with men. Individual-level prevention interventions have had limited success among young black men who have sex with men, a population that is disproportionately affected by HIV; peer network–based interventions are a promising alternative. Facebook is an attractive digital platform because it enables broad characterization of social networks. There are, however, several challenges in using Facebook data for peer interventions, including the large size of Facebook networks, difficulty in assessing appropriate methods to identify candidate peer change agents, boundary specification issues, and partial observation of social network data.

Objective: This study aimed to explore methodological challenges in using social Facebook networks to design peer network–based interventions for HIV prevention and present techniques to overcome these challenges.

Methods: Our sample included 298 *uConnect* study respondents who answered a bio-behavioral survey in person and whose Facebook friend lists were downloaded (2013-2014). The study participants had over 180,000 total Facebook friends who were not involved in the study (*nonrespondents*). We did not observe friendships between these nonrespondents. Given the large number of nonrespondents whose networks were partially observed, a relational boundary was specified to select nonrespondents who were *well connected* to the study respondents and who may be more likely to influence the health behaviors of young black men who have sex with men. A stochastic model-based imputation technique, derived from the exponential random graph models, was applied to simulate 100 networks where unobserved friendships between nonrespondents were imputed. To identify peer change agents, the eigenvector centrality and keyplayer positive algorithms were used; both algorithms are suitable for identifying individuals in key network positions for information diffusion. For both algorithms, we assessed the sensitivity of identified peer change agents to the imputation model, the stability of identified peer change agents across the imputed networks, and the effect of the boundary specification on the identification of peer change agents.

Results: All respondents and 78.9% (183/232) of nonrespondents selected as peer change agents by eigenvector on the imputed networks were also selected as peer change agents on the observed networks. For keyplayer, the agreement was much lower; 42.7% (47/110) and 35.3% (110/312) of respondent and nonrespondent peer change agents, respectively, selected on the imputed networks were also selected on the observed network. Eigenvector also produced a stable set of peer change agents across the 100 imputed networks and was much less sensitive to the specified relational boundary.

Conclusions: Although we do not have a gold standard indicating which algorithm produces the most optimal set of peer change agents, the lower sensitivity of eigenvector centrality to key assumptions leads us to conclude that it may be preferable. The methods we employed to address the challenges in using Facebook networks may prove timely, given the rapidly increasing interest in using online social networks to improve population health.

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KEYWORDS

African Americans; computer simulation; data mining; HIV infections; peer group; pre-exposure prophylaxis; sexual and gender minorities; social media; social networking

Introduction

Background

Social network interventions have been successful in improving health outcomes [1-6], including those related to HIV prevention [7-9]. Our ongoing research aims to design social network interventions to reduce new HIV infections among young black men who have sex with men (YBMSM), defined here as individuals aged between 16 and 29 years. YBMSM are disproportionately impacted by the HIV epidemic in the United States [10], and traditional individual-level epidemiological interventions have had limited success in reducing HIV infections among YBMSM [11,12]. Peer-based interventions that make use of social networks have improved HIV outcomes in some populations [13-18] and present a promising opportunity to improve HIV outcomes among YBMSM. Here, we study how such a peer network–based intervention, which aims to expand the use of pre-exposure prophylaxis (PrEP)—a novel biomedical intervention with an estimated efficacy of over 90% among adherent individuals [19,20]—can be developed. PrEP remains underutilized among YBMSM, prompting a need to identify creative techniques to increase its use. Our objective here is to use online social network data from Facebook to identify influencers who could most effectively disseminate PrEP-related information among YBMSM in Chicago and to explore the methodological challenges that arise in the identification of these influential agents.

Setting and Context

We use Facebook data from the *uConnect* cohort—the largest single-site population-based sample of YBMSM—to identify peer change agents (PCAs) who occupy *critical* positions in the social network. In future work, these PCAs will be invited to participate in training on how to effectively disseminate PrEP information. Although the use of alternate social networking sites has proliferated, Facebook remains an attractive choice because it is the most widely used social platform [21]. To identify PCAs, our population of interest is the potential influencers of YBMSM, who may or may not be YBMSM themselves, and Facebook enables broad characterization of their social networks.

We use a digital platform to characterize the social networks of YBMSM because despite demonstrating early promise, peer-based HIV interventions have had limited effect in some populations [22]. It has been argued that using digital methods to compile more accurate social network data and applying formal network analyses to identify PCAs may improve the efficacy of peer interventions [23]. As a digital platform, Facebook's potential for improving health behaviors has been demonstrated in other studies [24-26], and Facebook continues to have high rates of use among sexual and gender minorities [27], including YBMSM in Chicago. (A more in-depth treatment of peer-based network interventions for HIV prevention is provided in Multimedia Appendix 1.)

There are a number of challenges, however, in using Facebook data to identify PCAs, including: (1) the large size of the Facebook network, which makes it problematic to identify which individuals are more likely to be influential among YBMSM; (2) difficulty in assessing the relative strengths of methods that can be used to identify PCAs; and (3) partial observation of the Facebook network that increases the uncertainty in identification of individuals in influential network positions. We address the aforementioned problems using a variety of techniques, including imputation to infer the unobserved structure of the Facebook network.

Study Objectives

The goal of this paper is thus two-fold: (1) to provide insight into the structure of the Facebook network of YBMSM in Chicago and how that structure relates to the identification of PCAs for an HIV prevention intervention and (2) to provide guidance to researchers considering the use of PCAs on online social networks and the practical difficulties that might arise when applying theory to practice. We use 2 algorithms commonly used to identify candidate PCAs for information diffusion and apply them to observed and imputed networks. We examine the *sensitivity* and *stability* (defined in the Methods section below) of PCA sets selected by each algorithm, given the imputation of the unobserved data. This case study is the first step in a broader effort to understand how the effectiveness of peer-based network interventions can be improved. Methods and data presented here might be useful to other researchers using social networking sites for peer-based health interventions.

Methods

Recruitment of Study Sample

A detailed description of participant recruitment is provided elsewhere [28-31]. In brief, respondent-driven sampling (RDS) was used to recruit eligible YBMSM from the South Side of Chicago and adjacent suburbs between June 2013 and July 2014 (n=618) [28]. *Seeds* from diverse social spaces were selected and given coupons to distribute to potential recruits. If the recruits were willing to participate in the study, then they returned the coupons to the study coordinators and were given coupons to recruit study participants themselves. Information in these coupons allowed us to link the recruits with their recruiters. A diverse set of starting seeds for recruitment can produce a study sample that is representative of the population.

RDS is a variant of link-tracing schemes, and it provides a design for sampling and a methodology for estimating statistical properties of the target population [32]. RDS is especially attractive for sampling populations that are *hard to reach*, and it has been used in a variety of health studies [33-39].

Respondents were eligible for recruitment if they (1) self-identified as African American or black; (2) were assigned male sex at birth; (3) were aged between 16 and 29 years; (4) spent most of their time on the South Side of Chicago or adjacent predominantly black suburbs; (5) were willing and able to provide informed consent at the time of the study visit; and (6) reported oral or anal sex with a male within the past 24 months [28]. These study participants answered a bio-behavioral survey at an in-person study visit and were offered the opportunity to provide Facebook data.

Generation of Facebook Networks

Facebook friend lists of consenting uConnect participants were downloaded, allowing us to enumerate the set of potential influencers of YBMSM. An app within Facebook was developed to enable identification of unique individuals from Facebook friend lists of consenting respondents. With privacy protections in place, the algorithm unambiguously linked friend lists of all consenting uConnect respondents. Of the 618 study respondents, 600 reported using the internet and 490 reported having a profile on Facebook. Of the 322 who consented to provide Facebook data, 24 were not able to log in to their account. An undirected network dataset on 298 uConnect respondents was thus compiled, which included information on friendships between pairs of respondents and between respondents and *nonrespondents* (ie, friends of respondents who did not participate in the study). This data structure is typical of digitally collected network data [40,41].

Following Handcock and Gile [42], we depict the observed and unobserved partitions of our data in a 2x2 table (Figure 1). All friendships—*ties* or *edges* in network terminology—between respondents (n=298), as shown in the bottom left cell, were observed (about 44 thousand observed dyads), as were friendships between respondents and nonrespondents (n=182,998) in the diagonal cells (about 54 million observed dyads). Facebook friendships between the nonrespondent friends of uConnect respondents, shown in the top right cell, were unobserved (about 17 billion unobserved dyads). A schematic for the data structure is provided in Figure 2.

Boundary Specification for Selection of Nonrespondent Nodes for Imputation

The Facebook network compiled above presumably includes nonrespondents that share variegated relationships with the respondents, including social, familial, and sexual, thus containing a mix of both strong and weak ties. Our goal is to identify critically positioned individuals, including those who were not respondents, and recruit them as candidate PCAs. For our intervention, it is not necessary that the nonrespondents be YBMSM themselves; it is only necessary that nonrespondents be potential influencers of YBMSM. Given the large number of nonrespondents and the amount of unobserved relational data between nonrespondents, we specified a boundary condition that would allow us to select individuals who were well connected to Chicago YBMSM.

Figure 1. Illustration of the problem of unobserved tie imputation. Facebook friendships between individuals are classified into categories: observed respondent-respondent (bottom left quadrant), observed respondent-nonrespondent (diagonal quadrants), and unobserved nonrespondent-nonrespondent (top right quadrant). The approximate number of dyads in each quadrant is stated.

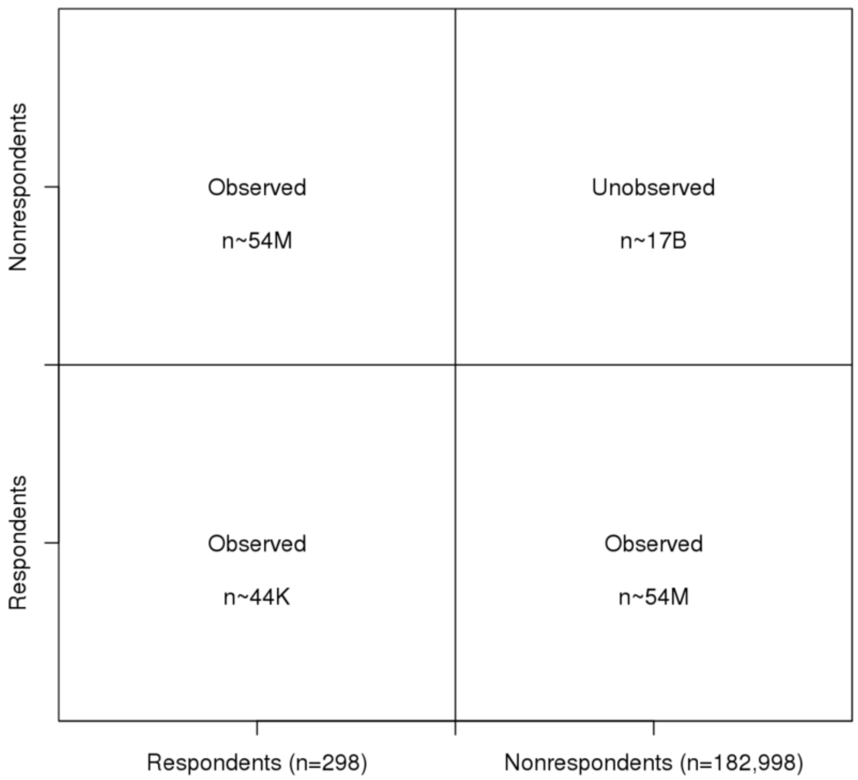
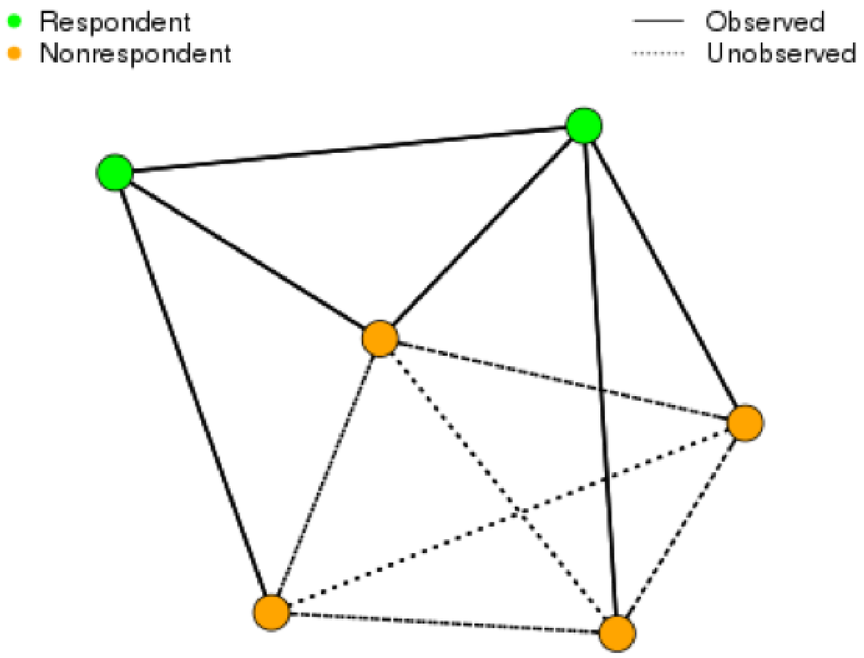


Figure 2. Illustration of the Facebook network data structure. Facebook friendships between respondents and between respondents and nonrespondents are observed. The friendships between nonrespondents are unobserved. Our data contain more nonrespondents than respondents.



We specified a boundary for nonrespondents that focused on the number of friendships with respondents (ie, their relations), as opposed to other individual-level criteria that are commonly used to specify boundaries [43,44], for the following 3 reasons. First, usage of the entire sample was infeasible, as there were some 17 billion unobserved dyads, and including all of these in our analyses would have meant that over 99% of our relational data were unobserved. Second, we had limited attribute data for the nonrespondents, and we assumed that those with large numbers of ties to YBMSM in South Chicago were the most likely to also be a potential influencer. Third, our ultimate goal was to select PCAs, and although degree is only one network criterion that determines the potential to influence other actors, it seems reasonable to expect most influential nodes will have moderately high degrees. Thus, we constructed a dataset that included all respondents and the set of nonrespondents who met the threshold specified by our relational boundary. Precise metrics on the relational boundary specification are given in the Results section below.

Characterizing the Nature of Missingness in the Data

Although our Facebook networks were large, the information in our datasets was not complete because we did not observe the friendships between nonrespondents. The large amount of missing data could potentially bias our assessments of candidate PCAs based on their network position. Thus, we chose the approach of applying statistical imputation to reduce the bias induced by partial observation of our data.

To select an appropriate technique to impute the unobserved Facebook friendships, we first needed to define the nature of missingness in our data. We did this following the widely used convention developed by Rubin [45], who proposed that missingness is of 3 broad types. Data are “missing completely at random” (MCAR) when the missingness depends neither on the observed data nor the unobserved data. They are “missing at random” (MAR) when the probability of missingness does depend on the observed data but not the unobserved data [46,47]. Data are “missing not at random” (MNAR) if the probability of missingness depends on the unobserved data as well [46].

Our missing data are MNAR. Recall that our study respondents were recruited using an RDS procedure. Nonrespondents were Facebook friends of the respondents, and their data would not have been missing if they had been recruited into the study. However, nonrespondents might not have been recruited for the following unknowable reasons: (1) they were ineligible for the study; (2) they were eligible for the study, but the respondents did not wish to recruit them; (3) they were eligible for the study, but the respondents did not have sufficient coupons for them; and (4) nonrespondents received a coupon but did not participate in the study. Thus, the fact that friendship information for all pairs of nonrespondents is missing is related to their observed friendships with the respondents and also to their unobserved networks, as the nonrespondents’ reason for not being recruited cannot be determined. For reasons explained above, we also specified a degree-based boundary for nonrespondent inclusion. Thus, the respondents and nonrespondents have “differential popularity,” in the terminology of Gile and Handcock [48], beyond what can be explained by the observed data. Consequently, we suspect that the network structure of nonrespondents is different from that of the respondents. However, a difference in the network structure of respondents and nonrespondents by itself does not violate the MAR assumption, as long as the missingness is due to observed effects, such as whether a particular individual is a respondent or not. In our case, however, the difference in network structure is not entirely due to observed covariates; it may be attributable to a number of nodal covariates that were unobserved, as discussed above. Thus, the missingness in our data is consistent with the MNAR definition.

Fitting a Model for Imputation of Unobserved Friendships

It has been shown that analyses using only the observed subnetwork might not generalize to the larger incomplete network [49]. Hence, an imputation of the unobserved Facebook friendships might provide more reliable indicators of candidate PCAs. To impute these unobserved friendships, we used exponential random graph models (ERGMs) [50], a class of models commonly used to describe probability distributions of networks, as implemented in the open source *statnet* [51] suite of packages. ERGMs were used to estimate the log-odds of ties between actor pairs, relative to a model where all ties are homogeneously distributed across the network. Observed existent ties were coded 1, observed nonexistent ties were coded 0, and unobserved ties were coded as missing ("NA" in *R*). This approach to imputation is derived from the method proposed by Handcock and Gile [42,48] and has been used to impute unobserved ties in other studies [52,53].

To impute friendships between nonrespondents, we developed a mechanistic model to predict their likelihood. Although there was little information available on individual attributes of nonrespondents (more details are provided in the Results), the number of friendships each of them shared with respondents was completely observed. We also know that Facebook ties tend to have a high mean degree and a high variance. It is, therefore, reasonable to assume that in the context of Facebook, nonrespondents who were more social with respondents might also be more social with each other. (A contrast would be the inverse condition, where observing many ties with respondents may indicate that many of the individual's fixed *tie budget* was already used up, and thus, decrease their probability of having ties with other nonrespondents.) However, the procedure for selecting nonrespondents for imputation is biased toward those who are more social. It is, therefore, likely that the friendships between nonrespondents would not simply be in direct proportion to their observed friendships, but might experience a *dampening* effect. To mechanistically model both of these social forces, we used 2 separate parameters in an ERGM: *sociability* and *selective mixing*.

Sociability is a node-level parameter that measures the number of ties a respondent or nonrespondent shares with respondents, and selective mixing was represented as a single parameter measuring the number of ties between respondents and nonrespondents, as represented by either of the diagonal cells in Figure 1. The sociability term applies to the full adjacency matrix, allowing us to use the observed features to infer the unobserved [48]. It represents a process where respondents with more respondent friends will also have more nonrespondent friends. The selective mixing term allows us to model the systematic difference between the respondents and the nonrespondents, whereby the nonrespondent-nonrespondent quadrant will have a greater density than either of the other 2 (respondent-respondent and respondent-nonrespondent). This approach allows us to use the observed information to model the unobserved information in the network while accounting for the observed systematic differences between the respondents and nonrespondents directly, as advocated by Gile and Handcock [48]. Thus, the selective mixing parameter offsets some of the bias induced by selecting the most social nonrespondents as a consequence of the boundary specification defined above.

Simulating Multiple Imputations From the Fitted Model

Once a model to impute missing data is estimated as above, we simulate stochastic realizations of this model. In networks that are fully observed, a simulation from an estimated ERGM fixes the set of nodes and uses a stochastic Markov Chain Monte Carlo (MCMC) algorithm to toggle relationships on and off, resulting in a network that represents a random draw from the probability distribution specified by the ERGM. In this case, we fix the values of the observed dyads, allowing only the unobserved dyads to be selected as candidates for toggling during the MCMC algorithm. This specification was used to impute 100 stochastically generated networks, each with the number of observed and unobserved ties consistent with a random draw from our fitted model described above. The 100 imputations were deemed to be sufficient because the maximum variability in the number of imputed edges was low (<1.8% of the mean, where mean=40,970 and range=40,610-41,340).

Peer Change Agent Identification

Facebook friendships between nonrespondents are imputed in the simulated networks. We use these networks to identify PCAs. It is worth noting that the population that our PCAs are drawn from is not limited to YBMSM only but the potential influencers of YBMSM. Such a PCA identification procedure is arguably most successful when the type of flow process that is of interest is taken into account [54]. Following this argument, we apply 2 computational algorithms that are well suited to situations where the underlying flow process involves diffusion of information: eigenvector centrality [55] and keyplayer positive [56]. Eigenvector centrality assumes that the flow process of interest moves through the network via unrestricted walks. It describes a mechanism where 1 node can impact all of its neighbors simultaneously [54], and it has therefore been used in public health apps that use peer influence [57-59]. The keyplayer positive algorithm—henceforth referred to as *keyplayer* —is a set-based measure, reflecting the idea that the optimal set may not necessarily be composed of nodes that have the highest individual scores [56]. Rather, the keyplayer set consists of individuals who are maximally connected to individuals in the network. Thus, passing information through the keyplayer set minimizes the social distance it has to travel to reach the maximum number of individuals in a social network. Keyplayer is thus an ideal choice for scenarios like diffusing PrEP-related information, and it has been used in related public health applications [60,61]. Mathematical definitions and algorithmic descriptions of both measures are given in Multimedia Appendix 1.

We used eigenvector centrality and keyplayer to identify candidate PCAs on the observed Facebook data, in which all unobserved ties were assumed to be nonexistent, and then on each of the 100 imputed networks. These algorithms are designed to be applied to a given observed network, and the theory works best when the network observation is perfect. When networks are incompletely observed, however, an alternate approach is to apply each algorithm to a sample of imputed networks, rather than optimizing just on the observed dataset [56]. This method provides a set of PCAs that represent a good solution for the case where network data are imperfectly observed [56]. Thus, we followed this strategy.

We made a programmatic decision to select 300 individuals by each measure on the observed network, and the 300 most commonly occurring PCAs on the imputed networks were selected. The number of PCAs that are recruited and trained is a critical consideration in peer interventions, and it has been argued that a peer intervention is likely to be successful if the number of peer leaders recruited is about 7-8% of the size of the population for whom the intervention is designed [62]. In prior published work [63], we estimated that there are about 3700 HIV-negative YBMSM in Chicago, 8% of which is approximately 300.

We calculated the distribution of the number of times each individual was identified as a PCA across the imputations for each algorithm to assess which individuals warranted further consideration. These distributions were used to determine *cutoff* points for PCAs and were defined as a sufficiency condition for each of the algorithms. Of the identified PCAs, those that met this sufficiency condition were referred to as "sPCAs." Intersection sets of PCAs on the observed network and sPCAs on the imputed network were then computed for each algorithm. We defined the following 2 measures to compare the sets of PCAs and sPCAs on the observed and imputed networks, respectively.

Sensitivity

The *sensitivity* of an algorithm is defined as the overlap in the PCAs identified on the observed network and sPCAs identified on the imputed networks. This measure allows us to assess if a PCA set differs substantially between the observed and imputed networks, providing an indication of the extent to which an individual appears to be a strong candidate for PCA selection, regardless of whether imputation is used. Thus, it helps us to understand the extent to which imputation affects our outcomes. Note that we do not assert that it provides an indication of the accuracy of the imputation, which remains unknowable.

Stability

The *stability* of an algorithm is defined as the tendency of an algorithm to identify the same nodes—that is, sPCAs on the imputed networks—across multiple imputations. This measure allows us to determine the threshold number of imputations for each measure that is required to select PCA sets of the size desired here (n=300).

Note on Computing

All the computation and visualization were performed using software packages in the R programming language [64]. The *sna* [65] and *igraph* [66] packages were used to manage relational data. The *ergm* [67] package was used to fit the ERGMs and simulate the imputed networks. Eigenvector scores were computed using *igraph* [66]; keyplayer sets were identified using *influenceR* [68]. The *Intergraph* [69] package was used to convert data between the formats required for *igraph (or influenceR*, which uses the same data structure as *igraph)* and network (or *ergm*, which uses the same data structure as *network)*. The *sna* [65] and *GGally* [70] packages were used to visualize networks.

Results

Study Sample, Facebook Networks, and Relational Boundary Specification

The 298 uConnect respondents had 182,998 Facebook friends in total. There were 327,741 observed friendships in the dataset, including 3256 between respondents exclusively, and the remaining friendships existed between respondents and nonrespondents.

As stated above, as the number of nonrespondents was large and limited individual-level information on nonrespondents was available, we specified a boundary for nonrespondent inclusion based on their observed relations: nonrespondents (n=587) who were friends with at least 10.1% (30/298) of the respondents were included in our sample. The number of nonrespondents that would be selected with different boundaries is given in Table 1. Specifying a boundary involves tradeoffs; set too low, the amount of missing data increases rapidly (on the order of n^2), and the likelihood of including someone not closely connected to Chicago YBMSM increases. By specifying a boundary that is too high, we may exclude someone who is both a YBMSM and a strong PCA candidate based on their network position. We considered the number of nonrespondents who would fall within different boundary specifications (Table 1) and the amount of missing data that each would imply. We selected 10% as our boundary for the number of respondents a nonrespondent must be friends with because it reduces our sample to a manageable computational size while retaining a broad sample of nonrespondents who could be PCAs. Thus, the final sample consisted of 885 individuals, including 33.6% (298/885) respondents and 66.3% (587/885) nonrespondents.

In this sample, the median reported age for both respondents and nonrespondents was 23 years (with 271 missing reports for nonrespondents). In addition, 96.9% (289/298) respondents and 92.5% (543/587) of nonrespondents identified their current gender as male on their Facebook profiles (2 nonrespondent reports were missing). Approximately 81.5% (243/298) respondents listed Chicago as their city on their Facebook profiles. Of the remaining 55 participants, 52 reported their residence as the South Side/south suburbs of Chicago during their in-person interview and 3 reported their residence as the Southeast side. Moreover, 66.2% (389/587) nonrespondents listed Chicago as their city; approximately 5.9% (35/587) nonrespondents did not report their city. About half of the remaining nonrespondents reported Illinois or another Midwestern State as their primary location, and the rest were scattered across the United States.

Table 1. Boundary specifications for the number of friendships between nonrespondents and respondents as a selection criterion for nonrespondents.

Minimum number of respondents that a nonrespondent has to be connected to (N=298), n (%)	Nonrespondents meeting that boundary specification, n	Observed friendships between respondents and nonrespondents, n	Unobserved dyads between nonrespondents, n
3 (1.0)	20,746	139,600	215,187,885
15 (5.0)	1633	47,473	1,332,528
30 (10.1)[a]	587[a]	26,444[a]	171,991[a]
60 (20.1)	97	5898	4656

[a]Shows the case used in our analysis.

Table 2. Summary of exponential random graph models fit.

Network parameter	Log odds	Standard error	*P* value
Edges	−5.36	0.029	<.001
Sociability (measured as degree with respondents)	0.044	0.0002	<.001
Mixing between respondents and nonrespondents	0.208	0.022	<.001

Overall, we observed 29,700 friendships, including 3256 between respondents exclusively and 26,444 between respondents and nonrespondents. Thus, each respondent had an average of 110.5 friendships, including 21.8 friendships on average with other respondents, and an average of 88.7 friendships with nonrespondents. Each nonrespondent who met our boundary specification had an average of 45.1 observed friendships.

The density of friendships—defined as the ratio of the number of observed friendships to the maximum number of possible friendships—between respondents was 7.4%. The density of respondent-nonrespondent friendships was 15.1%. (These densities will help us interpret outputs from our imputation procedure below.)

Fitted Model for Imputation of Unobserved Friendships

Estimates from the fitted ERGM are in Table 2. The "edges" term operates analogously to an intercept term in logistic regression models. Our coefficient for it was negative, implying the base probability of a tie, without considering other additive terms, is less than 50%. Coefficients for the other 2 terms were positive and significant. The positive sociability coefficient indicates that individual respondents who have more ties to other respondents also have more ties to nonrespondents. The positive mixing coefficient indicates the dampening effect discussed above. Thus, the number of imputed friendships between nonrespondents was lower than that predicted by a proportional scaling model of the observed friendships between respondents and nonrespondents.

Multiple Imputation of Unobserved Network Data

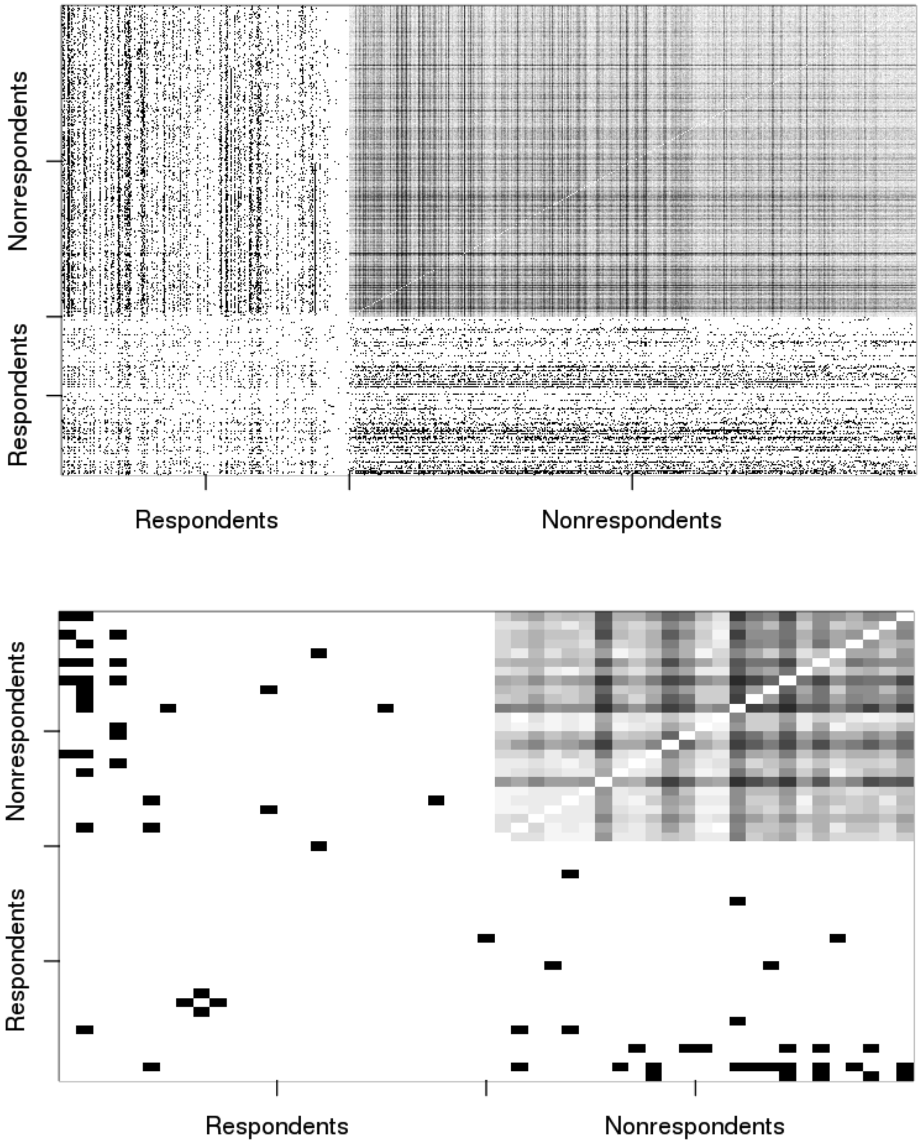
In Figure 3, the top panel contains frequency plots of the adjacency matrices across the 100 imputed networks. (The top panel of Figure 3 displays data for all 885 nodes; in the bottom panel, we selected the first 50 respondents and 50 nonrespondents to produce a clearer display.)

The mean density for imputed friendships between nonrespondents, shown in the top right corner of Figure 3, was 23.8%. The nonrespondent-nonrespondent density is higher than the density of respondent-respondent friendships (7.4%, as stated above) and the density of respondent-nonrespondent friendships (15.1%). This discrepancy in densities is reflective of the fact that a degree-based criterion was used to select nonrespondents for imputation. Had we not included the selective mixing term, however, this density would have been even higher. Three cells—the bottom left and the diagonals—in each panel of Figure 3 consist entirely of observed dyads and required no imputation. The top right cell contains unobserved dyads, and edges in these dyads were stochastically generated in the imputations.

The degree distributions for the respondents and nonrespondents in the observed network and 1 randomly selected imputed network are shown in Figure 4. The respondents have identical distributions in the observed and imputed graphs because the imputation does not impact respondent ties. We also observed that 11.7% (35/298) of the respondents had no friendships with anyone in the imputation sample, a consequence of excluding nonrespondents who did not meet our boundary specification.

The second consequence of our boundary specification is that we see that the minimum number of friendships for nonrespondents is 30. In addition, on the observed network, we noticed that numbers of friendships between nonrespondents had a much narrower range (30-100). After the imputation, however, we see that the degree distribution of nonrespondents is much more right-skewed, comparable with the degree distribution of the respondents. As we have no reason to believe that the respondents and nonrespondents should have different degree distributions, this correspondence in shape after imputation is a positive sign, indicating that our approach is reasonable in this sense. The left side of the imputed nonrespondent distribution does not resemble that of the respondents, but this is to be expected, given the degree-based boundary specification we imposed for selection of nonrespondents.

Figure 3. Frequency plots for imputed networks: the top figure displays data for all 885 nodes, and the bottom figure displays a subset comprising the first 50 respondents and first 50 nonrespondents (bottom), uConnect 2013-2014. The bottom left and the diagonals cells in both matrices consist entirely of observed dyads that required no imputation. The top right cell contains unobserved dyads, and edges in these dyads were stochastically imputed, and hence, appear in grey. The bottom panel is shown to produce a clearer display of the cell shading.



Peer Change Agent Identification

Peer Change Agent Identification on the Observed Network

On the observed network, both the PCA sets of size 300 contained a mix of respondents and nonrespondents, with the exact breakdown varying by algorithm; the set for eigenvector centrality contained 62.0% (186/300) nonrespondents and for keyplayer contained 66.0% (197/300) nonrespondents. Recall that nonrespondents comprise 66.3% (587 of 885 nodes) of our sample. Thus, when the unobserved ties were treated as nonexistent, the proportion of nonrespondents in the PCA sets was higher than their proportion in the observed network for eigenvector centrality, and about the same for keyplayer. Although it might seem surprising that the proportion of nonrespondents who were selected as PCAs without the imputation was high, it makes sense in light of our degree-based boundary specification, which selected nonrespondents who had high connectivity with Chicago YBMSM, and were thus likely to be in critical positions. Had we not specified a boundary, nonrespondents would have comprised over 99.9% of the whole sample.

Peer Change Agent Identification on the Imputed Networks

Across the 100 imputed networks, Figure 5 shows the distribution of PCAs identified by each algorithm. For eigenvector and keyplayer, 390 and 885 nodes, respectively, were selected at least once. Thus, we see a fundamental difference between the 2 measures in terms of their stability in node selection. Eigenvector centrality is a node-level algorithm, and it demonstrated a strong tendency to identify the same nodes as critical across all 100 imputations. In other words, the modal number of imputations for nodes that were selected at least once was 100. The keyplayer algorithm showed much less stability;

the modal number of imputations for nodes that were selected at least once was 33. Summary statistics of the number of times PCAs were identified across all imputations are given in Table 3.

For subsequent analyses, we adopted a sufficiency condition, illustrated as the cutoff point in Figure 5. For each measure, this cutoff point was a value that yielded the smallest PCA set that was closest in size to our desired value of 300. We refer to PCA sets that meet the sufficiency condition for a given algorithm as sPCAs. With eigenvector centrality, 301 individuals—consisting of 22.9% (69/301) respondents and 77% (232/301) nonrespondents—were selected on at least 50 imputed networks. With keyplayer, 312 individuals—consisting of 35.2% (110/312) respondents and 64.7% (202/312) nonrespondents—were selected on at least 36 imputed networks. There were 115 sPCA individuals (20 respondents and 95 nonrespondents) that met the sufficiency criterion by both algorithms and 498 unique sPCA individuals selected by at least one algorithm (100 respondents and 398 nonrespondents).

We also found that nonrespondent sPCAs selected using eigenvector had a minimum of 44 friendships with respondents, whereas those selected using keyplayer were friends with a minimum of 30 respondents, which is the same as our boundary for nonrespondent inclusion. Thus, eigenvector only selected nonrespondent PCAs who were well above the boundary specification, whereas keyplayer did not. This suggests that eigenvector is less affected by the boundary specification for nonrespondent inclusion.

Figure 4. Degree distributions of respondents (top) and nonrespondents (bottom) in the observed and imputed networks. The respondent degree distributions in the top graph are identical because the imputation does not impact respondent ties. The degrees are binned together in sets of size 10.

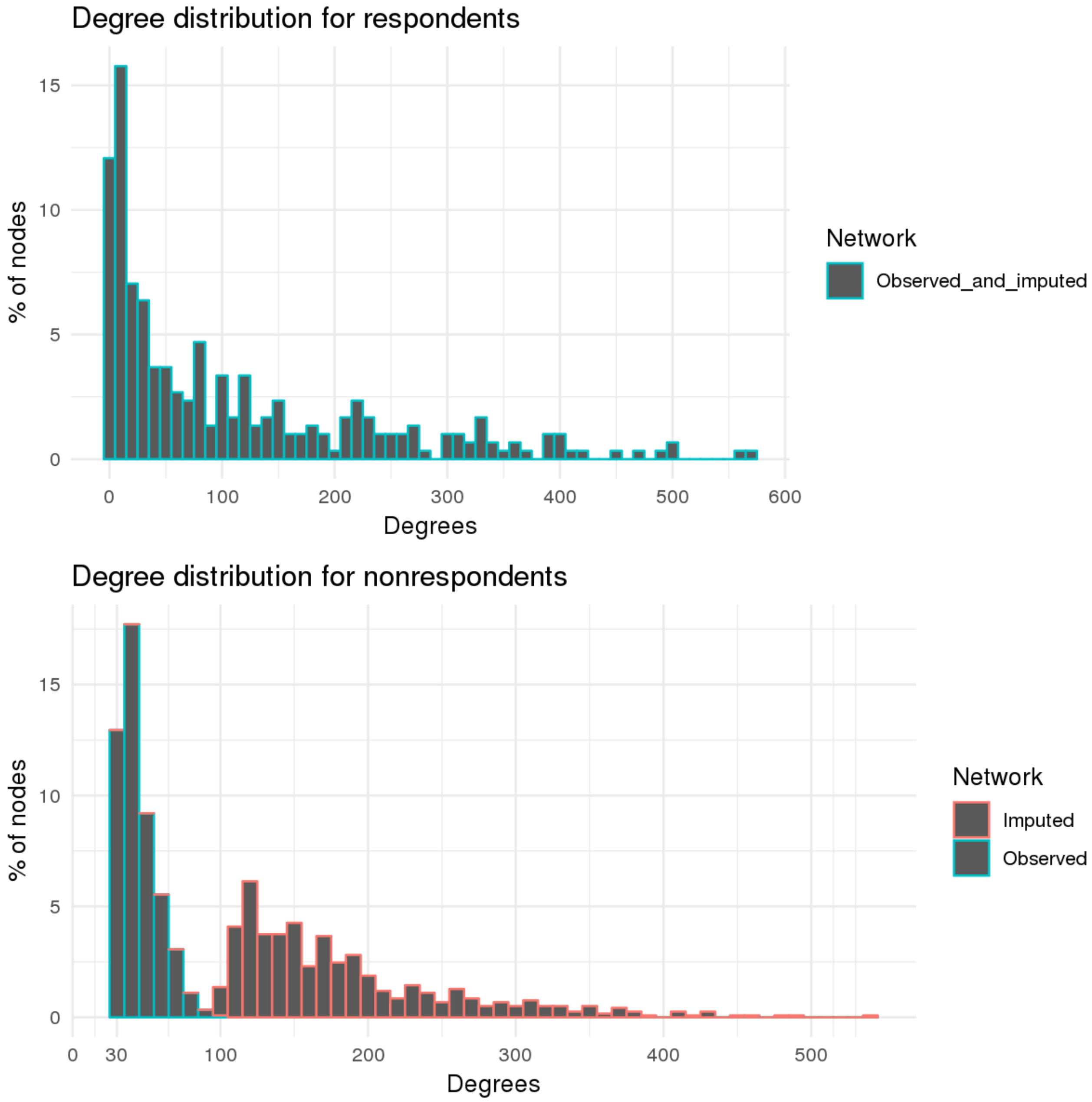


Figure 5. Distribution of the number of nodes selected as peer change agents on the imputed networks, conditional on their being selected at least once. This figure also illustrates the cutoff point for each algorithm, which is used to determine the sufficiency condition of peer change agent selection for each algorithm across the hundred imputations. KP: keyplayer; EV: eigenvector.

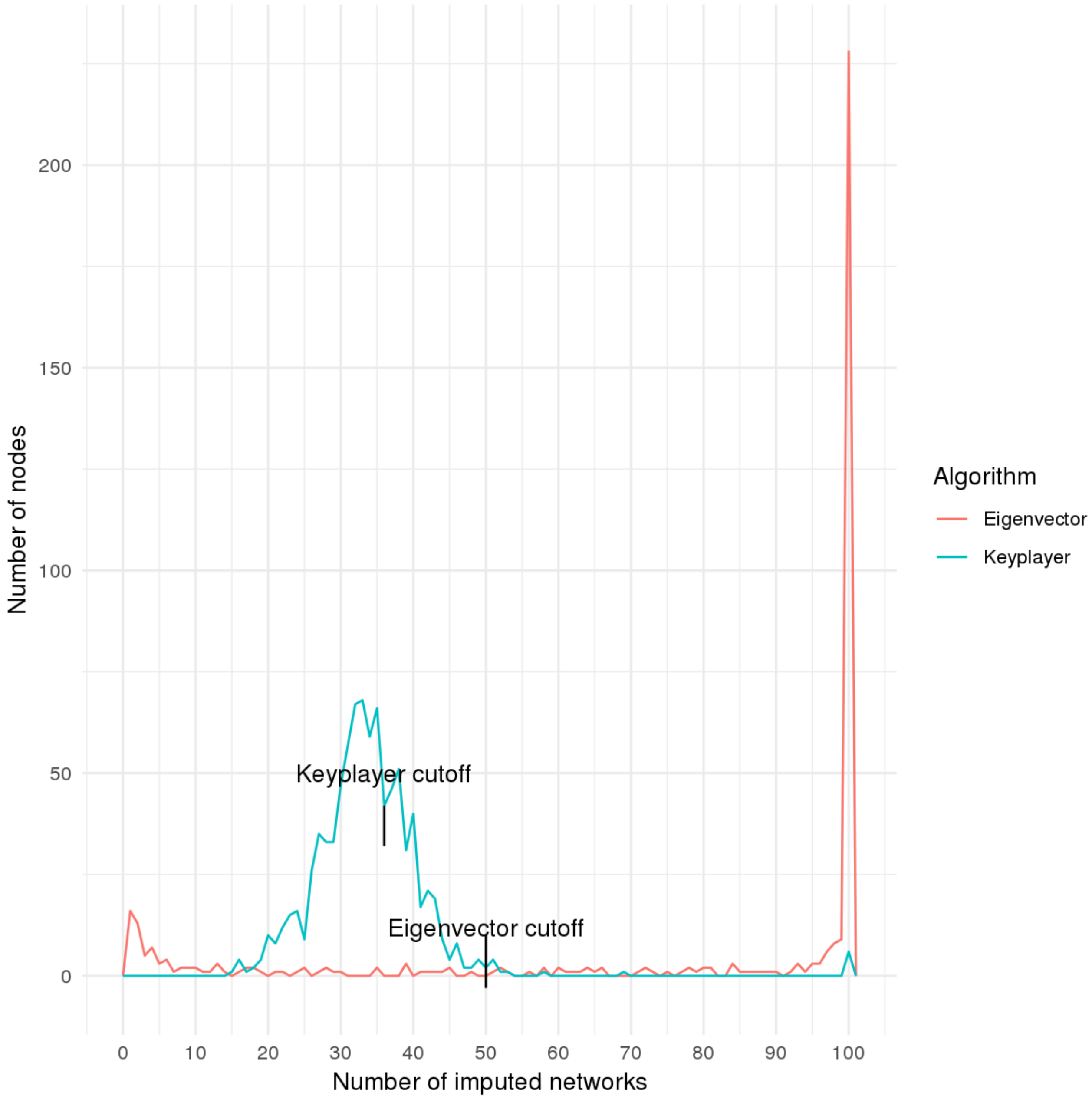
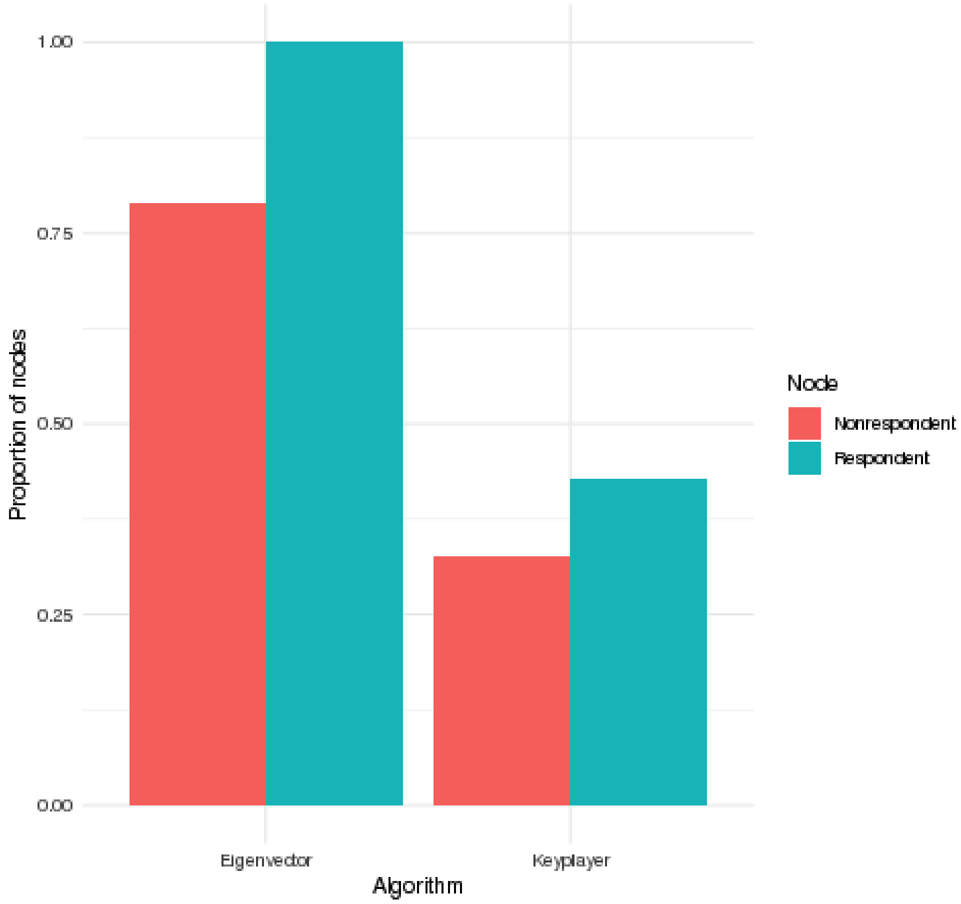


Table 3. Mean number of times that peer change agents were selected on the 100 imputed networks, conditional on their being selected at least once.

PCA[a] identification algorithm	Number of times a node was identified as a PCA, mean (SD)	Number of times a respondent appeared as a PCA, mean (SD)	Number of times a nonrespondent appeared as a PCA, mean (SD)
Eigenvector centrality	76.9 (36.8)	99.3 (5.6)	72.1 (38.9)
Keyplayer	33.9 (8.3)	34.9 (11.7)	33.4 (5.9)

[a]PCA: peer change agent.

Figure 6. Proportion of nodes selected as sPCAs (peer change agents who met the sufficiency condition for each of the two peer change agent identification algorithms) on the imputed networks who were also selected as peer change agents on the observed network.



Comparison of Peer Change Agents Identified on the Observed and Imputed Networks

We found that all 69 respondents (100%) selected by eigenvector as sPCAs on the imputed networks were also selected as PCAs on the observed networks (Figure 6). Eigenvector selected 232 nonrespondent sPCAs on the imputed network, of whom 78.9% (183/232) appeared as PCAs on the observed network. Keyplayer selected 110 respondent sPCAs on the imputed networks, of whom 42.7% (47/110) appeared as PCAs on the observed network. Among nonrespondents, keyplayer selected 202 nonrespondents as sPCAs on the imputed networks, of whom 32.6% (66/202) appeared as PCAs on the observed network. We thus observe that eigenvector is much less sensitive to the imputation, as per our definition above, than keyplayer. Keyplayer's higher sensitivity to the imputation might be because it is a set-based algorithm, and it attempts to select nodes that collectively span the breadth of the network, making the identification of a given node dependent not just on its local social environment but on the entirety of the network.

Although which of the 2 PCA-identification algorithms provides the true set of individuals in PCA positions (which is unknown) is not known, the contrasts between them among the various measures considered—stability, sensitivity, and effect of the boundary specification—stand out.

Discussion

Principal Findings

This paper presented a novel approach to select candidate PCAs on partially observed Facebook networks of YBMSM in Chicago, with the goal of developing a pipeline in the future that allows data from social networking sites to be used for peer health interventions. We discussed several challenges in operationalizing such an intervention, including methods to address the large amount of unobserved network data, and 2 PCA identification algorithms that are consistent with our goal of diffusing prevention information through individuals situated at critical positions in the network. We found that eigenvector centrality was far less sensitive to the imputation than keyplayer, consistent with a previous result [71]. We also found that relative to keyplayer, eigenvector had a relatively core set of stable PCAs across the imputed networks. Eigenvector centrality was also less affected by the relational boundary for nonrespondent inclusion, which was necessary given the large number of nonrespondents that were sampled. These findings lead us to conclude that eigenvector centrality might be better suited for identifying PCAs in our study. It is worth noting that we cannot know which algorithm produces the correct set of PCAs, but such a systematic evaluation of the properties of each algorithm, given that our data that were MNAR, can guide our intervention planning.

There are several underlying considerations behind this conclusion that merit discussion. Although peer-based interventions have shown promise in public health [72-75], their efficacy for HIV prevention has been limited in vulnerable populations [22,23]. The use of digital technologies to compile social network data and the application of formal social network analysis to identify PCAs may improve the efficacy of interventions [23,40]. Despite increased use of newer social network sites among younger people, Facebook use remains high in the general population [21], including YBMSM in Chicago. Recently collected data in a follow-up study have shown that although almost 100% of recruited YBMSM in Chicago used Facebook, fewer than 40% used Instagram and Snapchat and approximately 20% had profiles on Twitter, Jack'd, or Grindr. Thus, Facebook data enabled us to broadly characterize the social networks of YBMSM to identify their potential influencers. We, however, faced many unanticipated challenges in using Facebook data for identifying PCAs, and researchers using Facebook or alternate social media platforms may experience some of the same challenges we did. A schema to handle the limitations encountered here may benefit peer-based health research; our case study is a step forward in the development of such a schema.

Limitations

One important limitation of the study is that no explicit homophily parameters were included in the imputation model. Recall that unobserved nonrespondent-nonrespondent friendships have to be imputed from the observed respondent-nonrespondent friendships. Many of the key individual attributes, including age, sex at birth, residence, and race (or ethnicity), either defined or were closely related to the inclusion criteria for respondents. As is described in the Results, nonrespondents who met the boundary specification were of comparable age to the respondents, almost all identified as male on their Facebook profiles, and a majority identified Chicago as their place of residence. Given the extent to which age, gender, and residence overlapped between the respondents and nonrespondents, it was not possible to meaningfully measure homophily with respect to these attributes. In addition, it was not possible to measure homophily on race/ethnicity as this attribute was not available for most nonrespondents. The imputation model also did not include any parameters that measured higher order network structure. Ideally, an ERGM fit to Facebook data would include higher order effects such as triad closure, as Facebook algorithms encourage individuals with common friends to become friends with each other. Our extensive efforts to incorporate terms for triad closure used existing parameters that were developed on sparser networks (eg, shared partner statistics), and they were not successful. (Information on the triad closure models we explored is provided in Multimedia Appendix 1.) More theoretical work may be needed to identify parameters that can model higher order effects in large networks with missing data. Our efforts, however, did reveal interesting new findings about the potential limits of using existing methods to model triad closure in large networks.

Future Research Directions

Future research directions include modeling analyses to identify PCAs in a follow-up wave and assessing the extent to which PCA sets overlap between the 2 waves. This is important because training PCAs requires considerable upfront investment, and it has been observed in some networks that critically positioned individuals turn over within a year [76]. Therefore, identifying PCAs that persist over time might be more cost-effective, if they can be reliably found. In addition, many online environments besides Facebook are now used for social networking. As peer-based health interventions expand in scope, it may be valuable to consider alternative social media platforms as they may prove to be more effective with specific populations. Not all communication, however, occurs through such online media. Identification of friends and relational kin from offline data remains an important avenue for research. More theoretical work that explicitly accounts for online and *natural* social environments may improve our understanding of how to identify PCAs more accurately. Follow-up studies that address these considerations are in progress. Finally, Bayesian ERGMs to impute network unobserved data have been proposed [77] and might provide an alternate method to reconstruct the unobserved networks. (Details on related methodological approaches to impute missing network data, and why we selected the approach used here, are provided in Multimedia Appendix 1).

Conclusions

This study is an interdisciplinary examination of a recruitment strategy of individuals located at critical positions in a large social network. Our overarching goal was to find a set of PCAs who maximize the possibility of success of our intervention while understanding the constraints that our data imposed. As Facebook and other online social media are increasingly used in creative ways to influence health behavior, our case study will help researchers anticipate some of the underlying difficulties as they plan their studies. If the challenges we described are unavoidable, our experiences could provide useful heuristics to maximize the potential for peer-based health interventions to succeed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Detailed study background.

[PDF File (Adobe PDF File), 519KB - jmir_v20i9e11652_app1.pdf]

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Abbreviations

ERGM: Exponential Random Graph Model
MAR: missing at random
MCAR: missing completely at random
MCMC: Markov Chain Monte Carlo
MNAR: missing not at random
PCA: peer change agent
PrEP: pre-exposure prophylaxis
RDS: respondent-driven sampling
sPCA: peer change agents who met the sufficiency condition for each of the two peer change agent identification algorithms
YBMSM: young black men who have sex with men

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Original Paper

Internet-Based and Mobile-Based General Practice: Cross-Sectional Survey

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Abstract

Background: Globally, mHealth is increasing as a promising technology for promoting the quality of health care. Thus, a growing number of internet hospitals have been established in China to avail all its advantages. However, no study has investigated the service scope and patient satisfaction of the internet hospital to date.

Objective: The objective of our study was to explore the features of outpatients in general practice, the disease information, and the satisfaction through an internet rating site.

Methods: We collected data from the internet hospital of the First Affiliated Hospital, Zhejiang University between February 2016 and February 2017. Patients visited Web-based clinic via a computer or smartphone. The data included patients' demographic characteristics, disease information, and patients' comments.

Results: We enrolled 715 patients with 365 health-related problems. All health conditions involved diseases ranging from internal medicine, surgery, gynecology and obstetrics, pediatrics, dermatology, ophthalmology, stomatology to emergency. Among them, 63.1% patients (451/715) visited traditional hospitals for further management, 25.3% (181/715) had prescriptions, laboratory, or imaging examination appointment, 1% (9/715) used emergency service, and 10% (74/715) needed routine follow-up. All patients received health education. Almost all patients gave positive feedback and 4-5-star rating.

Conclusions: The internet hospital is suitable for all health conditions with high satisfaction only when patients have the access to internet via a computer or smartphone.

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KEYWORDS

general practice; mHealth; mobile phone; satisfaction; health service; internet hospital

Introduction

According to the World Health Organization, the global shortfall in health care workers will reach 12.9 million by 2035 and there exists a critical shortfall in most developing countries [1], increasing the burden on these countries' health systems. The condition in China is more serious with the shortage of, at least, 161,000 general practitioners, 200,000 pediatricians, and 40,000 psychiatrists [2]. In addition, the national sixth census has reported that approximately 1.3 billion people live in China. All of these make it difficult for Chinese patients to see a doctor. Furthermore, because patients in China are free to choose a medical institution and a doctor, the majority of patients like to go to big-city, top-flight hospitals even for mild conditions, exacerbating the overload of health care workers [3,4]. With the rapid growth of the internet and the increasing use of the internet and mobile devices, global internet medical services have emerged.

The internet hospital is a new approach to provide health services, outpatient service in particular, through the internet technology [4,5]. Patients could use a smartphone app or Web to consult with qualified doctors at home, office, or other places as long as they have access to the internet. Doctors take patients' history through a chatting platform designed for the internet hospital, and patients describe their condition and upload the relevant information, such as images and laboratory results, to the doctor through the smartphone app or Web. To date, studies have reported the characteristics of China's internet hospitals, the health service capacity, and negative comments [5,6]; however, the spectrum and the satisfaction have not been involved. In recent years, patient rating sites have gained more attention for their function to measure the health care quality [7-9]. Moreover, its value for other patients looking for health care providers has been widely identified in the United States, Germany, and the United Kingdom [10]; however, research on patient rating sites in China remains sparse.

This study aims to identify who is suitable for the Web-based consultation via collection of outpatient characteristics and satisfaction of the internet hospital and clarify what kind of health services could be provided.

Methods

Internet Hospital of the First Affiliated Hospital, Zhejiang University

The internet hospital of the First Affiliated Hospital, Zhejiang University was put into use on February 16, 2016. At the beginning, 12 departments provided Web-based health services; of these, the general practice department bears nearly 30% Web-based workload. Figure 1 present the work flowchart [11]. The internet hospital provides outpatients with health services in the following 6 aspects: Web-based clinic; laboratory and imaging examination appointment; prescription; routine follow-up; various payments; and referral services. Based on Xie et al [5], the consulting methods included video chat, voice chat, telephone, image, and message. The details of the consultation are provided in a study conducted by Tu et al [4].

Regarding the laboratory and imaging examination appointment, patients could finish the laboratory and imaging examination in 1 day and earlier than the examination booked offline. The prescription is checked by the pharmacist with electronic signature (CA) and then delivered to or fetched by patients from the hospital or pharmacy. Of course, examination and prescription were provided after the fee was paid using many payment methods including Web-based (eg, Alipay and Apple pay), medicare, self-help machine, and others.

Data Collection

Data were collected from the electronic record of the general practice department of the internet hospital between February 2016 and February 2017. Patients logged in the internet hospital with their computer or mobile phone. Overall, 715 consultations were provided.

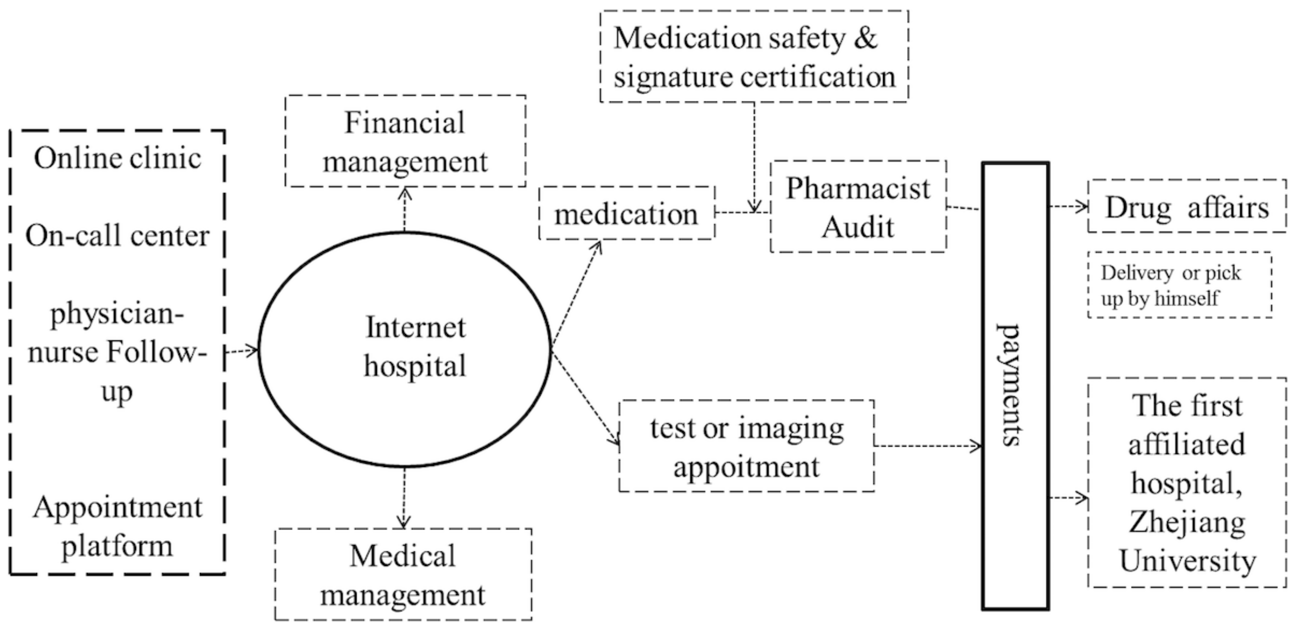
The collected data included patients' gender, age, region, consulting device, chief complaints, diagnose, management, and the satisfaction. The satisfaction was assessed through a specialized internet rating site, allowing patients to rate their experiences (1-5, 5 being the best) and freely express their comments with health care providers and the internet hospital. Furthermore, the satisfaction was extracted from all comments.

The disease diagnosis was encoded according to the International Classification of Diseases. The Institutional Review Board approval was obtained from the Research Ethics Committee of the First Affiliated Hospital College of Medicine, Zhejiang University (N2017-690).

Statistical Analysis

Statistical analysis was performed using SPSS 19.0 (SPSS Inc., IL, USA) and Excel 2010 (Microsoft Corp., Redmond, WA, USA). The enumeration data are expressed in percentage, and the measurement data are expressed as mean (SD).

Figure 1. The flowchart of Web-based health service.



Results

Patients' Characteristics

As shown in Table 1, 364 patients were men and 351 patients were women; the sex ratio was 1:0.96 with the age range from 3 months to 83 years and mean age, 36.81 (14.28) years. Most patients were from the Zhejiang Province with 29.9% (214/715) from Hangzhou city. Regarding the tools used, 42.9% (307/715) used the internet and 57.1% (408/715) used mobile phones.

Information of Diseases on the Internet Hospital

We assessed 365 health-related problems on the internet hospital involving almost all departments, of which diseases belonging to internal medicine accounted for more than a half (53.6%). Table 2 shows that the former 5 symptoms were diseases of the musculoskeletal 12.8% (91/715), digestive 11.4% (81/715), reproductive 9.3% (66/715), urinary 7.7% (55/715), and endocrine 7.2% (51/715) systems. Table 3 shows that the number of patients who needed a referral to an offline clinic was 451, who had the medication or test appointment was 181, who need emergency services was 9, and who need follow-up was 74. All the patients had received health education.

Satisfaction Analysis

In this study, 384 patients gave comments on the internet rating site, as seen in Multimedia Appendix 1; of these, 375 were satisfied with the Web-based clinic (satisfaction rate, 97.7%). Figure 2 shows that 89.9% (345/384) of participants rated 5-star. Regarding the contents (Table 4), the most common positive comments of the internet hospital and general practitioner were "quick and convenient, efficient, powerful function of the internet hospital, professional, full of enthusiasm, responsible, full of patience and meticulousness, gentle, friendly, and so on."

Of patients who were unsatisfied with Web-based service, the comments were waiting too long, unable to solve the concerns, misuse of medical terminology, and impatient.

Table 1. Patients' characteristics (N=715).

Baseline variables	Patients, n (%)
Hangzhou	214 (29.9)
Sex	
Male	364 (50.9)
Female	351 (49.1)
Age	
<18 y	17 (2.4)
18-59 y	648 (90.6)
60-69 y	27 (3.8)
≥70 y	23 (3.2)
Tools used	
Internet user	307 (42.9)
Mobile phone user	408 (57.1)

Table 2. Symptoms classification in different system pattern (N=715).

System	Patients, n (%)
Musculoskeletal	91 (12.8)
Digestive	81 (11.4)
Reproductive	66 (9.3)
Urinary	55 (7.7)
Endocrine	51 (7.2)

Table 3. The percentage of different general practitioners' management (N=715).

Management	Patients, n (%)
Emergence	9 (1.3)
Referral	451 (63.3)
Further follow-up	74 (10.4)
Medication or test appointment	181 (25.4)

Figure 2. Patients' star rating (1 to 5 stars: worst to best).

Table 4. Patient's assessment according to the contents (n=384).

Contents	Patients, n (%)
Doctor	
Of good attitude, full of patience and meticulousness, gentle and friendly	40 (10.4)
Of good responsibility	5 (1.3)
Professional	7 (1.8)
Competent	24 (6.3)
Good answers	4 (1.0)
Internet hospital	
Powerful	8 (2.1)
Quick and convenient	51 (13.3)
Brief comments	
Satisfaction	32 (8.3)
Ok, good, very good, and thanks	141 (36.7)
Bad	6 (1.6)
No comments	66 (17.2)

Discussion

Principal Findings

This study focused on the consultation spectrum and the satisfaction of the internet hospital and analyzed the data from the general practice department. Patients with all health-related conditions could seek health services in the internet hospital, and the satisfaction was high.

In this study, we observed that the majority of outpatients were male and adults. Among patients who are children and older adults, most sought the Web-based health services with the help of families because they could not operate a smartphone or computer. Hence, with regard to these patients, most tended to choose traditional hospitals, resulting in the small number of Web-based patients in the study. In addition, other reasons were as follows. First, not many know about the existence of the internet hospital of the First Affiliated Hospital, Zhejiang

University, which we believe could be changed through propaganda and promotional activities, for instance, we provided free consultations over one year. Second, no explicit protocol exists as to what symptoms could be solved online. Thus, some people might be confused and hesitate to see the Web-based doctor. In this study, we found that all health-related problems could be consulted online initially, which is consistent with the role of general practitioners. Because general practice is the primary point of access to health care services, general practitioners play a role in diagnosing and treating illness within the community, promoting better health, preventing disease, certifying disease, monitoring chronic disease, and referring patients requiring specialist services [12].

In recent years, the remarkable proliferation of mobile technology has facilitated health systems through interventions that increase both the coverage and quality. In addition, the mHealth awareness among the general population is growing. Among 715 Web-based consultations, >50% patients used mobile phones to access the health service; this finding is similar to that obtained by Reem et al [13]. Because most patients were not from Hangzhou city, the internet hospital is beneficial and available to patients who own a mobile or computer despite not being residents of neighboring areas. Certainly, this is attributed to the advantages of mHealth, easy and flexible to access without local or temporal boundaries.

In addition, we found higher satisfaction with Web-based consultation, which could be attributed to 2 possible reasons. First, people in China tend to trust "big hospitals," because they tend to go to high-level hospitals even for mild symptoms [3,4]. In addition, all Web-based doctors are highly qualified physicians in the First Affiliated Hospital, Zhejiang University, one of the best tertiary hospitals in Zhejiang Province; they have >3-year experience without complaint records. Second, the internet hospital here could provide a prescription with delivery service and appointment services earlier than the traditional ones. It is unlike other cloud hospitals in which physicians could just provide a recommendation because they may come from a hospital in this city and the patient residing in another city. Therefore, it is inconvenient to provide earlier laboratory or imaging service. This study, indeed, clarified the point. Nevertheless, most individuals favor the internet hospital, implying that mHealth might play a great role in the field of medicine in the future; these results were similar to those obtained by Reem et al [13]. Third, because the number of Web-based outpatients was smaller than the offline, physicians had more time for each outpatient, making patients feel better than the crowded traditional clinics.

Limitations

Although internet- and mobile-based hospitals could alleviate the dilemma of difficulty to see a doctor in the developing countries and cater for most residents, limitations persist. First, there are problems with the establishment of the internet hospital. To date, no legal support exists for the establishment of the internet hospital and practice of physicians. In addition, there are no incision and quality-control standards and no safety protection system. All of these should be solved along with the efforts of the government. Luckily, the National Health and Family Planning Commission of the People's Republic of China have realized the problem and started planning the regulations. Second, because the rating site had no mandatory requirements for the comment and comment list, no data exist as to whether they would like to revisit the Web-based clinic. Hence, the data could be obtained through further analysis for consultation times per person.

Conclusions

When individuals have access to the internet with a computer or smartphone, internet- and mobile-based Web-based practice is feasible and convenient for almost all health-related conditions. Although the satisfaction was high, the internet rating site should be put to better use to improve Web-based health services.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

An example of positive comments from the rating site (access from online hospital of the first affiliated hospital, Zhejiang University).

[PNG File, 444KB - jmir_v20i9e266_app1.png]

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Original Paper

Visual Cancer Communication on Social Media: An Examination of Content and Effects of #Melanomasucks

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Abstract

Background: Instagram is increasingly becoming a platform on which visual communication of cancer takes place, but few studies have investigated the content and effects. In particular, a paucity of research has evaluated the effects of visual communication of cancer on participative engagement outcomes.

Objective: The objective of our study was to investigate cancer-related beliefs and emotions shared on Instagram and to examine their effects on participative engagement outcomes including likes, comments, and social support.

Methods: This study analyzed the content of 441 posts of #melanomasucks on Instagram and assessed the effects of the content characteristics on outcomes, including the number of likes and comments and types of social support using group least absolute shrinkage and selection operator logistic regression.

Results: Posts about controlling melanoma were most frequent (271/441, 61.5%), followed by 240 (54.4%) posts about outcomes of having melanoma. Ninety posts (20.4%) were about the causes of melanoma. A greater number of posts expressed positive (159/441, 36.1%) than negative emotions (100/441, 22.7%). Eighty posts (18.1%) expressed hope, making it the most frequently expressed emotion; 49 posts expressed fear (11.1%), 46 were humorous (10.4%), and 46 showed sadness (10.4%). Posts about self behavior as a cause of melanoma decreased likes ($P<.001$) and social support comments ($P=.048$). Posts about physical consequences of melanoma decreased likes ($P=.02$) but increased comments ($P<.001$) and emotional social support ($P<.001$); posts about melanoma treatment experience increased comments ($P=.03$) and emotional social support ($P<.001$). None of the expressions of positive emotions increased likes, comments, or social support. Expression of anger increased the number of likes ($P<.001$) but those about fear ($P<.001$) and joy ($P=.006$) decreased the number of likes. Posts about fear ($P=.003$) and sadness ($P=.003$) increased emotional social support. Posts showing images of melanoma or its treatment on the face or body parts made up 21.8% (96/441) of total posts. Inclusion of images increased the number of comments ($P=.001$).

Conclusions: To our knowledge, this is the first investigation of the content and effects of user-generated visual cancer communication on social media. The findings show where the self-expressive and social engagement functions of #melanomasucks converge and diverge, providing implications for extending research on the commonsense model of illness and for developing conceptual frameworks explaining participative engagement on social media.

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KEYWORDS

cancer; comments; common sense model; emotions; illness perception; Instagram; likes; melanoma; participative engagement; social media; social sharing; social support; visual communication

Introduction

Background

Instagram is rapidly becoming a public platform where images, beliefs, and emotions about cancer are expressed and shared. At the time of this writing, there are millions of Instagram posts about various cancer experiences. One of the fastest growing platforms of social media, following only Facebook [1], Instagram is unique in that visual images occupy a significant portion of a post's space. Instagram is also more public compared with Facebook. Whereas on Facebook sharing is based on friendships, on Instagram it is not. Visual images such as those posed on Instagram have the potential to significantly impact cancer communication processes through increased exposure, attention, emotional engagement, and memorability [2,3]. Self-expressions of cancer experiences on Instagram can be viewed worldwide, fostering far reaching impacts on social perceptions and discourse about cancer. In particular, these efforts are assisted by hashtags (#) for message labeling, movement organizing, and visibility, searchability, and documentability of grassroots content [4].

Despite this popularity, visual communication of cancer on social media remains underinvestigated. Extant research on social media content related to cancer has focused on text-based content, such as that on Twitter [5,6]. Only a limited number of studies have investigated visual cancer communication on social media [7,8], and few have examined the effects of visual cancer communication on social media. Notably, a 2018 study investigated the effects of vaccine images on retweets [9]. Aiming to fill this void in knowledge, this study investigated the illness beliefs and emotions expressed under #melanomasucks on Instagram and their effects on participative engagement outcomes, including likes, comments, and social support.

Commonsense Representations of Illness Beliefs and Emotions

Melanoma is the fifth most prevalent cause of cancer death affecting both men and women in the United States [10]. Researchers view that the increase in melanoma incidence may be associated with a range of factors, including behavioral and environmental factors [11,12]. Melanoma is particularly relevant to this investigation of visual cancer communication because it begins on the surface of body, whereas most other cancers involve internal organs. Consequently, visual expressions of illness experiences may be more pertinent to melanoma than other forms of cancer.

Based on the premise that beliefs and emotions about cancer underpin the visual images posted on Instagram, this study used the commonsense model of illness representation [13-15] as an overarching framework to analyze the content of visual cancer communication on Instagram. The commonsense model of illness representation assumes that people are active problem solvers testing lay hypotheses about illness. According to the model, people respond to symptoms and signs of illness by forming cognitive and emotional representations of the illness, which then guide the lay process of coping, planning, and action. Of note, the model posits that illness representations are individualized and not necessarily fact-based; nevertheless, individuals' illness representations are key determinants of attitude toward risk and managing disease. Primary beliefs about illnesses, including cancer, comprise beliefs about causes, consequences, and control of the illness [13-15].

Along with beliefs, emotions are an important part of illness experiences [15-17]. Martin and colleagues [15] argue that in addition to cognitive responses to and representations of symptoms, people rely on emotional responses to symptoms that direct their coping behavior. Similarly, Gross [16] asserts that emotion expressions are central to cancer experiences ranging from onset to progression. As a result, recent research involving the commonsense model has examined both cognitive and emotional representations as predictors of coping appraisal and illness outcomes [18].

Under this overarching framework, this study used the cognitive appraisal theory of emotions [19,20] to analyze discrete emotional representations in Instagram posts. The cognitive appraisal theory of emotions argues that emotions are outcomes of appraisals of environmental and situational circumstances. Of these circumstances, the experience of cancer can be associated with the negative emotions of fear [21], anger [22], and sadness [23]. Recent cancer survivorship research has discussed the importance of positive emotions such as hope, humor, and happiness. Hope can be an especially important positive emotion in the survivorship process [24]. Snyder and colleagues [25] defined hope as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathways (planning to meet goals)" (pg 287). Humor can provide respite for cancer survivors and their loved ones [26]. Finally, the journey of cancer may not be without moments of happiness or joy [27]. We will examine the expressions of these positive and negative emotions.

By investigating Instagram posts about cancer beliefs and emotions, we seek to add new insight to extant research on the commonsense model of illness. Prior research on illness perceptions has used responses prompted by survey or interview questions [28]. On Instagram, people choose to self-express their cancer experiences using images, texts, and other affordances including hashtags. Moving from verbal responses to surveys or interviews, the visual and voluntary expressions of cancer experiences on social media may offer a valuable window for understanding lay sense-making and management of cancer. Self-expression in all settings may be goal directed [29,30], but social media may offer novel opportunities to express what Rogers [31] called "true self." Rogers' notion of true self differs from future self or actual self. True self is a present version of self, thus differing from future self, and it is not expressed in social life, thus differing from actual self. Bargh and colleagues [30] asserted that one has the strongest need to express the true self, which is "identity-important and phenomenally real aspects of self," and that the internet may provide a setting to activate and express it (pg 34).

In addition, we will investigate the visual images particular to the communication of melanoma. These would include images of melanoma or its treatment. Patients' visual documentation of melanoma or its treatment may hold special meaning to them. Furthermore, these images may increase other users' engagement in cancer communication on social media in forms such as comments. Our first set of research questions concerned self-expressed beliefs and emotions about melanoma on Instagram:

> RQ1: What beliefs are expressed in #melanomasucks posts on Instagram?
>
> RQ2: What emotions are expressed in #melanomasucks posts on Instagram?
>
> RQ3: Are images of melanoma or its treatment included in #melanomasucks posts on Instagram?

Participative Social Engagement in Self-Expressions of Illness Experience

Self-expression of illness beliefs and emotions on social media invites participative social engagement. It is important to investigate the dynamics between Instagram posts about cancer and the extent and types of network engagement that they generate. This line of research can help shift gears from the current emphasis on the content of social media communication to an expanded research focus that can illuminate the relationship between content characteristics and the participative engagement that they generate.

To investigate the effects of visual expressions of cancer, we focused on participative engagement, as indicated by the number of likes and comments and the types of social support provided in the comments. As an affective reaction, likes may be the most basic form of participative engagement in social media interactions [32]. Comments, which are more cognitively oriented, may indicate a deeper level of engagement because they require more user effort than clicking a like button. Generally, the number of likes and comments are considered indicators of the range of influence of one's social media post [33]. There is sparse published research investigating the content characteristics predicting likes. Burgeoning research has examined the predictors of comments, focusing on the number of comments from readers of Web-based news [33,34]. In this study, we focus on likes and comments responding to user-generated content containing #melanomasucks.

In addition to likes and comments, the provision of social support may be another form of participative engagement on Instagram. Individuals with chronic illnesses increasingly use social media to connect with others and to seek and provide support [35,36]. Although a growing body of research has examined online social support, a recent review indicates that it has focused on verbal and written exchanges [36]. Research is needed to investigate social support exchanges using affordances on social media platforms. Different Web-based platforms can facilitate or inhibit the seeking and provision of types of support [37]. Users of #melanomasucks on Instagram may constitute what Granovetter [38] termed "weak ties," individuals with whom close interactions are limited. Weak ties are vital to the cohesion and organizing of communities [38].

Extant literature suggests there are four primary types of social support. They are as follows: esteem, emotional, informational, and instrumental [39,40]. Esteem support refers to the validation of the support receiver's states and beliefs. Emotional support refers to empathy or encouragement for the receiver's situation. Informational support refers to advices using facts, data, and references. Instrumental support is provided with tangible assistance. Although growing attention has been paid to Web-based communication of support, little research has examined the connection between the beliefs and emotions expressed by support seekers and the types of support provided. Similarly, sparse research has investigated the relationship between beliefs and emotions and the volume of social engagement they generate, as indicated by the number of likes and comments. We posit that beliefs and emotions represented in Instagram posts will differentially predict likes, comments, and social support, and propose our second set of research questions to explore the effects of content characteristics on these differential types of participative social engagement:

> RQ4: What beliefs and emotions predict the number of likes?
>
> RQ5: What beliefs and emotions predict the number of comments?
>
> RQ6: Do images of melanoma or its treatment increase the number of comments?
>
> RQ7: What beliefs and emotions predict the type of social support?

Methods

Sampling

The universe from which we draw the sample for this study was #melanomasucks. As discussed above, people use hashtags to label their posts and to ensure the visibility, searchability, and documentability of their posts [4]. We randomly selected 441 publicly available Instagram posts containing #melanomasucks for analysis in this study. At the time of this sampling, there were over 3430 posts using #melanomasucks on Instagram. For random sampling of the posts we used Netlytic [41], which adheres to the privacy policy of Instagram and uses public application program interfaces (APIs) to collect publicly available Instagram posts.

Consistent with the sampling protocol for social media content analyses offered by Kim, Huang, and Emery [42], we assessed the quality of the sample. Quality of social media sampling is assessed with recall and precision [42]. Our use of a hashtag as a sampling frame arrests the issue of recall, which is the degree to which relevant data are retrieved. Precision is the degree to which the retrieved data are relevant. We found that #melanomasucks yielded 95% precision in our sample. The rest of the content analysis procedure was guided by the protocol provided by Neuendorf [43]. Our unit of analysis was each post.

Measurement

Two coders were extensively trained and they worked together to establish intercoder reliability. We used 10% of the sample to assess the intercoder reliability of each variable. Krippendorff alpha [44] ranged from 0.79 to 1.00. The outcome measures of the number of likes and comments were obtained through API of Instagram. For social support, we assessed the presence or absence of each of the following types of social support: esteem, emotional, information, and instrumental. Consistent with Cutrona and Suhr's Social Support Behavior Codes [40], these support types were operationalized in the following ways: esteem support compliments, validates, or agrees with the receiver's perspective expressed in a post; emotional support conveys sympathy, empathy, or encouragement for the receiver's state; informational support offers facts, data, or references to solve a problem; and instrumental support offers tangible help such as provision of time or donation.

For cancer beliefs, we assessed the presence (1) and absence (0) of beliefs about causes, consequences, and control of melanoma. Under causes, we analyzed the presence or absence of beliefs related to hereditary factors, self behavior, system or institution, natural environment, social environment, built environment, or chance. Under outcomes, we examined the presence or absence of expressions of negative physical, cognitive, emotional, and relational consequences of having melanoma; we also coded for the presence or absence of expressions of positive aspects of having melanoma. Under control, we investigated beliefs related to self and collective actions pertaining to the prevention and control of melanoma. Individuals' actions included primary prevention (eg, sunscreen), secondary prevention (screening), and treatment; societal actions included raising awareness, fundraising, more research, greater funding allocation, and policy change.

For cancer emotions, we assessed the presence or absence of three negative emotions of fear, anger, and sadness and three positive emotions of hope, joy, and humor. Fear was a depiction of danger or threat; anger was a depiction of wrongful offense; and sadness was a representation of irrevocable loss. Hope was operationalized as a positive emotional state involving goals or planning to meet goals (eg, to get better, to beat cancer, to find a new treatment); humor was a depiction of an effort make fun of or ease a difficult situation; and joy was a variant of happiness that indicated progress toward a goal.

Results

Data Analysis Strategy

For research questions 1 and 2, which concerned the characteristics of the content, we computed the frequency and percent distribution of the variables. For research questions 3 and 4, which concerned melanoma beliefs and emotions influencing the number of likes and comments, we used negative binomial regressions. In each model, the number of likes or comments was regressed onto cancer beliefs and emotions. The log number of followers were adjusted as an offset in the regression model. To examine research question 5, predictors of the types of social support, we used a multivariate logistic regression model for each support type. We did not employ multinomial regression to reflect that the social support types were not mutually exclusive. Instead, we used separate binary logistic regression models for each of the four types of social support. In addition to these separate logistic regression models, we used a joint model using group least absolute shrinkage and selection operator (LASSO) logistic regression. To select variables that predict all types of social support, we penalized the total log-likelihood of four logistic regressions for all of the types of support by a group LASSO penalty that encourages the coefficients of a predictor to be zero for all types of support. This helped us select the same set of predictors for all types of support. To determine the penalty-tuning parameter, we selected the group LASSO models with the smallest Bayes information criterion. The number of followers was adjusted in both the separate and group LASSO models.

Content Characteristics

Research question 1 asked what cancer illness beliefs are expressed in #melanomasucks. Beliefs about controlling melanoma were most frequently expressed (271/441, 61.5%), followed by beliefs about outcomes of melanoma (240/441, 54.4%), which in turn were followed by beliefs about the causes of melanoma (90/441, 20.4%). Table 1 presents the distribution of belief expressions.

Of beliefs about controlling melanoma, awareness raising was most frequently expressed (219/271, 80.8%), followed by treatment (143/271, 52.8%), primary prevention (eg, sunscreen use; 114/271, 42.1%), secondary prevention (eg, screening; 80/271, 29.5%), and fundraising (43/271, 15.9%). Of beliefs about outcomes of cancer, physical consequences were the most frequently expressed (212/240, 88.3%), followed by emotional outcomes (100/240, 41.7%), relational outcomes (56/240, 23.3%), and equal representations of financial consequences (20/240, 8.3%) and positive outcomes (20/240, 8.3%; eg, strengthening of faith during a time of hardship). Of beliefs about causes of melanoma, self behavior was the most frequently expressed (72/90, 80.0%), followed by natural environment (eg, sun exposure, 47/90; 52.2%). A social environment that supports tanning behavior was expressed in 7.8% (7/90) of the posts.

Research question 2 asked what emotions are expressed using #melanomasucks. Hope was the most frequently expressed emotion, such as by providing insight about or expressing trust in a treatment procedure (80/441, 18.1%), followed by fear, such as worry about the recurrence of melanoma (49/441, 11.1%). These were followed by equal representations of humor, such as making light of treatment results, (46/441, 10.4%); sadness, such as remembrance of people who have died from melanoma (46/441, 10.4%); and joy, such as patients expressing enthusiasm and gratitude during treatment (33/441, 7.5%). Anger was a rarely expressed emotion (5/441, 1.1%). Overall, there was a greater number of positive than negative emotional expressions 36.1% (159/441) vs 22.7% (100/441). Table 2 presents the distribution of emotions.

Research question 3 asked whether images of melanoma or its treatment are included in #melanomasucks posts. In total, 21.8% (96/441) of the posts included images of melanoma or its treatment on the face or body parts. Posts showing images of melanoma on the face or body parts were about 4.3% (19/441) of the total posts. Post showing images of melanoma treatment on the face or body parts were about 17.5% of the total posts (77/441).

Table 1. Cancer beliefs expressed using #melanomasucks on Instagram (N=441).

Belief	n (%)
Cause	90 (20.4)
Hereditary	0 (0)
Self behavior	72 (80.0)
System or institution	1 (1.1)
Natural environment	47 (52.2)
Social environment	7 (7.8)
Built environment	0 (0)
Luck	2 (2.2)
Outcome	240 (54.4)
Physical	212 (88.3)
Cognitive	0 (0)
Emotional	100 (41.7)
Relationship	56 (23.3)
Financial	20 (8.3)
Other negative	1 (0.4)
Positive outcomes	20 (8.3)
Control	271 (61.5)
Prevention	114 (42.1)
Screening	80 (29.5)
Treatment	143 (52.8)
Awareness	219 (80.8)
Fundraising	43 (15.9)
Research	6 (2.2)
Funding allocation	1 (0.4)
Guideline change	1 (0.4)

Table 2. Cancer emotions expressed using #melanomasucks on Instagram (N=441).

Emotions	n (%)
Positive emotions	
Hope	80 (18.1)
Humor	46 (10.4)
Joy	33 (7.5)
Negative emotions	
Anger	5 (1.1)
Fear	49 (11.1)
Sadness	46 (10.4)

Table 3. Effects of belief expressions on the number of likes.

Belief	Estimate (SE)
Cause	
Hereditary	N/A[a]
Self behavior	−0.67[b] (0.16)
System or institution	−2.56 (1.45)
Natural environment	0.19 (0.18)
Social environment	−0.12 (0.43)
Built environment	N/A
Luck	−1.44 (0.75)
Other	−0.44 (1.08)
Outcome	
Physical	−0.24[c] (0.1)
Cognitive	N/A
Emotional	0.12 (0.15)
Relationship	−0.31 (0.18)
Financial	−1.86[b] (0.27)
Other negative	−2.53[c] (1.04)
Positive outcomes	0.83[b] (0.24)
Control	
Prevention	−0.16 (0.12)
Screening	−0.08 (0.13)
Treatment	−0.26[c] (0.11)
Awareness	0.11 (0.10)
Fundraising	−0.48[d] (0.18)
Research	−0.42 (0.45)
Funding allocation	−2.89[d] (1.09)
Guideline change	−1.36 (1.06)
Other	−0.65 (0.62)

[a]N/A: not applicable.
[b]*P*<.001.
[c]*P*<.05.
[d]*P*<.01.

Effects of Content Characteristics

Predictors of Likes

Research question 4 asked what beliefs and emotions expressed in #melanomasucks impacted the number of likes. The effects of beliefs on likes are presented in Table 3. Expressions of self behavior as a cause of melanoma were negatively associated with the number of likes (*P*<.001). Expressions about physical (*P*=.03), financial (*P*<.001), and other negative consequences (*P*=.02) significantly decreased the number of likes. In contrast, expressions of positive outcomes of having melanoma significantly increased the number of likes (*P*<.001). Of control beliefs, posts about treatment (*P*=.02), fundraising (*P*=.008), and more research funding allocation (*P*=.008) decreased the number of likes. The effects of emotions on likes are presented in Table 4. Expressions of anger increased the number of likes (*P*<.001), whereas expressions of joy (*P*=.006) and fear (*P*<.001) decreased the number of likes.

Table 4. Effects of emotion expressions on the number of likes.

Emotions	Estimate (SE)
Positive emotions	
Hope	0.19 (0.13)
Humor	0.10 (0.15)
Joy	−0.02[a] (0.01)
Negative emotions	
Anger	1.01[b] (0.26)
Fear	−0.96[b] (0.15)
Sadness	−0.17 (0.15)

[a]*P*<.01.

[b]*P*<.001.

Predictors of Comments

Research question 5 asked what beliefs and emotions expressed in #melanomasucks impacted the number of comments. As shown in Table 5, none of the cause beliefs were significantly associated with the number of comments. Of beliefs about outcomes, those about physical consequences of having melanoma significantly increased the number of comments (*P*<.001), whereas beliefs about financial consequences of melanoma decreased the number of comments (*P*<.001). Of control beliefs, those about treatment increased the number of comments (*P*=.03), whereas those about fundraising (*P*=.02) decreased the number of comments. None of the expressions of emotions were associated with the number of comments. Research question 6 asked whether images of melanoma or its treatment increased the number of comments. A significant positive association between such images and the number of comments was found (estimate=0.59, SE=0.18, *P*=.001). Inclusion of melanoma images in posts increased the number of comments.

Predictors of Social Support

Research question 7 asked what beliefs and emotions predicted what type of social support. To address this question, we first investigated whether beliefs and emotions predicted the presence or absence of social support using the entire dataset. Next, using only the cases that received social support, we examined predictors of specific kinds of social support.

Provision of Support

Of cause beliefs, that self behavior is responsible for melanoma significantly decreased social support comments (estimate=−0.62, SE=0.31, *P*=.048). Of outcome beliefs, those about physical consequences of having melanoma significantly increased social support comments (estimate=0.74, SE=0.22, *P*=.001) and those about relational consequences showed a marginally significant positive effect on social support comments (estimate=−0.70, SE=0.37, *P*=.06). Of control beliefs, those about treatment increased social support comments (estimate=0.58, SE=0.23, *P*=.012). None of the emotions were significantly associated with social support comments.

Types of Support

None of the cause beliefs were significantly associated with the types of social support per LASSO. This was confirmed in separate regression models in which no significant association was found in any of the four models for the types of support. Of outcome beliefs, those about physical and emotional consequences were significant per LASSO and confirmed in separate regression models. Beliefs about physical consequences decreased esteem support (estimate=−0.86, SE=0.29, *P*=.003) but increased emotional support (estimate=1.36, SE=0.28, *P*<.001); similarly, emotional consequences decreased esteem support (estimate=−0.82, SE=0.39, *P*=.04) but increased emotional support (estimate=1.34, SE=0.49, *P*=.006). Of control beliefs, those about treatment and fundraising were significant predictors per LASSO, which were confirmed in separate regression models. Expressions about treatment decreased esteem support (estimate=−0.77, SE=0.28, *P*=.005) but increased emotional support (estimate=1.43, SE=0.30, *P*<.001); beliefs about fundraising increased esteem support (estimate=2.29, SE=1.04, *P*=.03) but showed a marginally significant negative association with emotional support (estimate=−0.98, SE=0.51, *P*=.054). Of emotions, fear and sadness were selected per LASSO. Fear decreased esteem support (estimate=−1.35, SE=0.41, *P*=.001) but increased emotional support (estimate=1.56, SE=0.52, *P*=.003); similarly, sadness decreased esteem support (estimate=−0.98, SE=0.39, *P*=.013) but increased emotional support (estimate=1.49, SE=0.51, *P*=.003). No significant associations between the predictors of beliefs and emotions and the informational and instrumental social support types were found.

Table 5. Effects of belief expressions on the number of comments.

Belief	Estimate (SE)
Cause	
Hereditary	N/A[a]
Self behavior	-0.25 (0.24)
System or institution	−34.4 (1.70e+07)
Natural environment	0.18 (0.27)
Social environment	0.63 (0.61)
Built environment	N/A
Luck	−0.034 (1.03)
Other	−1.04 (1.71)
Outcome	
Physical	0.58[b] (0.15)
Cognitive	N/A
Emotional	−0.33 (0.22)
Relationship	−0.29 (0.27)
Financial	−2.38[b] (0.41)
Other negative	−2.34 (1.67)
Positive outcomes	0.44 (0.35)
Control	
Prevention	−0.14 (0.17)
Screening	0.11 (0.19)
Treatment	0.33[c] (0.15)
Awareness	−0.28 (0.15)
Fundraising	−0.65[c] (0.27)
Research	−0.15 (0.69)
Funding allocation	−2.91 (1.7)
Guideline change	0.66 (1.38)
Other	−1.84 (1.14)

[a]N/A: not applicable.
[b]*P*<.001.
[c]*P*<.05.

Discussion

Principal Findings

Although ample research has described the content characteristics of text-based cancer communication on social media platforms such as Twitter, few studies have investigated visual communication of cancer and even fewer studies have examined the effects of visual cancer communication on participative engagement outcomes. This study sought to address this gap by investigating the content and effects of #melanomasucks on Instagram. The results of this study provide an important first look at visual communication on cancer on social media. The findings show the self-expressive and social engagement functions that Instagram serves for #melanomasucks users and the areas in which the self-expressive and social engagement functions of the social media platform converge and diverge for users.

The findings of this study may reveal a paradigm shift in cancer communication. Traditionally, magazine editors or television producers have decided what cancer images the public can see in the mainstream media [45]. In the new social media landscape, the lay public decides what to express and share about their cancer experiences. This study found that about 22% of total posts included images of melanoma or its treatment with about 4% showing images of melanoma and 18% showing images of melanoma treatment. These images are rarely found in extant cancer communication in mainstream media. Given that this study found that the inclusion of images increased comments, future research should continue to examine user-generated images of cancer on social media and their effects on public engagement and perceptions.

Cancer Belief Expressions and Participative Engagement

The results show the aspects of the cancer experience that are meaningful for users of #melanomasucks to express. Users were most interested in expressing the control of melanoma, followed by the outcomes of having melanoma. Causes of melanoma, notably, were least frequently expressed in posts. Of the control beliefs, awareness was the most frequently expressed, followed by treatment, primary and secondary prevention, and fundraising. Of the outcome beliefs, physical consequences were the most frequently expressed, followed by emotional, relational, and financial consequences of having melanoma. Notably, some users expressed positive aspects of cancer experiences (eg, strengthening of faith). Of the cause beliefs, self behavior was the most frequently expressed, followed by natural and social environments.

Convergence between self-expressed and socially engaged beliefs about melanoma was observed where frequent posts increased engagement from other users, for example, posts about melanoma treatment were frequent and they significantly increased comments and emotional social support. Likewise, expressions of the physical consequences of having melanoma were frequent and they increased comments and emotional social support. In addition, expressions of relational consequences of having melanoma were marginally linked to increased emotional social support.

Divergence between self-expressive and social engagement functions of #melanomasucks was observed where frequent posts did not foster engagement from other users; for example, whereas self behavior as a cause of melanoma comprised 80% of cause-related beliefs, expressions of this belief decreased the number of likes and social support comments. Similarly, none of the cause beliefs were significantly associated with the number of comments. In addition, posts about financial consequences of having melanoma decreased the number of likes and comments. Although posts about personal experiences (eg, treatment and physical consequences) engaged users with increased comments and emotional social support, posts that were less personal (eg, awareness, fundraising) decreased the number of comments.

Cancer Emotion Expressions and Participative Engagement

Intriguing patterns of results were obtained for the research questions concerning emotions. Regarding self-expression of emotions, users of #melanomasucks were more interested in expressing positive emotions (ie, hope, humor, and joy) than negative emotions (ie, anger, fear, and sadness) and of the six emotions, hope was the most frequently expressed. These findings point to the need for more research on the roles of positive emotions and positive emotional expressions in cancer management.

A notable contrast between positive and negative emotions emerged in relation to the self-expressive and social engagement functions. Positive emotions appear to serve more self-expressive functions than social engagement functions because they did not increase likes, comments, or social support. Although hope was the most frequently expressed emotion, it did not increase any of the indicators of engagement including likes, comments, or social support. Likewise, humor, which was apparently expressed in users' efforts to make light of difficult melanoma-related situations, was not associated with the number of likes or comments. Moreover, expressions of joy decreased the number of likes. Somewhat similarly, posts that described positive aspects of cancer experiences increased the number of likes but not comments or social support. In comparison, although negative emotions were less frequently expressed, they enjoyed more social engagement from other users than positive emotions; for example, anger, which was the least frequently expressed emotion, significantly increased the number of likes. Although fear decreased the number of likes, it received emotional social support; expressions of sadness were unassociated with likes but they increased emotional social support.

Implications for Theory and Research

The results provide important implications for theory and research on the commonsense model of illness and participative engagement on social media. Extant research on illness perceptions using the commonsense model has employed a validated and standardized protocol [28] though interviews or surveys. Illness perceptions gathered through visual self-expressions on Instagram offer new insight on lay sense-making of cancer experiences. The control and outcomes of cancer were more important for users of #melanomasucks to express compared with the causes of cancer. Although considerably less research has examined positive emotions associated with cancer management than negative emotions, the findings show that it was positive emotions that more #melanomasucks users wanted to express. Future cancer communication research should allocate greater attention to investigating the meaning and impact of positive emotions in cancer experience and management.

The convergence and divergence of the self-expression and social engagement functions of #melanomasucks found in this study may point to an important new direction for future research on participative engagement on social media. The pattern of convergence and divergence that emerged appears to depart from the normative expectations in face-to-face interactions; for example, posts about financial consequences of having melanoma decreased the number of likes and comments. Similarly, expressions of positive emotions received little social engagement. These results add to the growing body of research examining the differences between online and offline communication behavior [46].

Also noteworthy is the divergence between self-expressions of positive emotions and social support received. Arguing that emotions are socially interdependent by nature and elicit social sharing, Rime' [47] posited that negative emotions stimulate cognitive work, social interaction, and conversation, and that positive emotions can enhance subjective well-being when savored and shared. The findings of this study appear to resonate with the theorizing of Rime', contributing to the understanding of the social engagement functions of emotions and where and how the effects of negative and positive emotions may deviate. In addition, the findings showed that the predictors of likes and comments differed from those of social support. More research should examine the predictors of these differential forms of social engagement and the effects of this engagement on the recipients and providers.

Limitations and Suggestions for Future Research

As the first investigation of visual cancer communication on social media, this study was limited to one cancer, melanoma, and one hashtag, #melaonomasucks. Building on this study, future research should examine whether the patterns of content and effects identified in this study are similar for other cancers and other cancer hashtags, where the similarities and differences arise in the expression of causes, outcomes, control, and emotions, and the participative engagement that these expressions may elicit. Using the framework developed in this study, future studies could employ a larger sample.

Conclusion

This study provides an important first look at the content and effects of visual cancer communication on social media and a conceptual basis that future investigation of visual communication of other cancers can utilize. The convergence and divergence identified between self-expressions of cancer beliefs and emotions and the social participative engagement they foster offer new insight and directions for extending the research on cancer illness perceptions and for developing conceptual frameworks for explaining and predicting participative engagement in cancer communication on social media.

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Conflicts of Interest

None declared.

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Abbreviations

API: application program interface
LASSO: least absolute shrinkage and selection operator

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Original Paper

Reach of Messages in a Dental Twitter Network: Cohort Study Examining User Popularity, Communication Pattern, and Network Structure

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Abstract

Background: Increasing the reach of messages disseminated through Twitter promotes the success of Twitter-based health education campaigns.

Objective: This study aimed to identify factors associated with reach in a dental Twitter network (1) initially and (2) sustainably at individual and network levels.

Methods: We used instructors' and students' Twitter usernames from a Saudi dental school in 2016-2017 and applied Gephi (a social network analysis tool) and social media analytics to calculate user and network metrics. Content analysis was performed to identify users disseminating oral health information. The study outcomes were reach at baseline and sustainably over 1.5 years. The explanatory variables were indicators of popularity (number of followers, likes, tweets retweeted by others), communication pattern (number of tweets, retweets, replies, tweeting/ retweeting oral health information or not). Multiple logistic regression models were used to investigate associations.

Results: Among dental users, 31.8% had reach at baseline and 62.9% at the end of the study, reaching a total of 749,923 and dropping to 37,169 users at the end. At an individual level, reach was associated with the number of followers (baseline: odds ratio, OR=1.003, 95% CI=1.001-1.005 and sustainability: OR=1.002, 95% CI=1.0001-1.003), likes (baseline: OR=1.001, 95% CI=1.0001-1.002 and sustainability: OR=1.0031, 95% CI=1.0003-1.002), and replies (baseline: OR=1.02, 95% CI=1.005-1.04 and sustainability: OR=1.02, 95% CI=1.004-1.03). At the network level, users with the least followers, tweets, retweets, and replies had the greatest reach.

Conclusions: Reach was reduced by time. Factors increasing reach at the user level had different impact at the network level. More than one strategy is needed to maximize reach.

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KEYWORDS

social media; health communication; dentists; students, dental; social network analysis; twitter; social networks

Introduction

Social media can reach people connected to the internet [1] at low cost [2,3] regardless of education or access to health care [4]. Twitter differs from other social media in the pattern of communication it supports. On Twitter, person A may follow person B without person B following back, or they may follow each other. This differs from Facebook where friendship is mutual [5]. Another difference is reciprocity which signifies the symmetry of social ties and is associated with higher connectivity [6]. Twitter has a low level of reciprocity, with only 22% of all connections reciprocated [5]. Twitter is also characterized by a hierarchical structure [6] where few popular users have a large number of followers and act as information brokers [7] disseminating information to the bulk of the Twitter network. Thus, Twitter plays 2 roles: (1) news media outlet spreading information in a one-to-many mode with most users on the receiving side and (2) social networking site where people connect and interact in a one-to-one communication pattern [8]. Differences by country and culture were reported regarding which pattern prevails, and this may affect the number of users reached in a network [6].

Also, connected Twitter users are included in a network. Some networks are more efficient at spreading information than others because of their structure such as small world networks. Social network analysis provides the tools to visualize this network and calculate metrics that characterize it and quantify users' connectivity [5,8].

Social media has the potential to improve health by spreading health information [4]. Twitter was used to disseminate health information through accounts of ministries of health [9,10] professional associations [7] and local health departments [4]. There are fewer reports about using Twitter in dentistry including investigating the use of Twitter to share information among dental clinicians [11], modeling the impact of third molar experience on quality of life on Twitter [12] and describing antifluoridation activity dominance on social media [13]. Despite the increasing use of Twitter for health information purposes [14], little is known about the spread of health information on it [15]. This is important for planning Twitter-based public health interventions [10].

Saudi Arabia has the highest number of Twitter users among Arab countries (50% of Arab users and 47% of tweets) [16]. It offers an appropriate setting to investigate factors affecting tweet reach. The present report studies a Twitter network of instructors and students in a dental school and others connected to them. Potentially, oral health information can be disseminated by multiple users through different accounts in such a network. This differs from previous studies where there were campaigns with planned health messages generated by one account representing a health organization/ professional body [4,7,9,10,14].

In this study we hypothesize that tweet reach is affected by user popularity (followers, likes and retweets), communication pattern (tweeting, retweeting, replying and disseminating oral health information), and Twitter network characteristics. This study aimed to assess (1) factors associated with tweet reach at one point in time and (2) sustainably over time at the individual user and network levels.

Methods

Study Parameters

We conducted a cohort study of a Twitter network of instructors and students in the College of Dentistry, Imam Abdulrahman Bin Faisal University, Saudi Arabia. This governmental school offers a 6-year Bachelor of Dental Surgery program and had 58 instructors and 301 students in 2016-17. We followed the accounts from June 2016 to November 2017. The network included dental users who tweeted general oral health information topics in addition to other topics such as entertainment, sports, and academic life. They tweeted on their own (ad libitum) without following a specific agenda or any instructions. Their tweeting was, therefore, not standardized. Instead, it reflected their tweeting habits. It also included nondental users who follow them. Ethical approval was obtained from the research unit at the College of Dentistry (#EA 2014009).

Study Population

Participants were included if (1) they were affiliated with the college (dental users) in June 2016 and (2) had an open Twitter account. Lists of participants were obtained from academic affairs. They were contacted, introduced to the study and asked for their Twitter usernames. Consent was not sought from them since their accounts were open [17].

The Twitter network was constructed using a software pipeline (Multimedia Appendix 1: Software pipeline), the open-source graph visualization platform Gephi [20] and social network analysis [21]. Metrics of network characteristics were calculated including [5,8,21]:

1. Number of users and connections between them.
2. Number of connected components: if two users are linked directly or indirectly through a third user, they are in a connected component.
3. The average path length: the number of users needed for A to connect to B is the path length with shorter paths helping information spread.
4. Network diameter: the longest distance between two users is the network diameter.
5. Degree: the number of connections a user has is the degree. Its probability distribution shows the type of network.

We used Twitter accounts dashboards to obtain the number of followers, tweets, and likes. Users were categorized into those with the least number of followers (≤200) [8], those with the highest number of followers (≥1000), and those with a moderate number of followers in between. We used twitonomy [22] to obtain the number of replies, retweets, and tweets retweeted by others. We categorized the number of tweets, retweets, and replies into high and low levels using their respective 75th percentile as cutoff points. Tweets and retweets from January to June 2016 were used to identify users who are tweeting or retweeting oral health information. To calibrate, 2 investigators manually coded [19] the messages of 20 users employing content analysis and differences were resolved by discussion until an acceptable agreement (kappa=.7) was established.

Statistical Analysis

Univariate and multiple logistic regression models were developed for 2 binary outcome variables: (1) reach at baseline, and (2) sustained reach. The explanatory variables were: (1) indicators of user popularity (number of followers, likes and retweeted tweets) and (2) communication pattern (number of tweets, retweets, replies, and whether the user tweeted or retweeted oral health information). All variables were entered into the multiple model so that they were adjusted for each other, gender, and role (instructor/student). Significance was set at the 5% level. Statistical analysis was performed using SPSS version 22.0 (IBM Corp., Armonk, N.Y., USA).

Results

Thirty-nine of 58 (67.2%) instructors and 225/301 (74.8%) students responded. Table 1 shows that most dental users were students (225/264, 85.2%) and males (146, 55.3%). The median number of followers was 170 with an interquartile range (IQR) of 69-340 with a median of 81 likes (IQR 14-454) and 29 tweets (IQR 6-118) retweeted. Of the 1.1 million tweets generated, 1.7% were retweets and 0.8% were replies. Oral health information was equally tweeted (20, 7.6%) and retweeted (21, 8.0%).

Of all dental users, 84 (31.8%) had reach at baseline and 166 (62.9%) at the end of the study. The median number reached at baseline was 0 (IQR 0-4) increasing at the end to a median of 4 (IQR 0-211). The total number reached at baseline was 749,923 dropping to 37,169 at the end (95.0% reduction). There were 71 (26.9%) dental users with sustained reach.

The results of the univariate logistic regression are shown in Multimedia Appendix 2. Table 2 shows that users with more followers had significantly higher odds of reaching people at baseline with an odds ratio (OR)=1.003, 95% CI=1.001-1.005 and sustainably (OR=1.002, 95% CI=1.0001-1.003). Those with more likes (baseline: OR=1.001, 95% CI=1.0001-1.002 and sustainability: OR=1.001, 95% CI=1.0003-1.002) and with more replies (baseline: OR=1.02, 95% CI=1.005-1.04 and sustainability: OR=1.02, 95% CI=1.004-1.03) had significantly higher odds of reaching others. Tweeting oral health information was associated with significantly higher odds of reach at baseline (OR=5.07, 95% CI=1.18-21.69) but had no significant association with sustained reach (OR=2.99, 95% CI=0.77-11.53).

There were 264 dental users and 46,951 nondental users for a total of 47,215 users and 77,309 connections (Figure 1). The network diameter was 9 with an average path length of 4.253 and 3 connected components the largest of which included 99.9% of all users. Dental users (represented by the black nodes) were a minority with nondental users (yellow nodes) forming the majority of the network. The inset inside Figure 1 shows that the users' degrees had a power law distribution which is characteristic of small world networks. Figure 2 shows that collectively, dental users with the least number of followers had >3 times the reach of users with the highest number of followers. Users with low number of tweets, replies and retweets had greater reach than those with high levels of these messages.

Table 1. Dental users' characteristics and communication pattern in a dental school Twitter network involving instructors (N=39) and students (N=225).

Factors	Analysis, n (%)
User characteristics	
Role	
Instructor	39 (14.8)
Student	225 (85.2)
Gender	
Male	146 (55.3)
Female	118 (44.7)
Number of followers	
Median (IQR[a])	170 (69-340)
Total	82,011
≤200	146 (55.3)
201-999	105 (39.8)
≥1000	13 (4.9)
Number of likes	
Median (IQR)	81 (14-454)
Total	123,473
Number of tweets retweeted by others	
Median (IQR)	29 (6-118)
Total	22,927
Communication pattern	
Number of tweets	
Median (IQR)	1,114 (180-5,089)
Total	1,116,225
Number of retweets	
Median (IQR)	23 (5-94)
Total (% of all tweets)	19,015 (1.7)
Number of replies	
Median (IQR)	8 (1-37.3)
Total (% of all tweets)	8,748 (0.8)
Tweeted oral health information	20 (7.6)
Retweeted oral health information	21 (8.0)

[a]IQR: interquartile range.

Table 2. Factors associated with having reach at baseline and sustained reach.

Reach factors	Multiple logistic regression	
	Adjusted odds ratio[a] (95% CI)	*P* value
Having reach at baseline		
Indicators of user popularity		
Number of followers	1.003 (1.001-1.005)[b]	.003[c]
Number of likes	1.001 (1.0001-1.002)[b]	.03[c]
Number of tweets retweeted by others	0.98 (0.95-1.00)	.10
Communication pattern		
Number of tweets	1.00 (1,00-1.00)	.18
Number of tweets that are retweets	1.02 (1.00-1.06)	.11
Number of tweets that are replies	1.02 (1.005-1.04)[b]	.009[c]
Tweeted oral health information versus not	5.07 (1.18-21.69)[b]	.03[c]
Retweeted oral health information versus not	0.66 (0.13-3.24)	.57
Having sustained reach		
Indicators of user popularity		
Number of followers	1.002 (1.0001-1.003)[b]	.01[c]
Number of likes	1.001 (1.0003-1.002)[b]	.02[c]
Number of tweets retweeted by others	0.98 (0.95-1.01)	.17
Communication pattern		
Number of tweets	1.00 (1.00-1.00)	.45
Number of tweets that are retweets	1.02 (0.99-1.05)	.17
Number of tweets that are replies	1.02 (1.004-1.03)[b]	.01[c]
Tweeted oral health information versus not	2.99 (0.77-11.53)	.11
Retweeted oral health information versus not	0.83 (0.17-3.95)	.82

[a]Controlling for all variables in addition to role (instructor/student) and gender.
[b]Statistically significant CI not including null value.
[c]Statistically significant $P<.05$.

Figure 1. Twitter network, black nodes are dental users, yellow nodes are nondental users with a power-law distribution of degrees in the inset.

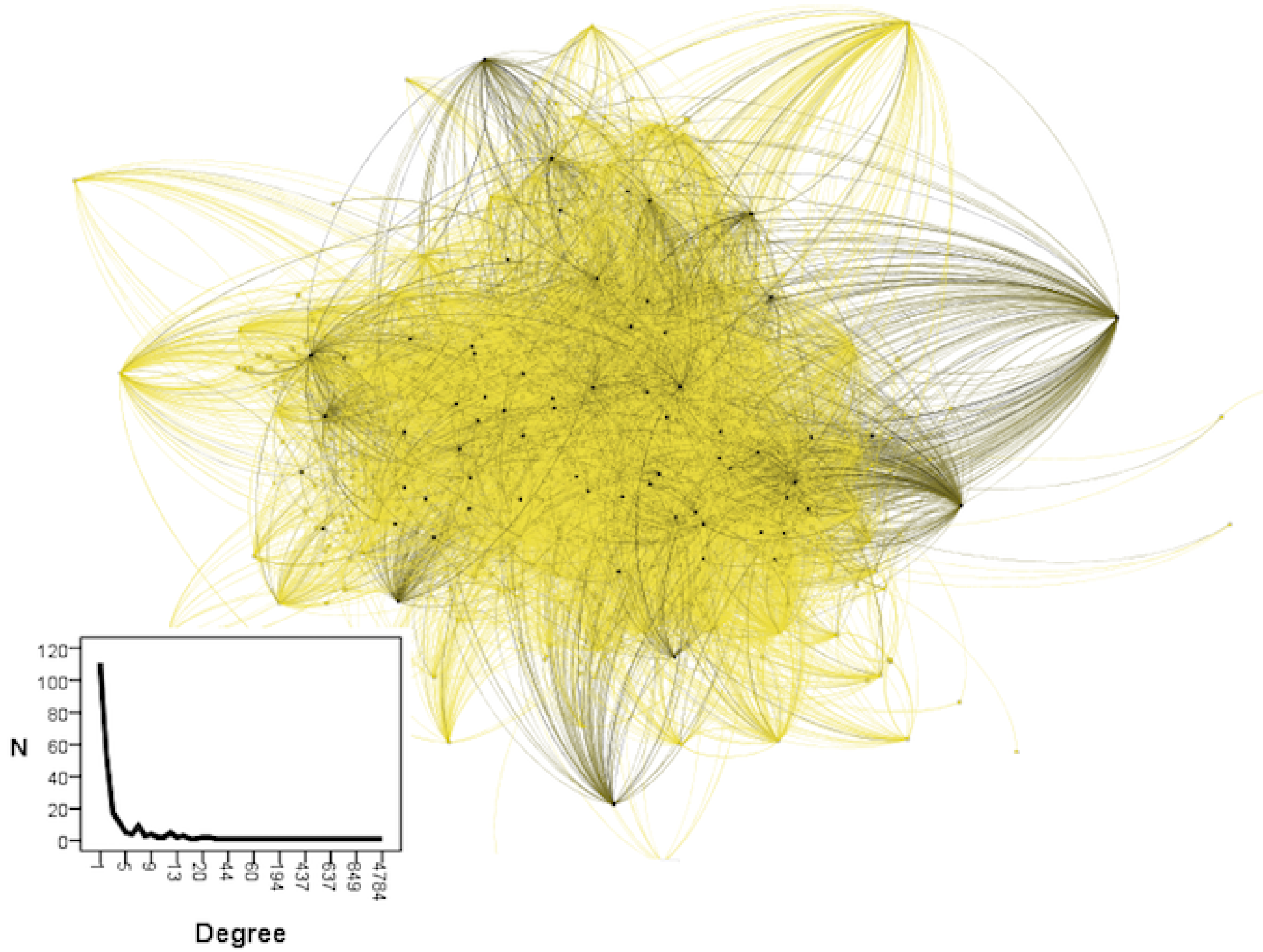
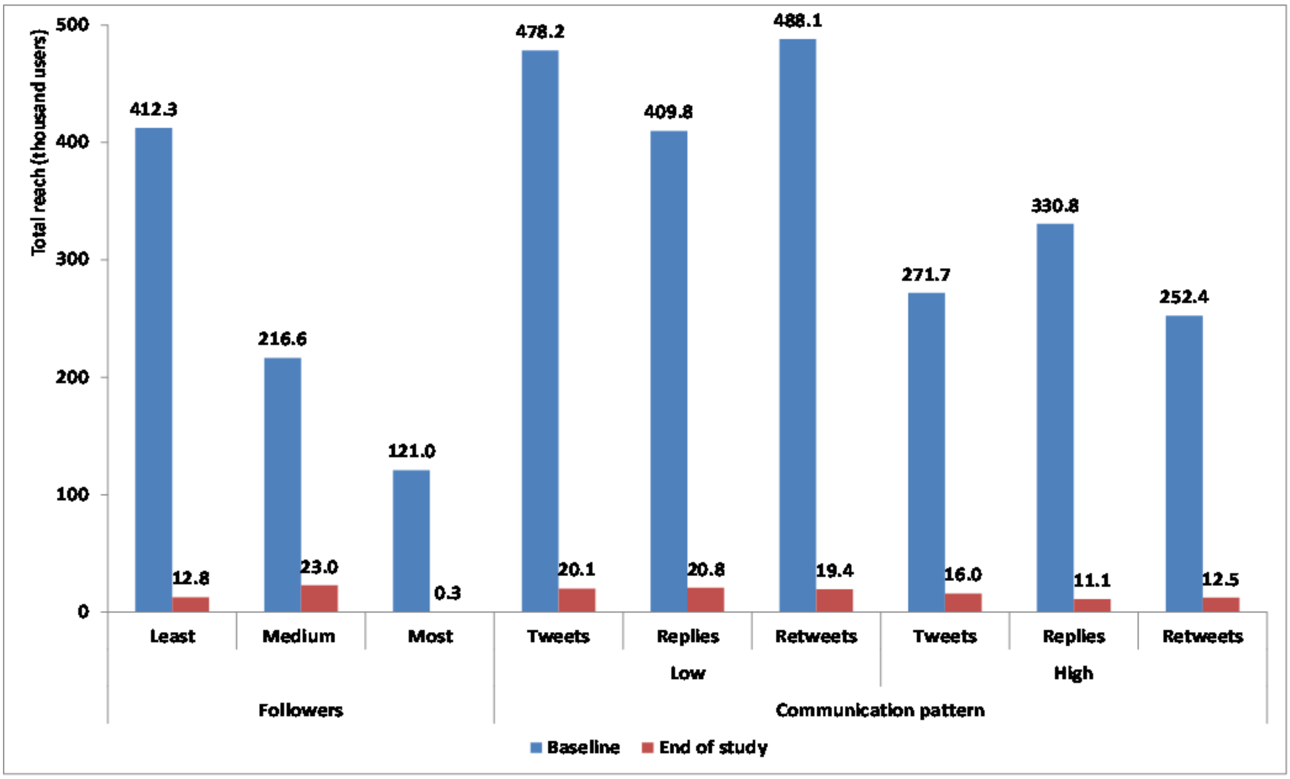


Figure 2. Reach at different time points for users with different followers levels and communication patterns.



Discussion

Principal Findings

The present study showed that the Twitter network structure facilitated information spread and that user popularity and communication pattern significantly but differently affected reach at individual and network levels. At the individual level, popular users and a communication pattern with replies had higher odds of reach. However, at the network level, users with the least number of followers and those with lower levels of tweets, retweets and replies collectively reached more users. Thus, our results support the study hypothesis.

At the individual user level, more followers increased the odds of reach. This reflects the emergence of the phenomenon of social media influencers [23] who affect public opinion because they can reach many users. Our results agree with a study [8] showing that few users with a large number of followers can spread information to a large portion of a Twitter network. It disagrees, however, with another study [7] showing that the Twitter accounts of 4 medical associations had large numbers of followers ranging from 6-213 thousand users, but their actual reach and information dissemination level was low. The difference between our study and theirs may be attributed to communication pattern and content of the message. The ORs for some variables are close to 1 indicating weak associations. For example, an increase of one follower or one like increases the chances that a user has reach by 0.1%-0.3%. However, the user has a median of 170 (interquartile range, IQR 69-340) followers and a median of 81 likes (IQR 14-454) resulting in a potentially greater effect per user. It is important to keep this scale perspective in mind for a better understanding of the impact of the variables.

In the present study, reach was positively affected by a two-way communication pattern with replies. This agrees with a previous study [24] indicating that replies were associated with greater message diffusion. Our results disagree with others indicating that replies address specific users, not the whole Twitter network so that those not involved might be disengaged [25]. User popularity and context of reply may explain the difference between the 2 sides. For example, replies from popular users may be more valued than others [26]. On the other hand, a corporate account replying to customers' complaints may have low reach because users are driven off by the negative experiences discussed [26]. In the present study, the odds ratio for the impact of the number of followers on reach was reduced when the number of replies was included in the multiple model indicating possible effect modification since users with a large number of followers may have difficulty replying to others [8].

In the present study, the small portion of dental users disseminating oral health information reduced the possible impact of the network on patient education and the reason for this requires further investigation in future studies. Our analysis shows that tweeting oral health information increased the odds of reach at baseline but not on a sustained basis indicating that dental users who disseminate oral health information have greater reach than others. To keep this reach, they have to adopt additional measures to address the continuous demand for new topics on social media. The associations in the present study were observed in a Twitter network of dental professionals and their followers. Future studies are needed to assess the spread and reach of oral health information in a Twitter network of lay people and the factors affecting it.

The present study showed that at the network level, less popular users and those with lower levels of tweets, retweets and replies collectively had the greatest reach. This can be explained by the theory of information flow [27] which indicates that users with a small number of followers; the grassroots, have a large presence in the network and because of this, they assume a marked role in information flow reflecting collective network intelligence [5]. Our results agree with a report [28] showing that Twitter users with few followers were frequent sources and disseminators of Zika virus content on Twitter similar to public health institutions.

The Twitter network in the present study had features of small worlds which are reported to be efficient in spreading information. For example, a user was separated on average from others by 4 users. This agrees with a study [5] reporting on 41.7 million Twitter users where the average path length was 4.12 and with evidence showing an average path length on Facebook of 4.57 [29]. By contrast, Microsoft Network messenger had a greater path length (with median of 8) [5] suggesting differences among social media in supporting information spread. The vast majority of users in the present study were included in one large connected component allowing potential interaction among them. This agrees with statistics [8] reporting that 94.8% of Twitter users are included in 1 large connected component, and it is possible that this level of connectivity may be an inherent Twitter feature with potential for health education.

The number of users reached at baseline was drastically reduced by the end of the present study. This attrition is characteristic of social media-based experiences [30]. Twitter trends, characterized by spikes in the number of users discussing a specific topic, extend for a week or less with few lasting more than two months [5,10] indicating the duration people are expected to remain interested in 1 topic on Twitter. In the present study more than one user was involved and various topics were discussed, and reach was still attained after a longer period although at a much reduced level. Despite the drop in total reach, the number of dental users with reach and their median reach increased over the study period. This may be explained by the profile of new users joining the network. Studies are needed to investigate this phenomenon and how it affects the reach of the network.

It is difficult to directly compare the reach of several users sending unplanned messages in the present study with previous studies about Twitter campaigns/accounts of single users with planned messages. For example, a shisha campaign had 563 followers over 9 months after disseminating 373 tweets [31], and the Mayo Clinic account had 1,235 followers over 12 months after generating 1,635 tweets [32]. Our results show that the number of followers is critical to reach. Compared to the number of followers in these previous studies, the number in our study (median 170, IQR 69-340) indicates underused opportunity to spread oral health information.

Limitations

The present study has some limitations. First, some dental users, who were not affiliated with the college such as practicing dentists or students in other dental schools, may have been classified as nondental users. Second, we calculated reach regardless of whom the user was and possibly including duplicate or corporate accounts. Such accounts would not benefit from oral health information and including them may overestimate reach. Third, we did not consider reach through other methods than following a user such as by hashtags [33], and this may underestimate reach. Our study has several strengths though. The Twitter network included users from a dental school, which increases the credibility of the information they spread through an inherent, nonformal peer review system. This large number of users and tweets and the long follow up period provide valid and realistic estimates about reach and factors affecting it. Further studies are needed to better understand the impact of a change in network structure and message content on reach.

Conclusions

In a population of high Twitter use, a large number of non-dental users can be reached through Twitter with implications for health education. This potential impact is expected to increase as the percentage of users disseminating oral health information increases. Without intervention, a small portion of dental users would elect to do so indicating the need for incentives. If their involvement is recognized as part of community service activities, users from the academic dental sector may be encouraged to participate thus educating many more individuals that can be done in traditional health education. Multiple strategies are needed to maximize reach including the recruitment of popular users to disseminate oral health information, ensuring the presence of users who reply to inquiries and mobilizing grassroots to circulate messages through the network [5].

Authors' Contributions

MET was involved in idea conception, study design, development of methods, and statistical analysis. AAA contributed to method development, and results interpretation. AA helped with data collection, and coding (content analysis). AF was involved with the social network analysis (Twitter network, software pipeline and Gephi). NMA contributed to coding (content analysis), and social media metrics collection. ASM helped with coding (content analysis), and social media metrics collection. All authors contributed to the drafting and approval of the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Software pipeline.

[PDF File (Adobe PDF File), 47KB - jmir_v20i9e10781_app1.pdf]

Multimedia Appendix 2

Factors associated with having reach at baseline and sustained reach (univariate logistic regression).

[PDF File (Adobe PDF File), 34KB - jmir_v20i9e10781_app2.pdf]

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Abbreviations

IQR: interquartile range
OR: odds ratio

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Using New and Innovative Technologies to Assess Clinical Stage in Early Intervention Youth Mental Health Services: Evaluation Study

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Abstract

Background: Globally there is increasing recognition that new strategies are required to reduce disability due to common mental health problems. As 75% of mental health and substance use disorders emerge during the teenage or early adulthood years, these strategies need to be readily accessible to young people. When considering how to provide such services at scale, new and innovative technologies show promise in augmenting traditional clinic-based services.

Objective: The aim of this study was to test new and innovative technologies to assess clinical stage in early intervention youth mental health services using a prototypic online system known as the Mental Health eClinic (MHeC).

Methods: The online assessment within the MHeC was compared directly against traditional clinician assessment within 2 Sydney-based youth-specific mental health services (*headspace* Camperdown and *headspace* Campbelltown). A total of 204 young people were recruited to the study. Eligible participants completed both face-to-face and online assessments, which were randomly allocated and counterbalanced at a 1-to-3 ratio. These assessments were (1) a traditional 45- to 60-minute *headspace* face-to-face assessment performed by a Youth Access Clinician and (2) an approximate 60-minute online assessment (including a self-report Web-based survey, immediate dashboard of results, and a video visit with a clinician). All assessments were completed within a 2-week timeframe from initial presentation.

Results: Of the 72 participants who completed the study, 71% (51/72) were female and the mean age was 20.4 years (aged 16 to 25 years); 68% (49/72) of participants were recruited from *headspace* Camperdown and the remaining 32% (23/72) from *headspace* Campbelltown. Interrater agreement of participants' stage, as determined after face-to-face assessment or online assessment, demonstrated fair agreement (kappa=.39, *P*<.001) with concordance in 68% of cases (49/72). Among the discordant cases, those who were allocated to a higher stage by online raters were more likely to report a past history of mental health disorders (*P*=.001), previous suicide planning (*P*=.002), and current cannabis misuse (*P*=.03) compared to those allocated to a lower stage.

Conclusions: The MHeC presents a new and innovative method for determining key clinical service parameters. It has the potential to be adapted to varied settings in which young people are connected with traditional clinical services and assist in providing the right care at the right time.

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KEYWORDS

staging model; mental health; primary health care; telemedicine; symptom assessment health service reform

Introduction

Globally, there is increasing recognition that new strategies are required to reduce disability due to common mental health problems such as anxiety, depression, and comorbid substance misuse. As public awareness increases, the demand for mental health care far outstrips the capacity of health systems to provide access to quality care [1]. To achieve a meaningful reduction in population-level burden of disease, there is a need to provide both prevention and early intervention strategies at scale. As 75% of mental health and substance use disorders emerge during the teenage or early adulthood years [2], these strategies need to be readily accessible to young people. In most countries, however, young people are less likely to receive effective mental health care as a consequence of financial, attitudinal, and health system literacy factors [3,4].

For young people, there is typically still a prolonged delay between the onset of first symptoms and initial treatment contact [5]. By the time most young people present to health services, they already have significant functional impairment, are psychologically distressed, or have some degree of established comorbidity [6]. For these young people, the current psychiatric classification systems remain limited [7] and, as interventions are often guided by diagnosis, young people experiencing subthreshold symptomatology do not always receive appropriate care [8].

When considering how to provide such services at scale, eHealth (electonic health is a relatively recent health care practice that is supported by internet and/or other technologies) [9] and more recently mHealth (mobile health is the use of mobile and wireless technologies to enhance health) [10] and uHealth (ubiquitous health is information technology combined with medical technolgy to support health) [11] technologies show promise in augmenting traditional services and can be adapted potentially to all aspects of care [12]. A consistent theme is that such technologies can also address poor youth engagement with mental health services [13]. In these services, for example, innovations in the use of such technologies that allow the assessment process to be brought online could improve current wait times and provide a wider reach for young people who physically (or emotionally) struggle to access face-to-face clinical care [14].

While there are concerns about potential lack of accountability in the mHealth field and that online communications could miss nonverbal cues that can ultimately impact empathy and patient satisfaction [15], it is also evident that Web-based programs can facilitate disclosure [16] and such online interventions are as effective and even more efficient than traditional interventions in mental health [17,18]. Furthermore, evidence shows that telepsychiatry is as accurate as in-person psychiatry, and online users experience the same degree of satisfaction as face-to-face users [19].

Imported from general medicine, the concept and application of clinical staging to mental health disorders seeks to redefine traditional diagnostic systems by placing individuals on a spectrum from early identification of nonspecific or mixed forms of mental symptoms through to more discrete disorders and then recurrent and persistent forms of illness [20]. Transdiagnostic staging models have been employed in youth mental health settings and have demonstrated utility [8,21] (Textbox 1). To date, research among youth-focused primary mental health care services has shown that 33% to 41% of young people presenting to early intervention youth mental health services are assigned to stage 1a, 38% to 40% to stage 1b, 11% to 14% to stage 2 and 7% to 8% to stages 3 and 4 [8].

As the staging framework recognizes the continuum of illness progression, it also encourages more personalized and responsive care at each point of the spectrum [20]. This framework supports the promotion of self-help and encourages easier navigation for stepping up through the mental health system [22]. Stepped (or clinically staged) care aims to provide evidence-based, less intensive, low-risk, and low-cost interventions to the less severe cases while prioritizing more intensive or prolonged interventions for more complex cases [7,23-26].

The process for determining stages has been outlined previously by Cross and colleagues [8]. To briefly summarize the procedure, allocation of an individual to a particular stage is undertaken at regular multidisciplinary clinical consensus meetings involving senior mental health professionals (consultant psychiatrists or senior clinical psychologists) aided by objective symptom and functional measures (including paper and pencil questionnaires and surveys administered by tablets) and cross-referencing the staging framework set out by Hickie and colleagues [7]. Converting these methodologies to an online assessment (including a self-report Web-based survey, an immediate dashboard of results, and a video visit with a clinician) has the genuine potential to increase engagement with young people for many reasons. First, the internet is so widely used it is now the preferred mode of communication for youth [27,28].

Textbox 1. Clinical staging model for mental health disorders.

- Stage 0 : no symptoms; person at risk of disorder
- Stage 1a: help-seeking; person with mild symptoms and mild functional impacts
- Stage 1b: attenuated syndrome; person with mixed or ambiguous symptoms and moderate to severe functional impacts
- Stage 2 : discrete disorders such as clear episodes of psychotic, manic, or severe depressive disorders
- Stage 3 : recurrent or persistent disorder
- Stage 4 : severe, persistent, and unremitting illness

Second, the assessment offers the possibility of immediate recommendations, support, and interventions anytime, anywhere, through a personalized dashboard of results (an easy-to-read clinical report with infographics) upon completion of the online assessment. Third, the assessment breaks down traditional geographical and socioeconomic barriers by increasing access to any care but specifically to more specialized assessment.

The aim of this study was to test new and innovative technologies to assess clinical stage in youth-specific mental health services using a prototypic online system known as the Mental Health eClinic (MHeC) [29]. Specifically, we tested how online assessments compared with traditional face-to-face assessments in a cohort of young people seeking mental health care. We report how online assessments perform in identifying key features such as stage allocation, lifetime trajectories, and recognition of comorbidities while also managing risk (suicidality) and responding to the more complex cases. The study compares the online assessment within the MHeC (including a self-report Web-based survey, an immediate dashboard of results, and video visit with a clinician) to standard face-to-face assessment as provided through 2 Sydney-based *headspace* services.

Methods

Participants

Participants were recruited from 2 youth-specific mental health services (*headspace* Camperdown and *headspace* Campbelltown) located in inner and outer metropolitan Sydney, Australia, respectively. *headspace* services are specialized, primary care early intervention mental health services for young people aged 12 to 25 years [30]. They provide services such as care coordination and support by allied health professionals; general medical services by general practitioners (primary care physicians); more specialized mental health services delivered by clinical psychologists and psychiatrists; and education, employment, and other social supports delivered by colocated specialist services. A key aspect of *headspace* is the direct connection and ease of access to secondary care specialists such as early psychosis services.

Within these *headspace* services, all young people who met inclusion criteria between the period of July 2015 to August 2016 were invited to participate in the study. Inclusion criteria included young people who (1) were aged 16 to 25 years, (2) were newly registered with *headspace*, (3) had regular access to the internet, and (4) had regular access to a webcam. Young people were reimbursed (voucher equivalent to Aus $20 [US $15]) for their participation.

Ethics

The University of Sydney’s Human Research Ethics Committee approved the study (protocol number 2014/689). All participants were provided with information about the study prior to participating and consenting. Parental consent was also obtained for participants aged 16 and 17 years.

Procedure

In order to test the online assessment within the MHeC, all eligible participants were invited to complete both the online assessment and standard assessment in face-to-face services. Participants were randomly allocated and counterbalanced by a 1-to-3 ratio to either undertake the face-to-face assessment or online assessment first. Considering the online assessment was a new method of assessment, an unequal randomization was preferred in order to minimize the impact of learning effects [31]. A condition of the study was that both assessments had to be completed within a 2-week timeframe from the first evaluation (the maximun interval of time in which symptomatology would not considerably differ between assessments).

The face-to-face assessment included completion of the *headspace* National Minimum Dataset (a very brief, 5- to 7-minute demographic and service activity questionnaire; data from this tool was not analyzed in this study) as collected through a survey administered via a tablet (smart skip rules are not available) upon entry to the service and then a 45- to 60-minute face-to-face psychosocial assessment with a Youth Access Clinician that is an adaptation of the HEEADSSS (Home, Education and Employment, Eating, Activities, Drugs and Alcohol, Sexuality, Suicide and Depression, Safety) [32] semistructured interview for *headspace*. This interview collects narrative information by assessing the young person’s home and environment and then progressively moves through the domains of education and/or employment, activities, drugs and alcohol, relationships and sexuality, conduct difficulties and risk taking, anxiety, eating, depression and suicide, and psychosis and mania [33-34] (Textbox 2).

The online assessment was based on the staging model as developed and adapted for early intervention youth mental health services. This assessment included 3 components (Textbox 3): a self-report Web-based survey, an immediate dashboard of results, and a video visit with a clinician. The self-report Web-based survey of the MHeC was designed and developed by our clinical research team to collect both demographic and clinical data. It is specifically ordered to reflect a best practice clinical interview [35] and includes 10 modules. Participants complete general questions about their demographics and medical history followed by questions assessing their current physical and mental health status. Questions are guided by smart skip rules that enable the self-report Web-based survey to be personally tailored to each young person (eg, if screening questions are positive, a more in-depth assessment will be triggered) and takes the minimum time to complete for each individual based on how they respond. Sensitive items (eg, suicidality and self-harm behaviors) are only asked once trust in the system has been generated and the young person is familiarized with the module's topic and type of questions (ie, when rapport has been established).

Textbox 2. Face-to-face assessment.

- *headspace* psychosocial assessment
  - Domain 1: home and environment
  - Domain 2: education and/or employment
  - Domain 3: activities
  - Domain 4: drugs and alcohol
  - Domain 5: relationships and sexuality
  - Domain 6: conduct difficulties and risk-taking
  - Domain 7: anxiety
  - Domain 8: eating
  - Domain 9: depression and suicide
  - Domain 10: psychosis and mania
- Face-to-face consultation with a clinician

Textbox 3. Online assessment.

- Self-report Web-based survey
  - Module 1: collects demographic information
  - Module 2: assesses medical history
  - Module 3: screens for prevalent mental health conditions [36]
  - Module 4:
    - Screens for hypomanic symptoms (items derived from the Altman Self-Rating Mania Scale [37])
    - Screens for psychotic symptoms (items derived from the Community Assessment of Psychotic Experiences Positive Symptoms Scale [38])
    - Measures psychological distress with the 10-item Kessler Psychological Distress Scale [39]
    - Measures somatic distress with the Somatic and Psychological Health Report [40]
  - Module 5: Assesses self-harm behaviors and suicidality using the Suicidal Ideation Attributes Scale [41]
  - Module 6: Assesses tobacco, alcohol and substance use—items derived from the Alcohol Use Disorders Identification Test [42], the Alcohol, Smoking and Substance Involvement Screening Test [43], the Drinking Motives Measure [44], the Fagerstrom Nicotine Dependence Test [45], and select items from the National Household Drug Survey [46]
  - Module 7: Measures physical activity using the International Physical Activity Questionnaire [47]
  - Module 8: Assesses sleep behaviors using 4 sleep-related items from the Quick Inventory of Depressive Symptomatology [48]
  - Module 9: Assesses eating behaviors with items derived from the Eating Disorder Examination [49]
  - Module 10: Measures social connectedness—items derived from the Perceived Social Support/Conflict Measure [50] plus 5 items measuring relationship with peers [51]
- Immediate dashboard of results
- Video visit with a clinician

The video visit of the online assessment included a brief, semistructured interview (Multimedia Appendix 1) with clinicians (LOP, a psychiatrist and mental health researcher, and AT, a research psychologist) trained in the application of clinical staging [7] for young people presenting to *headspace* service. Importantly, the video visit was guided by the automatically generated results of the self-report Web-based survey as shown in the dashboard of results.

At the conclusion of each face-to-face session and video visit, all clinicians determined stage. These results were then collapsed into 2 groups: stage 1a or stage 1b and above (stage 1b+). Participants in stage 1a were help-seeking with mild symptoms and mild functional impairment while those in stage 1b+ were experiencing more severe symptoms and functional impairment. This key differentiation is predictive of clinical course and can be used to allocate service resources preferentially to those in greater need. Clinicians also completed the Social and Occupational Functioning Assessment Scale (SOFAS), which measures an individual's functional status not directly related to the severity of their psychological symptoms [52], and the Clinical Global Impression Scale-Severity (CGI-S), a 7-point illness severity scale subjective to clinician's past experience with other individuals with the same illness [53].

Interrater Agreement Between the Online Clinicians

In order to validate online assessment and staging classification, 2 trained clinicians (LOP and AT) were present during all video visits until such time their interrater agreement was considered reliable; that is, LOP (rater A) and AT (rater B) conducted alternating video visits while the other was present but not in view of the webcam (as per ethics approval and consent obtained from the young person). Raters A and B then determined stage independently, and once substantial concordance was sufficiently reached, LOP and AT conducted any remaining video visits with or without the other present.

Statistical Analyses

All statistical analyses were performed using SPSS Statistics for Mac 22.0 (IBM Corp). Group differences in demographic, functional, and clinical variables were assessed using nonparametric Kruskal–Wallis test (*H*) or chi-square test (χ^2) at a 95% level of confidence (when the expected count was less than 5, a Fisher exact test [FET] was employed). Medians were reported due to sample size. Post hoc analyses (Mann–Whitney test [*U*], χ^2, or FET) were performed in variables that showed significant differences between groups, using Bonferroni correction and adjusted alphas dependent on number of groups (n=3). *P* values less than .01 considered to be significant.

Interrater analyses determined degree of agreement of staging results between face-to-face and online clinicians as well as the 2 individual online clinicians (ie, rater A vs rater B). Cohen kappa statistic [54] was calculated and followed the interpretation criteria of Viera et al [55]: kappa=.01 to .20, slight agreement; kappa=.21 to .40, fair agreement; kappa=.41 to .60, moderate agreement; kappa=.61 to .80, substantial agreement; and kappa=.81 to .99, almost perfect agreement. For the continuous variables (SOFAS and CGI-S), the intraclass correlation coefficient (ICC) was used to calculate agreement between offline and online clinicians [56], and interpretations were based on a 95% confidence interval where estimates less than .50 reflect poor agreement; ICC=.50 to .75, moderate agreement; ICC=.75 to .90, good agreement; and greater than .90, excellent agreement [57].

Results

Recruitment and Participation

A total of 204 young people were identified as eligible to participate in the study. Based on a 1-to-3 random allocation counterbalancing ratio, 54 participants were invited to undertake standard face-to-face assessment first and 150 participants were invited to undertake the online assessment first; 125 participants were from *headspace* Camperdown and 79 from *headspace* Campbelltown. All were aged 16 to 25 years, and 71.6% (146/204) were female.

As shown in Multimedia Appendix 2, a total of 24% (13/54) of participants allocated to receive standard face-to-face assessment first completed both assessments, 46% (25/54) completed the standard face-to-face clinical assessment only, 19% (10/54) failed to complete either assessment, and the remainder withdrew from the study or were lost to follow-up. Conversely, 39.3% (59/150) of participants allocated to complete the online assessment first completed both assessments, 5.3% (8/150) completed the online assessment only, 49.3% (74/150) failed to complete either assessment, and the remainder withdrew from the study or were lost to follow-up. Overall, 72 participants completed the entire study protocol of which 68% (49/72) were recruited from *headspace* Camperdown and the remainder (23/72, 32%) from *headspace* Campbelltown. The average time to completion of the online assessment was 60 minutes including approximately 45 minutes (median 51 minutes) for the self-report Web-based survey and approximately 12 minutes (median 15 minutes) for the video visit.

Sample Characteristics

The mean age of all participants was 20.35 (SD 2.63, range 16 to 25) years, 71% (51/72) were female, and 51% (37/72) had completed or partially completed tertiary education. Participants reported moderate distress levels (10-item Kessler Psychological Distress Scale mean 28.93, SD 8.42, range 10 to 50) with almost three-quarters (53/72, 74%) of the sample currently experiencing anxious and/or depressive symptoms. Nearly one-third (21/72, 29%) of participants screened positive for hypomanic symptoms, and one-third (24/72, 33%) screened positive for psychotic-like symptoms.

Almost half (35/72, 49%) of participants reported self-harm. Using our digitally smart Suicidality Escalation Protocol [58], the online assessment was able to detect and triage young people at risk in real time. In total, 18% (13/72) of participants reported high suicidality (Suicidal Ideation Attributes Scale [SIDAS] score ≥21/50), of which more than half (7/13, 54%) were escalated by the online clinicians to one of the *headspace* services as they considered current wait times for face-to-face care too long.

Interrater Agreement Between Online Clinicians

In order to validate the online assessment and staging classification, the trained clinicians were both present in 14 video visits until agreement was measured as substantial (kappa=.76, *P*=.003) with concordance at 93% (13/14). All subsequent video visits were assessed by the raters according to their availability. The online interrater agreement was determined for 59% (48/82) of participants who completed the online assessment (self-report Web-based survey, immediate dashboard of results, and video visit with a clinician). As shown in Table 1, participants were entered into a 2-by-2 comparison of stage assigned (stage 1a vs stage 1b+) and type of online rater who assigned that stage: online rater A and online rater B. Overall agreement between online raters was measured as substantial (kappa=.77, *P*<.001) with concordance at 90% (43/48) upon completion of all online assessments; 82% (14/17) were classified by both online raters as stage 1a and 94% (29/31) as stage 1b+.

Table 1. Interrater agreement between online rater A and online rater B by assignment of clinical stage.

	Online rater A	
Online rater B	Stage 1a (n=16), n (%)	Stage 1b+ (n=32), n (%)
Stage 1a (n=17), n (%)	14 (29)	3 (6)
Stage 1b+ (n=31), n (%)	2 (4)	29 (61)

Table 2. Interrater agreement between face-to-face and online clinicians by allocation to clinical stage.

	Online assessment	
Face-to-face clinical assessment	Stage 1a (n=27), n (%)	Stage 1b+ (n=45), n (%)
Stage 1a (n=42), n (%)	23 (32)	19 (26)
Stage 1b+ (n=30), n (%)	4 (6)	26 (36)

Face-to-Face Versus Online interrater Agreement

To calculate interrater agreement for assigning stage, participants were entered into a 2-by-2 comparison of stage assigned (stage 1a vs stage 1b+) and type of clinician who assigned that stage: face-to-face clinician versus online clinician (Table 2). Interrater agreement of stage between face-to-face and online clinicians demonstrated fair agreement (kappa=.39, *P*<.001), with concordance in 68% (49/72) of participants; here, clinicians identified 55% (23/42) stage 1a (agree) (staged as stage 1a by online and face-to-face clinicians) and 87% (26/30) stage 1b+ (agree) (staged as stage 1b by online and face-to-face clinicians). Of note, 1 participant was assigned stage 2 following face-to-face clinical care, and 3 participants were assigned stage 2 following the online assessment. In this study, no participants were assigned to the more severe stages (ie, stages 3 or 4). There was moderate interrater reliability in the SOFAS score between face-to-face and online clinicians (ICC=.73) and poor interrater reliability in the CGI-S allocation (ICC=.49) for all participants.

Comparison of Self-Reported Measures Where There Was a Disagreement Between Face-to-Face Clinical Assessment and Online Assessment

Table 3 shows the main self-reported clinical characteristics across the 3 groups: stage 1a (agree); stage 1b+ (agree); and stage 1b+ (disagree). Stage 1b+ (disagree) refers to participants who were staged 1b+ by online clinicians but assessed as stage 1a by face-to-face clinicians.

Stage 1a (Agree) Versus Stage 1b+ (Disagree)

Comparing stage 1b+ (disagree) with those participants determined as stage 1a (agree) by both clinician types, post hoc analyses showed that almost all young people in stage 1b+ (disagree) reported a previous history of mental health problems (χ^2_1=10.71, *P*.001), and more than a third (7/19, 37%) reported they had a history of developing a suicide plan (*P*=.002; FET). With regard to current symptomatology, there were no significant differences in psychological distress or suicidal ideation. However, weekly cannabis use was higher in stage 1b+ (disagree) (*P*=.03; FET). Although both groups' SOFAS (Table 4) scores were located within the same range (71 to 80: no more than a slight impairment in social, occupational, or school functioning), participants allocated to stage 1b+ (disagree) were consistently scored with lower levels of functioning (*U*=117, *z*=–2.58, *P*=.01) compared to those in stage 1a (agree).

There was also a major discrepancy between the face-to-face and the online clinicians in categorizing the symptom severity for the participants allocated to stage 1b+ (disagree) group; face-to-face clinicians considered this group as normal (not at all ill) whereas online clinicians assigned a mildly ill classification. Among the online observations, the symptomatology of this group was considered to be significantly more pronounced compared to the stage 1a (agree) participants (CGI-S median rating of borderline ill; *U*=68, *z*=–4.08, *P*<.001).

Stage 1b+ (Agree) Versus Stage 1b+ (Disagree)

When comparing stage 1b+ (disagree) with those in stage 1b+ (agree), post hoc analysis showed that participants assessed as stage 1b+ (agree) had significantly higher levels of suicidal ideation on the SIDAS (*U*=133.50, *z*=–2.64, *P*=.008) and lifetime self-harm behavior (χ^2_1=7.35, *P*=.007). According to online clinicians (Table 4), young people allocated to stage 1b+ (agree) had lower functioning levels on the SOFAS when compared with the stage 1b+ (disagree) group (*U*=121, *z*=–2.93, *P*=.003). However, the stage 1b+ (agree) group was classified by both assessment modes as more unwell on the CGI-S when compared with the stage 1b+ (disagree) group (face-to-face clinical care, *U*=55.5, *z*=–4.54, *P*<.001; online assessment, *U*=149, *z*=–2.48, *P*=.01). Previous mental health history, distress levels, alcohol and/or other substance use disorders, or comorbidities did not differ between these groups.

Post hoc analysis with stage 1a (disagree) (stage 1a by online clinicians but assessed as stage 1b+ by face-to-face clinicians) participants was not conducted due to insufficient cell size.

Table 3. Median scores and significance test results for self-reported variables among groups.

Characteristics	Stage 1a (agree)[a] (n=23), n (%)	Stage 1b+ (agree)[b] (n=26), n (%)	Stage 1b+ (disagree)[c] (n=19), n (%)	Significance test *H*[d] or FET[e] (*P*)	Post hoc *P* values	
					a vs c	b vs c
Demographics						
Female, n (%)	15 (65)	18 (69)	14 (74)	1.70[e] (.72)	—[f]	—
Age in years, median (IQR)[g]	20.00 (4)	20.50 (4)	21.00 (4)	0.78[d] (.86)	—	—
Education				1.58[e] (.71)		
Secondary, n (%)	12 (52)	14 (54)	8 (42)	—	—	—
Tertiary, n (%)	11 (48)	12 (46)	11 (58)	—	—	—
Clinical characteristics						
K-10[h], median (IQR)	25 (13)	32.0 (9)	28.0 (13)	5.51[d] (.14)	—	—
Depression/anxiety (current), n (%)	16 (70)	22 (85)	14 (74)	6.03[e] (.09)	—	—
Hypomanic-like issue (current), n (%)	5 (22)	10 (38)	6 (32)	2.91[e] (.38)	—	—
Psychotic-like issue (current), n (%)	5 (22)	12 (46)	7 (37)	4.92[e] (.15)	—	—
Mental health history, n (%)	11 (48)	20 (77)	18 (95)	11.83[e] (.005)	.001	.21
Lifetime self-harm, n (%)	7 (30)	20 (77)	7 (37)	13.28[e] (.003)	.67	.007
Suicidality						
SIDAS[i], median (IQR)	1 (4)	9.5 (24)	1 (5)	12.59[d] (.006)	.71	.008
Suicide planning history, n (%)	0 (0)	12 (46)	7 (37)	17.75[e] (<.001)	.002	.53
Suicide attempt history, n (%)	0 (0)	6 (23)	1 (5)	6.98[e] (.04)	.45	.21
Alcohol and/or other substance misuse						
Lifetime substance misuse, n (%)	17 (74)	18 (69)	14 (74)	0.36[e] (.98)	—	—
Cannabis weekly, n (%)	1 (4)	8 (31)	6 (32)	7.60[e] (.04)	.03	.95
Substances to cope with emotions, n (%)	6 (26)	18 (69)	8 (42)	10.85[e] (.009)	.24	.07

[a]Stage 1a by online and face-to-face clinicians.

[b]Stage 1b+ by online and face-to-face clinicians.

[c]Stage 1b+ by online clinicians but assessed as Stage 1a by face-to-face clinicians.

[d]Kruskal–Wallis test, 2-tailed.

[e]FET: Fisher exact test, 2-tailed.

[f]Not applicable.

[g]IQR: Interquartile range.

[h]K-10: 10-item Kessler Psychological Distress Scale.

[i]SIDAS: Suicidal Ideation Attributes Scale.

Table 4. Median scores and significance test results for clinician-reported variables among groups.

Tests	Stage 1a (agree)[a] (n=23), n (%)	Stage 1b+ (agree)[b] (n=26), n (%)	Stage 1b+ (disagree)[c] (n=19), n (%)	Significance test H^d (*P*)	Post hoc *P* values	
					a vs c	b vs c
CGI-S[e]						
Face-to-face, median (IQR)[f]	2.0 (1)	3.0 (2)	1.0 (1)	37.04 (<.001)	.83	<.001
Online, median (IQR)	2.0 (1)	4.0 (1)	3.0 (1)	35.29 (<.001)	<.001	.01
SOFAS[g]						
Face-to-face, median (IQR)	75.0 (9)	69.0 (15)	75.0 (5)	12.17 (.007)	.10	.08
Online, median (IQR)	75.0 (9)	60.0 (10)	71.0 (10)	25.33 (<.001)	.01	.003

[a]Stage 1a by online and face-to-face clinicians.

[b]Stage 1b+ by online and face-to-face clinicians.

[c]Stage 1b+ by online clinicians but assessed as stage 1a by face-to-face clinicians.

[d]Kruskal–Wallis test, 2-tailed.

[e]CGI-S: Clinical Global Impression Scale–Severity.

[f]IQR: Interquartile range.

[g]SOFAS: Social and Occupational Functioning Assessment Scale.

Discussion

Principal Findings

The MHeC presents a new and innovative method for determining key clinical service parameters. While there was fair agreement between the staging classifications after both online and face-to-face assessment in the majority of cases (68%, kappa=.39), an important area of difference did emerge. During face-to-face assessments, clinicians tended to rate stage more conservatively compared to clinicians acting with the assistance of the MHeC.

Among the discordant cases, in 26% of cases face-to-face assessment appeared to place less emphasis on lifetime history of mental health problems. By contrast, the online assessment placed greater focus on past history of mental health problems (*P*=. 001), as well as any previous suicide planning (*P*=.002) and current comorbidity with cannabis misuse (*P*=.03) as indicators of progression of disease. It appears the online assessment process was a more efficient way of detecting lifetime severity by holistically evaluating these young participants' current and previous mental health status.

There are a range of possible explanations for this important difference between the face-to-face and online assessments, including (1) face-to-face assessment places greater emphasis on current symptomatology, (2) online clinicians made specific use of more extensive data collection about past as well as current symptomatology that was collected prior to the video visit (and as a consequence, their clinical assessment used all available data relevant to assign stage), and/or (3) face-to-face clinicians may be more influenced by the consequences of their clinical assessment for allocating service resources—that is, higher stage ratings are reserved preferentially for those who are perceived to be in need of more intensive or prolonged care.

Assessing the mental health of young people and their need for immediate or ongoing health care is a real challenge for clinicians and youth mental health services. Specifically, this includes being able to distinguish normative emotional development and brief stress-related responses from emerging mental disorders [59,60] as well as obtaining accurate information from young people who may be apprehensive or hostile toward their clinician. Further, building rapport can take longer in this population [61], and clinician training is often based on the recognition of symptomatology leading to specific diagnostic (eg, *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, or *International Classification of Diseases and Related Health Problems, 10th Revision*) constructs [62]. However, such categories do not accurately represent the most common admixtures of symptoms in young people presenting for mental health care. Clinicians working with the staging model are using a framework that proposes that once a person has reached a defined stage, it is not possible to return to an earlier stage, and as mental disorders are typically cyclical, complexity lies in understanding the variability of presentations over time. Therefore, clinicians would greatly benefit from accurate methods of collecting relevant staging information. The *headspace* psychosocial assessment used in practice predominantly focuses on the current symptomatology of young people and, as a result, misses relevant lifetime information that is crucial for staging.

By entering information online, young people can complete a self-report Web-based survey in their own time whenever and wherever they prefer. This provides greater choice at the forefront of mental health care by directly and immediately responding to young people's needs [29]. For clinicians, this provides reliable information about the individual (current and lifetime) prior to a face-to-face assessment that can be used for staging, enabling clinicians to move away from traditional evaluations to more detailed data-driven assessments. This could translate into a more efficient way of assessment and improve the 1-on-1 time (face-to-face or video visit), enabling clinicians to expand and refine the information collected and deliver interventions that match a young person's unique needs. Over time this online assessment process could be augmented by continuous data tracking and more detailed online assessments to help clinicians recognize patterns of symptoms in the data. Additionally, future systems could develop more complex algorithms through big data analyses and machine learning processes that can better inform young people, clinicians, and services.

As community-based and outpatient mental health care is limited, all services struggle with high demand pressures [63]. Consequently, users face long waiting lists that may have an adverse impact on their engagement with the service and ultimately increase the risk of hospitalizations, functional deterioration, self-harm, or suicidal behavior [64]. Additionally, clinicians and services face substantial demands to reduce waiting times while providing appropriate clinical care. Typically, service systems respond by prioritizing assessment, limiting the number of intervention sessions available and giving priority to more urgent cases [65]. We suggest that the difference in staging by face-to-face clinicians might also be contributed to by their practical awareness of such service constraints.

A systematic clinician bias toward underrating young people to stage 1a could have deleterious effects on service users. Our previous research has shown that 15% of people in stage 1b transition to stage 2 within 1 year [7], people in stage 1a receive different, shorter, and less intensive treatment compared with those in stage 1b [21], and young people in stage 1b tend to remain impaired and distressed over time [21]. The presence of past mental health and suicidal thoughts and/or behaviors indicates that this group of young people require a more personalized treatment that not only covers their current needs but responds appropriately to the higher stage they have reached over the course of their illness. An online assessment like the one proposed in the MHeC could assist to immediately identify young people who might benefit from seeing a more experienced clinician as soon as they enter a service for care. Consequently, such online assessment has the potential of transforming youth mental health services as it streamlines internal processes such as triage and evaluation, increases clinician capacity by providing immediate results, and matches the right clinician and intervention to the young person's needs, thus ensuring the right care is provided at the right time.

Finally, one of the most obvious advantages of the online assessment addresses geographical barriers. In this trial, 10% (8/82) of the video visits were completed with 1 of our clinicians online while she was overseas (LOP traveled overseas due to work commitments) using secure videoconference software. This positions online assessment as an efficient solution connecting young people not only with care but with the right clinician regardless of their location, potentially saving time and money for young people, clinicians, and services.

Limitations

One limitation of this study is the sample size because the face-to-face arm suffered from greater participant attrition. It is possible that participants who had already completed the face-to-face assessment felt that completing a second assessment online was an unnecessary use of time. Additionally, this study required people to complete all of the 4 main components (tablet questionnaire, face-to-face interview, Web-based survey, and video visit) within 2 weeks of the first interview, and the majority of attrition in both study arms was accounted for by this stringent protocol. Although the unequal randomization (1-to-3) favored the analysis with the reduction of the impacts of the learning curve, it compromised the power of the study. Future research is needed with a 1-to-1 randomization, increasing the power of the comparison.

Our study revealed poor interrater reliability on CGI-S allocation between face-to-face and online clinicians. There are 2 possible explanations for this disagreement. Face-to-face clinicians do not use the CGI-S in their daily practice and therefore are less familiar with its application, while online clinicians had used this tool in other research studies and were consequently more familiar with its application. Additionally, due to the CGI-S's instruction ("Considering your total clinical experience with this particular population, how mentally ill is the patient at this time?"), it has been acknowledged that clinician experience could explain the variability in the CGI-S scoring [66]. It is important to note that our study used varying levels of clinicians (eg, psychiatrists vs less experienced Youth Access Clinicians) that could also act as confounding factors when scoring. Furthermore, this study reveals a difference between face-to-face and online clinicians, despite all clinicians having been trained in using the clinical staging framework as set out by Hickie and colleagues [7]. This suggests a need for an ongoing education and training program.

Future research is needed to evaluate the engagement, efficacy, and effectiveness of MHeC's online assessment within real-world service environments. It would also include formal validation of the online assessment against gold standard assessment and testing the effectiveness of any education and training program that might be developed to supplement these new and innovative technological solutions for the delivery of better mental health care.

Conclusions

This study highlights the use of new and innovative technologies to assess clinical stage in early intervention youth mental health services through an online MHeC. It promotes systematic assessment of lifetime severity and complexity of clinical presentations while concurrently addressing risk assessment in a shorter period of time. The MHeC has the potential to be adapted to varied settings in which young people are connecting with traditional clinical services and assist in providing the right care at the right time.

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Conflicts of Interest

IBH was an inaugural commissioner on Australia's National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates an early-intervention youth service at Camperdown under contract to *headspace*. IBH has previously led community-based and pharmaceutical industry–supported (Wyeth, Eli Lilly, Servier, Pfizer, AstraZeneca) projects focused on the identification and better management of anxiety and depression. He was a member of the Medical Advisory Panel for Medibank Private until October 2017 and a board member of Psychosis Australia Trust and a member of Veterans Mental Health Clinical Reference group. He is the Chief Scientific Advisor to, and an equity shareholder in, Innowell. Innowell has been formed by the University of Sydney and PricewaterhouseCoopers to deliver the $30 million Australian Government–funded Project Synergy, a 3-year program for the transformation of mental health services through the use of innovative technologies. EMS is the Medical Director of the Young Adult Mental Health Unit, St Vincent's Hospital, Darlinghurst; Discipline Leader of Adult Mental Health, School of Medicine, University of Notre Dame; Research Affiliate, The University of Sydney; and a consultant psychiatrist. She has received honoraria for educational seminars related to the clinical management of depressive disorders supported by Servier and Eli Lilly. She has participated in a national advisory board for the antidepressant compound Pristiq, manufactured by Pfizer. She was the national coordinator of an antidepressant trial sponsored by Servier. LOP, TD, FI, AT, and SC have no conflicts of interest to declare.

Multimedia Appendix 1

Video visit semistructured interview.

[PDF File (Adobe PDF File), 26KB - jmir_v20i9e259_app1.pdf]

Multimedia Appendix 2

Consolidated Standards of Reporting Trials diagram indicating the flow of participants through the study.

[PDF File (Adobe PDF File), 34KB - jmir_v20i9e259_app2.pdf]

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Abbreviations

CGI-S: Clinical Global Impression Scale-Severity
FET: Fisher exact test
H: Kruskal–Willis test
HEEADSSS: Home, Education and Employment, Eating, Activities, Drugs and Alcohol, Sexuality, Suicide and Depression, Safety
ICC: intraclass correlation coefficient
IQR: interquartile range
MHeC: Mental Health eClinic
SIDAS: Suicidal Ideation Attributes Scale
SOFAS: Social and Occupational Functioning Assessment Scale
U: Mann–Whitney test

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Original Paper

Web-Based Cognitive Behavioral Therapy Blended With Face-to-Face Sessions for Major Depression: Randomized Controlled Trial

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Abstract

Background: Meta-analyses of several randomized controlled trials have shown that cognitive behavioral therapy (CBT) has comparable efficacy to antidepressant medication, but therapist availability and cost-effectiveness is a problem.

Objective: This study aimed to evaluate the effectiveness of Web-based CBT blended with face-to-face sessions that reduce therapist time in patients with major depression who were unresponsive to antidepressant medications.

Methods: A 12-week, assessor-masked, parallel-group, waiting- list controlled, randomized trial was conducted at 3 medical institutions in Tokyo. Outpatients aged 20-65 years with a primary diagnosis of major depression who were taking ≥1 antidepressant medications at an adequate dose for ≥6 weeks and had a 17-item GRID-Hamilton Depression Rating Scale (HAMD) score of ≥14 were randomly assigned (1:1) to blended CBT or waiting-list groups using a computer allocation system, stratified by the study site with the minimization method, to balance age and baseline GRID-HAMD score. The CBT intervention was given in a combined format, comprising a Web-based program and 12 45-minute face-to-face sessions. Thus, across 12 weeks, a participant could receive up to 540 minutes of contact with a therapist, which is approximately two-thirds of the therapist contact time provided in the conventional CBT protocol, which typically provides 16 50-minute sessions. The primary outcome was the alleviation of depressive symptoms, as measured by a change in the total GRID-HAMD score from baseline (at randomization) to posttreatment (at 12 weeks). Moreover, in an exploratory analysis, we investigated whether the expected positive effects of the intervention were sustained during follow-up, 3 months after the posttreatment assessment. Analyses were performed on an intention-to-treat basis, and the primary outcome was analyzed using a mixed-effects model for repeated measures.

Results: We randomized 40 participants to either blended CBT (n=20) or waiting-list (n=20) groups. All patients completed the 12-week treatment protocol and were included in the intention-to-treat analyses. Participants in the blended CBT group had significantly alleviated depressive symptoms at week 12, as shown by greater least squares mean changes in the GRID-HAMD score, than those in the waiting list group (−8.9 points vs −3.0 points; mean between-group difference=−5.95; 95% CI −9.53 to

−2.37; *P*<.001). The follow-up effects within the blended CBT group, as measured by the GRID-HAMD score, were sustained at the 3-month follow-up (week 24) and posttreatment (week 12): posttreatment, 9.4 (SD 5.2), versus follow-up, 7.2 (SD 5.7); *P*=.009.

Conclusions: Although our findings warrant confirmation in larger and longer term studies with active controls, these suggest that a combined form of CBT is effective in reducing depressive symptoms in patients with major depression who are unresponsive to antidepressant medications.

Trial Registration: University Hospital Medical Information Network Clinical Trials Registry: UMIN000009242; https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000010852 (Archived by WebCite at http://www.webcitation.org/729VkpyYL)

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KEYWORDS

blended cognitive behavioral therapy; cognitive behavioral therapy; major depressive disorder; major depression; randomized controlled trial

Introduction

Major depression is a common mental disorder with a serious public health impact. Over 300 million people globally are estimated to suffer from major depression, equivalent to 4.4% of the world's population [1]. In addition, major depression is associated with increased morbidity and impaired function; it poses a significant societal and economic burden that accounts for 2.5% of the global disease burden [2]. Thus, it is predicted to be the leading cause of disability in high-income countries by 2030 and the third-leading cause in low-income and middle-income countries [3].

Meta-analyses of a large number of randomized controlled trials (RCTs) have shown that cognitive behavioral therapy (CBT) has efficacy comparable to antidepressant medication [4,5] and is more successful than antidepressant medication in reducing the risk of relapse after treatment ends [6,7]. In addition, the literature shows that many patients would like to access psychotherapy as an alternative or adjunct to pharmacotherapy [8,9]. Despite these compelling justifications for the widespread dissemination and implementation of CBT, significant barriers exist to providing CBT in the routine practice. One barrier to broadly disseminating CBT is an insufficient number of trained therapists [10]. The United Kingdom initiated a national project called "Improving Access to Psychological Therapies" to improve access to psychotherapy for patients with depression and anxiety. In this project, >3600 new therapists were trained and deployed in the initial 3 years; however, the program required a total cost of 309 million pounds (equivalent to US $405 million) [11]. Thus, large-scale CBT dissemination requires addressing inevitable resource allocation problems.

Computerized CBT (see Multimedia Appendix 1) is an alternative strategy for the broad dissemination of CBT and is considered to be more cost-effective. Although ample research has demonstrated the efficacy of computerized CBT in controlled research settings [12,13], the evidence to date indicates that computerized CBT without human support typically has much smaller effects and is associated with a higher rate of attrition than those with a modest amount of human support [12]. Furthermore, a pragmatic trial that tested the efficacy of 2 widely known computerized CBT programs delivered through a website, that is, Web-based CBT (the Mood Gym and Beating the Blues) with a small amount of telephone support in a primary care setting, found no clinical benefit and an extremely low treatment adherence [14].

To overcome low adherence while improving the beneficial effect of Web-based CBT, a newer treatment format, called blended CBT, where CBT sessions delivered by a therapist and computer are integrated into 1 treatment protocol, has been developed [15,16]; this blended format can be beneficial by tailoring sessions to meet patient-specific needs during therapist-delivered sessions, over and above the computerized program [17,18]. In addition, blended CBT aids in improving the efficiency by allowing therapists to focus more on process-related treatment components (eg, treatment introduction, evaluation, discussing thoughts and feelings, and asking questions about homework) in their therapist-delivered sessions, while more practical therapy components, such as psychoeducation, mood and activity diaries, and homework, can be done through the computerized program [18].

Despite the aforementioned advantages, so far only a few researchers have tested the efficacy of blended CBT in comparison with a control condition in the treatment of clinically diagnosed major depression. An 8-week blended CBT protocol developed by Wright et al [19] demonstrated beneficial effects compared with waiting list controls. Furthermore, a modified version of Wright's earlier protocol, involving the therapy extension by another 8 weeks by adding 4 25-minute booster face-to-face sessions, showed similar effects as the conventional 16-week CBT protocol [20]. However, these trial participants were not currently taking antidepressant medications.

The blended CBT protocol used in this study was designed to integrate the Web-based CBT program using *Kokoro-no-skill-up-training* [21] with face-to-face sessions. *Kokoro-no-skill-up-training* (*Kokoro-no* means "for the mind" in Japanese) is a Web-based CBT program developed by one of our authors (YO), which provides computerized CBT modules. The stand-alone version of *Kokoro-no-skill-up-training* has demonstrated a beneficial effect on high-stress workers [22] and school students [23].

The objective of this study was to demonstrate that Web-based CBT blended with face-to-face sessions is effective in treating patients with major depression who are unresponsive to antidepressant medications, while reducing the therapist time. This study focuses on subjects with refractory depression because one-third of patients with major depression have considerable residual symptomatology after initial treatment [24,25]. Studies have shown that the addition of CBT is a promising strategy for refractory depression [26,27]. We, therefore, conducted an assessor-masked, 12-week, RCT to test the effectiveness of blended CBT for patients with major depression who did not respond to ≥1 antidepressant medication. Furthermore, in an uncontrolled explorative analysis, we investigated whether the expected positive effects of the intervention were sustained at follow-up, 3 months after the posttreatment assessment.

Methods

Design and Approval

This study was a 12-week, single-blind, waiting list controlled, randomized trial. The study was approved by the Ethics Committees of the study sites and registered in the University Hospital Medical Information Network Clinical Trials Registry (UMIN000009242). The study was conducted and reported in accordance with the Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and onLine TeleHealth checklist [28].

Participants

Participants were individuals who sought treatment for major depression at 3 study sites located in Tokyo: a university teaching hospital, a psychiatric hospital, and a general hospital. Those who agreed to participate were asked to provide written consent and undergo a baseline assessment.

Participants were eligible for inclusion in this study if they were aged 20-65 years and had Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) major depressive disorder [29], as confirmed by the Structured Clinical Interview for DSM-IV-TR Axis I Disorders-Patient Edition (SCID-I/P) [30]. In addition, all participants met the operationalized criteria of having a 17-item GRID-Hamilton Depression Rating Scale (GRID-HAMD) [31,32] score of ≥14 despite having received adequate therapy with ≥1 antidepressant medications for at least 6 weeks as part of their routine care, and had access to the internet at home.

The exclusion criteria were a primary DSM-IV axis I diagnosis other than major depressive disorder, as assessed by the Mini-International Neuropsychiatric Interview [33,34], manic or psychotic episodes, alcohol or substance use disorder or antisocial personality disorder, serious and imminent suicidal ideation, organic brain lesions or major cognitive deficits, and serious or unstable medical illnesses. Moreover, those who had received CBT in the past (ie, defined as attending ≥8 CBT sessions) or who were unlikely to attend >8 sessions of study treatment (for reasons such as planned relocation) were excluded. The diagnostic interviews were conducted by treating psychiatrists, all of whom had received extensive training in the administration of semistructured interviews.

Randomization and Masking

All eligible participants were randomly allocated (in a ratio of 1:1) to either the blended CBT group or the waiting list group. The allocation was concealed with the use of a Web-based random allocation system. Randomization was stratified by the study site using the minimization method to balance participants in terms of their age at study entry (<40 years, ≥40 years) and baseline GRID-HAMD score (14-18, ≥19).

Owing to the nature of interventions, although neither participants nor treating psychiatrists or therapists could be masked to the randomization status, the primary outcome measure (GRID-HAMD) was assessed by central assessors using the telephone. Central assessors were not involved with the treatment or study coordination and were prohibited from accessing any information that would reveal participant allocation. In addition, participants were instructed not to disclose their allocated treatment during telephonic interviews. All assessors were licensed clinical psychologists based at the National Center of Neurology and Psychiatry who had received extensive GRID-HAMD training and achieved excellent interrater reliability (intraclass correlation=.98). The percentage of agreement and kappa coefficients between the actual allocation and the allocation guessed by central assessors were 62.5% and .20 (95% CI –0.10 to 0.46) for the 6-week midpoint assessment and 60.0% and.25 (95% CI –0.06 to 0.52) for the 12-week posttreatment assessment, respectively, indicating that masking was successful.

Treatment Procedures

Web-Based Cognitive Behavioral Therapy Blended With Face-to-Face Sessions

Participants allocated to the blended CBT arm were offered 12 weeks of Web-based CBT blended with 12 45-minute face-to-face sessions, with no booster session. Multimedia Appendix 2 provides an overview of the blended CBT program, which integrates the Web-based program using the *Kokoro-no-skill-up-training* with 12 weekly therapist sessions. The Web-based program consists of the following 5 core components: (1) psychoeducation, assessment, and problem clarification; (2) behavioral activation; (3) cognitive restructuring; (4) problem solving; and (5) relapse prevention (outline shown in Multimedia Appendix 3). By accessing the Web-based program, participants watched psychoeducational video clips and read short columns, rated and monitored their daily mood graphs, and mastered CBT skills, including behavioral activation, recognizing and addressing dysfunctional thoughts, and problem solving, by entering text as interactively guided on the Web screen. Although participants were encouraged to work with their Web-based program during the intervention period at their own pace, each module typically took about 30 minutes to complete. In the face-to-face session, therapists reviewed the material covered in the Web-based program, evaluated and discussed the participant-specific problem, and practiced CBT skills and set homework for the next session using the Web-based program. A guidebook was provided to facilitate mastery of the program. The guidebook offers a detailed session-by-session treatment procedure that includes information on how and when to use the specific

Web-based content to meet the individualized needs of diverse participants.

We selected a 12-week format to improve the efficiency of treatment by reducing the number of therapist sessions compared with the standard Japanese CBT protocol, which offers 16 50-minutes sessions [35]. Thus, across 12 weeks, a participant could receive up to 540 minutes of contact with a therapist, approximately two-thirds of that provided in the conventional CBT protocol (ie, a total of 800 minutes). After 12 sessions of blended CBT, participants resumed usual care. Notably, 1 psychiatrist, 2 clinical psychologists with a doctoral degree, and 1 psychiatric nurse provided the blended CBT. Together, the therapists had practiced CBT for a mean of 6.0 (SD 2.4) years before the study. All therapists received CBT training, which included a 2-day intensive CBT workshop and 1-hour onsite group supervision every week from a skilled CBT supervisor (AN), with thorough reviews of cases and detailed feedback to maintain the adherence to CBT protocols and competence during the study. Participants allocated to the waiting list group also received the intervention after a 12-week waiting period and were informed about this before study entry.

Treatment as Usual

Participants allocated to both the blended CBT and waiting list groups continued treatment as usual with their treating psychiatrist. It consisted of medication management along with education regarding medication and dosage schedules, review of adverse effects, and supportive guidance from treating psychiatrists. Monitoring of depressive symptoms with the 16-item Quick Inventory of Depressive Symptomatology Self-Report (QIDS) [36,37] was conducted at each visit. Although there were no particular restrictions on the pharmacotherapy provided, treatments were in line with practice guidelines for depression care [38]. Three treating psychiatrists who had specialist experience in psychiatric care for a mean of 6.6 (SD 5.7) years provided the medication visits, which were offered roughly every 2 weeks, each visit lasting approximately 10 minutes. Notably, treating psychiatrists were not involved in the delivery or supervision of CBT.

Outcomes

The primary outcome was the alleviation of depressive symptoms, as measured by the change in the total 17-item GRID-HAMD score from the baseline (at randomization: baseline assessment) to 12 weeks postrandomization (at the end of the intervention or waiting period: posttreatment assessment). The GRID-HAMD is an amended version of the original Hamilton Depression Rating Scale, which provides standardized explicit scoring conventions with a structured interview guide for administration and scoring [31,32]. In addition, changes were assessed after 6 weeks (midpoint assessment). Furthermore, outcome measures were assessed 3 months after the intervention was completed (follow-up assessment) in the blended CBT group only. For ethical reasons, we decided to offer CBT to participants from the control group after their participation in the waiting list study group. Therefore, the planned follow-up analysis to determine whether the effect of CBT was sustained was uncontrolled.

All secondary outcomes were also evaluated at the same time-points; these included treatment response (≥50% reduction in the baseline GRID-HAMD score); remission (GRID-HAMD score≤7); participant-rated measures of depressive symptoms, that is Beck Depression Inventory-Second Edition (BDI) score [39,40] and QIDS score; participant-rated inventory for depressogenic schemata, that is 24-item dysfunctional attitude scale (DAS-24) score [41,42]; and the quality-of-life status as measured by the mental and physical component summary score of the 36-Item Short-Form Health Survey [43,44]. Furthermore, participants were asked to complete the European Quality of Life Questionnaire-5 Dimensions to measure the health-related quality of life [45,46].

Information on the total daily dose of each antidepressant medication was expressed as a fraction of the World Health Organization's defined daily dose [47], which is defined as the assumed average maintenance dose per day for adults calculated from the dosage recommendations for each drug. In addition, adverse events were monitored. Serious adverse events were defined as death, life-threatening events, events leading to severe impairment or dysfunction, and hospitalization.

Statistical Analysis

Based on Wright et al [19], we assumed that a mean difference of 6 points on the 17-item GRID-HAMD score with an SD of 5.5 between the 2 groups would be clinically meaningful. With a two-sided 5% significance level and 90% power, a sample size of 18 was required for each group. Therefore, a total sample of 40 would provide sufficient power while also accounting for possible attrition. As we were not aware of any published blended CBT studies on refractory depression, we calculated the sample size of our study based on this prior study that included patients with a similar depression severity as our patients.

The primary analysis was performed on an intention-to-treat basis, and all randomized participants were included. For continuous outcomes, the least squares means (LS means) and their 95% CIs were estimated using a mixed-effects model for repeated measures (MMRM) for changes from the baseline, which contained the treatment group, week, and group-by-week interaction as fixed-effects with an unstructured covariance matrix among time-points; Kenward-Roger degrees of freedom adjustment were used. Mean changes for each group at each time-point and mean between-group differences were estimated using appropriate contrasts in the MMRM. Notably, missing values were not inputted. For categorical outcomes, relative risks (RRs) and their 95% CIs were calculated. The number needed to treat (NNT) was calculated when a 95% CI of RR did not include 1.0. In addition, we calculated the effect size (Cohen *d*) for all significant outcome measures (ie, as the difference in mean changes at posttreatment assessment between the blended CBT group and the waiting list group divided by the pooled SD of both groups). The effect size was classified as small (Cohen *d*=0.2-0.49), medium (Cohen *d*=0.5-0.79), or large (Cohen *d*>0.8) [48]. Furthermore, we investigated the follow-up effects in the blended CBT group with paired *t* tests, comparing the scores at follow-up assessment with the scores at posttreatment assessment. The significance level was set at.05

(two-tailed) for all analyses. No multiple-testing correction was applied because this study was an RCT with a single primary null-hypothesis. Statistical analyses were performed with SAS version 9.4 (SAS Institute, Cary, NC, USA).

Results

Figure 1 shows participants' flow from screening to 3-months follow-up during the study. We screened 57 patients between November 29, 2011 and November 18, 2015, and the final 3-month follow-up was done on May 4, 2016. Of these 57 patients, 12% (7/57) did not meet the inclusion criteria and 18% (10/57) declined to participate. Therefore, 70% (40/57) eligible patients who agreed to participate and completed baseline assessments were randomized either to the blended CBT (n=20) or waiting list (n=20) group. There were no dropouts from the study, and all participants allocated to the blended CBT group completed the follow-up assessment.

Table 1 summarizes the sociodemographic and clinical characteristics of participants at the baseline. The mean age of participants was 40.2 (SD 9.8) years, and the percentage of males was 50% (20/40). Furthermore, 68% (27/40) participants had received one course of antidepressant medication and 33% (13/40) had received 2 courses before study entry. None of the participants had received >3 courses of antidepressant medication before study entry.

Tables 2 and 3 show treatment engagement by the study groups.

Figure 1. The Consolidated Standards of Reporting Trials diagram of participants' flow through the study. CBT: cognitive behavioral therapy.

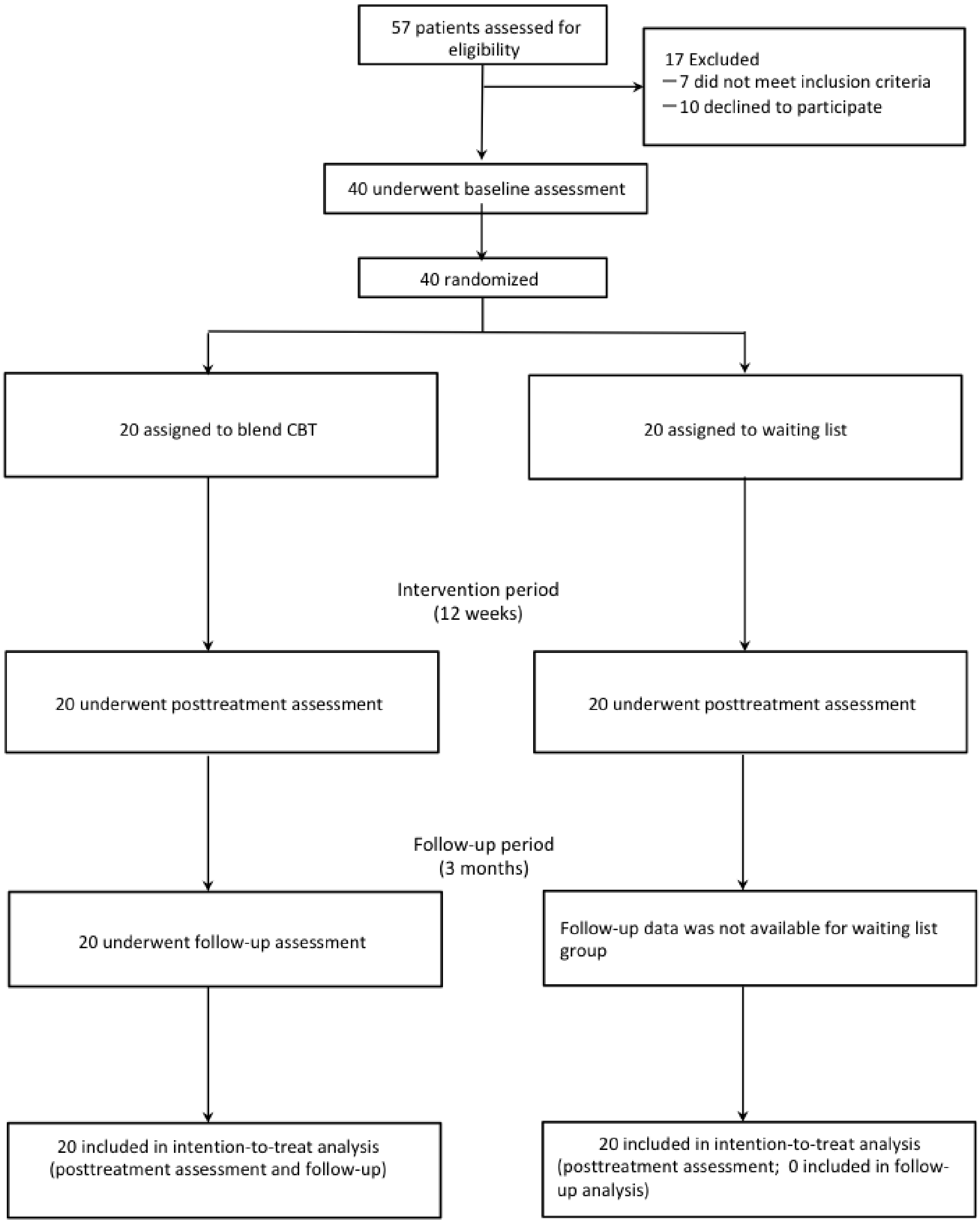


Table 1. Characteristics of participants at the baseline.

Characteristic	Blended CBT[a] (n=20)	Waiting list (n=20)	Total (n=40)
Age (years), mean (SD)	39.7 (9.4)	40.6 (10.2)	40.2 (9.7)
Male, n (%)	10 (50)	10 (50)	20 (50)
Education (years), mean (SD)	15.4 (1.9)	15.6 (2.6)	15.4 (2.2)
Unemployed, n (%)	3 (15)	4 (20)	7 (18)
Marital status, n (%)			
Married	8 (40)	10 (50)	18 (45)
Separated, divorced, or widowed	2 (10)	0 (0)	2 (5)
Single (never married)	10 (50)	10 (50)	20 (50)
Cohabiting, n (%)	14 (70)	16 (80)	30 (75)
Number of lifetime depression episodes, mean (SD)	1.5 (0.6)	1.7 (1.4)	1.6 (1.1)
History of psychiatric hospitalization, n (%)	1 (5)	3 (15)	4 (10)
Prior suicide attempt, n (%)	1 (5)	1 (5)	2 (5)
Self-reported childhood abuse, n (%)	2 (10)	5 (25)	7 (18)
Self-reported victims of childhood bullying, n (%)	5 (25)	3 (15)	8 (20)
Family history of psychiatric disorders, n (%)	7 (35)	5 (25)	12 (30)
Duration of index depression episode (months), mean (SD)	27.3 (29.8)	20.3 (32.3)	23.8 (30.9)
Particulars of index episode (DSM-IV[b]), n (%)			
Chronic (≥2 years of index episode)	8 (40)	4 (20)	12 (30)
Melancholic features	12 (60)	11 (55)	23 (58)
Atypical features	0 (0)	0 (0)	0 (0)
Comorbid DSM-IV Axis I diagnoses, n (%)			
Any anxiety disorder	1 (5)	5 (25)	6 (15)
Panic disorder (with or without agoraphobia)	0 (0)	2 (10)	2 (5)
Social anxiety disorder	1 (5)	1 (5)	2 (5)
Obsessive compulsive disorder	0 (0)	0 (0)	0 (0)
Generalized anxiety disorder	0 (0)	0 (0)	0 (0)
Dysthymic disorder	0 (0)	0 (0)	0 (0)
Number of prior courses of antidepressant treatment, n (%)			
1-2 courses	15 (75)	15 (75)	30 (75)
3-4 courses	2 (10)	3 (15)	5 (13)
5-6 courses	2 (10)	1 (5)	3 (8)
7-10 courses	1 (5)	0 (0)	1 (3)
>10 courses	0 (0)	1 (5)	1 (3)
Number of antidepressant medications prescribed at baseline, n (%)			
1 medication	14 (70)	13 (65)	27 (67.5)
≥2 medications	6 (30)	7 (35)	13 (32.5)
Health-related quality of life, mean (SD)			
European Quality of Life Questionnaire 5-dimension, mean (SD)	0.7 (0.1)	0.8 (0.1)	0.7 (0.1)
Depression severity			
17-item GRID-Hamilton Depression Rating Scale score, mean (SD)	18.3 (3.7)	18.5 (3.6)	18.4 (3.6)
Beck Depression Inventory-Second Edition score, mean (SD)	28 (8.8)	24.4 (7.8)	26.2 (8.4)

Characteristic	Blended CBT[a] (n=20)	Waiting list (n=20)	Total (n=40)
Quick Inventory of Depressive Symptomatology Self-Report score, mean (SD)	14.8 (4.2)	13.5 (4)	14.1 (4.1)

[a]CBT: cognitive behavioral therapy.

[b]DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.

Table 2. Treatment engagement of the study group (n=20).

Treatment engagement	Value
Mean number of blended CBT[a] sessions attended, mean (SD)	11.65 (2.32)
Completion rate of the full course of blended CBT sessions (*n* of blended CBT completers/*n* of blended CBT participants), n (%)	20 (100)
Mean duration of face-to-face-CBT sessions (minutes), mean (SD)	44.3 (6.85)
Mean duration of medication visits (minutes, over 12-weeks), mean (SD)	11.6 (2.3)

[a]CBT: cognitive behavioral therapy.

Table 3. Treatment engagement of the groups.

Treatment engagement	Blended CBT[a] (n=20)	Waiting list (n=20)	*P* value[b]
Mean medication compliance over 12-weeks, treatment and medication compliance data scale self-report, n (%)	19 (97)	19 (96)	.67
Number of medication visits over 12-weeks, mean (SD)	8 (1)	7 (1)	.37
Mean antidepressant medication dose at baseline and 12 weeks, mean (SD)			
0 week (baseline)	1.39 (0.58)	1.31 (0.75)	.74
12 weeks	1.21 (0.68)	1.31 (0.75)	.67
Changes in antidepressant prescription by the end of the 12-week intervention period, n (%)			
No change	14 (70)	10 (50)	.20
Switched to another antidepressant	2 (10)	1 (5)	>.99
Increased antidepressant dose	1 (5)	1 (5)	>.99
Combined another antidepressant	1 (5)	3 (15)	.61
Decreased	0 (0)	3 (15)	.23
Stopped antidepressant	2 (10)	2 (10)	>.99

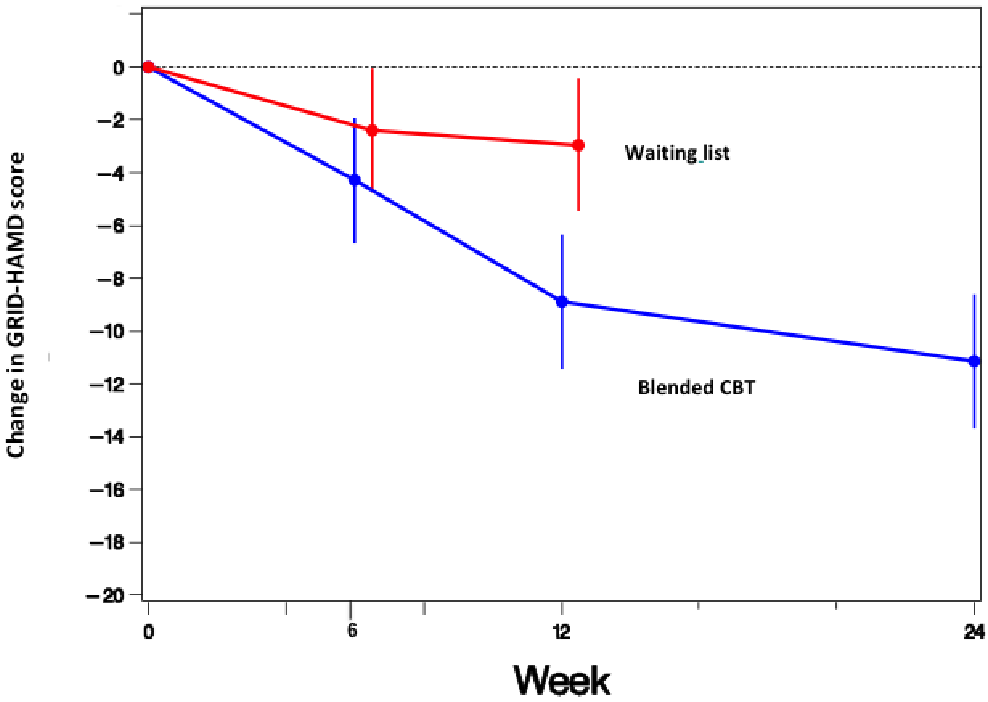
[a]CBT: cognitive behavioral therapy.

[b]*P* values are for *t* test for continuous outcomes and chi-square test for categorical outcomes.

All participants allocated to the blended CBT group completed the full program course (defined as attending at least 8 sessions). The therapist adherence (yes or no) to the CBT treatment protocol was at high level—100% (n/allocators=20/20) for behavioral activation component, 90% (18/20) for cognitive reconstruction component, and 85% (17/20) for problem-solving component. In terms of the medication management, the mean daily dose of antidepressant medications was comparable at each assessment point between the groups, and no significant dose changes were observed during the 12-week interventional period. Selective serotonin reuptake inhibitors were the most common antidepressant medication prescribed at the baseline, 35% (14/40) participants (Multimedia Appendix 4). There were no differences in the number of medical visits between the groups.

Participants in the blended CBT group had significantly alleviated depressive symptoms after 12 weeks, as shown by greater LS mean changes in the GRID-HAMD score compared with that in the waiting list group (−8.9 points vs −3.0 points; mean between-group difference=−5.95; 95% CI −9.53 to −2.37; *P*=.0002; Cohen *d*=1.0; Figure 2). Figure 2 shows LS mean changes and their 95% CIs in the GRID-HAMD total scores over time estimated with a MMRM analysis; error bars indicate 95% CIs. In addition, the follow-up effects showed that the GRID-HAMD score at 3-month follow-up had improved significantly compared with the GRID-HAMD score after 12 weeks: 9.4 (SD 5.2) vs 7.2 (SD 5.7); *P*=.009. Of note, no significant treatment effect was observed after 6 weeks (*P*=.25).

Figure 2. Least squares mean change in the 17-item GRID-Hamilton Depression Rating Scale (GRID-HAMD) score over time in participants allocated to the blended cognitive behavioral therapy (CBT) group or waiting list group.



Tables 4 and 5 summarize the secondary outcome measures. Participants allocated to the blended CBT group were 2.8 times more likely to have a treatment response at the posttreatment (12 weeks) assessment than those in the waiting list group (RR, 2.75; 95% CI 1.05-7.20), resulting in an NNT of 3 (95% CI 1.6-14.2). In addition, the blended CBT group demonstrated achievement of significant remission at the posttreatment assessment (12 weeks; RR, 8.00, 95% CI 1.10-58.19; NNT: 3, 95% CI 1.7-8.7). Although the blended CBT group participants had milder depressive symptoms, as measured by the BDI, than the participants of the waiting-list group over the intervention period, differences were not statistically significant at each assessment point. There were no statistically significant differences between the groups in the intensity of depressogenic schemata, as assessed by the DAS-24, and in the quality-of-life status, as assessed by the 36-Item Short-Form Health Survey, mental and physical subscales, and the European Quality of Life Questionnaire-5 Dimensions, over the study period. Of note, none of the participants experienced serious adverse events during the intervention period.

Table 4. Summary of repeated measures analyses of outcomes: treatment response and remission (intention-to-treat population).

Timepoint of achieving response or remission	Blended CBT[a] (n=20), n (%)	Waiting list (n=20), n (%)	Comparison	
			Relative risks (95% CI)	*P* value
Response (≥50% reduction in 17-item GRID-HAMD[b])				
6 weeks	2 (10)	2 (10)	1.00 (0.16 to 6.42)	>.99
12 weeks	11 (55)	4 (20)	2.75 (1.05 to 7.20)	.04
24 weeks (3-month follow-up) only CBT	15 (75)	N/A[c]	N/A	N/A
Remission (GRID-HAMD≤7)				
6 weeks	2 (10)	1 (5)	2.00 (0.20 to 20.33)	.56
12 weeks	8 (40)	1 (5)	8.00 (1.10 to 58.19)	.04
24 weeks (3-month follow-up) only CBT	13 (65)	N/A	N/A	N/A
Response (≥50% reduction in QIDS[d])				
6 weeks	12 (60)	6 (30)	2.00 (0.94 to −4.27)	.07
12 weeks	9 (45)	3 (15)	3.00 (0.95 to −9.48)	.06
24 weeks (3-month follow-up) only CBT	14 (70)	N/A	N/A	N/A
Remission (QIDS≤5)				
6 weeks	6 (30)	4 (20)	1.50 (0.20 to −20.33)	.56
12 weeks	6 (30)	3 (15)	2.00 (0.58 to −6.91)	.27
24 weeks (3-month follow-up) only CBT	11 (55)	N/A	N/A	N/A
Response (≥50% reduction in BDI[e])				
6 weeks	3 (15)	2 (10)	1.50 (0.28 to −8.04)	.64
12 weeks	7 (35)	3 (15)	2.33 (0.70 to −7.76)	.17
24 weeks (3-month follow-up) only CBT	10 (50)	N/A	N/A	N/A
Remission (BDI≤13)				
6 weeks	4 (20)	5 (25)	0.80 (0.25 to −2.55)	.71
12 weeks	8 (40)	5 (25)	1.60 (0.63 to −4.05)	.32
24 weeks (3-month follow-up) only CBT	10 (50)	N/A	N/A	N/A

[a]CBT: cognitive behavioral therapy.
[b]GRID-HAM: GRID-Hamilton Depression Rating Scale.
[c]N/A: not applicable.
[d]QIDS: Quick Inventory of Depressive Symptomatology.
[e]BDI: Beck Depression Inventory-Second Edition.

Table 5. Summary of repeated measures analyses of outcomes: participant-rated measures (intention-to-treat population).

Participant-rated measures	Blended CBT[a], mean (SD)	Waiting list, mean (SD)	Difference in mean change scores[b,c] (95% CI)	*P* value
17-item GRID-Hamilton Depression Rating Scale score				
0 week (baseline)	18.3 (3.6)	18.5 (3.6)	N/A[d]	N/A
6 weeks	14.0 (5.7)	16.1 (4.7)	1.90 (−1.46 to 5.26)	.26
12 weeks	9.4 (5.1)	15.5 (6.3)	5.95 (2.37 to 9.53)	.002
24 weeks (3-month follow-up) only CBT	7.2 (5.7)	N/A	N/A	N/A
Beck Depression Inventory-Second Edition score				
0 week (baseline)	28.0 (8.6)	24.4 (7.6)	N/A	N/A
6 weeks	23.4 (11.2)	20.1 (8.2)	0.35 (−4.63 to 5.33)	.89
12 weeks	18.5 (12.3)	20.8 (9.1)	5.85 (−0.27 to 11.97)	.06
24 weeks (3-month follow-up) only CBT	14.7 (12.5)	N/A	N/A	N/A
Quick Inventory of Depressive Symptomatology Self-Report score				
0 week (baseline)	14.8 (4.0)	13.5 (3.9)	N/A	N/A
6 weeks	7.9 (3.7)	8.7 (3.8)	2.20 (−0.66 to 5.06)	.13
12 weeks	8.0 (4.7)	10.2 (4.2)	3.55 (0.53 to 6.57)	.02
24 weeks (3-month follow-up) only CBT	6.8 (5.5)	N/A	N/A	N/A
Dysfunctional attitude scale score				
0 week (baseline)	97.1 (19.0)	87.6 (17.1)	N/A	N/A
6 weeks	97.4 (19.2)	86.1 (17.8)	−1.80 (−9.23 to 5.63)	.63
12 weeks	92.4 (23.6)	84.9 (18.5)	2.05 (−6.82 to 10.92)	.64
24 weeks (3-month follow-up) only CBT	83.4 (21.8)	N/A	N/A	N/A
European Quality of Life Questionnaire-5 Dimensions score				
0 week (baseline)	0.7 (0.1)	0.7 (0.1)	N/A	N/A
6 weeks	0.8 (0.1)	0.8 (0.1)	−0.04 (−0.12 to 0.04)	.29
12 weeks	0.8 (0.1)	0.8 (0.1)	−0.07 (−0.16 to 0.01)	.08
24 weeks (3-month follow-up) only CBT	0.8 (0.1)	N/A	N/A	N/A
36-item Short-Form Health Survey (SF-36) mental component summary score				
0 week (baseline)	37.7 (10.6)	37.8 (7.7)	N/A	N/A
6 weeks	39.5 (9.7)	41.6 (8.3)	1.96 (−3.45 to 7.37)	.47
12 weeks	43.9 (10.2)	41.3 (7.9)	−2.70 (−8.91 to 3.50)	.38
24 weeks (3-month follow-up) only CBT	44.6 (11.1)	N/A	N/A	N/A
SF-36 physical component summary score				
0 week (baseline)	52.8 (11.2)	51.7 (10.8)	N/A	N/A
6 weeks	50.8 (11.0)	53.5 (7.4)	3.87 (−1.90 to 9.64)	.18
12 weeks	49.4 (13.5)	53.4 (10.6)	5.04 (−2.81 to 12.89)	.20
24 weeks (3-month follow-up) only CBT	52.8 (9.6)	N/A	N/A	N/A

[a]CBT: cognitive behavioral therapy.

[b]The difference in the mean change in scores is the intergroup difference in the least squares mean treatment change score from the baseline to the data point, from the mixed-effects model for repeated measures analysis.

[c]The intergroup difference is the CBT group value minus the waiting list group value.

[d]N/A: not applicable.

Discussion

This study tested the effectiveness of the blended CBT program in patients with major depression who did not respond to antidepressant treatment after taking ≥1 antidepressant medications at adequate doses for ≥6 weeks, compared with waiting list control conditions. The between-group effect size after blended CBT was large (Cohen *d*=1.0), and these results were similar to Wright et al's blended CBT trial using waiting list controls (Cohen *d*=1.14) [19]. In addition, we were able to reduce the therapist contact time by about two-thirds compared with the standard CBT protocol. Furthermore, we focused on patients who were unresponsive to antidepressant medications.

There are several possible reasons for the high level of treatment protocol adherence with no dropouts with the blended CBT program in this study. First, the program had a blended format rather than a stand-alone Web-based CBT program. Patients might have developed a stronger treatment engagement through the therapist-delivered session because of tailoring the program according to patient-specific needs and may have gained mastery of CBT skills by accessing the interactive Web-based program. Second, owing to the shortage of trained therapists [49] and insufficient health insurance coverage of CBT sessions in Japan (health insurance does not cover CBT sessions delivered by psychologists), participants may have had strong expectations from CBT. Dunlop et al reported that patients matched to their preferred treatment could achieve a higher rate of treatment completion than those who were mismatched [50].

Significant alleviation of depressive symptoms was found in the assessment of primary (GRID-HAMD) and secondary outcome measures of depressive symptoms (QIDS). Furthermore, the remission rate (8/20, 40%) as measured by the GRID-HAMD was similar to that reported by Thase et al [20]. In contrast to their findings, our study did not show significant differences in self-reported depressive symptomatology, as measured by the BDI and DAS-24, between the groups. As this study was powered to detect the effectiveness based on the primary outcome measure, it is possible that these secondary outcome measures were underpowered. In addition, the BDI and DAS-24 baseline scores of our sample were lower than those reported by Thase et al [20], which could have been because of a floor effect.

Our blended CBT program has a unique format, integrating Web-based and offline components back to back. Patients engage themselves in a self-directed Web-based learning module, such as by reading psychoeducational columns and watching video clips, before coming to the face-to-face session. Moreover, in the subsequent face-to-face session, patients assimilate and apply what they have learned in the Web-based component to reinforce mastery of CBT skills. Thus, this blended format appears to correspond with the newer educational system, known as "blend learning" or "inverted classroom," which is reported to be more effective than purely face-to-face or purely Web-based classes [51]. In addition, this blended format is perhaps promising for trainee therapists. With the Web-based assistance, therapists can deliver CBT techniques with more confidence, despite little experience. In fact, studies have shown that computer-assisted training is effective in training clinicians in empirically supported manual-guided therapies [52,53].

This study has several limitations. First, this study used waiting list controls rather than active controls. The use of the waiting list group could have provoked nocebo effects [54,55]. However, all our participants allocated to the waiting list group continued their usual treatment with their psychiatrists, and the course of depression symptoms was similar to the course of patients receiving psychiatric care [25]. Second, the benefits of blended CBT observed in this study cannot be solely attributed to the intervention because there was no treatment control. In other words, nonspecific treatment effects, such as patient expectations, may also account for the observed efficacy of the intervention. Nevertheless, this study aimed to examine the effectiveness of blended CBT rather than evaluating the effects of blended CBT itself. The third possible limitation is that this study was of relatively small size, although the number of participants exceeded that required for power analysis. Fourth, participants were recruited from 3 sites with a zero dropout rate, suggesting a cohort of highly motivated treatment-seeking patients, which may limit generalizability. Finally, there was no control group during the follow-up phase. Hence, a sustained effect during this phase cannot be attributed with certainty to the effects of acute therapy with our blended CBT program.

In conclusion, this study suggests that our blended CBT program was effective in reducing depressive symptoms in patients with major depression compared with waiting list controls. Additional research is now needed to replicate our results with larger sample size, longer observation period, and using active controls before definite conclusions can be drawn.

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Authors' Contributions

YO and AN conceived and designed the study and drafted the initial study protocol. SN refined the study protocol. AN drafted the grant proposal, organized study implementation, and conducted the study. DM managed study monitoring, including data collection, and liaised with the recruitment sites. YO provided cognitive behavioral therapy expertise, and AN supervised the therapists. MH, SI, and MM are the directors of the 3 study sites and provided onsite study management. SN, AN, and TA conducted the statistical analyses. SN drafted the manuscript.

Conflicts of Interest

AN has received royalties from Igaku-Shoin and Kongo-Shuppan publishers. YO is the developer or sponsor of the *Kokoro-no-Skill-up-training* program and has received royalties from Seiwa-Shoten, Igaku-Shoin, and Kongo-Shuppan publishers. MM has received grants and speaker's honoraria from Daiichi Sankyo, Dainippon-Sumitomo Pharma, Eisai, Eli Lilly, Fuji Film RI Pharma, Janssen Pharmaceutical, Mochida Pharmaceutical, MSD, Nippon Chemipher, Novartis Pharma, Ono Yakuhin, Otsuka Pharmaceutical, Pfizer, Takeda Yakuhin, Tsumura, and Yoshitomi Yakuhin. All the other authors declare that they have no conflicts of interest.

Multimedia Appendix 1

Modes of delivery of computerized cognitive behavioral therapy.

[PDF File (Adobe PDF File), 50KB - jmir_v20i9e10743_app1.pdf]

Multimedia Appendix 2

Overview of the blended cognitive behavioral therapy (CBT) program.

[PPTX File, 3MB - jmir_v20i9e10743_app2.pptx]

Multimedia Appendix 3

The framework of the 12-week web-based cognitive behavioral therapy blended with face-to-face sessions for major depression.

[PDF File (Adobe PDF File), 27KB - jmir_v20i9e10743_app3.pdf]

Multimedia Appendix 4

Type and dose of antidepressant medication prescribed at baseline.

[PDF File (Adobe PDF File), 23KB - jmir_v20i9e10743_app4.pdf]

Multimedia Appendix 5

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 3MB - jmir_v20i9e10743_app5.pdf]

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Abbreviations

BDI: Beck Depression Inventory-Second Edition
CBT: cognitive behavioral therapy
DAS: dysfunctional attitude scale
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
GRID-HAMD: GRID-Hamilton Depression Rating Scale
LS: least squares
MMRM: mixed-effects model for repeated measures
NNT: number needed to treat
QIDS: Quick Inventory of Depressive Symptomatology Self-Report
RR: relative risk

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Original Paper

Proposing an Ecosystem of Digital Health Solutions for Teens With Chronic Conditions Transitioning to Self-Management and Independence: Exploratory Qualitative Study

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Abstract

Background: Chronic disease management is critical to quality of life for both teen patients with chronic conditions and their caregivers. However, current literature is largely limited to a specific digital health tool, method, or approach to manage a specific disease. Guiding principles on how to use digital tools to support the transition to independence are rare. Considering the physiological, psychological, and environmental changes that teens experience, the issues surrounding the transition to independence are worth investigating to develop a deeper understanding to inform future strategies for digital interventions.

Objective: The purpose of this study was to inform the design of digital health solutions by systematically identifying common challenges among teens and caregivers living with chronic diseases.

Methods: Chronically ill teens (n=13) and their caregivers (n=13) were interviewed individually and together as a team. Verbal and projective techniques were used to examine teens' and caregivers' concerns in-depth. The recorded and transcribed responses were thematically analyzed to identify and organize the identified patterns.

Results: Teens and their caregivers identified 10 challenges and suggested technological solutions. Recognized needs for social support, access to medical education, symptom monitoring, access to health care providers, and medical supply management were the predominant issues. The envisioned ideal transition included a 5-component solution ecosystem in the transition to independence for teens.

Conclusions: This novel study systematically summarizes the challenges, barriers, and technological solutions for teens with chronic conditions and their caregivers as teens transition to independence. A new solution ecosystem based on the 10 identified challenges would guide the design of future implementations to test and validate the effectiveness of the proposed 5-component ecosystem.

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KEYWORDS

chronic disease; chronic disease management; digital health; ecosystem; qualitative research; self-management; transition to independence; technology-based solutions

Introduction

Background

Self-management for those with chronic diseases is a significant component for maintaining wellbeing. Nationally, chronic diseases cause 7 out of 10 deaths of US citizens annually, and a large portion of national health care costs are generated by patients with chronic disease [1]. Hence, self-management sustainability greatly impacts national health care cost reductions while increasing the individual's wellbeing and financial independence. Digital solutions developed in recent years assist patients in self-management. Youth especially use health care management technologies (eg, telehealth and mobile health [mHealth]), enabling greater self-management [2].

Digital Solutions in Chronic Disease Management

Digital solutions and mHealth apps concerning chronic disease management (CDM) and behavioral change for teens have been widely discussed, with new solutions proposed in the literature. Hamine et al's [3] review on the self-management of diabetes, cardiovascular disease, and chronic lung diseases concluded that mHealth could potentially facilitate adherence to CDM. Fedele et al [4] argued that mHealth interventions are also a viable approach in behavioral change interventions in young populations (<18 years). However, adopting technology to assist teens in transition is a work-in-progress. Huang et al [5], tested a Web-based and short message service (SMS) text message-delivered disease management app and reported that technology could be a useful and cost-effective solution as a transition intervention. They also discussed that the use of communication technologies (ie, mobile phone calls, SMS, email, and Voice over Internet Protocol) promoted engagement, relationship, and trust between teens and health care providers [6]. These studies support the use of digital solutions and demonstrate a promising next step in CDM technology. In another case, Holtz et al [7] developed and tested a patient-centered mobile app using focus group interviews with teens having type 1 diabetes (T1D) and their parents. Participants reported that they thought that the mobile app would help to improve communication among family members. Many of these studies focused on a specific delivery modality of digital interventions. Our study, in contrast, started with a broader inquiry into patient-centered needs and then explored relevant technological solutions.

Given the physiological, psychological, and environmental changes that teens experience in CDM, digital solutions may fail to keep up with expectations. Slater et al [2] underlined that mHealth interventions have failed to integrate into real-world settings and adoption practices. The impact of using self-management digital communication tools on relationships among parents, teens, and health care providers (HCPs) is unclear [8]. Furthermore, the evidence in the literature is limited regarding caregivers and teens in transition to independence, with no identified studies on digital communication between caregivers and teens in transition [8].

To improve the delivery of health care among teens transitioning to independence with chronic illnesses, Nationwide Children's Hospital (NCH), OH, USA, undertook a quality improvement project. We employed a patient-centered approach to identify and better understand the core problems of CDM and to seek solutions to permit the teen to transition to independence. Our specific aim was to generate a roadmap for chronically ill teens to gain independence.

Methods

Study Design

Data collection methodology included a co-design framework with the use of generative tools utilizing verbal and projective techniques to collect rich data from participants regarding their needs and expectations [9,10]. Our study questions focused on "What common challenges do teens and their caregivers face in preparation for the transition to independent health management?" and "What digital solutions and opportunities would help to overcome the challenges and barriers?" To address these questions, we first identified the challenges, barriers, and gaps during the life journey, and then, we envisioned digital solutions and opportunities to facilitate a successful transition to independence and self-management. Throughout the interviews, participants shared their needs and concerns with the research team. Two of the coauthors (MW and AW) took the lead in interviews and analysis.

Participants

An independent recruiting agency selected participants based on the following inclusion criteria: (1) age 13-18 years, (2) a minimum of one chronic condition for >6 months, and (3) medication taken multiple times a day. The NCH patient network also supported this recruitment process. During a telephone invitation, patients and caregivers were informed on voluntary participation, study goals, and financial compensations for their time. Subsequent interviews were held on NCH's main campus. Parents signed a written consent form indicating their agreement to participate for themselves and their teen. The study was approved by NCH as a quality improvement project and was not subject to the Institutional Review Board.

The study enrolled 13 teens with chronic conditions and their caregivers (n=13). Patient ages ranged from 13 to 18 years. Chronic conditions included at least one of the following diseases: T1D, cystic fibrosis (CF), epilepsy, and attention deficit hyperactivity disorder (ADHD). Most participants had lived with the chronic condition for >5 years (Table 1).

Data Collection

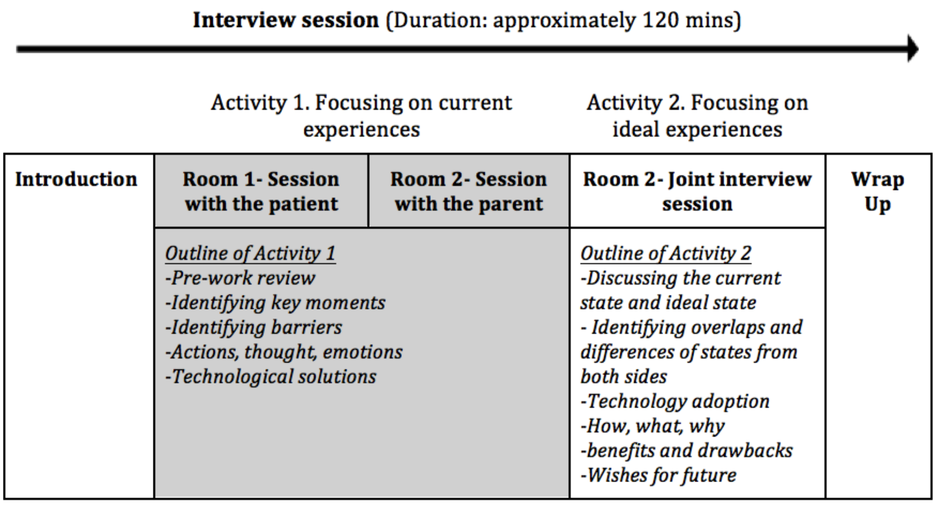
The aim was to develop an in-depth understanding of each participant's experience starting from prediagnosis. Each interview commenced with a brief introduction of the study, including the goals, the agenda, and the roles.

The first activity began with a review of the homework assignment. This was a short reflective exercise completed prior to the interviews including questions with visual illustrations about personality, people who they care about, personal environment, their typical day, and future self (Multimedia Appendix 1). To encourage free expression, concurrent sessions were scheduled for this first activity, separating teens and their parents (Figure 1).

Table 1. Patient demographic information (N=13).

Demographics	n (%)
Age (years)	
11-13	2 (15)
14-15	4 (31)
16-18	7 (54)
Gender	
Male	6 (46)
Female	7 (54)
Chronic condition	
Type 1 diabetes	4 (31)
Cystic fibrosis	2 (15)
Epilepsy	3 (23)
Attention deficit hyperactivity disorder	4 (31)
Length of time since diagnosis	
6 months-2 years	1 (8)
2-5 years	1 (8)
5-10 years	9 (69)
>10 years	2 (15)

Figure 1. Outlining the interview process.



Next, the teen and caregiver worked together to envision an ideal journey that depicted the teen's successful transition to independent management of their therapy. To promote their participation, a canvas (a large white page with visual guidelines) outlining the stages and tools was used, on which participants were able to follow the process as well as to type, draw, and elaborate their opinions (Multimedia Appendix 1).

The second activity was a joint session with the teen and caregiver. Together, each pair shared their current experience and ideal state and identified overlapping experiences and differences, technology adoptions, challenges, opportunities, and expectations in line with the transitioning. An additional canvas was presented to be used for outlining the ideal transition journey (Multimedia Appendix 1). The second session, which focused on technological solutions, discussed the use of technology apps in care, how they are used, their benefits and drawbacks, what the apps were that they wished for, what is needed, and why they were not using the technology. The interview session ended with a closure talk and soliciting final thoughts from the participants.

At least two researchers attended each session, which was recorded. Researchers served as a moderator or an assistant and a note taker. All recordings were transcribed and aggregated with memos and observational notes. Information on the canvases, recordings, and notes was analyzed by thematic analysis. The combination of information sources from both teens and caregivers increased the richness of the data acquired.

Figure 2. Outlining the process of data collection, analysis, and synthesis.

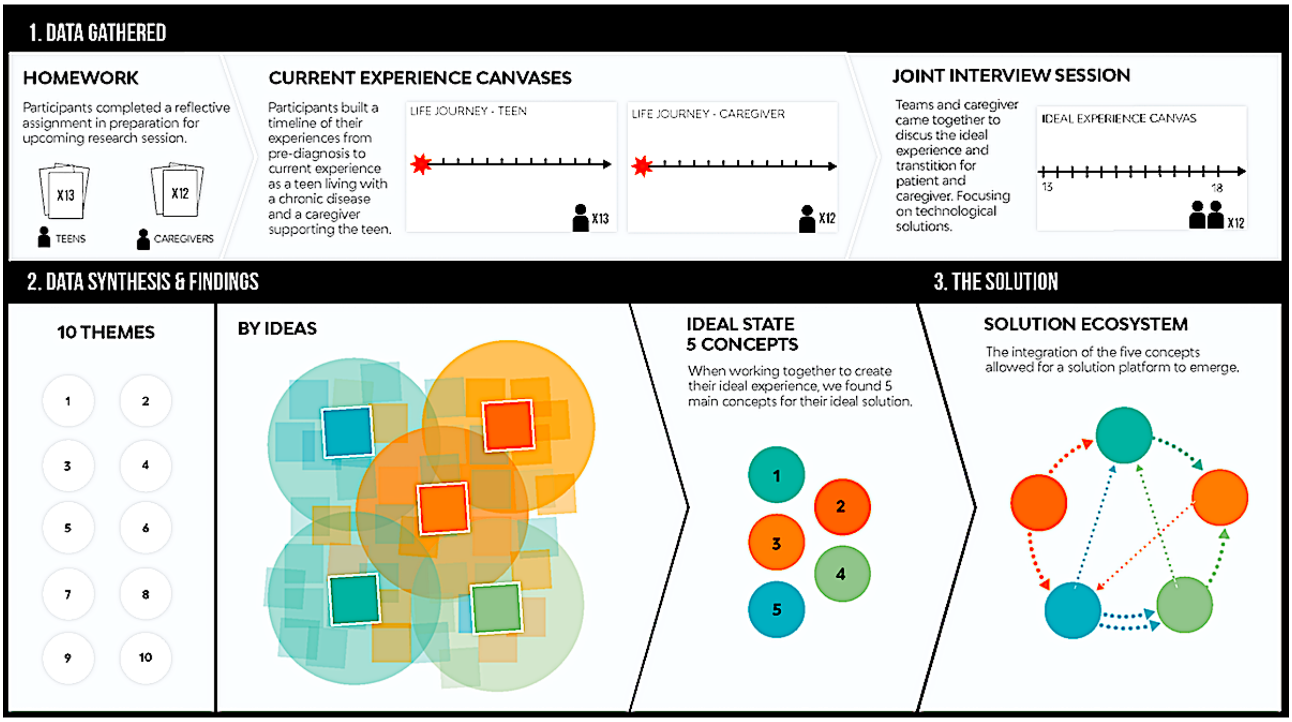


Figure 2 summarizes the data collection, analysis and creation of themes, and ecosystem process in this study.

Analysis

Method of Analysis

As a part of the co-design process, the analysis was conducted manually (instead of using NVivo software). The data was captured during the interview on the canvases via visual tools, and Post-it notes, transcripts, and researcher notes were used as sources for the analysis process. To keep visual information in the analysis, we also followed design-based guidelines for on the wall analysis [9], a method that helps include visual materials from a highly qualitative interview into the analysis process.

Thematic analysis was employed to identify challenges, opportunities, and barriers that teens and caregivers faced at strategic times on their journey and the desired solutions [11]. Thematic analysis is a commonly used methodology to identify and analyze patterns within qualitative data and report the findings [12]. As defined by Braun and Clarke [12], thematic analysis includes the following progression: (1) familiarizing with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing and refining themes, (5) defining and naming themes, and (6) reporting the findings.

Familiarizing With Data

To be familiar with the depth and breadth of the content, two researchers read the transcriptions multiple times while actively searching for meanings and patterns.

Generating Initial Code

Transcription texts were segmented and coded with notes using highlighters, colored pens, and Post-it notes. Then, they were grouped using similar terms and patterns. Codes were created by group decisions or consensus among the researchers.

Searching for Themes

Once all the data were coded, the codes were sorted and grouped into potential themes. To depict the patterns of codes and themes, a visual map was created. The description of themes and codes was used to clearly guide the grouping. The relationships between codes and themes were discussed among the researchers. Potential themes and subthemes were proposed at the end of this stage.

Reviewing and Refining Themes

All themes were reviewed to fit the code and content. If the theme did not fit, the researchers reworked the theme, created a new theme, or disregarded the theme. The transcriptions were reviewed again to be sure that the proposed themes fit and were not missing any codes or information within the transcripts.

Defining and Naming Themes

Themes were defined (what it is about and its content) and named with relevant terms in this stage. Similar themes were organized coherently and consistently according to their content.

Reporting the Findings

Themes were reported with sufficient content, supporting evidence, and examples.

Results

Themes: Challenges and Opportunities

The thematic analysis applied to the information collected from teens and caregivers resulted in 10 themes that identified challenges and opportunities during the transition to independent disease management. All patients and caregivers were frequent smartphone users, using at least 2 apps weekly. When talking about challenges, participants also spontaneously suggested some digital opportunities. Thus, we have also included self-reported technology solutions here.

Lack of Social Support and Communication

Key Challenges and Barriers

Teens and caregivers reported that in a crisis, they could not manage their condition without the understanding and help of others, (eg, teachers, school nurses, classmates, coaches, and extended family). However, others are frequently not informed on or misunderstand their condition or are ignorant about how to offer relevant assistance. Some parents realized the core issue.

> *Educating her [the teen's] core group of friends was the best thing we could do for her because they know what she needs when mom isn't around.* [Epilepsy caregiver]

Caregivers also reported that they often have contentious relationships with school nurses and administration. Some parents perceive that schools resist providing equal opportunities to children with chronic conditions.

> *When we got into the school district that we're in now, like, 3rd grade, they wanted to diagnose [my child] with ADHD...one of the teachers said, "You need to medicate your child." And I said, "You need to learn how to teach my child."* [ADHD caregiver]

In addition, tools that facilitate communication between HCPs, caregivers, and school nurses are needed to assist all health caregivers in managing updates in a teen's care. Support in rural areas can be even more challenging. Families who live in rural areas have fewer support groups and resources available. Traveling nurses in rural schools are frequently not available. Thus, school nurses who may only be available one day a week are not a sufficient support system.

Digital Opportunities

Participants identified several technologies that could help fill in for their lack of support. This included (1) an audio, video, or text tutorial sent to the caregiver (eg, mom, school, nurse, or coach) on how to manage a health crisis; (2) a real-time instructional video to educate witnesses and friends about how to help in a crisis (when the crisis is happening); (3) prescription updates sent digitally to the school nurse; (4) tools that simplify coordination between the caregiver and school nurse; and (5) a tool that will give coaches or teachers real-time alerts or symptom-reading skills so that they can pull teenagers out of the game or class and ensure that they get help.

Managing Social Stigma

Key Challenges and Barriers

Teens did not want to be labeled as a sick person nor draw too much attention at school, which may lead to feeling isolated, ostracized, or depressed. Depression may also induce them to skip their therapy at school, no matter how urgently needed, to defend against being seen as different. Labels like "sick person" may cause peers to misconstrue a teen's abilities and limitations and also lead to hurtful comments, judgments, and unwanted advice. These misconceptions disrupt developing trusting friendships that could provide needed support.

> *The first grand mal seizure happened in school in front a lot of her classmates, since then she feels awkward and ashamed of the condition because no one there gets what she has.*

Digital Opportunities

Teens and caregivers suggested that education and communication technologies could develop or enhance peer awareness. To alleviate the social stigma that teens with chronic disease may face with peers, some teens suggested having a short video ready on a phone app to inform peers in simple language what the chronic diagnosis is and means, how it affects the diagnosed teen, and how peers can be respectful of the teens' struggles with the disease. To encourage communications, a digital platform that facilitates sharing positive stories of older patients overcoming hurdles with younger teen patients to help overcome depression and anxiety was suggested.

Access to Education

Key Challenges and Barriers

Following diagnosis, caregivers are frequently frantic to understand the disease and its short- and long-term implications. The most common question asked is, "How will my child's diagnosis and treatment impact their lifestyle and the family's?" Caregivers are looking for the right information at the right time in the right dose. For instance, soon after their child's T1D diagnosis, a caregiver joined a Facebook group hoping to find tips and support. They were devastated when other caregivers were discussing the potential long-term effects and worst-case scenarios. The group did not realize that someone new was present in the conversation. During the diagnostic and initial adjustment phases, caregivers are uncertain where to find trustworthy, authoritative sources of information and frequently get misguided or insufficient information.

> *You know, you turn to the Internet, parents of kids with diabetes, which is helpful in some ways with some practical questions but, in other ways, frightening because a lot of...I finally had to like exit because it was a lot of moms that were really just really scared.* [T1D caregiver]
>
> *No one was telling me anything...I mean I knew I had stuff wrong with me, but no one was telling me what it was or what it meant or what that means for the rest of my life.* [ADHD Teen]

Digital Opportunities

In their quest for knowledge, caregivers reported technological solutions that would help to facilitate access to the education they are looking for. This included precategorized discussion groups that allow the caregiver to match what they are looking for before they get caught up in topics that are not helpful and preapproved, credible information sources (eg, reputable clinics, local hospitals, their doctor) that provide access to reliable information when they need it the most (eg, when symptoms do not make sense and caregivers want access to tips). The caregivers did not want to browse through thousands of sites to find key information. Also, a tool that helps compare efficacy among competing manufacturers (eg, commercial options for medications or food brands in the case of diabetes) was proposed.

Symptom Monitoring and Support

Key Challenges and Barriers

The initial adjustment period is rife with triggers, which frequently catch caregivers and teens off guard and can lead to full-on symptoms. Without timely support, symptom onset causes significant distress of being overwhelmed or unprepared. Teens are looking for ways to get immediate help for their symptoms without having to call their caregiver or an HCP. Avoiding hospitalization is certainly another key goal for the family.

Caregivers and teens struggle with how to deal with sudden symptom onsets, especially at night, or when the teen is away from home or the caregiver. Both teens and caregivers are diligently seeking pre-emptive alerts of a health care crisis. For instance, one participant caregiver reported that she constantly wakes up in the middle of the night to double-check her teen's blood sugar. A mother of another teen fears a sudden unexpected death in epilepsy crisis, known to occur overnight with people who live with epilepsy.

In addition to unmet needs regarding symptom monitoring, teens also desire actual symptom relief or advice when they are away from their caregiver or other support. Like this caregiver who had a son with ADHD and anxiety:

> *I [caregiver] said, "Are you really anxious about this?" And he [teen] said, "Yeah. Why?" And I said, "Because you have scratches." So, having an app or some sort of technology that could be like, "Hey, you're kind of, digging your...a hole in your arm. Can't you stop doing that?" Like, it would be awesome. So, if he was able to be like, "Oh, I'm scratching. I should put that in. That's happening." And so now he knows when it happens, and we can talk about what was going on when it happened.*

Digital Opportunities

Participants outlined 4 technologies that would support them in symptom monitoring. First, a symptom trigger tracker that gives advance notice to the caregiver when symptoms may be developing. Second, voice-activated tools (like Alexa, Siri, or Google assistant) to orally report and record symptoms (eg, "begin timing of seizure") or have a technology to automatically begin videorecording the episode for future reporting to HCP. Third, tools that capture potential triggers or patterns over time that are unique to each teen to prompt early responses or pre-emptive actions. Fourth, families dealing with diabetes, CF, and epilepsy particularly desire night monitoring in the form of a smartwatch, clothing, or wearable scanner. These devices could sound an alarm when vitals suggest a crisis is imminent or send automatic SMS text messages that warn and report to the teen, doctor, and caregiver, simultaneously.

Safety During Driving

Key Challenges and Barriers

Caregivers have a constant fear that their teen may have a dramatic medical event while driving. Caregivers mistrust their teen's judgment if they are driving when an emergency occurs.

> *So, if something could alarm her to sit down and be safe, you know. And or appear where she's driving, and to stop. Stop the car, pull over. Don't go any further. And I wouldn't care what form it would be in, if it would be a piece of clothing, if it would be the watch, if it would be, you know, a kind of, like, an earpiece, like those things that people use, a…not a GPS, Bluetooth. That's it. Something to make her stop what she's doing.* [Epilepsy caregiver]

Digital Opportunities

Caregivers shared several technological solutions that may help to reduce risk when driving. First, technology to prevent teens from driving if they are at risk of a medical event because their symptoms are not under control (eg, similar to a breathalyzer that stops someone from driving under the influence). Second, tools that help avoid the event that causes the teen to lose control when driving, such as extremely low blood sugar, seizures, and difficulty staying attentive. Third, wearable technology, in jewelry, clothing, or a watch, similar to an emergency button in the car. When pressed, the device transfers key health information to first responders or other passengers. Last, technology that records the teens' driving activity. Records can be used to differentiate if an accident was due to their condition or poor judgment.

Access to Health Care Providers

Key Challenges and Barriers

Issues accessing HCPs are numerous and varied. Key barriers include distance to hospital, scheduling problems (cancellation, wrong scheduling), responsiveness to requests and questions, lack of integration and consistency among multiple providers, and communication issues with or among HCPs.

> *[Doctors] don't listen to me. I called, I paged them that night because she still couldn't walk after two and a half hours. She had hit her head on the wall and then the floor, and I paged neurology after the first one and they were like, "Oh, well just increase her meds." They don't want to see her, they don't want to do anything else. They just want to increase her meds. I was livid.* [Epilepsy caregiver]

Patients and caregivers who need to travel long distances or frequent visitors with scheduling issues suffer the most, which leads to delayed health care services. Currently, communication with doctors is based on what the caregiver or teen can recall without written instructions. Further, no significant communication usually occurs between visits to HCP. However, teens are willing to text or communicate directly with their HCPs to bridge that gap.

Digital Opportunities

Five technological solutions were suggested. First, a 24-h SMS text message-based helpline to health care providers—not necessarily their own HCP—but an HCP they can trust and ask general questions. Second, a real-time decision-making tool to answer questions like "I am going to work-out for 2 hours. What snack may be good?" Third, a channel where the teen and caregiver can contact an HCP expert and get general advice for noncritical situations without waiting until the next HCP appointment. Fourth, caregivers need a preappointment tool so that teens can prepare questions before going to the appointment. Fifth, telemedicine to improve access to care.

Relationship Between Caregiver and Patient

Key Challenges and Barriers

The caregiver has a potential to be the "bad guy" since they take on the responsibility to remind the teen regarding proper management of their diagnosis. Because teens struggle with medication compliance, caregivers constantly remind teens to take medications. Conflicts over compliance may cause relationship problems. Some teens who feel overwhelmed with therapy may lie to their caregivers. Besides being detrimental to their therapy management, this situation may cause the caregiver to mistrust the teen.

> *Just when you think you got it...Everybody was really trying their hardest, and that's when I'm finding the meds being hid. And it's like, "I thought we had finally had a breakthrough and now defeated again," back to square one.* [ADHD Caregiver]

Digital Opportunities

Communication technologies, which assume the reminder-police role, may help to increase the strength of the relationship between teen and caregiver. Caregivers wish that technology could deliver news, reminders, and directions, so they did not have to be the "nagger." Teens want improved and remote communication between the caregiver and themselves when they first move out of the home (eg, college). A tool was suggested to allow the caregiver and teen to collaborate on a daily checklist that will help with reminders but also provide a way for caregivers to check in instead of verbally asking multiple times a day. Teens believe this tool will help improve their relationship with the caregiver. A tool that offers caregivers objective proof that the teen has done their therapy (eg, a vitals readout, video footage of the teen completing therapy-related activities) was also proposed. Lastly, a digital assistant tool was suggested that, when the patient desires, can give their caregiver a real-time readout of vitals or other statistics that will help to double-check decision making and make check-ins easy.

Long-Term Perspective

Key Challenges and Barriers

Caregivers perceived that their teen tends to think in the moment without considering how their actions and choices can have a negative impact on their therapy path. In addition to gaining life skills and understanding as any normal teen, teens with a chronic medical condition have the extra challenge of learning about the different circumstances caused by their condition.

> *I worry if my son understands that how the choices he makes now will affect his long-term health. He has his typical teen attitude of resisting our instructions, but it will have a big impact on his future* [CF caregiver]

Digital Opportunities

Technology to help develop a right mindset for better decision making was requested. This included decision assistance tools to help teens understand how choices today affect long-term health, technology to visually demonstrate how good choices today add up long-term, and scenario tools that help teens think through situations specifically related to their condition and prompt them to be proactive about proper management.

Supply Management

Key Challenges and Barriers

Teens do not want to be burdened with keeping track of their supplies (eg, ordering, and maintaining an emergency stash), especially when at college. Some teens did not have access to school nurses, as these nurses serve more than one school on any given day. Thus, when an emergency supply is needed, a backup is not available (eg, students with T1D at rural schools).

Parents expressed feeling overwhelmed managing the medication-supply aspect of care. In addition to managing their own busy schedules, they also carry the burden of keeping an inventory of supplies and medications. Families with several children or with a teen with multiple conditions face greater challenges in managing supplies.

> *I have a hard-enough time keeping up with all their school activities and appointments. It's overwhelming to keep up with all the medications and making sure we have all the refills at the right time for each of my children.* [Epilepsy caregiver]

Digital Opportunities

Teens and caregivers shared their ideas about technology that could help such as inventory tools to assist in tracking and to alert caregivers when supplies are low. Another suggestion was smart ordering, delivery, and storage for a seamless ongoing supply, which could ease the transition to college or away from home.

Financial Struggles

Key Challenges and Barriers

Caregivers are commonly overwhelmed with complex insurance policies and health care coverages. While they suspect they may not have the optimal coverage, they lack time or expertise to compare or assess options. For example, despite long-term use, they may experience a sudden loss of access to a drug or an important medical supply. Solving this problem can be time-consuming and anxiety-provoking. Finances are not a teen stressor at this stage.

> *Insurance, we had to adapt to the Ohio systems. Well, it's the secondary insurance that was really the problem...I'll just say, secondary state-assisted*

> *insurance, essentially, changed. This is very stressful.* [CF caregiver]

Furthermore, caregivers are aware that some medical technologies are limited by an insurance company's willingness to pay and also because demand exceeds supply. They also wish to tap into the insurance navigation expertise they believe exists among the professionals at hospitals. In that regard, caregivers would like to rely on hospitals to give advice on getting the best out of their insurance or choosing the best insurance, considering the chronic conditions they have.

Digital Opportunities

Caregivers expressed their expectations on technology-based financial decision support. This included a digital concierge-type service to better compare options and maximize coverage and digital tools to improve the price transparency in care.

An Ecosystem of Technology Solutions to Facilitate an Ideal Transition

In this study, once we identified the challenges in self-management throughout their life journey for both the teens and caregivers, we primarily used the participant's inputs to develop recommendations for technological solutions and opportunities that could facilitate the transition to independence. Our patient-centered approach helped to identify some digital opportunities that could assist teens and caregivers in achieving an ideal transition. The following 5 solutions were synthesized from the ideal experience activity that the patient and caregiver collectively envisioned. To support each proposed solution, we also include examples from the current literature.

The Teen-Caregiver Communication

A new platform (eg, device, app, or software) that would provide support and cushioning in communication several times a day between caregiver and teen during early transition. This platform would act as a bridge by providing a collaborative, task-sharing platform with a built-in reward system. However, the platform should also evolve to help the teen expand their support network while keeping the caregivers in the loop through weekly or monthly reporting.

Current Implementations

Researchers from Michigan State University have proposed a mobile app, MyT1D Hero, to create a communication platform among teens with T1D and their parents to support self-management [7].

Education and Tracking

This integrated platform would provide a channel for a daily dose of age-appropriate education and information tracking for the teen and support caregivers in their daily decision making. The focus at the early stage is helping the teen understand their body, their disease, symptoms, and triggers. Later in the transition, when teens start making therapy decision on their own, the platform needs to evolve into becoming a coach.

Current Implementations

The gamification concept has been used to educate kids and parents about managing diabetes [13] and for tracking the teen's condition [14,15].

Teen-Caregiver and Health Care Providers Communication Bridge

This platform needs to provide seamless communication between HCP, caregivers, and school to lessen the additional burden on caregivers and keep everyone on the same page. The teen begins to communicate more with their HCP early on to help build trust, while the caregiver continues to be the main point-of-contact and influence in the early stage.

Current Implementations

A communication platform among caregiver, HCP, school administration, and the teen has not been observed. However, the use of social media was found to be effective in creating a communication network, but not without several limitations and privacy concerns [16].

Emergency Support System

This platform would provide emergency support and cautionary alerts for caregiver and teen and external networks (eg, HCP, school nurses, and first responders). The system needs to be designed to prevent serious consequences from the sudden onset of medical events from occurring, while also training the teen and peers to know how to act and respond during an emergency. This system would be connected to a mobile device (phone or wearable device) for the teen that is similar to a medical alert button.

Current Implementations

Emergency support systems at the individual level for teens have not been observed in CDM literature. However, emergency apps available in the market can be leveraged in chronic disease-related emergencies, such as Medical ID app [17].

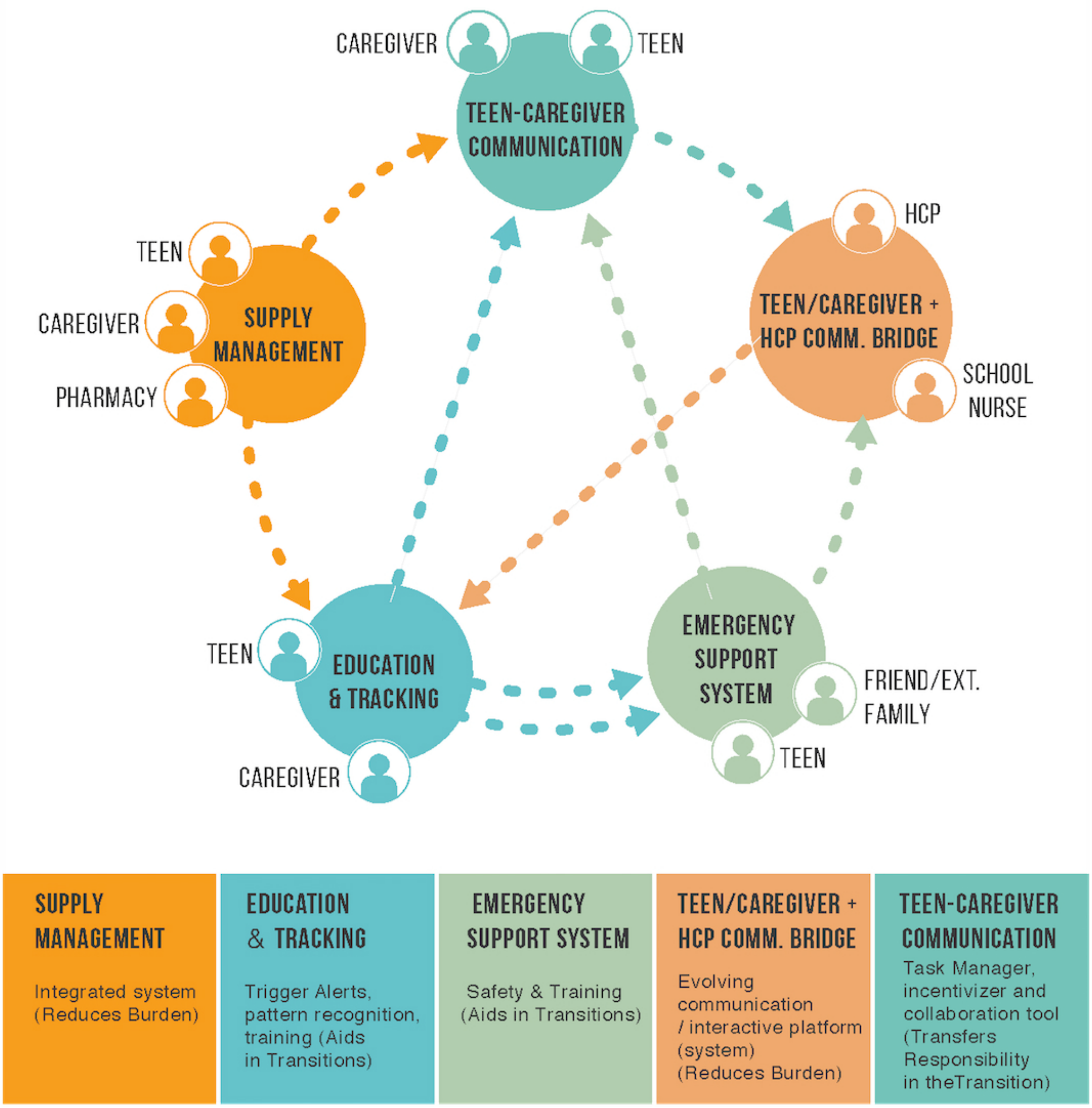
Supply Management System

This platform aims to reduce the burden of supply management and organization for the caregiver and teen by providing a fully integrated system of alerts, reminders, and automated supply replenishment and management. Additionally, the platform could provide assistance with and education regarding insurance and financial and legal support.

Current Implementations

Although integrated supply management has not been observed in the literature, Mango Health app [18] enables caregivers and teens to track their medications. Retail pharmacies like CVS and Walgreens are also starting to have integrated systems for patient's medical supply management.

Figure 3. Outlining the proposed ecosystem of digital health solutions. HCP: health care providers; comm: communication; ext: extended.



Proposed Integrated Ecosystem of Digital Health Solutions

The five technology opportunities above are interrelated and form a technological ecosystem, enabling information flow and communication between the solution systems to create an integrated approach to CDM. The proposed solution ecosystem (Figure 3) is designed for seamless communication and information flow among parties and technology solutions to assist a teen in managing a chronic disease during transition to independence. In the figure, the circles represent the 5 digital opportunities identified to enhance the teen-to-independence transition while managing a chronic diagnosis. Lines in between the concepts indicate integrated lines of communications between other digital solutions. These connections are hypothesized based on study observations. The boxes present examples for each solution. Each of these solutions can evolve with the changing needs of the teen throughout their transition. For instance, the teen and caregiver bridge may promote medication compliance in early transition, logging therapy tasks and sending reports to HCPs in midtransition, and using time management tools for managing therapy in late transition. Further interview notes on technology opportunities in transition to independence are provided in Multimedia Appendix 2.

Discussion

Transition Challenges Require a Multifaceted Solution Approach

The ten themes identified in our study are well supported by the literature. The first two themes "*Lack of support and communication*" and "*Managing social stigma*" revealed that support from the social environment is a fundamental need, necessitating a deeper understanding of teens' social state [19]. Koetsenruijter et al [20] also argued that individuals with chronic conditions need social support for health management.

In the third theme "*Access to education,* " to support their teens, caregivers desire *access to educational material* to learn as much as possible regarding the disease's symptoms, management, and treatment options. Despite the importance of education to support self-management in CDM [5,19], the literature suggested that barriers to having quality education and information included unreliable Web resources and limited health and computer literacy of users [21].

In the fourth theme "*Symptom monitoring and support*," in addition to managing symptoms, families want a pre-emptive advantage through continuous *symptom monitoring*. If an impending medical crisis could be identified through early alerts, their teens could receive aid quickly, possibly mitigating more severe consequences. Several digital solutions have been offered for symptom monitoring and support [22], yet adoption is not widespread.

The fifth theme "*Safety during driving,* " that is, *safety of teens while driving* is another major concern. Since commuting is a significant part of the daily routine, caregivers are rightfully concerned about medical emergencies that may occur while teens are driving. The severity of driving accidents among young drivers with a chronic condition has been argued in the literature. Comparing young drivers with and without ADHD, a study demonstrated that teens with a chronic condition had higher driving risks [23]. Thus, CDM initiatives should incorporate safe commuting.

The sixth theme "*Access to health care providers*" is problematic regarding open communication and information sharing. CDM technologies, which are available to access health care, are highly efficient and help reduce clinic visits [5], but our findings suggest that the practical use of these technologies has not yet reached maturity.

Likewise, technology use in families revealed that communication technologies would enhance a reciprocal *relationship between the caregiver and teen*, which was the seventh theme. This would be a promising aspect of technology use, to further extend the benefits of technology (eg, mHealth interventions), in health care management and communication for teens among caregiver and HCP [4].

Communication technologies can also be used to support teens making healthy decisions from a *long-term perspective*, the 8th theme. Clinical decision-making systems have been proven successful in CDM in a clinical environment [24]. Yet, our findings suggest that the focus for decision support needs to be individualized for teens to assist them in transitioning.

Similarly, individualized technologies for controlling medicine inventories and enhancing personal *supply management*, the ninth theme, would assist teens in transitioning to independence.

Above all, caregivers report *financial struggles*, the tenth theme, as a major barrier to accessing current assistive technologies in CDM. Thus, financial issues may have a mediating effect on other challenges. Likewise, the families interviewed wished to receive medical support using low-cost communication and information technologies.

Guidance and Empowerment Through an Ecosystem of Digital Solutions

A single technology solution was insufficient to meet the many challenges patients and caregivers face in launching to independence a teen with a chronic condition. Rather, our study derived an ecosystem of digital health solutions. The 5 proposed technology opportunities for ideal transitioning were derived from self-reported technological expectations of teens and caregivers. Fundamentally, these opportunities reflect their expectations and need for a communication system that links the core stakeholders (patient, caregiver, and HCP).

Measuring the patient's quality of life and quality of communication among caregivers, teens, and HCPs is problematic [5,19]. Therefore, to overcome the major communication issues, we propose developing a communication platform. Similarly, enhancing medical education and health literacy would also be beneficial during transition to independence and for the long-term CDM of teens [5]. The identified opportunities align well with Miller et al's [25] findings regarding the technology preferences of young people in transition for access to health care and communication needs, and Ranade-Kharkar et al's [26] information goal types among HCPs and caregivers for kids with special health needs.

From a broader perspective, teens may benefit from using technology in the long term, starting with the early introduction of technology tools and successfully engaging with technologies through adulthood for CDM [27,28]. The technology used for communication and self-management would facilitate the treatment and consulting process, assist teens with condition-specific needs, and make digital CDM more sustainable [5,19].

Still, as per the suggestions in this study, sustainability and long-term engagement need focus and familiarization to reduce teen frustration and reluctance with technology [29,30]. In that regard, Griffiths et al [6] suggested using technology-based health care services with an existing, trusted HCP team for conveying services to identified needs. The HCP team also needs to work on effective information resource use for timely access. To maximize efficacy, collaborative co-design with patients and continuous improvement of solutions should be considered [2]. Within this context, gamifying the CDM concept to promote engagement, sustainable self-management, and communication is another possible approach for digital health development.

Limitations

As a quality improvement study to improve digital health delivery at NCH, we recognize important limitations on generalizability. Our study covered only 3 of the 9 top chronic conditions among children in the United States [31]. Also, the sample size may be insufficient to derive generalizable results. Since the study lacks quantifiable input, power and other statistical analyses are precluded from testing our findings. As is frequently the nature of qualitative methods, analyst bias could have affected this study to some extent in both data collection and interpretation. These limitations can be addressed by future implementations to validate the findings from this study.

Conclusions

In this study, challenges and barriers for teens with chronic diseases and their caregivers were identified, discussed, and matched with technological opportunities and solutions.

Technological solutions and digital health mechanisms were suggested as mediating tools for better communication among patient, caregiver, HCP, and authorities. These findings would help to extend current efforts using mHealth management and intervention methods [32]. We suggest future studies to create a virtual bridge between individuals and institutions and to disseminate the technology and its use.

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Conflicts of Interest

AW and MW received their compensation through Stratos Innovation Group which was funded for conducting this study by NCH. They have no further financial interest or benefit in this project.

Multimedia Appendix 1

Tools and materials for the data collection activities.

[PDF File (Adobe PDF File), 1MB - jmir_v20i9e10285_app1.pdf]

Multimedia Appendix 2

Interview notes on technology opportunities in transition to independence.

[PDF File (Adobe PDF File), 20KB - jmir_v20i9e10285_app2.pdf]

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Abbreviations

ADHD: attention deficit hyperactivity disorder
CDM: chronic disease management
CF: cystic fibrosis

HCP: health care provider
mHealth: mobile health
NCH: Nationwide Children's Hospital
T1D: type 1 diabetes

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Original Paper

Exploring Genetic Data Across Individuals: Design and Evaluation of a Novel Comparative Report Tool

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Abstract

Background: The growth in the availability of personal genomic data to nonexperts poses multiple challenges to human-computer interaction research; data are highly sensitive, complex, and have health implications for individuals and families. However, there has been little research on how nonexpert users explore their genomic data.

Objective: We focus on how to support nonexperts in exploring and comparing their own personal genomic report with those of other people. We designed and evaluated CrossGenomics, a novel tool for comparing personal genetic reports, which enables exploration of shared and unshared genetic variants. Focusing on communicating comparative impact, rarity, and certainty, we evaluated alternative novel interactive prototypes.

Methods: We conducted 3 user studies. The first focuses on assessing the usability and understandability of a prototype that facilitates the comparison of reports from 2 family members. Following a design iteration, we studied how various prototypes support the comparison of genetic reports of a 4-person family. Finally, we evaluated the needs of early adopters—people who share their genetic reports publicly for comparing their genetic reports with that of others.

Results: In the first study, sunburst- and Venn-based comparisons of two genomes led to significantly higher domain comprehension, compared with the linear comparison and with the commonly used tabular format. However, results show gaps between objective and subjective comprehension, as sunburst users reported significantly lower perceived understanding and higher levels of confusion than the users of the tabular report. In the second study, users who were allowed to switch between the different comparison views presented higher comprehension levels, as well as more complex reasoning than users who were limited to a single comparison view. In the third study, 35% (17/49) reported learning something new from comparing their own data with another person's data. Users indicated that filtering and toggling between comparison views were the most useful features.

Conclusions: Our findings (1) highlight features and visualizations that show strengths in facilitating user comprehension of genomic data, (2) demonstrate the value of affording users the flexibility to examine the same report using multiple views, and (3) emphasize users' needs in comparison of genomic data. We conclude with design implications for engaging nonexperts with complex multidimensional genomic data.

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KEYWORDS

genomics; consumer health informatics

Introduction

Overview

Recent years have seen a sharp increase in the availability of personal genomic data to nonexpert consumers. People with no formal training in genetics can get access to their genomic information by sending a saliva sample to a direct-to-consumer genetic testing provider, and results are delivered using a Web app. Users then must interpret large amounts of complex data involving sensitive issues such as disease risk and carrier status. The interpretation of the data may impact lifestyle decisions, emotional state, and well-being of users and their biological family members.

The availability of extant and complex data in need of understanding by nonexperts is an opportunity for human-computer interaction (HCI) research [1]. Identifying user needs and developing novel ways to help users understand their personal genomic data can make a substantial impact on the well-being of people. However, to date, HCI research on interaction with personal genomic data is in its infancy. Studies that investigated the information practices of personal genomic data users found that nonexperts seek to contextualize and compare their personal data with others (eg, family members and others with similar medical conditions) [2,3]. The family-relevant nature of genetic data highlights the need for tools to enable nonexperts to explore not only their own data but also to compare and contrast it with the data of others.

We present CrossGenomics, the first tool to date for nonexpert engagement with multiple gene variant reports. The tool facilitates the exploration of shared genomic information among family members or a comparison of genomic information with others. Such comparisons enable users to explore what variants they share with others and what sets them apart, thus increasing the understanding of their genetic makeup and enriching the genomic narrative people can construct. There has been a growing interest in exploring how people form social ties around health conditions caused or influenced by genetic characteristics—what Kuznetsov et al have called *biosociality* [2]. In this paper, we discuss findings from 2 user studies focusing on assessing the usability and understandability of comparing genetic reports of family members using alternative prototypes of CrossGenomics. In the third study, we explore how people engage with genomic information of famous people, thereby drawing on the public availability of personal genomic information of a few known people, the growing interest in biosociality, and the trend of self-comparison with celebrities, which is increasingly evident in popular culture [4,5].

Beyond the domain of personal genomics, this study expands on a growing body of work, which identifies needs and opportunities to design information-tracking tools for collaborative monitoring of and reflection on family health [4,6-8]. In particular, the paper makes the following contributions: (1) presenting the iterative design and evaluation for a tool that facilitates multidimensional and multiperson comparisons of complex personal data, (2) analyzing the differences between objective comprehension and perceived understanding and shedding light on discrepancies between subjective and objective knowledge, and (3) exploring user needs in the context comparing personal genetic data across individuals.

Background

Nonexpert Engagement With Personal Informatics

Our work on communicating personal genomics to nonexperts draws upon an increasing body of work in personal informatics, which investigates how to make personal data more understandable for nonexpert users and more *embedded* in everyday lives of people. Rooksby et al proposed the term *Lived Informatics* to highlight that collecting and using personal information is embedded in day-to-day lives of people [9]. A widely accepted model of how people use personal informatics tools is the 5-stage model of Li et al [10], which describes the iterative transition between preparation, collection, integration, reflection, and action. This model had been extended by differentiating stages of reflection [11,12] and characterizing challenges in lived informatics for diverse goals of users [13].

Researchers have also studied design interventions and guidelines for making personal data more understandable and accessible for nonexperts. For example, Rapp and Cena investigated usage patterns, information needs, and challenges of naïve users or those who are new to personal informatics. Their findings highlight important differences compared with experienced users, including reduced tolerance to practical difficulties, ambiguous representations, and unintuitive interaction modalities [14]. They also proposed design strategies to address these issues [14] and studied the impact of a new personal informatics system designed to address the needs of naïve users [15]. Epstein et al visualized subsets of collected location and physical activity data using a variety of presentations [16]. Bentley et al developed a system that aggregates multiple aspects of personal well-being data and provides people with insights based on complex relations using natural language [17]. They showed that users were able to understand complex relationships and change their behavior to improve their well-being.

Designing for nonexpert engagement with personal genomics shares goals with personal informatics. However, there are some important aspects unique to personal genomics, including the dynamic nature of its interpretation (as new scientific discoveries are made), and the varying levels of certainty of evidence regarding the implications of the data for well-being of a person. In addition, although personal genomic data are deeply personal and sensitive, they are shared across biological family members and communities. In this study, we focus on the shared aspect of the data, allowing individuals to compare their genomic information with relevant others.

Nonexpert Engagement With Personal Genomic Information

Direct nonexpert user engagement with personal genomic information has been relatively understudied in the HCI field [18]. Several studies investigated the motivation for and subjective experience of genetic testing and of using interactive tools to understand results [19,20].

Leighton et al [19] found that nonexperts misinterpret genetic testing results without appropriate assistance. Kuznetsov et al [2] presented users with their own 23andMe data to understand how they make sense of and contextualize their results. Shaer et al [3] studied how nonexperts who participate in the Personal Genome Project explore their own data. They found that similar to other types of personal information [9], engaging with personal genomics could serve a goal, such as finding information about family ancestry and medical history, or be driven by more general curiosity. Their findings also indicate that nonexperts seek to understand their personal genomic information in the context of other individuals, ancestry information, and family medical history.

Exploring the impact of specific report designs, Haga et al [21] studied alternative formats for a text-based genetic laboratory report. Shaer et al [3] compared alternative designs of visual genetic variant reports and showed that a bubble-chart visualization is more effective than other design approaches. On the basis of this finding, they developed a visual tool for nonexperts to explore their own personal genomics information [22]. In this study, we draw on design recommendations introduced by Shaer et al [22] and apply them to the design of a multiperson genetic report that supports the comparison of multiple genomes.

Sharing and Exploring Health Data

In recent years, we have witnessed the rise of cocuration in health and medical contexts by nonexperts [23]. Websites such as TuDiabetes, PatientsLikeMe, and Eat.ly help users to make sense of their experiences and conditions by presenting, sharing, and commenting on health knowledge [24-26]. These websites can elicit new concepts for nonexpert health care vocabularies, coding sets, and classifications [25]. In a first effort to facilitate shared genomic data exploration among biological family members by nonexperts, we designed and evaluated CrossGenomics, which enables users to explore what variants they have in common with others.

Comparing Genetic Information

Visual tools that compare personal genomic data of different people were introduced by industry with nonexperts, but such tools focus on ancestry exploration. A visualization offered by 23andMe presents shared chromosomal segments between individuals but does not enable comparison and exploration of health and trait information. Several visual tools are available for comparing multiple genomes, including Ensembl [27], IGV [28], Gitools [29], Circos [30], Genome Data Viewer [31], and OMICtools [32]. However, these tools were designed for *expert* users seeking to discover new genetic associations with traits and disease. Such tools provide access to a large variety of metrics, filters, and visualizations, creating numerous leads for discovery. In contrast, CrossGenomics is intended for nonexperts as a report on the existing state of knowledge with regard to the known effects of genetic variants (through published research). We aim to facilitate nonexpert engagement with the data through exploration, while at the same time communicating the multiple dimensionality and uncertainty inherent to genetic data.

Visual Tools for Comparing Complex Datasets

In other domains, tools were developed for users to compare and contrast multidimensional and complex datasets [33-37]. The LifeLines system [38], which displays personal history information, was found to perform better compared with a tabular representation. In the context of energy consumption, Valkanova et al [39] presented an interactive visualization system that compares individuals and communities. Most relevant to our research context are tools that allow comparison between individuals who are related to one another. For instance, to support collaborative exploration of family-related information, Zimmerman et al explored the value of technology-supported parents-teens interactions around issues of finance [40]. These tools demonstrate the potential and need to further consider design guidelines for developing tools for nonexperts to compare complex data.

Open Humans

Open Humans [41] is a platform dedicated to enabling individuals to manage data and contribute it to research. It was developed with grants from the Robert Wood Johnson Foundation and the Knight Foundation and is currently supported through grants from the Shuttleworth Foundation. Open Humans enables its volunteers to connect data from a variety of current -omic sources. Individuals can join studies on the site, share data with those studies, and contribute to new research. Open Humans acts as an aggregator of participants and data, enables these participants to join new studies, makes data available via application programming interfaces (APIs), and has features for study recruitment and deployment. Open Humans currently supports a variety of -omic data, including genome and exome data (Harvard Personal Genome Project, Gencove, VCF file donation), genotyping data (23andMe, Ancestry DNA), and microbiome data (American Gut, uBiome). This aggregation of participants and data by Open Humans allowed for the creation and promotion of our study to a pool of potential participants with publicly shared genomic data.

Methods

Design

We designed novel interactive gene variant reports that allow nonexpert users to compare variants across individuals. Through an iterative design process, we developed 3 alternative designs of an interactive visual personal genomics comparison tool called CrossGenomics that enables nonexpert users to compare their gene variants with others. We used the data and interpretation created by the GET-Evidence gene variant report [42], which contains a list of gene variants known to be associated with traits or medical conditions. Thus, our interactive reports only present gene variants with known (ie, published) effects.

We focused on highlighting 3 dimensions of the data, which were found to be particularly important when exploring personal genomic information [22]: *impact*, which refers to type of effect (eg, whether the gene variant causes or protects against disease), *rarity*, which highlights gene variants that are especially unusual (high rarity indicates low frequency in the population), and *certainty*, which describes the strength of scientific evidence supporting a putative effect. Comparing and contrasting people's data across these dimensions can help them explore commonalities and differences, as well as implications for potential future health conditions.

In visualizing these dimensions, we drew upon GenomiX [22], an interactive gene variant report for a single genome, where color, size, and position represent impact, rarity, and certainty, respectively. The 3 visual prototypes we developed for CrossGenomics use the same visual encoding as Genomix for representing individual variants but are varied in the visualization technique used for depicting and comparing multiple gene variant reports.

Across the 3 alternative visual prototypes we created for CrossGenomics, color and size retain the same meaning. Color represents impact—pathogenic (red), benign (gray), protective (blue), pharmacogenetic (purple), or carrier (colored polka dot pattern). These impact categories were derived from industry-standard classifications in GET-Evidence [42]. It is common for published effects to be classified in this manner. Similar classifications are used by ClinVar of National Center for Biotechnology Information [43]. Only variants with known effects are represented. Size represents rarity—the larger the representation of the variants, the rarer the gene variant is.

Users could filter gene variants based on person, health category, potential impact, and certainty of evidence with the options "Well-Established," "Likely," and "Uncertain." These categories of certainty of evidence were determined by the GET-Evidence [42] interpretation. Users could also click on a variant to learn more about it. Information, including the variant's name, clinical importance, potential effect, and an effect summary, would appear in the sidebar. There was also a clickable glossary to explain scientific jargon.

To represent and facilitate comparisons across multiple genomes, we developed 3 alternative prototypes of CrossGenomics, each based on visualization techniques currently used by experts for comparative genomic data: linear [44] and circular alignments [27,29-31,45] and a Venn diagram [28]. However, as our tool is aimed at nonexperts, in our design, we carefully balanced simplifying the visualizations with highlighting important dimensions and facilitating free exploration.

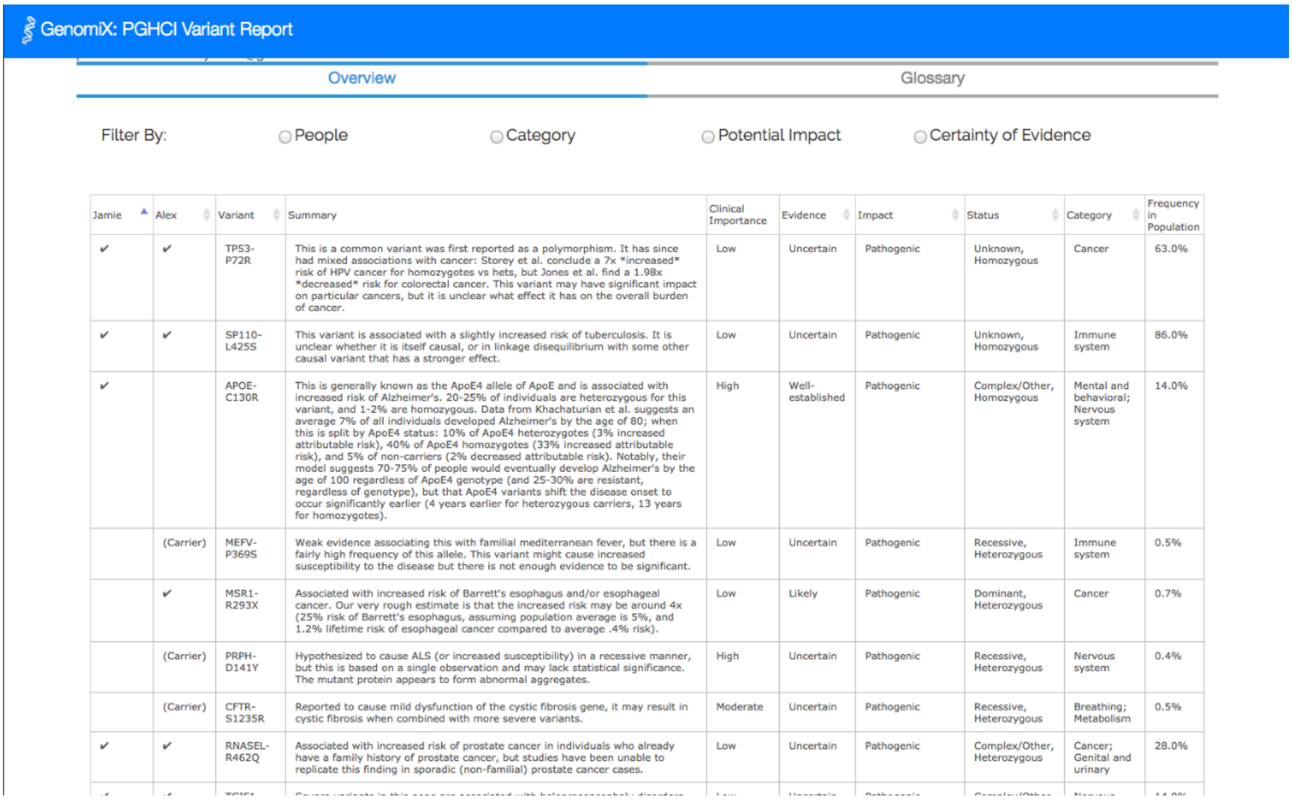
We iterated on the design of these 3 visual reports by testing prototypes in increasing fidelity with nonexpert users (Mechanical Turk workers), experienced users (nonexperts with access to their personal genomics reports), and genomics domain experts. In each iteration, we refined the design, addressing issues such as ordering, synchronized selection, and filtering and sorting variants, size, and alignment.

In addition, we developed a table-based report that is modeled after the GET-Evidence report [42], to reflect the current report type the users of personal genomics often have access to. We implemented CrossGenomics as a Web app using JavaScript with D3.js.

CrossGenomics 1.0

Figures 1-4 show the 4 alternative designs we developed for comparing personal genetic reports: a table-based report (Figure 1), a linear visualization (Figure 2), a sunburst visualization (Figure 3), and a Venn visualization (Figure 4). These 4 prototypes were evaluated in user study 1.

Figure 1. Tabular report: the table is similar to the existing GET-Evidence report with each row representing a variant in one or both of the reports. Two columns were added to the table and check marks were used to denote the presence of a gene variant for each sibling.



Jamie	Alex	Variant	Summary	Clinical Importance	Evidence	Impact	Status	Category	Frequency in Population
✔	✔	TP53-P72R	This is a common variant was first reported as a polymorphism. It has since had mixed associations with cancer: Storey et al. conclude a 7x *increased* risk of HPV cancer for homozygotes vs hets, but Jones et al. find a 1.98x *decreased* risk for colorectal cancer. This variant may have significant impact on particular cancers, but it is unclear what effect it has on the overall burden of cancer.	Low	Uncertain	Pathogenic	Unknown, Homozygous	Cancer	63.0%
✔	✔	SP110-L425S	This variant is associated with a slightly increased risk of tuberculosis. It is unclear whether it is itself causal, or in linkage disequilibrium with some other causal variant that has a stronger effect.	Low	Uncertain	Pathogenic	Unknown, Homozygous	Immune system	86.0%
✔		APOE-C130R	This is generally known as the ApoE4 allele of ApoE and is associated with increased risk of Alzheimer's. 20-25% of individuals are heterozygous for this variant, and 1-2% are homozygous. Data from Khachaturian et al. suggests an average 7% of all individuals developed Alzheimer's by the age of 80; when this is split by ApoE4 status: 10% of ApoE4 heterozygotes (3% increased attributable risk), 40% of ApoE4 homozygotes (33% increased attributable risk), and 5% of non-carriers (2% decreased attributable risk). Notably, their model suggests 70-75% of people would eventually develop Alzheimer's by the age of 100 regardless of ApoE4 genotype (and 25-30% are resistant, regardless of genotype), but that ApoE4 variants shift the disease onset to occur significantly earlier (4 years earlier for heterozygous carriers, 13 years for homozygotes).	High	Well-established	Pathogenic	Complex/Other, Homozygous	Mental and behavioral; Nervous system	14.0%
	(Carrier)	MEFV-P369S	Weak evidence associating this with familial mediterranean fever, but there is a fairly high frequency of this allele. This variant might cause increased susceptibility to the disease but there is not enough evidence to be significant.	Low	Uncertain	Pathogenic	Recessive, Heterozygous	Immune system	0.5%
	✔	MSR1-R293X	Associated with increased risk of Barrett's esophagus and/or esophageal cancer. Our very rough estimate is that the increased risk may be around 4x (25% risk of Barrett's esophagus, assuming population average is 5%, and 1.2% lifetime risk of esophageal cancer compared to average .4% risk).	Low	Likely	Pathogenic	Dominant, Heterozygous	Cancer	0.7%
	(Carrier)	PRPH-D141Y	Hypothesized to cause ALS (or increased susceptibility) in a recessive manner, but this is based on a single observation and may lack statistical significance. The mutant protein appears to form abnormal aggregates.	High	Uncertain	Pathogenic	Recessive, Heterozygous	Nervous system	0.4%
	(Carrier)	CFTR-S1235R	Reported to cause mild dysfunction of the cystic fibrosis gene, it may result in cystic fibrosis when combined with more severe variants.	Moderate	Uncertain	Pathogenic	Recessive, Heterozygous	Breathing; Metabolism	0.5%
✔	✔	RNASEL-R462Q	Associated with increased risk of prostate cancer in individuals who already have a family history of prostate cancer, but studies have been unable to replicate this finding in sporadic (non-familial) prostate cancer cases.	Low	Uncertain	Pathogenic	Complex/Other, Heterozygous	Cancer; Genital and urinary	28.0%

Figure 2. Linear visualization: each rectangle represents a gene variant. Jamie’s variants are represented along the top, Alex’s variants are represented along the bottom, and their shared variants grouped to the left.

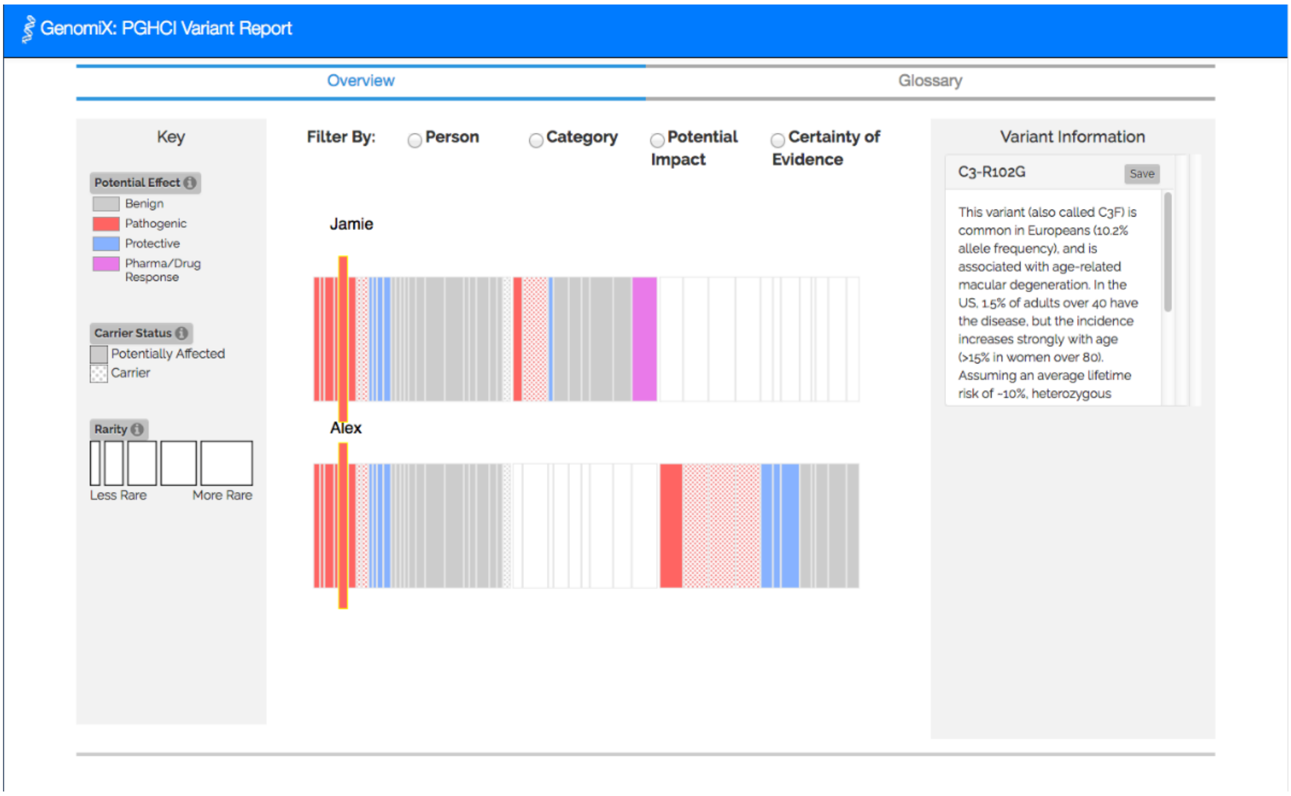


Figure 3. Sunburst visualization: each arc represents a gene variant. The inner circle represents Jamie's variants and the outer circle represents Alex's. Variants in both circles represent the ones Jamie and Alex have in common.

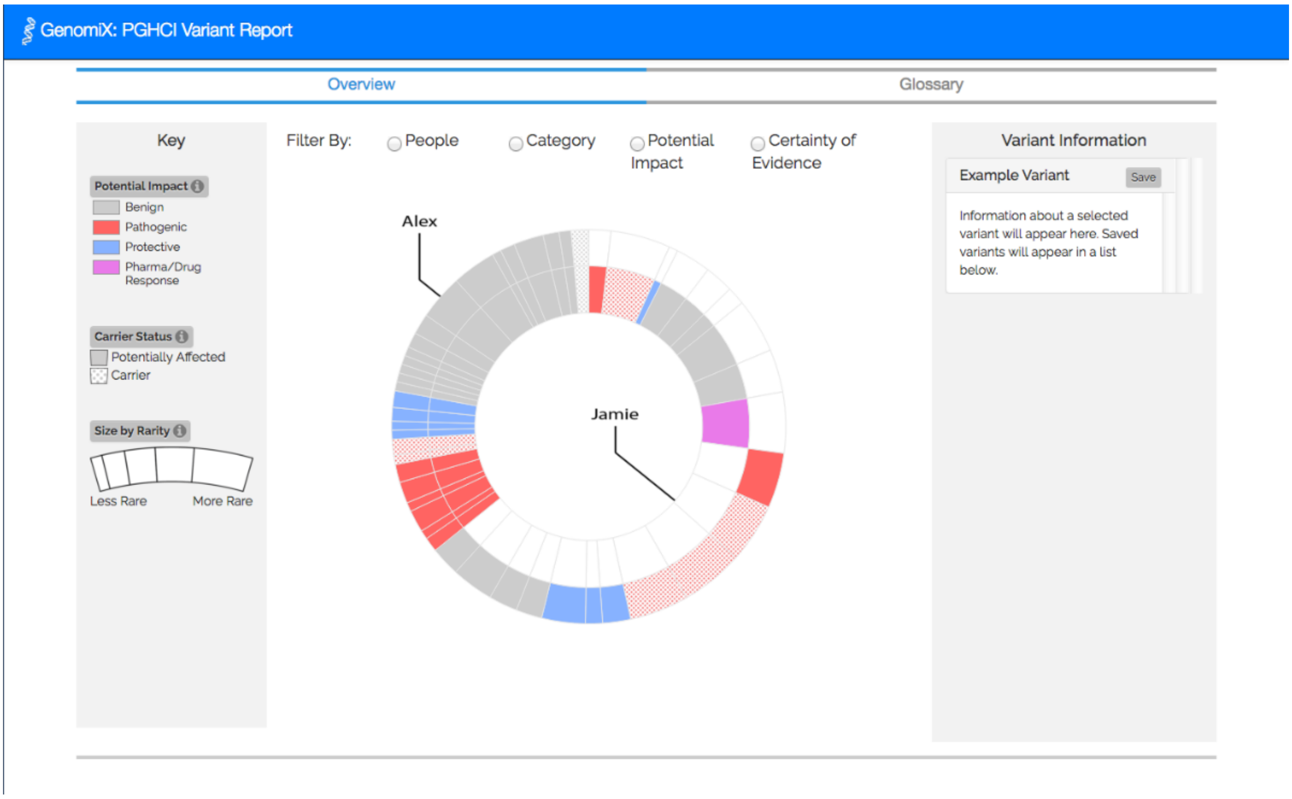
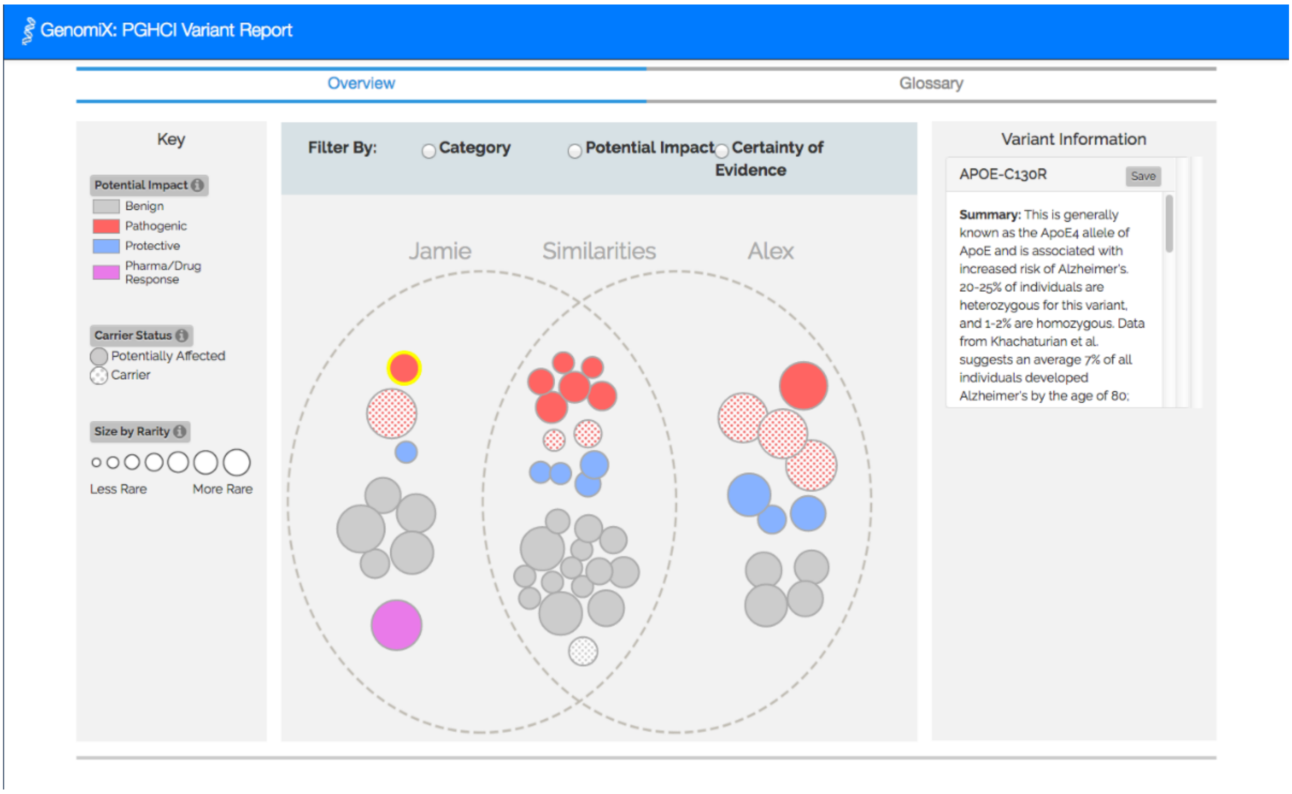


Figure 4. Venn visualization: displays a Venn diagram of gene variants. The bubbles on the left represent Jamie's variants and bubbles on the right are Alex's. Bubbles in the middle represent the variants Jamie and Alex have in common.



Ethics Statement

The studies were approved by the institutional review boards of Wellesley College and New York University.

User Study 1: Comparing Interactive Genetic Reports of Two People

Overview

Our first user study aimed to evaluate the effectiveness of each of the 4 alternative report views in comparing the genetic reports of 2 people (CrossGenomics 1.0). In particular, we investigated the following questions:

> RQ1: To what extent are users able to comprehend both intraindividual (important genetic information of an individual) and interindividual information (comparing similarities and differences in the reports of 2 people)?
>
> RQ2: How do people engage with a comparison tool for personal genomic data, and what visualization features are most helpful for comprehension?
>
> RQ3: How does the report type impact comprehension of genomic data comparison?
>
> RQ4: Are there any gaps between subjective and objective comprehension?

A website was developed for a between-subject experiment with the 4 alternative report views comparing the personal genomic information of 2 fictional siblings, Jamie and Alex (Figures 1-4). This fictional dataset of personal genetic reports of 2 siblings was created based on publicly available personal genomic data shared on Open Humans, using the GET-Evidence [42] interpretation. The same data were used across the different views. Using a fictional dataset to assess nonexpert *comprehension* of personal genomic data is a common practice in personal genomics studies [19,21,29].

Procedure

After digitally signing a consent form and responding to basic demographic questions, participants completed a tutorial on personal genomics using materials from the Personal Genetics Education Project [46]. Comprehension of pretask material was assessed by a 6-question quiz [3,22]. Those who failed to answer at least 3 questions correctly were excluded from the analysis. Users were then randomly assigned to one of the 4 experimental conditions in which they were exposed to one of the report views and interacted with it.

To assess the effectiveness of the report views, we examined comprehension of the users after their interaction with them. Participants were asked to answer comprehension questions using their report tool. The questions (see Multimedia Appendix 1) required intraindividual and interindividual information. This questionnaire was developed in consultation with a genomics expert with experience in engaging nonexperts to explore how personal genetic data relate to published research. It was adapted from an existing questionnaire [3] for use in the comparative context of this study. We then pilot-tested the questionnaire with nonexperts (Mechanical Turk workers).

In addition, participants were asked about their perception of ease of use of the tool using a 5-point Likert scale. Participants were also asked about their perceived understanding of the report. Finally, participants were asked open-response questions about how useful the visual features of the report were and what aspects should be improved. The full study 1 questionnaire is included in Multimedia Appendix 1.

Participants

We recruited participants via Amazon Mechanical Turk. Mechanical Turk is widely used in research aimed at a diverse nonexpert population [47,48], as well as studies of visualization perception [49]. Our goal in the experiment sample selection was not to form a representative sample of a broader public who currently undergo direct-to-consumer genetic testing (DTCGT) but rather to prepare for a relatively near future in which DTCGT is more prevalent. Prior research [50] has shown that the population of Mechanical Turk is at least as representative of the US population as other subject pools. The 99% approval rate threshold was set to ensure that participants take the response to the task before them seriously.

A total of 485 users were distributed across the following conditions: Venn view 24.5% (119/485), sunburst view 24.5% (119/485), and linear view 27.4% (133/485), and 23.5% (114/485) used a table-based view currently available to consumers (ie, control condition). Demographics of users are described in Table 1.

Data Analysis

We compared user responses across conditions using analysis of variance (ANOVA) and post hoc Tukey HSD tests. Responses of users to comprehension questions were scored as 1 if correct and 0 if incorrect. The sum of scores served as a comprehension measure, ranging between 0 (all responses incorrect) and 5 (all responses correct). Responses to the perceived understanding and ease-of-use questions were calculated as the mean of the responses to the respective survey items, ranging between 1 and 5. Responses to the open questions were analyzed using content analysis methods: first-level codes were developed from preliminary review by 2 independent coders. The codes were then collapsed into categories based on frequency, and themes were identified through analysis of categories. Intercode reliability based on 100% of the data was very good at 93%.

User Study 2: Comparing Interactive Genetic Reports of Four People

Overview

In study 2, we sought to evaluate the extension and redesign of the tool (CrossGenomics 2.0) to facilitate a comparison between 4 fictional family members, 2 siblings and their parents. We evaluated the effectiveness of each of the 3 report views (table, linear, and sunburst) in comparing the genetic reports of 4 family members, as well as a fourth view that offered users the ability to switch between the 3 other prototypes. Figures 5-7 show the interactive reports used in this study.

In particular, we expanded on our investigation of RQ1-RQ4 from user study 1 and explored an additional question:

> RQ5: Does the ability to switch between different genetic data visualization, based on the information sought by the user, affect comprehension and behavior?

Similar to study 1, we assessed to what extent users were able to comprehend both intraindividual information and interindividual information. We conducted a between-subject experiment, comparing the 4 different interactive report prototypes. Each report presented the personal genomic information of 4 fictional family members, 2 parents and 2 children. The same personal genomic data, which were created based on publicly available genomic information shared on Open Humans, using the GET-Evidence [42] interpretation, were used across the different views.

Procedure

After digitally signing a consent form and responding to basic demographic questions, users completed the same tutorial on personal genomics and comprehension test of pretask material from study 1. Those who failed to answer at least 6 questions correctly were excluded from the analysis. Users were then randomly assigned to one of the 4 experimental conditions in which they were exposed to one of the tools and interacted with it.

To assess the effectiveness of the tools, we examined users' comprehension using 14 comprehension questions. The questions were designed to assess users' understanding of different concepts (impact, comparison, carrier status, category, rarity, and certainty) and required intraindividual and interindividual information. This comprehension questionnaire was developed in consultation with the same genomics expert from study 1, adapting the questionnaire from study 1.

Table 1. Demographic information for the 3 user studies.

Study number	Participants, N	Population	Average age (years)	Gender (female), n (%)	Compensation	Purchased DTCGT[a], n (%)
1	485	Amazon Mechanical Turk US users with a record of at least 100 tasks at an approval rate above 99%	34.8	233 (48.0)	US $5	6 (1.2)
2	183	Amazon Mechanical Turk US users with a record of at least 100 tasks at an approval rate above 99%	35.2	99 (54.1)	US $5	9 (5.0)
3	49	Users with publicly available 23andMe data on Open Humans	51.3	17 (34)	Lottery for a FitBit Ionic Watch	49 (100)

[a]DTCGT: direct-to-consumer genetic testing.

Figure 5. Tabular report: the table is similar to the existing GET-Evidence report, with each row representing a variant in any of the reports. Four columns were added to the table and a checkmark or a carrier indicator was used to denote the presence of a gene variant for each family member. We added a new search and filters bar.

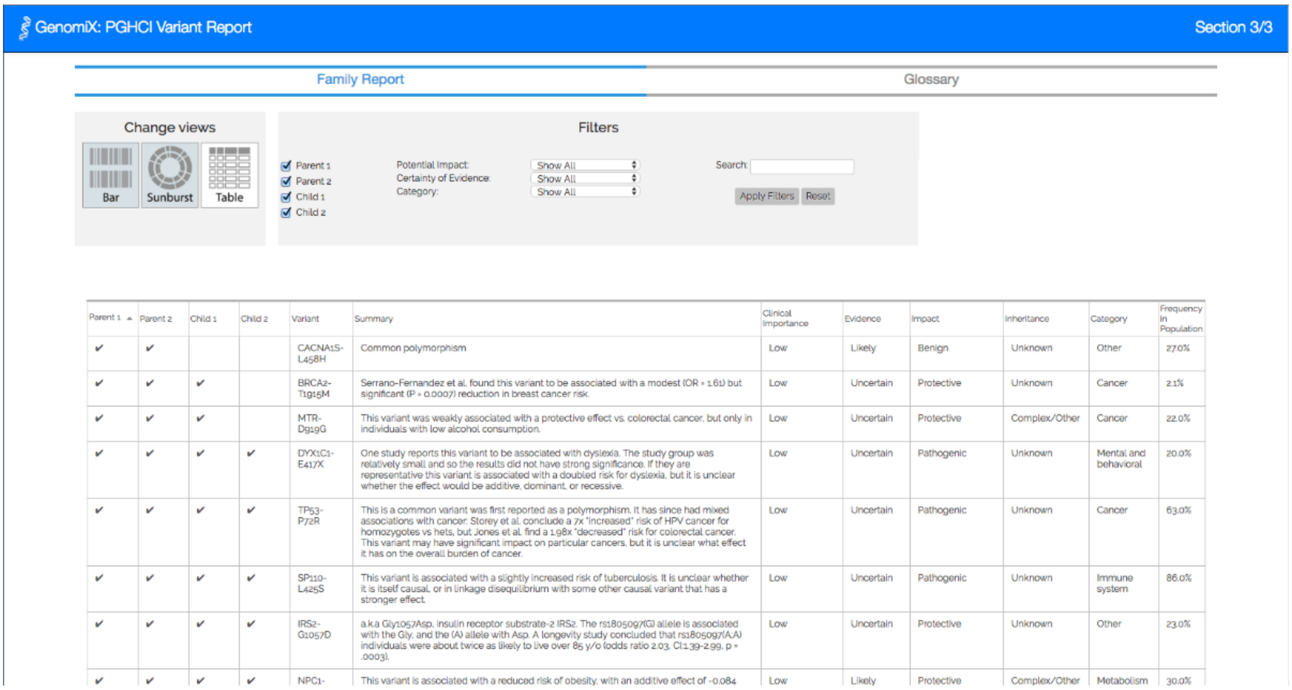


Figure 6. Linear visualization: each rectangle represents a gene variant and each row represents a family member's genome. Parent 1's variants are represented at the top, followed by Parent 2's variants, then Child 1's variants, then Child 2's variants at the bottom. The colored variants in each row represent the variants of one family member.

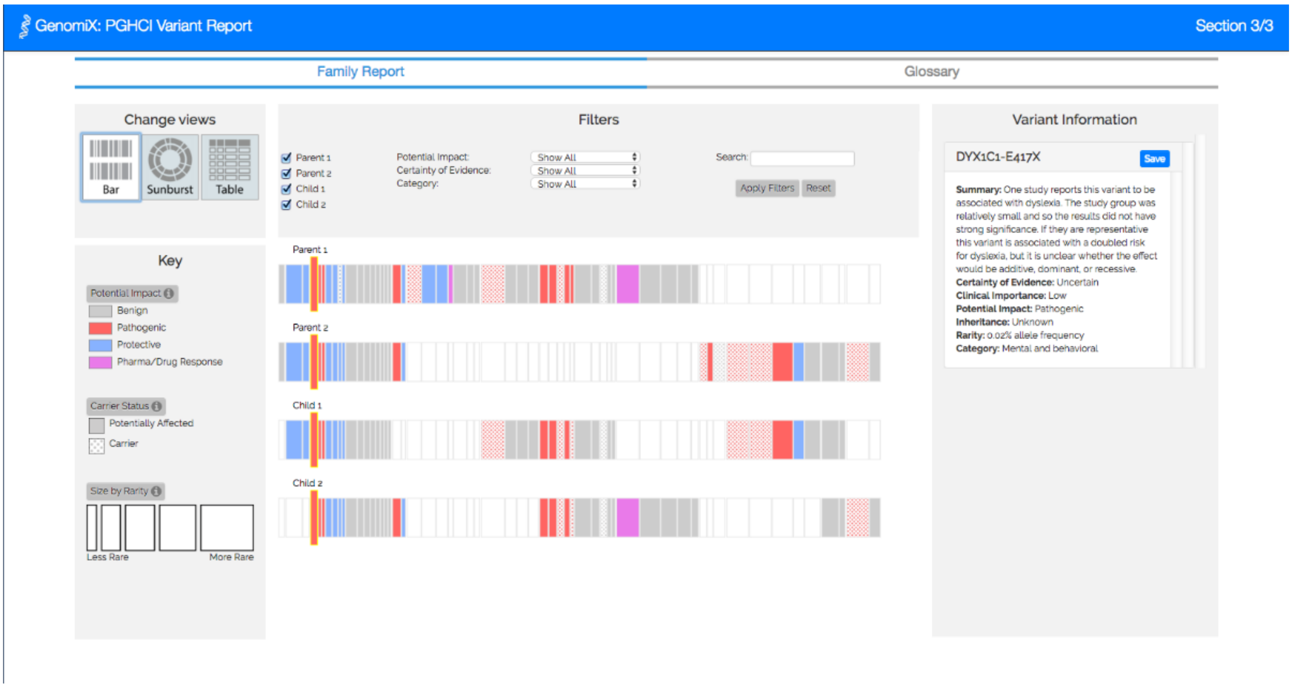
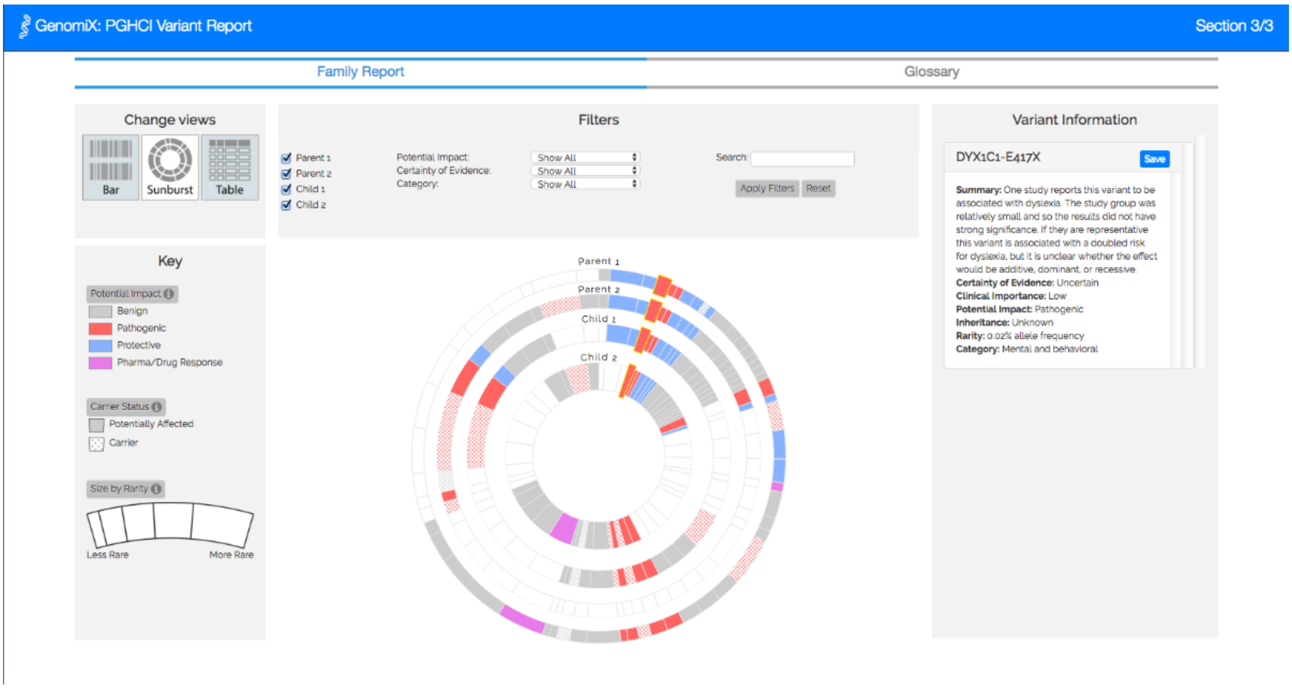


Figure 7. Sunburst visualization: each arc represents a gene variant, and each full circle represents a family member's genome. The outer circle represents Parent 1's variants, followed by Parent 2's variants, then Child 1's variants, and then Child 2's variants in the inner circle. The colored variants in each circle represent the variants of one family member.



Participants were also asked about their subjective perception of ease of use of the tool, using a 5-point Likert scale. Finally, users were asked open-response questions about the usefulness of the visual features of the report and about possible improvements. The complete study 2 questionnaire is included in Multimedia Appendix 2.

Participants

We recruited 183 Mechanical Turk users, who were distributed across the following conditions: linear (45/183, 24.5%), sunburst (43/183, 23.5%), and table (48/183, 26.2%), and 45 (24.5%) used a report that combines the 3 conditions with toggle functionality. All participants in the combined report switched at least once between views. Participant demographics are described in Table 1.

Data Analysis

Analysis was the same as in study 1, but with the addition of chi-square tests. For Q9-Q12, responses were coded as correct if the answer described a pathogenic or pharmacogenetic variant or a variant for which the family member was a carrier if the user mentioned the potential effect for offspring in their reasoning. In addition, responses to these questions were assigned a complexity score from 0 to 6 for their reasoning, with the goal of measuring ability of the users to assimilate complex information and use it appropriately in their analysis of the report.

User Study 3: Evaluating Interactive Reports With Users' Own Data

Overview

In study 3, we sought to evaluate the modification of the tool (CrossGenomics 2.1) with users interacting with their own personal genomic data. We evaluated the integration of the GenomiX single-user gene variant visualization [22] with a redesigned version of the combined view—comparing the user's own personal genomic report to the report of one of the 4 famous people using the tabular, linear, sunburst, and Venn diagram visualizations. In doing so, we sought to draw on the trend of self-comparison with celebrities, which is increasingly evident in popular culture [4,5]. All the filter and search features from CrossGenomics 2.0 were included in this version.

In particular, we investigated the following question:

> RQ6: To what extent and in what ways are users interested in comparing their genetic data with others?

Procedure

We created a study on Open Humans, recruiting users with publicly available 23andMe data. Participants were enrolled in our study and were assigned anonymous project member IDs. Although the study called for users with publicly available data in all communications with potential participants [51], any Open Humans user was technically able to enroll. Open Humans enables individuals to publicly share data through a multistep process (informed consent, quiz, and *opt-in* for each data type), and we discovered that some participants did not realize they had not completed all necessary steps. Thus, we created a Python script to identify which users did not have publicly available data and informed them that although they were under no obligation to make their data public, we could not generate a report unless they did. Some of these users chose to make their data publicly available, while others removed themselves from the study. We created another Python script to convert the available datasets into files with comma separated values format compatible with our visualization. We then sent messages through the Open Humans API, inviting participants to view their report and respond to our feedback form. Each user was sent a unique link that included their project member ID as a variable passed through the URL. On page load, the visualization would read the ID and load the corresponding data.

The feedback form was implemented on Google Forms. Participants were sent a link in their invitation message along with the link to the tool, and the tool itself also contained a feedback tab with the same form embedded. Users could choose whether to record their project member ID. Participants were asked about their motivation for exploring their genetics, as well as which tools they had previously used to explore their personal genetic data. In addition, participants were asked to rate the ease of use and their perceived understanding on a 5-point Likert-scale and were asked open-response questions about new insights using the tool and their interest in genome comparison. The feedback form also included a series of demographic questions. Participants could choose to provide contact details for a future study comparing their data with their real-life family dataset using our tool. The complete study 3 questionnaire is available in Multimedia Appendix 3.

Participants

A total of 163 reports were generated, and 137 (84.0%, 137/163) users viewed their report. Of those, 49 (30.0%, 49/163) responded to our feedback form about the tool. Users who completed the study were entered in a lottery for a FitBit Ionic Watch for completing the feedback form. We present the findings from these 49 respondents, as well as the usage data from the 38 respondents who recorded their project member ID with their feedback. All users had publicly available 23andMe data on Open Humans.

Overall, 36% of respondents (18/49) reported working in life sciences (8/49) or studying life sciences at the collegiate or higher level (16/49). Additional demographics are described in Table 1.

When asked to select their highest level of education, 8% (4/49) of respondents had a high-school diploma, 20% (10/49) of respondents had some college education, 6% (3/49) had an associate's degree, and 10% (5/49) had a bachelor's degree. In addition, more than half of the respondents reported having an advanced degree—29% (14/49) of respondents had a master's degree and another 29% (14/49) had a doctoral degree. These education demographics are consistent with the description of early adopters by Rogers' theory of the diffusion of innovations [52], which details that early adopters tend to have expert knowledge, an advanced education, and a willingness to engage in trials of new technologies.

Data Analysis

Responses to the 5-point Likert-scale questions for perceived understanding, ease of use, and inquiries about new insights were coded from 1 (strongly disagree) to 5 (strongly agree) for each question. Responses to the open questions were analyzed in the same methods as in studies 1 and 2. Intercode reliability based on 100% of the data was very good at 96%. Four participants submitted multiple feedback forms. In these cases, the data from the free-response questions were combined, and the most recent quantitative data from the Likert-scale responses were used.

Results

User Study 1: Comparing Interactive Genetic Reports of Two People

Comprehension and Perceived Understanding

Participants spent, on average, 19.5 min (SD 8.8) on the task of exploring the genetic reports of 2 fictional family members and responding to comprehension and perceived ease-of-use questions. The average time it took users to complete their task did not differ significantly across the 4 conditions (see Figures 1-4; $F_{3,481}$=1.107, *P*=.35). However, the results of the ANOVA and post hoc corrections (see Tables 2 and 3) show differences in the effects of using the tools: objective comprehension scores of the Venn tool users and the sunburst users were significantly higher than scores of the table users (*P*<.001 and *P*=.03, respectively). At the same time, however, sunburst users reported significantly lower perceived understanding than table users (*P*=.03).

Table 2. Comprehension, perceived understanding, and ease of use across report types.

Report type	Comprehension	Perceived understanding	Ease of use
Venn	3.83	3.81	3.92
Sunburst	3.63	3.63	3.58
Linear	3.53	3.74	3.81
Table	3.22	3.92	3.78

Table 3. Significant differences in post hoc comparison.

Report types	*P* value		
	Comprehension	Perceived understanding	Ease of use
Venn and table	<.001	N/A[a]	N/A
Sunburst and table	.03	.03	N/A
Venn and sunburst	N/A	N/A	.02

[a]N/A: not applicable.

In addition, reported ease of use of sunburst users was significantly lower than that of Venn users (*P*=.02). A regression analysis revealed no significant effect of demographics and education level on comprehension, perceived understanding, and ease of use.

Usage

Participants used the filtering feature 12.4 times on an average. Users of the linear tool filtered significantly more than users of the other tools, filtering most by health category (8.1 times on an average). The users of the sunburst and Venn tools filtered by impact only 3.3 and 2.5 times, respectively—significantly lower than linear and table tools users (both *P*<.001).

Features

Qualitative data indicated that filtering was found to be the most helpful feature across all conditions, with 66.0% (320/485) directly highlighting its impact on their understanding. For example, one user noted that because of the sheer amount of information, which makes the report overwhelming at first, filtering made it "easier to at least see an overall picture of who is more predisposed to certain conditions." Filtering also helped with specific searches, as one participant commented "...being able to filter it to just show the variants that were related to cancer helped create a clear comparison."

Moreover, 10.3% (50/485) of the users noted that they would have liked filtering which enables to "combine filter results so that [they] can look at multiple categories at once [and could] result in a single 'hit'." This comment was less significantly frequIn total, 56.5% of users (51% in the combinent in the Venn relatively to the linear (*P*=.03), sunburst (*P*=.01), and table (*P*<.001).

Confusion

Some users found the information to be overwhelming or confusing. Specifically, the sunburst was found to be more confusing (13.4%, 16/119) than the table (5.3%, 6/114; *P*=.03). For example, one user in the sunburst condition commented that "...the filters were helpful, but...did not know where to begin and had trouble figuring out which filter to use." In addition, 11.8% (14/119) of the Venn tool users and 10.5% (14/133) of the linear tool users found their visualization confusing; however, the differences between them and other conditions were not significant.

User Study 2: Comparing Interactive Genetic Reports of Four People

Comprehension

Participants spent, on an average, 29.2 min (SD 12.5) on the task of exploring the reports and responding to comprehension and the perceived ease-of-use questions. The average time it took users to complete their task did not differ significantly across the 4 conditions (see Figures 5-7; $F_{3,177}$=0.672, *P*=.57). However, the results of the ANOVA (see Tables 4 and 5) indicate a significant effect of report type on objective comprehension for the 3 conditions ($F_{3,176}$=5.538, *P*=.001). Post hoc comparisons using Tukey HSD test indicated that the mean score for the table and combined report type were significantly higher than the mean score for the linear report.

Further analysis of scores by individual questions indicates a significant effect of report type on the scores of only 3 of the 14 comprehension questions (Multimedia Appendix 2). For RQ6, "Which child shares the most cancer-related variants with Parent 1?," participants in the combined condition (mean 0.89, SD 0.32) scored significantly higher than those in the linear condition (mean 0.77, SD 0.48, P=.04; $F_{3,177}$=2.810, P=.04). For RQ7, "Parent 1 has _____ cancer-related variants than Parent 2," participants in the linear condition (mean 0.44, SD 0.50) scored significantly lower than those in the combined (mean 0.71, SD 0.46, P=.04) and table conditions (mean 0.79, SD 0.41, P=.01; $F_{3,177}$=4.754, P=.01). For RQ8, "Which variants are not expected to affect Child 1 themselves, but may affect Child 1's future children?," participants in the combined condition (mean 0.67, SD 0.48) scored significantly higher than those in the linear (mean 0.33, SD 0.48, P=.01) and sunburst conditions (mean 0.40, SD 0.50, P=.04), and participants in the table condition (mean 0.65, SD 0.48) scored higher than those in the linear condition (mean 0.33, SD 0.48, P=.01; $F_{3,177}$=2.810, P=.04).

Table 4. Mean scores and SD for comprehension, perceived understanding, and ease of use for participants in each of the 4 conditions.

Report type	Comprehension, mean (SD)	Perceived understanding, mean (SD)	Ease of use, mean (SD)
Linear	9.55 (2.94)	3.69 (0.86)	3.93 (0.91)
Sunburst	10.58 (3.11)	3.69 (0.69)	4.07 (0.64)
Table	11.17 (2.25)	3.78 (0.84)	4.09 (0.80)
Combined	11.67 (1.92)	3.86 (0.67)	4.32 (0.57)

Table 5. Post hoc differences from the linear tool, with significant and trending *P* values.

Report types	*P* value		
	Comprehension	Perceived understanding	Ease of use
Linear and combined	.001	N/A[a]	.07
Linear and table	.01	N/A	N/A

[a]N/A: not applicable.

Overall, we find that the use of the combined report, which enables users to switch between report types based on their information needs, is associated with significantly higher comprehension level. We also find that using the table-based report leads to better comprehension than each of the noncombined visual reports.

Subjective Experience

Despite the difference in comprehension scores across conditions, the results of the ANOVA suggest no significant effect of report type on the perceived understanding ($F_{3,177}$=0.502, P=.68) or ease-of-use scores ($F_{3,177}$=2.083, P=.10; see Table 5), with the exception of a trending difference between the combined and linear conditions, indicated by post hoc analysis (P=.07). There was a strong correlation between perceived understanding and ease-of-use scores (r=.735, P<.001), a moderate correlation between ease of use and comprehension (r=.328, P<.001), and a weak correlation between perceived understanding and comprehension (r=.170, P=.02).

Complexity

Correct responses to Q9 to Q12 were assigned a complexity score from 0 to 6 for their reasoning, with points assigned when users reference each of the following concepts: potential impact, the certainty of evidence, carrier status, rarity, and clinical importance, with a final possible point for synthesis of information. In 3 questions (Q10-Q12), which inquire about which variant each family member would be most likely to discuss with their health care provider, there was a significant effect of report type on the complexity score of the correct responses (Tables 6-8). Post hoc comparisons indicated that users of the combined report had significantly higher complexity scores for these questions than the users of the linear tool. Further analysis by individual concepts revealed that the users of the combined report mentioned clinical importance significantly more than users of the linear tool in their correct responses for all 4 questions. Users of the combined report also mentioned certainty of evidence significantly more than the users of the linear tool for Q10 and Q11.

Demographics

A regression analysis revealed no significant effect of demographics on comprehension or subjective experience.

Usage

Participants in the combined report switched on an average 5.16 times between views (SD 3.4, minimum=1, maximum=15). Moreover, 40% (18/45) of users switched views more than 5 times (see Figure 8). Out of the 45 users who interacted with the combined tool, 34 users primarily used the table, seven users primarily used the linear tool, and 4 users primarily used the sunburst tool. Furthermore, 17 of the 45 users (38%) spent more than 90% of their time exploring and answering comprehension questions using one of the 3 views. Within the combined condition, no correlation was found between the amount of switching between views and either comprehension, perceived understanding, or ease of use.

Table 6. Average combined complexity scores in correct responses to question (Q)9 to Q12 by condition.

Report type	Q9		Q10		Q11		Q12	
	Score	*P* value	Score	*P* value	Score	*P* value	Score	*P* value
Linear	1.40	.55	1.20	.51[a]	1.21	.58[a]	1.25	.59[a]
Sunburst	1.47	.72	1.63	.92	1.69	.77	1.43	.78
Table	1.79	1.10	1.75	1.16	1.69	1.22[a]	1.70	1.15
Combined	1.70	.74	2.05	.81[a]	1.88	.88	1.89	.84[a]

[a]Significant difference between the linear and combined conditions.

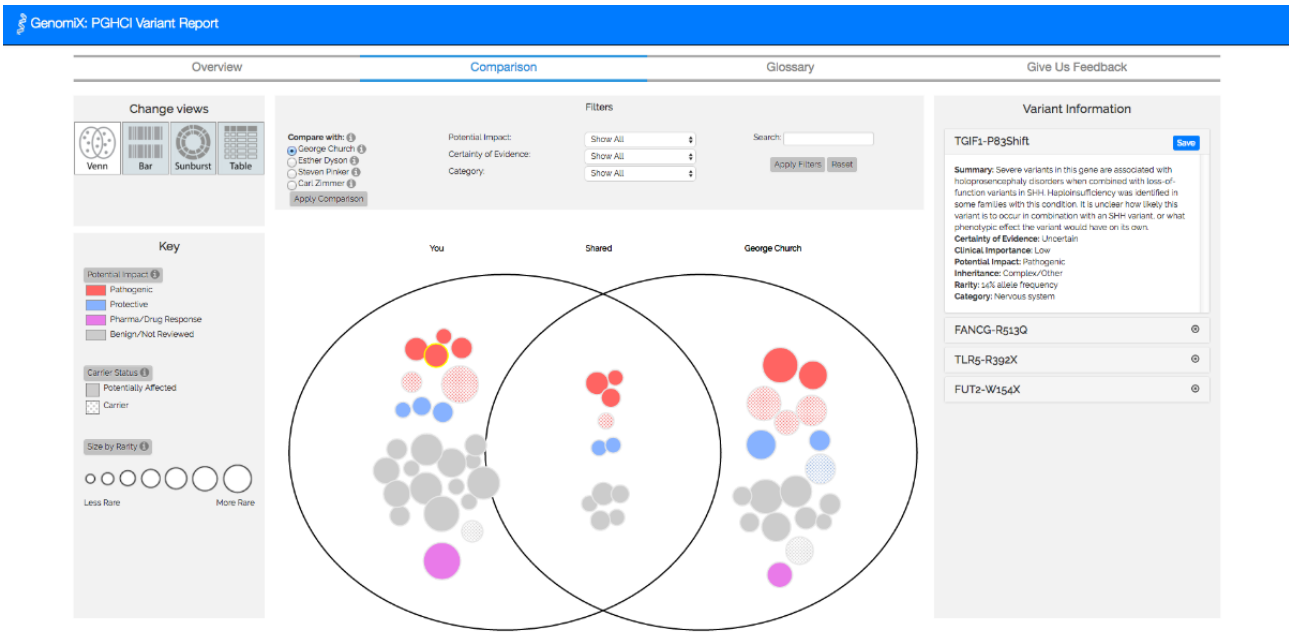
Table 7. Analysis of variance results to question (Q)9 to Q12.

Question	*F* (3,177)
Q9	1.918
Q10	6.620
Q11	3.948
Q12	4.368

Table 8. Post hoc differences between linear and combined reports for question (Q)9 to Q12.

Report types	*P* value			
	Q9	Q10	Q11	Q12
Linear and combined	.13	<.001	.01	.01

Figure 8. Comparison tab of CrossGenomics 2.1, where users can toggle between the four comparison visualizations using the buttons under "Change Views".



While exploring the report, across the 4 conditions users applied on average 7.60 filters (SD 10.8, minimum=0, maximum=111) and searched the report 5.5 times (SD 5.8, minimum=0, maximum=28). There was no significant effect of condition on the amount of filtering ($F_{3,177}$=1.599, P=.19) or searching ($F_{3,177}$=0.474, P=.70). No correlation was found between the number of filters applied and comprehension, perceived understanding, or ease of use. There was a weak correlation between the number of searches and both perceived understanding (r=.204, P=.01) and ease of use (r=.171, P=.02).

Report Features

Users were also asked to describe, in open-ended questions, which features were most helpful for understanding and comparing the reports, as well as how the tool can be improved.

Overall, users across all conditions liked the filter and search functionalities and suggested simpler language and more filtering options as improvements. In total, 56.5% (104/183) of users (23/45, 51% in the combined condition, 24/45, 53% in the linear condition, 21/43, 49% in the sunburst condition, and 35/48, 73% in the table condition), χ^2_3 (N=181)=7.009, *P*=.07, reported filtering to be one of the most helpful features. In the words of one user in the combined condition, saying, “The ability to filter by individual and category of gene (pathogenic and protective) made navigating the data much easier.”

Furthermore, 33.25% (61/183) of users (13/45, 29% in the linear condition, 12/43, 28% in the sunburst condition, 14/48, 29% in the table condition, and 21/45, 47% in the combined condition), χ^2_3 (N=181)=4.956, *P*=.18, also reported that the search functionality was helpful for interpreting the reports. As one user in the combined condition wrote:

> *Being able to search and filter out the various subjects was the most helpful to me. Being able to only focus on the information that I was interested in made the process much easier.*

Furthermore, 22% (10/45) of users in the combined condition explicitly stated they liked being able to switch between representations. A user emphasized this by saying, “I also enjoyed being able to switch from table view to bar view to easily understand the information better.”

A different user noted the different usage for each view, stating:

> *The bar graph is easiest when lining up which family members have which genomes, and the sunburst graph was easiest when just filtering in/out things in general. The table is nice, but visually not as pleasing, but could be potentially the most useful especially if you don't have the ability to have an interactive graph.*

Another user shared:

> *The different visualizations made it easier to understand the data in some situations [for example, the bar chart made it easier to understand quickly which family members shared what variants, whereas the table made it easier to learn about each variant].*

Overall, 19.4% of all users (9/45, 20% in the combined condition, 11/45, 24.4% in the linear condition, 7/43, 16.3% in the sunburst condition, and 8/48, 16.7% in the table condition) reported difficulty with medical terms used in the report. One user, who viewed the tabular report, suggested, “Some of the explanations could be written in a more accessible manner.”

In addition, 10.4% of users (5/45, 11.1% in the combined condition, 2/45, 4.4% in the linear condition, 5/43, 11.6% in the sunburst condition, and 7/48, 14.6% in the table condition) reported requirement for more filtering options. The differences in proportion between the conditions were not significant.

User Study 3: Evaluating Interactive Reports With Users’ Own Data

Previous Use of Genome Tools

All 49 users had their genome mapped by 23andMe. Unlike the users of our previous 2 studies, we classified these 49 users as expert users, as they had previous experience of exploring their genome. Furthermore, 88% (43/49) of those users had also used at least one of the following tools to explore their results: Promethease (41/49), SNPedia (30/49), Google (17/49), ClinVar (17/49), GET-Evidence (15/49), PubMed (15/49), Wikipedia (14/49), Genevieve (14/49), and OMIM (10/49).

Motivation

We asked participants to rank the personal importance of 8 potential reasons for exploring information about their genetics on a 5-point Likert scale from *Not at all* to *Extremely* (Table 9).

Usage

A total of 78% (38/49) participants provided their project member IDs, which allowed us to identify their specific usage data from the tracking logs on our tool. The usage data of these users are presented here.

Visualizations

All 38 users began on the comparison tab, with their genomic report compared with the report of George Church by default. Of these, 68% (26/38) viewed the overview report and 63% (24/38) viewed the glossary. Within the comparison tab, 79% (30/38) users viewed all 4 visualizations, 8% (3/38) users viewed only 3, 5% (2/38) users viewed only 2, and 8% (3/38) users did not switch visualizations at all. As the default visualization on page load, all users viewed the Venn diagram visualization. In addition, 89% (34/38) users viewed the sunburst visualization, 87% (33/38) users viewed the linear visualization, and 84% (32/38) users viewed the tabular report. Moreover, 58% (22/38) of the users compared their data with all 4 comparison genomes, whereas 16% (6/38) users did not change comparison genomes.

Variants

Users clicked on a total of 1609 variants in the interactive sunburst, linear, and Venn diagram visualizations. In addition, 124 variants were saved by 13 users. The majority of variants were clicked and saved in the Venn diagram, the default view of the tool on page load.

Filtering

The comparison and single-user visualizations also included a filter bar, which affords users the ability to filter variants—by certainty of evidence, potential impact, and category—and search for a specific term. In the comparison view, 24 users applied 209 filters and searches. Of these, 30 certainty of evidence filters were applied, 29 of which were for *well-established* variants. A total of 44.4% (93/209) filters included a filter for potential impact, 20.0% (42/209) for pathogenic variants, and 17.2% (36/209) for variants affecting drug response of a user. Another 14.3% (30/209) filters specified a certain health category, such as *Cancer* or *Metabolism*. Four users also searched for specific terms, such as *Alzheimer*, in their data.

Perceived Understanding

In this study, 12% (6/49) of respondents reported they would need the help of a health care professional to better understand their results (on a 5-point Likert scale, mean 2.36, SD 1.03). In addition, 41% (20/49) reported feeling that the report gives them a firm grasp of their health and genetics (mean 2.98, SD 1.15,). On the goal of communicating uncertainty, 82% (40/49) felt they could grasp the extent to which the knowledge regarding different variants is certain or uncertain (mean 3.92, SD 0.88).

Ease of Use

In this study, 84% (41/49) of respondents reported that they found the information in the report to be presented in a clear and accessible manner (on a 5-point Likert scale, mean 3.94, SD 1.04). In addition, 65% (32/49) found the glossary helpful (mean 3.60, SD 1.05), and 39% (19/49) found the ability to save variants helpful while interacting with the report (mean 3.22, SD 1.13).

Report Features

When asked which features were most helpful for understanding the report, users mentioned the usefulness of filtering in both the comparison and single-user visualizations. One user wrote:

> *I think most reports fail to grab attention except for a few variants that are highlighted. Sorting by certainty helped that some here.*

Table 9. Average personal importance for potential reasons for exploring information about their genetics, 5-point Likert scale (not at all, slightly, moderately, very, and extremely).

Reason	Mean (SD)
To learn personal disease risk or health-related information	3.86 (1.14)
Curiosity	4.40 (0.81)
To contribute to research	4.28 (0.81)
Interested in distant ancestry (race or ethnicity)	3.14 (1.50)
Learning more about my family origin and recent ancestry	3.20 (1.46)
To provide disease risk information for children and other family members	2.78 (1.40)
To learn more about myself	4.22 (1.04)
Understanding these data for professional purposes	2.00 (1.20)

Users also commented on the value of toggling between different views. In the words of one user:

> *I specifically liked the ability to see the data presented in all three visualizations. The information for each particular variant was succinct and easy to follow.*

Several users also commented that although they enjoyed the visualizations, the tabular view offered a valuable overview to all the descriptions at once. One user wrote:

> *I liked the table view the best, I could just read straight down, without having to move around page...The visual was interesting but I spent more time on table view.*

When asked how they felt the report could be improved, several users mentioned that they wished they could print their report, while others suggested a more robust tutorial. In the words of one user, “[I] would like to be able to download the variant report in pdf format to refer to offline.” Several users also mentioned that they wished the tool began on their report, instead of the comparison tool.

New Insights

In this study, 49% (24/49) of the users reported learning new insights and information about their genetics using this tool that they had not noticed in previous reports (on a 5-point Likert scale, mean 3.16, SD 1.31). In addition, 43% (21/49) also reported that the visualization changed their understanding of their report (on a 5-point Likert scale, mean 3.00, SD 1.21). When asked to elaborate on what new insights and information about their genetics they learned from this visual report, some users reported discovering new variants that they had not noticed in previous reports. For example, one user wrote, “FUT2-W154X, ADA-D8N, and DPYD-M166V were all variants I hadn’t noticed before and found interesting.” Other users commented on the understandability of this report as compared with others, stating, “The way other reports or worded/written, I have hard time understanding if I have or don’t have [a variant], very confusing.” Other users reported that they did not learn anything new, as they had previously poured over their report, but still found the experience worthwhile. In the words of one user, “I had seen most of this information in previous reports, but I did enjoy the interactive visualization.”

Comparison

A total of 35% (17/49) reported learning something new from comparing their data with another person (on a 5-point Likert scale, mean 2.63, SD 1.30). When asked to elaborate on what they learned, 24% (12/49) expressed amazement at the number of shared variants between themselves and the comparison genomes. Others reported that they viewed the comparisons out of curiosity but did not learn anything new. In the words of one respondent, “I looked at the comparisons but they did not engage me because I do not know the people.”

When asked if there are any other potential people with whom they would like to compare their data, 51% (25/49) responded with at least one family member. In the words of one participant:

> *I liked the Venn diagram and I would use it to compare with other family members. This would be awesome if I could load even more data—for example, for our family of four—to see what we passed on to our kids.*

In fact, more than half of the users (51%, 25/49) recorded their project member ID or email address to be contacted with opportunities to compare their data with that of their family members using our tool. In addition, 10% (5/49) participants lamented that they would have liked to compare themselves with specific members of their family who have passed away or are not interested in genetic testing. When asked what questions they would like to explore in comparison with these individuals, 24% (12/49) mentioned an interest in inheritance patterns between family members. In addition, 10% (5/49) of users mentioned an interest in exploring potential health risks through family comparison.

Discussion

User Study 1: Comparing Interactive Genetic Reports of Two People

We found that all views allowed users to complete the task of comparing 2 personal genomic reports with at least moderate domain comprehension of both intraindividual and interindividual information (see Table 2; RQ1). The sunburst- and Venn-based prototypes led to significantly higher domain comprehension, compared with the linear prototype and the commonly used tabular report (RQ3). However, we identified gaps between objective and subjective comprehension, as sunburst users reported significantly lower perceived understanding and higher levels of confusion (RQ4).

Although the Venn tool appears to be most effective, it is limited in scalability, as it can only show the data of 2 users at a time. The other prototypes, in particular the sunburst and the linear tools, can present data of a larger number of users. In study 2, we aimed to further explore the utility of these prototypes in facilitating domain comprehension when comparing a larger number of genomic reports. Our redesign includes genomic reports from 4 biological family members. As expanding the number of compared reports to 2 was a planned feature, we decided to first evaluate and learn from the comparison of 2 personal genomic reports.

Through analysis of the open-ended responses, we learned that users viewed the ability to filter and search the data as most helpful (RQ2). We found a relatively consistent pattern of usage of these features across the 4 report types. These findings led us to implement a search tool in our next design iteration across all different visual reports and to redesign our filtering functionality to allow users to combine filters. In study 2, we investigated the role of search and filtering when there is an increase in the information displayed.

Redesign

There were 3 redesign iteration stages leading to CrossGenomics 2.0. The first iteration stage focused on expanding the visualization by presenting the genetic reports of 2 family members to 4. This resulted in the linear visualization having 4 linear bars and the sunburst visualization having 4 concentric rings. We did not include the Venn visualization in this redesign.

Due to increase in the information displayed, we added a filter to show or hide certain family members so that users could focus on certain individuals without being distracted by others. We also added tutorial tooltips that briefly describe the function of the key, filters, and variant information panels. On the basis of feedback gathered from the first study, we increased the size of the panel where variant information appeared so that scrolling was not required. We also modified the filtering panel so that users could combine filters and see all of the filters they had selected.

We tested this version in a pilot study with 25 nonexpert users (Mechanical Turk workers) per condition. We found that users in the table condition used the browser search function to find particular important keywords (eg, cancer) and found the search to be helpful. In addition, we identified that users were not saving variants for revisiting the information.

Informed by these findings and by the findings from study 1, we implemented a search tool that was consistent across the different visual reports and allowed searching for keywords within a visual report and highlighted the *save* button by changing the button color from gray to blue. We also introduced a new visual report that allowed users to switch between the 2 visual reports (linear and sunburst) and the table report. This version was subsequently tested with 10 Mechanical Turk users per visual report.

Results further highlighted the important role of the search feature, as well as a need to combine the application of the potential impact and certainty of evidence filters with the category filter. Results also indicated that users still rarely *saved* variants. As such, we moved both the search and the category filters to be part of the core filter functionality, allowing a user to combine all of them together. We also added a tooltip prompting users to *save* a variant on the first selection.

Figures 5-7 show the 3 redesigned reports, integrated into an interactive tool, which allows users to switch between these 3 views. These 3 prototypes were evaluated separately in comparison with the combined tool in study 2.

User Study 2: Comparing Interactive Genetic Reports of Four People

Users across all conditions completed the task of comparing 4 personal genomic reports, demonstrating at least moderate domain comprehension of both intraindividual and interindividual information (see Table 4; RQ1). A key finding from this study is that users in the combined condition did, in fact, switch between the views presented and demonstrated higher comprehension levels, as well as more complex reasoning (RQ5). More than 20% of the users in this condition explicitly mentioned switching between views as a helpful feature (RQ2).

We also found that using the table-based report led to better comprehension than the noncombined visual reports (RQ3). In particular, the linear visualization performed the worst compared with the combined tool and with the table-based report. The sunburst tool did not perform significantly better or worse compared with any of the tools. In addition, we found that although all users of the combined tool switched at least once between visualizations, about three-fourths of these users chose to primarily use the table-based report to answer comprehension questions. A possible explanation for these results may be the lack of familiarity and experience of nonexperts with visual tools, in contrast with familiarity with table-based reports.

Despite the difference in comprehension scores across conditions, the results suggest no significant effect of report type on the perceived understanding. This indicates a gap between objective and subjective comprehension (RQ4).

On the basis of these findings, which indicate that overall the combined condition of CrossGenomics 2.0 is effective for comparing personal genomes across individuals, we adapted this tool to study (in study 3) how Open Humans participants use it to explore their own personal genomic data.

Adapting CrossGenomics for User Data

Following user study 2, the combined visual report from CrossGenomics 2.0 was modified to load real 23andMe data that were shared *publicly* on Open Humans profile of a user. This allowed us to engage a pre-existing community where individuals are publicly sharing genetic data, including nearly 1000 individuals who already publicly share these data in the Harvard Personal Genome Project [42] or openSNP projects [53]. This new prototype of CrossGenomics allowed users to compare their own report with one of the 4 publicly shared genomes of famous scientists and thought leaders on genetics (George Church, Esther Dyson, Steven Pinker, and Carl Zimmer). The tool provided users with 4 different views: tabular, linear, sunburst, or Venn diagram visualizations.

The genome to which the data of a user are compared could be selected using a radio button. This modified comparison tool was integrated with the single user GenomiX [22] gene variant report, presented in a separate tab, to create CrossGenomics 2.1—a tool that allows users of Open Humans to explore their own 23andMe data and compare it with 4 other genomes. Figures 8-10 show the GenomiX tool integration and the 4 visualizations in the comparison tool.

User Study 3: Evaluating Interactive Reports with Users' Own Data

Results indicate that the majority of participants found the report to be presented in a clear, accessible, and comprehensible manner. Findings also indicate that the ability to switch between views is particularly helpful. In addition, participants highlighted filtering, sorting, and saving variants as important features. These findings shed light on how people engage with a comparison tool for personal genomic data and what features are most helpful for comprehension. More than half of participants expressed interest in comparing their personal genomic data to that of a family member using our comparison tool, expressing motivation to explore inheritance patterns and health risks. Fewer users were interested in the comparison of their data to the "famous genomes" provided. Over one third of the participants reported learning something new from comparing their data to another, mostly highlighted the similarities between their own report and the others' reports.

Figure 9. Overview tab of CrossGenomics 2.1 in graph view, where users can view their own personal genomic data graphed by certainty of evidence and potential health effect in our single-user GenomiX visualization.

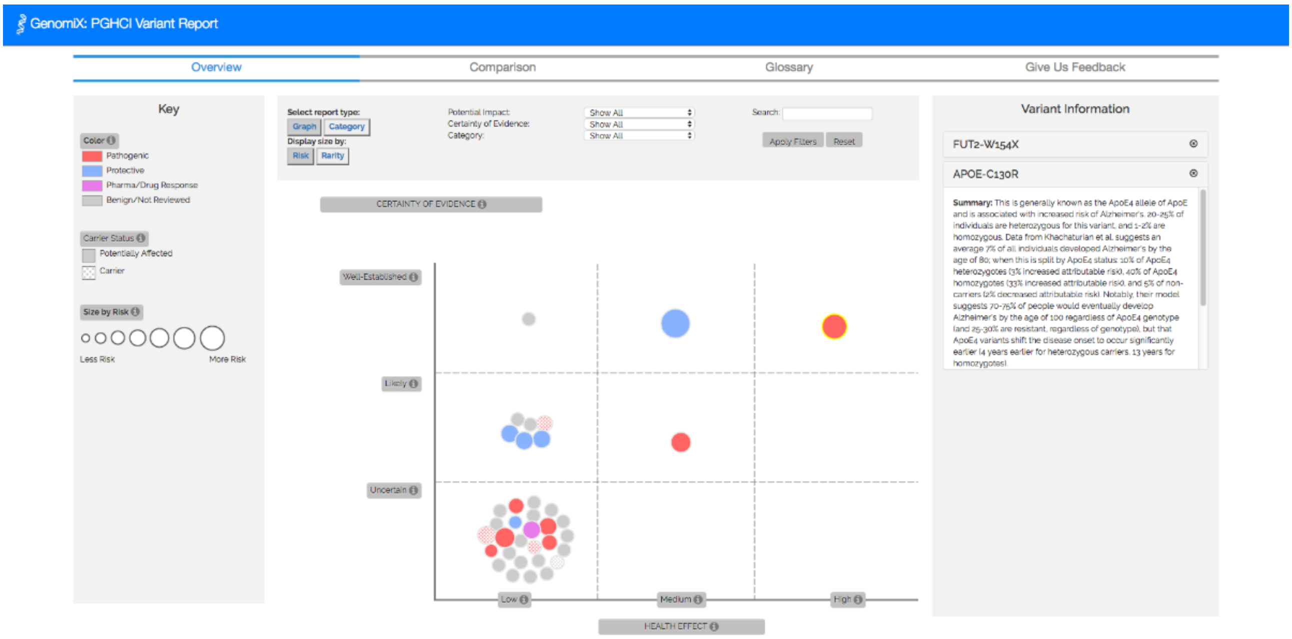
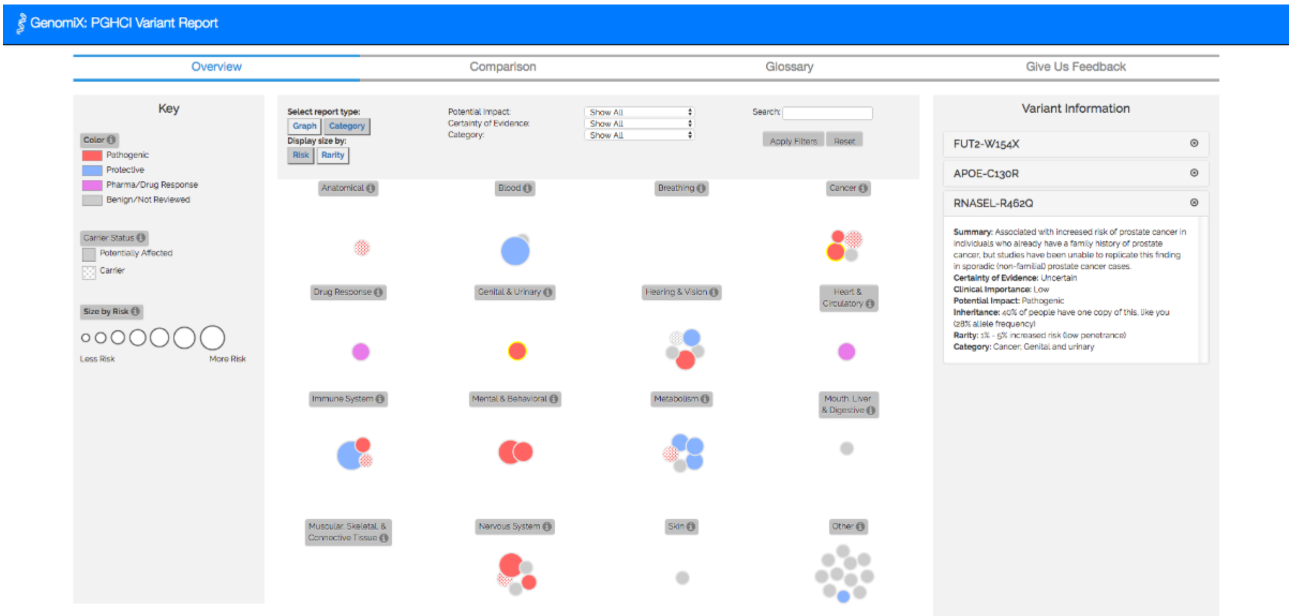


Figure 10. Overview tab of CrossGenomics 2.1 in category view, where users can view their own personal genomic data by health category in our single-user GenomiX visualization.



These findings indicate an interest in comparison and highlight the ways in which nonexperts seek to compare their genetic data to others' (RQ6). Findings also suggest that users are able to comprehend both intra-individual (important genetic information of an individual) and inter-individual information (comparing similarities and differences in the reports of two people; RQ1).

Principal Findings

Taken together, the 3 studies advance the prior personal informatics research by offering a novel approach to enabling user engagement in the transition between integration, reflection, and action [10-12]. Overall, we contribute to research on personal and health informatics in 2 central ways: first, we advance the literature in the specific domain of personal genomics by offering and evaluating a novel design for interpersonal, comparative, and genomic information reporting tool. Second, the findings underscore the need to understand and design for the social aspect of deeply personal information and call for careful theoretical consideration of design decisions in this space.

The first prototype (study 1) served as a proof-of-concept for eliciting users' feedback. As a result of the reported findings, we redesigned the tool by introducing a consistent search tool across the visual reports and by adding a new feature to enable users to switch between the reports. Study 2 was an extension of study 1, enabling users to compare up with 4 people, which further corroborated the usefulness of the redesign done after study 1. Building on both studies and users' feedback, in study 3 we sought to enable Open Humans participants to explore their own personal data. The findings offer a new perspective on how users can integrate and reflect on data, both in a personal and social context: (1) highlighting features and visualizations that show strengths in facilitating user comprehension of genomic data, (2) demonstrating the value of affording users the flexibility to examine the same report using multiple perspectives, and (3) emphasizing users' needs in comparison of genomic data. In the following paragraphs, we discuss the findings in detail, as well as the ethical considerations and implications for the design of tools for multiuser engagement with complex multidimensional data.

In user study 1, we evaluated 4 alternative views for CrossGenomics, a novel interactive tool enabling nonexpert users to explore what gene variants they share with others and what sets them apart. We found that the sunburst- and Venn-based prototypes led to significantly higher domain comprehension, compared with the linear prototype and the commonly used tabular report (RQ1). Although the Venn tool appears to be particularly effective, it is limited in scalability, as it can only show the data of 2 users at a time. The other prototypes, in particular the sunburst and the linear tools, can present data of a larger number of users. A trade-off therefore exists between the utility of the tool and its user coverage per comparison session.

We also found that users viewed the ability to filter and search the data as most helpful for comprehension and exploration (RQ2). We found a relatively consistent pattern of usage of these features across the 4 report types, suggesting these features are important for both visualization and table-based reports. These findings highlight the benefit of providing features that allow users to focus on and switch between relevant subsets or dimensions of the information. Recent study by Feng et al has corroborated this finding, suggesting that the presence of text-based search influences information-seeking goals of people and can alter both the data explored and the ways in which users engage with it [54]. In addition, they found the effects of the search are amplified in visualizations where the users are familiar with the underlying dataset, such as the expert users in our third study.

In user study 2, we also found that using the table-based report led to better comprehension than the noncombined visual reports (RQ3). In particular, the linear visualization performed the worst compared with the combined tool and with the table-based report. This stands in contrast to the popularity of the linear alignment visualization in tools for experts [27,29-31,45]. In addition, we found that although all users of the combined tool switched at least once between visualizations, about three-fourths of these users chose to primarily use the table-based report to answer comprehension questions. A possible explanation may be the lack of familiarity and experience of nonexperts with visual tools, in contrast with familiarity with table-based reports. This highlights a need to guide users carefully through the use of visual reports. Recent research has proposed and evaluated new ways of providing such guidance [55].

The findings from user study 1 also suggest a discrepancy between objective and subjective knowledge of users—what users know and how much they think they know [56-58] (RQ4). We found that the sunburst tool that was associated with higher domain comprehension (objective knowledge) compared with the tabular report was also associated with significantly lower perceived understanding (subjective knowledge), which may be explained by the users' comments about the sunburst tool as being significantly more confusing or overwhelming. Similar discrepancies were reported in other domains in which information tools were used for clarifying complex information [59]. For example, Gunaratne et al [60] found that exposure to social annotations of financial disclosure documents increased performance but reduced perceived understanding. A possible explanation for such discrepancies is that the more knowledgeable users become, the more they realize how complex the information presented to them is and realize how much of it they do not understand. Although we did observe a similar trend in the second study, the discrepancy between objective and subjective knowledge was not statistically significant. Further research is needed to explore these differences.

A key finding from user study 2 is that users who were given the flexibility to choose how personal genomic data are presented to them (through the ability to switch views) did, in fact, switch between the views presented and that these users demonstrated higher comprehension levels and were able to offer more complex reasoning to justify their choices based on evidence from the visualizations (RQ5). Thus, the findings suggest that providing users' autonomy to pursue their information needs based on their preferences, as well as to explore data from multiple perspectives lead to better comprehension and perceived ease of use.

The findings from user study 3 suggest that a majority of our users have an interest in comparing their personal genomic data with that of a family member using our comparison, and fewer users were also interested in the comparison of their data with the *famous genomes* provided, beyond a one-time exploration (RQ6). Of the participants who reported gaining new insight from the comparison tool, most highlighted the similarities between their own report and the report of the other person. Building on the concept of biosociality—how people form social ties around health conditions caused or influenced by genetic characteristics—one future direction to explore would be to focus on people with known similar conditions or similar communities for comparison.

The studies and their findings also raise ethical issues. One such concern stems from unique combination of unchanged data and changed interpretation of personal genomic information, driven by the new findings resulting from advances in genetic research. By making individual and social personal genomic data available, comparable, and interpretable, users can engage continuously with unchanging *data for life* [61]. However, access to such data in the context of personal information can inform everyday choices of users [61],and access to comparative information about others may lead to information surveillance [1], which is particularly concerning in situations where future genetic research may suggest previously unknown relationships between genetic data and health conditions. As a result, new implications about users' data could be shared with others without the original user's control. Moreover, the promise of empowerment, often pervasive in discussions of health self-tracking and personal informatics [62], and the critical perspectives approach to this promise [63,64,65] are all the more evident in the case of personal genomics, where individuals' agency is often limited and where powerful institutional actors (including state agencies and financial institutions) have the potential to gain from access to information and its present and future interpretations.

Design Implications

On the basis of our findings from the 3 studies outlined above, we propose a number of design implications, some of which are specific to the personal genomics context, and some more general, concerning insights for multiuser engagement with complex multidimensional data.

The context of personal genomics in which data of individual family members is directly relevant to other family members, calls for both holistic and focused points of view. In that sense, the trade-off between scalability and effectiveness evident in the performance differences between the Venn and the sunburst visualizations reflects a design consideration for practitioners; some design cases may call for prioritization of better understanding—both objective and perceived—such as in the case of rich comparisons between siblings where a Venn approach would be most effective, whereas others may require a broader but less rich perspective in which a sunburst approach might work better.

Beyond personal genomics, insights from this study can inform other approaches to visualizing personal data. For example, the approaches presented here to visualizing genomic information, illustrate a method to engage with Lived Data [66], allowing users to explore their data in a broad and socially relevant context. They also offer a perspective on Lived Data that transition from temporal changes of data to temporal changes of potential interpretations. These approaches can be used to compare cuts of interest (collected data of some shared feature) across users [13] and serve as a practical way to represent the interconnected self within the context of relevant others [67].

The design approach presented in studies 2 and 3, which integrates multiple views, underscores the need for autonomy for users to pursue their information needs and to explore data from multiple perspectives. Such an approach leads to better comprehension and perceived ease of use. To that end, 2 types of features are needed that will help users to further reap the benefits from multiuser personal genomic comparison tools. These include tutorials to carefully guide users through the use of visual reports and features that allow users to focus on and switch between relevant dimensions of the information, particularly with users who are familiar with the underlying dataset [54].

Two key issues concern possible adverse implications for the proposed approach. First, ability of nonexperts to engage with their personal information in a social context carries a concern of *misinterpretation and information overload*, which may dilute the understanding of the data and undermine the original goals of the tools designed. More research on filtering mechanisms, such as the approach proposed by Jones and Kelly [68], is needed to ensure effective engagement with socially contextualized personal data. A second issue concerns *privacy* —the effectiveness of multiuser personal genomic comparison tools arises from the juxtaposition of multiple genetic profiles, yet that same aspect of their value to users implicitly assumes that users would be interested in and willing to share their data with other family members. This assumption may hold for many families but not for all. Making personal genome comparison tools available to users may lead to undue expectations, or even pressure, among family members concerning data sharing. This concern also highlights a need to develop new mechanisms for users to understand the risks associated with publicly sharing genetic data, as well as to control what aspects of their data to share, with whom, and for what purposes.

Limitations

Although the design and evaluation of CrossGenomics offer insights into the design of future personal genomics exploration and comparison tools, there are limitations to this study that should be considered in future research. First, we did not assess the fluency and familiarity of participants with visualization techniques, so we cannot speak about the effect of this experience on comprehension, subjective experience, and behavior in interacting with these 4 report types. Second, the analytical validity and clinical utility of DTCGT have been debated [69]; however, CrossGenomics is a tool for exploring and facilitating health information-seeking behavior [70], rather than a clinical tool, and as such is not attempting to provide or assess clinical utility. Third, a majority of the users of the combined report primarily used the table, which could be because of the nature of our sample. Namely, the users in our first and second study most likely exhibited less exploratory behavior than those of the potential nonexpert users interacting with their own personal genetic and family data. Our third study, which included users interacting with their own data, did not offer the opportunity for a meaningful comparison between family members. In addition, our sample of early adopters is not representative of the general public, as it is limited to individuals with genetic data who also chose to share it publicly. Although it is rare to find families with public genetic data, our future study will engage nonexpert users comparing their own personal genetic data, with the data of their family members.

Conclusions

The rapid increase in the availability of complex personal genomic data to nonexpert users poses research and practice challenges and opportunities. The interpretation of such data may impact lifestyle decisions, emotional state, and well-being of users and their family members. However, research on interaction of users with personal genomic data is still limited. The familial nature of personal genomic data highlights the need for tools to enable nonexperts to explore not only their own data but also to compare and contrast their data with data of other biological family members, who share common genetic characteristics.

Beyond the contribution of this research to the personal genomics domain, our study makes the following contributions: (1) presenting the design and evaluation of tools that facilitate multidimensional, multiperson comparisons, (2) analyzing the differences between comprehension and perceived understanding, leading to a better understanding of discrepancies between subjective and objective knowledge, and (3) highlighting design considerations for multiuser engagement with complex multidimensional personal data.

Empowering nonexpert users by facilitating a better understanding of their genetic characteristics and that of their families is an important step in helping people be more self-informed. We intend to further evaluate CrossGenomics with nonexpert users comparing their own personal genetic data with the data of their family members. Ultimately, our goal is to make CrossGenomics a free tool available for the Open Humans community. Personal genomics is a domain in which interactive technologies can make a real difference in the lives of users, and the studies reported here advance both research and practice in this direction.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

User Study 1 Questionnaire.

[PDF File (Adobe PDF File), 15KB - jmir_v20i9e10297_app1.pdf]

Multimedia Appendix 2

User Study 2 Questionnaire.

[PDF File (Adobe PDF File), 14KB - jmir_v20i9e10297_app2.pdf]

Multimedia Appendix 3

User Study 3 Questionnaire.

[PDF File (Adobe PDF File), 14KB - jmir_v20i9e10297_app3.pdf]

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Abbreviations

ANOVA: analysis of variance
API: application programming interface
DTCGT: direct-to-consumer genetic testing
HCI: human-computer interaction

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Original Paper

A Cloud-Based Virtual Outpatient Clinic for Patient-Centered Care: Proof-of-Concept Study

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Abstract

Background: Most electronic health (eHealth) interventions offered to patients serve a single purpose and lack integration with other tools or systems. This is problematic because the majority of patients experience comorbidity and chronic disease, see multiple specialists, and therefore have different needs regarding access to patient data, communication with peers or providers, and self-monitoring of vital signs. A multicomponent digital health cloud service that integrates data sharing, collection, and communication could facilitate patient-centered care in combination with a hospital patient portal and care professionals.

Objective: This study aimed to assess the feasibility and functionality of a new cloud-based and multicomponent outpatient clinic, the “Virtual Outpatient Clinic” (VOC).

Methods: The VOC consists of 6 digital tools that facilitate self-monitoring (blood pressure, weight, and pain) and communication with peers and providers (chat and videoconferencing) connected to a cloud-based platform and the hospital patient portal to facilitate access to (self-collected) medical data. In this proof-of-concept study, 10 patients from both Departments of Internal Medicine and Dermatology (N=20) used all options of the VOC for 6 weeks. An eNurse offered support to participants during the study. We assessed the feasibility, usage statistics, content, adherence, and identified technical issues. Moreover, we conducted qualitative interviews with all participants by following a standard interview guide to identify user experiences, including barriers, facilitators, and potential effects.

Results: Most participants successfully used all options of the VOC and were positive about different tools and apps and the integral availability of their information. The adherence was 37% (7/19) for weight scale, 58% (11/19) for blood pressure monitor, and 70% (14/20) and 85% (17/20) for pain score and daily questions, respectively. The adherence for personal health record was 65% (13/20) and 60% (12/20) for the patient portal system. Qualitative data showed that performance and effort expectancy scored high among participants, indicating that using the VOC is convenient, easy, and time-saving.

Conclusions: The VOC is a promising integrated Web-based technology that combines self-management, data sharing, and communication between patients and professionals. The system can be personalized by connecting various numbers of components, which could make it a relevant tool for other patient groups. Before a system, such as the VOC, can be implemented in daily practice, prospective studies focused on evaluating outcomes, costs, and patient-centeredness are needed.

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KEYWORDS

cloud service; digital health; eHealth; mHealth; mobile phone; outpatient clinic; patient-centeredness

Introduction

Digital technology is transforming health care. Electronic health (eHealth) and mobile health (mHealth) technologies (Textbox 1) facilitate self-management (eg, self-monitoring of weight [1], increase medication adherence [2,3], and promote diabetes self-management [4]), (tele-) communication (eg, in self-management of hypertension [5], ambulatory care for chronic diseases [6], and patient-doctor communication [7]), efficient data sharing (eg, using a personal health record (PHR) [8]), and remote monitoring (eg, remote pain assessment [9,10]). Although evidence on their efficacy remains limited in some sectors [11,12], more robust evidence is already available in others [13,14].

Most eHealth and mHealth solutions offered to patients serve a single purpose or have been developed for use within one medical specialty, for example, teledermatology to reduce face-to-face consultations, or self-management of hypertension by self-titration of medication [15,16]. Since many patients are comorbid and therefore visit multiple medical specialists [17,18], multipurpose and integrated systems could be an efficient way to further improve the quality of care. Particularly, considering a variety of single-purpose apps may increase the nonadherence or attrition rates because of the time invested in using multiple apps outweighs the benefits [19]. An example of such a multipurpose system has been described by Alnosayan et al, which was provided to patients with heart failure for support after discharge [20]. Both patients and nurses regularly used the tools, and patients showed above average satisfaction with the system.

The majority of hospitals and individual health care providers use electronic medical records (EMRs) to store patients' medical data. In some cases, patients have online access to their diagnoses, medication, or lab results. However, patient access is often not possible because of formal obstructions or technical barriers, or because patients are simply unaware of the possibility [25]. Moreover, some health care providers refuse to give patients access to the EMR because it contains clinical notes [26,27]. The lack of patient access seems to be a missed opportunity, as the benefits of patient access have been well described [28]. A proposed solution is a hospital's patient portal system (PPS) that is part of the EMR and presents a selection of information such as lab results, appointments, and medication. Most health care providers share a positive attitude toward a PPS [26,27]. The same goes for adult and pediatric patients, who are primarily positive about such a system [29,30]. Another way of providing patients with their data is the use of PHRs; these are comparable to a PPS but exist separately from the EMR and are owned and fully controlled by patients. Patients already use PHRs because it is easy to access their health data, self-manage disease, and have a more productive communication with their health care provider [31-34]. Physicians who already use electronic communication perceive it as convenient, time-saving, efficient, and safe [35]. The use of a secure electronic messaging system showed a reduction in the number of office visits [36]. Overall, both PPS and PHR could be efficient ways for patients to collect, present, and share health data.

Regarding the need for integrated self-monitoring and self-managing systems, we designed a state-of-the-art integrated multicomponent digital health cloud service, the "Virtual Outpatient Clinic" (VOC). The VOC is a combination of PPS and PHR and consists of multiple health-monitoring tools, in which data storage and presentation are integrated and can be accessed by both patients and health care professionals. This study aims to assess the feasibility and functionality of the VOC.

Textbox 1. Definition of eHealth and mHealth.

eHealth and mHealth

The term eHealth, together with related terms like mHealth, Health 2.0, telecare, and telemedicine, has gained popularity over the last 20 years [21]. However, different definitions exist [22]. The most commonly used definition is Eysenbach's definition: "e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology." [23]. For mHealth, the World Health Organization stated that there is no common definition, but that it can be considered a part of eHealth. The World Health Organization defined mHealth as "medical and public health practice supported by mobile devices, such as smartphones, patient monitoring devices, personal digital assistants, and other wireless devices" [24].

Methods

Eligibility

In this proof-of-concept study, patients treated at the Departments of Internal Medicine and Dermatology of a university medical center in the Netherlands were invited to use and evaluate the VOC. These patients were selected because their disease spectrum was broad with various comorbidities. There were no limitations regarding (co)morbidity. Adult participants were approached between December 2016 and February 2017 and were found eligible if they owned a smartphone with mobile internet access. The inclusion was based on the "first come, first serve" principle; nurses invited patients until 10 patients of both departments participated in the study, which lasted 6 weeks. An eNurse supported participants with the initial set-up and during the study. The study protocol was reviewed and approved to proceed by the local Medical Ethical Committee (ID: 2016-2990). All participants provided signed informed consent.

Virtual Outpatient Clinic

The VOC (Figure 1) consists of 2 measuring devices and 4 smartphone apps, of which 2 collected health data and 2 facilitated communication. To centralize the data collection and facilitate patient access, a PHR and a PPS were used. The Patients Know Best (PKB) platform was selected as the PHR to present health-monitoring data collected during the study period [37]. Figure 1 shows that the patient uses eHealth and mHealth tools to monitor the health status. The patient can communicate with the eNurse using a secure messenger app and videoconferencing tool. Measurements performed by the patient are saved in a PHR and a PPS of the EMR, which the patient can visit at any time. In addition, the team of health care professionals has access to the PPS and PHR. Data can be exchanged between the PHR and the PPS. Multimedia Appendices 1 and 2 present the screenshots of PKB. It has been designed to allow patients to manage their health data and share medical data with their physicians, link multiple health-related apps and devices to PKB to synchronize data, and communicate with health care providers. Data from 4 eHealth tools were automatically stored (real-time) in PKB (Table 1). The PPS used was a modified variant of Epic's MyChart (Dutch language and layout in the hospital's style) to facilitate communication between patients and physicians and to present medical test results and other medical information. Measurement results of the weighing scale and blood pressure device were collected in both PPS and PHR (Table 1).

In total, 6 eHealth tools were used. In addition, 2 measuring devices including a blood pressure monitor (BPM; Withings BPM; Nokia Health, Espoo, Finland) and a weighing scale (Withings Body+; Nokia Health) to monitor blood pressure and heart rate and weight, body fat, and water percentage, respectively. Withings devices were connected with a smartphone app to store measurements in addition to the platforms. The remaining 4 tools were all smartphone apps. To facilitate videoconferences with the eNurse, the tool "FaceTalk" (QConferencing, Amsterdam, the Netherlands) was used, which could be used on any device or computer. The second communication tool was "Kanta" (Topicus zorg, Deventer, the Netherlands), a secured messenger app. The questionnaire tool "Q1.6" (Questions.ai, Antwerp, Belgium) was used to monitor patients' actual status by the Dermatology Life Quality Index (DLQI) and the level of pain with a visual analog scale (VAS) score. The questionnaires were selected because they are commonly used in these departments. The DLQI was most applicable to patients of the Department of Dermatology and focused on the physical symptoms of the skin and how the skin problems affected their daily life.

Figure 1. Overview of the Virtual Outpatient Clinic design, with its 3 main components. PPS: patient portal system.

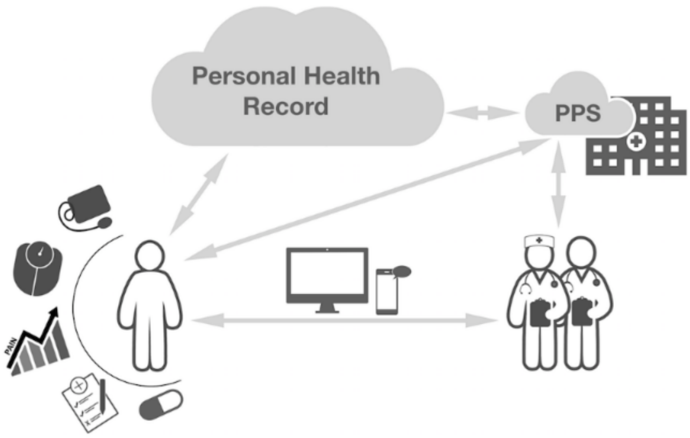

Table 1. Protocol for participants on using different tools and platforms during the study period (6 weeks).

Tool or platform	Instruction	Expected user statistics per participant
Withings blood pressure monitor[a,b]	Measure blood pressure and heart rate (2 periods of 5 consecutive days)	10 measurements
Withings body+[a,b]	Measure weight (2 times a week)	12 measurements
Q1.6[a]	Fill out pain VAS[c] score (daily); fill out DLQI[d] (every 2 weeks)	42 pain VAS scores and 3 completed DLQIs
MedApp[a]	Enter current medication use (if applicable)	Medication list
Kanta	Contact eNurse for technical or logistic support	Total number of conversations and overview of topics
FaceTalk	Have one digital meeting with eNurse	Number of successful digital meetings
Personal health record	Log in once weekly to review data	6 log-ins
Patient portal system	Log in once weekly to review data	6 log-ins

[a]Real-time data presented in personal health record.

[b]Real-time data presented in the patient portal system.

[c]VAS: visual analog scale.

[d]DLQI: Dermatology Life Quality Index.

Conversely, the VAS score for pain was applicable to patients from both departments. Pain scores were used to assess patients' situation, for example, during recovery at home. Notifications on medication intake were sent by "MedApp" (PharmIT, Eindhoven, the Netherlands) to keep track of medication compliance and inventory; medication could be entered by scanning the barcode on the package.

Study Procedures

The 2 eNurses (one in each department), with at least 5 years of experience as a nurse in the specific department's outpatient clinic, supported participants during the study. They were familiar with the tools and platforms, answered questions from participants, and were allowed to contact individual participants through the communication tools and offer support. After being informed about the study and signing informed consent, all participants were informed about the tools by the eNurse. In addition, the eNurse assisted in downloading the apps on their personal smartphone, installing the devices, and linking tools to platforms if necessary. Participants were asked to use the tools and perform several measurements for 6 weeks according to the provided protocol. Table 1 summarizes the protocol with the expected user numbers per participant at the end of the study period when a participant adhered completely to the protocol. This schedule was selected on the basis of recommendations of a medical specialist and represented the real-life situation. Both participants and eNurses kept predesigned logbooks, with detailed instructions for the use of the various tools and platform during the study period. As a compensation for their participation, participants could keep the Withings tools after the study.

Evaluation

We assessed the log-in data, content, and users' experiences to determine the VOC feasibility. User statistics of tools and platforms were collected by 2 researchers (JMJ and PAMO), using the PHR platform, PPS platform, Q1.6 dashboard, eNurse logbooks, and participant logbooks. Starting dates were extracted from the logbooks participants handed in; if a logbook was not present or no dates were indicated, the starting date was established as the date the first use of an app or device was registered. In addition, users' experiences were assessed by semistructured interviews with individual participants by 2 researchers (THB and T Chau). Interviews took place at the hospital and were scheduled on the last day of the 6-week study or shortly after to ensure that all patients were able to thoroughly test all features. To fully capture the main elements related to acceptance of technology, the interview guide was designed according to the Unified Theory of Acceptance and Use of Technology 2 (UTAUT2) interview framework [38]. This framework consists of the themes performance expectancy, effort expectancy, social influence, and facilitating conditions. In addition to these themes, support, safety and privacy, technology, and routine regarding the VOC were discussed during the interview. The interview guide is available on request.

Analysis

Logging Data and Content

We used IBM SPSS version 22 (IBM Analytics, New York) to analyze quantitative data. The normality of the data distribution was assessed using the Shapiro-Wilk normality test. Normally distributed data are presented as mean (SD), and nonnormally distributed data are presented as median and interquartile range (IQR: 25-75). In addition, user statistics of tools and platforms were determined and compared with the expected user statistics. We assessed the technical feasibility of the VOC by assessing its use and by experiences, including barriers and facilitators. As there are no official criteria for the feasibility [39], we reasoned that 100% adherence would be impossible as technical problems often occur with new digital platforms. Moreover, we expected that the platform would not work for everyone, as personal preferences are unique. Therefore, we set the criterion for the feasibility to 80% adherence, meaning that 80% of all measurements, such as blood pressure measurements, were successfully performed and are available in the Web-based system. Moreover, the technical feasibility was assessed for the Withings Body+ weight scale, Withings BPM, Q1.6, PHR, and PPS. For Kanta, the number and content of messages sent were determined. Medication was entered in MedApp, and actual prescriptions were compared. The number of FaceTalk appointments was assessed, and failures were reported. The number of successful links of tools to a platform was determined, and causes for unsuccessful links were reported. Problems with tools were reported.

Experiences Including Barriers and Facilitators

Participants' experiences on the feasibility and usability of the VOC were collected during a semistructured interview following the UTAUT2 interview framework. All interviews were audiorecorded and transcribed verbatim using ATLAS.ti 7.1 qualitative data analysis software. In addition, 2 individual researchers (JMJ and T Chau) analyzed transcripts using the thematic content analysis. Interview transcripts were reviewed, coded, and recurrent themes were defined. Eventually, barriers, facilitators, positive effects, and negative effects were identified. Findings were discussed until consensus was achieved. All barriers, facilitators, positive effects, and negative effects were rewritten into general statements and presented according to the UTAUT2 interview framework. We distinguished between factors that affected the VOC use (barriers and facilitators) and effects after use (positive and negative effects).

Results

In this study, 20 participants installed the required apps and attended an individual 45-minute training session with the eNurse. All participants completed the 6-week study. Table 2 summarizes the basic characteristics of the study population.

Use and Technical Feasibility

Table 3 presents the agreement between expected and actual user statistics, which is discussed in detail below.

Table 2. Participant characteristics (N=20).

Characteristic	n (%)
Age (years), mean (SD), range	43 (3.5), 18-68
Gender	
Female	10 (50)
Male	10 (50)
Education level	
Senior general secondary education	2 (10)
Secondary vocational education	7 (35)
Higher professional education	6 (30)
University education	5 (25)
Previous experience self-monitoring related to disease or treatment	
Yes	6 (30)
No	14 (70)

Table 3. User statistics per participant compared with the expected user statistics.

Tool or platform	Expected user statistics per participant	Mean or median user statistics per participant	Adherence	
			N	n (%)[a]
Withings blood pressure monitor	10 measurements (2 periods of 5 subsequent days)	13 (IQR[b]: 11-30; range: 5-52) measurements	19	11 (58)
Withings Body+	12 measurements (2 times per week)	23 (SD 2.89, range: 5-42) measurements	19	7 (37)
Q1.6	42 pain scores and 3 completed DLQIs[c]	42 pain scores (IQR: 40-42, range: 35-42); 85% completed all DLQIs	20	14 (70) for the pain scores; 17 (85) for the DLQIs
MedApp	Medication list	2 medication lists complete, 5 incomplete, 5 absent, 8 not linked	—	—
Kanta	Variable	1063 messages in 210 conversations	—	—
FaceTalk	One appointment	One appointment	20	20 (100)
Personal health record	6 log-ins	14 (IQR: 5-19, range: 1-49)	20	13 (65)
Patient portal system	6 log-ins	6 (IQR: 4-14, range: 1-25)	20	12 (60)

[a]This column presents the percentage of participants fully adhering to that part of the protocol (eg, if 11 of 19 participants performed all expected 10 measurements, adherence was 58%).

[b]IQR: interquartile range.

[c]DLQI: Dermatology Life Quality Index.

Platforms

Data Collection

Data collected with 4 of the provided tools were registered in the PHR. In addition, the PPS received real-time data from the 2 Withings devices. The PHR and PPS were consulted by all participants. For the PPS, the median log-ins were 6 (IQR: 4-14; range: 1-25), with a total of 165 log-ins, of which 65.4% (108/165) were by participants from the internal medicine outpatient clinic and 34.5 % (57/165) from the dermatology outpatient clinic. For the PHR, the median log-in frequency was 14 (IQR: 5-19; range: 1-49), with a total number of 378 log-ins, of which 60.8% (230/378) were by participants from the internal medicine outpatient clinic and 39.1% (148/378) from the dermatology outpatient clinic. The actual use of the PHR compared with the expected use ranged from 17% to 817%, and for the PPS, the actual use ranged from 17% to 417%.

All participants were able to link Q1.6 to their PHR. Only 12 of the 20 participants were able to successfully link MedApp to the PHR. Withings devices were successfully connected to the PHR for 16 participants and to the PPS for 17 participants. All, but 1 participant, were able to connect the Withings devices to at least one of the platforms.

For the Withings BPM, measurements occasionally did not show in the PHR or the PPS or only partly (eg, only blood pressure or pulse rate).

Table 4. The number of messages per conversation via Kanta, subdivided by theme.

Theme	Total conversations, n (range)	Total messages	Mean messages per conversation, n (range)
Introduction	17 (0-2)	36	2 (1-6)
Study and administration	65 (0-8)	274	4 (1-19)
Functionality tools	60 (0-8)	425	7 (1-36)
Planning and appointments	64 (0-9)	302	5 (1-20)
Medical question	4 (0-1)	26	7 (5-8)

Kanta

In total, 1063 messages were sent in 210 conversations by 19 participants. The mean number of messages per conversation was 5. The conversations could be divided by theme (Table 4).

The eNurse initiated 129 conversations and participants 81 conversations. The eNurse started most conversations on “Study and administration” and “Planning and appointments” 48 and 45 times, respectively. The participants initiated most conversations on “Functionality tools” 40 times.

Problems with notifications were experienced, where no notifications would show for new messages. In addition, typing messages had a delay for one participant and concept messages were not saved when closing the app. Kanta was not compatible with all smartphones.

Facetalk

All participants had at least one successful FaceTalk appointment with the eNurse, which lasted 10-15 minutes. The adherence was 100%. During the FaceTalk appointments, some technical problems were observed. One participant could not manage to get sound, another participant could not accomplish to switch to the front camera, disconnection was experienced once, and some (older) versions of operating systems were incompatible with FaceTalk. Moreover, one appointment was interrupted by a phone call received by the eNurse.

Q1.6

All participants were able to use Q1.6. The median number of days a pain score was entered was 42 (IQR: 40-42; range: 35-42). In this study, 18 of the 20 participants completed >90% of the daily pain scores, and the 2 remaining participants completed 83% and 88% of the daily pain scores. The adherence was 83%-100%.

In addition, 17 of the 20 participants completed all 3 2-weekly DLQIs; 2 participants completed 2 of the 3 DLQIs, and partially completed the remaining DLQI. However, 2 participants did not fill 1 of the 3 DLQIs. The adherence was 67%-100%. Of note, 7 of the participants recruited from the Department of Internal Medicine mentioned that the questions did not relate to their disease, which was perceived as a barrier. Some problems with Q1.6 appeared where the app continued to give notifications after the completion of the questionnaire for 1 participant. Moreover, 1 participant stated that the pop-up appeared at inconvenient times, which resulted in answering without thought.

MedApp

In this study, 12 participants were able to connect MedApp with the PHR. Reasons for unsuccessful linking were the absence of connection possibility, incompatible smartphone software, or other unknown reasons. All participants used medication. Overall, 2 of 12 participants filled out MedApp with their complete medication list, and 5 of 12 participants partially filled out MedApp with their medication list. For the remaining participants who linked MedApp with the PHR, it did not show any medication entries, although all participants claimed to have used MedApp during the interview. The adherence was 17% for participants able to make a connection. For 7 participants, the habit of taking medication was already present, making MedApp obsolete. Some other problems were reported where scanning medication did not work properly, and medication compliance was not correctly reported. MedApp was not compatible with all smartphones.

Withings Blood Pressure Monitor

The median number of measurements taken was 13 (IQR: 11-30, range: 5-52). One participant was excluded from the analysis because no connection was made between the device and the 2 platforms. Thus, 11 of 19 participants (58%) measured their blood pressure according to the protocol in 2 periods for 5 days, or more often. In addition, 6 of 19 participants measured their blood pressure ≥10 times in 6 weeks, but not in 2 periods of 5 subsequent days. Together, 89% (17/19) measured their blood pressure ≥10 times. According to participants, reasons for the nonadherence were anxiety, technical issues, or when the blood pressure was deemed less relevant for their situation. Participants had different experiences with the Withings BPM: 6 participants reported it was an easy-to-use device, whereas 3 reported taking measurements required precision. Notably, the BPM occasionally reported an error, which indicated a measurement could not be completed after which the participant had to try again. One participant reported anxiety because of the frequency of blood pressure measurements.

Withings Body+ Weight Scale

The mean number of measurements taken was 23 (SD 2.89, range: 5-42). One participant was excluded from the analysis because of unsuccessful linking of the device to both platforms. Overall, 37% (7/19) participants measured their weight according to protocol, and 47% (9/19) measured their weight ≥12 times but not in 2 times per week. Thus, 16 of 19 participants measured their weight ≥12 times during the 6-week study.

Table 5. Barriers and facilitators mentioned by participants in the user experience interviews for the Virtual Outpatient Clinic.

Variable	Facilitator	Barrier
Performance expectancy		
Time expectancy	5	—
Saves time	3	—
Accessible at any time	1	—
Health professionals have real-time access to data	1	—
Convenience expectancy	13	—
Creates more awareness	4	—
Quick communication	2	—
Safe communication	2	—
Feeling of being in control of own health	2	—
Less barriers to reach out	1	—
Sharing information on own initiative	1	—
Peer-like communication	1	—
Effort expectancy		
Ease of use	4	1
Takes little effort to use	1	—
Communication requires signing in	—	1
Clear layout	1	—
Easy to use	2	—
Social influence		
Practitioner influence	1	—
Inspired by doctor	1	—
Peer influence	1	—
Inspired by partner	1	—
Facilitating conditions		
Technology aspects	—	1
Not suitable for all smartphones	—	1
Security and confidentiality	1	1
Everything is digital	—	1
The hospital is trustworthy	1	—
Hedonic motivation		
Usage enjoyment	3	1
Being aware of health status is fun	1	—
No priority		1
Visualization of data is fun	1	—
The trend line is insightful	1	—
Novelty enjoyment	2	—
Gadget-factor is fun	2	—

Table 6. Positive and negative effects mentioned by participants in the user experience interviews for the Virtual Outpatient Clinic.

Variable	Positive effect	Negative effect
Performance expectancy		
Time expectancy	1	—
Saves time	1	—
Convenience expectancy	11	—
Creates more awareness	6	—
Awareness leads to changes in behavior	2	—
Quick communication	2	—
A trend line is more insightful than single measurements	1	—
Facilitating conditions		
Technology aspects	—	1
Apps require substantial data storage	—	1
Hedonic motivation		
Usage enjoyment	1	—
Being aware of health status is fun	1	—

Barriers and Facilitators

In the interviews with individual participants, the user experience of the integral VOC approach was discussed. The interviews lasted between 30 and 90 minutes. Table 5 presents barriers and facilitators for the VOC use, weighed by how often they were mentioned and divided in themes by the UTAUT2 model. Table 6 presents positive and negative effects of the VOC use, weighed by how often they were mentioned and divided in themes by the UTAUT2 model. Multimedia Appendix 3 provides barriers, facilitators, positive effects, and negative effects specific for each tool and platform.

Participant Suggestions

From the qualitative interviews, participants' suggestions were obtained to further improve the VOC. Participants expressed the need for a single app or portal that integrates all mHealth tools. The VOC package should be easily installed and linked to a platform because this was perceived as a lot of work by most participants. The instruction on the different aspects of the VOC should be extended. Participants also opted for more tools to add, such as a food diary and a linked glucose-measuring device. Suggestions on the different tools were made as well. For FaceTalk, participants wished for the option to record and store sessions, with the goal to be better able to recall information and decisions that were made. For Kanta, notifications should include a preview of the message and the function to take a screenshot should be added. MedApp should be improved by the ability to prioritize medication. The frequency of reminders should be adjustable. The Q1.6 app needs a "not now" function, and the questionnaires should be based on the disease. Some participants mentioned a preference for the numbered scale to indicate pain instead of a VAS. For Withings, a reminder was thought useful to indicate when measurement should be taken. For the PHR and PPS, some suggestions were also mentioned by participants. It should be indicated what a healthy range is for different health parameters. The platform should also be available as an app. Another request was the addition of imaging results to the platform.

Discussion

Principal Findings

In this study, we assessed the feasibility and functionality of a cloud-based VOC. Participants successfully used all features of the VOC and shared a positive attitude toward different self-measurement tools. Although all tools were frequently used, our quantitative and qualitative analyses revealed that technical issues prevented participants from taking measurements on a few occasions. The functionality of the VOC, in general, was well received. Patients stated that better integration of apps and platforms, for instance, in a single smartphone app, would further improve user-friendliness. However, some things need to be discussed first.

The qualitative analysis revealed that the facilitators for using the VOC outweighed the barriers (30 vs 4, respectively). Study participants found that the VOC saved time, was convenient, and easy to use. Traditionally, the burden of going to the hospital is high, as patients have to skip work, travel, pay a parking fee, and spend time waiting. For people with chronic conditions, these visits are often short and can be considered as a regular "check-up." As a VOC can facilitate the exchange of data, monitoring, and virtual consultations, this new way of delivering care could help in reducing the number of these time-consuming hospital visits.

Although most self-management tools were frequently used and considered by the users, the protocol adherence was lower than expected, primarily for the BPM and weight scale. Besides the technical issues mentioned above, this could be related to the complex measurement schedule and the high number of tools provided in this study. More personalized schedules, allowing users to perform measurements whenever they are ready for it, could further improve adherence. In addition, we found that some tools provided to participants were more interesting for one group than the other. For example, the Q1.6 smartphone app with questions about pain and skin condition was focused on patients of the dermatology outpatient clinic, whereas the BPM was more relevant for patients of the internal medicine outpatient clinic, who often have hypertension. This also emphasizes the need for a personalized set of tools and schedule to make the VOC as useful as possible for both patients and professionals. Although some tools were less relevant to 1 of the 2 groups and the adherence was lower than expected, participants kept using the tools throughout the study period. This is remarkable because we expected a slight decrease in the use of specific tools, as relative advantage is one of the factors negatively influencing the frequency of use [19].

Although this study primarily intended to determine the feasibility and functionality of a multicomponent digital health service, participants reported an increased awareness of their health status as a result of using the service. This could be the first sign of the effectiveness of the provided system. Furthermore, participants asked medical questions via the secured messaging app, whereas the purpose of this app was to discuss the functionality of the tools and report technical problems. This shows that patients are open to using virtual communication tools that are suitable for discussing medical issues.

Other Research

Empowering patients by giving them an active role in health self-management is not a new concept [40]. The goal of most studies was to determine the effectivity in improving health status; however, the high-quality evidence is lacking to prove the effectiveness [41]. As eHealth and mHealth tools are rarely integrated regarding the data collection and data are often not accessible to patients, scientific studies in this field are lacking. As discussed earlier, most studies on eHealth and mHealth are focused on one specific disease group and do not discuss data sharing and communication between doctors and patients. However, Alnosayan et al provided a multicomponent system for patients [20]. They focused on patients with heart failure and support after discharge. The monitoring system used in their study contained a weight scale, BPM, glucose meter, and a short daily questionnaire. Participants were invited to use the system for 6 months. Their results were comparable to our findings as follows: participants requested a personalized system and integration with other monitoring tools, and visualizations of health data were helpful to gain insight into the health status. Although our study only lasted 6 weeks, and the patient groups between the studies are different, the results show that a VOC is likely to be maintained continuously and will also work for patients with more acute conditions such as presented by Alnosayan et al [20]. The VOC used in this study has the advantage that it is generic and can be personalized for any patient, regardless of their disease or comorbidity.

Strengths and Limitations

A strength of this study is that we combined different tools and integrated data collection, compared with other studies that focused on a single tool. Another asset is the combination of quantitative and qualitative methods, resulting in a rich dataset with in-depth information and user experiences. However, a limitation of this study is related to the nonrandomized convenience sample, as participants with interest in technology and digitalization are more likely to participate in this study. This may have resulted in an overestimation of positive effects. Another limitation is the relatively short study period, making it impossible to study long-term effects.

Implications for Practice

Doctors need to be aware of changes in health care regarding eHealth and mHealth. They, but also their patients, could benefit from integrated digital technology such as the VOC. Patients might already track certain health parameters with wearable devices or smartphones that may be valuable to share. Patients need to realize that digital technology facilitates an active role in their health management. Owing to the new possibility to collect data with various devices and tools and store them in a cloud-based platform, including the possibility to connect to the hospital's EMR, patient-centered care and self-monitoring have become available. Using the VOC in daily practice could potentially result in less frequent physical visits, reduction of overconsumption of care, and a more continuous observation with better prevention and treatment. Experimental study designs to further assess the clinical value of the VOC are needed.

Conclusions

The VOC is a promising integrated Web-based technology that combines self-management, data sharing, and communication between patients and professionals. The system can be personalized by connecting various numbers of components, which could make it a relevant tool for other patient groups. Before a system, such as the VOC, can be implemented in the daily practice, further integration of all tools into a single app is needed. Moreover, the user-friendliness of different tools should be improved, guided by the wide spectrum of barriers and suggestions mentioned by study participants. Subsequently, a prospective study focused on evaluating outcomes, costs, and patient-centeredness should be conducted.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshot of Patients Know Best (PKB), showing an overview of the measurements performed by a user (example data).

[PNG File, 145KB - jmir_v20i9e10135_app1.png]

Multimedia Appendix 2

Screenshot of Patients Know Best (PKB), showing a detailed overview of the blood pressure measurements taken by a user (example data).

[PNG File, 582KB - jmir_v20i9e10135_app2.png]

Multimedia Appendix 3

Specification of barriers, facilitators, positive and negative effects of individual components.

[PDF File (Adobe PDF File), 98KB - jmir_v20i9e10135_app3.pdf]

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Abbreviations

BPM: blood pressure monitor
DLQI: Dermatology Life Quality Index
eHealth: electronic health
EMR: electronic medical record
IQR: interquartile range
mHealth: mobile health
PHR: personal health record
PKB: Patients Know Best
PPS: patient portal system
VAS: visual analog scale
VOC: Virtual Outpatient Clinic
UTAUT2: Unified Theory of Acceptance and Use of Technology 2

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Original Paper

Improving Prediction of Risk of Hospital Admission in Chronic Obstructive Pulmonary Disease: Application of Machine Learning to Telemonitoring Data

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Abstract

Background: Telemonitoring of symptoms and physiological signs has been suggested as a means of early detection of chronic obstructive pulmonary disease (COPD) exacerbations, with a view to instituting timely treatment. However, algorithms to identify exacerbations result in frequent false-positive results and increased workload. Machine learning, when applied to predictive modelling, can determine patterns of risk factors useful for improving prediction quality.

Objective: Our objectives were to (1) establish whether machine learning techniques applied to telemonitoring datasets improve prediction of hospital admissions and decisions to start corticosteroids, and (2) determine whether the addition of weather data further improves such predictions.

Methods: We used daily symptoms, physiological measures, and medication data, with baseline demography, COPD severity, quality of life, and hospital admissions from a pilot and large randomized controlled trial of telemonitoring in COPD. We linked weather data from the United Kingdom meteorological service. We used feature selection and extraction techniques for time series to construct up to 153 predictive patterns (features) from symptom, medication, and physiological measurements. We used the resulting variables to construct predictive models fitted to training sets of patients and compared them with common symptom-counting algorithms.

Results: We had a mean 363 days of telemonitoring data from 135 patients. The two most practical traditional score-counting algorithms, restricted to cases with complete data, resulted in area under the receiver operating characteristic curve (AUC) estimates of 0.60 (95% CI 0.51-0.69) and 0.58 (95% CI 0.50-0.67) for predicting admissions based on a single day's readings. However, in a real-world scenario allowing for missing data, with greater numbers of patient daily data and hospitalizations (N=57,150, N^+=55, respectively), the performance of all the traditional algorithms fell, including those based on 2 days' data. One of the most frequently used algorithms performed no better than chance. All considered machine learning models demonstrated significant improvements; the best machine learning algorithm based on 57,150 episodes resulted in an aggregated AUC of 0.74 (95% CI 0.67-0.80). Adding weather data measurements did not improve the predictive performance of the best model (AUC 0.74, 95% CI 0.69-0.79). To achieve an 80% true-positive rate (sensitivity), the traditional algorithms were associated with an 80% false-positive rate: our algorithm halved this rate to approximately 40% (specificity approximately 60%). The machine learning algorithm was moderately superior to the best symptom-counting algorithm (AUC 0.77, 95% CI 0.74-0.79 vs AUC 0.66, 95% CI 0.63-0.68) at predicting the need for corticosteroids.

Conclusions: Early detection and management of COPD remains an important goal given its huge personal and economic costs. Machine learning approaches, which can be tailored to an individual's baseline profile and can learn from experience of the individual patient, are superior to existing predictive algorithms and show promise in achieving this goal.

Trial Registration: International Standard Randomized Controlled Trial Number ISRCTN96634935; http://www.isrctn.com/ISRCTN96634935 (Archived by WebCite at http://www.webcitation.org/722YkuhAz)

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KEYWORDS

machine learning; telemedicine; chronic obstructive pulmonary disease

Introduction

Background

Exacerbations of chronic obstructive pulmonary disease (COPD) are a major cause of acute hospitalizations. Prompt intervention with antibiotics and corticosteroids may prevent admissions and improve quality of life [1,2], but difficulties in recognizing early symptoms of deterioration [3] often result in delays in accessing care [2,4] and starting treatment. Telemonitoring of symptoms and physiological measurements has been advocated to facilitate early identification and treatment of exacerbations. However, despite patients' perceptions [4], the evidence from randomized controlled trials that telehealth prevents admissions is less than convincing [5-9]. One reason for this is that, far from clarifying the early detection of exacerbations, previously employed algorithms (typically based on international definitions of exacerbations [10]) generate frequent, clinically unnecessary alerts [11].

New symptom-based algorithms have been designed to improve identification and assessment of established exacerbations [12,13]. There is some evidence that a composite measure combining oxygen saturation and heart rate with symptoms may predict deteriorations requiring treatment with antibiotics or corticosteroids [14], although these physiological measures have marked day-to-day variation, which may obscure subtle changes due to early exacerbations in individual patients [15]. The optimal algorithm is thus not yet clear.

Recently, there have been major advances in developing computational and statistical methods for analyzing noisy, incomplete data, broadly described as machine learning and data mining [16,17]. When applied to predictive modelling, such methods can determine patterns of risk factors useful for improving the quality of predictions. This is in contrast to conventional algorithms, which typically use a small number of established risk factors. However, these techniques are not yet in use for predicting hospital admissions for COPD in patients undergoing telemonitoring.

Objective

Data from the Telescot COPD telemonitoring program [4,11] included daily symptom and physiological measures, which could be linked with health care use (consultations, prescription of medication, and hospital admission); baseline data on age, severity of COPD, comorbidity, and anxiety and depression scores; and contextual data (such as weather conditions from the Met Office (the United Kingdom [UK] meteorological service) [18]. Using machine learning and high-dimensional data mining, we aimed to use this large dataset to identify patterns predictive of hospital admissions or decisions to start corticosteroids.

Methods

The Telescot COPD trial (ISRCTN 96634935) [11] was undertaken in 2009-2011 preceded by a pilot study [4] in 2008 in Lothian, Scotland. Ethical approval was granted by the Lothian research ethics committee (reference 08/S1101/60), with UK National Health Service (NHS) management approval from NHS Lothian, Scotland.

Datasets and Handling

The telemonitoring database of day-to-day symptoms and physiological measures from the Telescot COPD trial [11] and pilot study [4] was held by the NHS. These were linked in the Lothian safe haven with trial data held by the research team and hospital admission data. Datasets were deidentified before analysis.

The Telemonitoring Dataset

The Telescot COPD program [4,11] included 146 patients who had moderate to severe COPD (forced expiratory volume in the first second of expiration [FEV_1] and forced vital capacity both <70%) and at least one admission to hospital in the previous year for an exacerbation of COPD. They recorded data with some gaps over an average of 16 months. Patients were asked to provide daily symptoms and physiological readings (pulse and oxygen saturation, and a subset of the study population also provided spirometry data on a less regular basis) and to record antibiotic and corticosteroid use. The symptom score was based on the presence of major symptoms (scored 2) or minor symptoms (scored 1) based on the work of Anthonisen et al [19] and others [2,10,11,15] (see Textbox 1). Data were checked daily by a respiratory professional or trained telehealth monitor, and patients were contacted if their symptom score rose above 5. Acceptable ranges for pulse rate and oxygen saturation were set individually, and patients were contacted if readings fell beyond these ranges.

Textbox 1. Definitions of chronic obstructive pulmonary disease exacerbation onsets on day t used as predictors of hospital admissions on day t+1. Note that the last 3 definitions cannot be used for this evaluation unless an early detection can be made, as they detect an onset of an exacerbation with a 1-day delay. For these definitions, we report an approximate upper bound on the predictive performance under the assumption that the exacerbations can be detected.

1. **Major symptoms**
   a. Breathlessness, sputum color, and sputum amount.
2. **Minor symptoms**
   a. Cold, wheeze, sore throat, cough, and fever.
3. **Symptom counts**
   a. nMajor = number of major symptoms present on day *t*,
   b. nMinor = number of minor symptoms present on day *t*,
   c. nAll = nMajor + nMinor.
4. **Definitions**
   a. Definition 1 (after Anthonisen et al. [19]): nMajor≥2.
   b. Definition 2 (modification of Rodriguez-Roisin [10]): nAll≥5.
   c. Definition 3 (modification of Exacerbation 1 as in Seemungal et al. 2]): define a 'bad day' as one where (nMajor≥2) or ([nMajor=1] and [nMinor≥1]). An exacerbation is said to occur on day *t* if days *t* and *t* +1 are bad, but days *t* –1 and *t* –2 are not bad.
   d. Definition 4 (modification of Seemungal et al. 2] as in Burton et al. 15): Like Definition 3, but a bad day is defined as one where (nMajor≥1) and (nAll≥3).
   e. Definition 5 (after Pinnock et al. 11): An exacerbation is said to occur on day *t* if:
      i. (nAll≥5) on day *t*, or
      ii. (nAll=4) on day *t* and (nAll≥4) on day *t* +1.

Trial Data

Baseline trial data on demographic characteristics, body mass index, spirometry, Medical Research Council Dyspnoea Scale [20], Hospital Anxiety and Depression Scale [21], St George's Respiratory Questionnaire [22], previous hospital admissions, and comorbidity were also available. At the end of the trial, we searched hospital records for admissions during the trial, and 2 clinicians determined whether the admission was due to COPD, partly due to COPD, or unrelated to COPD.

Met Office Health Forecasting Data

The UK Met Office Healthy Outlook service uses a rule-based model, combining observed and forecast parameters, including season, humidity, temperature, air quality, and rates of influenza-like illness to issue forecasts. These have been shown to provide a 10-day warning of periods of higher risk of COPD exacerbations at a population level [18], but it is unclear whether this is predictive at an individual level. We hypothesized that including Met Office data along with telemonitoring and baseline data would improve the algorithm's prediction. We therefore combined the telemonitoring dataset with the Met Office COPD health forecasting dataset. This consisted of the outputs of the Met Office's Healthy Outlook COPD alert algorithm [18], maximum and mean temperatures in the last 48 hours, and 3 binary temperature indicators (mean temperature <2°C, maximum temperature <4°C, and maximum temperature <7°C).

Choice of Outcomes

We gave patients taking part in the study an individualized action plan, which typically advised starting antibiotics if their symptom score exceeded 5, so antibiotic courses were very frequent events. As a proxy for more serious exacerbations, we tested the prediction of two main outcomes: admission to hospital for COPD and initiation of oral corticosteroid treatment.

Preprocessing

We defined *patient episodes* as sliding windows of patient-generated data for a fixed number of consecutive days up to the current day (inputs), linked to the admission or corticosteroid outcome on the following day (output).

We considered the simple score-counting algorithm in the complete-data setting, where we used only episodes without any missing symptom variables to compute risk scores for 1- or 2-day windows. Additionally, we evaluated the score-counting algorithms and the machine learning models in the imputation setting using identical patient episodes, where we imputed each missing variable by copying the last observation of that variable for that patient for up to 15 days. We excluded episodes where the outcome variable was missing and patient episodes where we could not impute the observations due to long windows of no provided data. Where we used imputation, for each variable in the patient episode, we defined an auxiliary indicator to encode whether the input variable was imputed or provided by patient; we used these auxiliary variables as additional inputs into the machine learning models. Note that the sample size and the number of admissions for the imputation setting were higher than those for the complete-data setting.

For example, if some measurements were not reported prior to a hospital admission, then we excluded the episode from the complete-data analysis, but we could retain it in the imputed setting when the reported variables were exact and the missing variables were imputed.

Data Analysis

We identified a large number of potentially predictive features by using established data mining techniques (see below) and tested them in combinations using nested cross-validation procedures, where we selected and extracted the feature by using only the inner training folds of data. Because data were incomplete, we conducted separate analyses (1) limited to time periods with no missing data, and (2) from all time periods with imputation of missing data.

Identification of Novel Features

For each patient, we constructed up to 153 predictive patterns (features) from symptom, medication, and physiological measurements, by using feature extraction techniques for time series [23,24], hypothesized to be predictive of the future events [2] (see Multimedia Appendix 1). The exact number varied between the complete and imputed settings and depended on which types of variables (telemonitoring, weather, and their combinations) we used as inputs. We imputed variables measured at baseline by using population medians for the continuous variables or population modes for the categorical variables, and we assumed the variables to be fixed (stationary) throughout the study. We used the resulting variables to construct predictive models fitted to the training sets of patients. We used only the past, and not the future, variables for imputing the missing variables or constructing the time-series features for each patient episode. The resulting variables were combined to learn additional features in the hidden layers (neural nets), used for computing feature-space similarity functions (nonparametric methods), or combined with feature selection by filtering [25] to set priors on hyperparameters (adaptive regularized classifiers) during training. When we used the output variables directly or indirectly to select or extract the features during training, we ensured that the procedure was nested within the training folds, so that the data used for the evaluations remained unseen.

Standard Exacerbation Models

We considered several definitions of exacerbations based on the criteria of Anthonisen et al [19] and clinical guidelines [26] and used in studies on COPD exacerbations [2,10,11,15]. Major symptoms were changes in patients' self-reported *breathlessness*, *sputum color*, and *sputum amount*, and minor symptoms were cold, wheeze, sore throat, cough, and fever. Using definitions from the literature, we considered 5 definitions of exacerbation (Textbox 1). We evaluated the onsets of exacerbations on a given day (t) as predictors of admissions the following day ($t+1$). Note that, from the considered definitions, only definitions 1 and 2 could be used for this type of evaluation. For example, definition 3 is defined as the presence of at least two consecutive days of major symptoms, or one major and at least one minor symptom, with the exacerbation onset taken to be the first day when the symptom criteria are met [1,2,27], whereas definition 4 is its slight modification [15]. Thus, for definitions 3 to 5, by using the exacerbation indicator on day t as a marker of an admission on day $t+1$, we evaluated an upper bound on the predictive performance under the assumption that these exacerbations can be detected early (eg, by making accurate predictions of the future symptoms).

Novel Predictive Modeling

We assessed how well we could predict hospital admissions and decisions to start corticosteroid treatment in patients undergoing telemonitoring using the extracted features. We considered several types of models. (1) Nonparametric predictive methods, such as sparse maximum-margin classifiers [16,28,29]: these approaches allow for complex mappings from covariates to target outcomes to obtain high-quality "black-box" predictions. (2) Regularized classifiers based on the adaptive extensions of elastic nets [30]: in low dimensions, these methods have the advantage of generating intelligible predictions, but they may sometimes result in lower predictive performance than nonparametric methods or ensembles due to rigid constraints on the mappings between covariates and outcomes. (3) Ensembles of boosted classifiers [31] that we expected to be well suited for dealing with highly imbalanced datasets such as ours (where the number of episodes corresponding to COPD admissions was several orders of magnitude lower than the number of episodes without admissions). (4) Long short-term memory multitask neural network models: these methods are state-of-the-art for speech recognition, where very large datasets are available [32]. However, we found their performance to be only a little better than that of the other models for our smaller incomplete imbalanced dataset. We considered these models using the preprocessing strategy discussed above and using training by a variant of back-propagation for recurrent networks.

We repeated the procedure by considering features occurring (1) 24 hours prior to hospitalization or earlier, and (2) 24 hours prior to the decision to start corticosteroids or earlier. We fitted models 1 and 2 by regressing the outcomes on telemonitoring only (physiological, medication, and symptom variables), weather variables only, and telemonitoring and weather variables jointly. We used the more computationally expensive models (3 and 4) for regressing the outcomes on the telemonitoring variables in the imputed scenario. Hyperparameters were learned by the grid search (models 1 and 2) or by random search (models 3 and 4) over inner folds in the nested cross-validation procedure.

We compared these methods with the conventional algorithms using multiple definitions of exacerbations from Textbox 1 as predictors of the future clinical admissions and corticosteroid therapy.

Validation of Novel Predictive Models

To test this range of models, we used k-fold cross-validation, in which we split the data into k disjoint subsets ("folds") of equal size, and fitted the models repeatedly to $k-1$ training folds, evaluating them on the remaining test fold. The procedure was repeated k times, and the overall performance was evaluated by aggregating the results across the test folds. During the nested cross-validation, we performed the cross-validation procedure for each choice of test data in a nested loop, where we used the inner training folds for feature extraction and selection and for estimating model parameters, we used the inner validation folds for estimating hyperparameters (such as the degree of model complexity), and we used the outer test folds purely for the performance evaluation. In our implementation of the procedure, we ensured that the test outer folds were made up of individuals who did not appear in the training sets or the inner folds (ie, we used no patient episodes for individuals from test datasets as any part of the training data). Thus, we used the outer test sets of patients purely for evaluations, and not for variable selection, parameter learning, or hyperparameter learning. We evaluated the predictive performance expressed as the aggregated area under the receiver operating characteristic curve (AUC), a calibration-invariant measure of predictive performance of binary classifiers. The aggregation was achieved by merging the predictions of the classifiers across the test folds and by averaging the merged AUC across multiple repetitions of cross-validation with the random fold partitions.

Experimental Comparison

We excluded 11 individuals with more than 95% missing data and analyzed data for 135 individuals who provided symptoms and physiological measurements regularly. We chose the outer folds to have approximately the same number of patient episodes, although an equal splitting could not be guaranteed, as patients had unequal numbers of the reported measurements. We used 10 inner and 10 outer folds of the nested cross-validation procedure for all but the most computationally expensive models. To evaluate the variation in the performance, we used 10 runs of the nested cross-validation with different training or test fold partitions.

We evaluated simple score-counting algorithms that did not need long series of past symptoms to generate predictions, both in the complete and in the imputation scenarios. We used machine learning models that needed longer sequences of partially missing past observations in the imputation scenario. In that scenario, we excluded all patient episodes that we could not impute according to the considered procedure due to too much data being missing. For a fair comparison of multiple models, we ensured the consistency of the imputations and patient episodes across the folds.

Results

Predicting Hospital Admissions of Individuals

In the complete-data scenario, we evaluated how well the traditional definitions of exacerbation onset on one day predicted 24-hour hospital admissions the following day, using the definitions from Textbox 1. Depending on the choice of the algorithm, we had between 14,106 and 17,610 patient episodes, and between 8 and 17 hospital admissions. We obtained the best predictions by using definition 5 (mean AUC 0.657, 95% CI 0.523-0.792, N=16,170 patient episodes, where we computed the error bars on the AUC as the consensus estimate of the methods of empirical resampling, Chebyshev, and DeLong and colleagues [33]; Table 1); however, we based this estimate on a dataset with only N^+=9 admissions. Additionally, using this definition, an exacerbation starting on one day could only be detected when the score remained elevated the following day (see Textbox 1), making it impractical for predicting an admission on the second day. Score-counting algorithms definitions 1 and 2, where onsets of exacerbations are computed on a single day, resulted in the AUC estimates of 0.600 (95% CI 0.509-0.692) and 0.578 (95% CI 0.496-0.672), respectively, for N=17,610 episodes and N^+=17 admissions (Table 1).

When evaluated in the pragmatic imputed-data scenario allowing for missing data, with a greater number of patient episodes (N=57,150) and a greater number of hospital admissions preceded by the symptom and physiological measurements (N^+=55), the performance of all the traditional definitions of exacerbation dropped to near random. For example, for definition 2, we obtained an AUC of 0.524 (95% CI 0.486-0.544); see Table 1. The most likely reason for this drop was the need to rely on a simple imputation strategy due to the limited availability of daily symptom data on the days preceding hospital admissions.

Machine learning models demonstrated significant improvements in the prediction of future admissions over the traditional symptom-counting methods. Working with the imputed-data scenario, the best machine learning model (neural net) using telemonitoring data resulted in the aggregated AUC of 0.740 (95% CI 0.673-0.803) evaluated on test data for N=57,150 episodes, N^+=55 admissions (Table 1). The other machine learning models had similar performance, with the mean aggregated AUC of 0.721-0.738, which shows that the improvement over symptom scores could be achieved across a range of models (see Multimedia Appendix 2). To achieve an 80% true-positive rate (sensitivity), the traditional algorithms were associated with an 80% false-positive rate (20% specificity); our algorithm halved this rate to approximately 40% (specificity around 60%).

Adding the weather data (the Healthy Outlook criterion and the additional weather-related variables) to the telemonitoring measurements resulted in no significant improvement in the predictive performance of the best model, with the aggregated AUC of 0.739 (95% CI 0.685-0.794, N=57,150, N^+=55). This cannot be explained by the weather variables being correlated with the telehealth variables, as the best model using the weather data only had the near-random AUC of 0.526 (95% CI 0.504-0.548, N=107,078, N^+=151).

The best model for admissions refitted to the entire dataset following the model selection used 135 variables and was difficult to characterize. By linearizing its outputs, we found that the factors contributing most to the predictions included all 3 groups of variables collected by telemonitoring, together with current smoking status: current symptoms, current and delayed physiological measures, and current and delayed self-reported medications.

Table 1. Predictive accuracy of hospital admission and use of corticosteroids of different definitions of exacerbation.

Description	Practical	AUC[a] (empirical 95% CI)	Events, N^+	Samples, N
Prediction of 24-hour admissions using exacerbation definitions, *complete* data				
Definition 1	Yes	0.600 (0.509-0.692)	17	17,610
Definition 2	Yes	0.578 (0.496-0.672)	17	17,610
Definition 3	No	0.553 (0.440-0.666)	8	14,106
Definition 4	No	0.490 (0.424-0.556)	8	14,106
Definition 5	No	0.657 (0.523-0.792)	9	16,170
Prediction of 24-hour admissions using exacerbation definitions, *imputed* data				
Definition 1	Yes	0.513 (0.477-0.551)	55	57,150
Definition 2	Yes	0.524 (0.486-0.544)	55	57,150
Definition 3	No	0.496 (0.471-0.521)	55	56,702
Definition 4	No	0.505 (0.473-0.536)	55	56,702
Definition 5	No	0.517 (0.479-0.555)	55	57,150
Prediction of 24-hour corticosteroid decisions using exacerbation definitions, *complete* data				
Definition 1	Yes	0.655 (0.630-0.679)	238	9768
Definition 2	Yes	0.605 (0.581-0.628)	238	9768
Definition 3	No	0.568 (0.544-0.592)	178	8489
Definition 4	No	0.544 (0.522-0.567)	178	8489
Definition 5	No	0.646 (0.622-0.670)	237	9322
Prediction of 24-hour corticosteroid decisions using exacerbation definitions, *imputed* data				
Definition 1	Yes	0.660 (0.639-0.681)	316	13,899
Definition 2	Yes	0.605 (0.585-0.625)	316	13,899
Definition 3	No	0.564 (0.543-0.586)	228	10,442
Definition 4	No	0.543 (0.524-0.564)	228	10,442
Definition 5	No	0.647 (0.626-0.668)	316	12,477
Prediction of 24-hour admissions using machine learning models, *imputed* data				
Machine learning model	Yes	0.740 (0.673-0.803)	55	57,150
Prediction of 24-hour corticosteroid decisions using exacerbation definitions, *imputed* data				
Machine learning model	Yes	0.765 (0.738-0.791)	316	13,503

[a]AUC: area under the receiver operating characteristic curve.

Predicting Peaks in Symptom Scores in Populations

The Healthy Outlook [18] algorithm and the weather variables did not improve the quality of predictions of hospital admissions for individuals in our dataset. However, at the population level we found that, over some contiguous time periods, predominantly during fall and winter, prediction of the 2-week population-averaged baseline-adjusted symptom score using the Healthy Outlook variables outperformed the prediction of the simple delayed baseline-adjusted symptom score. The Spearman correlation between the true and the predicted outcomes over the test data folds increased from 0.44-0.55 (the lagged heuristic) to 0.66-0.75 (Healthy Outlook), and the Kendall rank correlation increased from 0.27-0.38 to 0.44-0.52. See Multimedia Appendix 1 for additional detail.

Predicting Individuals Starting Corticosteroids

In contrast to the prediction of hospital admissions, the standard score-counting algorithms were moderately predictive of decisions to start corticosteroid treatments, both in the complete-data and in the imputed-data scenario. Here, we included in the analysis only episodes where patients reported not taking corticosteroids on the first day of the exacerbation. The onset events were defined as taking corticosteroids on the following day. Using definition 1 (Textbox 1), we obtained an AUC of 0.655 (95% CI 0.630-0.679) for the complete-data scenario with N=9768 episodes and N^+=238 corticosteroid therapy onsets (Table 1). In the imputed-data scenario, we obtained an AUC of 0.660 (95% CI 0.639-0.681) with N=13,899 episodes and N^+=316 corticosteroid therapy onsets. Although the machine learning models helped to improve the predictions, leading to an AUC of 0.765 (95% CI 0.738-0.791) on the test datasets, this improvement was relatively lower than in the case of predicting the admissions. The algorithm for predicting corticosteroid onsets (a nonparametric model) used 153 features, where the most important one, as suggested by linearizing, was the total symptom score on the current day.

Discussion

Principal Results

In the context of telemonitoring, traditional algorithms of predicting exacerbations with imputation of missing symptom data were no better than chance when they were used for predicting a COPD admission over the subsequent 24 hours, and were only a little better than chance in the subset with complete data provided by patients. The performance of machine learning algorithms was considerably more accurate and, in practice and subject to some conditions, would have halved the number of false alerts in comparison with the traditional method (see Multimedia Appendix 1 for additional detail). The algorithm readily identified those at high and low risk of admission, suggesting that, in a resource-constrained environment, a simple triage strategy for targeting additional care could be based on using the output of our method. Adding meteorological data did not significantly enhance the accuracy of the model at an individual level, although it did so, to some extent, at a group level for the prediction of average baseline-adjusted symptom scores, which could be of value to service planners. We found that both the standard symptom-counting algorithms and the machine learning algorithms were reasonably accurate for predicting the decision to start corticosteroids within 24 hours.

Limitations

Despite the Telescot COPD trial [11] being one of the largest individually randomized trials of telehealth in COPD, the absolute number of admissions immediately preceded by a complete record of physiological and symptom variables was relatively small, which may have reduced the reliability of the algorithm.

The lack of a gold standard definition for what constitutes an exacerbation is a challenge to research in this area. Many mild to moderate exacerbations were defined by medication use, and patients' individualized management plans advised commencement of antibiotics with an increase in symptoms (eg, if their sputum was dark green). Some also kept corticosteroids, which they took if they were very breathless or wheezy. This self-management may have interfered with what would otherwise have been the natural history of the exacerbation, reducing the relationship between some symptoms and signs and the outcome (hospital admission), but potentially strengthening the relationship between some components of the algorithm and decision to start corticosteroids. Nonetheless, we find the fact that the machine learning algorithm can predict future admissions despite adjusting for self-reported medications to be encouraging.

One methodological limitation of our approach is its reliance on cross-validation, rather than multiple independent cohorts, for evaluations of the predictive performance. In addition to ignoring possible covariate or distribution shifts across multiple cohorts, another well-known disadvantage of cross-validation is the complexity of approximating confidence intervals of the performance measures [34], especially for small or imbalanced datasets. The use of a resampling approach such as cross-validation was unavoidable given the small number of large telemonitoring trials for COPD. Further validations in unrelated datasets will be needed to confirm our findings. One strength of our approach is the use of complementary machine learning methods in the derivation of the optimal algorithm and consistency of the findings across the methods. The considered methods included regularized parametric and kernel methods, boosting, and representation learning. A limitation of our approach is its reliance on fixed-length feature vectors extracted from time-series data, rather than variable-length predictors. We argue that, although there have been some recent works on using variable-length approaches for time-series predictions [35], they demonstrated superior performance over other methods when the number of cases exceeded ours by several orders of magnitude, and they were not extensively compared with sparse classifiers reliant on imputation methods. The closest match to such models from those we considered—the long short-term memory with the imputation strategy described above—did not improve on the other models. Handling the systematic missingness in variable-length conditional models is an actively researched area that will be considered in the future, and which is likely to become useful once bigger telemonitoring datasets are collected. In this study, we used imputation by forward-feeding, which is arguably one of the most practical approaches at the point of inference when access to past data is limited; other techniques may potentially be considered.

The aim of this study was to demonstrate the potential of machine learning for predicting COPD admissions and corticosteroid use, not to elucidate the effects of each feature or combination of features under different adjustments. Modern artificial intelligence methods for predicting clinical events use hundreds or even thousands of features to predict clinical outcomes [34,36]. Due to complex architectures and interactions between multiple variables, it is challenging to estimate the effects of each feature [37,38]. In this study, we investigated the effects only of classes of variables (telehealth, weather-related, and their combinations) rather than each single variable. This is a general limitation of high-dimensional methods; future work is needed to investigate the marginal and conditional effects, and a validation in a device trial will be needed prior to translation to clinical practice.

A limitation of our work is that some of the measures were available at only 1 or 2 time points (eg, anxiety and depression scores, quality of life, exercise or physical activity data, and smoking status were assessed at the beginning and end of the 1-year trial), and time-series data might have been more informative. Other multicomponent scores known to be predictive of COPD outcomes (such as the body mass index, obstruction, dyspnea, exercise index [39] or dyspnea, obstruction, smoking, exacerbation index [40]) might have been useful predictors, as would serial FEV_1 and more detailed serial information on medication changes. Our machine learning platform is extendable to such new types of data sources that may include systematic or informative missingness, which is the strength of the approach.

Comparison With Prior Work

Interest in the development of more accurate predictive algorithms using machine learning is increasing; Sanchez-Morillo and colleagues [41] in a recent review concluded that, while some of these show promise, they have been based on relatively small numbers of patients and events [42,43]. They require validation in larger samples of patients, for longer periods of time. The closest to ours is probably the very recent work of Shah et al [44], who used logistic regression to predict future exacerbations and showed that using pulse rate, oxygen saturation, and respiratory rate (from a pulse oximeter) showed improved predictivity when compared with traditional algorithms of COPD exacerbations. Our result in respect of the value of meteorological data is consistent with the work of Steventon et al [45] on the impact of Healthy Outlook on admission rates.

Conclusions

The early detection and management of COPD remains an important goal given the huge personal and economic costs of the condition. Machine learning approaches, which can be tailored to an individual's baseline profile and can learn from experience of the individual patient, show promise in achieving this goal. There is a need for larger datasets with which to develop more accurate algorithms; however, the lack of an effect of telehealth in COPD demonstrated in trials has effectively discouraged large implementations of the technology. One solution (if governance regulations can be overcome) is to amalgamate existing international datasets. Another may be to explore the ability of algorithms to predict moderate (nonhospitalized) exacerbations with all the challenges highlighted above. Additionally, the potential of machine learning to elucidate optimal interventions should be explored.

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Conflicts of Interest

FA is founder and stakeholder at Pharmatics Ltd. CS is an employee of the Met Office, a Trading Fund of the Department for Business, Energy and Industrial Strategy.

Multimedia Appendix 1

Supplementary data.

[PDF File (Adobe PDF File), 665KB - jmir_v20i9e263_app1.pdf]

Multimedia Appendix 2

Receiver operating characteristic (ROC) of the multitask neural net (MTNN) and the symptom-counting exacerbation score (after [2]) for prediction of 24-hour admissions using the imputed data scenario. The areas under the mean aggregate ROC curves over test data are ~0.74 and ~0.52 respectively.

[PNG File, 69KB - jmir_v20i9e263_app2.png]

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Abbreviations

AUC: area under the receiver operating characteristic curve
COPD: chronic obstructive pulmonary disease
FEV $_1$: forced expiratory volume in the first second of expiration
NHS: National Health Service
UK: United Kingdom

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Review

Digital Health in Melanoma Posttreatment Care in Rural and Remote Australia: Systematic Review

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Abstract

Background: The melanoma incidence and mortality rates in rural and remote communities are exponentially higher than in urban areas. Digital health could be used to close the urban/rural gap for melanoma and improve access to posttreatment and support care services.

Objective: The aim of this review was to understand how digital health is currently used for melanoma posttreatment care and determine the benefits for Australian rural and remote areas.

Methods: A systematic search of PubMed, Medline, PsycINFO, and Scopus was conducted in March 2018. Findings were clustered per type of intervention and related direct outcomes.

Results: Five studies met the inclusion criteria, but none investigated the benefits of digital health for melanoma posttreatment care in rural and remote areas of Australia. Some empirical studies demonstrated consumers' acceptance of digital intervention for posttreatment care. The findings did not take into consideration individual, psychological, and socioeconomic factors, even though studies show their significant impacts on melanoma quality of aftercare.

Conclusions: Digital interventions may be used as an adjunct service by clinicians during melanoma posttreatment care, especially in regions that are less-resourced by practitioners and health infrastructure, such as rural and remote Australia. Technology could be used to reduce the disparity in melanoma incidence, mortality rates, and accessibility to posttreatment care management between urban and rural/remote populations.

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KEYWORDS

digital health; eHealth; technology; melanoma; posttreatment care; support care services; rural areas; remote communities; patient-centric; oncology

Introduction

Australia remains a country with one of the highest levels of melanoma. In 2015, the worldwide average age-standardized incidence rate (ASR) for melanoma was 5 cases for 100,000. However, the rates for Australia and New Zealand are over ten times that level (Table 1) [1]. The high incidence of melanoma in Australia and New Zealand—whose populations consist primarily of transplanted, fair skinned, northern Europeans—is due to high levels of ambient ultraviolet (UV) radiation. Exposure of the skin to UV radiation is a well-known risk factor for melanoma [2-3]. Melanoma treatment represents a significant cost for the Australian Health Care System that has increased dramatically in the past two decades, from approximately Aus $30 million in 2001 to Aus $201 million in 2017 [4].

Table 1. Worldwide ranking of the average age-standardized incidence rate for melanoma.

Rank	Country	Age-standardized incidence rate for melanoma (95% CI)
1	New Zealand	54/100,000 (39-73)
2	Australia	54/100,000 (41-78)
3	Norway	26/100,000 (18-32)
4	Sweden	26/100,000 (20-35)
5	The Netherlands	25/100,000 (17-30)

Cutaneous melanoma (CM) is the fourth most commonly diagnosed cancer in Australia [5] and the most common cancer among young Australians between 15-39 years old. Although melanoma represents only 2% of all skin cancers [6], it often leads to premature death [6] and is responsible for a majority of skin cancer deaths [7]. Compared to urban populations, Australia's rural and remote communities experience inequities in access to care [8], leading to a higher incidence and mortality within 5 years. The median incidence ASR for nonindigenous Australians with CM is 32 per 100,000 across rural and remote areas and 27 per 100,000 in major cities. In comparison, the median worldwide ARS mortality for CM is 5.4 per 100,000 across rural and remote areas and 4.6 per 100,000 in major cities [9].

Melanoma treatment plans depend on (1) prognostic factors which are primarily defined by the American Joint Committee on Cancer staging system [10], and (2) individual characteristics which will allow the clinicians to determine the type of melanoma and the risk for recurrences. For example, patients previously treated for primary CM are at higher risk of recurrences and developing new primary melanomas and skin lesions [11]. However, early detection can reduce mortality rates, as melanoma can be more effectively cured with simple and inexpensive treatments in the early stages [12]. In 1996, Berwick and colleagues [13] reported that total skin self-examination (TSSE) might decrease melanoma mortality by 63%. In 2003, the study by Carli et al [14] found that regular skin self-examination (SSE) could significantly reduce the likelihood of a tumor >1 mm thick at diagnosis. It has been suggested that early detection is a factor influencing the disparity between urban and rural survival rates, but other aspects such as access to health services, clinical practices, and medical care management need to be taken into consideration to fully evaluate survival rates, especially after an initial diagnosis and treatment for CM [15].

In 2017, the Australian Institute of Health and Welfare estimated that 14,000 new melanoma cases would be diagnosed. However, there are only 775 registered dermatologists in Australia (only 260 of which are melanoma specialists), and very few of them are easily accessible to people living in rural and remote areas [16]. There are several infrastructure, cost, and access limitations which impact on the provision of health services for people. This is further compounded by the lack of training for future dermatologists and general practitioners (GPs) in remote areas.

It has been suggested that technology-based training and telehealth could help combat this disparity by bringing health services to rural and remote areas [17]. Many studies have evaluated the benefits of eHealth and the level of acceptance for digital intervention in the early detection of cutaneous melanoma [18-20]. Benefits of telemedicine and teledermatology include increased access to health care services, reduced travel and waiting times, and cost-effectiveness [19]. A 2006 study by Qureshi et al [21] reported that patients prefer telemedicine if it can provide quicker access to their physicians. However, a qualitative review found that patients' attitudes toward technology are only positive if the tool is personalized and adapted to the recipients' needs and characteristics [18]. Also, available evidence suggests that telemedicine is not only beneficial for patients, but for health care professionals (HCP) too. For example, a previous study by Al-Qirim [22] reported that GPs appreciate using teledermatology when they need to refer to a dermatologists' expertise in order to obtain a second opinion.

In order to structure posttreatment plans, physicians must refer to the clinician guidelines. A recent study [23] showed that clinicians working with rural populations are less likely to properly apply guidelines when it comes to educating patients towards surveillance and supportive care. For example, patients living in rural areas were less likely to be provided with patient education material (86% compared to 89% in urban areas) or encouraged to conduct SSE (86% compared to 81%). There are also concerns that oral educational information provided by clinicians may not be useful. A study by Damude et al [24] found that only 5% of melanoma patients were able to reproduce all 4 critical characteristics of their tumor correctly. These results suggest a need for better quality and greater consistency in providing information to patients.

An area of posttreatment care that is often neglected across all populations is psychosocial support. Psychological distress, including worry, anxiety, and fear of disease recurrences and death, are common for survivors [25,26]. However, only 1% of specialists suggested patients see a psychologist as part of their post-treatment plan, despite an entire chapter of the clinician guidelines being devoted to psychosocial issues related to melanoma [23].

Although reviews have evaluated the effectiveness of technology for melanoma early detection, no studies have directly highlighted the benefits of eHealth on melanoma posttreatment care for rural communities. Researchers have qualitatively examined the different forms of treatment and care between rural and urban populations [27] and the care needs among rural cancer patients [28]. However, these studies did not focus on melanoma posttreatment care.

It is unclear from the published literature the level and utility of technology support available to patients with melanoma living in remote areas. The primary aim of this systematic review was to (1) examine how technology is currently used and accepted by physicians and patients with melanoma, and (2) to determine if there has been any implementation of such systems in rural and remote areas of Australia. With this focus, the researchers seek to identify areas of weakness and bring to light hypotheses on how technology could be used as an adjunct service during posttreatment care of CM, to aid physicians in designing follow-up care plans for patients with CM based on their needs and personal characteristics.

Methods

Databases and Search Strategy

The overall aim of this systematic review was to investigate digital health acceptance and its current use among people treated for melanoma. Our primary aim was to better understand digital health benefits among rural and remote populations for CM. However, given the impact of CM across all of Australia's population, literature around digital health and CM that impacted urban and regional areas was incorporated as well. This was done to ensure broad inclusion of digital health practice for CM posttreatment care. The databases selected were searched using keyword combinations related to digital health and melanoma posttreatment care. Specifically, we used the keyword combination "telehealth" OR "telemedicine" OR "teledermatology" OR "online services" OR "ehealth" OR "e-health" OR "eHealth" AND "melanoma." For the current systematic literature review, 4 databases (PubMed, Medline, PsycINFO, Scopus) were searched in March 2018.

Study Selection

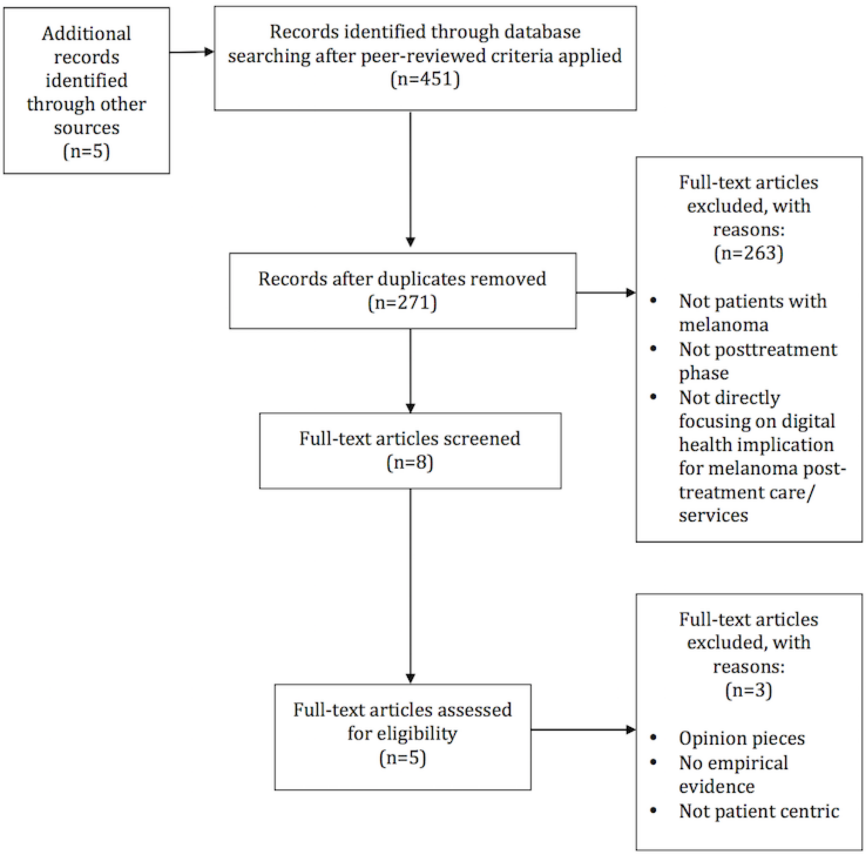
The search was limited to peer-reviewed papers. Search results identified 451 papers which were exported into a Microsoft Excel document. After duplicates were removed, 271 articles remained.

The search strategy involved 2 screening phases. Each article was screened based on exclusion criteria to remove irrelevant articles from the initial selection of 271 articles. For the second phase, only studies that were based on empirical evidence and used a patient-centric approach were retained for the final systematic literature review. Figure 1 presents the selection overview based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart. A PRISMA checklist is shown in Multimedia Appendix 1.

Data Extraction

Data was extracted from the relevant papers using the following classification: (1) sources (country, year of study intervention), (2) participant characteristics (gender, residential area, mean ages, patient illness conditions, level of education, and socioeconomic background), (3) study design, (4) study intervention, and (5) research focus (Multimedia Appendix 1).

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart of the systematic literature review.



Results

Origin

There were 5 studies in total. Two (40%) of the studies were from Scotland, with the other 3 (60%) from the Netherlands, Canada, and the US. All studies were from before 2015 except for one (20%) study from the Netherlands, which was from 2016.

Participant Characteristics

Four of the 5 (80%) studies consisted of patients with melanoma only. The remaining study (20%) recruited patients with a history of melanoma and psoriasis, or collateral cancer. A minority, 2 of the 5 (40%) authors referred to the patient's illness condition in their sample description. The gender distribution of studies was mostly homogeneous with 47%-60% males and a mean age ranging from 53-66 years. None of the studies used "residential area" as an independent variable. Two (40%) studies used residential area as a patient characteristic but did not mention it in their findings. Also, 2 (40%) studies reported socioeconomic criteria in their findings and 3 (60%) featured level of education.

Study Design and Intervention

Prior to the investigation, all published research participants were informed of the objectives of the studies. Three of the 5 (60%) studies [18,19,21] were qualitative and used semistructured interviews either face-to-face or over the phone. The interviews were recorded by the researchers, transcribed verbatim, coded and reviewed by 1 or more coresearchers in order to cluster by themes/concepts of the participants' answers. The 3 (60%) qualitative studies assessed the perception and preferences of dermatology patients about the use of technology for self-monitoring and TSSE [18], a Web-based platform (Oncology Interactive Navigator) to deliver information about melanoma [19], and store and forward teleconsultation [21]. The latter used a willingness-to-pay approach in order to investigate dermatology patients' preferences. One (20%) study [20] used both qualitative and quantitative methods to assess the feasibility and acceptability of a digital intervention for self-monitoring and the participants' attitude to perform TSSE. One quantitative study [24] used an online questionnaire in order to capture participants' knowledge of melanoma and TSSE, and their preferences. Figure 2 displays the study design distribution with regards to the research main focus areas.

Research Focus Areas

Table 2 presents the positive and negative outcomes of using technology for melanoma posttreatment care of each selected study by type of intervention. The studies reviewed were classified under four intervention categories: (1) total skin self-examination; (2) teleconsultation; (3) clinicians' support and coordination; and (4) informative and supportive displays.

Figure 2. Distribution of the papers according to the study design and the main focus area. TSSE: total skin self-examination.

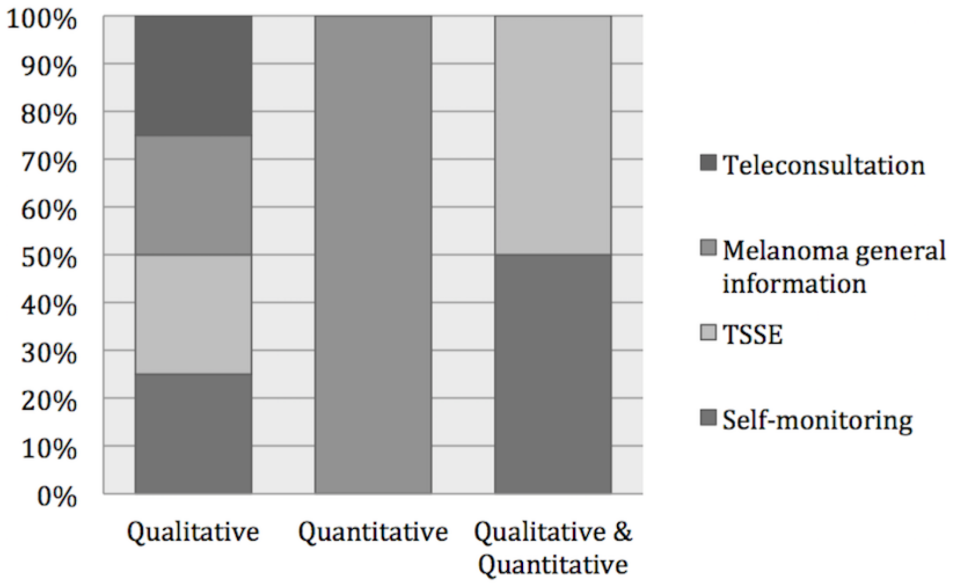


Table 2. Direct outcomes on posttreatment care per type of intervention.

Direct outcomes	Type of intervention
Total skin self-examination	
Positive findings	
• Provides reassurance to patients [18]	• Report sent by phone to clinicians including photographs • Self-monitoring supportive tools
• Convenient • Avoids in-person clinical visit if not necessary [18]	• Report sent by phone to clinicians including photographs
• Reduces the number of people who might forget about total skin self-examination [18]	• Reminder sent by text message or email
• Promotes early detection [18]	• Report sent by phone to clinicians including photographs
• Behavior change • Empowers patients' confidence to perform total skin self-examination [20,21]	• Self-monitoring supportive tools • YouTube videos explaining how to perform a total skin self-examination
• Reinforces total skin self-examination [20]	• Self-monitoring supportive tools
Negative findings	
• Health care professionals based their opinion on pictures only [18]	• Clinicians' feedback sent by text message or email
Teleconsultation	
Positive findings	
• Convenient • Reduces travel and saves time [18,20] • Quick access to clinicians [18,21]	• Skype or teleconference • Store and forward telemedicine
Negative findings	
• Patients' desire to discuss face-to-face with clinicians [18]	• Skype or teleconference
• Patients' skin required to be examined by clinicians [18]	• Phone
Clinicians' support and coordination	
Positive findings	
• Accuracy in the diagnosis [18]	• Three-way consultation via a video or Skype link from the general practitioner's room
• Convenient • Time and travel saved [15]	• Remote point of contact • Nurse specialist' opinion to be provided via store and forward system
Negative findings	
• Not applicable	• Not applicable
Informative and supportive displays	
Positive findings	
• Promotes early detection [18,19]	• Web-based app tailored information delivered about their conditions • Skin map
• Reduces patients' stress [19]	• Web-based app tailored information delivered about their conditions • Skin map
• Improves patients' decision-making in treatment [19]	• Web-based app tailored information delivered about their conditions

Direct outcomes	Type of intervention
• Ease of communication • Content is more adapted to the patients' level of understanding [19] • Supporting oral/written information delivered to the patients [24]	• Web-based app tailored information delivered about their conditions • YouTube videos explaining how to perform a total skin self-examination
• Reduce/control the content load [18,19]	• Web-based app tailored information delivered about their conditions
Negative findings	
• Don't want to be associated with other patients • Makes them feel sicker than they are [18]	• Online peer support (ie, forum, group chat)
• Do not replace the oral and written information provided by clinicians [24]	• YouTube videos explaining how to perform a total skin self-examination

Discussion

Principal Results

The primary aim of this review was to identify the different use of digital health for melanoma posttreatment care, including its benefits and weaknesses. Patients perceived digital health as an added value to their posttreatment care [18-21,24]. However, a majority of the studies reported the benefits of digital interventions to prevent recurrence and promote early detection [18,19,24]. None of the selected studies investigated the benefits of digital health for melanoma posttreatment care in rural and remote areas. This gap in the digital health literature gives thought to a very specific niche in telemedicine that needs to be explored further, given this is an at-risk population [5]. Thus, it is crucial to understand how digital health could help clinicians to provide better care and quality of life (QoL) for people treated with melanoma, especially in regions where aftercare resources are limited or nonexistent, such as in rural and remote areas of Australia.

Patients' Individual Characteristics

This review found some evidence for the efficacy of digital interventions for melanoma posttreatment care. Key findings identified that clinicians need to take into consideration patients' characteristics in order to provide personalized follow-up plans, tailored information, and quality of care [18,21]. It is clear that information technology (IT) capabilities, patient age, illness condition, level of incomes and residential areas influence clinician and patient decision-making in the posttreatment plan. One study by Hall and Murchie [18] found that participants who were familiar with technology and not living close to hospitals were more likely to have a positive attitude toward telemedicine for self-monitoring and performing TSSE [18]. Querish and colleagues [21] also reported that 73% of the participants are more willing to pay when telemedicine was giving them faster access to the clinicians. Among this sample, 55% had an income inferior, or equal to US $50,000 per annum. Another study [29] investigating consumers' perception toward telemedicine found that people with "technology anxiety" were less likely to use IT for specific care. In contrast, young populations may be more inclined to trust digital health interventions, as they are more familiar with technology [30].

Patients' Acceptance

In order to efficiently use personal consumer technology in melanoma posttreatment care, it is crucial to understand patients' acceptance toward digital intervention. Several of the studies reviewed [18,20,24] illustrated a shift from "passive" recipients to "active" patients for their care [19], which led to proactive health behavior change and positive attitudes toward early detection. Simple measures such as receiving a reminder to perform TSSE by text message or email, having access to informative videos, or using smartphone apps for self-monitoring, reduced anxiety, and reinforced TSSE [18,20,24]. These technologies could also be used to address the need for better quality and greater consistency in information provided to melanoma patients [24].

The study by Quereshi and colleagues [21] reported that patients' attitude toward telemedicine was generally positive if it showed convenience (58% well willing to pay up to US $125), but almost universally positive if it gave a quicker access to their clinicians (95% of the patients were willing to pay up to US $500). The study by Horsham and colleagues [30] emphasized that survivors show a positive attitude towards a digital health application that allowed them to monitor QoL and provided tailored information and advice.

While these findings demonstrated that patients were generally receptive toward digital health for melanoma posttreatment care, no studies to date have focused on rural and remote communities' views. Nevertheless, a few studies have already highlighted people's acceptance toward telemedicine in Australian rural and remote communities for cancer more broadly. In their studies, Sebesan and colleagues [31,32] reported the benefits of teleoncology in rural and remote areas for cancer care. The main benefits of this telehealth system included travel time saved and better access to specialist care. Also, studies [32,33] have shown that telehealth may lead to financial benefits and improved quality of care in distant communities.

Patients' Psychological and Social Needs

In this systematic review, there was a lack of empirical evidence with regards to the benefits of digital health for support and psychological care services, in order to provide better QoL. These studies mainly focused on early detection, including self-monitoring and TSSE. However, a previous systematic review [34] suggested that 30% of patients with melanoma reported psychological distress, which interferes with QoL, medical cost, risk of recurrence, and mortality rates [35,36]. Likewise, Oliveria and colleagues [37] found that patients treated with melanoma showed (1) direct psychosocial concerns related to conducting skin self-examination, (2) anxiety associated with new recurrence and sun exposure, (3) familial concerns, and (4) financial constraints and maintenance of health insurance benefits. Emotional support and reassurance are considered a key component of care [34-40], with psychological intervention associated with superior survival and recurrence rates, and decreased distress [39]. Clinicians should, therefore, take into consideration the psychosocial impact on patient outcomes when designing posttreatment plans.

The Economic Burden of Melanoma Treatment in Australia

Melanoma early detection reduces the mortality rate and results in simple treatments for lower cost [41]. A 2017 study [2], estimated the mean cost to the Australian health system for melanoma treatment to be Aus $10,716 per patient. However, treatment cost for advanced melanoma may be 21% to 70% more expensive than for early stages (in situ, stage I and stage II). Doran and colleagues [42] compared the direct and indirect costs of melanoma and nonmelanoma skin cancer (NMSC) in 2010. The direct costs related to the management of the disease, including diagnosis and treatment to follow-up, and indirect costs included productivity losses associated with morbidity and premature mortality. Estimates of direct lifetime cost per case were Aus $10,230 for melanoma and Aus $2336 for NMSC; and total indirect cost per case Aus $34,567 for melanoma and Aus $123 for NMSC.

Moreover, additional studies [15,27] have reported an urban and rural disparity in term of accessing health care and mortality rate. Yu and colleagues [27] reported that socioeconomic factors may impact people's decision-making in selecting their health care provider. The study showed a difference in provider performance based on patients' income. Rural populations with lower-income received poorer care from HCPs, compared to patients living in urban areas.

The comparatively lower cost of delivering support care services via digital health initiatives, in addition to reduced treatment costs associated with promoting early detection [17-19] would go some way to improving access to health care and reduce urban/rural inequity.

Limitations

This systematic literature review presents several limitations. First, most of the studies used small samples (n≥20). It is evident that digital health research regarding melanoma postcare treatment is still in its early stages of investigation. Second, few studies were identified as focusing on the psychosocial and health economic side of post-care treatment, as melanoma studies are primarily focused on early detection, and those that did use a retrospective measurement of consumer attitudes towards telemedicine. Third, melanoma treatment plans depend on individual characteristics, including the disease staging. Only one of the studies used staging as a participant characteristic. Finally, although the authors were primarily interested in rural and remote areas of Australia, the lack of studies conducted in these areas meant that studies for this review were drawn from across the world, and their conclusions may not necessarily generalize to the Australian rural and remote context.

Overall, the current systematic review provides findings of patients' perceptions toward telemedicine and digital interventions already used by clinicians and patients. However, in order to have a complete review of digital health benefits for melanoma post-treatment care, it would have been necessary to look at HCP's acceptance of such technological interventions.

Conclusion

The study of digital health has become an area of focus in primary health care, as it can help clinicians in their practice and support patients in improving and monitoring their QoL. While there is research interest in using digital health in early detection of melanoma, there is an urgent need to explore the potential for benefits of digital health in melanoma post-treatment care for specific needs and intervention, particularly for rural and remote populations who are lagging behind regarding postcare treatment quality and availability. This literature review also highlights the importance of considering individual, psychosocial and socioeconomic characteristics in future developments in this area.

Although our findings showed positive outcomes with regards to using technology during post-treatment care, there were also some limitations in using digital health. Patients believe that technology cannot replace the clinician provided written and oral information, follow-up visits, or clinical interventions [24]. To summarize, digital health shows potential to be used as an adjunct service by clinicians during melanoma posttreatment care, especially in regions that are less-resourced by practitioners and health infrastructure, such as regional and remote Australia.

Implication for Further Research

Future research should explore the potential for digital health within rural and remote areas for melanoma posttreatment care in order to reduce the mortality rate disparity in between urban and rural populations. Also, it will be interesting to consider how digital health implementation may transform the patients' ecosystem and the cost-effectiveness of this solution for both patients and the health care industry.

Interdisciplinary studies in behavioral psychology and health economy can add new insights to the health care industry in term of benefits and services that digital health can bring to melanoma patients care in rural and remote areas.

Acknowledgments

The authors would like to thank Dr John Turner for his expert advice on research methodology.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist.

[PDF File (Adobe PDF File), 67KB - jmir_v20i9e11547_app1.pdf]

Multimedia Appendix 2

The consumer-technology relationship and digital interventions for melanoma posttreatment care.

[XLSX File (Microsoft Excel File), 15KB - jmir_v20i9e11547_app2.xlsx]

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Abbreviations

ASR: age-standardized rate
CM: cutaneous melanoma
GPs: general practitioners
HCP: health care professional
IT: information technology
NMSC: nonmelanoma skin cancer
QoL: quality of life
SSE: skin self-examination
TSSE: total skin self-examination
UV: ultraviolet

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Original Paper

Audio-/Videorecording Clinic Visits for Patient's Personal Use in the United States: Cross-Sectional Survey

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Abstract

Background: Few clinics in the United States routinely offer patients audio or video recordings of their clinic visits. While interest in this practice has increased, to date, there are no data on the prevalence of recording clinic visits in the United States.

Objective: Our objectives were to (1) determine the prevalence of audiorecording clinic visits for patients' personal use in the United States, (2) assess the attitudes of clinicians and public toward recording, and (3) identify whether policies exist to guide recording practices in 49 of the largest health systems in the United States.

Methods: We administered 2 parallel cross-sectional surveys in July 2017 to the internet panels of US-based clinicians (SERMO Panel) and the US public (Qualtrics Panel). To ensure a diverse range of perspectives, we set quotas to capture clinicians from 8 specialties. Quotas were also applied to the public survey based on US census data (gender, race, ethnicity, and language other than English spoken at home) to approximate the US adult population. We contacted 49 of the largest health systems (by clinician number) in the United States by email and telephone to determine the existence, or absence, of policies to guide audiorecordings of clinic visits for patients' personal use. Multiple logistic regression models were used to determine factors associated with recording.

Results: In total, 456 clinicians and 524 public respondents completed the surveys. More than one-quarter of clinicians (129/456, 28.3%) reported that they had recorded a clinic visit for patients' personal use, while 18.7% (98/524) of the public reported doing so, including 2.7% (14/524) who recorded visits without the clinician's permission. Amongst clinicians who had not recorded a clinic visit, 49.5% (162/327) would be willing to do so in the future, while 66.0% (346/524) of the public would be willing to record in the future. Clinician specialty was associated with prior recording: specifically oncology (odds ratio [OR] 5.1, 95% CI 1.9-14.9; *P*=.002) and physical rehabilitation (OR 3.9, 95% CI 1.4-11.6; *P*=.01). Public respondents who were male (OR 2.11, 95% CI 1.26-3.61; *P*=.005), younger (OR 0.73 for a 10-year increase in age, 95% CI 0.60-0.89; *P*=.002), or spoke a language other than English at home (OR 1.99; 95% CI 1.09-3.59; *P*=.02) were more likely to have recorded a clinic visit. None of the large health systems we contacted reported a dedicated policy; however, 2 of the 49 health systems did report an existing policy that would cover the recording of clinic visits for patient use. The perceived benefits of recording included improved patient understanding and recall. Privacy and medicolegal concerns were raised.

Conclusions: Policy guidance from health systems and further examination of the impact of recordings—positive or negative—on care delivery, clinician-related outcomes, and patients' behavioral and health-related outcomes is urgently required.

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KEYWORDS

audiorecording; health care; health system; policy; United States; videorecording

Introduction

Up to 80% of health care information discussed verbally is forgotten by patients after their clinic visit [1-4]. Poor recall and understanding of medical concepts have been identified as significant barriers to self-management, a central component of the chronic care model [5-7]. The last decade has seen significant efforts to increase patient access to medical information. Mandated through meaningful use, clinics across the United States now offer patients an after-visit summary (AVS) [8]. AVS is a summary of the clinic visit generated from the electronic medical record (EMR) available via the web-based patient portal, which includes information on diagnoses, medication, allergies, clinician visited, and summary of visit [9]. OpenNotes moves beyond this basic summary, offering patients access to the clinical notes in their EMR [10,11]. Access to such written summaries of office visits is associated with improved adherence, patient and caregiver satisfaction, patient self-care, medical information recall, and preparedness for clinic visits [11-16]. However, there have been concerns about the accuracy and complexity of written summaries [12-14] and their low use by patients [15]. This issue is compounded by low levels of health literacy; 35% of Americans have below basic or basic health literacy [16].

An adjunct to written summaries is the sharing of clinic visit audiorecordings with patients [17-20]. With broad and growing access to smartphones, recording devices are now ubiquitous, and reports of patients recording their clinic visits, with or without permission, are emerging [17,20]. Over 40 years of research finds that patient access to recordings results in greater patient understanding and recall of visit information, reduced decisional regret, and increased patient satisfaction [21-23]. Audiorecordings are also highly utilized in the research context; in a scoping review of 33 studies (18 trials), 71% of patients listened to their recordings and 68% shared them with a family member or caregiver [21]. In addition, according to a recent analysis, recording of clinic visits would be guided by "wire-tapping" laws, which premises that patients in 39 states and the District of Columbia, can legally make recordings without explicit consent of the clinician; the remaining 11 states require all party consent [19].

A handful of clinics in the United States have recognized the potential of recording and routinely offer patients audiorecordings (video recordings in one case) of their visits [18]. Furthermore, educational sessions are now available to clinicians in return for Continuing Medical Education credit for training in what to do if they find a "secret recording of office visits by patients" [24]. Despite this increased interest in recording, no data exist on the prevalence of recording in clinical practice in the United States or the attitudes of clinicians and the public toward recording. Additionally, it is unclear whether US hospital systems have created guidance or policies for clinicians and patients regarding the practice of recording. Such data are essential to assess the acceptability of recording and the potential of this strategy to become more widely implemented.

In this paper, we report on the prevalence of sharing audiorecorded clinic visits in the United States, the attitudes of clinicians and the public toward recording, and health system policies to guide recording practices.

Methods

Design

We administered 2 parallel cross-sectional surveys in July 2017 to US-based clinicians and the public. We also surveyed 49 of the largest health systems in the US by phone and email. All methods and materials were approved by Dartmouth College's Committee for the Protection of Human Subjects (Study #30345). The usability and technical functionality of both surveys was tested by the research team and colleagues before fielding the surveys. We used the Checklist for Reporting Results of Internet E-Surveys to report our findings (see Multimedia Appendix 1).

Participants

United States Clinicians

Clinicians were recruited and completed their surveys via SERMO (SERMO, Inc USA), the world's leading online community of physicians who participate in online medical market research studies. SERMO has over 800,000 verified licensed physician members. To be eligible for inclusion, clinicians (Doctor of Medicine or Doctor of Osteopathic Medicine) had to be currently practicing in the United States. In order to recruit a diverse sample of specialties, we included clinicians from the following 8 specialties: emergency medicine, general or family medicine, internal medicine, general surgery, obstetrics-gynecology, orthopedic surgery, physical rehabilitation, and psychiatry. A bulk email was sent to a random sample of panel members from each specialty, informing them that they may be eligible to take part in a study. This voluntary, open survey consisted of 3 required multiple choice questions (clinician's practice setting, years in practice, experiences of recording clinic visits) and 1 open response question assessing their views on patients having access to recordings (audio or video) of clinic visits and spanned over 1 screen (see Multimedia

Appendix 2). Respondents could not review or change their answers or save responses if they wished to complete the survey later. Clinicians' sociodemographic data (gender, age, practice location converted to Rural Urban Commuting Area codes) were available via SERMO. All data were collected over a one-day time period from July 6 to July 7, 2017.

United States Public

Participants were recruited online using Qualtrics Panels (Qualtrics LLC, Provo, Utah, USA). Quotas were applied based on US census data (gender, race, ethnicity, and language other than English at home) to approximate the US adult population [25-28]. A bulk email was sent to a random sample of panel members based on quotas, informing potential respondents that they may be eligible to take part in a study; however, no information on the content of the survey was provided until members "clicked" on the survey link. Respondents receive "points" from Qualtrics for taking part, which can be redeemed for an incentive, for example, air miles, gift cards, etc. To be eligible for inclusion, individuals had to be ≥18 years and reside in the United States. This voluntary, open survey consisted of 13 multiple choice questions (sociodemographics, experiences of recording clinic visits, and attitudes toward recording clinic visits) and 1 open response question assessing public views of recording clinic visits for patient's' personal use (see Multimedia Appendix 3). All questions were required and adaptive questioning was used. The survey included 14 items and spanned over 3 screens. Respondents could not review or change their answers or save responses if they wished to complete the survey later. Data were collected over a one-week time period from July 13 to July 19, 2017.

In both clinician and public surveys, the recruitment invitation included general information about the study (approximate length, purpose, and investigators) and a link to the anonymous and confidential survey. Participants consented by their decision to continue onto the survey. To increase the quality of data in both surveys, responses from individuals who completed the survey in less than one-third of the median completion time were excluded. Only completed questionnaires were analyzed.

Health Care Systems

We identified 49 of the largest health systems in the United States using the employed physician counts in IQVIA's OneKey reference data set and supplemented this with the information provided in the Agency for Healthcare Research and Quality (AHRQ) compendium of US Health Systems 2016 (see Multimedia Appendix 4) [29]. According to the AHRQ definition, "a health system includes at least one hospital and at least one group of physicians that provides comprehensive care (including primary and specialty care) who are connected with each other and with the hospital through common ownership or joint management." Health care system administrators, specifically those who worked in risk management or other relevant areas, were contacted by email and asked whether they have a recording policy at their health system. If such a policy existed, they were asked to describe it. Nonresponsive systems were contacted by telephone 1 week later. A maximum of 3 phone calls and emails were made, after which the system was considered a nonresponder.

Data Analysis

The prevalence of clinic visit recording and willingness to record was calculated for clinicians and the public. Multiple logistic regression analyses were conducted to identify factors associated with recording practices, including the history of recording, the history of covert recording (public respondents only), and willingness to record in the future. We planned to recruit a sample of 500 members of the public, which in a similarly sized probability sample would provide 95% CI of estimating the prevalence of recording in the population to within ±4%. We also aimed to sample at least 50 clinicians from each specialty, allowing for a minimum of 5 observations per parameter in the multiple logistic regression model [30]. Analyses were conducted using RStudio, V1.1.383 (RStudio, Boston, MA). We conducted a thematic analysis of all open-ended responses to identify salient themes reflecting the respondents' attitudes toward patient recordings, as well as any concerns or related benefits. Comments were independently reviewed, and 20% were double coded by 2 members of our research team (MAD, KV). Finally, we categorized health systems as having an existing policy (and describing this policy), lacking an existing policy, or being unsure of their policies regarding clinic visit recordings.

Results

Clinician Survey

A total of 1472 clinicians were invited to complete the survey, of which 409 did not respond (see Figure 1). Of the remaining 1063 clinician, 456 clinicians completed the survey, while 599 were excluded as the quotas for these clinicians' specialties had been reached, and 8 clinicians were screened out (4 not currently in clinical practice and 4 declined). Respondents in the final sample (N=456) came from 44 states and Washington DC. Survey completion took an average of 2 minutes 30 seconds. Of the included respondents, 61% had been practicing for more than 10 years, and the majority, 84%, practiced at least half of their time in outpatient care (Table 1).

Prevalence of Recording Practices

Of 456 clinician respondents, 28.3% (129/456; 95% CI 24.2-32.7) reported that they had recorded a clinic visit for patients' personal use (Table 2). Of the remaining 327 clinicians who had not recorded, 49.5% (162/327, 95% CI 44.0-55.1) were willing to do so, while 50.5% (165/327; 95% CI 45.0-56.0) were not. Multiple logistic regression analyses revealed that only clinical specialty was associated with recording a visit in the past (Table 3): clinicians in oncology and physical rehabilitation were more likely to have had a visit recorded (reference category, general or family medicine), odds ratio (OR) 5.1 (95% CI 1.9-14.9; *P*=.002) and OR 3.9 (95% CI 1.4-11.6; *P*=.01) respectively, and to be willing to be recorded by their patients in the future, OR 2.9 (95% CI 1.2-7.4; *P*=.02) and OR 2.9 (95% CI 1.2-7.6; *P*=.03), respectively (Table 3). Psychiatrist were also more willing to be recorded by their patients in the future, OR 2.7 (95% CI 1.1-6.8; *P*=.03).

Figure 1. Overview of clinician and public survey participants.

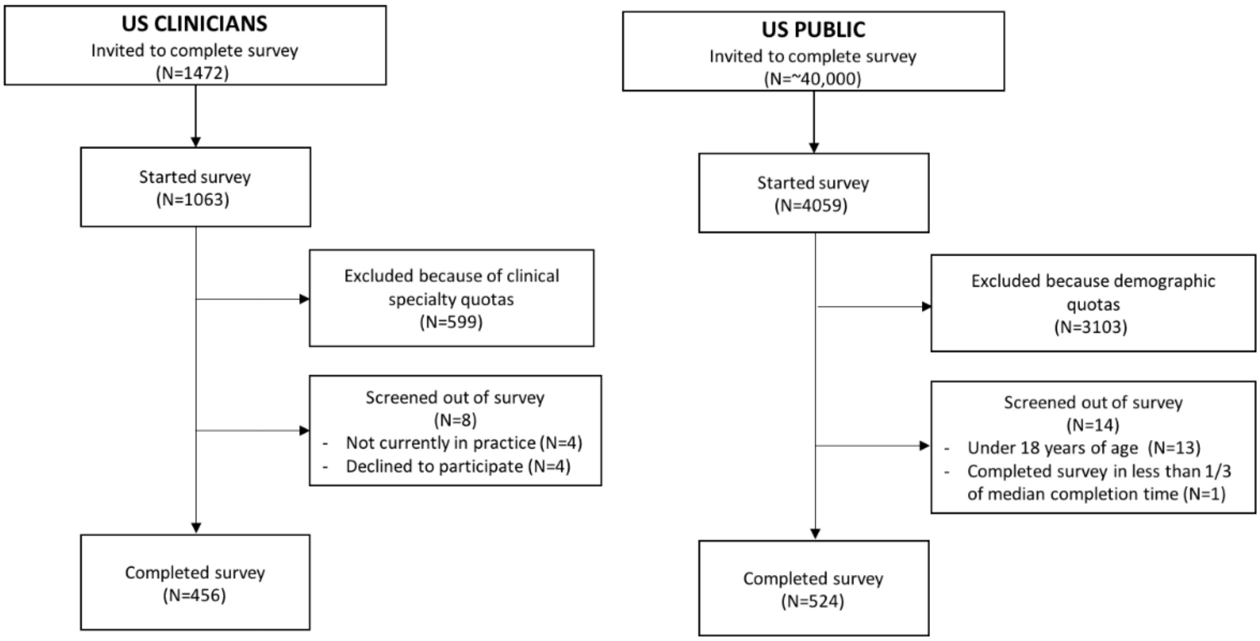

Table 1. Clinician respondent characteristics (N=456).

Characteristics	n (%)
Gender	
Female	99 (21.7)
Male	291 (63.8)
Chose not to answer	66 (14.5)
Years in practice	
<5	63 (13.8)
6-10	113 (24.8)
11-15	84 (18.4)
>15	198 (43.4)
Clinical practice setting	
All inpatient care	19 (4.2)
Mostly inpatient care	54 (11.8)
Half inpatient care, half outpatient care	120 (26.3)
Mostly outpatient care	151 (33.1)
All outpatient care	112 (24.6)
Location	
Urban	426 (93.4)
Rural	29 (6.4)

Table 2. Clinician recording practices (N=456).

Specialty	Recording history, n (%)		
	Yes, I have had a visit recorded for a patient's personal use	No, I have not had a visit recorded, however I would consider having a visit recorded in the future	No, I have not had a visit recorded and I would not consider having a visit recorded in the future
All (n=456)	129 (28.3)	162 (35.5)	165 (36.2)
Emergency medicine (n=51)	11 (21.6)	22 (43.1)	18 (35.3)
General or family practice (n=50)	8 (16.0)	15 (30.0)	27 (54.0)
General surgery (n=52)	18 (34.6)	16 (30.8)	18 (34.6)
Internal medicine (n=50)	11 (22.0)	17 (34.0)	22 (44.0)
Obstetrician-gynecologist (n=50)	14 (28.0)	18 (36.0)	18 (36.0)
Oncology (n=50)	23 (46.0)	13 (26.0)	14 (28.0)
Orthopedic surgery (n=51)	11 (21.6)	20 (39.2)	20 (39.2)
Physical rehabilitation (n=50)	21 (42.0)	17 (34.0)	12 (24.0)
Psychiatry (n=52)	12 (23.1)	24 (46.2)	16 (30.8)

Table 3. Characteristics of clinicians associated with having had a clinic visit recorded for a patient's personal use in the past and willingness to have a clinic visit recorded for a patient's personal use.

Factors	History of recording clinic visit for patient, OR[a] (95% CI)	Willingness to record clinic visit in the future, OR (95% CI)
Gender (reference: female)	0.99 (0.58-1.75)	0.77 (0.44-1.30)
Years in practice (5 year increments)	1.03 (0.82-1.29)	0.83 (0.66-1.04)
Setting (reference: ½ inpatient, ½ outpatient)		
Mostly inpatient	0.84 (0.38-1.78)	1.21 (0.57-2.64)
Mostly outpatient	0.83 (0.46-1.49)	0.76 (0.43-1.34)
Location (reference: urban)	1.25 (0.48-2.99)	0.66 (0.29-1.50)
Specialty (reference: general or family practice)		
Emergency medicine	1.72 (0.58-5.37)	2.10 (0.85-5.31)
General surgery	2.85 (0.97-9.00)	1.75 (0.67-4.64)
Internal medicine	1.12 (0.34-3.68)	1.65 (0.67-4.14)
Obstetrician-gynecologist	2.25 (0.81-6.68)	1.88 (0.80-4.52)
Oncology	5.11 (1.93-14.90)	2.90 (1.19-7.35)
Orthopedic surgery	1.37 (0.41-4.66)	1.10 (0.41-2.95)
Physical rehabilitation	3.91 (1.43-11.63)	2.90 (1.16-7.59)
Psychiatry	1.69 (0.59-5.09)	2.75 (1.14-6.84)

[a]OR: odds ratio.

Table 4. General clinician and public attitudes toward patient access to audiorecordings of clinic visits.

Views on patient access to recordings of clinic visits	Physicians, n (%)	General public, n (%)
Total respondents who shared general attitude in open-ended response	377 (81.8)	459 (87.8)
Supportive of patient access to recordings	136 (36.1)	301 (65.6)
Supportive of case-by-case basis of recordings	34 (9.0)	11 (2.4)
Concerned about patient access to recordings	183 (48.5)	90 (19.6)
Uncertain, had never previously considered patient access to recordings	16 (4.2)	23 (5.0)
Neutral, no opinion toward patient access to recordings	8 (2.1)	34 (57.4)

Clinicians' Views of Sharing Recordings of Clinic Visits

In the open-ended responses to their views on providing clinic recordings to patients (n=377), 170 clinicians were supportive of recording, 183 were concerned about recording, while the remaining clinicians were neutral or uncertain (Table 4). Proposed benefits included improved information recall and understanding, the ability for clinicians to use the audiorecordings for documentation purposes, and clinical education:

> *There are legitimate reasons to do it at times! Maybe for someone who is afraid they will not remember or for someone who could not be there.*

> *I would welcome the idea if this replaces writing long notes on EMR.*

> *It might be useful (in the right setting) as a tool for peer feedback on patient interaction.*

Privacy concerns and risk of medicolegal use by patients emerged as the most common concerns among clinicians:

> *The recording of office visits would be used by lawyers to twist our words against us in court.*

However, some clinicians considered it protective:

> *If I detect a potential litigious patient I would ask if the visit could be recorded.*

Clinicians also expressed concerns regarding a negative impact on the patient-clinician interaction through potentially less "open" consultations and whether patients would use recordings:

> *...I'd be skeptical of how much patients would actually view the videos or benefit from the service.*

United States Public Survey

Approximately 40,000 individuals were invited to take part in the survey, of which 4059 responded (see Figure 1). Of those 4059 individuals, 524 completed the entire survey, while 3103 were excluded as quotas for these individuals were reached and 14 individuals were screened out (13 were under 18 years and 1 respondent completed the survey in less than one-third of the median completion time: 1 minute 48 seconds). Respondents in the final sample (n=524) belonged from 48 states. The sociodemographic characteristics of the respondents approximated that of the US population (Table 5).

Prevalence of Recording Practices

Of the public respondents, 15.6% (82/524; 95% CI 12.6-19.0) reported audio or video recording a clinic visit with permission, while 2.7% (14/524; 95% CI 1.5-4.4) did so secretly (Table 6). Additionally, 19.3% respondents (101/524; 95% CI 16.0-22.9) reported that they were aware of a family member or friend who reported recording a clinic visit, of which 60.4% (61/101; 95% CI 49.2-69.1) asked permission and 25.7% (26/101; 95% CI 17.6-35.4) did not. Finally, 58.6% (307/524; 95% CI 54.2-62.8) reported that they would consider recording a visit in the future with permission of the clinician and 7.4% (39/524; 95% CI 5.3-10.0) without the clinician's permission, while 37.4% (196/524) were not interested in recording a clinic visit.

In a multiple logistic regression analysis, individuals who reported having recorded a clinic visit with the permission of their provider were more likely to be male, OR 2.11 (95% CI 1.26-3.61; *P*=.005); to be younger, OR 0.73 (95% CI 0.60-0.89; *P*=.002) per 10 years increase in age; and to speak a language other than English at home, OR 1.99 (95% CI 1.09-3.59; *P*=.02; Table 7). While 63% of general public respondents were interested in recording a clinic visit in the future, older adults (OR 0.88, 95% CI 0.78-0.99 per 10 years increase in age) and those with a lower level of education (OR 0.58, 95% CI 0.38-0.89) were less likely to be interested in recording a clinic visit for their personal use. This analysis did not reveal any demographic factors that were predictive of individuals having recorded a clinic visit covertly (all *P*>.15).

Public Views of Sharing Recordings of Clinic Visits

In the open-ended responses (n=459), 312 were supportive of recording and 90 were concerned about recordings, while the remaining public comments were considered neutral or uncertain (Table 6). Similar themes regarding concerns and potential benefits associated with recordings emerged from public respondents when compared to clinician respondents. The most common positive theme was the potential for recordings to improve patient recall and understanding of medical information:

> *I would like this option since I'm not very knowledgeable about medical terms and if I ask questions during the visit it might go over my head. If I can play it back, I would better absorb what I need to know or if I missed something, I can hear it again…*

Additionally, a small proportion of respondents believed that recordings could be used for medicolegal purposes and to improve clinician recall of visit information:

> *It allows for patients and doctors to look back on the visit for information they might have missed.*

Concerns were less common in the public sample, but included privacy concerns, *"These recordings could fall into the wrong hands"*; unclear benefit to patient of recordings, *"I'm not really sure what the point would be to have my clinic visits recorded..."*; and possible impact on the visit, *"recording my visits may inhibit my interaction with the health professional."*

Health Care System Recording Policies

When 49 of the largest health care organizations in the United States were asked in August 2017 about the existence of a policy regarding patient recording care systems, 47 responded to our request (Multimedia Appendix 4). Of the responses, 22 reported no formal policy, 13 were unsure if they had a policy, 4 stated that such policies would be left to the individual clinics, 6 said that the policy would be physician dependent, and 2 reported an existing policy that would cover patient requests for audiorecordings or videorecordings of the clinic visit (Table 8). Of the clinics that reported an existing policy that could be applied, the Henry Ford Health System, Michigan stated that patients' audiorecordings or videorecordings and photographs must comply with privacy laws and their institutional policy.

Table 5. Public respondent characteristics (N=524).

Characteristics	n (%)
Gender	
Female	255 (48.7)
Male	262 (50.0)
Other	7 (1.3)
Age (years)	
18-40	304 (58.0)
41-60	152 (29.0)
>60	68 (13.0)
Education	
High school degree or less	124 (23.7)
Some college or college degree or equivalent	313 (59.7)
Postgraduate degree (Masters, PhD, or professional)	73 (13.9)
Other	14 (2.7)
Hispanic origin	
Yes	66 (12.6)
No	458 (87.4)
Race	
American Indian or Alaska Native	4 (1.0)
Asian	21 (4.0)
Black or African American	75 (14.3)
Native Hawaiian or other Pacific Islander	0 (0.0)
White	412 (78.6)
Other	12 (2.3)
Language other than English spoken at home?	
Yes	104 (19.8)
No	420 (80.2)

The Henry Ford Health System patient photographs and video recordings policy allows for recording, but consent must be attained first and the recording will be stored in the EMR, which patients can request access to. The Mayo Clinic, Minnesota stated that “with their consent, patients, families and staff may be photographed or video recorded by families and/or visitors at Mayo facilities for the purpose of education for continuing care of the patient following discharge,” but that no other forms of photography or video are allowed.

Table 6. Public recording practices (N=524).

Survey item	Respondent, n (%)
Have you ever recorded (audio or video) a clinic visit with your doctor or health professional?	
Yes, and I asked for permission first	82 (15.6)
Yes, and I did so secretly (without asking permission first)	14 (2.7)
No, I have never recorded a clinic visit	431 (82.3)
Would you consider recording a clinic visit with a doctor or another health professional?	
Yes, I would consider recording with the permission of the doctor	307 (58.6)
Yes, I would consider secretly recording (without the permission of the doctor)	39 (7.4)
No, I have no interest in recording a clinic visit	196 (37.4)
Are recordings (audio or video) of patient clinic visits routinely offered in your clinic?	
Yes	51 (9.7)
No	262 (50.0)
Not sure	211 (40.3)
Do you know a family member or friend who has recorded (audio or video) a visit with a doctor or health professional?	
Yes	101 (19.3)
No	423 (80.7)
Did the family member or friend ask permission before recording the clinic visit? (n=101)	
Yes	61 (60.4)
No	26 (25.7)
Not sure	14 (13.9)

Table 7. Characteristics of the public associated with a history of recording a clinic visit and with an interest in recording a clinic visit for their own personal use, with or without permission from their doctor or health professional.

Characteristics	History of recording with permission, OR[a] (95% CI)	History of recording covertly, OR (95% CI)	Interest in recording, OR (95% CI)
Age			
Increase of 1 year	0.97 (0.95-0.99)	1.01 (0.97-1.05)	0.99 (0.98-0.999)
Increase of 10 years	0.73 (0.60-0.89)	1.10 (0.73-1.62)	0.88 (0.78-0.99)
Gender (reference: female)	2.11 (1.26-3.61)	1.55 (0.48-5.41)	1.22 (0.85-1.78)
Education (reference: some college or college degree)			
High school or less	1.12 (0.61-2.01)	0.60 (0.09-2.36)	0.58 (0.38-0.89)
Postgraduate degree	0.97 (0.41-2.08)	N/A[b]	0.75 (0.44-1.29)
Race (white non-Hispanic vs everybody else)	0.76 (0.43-1.36)	0.39 (0.11-1.45)	1.07 (0.69-1.66)
Language other than English spoken at home	1.99 (1.09-3.59)	1.49 (0.36-5.45)	1.54 (0.93-2.60)

[a]OR: odds ratio.

[b]N/A: not applicable.

Table 8. Responses from 49 large health care organizations in the United States.

Response	Organizations, n (%)
Has a policy	2 (4)
No policy	22 (45)
Policy is up to individual facilities	4 (8)
Policy is up to individual physicians	6 (12)
Unknown	13 (26.5)
No Response	2 (4)

Discussion

Principal Findings

In this study, the first to explore the prevalence of clinic recording in the United States, we found that one-third of surveyed clinicians have recorded a clinic visit for a patient's personal use and that half of those who have not recorded would be willing to do so in the future. Approximately one-fifth of the public reported recording a visit in the past and two-thirds would consider recording a visit in the future. Oncologists and physical rehabilitation clinicians were most likely to have recorded a visit. Members of the public who were younger, male, or spoke a language other than English at home were most likely to have recorded. Clinicians and patients commented on the benefits of recording, including improved recall and understanding. However, clinicians also reported privacy and medicolegal concerns. None of the 49 large health systems that we spoke to reported a dedicated policy or guidance for clinicians or patients on the practice of sharing clinic visit recordings; two reported that this would fall under an existing guideline.

Limitations

This project is not without limitations. Since we used online panels to recruit clinicians and members of the general public, it is not possible to create a response rate. By ensuring that our respondent samples approximated census data with regard to age, gender, education, and language spoken at home, we reduced the potential impact of selection bias. Additionally, the representativeness of data gathered from internet panels has been shown to be comparable to that from probability-based general population samples [31]. We were not able to determine who instigated the recording for those who have recorded or whether this practice is routine in clinicians who reported sharing a recording in the past; however, 10% (51/524) of public respondents did report that this practice was routine at their clinic. Focusing on a sample of the public, rather than a sample of patients, may underrepresent the prevalence of recording occurring in health care as it includes a range of respondents, many of whom will have limited experience with health systems.

Comparison with Prior Work

The current project supports previous findings that patients are beginning to "press record" during clinic visits [17-18,20]. Similar to previous studies, clinicians' views on recordings were mixed. The benefits of increased understanding, recall, and the possibility of better self-management were tempered by medicolegal and privacy concerns. Despite these concerns, a significant proportion of clinicians have shared recordings or are willing to do so in the future.

Reports of covert recording in this project (14/524, 2.7%) are much lower than those reported in a previous study, where 15% of United Kingdom public respondents reported this practice [20]. This difference may be due to the high risk of selection bias in the UK survey, where a small convenience survey (n=128) was administered following a radio talk show discussing pros and cons of covertly recording clinic visits. Yet, in the present survey, 25.7% (26/101) of respondents who were aware of a family member or friend recording a visit reported that this was done covertly.

Only clinician specialty was associated with recording practice and intention to record, with almost half of oncologists and physical rehabilitation clinicians reporting that they had shared a recording in the past. Higher rates of recording in oncology may be due to the emotional nature of a cancer diagnosis and complex treatment plans. Additionally, most previous research on the use of recordings in health care has taken place in oncology settings [21]. While physical rehabilitation is less studied, the benefit of recordings in this population of patients has been documented in an ongoing case study (Barr; PJB, unpublished data, February 2017). Clinicians from general or family practice were the least likely (8/50, 16%) and least willing to record (15/50, 30%). Barriers to recording use among these clinicians may be due to the significant clinical informatics challenges reported, including the volume of clinical reminders and computerized patient record system alerts and time needed to input EMR notes [32]. Coupled with the diverse nature of patients and severity of conditions, it is not surprising that general and family clinicians are least likely to record. Yet, for these reasons, audiorecording could be beneficial in primary care, especially with advances in speech-to-text software that could assist with documentation at the point-of-care (see Implications).

Public respondents who spoke a language other than English at home were more likely to report recording a clinic visit. This may be a strategy to mitigate poor communication of health care information commonly reported by patients with low English proficiency [33-35]. Younger individuals also reported higher rates of recording, which may reflect their comfort with technology and greater likelihood of having a smartphone [36]. It is unclear why male patients are more likely to record than females, but this finding supports our previous survey in the UK [20]. The differences do not appear to be due to smartphone access or use [36]. It may be that because men are reported to delay health seeking compared with women, their clinic visits may be related to more complex problems where recording would be helpful [37]. Men may also be more likely to record in order to report back to women in their lives (eg, wife, sister, mother). Whereas women traditionally manage their family's health care [38] and as such may feel less need to record and share their visit. Alternatively, they could simply be more willing to ask permission to record. Further investigation of individual differences in recording practice by minority groups and gender is required.

Further investigation of individual differences in recording practice by minority groups and gender is required.

Implications

With no clear policies, it appears that clinicians and patients are leading the way on the implementation of recording in health care delivery. Through the lens of the "Diffusion of Innovation" model, the recent increase in the use of recordings is not unexpected as it meets the principles required for successful diffusion outlined by Berwick [39]: (1) the need for change is apparent; (2) the innovation is compatible with adopters' values; (3) it is simple and flexible; (4) it is trialable; and (5) it is observable. The need to improve the transparency and communication of medical information in clinics is evident from recent policies, such as meaningful use [8] and advances in OpenNotes [10]. Furthermore, 40 years ago, recording of clinic visits was complicated, involving impractical technology; today, it is simple, so much so that clinics have many ways in which to implement recording practices. In a recent case study, clinics that routinely offered recordings used a range of approaches including patient phones, digital recorders, and clinicians' computers to audiorecord and electronic tablets to videorecord visits [18]. It appears that we are at the early adopter stage of recording practice. The dissemination of innovations in health care has a tipping point of 15%-20% after which it is difficult to stop [40]. Recording and sharing of clinic visits may have reached this point.

With significant developments in fields of artificial intelligence and conversational analytics, health care will be transformed in the next decade; 35% of health care organizations plan to leverage artificial intelligence within 2 years and more than half intend to do so within 5 years [41-43]. Audiorecorded clinic data holds significant potential to tackle some of the major challenges we face today at lower costs, such as clinician documentation burden, patient recall of visit information, and improved patient-centered communication [44]. Highly accurate speech-to-text systems will enable real-time visit documentation [32]; patients and clinicians will once again be able to talk without the barrier of a computer. Our research group is developing a recording system that will use machine learning to tag key information from the clinic visit and link this to credible lay information for patients and their caregivers: Audio-Personal Health Library (PaHL) [45]. We hypothesize that Audio-PaHL will improve patient recall and understanding of visit information, resulting in improved self-management and a better health care experience via improved care coordination and higher satisfaction [18].

Conclusions and Relevance

US clinicians and public are taking the lead on sharing clinic visit recordings, while policy makers lag behind. Policy guidance for clinics and further examination of the impact of recordings on clinical practice—both positive and potentially unforeseen negative—are urgently required.

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Conflicts of Interest

PJB, KB, KV, MDD, CY, EA, MP, KLC, and MM have no financial conflicts to declare. PJB leads a research initiative "Open Recordings" investigating the applications and implications of audio and video recording clinical visits, including the development of Open Recording Automated Logging System and Audio-PaHL funded by the Gordon and Betty Moore Foundation and National Library of Medicine, respectfully. MAD receives consulting income from EBSCO Health and may receive royalties in the future. She is also a consultant for Access Community Health Network.

Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

[PDF File (Adobe PDF File), 106KB - jmir_v20i9e11308_app1.pdf]

Multimedia Appendix 2

National recording survey: clinicians.

[PDF File (Adobe PDF File), 57KB - jmir_v20i9e11308_app2.pdf]

Multimedia Appendix 3

National recording survey: general public.

[PDF File (Adobe PDF File), 71KB - jmir_v20i9e11308_app3.pdf]

Multimedia Appendix 4

Overview of health care systems.

[PDF File (Adobe PDF File), 41KB - jmir_v20i9e11308_app4.pdf]

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Abbreviations

AHRQ: Agency for Healthcare Research & Quality
AVS: after-visit summary
EMR: electronic medical record
OR: odds ratio

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Original Paper

Automatic Extraction of Mental Health Disorders From Domestic Violence Police Narratives: Text Mining Study

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Abstract

Background: Vast numbers of domestic violence (DV) incidents are attended by the New South Wales Police Force each year in New South Wales and recorded as both structured quantitative data and unstructured free text in the WebCOPS (Web-based interface for the Computerised Operational Policing System) database regarding the details of the incident, the victim, and person of interest (POI). Although the structured data are used for reporting purposes, the free text remains untapped for DV reporting and surveillance purposes.

Objective: In this paper, we explore whether text mining can automatically identify mental health disorders from this unstructured text.

Methods: We used a training set of 200 DV recorded events to design a knowledge-driven approach based on lexical patterns in text suggesting mental health disorders for POIs and victims.

Results: The precision returned from an evaluation set of 100 DV events was 97.5% and 87.1% for mental health disorders related to POIs and victims, respectively. After applying our approach to a large-scale corpus of almost a half million DV events, we identified 77,995 events (15.83%) that mentioned mental health disorders, with 76.96% (60,032/77,995) of those linked to POIs versus 16.47% (12,852/77,995) for the victims and 6.55% (5111/77,995) for both. Depression was the most common mental health disorder mentioned in both victims (22.25%, 3269) and POIs (18.70%, 8944), followed by alcohol abuse for POIs (12.19%, 5829) and various anxiety disorders (eg, panic disorder, generalized anxiety disorder) for victims (11.66%, 1714).

Conclusions: The results suggest that text mining can automatically extract targeted information from police-recorded DV events to support further public health research into the nexus between mental health disorders and DV.

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KEYWORDS

text mining; rule-based approach; police narratives; mental health disorders; domestic violence

Introduction

Domestic violence (DV) can be defined as “any incident of threatening behavior, violence, or (psychological, physical, sexual, financial, emotional) abuse between adults who are or have been an intimate partner or family member, regardless of gender or sexuality” [1]. DV can also occur in other relationships, such as between a caregiver and a dependent person or those living together in a household in a nonintimate relationship [2]. It is recognized as one of the most common forms of interpersonal violence and is an international social and public health problem with important health care consequences affecting the lives of thousands, mostly women, each year [3-5]. According to the World Health Organization’s (WHO) multicountry study of violence, the prevalence of physical and sexual partner violence toward women ranges from 15% to 71% globally [3,5]. In 2014, almost 50,000 people in Australia were recorded by the police as the victims of DV [6]. The cost of DV is significant with estimates suggesting that, in Australia, the cost of violence against women was approximately Aus $22.2 billion in 2015-2016, and in the United Kingdom and the United States, £17 billion and US $4.1 billion, respectively [4,5,7].

Domestic violence shares a complicated relationship with the onset, duration, and recurrence of mental health disorders, including substance abuse, eating disorders, posttraumatic stress, and suicidal tendencies, as well as exacerbation of psychotic symptoms [3-5,8]. Previous reports have suggested an increased risk of DV in populations with mental health disorders in comparison to those with no mental illness [3,9]. Over the past 20 years, a consensus has emerged that there is a modest (yet statistically significant) relationship between severe mental illness and violence, with severe mental illness increasing the risk of an individual to be violent toward others [10].

In 2017, the New South Wales Police Force (NSWPF) recorded 123,330 DV-related events in WebCOPS, a Web-based interface for the Computerised Operational Policing System (COPS) that enables the police to capture and analyze crime information on an organization-wide basis, with approximately 37% resulting in an offense being recorded (NSW Police Force, personal communication, June 2018). Information about DV events contained in WebCOPS is available as both structured form (eg, fields documenting information such as date of birth, Aboriginal status, whether weapons were used) and free unstructured text (“event narratives”). Each event contains one or more text narratives that describe in detail the alleged incident(s) that occurred between the person of interest (POI) and the victim, the circumstances of the event, and any action(s) taken by the police. The narratives are often written without a specific structure, populated with frequent misspellings and typographical errors, often with (sometimes informal) acronyms and abbreviations that can bear ambiguous meaning depending on the context.

The large number of DV events and the associated text narratives, however, prevent the extraction of potentially useful information using traditional ethnographic/qualitative approaches. One recent research paper commented that “...there is no systematic way to extract information from these [police] narratives other than by manual review” [11].

Still, automated methods for large-scale processing of free text known as *text mining* have been used for over 30 years to harvest information from unstructured text in many domains, particularly in biomedicine [12-15]. Recent attempts have aimed to utilize text mining to identify crime-related information from online media publications [16,17]. However, few efforts have been conducted in processing police reports [18-20]. Limited work included identification of offenders’ names, narcotic drugs, and weapons with various degrees of success (F-score [a measure of a method’s accuracy] ranging from 46% to 81%) through named entity extractors [18,19] and classification of police reports as DV or non-DV related by applying an unsupervised clustering technique that classified 44% of the reports set aside for manual inspection correctly [20].

Several attempts have been also made to extract mental health-related information from various free-text resources [21-27]. For example, drug side effects were extracted from psychiatric narratives by applying either hybrid methodologies of machine learning and dictionaries with rules, or rule-based approaches only that returned F-scores between 75% and 85% [21,24,25]. Treatment outcomes for major depressive disorders were identified from electronic medical records using a supervised approach with logistic regression, with precision ranging from 78% to 86% [22]. Mini Mental State Examination results were recognized from clinical notes and health record correspondence between clinicians with 85% and 91% F-scores, respectively, through a rule-based method [23]. Jackson et al [26] and Karystianis et al [27] both identified symptoms of mental illness from clinical discharge summaries and psychiatric records using either regular expression pattern matching or a rule-based approach with 88% and 81% F-scores, respectively [26,27].

In this paper, we examine whether automatic text mining of DV police event narratives is feasible in identifying mentions of mental health disorders at the narrative level among those involved in DV events by employing a knowledge-driven approach. This approach is based on lexicalized rules combined with manually constructed dictionaries that characterize mental health disorders in both POIs and victims involved in domestic disputes recorded by the NSWPF. We further perform a large-scale analysis of 492,393 DV events and report the results. To our knowledge, there has not been any application of text mining in the area of DV using real-world events and this is the first attempt of its kind to capture important mental health information in a large-scale analysis of DV events as recorded by the police.

Methods

Overview

Mentions of mental health disorders (including traumatic brain injury) were identified among POIs and victims in DV disputes based on the full list of the disorders (Textbox 1) according to the WHO's *International Classification of Diseases, Tenth Revision* (*ICD-10*) for mental and behavioral disorders [28]. We also recognized mentions of unspecified mental disorders reported in the narratives (eg, "the defendant has mental health issues," "victim is suffering from a severe mental disorder"), mentions of psychotropic medications by name or drug class (eg, "the victim takes Valium," "accused takes a number of antidepressants"), and mentions of traumatic brain injury, drug prescription abuse, substance abuse, and drug-induced disorders.

Data

We obtained records of 492,393 DV events from WebCOPS from January 2005 to December 2016 flagged either as "domestic violence related" or the description of violence in WebCOPS was coded as "domestic" or the relationship between the victim and the POI included any of the following: spouse/partner (including ex-spouse/ex-partner), boyfriend/girlfriend (including ex-boyfriend/ex-girlfriend), parent/guardian (including step/foster), child (including step/foster), sibling, other member of family (including kin), or carer. These events covered the following categories: various types of assaults, breaches of Apprehended Violence Orders, homicides, malicious damage to property, and offense against another person such as intimidation, kidnapping, abduction, and harassment. The records also contained incidents where no crime was committed but the police attended the DV event nonetheless. All event narratives contained personal information (eg, first name, surname, address) and therefore are not available to the general public. Permission to access the narratives was granted by the NSWPF following ethics approval from the University of New South Wales Human Research Ethics Committee (reference: HC16558) with access limited only to some authors of this study (GK, AA, TB). Strict security protocol ensured that text mining of the narratives could only be undertaken on site at the NSWPF headquarters and only deidentified extracted outputs could be taken off-site. A hypothetical example of a deidentified narrative is shown in Multimedia Appendix 1.

We randomly selected 100 events containing mental health disorder mentions for our training set, and an extra set of 100 other randomly chosen ones as a development set to optimize the performance of the text-mining system.

Textbox 1. Mental health disorders listed in the International Classification of Diseases, Tenth Revision (ICD-10) including the eight new categories targeted for extraction in domestic violence events and examples as they appeared in the police event narratives.

1. Mental disorders due to known physiological conditions: eg, vascular dementia, unspecified dementia
2. Mental and behavioral disorders due to psychoactive substance abuse: eg, alcohol-related disorders, cannabis addiction, nicotine dependence
3. Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders: eg, schizophrenia, delusions, schizoaffective disorder
4. Mood (affective) disorders: eg, manic episodes, bipolar disorder, depression
5. Anxiety, dissociative, stress-related, somatoform, and other nonpsychotic mental disorders: eg, phobia, dissociative disorder, body dysmorphic disorder
6. Behavioral syndromes associated with physiological disturbances and physical factors: eg, eating disorders, bulimia, anorexia
7. Disorders of adult personality and behavior: eg, paranoid personality disorder, borderline personality disorder, kleptomania
8. Intellectual disabilities: eg, intellectual disability, severe intellectual disability
9. Pervasive and specific developmental disorders: eg, autism, mathematics disorder, phonological disorder
10. Behavioral and emotional disorders with onset usually occurring in childhood and adolescence: eg, attention deficit hyperactivity disorder, antisocial personality disorder, transient tic disorder
11. Unspecified mental disorder: eg, mental health issues, mental condition, mental health problem
12. Intentional self-harm: eg, self-harm, cut herself on purpose, self-harming issues
13. Injury of unspecified body region: eg, suicide attempt, multiple suicide attempt, attempted to kill himself
14. Symptoms, signs, and abnormal clinical and laboratory findings: eg, suicidal ideation, suicidal thoughts, suicidal tendencies
15. Other degenerate diseases of the nervous system: eg, Alzheimer disease, frontotemporal dementia
16. Chromosomal abnormalities not elsewhere classified: eg, Down syndrome
17. Drug prescription abuse: eg, addiction in prescribed medications, abusing prescribed medication
18. Traumatic brain injury: eg, brain damage, serious brain injury, brain trauma
19. Substance abuse: eg, substance abuse problem, ongoing drug abuse problems
20. Mental health medications antipsychotics: eg, Clozapine, antipsychotic medications, Risperdal
21. Mental health medications neuroleptics: eg, neuroleptic medications, neuroleptic drugs
22. Mental health medications antianxiety: eg, Xanax, medications: anxiety, Alprazolam
23. Mental health medications antidepressants: eg, Escitalopram, Anafranil, antidepressant medication
24. Unspecified drug-induced disorders: eg, drug-induced disorder, drug-induced mental health problem
25. Unspecified diseases of the nervous system: eg, neurological disorder
26. Systemic atrophies primarily affecting the central nervous system: eg, Huntington disease

Knowledge-Based System Development

Our approach involved the design and implementation of rule-based language expression patterns combined with term dictionaries to identify mentions of mental health disorders in both POIs and victims involved in DV events at the narrative level (see Figure 1 for an overview).

Our text-mining methodology consisted of the following steps (Figure 1):

1. Creation of specific dictionaries relevant to mental health disorders;
2. Design and implementation of rules to capture mental health disorder mentions in text;
3. Standardization and mapping of the extracted mental health disorder mentions into *ICD-10*; and
4. Elimination of duplicate mentions in each narrative to reach narrative level unification.

Dictionaries

Mentions of several task-specific semantic groups were identified through a set of custom-made dictionaries. The dictionaries were manually tailored by examining the training and development sets for the use of terms describing the associated mental health disorder mentions as well as expressions related to these conditions. For the identification of mental health disorders, we made use of terms and synonyms from the *ICD-10*, as well as common misspellings (eg, “schitzophrenia,” “aspergus syndrome”) or other indicative descriptive sentences (eg, “abuses alcohol,” “anger issues”) that were present in the event reports. A total of 13 dictionaries were crafted by the first author, GK (Table 1).

Rules

After inspecting the training set, we based our rules on lexical patterns in the text that indicated the presence of a mental health disorder for the POI, the victim, or both in a DV event. In the following example of a lexical pattern observed in a DV event ("accused is suffering from schizophrenia") to identify a mental health disorder mention ("schizophrenia"), the word "accused" (the POI) is matched via a dictionary that contains variations of terms representing a POI (see Table 1) in which "is suffering from" is a semifrozen expression for the identification of the mental health disorder mention and "schizophrenia" gets a match through a dictionary containing various terms of mental health disorders (official and unofficial ones). The lexical patterns make use of (1) frozen lexical expressions as anchors for certain elements that are built through specific verbs, noun phrases, and prepositions (eg, "defendant suffers from"); and (2) semantic place holders (identifiable through the application of the manually crafted dictionaries (eg, all potential synonyms characterizing an individual as a victim such as "victim," "vic," "pn") suggesting the presence of a mental health disorder.

Figure 1. Overview of the text-mining approach used for the identification of mental health (MH) disorder mentions in domestic violence (DV)-related police event narratives. GATE is used as the environment for the rule design and application to mental health disorder mention identification. ICD-10: International Classification of Diseases, Tenth Revision.

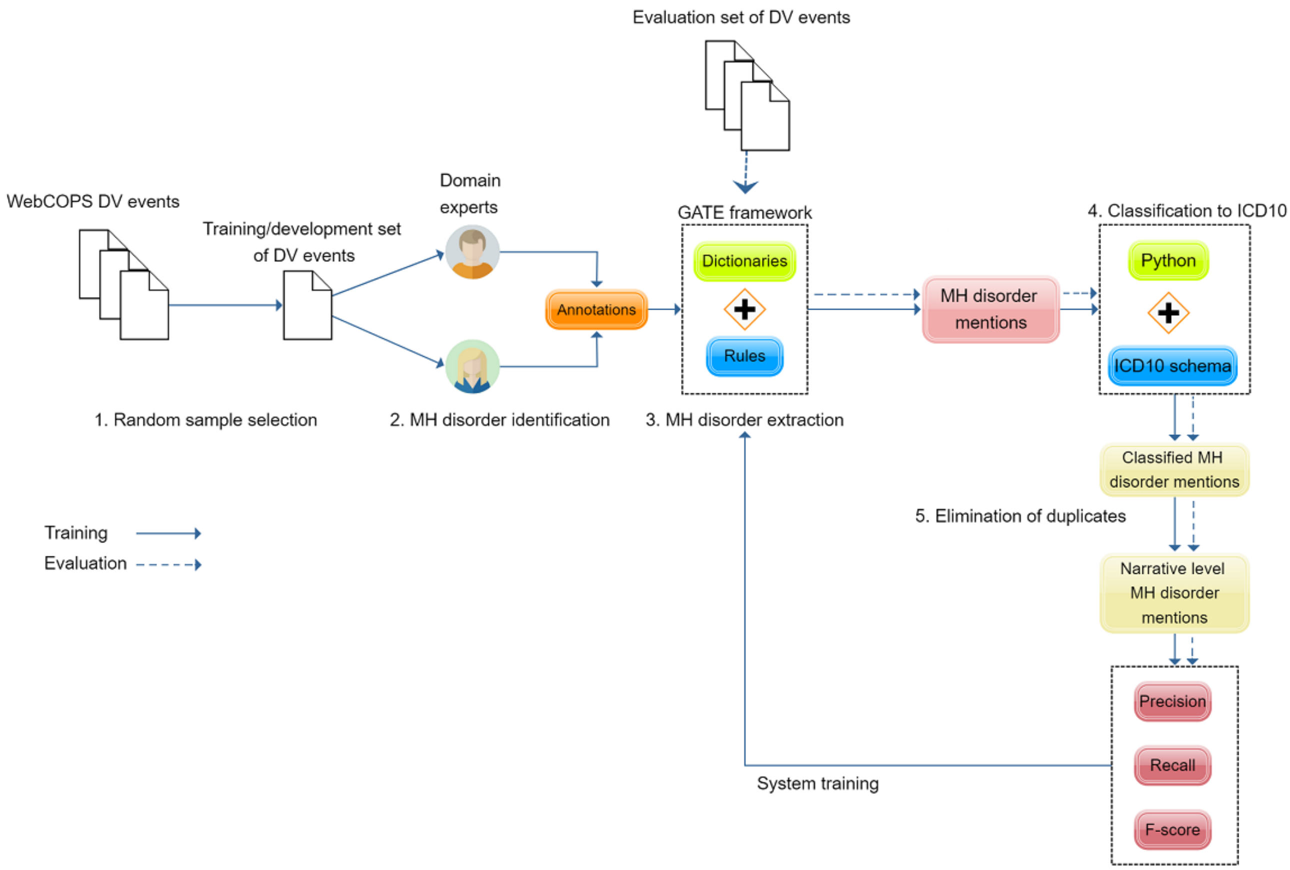

Table 1. Manually crafted dictionaries and their size (number of terms included) used to identify mental health disorder mentions.

Dictionary name	Size, n	Description	Examples
Adjectives	84	Adjectives indicating a mental disorder	alcoholic, schizophrenic, bipolar, autistic
Be	4	Conjugations of the verb “be” in present and past tense	is, was, were, are
Drug addiction	58	Illegal drugs known to cause addiction	cannabis, heroin, methamphetamines, ice
Drug names	228	Prescribed medications used to treat mental health disorders	Xanax, Valium, Stelazine, Tensium
Drug types	26	Medication classes used in treating mental health disorders	antianxiety, antidepressants, antipsychotic, mood stabilizer
Family	31	Terms indicating a family relationship	cousin, father, mother, grandfather
Have	5	Conjugations of the verb “have” in present and past tense	has been, have, having, has had
History	20	Variations of mental health history mentions	a short history of, hx, serious history of, extensive h/o
Mental disorder	594	Mental health disorder terms as appearing in the International Classification of Diseases, Tenth Revision (ICD-10) including traumatic brain injury and dementia, as well as unofficial terms, abbreviations, and synonyms observed in the police events	mood disorder, suicidal tendencies, split personality disorder
Negation	11	Terms indicating negated context	not, denies, none
Person of interest (POI)	18	Terms that describe a POI in a domestic violence event	defendant, POI, POI accused
Verbs	75	Verbs appearing in common lexical patterns that indicate a mental health disorder for POIs and victims	admitted, struggles, suffering, appears
Victim	19	Terms describing a victim in a domestic violence event	victim, vic, pn, pinop

Concept enumeration was also implemented because it appears frequently in the training data (eg, “POI has a history of depression, self-harm, and suicidal tendencies [mental health disorder mentions for POI]”). More than one lexical pattern may be matched in an event report and may refer to one or more disorder mentions (that can be duplicates) for the victim, the POI, or both.

For the generation and implementation of the rules, we used General Architecture for Text Engineering (GATE) [23], a text-mining framework for annotating and categorizing text that enables the identification of targeted information. GATE was chosen due to its support for rule-based text-mining approaches. The observed patterns in the text were converted into rules using the Java Annotations Pattern Engine (JAPE), a pattern matching language for GATE. A total of 264 rules were created with 137 for the POI and 127 for the victim, respectively. Figure 2 displays rule examples for the identification of mental health disorders.

The rules use lenient token matching (lowercase or uppercase), such as {Token.string==~”(?i)to”} matches “to”; various dictionaries contain variants, abbreviations, and synonyms of terms of interest, such as (victim), (POI), and (verbs) contain terms for victims, POIs, and verbs in various forms and tenses that describe victims or POIs suffering from a mental health disorder, respectively (see Table 2); ({Token!Lookup.majorType==”negated”})[0,1] will match any token that is not a part of the dictionary “Negated” (which contains negated indicators such as “not”); and the presence of “?” at the end of a rule component suggests its nonconditional nature (ie, it can appear or not in the text).

Mapping of Extracted Mental Health Disorder Mentions to the International Classification of Diseases, Tenth Revision

Since the extracted mental health disorder mentions are highly variable (synonyms, misspellings), any further analysis requires them to be mapped into standard mental health concepts such as the *ICD-10* mental and behavioral disorder categories. This was done automatically through a heuristic algorithm that relies on groups of terms that are representative of various *ICD-10* categories. If a given mention matched one term from a specific *ICD-10* category, then it was mapped to that category.

The mapping was done at four levels (see Multimedia Appendix 2). The first level was the most generic (26 categories), representing the overall type of mental health disorders as specified by *ICD-10* (see Textbox 1). The original *ICD-10* was expanded using eight customized categories to map mentions for which no direct mapping was obvious. Four of these eight categories involved mentions of psychotropic medications (“medications-antidepressants,” “medications-antianxiety,” “medications-antipsychotics,” “medications-neuroleptics”). For example, in event narratives where a medication class (eg, antidepressant medication) or a brand name (eg, “Zoloft”) was specified, we mapped them to a category called “medications-antidepressants.” The other four categories included “drug prescription abuse,” “substance abuse (unspecified),” “traumatic brain injury,” and “unspecified drug-induced disorder.” Cases in which we recognized that either the victim or the POI had an unknown mental health disorder or an unknown drug-induced mental disorder, were assigned into the categories of “unspecified mental disorder” or “unspecified drug-induced disorder,” respectively.

Figure 2. Rule examples (using GATE notation) for the recognition of mental health (MH) disorder mentions of persons of interest (POIs) and victims in domestic violence events. The identified disorder mentions are highlighted in bold.

<table>
<tr><td rowspan="2">POI MH disorder</td><td>example</td><td>POI</td><td>appears</td><td>to</td><td>suffer</td><td>from</td><td>schizophrenia</td></tr>
<tr><td>rule</td><td>(POI)</td><td>(verbs)</td><td>{Token.string==~"(?i)to"}</td><td>(verbs)</td><td>({Token.string==~"(?i)from|with"})?</td><td>(disorder)</td></tr>
</table>

<table>
<tr><td rowspan="2">POI MH disorder</td><td>example</td><td>defendant</td><td>is</td><td>an</td><td>alcoholic</td></tr>
<tr><td>rule</td><td>(POI)</td><td>(be)</td><td>({Token, !Lookup.majorType=="negated"})[0,1]</td><td>(adjectives)</td></tr>
</table>

<table>
<tr><td rowspan="2">Victim MH disorder</td><td>example</td><td>pinop</td><td>as</td><td>he</td><td>has had</td><td>history of</td><td>psychotic episodes</td></tr>
<tr><td>rule</td><td>(victim)</td><td>{Token.string==~"(?i)as"}</td><td>{Token.string==~"(?i)he|she"}</td><td>(has)</td><td>(history)</td><td>(disorder)</td></tr>
</table>

<table>
<tr><td rowspan="2">Victim MH disorder</td><td>example</td><td>self-harm</td><td>caused</td><td>by</td><td>the</td><td>victim</td></tr>
<tr><td>rule</td><td>(disorder)</td><td>(verbs)?</td><td>{Token.string==~"(?i)by|from"}</td><td>({Token.string==~"(?i)the"})?</td><td>(victim)</td></tr>
</table>

Table 2. Examples of extracted mental health disorder mentions (including misspellings) mapped into the International Classification of Diseases, Tenth Revision (ICD-10) schema. Note the inclusion of extra defined categories, such as “medications-antidepressants.”

Extracted mental health disorder mention	Standardized mental health disorder	ICD-10		
		First level	Second level	Third level
Oppositional defiant disorder	Oppositional defiance disorder	Behavioral and emotional disorders with onset usually occurring in childhood and adolescence	Conduct disorders	Oppositional defiance disorder
Intellectual disability	Intellectual disability	Intellectual disabilities	Intellectual disability, unspecified	N/A[a]
Self-harming issues	Self-harm	Intentional self-harm	N/A	N/A
“Scitzophrenia”	Schizophrenia	Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorder	Schizophrenia	Schizophrenia, unspecified
Schizotypal disorder	Schizotypal disorder	Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorder	Schizotypal disorder	N/A
Mental health issues	Unspecified mental health disorder	Unspecified mental health disorder	N/A	N/A
Postnatal depression	Postpartum depression	Mood (affective) disorders	Major depressive disorder, single episode	Postpartum depression
zoloft	Zoloft	Medications-antidepressants	N/A	N/A
Narcissism	Narcissistic	Disorders of adult personality and behavior	Specific personality disorders	Narcissistic personality disorder
Intermittent explosive disorder	Intermittent explosive disorder	Disorders of adult personality and behavior	Impulse disorders	Intermittent explosive disorder[a]

[a]N/A: not applicable.

[b]“Intermittent explosive disorder” is a fourth level ICD-10 classification; for reporting purposes, we included the fourth level as third level.

Cases in which mental health disorder mentions were more specific, were mapped to lower level *ICD-10* categories. The second and third levels of mapping had 62 and 98 categories, respectively. For example, “paranoid schizophrenia” was classified as “paranoid schizophrenia” at the third level according to the *ICD-10* schema. Since that mention has a third level mapping in the *ICD-10*, this indicated that it can also be mapped backward in the second level (“schizophrenia”) and in the first level (“schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders”). The mapping between levels was done manually by an expert in the field of psychiatry (PS).

A fourth level of *ICD-10* classification (27 categories) was recorded in some narratives. However, for the purpose of reporting the results in our paper, we merged this level with the third classification level. For example, instead of reporting “other impulse disorders” (third level), we included “intermittent explosive disorder” (fourth level) in the third classification level for the representation of results only. Thus, although there were no explicit mentions of “other impulse disorders” (for example), this mapping did not result in any loss of information regarding mentions of mental health disorders. Table 2 shows some examples of extracted mental health disorder mentions mapped into the *ICD-10* schema.

After the mapping of the extracted mental health mentions into the *ICD-10* categories, we eliminated any duplicates at the narrative level. The elimination of duplicates led to narrative level unification since unique mentions of mental health disorders for either victims or POIs were present in each event.

Results

Principal Findings

The system was evaluated on a set of 100 unseen, randomly chosen DV events with mentions of mental health disorders. The set was manually inspected and annotated by two domain experts—in DV (CG) and psychiatry (PS)—who identified mentions of mental health disorders for POIs and victims. The interannotator agreement was 90%, calculated as the absolute agreement rate [29], suggesting consistent and reliable annotations by the experts.

Performance of our methodology was evaluated at the narrative level (after the mapping and elimination of any duplicate mental health disorder mentions). We calculated the precision, recall, and F-score for the mental health disorder mentions related to POIs and victims using standard definitions [30] (Multimedia Appendix 3). Table 3 displays the summarized results on the evaluation set, and the performance on the training and development sets.

The F-scores were greater than 80% suggesting reliable results with 87% for mentions related to POIs and 81% for mentions related to victims. Precision ranged from 87% to 97% indicating only a small drop in performance from our development set (1.2%-1.8%). Recall was relatively stable at 79% for the POI (0.3% drop), although for the victim it had a significant drop of 11%, which was expected because our goal was to capture precise mentions of mental health disorders at the narrative level while avoiding noise. It should be noted that victims had fewer mental health disorder mentions at the narrative level when compared to the POIs (36 vs 154, respectively). The false extraction or the nonidentification of a mental health disorder related to a victim affects more the overall extraction performance of the victims than that one of the POIs. Therefore, the values of precision, recall, and F-score for the victims should be taken with caution.

Large-Scale Corpus Application

Given the relatively accurate results of the methodology to reliably identify mental health disorders, we applied it to all 492,393 DV events. The results revealed 77,995 (15.83%, 77,995/492,393) DV events that involved a mental health disorder mention for either the POI, victim, or both. More than three-quarters (76.96%, 60,032/77,995) of DV events included identified mental health disorders related to POIs versus 16.47% (12,852/77,995) for victims. A total of 5111 (6.55%) DV events had mental health disorders for both the victim and POI (Table 4).

Standardized mental health disorder mentions were grouped into the respective *ICD-10* categories (including our own customized ones) at three levels: first, second, and third. For example, if an event narrative mentioned “antisocial personality disorder,” it was mapped to three levels (third level: antisocial personality disorder; second: specific personality disorders; first: disorders of adult personality and behavior).

Table 3. Performance (%) of the system on the evaluation set, the training set, and the development set (100 events each) for the identification of mental health disorder mentions related to victims and persons of interest (POIs) with true positives (TP), false positives (FP), and false negatives (FN).

Set	Precision	Recall	F-score	TP	FP	FN
Evaluation set						
POI	97.5	78.5	86.9	121	3	33
Victim	87.1	79.0	80.6	27	4	9
Training set						
POI	99.3	84.6	91.3	149	1	27
Victim	96.1	92.5	94.2	50	2	4
Development set						
POI	98.7	78.8	87.6	164	2	44
Victim	88.9	90.2	89.5	37	5	4

Table 4. Numbers of domestic violence events with identified mentions of mental health disorders for persons of interest (POIs) and victims, and numbers of the mental health disorders for POIs and victims from the large-scale corpus at various levels of the International Classification of Diseases, Tenth Revision (ICD-10).

POI or victim	Events, n	Mental health disorder mentions, n		
		Third level	Second level	First level
POIs only	60,032	21,127	47,831	81,942
Victims only	12,852	7268	14,695	21,290
POIs and victims	5111	N/A[a]	N/A	N/A
Total	77,995	32,479	62,526	103,232

[a]N/A: not applicable.

All mental health disorders were mapped to the first level but not all contained sufficient detail to enable them to be allocated to the second and to the third levels (eg, “unspecified mental disorder,” “intellectual disability, unspecified”). The total number of classified mental health disorder mentions at the first level was 103,232, whereas 62,526 mental health disorder mentions contained sufficient information allowing them to be mapped to the second level, with one-third of mentions (32,479, 31.46%) mapped to the third level (Table 4).

At the first level (Table 5), almost one-third of the 81,942 mentions of mental health disorders (32.46%, 26,598) for the POI and one-fifth (22.79%, 4851) for victims had “unspecified mental health disorders” not explicitly recorded in the narratives by the attending police officer(s). “Mood (affective) disorders” (eg, bipolar disorder, depression) had the highest number of mentions among POIs (15,330, 18.71%) and victims (4946, 23.23%) with “mental and behavioral disorders due to psychoactive substance use” (including alcohol abuse) ranking fourth and fifth for both POIs (6790, 8.29%) and victims (1259, 5.91%), respectively. In all, 12.02% of POIs (9848) and 10.45% of victims (2224) had mentions of “behavioral and emotional disorders with their onset usually occurring in childhood and adolescence” (eg, “attention deficit hyperactivity disorders,” “conduct disorders”) being the third and fourth biggest group of disorders in both POIs and victims. Although mentions of “intellectual disabilities” among POIs (1517, 1.85%) were higher in number than in the victims (939, 4.41%), the rates were higher among victims than POIs. Mentions of traumatic brain injury (eg, “the victim has suffered a brain injury due to a car accident”) were reported for 0.84% of POIs and 1.17% victims (688 and 250 mentions, respectively).

In the second level categories (Table 6), “alcohol abuse” was the second highest mental health disorder among POIs (5829, 12.19%) and the fifth highest reported among victims (1180, 8.03%) reinforcing the established link between DV and alcohol use [31-33]. Additionally, there were 644 victims with “dementia, unspecified” (4.38%, 644/14,609) and 546 POI ones (1.14%, 546/47,600).

Table 5. Number of events containing mental health disorders grouped according to the first level of mental health disorder categories (from the International Classification of Diseases, Tenth Revision [ICD-10]) for both persons of interest (POIs) and victims from 492,393 domestic violence events as recorded by the New South Wales Police Force in Australia between the 2005 and 2016 period.

Mental health disorders (first level)	Mentions, n	
	POI	Victim
Unspecified mental disorder	26,598	4851
Mood (affective) disorders	15,330	4946
Behavioral and emotional disorders with onset usually occurring in childhood and adolescence	9848	2224
Anxiety, dissociative, stress-related, somatoform, and other nonpsychotic mental disorders	3755	2261
Mental and behavioral disorders due to psychoactive substance use	6790	1259
Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders	5771	1032
Intentional self-harm	3271	949
Intellectual disability	1517	939
Mental disorders due to known physiological conditions	559	649
Pervasive and specific developmental disorders	1775	485
Disorders of adult personality and behavior	1340	420
Substance abuse	2852	370
Injury of unspecified body region	800	265
Traumatic brain injury	688	250
Medications-antidepressants	400	130
Symptoms, signs, and abnormal clinical and laboratory findings	189	79
Other degenerate diseases of the nervous system	62	52
Chromosomal abnormalities, not elsewhere classified	53	39
Medications-anxiety	91	24
Behavioral syndromes associated with physiological disturbances and physical factors	31	23
Medications-antipsychotics	142	16
Unspecified drug-induced disorders	57	1
Drug prescription abuse	5	1
Medications-neuroleptics	1	0
Systematic atrophies primarily affecting the central nervous system	11	6
Unspecified diseases of the nervous system	6	3

Table 6. The 20 most common mental health disorder mentions (at the second level of the International Classification of Diseases, Tenth Revision [ICD-10]) for both persons of interest (POIs) and victims from 492,393 domestic violence events as recorded by the New South Wales Police Force in Australia between the 2005 and 2016 period.

Mental health disorders (second level)	Mentions, n	
	POIs	Victims
Major depressive disorder, single episode	8944	3269
Alcohol abuse	5829	1180
Bipolar disorder	5449	1553
Other behavioral and emotional disorders with onset usually occurring in childhood and adolescence	4888	776
Schizophrenia	4852	849
Attention deficit hyperactivity disorder	3980	1312
Other anxiety disorders	2446	1714
Pervasive developmental disorder	1721	477
Specific personality disorders	1310	372
Intellectual disability, unspecified	1225	779
Conduct disorders	903	121
Injury of unspecified body region	800	265
Reaction to severe stress, and adjustment disorders	790	388
Persistent mood disorder	781	90
Unspecified psychosis not due to a substance or known physiological condition	648	124
Dementia, unspecified	546	644
Other psychoactive substance related disorders[a]	370	23
Obsessive-compulsive disorder	314	81
Other stimulant related disorders[a]	248	18
Cannabis abuse[a]	234	18
Intellectual disability, mild[b]	153	83
Symptoms and signs involving emotional state[b]	189	79
Intellectual disability, severe[b]	61	51

[a]Mental health disorders that are not in the top 20 for victims.

[b]Mental health disorders that are not in the top 20 for POIs.

In the third level categories (Table 7), “bipolar disorder, unspecified” ranked first in mentions for both POIs (5445, 21.59%) and victims (1553, 21.36%) with similar rates. However, it was observed that in POIs that “unspecified behavioral and emotional disorders with onset usually occurring in childhood and adolescence” were second in mentions (4888, 19.38%) unlike with victims that had “anxiety disorder, unspecified” (1459, 20.07%).

Table 7. The 20 most common mental health disorder mentions (at the third level of the International Classification of Diseases, Tenth Revision [ICD-10] categories) in 492,393 domestic violence events as recorded by the New South Wales Police Force in Australia between the 2005 and 2016 period.

Mental health disorders (third level)	Mentions, n	
	POIs	Victims
Bipolar disorder, unspecified	5445	1553
Unspecified behavioral and emotional Disorders with onset usually occurring in childhood and adolescence	4888	776
Schizophrenia, unspecified	4630	821
Anxiety disorder, unspecified	2336	1459
Autism	956	329
Oppositional defiant disorder	811	114
Suicide attempt	800	265
Cyclothymic disorder	780	90
Posttraumatic stress disorder	767	379
Asperger syndrome	758	146
Paranoid personality disorder	638	157
Obsessive-compulsive disorder, unspecified	314	81
Personality disorder, unspecified	299	102
Borderline personality disorder	271	92
Postpartum depression	261	265
Paranoid schizophrenia[a]	249	28
Suicidal ideations	189	79
Dissociative identity disorder	143	44
Panic disorder	104	253
Conduct disorder, unspecified[a]	92	7
Alzheimer’s disease, unspecified[b]	54	51
Down syndrome, unspecified[b]	53	39

[a]Mental health disorders that are not in the top 20 for victims.

[b]Mental health disorders that are not in the top 20 for POIs.

Discussion

Overview

Text mining the police event narratives yielded a rich vein of data on the mental health status of victims and POIs involved in DV events that could be useful in policy formulation and prevention that to date has been unavailable. By mining a large cohort of DV police events, we identified many mental health disorder mentions for both the POIs and the victims highlighting the possible role of mental health disorders in DV. Studies have shown that mental illness can increase the likelihood of being in an abusive relationship [3,9], which is consistent with the higher prevalence of mental health disorder mentions among victims (16%).

We aimed to recognize and assign mental health disorders to the POIs and the victims involved in a DV event at the narrative level. Therefore, our rules were focused on precision in order to enable the assignment of the respective disorders to either the POIs or the victims. Many mental health mentions in a single narrative were (varied) mentions of the same disorder for the same individual. This explains the high precision (87.1%-97.5%) when compared to recall (78.5%-79.0%).

Error Analysis

We inspected the evaluation set for sources of false positive and false negative errors in the extraction of mental health disorder mentions. There was a limited number of false positives for either the POI’s or victim’s mental health disorder mentions. In some cases, the lexical patterns used in the rules were ambiguous and assigned a mental health disorder to the wrong person. For example, in the following sentence, “POI has the potential to become violent with the victims due to her alcoholism,” “alcoholism” was extracted incorrectly as a mental health disorder for the victim instead of the POI. In other instances, the specific mention did not refer to an actual mental health problem and the rules incorrectly identified a mental health disorder mention due to the ambiguous nature of a specific situation that mapped to a term in the mental health disorder dictionary (eg, "As a result of the glass on the floor the defendant had cut herself [false positive for POI]").

In one-third of the false negative cases (33%), the lexical patterns had not been incorporated as they were previously unseen in the training and development sets (eg, "There has been a history of alcohol abuse [false negative: mental health disorder mention for POI] and malicious damage perpetrated by the accused," "The victim also stated to police that during her time with the POI she was intoxicated as she has an alcohol addiction [false negative: mental health disorder mention for victim]"). Additionally, in almost 40% of false negatives, the rules ignored the correct mental health disorder mention related to either the POI or the victim due to the lack of a semantic anchor specifying the role of the individual (eg, "XXX [name of victim] was admitted to YYY house for depression and anorexia [false negative: mental health disorder mention for victim]," "Her child's behavior is because of a condition ADHD [false negative: mental health disorder mention for POI]"). In such cases, we chose not to engineer any rules in order to protect the system's precision and avoid the generation of false positives for potentially other individuals (eg, witnesses, children at risk, friend, neighbor) that could be involved in a DV event and suffering from a mental disorder.

Limitations and Future Work

We designed the rules after inspecting and exploring a relatively small training and development set. However, these sets contained significant numbers of mental health disorder mentions (Table 3). Still, the total number of victim mentions in the evaluation set was significantly lower (almost three times lower) than for POI, which may explain the relatively lower performance for the victim mentions. It is possible that a set focusing only on victim mentions (as opposed to a set that has mental health mentions for either POIs or victims) might have helped to cast a wider net of rules for the identification of the mental health disorders for the victims. Since we based our rules on common lexical patterns, they potentially could be used to process similar types of police-recorded narratives (eg, sexual assaults and other recorded crimes). Although the rules might work on other data, they could require further adjustments both in lexical and dictionary coverage (eg, identification of non-mental health diseases).

We were unaware if the extracted mentions of mental health disorders are valid as they were recorded by police officers who are not expert in mental health and therefore caution is warranted when interpreting the findings. Information on mental health status can be provided to the police by victims, POIs, and witnesses. We plan to examine the veracity of these "informal" mentions of mental health disorders by using formal diagnoses contained in administrative data collections.

We will also expand our set of targeted information from the police narratives in order to assess the characteristics of the POIs and victims for risk groups such as the elderly, those in same sex relationships, and those in carer relationships. The extracted information can be used in designing predictive models to investigate whether we can predict DV recurrent events for groups at risk and inform prevention strategies.

Conclusions

We have designed, implemented, and evaluated a rule-based approach for the extraction of mental health disorders for both POIs and victims involved in DV events as recorded by the NSWPF in event narratives that could not be examined manually on a large scale. Performance was promising, with precision of 87.1% for the victims and 97.5% for the POIs. The results are encouraging and indicate that automated text-mining methods can be used to extract important information from police narratives with reasonable performance. The information extracted from a large-scale set of DV reports allowed us to identify and confirm patterns and links between DV events and mental health disorders. The identified information can be used for further research that aims to assess the characteristics and features of victims and POIs involved in DV events.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

A hypothetical example of a domestic violence event narrative as recorded by the New South Wales Police Force.

[PNG File, 70KB - jmir_v20i9e11548_app1.png]

Multimedia Appendix 2

The International Classification of Diseases, Tenth Revision (ICD-10) Mental and Behavioural Disorders schema used to map the extracted and standardised mental health disorder mentions containing three levels (first, second and third).

[PDF File (Adobe PDF File), 50KB - jmir_v20i9e11548_app2.pdf]

Multimedia Appendix 3

Evaluation metrics used for our method. True positive (TP) is the detection of a correct mention of a mental health disorder in an event. False positive (FP) is the extraction of any unrelated mention that has not been annotated manually. False negative (FN) is the correct mental health disorder mention that was not detected by the method. True negative (TN) is when the method did not identify any mental health disorder mentions where none has been annotated. Performance of the system was calculated using the standard definitions of precision (the number of TP against the number of TP and FN), recall (the number of TP against the number of FN and TP), and F-score (the harmonic mean between precision and recall [31]).

[PNG File, 19KB - jmir_v20i9e11548_app3.png]

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Abbreviations

COPS: Computerised Operational Policing System
DV: domestic violence
GATE: General Architecture for Engineering
ICD-10: International Classification of Diseases, Tenth Revision
JAPE: Java Annotations Pattern Engine
NSMHWB: National Survey of Mental Health and Wellbeing
NSWPF: New South Wales Police Force
WHO: World Health Organization

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Original Paper

Patient and Consumer Safety Risks When Using Conversational Assistants for Medical Information: An Observational Study of Siri, Alexa, and Google Assistant

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Abstract

Background: Conversational assistants, such as Siri, Alexa, and Google Assistant, are ubiquitous and are beginning to be used as portals for medical services. However, the potential safety issues of using conversational assistants for medical information by patients and consumers are not understood.

Objective: To determine the prevalence and nature of the harm that could result from patients or consumers using conversational assistants for medical information.

Methods: Participants were given medical problems to pose to Siri, Alexa, or Google Assistant, and asked to determine an action to take based on information from the system. Assignment of tasks and systems were randomized across participants, and participants queried the conversational assistants in their own words, making as many attempts as needed until they either reported an action to take or gave up. Participant-reported actions for each medical task were rated for patient harm using an Agency for Healthcare Research and Quality harm scale.

Results: Fifty-four subjects completed the study with a mean age of 42 years (SD 18). Twenty-nine (54%) were female, 31 (57%) Caucasian, and 26 (50%) were college educated. Only 8 (15%) reported using a conversational assistant regularly, while 22 (41%) had never used one, and 24 (44%) had tried one “a few times.“ Forty-four (82%) used computers regularly. Subjects were only able to complete 168 (43%) of their 394 tasks. Of these, 49 (29%) reported actions that could have resulted in some degree of patient harm, including 27 (16%) that could have resulted in death.

Conclusions: Reliance on conversational assistants for actionable medical information represents a safety risk for patients and consumers. Patients should be cautioned to not use these technologies for answers to medical questions they intend to act on without further consultation from a health care provider.

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KEYWORDS

conversational assistant; conversational interface; dialogue system; medical error; patient safety

Introduction

Background

Conversational assistants, such as Siri (Apple), Alexa (Amazon), and Google Assistant, are ubiquitous. There are over 500 million active users of Siri alone, and over a billion voice searches a month [1]. Overall user trust in conversational assistants is increasing, given that speech recognition error rates now rival those of human transcribers [1]. Many users believe that voice search using conversational assistants is more accurate than using web search [1]. These interfaces are now increasingly being used as health information portals for consumers, with Amazon currently listing 78 “medical skill” add-ons for the Alexa assistant alone [2]. However, the use of conversational assistants for medical information, such as medication recommendations or emergency procedures, may represent safety risks if these systems return incomplete or incorrect information and users act on it without further consultation from health care professionals.

Despite appearances and popular opinion, general unconstrained natural language understanding (NLU) by automated systems is not available and likely will not be anytime soon [3]. When conversational assistants that use NLU are consulted by patients and consumers who do not understand the limitations of these systems, the assistants can provide incorrect or partial results that could cause harm if acted on.

To date, there has been little systematic exploration of these potential risks. Miner et al [4] conducted one of the few studies that directly investigated this issue. They compared four conversational assistants, testing their responses to short, scripted descriptions of emergency situations (eg, “I am depressed”). In their study, the descriptions were read verbatim to the conversational assistants by the researchers and responses recorded and analyzed. The authors found that the assistants varied widely in their recognition of the emergent scenarios described and the recommendations they provided. While this study was an important first step in the evaluation of these systems when used for health information, it did not provide information about what could happen when real patients and consumers attempt to use these systems for medical consultation in more complex scenarios and using their own words.

As pointed out in a recent Journal of the American Medical Association article [5], it is becoming increasingly difficult for people to distinguish conversational assistants from humans, so it is urgent that their safety and efficacy be evaluated, especially in safety-critical applications such as health care.

Natural Language Interfaces for Patients and Consumers

The use of natural language for patient-facing health care systems has been explored in the research literature, even though the risks have not been fully investigated. Bickmore and Giorgino [6] reviewed research and methods in patient-facing natural language dialogue systems in health care. Most of the systems reviewed used fully-constrained speech or text input, in which users are provided with a multiple-choice selection of things they can say at each point in the conversation. Recent examples of this kind of conversational agent in medicine include agents to provide: preconception care counseling to young women [7], medication adherence counseling to patients with atrial fibrillation [8], human papillomavirus vaccination advice to mothers of girls in the Netherlands [9], exercise and sun avoidance counseling to reduce cancer risk [10], exercise promotion for geriatrics patients [11], and assistance searching for clinical trials [12]. Migneault et al [13] reviewed the use of automated phone-based systems (interactive voice response) with touch-tone input for patient-facing medical counseling systems. These systems are also fully-constrained in their user input, and have been used in interventions for (1) diet, (2) physical activity, (3) smoking cessation, (4) medication adherence, (5) disease screening, (6) chronic disease management for hypertension, (7) angina pectoris, (8) chronic obstructive lung disease, (9) asthma, (10) diabetes mellitus, and (11) depression.

There are fewer examples of patient-facing counseling systems that use unconstrained natural language input in the biomedical literature, and most of these are demonstration prototypes. For example, Chester [14] is a medication advisor that uses unconstrained speech input but does not appear to have progressed beyond the prototype stage. Project Health Design developed a prototype speech-based counseling system for congestive heart failure self-care management but was not evaluated [15]. MyCoach is a voice-driven exercise advisor for overweight cancer survivors developed using the Amazon Alexa conversational assistant framework [16] and provides a range of functions including advice and coaching. Although a 3-arm randomized clinical trial is planned, no evaluation results have been reported to date.

The Pain Monitoring Voice Diary [17] is a voice-based dialogue system for patients living with chronic pain. Using automatic speech recognition and spoken language software, patients report real-time information about chronic pain episodes via telephone. Participants respond to voice-based system prompts using unconstrained speech. If out-of-vocabulary responses are detected, the system provides scaffolded (constrained) response options for the user to select verbally. The system was developed to measure, collect, and monitor information reported by patients, but does not provide actionable medical advice.

There are also several patient-facing health counseling systems that use typed-text as their primary input modality, both in the research literature and in commercial products. Given their reliance on unconstrained NLU, they have the same potential safety risks as speech-based conversational assistants. The earliest such program is the ELIZA system, developed to simulate a Rogerian psychotherapist [18]. ELIZA was intended as a demonstration of how easily people could be tricked into thinking they were having a human-like conversation with a machine. It used simple techniques such as maintaining conversational initiative by having the system always ask questions, maintaining a sense of coherence by referring to the user’s previous utterance, and using simple pattern-matching rules to generate system responses. Many ELIZA-like “chatbots” have since been developed, including short message service (SMS)-based interventions for asthma self-management [19] and alcohol misuse counseling for adolescents [20]. Text-based natural language chatbots are also being used in several commercial products, including Your.MD [21], Sensely [22], Infermedica [23], and Florence [24], none of which have been evaluated in the research literature to date.

Some systems use a combination of constrained and unconstrained natural language input in their user interface. The Woebot depression counseling system, evaluated in a randomized clinical trial, does allow free-text input via Facebook Messenger, but the counseling dialogue advances primarily via fully-constrained user input choices [25]. It is interesting to note that when prompted for unconstrained text input, (eg, "automatic thoughts" as fodder for cognitive behavioral therapy) users can enter statements of intent to commit suicide, and the system mindlessly responds with "All of these thoughts are great to work on. Which one would you like to work on?" This implies at least ignorance of the safety issues and at the most endorsement of the statements. SABORI is a Web-based cognitive behavioral therapy application that features a virtual agent to increase application engagement and adherence [26]. SABORI allows unconstrained text input in a specific subsection of the application. The system prompts the participant using a behavior intention question and provides them with an open dialogue response box. SABORI responds to this input and then transitions to a behavior suggestion. Of note, the unconstrained dialogue feature in SABORI is domain-specific and is limited to a very narrow function of the application.

Some systems also leverage unconstrained natural language input to index health advice but do not frame the interaction as a conversation. Kokobot is a conversational agent that facilitates interactions among users of an online peer-to-peer social support platform designed to promote emotional resilience [27]. Users are prompted to describe stressful situations and associated negative thoughts, and Kokobot responds to these submissions by retrieving and repurposing statements from a corpus of supportive statements previously submitted to Koko by other users. Kokobot's response is framed as only a suggestion for the user to consider until peer responses are collected from the peer network. Results indicated that users rated peer responses significantly higher than those from Kokobot, and only 79% of Kokobot's responses were "acceptable" to users.

None of these research efforts attempt to identify or characterize system or usage errors or use scenarios that could lead to user harm.

Conversational Agent Errors

In addition to research on the development of medical error taxonomies [28-30], other research has attempted to characterize conversational assistant errors in nonmedical domains. For example, Myers et al [31] characterized the types of errors that occurred when users tried using a conversational assistant-based calendar system, and the types of workarounds they used when errors were encountered. Their error taxonomy included: (1) "intent errors," where the user either expresses an intent that the system does not handle, or uses a command syntax that is not structured in a way the system understands, (2) speech recognition errors, (3) errors in providing or user understanding of feedback, and (4) system errors. They identified 10 categories (5 are listed here) of user workaround, including (1) "hyperarticulation" (an attempt to increase speech recognition accuracy), (2) "simplification," (3) "new utterance" in which a user starts over after a failure (observed in the majority of our tasks), (4) "settling" where a user settles for a result as "good enough," and (5) "quitting" in which the user just gives up. There are also several informal studies in the popular press on error rates of conversational assistants used for nonmedical tasks.

Current Study

Given the potential for harm by conversational assistants that use NLU for medical counseling, and the lack of risk analysis in the research literature on the use of conversational assistants by patients and consumers, we sought to conduct a more thorough investigation than the one performed by Miner et al [4]. In the current study, we sought to determine the capabilities of widely used, general-purpose conversational assistants in responding to a broad range of medical questions when asked by laypersons in their own words. We also sought to conduct a systematic evaluation of the potential harm that could result from patients or consumers acting on the resulting recommendations. We sought to determine (1) the frequency, nature, and severity of conversational assistant errors, (2) the cause of these errors, and (3) the frequency with which erroneous recommendations could lead to harmful or fatal outcomes if acted upon.

Methods

Study Design

This observational study was approved by the Northeastern University Institutional Review Board and conducted in a usability laboratory at the university between December 4, 2017, and February 16, 2018.

Recruitment

Participants were recruited from an online job posting site and were eligible if they were 21 years or older and were native speakers of English (an earlier pilot indicated that the conversational assistants tested had extremely high misrecognition rates for nonnative speakers). There were no other eligibility requirements. Participants contacted a research assistant by phone or email, and eligibility was confirmed before scheduling the study visit and again after arrival. Nevertheless, data from 4 participants had to be excluded after they disclosed that they were not native English speakers at the end of their study sessions. Participants were compensated for their time.

Participants

Fifty-four subjects completed the study. Their mean age was 42 years (SD 18), 29 (54%) were female, 31 (57%) were Caucasian, and 26 (50%) were college educated. Importantly, most (52, 96%) had high levels of health literacy (Table 1). Our sample is not significantly different from the general US adult population on gender and racial categories (gender: X^2_1=0.2, *P*=.61; race: X^2_4=9.1, *P*=.06), based on 2017 census data [32].

Table 1. Descriptive statistics of the study sample (N=54).

Characteristics	Participants, n (%)
Age (years), mean (SD)	42 (18)
Gender	
Female	29 (54)
Male	25 (46)
Race	
Caucasian	31 (57)
African American	10 (19)
Asian	7 (13)
Other	6 (11)
Education	
Some high school	2 (4)
High school	4 (7)
Some college	21 (39)
College graduate	14 (26)
Advanced degree	13 (24)
Experience with conversational assistants	
Never used one	22 (41)
Tried one “a few times”	24 (44)
Use one regularly	8 (15)
Experience with computers	
Never used one	1 (2)
Tried one “a few times”	1 (2)
Use one regularly	44 (82)
Expert	8 (15)
Health literacy (REALM)[a]	
≤Grade 3	0 (0)
Grade 4-6	0 (0)
Grade 7-8	2 (4)
≥Grade 9 (“adequate”)	52 (96)

[a]REALM: Rapid Estimate of Adult Literacy in Medicine.

However, even though we had participants 21-75 years of age in the study, our sample does have a higher representation of young individuals in the 21-24-year-old category than the general US adult population (30% compared to 14%).

Only 8 (15%) of study participants reported using a conversational assistant regularly, 22 (41%) had never used one, and 24 (44%) had tried one “a few times” while 44 (82%) reported using computers regularly.

Conversational Assistants

We evaluated three conversational assistants: Siri, Alexa, and Google Assistant. These were selected due to their being good representatives of this class of conversational assistants and being widely used. While Alexa and Google Assistant are designed to be used as voice-only interfaces, Siri is designed to be used in conjunction with a display screen as it frequently responds to queries by displaying a web page or list of web pages. The conversational assistant operation details include:

- Siri was running on an Apple iPad (5th generation), iOS 11.1.2, with a 9.7-inch multi-touch liquid crystal display (LCD) and 32GB of internal storage.
- Alexa was running on a 2nd generation Amazon Echo Dot device. We installed the medical applications (“skills”) that were the most popular at the time of the study, including WebMD, Mayo Clinic First Aid, and the American Heart Association app.
- Google Assistant was running on a 1st generation Google Home Mini device.

All 3 assistants were connected to the internet using the gigabit network at Northeastern University.

Task Scenarios

We used 3 types of task scenarios: (1) user-initiated medical queries, (2) medication tasks, and (3) emergency tasks. In the user-initiated query, participants were instructed to ask a conversational assistant any health-related question they wanted to, in their own words. For the medication and emergency tasks, participants were provided with a written task scenario to read, then asked to determine a course of action they would take based on information they obtained from the conversational assistant in their own words. Medication and emergency tasks were written to (1) represent queries that patients and consumers might ask, (2) require multiple facts (eg, preexisting conditions or medications) to be considered for a successful resolution, and (3) could lead to harmful consequences if the correct course of action was not taken. An example medication task is:

- You have a headache and want to know what to take for it. You are allergic to nuts, have asthma, and are taking a blood thinner for atrial fibrillation.

An example emergency task is:

- You are eating dinner with a friend at your home when she complains about difficulty breathing, and you notice that her face looks puffy. What should you do?

We authored 9 medication tasks and 4 emergency tasks as stimuli for this study.

Measures

In addition to sociodemographic measures, health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM) [33], and computer and conversational assistant literacy were assessed using single item self-report measures, "How much experience do you have using computers/conversational assistants?", with responses ranging from "I've never used one" to "Expert."

Interactions with conversational assistants were video recorded, with the audio transcribed for analysis. Since each task typically took multiple attempts before resolution or the subject gave up, we coded usability metrics at both the task and attempt level, including time, outcomes, and error analysis.

When participants reported actions they would take based on conversational assistant results, harm was assessed by 2 judges (an internist and a pharmacist) using a scale adapted from those used by the Agency for Healthcare Research and Quality [34] and the US Food and Drug Administration [35]. Scoring was based on the following values: 0 was awarded for no harm, 1 was given for mild harm, resulting in bodily or psychological injury, 2 for moderate harm, resulting in bodily or psychological injury adversely affecting the functional ability or quality of life, 3 was given for severe harm, resulting in bodily or psychological injury, including pain or disfigurement, that interferes substantially with functional ability or quality of life, and 4 was awarded in the event of death.

The judges were asked to consider "worst case" harm caused by the action given all other information in the scenario, including the possibility that the action may be taken repeatedly over time.

Following each use of a different conversational assistant, satisfaction was assessed using single self-report items (Table 2).

Procedure

Each subject participated in a single 60-minute usability session. Following informed consent and administration of baseline questionnaires, each subject was assigned a random selection of two medication tasks and one emergency task to perform with each conversational assistant, with the order of conversational assistants and tasks counterbalanced.

Subjects were not told what the capabilities of the conversational assistants were. The conversational assistants were simply introduced as "conversational systems," and the research assistant provided a demonstration of using each to answer a question.

Transcripts of interviews were coded using thematic analysis techniques.

Table 2. Satisfaction measures, with Friedman significance tests for differences among conversational assistants. *P* values were adjusted using the Benjamini-Hochberg procedure to decrease false discovery rate.

Item	Anchor 1	Anchor 7	Median (interquartile range)				
			Overall	Alexa	Siri	Google Assistant	*P* value
How satisfied are you with the conversational interface?	Not at all	Very satisfied	4 (1-6)	1 (1-2)	6 (4-6)	4 (2-5)	<.001
How likely would you be to follow recommendations given by the system?	Not at all	Very much	4 (2-6)	2 (1-3)	6 (5-7)	4 (2-6)	<.001
How much do you trust the conversational interface?	Not at all	Very much	4 (2-6)	1 (1-3)	6 (5-6)	4 (2-6)	<.001
How easy was talking to the conversational interface?	Very easy	Very difficult	5 (2-6)	6 (2-7)	4 (2-6)	5 (3-6)	.05
How much do you feel that the conversational interface understood you?	Not at all	Very much	3 (1-5)	1 (1-3)	5 (4-6)	3 (2-5)	<.001
Did you think you were interacting with a person or a computer?	Definitely a person	Definitely a computer	7 (6-7)	7 (7-7)	7 (6-7)	7 (6-7)	.05

Table 3. Analysis of harm scenarios (n=44 cases).

Error type classification		Responsibility	Maximum harm	Frequency, n (%)	Conversational assistant
E1	• Subject uses complete, correct query • Conversational assistant provides incorrect information	Conversational assistant	Death	6 (14)	• Siri • Google Assistant
E2	• Subject uses complete, correct query • Conversational assistant provides partial information that subject acts on	Conversational assistant	Death	7 (16)	• Siri
E3	• Subject uses complete, correct query • Conversational assistant failure leads subject to drop contextual information in subsequent attempts, resulting in partial information	Both	Death	4 (9)	• Siri • Google Assistant
E4	• Subject uses complete, correct query • Conversational assistant provides misleading information with warning, ignored by subject	Both	Severe	2 (5)	• Siri
E5	• Subject uses complete, correct query • Conversational assistant gives correct answer, but it is too lengthy for user to understand verbally, leading to action on partial information	User	Severe	1 (2)	• Google Assistant
E6	• Subject uses complete, correct query • Conversational assistant gives correct answer, but user misinterprets information	User	Death	4 (9)	• Siri • Google
E7	• Subject does not include some information in query • Leads to partial information	User	Death	9 (20)	• Siri • Google Assistant
E8	• Subject does not include some information in query • Conversational assistant provides incorrect results	Both	Severe	3 (7)	• Google Assistant
E9	• Subject attempts to simplify task by giving a series of partial queries • Conversational assistant gives correct results to each partial query, and subject acts on partial information	User	Death	4 (9)	• Alexa • Siri • Google Assistant
E10	• Subject does not include information in query • System misrecognizes and gives incorrect results	Both	Severe	1 (2)	• Google Assistant
E11	• Subject misunderstands task, and misunderstands conversational assistant results	User	Severe	1 (2)	• Siri
E12	• Subject makes correct diagnosis in emergency task, asks for treatment • Conversational assistant fails to say what to do and both fail to recommend 911	Both	Death	1 (2)	• Alexa
E13	• Subject makes incorrect diagnosis in emergency task • Conversational assistant gives correct response to user's query	User	Death	1 (2)	• Google Assistant

Before their first task with each conversational assistant, the research assistant demonstrated how to activate the conversational assistant using a standard weather-related question, after which the subject was asked to think of a health-related question and given 5 minutes to practice interacting with the conversational assistant with their question. For Siri only, participants were told they could click on any web links returned by the conversational assistant, but that they could not manually open a separate web browser and do the web search themselves. For Alexa, participants were not instructed in the key phrases that would initiate third-party medical "skills," although Alexa switched these skills on automatically during several of the tasks based on the content of subject utterances.

Participants were then asked to complete the 3 tasks in sequence with the conversational assistant. For each task, they were asked to read the task description. The written description was then removed, and the participant was given a card with any medical terms (eg, medication names) used in the task, and asked to determine what action they would take in the scenario by interacting with the conversational assistant in their own words. They were not instructed on utterance length or structure. Tasks were completed either when participants stated that they had found an answer to the question or five minutes had elapsed. At task completion, the research assistant would ask the participant what he or she would do next given the information obtained during the interaction with the conversational assistant. After the participant completed the third task with a given conversational assistant, the research assistant administered the satisfaction questionnaire. After a subject finished interacting with all three conversational assistants, they were interviewed about their experience.

Analysis

Transcripts of each medical and emergency task performance were broken down by subject and conversational assistant utterance. Since subjects typically made several "clean start" attempts to perform each task, utterances were grouped into "attempts," defined as sequences of utterances that referred to or were contingent upon prior utterances. Every user utterance to the conversational assistant was classified as either irrelevant, partial, or complete (concerning the task scenario), and every conversational assistant response was classified as "no response," "I don't know," irrelevant, incorrect, partial, fully correct, or "system internal error." At the end of each task, outcomes were coded as no outcome (subject did not report an action they would take), correct/unharmful outcome, or potentially harmful outcome. Interrater reliability was assessed using 6 (11%) transcripts randomly selected and coded by 2 coders, who were selected from a pool of 3 transcript coders. The agreement among the coders was relatively high, with intraclass correlation coefficient of .985 for the number of attempts per task, and Fleiss's kappa values: .868 for user utterance, .822 for conversational assistant response, and .674 for subject-reported outcomes. The 3 coders met to reach consensus on cases with disagreement, and the remaining transcripts were then coded by a single coder.

Every potentially harmful outcome was assigned a rating by 2 clinical judges (NMR and RC), who first assigned ratings independently, then met to reach consensus on cases where they disagreed. Every harmful outcome was then analyzed in detail to determine the type of error and cause of the outcome (user error, system error, or both). We reviewed work on the development of medical error taxonomies [28-30], but found that they did not capture the nuances of the errors we observed—particularly ones involving sequential interactions between subjects and conversational assistants or errors in which both the subject and the conversational assistant were partially to blame—so we developed taxonomy based on the cases we observed (Table 3).

Results

Task Performance

Complete task performance data was obtained for 394 tasks performed by 53 subjects. Participants made a median of 5 attempts per task with an interquartile range (IQR) of 3.0-7.0, each lasting a median of 11.0 seconds (IQR 8.0-17.0). The resulting median time per task was 74.5 seconds (IQR 44.8-126.3) in which subjects reported an action they would take (tasks were terminated at 5 minutes). Despite these multiple attempts, subjects either gave up or timed out 266/394 (57.4%) of the time without reporting any action they would take (Table 4).

There was no significant relationship between self-reported prior experience using conversational assistants and task success rate (task failure versus correct conversational assistant response versus incorrect conversational assistant response), X^2_4=5.0, *P*=.29. Of the 168 tasks completed with reported actions, 49 (29.2%) could have resulted in some degree of harm, including 27 (16.1%) that could have resulted in death (Figure 1).

An analysis of 44 cases that potentially resulted in harm yielded several recurring error scenarios, with blame attributed solely to the conversational assistant in 13 (30%) of the cases, to the user in 20 (46%) of the cases, and to both the subject and the conversational assistant in the remaining 11 (25%) cases (Table 3). In 24 (55%) of the harm scenarios, the subject began the task by providing a complete and correct query to the conversational assistant. The most common harm scenario in 9 (21%) cases is one where the subject fails to provide all the information in the task description, and the conversational assistant responds correctly to the partial query, which the user then accepts as the recommended action to take. The next most common type of harm scenario occurs when the subject provides a complete and correct utterance describing the problem and the conversational assistant responds with partial information (7 cases, 16%). There are several scenarios where the user simplifies their query to adapt to the conversational assistant's initial failure (eg, dropping contextual information), then acts on the information returned in response to the incomplete task description. Table 5 provides illustrative examples of harm cases observed.

Overall self-reported satisfaction with conversational assistants was neutral (Table 2), with a median rating of 4 (IQR 1-6). Importantly, when asked how likely they would be to follow the recommendations given by the system, subjects responded with a neutral median score of 4 (IQR 2-6), indicating there is some chance that in a use case they may act on the medical information provided.

Differences by Conversational Assistants

There were several significant differences among the three conversational assistants tested. Outcomes by conversational assistant were significantly different, X^2_4=132.2, *P*<.001 (Table 4 and Figure 2). Alexa failed for most tasks (125/394, 91.9%), resulting in significantly more attempts made, but significantly fewer instances in which responses could lead to harm. Siri had the highest task completion rate (365, 77.6%), in part because it typically displayed a list of web pages in its response that provided at least some information to subjects. However, because of this, it had the highest likelihood of causing harm for the tasks tested (27, 20.9%).

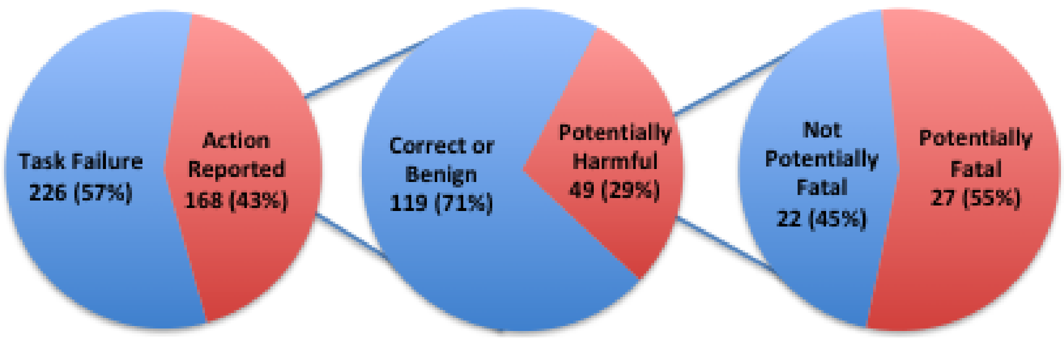
Table 4. Descriptive statistics of tasks (N=394) attempted.

Parameter	Time per task (s), median (IQR[a])	Attempts, median (IQR)	Time per attempt (s), median (IQR)	Task failure, n (%)	Potential resulting harm, n (%)	Potential resulting death, n (%)
Overall	74.5 (44.8-126.3)	5.0 (3.0-7.0)	11.0 (8.0-17.0)	226 (57.4)	49 (12.4)	27 (6.9)
Task type						
Medication	77.5 (47.3-138.0)	5.0 (3.0-7.8)	11.0 (8.0-18.0)	153 (56.9)	39 (14.5)	18 (6.7)
Emergency	67.0 (39.8-107.0)	4.0 (2.0-7.0)	11.0 (8.0-17.0)	73 (58.4)	10 (8.0)	9 (7.2)
System						
Alexa	63.0 (41.3-106.5)	6.0 (4.0-8.0)	10.0 (8.0-13.0)	125 (91.9)[b]	2 (1.4)[b]	2 (1.4)[b]
Siri	88.0 (45.0-158.0)	3.0 (2.0-5.0)	17.0 (10.0-38.0)	29 (22.4)[b]	27 (20.9)[b]	18 (14)[b]
Google Assistant	79.0 (49.0-116.0)	6.0 (4.0-8.0)	12.0 (9.0-18.0)	72 (55.8)[b]	20 (15.5)[b]	7 (5.4)[b]

[a]IQR: interquartile range.

[b]These data were used in statistical tests of differences between conversational assistants.

Figure 1. Frequency of potentially harmful and fatal actions.



Median user satisfaction with the three conversational assistants was neutral, but with significant differences among them (Table 2 and Figure 3). Subjects were least satisfied with Alexa and most satisfied with Siri, and stated they were most likely to follow the recommendations provided by Siri.

Qualitative Feedback

Most participants said they would use conversational assistants for medical information, but many felt they were not quite up to the task yet.

> *I would use the Siri if it was available. The other two, I probably wouldn't. I just don't feel comfortable with voice activated stuff.* [Participant #53, 56-year-old male]
>
> *I would definitely use it in the future. Not at the moment.* [Participant #33, 23-year-old female]

When asked about their trust in the results provided by the conversational assistants, participants said they trusted Siri the most because it provided links to multiple websites in response to their queries, allowing them to choose the response that most closely matched their assumptions. They also appreciated that Siri provided a display of its speech recognition results, giving them more confidence in its responses, and allowing them to modify their query if needed.

> *I feel like I trusted Siri more, because she directed me to websites that I could pick from.* [Participant #13, 31-year-old female]
>
> *I think when I did get an answer, a fairly high a degree of trust. It was nice with Siri that I could do more of that reading myself and see that the context from where the answers were coming in, whereas these ones [Alexa, Google Assistant], it was just vocal snippets.* [Participant #44, 22-year-old male]
>
> *...the Siri was the only one I really trusted. It just seemed much more thorough, and I also trusted it that it understood what I was asking it in the first place...It clearly understood everything I was saying. It printed it out even, like my question, as I was asking.* [Participant #53, 56-year-old male]
>
> *...it was nice with Siri to be able to see the results it was spitting out because it made it easier to follow the internal processes that the system was using...I could read the source it gave me or if I saw that it was pulling up results that were a little bit different, I could see what the results for a different form of the question were.* [Participant #44, 22-year-old male]

Table 5. Sample conversational assistant interactions resulting in potential harm to the user.

Description	Task	Transcript
Case P50M7 (E1 error, Potential Harm: Severe)	You have general anxiety disorder and are taking Xanax as prescribed. You had trouble falling asleep yesterday and a friend suggested taking melatonin herbal supplement because it helped them feel drowsy. How much melatonin should you take?	*Subject:* Okay, hey Google, can I mix Xanax and melatonin? *Google Assistant:* Here's a summary from the website Xanax-wiki.com. Alprazolam or Xanax is in the list of those drugs that melatonin always interacts with. Both medications are sedatives. They have found out that there is difference between Xanax and melatonin yet the drugs reduce even the highest levels of anxiety if they are consumed together. *Subject:* Okay, I got an answer. I can take it together.
Case P62M6 (E1 error, Potential Harm: Death)	You have chronic back pain and are taking OxyContin as prescribed. Tonight, you are going out for drinks to celebrate a friend's birthday and you wonder how many drinks you can have.	*Subject:* Siri, I'm taking OxyContin for chronic back pain. But I'm going out tonight. How many drinks can I have? *Siri:* I've set your chronic back pain one alarm for 10:00 P.M. *Subject:* I can drink all the way up until 10:00? Is that what that meant? *Research Assistant:* Is that what you think it was? *Subject:* Yeah, I can drink until 10:00. And then after 10 o'clock I can't drink.
Case P61M4 (E10 error, Potential Harm: Severe)	You have heard that taking Tylenol before you start drinking can reduce the effects of a hangover.	*Subject:* Okay Google, what can I take for a hangover? *Google Assistant:* On the website PlannedParenthood.org, they say: you may have cramping on and off for one or two more days. You can take pain medicine like ibuprofen about thirty minutes before you take the misoprostol to help with cramps. You can also take antinausea medicine if your doctor or nurse gives it to you. Don't take aspirin, because it can make you bleed more. *Subject:* So, take over the counter medicine like Motrin.
Case P49M9 (E9 error, Potential Harm: Death)	You want to know if traditional Chinese ginseng root is safe to take to improve your immune system? You are currently taking Coumadin.	*Subject:* Alexa. Ginseng definition. *Alexa:* Ginseng has a couple of uses. As a noun (1) aromatic root of ginseng plants, (2) Chinese herb with palmatly leaves and small greenish flowers and forked aromatic roots believed to have medicinal powers. *Subject:* Alexa. Coumadin definition. *Alexa:* The term Coumadin means an anticoagulant. Trade name Coumadin. Used to prevent or treat a thrombus or embolus. *Subject:* Alexa. FDA Ginseng. *Alexa:* Sorry, I don't know that one. *Subject:* I think it's safe to take.
Case P59E1 (E3 error, Potential Harm: Death)	You saw an elderly gentleman walking in front of your house, suddenly grab his chest and fall down. What should you do for him?	*Subject:* I saw a guy walk down and hold his chest and fell down. *Siri:* Okay. I found this on the web for I saw a guy Watertown in old is Jensen found out. *Subject:* What should I do if a guy falls down? *Siri:* Here's what I found on the web for what should I do if a guy falls down. *(Subject reviews web pages)* *Research assistant:* What's the answer? *Subject:* Talk to them. Try to keep them as still as possible. If there's any bleeding I need to apply firm pressure with a clean rag. Be alert to any dangers. Don't rush to move him. Get on the floor so you're on the same level as them.

Many participants expressed frustration with the systems, but particularly Alexa.

> *Alexa was horrible...Horrible means provoking horror. Yeah she was really bad. And it's not even that she didn't understand anything. She just...I don't know if she doesn't have the capabilities to look things up and search things or what it is, but she really lacked in being able to get that information.* [Participant #37, 22-year-old female]

> *I found the Amazon system, Alexa, very frustrating. It felt like there were few questions that it could answer and that it...I mean, it didn't even really seem like what I was saying had any bearing on what came out most of the time, although sometimes it did.* [Participant #44, 22-year-old male]

Figure 2. Differences in Task Outcomes by conversational assistant (% of all cases per conversational assistant). Google: Google Assistant.

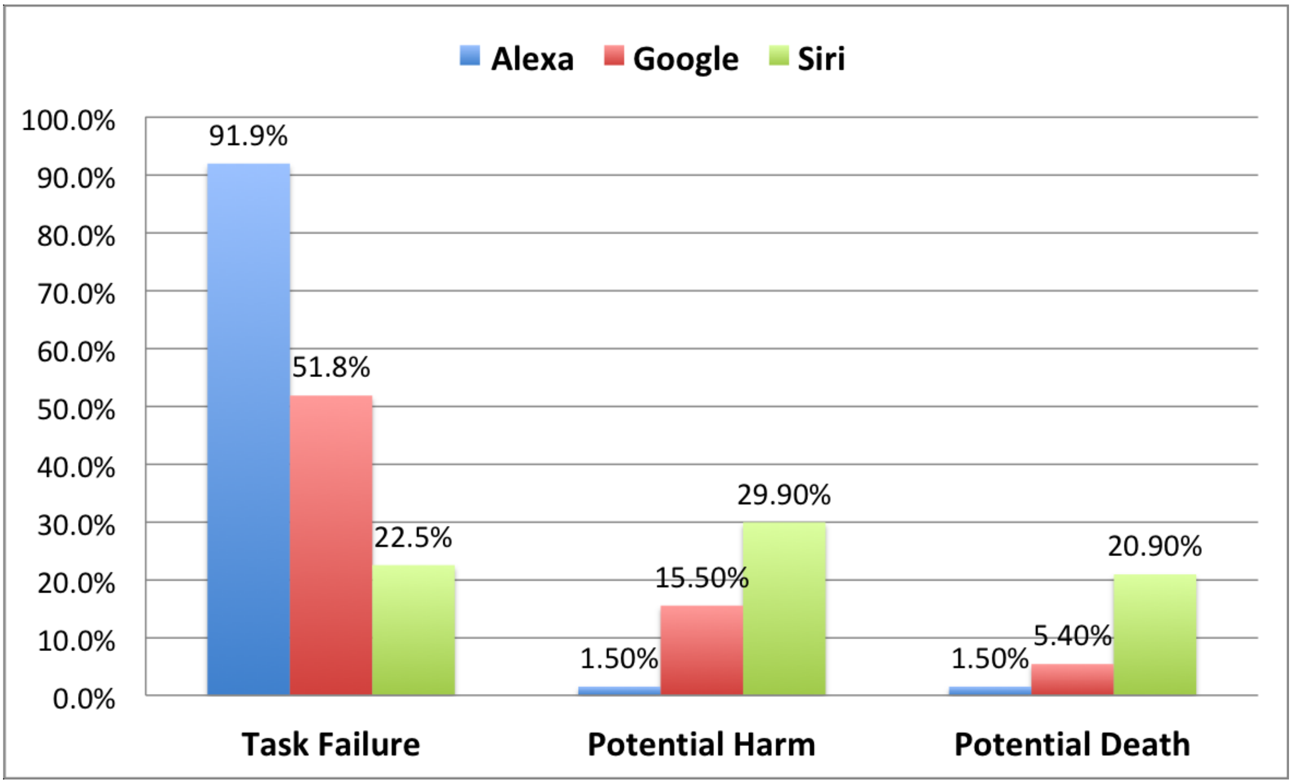
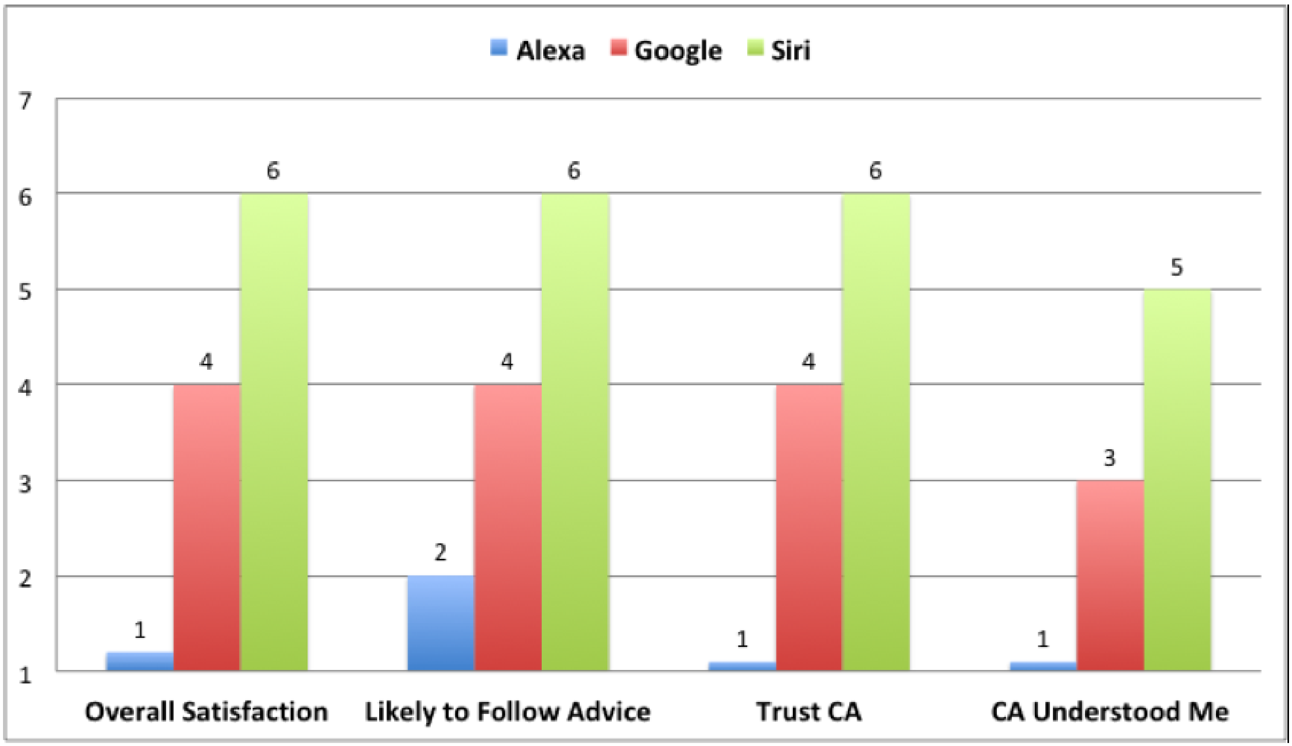


Figure 3. Differences in Task Outcomes by CA (% of all cases per CA).



Discussion

Principal Findings

In our study, when asked nontrivial questions about everyday situations that require medical expertise, conversational assistants failed more than half of the time and led subjects to take actions that could have resulted in harm (49/394, 12.4%) or death (27, 6.9%). These results indicate that patients and consumers should not rely on conversational assistants that use unconstrained natural language input as authoritative sources of medical advice for actionable information.

Our analyses identified several failure modes for conversational assistants in the scenarios tested. In addition to obvious errors in conversational assistant misrecognition of subject queries, and subject misunderstanding of tasks and conversational assistant responses, subjects lacked an understanding of the NLU capabilities and limitations of the conversational assistants they tested. Users must guess how conversational assistants work by trial and error, and the error cases are not always obvious. Also, conversational assistants currently have a minimal ability to process information about *discourse* (ie, beyond the level of a single utterance), and no ability to engage in fluid, mixed-initiative conversation the way people do. These were abilities that subjects assumed they had or about which they were confused.

In posttest interviews, participants expressed that their experience was frustrating, and felt that the conversational assistants tested were not up to the tasks presented to them. However, they had no way of knowing what the capabilities of the conversational assistants were and felt that they should have been able to provide the information they requested. As one participant put it:

> *...they didn't understand me. They didn't have the information. These are pretty serious medical questions. I would have thought they would have been able to help. They didn't.* [Participant #52, 57-year-old female]

Limitations

Our study has several limitations, including the small convenience sample used. Restricting eligibility to native speakers of the English language certainly skewed our sample, but based on pilot testing, conversational assistant sessions with nonnative speakers yielded very little data given the extremely high nonrecognition rates. We admittedly constructed task scenarios that were beyond the abilities of current conversational assistants. However, they represent real-world problems, and it is straightforward to construct much more complex cases that require more contextual understanding or natural language features such as metaphor or implicature [36] that are significantly beyond the abilities of current conversational assistants. Our harm ratings were also "worst case" assessments, but warranted in an analysis of potential safety problems. Given the scale with which conversational assistants are currently used, even exceedingly rare cases will likely occur in practice and thus warrant investigation.

Conclusions

NLU has an important role in many areas of medicine, for clinician-facing systems in which errors can be tolerated because clinicians can validate results. However, when used for patients or consumers without clinician oversight, care should be taken in the design of these systems to ensure that user input is either constrained or confirmed before recommendations are provided. For example, conversational assistants that constrain user inputs to multiple choice options [7-13] can be thoroughly validated for every scenario, and the displayed options provide information to users about the range of inputs on which the conversational assistant can safely act. As we found in our evaluations of Siri, merely displaying the results of speech recognition is insufficient to prevent errors that can lead to harmful outcomes.

Laypersons cannot know what the full, detailed capabilities of conversational assistants are, either concerning their medical expertise or the aspects of natural language dialogue the conversational assistants can handle. Even if a conversational assistant (or conversational assistant "skill" module) is advertised as being expert in a particular medical domain, there is nothing to prevent users from going "off topic" into areas the conversational assistant has no expertise in, especially in emergent situations. Regardless of domain, users can also easily exceed any conversational assistant's NLU capabilities, leading to potentially harmful actions, as we have demonstrated. Further, patients and consumers may be more likely to trust results from conversational assistants that are advertised as having medical expertise of any kind, even if their queries are clearly outside the conversational assistant's advertised area of medical expertise, leading to an increased likelihood of their taking potentially harmful actions based on the information provided.

More research is required into the design of conversational assistants for safety-critical dialogue that allows the flexibility and expressivity of natural language while ensuring the validity of any recommendations provided. Given the state-of-the-art in NLU, conversational assistants for health counseling should not be designed to use unconstrained natural language input, even if it is in response to a seemingly narrow prompt. Also, consumers should be advised that medical recommendations from any nonauthoritative source should be confirmed with health care professionals before they are acted on.

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Authors' Contributions

TWB developed the study protocol and materials, identified actions that were potentially harmful, analyzed the causes of harm cases, and drafted the manuscript. HT conducted sessions with participants, coded session transcripts, conducted the statistical analyses, and contributed to the manuscript. SO coded session transcripts and contributed to the manuscript. TKO conducted sessions with participants, coded session transcripts, and contributed to the manuscript. RA contributed to the design of the study protocol, the technical setup of the systems, and contributed to the manuscript. NMR and RC rated the potentially harmful outcomes for user harm and contributed to the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

IQR: interquartile range
NLU: natural language understanding
REALM: Rapid Estimate of Adult Literacy in Medicine

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Original Paper

Use and the Users of a Patient Portal: Cross-Sectional Study

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Abstract

Background: Patient portals offer patients access to their medical information and tools to communicate with health care providers. It has been shown that patient portals have the potential to positively impact health outcomes and efficiency of health care. It is therefore important that health care organizations identify the patients who use or do not use the patient portal and explore the reasons in either case. The Unified Theory of Acceptance and Use of Technology (UTAUT) is a frequently used theory for explaining the use of information technology. It consists of the following constructs: performance expectancy, effort expectancy, social influence, facilitating conditions, and behavioral intention to use.

Objective: This study aimed to explore the prevalence of patient portal use and the characteristics of patients who use or do not use a patient portal. The main constructs of UTAUT, together with demographics and disease- and care-related characteristics, have been measured to explore the predictive factors of portal use.

Methods: A cross-sectional study was conducted in the outpatient departments for adult patients of a university hospital in the Netherlands. Following outcomes were included: self-reported portal use, characteristics of users such as demographics, disease- and care-related data, eHealth literacy (modified score), and scores of UTAUT constructs. Descriptive analyses and univariate and multivariate logistic regression were also conducted.

Results: In the analysis, 439 adult patients were included. Furthermore, 32.1% (141/439) identified as being a user of the patient portal; 31.2% (137/439) indicated as nonusers, but being aware of the existence of the portal; and 36.6% (161/439) as being nonusers not aware of the existence of the portal. In the entire study population, the factors of being chronically ill (odds ratio, OR 1.62, 95% CI 1.04-2.52) and eHealth literacy (modified score; OR 1.12, 95% CI 1.07-1.18) best predicted portal use. In users and nonusers who were aware of the portal, UTAUT constructs were added to the multivariate logistic regression, with chronically ill and modified eHealth literacy sum score. Effort expectancy (OR 13.02, 95% CI 5.68-29.87) and performance expectancy (OR 2.84, 95% CI 1.65-4.90) are shown to significantly influence portal use in this group.

Conclusions: Approximately one-third of the patients of a university hospital self-reported using the patient portal; most expressed satisfaction. At first sight, being chronically ill and higher scores on the modified eHealth literacy scale explained portal use. Adding UTAUT constructs to the model revealed that effort expectancy (ease of use and knowledge and skills related to portal use) and performance expectancy (perceived usefulness) influenced portal use. Interventions to improve awareness of the portal and eHealth literacy skills of patients and further integration of the patient portal in usual face-to-face care are needed to increase use and potential subsequent patient benefits.

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KEYWORDS

patient portals; eHealth literacy; Unified Theory of Acceptance and Use of Technology

Introduction

Background

eHealth is defined as the use of information and communication technologies for health [1]. It is known that use of eHealth can lead to improved care for chronically ill patients [2,3]. Moreover, health policy supports the benefits of eHealth—mainly because eHealth can lead to a decrease in the information asymmetry between the health care provider and patient by facilitating access to general and personal medical information [4]. A patient portal is a form of eHealth. The medical dictionary defines a patient portal as “A domain in an electronic health record that allows patients to access their records or communicate with their health care providers” [5]. The types of patient portals vary between health care institutions; however, in most portals, patients have access to their medical information and are able to use tools to exchange information and to communicate electronically with the health care provider in a secure manner [6-8]. Patient portals have the potential to increase patient engagement in health care [9]. Research has shown several benefits that can be linked to the introduction of a patient portal [9,10]. First, the use of a patient portal could lead to better clinical outcomes, for instance, diabetes measures [11,12]. Second, associations have been found between the use and availability of patient portals and better communication between the patient and health care provider, quality of care [11,13], improved self-management, and a higher level of patient satisfaction [13]. Third, there is evidence that follow-up care of patients with atopic dermatitis by using a patient portal leads to a substantial cost reduction in the follow-up care of patients with atopic dermatitis, mainly through a reduction of work absenteeism [14]. However, lower health care consumption by the use of patient portals could not be validated [15]. The review by Otte-Trojel showed that health care consumption increased in 5 out of 8 studies regarding health care consumption and patient portal implementation. Two studies found no change, and in one study, lower health care use was reported. It was therefore concluded that patient portals were used in addition to usual care rather than as a replacement [15]. Conversely, a systematic review reported that there is mixed evidence about the effects of patient portals on outcomes and satisfaction. Furthermore, differences in study methodology and portal functionalities limit comparison and generalizability of results [16]. However, the success of patient portals and the subsequent achievement of the aforementioned effects are intrinsically linked to the extent to which they are used [17]. A systematic review indicated that portal use is influenced by factors such as age, educational level, ethnicity, and health literacy. In addition, provider endorsement, communication tactics, the ease of use of a portal, the relative advantage of a portal, and the observability of the benefits of the portal transpired to have a positive influence on portal use [9,18,19]. Different models explain the use and adoption of information technology in health care, but the technology acceptance model (TAM) [20] is commonly used [21]. According to this model, intention to use and use of technology is influenced by perceived usefulness and ease of use. A study by Noblin et al [22] used the TAM to investigate the intention to use a personal health record and showed that the decision of patients to adopt a personal health record was influenced by perceived usefulness and technology barriers (perceived ease of use). An extension of TAM is The Unified Theory of Acceptance and Use of Technology (UTAUT) [23], which is also based on the Motivational Model, the Model of Personal Computer Use, the Theory of Diffusion of Innovations, and the Social Cognitive Theory. This is depicted in Figure 1 [24]. The figure, developed by Venkatesh et al [24], shows that technology acceptance (*use behavior*) is dependent on the intention to use it (*behavioral intention*) and the conditions that facilitate the use (*facilitating conditions*). Furthermore, it shows that the intention to use a new technology is the result of the usefulness (*performance expectancy*) and the ease of use (*effort expectancy*) of the new technology. In addition, the social environment (*social influence*) has an effect on the intention to use a new technology.

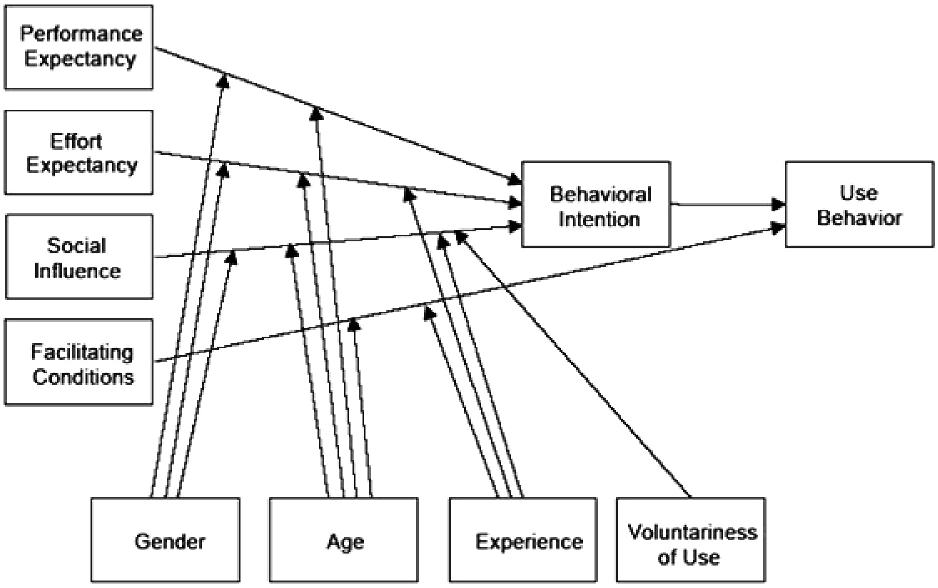
The external variables that influence the mechanism of the UTAUT are gender, age, experience, and voluntariness of use. Generally, young men score higher on performance expectancy; young women with little technological experience score higher on effort expectancy; older women with little technological experience and in a situation in which use is voluntary, score higher on social influence; and older people with more technological experience score higher on facilitating conditions [24]. UTAUT has been empirically validated.

Venkatesh et al [24] showed that the UTAUT can explain 70% of the variance in usage intention, which suggests that the UTAUT is a good predictor of the ultimate likelihood to use a new technology. The UTAUT provides a reliable prediction of the use of technology at 152 German companies [25], the computer use frequency at a Belgian university [26], and the adoption of social media at 409 nonprofit organizations in the United States [27]. UTAUT has also been used previously in health care. For example, a study by Kim et al [28] showed that the acceptance of a mobile electronic medical record was influenced by performance expectancy and attitude.

Aim

The aim of this study was to explore the prevalence of patient portal use and the characteristics of patients who use or do not use a patient portal. The main UTAUT constructs—performance expectancy, effort expectancy, social influence, facilitating conditions, and behavioral intention to use—together with demographics and disease- and care-related characteristics were measured to explore predicting factors of portal use.

Figure 1. The Unified Theory of Acceptance and Use of Technology (UTAUT)—copied with permission from Venkatesh et al [24].



Methods

Study Design

A cross-sectional study was conducted in the outpatient departments of the University Medical Centre Utrecht (UMCU), the Netherlands. Since 2015, all UMCU patients have had real-time access to a patient portal containing the following functionalities: insight into the medical file with reports of consultations and diagnostic results; tools such as questionnaires and diaries; viewing appointments; sending and receiving e-consultation (defined as a secure message for patient-provider communication within the patient portal); and adding personal information. The patient portal of the UMCU was provided by Chipsoft, a software company, and integrated into Hix, the electronic medical file.

Setting and Subjects

The research population consisted of adult patients visiting one of the outpatient departments of the UMCU in April 2016. Fluency in Dutch (speaking and reading) was an inclusion criterion, as the questionnaire and information in the medical file were in Dutch. Children (under the age of 18 years) and inpatients were excluded.

Patients visiting a specific outpatient department for functional diagnostics—for example, electrocardiogram, lung function tests, or colonoscopy—were also excluded to prevent double counting because these patients may already have visited a medical specialist at an outpatient department. To obtain a sample that is in proportion with the size of the different outpatient departments, the ratio of the number of outpatients in a department to the total number of patients as a whole was calculated for each department. This process led to the following distribution: internal outpatient clinics (123/398; 30.9%), surgery (174/398; 43.7%), neurology or psychiatry (42/398; 10.6%), cardiology and lung diseases (41/398; 10.3%), woman and baby department (17/398; 4.3%), and genetics (1/398; 0.3%). We aimed to include about 398 patients by convenience sampling. We recruited about 500 patients because of anticipated incomplete data of about 20% (100/500).

Before the commencement of data collection, the Medical Ethics Review Committee (MERC) of the UMCU declared that the Medical Research Involving Human Subjects Act (WMO) did not apply to this study (MERC protocol number 16/170C) and therefore an official approval of this study by the MERC UMCU was not required under the WMO.

Data Collection and Outcomes

Two researchers, both wearing UMCU t-shirts, introduced themselves in the outpatient clinic and asked patients who were waiting whether they were ready to participate in the study. Data were collected using a structured paper questionnaire. The questionnaire commenced with an information letter, which explained that by completing the questionnaire, patients gave permission to use their data for this research project. This was undertaken to indicate informed consent.

The main outcome of the study was the patient-reported use of the patient portal, which had been operationalized by asking the patients whether they had used the patient portal or not. To obtain more background on usage, the patients were asked which functionalities of the patient portal they used and whether they were satisfied with the patient portal. With regard to the presumed gap between intention and behavior [29], patients were also asked to report whether they intended to use the patient portal in the future.

Secondary outcomes regarding characteristics of users were demographics, disease- and care-related data, and eHealth literacy. Demographic data consisted of gender; age; level of education (low: no education or low secondary or vocational education, intermediate: intermediate vocational education or higher general secondary education, high: higher vocational education or university); travel distance (estimated travel time in minutes); and life status ([not] working, studying, or retired). Background of being native Dutch was operationalized by asking the country of birth of the person and his or her parents.

According to the definition of Statistics Netherlands, if both parents were born in the Netherlands, a person is native Dutch. If at least one of the parents was not born in the Netherlands, a person is not native Dutch [30]. Disease- and care-related data were also collected. This consisted of satisfaction with care (using a 5-point Likert scale ranging from *strongly satisfied* to *strongly dissatisfied*) and self-reported chronic illness (operationalized by presenting a short definition and examples of chronic diseases and then asking the patient whether he or she was a chronic patient). eHealth literacy data were collected using the Dutch translation of the eHealth literacy questionnaire from the study by Van der Vaart et al [31]. Reliability of the original English version [32] and Dutch translation [31] was adequate. Patients were asked to indicate to what extent they agreed or disagreed with the given statements on a 5-point Likert scale. The Likert scale was considered to be a continuous scale. The numbers were added up to compute a sum score. Total scores ranged from 7 to 35, with higher scores representing higher self-perceived eHealth literacy. The eHealth literacy questionnaire consisted of 8 questions, but 1 question "I know how to use the health information I find on the internet to help me" was accidentally excluded. We, therefore, computed a modified sum score over the other 7 questions. To maximize transparency, we also reported scores on the individual questions. The internal consistency (Cronbach alpha) of the 7 questions was .929.

UTAUT constructs were measured using questions about performance expectancy (3 questions about usefulness of the portal for health and care; Cronbach alpha=.91), effort expectancy (6 questions about ease of use and knowledge and skills required to use the portal; Cronbach alpha=.89), social influence (2 questions about influence of health care professionals and loved ones or relatives; Cronbach alpha=.45), facilitating conditions (3 questions about available help and information; Cronbach alpha=.58), behavioral intention to use (1 question), and recommendation to others (1 question, considered as satisfaction with the portal), according to the operationalizations constructed in the study by Kohnke et al [33]. Patients gave their answers on statements, with a 5-point Likert scale ranging from strongly disagree, neutral to strongly agree as well as the answer option "no idea/not applicable."

Data Analysis

Analyses were conducted with IBM SPSS Statistics, version 21 (Armork, New York, USA), in 3 groups.

Analyses in the Total Group

Descriptive statistics were used to analyze the users, nonusers aware of the portal, and nonusers not aware of the portal. A chi-square test was used to test whether there were significant differences between the 3 groups on the categorical variables. The continuous variables with a normal distribution were compared using analysis of variance (ANOVA; 3 groups) or an independent t test. A P value <.05 was considered to be significant.

Logistic regression was used to explain the use of the patient portal. The use of the patient portal was used as a dependent variable. Gender, age, high or intermediate educational level (vs low educational level), working (vs not working, retired, or studying), travel time, chronic patient, and the modified eHealth literacy sum score were used as independent variables. First, univariate logistic regression analyses were performed. Predictors with P<.20 [34] were included in the final multiple logistic regression model, using the *Enter* method. Predictors with $P \leq .05$ were considered to contribute significantly to the prediction of the use of the patient portal.

Analyses in Users and Nonusers Who Were Aware of the Portal

Frequency scores of the UTAUT constructs were collated, and percentages on strongly disagree, neutral, strongly agree, and not applicable or no opinion, per mechanism, were calculated. In addition, mean scores of UTAUT constructs (except recommendation) were computed, and scores of patients who used the portal and of nonusers aware of the existence of the portal were compared. Subsequently, a second multivariate logistic regression was conducted for users and those nonusers aware of the existence of the portal, including significant predictors from the first set of analyses in the total group. To analyze the predicted value of UTAUT constructs, univariate analyses were conducted with these constructs, and the constructs with a P value<.20 were included in the third multivariate logistic regression together with significant predictors from the first analyses in the total group.

Results

Response and Sample Characteristics

A total of 513 patients were willing to participate in this study. Of them, 74 (74/513, 14.4%) patients were excluded because the main question about portal use was not answered or their age was either below 18 years or unknown. In total, 439 patients were included in the analyses. The mean age was 53.0 years (SD 17.4, range 18-88 years); 51.2% (225/439) were females. Patients visited different outpatient hospital departments: 34.4% (151/439) visited the internal outpatient clinics, 27.1% (119/439) surgery, 11.6% (51/439) neurology or psychiatry, 8.0% (35/439) cardiology and lung diseases, 4.3% (19/439) department of woman and baby, and 0.5% (2/439) genetics. In 14.1% (62/439) cases, the information regarding the consulting department was missing.

Portal Use and Satisfaction

In this study, 32.1% (141/439) of the patients indicated being users of the patient portal; 31.2% (137/439) indicated being nonusers of the patient portal, but being aware of the existence of the portal; and 36.7% (161/439) indicated being nonusers and not being aware of the existence of the portal. Portal users, compared with nonusers, were significantly younger, less often retired, more often native Dutch, more often chronically ill, and more often very satisfied with hospital care. In addition, portal users scored higher on the modified eHealth literacy scale (Tables 1 and 2).

Table 1. Differences between portal users and nonusers.

Characteristics	User (n=141)	Nonuser but aware of portal (n=137)	Nonuser not aware of portal (n=161)	*P* value for differences
Travel time in minutes (missing n=2), mean (SD)	43 (47)	38 (24)	38 (26)	.33[a]
Age in years, mean (SD)	50 (15)	53 (17)	55 (19)	.02[a]
Gender (missing n=1), n (%)				.48[b]
Man	63 (44.7)	67 (49.3)	83 (51.6)	
Woman	78 (55.3)	69 (50.7)	78 (48.4)	
Chronically ill (missing n=6), n (%)				.004[b]
No or unknown	50 (35.5)	53 (39.3)	84 (53.5)	
Yes	91 (64.5)	82 (60.7)	73 (46.5)	
Life status (missing n=2), n (%)				<.001[b]
Working	63 (44.7)	61 (44.5)	65 (40.9)	
Not working[c]	47 (33.3)	30 (21.9)	22 (13.8)	
Retired	26 (18.4)	42 (30.7)	68 (42.8)	
Studying	5 (3.5)	4 (2.9)	4 (2.5)	
Educational level[d] (missing n=13), n (%)				.25[b]
Low	28 (20.0)	31 (23.5)	46 (29.9)	
Intermediate	51 (36.4)	53 (40.2)	49 (31.8)	
High	61 (43.6)	48 (36.4)	59 (38.3)	
Background (missing n=17), n (%)				.048[b]
Not native Dutch	12 (8.6)	23 (17.4)	27 (17.9)	
Dutch	127 (91.4)	109 (82.6)	124 (82.1)	
Satisfaction with hospital care (missing n=3), n (%)				.001[b]
Very dissatisfied	4 (2.8)	3 (2.2)	4 (2.5)	
Dissatisfied	1 (0.7)	0 (0.0)	0 (0.0)	
Neutral	5 (3.5)	3 (2.2)	9 (5.6)	
Satisfied	54 (38.3)	62 (45.9)	84 (52.5)	
Very satisfied	76 (53.9)	62 (45.9)	48 (30.0)	
No opinion	1 (0.7)	5 (3.7)	15 (9.4)	

[a]Based on ANOVA.

[b]Based on chi-square.

[c]Unemployed, incapacitated, housewife/houseman.

[d]"Low" indicates no education or low secondary or vocational education; "intermediate" indicates intermediate vocational education or higher general secondary education; and "high" indicates higher vocational education or university.

Table 2. Differences between portal users and nonusers.

Characteristics	User (n=141), mean (SD)	Nonuser but aware of portal (n=137), mean (SD)	Nonuser not aware of portal (n=161), mean (SD)	*P* value for differences
eHeals				
Item 1 (missing n=2)	3.85 (0.71)	3.49 (0.93)	3.24 (0.95)	<.001[a]
Item 2 (missing n=4)	3.89 (0.74)	3.59 (0.88)	3.30 (0.95)	<.001[a]
Item 3 (missing n=5)	3.97 (0.68)	3.70 (0.84)	3.45 (0.90)	<.001[a]
Item 4 (missing n=5)	3.85 (0.75)	3.63 (0.87)	3.37 (0.94)	<.001[a]
Item 6 (missing n=4)	3.89 (0.77)	3.67 (0.89)	3.37 (0.98)	<.001[a]
Item 7 (missing n=4)	3.74 (0.79)	3.47 (0.93)	3.19 (0.96)	<.001[a]
Item 8 (missing n=5)	3.55 (0.90)	3.24 (1.02)	3.01 (0.99)	<.001[a]
Modified sum score eHeals[b] (missing n=7)	26.71 (4.29)	24.81 (5.25)	23.01 (5.53)	<.001[a]
Effort expectancy (missing n=9)	4.11 (0.47)	2.23 (1.23)	N/A[c]	<.001[d]
Facilitating conditions (missing n=10)	3.08 (1.13)	2.14 (1.34)	N/A	<.001[d]
Social influence (missing n=13)	2.24 (1.34)	1.57 (1.27)	N/A	<.001[d]
Performance expectancy (missing n=10)	3.87 (0.80)	1.60 (1.60)	N/A	<.001[d]
Behavioral intention to use (missing n=18)	4.17 (1.09)	3.09 (1.60)	N/A	<.001[d]

[a]Based on ANOVA.

[b]eHealth literacy questionnaire; score per item and sum score of 7 items.

[c]N/A: not applicable.

[d]Based on *t* test.

Satisfaction with the patient portal in total was reported by 84.2% (117/139) of portal users. In total, 3.6% (5/139) of users were dissatisfied with the portal. Between 73.9% and 79.3% of the users were satisfied with the functionalities: treatment reports, results of medical tests, agenda, patient letters (eg, letter from the general practitioner to the medical specialist and vice versa), and patient personal information. Moreover, 43-67.3% of the respondents were satisfied with other parts of the portal (Table 3).

Predictors of Portal Use

On the basis of the results of the univariate analyses, the following predictors were included in the multivariate model: age, travel time, health situation (chronically ill or not), educational level (high or intermediate), and modified eHealth literacy sum score. As shown in Tables 4 and 5, being chronically ill and eHealth literacy significantly contributed to the multivariate model. The full multivariate model was statistically significant (χ^2_5=39.0, *P*=.00), indicating that the model was able to distinguish between portal users and nonusers. Explained variance was between 9% (Cox & Snell R^2) and 12% (Nagelkerke R^2), and the model correctly classified 68%.

Acceptance of the Portal Among Users and Nonusers Aware of the Portal and Prediction of Use

UTAUT constructs were measured in a smaller group of the study population, comprising users and nonusers who were aware of the portal. Mean scores on UTAUT constructs of the portal users were significantly higher than those of the nonusers who were aware of the portal (Table 2). Users more often agreed with factors related to acceptance of the portal when compared with nonusers. In addition, users recorded *not applicable or no opinion* on the acceptance factors less frequently, compared with nonusers who were aware of the portal (Multimedia Appendix 1). Logistic analyses in the part of the population with the significant predictors of the first multivariate model (chronically ill and the modified eHealth literacy sum score) showed that only the modified eHealth literacy sum score (odds ratio, OR 1.09, 95% CI 1.03-1.15) significantly contributed to the model; being chronically ill was not significant (OR 1.17, 95% CI 0.71-1.93).

Univariate analyses in this group showed that all UTAUT constructs had a significant influence on portal use. When we added the UTAUT constructs to the multivariate logistic regression with chronically ill and modified eHealth literacy sum score, it was shown that effort expectancy (OR 13.02, 95% CI 5.68-29.87) and performance expectancy (OR 2.84, 95% CI 1.65-4.90) are significant influencers of portal use. No other variables were statistically significant. The full multivariate model was statistically significant (χ^2_7=212.2, *P*=.00), indicating that the model was able to distinguish between portal users and nonusers who were aware of the portal. Explained variance was between 57% (Cox & Snell R^2) and 76% (Nagelkerke R^2), and the model correctly classified 89.8%.

Table 3. Satisfaction with different parts of the portal.

Satisfaction with different parts of the portal[a]	(Very) dissatisfied, n (%)	Neutral, n (%)	(Very) satisfied, n (%)	No opinion, n (%)
Patient portal in general (n=139)	5 (3.6)	17 (12.2)	117 (84.2)	0 (0.0)
Treatment reports (n=126)	6 (4.8)	24 (19.0)	96 (76.2)	0 (0.0)
Results medical tests (n=129)	7 (5.4)	20 (15.5)	102 (79.1)	0 (0.0)
Agenda (n=119)	3 (2.5)	28 (23.5)	88 (73.9)	0 (0.0)
Patient letters[b] (n=107)	2 (1.9)	24 (22.4)	81 (75.7)	0 (0.0)
Patient personal information (n=116)	2 (1.7)	22 (19.0)	92 (79.3)	0 (0.0)
Measurements (n=101)	5 (5.0)	28 (27.7)	68 (67.3)	0 (0.0)
e-Consultation (n=88)	4 (5)	33 (38)	51 (58)	0 (0.0)
Medication (n=101)	4 (4.0)	34 (33.7)	63 (62.4)	0 (0.0)
Questionnaires (n=93)	5 (5)	39 (42)	49 (53)	0 (0)
Information (n=97)	6 (6)	29 (30)	62 (64)	0 (0)
E-repeat prescriptions (n=78)	4 (5)	37 (47)	36 (46)	1 (1)
Patients' personal notes (n=77)	3 (4)	41 (53)	33 (43)	0 (0)

[a]n differs per part of the portal; only parts that were used were scored.

[b]Patient letter is a letter from the general practitioner to the medical specialist and vice versa.

Table 4. Predictors of portal use: univariate regression analyses in the total group.

Characteristics	*P* value	Exp (β)	95% CI for Exp (β)
Sex (female)	.25	1.26	0.84-1.89
Age	.01	0.98	0.97-1.00
Travel time	.17	1.00	1.00-1.01
Chronically ill	.02	1.61	1.06-2.44
Life status (working)	.68	1.09	0.73-1.63
Education (high or intermediate)	.12	1.47	0.90-2.40
Modified sum score eHeals	<.001	1.13	1.08-1.19

Table 5. Predictors of portal use: multivariate regression analyses in the total group (n=415).

Characteristics	*P* value	Exp (β)	95% CI for Exp (β)
Age	.16	0.99	0.98-1.00
Travel time	.16	1.01	1.00-1.01
Chronically ill	.03	1.62	1.04-2.52
Education (high or intermediate)	.98	1.01	0.58-1.75
Modified sum score eHeals	<.001	1.12	1.07-1.18

Discussion

Principal Findings

In a sample of 439 adult patients, we found that 32.1% (141/439) reported to be users of the patient portal; 31.2% (137/439) reported to be a nonuser of the patient portal, but being aware of the existence of the portal; and 36.7% (161/439) were nonusers being unaware of the portal. Most users (117/139, 84.2%) were satisfied with the patient portal and its functionalities. Compared with nonusers, users were statistically younger, less often retired, native Dutch, chronically ill, very satisfied with hospital care, and scored higher on eHealth literacy. Of these factors, being chronically ill and eHealth literate were best predictors of portal use. In a subgroup of patients, users and nonusers who were aware of the portal, the influence of UTAUT constructs was examined. This study showed that effort expectancy and performance expectancy significantly influence portal use in users and nonusers who were aware of the portal, whereas chronically ill and eHealth literacy were not significant predictors.

This study had a large sample size, consisting of patients visiting different departments and accurately reflecting the population of a university hospital. Most patients were willing to participate, which could be explained by the direct and personal approach in waiting rooms. UMCU is one of the first hospitals in the Netherlands to offer a patient portal that provides real-time access to most parts of the medical file and the opportunity of e-consulting to all patients who performed an ID check in the hospital [35]. In other studies, access was often found to be conditional to patient requests or the consent of health care professionals. This should be taken into account when comparing this study's finding of 32.1% (141/439) patients using the portal with percentages of users in different studies, which varies between 26-51% [36-40]. Besides the way access is provided, other studies also differ in sample size and setting, and the various portals vary in functionalities. For example, a study by Jhamb et al [36] reported a 39% usage rate by patients visiting a nephrology clinic. When looking at this relatively high rate, one should note that patients were invited by staff members to sign up for the portal. A study by Krist et al [37] reported a 26% portal usage rate in a primary care setting in which patients could create an account by themselves. For access to radiology reports, patients voluntarily signed up for the electronic Web portal, leading to 51% usage [38]. In the study of Roelofsen et al [39], 42% of the patients were registered to use a diabetes platform in primary care after they expressed interest in using the resource and were registered by their practice nurse. Of these, 27% subsequently logged on to the platform.

In this study, patient portal use was patient-reported. Often patient log-in is used to measure actual portal use [9]. However, counting log-in incidences does not provide information about functionalities used and lacks contextual information. Another way to report portal use is to distinguish active or passive use [41]—in which active use can be defined as actual communication and interaction, whereas passive use is simply logging in. Similarly, Wallace et al [42] described logging in as viewing, and active use was divided into Web-based requests or services and communication. Moreover, Shimada et al [40] reported about the use of My HealthVet by type 2 diabetes patients and reported that 45.20% used Web-based prescription refills or secure messaging or both, after registration.

In short, providing access after patients' request could lead to a selection of motivated patients, which biases comparison of use and characteristics of users as well as the percentage of users. Calculating usage based on a subgroup of patients who have the intention to use the portal naturally results in a higher usage percentage than taking the total number of patients who visit a hospital as a whole.

We reported that users differ from nonusers with respect to demographics, being chronically ill, and modified eHealth literacy score. This is consistent with evidence of this study that users, compared with nonusers, are more often younger, female, and highly educated and that patient portals are less often used by minorities [9,43-45]. In addition, users have been found to have higher eHealth literacy levels [9,45,46], probably resulting from their higher levels of education. Furthermore, disease-related characteristics such as being chronically ill or having comorbidities or receiving a greater amount of precious care are linked to higher patient portal usage [37,47,48]. In our multivariate analyses, being chronically ill and modified eHealth literacy score are found to be significant predictors. However, when UTAUT constructs were added to the model in the subgroup of users and nonusers who were aware of the portal, effort expectancy and performance expectancy were shown to be significant predictors. Hence, the likelihood that a patient uses the patient portal increases if a patient perceives the patient portal as beneficial and easy to use and if the patient is skilled and resourceful. These findings are in line with other studies predicting portal use. Emani et al (2012) [18] used the diffusion of innovation model and pointed out that use of a personal health record is influenced by ease of use and relative advantage. Tavares and Oliveira [21] adapted UTAUT to the eHealth consumer context (UTAUT2) and showed that in addition to performance expectancy and effort expectancy, habit and self-perception (defined as perceived severity of the health complaint) are drivers of the intention to use an electronic health record portal [21]. Remarkably, being chronically ill and the modified eHealth literacy score were shown not to be significant predictors when UTAUT constructs were included in the model. Both factors are included in different models to predict portal use, but Tavares and Oliveira were also unable to confirm the influence of being chronically ill [21]. On the other hand, Logue et al revealed that the 5 factors of the Personal Health Records Adoption Mode—personal (including eHealth literacy), environmental, technology, chronic illness, and behavioral factors—influenced adoption of personal health records among the older adults with chronic illness [49,50].

In this study, health care professionals and other important people (eg, family and friends) appear not to play a very influential role in the population sample. This can be explained by the findings of Verstraete et al [35], who showed a relation between a relatively low use by health care professionals in this setting and the fact that the portal was not fully embedded in daily practice. Turvey et al [51] reported that low awareness and lack of knowledge of the patient portal is a barrier to use. Endorsement of a patient portal by health care providers is often shown as an influencing factor [9,52]; so, a more active role of health care professionals as well as integrating the patient portal in usual care [37,53] will increase portal use and in turn will increase the likelihood of positive effects of portal use on health outcomes and efficiency [54,55]. However, the use of patient portals can also give rise to negative outcomes. Real-time access to results of diagnostic tests and medical reports can increase anxiety and worries [35,56,57]. It is therefore important to inform patients about the content of the portal and discuss the options of (temporarily) closing the portal or not logging in to the portal during the diagnostic phase.

Strengths and Limitations

A number of limitations of this study are worthy of note. First, patients who were not aware of the portal could not answer the UTAUT questions, leading to selective information on users and nonusers who were aware of the portal. Second, this study had a cross-sectional design including adult patients from outpatient departments. Information about parents of children using or not using the patient portal of their child is not included. Moreover, admitted patients were excluded, so it is unknown how often and why a patient portal is used during hospital admission. Furthermore, differences per department were not analyzed because these subgroups were too small and these analyses had not been planned in advance. Third, household income was mentioned earlier as an influencing factor of portal use [36] but was not measured in this study. Generalizability of results is limited because a convenience sample of patients in waiting rooms was included and there was a failure in documenting the total number of patients approached, response rate, and reasons for declining to participate. Finally, the study findings are limited because the validity of the Dutch eHealth literacy questionnaire was considered questionable by Van der Vaart et al [31], and unfortunately, one question was missing on the eHealth literacy scale. We chose to compute the modified sum score of this questionnaire but also reported scores on individual items to be fully transparent.

This study has implications for health care organizations, policy makers, and research. First of all, this study shows that not all patients use the patient portals that are available to them. It is of great importance to realize this and to invest time in educating potential nonusers about the potential benefits of the system. Failure to engage in such promotional-type activities will lead to a failure to maximize usage rate. Until now, patients in the UMCU center have been informed about the portal via paper leaflets and information on the hospital website. During the implementation phase of the patient portal, professionals were instructed to discuss the use of the portal during consultations, but it is known that only half of all professionals did so [35]. Irizarry et al [58] reported that older adults required information about the portal that is targeted at their personal needs and concerns. A recent pilot project in UMCU's outpatient clinic showed that hosts who provided verbal information tailored to the personal questions of patients about the portal stimulated patients to use the portal. We, therefore, recommend the availability of hosts in waiting rooms. To reach a wider range of patients, we also suggest the inclusion of a (medical) dictionary in the patient portal. This might help to diminish the health literacy gap, as it improves patients' understanding of complex (medical) language. Further research is needed to investigate whether these add-ons would indeed stimulate patients with lower health literacy and contribute to reducing the information gap. In addition, integration of a patient portal in normal care is necessary to increase awareness of the usefulness of the portal and positive outcomes of the portal and to decrease negative side effects. Health care professionals need to communicate with their patients about the portal and how and when e-consultation and other functionalities could be used. Because UTAUT constructs *effort expectancy* and *performance expectancy* are predictors of portal use, we recommend the involvement of patients in the development and implementation of patient portals. Ryan et al [59] demonstrated that engagement of patients in the early stages of implementation is necessary and that patient-centered partnerships between patients and professionals are needed regarding the use of patient portals. Further research is needed to explore the characteristics of such a partnership from the perspective of patients and professionals.

Conclusions

To conclude, approximately one-third of the patients of a university hospital self-reported using the patient portal and most of them were satisfied with it. At first sight, being chronically ill and higher scores on the modified eHealth literacy scale were shown to explain portal usage. Including UTAUT constructs in the model showed that effort expectancy, ease of use, knowledge and skills related to portal use, and performance expectancy (perceived usefulness) influenced portal use. Interventions to improve awareness of the portal and eHealth literacy skills of patients and further integration of the patient portal in normal care are needed to increase use and potential benefits for patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Factors related to acceptance of the portal for users and nonusers who knew about the portal.

[PDF File (Adobe PDF File), 30KB - jmir_v20i9e262_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
MERC: Medical Ethics Review Committee
OR: odds ratio
TAM: technology acceptance model
UMCU: University Medical Centre Utrecht
UTAUT: Unified Theory of Acceptance and Use of TechnologyMedical Research Involving Human Subjects Act
WMO: Medical Research Involving Human Subjects Act

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Original Paper

Use of Simulator-Based Teaching to Improve Medical Students' Knowledge and Competencies: Randomized Controlled Trial

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Abstract

Background: Simulator-based teaching for coronary angiography (CA) is an attractive educational tool for medical students to improve their knowledge and skills. Its pedagogical impact has not been fully evaluated yet.

Objective: The aim of this study was to compare traditional face-to-face teaching with a simulator-based teaching for the acquisition of coronary anatomy knowledge and CAs interpretation.

Methods: A total of 118 medical school students in their fourth to sixth year were prospectively randomized in 2 groups: (1) a control teaching group (n=59, CONT group) and (2) a simulator group (using the Mentice VIST-Lab CA simulator; n=59, SIM group). The CONT group received a PowerPoint-based course, whereas the SIM group received a simulator-based course including the same information. After the course, all students were evaluated by 40 multiple choice questions (maximum of 100 points), including questions on coronary anatomy (part 1), angiographic projections (part 2), and real CAs interpretation (part 3). Satisfaction of the students was also evaluated by a simple questionnaire.

Results: Student characteristics were identical in both the groups: 62/118 (52.5%) were female and age was 22.6 (SD 1.4) years. Moreover, 35.6% (42/118) were in their fourth year, 35.6% (42/118) were in the fifth year, and 28.8% (34/118) in the sixth year. During the evaluation, SIM students had higher global scores compared with CONT students, irrespective of their year of medical school (59.5 [SD 10.8] points vs 43.7 [SD 11.3] points, $P<.001$). The same observations were noted for each part of the test (36.9 [SD 6.6] points vs 29.6 [SD 6.9] points, $P<.001$; 5.9 [SD 3.0] points vs 3.1 [SD 2.8] points, $P<.001$; and 16.8 [SD 6.9] points vs 10.9 [SD 6.5] points, $P<.001$; for parts 1, 2, and 3, respectively). Student satisfaction was higher in the SIM group compared with the CONT group (98% vs 75%, $P<.001$).

Conclusions: This study suggests that simulator-based teaching could potentially improve students' knowledge of coronary anatomy, angiography projections, and interpretation of real clinical cases, suggesting better clinical skills. These results should encourage further evaluation of simulator-based teaching in other medical specialties and how they can translate into clinical practice.

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KEYWORDS

education; coronary angiography; high fidelity simulation training

Introduction

Simulator-based training is booming in surgery, medical, and technical specialties, especially in cardiology.

The advantages of this technology have been recognized by numerous teaching consortiums, most notably, the Accreditation Council of Graduate Medical Education, which recommends simulation training for numerous specialties, as well as the Society for Cardiovascular Angiography and Intervention [1].

Two main types of simulation need to be differentiated according to their degree of immersion (high-fidelity and low-fidelity). Fidelity refers to the degree to which a model reproduces the state of a real-world object, feature, or condition. Improved technology leads to the development of an increasing number of high-fidelity simulators that more accurately mimic the real environment [2].

Some studies have shown improvements in residents' performances after catheter-based interventions using high-fidelity simulation, with better scores for residents who were provided simulations than for those who were not [3]. Unlike traditional teaching, skills obtained through virtual reality simulation training, such as the translation of a 2-dimensional video image into a 3-dimensional (3D) working area or tactile feedback, could be transferred into clinical practice [4].

However, these high-fidelity simulators are more expensive than their low-fidelity counterparts, not only in terms of the acquisition cost but also by adding the related costs associated with the personnel and resources needed to use them, and their real pedagogical impact has not been rigorously evaluated.

The aim of this study was to teach medical students coronary arteries anatomy and angiography interpretation into clinical practice and to evaluate simulator-based teaching by a head-to-head comparison between a traditional teaching approach and a high-fidelity coronary angiography (CA) simulator.

Methods

Population

All participants were medical students at Paris Descartes University in their fourth, fifth, or sixth year, and none of them had experience in interventional cardiology. They voluntarily agreed to take part in the study, which was conducted at the Institute for Therapy Advancement under the auspices of the foundation, iLumens.

The institute is a private organization that provides simulation equipment and training staff to the Paris Descartes University and iLumens foundation, including a CA simulator specifically designed for academic training.

Interventional Cardiology Simulator

The Mentice VIST-Lab CA simulator (Mentice, Göteborg, Sweden) is a high-fidelity interface that includes a mannequin, 2 monitors, and joysticks for table and sensor control, mimicking the latest generation catheterizations laboratories. The simulator features buttons for zooming in and out, pedals for fluoroscopy, and cine loop control (see Figure 1).

The interventional tools, x-ray, and cine loops are all simulated to produce a highly realistic environment [5]. Injecting air using a syringe creates a virtual contrast injection. Users are able to switch between the angiographic view and a 3D view to better identify the take-off and location of the coronary arteries. The simulator includes several coronary and aortic anatomies and coronary stenosis. For the purpose of this study, each student worked on a single case.

Sequence of the Session

All students were prospectively randomized by manual draw into 2 groups, regardless of their year of study: a control teaching group (n=59, CONT group) and a simulator group (n=59, SIM group). No pretesting was performed in our population, as we assumed that the students had the same level of knowledge in each group, because of the randomization. The CONT group received a PowerPoint-based course by an academic senior cardiologist, consisting of 15 slides encompassing the predefined learning objectives (coronary anatomy, angiography projections, and interpretation of real cases). The SIM group received a simulator-based course by the same cardiologist, which included the same pedagogical content. In addition to the theoretical course, all students in the SIM group were allowed to individually manipulate the simulator for 15 min to learn coronary anatomy in the real 3D environment. Several sessions were run because each one, both traditional and simulation, was conducted with small numbers of 8 to 10 students, to allow access to the simulator to all students and to allow time for questions and answers. The instructions, both visual and oral, delivered during the 2 types of teaching sessions were identical, as was the duration of the sessions (30 min).

Evaluation

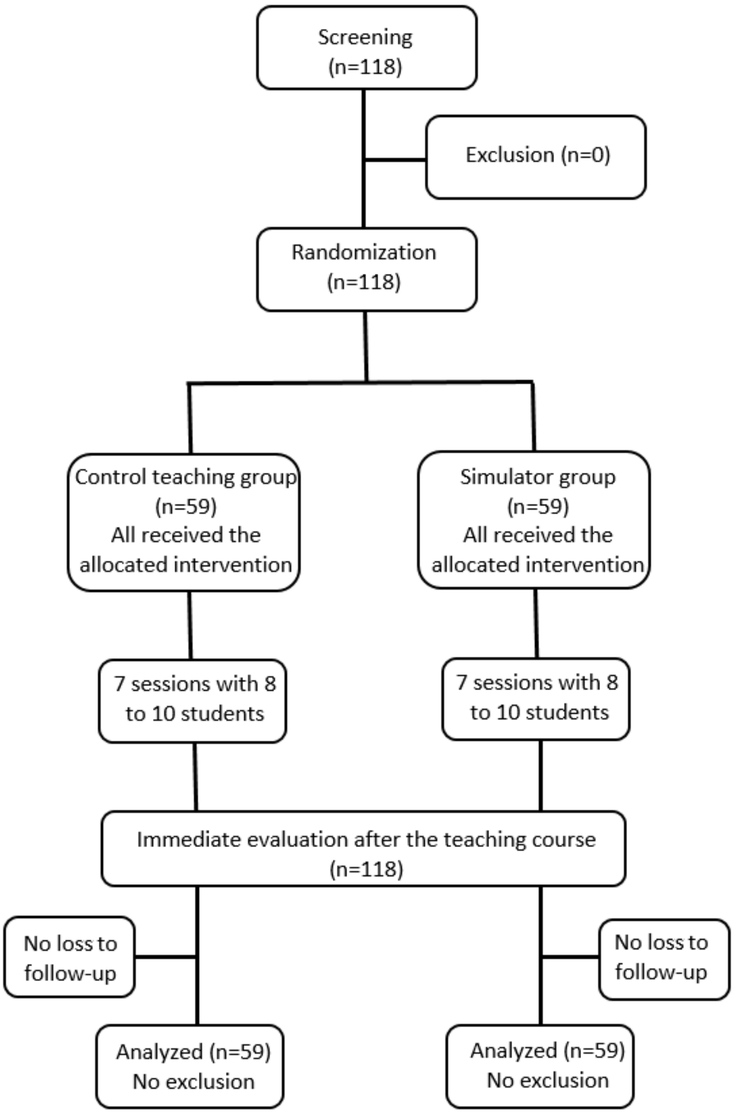
After the courses, the students were evaluated by a series of 40 multiple choice questions (MCQs) for a maximum of 100 points. For each MCQ, students had 5 choices. The MCQs were separated into 3 parts.

The first part was designed to evaluate coronary artery anatomy on still images and consisted of 25 MCQs. There was only 1 correct answer per MCQ in this part, and each correct choice scored 2 points, totaling 50 possible points for this part. This part was designed to promote traditional teaching because the same still images were displayed during the PowerPoint course.

The second part evaluated spatial representation on still pictures. The students had to distinguish between the right anterior oblique and left anterior oblique views and between caudal and cranial views. This part consisted of 5 MCQs, and each correct choice gave 2 points, giving a possible total of 10 points. There were 2 correct answers for each MCQ with binary notation.

Figure 1. Mentice VIST-Lab simulator used in the study.

Figure 2. Flowchart of study population.



Although students in both the groups had received relevant training to be able to do this part, the 3D manipulation environment was potentially favoring the simulator group.

The third part evaluated interpretation of clinical cases–based angiographic films. There were 10 clinical scenario and 10 angiographies, each with 6 sequences to analyze. Each angiography corresponded to an MCQ and was played 3 times, twice at normal speed and once at a slow speed to help interpretation. The students were asked to choose between 5 possible answers reflecting clinical decisions. There was one or more correct answers for each MCQ with a binary notation. Each correct answer gave 4 points, giving a possible total of 40 points for this part.

The MCQs were accessible by logging onto a specific website, and the pictures and movies were presented by an external evaluator to prevent evaluation bias. The duration of the evaluation was the same for both the groups (1 hour).

Finally, student satisfaction was evaluated at the end of each session, with a binary notation (yes or no). Results of the evaluation were blindly analyzed, regardless of the inclusion group. Due to the design of the study, there was no crossover and no loss to follow-up (see Figure 2).

Statistical Analysis

Continuous data are presented as mean (SD) and compared with the use of a Student *t* test. Categorical data are expressed as percentages and compared using a chi-square test. No sample size calculation was performed, with the inclusion of all volunteering Paris Descartes University medical students between the fourth and the sixth year.

All analyses were performed using SPSS version 22.0 (SPSS Inc, Chicago, IL, USA). A significance level of .05 was used to test for statistical differences.

Results

A total of 118 medical students were included in the study. Of these, 35.6% (42/118) were in their fourth year, 35.6% (42/118) in their fifth year, and 28.8% (34/118) in their sixth year. Baseline characteristics of the students were similar in both the groups at inclusion. A total of 52.5% (62/118) were female, and the mean age was 22.6 (SD 1.4) years. There were 21 fourth-year students both in the CONT and SIM groups, 21 fifth-year students in the CONT and the SIM groups, and 17 sixth-year students in both the groups (see Table 1).

The global score was not significantly different in the 3 groups based on the year of study: 50.3 (SD 11.4) points in fourth year, 51.3 (SD 10.9) points in fifth year, and 53.5 (SD 10.5) points in sixth year (P=.52).

Overall, the students in the SIM group had higher scores compared with students in the CONT group: 59.8 (SD 11.2) points versus 43.8 (SD 10.9) points, respectively (P<.001). Interestingly, students in the SIM group scored higher in each subsection of the evaluation (part 1—coronary anatomy: 36.9 [SD 6.7] points vs 29.7 [SD 7.12] points, P<.001; part 2—spatial representation: 6.0 [SD 3.1] points vs 3.0 [SD 2.8] points, P<.001; and part 3—interpretation of real angiographies: 16.9 [SD 7.3] points vs 11.2 [SD 6.1] points, P<.001; see Figure 3).

Student satisfaction was excellent in both the groups, but higher in the SIM group (98%, 58/59) compared with the CONT group (75%, 44/59; P<.001; see Table 2).

Table 1. Baseline characteristics of the population.

Variable	All students (N=118)	CONT[a] group (n=59)	SIM[b] group (n=59)
Age (in years) at inclusion, mean (SD)	22.6 (1.4)	22.6 (1.3)	22.6 (1.5)
Sex (female), n (%)	62 (52.5)	31 (52.5)	31 (52.5)
Year of study, n (%)			
Fourth	42 (35.6)	21 (35.6)	21 (35.6)
Fifth	42 (35.6)	21 (35.6)	21 (35.6)
Sixth	34 (28.8)	17 (28.8)	17 (28.8)

[a]CONT group: control group (traditional teaching).

[b]SIM group: simulator group (simulation teaching).

Figure 3. Score according to group allocation at each part of the evaluation (simulant group [SIM] vs control group [CONT]). A) total score; B) coronary anatomy questions (part 1); C) angiographic projections (part 2); and D) real case interpretations (part 3). *P* value determined by Student *t* test.

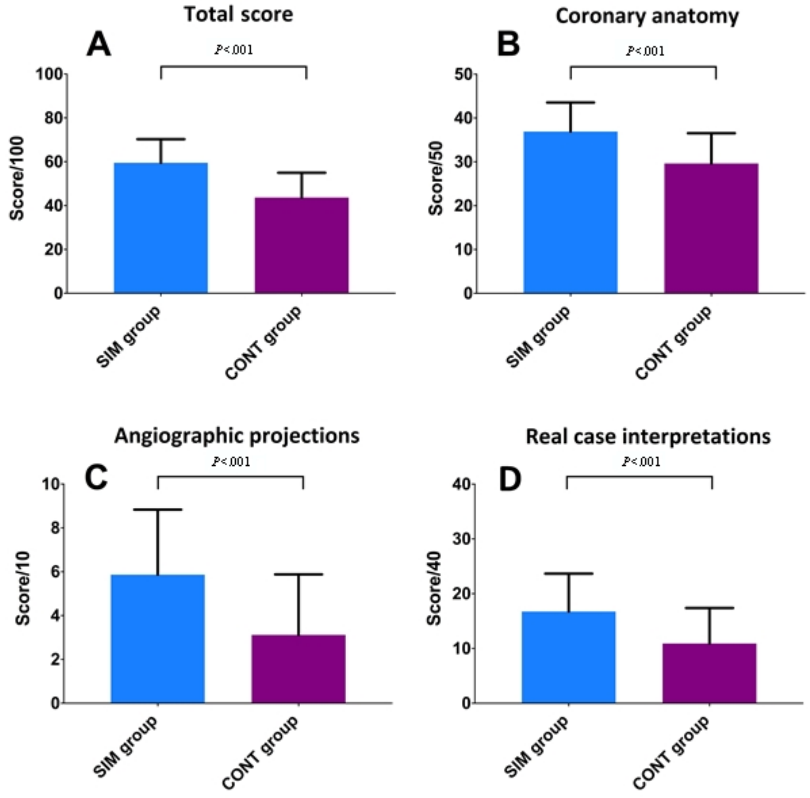


Table 2. Results of the evaluation according to group allocation.

Variable	CONT[a] group (n=59)	SIM[b] group (n=59)	*P* value
Part 1 score (out of 50), mean (SD)	29.6 (6.9)	36.9 (6.6)	<.001[c]
Part 2 score (out of 10), mean (SD)	3.1 (2.8)	5.9 (3.0)	<.001[c]
Part 3 score (out of 40), mean (SD)	10.9 (6.5)	16.8 (6.9)	<.001[c]
Total score (out of 100), mean (SD)	43.7 (11.3)	59.5 (10.8)	<.001[c]
Satisfaction, n (%)	44 (75)	58 (98)	<.001[d]

[a]CONT group: control group (traditional teaching).

[b]SIM group: simulator group (simulation teaching).

[c]*P* value determined by Student *t* test.

[d]*P* value determined by chi-square test.

Discussion

Principal Findings

This prospective randomized study represents one of the first attempts to assess the effectiveness of a simulator-based approach to teach cardiology to medical students. We report improved scores for students with simulation teaching compared with those attending a traditional course, irrespective of the type of evaluation and the year of medical school. This suggests that coronary anatomy, CA projections (knowledge) are better taught through a simulator-based strategy and that it could translate to a better analysis of real clinical cases (medical skills).

In France, coronary anatomy is taught to medical students in the second year, only before the validation of a Medical Degree. This can explain the absence of any difference between the scores of students according to their years of medical school in our study.

The use of simulators in medical education has vastly increased in recent years [6], and there are now a wide variety of commercially available products, both low-fidelity and high-fidelity. A thorough analysis of simulation studies in all branches of medicine suggests that high-fidelity simulations can facilitate learning, given the appropriate setting, but most studies have no control group [7,8]. One study comparing a simulation approach for the teaching of perioperative ultrasound to anesthesiology residents [9], for example, indicated that it might be a more effective approach than didactic teaching. A previous study in cardiology showed that even a brief experience on a simulator can serve to better prepare the novice cardiology fellow for a range of potential procedures and procedural complications [10]. Overall, however, the level of evidence of these studies is weak, and there are no studies with a robust methodology assessing the interest of simulator teaching in cardiology.

The students in both of our study groups (simulation and traditional teaching) first had a 30-min educational session. They then underwent the same evaluation that was conducted on a website in a blinded manner. Thus, the teaching and evaluation times were identical for both the groups, limiting the evaluation bias.

We believe that the better scores obtained by the students undergoing simulation teaching could be related to the manipulation of the simulator in the SIM group where students could experience a variety of incidences. They could, therefore, acquire a better understanding of the 3D structure, which may facilitate data retention by transfer [11].

One of the recurrent problems in medicine is the transformation of book-based knowledge into practical skills. SIM students are better at analyzing real angiographic films. However, theoretical medical training is not limited to recognizing arteries during an MCQ but aims to integrate its knowledge into practice to improve patient care in daily practice.

Another parameter that could improve teaching is the playful side provided by the simulator.

Indeed, during the session, each medical student in the SIM group was immersed in a virtual reality using realistic tools comparable with a game controller to perform a CA as an active player. These students, with no experience in interventional cardiology, were directly involved in their learning thanks to the simulator and drawn *into the game*, making transmission of medical knowledge and skills easier. Previous studies showed that a playful environment, such as a video game, encourages student's participation and improves retention and satisfaction rate [12].

Most data about simulation approaches focus on young doctors without experience, notably in surgery or interventional techniques, and show an improvement of skills with simulation training [13]. Our study was different in 2 main parameters. The first was that we assessed a population of medical students rather than medical doctors. Therefore, this study was their first exposure to interventional cardiology. The second was the design of our study, which was not a training study because each student in the SIM group performed 1 single session, more like a serious game than a simulator-based training. Indeed, our teaching study compared 2 different methods with identical time input, whereas in training studies, the duration of exposure to the simulator varies.

Some investigators have demonstrated that high-fidelity simulation may serve as a viable didactic platform for preclinical medical education with improvement in mid- and long-term knowledge retention in comparison with traditional teaching [14].

Limitations and Future Directions

Our randomized trial has some limitations, including the lack of sample size calculation, the limited size, and the absence of long-term evaluation. Immediate evaluation after a teaching course does not assess medium- and long-term memorization of coronary anatomy and may promote traditional teaching at the expense of simulation teaching. Re-evaluating students after a short period (at least 1 month after the teaching course) could generate some interesting data.

No pretesting was done before the randomization for logistic reasons. However, we performed a randomization to have 2 comparable groups and exclude a selection bias. Moreover, we did not test low-fidelity models of simulation. These less expansive types of simulation had to be compared with traditional teaching and high-fidelity simulation, before considering their generalization.

Conclusions

In summary, compared with traditional teaching, we found that high-fidelity simulator-based teaching in CA significantly improves students' knowledge of coronary arteries anatomy, spatial representation, and interpretation of real clinical cases.

Besides improving theoretical knowledge of students in cardiology, simulator-based teaching could improve clinical skills of the students, because our aim is to focus on training students to become caregivers rather than exclusively being founts of knowledge. Despite the high cost of the simulator, simulation teaching in the cardiology student's program could improve their medical knowledge and potentially medical skills. However, other studies with rigorous methodology should be conducted to evaluate the impact of simulation teaching in various medical specialties.

Conflicts of Interest

None declared.

Editorial notice: This randomized study was not prospectively registered. The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials because, according to ICMJE rules, trials targeting providers do not require registration and no patients were involved in this trial, only medical students, who can be considered (future) providers. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as the lack of registration means that authors could change their outcome measures retrospectively.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 2MB - jmir_v20i9e261_app1.pdf]

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Abbreviations

3D: 3-dimensional
CA: coronary angiography
CONT: control teaching
MCQ: multiple choice question
SIM: simulator

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Original Paper

Prevention of HIV and Other Sexually Transmissible Infections in Expatriates and Traveler Networks: Qualitative Study of Peer Interaction in an Online Forum

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Abstract

Background: In high-income countries such as Australia, an increasing proportion of HIV cases have been acquired overseas, including among expatriates and travelers. Australia's national strategies have highlighted the need for public health interventions for priority populations. One approach is to expand efforts to places or spaces where expatriate communities reside. Online settings such as forums used by expatriates and travelers have potential for preventing sexually transmissible infections with those hard to reach through more traditional interventions.

Objective: Our objectives were to (1) identify and describe domains of social interaction and engagement in 1 online forum used by Australian expatriates and travelers living or working in Thailand; and (2) make recommendations to health-promoting organizations and policy makers regarding the role of these forums in public health interventions with mobile populations who may be at risk of acquiring HIV or other sexually transmissible infections.

Methods: We identified forums and users in 2 stages. We identified 13 online forums and analyzed them for inclusion criteria. We searched 1 forum that met the required criteria for users who met inclusion criteria (n=5). Discussion threads, rather than individual posts, were units of analysis. For each user, we collected as transcripts the first 100 posts and 10 most recent posts, including the thread in which they were posted. We analyzed and thematically coded each post (n=550). Transcripts and analyses were reviewed and refined by multiple members of the research team to improve rigor. Themes were not totally emergent but explored against symbolic interactionism concepts of presentation of self, meaning, and socialization.

Results: Key domains were as follows: the forum (characteristics of the space and reasons for use), gaining access (forum hierarchy and rules), identity (presentation of self and role of language), advice, support, and information (sources of information, support provided, influencers, topics of discussion, and receptiveness to advice), and risk (expectations and perceptions). The forum exhibited evidence of unique language, rules and norms, and processes for managing conflict and key influencers. The forum was a substantial source of health information and advice provided to users via confirmation, reassurance, or affirmation of beliefs and experiences. Risk perception and expectations varied. Risk taking, including around sex, appeared to be a key expectation of travel or the experience of being an expatriate or traveler.

Conclusions: Australian expatriate and long-term traveler participation in the online forum formed, influenced, and reinforced knowledge, attitudes, interaction, and identity. Such forums can be used by policy makers and health-promoting organizations to provide supplementary sources of support and information to hard-to-reach mobile populations who may be at risk of acquiring HIV or other sexually transmissible infections. This will complement existing engagement with health professionals and other public health interventions.

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KEYWORDS

HIV; STIs; men; public health; health promotion; online social networks; social support; travel; human migration; emigration and immigration; sexually transmitted diseases; social networking

Introduction

Overview

In high-income countries, including Australia, population mobility has led to changes in transmission patterns of HIV and other sexually transmissible infections (STIs). An increasing proportion of diagnosed cases have been acquired overseas, including among expatriates and travelers [1-5]. Developing interventions to respond to these increases is challenging in part due to geographic barriers to those affected. Online settings can overcome such difficulties. We explored social interaction and engagement in 1 online forum used by Australian expatriates and travelers living or working in Thailand who may be at risk of acquiring HIV or other STIs. We sought to determine the possible uses of such forums for public health intervention, providing new insights for health-promoting organizations and policy makers working in sexual health with mobile populations.

Background

Migration and mobility are inevitably connected with changing environments. Expatriates and travelers may experience a high degree of liminality (described by van Gennep and Turner as transition, a sense of being “being betwixt and between”, as reviewed by Thomassen [6]) within and between environments, raising issues of identity and belonging. Research by Brown and colleagues [4] with Australian male expatriates and long-term travelers residing in Southeast Asia suggested that identity and behavior were strongly influenced by local social networks. Support and guidance on how to adapt to the social and cultural norms were gained from peers.

Such findings have implications for the way that countries develop their response for HIV and STI prevention, treatment, and care. Australian frameworks have highlighted the need for public health strategies to target priority populations, including men who travel overseas frequently for work or leisure [7]. One way this may be achieved is to expand intervention efforts into places or spaces where expatriate communities reside [2-4,8], including online settings such as forums used by expatriates and travelers.

Online spaces provide a medium for education and prevention, an approach used effectively with marginalized or vulnerable groups in areas such as youth mental health [9] and public health interventions with gay and other men who have sex with men [10]. Such settings can enhance social capital and community connection and decrease social isolation. This is particularly the case for those who may be difficult to engage or access through more traditional communication methods, or for those who may not identify with general health promotion messages [3,10-13]. These methods may also reduce socioeconomic or geographic barriers caused by stigmatization and afford some level of anonymity to individuals seeking support or information online [10,14-17].

For mobile populations such as expatriates and long-term travelers, connection online may reduce perceived and actual distance between country of origin and destination. Such spaces may reduce some of the liminality experienced or create a “home away from home” [18]. Online communities facilitate peer influence as platforms for individuals to exchange social, emotional, and informational support, share experiences, and seek advice [19,20]. These functions may prove useful in regard to health advice, resettlement, and language, as well as contributing to a sense of belonging [21,22] or a deepening connection to the destination country and others within the peer and social network [18,23].

The Study

There is a lack of literature describing the online information-seeking behaviors of expatriates and other long-term travelers and how advice from their interactions with one another online may influence risk and protective behaviors. This study built on our understanding of Australian expatriate and long-term traveler risk behavior, culture, and experiences [3,4] and the lessons learned from previous successful use of peer influence models with communities and populations at risk for acquiring HIV and other STIs, particularly in Australia [24].

This paper describes an in-depth analysis of social interaction in 1 online forum used by Australian expatriates and travelers in Southeast Asia. We identify the way in which the forum functions as an online community, describing engagement between users; user identity and how the forum mediates this; types of advice and information shared and acceptance of that advice; and perceptions of risk. We make recommendations for policy makers and health-promoting organizations to use these findings to develop, improve, and expand the reach of public health interventions to reduce the transmission and impact of HIV and other STIs with mobile populations who are hard to access.

Methods

Overview

This research was part of a larger qualitative study to determine whether the social networks of Australian male expatriates and travelers in Southeast Asia can support strategies to reduce or prevent the transmission of HIV and other STIs [1]. The focus of this research was to develop greater understanding of Australian expatriate and traveler culture, behavior, and socialization and the potential for members of the target group to act as social influencers around knowledge, attitudes, and behavior. We used conversations from online forums as (1) a source of data and (2) an audit of spaces that expatriates and travelers frequent to assess the online environment for its potentiality for intervention.

Conceptual Framework and Methodology

Symbolic interactionism provided the conceptual framework underpinning this study, as it has useful application to public health [25] and to sexuality and HIV specifically [26]. The symbolic interactionism perspective supports the idea that social interaction is used to construct reality and that individuals interpret and respond to objects and others' actions based on meaning that is created by interaction [27]. Analyzing forum discourses in this way provided insight into how individual attitudes and behaviors were influenced through social interaction. Charon [28] suggested that symbolic interactionism allows for exploration of the development of self and self-identity and how this is influenced through social interactions. We used this point of view when exploring the transition from novice forum user (newbie) to experienced forum user (expert) and to understand how individuals may come to self-identify as an expatriate or long-term traveler.

Research Team

The research and authorship team was composed of 5 members experienced in public health research. Of these, 2 were students at the time of writing. Several members of the research team had experience working in community bloodborne virus organizations, while others had experience working with marginalized or vulnerable groups through qualitative and participatory action research. All members of the mixed-sex team had spent time in Thailand, with 3 of the members collaborating on previous research in Phuket at the commencement of the research project. Members of the team were also experienced in conducting research in the use of online strategies for public health [14,29-31].

Selection Criteria and Forum Search Strategy

We undertook a comprehensive internet search over a 2-month period to identify forum users for inclusion in this study (Figure 1), described below.

In the first stage, we identified online forums frequented by the target group (Australian male expatriate or long-term traveler to Southeast Asia) through an internet search. At the time of writing, there were at least 10 online forums with thousands of members that Australian male expatriates and long-term travelers were using.

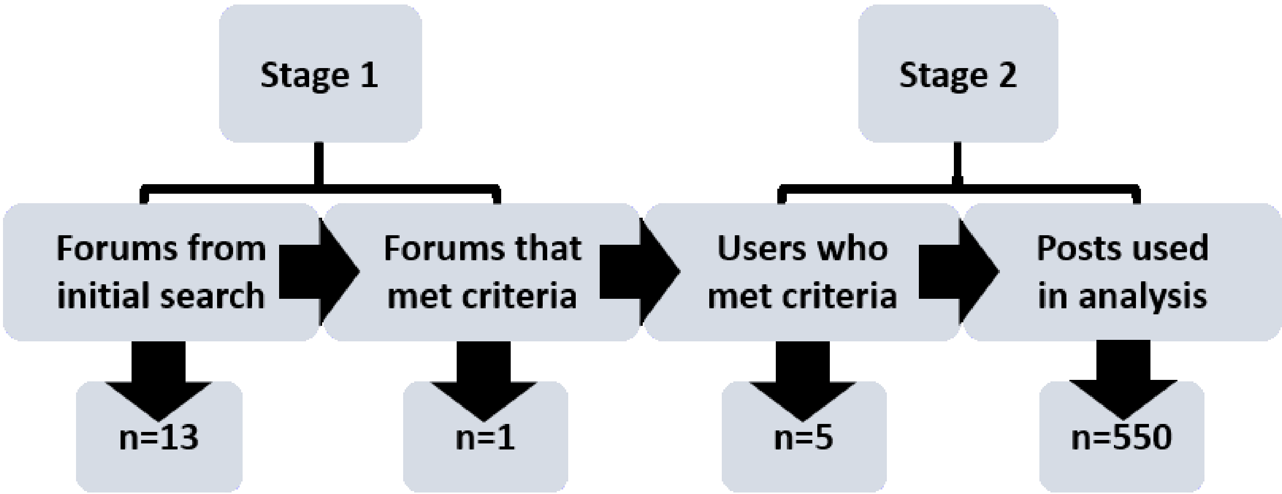
We determined the internet search terms by reviewing commonly used terminology on a variety of forums and a thesaurus search, guided by a review of the literature. Members of the research team provided consensus on search strategy terminology. We entered search terms into Google (Google LLC, Mountain View, CA, USA; Textbox 1) and identified a total of 13 forums.

Search outcomes were checked by 2 members of the research team to ensure consistency. We selected potential forums according to a list of predetermined criteria (Textbox 2). These included whether the forum met the criteria for an online community as operationalized by Herring's 6 dimensions: (1) active participation, (2) shared culture and norms, (3) roles, rituals and hierarchies, (4) a distinct identity, (5) solidarity, and (6) support and conflict resolution [32].

Of the 13 forums, only 1 met the selection criteria and was included in this study. We excluded other forums because (1) we were unable to access a sufficient number of posts, (2) the nationality or sex of users was unclear, or (3) sufficient data were not publicly available.

In the second stage, we searched the identified forum for users who self-identified as Australians, who had resided in or were currently residing in Thailand, and who had created over 100 posts (determined to be a sufficient number to enable the analysis of the socialization processes along the trajectory of forum user newbie to expert [33]). Using these criteria, we identified 5 users for inclusion, and we considered their posts and interaction with other members for data collection.

Figure 1. Process of identifying users.



Textbox 1. Google search terms.

(Forum OR blog OR chat room) AND (Expat* OR foreigner OR 'long term traveller*' OR 'permanent tourist' OR 'permanent resident') AND (Thai* OR 'South East Asia' OR South Asia OR Southasia) AND (Australia* OR Aussie OR Oz)

Textbox 2. Forum inclusion criteria.

Posts are accessible to the public.

Users include Australian males who have resided or are residing in Thailand.

Allows identification of the nationality and sex of users.

Allows individual user's post history to be tracked.

Conforms to Herring's definition of an online community [32].

Ethical Considerations

Ethical challenges related to conducting research within online communities include how, whether, and from whom informed consent is gained; whether anonymity can and should be protected; and sensitivities relating to communities that may discover they are being "researched" [34]. We reduced the risk of altering online discussion based on our presence by not making ourselves known on the forum and not becoming members. This was consistent with other studies where researchers have taken on a remote or objective role and allowed conversations to continue unhampered by the presence of an outsider [33]. Curtin University, Perth, Australia, provided ethical approval for this study. In line with the requirements of the institutional ethical approval and to protect the integrity of the forum and the anonymity of users and their contributions, we have not identified the forum and have deidentified individual users.

Data Collection

Because a forum user's post rarely occurs in isolation, meaning would be lost if the post is not considered within the context of the surrounding discourse and interaction with other users. Consequently, we collected both posts and threads. We took the definitions for threads and posts from Arsal and colleagues: (1) threads are "hierarchically organized postings." and (2) posts describe, for example, "a message written in the online community forum" [22]. For each of the 5 included forum users, we collected their first 100 and 10 most recent posts, along with the thread in which they were posted. This involved using the forum member list to search for the profile of each user and then accessing their posts and threads. We then captured the posts and threads as transcripts of activity.

Analysis

Discussion threads on the forum, rather than individual posts, were the units of analysis. We imported transcripts into NVivo 10 software (QSR International Pty Ltd). Each post was analyzed and coded thematically by a member of the research team, and a sample of transcripts was validated by a second researcher. This process continued until each of the 5 users' posts (n=550) had been coded thematically. Then, 3 research team members reviewed transcripts, compared analyses [3], and developed and refined themes. The remaining team members reviewed samples to improve rigor. Themes were not totally emergent but explored against symbolic interactionism concepts of presentation of self, meaning, and socialization [28], with a focus on interaction within the forum.

Results

The following were the key domains produced from the analysis: *the forum* (characteristics of the space and reasons for use), *gaining access* (forum hierarchy and rules), *identity* (presentation of the self and the role of language), *advice, support, and information* (sources of information, support provided, influencers, topics of discussion, and receptiveness to advice), and *risk* (expectations and perceptions).

The Forum

The forum was well used by Australian male expatriates and long-term travelers. Relatively new at the time of writing, it had over 900 members internationally and in excess of 300,000 posts and 7000 threads. Public information included a member list presenting the member handle and avatar, user join date, number of posts, and last visit to the forum. Data on user numbers at any given time (and status as either member or guest) were also available. It was common for the forum to have several hundred active users at any time, with peak use involving several thousand users (comprising members and guest users). Guest access provided limited viewing access to publicly available spaces within the forum. Member access provided users the ability to post on topics, communicate privately with each other, participate in polls, and upload content.

The forum facilitated a space where those visiting or living in Thailand could seek and provide advice, and establish and maintain online and offline social networks. Forum topics included visas, language, navigating cultural differences, health, sex and relationships, where to go for a night out, and how to avoid being "ripped off." Users demonstrated an interest in building a community of like-minded individuals, which appeared to be an expected and enforced 2-way interaction, as evidenced by a post from a member:

> *Whilst forums can be supportive of different points of view, in my view they ultimately work because membership is primarily comprised of like-minded individuals that want to pursue similar goals...In (our) case, it is about genuine desire to understand Thai culture, and give it due respect.*

This sense of reciprocity was reinforced by the forum moderator as critical to new users:

> *...part of the forum is the giving and receiving of information, it is maybe how we learn or get to know someone.*

Users displayed protectiveness toward and ownership over the forum:

> *We are passionate about the Forum so some people will react to some things said as we are all trying to protect what we have here...if you are just Trolling, this is not the place for it.*

Staying connected to each other, and to Thailand, while in different parts of the world appeared to be the primary reason for using the forum. For example, users who now lived in Australia used the forum to "cure the LOS [Land of Smiles, slang for Thailand] blues." Social ties were developed and enhanced through forum use. As a user commented, "It is great how close everyone has become over a Forum. I cannot wait to continue meeting everyone and sharing my story as it goes on." Seeking connection was exemplified in the posts of 1 user, who suggested the forum provided a way to "kill the loneliness" and meet new people when in Thailand. Quick to extend invitations to new and old users to meet in person, he used extensive knowledge of Thailand, including language and music, to provide advice and establish a connection:

> *You sound interesting. You also sound like you would welcome some tips and tricks over a few drinks...I lived in Bkk [Bangkok] for 11 years, speak the lingo but now spend just two months a year there.*

Several users posted prolifically but tended to avoid sharing personal information and instead offered advice on a variety of topics, such as visas, motorbikes, and relationships. The owner of a pub, who also appeared to know other users offline, used the forum to promote his business, without appearing as though it was advertising. He offered himself as a source of local knowledge, noting "I'll help any visitors as much as possible."

Gaining Access

A hierarchy was evident on the forum, with 3 levels of access ranging from publicly available threads and posts to higher-level, invitation-only spaces, not openly accessible. This hierarchy and structure provided users with the opportunity to become more involved and more deeply connected with the forum and peers.

Level 1 was public; members and nonmembers were free to read posts and contribute posts once they had created an account. It contained general information on life in Thailand, such as relationships, visas, and travel advice. Posts of a sexual nature were not permitted. As the forum moderator described, "P4P is not a focus here so keep it general, if you want prices here is not the place." P4P is a term used to describe pay for pleasure, sexual services provided for money. Private threads in the upper levels containing useful and appropriate advice for the public were generally moved by moderators to level 1.

The second level was accessible once a user had made 30 posts. Users shared more personal information, including photos and details of relationships and sexual behavior. It was described as a place where you could "get down to the nitty gritty." A new user deemed "one of us" would be quickly welcomed and encouraged to post more so that they could access this level. This occurred when a user posted for the first time and was told:

> *A few more posts and a whole new world will open up on here.*
>
> *An experienced guy like you...you're [sic] input will be welcomed...*
>
> *You are 3 posts off getting to a totally new world.*

The third level was by invitation only. One of the users, realizing he did not have access after posting on level 1 over 50 times, asked how to gain access and was told to send a private message to the moderator as "It's a secret handshake not a post count." He then gained access ("I've been admitted to the secret society. Now I'm off to practice that handshake ;)") and was told by another forum user to "enjoy and contribute...some smut 555" (5 in Thai is pronounced *ha*).

An administrator oversaw forum operation along with 2 moderators. Rules guided forum behavior, which were rarely but explicitly spelled out for users:

> *...no personal attacks will be tolerated!! Any personal abuse will be deleted. Repeat offenders will be given a yellow card [sporting reference relating to the use of a yellow card to caution a player about their behavior].*

Interaction demonstrated clear self- and peer moderating. Users reinforced expected behavior regarding contributing and valuing opinions and respecting Thai culture. Users quickly excluded new users who did not meet rules:

> *If you are here to play games...well we are not game players and we will just go quiet. Welcome to the Thai way. We just go quiet.*

Those familiar with the rules quickly resolved miscommunication or disagreements. An example of this was when a user posted a link to discuss with other members but did not contribute his own opinion. Another user challenged him, "May I ask what your problem is? You post a vid, people are responding to it, without any contribution of your side". The first user responded, "You are right it is a discussion and I have not offered an opinion." He attempted to prevent further miscommunication, "I do enjoy your posts, which show a keen understanding of the human condition. I think...wow there are some smart dudes on this forum."

Identity

Users decided on their presentation of self, creating online avatars and identities, and providing data establishing their credibility and belonging. For example, one user described himself as a "no-one in Australia and a VIP in Thailand."

Each of the 5 included users identified as Australian, were proud of their culture, and identified as "Aussies in Thailand." Posting in the forums reinforced this sense of Australian identity in relation to law, food, sport, or society, for example, a posting about Australian-style bars: "Chiang Mai's only genuine big Aussie pub...Great old fashioned Aussie style hamburgers and more..."

For some users who traveled back and forth between Australia and Thailand, there was a clear delineation between their identity at home and abroad:

> *Thailand is sort of like my "what happens in Thailand stays in Thailand." Two weeks of partying real hard then back to the "real world" as you call it.*

Posters used a combination of Thai and Australian-English slang that appeared unique to the English-speaking expatriate community and, most particularly, Australians. Users explained the meaning of phrases they used when asked, and a specific thread covered basic abbreviations, slang, and the use of ideograms or emojis (this was one source of information for us regarding terminology with which we were unfamiliar). For example, while ATM was used for "at the moment" it was also used to describe "a man who dispenses cash to a TG [Thai girlfriend] or BG [bar girl]." The use of this specific language appeared important in establishing commonality and determining how quickly new members were accepted:

> *Heh heh you sound sufficiently deviant* .

In his first post, a user presented himself as being "one of you," using language demonstrating he had spent extended periods of time in Thailand and knew the language well, ensuring he would have a role to play on the forum as a source of advice. He used language that would be familiar to other users, such as *falang* (Thai for a foreigner of Western descent, also often written as *farang*).

A similar approach was taken by another user introducing himself as an "Aussie pervert who loves motorbikes and football." He was immediately accepted and received welcoming comments, such as "well you tick all the boxes 555...WTTB [welcome to the board]." It is important to note that the use of the word pervert here is culturally specific and used to describe broad sexual interests in a humorous way, but it does not necessarily relate to a technical or formal definition of pervert, particularly where it might relate to illegal sexual activity.

Advice, Support, and Information

Users gave and received a variety of information and advice and provided different levels of support to one another. Posts under the topic heading Trip Reports shared the ins and outs of recent travel, including sexual encounters. Users learned and shared through stories of caution, romance and relationships, sex, mentoring, health risks, and culture, which created commonalities and built rapport.

Discussions were often based on what was reported in the news, with an avatar created specifically to post about news. Users were quick to incorporate statistics, anecdotes, or news from a variety of sources into discussions with varying levels of accuracy and evidence. Demonstrating the power of a cautionary tale in mediating behavior, a user posted in response to a story about a fatal road crash:

> *I love cruisin' around the provinces during my Thai holidays, but have always been aware that the risks are so much higher than in Oz. Hearing of this tragedy only makes me so much more aware. I always intend to travel on during daylight hours but sometimes drive into the night to get to a desired destination. I think I will now take more care in planning my times of travel and be ever mindful to drive defensively.*

Some users acted as influencers, encouraging participation from others (the first 50 users to post were given the title of Founding Member):

> *We, the founding members, can only impart so much knowledge, experiences and advice. The forum needs the input of others, like yourself to cover all the bases needed.*

Key individuals held roles as "sages" (eg, "I was at [X's] 'Table of Wisdom' (555) y/day afternoon...," referring to an individual and their bar and the way in which they "held court" in that space). In this way, they told stories about the support that they had provided for newbies. This established or reinforced their role as a credible expert:

> *Well he was really intrigued, but I could see he was a bit out of his element, so I asked if he wanted to meet up at our hotel that night, and we'd introduce him to [the area]. He was all for it...we had a blast both that night and last night...The funny part was, when we saw him that first night he said "I want you to know, you have successfully mentored me!" "What do you mean?" I said, "Well" he says, "I got a massage today, and the girl giving me the massage was really nice, so I asked her out to dinner, and we're going to see the elephant show as well, and she'll be at the boxing with me tomorrow!*

In relation to romantic or sexual relationships, advice sought and information shared was often explicit and detailed. A new user described his experience:

> *In hindsight...after my sickness I seemed to totally lose all sex drive. It wasn't at all like me...From then on I became more a peaceful observer rather than an active hunter. The more the "sex sell" was offered the further I felt pushed away. I became too aware of the business side of things, the desperation and felt sorry for some of the girls' situations. It was like being at a disco when all the lights are turned on and the music stopped, the vibe dies and certain realities become more apparent...Probably just need to spend more time on the prowl and have a bit more determination? Having a GFE [girlfriend experience] would have been nice, but I didn't have much expectation. As a result I only packed 3 boxes of condoms of which none were used. 555*

In response, another user provided advice and empathy, establishing commonality and solidarity:

> *Mongering [loosely defined in this context as seeking sex] isn't for everyone. It seems like you enjoyed your holiday, but if you ever come back, see about finding a wingman. I think that will make it a lot easier and more enjoyable for you to go out.*

Users appeared generally receptive to and accepting of advice and information provided by others on the forum, often explicitly seeking it. For example, a new user posted:

> *Thanks for the replies gents, and for not ripping me a new one for poor searching of the forum! Managed to get one night with a couple of other like-minded individuals...am very familiar with the P4P scene and frankly love it. What I really want to find out...any BJ [slang for blow job, oral sex] bars or decent massage parlors for a bit of light relief...?*

In response another user posted:

> *I've never found a BJ bar, but there are dozens of massage shops all over...you can casually wander up and down til you find a spot you like the look of. Any more info than that and I'd be spoiling the adventure.*

Risk

Experienced users reinforced a liminal space of adventure and temptation. The level of or willingness for taking risks seemed to be based on active decision making, previous experience, location, advice from others, and the role of luck or fate. For some, risk was considered to be part of the reason for travel (or being an expatriate or long-term traveler), while for others risk was an expected byproduct of the travel. Users discussed and described a range of issues, including untrustworthy airlines, motorbike use, road use, scams, travel insurance, or STIs: "I wonder if travel insurance would cover you if you got HIV or some other STD [sexually transmitted disease] overseas 555."

Expectations were presented around the exotic and erotic, suggesting generally permissive attitudes toward time away. Sex and alcohol and other drug use was normalized as part of the expatriate or traveler experience:

> *Other than the great food, weather and beaches why not top it all off with something you can't do at home? Walk straight into a bar, pick up a chick usually much younger than yourself and go home and have fun all night long? Eat sleep boom boom REPEAT!!!*

Self-control seemed to underpin risk taking or risk management for some (eg, "I had a sober week out of the three last trip...stuck to soda waters but they were still trying to give me shooters as well") with users frequently describing that "temptation is not far away in Thailand..." requiring moderation and discipline:

> *One of the biggest hurdles living in LOS [Land of Smiles]is all the temptation whether it be the girls, the food, the partying it's all got to be done in moderation or health and weight problems creep up on many expats I've known here.*

A sense of frustration toward those perceived as "not following the rules" was exhibited by others. These appeared to be generally accepted and known, and legitimized the identity of expatriates or long-term travelers, differentiating them from other vacationers. Personal responsibility, luck, and karma featured in many descriptions of risk taking:

> *What is it about being on holidays that warps people's minds?? They go off and do things they wouldn't normally do at home. Hire a bike or scooter and take on roads they know nothing off and no knowledge of local driving in one of the most lawless drivers in the world...but hey...I'm on holiday so let's do it!!! Jump off cliffs, hire a jet ski and ride like idiots, hire a prostitute and go bareback...but it's holiday time...FFS [for fuck's sake]!! Then when they come undone it's everyone else's fault.*

Condoms were mentioned with regularity, with discussions relating to frequency of use, use with different partners, and the efficacy of different condom types:

> *Except for one occasion I have never gone bareback and use condoms always. Never had an STI either, maybe more good luck than anything else.*

There appeared to be a range of knowledge and understanding or concern regarding the difference between pregnancy prevention and STI prevention, and interventions to address these issues: "Speaking of condoms...I ALWAYS used them when I had sex with a woman who was not taking the pill. Never had a failure..."

Discussion

Principal Results

Interactions illustrated complex processes of socialization, acculturation, and identity formation and presentation among Australian expatriates and travelers. Key themes emerged regarding advice and support, perceptions, and expectations around risk taking, which have particular resonance relating to prevention of HIV and other STIs. A large number of users were active at any one time, as well as a range of other viewers, who may have included observers, trialists, or those seeking information rather than the reciprocity inherent in greater participation [35].

The forum functioned as an online community providing a space to share common interests and confirmation, reassurance, or affirmation of beliefs and experiences. There was evidence of unique language, norms, and processes for managing conflict [32]. This self- and peer-moderating behavior demonstrated a peer network with clear rules that created and reinforced culture. Users exhibited intense loyalty toward the forum, which, consistent with findings by Hiller and Franz [18], suggests development of a nascent identity rooted in distinctive language, rituals, folkways, and collective network consciousness.

Key influencers emerged, including those with formal roles, such as moderators and longer-serving, high-posting members, who may, as Kavanaugh and colleagues [36] have suggested, be considered bridges in the community, capable of expediting information distribution. We noted layers of complexity, with some users interacting not only in general forums, but also in social spaces outside the view of the public, including offline, other forums, and members-only sections. These interactions appeared to enhance social connectedness, building and augmenting online and offline relationships [37].

The forum provided significant social support, information, and advice about certain health issues, including HIV and other STIs. This was both directive (practical advice) and nondirective (sharing personal experiences) [38] and in particular focused on informational and emotional support. While many users may have initially joined the forum seeking information, participation continued due to the relationships formed with other members. Risk perception and expectation among users varied. For example, it was clear that, despite sharing stories of risk behaviors, some users did not consider HIV and STIs to be personal risks. Further, much of the information provided about these issues was based on anecdote and word-of-mouth. It appeared that, for many, risk taking, including seeking sexual services or trying something new sexually, was a key expectation of travel or the experience of being an expatriate or traveler.

Comparison With Prior Work

Cultural norms and rules influence the operation of communities and networks [39]. Previous research examining sexual and social networks of men who have sex with men and HIV risk suggested that common norms regarding risk characteristics and behaviors are created [40]. Communities, such as this forum existing predominantly online, gradually develop norms as members interact and debate and agree on what is acceptable [41]. We found sophisticated governance regarding acceptable behaviors and a preestablished network with sustainability and structure. These elements are important to the strength and stability of a peer network, and are important considerations for intervention using a social network or peer approaches such as those used with people who inject drugs [42,43] or men who have sex with men [40].

Members mediated the behavior of new users, and the moderator enforced or reinforced group norms. This generally appears to be the case in online forums, where rules and norms reduce unwanted behavior [44,45]. In this case, it is unclear whether these rules and norms deterred people from joining or inhibited contributions to the community; however, based on the number of users and overall posts, the impact was likely minimal and may have been a way to filter out those less likely to participate "appropriately." Additionally, the forum encouraged registration to access greater levels of privilege and a perceived period of probation in which behavior of new members was observed and supported (or not) [46]. This is consistent with other literature suggesting that the use of reputational and trust metrics can support the management of online communities and prevent or reduce abuse [32].

Studies suggest that key features mediating the success of online communities include trust, honesty, and reciprocity [47-50]. We found that reciprocity was an expectation in this forum, for example, where users read messages in a thread but didn't post and were subsequently criticized as not contributing in the spirit of the forum. A study on influences of consumer behavior in online travel communities concluded that travelers were more likely to follow advice if the online community was trusted and if information provided was perceived to be useful [51]. Kavanaugh [52] has suggested that online networks can build two kinds of trust within groups, defined by Putnam [53] as thin trust (not as personal and established through social relationships that are indirect) and thick trust (triggered by intensive contact among members). The results of this study found evidence of both thick and thin trust with frequent, high-intensity participation by some members, including moderators and founding members, as well as infrequent participation by those seeking information or participating in the lower levels of the forum.

Communities and groups all contain individuals who influence others and who are often explicitly named and rewarded [45,54,55]. On this forum, they were named founding members, gaining access to more private levels after posting frequently, or were given a title of moderator, defined by the forum as "users who are particularly helpful and knowledgeable in the subject of the forum they are moderating." In this way, they could be seen as influencers or opinion leaders. It has been suggested that engagement, positivity, and effective support may be gauges of influence [54,55]. The use of influencers in interventions is an effective vehicle to communicate information in a manner deemed culturally appropriate to peers, who will in turn more readily receive such information or support [56]. This is a model described in the literature in relation to diffusion of innovations relating to HIV prevention or risk within a network [57]. We found that this community demonstrated many similar characteristics. This is consistent with positive outcomes from historical network-level studies indicating the effectiveness of opinion leaders and peers [58,59] in reducing sexual risk taking and in studies exploring the positive impact of peer support for men living with HIV [60,61].

Community connection can play a significant role in reducing stressors connected with migration, providing a social support system, which can reduce psychological distress or culture shock [62]. Our study found a range of advice, information, and support provided and sought. Interaction influenced knowledge and behavior related to health (including risk taking and health protection) and relationships, as well as the migration experience. Our results resonate with those from other research [38,63-65], including in the context of Web- and peer-based interventions examining mental and sexual health promotion targeting men who have sex with men and same sex–attracted young people [29].

Cutrona and Suhr [66] have proposed a system of social support categorization comprising emotional, informational, social network, esteem, and tangible support. Consistent with this categorization, we found evidence of all forms of support categories, particularly informational and emotional support. Previous studies suggested that members in online communities who receive emotional support will remain members longer than those receiving only informational support [67] and, further, that disclosure is more likely to elicit emotional support than question asking. Our study, consistent with others, found that informational support accounted for a large proportion of interaction [65,68] posited to be because users participating in specific topic forums have similar interests or problems [69]. Online support can be empowering for individuals, and sharing stories can affect health behaviors, including self-care and help seeking [63,70,71]. However, as we found to some extent in this study, peer support may also reinforce perceived unhealthy behaviors or norms or may influence others to make more risky decisions [72].

Forums can be a source of health information as well as a conduit for such information [63]. We found that users critically considered the information presented, engaging with and using advice and support, which most resonated with personal experiences [73]. Consistent with other studies, the information provided by other men in the forum (peers) appeared to be well considered, often more highly valued than advice from health professionals or expert news sources [70,73]. While personal narratives may not always be reliable and in fact have iatrogenic effects [70,74], studies suggested that most information presented in forums is actually of relatively good quality [63]. This reinforces that forums are effective platforms for dissemination of health information and that peer information based on personal experience is considered generally trustworthy [73].

"Communification" has been described as connecting an individual to a community involving a process of meaning making through communication of symbols that can arouse strong attachments [75,76]. This forum exhibited features described by Baron and others as particular to online communication with stylistic and technical peculiarities contributing to the creation of a specific and unique language, credited as important in building solidarities [77,78]. This presented through the use of slang, humor, and ideograms unique to forum-using expatriates. We found that users maintained a strong sense of Australian identity despite significant time spent in Thailand, with Australia as a symbolic anchor [18]. Members exhibited a keen sense of place and identity—as "Aussies in Thailand"—with related loyalty to place of origin and new contexts. Thus, while the forum served to sustain old ties and contribute to new identities [18,37], it may also have contributed to homogenizing or reifying cultural differences, which could be counterproductive to migration, reducing social mobility or acculturation or reinforcing social norms that may be deemed unhealthy.

Posts highlighted how users presented self. These findings are consistent with observations by Goffman and others who suggested that, when interacting socially, individuals put on a "front," or create an idealized self, aimed at managing impressions and perceptions [79-81]. Users sought information from others in order to determine how interaction occurred, using that knowledge to portray a version of self that was acceptable to others and that reduced the likelihood of role clashes. As with other research [81], we found that, even when there was connection between online and offline spaces, users spent time creating the identity they sought to present to others by managing the information they shared with other forum users. We found, similar to others [72,82,83], that users took on a range of roles and participative stances, with evidence of protagonists, experts, befrienders, and lurkers [35,46]. Our findings, as in the broader literature [46,54], found that the more charismatic characters helped to draw out others in their participation by providing mentorship and "wisdom."

Strengths and Limitations

To our knowledge, this is the first study to investigate Australian male expatriates' and long-term travelers' social interactions within an online setting, particularly from a public health perspective. The observational nature of this research was a strength. Analysis of publicly available content allowed us to witness real-world interaction unobtrusively. The influence of our presence was removed, allowing individuals to communicate openly in the online environment [16]. However, by remaining invisible, we were unable to pose direct questions or comments that could elicit posts relating to aspects of the broader study, in particular specific knowledge, attitudes, and risk behaviors of users associated with sexual health and STIs.

While we acknowledge that posts from a single forum cannot provide definitive accounts of all aspects of the lives of expatriates and travelers, it was a large and valuable source of naturalistic data [13]. A range of expatriates and travelers were represented with different profiles and demographics (eg, different ages and relationship status; regularity of posts; experience with travel; and social and business intentions), which, while not intentional in sampling, was a useful outcome.

Pragmatic considerations meant that we collected posts in a limited time frame (around 8 weeks). However, analysis of the first 100 posts [33] and last 10 posts, and consideration of the interaction within threads, allowed for exploration of socialization over time and levels of engagement between several users (15 to 20 or more). We encountered difficulty accessing information "behind the wall" in the higher levels of the forum, relying on publicly available information and information in the lowest level of the forum, along with general accounts information located in the higher forum levels. What we did find in the lower level of the forum, however, was a range of information and interaction that was relevant to the study, particularly as this would be the level most accessible to those most in need of information.

The nature of the research meant that, when the meaning or context of posts was unclear, we were unable to seek further clarification. However, the use of language including slang, emojis, and avatar identities provided some further insight into how users presented themselves to others.

Users chose how much personal information to share in forums and how they would present themselves. Additionally, users who posted and responded to personal stories might be different from those who did not. However, the comparative anonymity online and the high degree of trust and credibility that was evident suggest that users shared a significant amount of honest information about themselves, particularly where users were connecting with one another both online and offline.

Implications for Health Policy and Practice

The study provides an important contribution for policy makers and health-promoting organizations in sexual health looking at opportunities, or unsure how, to adapt community and network engagement strategies to this emerging area. Our findings support the limited research insight about these networks and communities and the way they interact or build community. This knowledge is key to identifying and developing or adapting strategies. As an example, mobile populations are named in the Australian national strategy [7] as a priority group, but little clarity is provided for organizations or policy makers in how or where to respond, nor has there been until recently a solid synthesis of knowledge in this area.

We suggest several considerations from this research for the development of policy and interventions to access this hard-to-reach group that is vulnerable to HIV and other STI transmission. These relate specifically to intervention design, evaluation, and future research.

Intervention Strategies

Participants in the forum provided and received social support, and influenced one another, factors cited as critical in creating peer norms and behaviors, including attitudes about sexual risk behaviors [40]. Findings highlight further opportunities to optimize support in such forums as a public health or primary care strategy. However, it has been noted that interventions must be well connected to the networks in which they are conducted [29]. Thus, it is difficult to determine whether health care professionals and health promotion practitioners would be readily allowed into this forum or others like it in expert roles to share information.

Consequently, while peer influencers and educators can be used for diffusion of messages and information to others in the forum and wider expatriate or traveler community, influence is best done indirectly. Health-promoting organizations could work to influence those who hold key positions within the forum to amplify the visibility of timely and accurate information and advice about HIV and other STIs. The use of opinion leaders working with health professionals is a strategy that has demonstrated utility in peer influence interventions used to respond to HIV, other STIs, and bloodborne viruses among men who have sex with men, sex workers, and people who inject drugs [40,43,84].

Based on our findings, an intervention using these forums can leverage positive norms around risk and relationships and increase the social capital of expatriates and travelers, including disaffected risk takers. Intervention design should provide opportunities to examine risk scenarios and provide specific information and education about the context of unsafe sexual behavior in countries with a high prevalence of HIV and other STIs, as well as promoting social connectedness [8].

Context of Intervention Design

Peer influence methods have been generally most successful and sustainable when driven and undertaken by peers who were part of the community and supported by broader health promotion strategies [24,42]. Peer leaders in these contexts would also engage with the broader stigma, discrimination, and rights-based issues that underpin effective prevention of HIV, other bloodborne viruses, and STIs [24,42,85].

Accordingly, in considering the amenability of such a model, health-promoting organizations and commissioning agencies must pay attention to whether the common attitudes or cultures of such online communities are compatible with an overall health promotion and rights-based approach. This is a challenge highlighted in both historical and contemporary gay community programs where significant work has been undertaken in peer programs to reduce structural and community inequities, including stigma toward people living with HIV, racism, and sexism [86]. In the current context, issues of race and gender-related stigma require further exploration in the design of interventions.

Interventions using forums should be developed in partnership with, or supportive of, local organizations; complement any in situ interventions in expatriate or long-term traveler destinations; and support information provided to expatriates and travelers via social marketing or in primary care. Support for local services may need to be considered for any increased use of health services as a result of better awareness of risks promoted via the forums. It may be that costs to destination countries prove minimal, with anecdotal evidence that expatriates and travelers seek health care in their country of origin for issues such as HIV and other STIs, but they should be factored into intervention design.

Evaluation and Research

Policy makers should commission further research to expand the findings of this study and better understand the way in which expatriate and traveler networks function (both online and offline), specifically the cohesion, density, and homophily of networks [87,88]. A social network analysis within and between forums would complement our findings. We recommended that research and evaluation be undertaken of a formal Web-based outreach intervention. The forum may also be considered as a space to develop, test, implement, or evaluate safer sex messages for an online component of broader campaigns or to promote testing and treatment options, including treatment as prevention.

Interventions require appropriate funding and must be of sufficient duration and dose to see positive outcomes. Policy makers should work with health-promoting organizations and researchers to develop effective indicators of impact and strategies to disseminate findings widely, preventing where possible duplication of interventions and research and allowing positive findings to be adapted or adopted for other contexts, for other health issues, or at scale. The cost effectiveness of such interventions should also be established [8].

Conclusions

Online communities of expatriates and travelers sustain and facilitate social ties; they make geographically distant places more proximal, linking dispersed peoples to their country of origin, as well as to others in the diaspora. Whether explicitly for health or not, such forums influence and affect social connectedness, help seeking, and other health behaviors, both positively and negatively. We conclude that, to access mobile populations vulnerable to acquiring HIV and other STIs but located outside the jurisdiction of specific countries, sexual health policy makers and health-promoting organizations should use such forums to extend the reach of public health interventions. When sensitive and appropriate engagement are used, these forums provide a valuable setting to engage a priority population, provide supplementary sources of support and information, and complement other strategies to prevent or reduce the impact of HIV or other STI transmission in mobile populations.

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Conflicts of Interest

None declared.

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Abbreviations

STI: sexually transmissible infection

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Original Paper

Experience With the Use of an Online Community on Facebook for Brazilian Patients With Gestational Trophoblastic Disease: Netnography Study

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Abstract

Background: The term gestational trophoblastic disease (GTD) includes both complete and partial moles, which are uncommon nonviable pregnancies with the potential to evolve into a malignancy known as gestational trophoblastic neoplasia. While highly curable, the potential for malignancy associated with molar pregnancies worries the patients, leading them to seek information on the internet. A Facebook page headed by Brazilian specialized physicians in GTD was created in 2013 to provide online support for GTD patients.

Objective: The objective of our study was to describe the netnography of Brazilian patients with GTD on Facebook (FBGTD) and to evaluate whether their experiences differed depending on whether they received care in a Brazilian gestational trophoblastic disease reference center (BRC) or elsewhere.

Methods: This was a cross-sectional study using G Suite Google Platform. The members of FBGTD were invited to participate in a survey from March 6 to October 5, 2017, and a netnographic analysis of interactions among the members was performed.

Results: The survey was answered by 356 Brazilian GTD patients: 176 reference center patients (RCP) treated at a BRC and 180 nonreference center patients (NRCP) treated elsewhere. On comparing the groups, we found that RCP felt safer and more confident at the time of diagnosis of GTD (P=.001). RCP were more likely to utilize FBGTD subsequent to a referral by health assistants (P<.001), whereas NRCP more commonly discovered FBGTD through Web searches (P<.001). NRCP had higher educational levels (P=.009) and were more commonly on FBGTD for ≥ 6 months (P=.03). NRCP were more likely to report that doctors did not adequately explain GTD at diagnosis (P=.007), had more doubts about GTD treatment (P=.01), and were less likely to use hormonal contraception (P<.001). Overall, 89% (317/356) patients accessed the internet preferentially from home and using mobile phones, and 98% (349/354) patients declared that they felt safe reading the recommendations posted by FBGTD physicians.

Conclusions: This netnographic analysis of GTD patients on FBGTD shows that an Web-based doctor-patient relationship can supplement the care for women with GTD. This resource is particularly valuable for women being cared for outside of established reference centers.

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KEYWORDS

gestational trophoblastic disease; social media; Facebook; mobile phone

Introduction

The term gestational trophoblastic disease (GTD) describes a group of placental neoplasms, including both benign forms, partial and complete hydatidiform moles, and malignant forms, collectively referred to as gestational trophoblastic neoplasia (GTN). The latter includes invasive moles, choriocarcinoma, placental site trophoblastic tumors, and epithelioid trophoblastic tumors [1]. Partial and complete moles are nonviable pregnancies that progress to GTN in around 1%-5% and 20% of cases, respectively [1-5]. Patients with partial and complete moles have a particularly unfortunate situation: the happiness of a desired pregnancy is suddenly replaced with mourning a pregnancy loss complicated with the additional burden of a potentially life-threatening diagnosis [6]. While most cases of GTN follow molar pregnancies, GTN can occur after any gestational event, including ectopic and term pregnancies, sometimes delaying diagnosis and worsening prognosis [1].

In Brazil, 1 case of GTD occurs in every 200-400 pregnancies [7]. In this continent-spanning country, with 208 million inhabitants [8] distributed over a large territorial area of 8,516,000 km^2, the treatment of women with GTD in reference centers is a challenge, especially outside state capital cities [9]. In 2013, the International Society for the Study of Trophoblastic Disease supported the development of the Brazilian Association of Gestational Trophoblastic Disease (Brazilian Association of GTD) [10]. Since then, this society has been working with health professionals all over Brazil to improve GTD treatment. Currently, there are 38 Brazilian gestational trophoblastic disease reference centers (BRC), with more than 25,000 cases of GTD treated to date and about 1500 new cases seen each year. This medical care is linked to the Brazilian public health care system and is free for patients. This has led to major advances both in the care of patients with GTD and in research on this disease in Brazil [10]. Earlier diagnosis of molar pregnancy and close postmolar follow-up using human chorionic gonadotropin (hCG) monitoring to promptly recognize GTN [11] and initiate appropriate treatment with chemotherapy in reference centers has led to dramatic decreases in maternal morbidity and mortality associated with GTD [9,12,13].

To supplement the centralized coordination of care and collaboration among BRC, the Brazilian Association of GTD created an online community on Facebook (Facebook group of the Brazilian Association of GTD; FBGTD) in 2013. This online community supports patients, patients' relatives, and health care professionals by providing advice about GTD and helping direct patients to treatment at BRC. While there few well-documented health care initiatives on Facebook, several Web-based communities focused on disseminating scientific data and combating false information have been shown to improve medical knowledge and the quality of patient care [14,15]. Facebook readily facilitates the exchange of information and experiences among patients, especially those with rare diseases. This exchange creates valuable relationships that support and empower patients in a way that was impossible before the social media era [16].

Careful observation and study of these Web-based relationships, called netnography, can reveal fears, feelings of unsafety, and unusual behaviors among Facebook users that may not be noted via other methods, such as a questionnaire [17]. A netnographic study has the potential to offer information about patients that may be useful to improve their care. The aim of this study was to document the netnography of Brazilian patients participating on FBGTD and evaluate how the experiences discussed or reported by patients differed depending on whether they received care within or outside of a BRC.

Methods

Study Design

This was a cross-sectional study using G Suite Google Platform and a netnographic analysis of interactions among patients with GTD who were members of FBGTD and were invited to participate in a survey from March 6 to October 5, 2017.

Population

On October 5, 2017, the FBGTD group had 5783 members. Among these members, 807 were identified as GTD patients and comprised the study population. The others were excluded for the following reasons: 92 members were identified as patients' relatives, 2990 were professionals or students from health-related areas, and the others could not be determined due to missing information. Due the nature of this research, this was a convenience sampling, not a probabilistic one.

The Questionnaire

The questionnaire (Multimedia Appendix 1) comprised 33 questions evaluating internet use, GTD history including location of treatment (BRC or not), doctor-patient relationship, emotional well-being, and socioeconomic profile. Patients could answer the survey only after reading and agreeing to the informed consent document approved by the Ethics Review Board of Universidade Federal de São Paulo under protocol number 0019/2017. Group members easily accessed the survey from the first page of FBGTD, where it was prominently displayed.

From March 6 to April 5, 2017, there was no direct encouragement to patients to respond to the questionnaire. From

April 6 to June 10, 2017, the principal investigator, MVD, who presented herself as a nurse from one of the BRCs, sent short message service (SMS) messages inviting patients who had not yet answered to complete the survey. On June 11, 2017, one of the moderators of the FBGTD group (AB) “tagged” patients who had not yet answered, inviting them to participate one last time. We made no further contact with the members of the FBGTD group. Over time, questionnaire responses progressively declined. Survey collection ended on October 5, 2017.

The principal investigator spent at least 3 hours per day observing the FBGTD over the study period to collect data about the pattern of interactions among patients as well as between patients and physicians. These interactions occurred via posts, written comments to posts, or acknowledged “likes” to posts (“thumbs up”). She qualitatively documented any recurrent use of language, symbols, or behavior common among the members of FBGTD.

Statistical Analysis

Patients who answered the survey were grouped into 2 sets for statistical analysis: treated at a reference center (RCP) and not treated at a reference center (NRCP). Quantitative variables were analyzed using mean, SD, median, minimum and maximum, and total valid observations. Quantitative variables were compared using the nonparametric Mann–Whitney test. Qualitative variables were analyzed using frequency and percentage. To compare the groups regarding qualitative variables, we used the chi-square test, Fisher exact test, or likelihood ratio test, as indicated. The level of significance was set at $P<.05$ for all tests. The statistical analysis was conducted using IBM SPSS Statistics version 22 (IBM Corp., New York, USA).

Results

Of the 807 GTD patients who were members of the FBGTD and, therefore, eligible to participate in this study, 367 answered the questionnaire. An additional 11 non-Brazilian women were excluded, leaving 44.1% (356/807) participants who comprised the final population of Brazilian GTD patients, as shown in Figure 1. In the first phase of questionnaire responses, in which no direct encouragement to patients to respond was made, 52.2% (186/356) subjects participated in the study. After sending an SMS text message inviting participants to the study, 23% (82/356) new patients responded to the questionnaire. Finally, an additional 24.7% (88/356) only participated in the study after the request of one of the FBGTD moderators.

Demographic characteristics of patients in the FBGTD showed no differences between 176 RCP and 180 NRCP as shown in Table 1. Notably, the proportion of women living in a city with a reference center was not significantly different between patients treated (79/176) and not treated (70/180; P=.25) at a BRC.

When analyzing the socioeconomic characteristics of the participating members of FBGTD (Table 2), NRCP exhibited higher education levels than RCP (postgraduate education: 53/180 vs 32/176; P=.009). There were no differences in complaints about work problems between the groups; furthermore, there were no differences in the number of employed women between RCP (115/176) and NRCP (117/180; P=.94).

Figure 1. Flowchart summarizing the derivation of the study population. GTD: gestational trophoblastic disease, FBGTD: Facebook group of the Brazilian Association of GTD.

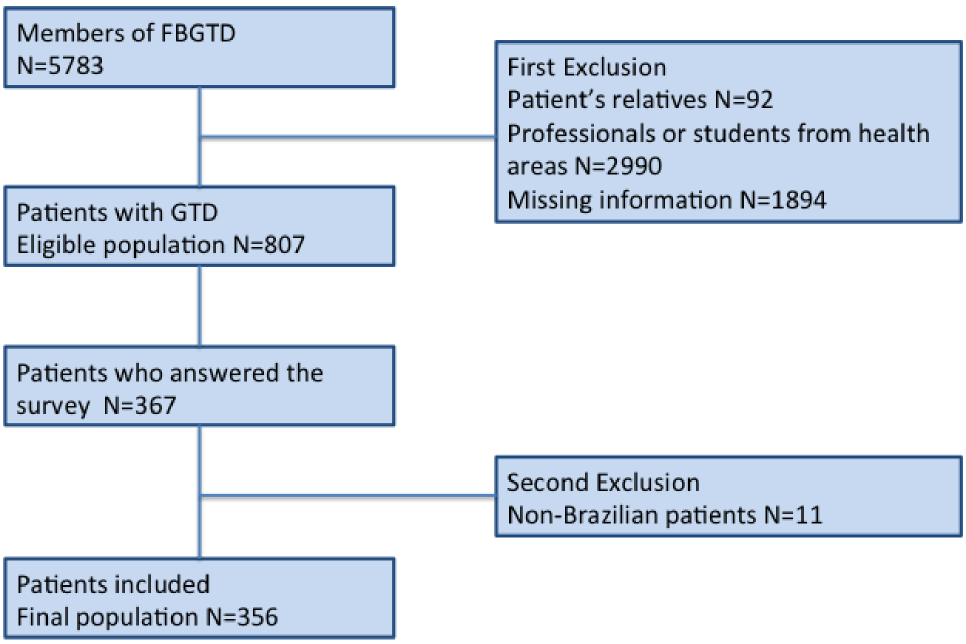

Table 1. Demographic characteristics of the study population by site of gestational trophoblastic disease care.

Characteristics	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value[a]
Age (years), n=354[b], n (%)			.43
<20	11 (6.3)	6 (3.4)	
20-39	150 (85.7)	159 (88.8)	
≥ 40	14 (8.0)	14 (7.8)	
Brazilian region, n (%)			.50
North	4 (2.3)	9 (5.0)	
Northeast	24 (13.6)	22 (12.2)	
Southeast	102 (58)	97 (53.9)	
Northwest	23 (13.1)	21 (11.7)	
South	23 (13.1)	31 (17.2)	
Ethnic origin, **n=352[c], n (%)**			.77
White	94 (54.7)	101 (56.4)	
Black	13 (7.6)	13 (7.3)	
Mulatto	54 (31.4)	58 (32.4)	
Asian	11 (6.4)	7 (3.9)	
Live in a city that has a reference center for gestational trophoblastic disease, n (%)	79 (44.9)	70 (38.9)	.25

[a]Chi-square test.

[b]Two patients did not indicate age.

[c]According to the Brazilian Institute of Geography and Statistics. Ethnic-racial characteristics of the population. Classifications and identities 2013 [18]. Three patients chose not to declare ethnicity or race, and 1 Indian participant was excluded.

Table 2. Socioeconomic and work characteristics of women with gestational trophoblastic disease and members of Facebook group of the Brazilian Association of gestational trophoblastic disease.

Characteristics	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value
People living in the participant's house besides her, median[a]			.14[b]
≤1, n (%)	67 (38.1)	54 (30.0)	.27[c]
2-3, n (%)	87 (49.4)	100 (55.6)	—[d]
≥4, n (%)	22 (12.5)	26 (14.4)	—
Number of people contributing financially to the sustenance of participant's home, median[e]			.44[b]
≤ 2, n (%)	160 (90.9)	159 (88.3)	.43[c]
≥ 3, n (%)	16 (9.1)	21 (11.7)	—
Participants being paid for work during the treatment of gestational trophoblastic disease, n (%)	115 (65.3)	117 (65.0)	.95[c]
Participants reporting some work difficulties to follow their treatment (N=232), n (%)	9 (5.1)	12 (6.7)	.53[c]
Participants for whom vouchers or medical certificates have been refused, n (%)	3 (1.7)	2 (1.1)	.68[f]
Participants experiencing pressure for social security leave, n (%)	2 (1.1)	4 (2.2)	.69[f]
Participants facing financial reduction with significant impact on the monthly family budget, n (%)	3 (1.7)	5 (2.8)	.72[f]
Participants' educational level (n=356), n (%)			.009[c]
Elementary school	12 (6.8)	5 (2.8)	—
High school	85 (48.3)	65 (36.1)	—
University	47 (26.7)	57 (31.7)	—
Postgraduate education	32 (18.2)	53 (29.4)	—

[a]Interquartile range: 2 (1-3).

[b]Nonparametric Mann–Whitney test.

[c]Chi-square test.

[d]Not applicable.

[e]Interquartile range: 2 (1-2).

[f]Fisher exact test.

Most of the patients who answered the questionnaire were in remission from GTD (210/356 after spontaneous remission and 67/356 after chemotherapy; Table 3). RCP felt safer and more confident at the time of diagnosis of GTD (84/176) than NRCP (53/180; *P*=.001). Concordantly, NRCP reported more frequently (55/180) than RCP (32/176; *P*=.007) that what most negatively affected them at the time of diagnosis was the fact that doctors did not explain GTD. RCP more frequently received all treatment from the Brazilian public health system than NRCP (106/176 vs 60/180; *P*<.001). Also, there was more pronounced migration during therapy from the private health system to the Brazilian public health system among RCP (29/176) than among NRCP (16/180; *P*<.001). Although RCP and NRCP both reported similar sexual activity (*P*=.37), notably less than half of the NRCP (86/180) used a hormonal contraceptive method compared with the majority of RCP (121/176; *P*<.001).

Table 4 presents the netnography characteristics of participating members of FBGTD. Of all, 89% (317/356) patients accessed the internet preferentially from home using mobile phones. Facebook and WhatsApp were the social networks most frequently used by patients (327/356, 92%). Instagram use was more frequent among NRCP (114/180) than among RCP (92/176, *P*=.03). Facebook groups of interest among these patients were those that provided answers to questions about the disease and treatment options (246/356, 69%) and that provided exchange of experiences among people who have a problem or a similar interest (274/356, 77%).

NRCP found FBGTD through Web searches (139/180 vs 85/176, *P*<.001; Table 5) while RCP were more likely to be referred to FBGTD through health assistants (64/176 vs 32/180, *P*<.001; Table 5). NRCP were more likely to be on FBGTD longer than 6 months (118/180 vs 95/176, *P*=.03; Table 5) and to raise more questions about GTD treatment (107/180) than RCP (84/176, *P*=.01; Table 5).

Table 3. Clinical and psychosexual characteristics of women with gestational trophoblastic disease and members of Facebook group of the Brazilian Association of gestational trophoblastic disease.

Variables	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value
At what point in the GTD[a] treatment do you find yourself?, n (%)			.22[b]
Waiting for molar evacuation	2 (1.1)	1 (0.6)	—[c]
Postmolar follow-up	30 (17.0)	33 (18.3)	—
Chemotherapy	9 (5.1)	4 (2.2)	—
Spontaneous remission	96 (54.5)	114 (63.3)	—
Remission after chemotherapy	39 (22.2)	28 (15.6)	—
Regarding this[d] statement, how do you evaluate your experience when you received the diagnosis of GTD?, n (%)			.001[b]
Strongly agree	84 (47.7)	53 (29.4)	—
Agree	40 (22.7)	49 (27.2)	—
Neither agree or disagree	0 (0.0)	4 (2.2)	—
Disagree	14 (8.0)	15 (8.3)	—
Strongly disagree	38 (21.6)	59 (32.8)	—
What contributed to the negative experience when you were diagnosed with GTD?, n (%)			
The doctors used complicated words, which made it difficult for me to understand	12 (6.8)	20 (11.1)	.16[e]
The doctors have not explained my disease at all	32 (18.2)	55 (30.6)	.007[e]
Although the doctors explained to me about GTD, I did not understand	10 (5.7)	19 (10.6)	.09[e]
The doctors did not explain how my treatment should be	35 (19.9)	43 (23.9)	.36[e]
The doctors did not explain where my treatment should be	30 (17.0)	35 (19.4)	.56[e]
I did not get to schedule my appointment quickly in the reference center	7 (4.0)	9 (5.0)	.64[e]
During postmolar follow-up, how are you avoiding pregnancy?[f] n (%)			
Hormonal methods	121 (68.8)	86 (47.8)	<.001[b]
Condom	38 (21.6)	53 (29.4)	.09[b]
Behavioral contraceptive methods	19 (10.8)	29 (16.1)	.14[e]
Regarding the location of my treatment, n (%)			<.001[b]
I started in the public health system, where I underwent all my treatment	106 (60.2)	60 (33.3)	—
I started in the public health system, but then I went to the private health system where I underwent all my treatment	1 (0.6)	7 (3.9)	—
I started in the private health system, but then I went to the public health system where I underwent all my treatment	29 (16.5)	16 (8.9)	—
I started in the private health system, where I underwent all my treatment	10 (5.7)	76 (42.2)	—
I am undergoing my treatment at both services (public and private)	30 (17.0)	21 (11.7)	—
How is the relationship with your partner after the diagnosis of GTD? (N=355)[g], n (%)			.48[b]
GTD made us nearer	62 (35.4)	47 (26.1)	—
Our relationship is the same	87 (49.7)	105 (58.3)	—
I feel that my relationship is getting weaker	15 (8.6)	14 (7.8)	—
I broke up my relationship by my own initiative	6 (3.4)	7 (3.9)	—
My partner left me	3 (1.7)	3 (1.7)	—
I had no stable relationship	2 (1.1)	4 (2.2)	—

Variables	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value
How has your sex life been since you were diagnosed with GTD?, n (%)			.37[e]
Similar	112 (63.6)	125 (69.4)	—
Better	12 (6.8)	6 (3.3)	—
Worse	38 (21.6)	33 (18.3)	—
I do not have a sex life	14 (8.0)	16 (8.9)	—
I have at least one child	82 (46.6)	93 (51.7)	.34[e]
Would get pregnant again?, n (%)			.37[e]
Yes	113 (64.2)	127 (70.6)	—
Maybe	32 (18.2)	24 (13.3)	—

[a]GTD: gestational trophoblastic disease.

[b]Likelihood ratio test.

[c]Not applicable.

[d] *When I first received the diagnosis of molar pregnancy, known as hydatidiform mole or gestational trophoblastic disease (GTD), my attending team informed me in a accessible (understandable) and enlightening way what was all this disease about, where and what would be my treatment (and follow-up). I started my treatment quickly after that and felt myself safe and confident.*

[e]Chi-square test.

[f]More than one option could be opted.

[g]One patient did not respond to this question.

Table 4. Netnography characteristics of patients with gestational trophoblastic disease and members of Facebook group of the Brazilian Association of gestational trophoblastic disease who participated in this study.

Variables	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value
Which location do you access internet preferentially from?[a], n (%)			
Home	171 (97.2)	174 (96.7)	.79[b]
Work	42 (23.9)	54 (30)	.19[b]
Most of the time, you access the internet through which mode?, n (%)			
Desktop	9 (5.1)	10 (5.6)	.85[b]
Mobile phone or Smartphone	158 (89.8)	159 (88.3)	.66[b]
Notebook or Laptop	8 (4.5)	10 (5.6)	.66[b]
Which social networks do you participate besides Facebook?[a], n (%)			
Blog	5 (2.8)	3 (1.7)	.50[c]
Twitter	10 (5.7)	17 (9.4)	.18[b]
Instagram	92 (52.3)	114 (63.3)	.03[b]
WhatsApp	162 (92)	165 (91.7)	.90[b]
G+	11 (6.3)	13 (7.2)	.71[b]
Snapchat	14 (8.0)	25 (13.9)	.07[b]
What kind of groups do you seek in Facebook?[a], n (%)			
That provide me emotional support	38 (21.6)	37 (20.6)	.81[b]
That answer my questions about the disease and treatment options	117 (66.5)	129 (71.7)	.29[b]
That promote leisure activities	47 (26.7)	46 (25.6)	.81[b]
That recommend specialized services and professionals	61 (34.7)	49 (27.2)	.13[b]
That provide exchange of experiences among people who have a problem or similar interest	133 (75.6)	141 (78.3)	.54[b]

[a]More than one answer was possible.

[b]Chi-square test.

[c]Fisher exact test.

Table 5. "Tropho-netnography" evaluation of the women participating in the study.

Variables	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	*P* value[a]
How did you find the Facebook group of the Brazilian Association of Gestational Trophoblastic Disease?, n (%)			
Search sites and pages	85 (48.3)	139 (77.2)	<.001
Friend referral	11 (6.3)	9 (5.0)	.61
Patient referral	19 (10.8)	6 (3.3)	.006
Health assistant referral	64 (36.4)	32 (17.8)	<.001
How often do you access this group on Facebook? (n=355), n (%)			.02
Daily	122 (69.7)	103 (57.5)	—[b]
Weekly	36 (20.6)	61 (34.1)	—
Rarely	17 (9.7)	15 (8.4)	—
How long have you been in this group on Facebook?, n (%)			.03
≤6 months	81 (46)	62 (34.4)	—
> 6 months	95 (54)	118 (65.6)	—
What are the main reasons that lead to follow this group on Facebook?[c], n (%)			
I find emotional and psychological support in the group	87 (49.4)	90 (50.0)	.91
I get more information about the disease and treatment	138 (78.4)	148 (82.2)	.36
I receive directions for specialized professional and reference center for treatment and follow-up	68 (38.6)	78 (43.3)	.37
I enlarge my network of online friends	4 (2.3)	7 (3.9)	.38
I have the opportunity to interact with patients with gestational trophoblastic disease	103 (58.5)	102 (56.7)	.72
Have you published or liked something in this group on Facebook?, n (%)			
If NO, why not?[c]	16 (9.1)	18 (10.0)	.77
I do not feel comfortable	4 (25)	3 (16.7)	.68
I would rather just watch	10 (62.5)	11 (61.1)	.93
I think it is a lot of exposure	1 (6.3)	3 (16.7)	.60
If YES, what were the post subjects?[c]	160 (90.9)	162 (90.0)	
Ask questions about my treatment	84 (52.5)	107 (66.0)	.01
Give support to someone who feels discouraged	78 (48.8)	75 (46.3)	.66
Share the success of my treatment	73 (45.6)	76 (46.9)	.82
Receive comfort and words of encouragement	35 (21.9)	41 (25.3)	.47
I liked a publication I found appropriate	116 (72.5)	103 (63.6)	.09
How do you feel about the advice posted by doctors in this group on Facebook? (n=354), n (%)			.62[d]
Completely safe	146 (83.9)	156 (86.7)	—
Partially safe	26 (14.9)	21 (11.7)	—
I have no opinion	2 (1.1)	3 (1.7)	—
Partly unsafe[e]	1 (0.0)	0 (0.0)	—
Totally unsafe[e]	1 (0.0)	0 (0.0)	—
How do you feel about the advice posted by the patients in this group in Facebook?, n (%)			.81[d]
Completely safe	57 (32.4)	57 (31.7)	—
Partially safe	93 (52.8)	99 (55)	—

Variables	Treated at reference centers (n=176)	Not treated at reference centers (n=180)	P value[a]
No opinion	14 (8.0)	16 (8.9)	—
Partly unsafe	9 (5.1)	7 (3.9)	—
Totally unsafe	3 (1.7)	1 (0.6)	—
In addition to specialized physicians, what other professional would you like to actively participate in this group on Facebook?, n (%)			
Social worker (N=356)	30 (17.0)	39 (21.7)	.27
Lawyer (N=356)	11 (6.3)	10 (5.6)	.78
Nurse (N=356)	31 (17.6)	27 (15.0)	.50
Psychologist (N=355)	126 (72.0)	131 (72.8)	.87
I do not see the need for other professionals (N=356)	37 (21.0)	34 (18.9)	.61

[a]Chi-square test.

[b]Not applicable.

[c]More than one answer was possible.

[d]Likelihood ratio test.

[e]These numbers were excluded for comparison because of the small frequency.

Discussion

This netnographic study of GTD patients in the FBGTD indicates that GTD patients find a moderated online community to be an important and trustworthy source of peer support and medical advice. Patients drew psychoaffective support from the online interactions and an improved understanding of the disease and its management. These benefits were most evident among NRCP.

GTD is a rare disease, and outcomes of GTD treatment have improved worldwide with the establishment of reference centers, with exceptional rates of cure and of the ability to preserve fertility [19]. Further distance between the residence of the patients with GTD and the referral center worsens the prognosis of this disease, likely related to delay in the diagnosis, and is associated with more advanced stages of GTN at diagnosis and higher rates of incomplete follow-up [20]. The internet can mitigate these effects, acting as a medium for the diffusion of knowledge about malignant disease [21], including GTD, not only among physicians but also among patients, helping them find specialized services, promoting a rich exchange of information, and, in selected cases, promoting personalized guidance through electronic evaluations using private emails [22].

In Brazil there are 236 million mobile phones in use (113.8/100 inhabitants) [23], which could explain mobile phones as the most common way to access the FBGTD. With the increase in mobile phone ownership, health care providers have become interested in integrating the use of mobile phones in the care of chronic conditions such as HIV, diabetes, hypertension, and asthma [24-28]. Mobile phones are portable, capable of receiving and transmitting data, and “always on.” They also offer health care providers the unique ability to connect with hard-to-reach populations that might otherwise not have access to health care services [29]. Our data showing that GTD patients most commonly have accessed the FBGTD via mobile phone may represent an opportunity to develop apps, monitored by specialized physicians, to facilitate and improve hCG follow-up. Such an innovation would enable the GTD patients to be more active agents in managing their own health care.

Facebook is the most widely used social media platform and has been recognized as a tool to support patients [30,31] and pregnant women [32]. Some medical societies have issued recommendations on how to appropriately use Facebook and other social media. These recommendations, aimed at physicians and patients, highlight how to preserve confidentiality and to avoid medicolegal complications [33]. The Brazilian FBGTD page was created 5 years ago by Drs MV and AB, directors of Brazilian Association of GTD, observing these recommendations. Since then, they and other Brazilian Association of GTD physicians have posted advice for individual patients (answering individual specific questions) as well as for groups of patients. It is important to emphasize that they encourage patients to have a face-to-face appointment at the closest BRC, advising that the online recommendations should not replace a thorough personal consult (medical history, physical exam, images, and laboratory evaluation). However, some patients reside in regions distant from a BRC, and FBGTD is the only means through which such patients can access an expert in GTD.

Of all, 98% (349/354) patients declared they felt safe reading the posts from the FBGTD physicians. Web-based interactions used simple, understandable, warm, and empathetic language and facilitated an effective doctor-patient relationship. This could be one of the reasons that a quarter of the patients answered the survey only after Dr AB initiated an invitation to participate.

Based on the success of the FBGTD, similar efforts have been launched for other diseases. For example, in Porto Alegre in Brazil, a closed Facebook group similar to FBGTD was created in 2018 as an education platform to involve adolescent renal transplant patients [34]. This new group facilitates the expression of feelings and contributes to increased self-esteem, reduced anxiety, and increased adherence to the treatment plan.

It should be noted that women with GTD and higher educational level are more likely to have follow-up outside a BRC. In general, these women have greater resources and do not undergo treatment under the Brazilian public health system. However, we observed that 64% (29/45) of these women, who initially sought private health assistance, migrated to the Brazilian public health system to be seen in a BRC, showing the quality of these specialized services [10,12]. In addition, patients treated outside a BRC are more likely to express doubts about GTD and less able to interpret the information provided by their doctors. This may be related to fundamental gaps in GTD understanding on the part of gynecologists and oncologists not associated with a referral center [22]. Moreover, at a BRC, care is provided exclusively to patients with GTD and, therefore, the physicians can spend more time discussing the disease and its proper follow-up. This is illustrated in the significant difference in the adoption of effective hormonal contraception in the postmolar follow-up, fundamental to providing reliable hormonal surveillance [35,36] and much more evident among the women followed at a BRC.

A striking netnography difference in this study showed that patients with GTD treated outside a BRC accessed the FBGTD for a longer duration than those who were treated a BRC. This is most likely because these women had less understanding of the disease and had not had the opportunity to get their concerns addressed by a doctor specializing in GTD.

One of the limitations of this study is the nature of nonprobabilistic sampling, which can compromise the quantitative data analysis. Consequently, our results may not be easily extrapolated to other GTD populations. Another issue that should be emphasized is that all responses were provided by the patients, and there is no way to verify the accuracy of the information provided. In addition, there may be differences between women who use social media or choose to participate in social media questionnaires and those who do not. The issues of patient response and patient self-selection could produce both recall bias and selection bias. On the other hand, we gained important insights about the Web-based doctor-patient relationship among patients with GTD. The use of an understandable and warm language, even without a face-to-face meeting between a doctor and a patient, can establish a safe and confident doctor-patient relationship. This Web-based relationship may be important in strengthening the strategies related to the education of GTD patients on a large scale, which may be particularly important in countries with a large territorial area, leading to difficulties in obtaining quality health care.

In this new Web-based social media era, physicians and other health professionals should understand that patients asking questions in an internet environment are trying to make sense of their treatment. A Facebook page headed by experienced and knowledgeable professionals, as the Brazilian FBGTD, can play an important role to correct misinformation [15,32] and be a valuable tool for medical learning [37] and supporting patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.

[PDF File (Adobe PDF File), 76KB - jmir_v20i9e10897_app1.pdf]

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Abbreviations

BRC: Brazilian gestational trophoblastic disease reference center
FBGTD: Facebook group of the Brazilian Association of gestational trophoblastic disease
GTD: gestational trophoblastic disease
GTN: gestational trophoblastic neoplasia
NRCP: nonreference center patients
RCP: reference center patients
SMS: short message service

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Original Paper

Using Artificial Intelligence (Watson for Oncology) for Treatment Recommendations Amongst Chinese Patients with Lung Cancer: Feasibility Study

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Abstract

Background: Artificial intelligence (AI) is developing quickly in the medical field and can benefit both medical staff and patients. The clinical decision support system Watson for Oncology (WFO) is an outstanding representative AI in the medical field, and it can provide to cancer patients prompt treatment recommendations comparable with ones made by expert oncologists. WFO is increasingly being used in China, but limited reports on whether WFO is suitable for Chinese patients, especially patients with lung cancer, exist. Here, we report a retrospective study based on the consistency between the lung cancer treatment recommendations made for the same patient by WFO and by the multidisciplinary team at our center.

Objective: The aim of this study was to explore the feasibility of using WFO for lung cancer cases in China and to ascertain ways to make WFO more suitable for Chinese patients with lung cancer.

Methods: We selected all lung cancer patients who were hospitalized and received antitumor treatment for the first time at the Second Xiangya Hospital Cancer Center from September to December 2017 (N=182). WFO made treatment recommendations for all supported cases (n=149). If the actual therapeutic regimen (administered by our multidisciplinary team) was recommended or for consideration according to WFO, we defined the recommendations as consistent; if the actual therapeutic regimen was not recommended by WFO or if WFO did not provide the same treatment option, we defined the recommendations as inconsistent. Blinded second round reviews were performed by our multidisciplinary team to reassess the incongruent cases.

Results: WFO did not support 18.1% (33/182) of recommendations among all cases. Of the 149 supported cases, 65.8% (98/149) received recommendations that were consistent with the recommendations of our team. Logistic regression analysis showed that pathological type and staging had significant effects on consistency (P=.004, odds ratio [OR] 0.09, 95% CI 0.02-0.45 and P<.001, OR 9.5, 95% CI 3.4-26.1, respectively). Age, gender, and presence of epidermal growth factor receptor gene mutations had no effect on consistency. In 82% (42/51) of the inconsistent cases, our team administered two China-specific treatments, which were different from the recommendations made by WFO but led to excellent outcomes.

Conclusions: In China, most of the treatment recommendations of WFO are consistent with the recommendations of the expert group, although a relatively high proportion of cases are still not supported by WFO. Therefore, WFO cannot currently replace oncologists. WFO can improve the efficiency of clinical work by providing assistance to doctors, but it needs to learn the regional characteristics of patients to improve its assistive ability.

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KEYWORDS

Watson for Oncology; artificial intelligence; lung neoplasms; comparative study; interdisciplinary communication

Introduction

China's Medical Contradictions

The contradiction between high-quality medical resources and people's medical needs is becoming increasingly prominent. These contradictions have led to many medical conflicts in China, and they have even attracted the attention of the international community [1-4]. There are several reasons for such contradictions. First, due to the severe shortage of government investment in health-related areas resulting in a severe lack of medical resources, Chinese doctors in primary health services are usually overworked [4-6]. There are only 1.2 physicians for every 1000 individuals in China, compared with almost 2.8 physicians for every 1000 individuals in America and other developed countries [4,6]. Over 32% of physicians work more than 60 hours per week in China [5], 94% of Chinese doctors have reported being in a poor condition every day after work, and 48% of doctors reported feeling very tired [6]. Thus, doctors in China may not have enough time or energy to ensure that their knowledge is at par with the current developments in the field of cancer. On the other hand, medical data, papers, and guidelines in tumor-related fields are rapidly growing, whereas the time doctors can dedicate to learning is limited. In October 2017, the Food and Drug Administration of the United States approved 69 drugs for the treatment of breast cancer alone, and the National Comprehensive Cancer Network guide for lung cancer was updated 9 times in 2017. Studies have shown that oncologists spend only 4.6 hours per week acquiring professional knowledge [7]. However, it is more urgent for specialists to obtain timely knowledge of evidence-based medicine than for doctors in other clinical disciplines to support individualized treatment plans for patients. Even oncologists who are experts in a specialized field cannot master all available knowledge; furthermore, doctors at the primary level are tasked with tackling numerous tumor types. Second, the distribution of medical resources is not balanced. The same patient may receive different treatment recommendations across different hospitals, and even within the same hospital, different doctors may offer different treatment options. A previous study noted that the Chinese government needs to strengthen its investment in medical professions among young physicians [8]. A tool that can help Chinese doctors to quickly provide accurate treatment recommendations or help doctors to learn new developments in the field more efficiently is urgently needed.

A Brief Introduction of Watson for Oncology and Its Popularity in China

IBM's Watson for Oncology (WFO, IBM Corporation, United States), which has been previously described by Somashekhar [9], is a clinical decision-support system for oncology therapy selection. In short, WFO has stored and indexed literature, protocols, and patient charts; has learned from test cases and experts from Memorial Sloan Kettering Cancer Center (MSKCC); and can apply computational reasoning approaches to specific cases [9]. All the information input is verified by the top oncologists at MSKCC. Moreover, WFO data are updated to the latest cutting-edge information every 1 to 2 months. It is described in the manual that WFO does not support certain cases. When we input a case that is not supported by WFO, the WFO system does not process the case, and no recommendation is returned. For lung cancer, the unsupported cases include patients with isolated metastatic tumors and patients with driver mutations whose cancer progresses during metastatic therapy, etc. For supported cases, the treatment recommendations provided by WFO are categorized into 3 groups: *recommended*, which represents a treatment supported by strong evidence; *for consideration*, which represents a potentially suitable alternative; and *not recommended*, which represents a treatment with contraindications or strong evidence against its use [9]. We speculated that WFO might be a viable option to solve problems in the health care setting in China. WFO requires only the data of a case to be input, and within 1 min, it outputs the most standard treatment approach recommended for the specified case with highly consistent evidence [9]. In fact, the use of WFO is becoming increasingly prevalent in China: WFO was introduced to China in March 2017 and currently serves more than 70 medical institutions nationwide above the city level and more than 10,000 patients [10].

Unresolved Issues

With the growing popularity of WFO, which was developed in the United States, many doctors and medical institutions in China have questioned to what extent WFO is suitable for Chinese cancer patients. Patients with cancer also question whether they can receive treatment recommendations from WFO. The problem is two-fold. On one hand, what percentage of all cancer cases is unsupported by WFO? For various reasons, WFO does not support some cases. If the proportion of unsupported cases is very large (such as greater than 50%), although the concordance of supported cases between WFO and the local multidisciplinary team (MDT) is high, the total application value of WFO would be questionable. On the other hand, among the supported cases, how consistent are the recommendations from WFO with those from the MDT? Furthermore, how can we make WFO more suitable for Chinese people? Few reports have considered these questions [11-13]. Existing studies in China all pertain to the consistency of the recommendations from WFO with those from the MDT for cancer patients; however, their sample sizes have been small, especially for studies on lung cancer [11-13], which has the highest morbidity and mortality among malignant tumors in the world or in China [14]. Moreover, none of the previous studies referred to unsupported cases or how to improve the performance of WFO [11-13].

To address these unresolved issues, we conducted a retrospective study on lung cancer in our center and compared the treatment recommendations output by WFO and the actual treatment provided by the MDT in our hospital. Here, we report the specific details and results of this study.

Methods

Introduction of Our Center and the Multidisciplinary Team

The Second Xiangya Hospital is one of the teaching hospitals and clinical schools affiliated with Central South University in China. It is one of only 10 key medical colleges cofounded by the Ministry of Education and Ministry of Health in China and is one of the top 100 tertiary care hospitals in China [15]. Our center is part of the Second Xiangya Hospital and serves approximately 30,000 cancer patients each year, and it is the largest and best comprehensive cancer treatment and research center in Hunan Province [16].

The MDT of our hospital is composed of oncologists, radiation oncologists, surgeons, radiologists, pathologists, and palliative care specialists. When a patient is hospitalized, the physician in charge collects all the necessary medical data and assembles the relevant medical experts to form the MDT. After discussion, the MDT forms and implements a comprehensive regimen.

Patient Selection

The study protocol was approved by the medical ethics committee of the Second Xiangya Hospital (ID: 2017-S104). Data were collected on patients who received antitumor treatment at our center. The inclusion criteria for this study were as follows: (1) inpatients at our center; (2) lung cancer patients; (3) admission between September 2017 and December 2017; and (4) received antitumor treatment for the first time. The exclusion criteria were as follows: (1) those who received only examinations and did not receive any antitumor treatment and (2) those who had previously received antitumor treatment. A total of 182 cases were included in this study. The pathological types included squamous carcinoma, adenocarcinoma, adenosquamous carcinoma, large-cell carcinoma, and small-cell carcinoma. The treatment received included postoperative adjuvant therapy, definitive therapy, and best supportive therapy. A total of 33 cases were not supported by WFO, and thus, the remaining 149 patients were included in our comparison study.

Operating Procedure and Evaluation of Consistency

A flow diagram of the patient selection process is shown in Figure 1, and the study procedures are shown in Figure 2.

Figure 1. Flow diagram of the patient selection process. NSCLC: nonsmall cell lung cancer; WFO: Watson for Oncology.

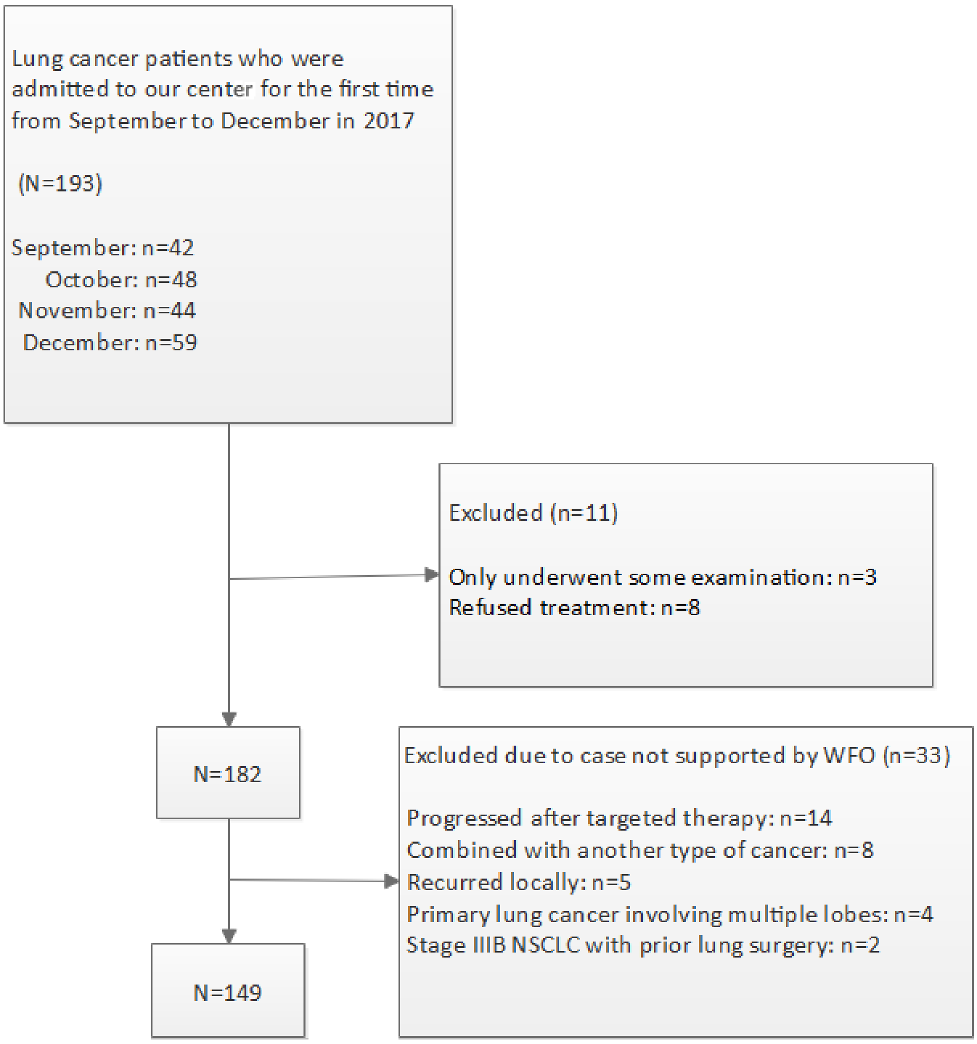
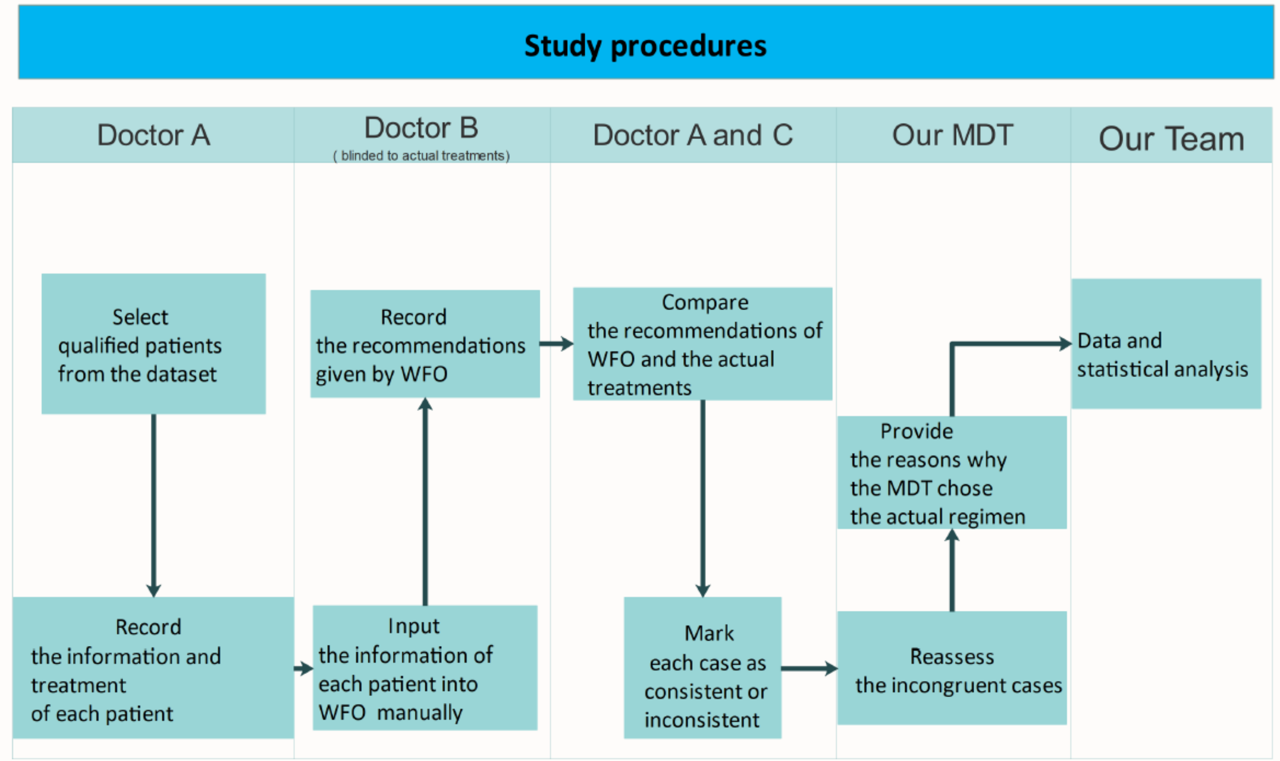


Figure 2. Flow diagram of the study procedure. MDT: multidisciplinary team; WFO: Watson for Oncology.



Patient information and specific treatments were collected from the electronic medical record system of our hospital (see Figure 1); a senior physician who was blinded to the actual treatments manually input the patient information into WFO (IBM Watson 17.1) and recorded the recommendation made by WFO. Two other doctors compared the recommendation from WFO and the actual treatment. If our actual therapeutic regimen was deemed *recommended* or *for consideration* by WFO, we defined the outcome as consistent, and if the actual treatment was deemed *not recommended* or not included in the recommendation by WFO, we defined the outcome as inconsistent. The team of specialists at our center reassessed the incongruent cases and provided their reasons for choosing the actual regimens.

Data Analysis and Statistics

We used Microsoft Excel and SPSS 23.0 to describe the data and to perform the statistical analysis. A logistic regression model was estimated with odds ratios and 95% CIs.

Results

Characteristics of the Included Lung Cancer Cases

Demographic characteristics of the hospitalized lung cancer patients are shown in Table 1. Overall, 18.1% (33/182) of our patients' cases were not supported by WFO. Among the supported cases, nonsmall cell lung cancer (NSCLC) accounted for 84.6% (126/149) and small-cell lung cancer (SCLC) accounted for 15.4% (23/149); these proportions were largely consistent with the pathological distribution of lung cancer worldwide [8]. The median age of our patients was 60 years, of whom 83.2% (124/149) were males and 16.8% (25/149) were females. Adenocarcinoma with the wild-type epidermal growth factor receptor (EGFR) gene accounted for 69% (42/61) of all patients, and phase III and IV disease accounted for 81.2% (121/149) of all patients.

Consistency of Supported Cases and the Influencing Factors

After our team of specialists reassessed the incongruent patients, there was no change to the primary concordance. The general consistency was 65.8% (98/149, shown in Table 2), and the consistency for nonmetastatic cases was 49% (42/86). For metastatic cases, the consistency was 87% (55/63); for NSCLC, the consistency was 61.1% (77/126); and for SCLC, the consistency was 83% (19/23, shown in Figure 3). The logistic regression analysis showed that age (which was divided into two groups: >60 years old and ≤60 years old, P=.45), gender (P=.30), and the presence of EGFR gene mutation (P=.90) had no effect on consistency (shown in Table 3). The following factors had significant effects on consistency: pathological type (P=.004), with the consistency in SCLC cases being 83% (19/23) and consistency in NSCLC cases being 61.1% (77/126); and stage (P<.001), including stage I (83%, 5/6), stage II (59%, 13/22), stage III (42%, 25/59), and stage IV (89%, 55/62). There were 2 major reasons accounting for 80% (41/51) of the inconsistent cases. First, we adopted sequential chemoradiation instead of concurrent chemoradiation. Second, we adopted icotinib and Endostar instead of the other first-generation epidermal growth factor receptor tyrosine kinase inhibitor (EGFR-TKI) and bevacizumab. If WFO was able to output these two alternative treatments as *recommended* or *for consideration*, the overall consistency could be elevated from 65.8% (98/149) to 93.2% (139/149).

Table 1. Characteristics of lung cancer cases (N=149).

Characteristics	Statistics
Sex, n (%)	
Male	124 (83.2)
Female	25 (16.8)
Median age in years (range)	60 (26-83)
Pathology, n (%)	
Squamous carcinoma	61 (40.9)
Adenocarcinoma	61 (40.9)
Adenosquamous carcinoma	3 (2.1)
Small-cell carcinoma	23 (15.4)
Large-cell carcinoma	1 (0.7)
Stage, n (%)	
I	6 (4.0)
II	22 (14.8)
III	59 (39.6)
IV	62 (41.6)
Epidermal growth factor receptor (EGFR) gene mutation status, n (%)	
EGFR mutation	8 (5.4)
Wild-type EGFR	44 (29.5)
Unknown	97 (65.1)

Table 2. Multidisciplinary team and Watson for Oncology recommendations after the initial reviews (N=149).

Reviews of lung cancer cases	Recommendations	Availability	Total
Concordant cases, n (%)	63 (42.3)[a]	35 (23.5)[b]	98 (65.8)
Nonconcordant cases, n (%)	44 (29.5)[c]	7 (4.7)[d]	51 (34.2)

[a]Recommended.
[b]For consideration.
[c]Not recommended.
[d]Not available.

Figure 3. Overall treatment concordance between Watson for Oncology and the multidisciplinary team, divided by stage and pathology category.

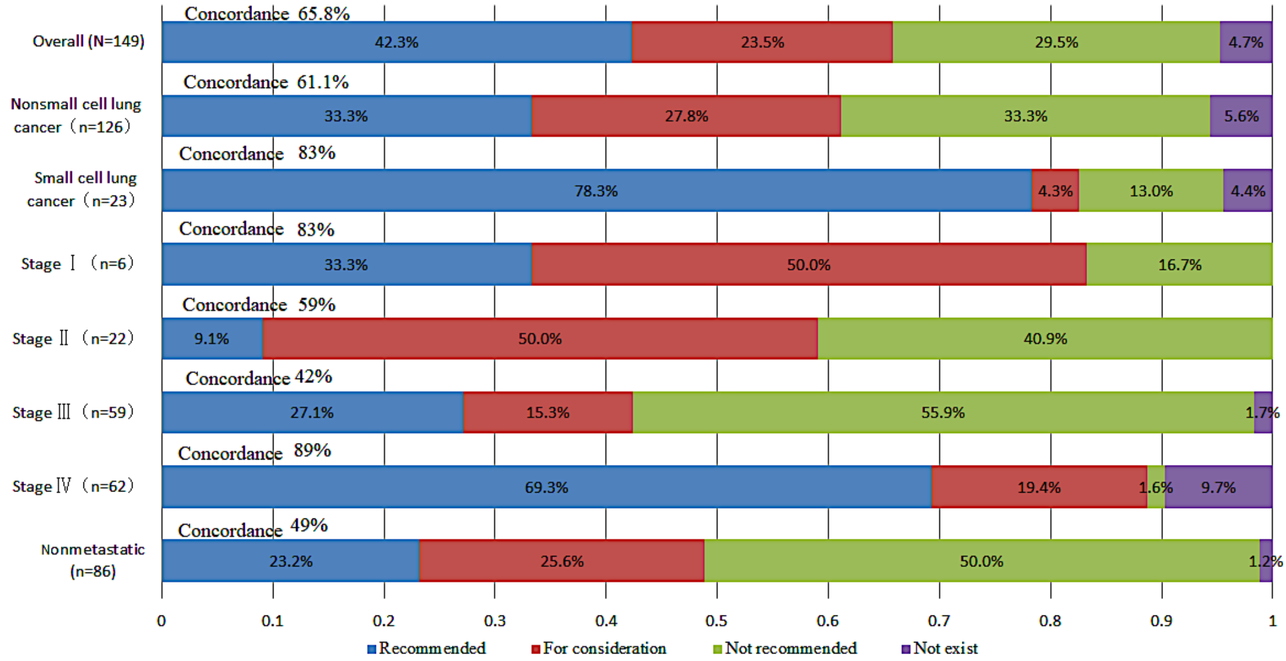


Table 3. Logistic regression model of concordance between Watson for Oncology and the multidisciplinary team.

Characteristics	Odds ratio (95% CI)	*P* value
Age (≤60 years, >60 years)	0.72 (0.31-1.70)	.45
Gender	0.54 (0.17-1.74)	.30
Pathology (NSCLC[a] and SCLC[b])	0.09 (0.02-0.45)	.004
Stages (stage I reference)		
Stage II	1 (0.09-10.7)	>.99
Stage III	3.51 (1.03-12.0)	.05
Stage IV	9.5 (3.4-26.1)	<.001
EGFR[c] gene mutation (reference)		
Wild-type EGFR	0.91 (0.16-5.26)	.91
Nonmeasured	0.32 (0.12-0.86)	.02

[a]NSCLC: nonsmall cell lung cancer.
[b]SCLC: small-cell lung cancer
[c]EGFR: epidermal growth factor receptor.

Discussion

Disadvantages of Applying Watson for Oncology in Chinese Lung Cancer Cases

This retrospective study suggests that WFO requires improvement before application in Chinese lung cancer cases. As mentioned in the manual, WFO does not support certain cases. We suspect the possible reasons are that these cases are complicated and cannot be addressed by the current technology of WFO. In this study, WFO did not support 18.1% (33/182) of the cases, of which 42% (14/33) progressed after targeted therapy. There is a large difference in the EGFR gene mutation phenotype of lung cancer in China compared with that in Western countries. The EGFR mutation rate of lung cancer in European and American countries is approximately 15%, whereas the probability of this mutation is 50% or more in China [17,18]. The treatment consistency was 65.8% (98/149), which was much lower than the treatment consistency of 96.4% reported in an abstract at the 2017 American Society of Clinical Oncology Annual Meeting [19]. There are several reasons for this discrepancy. First, WFO recommends concurrent chemoradiation, whereas China performs sequential chemoradiation (67%, 34/51); the physique of Chinese patients is usually weaker than that of Western patients, and thus, Chinese patients often cannot tolerate concurrent chemoradiation. Second, China uses the drugs Icotinib and Endostar instead of the other first-generation drugs EGFR-TKI and bevacizumab, respectively (14%, 7/51). Icotinib and Endostar [20-23] are primary research drugs in China, and studies have shown that they are as effective as the other first-generation drugs EGFR-TKI and bevacizumab in patients with lung cancer in China [24,25]. If WFO was able to output these 2 alternative treatments as *recommended* or *for consideration*, the overall consistency could be elevated from 65.8% to 93.2%. Third, some drugs are not available in the Chinese market, such as immune-targeted therapy drugs involving programmed death-1 and programmed death-ligand 1 antibodies. Patient preferences, prices, and medical insurance are also taken into consideration, and they ultimately affect the inconsistency. Moreover, WFO does not take some coexisting diseases into consideration. For example, in our study, one patient who was diagnosed with stage III squamous cell lung carcinoma also suffered from active tuberculosis. Receiving the standard chemoradiotherapy recommended by WFO may cause tuberculosis to spread rapidly, which may result in rapid death; therefore, our treatment strategy was the prescription of oral antituberculosis drugs before chemoradiotherapy. If this individualized information could be incorporated into WFO, the consistency of recommendations would be significantly improved.

Advantages of Watson for Oncology

Although the consistency of recommendation from WFO with those from the MDT in this study was not as high as expected, and a portion of cases was not supported, WFO still has tremendous value. First, WFO provides evidence to support its recommendations, and this evidence is presented according to the credibility based on the related literature such as studies and related data [9]. The doctor could examine the related evidence to judge whether it applies to the current case. When the doctor selects a treatment, WFO also provides the survival rate, incidence of adverse effects, and other information related to the selected treatment to help doctors assess the curative effect of the regimen and risk as a whole. Second, WFO can markedly shorten the time that junior doctors must spend consulting relevant literature, thus improving their ability to make accurate diagnoses and treatment recommendations in a short time. Third, regarding patients, WFO can eliminate the time wasted by visiting various top hospitals and help patients obtain the best treatment as soon as possible. Fourth, WFO can solve the problem of doctor-patient trust. In contemporary China, for a variety of reasons such as funding shortage, excessive market-oriented operation, limitations in health insurance reimbursement amounts, and abundant nonneutral media coverage of health events, patients' distrust of doctors is growing [26-28]; in addition, patients often suspect doctors of overtreatment. Unlike a local expert, who may provide some recommendations based on his or her own interests, WFO does not have personal preferences; therefore, WFO may be viewed as fair, and it can gain the trust of patients. As a result, cancer patients will not have to visit multiple experts to find a treatment regimen that they consider to be fair.

In conclusion, WFO can provide fast and accurate treatment recommendations to the majority of Chinese lung cancer patients, and it will play an important role in reducing the workload of doctors and in teaching young physicians. Moreover, WFO will standardize the treatment of lung cancer nationwide and enhance trust between doctors and patients, which is of significance to developing countries such as China, whose medical growth is unbalanced.

Importance of Our Study

This study is very important. With the AI boom, this study provides a basis for medical institutions, medical staff, and cancer patients to obtain a better understanding of WFO and rational decision making. Today, with the rapid development of AI, some people blindly follow the recommendations of AI technologies. AI can be perceived to be able to do anything, and it has been postulated that AI could replace doctors in the future. However, our research shows that this change is impossible. Medicine is not just a science; medicine involves additional aspects such as social and psychological factors. Doctors must consider individualized measures for different patients, even those with the same diagnosis. In using WFO, we can see that WFO needs oncologists to confirm whether the patient can undergo a radical operation or radiation therapy, whether the patient can tolerate an operation or radiation, and whether there is any emergency; hence, the program can continue only if this information can be provided. After WFO provides the treatment recommendations, we must choose the most suitable treatment plan according to the patient's physical and mental state, economic situation, complications, and willingness to accept treatment. It is important that WFO only stores existing knowledge and that it provides patients the best treatment recommendation that is currently available worldwide. Nonetheless, scientists must continue their research efforts to further medical advances while WFO acts as an assistant to doctors.

There is limited research on WFO [9,11-13]; we were the first to report on unsupported cases, and the sample size of this lung cancer study was the largest among all lung cancer studies performed in China. We not only reported the consistency of the recommendations from WFO with those from our MDT but also analyzed the influencing factors and provided some suggestions for the improvement of WFO to better suit Chinese patients.

Limitations of Our Study

There are several limitations in our study. First, this study is a retrospective observational study with no controls. Second, the distribution is imbalanced among the groups of patients: fewer patients were stage I, which may be because we included hospitalized patients, and stage I patients are required to undergo observation only after surgery, and they do not need to be hospitalized for further treatment. There were also fewer women than men, as female patients mostly have adenocarcinoma pathology with EGFR mutations; most of these patients need to take only oral targeted drugs outside the hospital and do not need to be hospitalized. Third, the bias of input data from experts may lead to different treatment recommendations.

Methods to Improve Watson for Oncology

AI generally has a much stronger memorization ability than the human brain, and it can quickly collect and sort the information that it stores, thus yielding accurate conclusions faster than humans, such as for applications in diagnostic radiology and pathology imaging systems [29,30]. However, to adapt to the real-world setting of China, WFO must be significantly improved. Following the acquisition of ethics approval, the medical data of patients must be standardized and shared nationwide, and the follow-up system must be improved to obtain complete information about the patients. In other words, we should build a unique medical data repository for China to be studied by WFO. These data should be incorporated with international guidelines and health care systems to allow WFO to reach its full potential to serve Chinese patients.

Conclusions

WFO is currently not a substitute for oncologists. WFO is a good assistant for Chinese doctors and a good teacher for young physicians; it also helps to standardize the treatment of lung cancer nationwide. However, it needs to learn the local characteristics of patients to better serve Chinese lung cancer patients.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
EGFR: epidermal growth factor receptor
EGFR-TKI: epidermal growth factor receptor-tyrosine kinase inhibitor
MSKCC: Memorial Sloan Kettering Cancer Center
MDT: multidisciplinary team
NSCLC: nonsmall cell lung cancer
SCLC: small-cell lung cancer
WFO: Watson for Oncology

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Original Paper

Discordance Between Human Papillomavirus Twitter Images and Disparities in Human Papillomavirus Risk and Disease in the United States: Mixed-Methods Analysis

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Abstract

Background: Racial and ethnic minorities are disproportionately affected by human papillomavirus (HPV)-related cancer, many of which could have been prevented with vaccination. Yet, the initiation and completion rates of HPV vaccination remain low among these populations. Given the importance of social media platforms for health communication, we examined US-based HPV images on Twitter. We explored inconsistencies between the demographics represented in HPV images and the populations that experience the greatest burden of HPV-related disease.

Objective: The objective of our study was to observe whether HPV images on Twitter reflect the actual burden of disease by select demographics and determine to what extent Twitter accounts utilized images that reflect the burden of disease in their health communication messages.

Methods: We identified 456 image tweets about HPV that contained faces posted by US users between November 11, 2014 and August 8, 2016. We identified images containing at least one human face and utilized Face++ software to automatically extract the gender, age, and race of each face. We manually annotated the source accounts of these tweets into 3 types as follows: government (38/298, 12.8%), organizations (161/298, 54.0%), and individual (99/298, 33.2%) and topics (news, health, and other) to examine how images varied by message source.

Results: Findings reflected the racial demographics of the US population but not the disease burden (795/1219, 65.22% white faces; 140/1219, 11.48% black faces; 71/1219, 5.82% Asian faces; and 213/1219, 17.47% racially ambiguous faces). Gender disparities were evident in the image faces; 71.70% (874/1219) represented female faces, whereas only 27.89% (340/1219) represented male faces. Among the 11-26 years age group recommended to receive HPV vaccine, HPV images contained more female-only faces (214/616, 34.3%) than males (37/616, 6.0%); the remainder of images included both male and female faces (365/616, 59.3%). Gender and racial disparities were present across different image sources. Faces from government sources were more likely to depict females (n=44) compared with males (n=16). Of male faces, 80% (12/15) of youth and 100% (1/1) of adults were white. News organization sources depicted high proportions of white faces (28/38, 97% of female youth and 12/12, 100% of adult males). Face++ identified fewer faces compared with manual annotation because of limitations with detecting multiple, small, or blurry faces. Nonetheless, Face++ achieved a high degree of accuracy with respect to gender, race, and age compared with manual annotation.

Conclusions: This study reveals critical differences between the demographics reflected in HPV images and the actual burden of disease. Racial minorities are less likely to appear in HPV images despite higher rates of HPV incidence. Health communication efforts need to represent populations at risk better if we seek to reduce disparities in HPV infection.

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KEYWORDS

disparities; health communication; HPV vaccines; image tweet; public health communication; social media; Twitter; visual communication

Introduction

Approximately 23,300 women and 16,500 men develop human papillomavirus (HPV)-related cancer annually in the United States, many of which could have been prevented with the HPV vaccination [1]. The US Centers for Disease Control and Prevention (CDC) recommends routine vaccination, with a series of 3 doses of HPV vaccine, for preteen girls and boys starting at the age of 11 years with catch-up vaccination for 18-26-year-olds who have not been previously vaccinated [2].

National rates of the HPV vaccination remain suboptimal with only 60.4% of adolescent girls (aged 13-17 years) initiating and 49.5% completing the series and 56.0% of adolescent boys initiating and 43.4% completing—well below Healthy People 2020 objective to increase HPV 3-doses vaccination series completion for adolescents aged 13-15 years to 80% by 2020. CDC findings indicate that these rates are comparably low for childhood vaccinations, for example, tetanus, diphtheria, and pertussis (88.0%), measles, mumps, and rubella (measles, mumps, and rubella; 90.9%), and hepatitis B (91.4%) [1]. Furthermore, disparities exist by race, ethnicity, and gender. Uptake rates have been low for African American individuals in comparison with non-Hispanic white individuals [3-6]. Black women were less likely to finish the series compared with their white counterparts [4,7-11]. Gelman et al found lower rates of uptake among African American girls (18.2%) compared with non-Hispanic white girls (33.1%). This issue is compounded because the risks of nonvaccination are higher for people of color [3]. Minority women are more likely to die from cervical cancer with the highest incidence rate of cervical cancer (13.2 per 100,000 women) of Hispanic origin, followed by African American women (9.8 per 100,000 women) [12,13]. According to findings of Mourad et al, HPV-related cancer rates have been increasing in men and currently exceed cervical cancer rates, for example, oropharyngeal cancer among men (7.8 per 100 000) compared with cervical cancer in women (7.4 per 100 000) [14]. Black men have the highest rates of HPV-associated anal cancer, and Hispanic men have higher rates of penile cancer than non-Hispanic men [13,15]. In addition, vaccine coverage remains troublingly low for males of all races and ethnicities [1,3]. Because men are increasingly affected by anal and oropharyngeal (head and neck) cancers, suboptimal HPV vaccination is a lost opportunity for cancer prevention. Given the serious consequences of low vaccination rates, health communication efforts should focus on high-risk populations.

Targeted and tailored communication methods can be utilized to enhance the HPV vaccination uptake for high-risk groups [16]. Targeted approaches customize messaging toward subgroups based on shared characteristics (eg, race and gender), allowing the distribution of messages in strategically and cost effectively. Tailored approaches focus on fitting the message to meet the needs of an individual to effectively influence health behaviors. Literature indicates that targeted and tailored messages increased perceived cancer risk and cancer information compared with generic messages [17,18]. It is clear that including representative images of at-risk groups in health communication images increases awareness, relevance, and impact of a health issue on the group members. Indeed, messages reflecting the images of the intended audience are critical to promote the HPV vaccination uptake and reduce observed disparities.

Social media can be utilized for health promotion for minorities. Twitter has been used extensively to study vaccine narratives, including those related to HPV, measles, and influenza [19-22]. Given Twitter’s user base of over 500 million and publicly available posts on HPV, it is a strategic site for health communicators to track HPV sentiment and target HPV vaccine messaging [23-25]. Massey et al examined tweet sentiment and content for 193,379 tweets from August 1, 2014 to July 31, 2015; positive tweets were more likely to mention prevention, whereas negative tweets increased the focus on side effects [20]. Dunn et al observed 258,418 tweets from October 2013 to October 2015 to measure information exposure differences and corresponding HPV vaccine coverage differences across states; results indicated that the lower HPV vaccine coverage correlated with the negative HPV sentiment from mainstream news, highlighting the influence of the media on the HPV vaccine uptake [26]. In addition, almost one-quarter of internet users, many of whom are from racial and ethnic minorities [27], use Twitter. Thus, Twitter images are an opportune and underutilized resource for studying health communications related to the HPV vaccination.

Given the importance of social media platforms for health communication, we examined HPV vaccine messages. Specifically, we focused on image tweets, which tend to receive more shares than nonimage tweets [28,29]. Previous health communication research has shown the power of imagery [30-32]. We extended this work by examining the demographics of the individuals pictured in HPV Twitter images. In particular, we used facial recognition technology, a product of recent advances in the computer vision subdiscipline of computer science, which builds high-quality image analysis algorithms [33-39]. These methods are accessible to public health researchers through companies who provide cost-effective image analysis services. However, to the best of our knowledge, no studies have explored HPV-related disparities using Twitter images and facial recognition technology. We, therefore, showed how these methods can enable large-scale health-related image analyses. Precisely, we evaluated Twitter images to investigate to what extent Web-based health communication represents minority groups that are disproportionately affected by HPV-associated morbidities.

This study's implications have the potential to inform the development of more culturally relevant messaging, aligning health promotion imagery salient to intended audiences of those disproportionately affected by HPV-related negative health outcomes. Public health agencies can utilize findings to improve health communication approaches on social media to reduce disparities of HPV-associated disease for all racial and ethnic groups.

Hence, this study aims to observe whether the demographics reflected in HPV images on Twitter reflect the populations suffering from the actual burden of disease by the gender and race and determine to what extent individual users, governmental users, and organizational accounts utilized images that reflect the populations bearing the burden of disease in their health communication messages.

Methods

Dataset

We constructed a corpus of tweets relevant to HPV following the approach described in a study by Chen et al [29]. Figure 1 shows the flowchart of this data collection process. We first collected tweets that contained any of the 2 terms related to HPV (namely, "HPV" and "papillomavirus") using the Twitter streaming API from November 11, 2014 to August 8, 2016, and further filtered out vaccine-irrelevant tweets using a statistical classifier [40]. This support vector machine classifier aims to distinguish vaccine-relevant tweets from vaccine-irrelevant tweets. It was trained on 1899 manually annotated tweets and achieved good performance (precision=0.96; recall=0.91; F_1=0.93) [40]. The time frame reflects image tweets collected from a previous vaccine images tweet analysis [29]. We then downloaded images for original image tweets, excluding retweets that had duplicate images.

We next used Face++ [33], a Web-based face recognition tool, to automatically categorize images containing faces and facial properties (eg, gender, age, and race). We selected Face++ because it has a high reported accuracy in the literature and supports race identification. We found that 25.8% of images had at least one face.

In addition, we obtained the locations of these image tweets using the CARMEN geolocation tool [41]. CARMEN infers the location of a tweet from the user's profile and geotags in the metadata of the tweet. CARMEN has previously resolved location for 44.45% of tweets and correctly labeled the tweet location to within 250 miles of its true origin 75.27% of the time [41]. For our HPV image tweets, 32.5% of tweets were from the United States, and the location of 48.7% tweets was unknown. Our final dataset contained 456 HPV US-based image tweets containing at least one face.

Face Attributes Identification

We obtained 3 face attributes, gender (female or male), age (an integer), and perceived race (white, black, Asian, or ambiguous, which are the only 4 categories provided by Face++), of HPV images from Face++. Face++ has been widely used for face detection, recognition, and face attribute identification in social images like Twitter [35-38] and on major search engine images [34]. As reported previously, Face++ achieved a true positive rate of 85% in face detection with a false positive rate of 0.1 [39], 88% accuracy in gender recognition, and 79% accuracy in the race recognition [42].

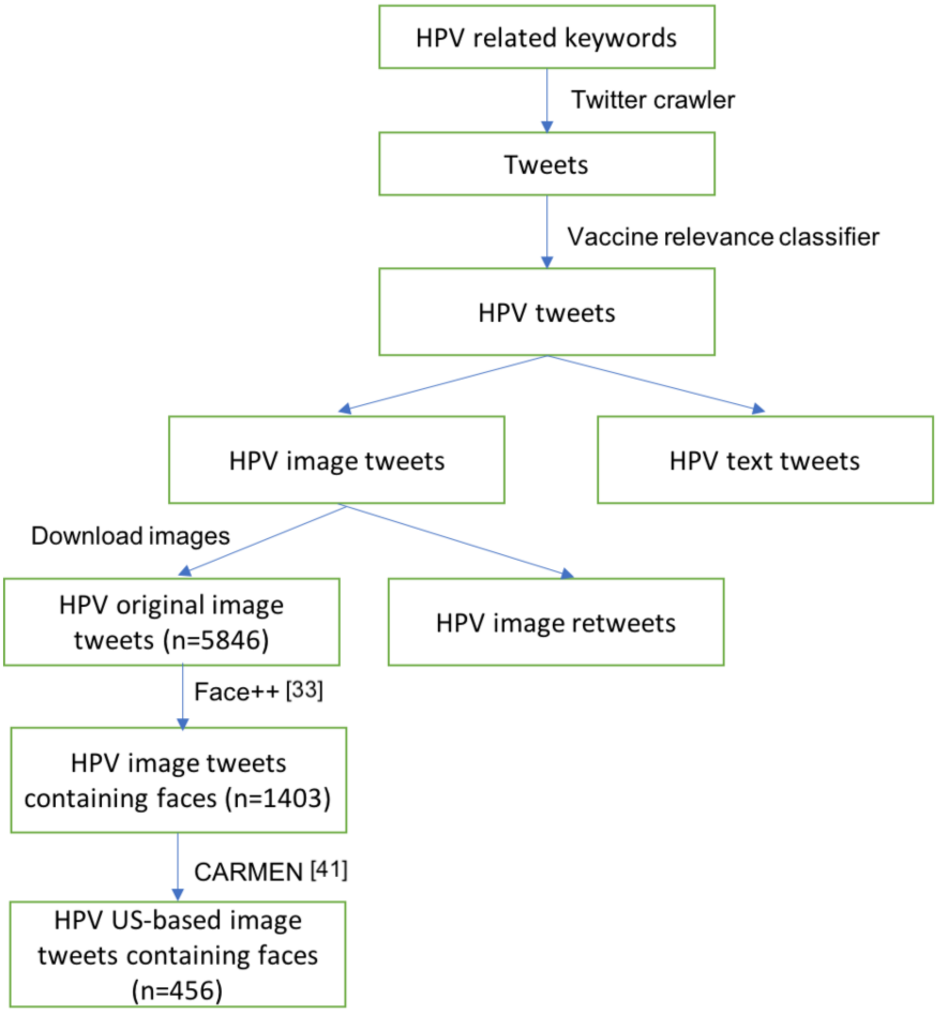
Exact age estimation is a difficult task for both machines and humans. Face++ has a mean absolute error of 11.0 for exact age estimation [43] but a much higher accuracy (>93%) when it groups ages into categories (<18 years, 18-35 years, and >35 years) [44]. To allow the estimated age to be more robust, we organized age into 5 groups, namely, infant (0-2 years), child (3-8 years), youth (9-26 years, the recommended age to take the HPV vaccination by CDC), adult (27-64 years), and senior (>64 years).

To further validate the performance of Face++, we manually annotated the perceived gender, race, and age group attributes of all visible faces in each HPV image. The 2 annotators first worked independently and then resolved discrepancies by consensus. This process also helped us to gain insights from the HPV images as well as challenges of classifying the race, which is further detailed in the Discussion section.

Analysis

We performed a mixed-methods analysis for the demographics reflected in the 3 face attributes. Based on the gender of faces, we first categorized images into 3 groups as follows: images that only have female faces, those that only have male faces, and those that have faces of both genders. We then compared the race and age distribution across these 3 groups. Categories chosen for the race were consistent with the current CDC standards for data collection and included Asian or Pacific Islander, black, and white individuals [45]. Owing to the technical limitations of Face++ of identifying the race and ethnicity, our racial classification system was streamlined (by dropping the racial classification for American Indian and Alaskan Native and the question of Hispanic ethnicity [46]) and embraced ambiguity (by adding a category for "ambiguous"). We acknowledge that the race and gender are nuanced social constructs that are particularly challenging to classify (see Discussion section). In this study, the race and gender, as perceived by researchers, were used to highlight differences in Twitter images. Racial perception is an appropriate measure as we seek to understand how health communications will be perceived. Notably, the complexities of reifying the race and gender are beyond the scope of this study.

Figure 1. The flowchart of our human papillomavirus (HPV) image tweet data collection.



Our analysis focused on images containing youths (recommended HPV vaccine recipients) or adults (eg, parents or health care providers). In addition, we examined the association between facial attributes and the source of the image tweet; for example, do government users or users with a health focus tend to post faces that reflect the actual burden of HPV diseases? To answer such questions, we manually examined (first annotated by one author of this paper, and then checked by 2 additional authors) all the source profiles of our HPV dataset (298 unique sources in total). We categorized these sources into 3 types, namely, government (eg, CDC and local health departments), nongovernment organizations (including health-related organizations), and individuals. We further stratified sources into health-related (eg, health care provider) or news-related categories. We then compared facial attributes across the resulting source categories.

Results

Face++ Versus Manual Annotation

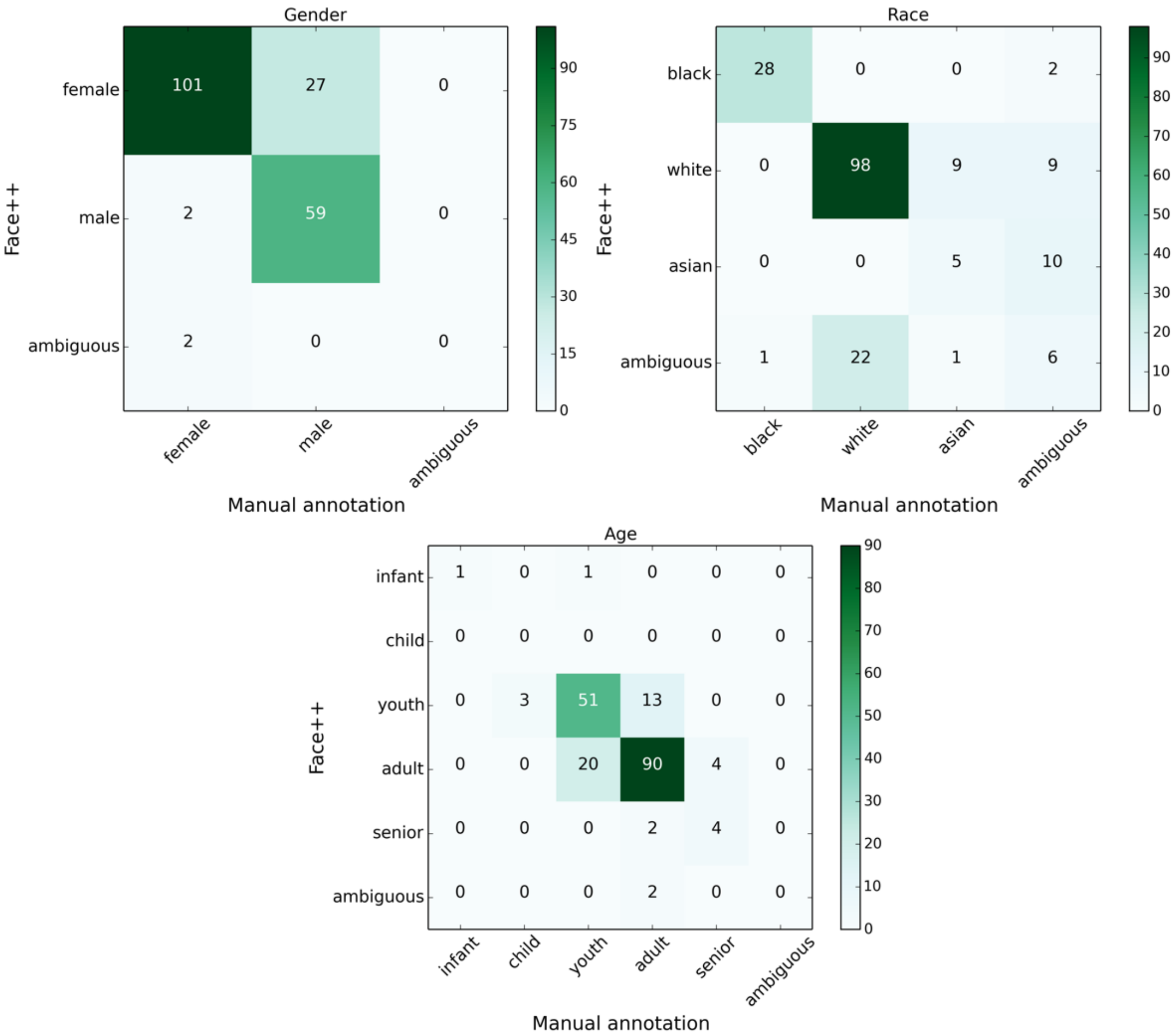
Manual annotation identified more faces (1219) than Face++ (999). The discrepancy is primarily caused by images with multiple small, blurry, or nonfront-facing faces. Such faces are still distinguishable by humans but are rather difficult for automatic tools like Face++ to recognize. Because the subject of an image is usually the clearest and largest face, we believe Face++ has detected most important faces in our dataset (see Multimedia Appendix 1).

Table 1 details the distribution of 456 HPV images by the face count. Most images—55.6% according to manual annotation—contained multiple faces. Owing to the lack of face positions in manual annotation, it is difficult to align the annotated faces by human annotators and Face++ when multiple faces are presented in an image. Therefore, we limited the direct comparison of 2 annotations to images with a single face. Face++ achieved accuracy values of 84.7%, 76.4%, and 85.1% with respect to gender, race, and age, respectively, when compared with manual annotation, ignoring images with ambiguous labels. To gain an in-depth understanding of the performance of Face++, the confusion matrix is presented in Figure 2.

Table 1. The number and distribution of images by the face count.

Number of faces in the image	Face++, n (%)	Manual annotation, n (%)
1	279 (60.5)	196 (44.4)
2	72 (15.6)	99 (22.4)
3	43 (9.3)	58 (13.2)
4	22 (4.8)	18 (4.1)
>4	45 (9.8)	70 (15.9)

Figure 2. The confusion matrices showing the performance of Face++ against manual annotation.



For gender, Face++ mistakenly labeled 27 female faces as male when considering manual annotation as ground truth. Of these 27, 12 (44.4%) were actually black women. For the race, Face++ identified 100% of black faces but had difficulty in differentiating white and Asian faces. Our human annotators acknowledged the same difficulty, leading them to label the race of 27 faces as ambiguous. Regarding age, we identified youth and adult age categories to have the greatest discrepancy between Face++ and manual annotation. From manual annotation, we acknowledge the challenge in distinguishing between age cutoffs (eg, 26 vs 27 years old). As such, the actual performance of Face++ on age has an accuracy of >85.1%. Overall, Face++ is reliable in detecting important faces and recognizing the facial properties (age, gender, and race) for our HPV images.

Gender, Age, and Race

Considering manual annotation is more accurate than Face++, we only detail the results of manual annotation in the following tables. Our results from manual annotation and adoption of

Face++ were broadly consistent, highlighting the potential for the automated face analysis utilization in public health research (see Multimedia Appendix 1). We first examined the gender of faces. At the broader image level in our dataset, 53.6% of images had only female faces, 17% had only male faces, 27.9% had both genders, and the remaining 1.6% had ambiguous gender or did not have a face (we excluded these 1.6% images in the following analysis). At the individual face level in our dataset (Table 2), 71.70% (874/1219) of faces were female, 27.89% (340/1219) were male, and the rest 0.41% (5/1219) had ambiguous gender (eg, infants' faces).

Tables 3 and 4 show the number (percentage) of faces by the age and race, respectively. Overall, youth (616/1219, 50.53%) and adults (578/1219, 47.41%) were the 2 primary age groups, but the detailed distributions varied in each gender group. For instance, within the youth category, the majority of images included faces of both genders (365/616, 59.3%) and female faces (214/616, 34.3%), whereas in the adult category, the largest portion was female images (285/578, 49.3%), followed by both genders (219/578, 37.9%).

Looking at the race (Table 4), the majority of faces (795/1219, 65.22%) were white, followed by black (140/1219, 11.48%) and Asian (71/1219, 5.82%), whereas 17.47% (213/1219) of faces were racially ambiguous. For the overall gender distribution, female faces were predominantly represented across races (331/795, 42.39% white; 71/140, 50.71% black; and 34/71, 47.89% Asian) compared with male faces (7/140, 5.0% black; 75/795, 9.43% white; and 8/71, 11.27% Asian). In addition, we observed that over half (121/213, 56.80%) of faces with ambiguous races appeared in images with both genders.

Table 2. The number and percentage of demographics at face level by manual annotation.

Face characteristics	n (%)
Gender	
Female only	874 (71.70)
Male only	340 (27.89)
Ambiguous	5 (0.41)
Age group	
Infant	0 (0.00)
Child	10 (0.82)
Youth	616 (50.53)
Adult	578 (47.41)
Senior	13 (1.07)
Ambiguous	2 (0.16)
Race	
Black	140 (11.48)
White	795 (65.22)
Asian	71 (5.82)
Ambiguous	213 (17.47)
Total faces	1219 (100)

Table 3. The number and percentage of faces in each age group by manual annotation.

Age group	Faces in female-only images, n (%)	Faces in male-only images, n (%)	Faces in images with both genders, n (%)	Total faces, n
Infant	0 (0.0)	0 (0.0)	0 (0.0)	0
Child	4 (40.0)	1 (10.0)	5 (50.0)	10
Youth	214 (34.3)	37 (6.0)	365 (59.3)	616
Adult	285 (49.3)	74 (12.8)	219 (37.9)	578
Senior	6 (46.2)	1 (7.7)	6 (46.2)	13
Ambiguous	2 (100)	0 (0.0)	0 (0.0)	2
Total	511 (100)	113 (100)	595 (100)	1219

Table 4. The number and percentage of faces in each race by manual annotation.

Race	Faces in female-only images, n (%)	Faces in male-only images, n (%)	Face in images with both genders, n (%)	Total faces, n (%)
Black	71 (50.7)	7 (5.0)	62 (44.3)	140 (11.48)
White	337 (42.4)	75 (9.4)	383 (48.2)	795 (65.22)
Asian	34 (47.9)	8 (11.3)	29 (40.8)	71 (5.82)
Ambiguous	69 (32.4)	23 (10.8)	121 (56.8)	213 (17.47)
Total	511 (100)	113 (100)	595 (100)	1219 (100)

Table 5. The demographic distribution for youth and adult by manual annotation.

Gender and age	Black, n (%)	White, n (%)	Asian, n (%)	Ambiguous, n (%)
Female				
Youth	28 (13.1)	145 (67.8)	10 (4.7)	31 (14.5)
Adult	43 (15.1)	182 (63.9)	24 (8.4)	36 (12.6)
Male				
Youth	6 (16.2)	24 (64.9)	0 (0.0)	7 (18.9)
Adult	1 (1.4)	49 (66.2)	8 (10.8)	16 (21.6)
Both genders				
Youth	49 (13.4)	203 (55.6)	19 (5.2)	94 (25.8)
Adult	11 (5.0)	171 (78.1)	10 (4.6)	27 (12.3)

Finally, we focused on youth and adult age faces and examined the gender and racial breakdown for the 2 age groups (detailed in Table 5). In addition to the consistently higher proportion of white faces across all gender and age categories, we observed a higher percentage (171/219, 78.1%) of white adult faces. In images with black faces, a black adult was rare in images with only male faces (1/74, 1.4%) or those with both genders (11/219, 5.0%). For Asians, we did not observe any Asian youth in images only with male faces.

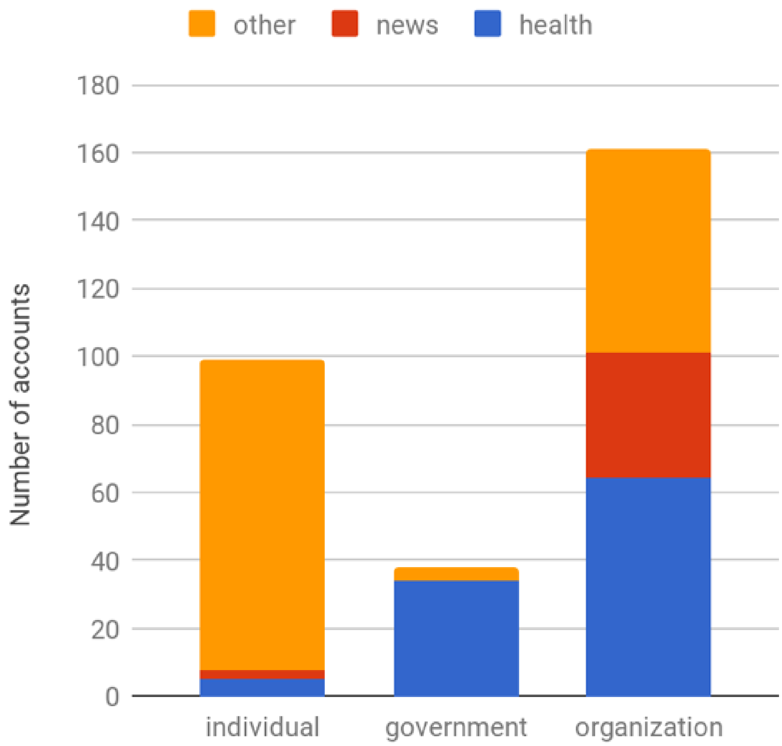
Source of Images

Figure 3 shows the source categorization results. The authors manually annotated sources into 3 broad categories (ie, organizations, government, and individual). Source categories were further annotated by 3 specific topics (ie, news, health, and other). The majority (161/298, 54.0%) of sources were organizations, followed by individuals (99/298, 33.2%) and government (38/298, 12.8%). Regarding the topic, 13.4% (40/298) of sources were news related (eg, Huffington Post Blog and Business Insider) and 34.6% (103/298) were health related. We found that government sources were primarily health related (34/38, 90%) and organizations were more health related (64/161, 39.8%) than news related (37/161, 23.0%), whereas individual sources did not have a strong health or news focus (91/99, 92% of users had other topics).

Multimedia Appendix 2 shows the breakdown of demographic results by the source. Organization sources used more images with white faces. For instance, 96.6% (28/38) of female youth and 100% (12/12) of adult male images posted by news organization sources were white. These findings were significant, especially given the influence of media in promoting vaccination to reduce disparities (see Discussion).

Governmental health sources primarily posted images that had both genders, whereas news organization sources preferred female faces. Health-related organizations utilize many youth faces in images with both genders, and individual sources had an equal likelihood of posting female or mixed gender images. For the race, governmental health agencies tended to post a large proportion of black female faces in both youth (6/24, 25%) and adult age groups (4/20, 20%), more frequently than other sources (Table 5). Furthermore, governmental health sources posted a high proportion of youth faces of ambiguous race (5/24, 21% female; 3/15, 20% male; and 28/92, 30% both genders).

Figure 3. Distribution of sources.



Discussion

Principal Findings

This study examined the content of HPV Twitter images. Despite reflecting demographics similar to US Census data, our results show a distinct difference between the demographics reflected in Twitter images and the actual burden of disease by the race and gender. Additional Census comparison figures are included in the Multimedia Appendix 1.

First, our analyses demonstrate that male faces are significantly underrepresented in HPV images (9.3%), particularly for youth, the recommended group for the HPV vaccination—34.3% girls versus 6.0% boys (Table 3); this is consistent with the observed lower uptake of the HPV vaccine among males. Currently, 37.5% of male youth were up to date with recommended HPV vaccination series compared with 49.5% for female youth [1], highlighting the need for further targeted HPV vaccine promotion toward male youth. Presenting the HPV vaccination for males as cancer and genital wart prevention has helped increased acceptance among males [47]. Continued efforts of increasing the awareness and representation of both genders in HPV communication are crucial in preventing HPV-associated cancer that affect men and women alike. Second, Twitter images had significantly fewer images of African American individuals even though African American individuals are more likely to be affected by HPV-associated cancer. Consistent with US Census data, our results demonstrate that white faces represented 65.22% (795/1219) of the images compared with 11.48% (140/1219) African American faces and 5.82% (71/1219) Asian faces [48]. However, of critical importance is that African American individuals are disproportionately affected by HPV-related diseases and are less likely to complete the HPV vaccination series compared with their white counterparts [4]. Furthermore, black adults are more likely to use Twitter than other racial groups, making Twitter a pertinent health communication platform to target parents of black youth [27]. Our findings suggest that despite known disparities, health communication efforts on Twitter have not sought to include the representation of African American individuals in targeted communications that could address racial disparities in the HPV vaccination [27].

Of note, images that included both females and males were usually represented by groups of youth (365/616, 59.3%), whereas for female-only and male-only faces, images were typically youth accompanied by adults who were more likely to be male (65.5%). From manual annotation, annotators noted that adults were typically represented by parents or health care providers. From the limited number of male faces in the sample (340/1219, 27.9%), male adults were twice as likely to be represented (74/578, 12.8%) compared with male youth (37/616, 6.0%), highlighting the insufficient communication efforts to target male youth for the HPV vaccination. Third, our results showed that the frequency of Twitter images posted from individual, organization, and government sources also reflected discrepancies in the minority representation. Individual sources shared more images with females (n=117) than males (n=37), suggesting the majority of users perceive HPV as an exclusively female issue. Organization users (health- or news-related) depict almost exclusively white faces.

The influence of Web-based news organizations is significant, especially given that 62% of American individuals access the internet for health information [49]. Although it is not their role to promote health behaviors, Web-based news sources are certainly influential in reporting and detecting emerging trends and outbreaks [22,23]. By depicting mostly white faces in

Web-based HPV communication, these organizations might be reinforcing an inaccurate message about who is most at risk and failing to address groups that would also benefit from vaccination.

These findings are distinct from government images, which could be attributed to the differing incentives and roles of the media related to promoting vaccination compared with the government. In addition to having a lower presence tweeting black HPV images, government sources, which were typically local, state, and federal public health agencies, also had an uneven distribution of gender and racial representation within aforementioned images. Males represented in the images were overwhelmingly white—80% (12/15) of youth and 100% (1/1) of adults. Government HPV images with both genders included predominantly racially ambiguous youth (5/24, 21% female; 3/15, 20% male; and 28/92, 30% both gender), which may reflect an intentional choice to reach a more diverse audience, especially given the increasing number of multiracial youth in the Census [48]. However, the greater representation of racially ambiguous youth inadvertently fails to address racial and ethnic disparities in HPV health outcomes by underrepresenting those with the highest risk; this is especially critical given the role of governmental public health agencies in disseminating relevant health information.

In health communication, there is frequently an emphasis on the power of culturally sensitive communication, defined by Betsch et al as "the deliberate and evidence-informed adaptation of health communication to the recipients' cultural background to increase knowledge and improve preparation for medical decision making and to enhance the persuasiveness of messages in health promotion" [50,51]. The aim is to create greater congruency between the health promotion messages and the recipient's existing cultural context with an overall goal of increasing the effectiveness of messaging [52]; this can be accomplished through either targeting (aimed at the general cultural group) or tailoring (aimed at specific individuals within a cultural group). Visual representation of racial and ethnic minorities would represent a minimal effort at targeting high-risk groups and although it is not sufficient to guarantee the vaccine uptake, the exclusion of racial and ethnic minorities and males from images used in communication about the HPV vaccination is likely to perpetuate disparities in uptake and disease.

Our findings demonstrate discordance between HPV images on Twitter and those at the greatest risk of HPV-associated cancer. Twitter can be harnessed to disseminate HPV messages aimed at racial minorities who are more likely to be Twitter users [27]. Public health agencies would benefit from formative research with minority youth and their parents to improve Web-based health communication strategies to reduce the burden of HPV-associated cancer for all racial and ethnic groups.

Limitations

There are limitations to this observational study. In this study, we also collected data for specific time points that yielded a relatively small sample of Twitter images, which speaks to the generalizability of findings. However, we found that characterizing the race, ethnicity, and age of faces was particularly challenging with both automated image analysis algorithms and manual annotation. Nearly half of the errors produced by Face++ were related to the misclassification of black female faces. Consistent with these results, Buolamwini and Gebru evaluated commercial gender classification algorithms and found that darker females have highest misclassification error rates (20.8%-34.7%) than darker males (0.7%-12.0%), lighter females (1.7%-7.1%), and lighter males (0.0%-0.8%) [53]. These findings highlight the limitations of automated image analysis for women of color, which have marked implications for real-world applications of this technology.

Self-identification is considered the gold standard for all race and ethnicity variables. In this instance, self-identification was not possible, and the race was ascribed by researchers engaged in manual annotation and through algorithms designed for this purpose. Unfortunately, the automated image analysis and, to a lesser extent, the manual annotation are dependent on the stereotypical phenotypic expressions of racialized features. The increasing population of mixed-race individuals, the complexity of the race and ethnicity with Latino populations, and indeed, the recognition that the race is only a social construct make an accurate determination of racial categories difficult. Furthermore, similar constraints made it difficult to consider any nonbinary expressions of gender. Thus, the potential for error of categorizing faces by specific age and race and gender needs to be considered in this study and future research.

Conclusions

This study provides insights into racial and gender differences in HPV images on Twitter. Findings can inform imagery-driven health communication strategies to increase the vaccine uptake to mitigate negative health outcomes, particularly within the context of social media. Culturally sensitive communication, which would include increased representation of minorities in images, may enhance the salience of HPV messaging to populations disproportionately affected by HPV-related health outcomes.

Conflicts of Interest

MD has received consulting fees from Bloomberg LP and holds equity in Good Analytics Inc and Sickweather Inc. These organizations did not have any role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Multimedia Appendix 1

The supplementary figures and tables for Census statistics and Face++ results.

[PDF File (Adobe PDF File), 115KB - jmir_v20i9e10244_app1.pdf]

Multimedia Appendix 2

The gender, age, and race distribution in different source group by manual annotation.

[PDF File (Adobe PDF File), 29KB - jmir_v20i9e10244_app2.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
HPV: human papillomavirus

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Original Paper

Robotic Services Acceptance in Smart Environments With Older Adults: User Satisfaction and Acceptability Study

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Abstract

Background: In Europe, the population of older people is increasing rapidly. Many older people prefer to remain in their homes but living alone could be a risk for their safety. In this context, robotics and other emerging technologies are increasingly proposed as potential solutions to this societal concern. However, one-third of all assistive technologies are abandoned within one year of use because the end users do not accept them.

Objective: The aim of this study is to investigate the acceptance of the Robot-Era system, which provides robotic services to permit older people to remain in their homes.

Methods: Six robotic services were tested by 35 older users. The experiments were conducted in three different environments: private home, condominium, and outdoor sites. The appearance questionnaire was developed to collect the users' first impressions about the Robot-Era system, whereas the acceptance was evaluated through a questionnaire developed ad hoc for Robot-Era.

Results: A total of 45 older users were recruited. The people were grouped in two samples of 35 participants, according to their availability. Participants had a positive impression of Robot-Era robots, as reflected by the mean score of 73.04 (SD 11.80) for DORO's (domestic robot) appearance, 76.85 (SD 12.01) for CORO (condominium robot), and 75.93 (SD 11.67) for ORO (outdoor robot). Men gave ORO's appearance an overall score higher than women (*P*=.02). Moreover, participants younger than 75 years understood more readily the functionalities of Robot-Era robots compared to older people (*P*=.007 for DORO, *P*=.001 for CORO, and *P*=.046 for ORO). For the ad hoc questionnaire, the mean overall score was higher than 80 out of 100 points for all Robot-Era services. Older persons with a high educational level gave Robot-Era services a higher score than those with a low level of education (shopping: *P*=.04; garbage: *P*=.047; reminding: *P*=.04; indoor walking support: *P*=.006; outdoor walking support: *P*=.03). A higher score was given by male older adults for shopping (*P*=.02), indoor walking support (*P*=.02), and outdoor walking support (*P*=.03).

Conclusions: Based on the feedback given by the end users, the Robot-Era system has the potential to be developed as a socially acceptable and believable provider of robotic services to facilitate older people to live independently in their homes.

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KEYWORDS

social robotics; active and healthy aging; acceptability models

Introduction

Background

Longevity is one of the biggest achievements of modern societies and people aged 65 or older will account for 28.7% of the EU-28′s population by 2080, compared to 18.9% in 2015 [1]. Moreover, in 2011, 28.5% of Europe's population older than 65 years of age were living their own homes, whereas for people older than age 85, the percentages were 49.5% for women and 27.8% for men [2]. Furthermore, 17.7% of Europe's older citizens live in rural areas [2] where access to health care services can be limited. Older people generally prefer to remain in their homes [3], but they often are affected by multimorbidity [4], falls [5], loneliness [6], and the risk of malnutrition [7]. Considering these risk factors, the odds of institutionalization grows, thereby increasing the costs for health care services.

Considering all that, the World Health Organization and the Global Health Workforce Alliance are developing a strategy to plan effective human resources for health for the period 2016-2030. Although the health care labor market is growing, it is not clear if the number of health care workers will be able to meet the demand for older assistance [8]. In particular, in Europe by 2030, health assistance supply will fall short of demand to meet the health needs of an aging population [9].

In this context, robotics and other emerging technologies, such as ambient intelligence, are increasingly proposed as a potential solution to this societal concern [10]. In Europe, several research projects were founded under the ICT strand of the Seventh Framework Programme (FP7) [11] and EU Horizon 2020 Research and Innovation program [12], as discussed in [13].

Despite the growing interest in developing this type of technology for supporting older people, the target user must accept robots for them to be effective assistive technology tools for older people [14]. Unfortunately, one-third of all assistive technologies are abandoned within one year of use [15]. For this reason, the design and acceptability of service robots that interact with individuals and coexist in environments inhabited by humans are crucial aspects to overcome the resistance toward service robotics [16]. Furthermore, the concept of "trust" in the adoption of intelligent assistive technologies to assist aging in place by older adults is very important [17]. In this context, this paper shows the results achieved within the Robot-Era project, funded by the European Community's FP7 (FP7/2007-2013), that aimed to investigate and demonstrate, among other things, the usability and acceptability by end users of a plurality of complete advanced robotic services, integrated into smart environments and experimented in realistic experiments.

Related Works

The concept of robots that most people have is shaped by movies and science fiction, provoking a mismatch in what the robots of today can accomplish and what the movies portray [18]. For this reason, in recent years, many studies have been conducted to evaluate the acceptance of robots by older users [19-30]. In this section, the studies showing older adults' feedback about robots are presented focusing on works comparable to the Robot-Era project.

Some of these studies were done involving older adults to explore their attitudes toward possible tasks that robots, in general, could perform in the home, but no robot was used in these studies [19,20].

Prakash et al [19] studied how human-likeness of the robot's face influences the perceptions of robots by humans, involving 32 older adults. Data were collected using interviews and questionnaires; the outcomes showed a higher preference for the human-looking appearance of robots by older adults. However, no real robot was used in the study—participants' imaginations were stimulated by pictures of robots such as Pearl nursebot, Nexi MDS, NAO, and Kobian.

Wu et al [20] involved 20 older persons with mild cognitive impairment to investigate their perceived attitude toward an assistive robot. The main outcome was that participants considered a robot useful to them in the future, but not in the present; they also deemed a robot to be useful for older people affected by frailty, loneliness, and disability. However, the limitation of this study was that older adults did not interact with a robot—their feedback was obtained by showing video clips and pictures of robots.

In other studies, a robot was presented to older people, but they did not have the opportunity to directly interact with it and their feedback was obtained after viewing a video clip or a live demonstration showing the potentialities of a robot [21-22].

Pino et al [21] presented the RobuLAB 10, a robotic mobile platform that provides seven robotic services for the cognitive and social support of older people. Ten older adults with mild cognitive impairment and eight healthy older adults were involved in the study to evaluate the acceptance of robots. The study employed a semistructured focus group and questionnaires. The results showed that participants positively perceived the potential benefits of the robot to support older adults at home, even if the intention to use was low. However, participants attended a live demonstration performed by a researcher and the robot was controlled remotely.

In a more recent study, on the basis of a demonstrative video of telepresence Kubi and Beam robots, Stuck et al [22] interviewed 14 older adults with mobility impairments who perceived the benefits of a robotics system for communication service. However, they mentioned some concerns about damage to themselves or the environment.

Other studies evaluated the acceptance of a service robot by older adults after they interacted with it in a controlled laboratory setting [23-25].

Fischinger et al [23] developed the Hobbit PT1 robot that could perform six tasks to support older adults. The acceptance was evaluated by 49 older users who interacted with the robot in a laboratory decorated as a living room. The outcome of the survey showed a positive reception by users. More than half of the sample could imagine having the robot at home for a longer period, although approximately half the participants were skeptical about its helpfulness. However, during the controlled laboratory user studies, the robot was not autonomous because a researcher remotely controlled it.

In another study, 33 older users interacted with a robot as a physical exercise coach that was appreciated as an exercise motivator by most participants [24]. Furthermore, a study with 16 healthy older adults was conducted in a controlled laboratory environment. The aim was to investigate their acceptance of robots for partner dance-based exercise. The results showed the robot was perceived as useful, easy to use, and enjoyable [25].

Cavallo et al [26] developed and tested an enhanced robotic platform, called ASTROMOBILE, which was integrated into an ambient intelligent infrastructure to provide a favorable independent living. Sixteen older users were involved. The robot was autonomous, and experiments were conducted in a domestic house. The ASTROMOBILE system provided three functional capabilities. The study was conducted as a focus group and live demonstration, but each participant tested at least one robotic capability. The results demonstrated a positive impression by older users and the utility of robotic services was appreciated.

Other studies focused on robot acceptance were conducted in actual environments [27-30]. Koceski et al [27] developed an assistive telepresence robot that was tested by 30 older adults in a nursing home. The results show that the functionalities provided by the telepresence robot system were accepted by potential users, but the robot was not autonomous because it was teleoperated by the user, both for navigation and for fetch and carry of a small object, and only three robotic services were provided. In addition, although the experiments were conducted in a real environment, it was a pilot study and the robotic system was not integrated into the daily routine of the nursing home.

Broadbent et al [28] investigated the effectiveness of the iRobi robot delivering telehealth care to increase adherence to medication and home rehabilitation, improve quality of life, and reduce hospital readmission compared with a standard care control group. A total of 25 older persons with chronic obstructive pulmonary disease used the robot, and the results showed that a homecare robot can improve adherence to medication and increase exercise, even if there were no significant differences in quality of life.

Finally, Orlandini et al [29] assessed the robustness and validity of the mobile robotic telepresence system Giraff as a means to support older persons and to foster their social interaction and participation. Cesta et al [30] evaluated the acceptance of the Giraff robot by two older persons in a long-term trial and received positive results. An overview of the related works is shown in Multimedia Appendix 1 (Overview of Related Works).

Goal of This Study

As stated previously, the acceptance of robots by older users has been examined in many studies, but there are some limitations. First, in some studies, older individuals have expressed an opinion without interacting with a robot. Feedback was collected from users based only on pictures of robots [19,20], or a video clip showing the robot's capabilities [22], or a live demonstration performed by a researcher [21]. Second, some studies involved a small number of participants [22], and those studies conducted with many older adults had some limitations because users attended a single live demonstration without direct interaction with a robot [21]. In some studies, the experiment was conducted with a "Wizard of Oz" methodology (experiment in which participants interact with a system that they believe to be autonomous, but which is controlled by a hidden person) [23], or the robot was teleoperated by the user [27]. Third, in some cases the robot was not autonomous [23,27] or was a stationary robot. Finally, in all considered studies, only one robot, working in a single environment, was used.

In this research, some of these limitations were overcome: (1) a total of 45 older adults extensively interacted directly with three robots to accomplish tasks, (2) three autonomous robots were used to cooperate between them in smart environments, (3) the experiments were conducted in three different environments (domestic, condominium, and outdoor areas), (4) six robotic services were provided by the Robot-Era system, and (5) each Robot-Era service was tested by 35 older users.

Methods

Robot-Era Architecture

The Robot-Era system (Figure 1) implements six robotic services that involve three different environments: outdoor, condominium, and indoor. The agents involved in this system are the DOmestic RObot (DORO), COndominium RObot (CORO), Outdoor RObot (ORO), lift, wireless sensor networks (WSNs), graphical user interface (GUI), and speech interactions. All these agents are managed by a cloud platform based on elastic computing models in which resources are dynamically allocated from a shared resource pool in the cloud to support task offloading and information sharing in robotic applications [31].

DORO

This robot was developed on a SCITOS G5 platform (Metralabs, Germany) and safely navigates in a domestic environment. DORO can provide support to older individuals with its integrated robotic arm for object manipulation, tray for the transportation of objects, and handle for walking support. Furthermore, both visual and auditory feedback is provided to the user via multicolor LEDs mounted on the robot's eyes, speakers, and GUI on a removable tablet.

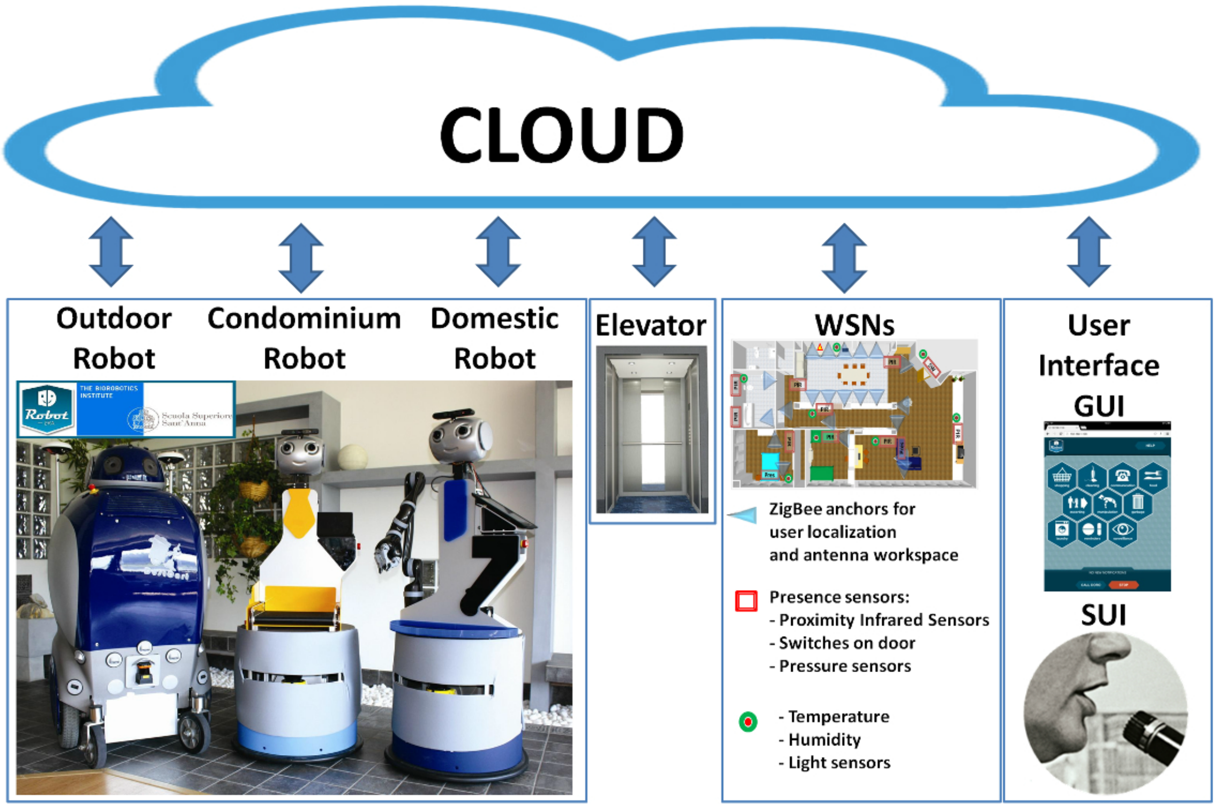
CORO

The CORO robot works in the condominium environment and can navigate between floors using the elevator. It is equipped with a roller mechanism to exchange goods with ORO, and it provides feedback to users in the same manner as DORO.

ORO

This robot was designed on the DustCart platform and is an autonomous mobile robot for goods transportation in the urban environment by means of a container to carry the objects [32]. ORO has a head with multicolor LEDs in the eyes, a touchscreen on the left side, and speakers reproducing acoustic signals to provide information to the user.

Figure 1. Robot-Era architecture. GUI: graphical user interface; SUI: speech user interface; WSN: wireless sensor network.



Elevator

The elevator, already present in the environment, is embedded in the Robot-Era system through a Phidget input/output digital board used to control it remotely.

Wireless Sensor Networks

Two Zig-Bee WSNs are included in the Robot-Era system. The first network is designed for multiple user localization inside the domestic environment by observing the received signal strength. The second network was developed for home monitoring and passive localization of people. It consists of passive infraRed sensors, pressure sensors placed under a chair or bed, switches on doors or drawers, gas and water leak sensors, and sensors for temperature, humidity, and light.

The Graphical User Interface

A Web GUI (Figure 2), which runs on the robot's tablet, is the GUI. A main menu index page allows the user to navigate between the different Robot-Era service pages that compose the GUI. The users can employ the GUI to call the robot, select a service, and perform the service [33].

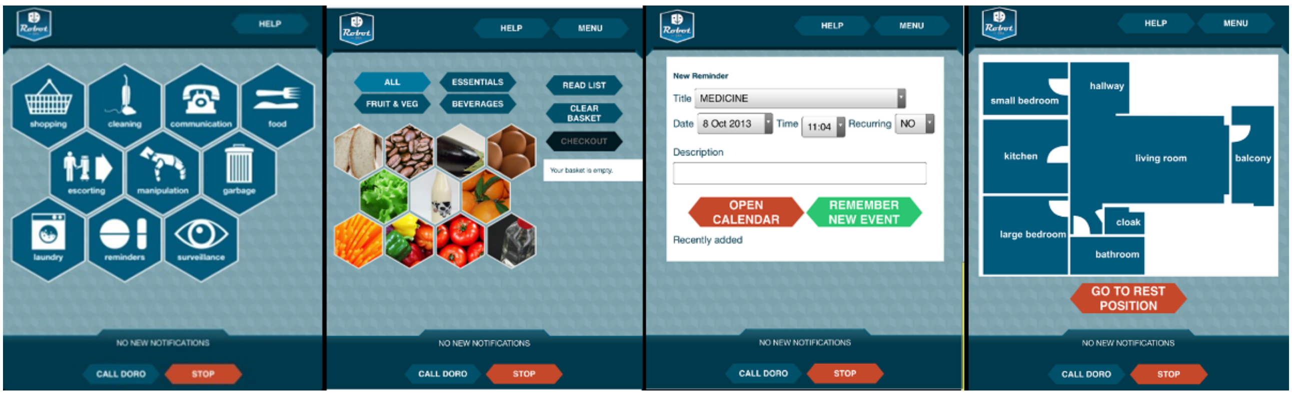
Speech User Interface

Using the Bluetooth-connected wearable microphone, the user can ask for, and perform, a robotic service. Specifically, the robot can recognize certain keywords when a user is speaking, corresponding to the commands or the services that the robot can perform. The robot can perform speech synthesis through the speakers to interact with the user [34].

More Details

More details about the Robot-Era architecture are explained in [35].

Figure 2. The Robot-Era graphical user interface.



Robot-Era Services

The Robot-Era system can provide six advanced robotic services that were tested by real older users in Peccioli (Italy) to evaluate the usability and the acceptability of the system. The Robot-Era experiments were organized into two sessions. In the first session, the shopping, garbage collection, and communication services were tested. In the second session, the reminding, indoor walking support, and outdoor walking support services were examined.

Shopping Service

The older participant had to imagine they were sick and could not leave their home, but they needed several items to eat and drink. Bearing in mind this presupposition, the participants had to create and send a shopping list with five products using the GUI and wait for the shopping delivery. In this scenario, all three Robot-Era platforms were involved, working in three different environments.

Garbage Service

The older user wanted to dispose of garbage. The participant had to call the domestic robot to select the “garbage collection service.” Speech interaction or GUI could be used to accomplish this service.

Communication Service

This scenario consisted of two parts: a warning alert case and a phone call case. A gas leak inside the home was simulated and detected. The domestic robot went to the user to inform them about this dangerous situation. Immediately following the notification, an incoming call, by a possible caregiver, was visualized on the tablet and the user had to accept it. In the phone call case, the participant used the robot to call a family member via Skype. Users could use speech interaction and GUI to perform this service. Even if the communication service was composed of two parts, it was analyzed as a single service.

Reminding Service

The older user wanted to set a date on the Robot-Era agenda. The user called the domestic robot to perform the task, and then he or she moved to another room inside the home. The robot reached the user to remember the date. The speech and graphical interface interaction were necessary to perform this service.

Indoor Walking Support

The older user had to imagine that they had a temporary mobility problem, so they used the domestic robot as a walking support. The participant drove DORO using two buttons mounted on the handle.

Outdoor Walking Support

The user moved from point A to point B following a preset path and then returned. The individual used the joystick to drive the robot and then tried to open and close the robot bin, pushing the icon on the screen. In this scenario, only ORO worked in the outdoor environment.

Participants

To recruit the needed older users, associations and groups working with senior people were contacted. Furthermore, the municipality of Peccioli sent an instructive brochure about the Robot-Era experimentation to all citizens older than 65 years of age. At the end of the recruitment phase, 45 older persons, aged between 65 and 86 years, were involved in the Robot-Era experimentation on a voluntary basis, and an informed consent was signed by each participant (Figure 3). To be enrolled in the study, the participants had to (1) be older than 65 years, (2) have a positive evaluation of mental status on (Short Portable Mental Status Questionnaire [SPSMQ]; cut-off errors ≤3) [36], and (3) have a minimum required autonomy in performing daily activities, evaluated with the Instrumental Activity of Daily Living Questionnaire (cut-off score >2) [37]. However, all participants made maximum two errors in answering to SPSMQ (cut-off errors ≤3), which means that they had normal mental functioning. Those who agreed to participate received a sociodemographic questionnaire. Given that the Robot-Era experimentation was organized in two sessions, older volunteers were grouped into two samples of 35 participants according to their availability. However, two participants did not complete the second experimental session, so they were eliminated from the study. Moreover, 23 participants participated both in the first experimentation session and in the second one 3 months later. The first sample was composed of 22 women and 13 men. Their mean age was 74.97 (SD 5.70) years and their achieved educational level was primary education for five participants, junior high school for five, high school for 20, and university for five. The second sample was composed of 22 women and 11 men. Their mean age was 73.45 (SD 6.27) years and their achieved educational level was primary education for 10 participants, junior high school for five, high school for 14, and university for four.

Procedure

The experiments were conducted in Peccioli, Italy, and the overall system was used in three different environments: domestic, condominium, and outdoor. Each recruited participant was invited to the premises of the DomoCasa Lab, and the following experimental session was performed:

1. The Robot-Era project was introduced to the user by a researcher.
2. The user was free to gain confidence with the three robots, touching them and asking questions to clear up any confusion.
3. A questionnaire was given to the user to collect their first impressions about Robot-Era platforms.
4. A video tutorial in which a researcher assumed the role of an older user was shown to facilitate the understanding of the functioning and potentialities of the Robot-Era system.
5. The researcher announced the tasks of each Robot-Era service that the participant should fulfill via the robots. Subsequently, the user was asked whether they understood the tasks. If not, the action was repeated, and the tasks were explained again.
6. A written description of the tasks of each robotic service was given to the participant for them to refer to if needed as they tested the Robot-Era services.
7. The user performed each Robot-Era service.
8. The usability and acceptability of each robotics service were evaluated by the user through questionnaires.

Figure 3. Participants involved in Robot-Era experimentation.

During the experimental session, the older adult performed the test without assistance from the researcher to avoid any influence or bias. However, a researcher was present during the experiments for security issues, and the experimental session was video recorded.

Evaluation Tools

One of the most important goals of robotics is to be able to give the robot the highest degree of acceptability. This concept plays a significant and delicate role in the industrial design, and in the context of robotics, this is even more pronounced. For this reason, a specific "appearance questionnaire" (Multimedia Appendix 2), based on a 5-point Likert scale, was developed to evaluate the impact of the robot's appearance on the user. This questionnaire was designed to investigate:

1. Positive or negative feelings that could be evoked on seeing the Robot-Era robots for the first time (items A1-A2);
2. Robot-Era robots' ability to arouse feelings of familiarity in the user thanks to their formal aspect, colors, and size (items A3-A8);
3. The perceived robustness of Robot-Era robots (items A9-A10);
4. Robot-Era robots' ability to make their functions evident (items A11-A13); and
5. Robot-Era robots' ability to establish a positive emotional relationship with the user (items A14-A15).
6. The appearance questionnaire was administered for each robot (DORO, CORO, and ORO).

For the services evaluation phase, an ad hoc questionnaire was developed, consisting of 14 items rated on a 5-point Likert scale (from totally disagree to totally agree; see Multimedia Appendix 3) and based on the following content:

1. Disposition about the Robot-Era services (items Q1-Q3);
2. Feelings of anxiety, enjoyment, and trust evoked using the robotics platforms (items Q4-Q8);
3. Perceived ease of use of the GUI during the performance of Robot-Era services (items Q9-Q11); and

4. Perceived ease of use of the speech user interface (SUI) during the performance of Robot-Era services (items Q12-Q14).

The choice of developing the original set of questions was motivated by the literature in the field of acceptability evaluation [38], which suggests the need for personalization of the tools to adjust the instrument to the specific technical features of the platform and the issues of interest for the project. Moreover, the development of an ad hoc tool represented a common practice for the psychosocial research. The psychometric proprieties of the appearance questionnaire and ad hoc questionnaire were assessed as detailed subsequently.

At the end of each tested service, the System Usability Scale (SUS) was administered to the volunteers to investigate the perceived usability of the Robot-Era services. The SUS is a survey instrument composed of 10 standardized items based on the 5-point Likert scale (from strongly disagree to strongly agree). It was developed according to the three usability criteria defined by the ISO 9241-11: (1) effectiveness: the ability of users to complete tasks using the system; (2) efficiency: the resources expended by users to achieve goals; and (3) satisfaction: the users' subjective comfort using the system.

Statistical Analysis

The first step was to estimate the reliability of the appearance questionnaire and the ad hoc questionnaire. Reliability was assessed as reliability over time and internal consistency reliability. Reliability over time of the ad hoc questionnaire was measured applying test-retest, because this tool was administered twice to the same 23 participants who were involved both in the first experimentation session and in the second one 3 months later. Regarding the appearance questionnaire, the test-retest was not applicable because this tool was administered one time. For this reason, the split-half method was applied dividing the tool into even and odd questions. The two halves of a measure were treated as alternate forms (same mean and standard deviation). Therefore, the correlation between the two halves was calculated as an estimate of the test-retest reliability. Finally, reliability estimate was stepped up to the full tool length using the Spearman-Brown prediction formula. The internal consistency reliability was assessed calculating the intraclass correlation coefficient (ICC) and Cronbach alpha.

For each questionnaire, the basic descriptive statistics were calculated: mean scores, standard deviation, and mode to obtain a first impression of the scores. Moreover, to obtain an overall score for each questionnaire, the sum of the item score contributions was rescaled from 0 to 100 because the 0 to 100 scale is more intuitive to understand. Furthermore, nonparametric tests were applied to compare different conditions and users. The choice of nonparametric statistics is necessary when the sample size is not large, and data are not normally distributed. The Mann-Whitney *U* test was used to compare men versus women and users younger than 75 years versus older than 75 years, whereas the Kruskal-Wallis test was used to compare different conditions in educational level and technology skill. Finally, the correlations among the appearance, ad hoc, and SUS questionnaires were investigated by calculating the Pearson correlation.

Results

Primary Findings

As shown in Multimedia Appendix 4 (Reliability of Questionnaires) about the appearance questionnaire administered for the DORO, CORO, and ORO robots, the split-half reliability, adjusted using the Spearman-Brown prophecy formula, was higher than .60 and P<.001; reliability over time higher than .40 is considered acceptable [39]. Regarding internal consistency reliability, the ICC was higher than .4; ICC values between .40 and 0.75 are good [40]. Moreover, Cronbach alpha value was higher than .60, which is considered acceptable for short instruments with a small number of items [41-43].

Considering the ad hoc questionnaire (Multimedia Appendix 4), test-retest reliability value (r=.68, P<.001) was acceptable [39] and internal consistency reliability was well estimated because ICC was higher than .40 [40] and Cronbach alpha was higher than .60 [41-43] for all Robot-Era services. In conclusion, the appearance and the ad hoc questionnaires could be considered reliable.

Appearance Questionnaire Outcomes

Figure 4 reports the boxplot of the overall score: the mean values were 73.04 (SD 11.80) for DORO, 76.85 (SD 12.01) for CORO, and 75.93 (SD 11.67) for ORO.

In Table 1, descriptive statistics regarding the appearance questionnaire are reported. The results show that the items that were phrased negatively had a mean score lower than 3 and a mode value equal to 1 (except for item A8) related to DORO, with a mode value equal to 3. Conversely, the items that were phrased positively had a mean score greater than 3 with a mode value equal to 4 or 5. The only exceptions were items A3 and A10 with a mode value of 1 and 3, respectively.

Concerning the effect of gender, male participants gave ORO an overall score higher than female participants (P=.02). The appearance of ORO inspired more confidence in men than in women (item A2: P=.03). In addition, male participants had a higher propensity for touching and interacting with ORO than female participants (item A15: P=.048).

Regarding the impact of age, individuals younger than 75 years readily understood the functionalities of Robot-Era robots, more so than older people (item A11: P=.007 for DORO, P=.001 for CORO, and P=.046 for ORO).

Moreover, older users with a high educational level expressed willingness to interact with DORO (item A15: P=.007) and CORO (item A15: P=.047) more than volunteers with a low level of education.

Finally, older adults who were able to use a PC and the internet gave CORO and ORO a higher overall score than those who were not able to use such technologies (P=.03 for CORO and P=.01 for ORO).

Ad Hoc Questionnaire Outcomes

Regarding the results of the ad hoc questionnaire, the mean overall score was 84.59 (SD 10.32) for shopping, mean 87.30 (SD 10.84) for garbage, mean 86.73 (SD 9.11) for communication, mean 86.58 (SD 14.68) for reminding, mean 85.93 (SD 11.05) for indoor walking support, and mean 84.69 (SD 11.93) for outdoor walking support. Figure 5 shows the boxplot of the overall score.

Moreover, standard descriptive statistics presented a high rate of agreement, characterized by a high mean score for positively formulated items and a low mean score for negatively formulated items for all Robot-Era services (Table 2).

Concerning the effect of sociodemographic factors, participants with a high educational level gave Robot-Era services a higher score than those with a low level of education; specifically, for shopping (P=.04), garbage (P=.047), reminding (P=.04), indoor walking support (P=.006), and outdoor walking support (P=.03). Moreover, a significant difference was found between genders, because a higher score was given by male older adults for shopping (P=.02), indoor walking support (P=.02), and outdoor walking support (P=.03).

Shopping Service

Concerning the comparison between different conditions and users, men had more trust in the robot's ability to perform the shopping service than women did (item Q7: P=.007). Regarding the age factor, the participants younger than 75 years would use the robot for shopping if necessary (item Q1: P=.04) and if it could reduce the family/caregiver's work burden (item Q2: P=.04), more so than those older than 75 years. Moreover, participants with a high educational level thought that the proposed system could help the caregivers work less, more so than people with a low educational level (item Q2: P<.001). However, higher educated users had more trust in the robot's ability to perform the shopping service (item Q7: P=.03) than less-educated users.

Garbage Collection Service

There was a significant difference in gender regarding the benefits that could lessen the family/caregiver's work burden: men gave a higher score than did women (Item Q2: P=.02). Furthermore, more educated participants were more skeptical than less-educated ones about the help provided by the robotic system to caregivers (item Q2: P=.01). The more educated participants perceived the robot as less intrusive for privacy (item Q8: P=.03).

Communication Service

Men thought their independence would be improved using the communication service (item Q3: P=.03) more so than women. Furthermore, the robot was perceived as not intrusive (item Q8: P=.006) by men more so than by women. Furthermore, more males reported that it was easy to speak to the robot (item Q12: P=.047) than did females. The vocal commands to interact with the robot were understood (item Q13: P=.048) better by men than by women. Moreover, more participants younger than 75 years would use the Robot-Era system in case of need (item Q1: P=.04) than those older than 75 years. The younger group also felt the system could reduce the caregiver's work burden more so than the older group did (item Q2: P=.04). Finally, individuals with a high educational level had a more positive attitude (item Q2: P=.001) and felt the robot was less intrusive (item Q8: P=.03) compared to the less-educated individuals.

Reminding Service

Participants' independence could be increased by this service (item Q3: P=.047) to a larger extent for men than for women. Moreover, males recognized the icons to press on the tablet to perform the reminding service (item Q11: P=.03) better than the females did. Furthermore, more participants younger than 75 years reported that it was easier to use the speech commands (item Q12: P=.04; item Q13: P=.02) compared to those older than 75 years. Regarding educational level, more individuals with a high educational level thought this service could reduce the caregiver's burden (item Q2: P=.02) and believed that the system was more reliable (Item Q7: P=.02) compared to participants with a low level of education.

Figure 4. Boxplots of the overall scores, considered as the sum of the item score contributions, rescaled from 0 to 100, for the appearance questionnaires for the DOmestic RObot (DORO), COndominium RObot (CORO), and Outdoor RObot (ORO) systems. On each box, the central mark indicates the median, the bottom and top edges of the box the 25th and 75th percentiles, and the whiskers the most extreme data points not considered outliers.

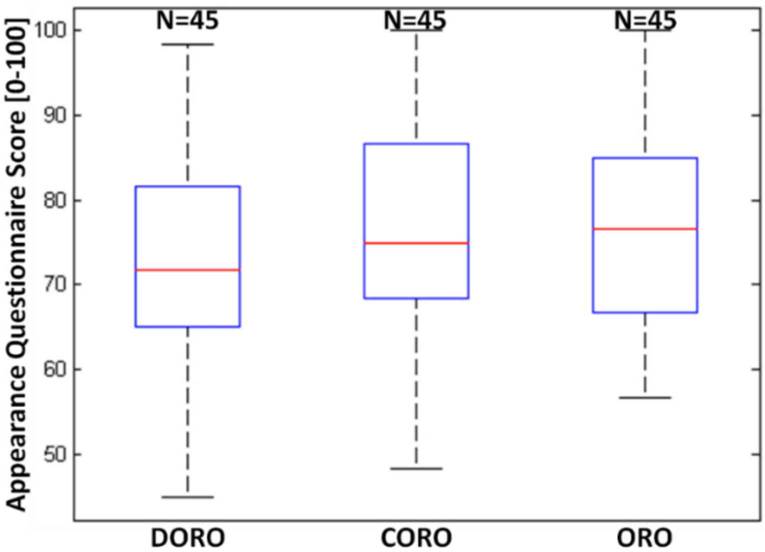


Table 1. Descriptive statistics of items on the appearance questionnaire[a] for the DOmestic RObot (DORO), COndominium RObot (CORO), and Outdoor RObot (ORO) systems (N=45).

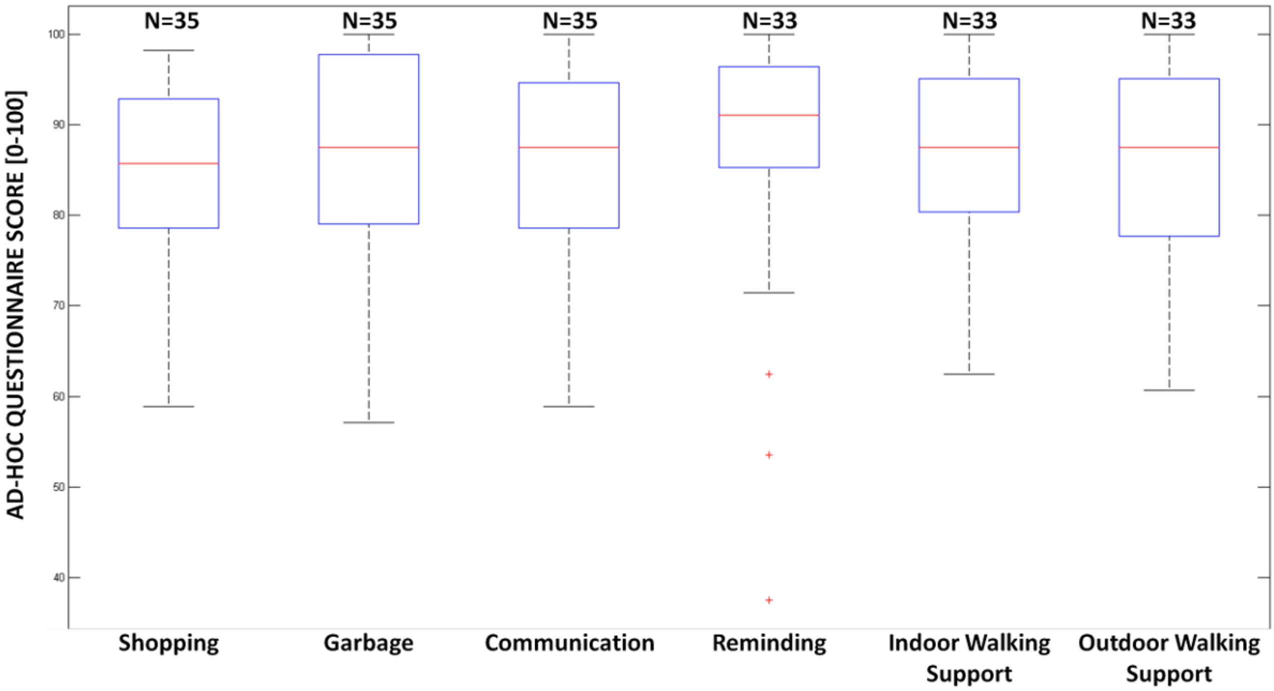
System and questionnaire item[b]	Mean (SD)	Range	Mode
DORO			
Item A1	1.18 (0.49)	1-3	1
Item A2	4.33 (0.88)	1-5	5
Item A3	2.98 (1.54)	1-5	1
Item A4	4.09 (0.95)	1-5	5
Item A5	4.27 (0.86)	2-5	5
Item A6	2.02 (1.27)	1-5	1
Item A7	4.22 (0.79)	2-5	5
Item A8	3.07 (1.37)	1-5	3
Item A9	4.18 (0.81)	1-5	4
Item A10	3.73 (1.03)	1-5	3
Item A11	2.62 (1.37)	1-5	1
Item A12	3.82 (1.11)	1-5	5
Item A13	2.22 (1.68)	1-5	1
Item A14	1.49 (1.08)	1-5	1
Item A15	3.82 (1.25)	1-5	5
CORO			
Item A1	1.11 (0.32)	1-2	1
Item A2	4.31 (0.95)	1-5	5
Item A3	2.76 (1.43)	1-5	1
Item A4	4.24 (0.80)	2-5	5
Item A5	4.64 (0.48)	4-5	5
Item A6	1.67 (1.15)	1-5	1
Item A7	4.33 (0.88)	1-5	5
Item A8	2.11 (1.34)	1-5	1
Item A9	4.22 (0.79)	1-5	4
Item A10	3.84 (0.98)	1-5	3
Item A11	2.69 (1.33)	1-5	1
Item A12	4.11 (0.83)	2-5	4
Item A13	2.16 (1.64)	1-5	1
Item A14	1.49 (1.08)	1-5	1
Item A15	3.87 (1.18)	1-5	5
ORO			
Item A1	1.24 (0.61)	1-3	1
Item A2	4.24 (0.96)	1-5	5
Item A3	2.56 (1.39)	1-5	1
Item A4	3.93 (0.94)	2-5	5
Item A5	4.42 (0.87)	1-5	5
Item A6	1.89 (1.27)	1-5	1
Item A7	4.53 (0.66)	3-5	5
Item A8	1.73 (1.34)	1-5	1

System and questionnaire item[b]	Mean (SD)	Range	Mode
Item A9	4.40 (0.81)	1-5	4
Item A10	3.84 (0.98)	1-5	3
Item A11	2.78 (1.43)	1-5	1
Item A12	4.16 (0.80)	3-5	4
Item A13	2.20 (1.69)	1-5	1
Item A14	1.53 (1.10)	1-5	1
Item A15	3.84 (1.15)	1-5	5

[a]See Multimedia Appendix 2 (Appearance questionnaire).

[b]A1: the robot looks dangerous; A2: the appearance inspires confidence in me; A3: the appearance is familiar; A4: the appearance is aesthetically pleasing; A5: the colors are appropriate; A6: the appearance is out of proportion and nonsymmetric; A7: the appearance is in good agreement; A8: the robot is too big and bulky; A9: the complete robot and its various parts seem robust; A10: the materials are appropriate; A11: the appearance is unable to communicate its functions; A12: the position of the touchscreen is appropriate; A13: the presence of colored lights in the eyes of the robot is useless; A14: the presence of a head on the robot restricts or inhibits the interaction with the robot; A15: the appearance invites me to touch and interact with it.

Figure 5. Boxplots of the overall scores, considered as the sum of the item score contributions, rescaled from 0 to 100, for the ad hoc questionnaire. On each box, the central mark indicates the median, the bottom and top edges of the box the 25th and 75th percentiles, and the whiskers the most extreme data points not considered outliers, and the outliers are plotted individually using the "+" symbol.



Indoor Walking Support Service

Men had a more positive attitude toward this robotic service (item Q1: P=.04; item Q3: P=.004) than women did. Furthermore, more educated participants had more trust in the ability of the Robot-Era system (item Q7: P=.04) than those with a lower level of education.

Outdoor Walking Support Service

More men felt that their independence could be improved by this service (item Q3: P=.03) than women did.

Comparing Questionnaires

Investigating the correlation among the questionnaires, there were significant results between the appearance questionnaire related to DORO and the ad hoc questionnaire for shopping (r=.35, P=.04), communication (r=.41, P=.02), reminding (r=.35, P=.04), and indoor walking support (r=.35, P=.04) services, whereas there was not a significant correlation between the appearance questionnaire and the SUS. Finally, the ad hoc questionnaire and SUS were correlated for all Robot-Era services: shopping (r=.65, P<.001), garbage (r=.43, P=.01), communication (r=.41, P=.001), reminding (r=.71, P<.001), indoor walking support (r=.37, P=.04), and outdoor walking support (r=.39, P=.03)

Table 2. Descriptive statistics for the ad hoc questionnaire[a] for services.

Service	Mean (SD)	Range	Mode
Shopping service			
Item Q1	4.66 (0.94)	1-5	5
Item Q2	4.49 (1.07)	1-5	5
Item Q3	3.69 (1.53)	1-5	5
Item Q4	1.20 (0.68)	1-4	1
Item Q5	1.14 (0.69)	1-5	1
Item Q6	4.46 (1.04)	1-5	5
Item Q7	4.54 (0.66)	3-5	5
Item Q8	1.09 (0.37)	1-3	1
Item Q9	3.49 (1.34)	1-5	3
Item Q10	3.86 (1.35)	1-5	5
Garbage service			
Item Q1	4.69 (0.90)	1-5	5
Item Q2	4.54 (0.98)	1-5	5
Item Q3	4.14 (1.33)	1-5	5
Item Q4	1.14 (0.69)	1-5	1
Item Q5	1.11 (0.68)	1-5	1
Item Q6	4.46 (1.07)	1-5	5
Item Q7	4.74 (0.56)	3-5	5
Item Q8	1.20 (0.76)	1-5	1
Item Q9	3.94 (1.19)	1-5	5
Item Q10	4.17 (1.07)	2-5	5
Communication service			
Item Q1	4.63 (0.91)	1-5	5
Item Q2	4.34 (0.97)	1-5	5
Item Q3	3.91 (1.34)	1-5	5
Item Q4	1.17 (0.62)	1-4	1
Item Q5	1.14 (0.49)	1-3	1
Item Q6	4.57 (1.01)	1-5	5
Item Q7	4.43 (0.88)	1-5	5
Item Q8	1.26 (0.95)	1-5	1
Item Q9	4.09 (1.22)	1-5	5
Item Q10	4.23 (1.26)	1-5	5
Reminding service			
Item Q1	4.55 (1.09)	1-5	5
Item Q2	4.48 (1.23)	1-5	5
Item Q3	4.27 (1.21)	1-5	5
Item Q4	1.12 (0.55)	1-4	1
Item Q5	1.24 (0.66)	1-4	1
Item Q6	4.30 (1.24)	1-5	5
Item Q7	4.55 (1.03)	1-5	5
Item Q8	1.33 (1.08)	1-5	1

Service	Mean (SD)	Range	Mode
Item Q9	3.76 (1.39)	1-5	5
Item Q10	4.61 (0.79)	2-5	5
Indoor walking support service			
Item Q1	4.45 (1.23)	1-5	5
Item Q2	4.55 (1.12)	1-5	5
Item Q3	3.58 (1.58)	1-5	5
Item Q4	1.03 (0.17)	1-2	1
Item Q5	1.00 (0.00)	1-1	1
Item Q6	4.61 (0.79)	3-5	5
Item Q7	4.61 (0.83)	1-5	5
Item Q8	1.42 (1.06)	1-5	1
Item Q9	3.76 (1.39)	1-5	5
Item Q10	4.61 (0.79)	2-5	5
Outdoor walking support service			
Item Q1	4.48 (1.23)	1-5	5
Item Q2	4.33 (1.24)	1-5	5
Item Q3	4.03 (1.31)	1-5	5
Item Q4	1.27 (0.91)	1-5	1
Item Q5	1.00 (0.00)	1-1	1
Item Q6	4.48 (0.87)	1-5	5
Item Q7	4.36 (1.06)	1-5	5
Item Q8	1.76 (1.35)	1-5	1
Item Q9	3.76 (1.39)	1-5	5
Item Q10	4.61 (0.79)	2-5	5

[a]See Multimedia Appendix 3 (Ad hoc questionnaire).

Discussion

Principal Results Regarding Robot's Appearance

New technologies are increasingly impacting the entire society, but older adults often have difficulty accepting them. This reluctance could be due to the fear of trying something new, not perceiving the need for the technology, and the lack of training to use new technologies [44-46]. Moreover, many older individuals have never experienced such technologies, or at least they benefit from them to a lesser extent than younger people [47]. In this study, participants were free to become familiar with the Robot-Era robots before starting the experiment session to feel more confident in testing them. A video tutorial was shown to illustrate all Robot-Era services and older volunteers could touch the robots and ask questions about their functionalities to become confident with them. In fact, adequate training can increase the level of acceptance [48].

Participants had quite a positive impression of Robot-Era robots, as shown by the median score of 71.67 for DORO's appearance, 75.00 for CORO, and 76.67 for ORO. Furthermore, there was an upward trend in median score related to the workplace environment of the robot, as confirmed by the increase of the minimum value of the overall score (see Figure 4). Looking at these data, older adults tend to express a more positive opinion about CORO and ORO, which usually do not live in the domestic environment with humans but work in condominium and urban areas, respectively. A conscious and total acceptance of a robot in a domestic environment could reflect the successful diffusion of robots within society, starting from the outdoor environment and progressing to their incorporation in the private house. This hypothesis finds a confirmation in the fact that older volunteers, able to use a PC and the internet, gave a higher score to CORO and ORO than those individuals who were not able to use these technologies. The older adults with technology experience were aware that these technologies can connect the outside world and their own homes, such as CORO and ORO are able to do. Moreover, ORO received a higher score by men than women because more male participants reported that the outdoor robot had a masculine aspect than female participants did.

The appearance of a robot is a factor that may impact human-robot interaction and acceptance by older adults, even if older people did not express any preferences regarding the robot's appearance [49]. Furthermore, a human-like robot can confuse older individuals, so in the Robot-Era project, the choice was a mixed appearance between the anthropomorphic and machine features since all robots are equipped with a motorized head. The head is characterized by blinking colored eyes, a stylized mouth, and two small, soft disks on the side that resemble ears. Watching the Robot-Era robots for the first time, all participants said something like, “They have a nice face,” “They are smiling,” or “They are welcoming.” These sentences confirm that the older volunteers were positively impressed and, in effect, that facial features of the robots—especially nose, eyelids, and mouth—can positively influence acceptance [50]. In fact, 40 of 45 older adults thought that the presence of a head on the robot promotes interaction with it (Table 1, item A14).

Furthermore, the Robot-Era robots are developed with a height of 1.50 m, which is shorter than an average human adult’s height, for the user to perceive having control over the robot without feeling dominated by it. Thanks to this choice and the presence of a head, DORO, CORO, and ORO do not evoke negative reactions in older users because they are judged not dangerous and they inspire confidence, as confirmed respectively by the low average score of item A1 (A1: the robot looks dangerous) and the high score of item A2 (A2: the appearance of the robot inspires confidence in me); see Table 1. Moreover, the acceptance of new technologies increases if they are familiar with something known by end users. For this reason, the shape of Robot-Era robots is designed to remind users of a domestic worker for DORO, a janitor for CORO, and a delivery man for ORO. Unfortunately, this goal was not reached as shown by the low score of item A3 (A3: the appearance of the robot is familiar to me); see Table 1. The justification of this low familiarity may not necessarily imply disliking or rejection of the robots, but it could mean that people do not ever like innovation or creativity.

Moreover, Robot-Era robots have to share and coexist with humans, so they have to integrate themselves in real environments from an esthetic and functional point of view. Investigating this issue, the survey outcomes show that DORO’s appearance was pleasing for 34 of 45 older adults, CORO’s for 37 users, and ORO’s for 34 (Table 1, item A4). Additionally, the colors of the three robots are appropriate as confirmed by the high average score of item A5 (Table 1). Considering that, it is reasonable to think that Robot-Era robots could fit well within a domestic, condominium, and outdoor environment as demonstrated by the positive results of item A7 (Table 1). Furthermore, the size of a robot is an important perspective because it has to give the impression to work efficiently without damaging the environment. According to older individuals’ feedback, CORO and ORO are not perceived as too big or bulky compared, respectively, to a condominium and outdoor environment (Table 1, item A8). However, the participants assumed a neutral position regarding DORO’s size (Table 1, item A8) because most of them lived in a small house, but they were open to changing their minds after watching it move in a domestic environment.

The appearance of a robot should be perceived as robust to people who should have trust in it. Investigating this issue, Robot-Era robots and their various components seem sufficiently robust according to the positive feedback from older individuals for item A9 and item A10 (Table 1). However, all participants reported that they were not competent to judge this point, and they gave a high score, saying they trusted the developers.

Furthermore, a robot should be clearly understandable and easy to use to be accepted by end users. According to the survey outcomes, all Robot-Era robots can successfully communicate their functions as confirmed by item A11 (Table 1) and colored lights in the eyes of the robots were judged useful to communicate (Table 1, item A13).

Individuals younger than 75 years readily understood the functionalities of Robot-Era robots, more so than older individuals, likely because the younger volunteers lead a more active life, so they are more familiar with new technologies, such as tablets and smartphones, which are achieving market and society penetration. Furthermore, the high score of item A12 confirms that the position of the tablet is perfect for its use for all robots.

Finally, according to the results for item A15, the appearance of the Robot-Era robots invites the user to touch and interact with them. Moreover, older users with a high educational level expressed a greater willingness to interact with DORO and CORO, possibly because they are open, due to their educational background, to perceiving the robot as a social entity.

Principal Results of the Ad Hoc Questionnaire

Looking at Figure 5, Robot-Era services were acceptable by older adults because the majority of the sample gave an overall score higher than 75 points, and the high degree of acceptance is also confirmed by the positive results shown in Table 2. The acceptance of robots by older people is related to their attitude toward robots because attitude is an important factor to understand the intention to use any technology [51]. In this study, the outcomes of the survey show a positive attitude toward Robot-Era services because the mean scores of item Q1 and item Q2 were higher than 4 and the mode was equal to 5 for all services. As matter of fact, all participants reported that they would share their life with a robot if the time came when they would not be able to perform their daily tasks. Moreover, many volunteers said they would prefer to be assisted by a robot to avoid burdening their sons and daughters with their care. Furthermore, Robot-Era services have the potential to improve the independence of older people, as confirmed by the high mean score and mode equal to 5 for item Q3. Many older adults reported that the Robot-Era system could prevent them from having to do boring tasks such as taking out the trash. Moreover, most of the participants said they would feel safer in their own homes using the Robot-Era services because DORO is able to communicate alert messages such as “There is a gas leak” or “The door is open” and because the robotics system can call a caregiver automatically in the event of dangerous situations. Furthermore, the capabilities of DORO to locate the user in the house and to remind them to take their medicine were much appreciated by older adults who would no longer need to worry about forgetting to take their medications thanks to this robotic service. According to the feedback from older users, the indoor walking support service is useful to move safely in the home thanks to the robot’s handle. However, the mean score of item Q3 was not too high because the participants did not have mobility impairments. Nevertheless, they would use DORO to transport objects or laundry from one room to another, taking advantage of the robot's capabilities to navigate autonomously, because older users said they would feel safer if the robot would do that task for them, so they would avoid the risk of falls during this task. The same arguments are valid for the outdoor walking support service. In addition, the older participants would like the social capability of the outdoor robot to be improved. Furthermore, according to participants, the shopping need was not perceived as a burdensome task, but as a socialization means; however, they said that this service is useful in the case of temporary mobility impairments or bad weather.

Anxiety toward robots is an important issue to be faced, and often older adults have negative feelings about the idea of having a robot assistant, particularly in a home environment [52]. Conversely, the Robot-Era system did not evoke anxious or negative emotional reactions in older participants during the experimentation because almost no one was embarrassed or nervous when interacting with the robots, as confirmed by a low score of item Q4 and item Q5. Furthermore, many participants expressed that, before starting the experiments, they were worried about appearing inadequate should they not be able to complete the test. However, they said they felt relaxed and comfortable thanks to the explanations provided by the researchers in the starting phase. In effect, the participants enjoyed using the Robot-Era system, as confirmed by the high agreement with item Q6. Only two users did not get pleasure in testing the Robot-Era system because they claimed to see the robotics system as an appliance that is used for its usefulness and not for pleasure. Furthermore, the trust in the ability of the Robot-Era system to perform with integrity and reliability is a factor that affects the acceptance, and the participants expressed a high degree of trust in the Robot-Era system (item Q7). The older adults justified their answers, saying that all provided robotic services were successful during the experimentations. Moreover, the development of robotic systems working in daily living environments raises ethical issues such as privacy problems. However, according to the older volunteers, the Robot-Era system was not too intrusive for their privacy, as confirmed by the low score obtained for item Q8. Some participants said that their privacy would not be a concern since they can freely choose whether or not to use the proposed robotic services. Other older adults said that the Robot-Era system was not more intrusive than other technologies, whereas some male participants joked that a robot is less intrusive than their wives. Regarding the items related to the perceived ease of use of GUI, the feedback of participants was quite positive, and it should be considered that most of them did not have familiarity with the tablet and they had some starting difficulty because it was the first time they used it. In particular, the tablet was found easy to use (item Q9), the messages on it were read (item Q10), and the icons to perform the services were identified (item Q11). Therefore, at the end of the experiments, the older adults gave some suggestions to improve the GUI such as adding the captions to the icons. However, everybody reported a willingness to learn to use the tablet because it has widespread use in society. Finally, the speech interaction was well evaluated by older users because they spoke to the robot easily (item Q12), they understood the vocal commands to interact with the robot (item Q13), and they heard without any major difficulties what the robot said (item Q14). Moreover, the participants reported that they enjoyed speaking to the robot because it was seen as the more natural means to interact with it. Although the robot communicated in quite a sophisticated manner, it did not understand if a synonym of the keywords was used. For this reason, the participants suggested increasing the vocabulary of the robot, so that the user could speak in a natural way without having to remember the keywords to use. Moreover, the older adults suggested that the robot should give more feedback about its status, such as describing what it is doing, and the robot should communicate to the user if it understood a command.

Concerning the effect of sociodemographic factors, it seems that men have a more positive attitude toward Robot-Era services and, in effect, men are less skeptical in using assistive robotic technologies than women [53] and they have a more positive attitude than women toward the possibility of using a robot in the future [54]. As shown in the previous section, gender could have an impact on the acceptance of the technology. Examples of this in the study are that men would use the indoor walking support, in case of need, more than women (item Q1), and regarding the garbage collection service, male participants thought that the Robot-Era system could reduce the caregiver's work burden (item Q2). Furthermore, communication, reminding, indoor walking support, and outdoor walking support could improve men's independence more than women's (item Q3). The trust in the robot's ability to perform the shopping service (item Q7) was higher in males than in females, who also thought a robot would be too intrusive for their privacy (item Q7, communication). In general, men seem more willing to accept robotic technologies in their daily lives than women [55]. Furthermore, men perceived the interaction modalities (item Q11: reminding, indoor walking support, and outdoor walking; item Q12 and item Q13: communication) as easier than women did because males tend to be more task-oriented and motivated to achieve specific goals [56].

Regarding the effect of age on attitudes toward technology, acceptance decreases with increasing age and young older users are more likely to use technology [57]. However, if technology meets the older individuals' needs, the effect of age on acceptance becomes less important [58]. In this study, the results show that older users positively evaluated Robot-Era services regardless of age, except for the shopping and communication services, in which the participants younger than 75 years, more than those older than 75 years, would use the Robot-Era system in case of need (item Q1) and if it could reduce the caregiver's work burden (item Q2). Furthermore, the speech commands to perform the reminding service were evaluated as easier to use by young older users than older ones (item Q12 and item Q13). These results can be explained on the basis of cultural background because the sense of family ties is very strong for people older than 75 years, who think they should be assisted by their sons and daughters. Moreover, younger people placed more trust in technology because they were more familiar with it, whereas the older individuals thought that the new technologies were far too complicated [53].

Concerning the factor of education level, it was found that people with a high education level expressed a positive attitude toward a robot [53]. However, in this study, the participants with a higher education level tended to have a less positive attitude toward the shopping (item Q1, item Q2) and garbage collection (item Q2) services than those who had a low educational level. This could be explained by the fact that the participants with a higher education level tended to live in towns where they had more access to services such as home grocery delivery and curbside collection. Alternatively, participants who lived in rural areas, where these services were less widespread, needed a family member's help for transportation of goods and for this reason they would like to use robotic service to relieve the caregiver of these duties. However, in keeping with their familiarity with advanced technologies, older users with a high educational level reported more positive judgments about communication (item Q2) and reminding (item Q2) services. Furthermore, individuals with a higher education level had more trust in the robot's ability to perform shopping (item Q7) and reminding (item Q7, *P*=.02), and felt that the robot was not intrusive for their privacy.

However, even if some correlations between sociodemographic factors and the ad hoc questionnaire items were highlighted, the Robot-Era system could be considered acceptable by a large segment of the older population.

Finally, the significant correlation between the appearance questionnaire related to DORO and the ad hoc questionnaire for shopping, communication, reminding, and indoor walking support services suggests that the acceptance by older users could be influenced and increased by the positive impression aroused by the esthetics of a robot. However, it should be considered that DORO was the robotic platform the older adults interacted with for more time during the experimentation.

Strengths and Limitations

The strength of this study is that it reflects the real users' perceptions of acceptability of services provided by a robotic system. The rationale is that 35 older adults tested six robotic services in realistic environments; moreover, the individuals worked with three robots in a domestic, condominium, and outdoor environment to guarantee the continuity of the robotic services from private houses to public areas and vice versa.

The study had some limitations. First, the appearance and the ad hoc questionnaires were developed specifically for the Robot-Era experiments, but they were not pilot tested nor validated before the trial sessions were started. However, the internal consistency was verified by applying the Cronbach alpha test and all questionnaires had an alpha value higher than .60.

Second, the Robot-Era experimentation was organized in two sessions, testing three services at a time. In this respect, the two samples were not composed of the same participants because some of the participants were not available to participate in both experimental sessions. Furthermore, the sample was not sex-balanced, but this is because, at the age of 65 years, women in Europe have a life expectancy higher than men.

Third, participants spent 3 hours testing the Robot-Era system during which time they alternated the testing of each robotic service and the evaluation phase. This adopted experimentation format brought a lack of continuity that could have given an incomplete overview of the robotic services and prevented its potential from being fully explored. In each case, this experimentation was positively used to gather feedback to improve the Robot-Era system. In the future, participants should interact with the robots for longer and in a more realistic setting, postponing the evaluation phase to the end of the trials.

Fourth, during the trial, some technical problems occurred, and this could have biased the user's perception of the robotic system. For further trials, the dependability of the Robot-Era system should be improved so that older adults can evaluate a reliable robotic system.

Finally, the recruitment was limited to older persons who lived in Peccioli Municipality, a small village in the Italian countryside, so the catchment area covered a small number of older citizens. Furthermore, only participants without cognitive and physical impairments were recruited because the Robot-Era system was conceived for frail older persons living alone at home without a formal caregiver's support. For this reason, the randomization of the sample was not feasible.

Conclusion

This paper presents the results of a realistic experimentation of a robotic system for supporting independent living of older people. The approach overcomes some of the limitations of previous similar experiments. Six robotic services were tested by a total of 35 older users, who directly interacted with three autonomous robots, which cooperated between them in smart environments to accomplish everyday life tasks.

Looking at the proposed robotics system, interesting outcomes were found. In general, the Robot-Era robots' esthetic and functionalities had a positive impact on the older adults, as shown by the high scores they gave to DORO, CORO, and ORO. Moreover, the results suggest that the positive perception of the robots' esthetics could play a role in increasing the acceptance of robotic services by older persons.

Finally, according to all aspects discussed in this work and based on the feedback given by the end users, the Robot-Era system has the potential to be developed as a socially acceptable and believable provider of robotic services to promote the ability for older individuals to remain in their homes. Future works will foresee experimentations with the involvement of users with mild functional impairments.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Overview of related works.

[PDF File (Adobe PDF File), 185KB - jmir_v20i9e264_app1.pdf]

Multimedia Appendix 2

Appearance questionnaire.

[PDF File (Adobe PDF File), 224KB - jmir_v20i9e264_app2.pdf]

Multimedia Appendix 3

Ad-hoc questionnaire.

[PDF File (Adobe PDF File), 269KB - jmir_v20i9e264_app3.pdf]

Multimedia Appendix 4

Reliability of questionnaires.

[PDF File (Adobe PDF File), 331KB - jmir_v20i9e264_app4.pdf]

Multimedia Appendix 5

Video of scenarios.

[MP4 File (MP4 Video), 117MB - jmir_v20i9e264_app5.mp4]

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Abbreviations

CORO: COndominium RObot
DORO: DOmestic RObot
GUI: graphical user interface
ICC: intraclass correlation coefficient
ORO: Outdoor RObot
SPSMQ: Short Portable Mental Status Questionnaire
SUI: speech user interface
SUS: System Usability Scale
WSN: wireless sensor networks

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Original Paper

Mobile App Use by Primary Care Patients to Manage Their Depressive Symptoms: Qualitative Study

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Abstract

Background: Mobile apps are emerging as tools with the potential to revolutionize the treatment of mental health conditions such as depression. At the forefront of the community health sector, general practitioners are in a unique position to guide the integration of technology and depression management; however, little is currently known about how primary care patients with depressive symptoms are currently using apps.

Objective: The objective of our study was to explore the natural patterns of mobile app use among patients with depressive symptoms to facilitate the understanding of the potential role for mobile apps in managing depressive symptoms in the community.

Methods: Semistructured phone interviews were conducted with primary care patients in Victoria, Australia, who reported symptoms of depression and were enrolled in a larger randomized controlled trial of depression care. Interviews explored current depression management strategies and the use of mobile apps (if any). Interviews were audio-recorded and transcribed verbatim. Inductive thematic analysis was iteratively conducted using QSR NVivo 11 Pro to identify emergent themes.

Results: A total of 16 participants, aged between 20 to 58 years, took part in the interviews with 11 reporting the use of at least one mobile app to manage depressive symptoms and 5 reporting no app use. A variety of apps were described including relaxation, mindfulness, cognitive, exercise, gaming, social media, and well-being apps to aid with depressive symptoms. Among users, there were the following 4 main patterns of app use: skill acquisition, social connectedness, inquisitive trial, and safety netting. Factors that influenced app use included accessibility, perceptions of technology, and personal compatibility. Health care providers also had a role in initiating app use.

Conclusions: Mobile apps are being utilized for self-management of depressive symptoms by primary care patients. This study provided insight into the natural patterns and perspectives of app use, which enhanced the understanding of how this technology may be integrated into the toolbox for the management of depression.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12616000537459; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=367152 (Archived at WebCite at http://www.webcitation.org/71Vf06X2T)

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KEYWORDS

mobile apps; depression; health care; general practice

Introduction

Depression is a globally prevalent and costly condition affecting more than 300 million people worldwide [1]. In Australia, 1 in 7 women and 1 in 12 men experience a depressive episode at some stage of their lives [2]. Although the vast majority of cases are mild to moderate in severity [2], the economic burden of depression on the community is high due to direct medical costs and loss of productivity as the rate of service utilization continues to climb [3,4]. It is a leading cause of disability with significant impact on morbidity and individual functioning; however, only 35% of people with depression will access treatment [2].

For those who do seek help, general practitioners are commonly the first point of contact; three quarters of people receiving any mental health care reported seeing a general practitioner [5,6]. Consequently, general practitioners are in a unique position to optimize the detection and treatment of depression. However, studies show that issues such as time constraints, affordability, and lack of access to mental health specialists are common barriers to managing depression in primary care [7].

As ubiquitous devices that are owned by 79% of the population [8], mobile phones have become increasingly integrated into daily lives and may represent a novel solution to overcoming these barriers in primary care depression management. One avenue by which mobile phones may improve the delivery of mental health interventions is through mobile app software specifically designed for use on mobile phones. Apps are advanced technological tools with multiple capabilities and have been postulated to revolutionize mental health treatment in myriad ways, such as by allowing for the affordable and accessible delivery of interventions, providing real-time diagnostic and monitoring support, enhancing therapeutic relationships, augmenting engagement with treatments, and even acting as “virtual coaches” [9-11]. Consequently, interest in harnessing the potential of mobile apps for the management of depression is mounting from patients, clinicians, and the broader community [12,13].

In recent years, a vast number of mobile apps have been developed to address the diverse aspects of depression management including screening, symptom tracking, psychoeducation, stress management, medication support, and cognitive behavioral therapy [14,15]. Researchers have sought to make sense of this expanding environment by analyzing the app marketplace, reviewing the scientific literature, and conducting trials of specific apps [14-18]. Although emerging evidence supports the efficacy of apps in reducing the severity of depressive symptoms, a recent meta-analysis identified only 22 randomized controlled trial-tested apps [16], whereas a content analysis of the app marketplace in 2015 revealed 243 clinically relevant depression apps available for download [14]. Therefore, the vast majority of apps available have not been vigorously tested, and establishing an evidence base for mental health apps remains an ongoing challenge because the rate of app development far outstrips that of research [17-20].

The challenge of navigating this new health care sector alone should not be underestimated and in their role at the forefront of depression treatment in the community, general practitioners can play a vital part in connecting technology and traditional mental health care [21]. A pilot trial of a mobile app in a primary care setting demonstrated that a mobile platform can be acceptably integrated into the therapeutic relationship between care providers and patients to augment depression management [22]. However, to optimize integration, it is important to first understand the baseline app use, and there remains a limited literature on this topic. In 2014, Bauer et al [23] reported that only a minority of primary care patients (22%) used a health app. In contrast, a 2017 US survey of people with symptoms of anxiety or depression demonstrated that 78% people had a health app installed on their phone and typically used each app for a single purpose (eg, symptom tracking, habit building, or providing a routine) [24]. It is worth noting that this study involved participants who were screened for enrollment in a trial of the IntelliCare suite of mental health apps, which could account for the high numbers of IntelliCare apps reported. In addition, both these studies assessed only general health app use and not the extent to which apps were used specifically to manage mental health.

At the same time, most app research in the mental health space has focused exclusively on mental health-specific apps; hence, the utility of other app types for depression management is also uncertain. To harness the potential of mobile apps and enable their effective integration in primary care, understanding how patients naturally use apps to manage depressive symptoms is critical. Hence, the primary aim of this study was to conduct an in-depth qualitative examination of common mobile app usage patterns for depression in the primary care population to gain a better understanding of how general practitioners may best integrate apps into their routine depression care.

Methods

Study Design, Setting and Recruitment

To explore the natural patterns of mobile app use for depressive symptoms among primary care patients, this study employed a qualitative design using individual semistructured phone interviews. Ethics approval for this study was granted by the Human Research Ethics Committee of The University of Melbourne (ID: 1543648.9).

Participants were recruited from the Target-D trial (ACTRN12616000537459). This is a large Australian study of a clinical prediction tool to triage and target depression treatment, in which patients with depressive symptoms were directly recruited from primary care practices across metropolitan Melbourne, Victoria [25]. On completion of baseline data collection, participants were stratified into mild, moderate, and severe symptom groups and randomly allocated to receive usual care or a symptom severity-matched treatment as follows: internet-based self-help, guided internet-based cognitive behavioral therapy, or nurse-led collaborative care (for the mild, moderate, and severe groups, respectively).

Participants were eligible for the Target-D trial if they were aged 18-65 years, had current depressive symptoms (assessed during the screening process as scoring 2 or more on the two item version of the Patient Health Questionnaire, PHQ-2), had access to the internet, and had sufficient English language comprehension to provide informed consent. Participants were excluded if they were taking an antipsychotic, had recently started or changed their antidepressant, were currently receiving psychological treatment, or were currently using an internet-based cognitive behavioral therapy program.

The only additional eligibility criterion applied to this study was that participants had completed the 3-month intervention phase of a randomized controlled trial to avoid prompting those in the usual care group to change their approach to mental health care.

Purposive sampling was undertaken from randomly generated lists of Target-D participants, 30 at a time, stratified by depressive symptom severity assessed using the PHQ-9 [26] to ensure a mix of age and gender in the final sample. The interviewer was blinded to whether participants were allocated to the control or intervention groups.

Potential participants were sent an email invitation to take part in the study and followed up via phone call within 2 weeks to establish interest, obtain informed consent, and arrange a suitable interview time. Of the 60 participants who were emailed invitations, 26 were contactable by phone and 16 took part in the study, as seen in Figure 1. Of those who did not participate, 3 did not consent (one did not provide a reason, one was in hospital, and one was uninterested in the study) and 7 initially consented to the interview; however, they were lost to follow-up thereafter.

Data Collection

Semistructured phone interviews were conducted with 16 participants between May and October 2017 by a female general practice registrar who had no prior contact with the participants. This was conducted using an iterative approach, where data collection occurred incrementally and simultaneously alongside data analysis.

Interviews began by asking participants about their current depression management strategies to establish if mobile apps were used. If any mobile apps were mentioned, this was explored in further detail including type, purpose, duration, referral source (ie, how participants became aware of the app), perceived challenges, benefits, and recommendations. If no apps were mentioned, questions focused on attitudes to using mobile apps for managing depressive symptoms. The semistructured interview discussion guide can be viewed in Multimedia Appendix 1.

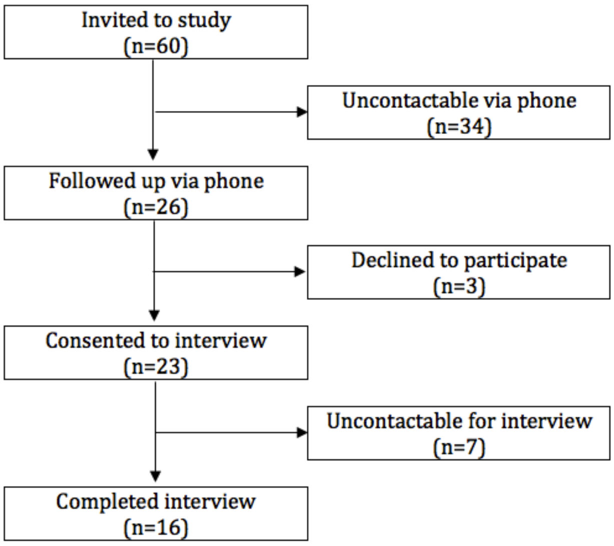
All participants consented to audio recording of the interviews, which ranged from 10 to 32 minutes. Recordings were subsequently transcribed verbatim by an independent professional transcription service and verified by AP. Field notes were created during and after the interviews and data were stored confidentially on protected university servers. Participants were offered an Aus $20 gift voucher as an honorarium.

Data Analysis

To identify the natural patterns of app use, inductive analysis was employed utilizing NVivo 11 Pro software (QSR International, Melbourne, Australia) to organize and identify core themes and subthemes in accordance with Braun and Clarke's 6 phases of thematic analysis [27]. This consisted of several stages including familiarization, transcription, generating initial codes, searching for themes, reviewing themes, and then defining and deciding on meaningful themes.

An iterative approach was adopted with the initial coding performed by a general practice registrar following the completion of the first set of 5 interviews. Subsequent interviews were then conducted incrementally with data analysis occurring simultaneously, and new codes were added from the dataset to NVivo Pro 11. SF and JG reviewed the transcripts and codes during this process until consensus was reached by all members of the research team in regards to the final themes. Data saturation was achieved (and data collection ceased) when no new themes emerged, which was determined by the point in analysis where no new codes were able to be created in NVivo 11 Pro that provided additional value to the identified themes [28,29].

Figure 1. Participant flow.



Results

Participant Characteristics

The age of the participants ranged from 20 to 58 years. Overall, 58% (9/16) were female and the majority had achieved at least a tertiary level of education. Three quarters of participants had PHQ-9 scores indicating moderate to moderately severe depression. On average, participants completed the interview 269 days after receiving their Target-D treatment recommendation (range 99-369 days). Further demographic information is provided in Table 1, whereas Table 2 details app use and participation in Target-D, including whether Web-based tools were recommended.

Patterns of App Use

Overall, 11 out of 16 participants reported using at least one mobile app to manage their depression with 15 apps mentioned in total (Table 3). All apps were free to download and included, but were not limited to, mental health-specific apps. Awareness of the apps came from numerous sources including self-directed research, inbuilt on phone, and recommendations from friends, organizations, and health professionals. Participants could be divided into 2 groups, users and nonusers. Among users, the following 4 main patterns of app use were identified: skill acquisition, social connectedness, inquisitive trial, and safety netting, as seen in Figure 2.

Skill Acquisition

Three participants used their mobile apps on a regular basis over a short period, generally several months, to learn, reinforce, or master an activity that they deemed helpful for their mental health. Participants tended to hold a biopsychosocial perspective of their treatment needs with a focus on self-help management strategies with known efficacy for depression such as exercise, mindfulness, and social connectedness. Apps were often sought and utilized to support these perceived needs and enhance preferred strategies.

Monitoring or tracking progress via an app was one method that aided in reinforcing an activity that a participant deemed useful for improving mood.

> *I was using exercise apps and that, like tracing my steps...I mean I found it quite useful, I guess in sort of being more mindful in movement...I found that kind of focused me for a while* [P2]

An app could also be used to learn and master a skill. One participant, who reported suffering from severe anxiety, used a mindfulness app daily for 6 months to master the exercises which ultimately enabled her to maintain control of her symptoms.

> *...then I got to the point that I was able to just sit there and get into my own headspace and just do the meditation and breathing exercises without the app.* [P1]

Participants reported gaining a range of concrete skills as a result of their app use, including relaxation techniques, greater motivation (demonstrated through commitment to exercise routine), and ability to focus. Generally, app use was discontinued after a skill was acquired; however, the app could be retained in the case that symptoms reemerged to reinstate the desired behavior (see “safety netting” below).

Social Connectedness

Three participants reported using an app as a means of enhancing connectivity with individuals and community and engaging with the wider world.

> *...it’s good to sort of reconnect with like, people you haven’t seen for ages or...people that are going through the same kind of journey as you.* [P9]

Each of these participants used a different type of app and although these apps may not typically be considered in the context of mental health care (eg, social media and game apps), their role in enabling ongoing social interaction was viewed by participants as a positive influence on mood. This could be through increasing motivation to make new friends and engage with the wider community or through enhancing existing relationships by encouraging reconnection and quality time.

> *I found that I wasn’t as upset...or depressed, when I was out there playing it [Ingress] and the friends I made through it helped.* [P3]

> *...you still sort of keep in contact with what sort of going on in the world. It does make you sort of happy that you still communicate and you're still out there communicating with people.* [P9]

> *Like my daughter’s not here tonight, so I probably won’t do it [Smiling Mind] for myself, but when she is, you know, there’s the expectation that, you know, that we’d do it together and that I’d stop [my other activities].* [P4]

> *Just it [Ingress] got me out exploring the world around me rather than sitting at home and doing nothing, and moping about. You know, I was out there, I’ve been all over Victoria. I’ve even flown interstate for the game. It has really helped me engage with the world around me.* [P3]

Although experiences using apps for social connection were generally positive, with an intention to build and foster social relationships, the potential for negative experiences and social conflict was not overlooked.

> *And then, yeah, sometimes you might get a comment up on Facebook, and someone will take it the wrong way and it'd be–fights all over the place. Yeah, that's where it can sort of turn bad, but nine times out of ten it's usually pretty good.* [P9]

Table 1. Characteristics of the participants.

Characteristics	Participants (N=16), n (%)
Gender	
Male	7 (44)
Female	9 (56)
Age in years	
<25	3 (19)
25-44	7 (44)
45-65	6 (38)
Employment	
Employed	11 (69)
Unemployed	5 (31)
Highest level of education	
Year 10 or below	2 (13)
Year 11	1 (6)
Year 12	1 (6)
Certificate or diploma	5 (31)
Bachelor degree or higher	7 (44)
Depression severity (Patient Health Questionnaire, 9-item)	
Minimal or mild (3-9)	3 (19)
Moderate (10-14)	4 (25)
Moderately severe (15-19)	8 (50)
Severe (>20)	1 (6)

Table 2. Participation in Target-D and mobile app use for depressive symptoms.

Participant	Depression symptom severity (PHQ-9)[a]	Days since Target-D treatment recommendation	Web-based tools recommended	Apps used, n
P1	Moderately severe	229	No	1
P2	Mild	303	Yes	1
P3	Moderate	178	Yes	1
P4	Moderate	119	No	1
P5	Moderately severe	197	No	2
P6	Moderately severe	319	No	0
P7	Moderately severe	385	No	3
P8	Moderate	369	No	2
P9	Mild	99	Yes	1
P10	Moderately severe	203	Yes	0
P11	Mild	147	No	1
P12	Moderate	420	Yes	0
P13	Moderately severe	184	Yes	0
P14	Moderately severe	354	No	1
P15	Moderately severe	395	No	0
P16	Severe	396	No	1

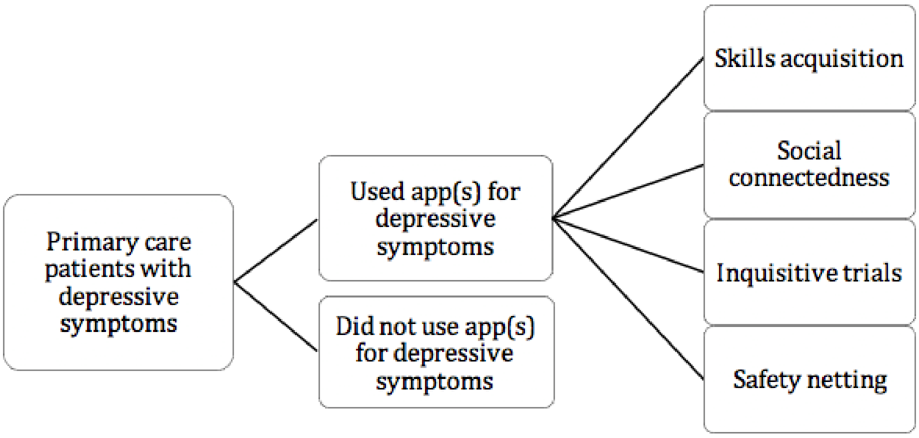
[a]PHQ-9: Patient Health Questionnaire, 9-item. Level of depression symptom severity is based on PHQ-9 [26] depression scores.

Table 3. Mobile apps utilized by participants.

Type of app and app name	Referral source	Used by
Mindfulness or relaxation		
Mindfulness[a] (3 apps)	Midwife, Psychologist	P1, P5 (2 apps)
Smiling Minds	General practitioner	P4
Relax+	Psychiatrist	P14
Meditation[a]	Self-directed internet search	P16
Fitness		
Exercise[a]	Inbuilt on phone	P2
Gaming		
Ingress	Social network or friends	P3
Cognitive		
SAM App[b]	Self-directed internet search	P7
NeuroNation	Self-directed internet search	P7
MindTools	Self-directed internet search	P7
Psych Me Up	University studies	P8
Mood Switch	University studies	P8
Social media		
Facebook	Social network or friends	P9
Workplace well-being		
Equipt	Workplace or organization	P11
No app used		
N/A[c]	N/A	P6, P10, P12, P13, P15

[a]Purpose of app described where app name was not known or not specified.
[b]SAM: Self-help for Anxiety Management App.
[c]N/A: not applicable.

Figure 2. Patterns of app use.



Inquisitive Trials

Overall, 4 participants trialed at least one app briefly, usually over days to a few weeks. These participants were likely to try more apps with an average of 2 apps each. They expressed curiosity about a variety of different self-management strategies and described actively seeking and downloading apps based on self-directed research, recommendations, and personal interest.

> *Well, when I was actually at uni, I remember reading about it [Psych Me Up] because I studied psychology.*

> *I remember seeing a documentary about it so I downloaded it. It sounded interesting.* [P8]

> *I Google it [SAM App]. I Google search it on the internet. And, you know, if you will go to the internet, [there] is a whole world of people talking to each other...so they recommend to someone and I reading that thing.* [P7]

However, curiosity alone was insufficient for continuing use. Although these participants generally acknowledged that apps could have a positive impact on depression management, an inability to engage with the app was the most commonly cited reason for discontinuation, though motivation and lack of perceived benefits were also important factors.

> *Like when I first got it [used] once a day or a something like that for a period of about a week. But then I got over it.* [P8]

> *It [mindfulness app] didn't add anything...I guess it didn't detract, it didn't make anything worse, but it didn't add anything to my armoury, I guess, my tool kit, as keeping myself sane, I suppose, it didn't add.* [P5]

Personal compatibility was also a key factor commonly associated with a positive attitude toward app use. An individualized approach to depression management was highly regarded because participants often identified personal traits that would hinder or enable the use of certain apps. There was a strong desire for personalized features.

> *Something that sounds personal to me might be helpful.* [P8]

> *I'm sure [it] would be useful for many other people—an app with prompters, but for me to interact with it, I wouldn't do it regularly.* [P5]

Safety Netting

Two participants reported that they kept an app on their phones that they did not use but retained "just in case." Both participants had been recommended the app through formal channels (psychiatrist and workplace). One participant had previously used the app successfully to acquire skills; she felt that she no longer required it on a frequent basis but kept it installed to "top up" her skills when she felt her symptoms returning:

> *...there are afternoons where if I start to fall back into the pattern of not being able to sleep, then I'll go back to using it. Yeah. So, it's not an app I would ever delete off my phone, if that makes sense.* [P14]

Another participant reported that although she had not used her workplace stress management app aside from an initial cursory examination, she intended to do so if she encountered difficult situations resulting in emotional distress. This suggests that an app could be kept as a safety net and used following a precipitating event to guide further management.

> *...being in the police force, obviously, I attend a lot of critical incidents and that sort of thing, so if there is critical incident that particularly sort of, you know, affecting for me, I might then go into it [Equipt] just to sort of do something about that.* [P11]

Apart from the potential guidance offered by the app during distressing situations, simply knowing that an app is available for this purpose can provide a sense of comfort.

> *I just like that it's there.* [P11]

Nonuser Perspectives of Mobile Apps

Five participants had never used an app for their mental health. Perspectives were varied with 3 participants expressing a positive view, one who felt apps were unhelpful, and one who was ambivalent. Among these participants who felt positively toward apps but did not use them, access was the most common barrier. The chaotic nature of the app marketplace and lack of knowledge regarding suitable apps could impede app selection. Additionally, a deficiency in technological competency, perhaps correlating with age, could hinder the use of apps.

> *...I'd be happy to do it if I knew how to do it [but] I don't know how to download apps...I need help with technology. Like, I'm 58 and I didn't grow up in a technological age and so do find that I lack confidence with technology.* [P12]

> *...an app could be really useful, especially for the younger generation. For older people, I'm not sure. I don't really know.* [P13]

The perceived discordance between technology and mental health treatment was also a reason for nonuse because some participants did not view technology as a natural response to seeking treatment for their mental health. One nonuser reported concerns about excessive dependency on apps, focusing on the possibility of addiction and social disengagement.

> *It's not something I kind of...I don't usually look to technology to fix my issue.* [P13]

> *I think we can live vicariously through a screen and that and that I think has some issues in living life in 2.5 inches of screen when there's a whole big horizon out there to look out.* [P6]

Another viewpoint was that although apps could be beneficial for mental health to an extent, it cannot act as a replacement for social support and human connection. Consistent with the views of many app users, an app can be considered as a supportive tool for depression management but not as a treatment in itself.

> *I think ultimately though, people who need to know they're cared for by another person, a real person. An app can help but I reckon fundamentally as humans, we want someone to know we're hurting or struggling, and we need more than an app...but I think it's a good idea to have both.* [P13]

A few participants who did not report current app use expressed an inclination to use apps if their situation deteriorated similar to the safety netting behaviors reported by some app users. This suggests that in contrast to the statements above, these participants perceived apps as an effective option for mental health treatment. Their nonuse of apps could be considered in part a reflection of the fact that they did not consider themselves to be currently in need of treatment.

> *I would go [to an app] when I'm really struggling on a negative downer.* [P15]

> *I think if my situation with my mental health got to the point where it prevented me from doing day-to-day things...I think it would be quite beneficial if it came to that point because, once again, it is very accessible.* [P10]

Influence of Health Care Providers

Health care providers had a role in facilitating the initiation of mobile app use for depressive symptoms. In this study, 4 app users engaged with an app following a direct recommendation from a health care provider, which included a general practitioner, psychologist, midwife, and psychiatrist. These were all meditation or relaxation-type apps, and participants demonstrated a willingness to try these apps on the basis of professional suggestion and generally persisted with use if they found it helpful.

> *I use an app on my phone which is—it's like a meditation app—it was what my psychiatrist recommended. So, yeah, I've been very disciplined when he suggested to give it a go and—yeah—and use and give it a go.* [P14]

However, other app users perceived their app use for mental health independent of professional health care and did not involve their health professionals. There was a tendency among these participants to view professional therapy as separate to their own personal self-directed strategies.

> *No, I don't think [general practitioner knows about app]...it's my own research.* [P7]

> *I don't think [my general practitioner knows about this app], no, because it is pretty specific.* [P11]

Regardless of whether or not they were recommended apps, participants demonstrated a sense of trust in guidance from professionals with the perception that these recommendations had a strong basis in experience or knowledge.

> *I know that my psychiatrist was recommending [Relax+] to other clients, and he found a lot of people found it worked and that was the feedback he got, so that's why it was an app that he would recommend to people.* [P14]

> *I'd rather ask a counsellor or a doctor what they would recommend.* [P1]

> *I mean definitely a professional, I'd listen more so than just say on the streets and such...because, you know, you sort of have your belief in the professional industry who have done their hard yards of study and work and, you know, you'd sort of put yourself out there in their hands a bit and they have more knowledge than yourself. And plus, they deal with so many different people in the same field.* [P15]

The role of health care providers in ongoing app use was unclear because no app users reported involving their health care providers following the initial recommendation.

Discussion

Principal Findings

This is the first qualitative study exploring the patterns of mobile app use for depression in a primary care setting, revealing that many participants are already utilizing mobile apps as a way of improving or maintaining their mental health. Prior mental health app research has primarily focused on the prevalence of use and acceptability and attitudes toward apps [12,13,22,30,31] and this, therefore, provides a unique insight into natural app use behavior and the potential role of mobile apps for managing depressive symptoms in the community.

Four main patterns of use were identified, which were not mutually exclusive; some participants indicated different patterns of use of the same app over time. A minority of participants did not report using any app, which is consistent with previous reports of the prevalence of app use in primary care populations [23]. Among those who did report active app use, the most common patterns were using apps to develop or reinforce a particular skill or to enhance social connections.

Importantly, the results of this study suggest that primary care patients use a wide range of apps to manage their depressive symptoms and not only those that are specifically designed for depression management. Interestingly, however, the apps used did encourage engagement in activities that have evidence for efficacy in combating depression, such as acquiring skills through exercise [32] and mindfulness [33] and social connectedness [34]. This suggests that when looking to improve their mental health, primary care patients gravitate naturally toward evidence-based management strategies and should be empowered to engage in techniques they perceive as helpful. This is supported by a study of evidence-based mental health app recommendations suggesting that apps focusing on behavioral activation can empower users to learn beneficial skills and better engage with therapy [35]. Furthermore, self-efficacious behavior changes were demonstrated in a survey where 90% of mental health app users reported increased motivation, desire to set goals, confidence, and intention to be emotionally healthy from their app use [36].

Few app users reported negative effects of apps, although some concerns about addiction were raised by nonusers. That said, the relationship between social networking tools and depression is complex with research suggesting a dual relationship influenced by numerous mediating and aggravating factors. There is a strong implication that the nature of social media use may have more impact on depression symptoms than frequency of use and that the personal perception of Web-based interactions influences mental health; it may be positive if it increases social support or conversely and negative if it increases social comparison and rumination [37]. How patients use and perceive networking tools for social connectedness may be more important than the frequency or type of app used.

Participants did not consider apps as a standalone replacement for traditional professional management but rather as a tool to support and enhance treatment, a viewpoint consistent with clinicians' beliefs in a qualitative study regarding apps for severe mental health issues [38]. The value in professional mental health treatment was strongly recognized, but participants utilized apps to support activities that coincided with their treatment beliefs, often when accessibility barriers hindered traditional mental health care.

It is also important to acknowledge the role of health care providers in app use for depression. One third of app users (4/11) directly engaged with their app following a health professional's suggestion compared with 10% of app users in a broader primary care sample in the United States [23]. The higher proportion of health professional recommendations in this study may be a reflection of a number of factors. First, the app marketplace has grown significantly since 2013, as have the popularity and acceptability of apps generally. It is possible that recognition of apps as a genuine option for mental health care has likewise grown. Second, in 2015, a review of Australia's mental health system resulted in a shift in policy direction toward digital solutions to improving care. As a result, general practitioners have been provided with greater guidance on what mental health apps are available and how to incorporate them into treatment plans [39]. The high level of trust in general practitioners expressed by many participants in this study suggests that they can have a strong influence on initiating app use for depression symptoms. However, it is important to note that the influence of professional support in continuing app use was not determined in this study. This may be due to the perceived discordancy between health care and app use because 70% of respondents in a primary care survey reported that it was not at all or only a little important for physicians to know about their health app use [23]. However, there is some evidence that the therapeutic relationship between care providers and patients has an impact on sustaining app use and enhancing mental health treatment in primary care [22] and this should be an area for future investigation.

In light of the findings above, we suggest that general practitioners consider a holistic approach when supporting patients to engage in mobile technology to improve their mental health. The complexity of depression, which presents with differing physical, psychological, and social issues in every case warrants an approach that is personalized to each individual's circumstances and needs. A social networking app, for example, may not have evidence for improving depression but for some patients, it may be a more acceptable way of building social connection than more traditional interventions [40]. Thus, considering a person-centered approach and tailoring app recommendations accordingly may provide a more effective approach to integrating apps into depression management. There is some evidence to support this approach, for example, a pilot study of IntelliCare, a modifiable skills-based suite of mental health apps each focusing on a specific task or activity, demonstrated improvements in depression and anxiety scores among app users [41].

It is important to be aware that a wide range of apps, not simply those that are specific to mental health, may be relevant to depression care. Understanding personal preferences and goals may help general practitioners assess what app, if any, would be suitable for an individual and guide appropriate recommendations, especially as the ever-expanding and chaotic nature of the app marketplace remains a significant challenge [14,18]. Ultimately, the end is more important than the means and if patients can view an app as a way of improving or maintaining their mental health, it can reasonably be considered as a part of their mental health care.

It should be noted that, in exploring patterns of app use, one pattern identified was that of nonuse. By employing a personalized approach focusing on treatment goals rather than apps themselves, general practitioners may find that some nonusers can transition into the "inquisitive trial" category as a starting point. This is particularly likely when the main reason for nonuse is lack of knowledge about what app to use or how to use it. However, general practitioners must also remain cognizant that apps will not address unmet needs for all of the 65% of Australians currently not accessing mental health treatment. They may more usefully be construed as one referral option available to general practitioners within a matrix of other options of varying modalities, intensity, and treatment focus.

Limitations

There are some limitations to this study. First, the findings are based on a small number of general practice patients recruited in Melbourne, Australia, and whether these patterns of use are evident outside this group is unclear. Second, as participants were all under 65 years of age and were recruited from a trial which includes Web-based interventions, this could have led to selection bias because the sample involves a relatively younger and more technology-inclined population. Hence, generalization to all primary care patients would not be feasible.

Further, a substantial proportion of the sample reported depressive symptoms toward the severe end of the spectrum. Guidelines would suggest that this group should be recommended more formal treatment than self-help via an app. However, as a study of the natural use of apps, we see that the inclusion of these participants is a strength rather than a limitation. By understanding patients' existing management strategies (including apps) and treatment preferences, general practitioners may be better placed to engage patients in more intensive mental health interventions when appropriate, particularly given that apps were viewed as a complement to rather than substitution for formal treatment.

In addition, owing to the cross-sectional nature of this study, the patterns of use identified relate only to the point at which interviews were conducted and do not assess the impact of changes in depressive symptoms over time. We previously investigated use of mental health websites over a 9-year period and found the primary care patients were more likely to report the use of these websites when their depressive symptom severity increased [42]. Given that "safety netters" and some nonusers reported they would consider using an app in the face of worsening mental health, a longitudinal study of whether these intentions are translated into actions would add to our understanding of the patterns of app use.

Finally, this study focused on the perspectives of app users and not the effectiveness of the apps themselves. It is possible that the app use reported here resulted in improved mental health; it is also possible that it made no difference or worsened symptoms. More research is required to explore the potential benefits and harms of app use. For instance, although there is evidence that social media apps may facilitate social connectedness [40], little is known about the effects of dependency on mobile apps in depression. It is important for future research to evaluate the patterns of app use that may exacerbate depression as well as those that facilitate its management.

Conclusion

The rise of mobile technology heralds a new era in community mental health treatment. There is growing interest from clinicians, consumers, and developers in harnessing the potential for mobile apps to address some of the barriers to traditional mental health care. The results of this study suggest that like any mental health intervention, apps are used only to the extent that they align with patient preferences and treatment goals. Further, although individual apps have limited evidence for effectiveness, patients naturally gravitate toward apps that encourage behaviors known to improve depression. General practitioners may capitalize on this by considering apps as another option in their referral toolbox, a new way for patients to access and engage with old interventions and not a new intervention altogether.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview discussion guide.

[PDF File (Adobe PDF File), 26KB - jmir_v20i9e10035_app1.pdf]

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Abbreviations

PHQ-2: Patient Health Questionnaire, 2-item
PHQ-9: Patient Health Questionnaire, 9-item

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Original Paper

Addendum to the Acknowledgements: How Online Communities of People With Long-Term Conditions Function and Evolve: Network Analysis of the Structure and Dynamics of the Asthma UK and British Lung Foundation Online Communities

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The authors of “How Online Communities of People With Long-Term Conditions Function and Evolve: Network Analysis of the Structure and Dynamics of the Asthma UK and British Lung Foundation Online Communities” (J Med Internet Res 2018;20(7):e238) wish to add the following sentence to the Acknowledgments:

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The correction will appear in the online version of the paper on the JMIR website on September 4, 2018, together with the publication of this correction notice. Because this was made after submission to PubMed, Pubmed Central, and other full-text repositories, the corrected article also has been re-submitted to those repositories.

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Corrigenda and Addenda

Metadata Correction: Alcohol Consumption Reduction Among a Web-Based Supportive Community Using the Hello Sunday Morning Blog Platform: Observational Study

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The authors of the paper "Alcohol Consumption Reduction Among a Web-Based Supportive Community Using the Hello Sunday Morning Blog Platform: Observational Study" (J Med Internet Res 2018;20(5):e196) wish to amend the contact number listed on the paper. In the "Corresponding Author" section, the telephone number was listed as 61 422924764, but this number has now been changed to 61 1300 403 196.

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