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Original Paper

Use of Patient-Reported Outcome (PRO) Measures at Group and Patient Levels: Experiences From the Generic Integrated PRO System, WestChronic

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Abstract

Background: Patient-reported outcome (PRO) measures may be used at a group level for research and quality improvement and at the individual patient level to support clinical decision making and ensure efficient use of resources. The challenges involved in implementing PRO measures are mostly the same regardless of aims and diagnostic groups and include logistic feasibility, high response rates, robustness, and ability to adapt to the needs of patient groups and settings. If generic PRO systems can adapt to specific needs, advanced technology can be shared between medical specialties and for different aims.

Objective: We describe methodological, organizational, and practical experiences with a generic PRO system, WestChronic, which is in use among a range of diagnostic groups and for a range of purposes.

Methods: The WestChronic system supports PRO data collection, with integration of Web and paper PRO questionnaires (mixed-mode) and automated procedures that enable adherence to implementation-specific schedules for the collection of PRO. For analysis, we divided functionalities into four elements: basic PRO data collection and logistics, PRO-based clinical decision support, PRO-based automated decision algorithms, and other forms of communication. While the first element is ubiquitous, the others are optional and only applicable at a patient level. Methodological and organizational experiences were described according to each element.

Results: WestChronic has, to date, been implemented in 22 PRO projects within 18 diagnostic groups, including cardiology, neurology, rheumatology, nephrology, orthopedic surgery, gynecology, oncology, and psychiatry. The aims of the individual projects included epidemiological research, quality improvement, hospital evaluation, clinical decision support, efficient use of outpatient clinic resources, and screening for side effects and comorbidity. In total 30,174 patients have been included, and 59,232 PRO assessments have been collected using 92 different PRO questionnaires. Response rates of up to 93% were achieved for first-round questionnaires and up to 99% during follow-up. For 6 diagnostic groups, PRO data were displayed graphically to the clinician to facilitate flagging of important symptoms and decision support, and in 5 diagnostic groups PRO data were used for automatic algorithm-based decisions.

Conclusions: WestChronic has allowed the implementation of all proposed protocol for data collection and processing. The system has achieved high response rates, and longitudinal attrition is limited. The relevance of the questions, the mixed-mode principle, and automated procedures has contributed to the high response rates. Furthermore, development and implementation of a number of approaches and methods for clinical use of PRO has been possible without challenging the generic property.

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Generic multipurpose PRO systems may enable sharing of automated and efficient logistics, optimal response rates, and other advanced options for PRO data collection and processing, while still allowing adaptation to specific aims and patient groups.

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KEYWORDS

data collection; decision support systems; health care economics and organizations; health education; Internet; longitudinal studies; outcome assessment; patient-reported outcomes; questionnaires; quality improvement

Introduction

The US Food and Drug Administration defines patient-reported outcome (PRO) as a measurement based on "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [1]. This definition emphasizes a generic and patient-oriented perspective, but also a systematic aspect. From the time of Hippocrates, information originating from the patient has been considered indispensable, and still today, few diagnoses can be established and few treatments be monitored without information from the patients. However, information from the patient is normally interpreted and reported by a clinician [2], and consequently this information is not in the form of a PRO.

PRO was initially developed for research, and with the introduction of the term health-related quality of life, systematic measurement of PRO was adopted for research in a number of clinical specialties [3]. During the last decades, PRO has been identified as a tool for hospital performance assessment [4], and recent initiatives include the United Kingdom's policy to encourage and request use of PRO for assessment [5,6] and the nationwide use of PRO to compare Medicare health plans in the United States [7]. In Sweden and Denmark, nationwide use of PRO was initially driven by the medical profession's focusing on improving clinical care, and PRO was introduced in some disease-specific national clinical registers in 2000 [8,9].

The evolution of PRO is now tending to return to its origin: the interaction between the patient and the clinician in daily clinical practice. The applications of PRO in clinical practice, include screening tools, monitoring tools, decision aids, and as a means of monitoring the quality of patient care [10-12]. Reviews find evidence of improved patient care, patient-clinician communication, and better identification of treatment symptoms and psychosocial problems, while findings with respect to an effect on subsequent patient outcomes are less consistent [10,12-15]. In a recent comprehensive review of randomized trials, it was concluded that PRO used for consultation support provides patient-centered care, ensuring that patient-reported symptoms guides the clinical decisions [15], and it has been found that PRO and clinical judgments produce complementary data, which, when combined, provide a more accurate description of the patients' symptoms [14]. PRO data collected for individual patients may also be aggregated and used at a group level for research and to compare quality of care across providers [11,16].

Challenges to the use of PRO vary according to the specific aims, but high response rates are almost always warranted. At the group level (research and performance assessment), estimates based on low response rates are prone to selection bias. At the individual level (eg, in PRO-based outpatient clinics), low participation rates undermine the usefulness of any clinical PRO application. If a PRO assessment is to be completed while the patient is physically present in the hospital outpatient clinic, patient kiosks may be used to collect PRO data electronically (ePRO) [17]. In these systems, patients are required to fill out forms before a scheduled appointment, and high response rates may be obtained with some gentle prompting from the hospital staff. However, when the aim of a PRO assessment is to evaluate the need for a hospital visit, the PRO assessment must be obtained while the patient is still at home (TelePRO). The same is the case in most epidemiological and quality assurance projects. A number of PRO systems have introduced Web-based questionnaires in which the data could be used for such purposes, and there have been high expectations of easy and costless Web-based data collection, once the vast majority of the population is online. Unfortunately, it is evident from randomized studies that data collection that relies only on Web-based questionnaires filled in at home reaches response rates of only 20% to 45% [4,18-20], while combined with paper-based methods (mixed-mode) may reach 75% or more dependent on the number of reminders [20]. Reports of high rates in Web-based systems are generally from populations selected on actual Web use (eg, studies in which Web use is a prerequisite for enrollment) [21]. As a consequence, TelePRO data collection can seldom rely only on a Web-based solution. However, solutions that apply paper questionnaires are normally considered to increase the logistic challenges considerably, and may delay the timely availability of the data for the clinicians.

The response is highly dependent on successful logistics, and adherence to a proper protocol (eg, nonrespondents reminded as scheduled) is crucial to obtain a high response rate and low attrition. Questionnaire logistic often receives little scientific attention and may even be considered a trivial technical issue. Even though logistic and scientific challenges are similar across diagnostic groups and applications, most PRO systems have been applied to a single-patient group [22]. By development of generic (not diagnosis-specific) systems, methodological and economical large-scale benefits may be achieved, and, moreover, new possibilities for PRO-based research across traditional medical specialties may emerge [22].

The aim of the present paper was to describe methodological and organizational experiences with a generic PRO system, WestChronic, which has been used to collect PRO data among a range of diagnostic groups and for a range of purposes.

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Methods

Overview

This paper reports and discusses all projects implemented in the PRO system WestChronic. We found no appropriate analytical frameworks in the literature, and the classification was defined as post-hoc, based on actual experiences.

The WestChronic System

The first version of the generic PRO system, WestChronic, was developed in 2004 by the first author for mixed-mode (Web and paper) collection of PRO data for research purposes in clinical epidemiological studies with repetitive measurements. Due to feasibility and high response rates, it was decided to develop this system into a flexible, multipurpose PRO system intended to facilitate adaption to the projects needs instead of requesting projects to adapt to a system. WestChronic supports dynamic mixed-mode data collection [23] with Web or paper forms as well as communication to the patient and clinician with personalized postal letters, emails, and text messages. All information regarding implemented projects, items and questionnaires, communication, users, and patients resides in tables in a Structured Query Language database, and all administration of projects, questionnaires, users, and patients is supported by the server software and managed in browser windows. The system automatically encourages patients to adopt the Web method and to be approached by email. A description of the dynamic mode-switching algorithms can be found in Multimedia Appendix 1. All Danish citizens are assigned a unique 10-digit central personal registry (CPR) number, and constantly updated information on current postal address and vital status is available from the national CPR registry. This information is automatically collected online prior to any approach to patients. On-demand printing of questionnaires and letters as well as scanning of incoming questionnaires and subsequent optical character recognition is controlled by the server software, and results with regard to all variables end up in result tables for the individual implemented projects in the same database, irrespective of whether Web or paper forms are used and are instantaneously accessible. All data transactions fulfill conditions established by the Danish Data Protection Agency. WestChronic may implement an arbitrary number of PRO projects with individual questionnaires, protocols, patients, and users. For the patient and clinician, each implemented project appears as a unique PRO project with its own logo, domain, website, email address, accompanying letters, contact information, etc. At present WestChronic includes 1756 items in 92 questionnaires, and 158 templates for personalized letters and emails.

Data Collection and Analysis

Overview

Data from all implemented projects were collected according to routine by the WestChronic system. Response rates were calculated as the minimal response rate (RR1) [23].

We divided the function of the PRO system into a number of elements, the first of which is ubiquitous in any PRO application, while the other three are optional (Table 1 and Figure 1).

PRO data may be collected in the outpatient clinic or at a distance (eg, from home). We will refer to the latter as TelePRO. The mode to record the PRO data may be based on paper forms or electronic devices. Although paper modes may involve sophisticated electronic procedures like on-demand printing and optical character recognition, we will restrict the term ePRO to Web-based interfaces, tablet computers, other hand-held devices, and interactive voice response [17].

Table 1. Elements of clinical application of patient-reported outcomes (PRO).

Element		Content
Base element	PRO data collection and logistics	Questionnaire (items)
		Criteria for inclusion and termination
		Data collection modes: Web, paper, interview
		Approach modes: letter, email, telephone, texting
		Schedules of questionnaires/reminders
Optional element 1	PRO overview for clinical decision support	Categorization of PRO for clinical decision support
		Course-oriented graphic overview
Optional element 2	PRO-based automated decision algorithms	Decision tree
		Action protocol
Optional element 3	Other forms of communication	Two-way communication
		One-to-many communication

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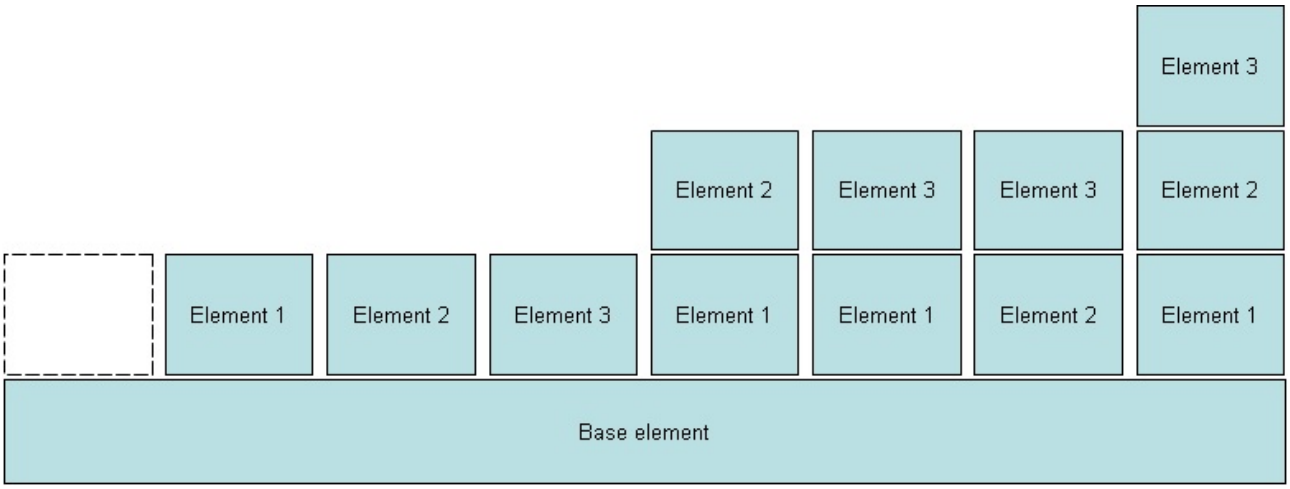
Figure 1. Possible combinations of the base element and three optional elements involved in clinical use of PRO. Base: PRO data collection and logistic, Element 1: PRO-based overview for clinical decision support, Element 2: PRO-based automated decision algorithms, Element 3: Other forms of communication.



PRO Data Collection and Logistic (Base Element)

The base element is mandatory for any application of PRO, and may range from a photocopied paper form handed out to patients on arrival, filled in and used as is in the subsequent visit, to advanced computerized systems handling all processes. A PRO system may implement and manage some or all relevant elements of a protocol and may also support the logistics for the collection of PRO data. Crucial issues include the definition of content and development of the actual PRO questionnaire: the validity, reliability, acceptability to patients and clinicians, and the relevance with respect to the purpose of the collection of PRO data [24,25]. Other issues include the process of implementation, pilot-tests, and methods to collect and integrate user feedback and experiences. Issues of importance to response rate and usability, include the offered modalities (Web-based, paper-based), the offered options, and level of automation of the protocol (administration of implementations, items, handling of subjects, reminders, data import and export).

Optional Element 1: PRO Overview for Clinical Decision Support

A PRO system may enable the clinician to access and overview systematically collected PRO data on symptoms, functional status, and health-related quality of life that can support symptom monitoring, consultation support, and clinical decision-making [11,26]. The results of PRO assessments may be used longitudinally to monitor the course of symptoms and to flag symptoms that need further attention during an outpatient visit. The procedure may range from using the paper form as is as a checklist during the interview, to using graphical display systems fully integrated within an electronic health record (EHR) system, in which an overview is presented to the clinician, who can use it for clinical decisions together with other available clinical and laboratory data. It is crucial that the items used for decision support are relevant for the situation seen from the point of view of the patient as well as the clinician.

Optional Element 2: PRO-Based Automated Decision Algorithms

A PRO system may be designed to make automatic decisions. As a screening tool, PRO assessments may be used to identify patients that need attention as well as patients that do not need attention at the moment. The design may range from a simple score calculated by hand by the clinician and compared with published cut-off values, to automated computer algorithms that include actual absolute scores and intra-individual changes with respect to previous scores. Crucial issues include the risk of false-positive and false-negative results of the algorithm. In statistical terms this is expressed by sensitivity, specificity, and predictive values. Furthermore, the algorithm should be acceptable and meaningful for both patient and clinician.

Optional Element 3: Other Forms of Communication

Normally, researchers or clinicians define the content of the PRO questionnaire, prompt the patient to answer, and collect the data, but some functions in a PRO system may go beyond the one-way, one-to-one flow of information. It is noteworthy that the definition of PRO does not impose strict demands on the origin of a PRO assessment or prerequisites regarding who initiates the communication.

Figure 1 displays the eight possible combinations of the base element and the three optional elements.

Results

Summary

Overall, the WestChronic system has so far implemented 22 PRO projects within 18 diagnostic groups. By January 2014, a total number of 59,232 questionnaires have been collected from 30,174 patients. The characteristics of all the PRO projects are presented in Tables 2 and 3 by primary aim in order of increasing logistic and organizational complexity.

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Table 2. Characteristics of 22 projects involving implementations of a generic PRO system. Projects with group level use (n=8).

	A: Clinical epidemiological research	B: PRO for clinical databases	C: PRO monitoring for administrative purposes
Level of aggregation	Group	Group	Group
Implemented projects	3	4	1
Invoked elements (Figure 1)	Base	Base	Base
Patients	Breast cancer IHD Stroke	Prostatic cancer Renal cancer Esophageal cancer Lung cancer	Stroke
Recruitment	Hospital registers/clinical databases	Clinical databases	Hospital registers
Primary aim	Research	Hospital performance assessment	Hospital performance assessment
Extension	Regional	National	Regional
In operation from	2004	2011	2012
Patients (Jan 2014)	11,898	8278	2735
Questionnaires/ patient	2-23	1-2	3
Response rate (primary)	81%-85%	93%	78%
Response rate follow-up	91%-99%	N/A[a]	96%

[a]Not applicable

Table 3. Characteristics of 22 projects involving implementations of a generic PRO system. Projects with patient level use (n=14).

	D: PRO for clinical overview (AmbuFlex I)	E: PRO for automated cancelling of visits	F: PRO for screening	G: PRO for clinical decision support (AmbuFlex II)	H: Other forms of communication
Level of aggregation	Patient	Group/patient	Group/patient	Patient	Patient
Implemented projects	5	3	2	3	1
Invoked elements (Figure 1)	Base+element 1	Base+element 2	Base+element 2	Base+element 1, 2	Base+element 1, 3
Patients	Chronic heart failure Rheumatoid arthritis Renal failure Lung cancer Prostatic cancer	Hip/knee replacement Endometriosis	Acute Coronary Syndrome Heart transplant	Epilepsy Sleep disorders Neuromuscular diseases	ADHD[a]
Recruitment	Preadmission assessment	Clinic referral	Hospital registers/clinical referral	Clinic referral	Clinic referral
Primary aim	Clinical decision support	Efficient use of resources	Screening for depression	Clinical decision support	Communication (therapists and patient)
Extension	Local	National, selected hospitals	Local	Regional	Local
In operation from	2009	2011	2011	2012	2012
Patients (Jan 2014)	741	1639	1740	3120	23
Questionnaires/ patient	No limit	3	1/no limit	No limit	No limit
Response rate (primary)	75%	N/A	88%	93%	N/A
Response rate follow-up	82%	97%	N/A	99%	N/A

[a]Attention deficit hyperactivity disorder

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PRO Data Collection and Logistic (Base Element)

Overview

PRO data were collected in mixed-mode with paper- and Web-based questionnaires in all projects except three, where only the Web-based method was applied. Three reminders were applied in project type G and two in all other, except in project type A/stroke, where no reminders were applied.

Participation Rates and Attrition

The participation rates for the implemented projects are displayed in Table 2. In all projects, the patient was clearly informed that participation was voluntary. The range in response rates to the first PRO questionnaires was between 75% and 93% (median value 85%). The highest rates (93%) were found in project type G/epilepsy (clinical decision support, n=2882 patients) and project type B/prostatic cancer patients (hospital assessment, n=7423), while the lowest (77%) were found among stroke patients (epidemiological research, n=3575). During follow-up, the rates were between 82% and 99% (median value 96%). Due to different protocols (eg, number of reminders varied between zero and three), the rates are not directly comparable.

In project types A, B, and C (Table 2) PRO data from 8 different diagnostic groups were collected for use at a group level, and therefore none of the three optional elements were in use. Experiences related to the content of the PRO questionnaires for these projects will be described here.

In project type A, the three projects, include patients with breast cancer, ischemic heart disease, and stroke. Patients are monitored with PRO by multiple measurements over a span of 2 to 6 years. The aim is to describe prognosis using PRO data regarding symptoms and functioning, and to analyze PRO variables as risk factors for medical and social outcomes [20,27-30].

In project type B, PRO data are collected nationwide for patients with four malignant diseases: prostatic cancer, renal cancer, esophageal cancer, and lung cancer. The aim is to include PRO measures in existing national clinical registers used for research and hospital performance assessment.

In project type C, in an ongoing reorganization of the treatment of stroke in the Central Region of Denmark, it was decided to collect PRO data consecutively in all patients to monitor possible effects.

Development of PRO for Use at the Group Level

PRO data collected for use at the group level (clinical epidemiological research and hospital performance assessments) must comply with the usual demands regarding validity and reliability [1], and these issues will not be described further here. Due to the generic property of WestChronic, valid scales can be applied across projects, which make it easy to implement new projects using scales already in the bank simply by selecting them from drop-down menus. In such cases, new projects may be implemented very quickly.

Experiences related to the content of PRO for projects with applications at a patient level will be described below in connection with the corresponding optional element.

PRO Overview for Clinical Decision Support (Optional Element 1)

Overview

In projects aiming at clinical decision support, the core element is a graphical overview over the course of PRO. The clinician is presented with a graphical view of the course of selected PRO variables displayed within an EHR in the same context as the clinical data. A screen shot capturing the AmbuFlex II implementation is shown in Figure 2. Each column represents a PRO assessment. Color codes signal the severity of the symptom. The actual wording of the question as well as the answer is displayed as a “pop-up tip” when the user puts the mouse icon over the displayed bar. Vertically, the overview presents the actual situation and horizontally the PRO course over time with regard to symptoms, functional level, etc.

The PRO overview is used in two different situations: (1) in telePRO to evaluate and decide whether the patient needs a visit, and (2) as consultation support to identify and flag important symptoms that need focus and attention at an outpatient visit or in a telephone consultation.

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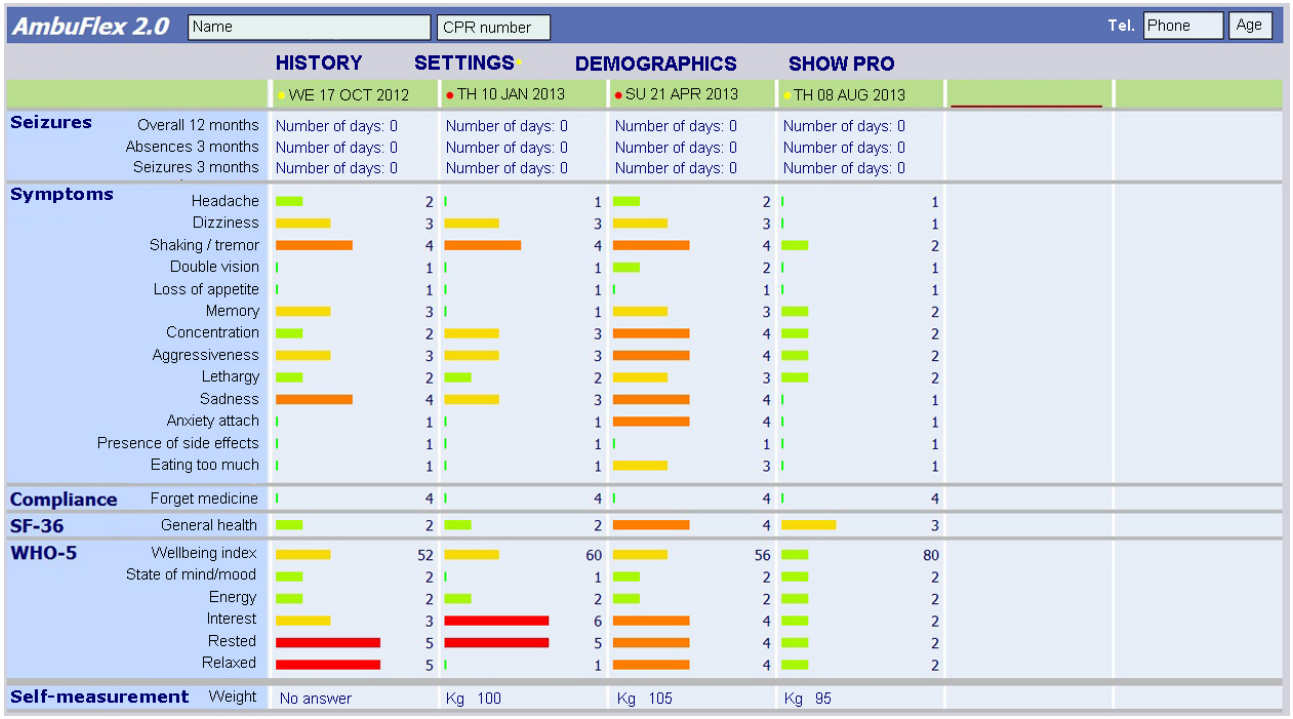
Figure 2. Screenshot captured from the PRO-based overview accessed from the EHR of the Central Denmark Region. The color codes in the upper row indicate the result of the automated PRO algorithm (red: definite need of contact; yellow: possible need of contact; green: no need of contact). Labels were translated from Danish.



Facilitation of Efficient Visits in Outpatients With Heart Failure (AmbuFlex I: Project Type D)

Patients with chronic heart failure often need treatment with multiple pharmacological substances. During the period in which patients are seen in the outpatient clinic, medical therapy is up-titrated, and patients are scheduled for frequent visits to monitor treatment results, identify side effects, and ensure compliance. PRO questionnaires were filled out by the patient before the visit to facilitate more efficient visits by flagging important symptoms. Furthermore, the overview is used for telephone consultations, enabling these to be shorter and more comprehensive [31]. The application as a screening tool before a telephone consultation was not a specific aim, but turned out to be the most significant issue with respect to both quality and time saving in PRO projects using a graphical PRO overview. The same method is used in patients with epilepsy, rheumatoid arthritis, renal failure, sleep disorders, neuromuscular diseases, lung and prostatic cancer, and endometriosis (Project type D+G).

Decision Support in Outpatients With Epilepsy (AmbuFlex II, Project Type G)

Patients with epilepsy are normally followed-up as outpatients at a neurological clinic, usually with 1 to 4 appointments yearly. PRO questionnaires are used to evaluate whether the patient needs a visit or not. If not, the patient automatically receives a new PRO questionnaire after a preset interval (eg, 3 months). The procedure consists of two steps: an automated decision in patients with obvious clinical problems and patients with no obvious problems at the moment (optional element 2) and a PRO-based clinical decision support in the remaining patients. Overall, for 48.75% of the PRO questionnaires no additional contact to the patient was needed, while the remaining 51.25% had a subsequent follow-up visit or a telephone consultation. The same method is used in patients with sleep disorders, neuromuscular diseases, and prostatic cancer.

Development of PRO for Clinical Overview

The PRO-based overviews use a PRO assessment to reflect clinical aspects as they are met in the daily clinical practice for that particular group of patients. The clinician, who makes the decision based on the PRO overview, still has the professional responsibility in case of an erroneous decision. Our experience is that it is vital that clinicians have full confidence in the system, even at the item level (face validity). The content of the PRO is negotiated based on iterative inputs from clinicians, review of the literature, and anthropological interviews with patients [25,32]. For new items constructed in this way, identical 5-point Likert scales are used to assess severity and frequency of symptoms. Pilot tests and semistructured interviews before implementation are used to identify problems such as relevance of items, clarity of wording, ambiguity of items, and lack of important issues. After a pilot test, the PRO application is put in operation, and a parallel iterative process is launched in which experiences are continuously evaluated, and items and mode of display revised as a running process until saturation is reached after 2 to 4 months. We have experienced that such projects are easily transferred to outpatient clinics for the same patient group without any modification, even though the clinicians are invited to suggest such. Thus, an implementation seems to be specific for a patient group, not for a location. The implementations have been evaluated from a clinical as well as a patient perspective with positive conclusions [33].

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PRO-Based Automated Decision Algorithms (Optional Element 2)

Overview

An automated PRO algorithm was applied in project types E, F, and G. As a part of the implementation process, an algorithm for each specific group of patients was developed and programmed into the server software.

Screening for Depression and Anxiety (Project F)

According to Danish clinical guidelines, all patients discharged from hospital after an ischemic heart attack should be screened for depression and anxiety 6 weeks after admission. Due to logistic challenges, this is rarely accomplished. The patients are recruited consecutively from hospital discharge registers, and 6 weeks after admission they are mailed a generic questionnaire on depression and anxiety [34]. An automated algorithm based on published cut-off values divide patients into nine groups according to no, moderate, or severe symptoms on the two scales. Based on these values, WestChronic automatically generates a personalized letter with the results of the screening, and if moderate or severe symptoms are present, the patient is advised to consult a general practitioner and bring along the letter. The same method is now extended to heart transplanted patients.

Automated Canceling of Postoperative Follow-Up Visits (Project Type E)

According to guidelines, patients with hip and knee replacements are invited to a follow-up visit 3 months after surgery. Several studies have documented that few of these visits have any clinical consequences and could be cancelled if satisfactory information on, for example, pain and difficulty in walking were available [35]. Patients were included at the preoperative examination in selected hospitals in 4 of 5 Danish regions. The automated algorithm was based on published values from well-established disease-specific questionnaires on symptoms and functioning [36,37]. At the beginning of the questionnaire we included an additional item: “You may wish to have an outpatient clinic visit regardless of these clinical factors and you can indicate your preference here”. This option was ticked off by 291 patients (27.3%). If scores were below thresholds and the patient did not indicated an absolute wish for a follow-up visit, the department was electronically informed that the scheduled follow-up visit should be cancelled. The same method is used in patients with endometriosis, where the algorithm is based solely on the patient’s wish of a visit.

Automated Handling of Patients that Clearly Need Attention and Those that Do Not Prior to Clinical Decision Support (Project Type G)

Clinical decision support among outpatients with epilepsy is described above. First, however, patients obviously needing attention and those that do not are handled automatically. Based on the incoming PRO data, the server algorithms simultaneously categorize the patients’ present condition into red, yellow, or green status (red status: the patient should be seen or contacted; green status: no action is needed). In the latter case, clinicians are not notified or involved at all, and at the scheduled time (eg, 3 months) a new questionnaire is automatically printed out and mailed or emailed to the patient. The PRO assessments that could not be processed automatically are assigned yellow status, meaning that a clinician shall inspect the PRO overview (decision support; optional element 1). Examples of inducers of red status are self-reported aggravation of seizures or planning of pregnancy. We allow the patient to overrule the automated decision with the same question as mentioned above. Nonresponders and patients who indicate they want a personal clinical contact are categorized to red status. WestChronic keeps track of patients with red and yellow status, and, if no action is taken by a clinician before a deadline, the server software reacts with reminders to the clinician on duty and, if ignored, alarms the system supervisors. Among 2766 questionnaires (November 2013) 37.8% were handled automatically (10.3% green and 27.5% red). Among patients with epilepsy, 27.3% indicated an absolute wish for a clinical contact.

Development of PRO for Automated Decisions

For simple screening purposes with defined binary outcomes (depression, inadequate function after surgery) existing PRO scales with documented sensitivity and predictive values were used. In more complex clinical decisions in which the whole situation of a patient needs to be evaluated, in several cases no PRO instrument was available or applicable. In these applications the goal is to have a false negative rate of zero, whereas the rate of false positive is of less concern. When PRO is intended for automated decisions, both content (items) and threshold need to be defined and documented with respect to sensitivity and specificity. Even if an obvious candidate for the PRO questionnaire exists, it is only possible to extract a cut-off value from the literature if the aims are identical. This was the case in screening for depression and canceling of postoperative visits. In the other projects, we had no predefined cut-offs to rely on. Initially, we gave priority to sensitivity in order to identify all cases that would be identified in a normal practice. When experience was gathered, cut-offs were adjusted by consensus conferences.

Other Forms of Communication (Optional Element 3)

Overview

In some projects there was need for information beyond that provided by predefined PRO questionnaires delivered from the patient to one or more clinicians.

In the very first PRO project (breast cancer, project type A), we gave the patient the possibility to log on and review her own course of symptoms over time. However, to comply with the demands from the Danish Data Protection Agency, we had to apply rather complicated procedures. A shared secure log-on procedure has now been provided at the national health website from which the patient can obtain a link to the personal site at WestChronic. In future implementations, the patient will be able to see an overview similar to what is presented to the clinician (optional element 1).

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Communication and Shared Knowledge in Patients With Attention Deficit Hyperactivity Disorder (ADHD)

The treatment of patients with severe ADHD may involve several therapists and social workers (project H). The project attempts to promote an overview of the situation among a group of complex patients with often quick shifts in condition and surroundings, and where continually shared updated knowledge is crucial for all partners, including the patient and relatives. The system includes PRO as well as a Web-based communication area in which structured as well as unstructured information can be shared between all parties, including the patient. The psychiatric department creates a record for new patients and decides which partners are relevant in each particular case. Partners are labeled according to their role (eg, patient, community psychiatric nurse, municipal social worker, outpatient clinic nurse, relative). Each patient is assigned 1 main contact person at a time. At the beginning of treatment, this would typically be a member of the psychiatric team. Any partner, including the patient, can create a new communication. The communication element is accessed from the PRO-based graphical overview for the particular patient. The patient participates in the following ways: first, s/he fills in the PRO questionnaire, which is graphically displayed at the initial page where all partners enter the system. Second, s/he has access to exactly the same written information as all other partners. Finally, s/he may create a communication to all partners. The psychiatric team accesses the system through the EHR system, while other professional partners obtain accesses after logon to their local area network. The patient obtains access via secure login at the national health website.

Discussion

Principal Findings

The generic PRO system WestChronic has so far enabled implementation of 22 PRO projects. It has been possible to develop and integrate all proposed protocols for data collection and processing. The system has achieved high response rates, and the attrition in longitudinal projects has been limited. We presume that the relevance of the PRO, the mixed-mode principle with integration of Web and paper PRO together with automated procedures that enable strict adherence to the schedules of reminders, has contributed to the high response rates. Furthermore, it has been possible to develop a number of approaches and methods for the clinical use of PRO without challenging the generic nature of the system.

Several articles dealing with features of and experiences with PRO systems have been published [11,14,15,22,26,38-40], but we are aware that other systems exist that have not been reported in the scientific literature. This reflects the notion that PRO systems are often considered a simple product rather than a key feature of clinical or scientific practice. As a consequence, a number of systems have been developed and promoted for specific aims and patient groups, and the potentials for sharing of expensive technologies and large-scale advantages are lost [22]. A fully equipped PRO system with maximal automation of procedures is technologically advanced, albeit essentially generic in nature. Any aim regarding the collection of PRO measures (epidemiological and clinical research, quality assurance, hospital performance assessments, and clinical use at the patient level) may benefit from systems capable of easy implementation, connection to external databases, and high performance with respect to response rates no matter for what purpose. As an example, in WestChronic 83 programmed scripts meet the needs of all functions, including the integration of Web and paper forms. Only two of these scripts are dedicated to specific projects (project type D+G). We believe that we can benefit from these generic features and still allow patients and clinicians to adapt to the specific demands and wishes in the individual projects.

The potential benefits of PRO measures in clinical practice have been described with respect to improvement of quality of care, better symptom assessment, more patient-centered care, and more efficient use of resources [4,12,26,41]. However, as pointed out by Donaldson et al [42], implementation of PRO as an adjunct and added task to usual care will not ensure that these aims are fulfilled. The potential emerges when PRO measures are fully incorporated into health care by clinicians as well as administrative leaders [42]. If PRO systems are to be a central part of patient care, they must allow the majority of the patients to be included. Few departments will invest time in systems that just create an additional pathway for patients. The goal should be to include the vast majority of the outpatients, acknowledging that a small proportion will always need individualized services and care.

Modes of PRO Collection

The term TeleHealth emphasizes a physical distance between patient and clinician, while the term ePRO just signals that the mode includes some electronic device in the hospital or at home. We recommend the use of the term TelePRO when PRO is collected at a distance, regardless of which mode is used.

While nearly all patients have access to the internet, about 50% of patients are not capable or willing to fill out TelePRO questionnaires on the Web when they are asked to do so. This is a consistent finding in all published randomized studies in patient populations [18-20]. Consequently, ePRO systems alone cannot be used for TelePRO when high participation rates are wanted. This problem is frequently ignored, and reports of ePRO data collection should at least document and report the actual proportion of patients included [23]. A mixed-mode approach may overcome this limitation and reach a Web-share of 55% to 60% without jeopardizing the response rate. When all functions, including printing and scanning of paper forms, are fully automated, the marginal cost of using paper forms as a fall-back method is limited compared with the advantage of response rates of up to 93%. Finally, ePRO solutions also require resources [42]. A large number of the support inquiries concerning projects implemented within WestChronic are about the patients' problems with the Internet, browser, or email account.

ePRO questionnaires are generally supposed to produce data that are equivalent to the data produced from the paper version if modifications of content and format are minimal [17,25]. We use the same software to generate both versions, which means the two modes as close to each other as possible.

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Content of Questionnaires for Clinical Use

Validity and reliability are cornerstones in clinical epidemiology, and other key attributes, include interpretability of scores and acceptable burdens for both patients and clinicians [24]. However, it all depends on the type of inference to be drawn from the PRO measure. To analyze group-level PRO, we should be concerned about biased estimates, whereas when PRO is used for screening, we should focus on sensitivity and predictive values. Each instrument must be evaluated for the exact clinical application. In the DanPROM project, such questionnaires were used for assessment of need for control after hip or knee replacement [36,37]. However, they were not able to discriminate between symptoms from the contralateral knee or hip. Bilateral symptoms are common, and high symptom scores may just mean that the patient is waiting for surgery of the other hip or knee. This is an example of an instrument that may be valid for some purposes, but may turn out to be less useful at an individual level.

Most clinical decisions are of qualitative nature and based on a number of inputs. When PRO measures are used for clinical decision support, they are also most often used together with clinical information (eg, in an EHR system). When PRO measures are used to decide whether a patient should be seen or not, the covariates for this dichotomous decision may not be operational in epidemiological terms, and the actual decisions not based on empirical evidence but on clinical experience and practice [24]. Group level PRO questionnaires, if available, may not be relevant or accepted by patients or the clinicians, who have to rely on them when evaluating the PRO overview (optional element 1). This form of validity, face validity, is fundamental as seen from the clinician's point of view and should be ensured during the implementation process for each new patient group. While a number of recommendations can be considered for group level PRO [24,25], these are not applicable to all aspects and domains at the patient level. Furthermore, summary scores or empirically based cut-offs are often not clinically relevant or applicable. Because the clinician still has the full responsibility for the decision, we constructed the wording as close as possible to the actual wording of questions the clinician asks the patients in daily practice. In this way we ensured the face validity.

Clinicians may be reluctant to gather too much information because they have to respond and react to issues with regard to which they may feel they lack competence (eg, assessment of signs of depression). The development of guidelines on how to react has been proposed to comply with this problem [43].

Patient Safety in PRO for Clinical Use

When PRO measures are used for clinical monitoring and decisions, it is considered a medical device and should comply with regulations with respect to documentation of safety [44]. Sensitivity of automatic procedures, for example cancelling of appointments, should be maximal, but often hardly possible to describe in relevant quantitative terms. Furthermore, there may be issues not included in the questionnaire that definitely necessitate a consultation. We recommend that PRO questionnaires for automated decisions should include items that give a possibility for the patient to overrule an automated decision. This is not only important for patient safety, but since the patient most likely can deduce which answers qualify for a desired algorithm-based decision, it is a prerequisite for getting trustworthy answers. It is also vital to ensure that nonresponding patients are not lost from clinical follow-up if they do not react to questionnaires or reminders. Such patients should be invited to a normal outpatient visit.

Implementation in Clinical Practice

AmbuFlex (project types D+G) has been implemented in clinical practice for different groups of patients and for different purposes, and the Central Region of Denmark has recently decided to extend the use of AmbuFlex to three new diagnostic groups every year. The integration into the EHR system has increased the impact considerably. The data available so far suggest that PRO-based clinical systems implemented in close teamwork with involved clinicians may be a suitable instrument with respect to quality improvement and intelligent resource utilization. However, not all groups of outpatients are suitable for systems like AmbuFlex. Information obtained from the patient should be of major importance in the clinical assessment of the disease, if necessary with support from biochemical or other laboratory and imaging data, but a physical examination should not be central for evaluation of the clinical status. If PRO is used to avoid needless consultations, the variation in turn-around time for PRO collection should be considered. Special appointments reserved for PRO patients are recommended instead of cancellation of prescheduled appointments. In the implementation process for a new diagnostic group, involvement of the patients as well as support from frontline clinicians and administrative leaders are essential.

Conclusions

Organizational research has introduced the concept of disruptive innovation and applied it to health care [42]. Incorporating PRO at the center of health care, not as an adjunct and added task to usual care, can be viewed as a disruptive innovation. This could occur if clinicians and administrative leaders take patient-centered care so seriously that PRO, not the patient visit, are the center of the model [42]. If this point is reached, overloaded outpatient clinics would potentially be able to skip large numbers of prescheduled routine review visits, which often occur despite the patient being well and no action being required, and instead direct resources toward the patients with real needs [45].

PRO have been collected and used for decades, but mostly as part of projects sharply confined in time and space. Based on our experiences, we can put forward the following suggestions to promote PRO collection as a permanent activity.

First, the focus should be on development of generic (not diagnosis-specific) models. Most long-term conditions have communalities that make the use of the same technology desirable [22].

Second, response rates are important for any purpose. If the target group is patients who show up at the outpatient clinic, a patient kiosk system at the hospital is a relatively simple solution. If the target group is all patients, a TelePRO solution

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is needed, and mixed-mode PRO collection should be considered to reach the majority of the patient group.

Finally, the PRO data should be relevant for several purposes. Data collected according to routine may be useful at a group level for assessment of hospital performance as well as clinical research. If PRO data can be used at both individual and group levels (eg, clinical research or quality improvement), collection of such data is more likely to be considered worthwhile, and thus to be implemented on a permanent basis.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Automatic optimization of paper/ePRO modes in WestChronic, a mixed-mode PRO system.

[PDF File (Adobe PDF File), 194KB - ijmr_v3i1e5_app1.pdf]

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Abbreviations

ADHD: attention deficit hyperactivity disorder
CPR: central personal registry
EHR: electronic health record
ePRO: patient-reported outcome data electronically
N/A: not applicable
PRO: patient-reported outcome
RR1: minimal response rate TeleHealth: a physical distance between patient and clinician
TelePRO: patient-reported outcome data provided at a distance

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Original Paper

Speed and Accuracy of a Point of Care Web-Based Knowledge Resource for Clinicians: A Controlled Crossover Trial

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Abstract

Background: Effective knowledge translation at the point of care requires that clinicians quickly find correct answers to clinical questions, and that they have appropriate confidence in their answers. Web-based knowledge resources can facilitate this process.

Objective: The objective of our study was to evaluate a novel Web-based knowledge resource in comparison with other available Web-based resources, using outcomes of accuracy, time, and confidence.

Methods: We conducted a controlled, crossover trial involving 59 practicing clinicians. Each participant answered questions related to two clinical scenarios. For one scenario, participants used a locally developed Web-based resource, and for the second scenario, they used other self-selected Web-based resources. The local knowledge resource ("AskMayoExpert") was designed to provide very concise evidence-based answers to commonly asked clinical questions. Outcomes included time to a correct response with at least 80% confidence (primary outcome), accuracy, time, and confidence.

Results: Answers were more often accurate when using the local resource than when using other Web-based resources, with odds ratio 6.2 (95% CI 2.6-14.5; $P<.001$) when averaged across scenarios. Time to find an answer was faster, and confidence in that answer was consistently higher, for the local resource ($P<.001$). Overconfidence was also less frequent with the local resource. In a time-to-event analysis, the chance of responding correctly with at least 80% confidence was 2.5 times greater when using the local resource than with other resources (95% CI 1.6-3.8; $P<.001$).

Conclusions: Clinicians using a Web-based knowledge resource designed to provide quick, concise answers at the point of care found answers with greater accuracy and confidence than when using other self-selected Web-based resources. Further study to improve the design and implementation of knowledge resources may improve point of care learning.

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KEYWORDS

medical education; Web-based learning; educational technology; clinical decision support; health information technology

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Introduction

Point of Care Questions

Ongoing advances in clinical medicine create new opportunities for patient-centered, high-value, personalized care, but the realization of this potential will require new models for translating evidence into practice. Clinicians frequently identify knowledge gaps while seeing patients [1,2], but many such point of care questions remain unanswered because busy clinicians cannot find answers in a timely fashion [3-5]. Increased speed and ease in finding accurate answers would improve practice efficiency and productivity; and over time might prompt clinicians to seek point of care information support as a routine part of their daily practice. In addition to speed and accuracy, effective knowledge translation requires that clinicians be appropriately confident in the answers they find—both overconfidence and lack of confidence will lead to suboptimal care [6].

Web-based knowledge resources can facilitate the translation of evidence into point of care practice [7], but current resources do not optimally address the potentially conflicting requirements of concise, complete, timely, balanced, and practical information [8-11]. To address these needs, we have developed a knowledge resource—"AskMayoExpert"—designed to provide very concise evidence-based answers to clinical questions (Textbox 1) [12]. The "frequently asked questions" (FAQ) feature of this multifaceted resource offers highly synthesized synopses of evidence [13] to satisfy focused point of care information needs. A comprehensive description and initial evaluation of AskMayoExpert has been published separately [12]; the present paper describes a study evaluating AskMayoExpert's FAQ feature.

Purpose of the Present Study

The purpose of the present study was to evaluate this new knowledge resource in comparison with other available Web-based resources (such as, but not limited to or specifically targeting, UpToDate, MD Consult, PubMed, and Google). We hypothesized that the local resource would facilitate faster and equally accurate answers to clinical questions.

Textbox 1. Development and features of the AskMayoExpert Web-based knowledge resource.

The AskMayoExpert Web-based knowledge resource [12] provides highly synthesized synopses of evidence to support rapid, accurate point of care decision making, and to facilitate the development of "gist" learning for long-term retention [14]. Each evidence synopsis is written as an answer to a common clinical FAQ, and is targeted to the needs and background understanding of a nonspecialist in that topic. All content is reviewed, revised, and approved by a content board of subspecialist experts and a senior physician editor, and is reviewed at least annually. Institutional leaders have endorsed this information as a quality standard for the entire institution.

Topics and FAQs have been added gradually, with priority determined by frequency, implications of mismanagement, and novelty of information (common, serious, and new/controversial topics receive top priority). At the time of this study AskMayoExpert contained 2478 FAQs on 490 disease-oriented topics.

Additional features (not relevant to the present study) include a directory of local topic experts, care process models (algorithms describing institution-approved ideal care pathways), clinical notifications of urgent test results, and patient education information. AskMayoExpert is available on the institution Intranet.

Methods

Overview and Setting

We conducted a controlled crossover trial in which clinicians answered one case-based question using a locally developed resource designed to provide concise answers, and another question using other Web-based resources of their choosing. The study took place at campuses of an academic medical center in Rochester, Minnesota; Jacksonville, Florida; and Scottsdale, Arizona, and an affiliated primary care clinic in Mankato, Minnesota, during March and April 2009. All staff at all sites have institution-sponsored access to several commercial knowledge resources including UpToDate, MD Consult, and Micromedex, in addition to publicly available Web-based resources. The Mayo Clinic Institutional Review Board approved the study protocol.

Independent Variable

We created paper booklets containing two brief clinical scenarios (one scenario for each knowledge resource condition; Textbox 2), each with one key question about management. Scenario A focused on a common problem that is often managed without consideration of current evidence (atrial fibrillation—indications for stroke prevention anticoagulation), while Scenario B focused on an infrequently diagnosed condition for which management would be unfamiliar (apical ballooning syndrome—timing of follow-up). We created two versions of the booklets, one with Scenario A coming first (booklet A), and the other with Scenario B coming first (booklet B). Each booklet instructed participants to use AskMayoExpert to answer the first question, and to use any other Web-based resource to answer the second question (crossover design). Rather than selecting a specific "other" resource, we allowed participants to make this choice so that they could use a resource they felt was likely to give them an answer and with which they were comfortable.

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Textbox 2. Outcome measures—scenarios and questions.

Scenario A.

Please answer the following question using [assigned format].

A 56-year-old male was readmitted to the hospital with his second episode of atrial fibrillation and a rapid ventricular response in the last 2 months. He has severe sleep apnea and he uses CPAP[a] at home. There is no prior history of stroke, coronary artery disease, diabetes, or hypertension. He is a one-pack-per-day smoker, but is trying to quit (20 pack-years). He began taking diltiazem, metoprolol and aspirin after his first episode one month ago. His initial blood pressure is 110/70 and his heart rate is 110.

Record start time—

Mark only one best answer—The moderate or high-risk indication for stroke prevention using Coumadin and not aspirin is which of the following?
CPAP: continuous positive airway pressure; ECG: electrocardiogram; CCU: coronary care unit; Echo: echocardiogram; EF: ejection fraction.

1. Uncontrolled heart rate
2. Severe sleep apnea
3. Smoking history
4. Patient's age
5. None, aspirin is appropriate for this patient [correct response]

Record end time—

Indicate your confidence about the above answer. [11-point scale ranging from 0%-100%]

Did you know the answer beforehand? Yes / No

Scenario B.

Please answer the following question using [assigned format].

A 72-year-old female was admitted to the hospital for severe constipation. During a digital disimpaction, she developed chest pain and shortness of breath. Initial ECG revealed new ST segment depression consistent with ischemia. Initial troponin T was slightly elevated at 0.04. She was transferred to CCU. Cardiac catheterization revealed normal coronary arteries. An Echo (EF=25%; 6 months prior EF=56%) was consistent with apical ballooning syndrome.

Record start time—

Mark only one best answer—What is the recommendation for follow up Echo to assess ejection fraction progression?

1. 48-72 hours
2. 1-2 weeks
3. 4-6 weeks [correct response]
4. 8-10 weeks

Record end time—

Indicate your confidence about the above answer. [11-point scale ranging from 0%-100%]

Did you know the answer beforehand? Yes / No

Participants, Group Allocation, and Procedures

We sent an email to all clinicians (practicing physicians, physicians in training, senior medical students, physician assistants, and nurse practitioners) who had used AskMayoExpert at least once (N=1474), inviting them to attend a noon study session to evaluate AskMayoExpert. There were two date options in Rochester and one at each other site. Those who were willing to participate and available at the required time came to one of the five face-to-face sessions. At each session booklets A and B were placed in a single stack with alternating format. Participants took the top booklet as they entered the room, and this determined group allocation (ie, to answer the atrial fibrillation scenario first, with the local resource, or second, using other resources). Each clinician then used a separate computer to answer the two questions using Web-based resources, as instructed. Participants were asked not to discuss the scenarios or answers with one another. No incentives were provided other than lunch during the session.

Outcome Measures and Data Collection

Main dependent variables were accuracy of response, confidence in that response, and time to generate that response. Each scenario was associated with one multiple choice question (Textbox 2). Scenarios and questions were developed by a general internist (author FJL) and revised with input from two

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cardiology experts (author JL and another cardiologist). This group determined answers by reference to specific literature sources. During the session participants recorded the time they started and ended their search to answer the question. They also indicated their confidence in their answer (11-point ordinal scale ranging 0% to 100% confident) and whether they knew the answer beforehand. We asked, "What resources do you use to answer clinical questions?," but did not verify whether they used these resources during this test session. We also collected demographic information (gender and specialty).

Statistical Analysis

The prespecified primary outcome was the time to a correct response with at least 80% confidence. Secondary outcomes included percent correct, time to an incorrect response, and confidence in the response.

We report median rather than mean confidence score and time because these did not follow a normal distribution. To compare accuracy between resource formats across both scenarios, we used generalized linear models with a logit link function and repeated measures on subjects. To compare time and confidence between resource formats, we performed a similar repeated measures analysis using mixed effects analysis of variance on the ranked outcomes. In a sensitivity analysis, we repeated these analyses separately for practicing physicians, nonphysician practitioners, and physician trainees. The time to a confident, correct answer was evaluated with a competing risks model [15] predicted by scenario, study intervention, and the interaction of outcome type and study intervention, with repeated measures on subjects. A two-sided 5% type I error was used for all analyses. As a pilot study, we powered the study for a large effect (Cohen's d 0.8), which required 52 participants to achieve 80% power. Author FE (a PhD statistician) planned all analyses. We used SAS 9.1.3 for all analyses.

Results

Participants

There were 59 clinicians that participated, including 28 practicing physicians, 14 physician assistants/nurse practitioners, 10 postgraduate physician trainees, 6 senior medical students, and 1 licensed clinical social worker. Table 1 contains additional demographic information. The 59 participants were similar to those invited, but not participating, in characteristics of gender, years of service, and training level (P>.10; data not shown). The proportions of participants who reported knowing the answer beforehand were similar for the local and other resources. The number of participants per session varied from 2 to 22.

Accuracy, Confidence, and Time

Overall accuracy, confidence, and time are shown in Table 2. Answers were more often accurate when using the local resource than when using other Web-based resources, with odds ratio 6.2 (95% CI 2.6-14.5; P<.001) when averaged across scenarios. Time to find an answer was faster, and confidence in that answer was consistently higher, for the local resource (P<.001; Table 2). In a sensitivity analysis, we performed these analyses separately for practicing physicians, nonphysician practitioners, and trainees; results showed the same direction of effect, but given low power did not always reach statistical significance (data not reported).

Table 3 shows that inappropriate confidence (overconfidence) was less frequent with the local resource. Among confident clinicians (those with ≥80% confidence), the odds of being correct (vs incorrect) were 10.0 times higher for the local resource than for other resources for Scenario A (95% CI 1.4-78), and for Scenario B the odds ratio was 3.4 (95% CI 0.6-23.6).

Time to an Accurate and Confident Response

In the primary outcome analysis, a time-to-event competing risk model, only clinicians who achieved an accurate and confident (≥80%) response were considered to have a positive outcome. In this analysis, the chance of being correct and confident at a given time was 2.5 times higher for the local resource than with other resources (95% CI 1.6-3.8; P<.001).

Other Resources Used in Practice

We asked participants what resources other than AskMayoExpert they use to answer clinical questions, but did not verify that they used these resources during this test session. The resources most commonly reported were UpToDate (48/58, 83% respondents), Micromedex (38/58, 66%), PubMed and Google (34/58, 59% each), and MEDLINE (24/58, 41%).

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Table 1. Participant demographics.

Feature		All, N=59	AskMayoExpert for Scenario A, n=30	Other for Scenario A, n=29
Training level [a] , n (%)				
	Staff MD	28 (47)	12 (40)	16 (55)
	PA/NP	14 (24)	10 (33)	4 (14)
	PG	10 (17)	5 (17)	5 (17)
	MS	6 (10)	3 (10)	3 (10)
	LCSW	1 (2)	0	1 (4)
Gender [b] , n (%)				
	Male	35 (59)	15 (50)	20 (69)
Site [c] , n (%)				
	Rochester, MN	23 (39)	12 (40)	11 (38)
	Jacksonville, FL	22 (37)	11 (37)	11 (38)
	Scottsdale, AZ	13 (22)	7 (23)	6 (21)
	Mankato, MN	1 (2)	0	1 (4)[c]
Knew answer beforehand [d] , n (%)				
	Scenario A	5 (9)	3 (10)	2 (8)
	Scenario B	11 (20)	7 (24)	4 (15)

[a]Between-groups comparison across all training levels: *P*=.38. Staff MD: staff physician; PA/NP: physician's assistant/nurse practitioner; PG: postgraduate physician trainee; MS: medical student; and LCSW: licensed clinical social worker.

[b]Between-groups comparison: *P*=.19.

[c]Between-groups comparison across all sites: *P*=1.0. One additional person participated in Mankato, but data were largely incomplete and this participant's data are not included in any analyses.

[d]Reported by participants after answering the question. Between-groups comparison, Scenario A: *P*=1.0; Scenario B: *P*=.51.

Table 2. Accuracy, confidence, and time to answer question.

	Scenario A			Scenario B		
	Accuracy n correct (%)	Confidence[a] median (IQR)	Time[a] median (IQR)	Accuracy n correct (%)	Confidence[a] median (IQR)	Time[a] median (IQR)
Local resource	27/30 (90)	100 (95, 100)	2 (1, 3)	24/29 (83)	90 (70, 100)	4 (3, 5)
Other Web-based resources	14/29 (48)	60 (30, 80)	3.5 (2, 8)	16/30 (53)	80 (70, 90)	4 (3, 6)

[a]Confidence measured using an ordinal scale, 0%, 10%, …100% confident; time measured in minutes; IQR: interquartile range.

Table 3. Accuracy of and confidence in responses.

	Incorrect, but confident[a] n confident (%)		Correct, but not confident[a] n confident (%)	
	Scenario A	Scenario B	Scenario A	Scenario B
Local	3/28 (11)	3/22 (14)	2/2 (100)	4/7 (57)
Other	6/11 (55)	7/20 (35)	9/18 (50)	3/10 (30)

[a]Confidence > 80%

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Discussion

Summary of Findings

We found that accuracy was significantly higher, and overconfidence was lower, when using a concise locally developed resource (AskMayoExpert) than when using another Web-based resource selected by the participant. Time slightly favored the local resource, but the difference was not statistically significant. However, in the prespecified primary analysis, after accounting for time, the chance of correctly and confidently answering the question was 2.5 times higher for the local resource.

Limitations and Strengths

The use of a locally developed knowledge resource, and clinical scenarios restricted to cardiology, limit the generalizability of our findings. Moreover, these scenarios could have inadvertently targeted content unique to the local resource (ie, giving it an unfair advantage), although we are not aware of such bias. We did not track the resources used when addressing the second scenario. Time was recorded by participants, and thus susceptible to error. Although we achieved overall statistical significance in the primary outcome, Scenario A accounts for the majority of the difference in time in this analysis. We had low response to our initial invitation, and although measured demographics were similar, participants could be systematically different than nonparticipants in unmeasured attributes. Confidence in the local resource could have been influenced by knowledge that local colleagues created information. Group assignment was not strictly random; but since participants used both knowledge resources during the study, neither they nor the study proctor had incentive to deliberately influence the assignment process. Moreover, the crossover design offers within-subjects control for individual differences. Another strength is the measurement of three key outcomes (accuracy, time, and confidence).

Comparison With Prior Work

Synthesized knowledge resources (in which experts attempt to present a balanced summary of evidence, such as UpToDate, DynaMed, and MD Consult) have been compared with one another [16-19] and with unsynthesized resources (that provide access to primary literature, such as PubMed) [18,20,21] in both clinical practice and in test settings. In these studies, the synthesized knowledge resource is consistently faster and/or more accurate. The findings of the present study show a similar effect, namely, that a concise evidence-based resource designed expressly for point of care learning facilitates quick, accurate answers to clinical questions.

Implications and Conclusions

Although this pilot study has several limitations, it demonstrates that important differences exist among knowledge resources. Specifically, a resource crafted to provide quick, concise answers at the point of care was associated with more accurate responses, and faster time to an accurate response, than other clinician-selected Web-based resources. Future research might explore how to design and implement knowledge resources more effectively, investigate how to encourage clinicians to optimally use them to enhance patient care, and determine their clinical impact on patient health and systems outcomes.

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Conflicts of Interest

None declared.

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Abbreviations

CI: confidence interval
FAQ: frequently asked questions

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Original Paper

Feasibility of a Web-Based Survey of Hallucinations and Assessment of Visual Function in Patients With Parkinson's Disease

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Abstract

Background: Patients with Parkinson's disease (PD) experience visual hallucinations, which may be related to decreased contrast sensitivity (ie, the ability to discern shades of grey).

Objective: The objective of this study was to investigate if an online research platform can be used to survey patients with Parkinson's disease regarding visual hallucinations, and also be used to assess visual contrast perception.

Methods: From the online patient community, PatientsLikeMe, 964 members were invited via email to participate in this study. Participants completed a modified version of the University of Miami Parkinson's disease hallucinations questionnaire and an online vision test.

Results: The study was completed by 27.9% (269/964) of those who were invited: 56.9% of this group had PD (153/269) and 43.1% (116/269) were non-Parkinson's controls. Hallucinations were reported by 18.3% (28/153) of the Parkinson's group. Although 10 subjects (9%) in the control group reported experiencing hallucinations, only 2 of them actually described formed hallucinations. Participants with Parkinson's disease with a mean of 1.75 (SD 0.35) and the control group with a mean of 1.85 (SD 0.36) showed relatively good contrast perception as measured with the online letter test (P=.07). People who reported hallucinations showed contrast sensitivity levels that did not differ from levels shown by people without hallucinations (P=.96), although there was a trend towards lower contrast sensitivity in hallucinators.

Conclusions: Although more Parkinson's responders reported visual hallucinations, a significant number of non-Parkinson's control group responders also reported visual hallucinations. The online survey method may have failed to distinguish between formed hallucinations, which are typical in Parkinson's disease, and non-formed hallucinations that have less diagnostic specificity. Multiple questions outlining the nature of the hallucinations are required. In a clinical interview, the specific nature of the hallucination would be further refined to rule out a vague description that does not indicate a true, formed visual hallucination. Contrary to previous literature, both groups showed relatively good contrast sensitivity, perhaps representing a ceiling effect or limitations of online testing conditions that are difficult to standardize. Steps can be taken in future trials to further standardize online visual function testing, to refine control group parameters and to take steps to rule out confounding variables such as comorbid disease that could be associated with hallucinations. Contacting subjects via an online health social network is a novel,

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cost-effective method of conducting vision research that allows large numbers of individuals to be contacted quickly, and refinement of questionnaires and visual function testing may allow more robust findings in future research.

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KEYWORDS

Parkinson's disease; hallucinations; contrast sensitivity; Charles Bonnet Syndrome

Introduction

Parkinson's disease (PD) is a disorder that typically occurs in mid to late life, with symptoms including tremor, rigidity, bradykinesia, stooped posture and shuffling gait. Approximately 1/3 of PD patients report visual hallucinations such as seeing people or animals [1,2]; thought to be either related to the disease or pharmacological treatments [3].

Hallucinations are also experienced by patients with reduced vision, and this is known as Charles Bonnet Syndrome (CBS) [4-6]. CBS patients usually retain insight into the hallucinatory nature of their visual experiences [7] yet hesitate to discuss the symptom with health care providers for concern of being viewed as mentally ill [8]. A prospective evaluation of 224 patients presenting for vision rehabilitation identified a high prevalence of CBS (33%) and a correlation with impaired contrast sensitivity (CS), the ability to discern shades of grey [7,9]. Patients reported seeing formed images of different things such as animals, faces, patterns or other objects. PD patients who report visual hallucinations are reported to have poorer CS using vision tests in a controlled clinical environment [10]. It is arduous and costly to conduct large trials of patients to assess correlates of hallucinations and visual functions, and as a result, quicker novel methods of conducting research are desirable.

PatientsLikeMe (PLM) is an online platform with over 190,000 members which offers patients tools to track their illness, share their data with peers and participate in research studies. There is evidence suggesting that use of the platform may even benefit patient outcomes [11]. PLM has an advanced system for patients with PD that offers the ability to use a patient-reported version of the Unified Parkinson's Disease Rating Scale (UPDRS-III) [12] to record the impact of their condition over time. Comparison of such data with clinical trial data suggests a high degree of week to week variability in PD symptoms reported on the platform [13]. Members of the PLM PD community have previously contributed to research in sensitive areas such as pathological gambling [14] using a built-in survey tool. Hallucination is also a sensitive topic for many patients who have insight into the unreal nature of what they see and, therefore, the online survey method was of interest.

Ongoing clinical evaluation and testing for patients with PD are resource intensive. Recent efforts to address this include telemedicine allowing "virtual house calls" for PD patients [15]. Enrolling and conducting the vision test with a large sample of PD patients can also be difficult and resource intensive [15]. In this study we aimed to explore the feasibility of using an online platform to examine the relationship between reported hallucinations and contrast perception in patients with Parkinson's disease compared to controls.

Methods

Enrollment

This study used an online survey of visual hallucinations with a standardized questionnaire and a novel test of contrast sensitivity. After institutional review board approval by the Human Studies Committee at the Massachusetts Eye and Ear Infirmary, email invitations were sent to members of the PLM community. The protocol and the study complied fully with the declaration of Helsinki. Patients who were members of the PLM community had previously self-identified themselves as being diagnosed with Parkinson's disease. If patients chose to participate in the study, they were asked to click on an email link to access the consent document, and after reading the consent, to click on a link to indicate their agreement to participate. If no response was received, participants were sent an automated reminder message after three days.

Online Survey of Hallucinations

Participants completed the University of Miami Parkinson's disease hallucinations questionnaire (UM-PDHQ), which had been previously developed by Papapetropoulos et al to assess and characterize hallucinations in Parkinson's patients [16]. The questions enquired whether the individual experienced hallucinations, and asked questions about frequency, types, and insight into the unreal nature of the images. Three questions in the UM-PDHQ clarified the nature of the hallucinations, (ie, whether they were solid, colored, and normal in size). Three additional questions were added to the UM-PDHQ regarding history of eye disease and whether hallucinations were monocular or binocular (see Multimedia Appendix 1). Patients participating in this study were encouraged to discuss the symptom with their physician if they had concerns or questions.

Contrast Sensitivity Test

Patients completed a vision test of contrast sensitivity that was similar to a commonly used test, the Pelli-Robson chart [17]. Three letters of the same contrast were shown and the subject was asked to type the letters seen. Each subsequent triplet was of reduced contrast (Figure 1). If no letters could be detected, the participant would receive a score of 0.00, and the highest possible score was 2.25. A person with normal vision would score 1.95. The size of the letters created a 0.5° target viewed on a monitor with an average of 44 pixels/cm at a typical viewing distance of 56 cm [18]. The luminance of the display was assumed to have a gamma value of 2.0 (gamma=1.8 for Mac OS and gamma=2.2 for Windows OS) [19], with 8 bit grey scale resolution (256 luminance levels). Letters were presented in triplets of the same contrast and contrast decreased by a factor of $1/\sqrt{2}$ each line. Regardless of the brightness setting of the subject's display, maximum achievable Michelson contrast

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(L_{min}=0, L_{max}=255) approached 100% and minimum achievable Michelson contrast (L_{min}=254, L_{max}=255) approached 0.02%. The worst case would be a 6 bit display where the lowest presentable Michelson contrast would be 1.2%, (L_{min}=63, L_{max}=64). There are many assumptions in these values, and the contrast sensitivity assessment can only be approximate. Nevertheless, small changes in letter size, gamma and brightness have relatively limited effect on presented contrasts, composed of only 2 values (light grey letter on white background), and there is no reason to assume that there was any systematic difference in the displays used by different subject groups. Consequently, these data allowed a crude classification of contrast sensitivity.

Statistical Analysis

The main comparison assessed the impact of PD and hallucinations on contrast sensitivity. Results from the UM-PDHQ divided participants into the following three goups: (1) currently hallucinating, (2) reported never having hallucinations, (3) and those who hallucinated previously but not within the past month. Preliminary analyses showed that the results did not change when collapsing the group “currently hallucinates” and “previously hallucinated”; thus, a two-way between-groups analysis of variance was conducted to explore the impact of Parkinson’s disease (PD vs no PD) and hallucinations (currently/previously vs never hallucinated) on contrast sensitivity. Chi-square tests of independence were performed to examine potential differences in proportions of PD versus control subjects. All analyses were computed using SPSS (version 17.0).

Figure 1. The contrast sensitivity test stimuli letters. A total of 16 rows of letter triplets were presented to the respondents, with row 1 letter triplet being of highest contrast and row 16 letter triplet being of lowest contrast. Represented from top to bottom are row 1, row 2, row 3, row 9, row 10 and row 11 of the letter triplets.

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Results

Enrollment

Email invitations were sent to 964 PLM members: 482 with PD and 482 controls (Table 1). At the end of data collection (14 days after email invitation), 269 had completed the study: 153 PD subjects and 116 controls, including 80 patients with amyotrophic lateral sclerosis and 36 with depressive disorder.

Contrast Sensitivity Test

Both groups, participants with PD (mean 1.75, SD 0.35) and the control group (mean 1.85, SD 0.36), showed relatively good CS, and there was no difference between the groups (main effect of Parkinson's disease, *P*=.07). Neither the control nor the PD group showed a difference in CS between those who reported and did not report hallucinations (interaction Parkinson's disease and hallucinations, *P*=.96).

Data: Online Survey of Hallucinations

As seen in Table 1, 18.3% (28/153) of PD patients and 9% (10/116) of controls reported current visual hallucinations (*P*=.004). Hallucinations reported by participants with PD included mice, cats, people, distorted faces, furniture or complex patterns. Only 2 of the 10 control subjects reported formed images and the remainder reported seeing lights, vague peripheral images or hallucinations that were related to drug ingestion.

Table 1. Parkinson's and control group characteristics (N=269).

	Controls n=116	Parkinson's disease n=153
Age (years), mean (SD, range)	51.8 (10.2, 21-74)	61.5 (9.6, 36-86)
Gender, n (%) [a]		
Female	70 (60.3)	87 (56.9)
Male	45 (38.8)	64 (41.8)
Contrast sensitivity (score), mean (SD)	1.85 (0.36)	1.75 (0.35)
Currently hallucinating, n (%)	10 (9)	28 (18.3)
Previously hallucinated, n (%)	16 (13.8)	23 (15.0)
Never hallucinated, n (%)	90 (77.6)	102 (66.7)

[a]Gender not reported by 1 control and 2 PD subjects.

Discussion

Principal Results

This research confirms the feasibility of conducting rapid online vision testing and efficiently gathering questionnaire data from large numbers of individuals; however, it also points to limitations of such research. Our findings confirm previous reports describing that hallucinations exist in PD patients [1] and the number of subjects reporting hallucinations is similar to previous clinical research suggesting that the online tool was successful for this patient group. However, the report of hallucinations by controls indicates that online questionnaires need to be more explicit to gain accurate reports in this group. Two of the authors (MLJ, JE) have extensive clinical experience interviewing patients with a symptom of hallucinations and such clinical experience suggests that targeted questioning is required to discern true visual hallucinations, illusions of mistaking items, or vague complaints that do not fulfill the criteria for formed hallucinations.

Limitations

Control subjects' descriptions of hallucinations were vague, or attributed to medications, in more than 80%, hence the rate of hallucinations in the control group was exaggerated. In-person interview would have clarified these reports. It is also possible that the study attracted those who were interested in the topic of hallucinations and this may have also contributed to over-reporting of such a symptom in control subjects. A limitation of this study was that the control group was "disease controls" rather than "healthy controls" as these were the most convenient comparison sample available from PLM at the time. This could be addressed in future trials by using a sample of caregivers who are members of the PLM community and, in addition, an attempt could be made to screen for both comorbid disease and cognitive status. No test of cognitive performance was used and PD subjects with less severe PD may have been selected. Hallucinations have been reported early in the PD disease course [3], but they may be less frequent in this group. As a result, this may have led to an underreporting of hallucinations in the PD group.

We did not find any statistically significant difference in contrast sensitivity between PD patients and controls. This is in contrast to previous literature that shows PD patients have reduced contrast sensitivity. Our study may have suffered from selection bias in that subjects with good contrast sensitivity may be those who continue to use a computer, while subjects with poor contrast sensitivity may not use a computer at all. In future trials the severity of PD could be ascertained. A further reason for our failure to dissociate the two groups might be that the test was too easy (ie, ceiling effect); however, it is worth noting that later triplets were very difficult to see even for the experimenters. The lack of standardization of computer monitors, home lighting, and the distance participants sit from their monitors are factors that require attention in future trials.

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More precise directions for vision testing may lead to greater standardization of the online testing. Novel methods of standardization for spatial frequency, for example, could include matching a common object such as dollar bill to a shape on the screen. Future research could compare online and in-person results to validate online methods.

Potential Benefits

Collecting data from online patient communities offers potential to create new knowledge from the real-world experience of patients and; therefore, the techniques used in this study will become increasingly important as costs of research are increasingly scrutinized. These research methods may become very important in future years to reduce the burden of conducting research using in-person examinations, and to shorten the time of conducting trials. We have demonstrated a novel research that combines patient reported symptoms and measured visual function, and this method can be further expanded in the future to understand the symptom of hallucinations in patients who retain insight into the unreal nature of what they see.

Conclusions

This research identified that hallucinations are more common in PD than controls but did not show a relationship between hallucinations and measured contrast perception. Our research directs how useful data may be collected in future studies as more standardized online techniques are developed. This research is an example of using an online community to conduct a survey of symptoms and vision that is quick, economical, and convenient for subjects. This has great potential for future online research. Patients are often hesitant to discuss hallucinations with a health care professional. In fact, we are certain that the majority of patients with CBS do not voluntarily report such symptoms to clinicians out of concern that they will be regarded as mentally ill [7,8]. Our pilot study shows the feasibility of enrolling and collecting data about hallucinations in this patient group. In addition, a survey such as the one used in this study offers patient education. Patients may not volunteer the symptom of hallucinations to their physicians due to the fear of being labeled as having a mental disorder. However, in our survey patients were advised that such a symptom may not indicate mental incompetence, hence reducing the stigma of reporting the symptom. Perhaps future research can determine if patients who participate in such a study do volunteer the symptom to physicians subsequently.

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Conflicts of Interest

MLJ: Humanware Scientific Advisory; PW: PW is an employee of PatientsLikeMe and holds stock/options in the company. The PatientsLikeMe R&D team has received research support from: Abbott, Acorda, the AKU Society, AstraZeneca, Avanir, Biogen, Genzyme, Johnson & Johnson, Merck, Novartis, the Robert Wood Johnson Foundation, Sanofi, and UCB.

Multimedia Appendix 1

A screenshot of the PatientsLikeMe online survey distributed to all participants.

[PDF File (Adobe PDF File), 161KB - ijmr_v2i2e30_app1.pdf]

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Abbreviations

CBS: Charles Bonnet Syndrome
CS: Contrast sensitivity
PD: Parkinson’s disease
PLM: PatientsLikeMe
UM-PDHQ: University of Miami Parkinson’s Disease Hallucinations Questionnaire

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Original Paper

Designing Consumer Health Technologies for the Treatment of Patients With Depression: A Health Practitioner's Perspective

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Abstract

Background: The consumer health technologies used by patients on a daily basis can be effectively leveraged to assist them in the treatment of depression. However, because treatment for depression is a collaborative endeavor, it is important to understand health practitioners' perspectives on the benefits, drawbacks, and design of such technologies.

Objective: The objective of this research was to understand how patients and health practitioners can effectively and successfully influence the design of consumer health treatment technologies for treating patients with depression.

Methods: A group of 10 health practitioners participated in individual semistructured contextual interviews at their offices. Health practitioners rated an a priori identified list of depression indicators using a 7-point Likert scale and generated a list of depression indicators. Finally, health practitioners were asked to rate the perceived usefulness of an a priori identified list of depression treatment technologies using a 7-point Likert scale.

Results: Of the 10 health practitioners interviewed, 5 (50%) were mental health practitioners, 3 (30%) nurses, and 2 (20%) general practitioners. A total of 29 unique depression indicators were generated by the health practitioners. These indicators were grouped into 5 high-level categories that were identified by the research team and 2 clinical experts: (1) daily and social functioning, (2) medication, (3) nutrition and physical activity, (4) demographics and environment, and (5) suicidal thoughts. These indicators represent opportunities for designing technologies to support health practitioners who treat patients with depression. The interviews revealed nuances of the different health practitioners' clinical practices and also barriers to using technology to guide the treatment of depression. These barriers included (1) technology that did not fit within the current practice or work infrastructure, (2) technology that would not benefit the current treatment process, (3) patients forgetting to use the technology, and (4) patients not being able to afford the technology.

Conclusions: In order to be successful in the treatment of depression, consumer health treatment technologies must address health practitioners' technology concerns early on in the design phase, account for the various types of health practitioners, treatment methods, and clinical practices, and also strive to seamlessly integrate traditional and nontraditional depression indicators within various health practitioners' clinical practices.

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KEYWORDS

depression; health care providers; technology; user-computer interface

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Introduction

Overview

Depression is a mental illness that affects millions of Americans every year [1]. Both adolescents and adults, spanning almost all ethnic and economic backgrounds, fall into depression. Depression is defined as a mood disturbance characterized by a depressed mood for a duration of 2 weeks or more or loss of interest or pleasure, and at least 4 other symptoms such as a change in functioning such as sleeping and eating habits, energy levels, and self-image [2]. Although the symptoms greatly vary between individuals and can change throughout the duration of depression, depressed individuals typically experience symptoms such as fatigue, feelings of hopelessness and helplessness, change in sleeping patterns, inability to concentrate or make decisions, change in appetite and energy levels, withdrawal, and thoughts of suicide [2].

Individuals affected by depression who seek treatment typically are prescribed medication or undergo in-person psychotherapy sessions with a professional [3]. However, a recent trend is observed among consumers who use online or mobile mental health treatment technologies with the intention of eliminating social stigma [4] and preserving anonymity [5]. Because the treatment of depression, in both online and office settings, is a collaborative effort between the patient and the physician, it becomes important to understand the needs of both. It is also essential to understand the perspective of several types of physicians since patients often receive care from different types of practitioners depending on their needs, established relationships [6], and comfort levels.

Currently, user adoption of consumer health treatment technologies is promising and more researchers are seeking to improve upon existing technologies. Although some researchers have presented guidelines to aid in the development of health technologies [7-9], only a few have incorporated the perspectives of various types of health practitioners. The aim of the present research is to understand how insights from health practitioners who treat depression may possibly inform future designs of consumer health technologies that may be used for treating depression. This study also helps to analyze how current successful patient-empowering treatment plans that are developed by both patient and the physician can translate into future consumer health technologies, as well as to determine how these technologies can be better designed to fit both the needs of the patient and the physician.

In 2009, approximately 6.1 million adults (aged 18 years or older) in the United States reported an unmet need or did not receive care or services for their mental health needs [1]. Unfortunately, many depressed individuals are unaware of the various treatment services available [3]. In the following sections, an overview of these treatment services is provided. The first section focuses on the different types of health practitioners who provide treatment for depression. This section discusses different types of mental health providers and the frequency and characteristics of services offered by them. The second section presents an overview of the technologies that are emerging as potential treatment options for depression.

Types of Mental Health Providers

Most individuals who require treatment for their mental health problems seek help from their family physician or go to nearby emergency facilities [6]. As a result, general practitioners increasingly feel a need to train themselves to assess not only the physical symptoms of patients but also the psychological aspects [10]. Traditionally, nurses and general practitioners are trained to assess the physical aspects of a patient and therefore often overlook any psychological symptoms that may be present [11]. Office visits to medical practitioners tend to be shorter than that to mental health practitioners, and importantly, the diagnosis lacks psychological content [12]. Most nurses and general practitioners refer patients with depression to mental health practitioners. At the point of referral, patients' medical and physical symptoms are assessed and reviewed, so the mental health practitioner can review the physical symptoms and concentrate on the psychological aspect of depression. Mental health practitioners spend their initial therapy sessions by engaging in get-to-know-you sessions with the patients [13]. These sessions are often longer than the usual standard office visits with medical practitioners, involve questioning related to everyday responsibilities and challenges, and focus more on understanding the events and causes that led to the patient's depression [14]. After these in-depth sessions, mental health providers can build rapport with patients and acquire information that patients are usually not comfortable sharing. The longer sessions with mental health practitioners are ideal for facilitating recovery from depression [15].

Emerging Technologies for the Treatment of Depression

In the recent years, many technologies have been developed to help track and understand the physical and psychological aspects of mental illness. Some of them help assess severity [16] and sometimes aid in the treatment of depression [17-21]. Some technologies monitor specific symptoms of depression such as mood and behavior changes [22-24], quality and quantity of sleep [25-27], eating habits [28], and physical activity [29]. Many of these technologies, especially online treatment applications, enjoy positive patient adoption and provide satisfactory solutions [30,31]. Many patients opt to use such technologies so that they can remain anonymous, thus avoiding the stigma and embarrassment that they have to endure while seeking treatment from a traditional behavioral health center [5]. These technologies also allow individuals to seek treatment from the comfort of their home [32] and avoid what could be costly in-person treatment and services [33].

Although many of these health technologies have been adopted by patients independently, a few mental health technologies have been successfully influenced by clinicians. These technologies are not employed with the assistance or presence of a mental health or medical practitioner, or not integrated within the treatment plan. However, if the technologies are to be included as part of the overall therapy plan, the needs and perspectives of the health practitioners who treat depression must be understood.

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Aims of the Study

Information gathering and context-sensitive technologies hold a great potential for making depression treatment more effective. However, prior research has focused almost exclusively on technology development, and to a lesser extent on patient's perspectives on technology adoption outside of the clinical setting. Only a few studies focus on understanding the clinicians' perspectives with respect to treating depression [34-36], and even fewer studies examine the differences in needs and practices between health practitioner types [37,38]. This paper presents results from a study examining how various clinical styles of treating depression can potentially inform the design of useful patient-empowering consumer health treatment technologies.

Methods

General Method

The qualitative contextual interview method [39] was chosen to examine the current method of treatment of individuals suffering from behavioral health issues and to gain feedback about potential technologies that may be integrated to a treatment regime. The main reason for choosing the contextual interview method is because health practitioners' perceptions, in particular differences in perceptions between health practitioner types, have not been systematically studied. In this study, we used qualitative inquiry to gather the local vocabulary and practices of the 3 health practitioner types: 3 nurses, 2 general practitioners, and 5 mental health practitioners. In addition, as we were interested in understanding the differences between health practitioner types, it was important to limit this investigation to the study of participants from within a single organization and region to the standardize organizational culture and treatment population. Those nuances would be hard to tease out and isolate using a study method such as a questionnaire that is targeted at a larger population, but are particularly sensitive to qualitative inquiry.

Participants

A group of 10 health practitioners, including 3 (30%) nurses, 2 (20%) general practitioners, and 5 (50%) mental health practitioners volunteered to be part of this study. Hereafter, nurses and general practitioners will be referred to as medical practitioners. Mental health practitioners are defined as professionals who specialize in treating behavioral disorders. The age of health practitioners participating in the study varied between 29 and 61 years (mean 42.50, SD 10.98), and they had been practicing on an average for 10 years (mean 9.65, SD 7.08). Across all clinician types, the study participants reported that more than half (52.5%) of their patients suffered from depression. Clinicians reported using computers, the Internet, various rating scales, feedback systems, and intake assessments during the course of their work. Technologies used outside of the work included computers, the Internet, and smartphones. Prior to clinician recruitment for the study, institutional review board (IRB) approval was obtained from the Centerstone Research Institute IRB and was also reciprocally given by the Indiana University IRB.

Procedure

Individual semistructured contextual interviews with each of the 10 study participants were conducted at their offices. Each interview lasted approximately 30 minutes. The interview focused on understanding the clinician's perception of indicators related to patients' depression status, and feedback was elicited on types of technology that could possibly be helpful in treating depression. The goal of the interviews was to understand clinicians' actual practices rather than what they were "supposed" to do as indicated by training or organizational protocol. The authors defined indicators as the type of patient information that can be used to help treat depression. The first section of the interview focused on understanding current clinician practices in treating patients with depression. The second section of the interview focused on identifying the type of patient information clinicians would obtain from patients if it were possible to do so. Finally, clinicians were presented with technology concepts and asked to rate them in terms of perceived usefulness. Participants did not receive monetary remuneration for their participation in the study but were thanked for their participation.

Daily Indicators

The first section of the interview focused on understanding current clinician practices for treating depression. This section consisted of 6 open-ended questions that were posed to health practitioners with a view of understanding the most relevant symptoms reported by patients and the type of patient information currently used in treating depression. Health practitioners were asked to rate their responses based on overall effectiveness in treating depression using a 7-point Likert-type scale. Following this rating, health practitioners were provided with a predetermined list of indicators by the research team. The list of indicators was compiled in collaboration with a team of clinical researchers and included suicidal ideation, sleep quality and quantity, social interactions, ability to focus, physical activity, service reimbursement method, and astrological sign. Participants were asked to rate the indicators based on overall effectiveness in treating depression. Responses were again rated using a 7-point Likert-type scale. The authors believed that collecting information on the bases of indicators would lead to insights, which in turn could be used to develop useful consumer health technologies.

Technology Concepts

The goal of the second section of the interview was to gather health practitioners' perceptions of the types of patient information health practitioners would be able to gain if a technology existed to enable them to collect and access this information. Participants were presented with 5 technology concepts and were asked to rate them in terms of perceived usefulness using a 7-point Likert scale. The technology concepts were gathered in collaboration with a team of clinical researchers and focused on covering a range of depression symptoms and feasible technologies. The technology concepts consisted of collecting information about patients' home cleanliness, physical activity, social interactions, nutrition, and life space (movement in and outside of the home) (Table 1).

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Table 1. Overview of technology concepts.

Technology concept	Motivation for depression	Implementation
Physical activity: Allows patients to track their physical activity levels and provide summary information to clinicians.	Individuals who are depressed typically show decreased physical activity [2]. Both clinicians and patients can be benefitted by understanding how the depression is affecting the physical activity level. Such information can be used in devising a treatment plan.	Several free and low-cost physical activity tracking applications are currently available on the Web and mobile devices. Pedometers are also popular low-cost devices used by individuals of all ages. Using already popular consumer-based health devices decreases the chance of having a stigma associated with using the devices.
Nutrition: Allows patients to track their nutrition intake and eating habits and provides summary information to clinicians.	Individuals with depression are known to have a decrease in appetite [2] and run the risk of becoming malnourished. If information regarding one's nutrition level was observed early and often, clinicians could design treatment plans that can prevent such incidents.	Currently, several online and mobile consumer health applications that focus on capturing one's nutrition levels are present. Previous research has also shown successful implementation and adoption of consumer health devices that are designed to track nutrition levels [40].
LifeSpace: Records patients' movement in and outside of their home and would provide clinicians with summary data about the locations where participants spend time.	Individuals with depression often have a change in their mood and behavior [2], a decrease in mobility, and a change in their typical routine in and around the home. It has been shown that one's ability to be mobile correlates directly with one's overall health and mental status [41]. Being able to track these changes allows patients to observe how the depression is affecting their daily life and afford them the opportunity to make a change in their current coping mechanisms.	To implement a consumer health technology that can track one's behavior and movement inside the home, video cameras or motion sensors can be installed around the home. To track movement outside of the home, one of the many several mobile global positioning system applications can be used.
Social Interactions: Measures the number of social interactions a patient has, the number of people with whom he or she interacts, and the amount of time spent with each individual.	Depressed individuals often display some type of social withdrawal and even long periods of social isolation [2]. Having technology that can track one's social activity level can potentially detect negative trends in one's social activity level early on. Information such as this can potentially help individuals with depression seek intervention in a timely manner.	Technology such as Bluetooth and audio recognition could be utilized in a consumer health technology. Bluetooth technology detects Bluetooth-enabled devices in close proximity of the device of the patient with depression. This gives some information of the number of people who are possibly around the individual with depression. Additionally, one could utilize a microphone to pick up any audio frequency to determine if the individual with depression is engaged in any social activities or conversations.
Cleanliness (as an indicator of personal and household daily care): Allows patients to monitor their personal and household upkeep to understand a positive or negative change within their typical home routine.	Individuals with depression often display a change in their typical routine and behavior [2]. This can lead to a decrease in one's ability to maintain a positive sense of self and complete personal responsibilities in and around the home. If patients are able to track their ability to maintain their typical home routine, they can better understand how depression is affecting their home life and get any help they may need early on.	To implement a consumer health technology that can track an individual's ability to complete personal responsibilities in and around the home, one can potentially utilize a video-monitoring device. For example, the device could capture samples of the patient's home and then automatically analyze these samples to detect changes in the environment.

Data Collection and Preparation

All interviews were audio recorded that took place at health practitioner offices. A member of the research team also took notes during each interview. Interviews were transcribed verbatim and then transcriptions were analyzed.

Results

Overview

The following section first presents quantitative results related to the indicators that health practitioners generated independently followed by the results of the health practitioner ratings to a set of a priori identified treatment indicators. Next, the results of health practitioner ratings of a priori identified technology concepts are presented. In the discussion section, the design implications related to each of these results are discussed.

Health Practitioner-Generated Indicators

To get a complete understanding that is not limited by current clinical practice and guidelines, health practitioners were asked to generate a list of indicators that would be useful for treating depression. From this exercise, a total of 29 unique indicators were identified. These indicators were grouped into 7 high-level categories identified by the first 3 authors. The groupings were arrived at by consensus. Labels such as daily and social functioning, demographics and environment, medication, nutrition and health, and suicidal tendency were assigned to each category. Subsequently, 2 clinical experts from the research

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team were asked to label 29 unique indicators with one of the 7 high-level categories, or "other" with an associated description for what the "other" should be. This labeling activity reduced the number of categories to 5, in which daily status and social functioning were grouped into one category and demographics and environment into another. Based on the clinical experts' labeling, 3 of the indicators were also moved from one category to another. The final 5 categories are shown in Table 2. For the purposes of the following analysis, nurses and general practitioners were combined into a medical practitioner group, resulting in 5 practitioners each in both the medical practitioner group and the mental health practitioner group.

Table 2 shows the indicators that the health practitioners believed would be helpful in guiding depression treatment. All of the health practitioners were interested in knowing more about patients' daily and social functioning. Within the daily and social functioning category, medical practitioners generated items that were associated with the patient's family and friends' perspective on helping to treat depression, whereas the mental health practitioners generated items relating to patients' support systems and social interactions. A larger percentage of mental health practitioners were particularly interested in medication used by the patients and their demographics and environment than were medical practitioners. Mental health professionals were also the only health practitioner type interested in patients' suicidal risk. Medical and mental health practitioners were similarly interested in patients' medication use, but more medical practitioners in the study group were interested in patients' nutrition and physical activity levels than the mental health practitioners. Especially within the nutrition and physical activity category, medical practitioners were interested in the patients' eating habits, whereas mental health practitioners were interested in the typical daily movement of the patients. Overall, health practitioners stated that patients' changes in behavior would be less helpful in guiding treatment for depression.

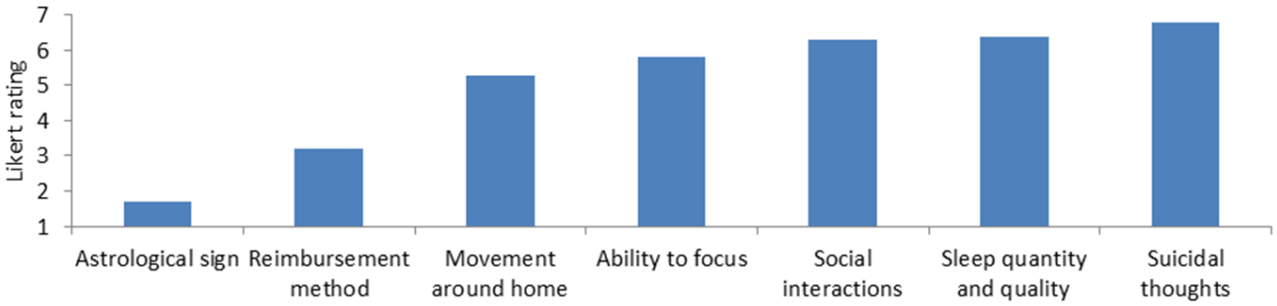
Table 2. Clinician-generated indicators.

Indicator	Total mental health practitioner (N=5) n (%)	Total medical practitioner (N=5) n (%)	Total clinicians (N=10) n (%)
Daily and social functioning	5 (100)	5 (100)	10 (100)
Medication	2 (40)	2 (40)	4 (40)
Nutrition and physical activity	2 (40)	3 (60)	5 (50)
Demographics and environment	2 (40)	2 (40)	4 (40)
Suicidal tendency	3 (60)	0 (0)	3 (30)

A Priori Identified Treatment Indicators

To ensure cross-health practitioner type comparisons, depression indicators were identified by examining the literature associated with depression treatment and by collaborating with clinical experts. The indicators thus identified were chosen to represent a range of potential usefulness (eg, sleep was thought to be highly relevant, whereas astrological sign was thought to be irrelevant). To understand the level of usefulness of indicators, the Likert ratings that the clinicians provided for each of the 7 indicators were examined. Overall, clinicians believed that information concerning patient's quantity and quality of sleep (mean 6.50, SD 0.71) and self-report of suicidal ideation (mean 6.80, SD 0.42) would be helpful in treating depression. Clinicians were less interested in using reimbursement method or astrological sign as essential information to treat depression (Figure 1).

Figure 1. Perceived usefulness of indicators in guiding treatment.



Technology Concepts

Table 3 shows health practitioners' perceptions of the types of patient information that they could obtain if a technology existed to enable them to collect and access such information. In this section, general practitioners and nurses are not combined. Overall, tracking patients' physical activity and social interactions were rated the highest by the health practitioners (numerically). In particular, general practitioners were very, interested (mean 7.00 and 6.50 and SD 0.00 and 0.71, respectively) in having a technology that allowed them to understand their depressed patients' physical activities and

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social interactions. Health practitioners were interested in using a technology to track the nutrition status and cleanliness of the patients. General practitioners rated these technologies higher overall than either the mental health providers or the nurses. LifeSpace was rated as having the lowest utility overall, but had the greatest variability among ratings. Notably, nurses disagreed that the LifeSpace technology concept would be helpful to them in their practice (as this was the only technology that was rated unfavorable by any group); however, general practitioners strongly agreed that the LifeSpace technology concept would be helpful in their practice. The next section discusses these two sets of findings in the context of our qualitative results and uses them to suggest design opportunities.

Table 3. Mean rating of technology concepts (1=strongly disagree, 7=strongly agree).

Technology concept	Mental health practitioners (n=5) Mean (SD)	General practitioners (n=2) Mean (SD)	Nurses (n=3) Mean (SD)	Overall mean (N=10) Mean (SD)
Physical activities	5.40 (2.51)	7.00 (0.00)	5.30 (0.58)	4.80 (1.62)
Social interactions	5.40 (2.61)	6.50 (0.71)	5.00 (0.00)	4.50 (2.51)
Nutrition	5.00 (2.35)	6.00 (1.41)	4.00 (2.65)	5.70 (1.83)
Cleanliness	4.40 (1.95)	5.50 (0.71)	5.00 (1.73)	4.90 (2.18)
LifeSpace	4.60 (2.88)	6.50 (0.71)	3.00 (2.00)	5.50 (1.84)

Design Opportunities for Health Practitioners to Treat Patients With Depression

Overview

Interview discussions and health practitioner ratings of the list of a priori identified technology concepts clearly indicated that the health practitioners were favorable to using technology to help treat depression (Table 3). Health practitioners also expressed an interest in having technology that could assist in patient data collection.

> *So that's why I encourage them to write things down, because they don't have the information to bring to me, and if they could understand how to use technology and gather the information, then I think that would be great.* [General practitioner 8]

These findings suggest that there is an unexplored design space for creating technologies that can assist health practitioners who treat patients with depression. Particularly, 2 design opportunities are available: (1) designing technologies to help health practitioners collect accurate and real-time data about patients' depression status and (2) designing technologies to help health practitioners interpret and incorporate nontraditional depression symptoms in their current treatment methods.

Design Opportunity 1: Designing Technologies to Help Health Practitioners Collect Accurate and Consistent Data

Treating depression can be difficult because the severity of the condition is mostly based on the perceptions of the patient and the clinician. Currently, patients provide information through their interaction with the health practitioners during office visits and through information that is recorded in their journals. These journals are often incomplete and do not provide the health practitioner with information recorded on a daily basis. When the health practitioners were asked to generate an indicator list that would be helpful in guiding the treatment of depression, many of the health practitioners listed patients' daily and social functioning activities (Table 2). This was also reflected throughout the interviews with the health practitioners.

> *A level of functioning [would be helpful in guiding the treatment of depression].* [Mental health practitioner 3]

> *[I would like to know] how they're acting, whether it's a normal thing for them, or whether it's a new change, or a sudden change, or a gradual change....* [Nurse 4]

> *And during the day, several times of, kind of a mental pulse taking, how are they doing, how are they facing life, how are their emotions, basically, during that day.* [Nurse 5]

Health practitioners rely on patient self-report to accurately assess the patient's condition and develop treatment plans. Consumer health technology has a great potential to help health practitioners collect accurate data on an ongoing basis that can be used to help treat depression.

Design Opportunity 2: Designing Technologies to Help Health Practitioners Use Nontraditional Depression Indicators

Typical depression indicators include depressed mood, loss of interest or pleasure, irregular sleeping and eating habits, and behavioral changes. However, when health practitioners were asked to generate a list of indicators that would be helpful in guiding depression treatment, many of the health practitioners suggested nontraditional indicators (Table 2) and strongly believed that overall patients' changes in behavior would be less helpful in guiding depression treatment. The generated list and interviews revealed that medical practitioners were interested in using atypical indicators such as the perspective of the family and friends of the patients to help guide treatment of depression.

> *someone else's objective observations of the patient's symptoms [would help guide treatment].* [Nurse 4]

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> *...perception of those with whom the patient lives or works [would help guide treatment].* [General practitioner 9]

The mental health practitioners also listed and pointed to an interest in using nontraditional indicators to help practitioners with a guide to the treatment of depression. Mental health practitioners were very interested in obtaining more information pertaining to patients' medical and medication records.

> *[I would like to know more about] all the medications they are on. All the medications they have tried, whether they have worked or not.* [Mental health practitioner 7]

> *Certain symptoms or side effects of medication can be important, some medications can really raise heart rate or blood pressure and having those data if not daily, then at least 2 or 3 times a week, can be really important data.* [General practitioner 9]

Since health practitioners were interested in incorporating other indicators within their current treatment methods. Consumer health technology could help health practitioners collect and interpret nontraditional indicators that will provide a more accurate depiction of patients' depression status.

Barriers to the Use of Technology in Depression Treatment

Overview

Although health practitioners expressed an interest in technologies, they also expressed concerns about several potential barriers to using technology to help treat depression. These concerns should be taken into consideration when designing consumer health technologies to assist health practitioners in treating patients with depression.

For example, while health practitioners were in favor of incorporating technology in their practice, many were skeptical of how it could be implemented within their current work infrastructure:

> *I think patients would like [using technology], but I would really see that being problematic with [our company] because we just don't have the staff to be able to do that, number one, and we don't have the hardware to be able to do that, number two. We're kind of low tech here.* [Nurse 4]

Design Implication 1

Consumer health technology should enhance the treatment process but not make it more cumbersome for the patient or the health practitioner.

Some health practitioners were concerned that technology would interfere with the treatment process. However, many health practitioners tried to actively involve their patients in the treatment process by asking them to track specific information concerning their depression. This act of collecting data within the data that is already available provides insight into the patients' motivation levels:

> *Part of the treatment is what they don't remember, as much as what they do.* [Mental health practitioner 1]

Indeed, some health practitioners felt that technology would hinder this process and would not allow for active patient participation:

> *Does this take away from the actual patient doing something?* [Nurse 6]

Design Implication 2

Consumer health technology should not remove patients' involvement in data collection and reflection opportunities that are important clinical indicators of patients' depression status.

At the same time, health practitioners were concerned that patients' adoption would be low because patients were prone to forgetting to use the tool provided. In particular, patients already have difficulty remembering things and thus do not complete the current treatment activities that are assigned by the clinicians:

> *A lot of their memory is so horrible they can't remember when their first episode of depression or when their first hospitalization was.* [Mental health practitioner 7]

> *Memory impairment is a common feature of, especially certain types of, mood disorder. A lot of times people report they can't store memory well or recall well.* [General practitioner 9]

Design Implication 3

To compensate for memory impairment, consumer health technology should initiate use and encourage patients to complete the proscribed treatment task.

In addition, there are some types of data that could provide health practitioners with a better understanding of their patient's current mental health, to which health practitioners currently cannot always have access. For example, some health practitioners desired to obtain specific information about patients' medication use and side effects.

> *[I would like to know more about] all the medications they are on. All the medications they have tried, and whether they have worked or not.* [Mental health practitioner 7]

> *[I would like to know] are they taking their medication?* [General practitioner 8]

While patients may report on their subjective perception of the impact of medication, technology could provide objective data about medication quality that allow the health practitioner to determine if side effects from various medications could be contributing to their patients' depression.

While this type of data could automatically be collected by using technology, the second design implication is important and must be considered.

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Design Implication 4

Consumer health technology could be used to automatically collect data that would provide a more complete picture of the patient's status to health practitioners, yet there must be a balance between automatic data collection and manual tracking to keep patients actively involved in the treatment process.

Finally, while health practitioners felt that patients would be able to use the technology, they noted that its cost may be prohibitive with their patient population:

> *Some of them wish they had better access to technologies. Some of them know a lot more about their technology than I do...they don't have the money for technology.* [Mental health practitioner 7]

Design Implication 5

Whenever possible, use the technologies that patients already own, or use low-cost, commonly available commercial technologies.

Existing Diagnostic and Treatment Paradigms Suggested by Health Practitioners' Practices

Previous and Current Treatment Indicators

According to the Diagnostic and Statistical Manual of Mental Disorders IV-TR (DSM IV-TR), the primary symptoms that are required for a depression diagnosis are (1) depressed mood and/or (2) markedly diminished interest in activities or loss of pleasure for an extended period of time (days/weeks). Other symptoms such as sleep quality, social interactions, and inability to focus are also typical indicators of depression. Because health practitioners historically used these indicators to diagnose and treat depression, it was not surprising that these indicators were seen as better indicators of depression when we arrived at our quantitative data. However, when we asked health practitioners to describe their current treatment practices in their own words during the interview, differences in practices across health practitioner types emerged. For example, medical practitioners (nurses and general practitioners) tended to report relying on patients' physical symptoms, overall health, medication use, and financial health:

> *Well I'll need to know their past medical history, any medications that they take, their social history including their home state, married versus single, with whom do they live, parents, and do they have children? [Also their] occupation, history of drug and alcohol use, smoking. We usually want to know [their] family history.* [General practitioner 9]

> *I always ask my patients about their social economic status, their finances, social support, how they're doing with nutrition. I want to know what exactly they do to alleviate symptoms. I also want to know how they medicate themselves and treat themselves...if they're doing any supplements and drug use...I also want to know about any outside sources of help that they may have, church organizations, outside support groups.* [Nurse 6]

In contrast, mental health practitioners tended to use a less medical-centric, more client-feeling-centered approach to treatment:

> *I practice a very client-centered approach to treatment, so I'm going start where the client is. Primary for me is how the person is feeling and doing.* [Mental health practitioner 1]

> *We just make sure we take some time to assess what the client feels their strengths are or their parent or whoever their collateral support is gathering their strengths and so those are identified from the very beginning and carried out through their treatment so that we can maximize on those if needed.* [Mental health practitioner 2]

Mental health practitioners described taking advantage of the time they have with patients (multiple 30-minute to 1-hour-long sessions) to get a deep insight into their unique situations and find treatment plans tailored to them, whereas medical practitioners' approach focused on medical history and current medical status. These qualitative differences suggest the way in which each type of health practitioners deals with patients. While these differences are not surprising given health practitioners' different goals, training, and resources (eg, medical practitioners have been trained in a medical model), it is worth noting that these differences were not apparent in the quantitative results, though they were apparent in the list of health practitioner-generated indicators (see Table 2). One of the strengths of the mixed-methods approach adopted in this study is the ability to more fully understand and explain quantitative results. In this case, no differences were observed in the ratings that health practitioners gave to a set of a priori identified indicators. However, health practitioners reported differences in using these indicators in practice.

Design Implication 6

Technology designs should take into account the type of health practitioner who will use it, so that the technology fits with current clinical needs and practices recognizing that these practices may differ by the type of health practitioner.

As an example of how this design implication would play out in practice, one could imagine creating different versions of technology support for different types of health practitioners. For example, the technology mode designed for medical practitioners could focus on enabling an understanding of patients' emotional levels and family and friends' perspective as well as patient information relating to nutrition and physical activities, while a technology mode designed for mental health practitioners should focus on enabling clients' reflections related to their own strengths, or client-specific symptoms (eg, sexual interactions).

Notably, both types of technology described above focus on indicators not considered as typical indicators of depression in the existing treatment paradigm. Instead, health practitioners often discussed other indicators that they used during treatment that were broader than the indicators outlined in current treatment theories. Thus, current theories of depression treatment need to be extended, adapted, or supplemented to account for

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varying practices of health practitioners as well as additional indicators health practitioners use during treatment. Also, while health practitioners of all types understand the value of a range of indicators (standard and nonstandard), a gap can be felt when it comes to using those indicators in their practice.

Design Implication 7

Consumer health technology designs could help bridge the gap between theory and practice by assisting health practitioners in collecting, interpreting, and integrating nonstandard, patient-centered depression indicators, and understanding how these additional variables affect recovery.

Discussion

Principal Findings

The present study provided several insights from health practitioners that can inform the design of novel consumer health depression treatment technologies. In general, health practitioners expressed an interest in using technology to help treat depression but had concerns about their adoption by patients with depression. To successfully create consumer health treatment technologies for depression, these concerns must be addressed early on during the design phase. Health practitioners' training backgrounds also differed and each health practitioner type relied on different indicators to treat depression. Flexible technologies that can accommodate these differences should be created. Finally, health practitioners reported using additional indicators that are not explicitly outlined in the DSM IV-TR to treat depression. To translate depression treatment theory into practice, technology should help health practitioners successfully integrate traditional and nontraditional indicators within their treatment methods.

This paper presented design opportunities and challenges in designing depression treatment technologies. However, the current study was limited to a small number of health practitioners. While we are confident in our findings related to the existence of differences across health practitioner types, interviews with additional health practitioners are needed to gain a more accurate perspective of the needs and practices of each health practitioner type. In addition, health practitioners' perspectives represent only one aspect of the treatment whereas patients represent the other aspect. We plan to incorporate patients' perspectives of technology through field studies and observations in the near future to evolve a set of guidelines into a framework that can aid in the design of consumer health depression treatment technologies.

Conclusions

This study examined various treatment styles of two categories of health practitioners as they relate to treating depression. The study also helped gather perspectives of different health practitioners on using consumer health technology to help guide the treatment of depression. The health practitioners were found favorable to using technology to help guide depression treatment but had concerns about its actual implementation. Based on these concerns, several design implications that can be used to help health practitioners feel more comfortable with using technology to treat depression were identified. In addition, the differences within each health practitioner's clinical practice and treatment methods were also observed. Each type of health practitioner has a unique treatment method and relies on different depression indicators to guide treatment of depression. Technology should reflect these differences and be flexible enough to accommodate each health practitioner's training background and clinical practices. Because health practitioners reported using additional indicators that were not outlined in the DSM IV-TR, technology should also strive to help various types of health practitioners understand, interpret, and integrate depression indicators within their current treatment methods. The findings in this study highlight design opportunities and provide an understanding of how both patients and health practitioners can effectively and successfully influence the design of consumer health technologies for the treatment of depression.

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Conflicts of Interest

None declared.

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Abbreviations

DSM IV-TR: Diagnostic and Statistical Manual of Mental Disorders IV-TR

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Original Paper

Health Literacy Association With Health Behaviors and Health Care Utilization in Multiple Sclerosis: A Cross-Sectional Study

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Abstract

Background: Low health literacy is generally associated with poor health outcomes; however, health literacy has received little attention in multiple sclerosis (MS).

Objective: The aim of this study was to investigate the health literacy of persons with MS using the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry.

Methods: In 2012, we conducted a cross-sectional study of health literacy among NARCOMS participants. Respondents completed the Medical Term Recognition Test (METER) which assesses the ability to distinguish medical and nonmedical words, and the Newest Vital Sign (NVS) instrument which evaluates reading, interpretation, and numeracy skills. Respondents reported their sociodemographic characteristics, health behaviors, comorbidities, visits to the emergency room (ER), and hospitalizations in the last 6 months. We used logistic regression to evaluate the characteristics associated with functional literacy, and the association between functional literacy and health care utilization.

Results: Of 13,020 eligible participants, 8934 (68.6%) completed the questionnaire and were US residents. Most of them performed well on the instruments with 81.04% (7066/8719) having functional literacy on the METER and 74.62% (6666/8933) having adequate literacy on the NVS. Low literacy on the METER or the NVS was associated with smoking, being overweight or obese (all $P<.001$). After adjustment, low literacy on the METER was associated with ER visits (OR 1.28, 95% CI 1.10-1.48) and hospitalizations (OR 1.19, 95% CI 0.98-1.44). Findings were similar for the NVS.

Conclusions: In the NARCOMS cohort, functional health literacy is high. However, lower levels of health literacy are associated with adverse health behaviors and greater health care utilization.

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KEYWORDS

multiple sclerosis; health literacy; health care utilization; comorbidity; health behaviors

Introduction

The elements of general literacy include the knowledge and skills to comprehend and use written information, to locate and use information captured in documents such as maps, and numeracy. Health literacy builds on these concepts [1], and refers to the capacity of individuals to gather, process, and comprehend the basic health information and services needed to support health-related decision making. Individuals need to be able to understand written health information and to communicate verbally about health, so that they can make decisions about health promotion, health protection, disease

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prevention, health care maintenance, and to navigate the health care system [2].

A growing literature suggests that lower health literacy is associated with higher rates of health care utilization and mortality, lower rates of health promoting activities, lower adherence to therapy and less successful disease control [1,3-7]. Despite this recognition in other populations, and the frequent interactions with the health system required by affected people [8,9], the issue of health literacy has received little attention in multiple sclerosis (MS) population [10].

We aimed to investigate the health literacy of persons with MS in a sociodemographically diverse population from the United States, and to estimate the associations between health literacy and health behaviors, comorbidities, and health care utilization. We hypothesized that lower health literacy would be associated with a higher frequency of smoking, obesity, and greater health care utilization.

Methods

North American Research Committee on Multiple Sclerosis Registry

The North American Research Committee on Multiple Sclerosis (NARCOMS) Registry is a voluntary self-report registry for people with MS, developed by the Consortium of MS Centers [11]. We have validated diagnoses of MS in a randomly selected sample of participants [12]. NARCOMS participants agree to the use of their de-identified data for research purposes, and the Registry is approved by the Institutional Review Board at the University of Alabama at Birmingham.

Participants may enroll by completing a questionnaire online, or by mailing in a questionnaire [11]. After enrollment, participants are asked to complete surveys semi-annually, on paper or online per their preference. On each survey participants report sociodemographic and clinical information, including disability status using Patient Determined Disease Steps (PDDS) and Performance Scales (PS) [13,14]. The PDDS is a validated measure which correlates highly with a physician-scored Expanded Disability Status Scale (EDSS) [13,15]. It is scored ordinally from 0 to 8, where a score of 0 approximates an EDSS score of 0, a score of 3 represents early gait disability without needing an assistive device and approximates an EDSS score of 4.0 to 4.5; and scores of 4, 5, and 6 represent EDSS scores of 6.0 to 6.5. PS uses a single question to assess eight domains, including mobility, bowel/bladder, fatigue, sensory, vision, cognition, spasticity, and hand [14]. All of the subscales are scored as follows: 0 (normal), 1 (minimal), 2 (mild), 3 (moderate), 4 (severe), or 5 (total disability), except mobility which is scored from 0 to 6. The cognition subscale correlates strongly with the Perceived Deficits Questionnaire (r=.71, P<.001) [13], a 20-item self-reported questionnaire for cognition incorporated in the Multiple Sclerosis Quality of Life Inventory [16]. Construct validity of the cognitive subscale is supported by moderate correlations (r=.70, P<.001) with the Modified Fatigue Impact Scale (convergent validity) but not with age (r=.11, P=.46, divergent validity) [13].

Participants report the presence or absence of specific comorbidities using the following question format “Has a doctor ever told you that you have…?”[17]. We have previously shown the validity of our self-reported comorbidity questionnaire [18]. Based on our prior work, the comorbidities of interest were diabetes, hypertension, hyperlipidemia, heart disease, migraine, irritable bowel syndrome, chronic lung disease, cancer, obstructive sleep apnea, autoimmune thyroid disease, depression, and anxiety [19,20].

Current smoking status is assessed using a validated question from the Behavioral Risk Factor Surveillance System, and reported as none, some days or every day [21]. We assess the frequency of alcohol intake in the prior 6 months with the first question from the AUDIT-C, a screening instrument developed to identify persons with recent heavy drinking and alcohol dependence [22]. Responses are never, monthly or less, two to four times a month, three to four times a week, and four or more times a week. Body mass index (BMI) is calculated from self-reported height and weight. Overweight is defined as BMI≥25 and BMI<30, and obesity as BMI≥30 [23].

With respect to health care utilization in the last 6 months, participants report whether they had any visits to an emergency room (ER), and whether they were hospitalized overnight.

Health Literacy

We asked NARCOMS participants about health literacy in 2012. Multiple generic health literacy instruments have been developed [24]. We selected three instruments validated in other populations based on several considerations. First, no instrument fully captures the construct of health literacy as defined by a person’s ability to seek, understand, and use health information [24]; thus multiple instruments were needed. Second, we selected instruments that were brief and easy to administer to minimize participant burden. We used the eHealth Literacy Scale (eHEALS) which includes eight items that assess the knowledge, comfort and perceived skills of persons completing the scale, who are seeking and using electronic health information to address health concerns. It also includes two optional questions designed to assess the participant’s interest in using e-health tools. The instrument was developed based on social cognitive and self-efficacy theory. It has been validated and showed good internal consistency (alpha=.88) and test-retest reliability [25].

The Medical Term Recognition Test (METER) is a brief, self-administered questionnaire that was developed to address other instruments’ limitations such as excessive length, or the requirement that a practitioner administers the tool. The METER is composed of 40 medical words and 30 nonwords [26]. The respondent is asked to mark the words they recognize as actual words, and the METER is scored as the number of correctly identified words minus the number of incorrectly identified words. According to the developers, the format of the instrument was based on tests such as the Author Recognition Test and other similar tests which correlate highly with measures of vocabulary, reading comprehension, and verbal fluency. Scores of 0-20 indicate low literacy, 21-34 indicate marginal literacy, and 35-40 indicate functional literacy. The instrument has high internal consistency (alpha=.93), which correlates highly with

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the Rapid Estimate of Adult Literacy in Medicine (REALM) questionnaire (r=.74), an interviewer-administered measure of literacy, and is associated with cardiovascular health.

The Newest Vital Sign (NVS) Instrument is a nutrition label from an ice cream container that is accompanied by six questions aimed to test reading, interpretation, and numeracy skills [27]. For example one question asks how many calories would be consumed if an entire container were eaten, while another asks whether it is safe for a person with peanut allergy to eat the ice cream. One point is scored for each correct answer. Scores from 0-1 suggest a high likelihood of marginal or inadequate literacy; 2-3 suggest possible marginal or inadequate literacy, while scores of 4-6 indicate adequate literacy. The NVS requires about three minutes for administration. Scores of less than 4 suggest low health literacy. The internal consistency of the instrument is good (alpha=.76), and it has good criterion validity as compared to the Test of Functional Health Literacy in Adults (TOFLHA).

Analysis

We restricted our analysis to NARCOMS participants living in the United States. Missing responses were not imputed. Performance on each of the instruments was scored as described above.

Given that the three instruments used to assess health literacy have not been used in the MS population previously, we also report the internal consistency for the two multi-item instruments (NVS, eHEALS) as measured using Cronbach's alpha [28]. We summarized categorical variables using frequency (percent [%]), and continuous variables using mean (standard deviation [SD]) or median (interquartile range [IQR]) as appropriate.

After categorizing the scores for the METER and NVS as described above, we estimated the associations between health literacy and health behaviors, comorbidity, and health care utilization. Health behaviors included current smoking (yes vs no), overweight or obesity versus normal weight, any alcohol intake (yes vs no). Comorbidity was evaluated as any comorbidity versus no comorbidity, and as the number of comorbidities. Health care utilization included ER visits (yes vs no) and hospitalizations (yes vs no). Univariate analyses employed chi-square tests.

Multivariable analyses employed binary logistic regression. For these analyses we dichotomized the METER at the cutpoint for functional literacy (≤34 [low literacy] vs >35 [functional literacy]), and the NVS at the cutpoint for adequate literacy (<4 [low literacy] vs ≥4 [adequate literacy]). First we evaluated the association between participant characteristics and having functional/adequate literacy. We constructed separate models for the METER and the NVS. Second, we separately modeled the association of health literacy with the outcomes of any ER visits and any hospitalizations. The independent variables considered for each regression model are described below.

Covariates

For gender, female was the reference category. Race was categorized as white (reference group), and nonwhite. Education was included as indicator variables for high school diploma or less (reference group), Associate's Degree or Technical Degree, Bachelor's Degree, and post-graduate degree. Annual household income was included as indicator variables for <$15,000 (reference group), $15,000-29,999, $30,000-49,999, $50,000-100,000, and >$100,000, or declined to answer. Insurance status was included as indicator variables for private, public only (reference group), or none. Age was categorized as ≤35 (reference group), >35 to ≤50, >50 to ≤65, and >65 years. Using PDDS, participants were classified as having mild (0-2), moderate (3-4), or severe (5-8, reference group) disability [29]. Using PS cognition subscale, participants were classified as having normal (0, reference group), mildly impaired (1-2), or moderately to severely (3-5) impaired cognition.

Assumptions of models were tested using standard methods [30]. For each logistic regression model we used adjusted odds ratios (OR) and 95% confidence intervals (CI) as measures of association. We report a c-statistic as a measure of discriminating ability (estimate of area under the curve) and the Hosmer Lemeshow test as a measure of goodness of fit. Analyses were performed using SAS V9.2 (SAS Institute Inc, Cary, NC).

Results

Respondents

Of 13,020 eligible participants, 9019 (69.27%) completed the spring 2012 questionnaire. As compared to responders, nonresponders were more likely to be nonwhite (P<.001), to have a lower level of education (P<.001) and lower annual income (P=.007). They did not differ with respect to gender. Nonresponders were slightly younger (mean 53.70, SD 11.69) than responders (mean 57.02, SD 10.39, P<.001). Mean age at onset of MS symptoms was also younger in nonresponders (mean 30.12, SD 9.99) than responders (mean 30.97, SD 10.04, P<.001), but the difference of less than a year is unlikely to be clinically relevant. Of those who completed the questionnaire, 8934 (99.06%) were US residents and were included in this analysis. The demographic and clinical characteristics of the responders are summarized in Table 1.

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Table 1. Characteristics of eligible responders to the NARCOMS Spring 2012 Questionnaire (n=8934[a]).

Characteristic	n (%) or mean (SD)
Gender, n (%)	
Female	6984/8934 (78.17)
Male	1950/8934 (21.83)
Race, n (%)	
White	7818/8198 (95.36)
Other	380/8198 (4.64)
Education, n (%)	
High school diploma or less	2364/8792 (26.89)
Associate's/technical degree	1804/8792 (20.52)
Bachelor's degree	2258/8792 (29.09)
Post-graduate degree	2066/8792 (23.50)
Annual income, n (%)	
<$15,000	725/8753 (8.28)
$15,000-29,999	1278/8753 (14.60)
$30,000-49,999	1410/8753 (16.11)
$50,000-100,000	2201/8753 (25.15)
>$100,000	1315/8753 (15.02)
I do not wish to answer	1824/8753 (20.84)
Health insurance, n (%)	
Private	3869/7978 (48.50)
Public only	3867/7978 (48.47)
None	242/7978 (3.03)
Current age (years), mean (SD)	57.07 (10.39)
Age of symptom onset (years), mean (SD)	30.97 (10.04)
Patient Determined Disease Steps, n (%)	
Mild (0-2)	3146/8845 (35.57)
Moderate (3-4)	2301/8845 (26.01)
Severe (5-8)	3398/8845 (38.42)
Cognition, n (%)	
Normal	1969/8840 (22.3)
Mild	4695/8840 (53.1)
Moderate-severe	2176/8840 (24.6)

[a]The number of total responses for each characteristic varied as the respondents were not required to answer every question.

Electronic Health Information and Health Literacy

The internal consistency reliability of the NVS was .74, and of the eHEALS was .94. Most respondents performed well on the health literacy instruments. On the METER, 1.84% (160/8719) had low literacy, 17.12% (1493/8719) had marginal literacy, and 81.04% (7066/8719) had functional literacy. On the NVS, 10.81% (966/8933) of respondents had a high likelihood of inadequate literacy, 14.56% (2267/8933) possibly had inadequate literacy, while 74.62% (6666/8933) had adequate literacy. Only 1.03% (90/8718) of participants had low literacy on both the METER and the NVS, while 65.52% (5712/8718) had functional literacy/numeracy on both instruments. METER scores correlated weakly with NVS scores (r=.31, P<.001).

The mean (SD) score on the eHEALS was 28.15 (18.57). eHEALS scores correlated quite weakly with scores on the METER (r=.14, P<.001) and the NVS (r=.24, P<.001). The mean (SD) eHEALS score was lower among persons with low literacy on the METER (mean 16.89, SD 16.86) than among persons with functional literacy (mean 29.24, SD 18.35, P<.001). Similarly, the mean (SD) eHEALS score was lower

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among persons with a high likelihood of inadequate literacy on the NVS (mean 17.36, SD 17.22) than among persons with adequate literacy (mean 30.40, SD 18.02, $P<.001$).

On univariate analysis, several sociodemographic characteristics were associated with functional health literacy (Tables 2 and 3). When assessed using the METER and the NVS, women, respondents with a higher level of education, higher level of income, and private health insurance were more likely to have functional literacy. Lower levels of self-reported disability and cognitive impairment, and shorter disease duration were also associated with an increased frequency of functional literacy based on the METER and the NVS.

Using multivariable logistic regression, gender (females), higher levels of education, higher levels of income, and older age, were associated with higher odds of having functional health literacy as assessed by the METER (Table 4). Higher levels of cognitive impairment were associated with lower odds of functional literacy. When literacy was assessed using the NVS, the findings were similar with the exception that higher levels of disability, as measured by the PDDS, were also associated with decreased odds of adequate literacy.

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Table 2. Univariate associations between participant characteristics and health literacy as measured by the Medical Term Recognition Test (METER).

Characteristic[a]	METER			*P* value
	0-20	21-34	35-40	
Gender, n (%), n=8719				
Female	109 (68.13)	1013 (67.85)	5708 (80.78)	<.001
Male	51 (31.88)	480 (32.15)	1358 (19.22)	
Race, n (%), n=7996				
White	139 (94.56)	1278 (94.53)	6211 (95.60)	.20
Other	8 (5.44)	74 (5.5)	286 (4.4)	
Education, n (%), n=8661				
High school diploma or less	67 (42.41)	534 (36.11)	1714 (24.40)	<.001
Associate's/technical degree	36 (22.78)	397 (26.84)	1345 (19.15)	
Bachelor's degree	30 (18.99)	355 (24.00)	2147 (30.57)	
Post-graduate degree	25 (15.82)	193 (13.05)	1818 (25.88)	
Annual income, n (%), n=8625				
<$15,000	31 (20.81)	171 (11.67)	497 (7.09)	<.001
$15,000-29,999	33 (22.15)	257 (17.54)	966 (13.78)	
$30,000-49,999	26 (17.45)	270 (18.43)	1106 (15.78)	
$50,000-100,000	16 (10.74)	334 (22.80)	1829 (26.09)	
>$100,000	15 (10.07)	129 (8.81)	1163 (16.59)	
I do not wish to answer	28 (18.79)	304 (20.75)	1450 (20.68)	
Health insurance, n (%), n=7780				
Private	36 (24.49)	526 (38.73)	3191 (50.85)	<.001
Public only	97 (65.99)	777 (57.22)	2917 (46.49)	
None	14 (9.52)	55 (4.05)	167 (2.66)	
Current age (years), mean (SD)	59.59 (10.19)	56.69 (10.86)	57.03 (10.26)	.007
Disease duration (years), mean (SD)	29.01 (12.16)	26.19 (12.00)	25.95 (11.97)	.007
Patient Determined Disease Steps, n (%), n=8646				
Mild	37 (24.18)	469 (31.71)	2580 (36.78)	<.001
Moderate	37 (24.18)	391 (26.44)	1831 (26.10)	
Severe	79 (51.63)	619 (41.85)	2603 (37.11)	
Cognition, n (%), n=8652				
Normal	28 (18.06)	278 (18.86)	1626 (23.15)	<.001
Mild	73 (47.10)	771 (52.31)	3766 (53.62)	
Moderate-severe	54 (34.84)	425 (28.83)	1631 (23.22)	

[a]The number of total responses for each characteristic varied as the respondents were not required to answer every question.

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Table 3. Univariate associations between participant characteristics and health literacy as measured by the Newest Vital Sign (NVS).

Characteristic[a]	NVS			*P* value
	0-1	2-3	4-6	
Gender, n (%), n=8933				
Female	654 (67.70)	926 (71.18)	5404 (81.07)	<.001
Male	312 (32.30)	375 (28.82)	1262 (18.93)	
Race, n (%), n=8197				
White	861 (94.93)	1124 (93.74)	5832 (95.75)	.0085
Other	46 (5.07)	75 (6.26)	259 (4.25)	
Education, n (%), n=8791				
High school diploma or less	357 (40.99)	457 (35.56)	1550 (23.36)	<.001
Associate's/technical degree	197 (22.62)	298 (23.19)	1309 (19.73)	
Bachelor's degree	185 (21.24)	323 (25.14)	2050 (30.90)	
Post-graduate degree	132 (15.15)	207 (16.11)	1726 (26.01)	
Annual income, n (%), n=8752				
<$15,000	163 (19.24)	153 (11.99)	409 (6.17)	<.001
$15,000-29,999	163 (19.24)	268 (21.00)	846 (12.76)	
$30,000-49,999	138 (16.29)	217 (17.01)	1055 (15.91)	
$50,000-100,000	127 (14.99)	288 (22.57)	1786 (26.94)	
>$100,000	59 (6.97)	120 (9.40)	1136 (17.14)	
I do not wish to answer	197 (23.26)	230 (18.03)	1397 (21.07)	
Health insurance, n (%), n=7977				
Private	300 (34.25)	421 (36.90)	3148 (52.82)	<.001
Public	530 (60.50)	685 (60.04)	2651 (44.48)	
None	46 (5.25)	35 (3.07)	161 (2.70)	
Current age (years), mean (SD)	61.25 (10.51)	59.58 (10.16)	55.97 (10.18)	<.001
Disease duration (years), mean (SD)	30.38 (12.76)	28.70 (12.27)	24.99 (11.65)	<.001
Patient Determined Disease Steps, n (%), n=8844				
Mild	216 (23.05)	347 (27.17)	2583 (38.96)	<.001
Moderate	218 (23.27)	337 (26.39)	1746 (26.33)	
Severe	503 (53.68)	593 (46.44)	2301 (34.71)	
Cognition, n (%), n=8839				
Normal	169 (18.15)	233 (18.17)	1566 (23.63)	<.001
Mild	455 (48.87)	679 (52.96)	3561 (53.74)	
Moderate-severe	307 (32.98)	370 (28.86)	1499 (22.62)	

[a]The number of total responses for each characteristic varied as the respondents were not required to answer every question.

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Table 4. Multivariable logistic regression: characteristics associated with functional health literacy.

Characteristic		METER[a]		NVS[b,c]	
		OR	95% CI	OR	95% CI
Gender					
	Male	1.0		1.0	
	Female	2.26	1.97, 2.59	1.83	1.60, 2.08
Age					
	≤35	1.0		1.0	
	>35 to ≤50	1.52	1.10, 2.11	0.99	0.65, 1.53
	>50 to ≤65	1.78	1.30, 2.44	0.61	0.40, 0.92
	>65	1.66	1.18, 2.33	0.36	0.24, 0.56
Education					
	High school diploma or less	1.0		1.0	
	Associate's/technical degree	1.08	0.92, 1.26	1.88	1.58, 2.24
	Bachelor's degree	1.82	1.55, 2.14	1.67	1.43, 1.95
	Post-graduate degree	2.72	1.24, 3.31	1.19	1.02, 1.40
Annual income					
	<$15,000	1.0		1.0	
	$15,000-29,999	1.33	1.05, 1.68	1.45	1.16, 1.81
	$30,000-49,999	1.40	1.10, 1.76	2.13	1.70, 2.66
	$50,000-100,000	1.76	1.40, 2.21	2.45	1.98, 3.04
	>$100,000	2.38	1.81, 3.12	3.02	2.33, 3.91
	I do not wish to answer	1.47	1.17, 1.85	2.06	1.66, 2.55
Cognition					
	Normal	1.0		1.0	
	Mild	0.94	0.80, 1.11	0.86	0.74, 1.01
	Moderate-severe	0.80	0.67, 0.96	0.67	0.56, 0.80
Patient Determined Disease Steps					
	Mild	-		1.0	
	Moderate			0.95	0.81, 1.11
	Severe			0.73	0.63, 0.84

[a]c-statistic = 0.67; Hosmer Lemeshow Goodness of Fit χ^2_8 =5.4, *P*=.72

[b]c-statistic = 0.70; Hosmer Lemeshow Goodness of fit χ^2_8=13.5, *P*=.09

[c]NVS = Newest Vital Sign

Comorbidities and Health Behaviors

In total, 6973 (78.05%) of 8934 participants reported one or more comorbid conditions with 2868 (32.1%) reporting hypertension, 3328 (37.25%) depression, 2804 (31.39%) hyperlipidemia, 1413 (15.82%) migraine, 1152 (12.89%) autoimmune thyroid disease, and 1032 (11.55%) reporting cancer. The remaining comorbidities were reported by fewer than 10% of respondents. Most respondents did not smoke currently (7708/8811, 87.48%) and 3061/8797 (34.78%) denied any alcohol consumption. The mean (SD) BMI of respondents was 26.93 (6.48), with 2625/8741 (30.03%) being overweight and 2239/8741 (25.61%) being obese.

The proportion of respondents with any comorbidity was slightly higher among those with greater health literacy on the METER (Z=-1.81, *P*=.07 for linear trend) and on the NVS (Z=-5.57, *P*<.001 for linear trend). Respondents who reported being nonsmokers were more likely to have functional literacy on the METER and adequate literacy on the NVS than smokers (both *P*<.001, Multimedia Appendix 1). However, the frequency of any alcohol consumption was higher among respondents with higher health literacy than among those with lower health literacy as measured by the METER and the NVS (both *P*<.001, Multimedia Appendix 1). Overweight and obesity were more

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common among those with lower health literacy (METER *P*=.006; NVS *P*=.007).

Health Care Utilization

During 6 months prior to survey administration, 1275/8807 (14.48%) respondents presented to an emergency room and 831/8792 (9.45%) were hospitalized. Participants were less likely to report an ER visit (*P*=.002) or hospitalization (*P*<.001) if they had higher literacy on the METER (Multimedia Appendix 1, Figure 1A). Similarly, participants were less likely to report an ER visit or hospitalization if they had adequate literacy on the NVS (both *P*<.001, Multimedia Appendix 1, Figure 1B).

In an unadjusted logistic regression model, low literacy on the METER was associated with 28% increased odds of any ER visit (OR 1.28; 95% CI 1.11-1.48). In a multivariable logistic regression model adjusting for income, disability, and cognitive impairment, low literacy on the METER was associated with 13% increased odds of any ER visit (OR 1.13; 95% CI 0.96-1.33) (Table 5).

Table 5. Association of health literacy assessed by the Medical Term Recognition Test (METER) with emergency room (ER) visits and hospitalizations.

Characteristic	ER visits[a]		Hospitalizations[b]	
	OR	95% CI	OR	95% CI
METER				
Functional literacy	1.0		1.0	
Low literacy	1.13	0.96, 1.33	1.19	0.98, 1.44
Gender				
Male			1.0	
Female			0.75	0.62, 0.90
Annual income				
<$15,000	1.0		1.0	
$15,000-29,999	0.65	0.51, 0.84	0.72	0.53, 0.97
$30,000-49,999	0.56	0.44, 0.72	0.63	0.47, 0.85
$50,000-100,000	0.50	0.40, 0.63	0.52	0.39, 0.69
>$100,000	0.48	0.37, 0.63	0.51	0.36, 0.72
I do not wish to answer	0.44	0.34, 0.56	0.57	0.43, 0.77
Cognition				
Normal	1.0		1.0	
Mild	1.18	0.99, 1.42	1.26	1.01, 1.58
Moderate-severe	1.73	1.42, 2.12	1.62	1.27, 2.07
Patient Determined Disease Steps				
Mild	1.0		1.0	
Moderate	1.40	1.17, 1.68	1.33	1.03, 1.71
Severe	1.92	1.63, 2.26	2.93	2.37, 3.62

[a]c-statistic = 0.64; Hosmer Lemeshow Goodness of fit χ^2_8 = 2.96 *P*=.89

[b]c-statistic = 0.68; Hosmer Lemeshow Goodness of fit χ^2_8 =10.7 *P*=.22

In an unadjusted logistic regression model, low literacy on the NVS was associated with 58% increased odds of any ER visit (OR 1.58; 95% CI 1.39-1.79). In a multivariable model adjusting for income, disability, and cognitive impairment, low literacy on the NVS was still associated with increased odds of any ER visit (OR 1.28; 95% CI 1.10-1.48) (Table 6).

In an unadjusted logistic regression model, low literacy on the METER was associated with 28% increased odds of any overnight hospitalization (OR 1.28; 95% CI 1.11-1.48). In a multivariable logistic regression model adjusting for gender, income, disability and cognitive impairment, low literacy on the METER was associated with 19% increased odds of any hospitalization (OR 1.19; 95% CI 0.98-1.44) (Table 5).

In an unadjusted logistic regression model, low literacy on the NVS was associated with 58% increased odds of any overnight hospitalization (OR 1.58; 95% CI 1.36-1.85). In a multivariable logistic regression model, low literacy on the NVS was associated with 17% increased odds of any hospitalization (OR 1.17; 95% CI 0.97-1.40) (Table 6).

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Table 6. Association of health literacy (NVS) with emergency room (ER) visits and hospitalizations.

Characteristic		ER visits[a]		Hospitalizations[b]	
		OR	95% CI	OR	95% CI
NVS					
	Functional literacy	1.0		1.0	
	Low literacy	1.28	1.10, 1.48	1.17	0.97, 1.40
Gender					
	Male			1.0	
	Female			0.72	0.60, 0.87
Annual income					
	<$15,000	1.0		1.0	
	$15,000-29,999	0.68	0.53, 0.87	0.77	0.57, 1.04
	$30,000-49,999	0.59	0.46, 0.75	0.67	0.50, 0.91
	$50,000-100,000	0.53	0.42, 0.66	0.54	0.40, 0.72
	>$100,000	0.50	0.38, 0.65	0.51	0.36, 0.73
	I do not wish to answer	0.46	0.36, 0.59	0.60	0.45, 0.81
Cognition					
	Normal	1.0		1.0	
	Mild	1.17	0.98, 1.41	1.25	0.99, 1.57
	Moderate-severe	1.73	1.42, 2.11	1.63	1.27, 2.09
Patient Determined Disease Steps					
	Mild	1.0		1.0	
	Moderate	1.37	1.14, 1.64	1.31	1.02, 1.69
	Severe	1.86	1.58, 2.20	2.97	2.39, 3.68

[a]c-statistic = 0.64; Hosmer Lemeshow Goodness of Fit χ^2_8=12.9, *P*=.12

[b]c-statistic = 0.68; Hosmer Lemeshow Goodness of Fit χ^2_8=6.67, *P*=.57

Discussion

Principal Results

We investigated health literacy in a sociodemographically diverse population of persons with MS. We found that 65.52% of respondents had functional health literacy on both the METER and the NVS. Furthermore, functional literacy was associated with greater comfort and perceived skill at using electronic health information as assessed using eHEALS. Although most respondents performed well on the METER and the NVS instruments, lower health literacy was associated with an increased risk of smoking, overweight and obesity, comorbidity, visits to the emergency room and overnight hospitalizations.

As assessed by the METER, 81% of the NARCOMS population had functional literacy while nearly 75% had adequate literacy as assessed by the NVS; the latter instrument has a greater emphasis on numeracy. We were unable to identify other studies which have evaluated this issue in MS. Findings varied in other chronic diseases. Approximately 70% of individuals diagnosed with COPD have functional health literacy [31], as compared to 88% in persons with rheumatoid arthritis, and 82.5-85% in persons with heart disease [3,32].

Sociodemographic characteristics associated with greater odds of having functional health literacy included females, older age, higher socioeconomic status, normal self-reported cognition, and lower levels of disability. The association of socioeconomic status and health literacy is consistent across populations, including those with heart failure [3], chronic obstructive pulmonary disease [31], and rheumatoid arthritis [33], among others. In some populations older age is associated with lower rather than higher health literacy, and the association of age with health literacy also varies with the instrument used [3,33]. As we found in our population, lower health literacy is associated with worse health status [31]. This is a complicated issue to understand in MS where cognitive impairment may develop over the course of the disease and could lead to declines in health literacy. Longitudinal studies will be needed to determine the directionality of these relationships in MS.

Lower health literacy was associated with a greater frequency of smoking and obesity, but a lower frequency of regular alcohol use and comorbidity. Findings in other populations regarding these associations have been inconsistent [7]. Our findings may

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reflect unmeasured confounders, differential health behaviors according to health literacy, or differential reporting according to health literacy. Persons with lower health literacy have less knowledge of chronic diseases, and we speculate that they may not report comorbidity as accurately. These findings will require further evaluation in future studies. Respondents who did not have functional health literacy had increased odds of emergency room visits, after accounting for potential confounders. This association was stronger for the NVS (OR 1.28; 95% CI 1.10-1.48), which captures numeracy, than for the METER (OR 1.13; 95% CI 0.96-1.33). Similarly, respondents who did not have functional health literacy had increased odds of hospitalization although these associations were marginally nonsignificant for the METER (OR 1.19; 95% CI 0.98-1.44) and the NVS (OR 1.17; 95% CI 0.97-1.40). Lower health literacy is consistently associated with greater health care utilization in other populations, although the magnitude of the association varies across populations and outcomes studied [7].

Limitations

The response rate was 69.27% and responders were more likely to be white and to have a higher annual income; thus, our findings may not be applicable to nonwhites and those of lower socioeconomic status. The NARCOMS population does not fully represent the MS population in the United States, but its characteristics are similar to those reported for other MS populations [34,35]. Furthermore, it is a large, sociodemographically diverse population comprised of participants who receive care in community-based and academic centers. The NVS was not designed to be self-administered; however, it has been successfully self-administered in other studies [36]. None of the health literacy measures used was ideal, and the literature does not provide a clear understanding of the relationships between them. In their critical appraisal of health literacy tools, Jordan et al found that no existing instrument fully measured health literacy with respect to the person's ability to seek, understand, and use health information [24]. Moreover, construct validity was variable and the sensitivity to change of most instruments has not been evaluated. These challenges are supported by the relatively weak correlations among the three instruments used in this study. At least one study has raised concerns about the validity of the eHEALS due to low correlations with internet use [37]. Although we included a measure of cognition, it is unlikely that this fully accounted for cognitive impairment, given the complex relationships between subjective and objective measures of cognition [38]. Because this was an initial study evaluating health literacy, the design was cross-sectional, limiting our ability to assess causal relationships between health literacy and the outcomes of interest.

Conclusions

Health literacy is under-studied in MS. Our findings suggest that it is associated with adverse health behaviors, and increased health care utilization. Future work should seek to develop better methods of defining and assessing health literacy in MS population, confirm these findings, elucidate causal pathways, examine a broader range of health outcomes including adherence to therapy, and ultimately, evaluate the impact of interventions aimed at improving health literacy in the MS population.

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Conflicts of Interest

Ruth Ann Marrie receives research funding from: Canadian Institutes of Health Research, Public Health Agency of Canada, Manitoba Health Research Council, Health Sciences Centre Foundation, Multiple Sclerosis Society of Canada, Multiple Sclerosis Scientific Foundation, Rx & D Health Research Foundation, and has conducted clinical trials funded by Sanofi-Aventis.

Amber Salter has no conflicts of interest to declare.

Tuula Tyry has no conflicts of interest to declare.

Robert Fox has received personal consulting fees from Avanir, Biogen Idec, Novartis, Questcor, and Teva Neurosciences; has served on clinical trial advisory committees for Biogen Idec and Novartis; has received research support from the National Multiple Sclerosis Society (RG 4091A3/1; RG 4103A4/2; RC 1004-A-5) and Novartis; and serves on the editorial boards of Neurology and Multiple Sclerosis Journal.

Gary Cutter has served on scientific advisory boards for and/or received funding for travel from Alexion, Allozyne,Bayer, Celgene, Consortium of MS Centers, Coronado Biosciences, Diogenix, Klein-Buendel Incorporated, Merck, Novartis, Nuron Biotech, Receptos, Somnus Pharmaceuticals, Spinifex Pharmaceuticals, St. Louis University, Teva pharmaceuticals; receives royalties from publishing Evaluation of Health Promotion and Disease Prevention (The McGraw Hill Companies, 1984); has received honoraria from GlaxoSmithKline, Novartis, Advanced Health Media Inc., Biogen Idec, EMD Serono Inc., EDJ Associates, Inc., the National Heart, Lung, and Blood Institute, National Institute of Neurological Diseases and Stroke, National Marrow Donor Program, Consortium of Multiple Sclerosis Centers; serves as a consultant to Novartis, National Industrial Sand Association, Bayer Pharmaceuticals, and Teva Pharmaceuticals Industries Ltd.; has served on independent data and safety monitoring committees for Apotek, Biogen, Cleveland Clinic, EliLilly, Glaxo Smith Klein Pharmaceuticals, Medivation, Modigenetech, NHLBI, NINDS, NMSS, Ono Pharmaceuticals, Prolor, Sanofi-Aventis, Teva.

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Multimedia Appendix 1

Frequency of health behaviours and health care utilization according to health literacy scores.

[PDF File (Adobe PDF File), 35KB - ijmr_v3i1e3_app1.pdf]

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Abbreviations

BMI: body mass index
CI: confidence interval
eHEALS: eHealth Literacy Scale
ER: emergency room visits
METER: Medical Term Recognition Test
MS: multiple sclerosis
NARCOMS: North American Research Committee on Multiple Sclerosis Registry
NVS: Newest Vital Sign
OR: odds ratio
PCA: principal components analysis
PDDS: Patient Determined Disease Steps
SD: standard deviation

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Original Paper

Telemedicine-Based Approach for Obstructive Sleep Apnea Management: Building Evidence

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Abstract

Background: Telemedicine seems to offer reliable solutions to health care challenges, but significant contradictory results were recently found. Therefore, it is crucial to carefully select outcomes and target patients who may take advantage of this technology. Continuous positive airway pressure (CPAP) therapy compliance is essential to treat patients with obstructive sleep apnea (OSA). We believe that OSA patients could benefit greatly from a telemedicine approach for CPAP therapy management.

Objective: The objective of our study was to evaluate the application of a telemedicine-based approach in the CPAP therapy management, focusing on patients' CPAP follow-up and training.

Methods: We performed two studies. First, (study 1) we enrolled 50 consecutive OSA patients who came to our sleep center for the CPAP follow-up visit. Patients performed a teleconsultation with a physician, and once finalized, they were asked to answer anonymously to a questionnaire regarding their opinion about the teleconsultation. In a second randomized controlled trial (RCT) (study 2), we included 40 OSA patients scheduled for CPAP training. There were 20 that received the usual face-to-face training and 20 that received the training via videoconference. After the session, they were blindly evaluated on what they learned about OSA and mask placement.

Results: More than 95% (49/50) of the interviewed patients were satisfied with the teleconsultation, and 66% (33/50) of them answered that the teleconsultation could replace 50%-100% of their CPAP follow-up visits. Regarding the RCT, patients who received the CPAP training via videoconference demonstrated the same knowledge about OSA and CPAP therapy as the face-to-face group (mean 93.6% of correct answers vs mean 92.1%; P=.935). Performance on practical skills (mask and headgear placement, leaks avoidance) was also similar between the two groups.

Conclusions: OSA patients gave a positive feedback about the use of teleconsultation for CPAP follow-up, and the CPAP training based on a telemedicine approach proved to be as effective as face-to-face training. These results support the use of this telemedicine-based approach as a valuable strategy for patients' CPAP training and clinical follow-up.

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KEYWORDS

telemedicine; sleep apnea; CPAP therapy; teleconsultation

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Introduction

The New Challenge of Telemedicine

Born as a method to deliver health care at a distance, telemedicine seems to offer credible solutions, tested in real medical settings, to the main challenges facing our society, such as population aging, chronic patients' management, and health costs reduction. However, recently published results questioned the validity of this technology as a health care delivery method for all populations [1]. Consequently, it appears crucial to carefully select proper outcomes and most receptive target patients' groups.

Obstructive Sleep Apnea in the Population

Obstructive sleep apnea (OSA) is a very prevalent disorder that is estimated to affect 2%-4% of adult men and 1%-2% of adult women in Western countries [2,3]. OSA entails repetitive obstructions of the upper airway resulting in brain arousal, intermittent hypoxia, large negative intrathoracic pressures, and increased sympathetic activation. All these phenomena induce intermediate systemic changes such as inflammation, oxidative stress, or metabolic changes that result in different clinical symptoms, including fatigue and daytime somnolence [4]. Recently, the awareness of OSA in the media and in medical and patients' circles has exponentially increased, and therefore the number of patients for evaluation. At present, OSA is considered as a major factor responsible for different cardiovascular, neurologic, and metabolic diseases. In addition, OSA prevalence is likely to increase due to its strong association to obesity, which is considered epidemic currently, and for its higher incidence in the aging population, another rising part of the population. Finally, there is a growing evidence of OSA as a risk factor for traffic accidents [5].

This increase in demand, however, has not been accompanied by any improvements to deal with this problem. The European and Spanish public health resources assigned to sleep related breathing disorders have proved to be relatively inadequate and unlikely to handle the increase in OSA cases [6], therefore alternative and cost-effective management approaches are needed.

Continuous Positive Airway Pressure Treatment

The treatment of choice for OSA is continuous positive airway pressure (CPAP) applied usually through a mask to the patient's nose during sleep. This pressure in the mask is transmitted to the pharyngeal area, thereby avoiding upper airway obstruction. CPAP therapy compliance is essential to guarantee its effectiveness to treat OSA patients [7]. Despite the documented clinical efficacy of CPAP, it is estimated that 30% up to 80% of patients underuse or even suspend CPAP treatment [8], mainly due to its discomforting side effects and lack of improvement perception. Main CPAP therapy side effects are pressure intolerance, claustrophobic reaction to the mask, mask displacement, and machine noise [9], which may even disrupt sleep or provoke hypertension at night [10]. Many of these problems could be solved by a closer follow-up, but the overloaded sleep centers have troubles to provide such support. Therefore, innovative interventions are needed to enhance the CPAP compliance, especially in the first few months of treatment when the long-term compliance level of a patient is usually defined [11]. In addition, it is worth noting the great socioeconomic impact of CPAP treatment, whose prevalence is estimated at 0.6% up to 2% of the entire population [12,13], being two-thirds of all respiratory therapies provided at home [14]. Consequently, we believe that a telemedicine-based approach for CPAP therapy management could be of great interest and benefit for OSA patients.

A Telemedicine-Based Approach for Continuous Positive Airway Pressure Treatment

Our aim was to evaluate the application of a telemedicine-based approach in CPAP therapy management, particularly focusing on the application of teleconsultation, that is, a medical visit via videoconference, to patients' CPAP follow-up and training. In a previous study, we received positive feedback from a group of physicians who declared that teleconsultation could avoid 45% of face-to-face follow-up visits [15]. The present work was focused on OSA patients, whose acceptance level and opinion for this specific application are still unclear. First, after performing a CPAP follow-up visit via videoconference, we asked a group of OSA patients to give us feedback about it. In a second randomized controlled trial (RCT), we performed a blinded comparison between the knowledge and skills of a group of OSA patients who received the standard face-to-face CPAP training and another group who received it via videoconference. The Hospital Clínic of Barcelona Ethics Committee authorized both studies.

Methods

Study 1: Continuous Positive Airway Pressure Follow-Up

We recruited 50 consecutive OSA patients who came to the Hospital Clínic sleep center for a routine CPAP therapy follow-up visit. After finalizing the visit, the nurse asked the patient to participate in the study. The exclusion criteria were illiteracy, deafness, and refusal to participate. Upon signature of the informed consent, the patient was accompanied to the next room, which was equipped with an Internet-connected personal computer (PC) with a web-cam and the free videoconference software Skype installed. The patient was connected with a physician who was waiting in his/her office. After checking the audio-video quality of the conference call, the patient was left alone for the interview with the physician. The brief consultation was composed of structured questions about the CPAP therapy and possible problems and discomforts. Once the teleconsultation finalized, the patient, still alone in the room, answered a multiple choice questionnaire regarding his/her opinion about the teleconsultation and then delivered it in a sealed envelope to keep it anonymous.

Study 2: Continuous Positive Airway Pressure Training

We enrolled 40 consecutive recently diagnosed OSA patients who came to our sleep center for CPAP training before starting the therapy. In this second study, the exclusion criteria were the same as the first one–illiteracy, deafness, and refusal to

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participate. After signing the informed consent, they were randomized in two groups–20 patients received the usual face-to-face CPAP training, while the other 20 received it via videoconference. The training session was the same as it is usually performed in our hospital before starting the CPAP therapy, and the same specialized nurse carried it out for both groups. It consisted of a theoretical part, where the patient received education about the nature, complications, and treatment of OSA with CPAP, and a practical part, in which the nurse gave full training on CPAP machine functioning, mask and headgear placement, and strategies to avoid mask leaks. Then, the patient was left for a few minutes with the mask placed and a fixed air pressure to familiarize him or herself with the therapy.

Once the session was finalized, patients were blindly evaluated by an expert on what they had learned. First, they were asked to answer a multiple choice test to assess what they had learned during the theoretical part of the session about OSA and CPAP therapy (see Multimedia Appendix 1). Then, they were asked to perform three simple tasks: (1) putting the mask on themselves, (2) placing the headgear, and (3) achieving an absence of mask leaks. Their skills were blindly evaluated on the following discrete scale–0 (bad), 1 (average), and 2 (good).

Statistical Analysis

The normal distributed continuous variables are shown as mean (SD). Discrete variables are presented as absolute and relative frequencies (percentages). The comparison of discrete variables was done through the $\chi 2$ test or the Fisher exact test. Comparisons of the groups for continuous variables were performed with the unpaired *t* test for independent samples or the Mann-Whitney Rank Sum test (when continuous variable was not normally distributed).

Results

Study 1: Continuous Positive Airway Pressure Follow-Up

Of the 50 consecutive patients approached, all of them were included in the study. Table 1 describes some demographic characteristics of the patients included. The frequency distribution of the answers to the satisfaction survey is summarized in Table 2. The majority of the patients answered positively to all questions. More than 95% (49/50) of the patients were satisfied with the teleconsultation, and 66% (33/50) of them answered that teleconsultation could replace between 50% and 100% of the CPAP therapy follow-up visits (questions A and B of Table 2). In addition, 80% (40/50) of the interviewed patients would recommend teleconsultation to others (question C of Table 2). It is also noteworthy that the majority of patients did not find any problem regarding the audio-video quality of the videoconference, comfort, and safety during the teleconsultation (questions D, E, and F of Table 2).

Besides, we further analyzed the answers to the first three questions (A–satisfaction with the teleconsultation, B–percentage of face-to-face that teleconsultation could replace, and C–inclination to recommend teleconsultation to others) to assess the potential impact of some relevant population characteristics to the results. Accordingly, we stratified the interviewed population by gender, age, education, and Internet use, and we assessed the frequency distribution of the answers (Figure 1 shows the frequency distribution of Table 1, questions A, B, and C). Younger patients (<65 years) showed to be more inclined to recommend teleconsultation to others and Internet-users would replace a higher percentage of face-to-face follow-up visits with teleconsultation. Gender and education (graduated or not) seemed to have no impact to the patients' opinion.

Table 1. Demographic characteristics of patients included in study 1 (n=50).

Demographic variable	Value
Male, (%)	64
Age–years, mean (SD)	62.1 (13.5)
BMI–mean (SD)	32.4 (6.4)
Graduate studies, (%)	26
Internet users, (%)	44

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Table 2. Frequency distribution of the patients' answers to the opinion questionnaire about the teleconsultation (study 1; n=50).

Question	Multiple choice answers	Results[a] n (%)
1. Which is your level of satisfaction with the teleconsultation?	Very dissatisfied	0 (0)
	Dissatisfied	0 (0)
	Indifferent	1 (2)
	Satisfied	15 (30)
	Very satisfied	*34 (68)*
2. Do you believe that such teleconsultations could replace the follow-up visits to monitor your condition?	No, never	3 (6)
	Yes, but only rarely (10%-20%)	6 (12)
	Yes, several times (30%-50%)	8 (16)
	Yes, many times (50%-70%)	*19 (38)*
	Almost always (80%-100%)	14 (28)
3. Would you recommend this telemedicine system to others?	No	2 (4)
	Perhaps	8 (16)
	Yes	*40 (80)*
4. Could you hear and see well the doctor during the interview?	No, I could not	0 (0)
	Yes, with some problems	6 (12)
	Yes, perfectly	*43 (88)*
5. Did you feel comfortable during the interview?	No	1 (2)
	Quite	10 (20)
	Very	*39 (78)*
6. Did you feel safe about your privacy and confidentiality in the interview?	No	0 (0)
	Indifferent	4 (8)
	Yes	*46 (92)*

[a]For each question the highest frequencies are shown in italic.

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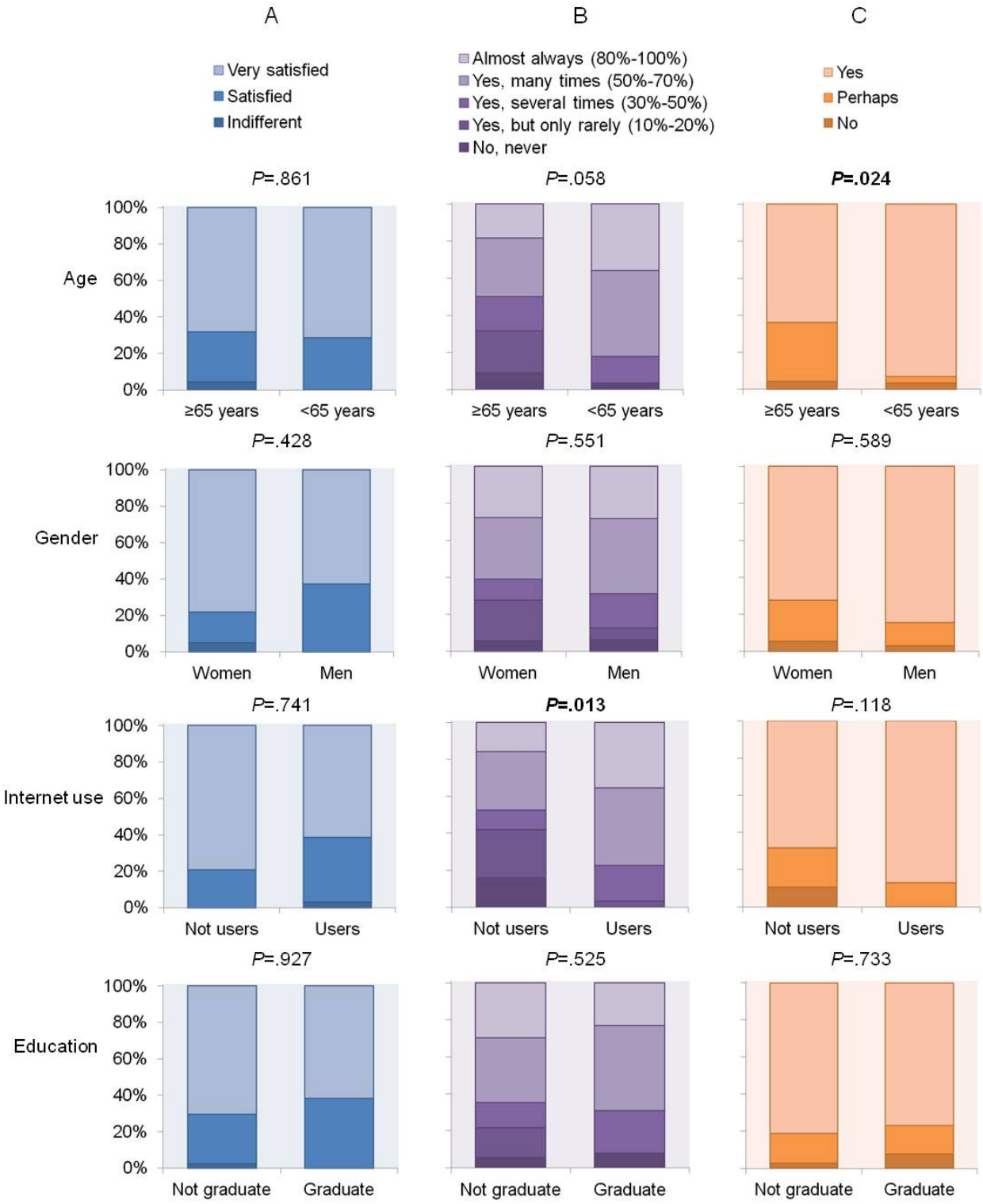
Figure 1. Frequency distribution of the answers to question A (satisfaction with the teleconsultation), B (percentage of face-to-face that could be replaced by teleconsultation), and C (inclination to recommend teleconsultation to others) of the opinion questionnaire stratified by age, gender, Internet use, and education (graduate studies or not) of the patients included in the first study. Significant differences between distributions (P<.05) are shown in italics.



Study 2: Continuous Positive Airway Pressure Training

All of the 40 patients approached gave their consent to participate. The two randomized groups had similar demographic data (Table 3).

Regarding the theoretical part of the evaluation, Figure 2 shows the percentage of correct answers to the multiple choice test of the two study groups. Patients who received the CPAP training via videoconference demonstrated the same knowledge about OSA and CPAP therapy as the face-to-face group (mean 93.6% of correct answers vs mean 92.1%; P=.935). Concerning the practical evaluation performed by the blinded expert, patients who received the CPAP training via videoconference showed similar performances to the ones who received the face-to-face

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training on mask placement (*P*=.198) and mask leaks avoidance (*P*=1.00). The videoconference group showed a slightly better performance in placing the headgear compared to the face-to-face group (*P*=.043). Figure 3 shows the results summarized graphically.

Table 3. Demographic characteristics of patients included in the RCT study (study 2; n=40).

	Face-to-face	Videoconference	*P*
n	20	20	
Male (%)	80	65	.480
Age years, mean (SD)	58.8 (12.8)	56.9 (8.9)	.587

Figure 2. Results of the first part of patients' evaluation regarding what they learned about OSA and CPAP therapy during the training session (study 2). The box-and-whickers plot shows the percentage of correct answers to the multiple choice test performed by the two randomized groups.

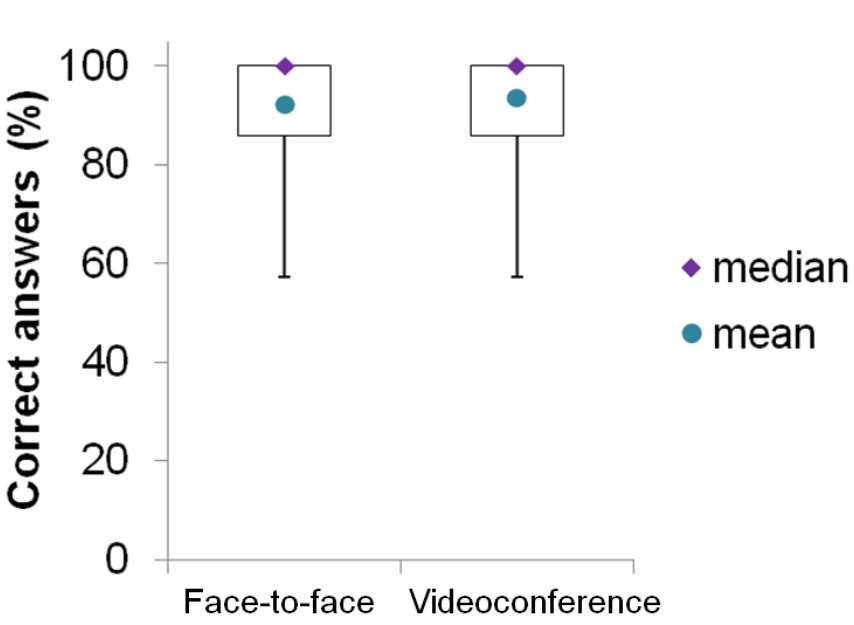
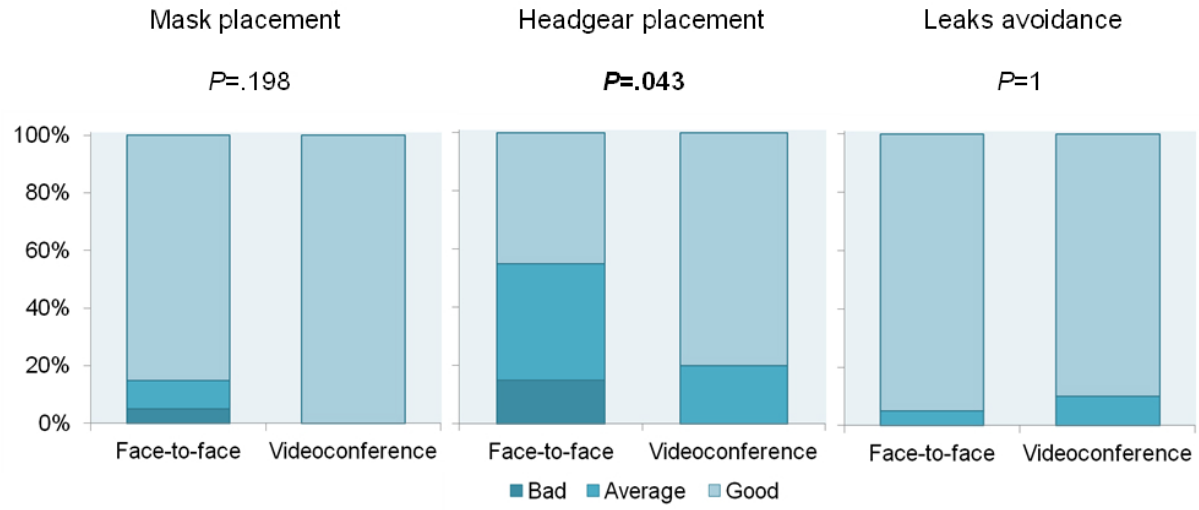


Figure 3. Results distribution of the practical evaluation of patients' skills on placing the mask, the headgear, and avoiding leaks from the mask (study 2). A blinded expert scored patients' performance on a ascendant scale: 0 (bad), 1 (average), and 2 (good).



Discussion

Principal Findings

In this paper, we assessed the potential usefulness of a telemedicine-based approach in the management of OSA patients under CPAP treatment. Specifically, we evaluated the application of videoconference to two essential phases of the OSA patients' management–the CPAP therapy follow-up, and training. In the first study, we obtained a positive feedback from a group of 50 consecutive OSA patients who were interviewed after performing a CPAP follow-up visit via teleconsultation

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with a physician. Almost all of them were satisfied with this new approach and many would replace their usual face-to-face follow-up visit with teleconsultation, especially Internet users, and would recommend this approach to others, in particular, patients under 65 years old. In the second study, the two groups demonstrated similar results on what they learned during the CPAP training session in terms of both theoretical and practical skills, confirming the teleconsultation as effective as the classic face-to-face approach to deliver education and training to this kind of patient. To our knowledge, this is the first study in which a telemedicine-based approach for CPAP training is implemented and objectively evaluated in a RCT with OSA patients.

Comparison With Previous Studies

In the last decades, it has been shown that simple telemedicine interventions, such as weekly phone calls to clarify doubts and encourage CPAP use, can markedly improve compliance [16]. An RCT showed that the use of a telephone-linked communication system providing feedback and counseling to OSA patients at home improved CPAP adherence, patients' functional status, and reduced symptoms of depression [17]. Furthermore, another previous study employed an Internet-based informational support service for problems experienced with CPAP use [18]. Despite the organizational limitations and the poor differences between intervention and control group follow-up, the authors obtained good patients' acceptance on this monitoring approach.

Considering a more technical approach, an RCT study assessed the impact on CPAP compliance and OSA outcomes of a wireless telemonitoring of CPAP compliance and efficacy data, compared to usual clinical care [19]. In this study, the intervention group was equipped with a CPAP machine outfitted with a wireless transmitter, which allowed the remote data transmission of compliance and therapy efficacy information to a computer server. Physicians could access it and use this information for the management of the patients. In contrast with a previous pilot study [20], a significant difference in terms of CPAP compliance was found between the study groups after 3 months, though more technician time was spent on patients in the telemedicine arm, entailing an extra cost for this strategy. It is also remarkable that teleconsultations have been found to improve CPAP adherence in a small group of nonadherent patients versus a placebo-controlled group [21]. The cost of the interventions, including the telehealth monitor, home installation, and telephone charges, was lower than the same number of face-to-face visits. Nevertheless, larger studies are needed to generalize any conclusion.

More in general, videoconferencing has demonstrated to be a valuable means for delivering health care interventions for chronic patients. Results of several studies indicated that interventions for a variety of psychological and physical conditions delivered by videoconferencing produce similar outcomes to treatment delivered in-person and a high level of patients' satisfaction [22]. In the present study, we chose to employ the free videoconference tool Skype for its fast availability, ease of use, and good performance. Even though the risks and benefits of the use of Skype for clinical purposes should be accurately assessed [23], relevant scientific circles have recently started to discuss the potential value of Skype in different clinical applications [24-27].

Recently, there is a growing awareness of the need of further analyses about health care strategies based on telemedicine, which is also justified by recently published results that questioned the validity of this technology as a health care delivery method. Takahashi et al [28] reported on the results of an RCT of telemonitoring in older adults at high risk for hospitalization. They found that in-home monitoring of biometrics (eg, blood pressure and weight) and symptoms failed to reduce hospital readmissions or the need for emergency department visits compared with usual care. A few months later another study ran into similar results [1]. The data of these reports are important to make thorough considerations about research on telemedicine and its future clinical applications. First, we need a better understanding of the factors that depend on patients, physicians, the health system, and telemedicine programs that predict success. This would allow us to target and customize these interventions to patients who are most likely to benefit from them. Moreover, we should carefully select the appropriate outcomes that telemedicine health care strategies seek to effect [29].

While patients' perception of a telemedicine intervention is usually assessed, clinical staff's opinion and acceptance level are often poorly analyzed. Although the few available data are encouraging, showing a good clinical staff's acceptance level of telemedicine [30,31] and also of a specific application in OSA management [15], clinicians' feedback should be further assessed and their involvement promoted as main actor to guarantee a successful telemedicine intervention.

OSA patients, for their characteristics and the chronic nature of their pathology, seem to be a population that could particularly benefit from a telemedicine-based approach for its management. As mentioned before, despite the previous encouraging results, the actual usefulness of telemedicine for OSA patients under CPAP treatment is still to be fully proved. With this work, we wanted to contribute with straightforward and practical solutions to provide reliable data to assess the actual impact of telemedicine on OSA management.

Limitations

In the two studies described in this paper, patients performed the teleconsultation and the CPAP training via videoconference in a room of our outpatient clinic, which could be argued to be an unrealistic setting. For this reason, patients' opinions about audio-video quality of the teleconsultation, comfort, and safety should be taken with caution, as this survey did not imply that the subjects would feel the same at home, with their own video/computer resources and uncontrolled environment. Nevertheless, the patients included in our studies were left alone in the room in front of an Internet-connected PC and did not receive any assistance during the videoconference, except being previously briefly informed about the use of the videoconference tool, which could be done by a family member or a technician at home. Thus, we believe that this did not influence the results of our study, whose aim was to gather objective and consistent

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data to evaluate the feasibility and patients' opinion of this new OSA management approach.

Future Directions

Despite the encouraging findings of this work, additional large multicenter randomized studies are needed to further clarify the role of telemedicine in OSA management. Besides assessing clinical important issues, such as the enhancement of CPAP adherence and patients' quality of life, cost-effectiveness analysis should be performed. In fact, this new management strategy could potentially lead to cost savings by reducing face-to-face visits, training sessions, and extending access to them for big rural areas inhabitants, like in Australia or Canada.

Although positive results in terms of cost-effectiveness of telemedicine-based strategies have been found in several fields [32-34] and even in OSA diagnosis [35], these should be confirmed also for CPAP therapy management.

Conclusions

The interviewed OSA patients gave a positive feedback about the use of teleconsultation for their clinical follow-up, as well as physicians did in our previous study [15]. For the first time in this study, to our knowledge, we implemented a telemedicine-based CPAP training and objectively evaluated its impact on patients. The CPAP training performed via videoconference proved to be as effective as the face-to-face training, confirming the teleconsultation as a useful tool to deliver education and training to OSA patients. Our results support the use of this telemedicine-based approach as a valuable strategy for the management of OSA patients under CPAP treatment, which is a particularly relevant issue from both a clinical and socioeconomic point of view.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Multiple choice test to evaluate the patients' knowledge after receiving the CPAP training session (either face-to-face or via videoconference).

[PNG File, 44KB - ijmr_v3i1e6_app1.png]

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Abbreviations

CPAP: continuous positive airway pressure
OSA: obstructive sleep apnea
PC: personal computer
RCT: randomized controlled trial
SEPAR: Spanish Society of Pneumology

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Original Paper

What Influences Patient Participation in an Online Forum for Weight Loss Surgery? A Qualitative Case Study

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Abstract

Background: Many patients who undergo weight loss (bariatric) surgery seek information and social support in online discussion forums, but the vast amount of available information raises concerns about the impact of such information. A secure online discussion forum was developed and offered to bariatric surgery patients. The forum was moderated and allowed contact with peers and health care professionals.

Objective: The purposes of this study were to explore how individuals undergoing bariatric surgery used the moderated discussion forum and to better understand what influenced their participation in the forum.

Methods: The study was designed as an explorative case study. We conducted participant observation of the discussion forum over a time period of approximately six months. For further insight, we carried out in-depth semistructured interviews with seven patients who had access to the forum. We analyzed the material inductively, using content and thematic analysis.

Results: The patients used the forum as an arena in which to interact with peers and providers, as well as to provide and achieve informational and social support. The analysis suggests that there are three major themes that influenced participation in the online discussion forum: (1) the participant's motivation to seek information, advice, and guidance, (2) the need for social support and networking among peers, and (3) concerns regarding self-disclosure.

Conclusions: The findings of this study imply that a moderated discussion forum for bariatric surgery patients has potential for use in a therapeutic context. The discussion forum fulfilled the informational and support needs of the bariatric surgery patients and was particularly useful for those who excluded themselves from the traditional program and experienced barriers to expressing their own needs. Even though our findings imply that the patients benefitted from using the forum regardless of their active or passive participation, restraining factors, such as considerations regarding self-disclosure, must be further investigated to prevent certain users from being precluded from participation.

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KEYWORDS

obesity; eHealth; bariatric surgery; online forum; communication; social support

Introduction

Bariatric Surgery Patients

The number of people suffering from obesity has risen globally in the last decade, and comorbidities such as metabolic syndromes, respiratory problems, coronary heart disease, cancer, and psychosocial challenges are all closely associated with obesity [1-3]. Weight reduction has beneficial health effects on obesity-related comorbidities and mortality, and the demand for weight loss interventions has therefore risen [4,5]. Weight loss can be achieved through lifestyle interventions, pharmacotherapy, and/or surgery, but a number of people do not achieve the desired weight reduction [6,7]. Bariatric surgery

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has been shown to be the most effective intervention and to produce significant initial weight reduction in the great majority of patients, but it is mainly reserved for the severely obese who fail to lose weight through conventional methods [8]. The purpose of the surgery is to restrict food intake, but it also contributes to reduced absorption, which leads to poor digestion and the reduced uptake of several nutrients. Thus, patients must take lifelong vitamin supplements [9,10]. Also, the surgery requires patients to undergo substantial lifestyle changes, including adjustments to eating behavior and physical activity. However, noncompliance with the postsurgery recommendations is pervasive, and a number of patients regain weight and experience nutritional deficiencies after some time has elapsed [11-17]. Providing support for bariatric surgery patients is an essential part of the treatment program because weight regain, nutritional problems, and metabolic problems can be prevented or treated [16,18].

Online Support Forums

The Internet has become an important health care medium, giving people the opportunity to search for information, guidance, and social support. Online health resources are particularly relevant for patients who may encounter barriers to obtaining information on self-management and coping strategies [19,20]. In general, self-management activities are associated with successful long-term weight maintenance [14,21-25], and studies imply that social support may encourage compliance with postsurgery recommendations [26-28]. Studies on other patient groups show that online social support may include benefits such as enhanced health literacy, improved quality of life, and patient empowerment [29-32]. Some patients achieve considerable social support in their real-life environments, but a number of patients also participate in health-related forums on the Internet. Being aware of the lack of social support that some patients experience is important in providing complete health care service for these patients. Using health-related online forums has been shown to have an overall positive effect on the degree to which people are able to cope with the situations they are facing, both socially and as regards their conditions [20]. Hwang et al suggest that by addressing diet, physical activity, and motivation in a comprehensive approach, one can meet the needs of obese patients after surgery [33]. Using online forums to address these issues has the potential to support this patient group.

Most health-related online forums are dominated by peer-to-peer communication, without professional supervision or involvement [20]. In these forums, the quality and credibility of the available health information is mixed, which raises concerns about their impact and value [34]. Eysenbach et al reviewed publications on the effect of online peer support groups, but could not find any isolated outcomes of the peer support groups controlling for other interventions [35]. Research shows that patients want professionals to take an active role in such forums [36,37], and some studies indicate that facilitated or moderated communities are more beneficial [19,38]. Lindsay et al found that having a moderator in an online support group influences compliance in terms of maintaining healthy behaviors and reducing health care visits [19]. Klemm identified that the participants in moderated online support groups for breast cancer patients read and posted significantly more than in peer-led groups [39]. Ryan performed a study on trust and participation in two online self-help communities, one moderated and one unmoderated, and his primary finding was that the moderation process prevented any communication from disruptive individuals [38]. The unmoderated community challenged disruptive and suspicious individuals, resulting in hostile discussions, while the moderated community encouraged social communication, experienced more participation, and facilitated the accumulation of a history-based trust [38].

We here report from a case study exploring how bariatric surgery patients used a moderated discussion forum in the context of bariatric surgery treatment. It is further intended to address the factors that influence their participation. By identifying these aspects, we aim to gain an improved knowledge of how such a solution can be used as part of a bariatric surgery program.

Methods

Study Setting

The online discussion forum under study was one of many features of a secure eHealth portal. The eHealth portal was developed for patients undergoing bariatric surgery and included health-related information, self-management tools, and communication features [37,40]. The portal was developed through a human-centered design process [41], and according to the security and privacy concerns that are required for such solutions in Norway [37,40]. To gain access to the portal, the user was required to be registered in the system and obtain a username and password. For authentication purposes, the user would receive a one-time pin code via text message that he or she would then enter during the log-on process.

The communication features of the portal included an online discussion forum and personal one-to-one communication (patient-to-patient and health care professional-to-patient or vice-versa). Posting on the forum required that the users appeared with their real names, which was necessary in order for it to be used in a medical context. One person from the research team had the role of moderator of the forum and could monitor the discussions and take action if inappropriate messages were posted, which was one of the requirements that was identified during the human-centered design process. The moderator was educated in nursing and could comment on the postings that were within her field of competence. She also had the responsibility of posting weekly topics that were relevant to the patient group. These topics were either initiated by the clinic or created after requests from the patients. There were five health care professionals (one psychiatric nurse, one head nurse, two nurses, and one dietician) at the clinic that had access to the eHealth portal and had the responsibility of facilitating the patients through the portal and answering their requests. Further, these five professionals could make contact with other professionals for additional counseling if necessary.

Participant Inclusion

This study was designed as an explorative case study. The selection criteria for patient inclusion were as follows–18 years

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or older, basic proficiency in the Norwegian language, and enrollment in a bariatric weight loss program at the hospital. Participants provided written consent when enrolling in the study. The study followed the guidelines of the Declaration of Helsinki and was approved by the regional Ethics Committee (Trondheim, Central Norway) and by the Norwegian Social Science Data Services. Participants were recruited at the bariatric surgery clinic, where the first author made contact with potential participants, provided information about the study, and invited them to participate. The inclusion period lasted for one month, from the middle of May to the middle of June of 2011. Initially, 65 patients were asked to participate. There were 60 patients that agreed and obtained access from the time of recruitment until the middle of December of 2011. Demographic data were collected through questionnaires developed for this study (Tables 1 and 2).

Table 1. Demographic data of the patients who had access to the discussion forum through the eHealth portal.

Characteristic	Total n available	n (%) or mean (SD)
Age, mean (SD)	60	40 (SD 9.3)
Female, n (%)	60	45 (75)
Highest education completed, n (%)	57	
Primary school		4 (7)
High school		30 (53)
University/College		23 (40)
Employment status, n (%)	60	
Full/part time work		40 (66)
Student		3 (5)
On sick leave		4 (7)
Unable to work/disabled		9 (15)
Unemployed		3 (5)
Other		1 (2)
Have undergone surgery, n (%)	60	56 (94)

Table 2. Demographic data, interview participants.

Informant	Age	Gender	Highest education completed	Time of surgery
Anne	30-35	Female	University/College	Spring 2011
Kari	50-55	Female	University/College	Winter 2010/2011
Frank	45-49	Male	High school	Spring 2011
Linn	25-29	Female	High school	Waiting to undergo
Monica	30-35	Female	Primary school	Summer 2010
Nina	40-45	Female	High school	Spring 2011
Kristin	30-35	Female	High school	Autumn 2010

Discussion Forum

Via the eHealth portal, the patients had access to the online discussion forum. We conducted participant observation of the forum during the access period, and when the period ended, we retrieved all postings to the online forum and analyzed the posts inductively using qualitative content analysis [42]. The analysis was performed in a stepwise process in which both authors reviewed and coded the transcripts individually before the findings were compared and refined in a consensus decision-making process. We used English terms and concepts during the analysis and used HyperResearch software to facilitate the process. The extracts from the discussion forum that are reported in this paper were translated from Norwegian into English by the first author before the second author reviewed the translation.

Interviews

To obtain a better understanding of the users' activities in the discussion forum, we conducted interviews with users who had access to the portal. Informants were recruited through the discussion forum, where the first author posted an invitation to take part in interviews. A stratified purposeful sampling was made in terms of the variables age, gender, and time of surgery in order to ensure variation among the participants. There were 8 patients that agreed to interviews, but one failed to show up. We carried out semistructured, in-depth interviews with seven informants at the university research center between September and December of 2011. The interviews were conducted in

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Norwegian and lasted between 44-108 minutes, having a typical duration of 60 minutes. We used open-ended questions, for example, "How is your daily life (if operated on, after surgery)?" "What are your experiences with using the discussion forum?" "How do you experience the fact that your real name appears when you post to the forum?" "What are your feelings about the lack of anonymity?" The semistructured form of the interviews allowed the researcher to include questions related to emerging themes during the interview. All interviews were sound recorded and transcribed verbatim before analysis. When the last two interviews were analyzed, we did not identify new emerging themes and decided that we had reached saturation. HyperResearch software was used to facilitate the process of analysis, which was done inductively by using thematic analysis [43]. Both authors reviewed the interviews and analyzed the data. In the first stage of the thematic analysis, both authors made themselves familiar with the data and read through all the transcripts before they created initial codes of the data individually. In the next stage of the process, the codes were collated, and concepts were generated. These were then compared, contrasted, and discussed in light of the relevant literature and theory, and the final themes were achieved via consensus. This was done to ensure that our findings were coherent and increase the validity of the findings. The interview transcripts were in Norwegian, but the process of analysis was performed in English, using English codes and concepts. The quotes in this paper were translated from Norwegian into English by the first author before the second author reviewed the translation. The names reported in this paper are pseudonyms and not the real names of the participants.

Results

The Three Themes

Through the analysis, we identified three major themes that influenced participation in the online discussion forum: (1) the participant's motivation to seek information, advice, and guidance; (2) the need for social support and networking among peers; and (3) concerns regarding self-disclosure.

Informational Support, Guidance, and Advice

By observing the discussion forum, we identified the fact that the patients used the forum as an arena in which to provide and obtain informational support. Patients that undergo bariatric surgery must perform a number of self-management activities in order to achieve and maintain weight loss. Also, they must adjust their dietary habits to avoid malnutrition and other negative repercussions of the surgery. The informants who had undergone surgery mentioned that these considerations made them feel insecure. Therefore, they began to search for information and guidance regarding how to manage their "new lives." Frank had undergone surgery six months before the interview and found himself continually searching for information.

> *You are afraid about what you can eat. It says that you should be aware of rice and such, but you haven't got any information about whether you can to eat it now, after so long a time. You don't know anything about that. It is the first phase that is [described]…and then you have to try things yourself.* [Frank]

Insecurity related to coping with their new lives was a recurring topic, and the possibility of contacting health care professionals through the forum was highly appreciated by all the informants. Kristin remarked that she found it "brilliant" to have this opportunity. Anne described the professional guidance one could obtain as "the advantage of this forum as compared to the other ones." Forum observations revealed that some patients approached the health care professionals directly with specific questions, for example, "How often are we supposed to take blood tests at our primary care doctor to determine whether we are taking the correct dose of vitamins?" Others simply reported their general experiences, for example, "When the weather is hot, I experience dumping (repercussion of the operation, experienced as uneasiness) more quickly, and it is caused by foods and drinks that I normally tolerate," to which the professionals could then respond. The moderation process involved health care workers understanding patient challenges and taking actions accordingly, such as assigning the patient to a regular consultation for further investigation if necessary. We observed that in some cases the patients required informational and instrumental support, while in other instances the needs were of a more emotional or social character. Every week the moderator published a relevant topic on the discussion forum, and the participants would receive a reminder about it on email. The topics related to food, diet, nutrition, exercise, and practical information. We observed that these postings triggered further comments and questions from the patients, and those interviewed commented that these weekly topics motivated them to continue using the forum–"I like that I get that email about the weekly topic because then, I get a reminder to go in" (Kristin).

Some informants reported that they experienced difficulties in making direct contact with the professionals due to personal barriers. When they began using the forum they discovered the benefit of connecting with professionals via the forum, rather than waiting for an appointment or making contact via phone, as Monica expressed.

> *I think it is very positive that you can ask questions that are conveyed to a dietician or a doctor because I must admit that picking up the phone and asking someone is very challenging. That barrier–I think it is difficult. What if it's only me? How ridiculous! You get that feeling. Then, it is easier to write online.* [Monica]

This was supported by the other informants, and the convenience of the asynchronous aspects of such communications were also seen to be beneficial–"It's easier to go in here, ask questions, and get answers, rather than calling around and stuff" (Anne). Kristin underlined the advantage of connecting with both peers and professionals through the forum.

> *The fact that you have others who have gone through it themselves to talk to and that you can ask health care workers about things you wonder about makes participating in the forum easier than persuading oneself to make a phone call…so this is good…one has complete health care service.* [Kristin]

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Thus, the possibility of making contact with both professionals and peers through the same forum was an advantage that they had not experienced before.

Social Support and Networking Among Peers

Some patients experienced the first period after surgery as particularly difficult because it was characterized by uncertainty and a lack of information.

> *It is undoubtedly the first period, the first three weeks [after surgery], when you have the most questions. Can I eat this? What can I do now? Because clearly, it is mentally tough too.* [Kari]

The emotional and psychological factors related to surgery were recurring topics among the patients, and the need for social and emotional support was clear. The online forum became an arena in which they could introduce and discuss sensitive matters that they would not have discussed in another setting. As Anne said, "I think it is easier to talk about them (sensitive issues) in a place like this than face-to-face." Kristin remarked that one could have different attributes online than in real life, enabling the discussion of problems that one otherwise would have kept to oneself.

> *You can be much tougher on the Net, write things that you might not want to say to people because they are difficult to talk about. This becomes easier when you have a screen you can hide behind.* [Kristin]

Many of them experienced challenges in their daily lives related to the weight loss treatment, many of which were of a motivational or psychosocial character. In some cases, the value of peer support and understanding was extremely important in order to maintain inner motivation, as Linn revealed.

> *So you go into a downturn just by talking to a person that doesn't know what you are talking about. Then, it is more important to talk to a person who has been there, who knows what you have been through, who can encourage you to continue.* [Linn]

Sharing personal stories and narratives was an important part of the forum, and the topics covered related to the challenges of losing weight, motivational difficulties, and the everyday experiences of the patients. When asked about the motivation behind this, they reported that the aim was to promote acknowledgement, emotional support, and approval. Anne explained this as follows–"It is actually the support and the approval regarding what you are doing, feedback regarding whether it is right, and feedback regarding insecurities." A few patients created "threads" in the discussion forum that they named "diaries," where they wrote their personal diary notes with details about their daily life experiences and challenges. The following excerpt is from the initial post written by one of the diary writers.

> *I think it is more enjoyable to write a "diary" that everyone can read and comment on. I like to get feedback on how I do things, what I eat, and thoughts that I have about the surgery and about life after the operation, so here comes a little of everything…Hope you will read and comment.* [Diary writer]

The excerpt shows that the diary writer was aware and honest about her own intentions to share her personal experiences from the beginning. We observed that the diary writers received feedback and comments on their writings from other patients, as well as from the health care professionals. The replies were often of a supportive and motivational nature and were regularly offered when the narrator expressed the need for emotional and social support. Even though the diary writers wrote to achieve something in return, their postings also had value for the other readers.

> *I think they are really brave. I like to read in other peoples' diaries [laughs]. I can recognize myself [in their writings] and see how other people cope.* [Kristin]

Some preferred not to write anything on the forum themselves, they accessed the online forum solely to read others' stories and contributions, and quite a few reported that they learned from reading other patients' tips and advice. Kristin felt that she had difficulties in expressing herself in writing, but she said that she found great value in recognizing herself in other patients' stories.

> *I am not any good at writing myself, so I haven't. It holds me back. I am not any good at formulating myself. When I read others' postings, yeah, that is actually how I feel myself. To put things into words is not something I am good at.* [Kristin]

By reading other peoples' articulations, we observed that some patients found that their experiences were similar, providing a kind of relief and support because these experiences were seen as being within the "scope of normality." Some patients accessed the online forum to achieve contact with other peers. In some cases, this was articulated directly as presentation rounds, while others were more indirect in their appearances. The possibility of peer communication was more greatly appreciated in some cases than others. Monica, for example, described the fact that her daily life limited her ability to meet others face-to-face.

> *I think it is alright. I don't have the physical ability to go out several times a week to meet people. The computer has become my second home [laughs]. Yeah, so I have much contact with others, and my social life is through the computer. Therefore, I have this idea about getting to know people in the same situation.* [Monica]

The need to come in contact with other patients became evident through the forum observations, and the patients experienced benefits from having access to it, regardless of whether they were active contributors or passive participants.

Concerns Regarding Self-Disclosure

Observations indicated that some patients were active contributors to the forum, others posted little, and certain patients did not post at all, but followed the discussions. They could therefore be described as lurkers. Linn, who at the time of the interviews was waiting for her operation, expressed that she would very much like to post questions on the forum.

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> *I was really looking forwards to ask about the experiences of the others who are operated. To get some of their experiences, "harvest" of their knowledge, right? That would have been extremely valuable. But then, I think it is really scary to ask the questions, you know?* [Linn]

She explained that she perceived her literacy abilities as what precluded her from writing on the forum.

> *I have reading and writing difficulties as well, so when I start writing, it comes out weird. Then, I become even more reserved regarding writing.* [Linn]

The fear of disclosing her own writing disabilities turned her into a lurker. Observations revealed that a minority of those who had access to the forum were active contributors, and some informants revealed that they often followed the discussion without disclosing their own presence. Some said that they considered their own experiences to be insignificant and therefore did not write anything themselves. However, they reported appreciating reading other peoples' stories despite the fact that these were without particular highlights or events. Reading these narrations was mentioned as one of the main reasons they accessed the forum. The process of moving from passive participant to active contributor was suggested to be a result of experience. Anne described herself as a "forum person" because she was an experienced and active participant, but she recalled that she had only become this way through a slow transformation.

> *I was like that in the beginning. I read a lot before I took the step and started writing myself.* [Anne]

The fear of disclosing more than one might be comfortable with can be a barrier to actively contributing to such a forum. Hence, Anne's strategy was to gain confidence by reading forum posts in order to feel eligible to post.

Unlike many online forums, the discussion forum under study did not allow the participants to use nicknames, and the users appeared with their real names when posting. Most said that they did not mind posting to the forum despite the absence of anonymity, but Kristin expressed her view that she would prefer to be anonymous because this would make it easier to introduce sensitive issues and ask difficult questions. Using nicknames provides some degree of anonymity, but there are always certain degrees of self-disclosure related to posting online, as Anne expressed.

> *It does not bother me. On other forums, even though you don't have your name, with a nickname, you can find out who the person is anyway. You have to be very careful if you want to be anonymous.* [Anne]

Even though most did not perceive the lack of anonymity as a personal barrier, some questioned whether this might influence *other* patients' contributions, as Frank suggested.

> *For me, it doesn't matter, because I don't write anything I don't want people to know about. So, for my own sake, it doesn't have any influence, but perhaps, there could be an added feature via which you could post anonymously? There might be those who… not everybody is as open about everything.* [Frank]

Also, the fact that posting to the forum would reveal that they were part of a bariatric surgery community could be perceived as a barrier to active participation, which is something Kari had thought about–"I think it could be a limitation for others, and many wouldn't like the fact that other people could know about what they have gone through." Hence, being open about the surgery is not something everyone likes. Nina mentioned that the fact that only bariatric surgery patients had access made it easier to use the forum. However, she knew several others who had undergone surgery, but preferred to keep it a secret.

> *I don't have any problems with it, but others do because I see that among those I have contact with who have had the operation, I know two principals who have undergone surgery. They don't want to be open and talk about it. They want it to be kept secret…Thus, I think it can be a challenge for some.* [Nina]

Monica believed that the fact that the forum was moderated meant that it was perceived as more serious than other online health forums, and she held that this prevented people from harassing each other, as she had experienced in other forums–"I believe that when you know that this is more serious, when there are doctors and others (from the clinic) that go through (the postings), then I don't think people become that childish, letting themselves sink that low…" Forum observations did not identify any form for bullying, harassment, or other negative comments among the participants, and the peer interactions we identified were of a purely supportive character. Everyone has his or her personal limits regarding what he or she is comfortable sharing with others. Because the discussion forum under study was moderated and posting to it did not entail full anonymity, some expressed the feeling that this might increase the participants' consciousness of what they shared. Kari felt that the demarcation between personal to private sometimes disappeared when people posted online.

> *I can be personal, but I don't want to be private…Because there are many things that I think are too private to talk about. People reveal too much. I do not want all that information. Some people need to be protected against themselves. That is just something one has to realize. Some people have no boundaries. You see that on Facebook as well.* [Kari]

The various degrees of self-disclosure seemed to influence whether the participants felt eligible to actively participate or not. Also, the fact that the forum was moderated appeared to influence how the participants used the forum.

Discussion

A Moderated Forum

This study shows that patients who undergo bariatric surgery can obtain information and social support through a moderated online forum and that making such a forum available creates various practices among the patients. The patients were motivated to use the forum by the fact that they must undergo

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major lifestyle changes that affect both their physical and emotional health. Thus, there is a need for informational and social support. This finding is consistent with previous research that suggests that the desire for both information and social support is a prominent reason for online interaction [26]. The fact that the forum was moderated, and the patients could make contact with health care professionals, meant that the participants experienced the forum under study as being reliable and trustworthy. The participants provided emotional and social support to one another, and we did not identify any communication that was of a disruptive character. This was suggested to be a result of the moderation process, which is in accordance with the findings of Ryan [38].

The Digital Divide

The digital divide refers to a gap in the access and use of information and communication technology [44,45], and has been a threat to access for poor, minority, and older patients [46-49]. In a recent study that examined underserved patients' readiness towards patient portal use, Sanders et al found that the majority of the patients did have Internet access and were interested in using a patient portal as a way to manage their care [50]. However, they identified that among those who reported barriers to using the Internet, these were due to interests, know-how, and costs [50]. Because most people have access to computers and the Internet, the challenge of adopting and using these technologies becomes more prevalent, as illustrated in our study. Our findings indicate that some patients experience barriers in participating actively in the forum, implying that there might be a digital divide in this patient population that must be considered when introducing such a solution. Sarkar et al did a study on Internet patient portals in diabetes, and concluded that with the health systems increasingly relying on the Internet, those who are at most risk of poor health outcomes might fall further behind, underpinning that the digital divide extends beyond access [49].

Lurking

The discussion forum served as a source for information and advice, a place for mutual social support and networking with peers. The existence of online forums and communities is dependent on active participation and contributions, but many prefer not to participate publicly [51]. Based on our observations, we found that most were passive participants, who did not reveal their presence in the forum. This behavior can be defined as lurking, which involves seeking answers to questions and viewing and browsing others' postings, but not actually contributing [51-53]. Participation was uneven in that a minority of the patients contributed to most of the patient-generated content. This is in line with the description of lurkers and posters reported by numerous others [51-54]. There are many reasons for lurking, ranging from the personal to the work-related [51]. In our study, the consideration of self-disclosure, for example, where to draw the boundary between what to share in an online space and what not to, was identified as a factor that restrained active participation. The patients who contributed little or nothing still benefitted from having access to the contributions of other patients because the experiences of these closely resembled their own experiences. This finding is consistent with past studies showing that reading in itself benefit those who lurk in online support groups [30,32,55,56]. Despite their lack of participation, lurkers have the potential for enhanced health promotion through observing or by listening in on others conversations [55]. The fact that the users did not have the opportunity to be anonymous influenced participation. Even though some patients were reluctant to actively participate due to personal barriers, it appears that for others obtaining social support and guidance was of more importance than the issue of self-disclosure. That some patients shared their personal stories shows that the personal benefits of revealing such information are, in some cases, greater than the disadvantages. The fact that patients discussed personal problems online regardless of full anonymity indicates that not being face-to-face with the other participants made it easier to reveal such information. These findings are opposed to those of Kummervold et al, who studied mental health forums in Norway [36]. In their study, the majority of the respondents reported that they would not have participated had they not had the opportunity to use a pseudonym, thus providing full anonymity [36]. However, their respondents also found it easier to discuss personal problems online rather than face-to-face, a finding that is supported by our study [36].

Study Limitations and Implications

Our study was limited to a qualitative case study, and the findings therefore cannot be generalized. One subject of limitation was the method of recruitment to the interviews, which was done by posting an invitation on the discussion forum. This involved that only those who accessed the discussion forum would see this invitation. One might have achieved contact with other participants if one had used other recruitment methods, such as approaching them by phone. However, this would have involved far more resources than we had available at the time of the study. This study was limited to one discussion forum for bariatric surgery patients, and the results cannot be transferred to other patient populations or other health forums.

There are factors that influence forum participation, thus, determining the degree of engagement and activity. In our study, the mean age of the forum participants was 40 years, indicating that the users were not in the young segment of the population, which uses online communities as an integral part of their daily lives. However, the individuals who obtained access represent a cohort within the population of bariatric surgery patients and therefore provide some implications for future directions. Our findings imply that previous forum experience may influence participation, in that those familiar with online forums may be the individuals who contribute the most. In the literature, a phenomenon called "de-lurking" is described-unfamiliar users begin with reading and getting to know the community to educate and prepare themselves for a more active participation, and eventually write and post themselves [57,58]. It is reasonable to believe that with time, the number of people familiar with such forms of communication will increase and that those who were lurkers in the current study may "de-lurk" with time.

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Our findings have some practical implications regarding how such a solution can be used in the context of a bariatric surgery program. First, the patients are unambiguous regarding the value and usefulness of such a moderated discussion forum. Through the forum, the providers have the ability to reach out to those patients that exclude themselves from traditional programs–those who do not show up for traditional consultations, those who experience difficulties in expressing their problems in a face-to-face situation, and those who experience barriers to making contact through conventional methods. Considering the severe outcomes that patients may experience as a result of bariatric surgery, reaching out to those who are in need of informational and social support is crucial. Second, the fact that the users access the forum to read about "new" topics, for example, the weekly topic of relevance, and to read new postings from their peers implies that the forum must be dynamic. This requires the continuous facilitation of the forum, a responsibility of the relevant health care clinic. Third, the fact that the users experience the forum as trustworthy compared to other online forums indicates a great potential for the health care providers to use this channel to deliver the validated health information that the patients need. Thus, one may prevent misinformation and hopefully support the patients' coping strategies and self-management activities.

In summary, benefits such as social support obtained through interactions with peers and providers motivate patients to actively contribute in an online eHealth forum. However, issues concerning self-disclosure influence whether the patients are comfortable participating actively in the forum or prefer to lurk. Our findings indicate that previous experience with using online forums seems to have an impact because those familiar with the technology may be the individuals who contribute the most. The patients reported benefits from using an online discussion forum, regardless of their active or passive participation, even though active members obtained the greatest advantages in regard to social support and approval.

Conclusions

The findings of this study imply that a moderated discussion forum for bariatric surgery patients has potential for use in a therapeutic context. The discussion forum fulfills some of the informational and supportive needs of the patients and is particularly useful for those who exclude themselves from traditional programs or experience barriers to making contact with professionals. Even though our findings imply that the patients benefit from using the forum regardless of their active or passive participation, restraining factors, such as considerations regarding self-disclosure, must be further investigated to prevent certain users from being precluded from using such forums in the future.

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Conflicts of Interest

None declared.

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Original Paper

A Qualitative Analysis of User Experiences With a Self-Tracker for Activity, Sleep, and Diet

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Abstract

Background: The recent increase in chronic diseases and an aging population warrant the necessity of health self-management. As small electronic devices that track one's activity, sleep, and diet, called self-trackers, are being widely distributed, it is prudent to investigate the user experience and the effectiveness of these devices, and use the information toward engineering better devices that would result in increased efficiency and usability.

Objective: The aim of this study was to abstract the constructs that constitute the user experiences of the self-tracker for activity, sleep, and diet. Additionally, we aimed to develop and verify the Health Information Technology Acceptance Model-II (HITAM-II) through a qualitative data analysis approach.

Methods: The study group consisted of 18 female college students who participated in an in-depth interview after completing a 3-month study of utilizing a self-tracker designed to monitor activity, sleep, and diet. The steps followed in the analysis were: (1) extraction of constructs from theoretical frameworks, (2) extraction of constructs from interview data using a qualitative methodology, and (3) abstraction of constructs and modeling of the HITAM-II.

Results: The constructs that constitute the HITAM-II are information technology factors, personal factors, social factors, attitude, behavioral intention, and behavior. These constructs are further divided into subconstructs to additionally support the HITAM-II.

Conclusions: The HITAM-II was found to successfully describe the health consumer's attitude, behavioral intention, and behavior from another perspective. The result serves as the basis for a unique understanding of the user experiences of HIT.

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KEYWORDS

self-tracker; quantified-self; health consumer; qualitative research

Introduction

Self-Tracking Benefits

The philosophy behind the Quantified Self movement is best described by the phrase "You are your data;" it aims to improve various aspects of life and health through recording and reviewing daily activities and biometrics. It is noted that people seeking greater self-knowledge, when using numbers on this quest to understand themselves, experienced a positive and accelerated path towards their desired goals [1]. Appropriately, many new online communities are being founded where people with shared interest in self-tracking can have active discussions and share their knowledge with others. CureTogether is one of the prime examples where patients can share data and self-report symptoms, treatments, and triggers for over 300 conditions. The quantitative data at CureTogether enables decision support and hypothesis generation [2]. Another example of a similar health community is PatientsLikeMe, a health social network service. Within it, patients suffering from a motor neuron disease (namely, amyotrophic lateral sclerosis) curated a huge database on the outcomes of lithium carbonate treatment. Based on this database, the patients found that within the first 12 months lithium had no effect on the progression of their diseases. This was a powerful case of data curated through patients on the Internet serving as a critical tool for accelerating clinical

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discovery and evaluating the effectiveness of drugs already in use [3]. Ultimately, self-tracking not only benefits the individuals who are actively collecting the data in diagnosis and finding the best possible treatments, but also the sharing of such data can be integrated into traditional pharmaceutical and medical research that may result in wider impacts to the health community. Therefore, it is imperative to formally investigate these new devices so that significant improvements in the health care industry can be made.

Medicine 2.0 and Web 2.0

On the other hand, Medicine 2.0 emerged in the market nearly simultaneously and provides Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers. Those using Web 2.0 technologies and/or semantic Web and virtual-reality tools are able to facilitate social networking, participation, apomediation, collaboration, and openness within and between user groups [4]. However, for Medicine 2.0 to deliver on its promises of collaboration, participation, and social network applications, an infrastructure that allows accurate measurement, systematic classification, and continuous management of the health record is required.

> *Unless something can be measured, it cannot be improved. So we are on a quest to collect as many personal tools that will assist us in quantifiable measurement of ourselves [2].* [Kevin Kelly of the Quantified Self blog]

This suggests that health consumers need a set of easy-to-use tools that keep them motivated to track themselves, as well as tools that make sense of the tracked data and provide actionable lessons; and it is very likely that self-trackers will be able to address these various issues [1].

Self-Trackers and Smartphones

The use of self-trackers is increasing rapidly. The rapid advances in smartphone technology have resulted in a strange new concept of an “external brain” that expands the capacity of the biological counterpart. The modern population now relies on their smartphones and mobile computers with an emotional and cognitive fervor that was never before seen. By possessing a second self, people communicate, think, and act through these devices. This phenomenon is now accompanied by the so-called “digital dementia,” where people store their knowledge in external devices and no longer “remember” them in the traditional sense. Ray Kurzweil, the author of “The Singularity is Near,” has said that smartphones are “brain extenders,” and that even without being physically embedded into one’s body, people are already deeply reliant on it [5]. Aside from smartphones, new self-tracking devices like Fitbit [6], Flex, Aria, and BodyMedia are available to track and record people’s activity, sleep, and diet, as well as providing supplementary services like Web-based data management tools, data sync, and storage.

People Accepting Health Information Technology

There are many factors contributing to people using health information technology and self-trackers to manage their health. Several studies have addressed factors like technology acceptance or innovation adoption, that describe the acceptance, adoption, and utilization of information technology, and two major theories have resulted from these studies. These theories are the Technology Acceptance Model (TAM) by Davis [7] and the Diffusion of Innovation by Rogers [8]. Building upon these theories, Kim and Park developed a model that describes the process of people’s acceptance and use of Health Information Technology (HIT) for health management called the Health Information TAM (HITAM).

In 2011, IBM conducted research on health and wellness devices to identify the requirements for health devices that would enable wide distribution and increased benefits. Using an interviewing methodology, the research cast a wide net on current device users, caregivers, medical device makers, and consumer electronics companies alike. There is no precedence of investigations into the user’s perspectives and experiences using in-depth data analysis [9]. This study aims to address this gap by using a prime example of HIT, self-trackers, and individually interviewing the device users. The study proposes to process and analyze the user experience.

The questions for this research are: (1) What are the experiences of self-tracker users with activity, sleep, and diet?; (2) how to describe those experiences using relevant constructs and a model of HITAM; and (3) As a model describing health information technology acceptance, what are the differences between the results of construct modeling through quantitative analysis and construct extraction through qualitative analysis?

To address the research questions: (1) the first aim of this study is to abstract the constructs that constitute the user experiences of the self-tracker for activity, sleep, and diet; and (2) the second aim of this study is to develop and verify the HIT Acceptance Model-II (HITAM-II) by the qualitative data analysis approach.

The findings of the research will provide unique perspectives on various aspects of user attitude, intention, and actual usage behavior when accepting HIT.

Methods

Participant Age Range for the Study

Even though the aged population and the patients who suffer from chronic diseases would most benefit from utilizing self-tracking and monitoring of their health status, this population has not yet adopted it. Because of that reason, to survey the experiences of self-tracker users, participation requests were sent out to female university students 20-29 years of age. They were chosen because they possess a high level of interest in diet and health related issues, and a negligible amount of resistance towards experimenting with new technology. Since the methodology uses quasi-experimental research, the participation was strictly volunteer based, and the Institutional Review Board of the educational institute’s approval was secured prior to the start of the survey.

Participant Recruitment

Initially, the authors approached and verbally recruited the participants. Snowball sampling was then used to identify additional participants until the desired number was recruited.

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They were given the self-tracker named Fitbit, and the self-tracking survey began in December 2010 and ended in March 2011, with a total of 44 participants. The participants were asked to attend an hour long orientation session. The session consisted of presentations on the research objectives and methodology, instructions on how to use the self-tracker device, consent forms completion, registration of user accounts on the self-tracker website, and instructions on how to contact the survey administrators in case of questions or concerns. The participants were asked to track and monitor their activity, sleep, and diet for a minimum of three months.

Group Interview

At the end of the survey, 18 students consented to participate in a group interview designed to gather various opinions and impressions regarding the self-tracker. The interview was based on the focus group interview format where questions are posed to the entire group and people are encouraged to answer freely in a conversational setting. The interview lasted approximately two hours and the questions were predetermined in a semistructured questionnaire format (Table 1). However, the questionnaire was used in a flexible manner according to the flow of the interview. The entire proceeding was audio-recorded, which was transcribed into a text file afterwards.

To validate the emergent constructs using the experimental data, a structured qualitative analysis was conducted. The procedure of the analysis is as follows: (1) Stage 1-extraction of constructs from theoretical frameworks-through literature survey, seven theories regarding the information technology acceptance, adoption, and user behavior were identified [7,8,10-14]. For systematic extraction of constructs from theoretical frameworks, the primary constructs of the seven theories were compiled (Table 2). Based on the analysis, we identified the constructs unique to each theory and the constructs common to all theories. These constructs were categorized into two levels-upper and lower levels-according to the scope. The upper level included Information technology (IT) factors, Personal factors, Social factors, Attitude, Behavioral intention, and Behavior, and the lower level included the rest of the constructs. (2) Stage 2-extraction of constructs from the interview data using qualitative methodology-for systematic analysis of the qualitative data, NVivo v10.0 was used to maximally extract the various constructs expressed by the participants' languages (Figure 1 shows the constructs coding). The extraction of constructs workflow was performed iteratively, where the content of the data were analyzed repeatedly and investigated following the standard qualitative methodology. To visually represent the connectivity between the constructs, a mind map diagram was used (Figure 2 shows the mind map diagram). And finally, (3) Stage 3-abstraction of constructs and modeling of the HITAM-II-The union set of constructs identified through the literature survey in Stage 1 and the constructs extracted from qualitative analysis of the experimental data in Stage 2 were compared. Because the two stages were conducted independently of each other, the initial analysis yielded some disagreements over the various constructs, and settling the different tiers proved difficult. However, through in-depth comparative analysis of reconciling the constructs from both stages, a unified framework was established. In the framework, the constructs that were identified in Stage 1 that were not extracted in Stage 2 were eliminated, whereas newly identified constructs from Stage 2 that were not present in Stage 1 were added.

Figure 1. Screen capture of the constructs coding using NVivo qualitative analysis software.

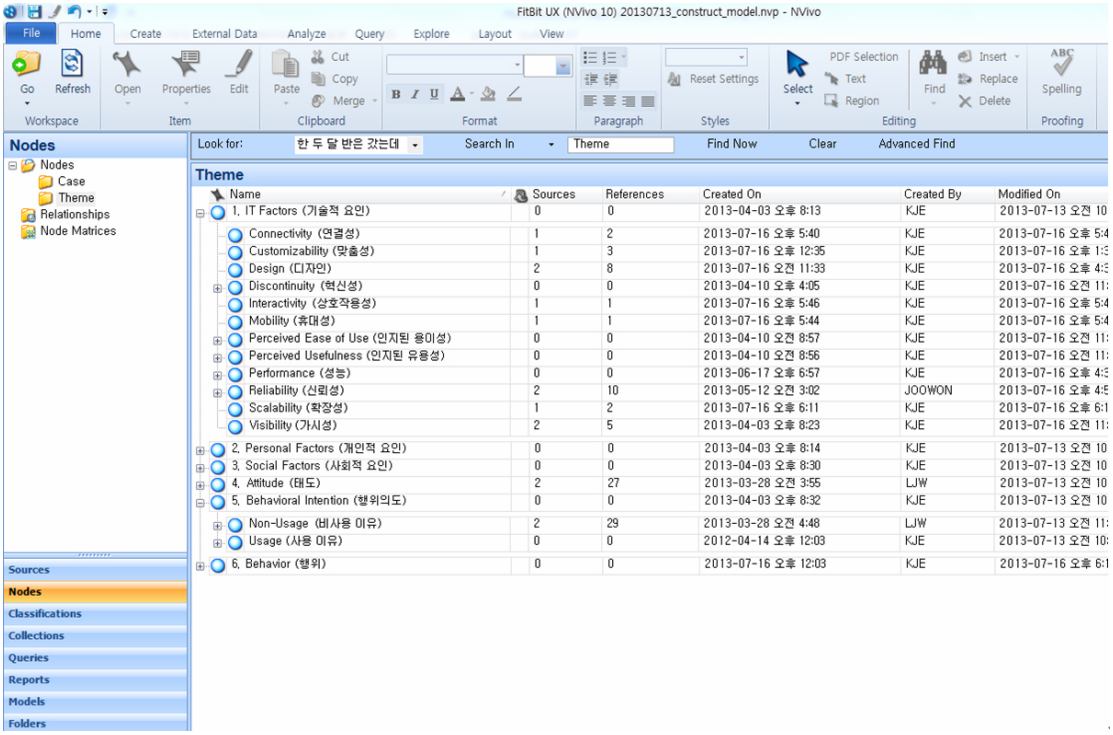

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Figure 2. The first two out of three tiers of constructs in HITAM-II.

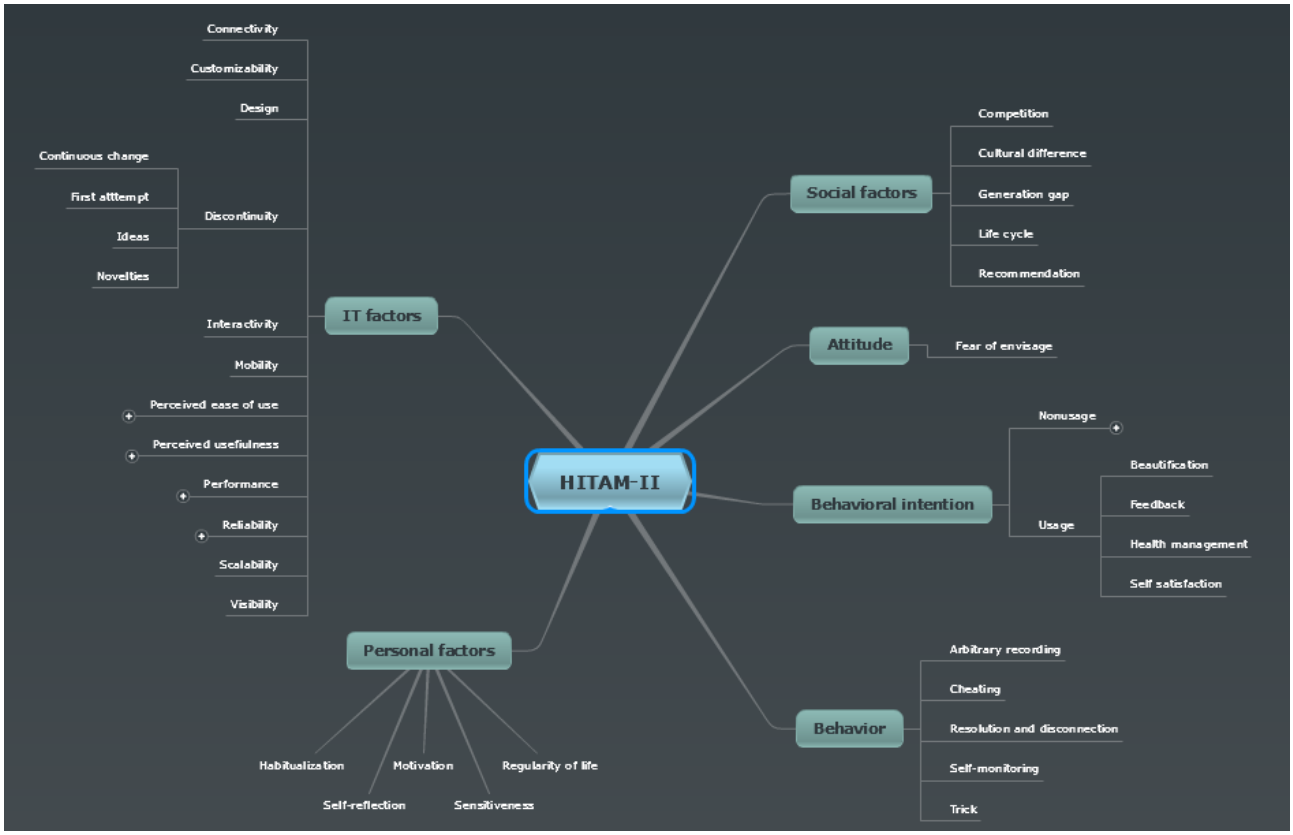

Table 1. Sessions and guiding questions of the focus group interview.

Session	Questions	Category
Intro	Simple “ice-breaking comments” and questions to make the participants understand the objectives of the research and ready for the interview.	
Transition	Have you ever heard about the cutting-edge information technology that could be used in health care and heath management?	
	Have you ever used any health devices or smartphone applications other than the device used for this research?	
Main issue	What were the main benefits that you have had using the Fitbit device?	Pros
	Was it useful for health promotion in general, or diet in specific, for example?	
	What was the most difficult aspect of using the device?	Cons
	–methods of the usage of the device itself	
	–management and/or utilization of the device	
	Do you have any good ideas to resolve these difficulties?	Upgrade
	What should be revised or added to make the device smarter to use?	
	How was your experience of using the website of the device?	Website
	Did you ever utilize the information uploaded for health promotion or diet?	
	Did you have any difficulties in information management or utilization of the website?	
	Have you ever recommended the use of the device to your family, friends, and colleagues?	Utilization
	Would you recommend the device to your family, friends, and colleagues?	
	Who do you think would get the benefit of using the device from the perspective of consumer?	
	Are you willing to purchase the device for $99.95 and pay $49.99/year to purchase the premium membership of the device?	Value
	What is your overall experience with the device? Was it positive or negative? Please explain it in detail.	Evaluation
Wrap-up	Summary and revisit any issue if needed.	

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Table 2. Constructs from relevant theories explaining the acceptance/adoption of information technology by users.

	Constructs emerged	HITAM [10]	TAM [7]	TAM 2 [11]	UTAUT[a] [12]	Attributes of innovation [8]	Adoption of information technology innovation [13]	Innovation adoption model [14]
IT factors	HIT characteristics	HIT characteristics						
	Perceived usefulness	Perceived usefulness	Perceived usefulness	Perceived usefulness				
	Perceived ease of use	Perceived ease of use	Perceived ease of use	Perceived ease of use			Ease of use	
	Output quality			Output quality				
	Product performance							Product performance
	Performance expectancy				Performance expectancy			
	Customizability							Customizability
	Observability					Observability		Observability
	Result demonstrability			Result demonstrability			Result demonstrability	
	Visibility						Visibility	
	Communicability							Communicability
	Discontinuity							Discontinuity
	Category risk							Category risk
	Image			Image			Image	
	Job relevance			Job relevance				
	Complexity					Complexity		
	Complexity in use							Complexity in use
	Complexity in design							Complexity in design
	Trialability					Trialability	Trialability	Trialability
Personal factors	Demographic variables	Demographic variables			Gender, age			
	Subjective norm	Subjective norm		Subjective norm				
	HIT self-efficacy	HIT self-efficacy						
	Experience			Experience	Experience			
	Effort expectancy				Effort expectancy			
	Personal compatibility							Personal compatibility
Social factors	External variables		External variables					
	Social influence				Social influence			

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	Constructs emerged	HITAM [10]	TAM [7]	TAM 2 [11]	UTAUT[a] [12]	Attributes of innovation [8]	Adoption of information technology innovation [13]	Innovation adoption model [14]
	Facilitating conditions				Facilitating conditions			
	Compatibility					Compatibility	Compatibility	
	Social compatibility							Social compatibility
	Relative advantage					Relative advantage	Relative advantage	Relative advantage
	Social advantage							Social advantage
	Relative economic advantage							Relative economic advantage
Attitude		Attitude	Attitude					
Behavioral intention		Behavioral intention	Behavioral intention to use	Intention to use	Behavioral intention			
	Volition							Volition
	Voluntariness			Voluntariness	Voluntariness of use		Voluntariness	
Behavior		Behavior	Actual system use	Usage behavior	Use behavior			

[a]UTAUT: Unified Theory of Acceptance and Use of Technology

Results

The Theoretical Framework

The theoretical framework established is a version of the HITAM proposed by Kim and Park [10] with modifications based on the findings of the survey. Primarily, the factors that affect the experiences of the user in HIT devices, such as self-trackers, are categorized into IT, Personal, and Social factors. In addition, the unique aspects were presented in the Attitude, Behavioral intention, and Behavior categories.

The Constructs and Subconstructs

First, the IT factors yielded a total of 11 constructs–Connectivity, Customizability, Design, Discontinuity, Interactivity, Mobility, Perceived ease of use, Perceived usefulness, Reliability, Scalability, and Visibility (Figure 3 shows these constructs). Among them, the following constructs were further divided into subconstructs (shown in parenthesis)–Discontinuity (Continuous change, First attempt, Ideas, and Novelties), Perceived ease of use (Automation, Convenience, and Fun), Perceived usefulness (Effectiveness, Functional usefulness, and Health management), Performance (Guideline, Multipurpose, and Self-tracking), and Reliability (Inferior goods, and Operational error). Second, the Personal factors yielded a total of 5 constructs–Habituation, Motivation, Regularity of life, Self-reflection, and Sensitiveness. Third, the Social factors yielded a total of 5 constructs–Competition, Cultural difference, Generation gap, Life cycle, and Recommendation. Fourth, the Attitude aspect yielded a single construct, Fear of envisage, and the Behavioral intention aspect yielded two constructs Nonusage and Usage. These two constructs are divided into the following 13 (shown in parenthesis) and 4 subconstructs (shown in parenthesis)–Nonusage (Abandonment, Cost, Forgetfulness, Inconvenience, Language barrier, Life pattern change, Lost, Lost willpower, Low priority, Reliance, Seriousness, Sustainability, and Uselessness), and Usage (Beautification, Feedback, Health management, and Self-satisfaction). Finally, the Behavior aspect yielded five constructs, Arbitrary recording, Cheating, Resolution and disconnection, Self-monitoring, and Trick. The extracted constructs, their detailed structure, and each subconstruct accompanied by a representative transcription of the interview are summarized in a supplementary table (see Multimedia Appendix 1).

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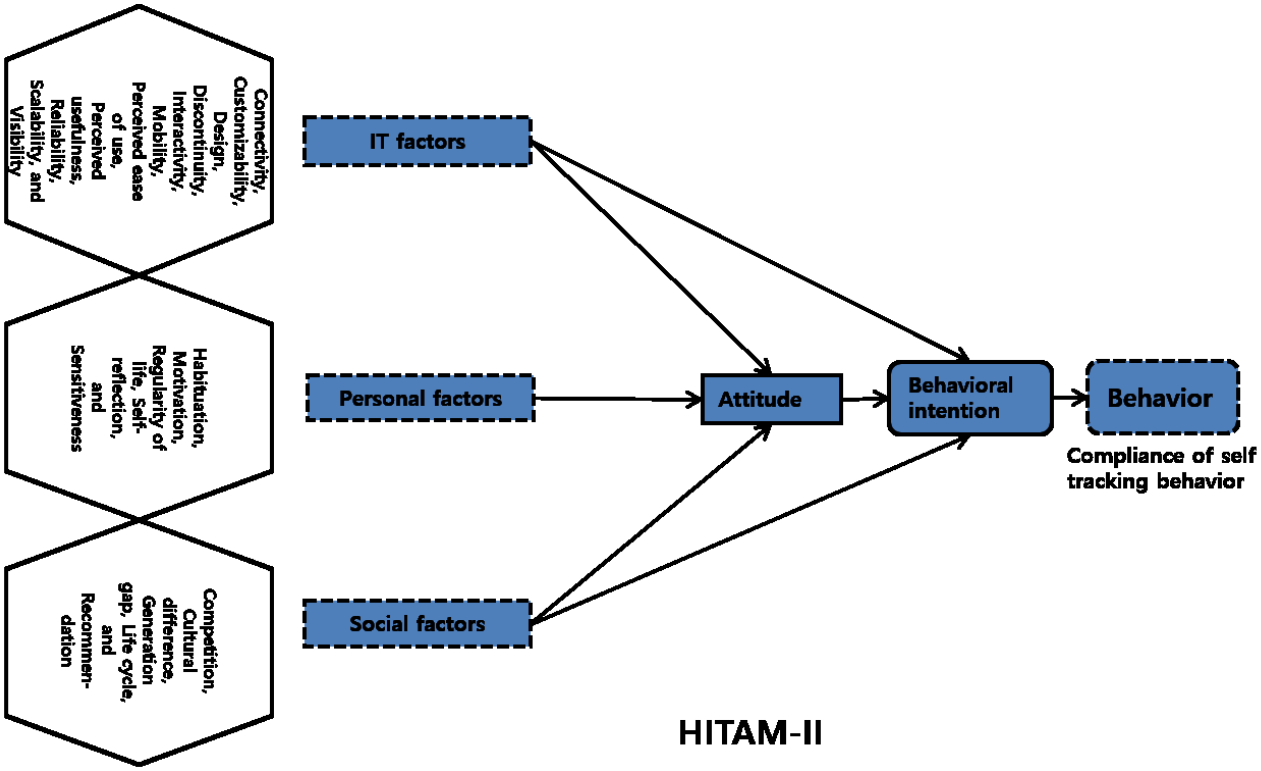
Figure 3. Theoretical framework of HITAM-II.



Discussion

Principal Findings

Our research employed qualitative data analysis methodology in order to complement the original efforts in developing the HITAM [10], as well as to supplement it with more in-depth analysis of user experience. The basis that formed the model was collected from the various information technology acceptance/adoption theories that share mutual objectives with this study and the constructs that compose the theoretical frameworks [7,8,11-14]. Our findings are unique from the previous approaches in that, instead of being the result of focusing on the description of technology acceptance/adoption, various health related factors were the main focal points of the study. Therefore, many nonoverlapping concepts were newly uncovered in this study, while some of the concepts previously identified did not emerge in our result. Additionally, the research confirmed the primary distinction between quantitative and qualitative analysis methodologies previously observed; as opposed to quantitative analysis methodologies where the majority of the survey variables are predetermined, qualitative analysis accepts new concepts that get uncovered throughout the analysis process. This highlighted the relatively construct-free analytical approach where a priori knowledge of the surveyor does not limit the outcome of the analysis.

Quantitative and Qualitative Research Methodologies

In this study, we employed a hybrid approach called methodological triangulation, where both quantitative and qualitative research methodologies are used depending on the research objectives and various stages of the research. There are three advantages to using methodological triangulation. The first advantage is completeness-quantitative methods can further develop findings derived from qualitative research and vice versa. These methods complement each other, providing richness or detail that would be unavailable from using one method alone. The second advantage is abductive inspiration. In the cases of research where a phenomenon is poorly understood, interviews with participants can orient the investigators to the appropriate material. This can lead to hypotheses that can be verified through quantitative methods. Furthermore, qualitative investigation can also help organize quantitative data that has already been gathered or suggest new ways of approaching the phenomenon. The third and the most controversial advantage is confirmation. Qualitative methods can clarify apparently inconsistent findings found in quantitative results, even in its most modest form. More tendentiously, qualitative and quantitative results can sometimes support each other. Triangulation would thus yield a stronger result than either method could yield alone [15]. Therefore, one of the contributions of the study lies in implementing a relatively novel research methodology in approaching a research question where a previously unidentified phenomenon is investigated.

The rapid advance in computer and Internet technology in the 21st century caused nearly all manner of human and environmental aspects–including methods and philosophy in scientific research–to gravitate towards digitalization. The phrase “Big Data” did not even exist a decade ago, but is now an integral phrase in countless research disciplines, and a fundamental shift in statistical methodologies that handle “Big Data” is predicted. Furthermore, it is predicted that the research methodologies for collecting and interpreting human knowledge will become more diversified as well as refined.

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Conclusions

This study contributed to such a trend in research methodology by addressing the user experience of HIT adopters, where a number of questions arise at the interface of health and information technology. Strikingly, we identified various subtle changes in the user emotion and psyche caused by self-tracking, self-reflection, self-management, and data recording. Some interesting examples included falsifying their records (both intentionally and unintentionally), failing to meet self-set goals when users temporarily felt relieved from the constant "survey" by the self-tracker, and altering their daily behaviors in order to simplify the recording process. All of these user experience accounts—including psychological and behavioral changes—will provide invaluable insights into developing the next generation of HIT devices that will seamlessly integrate into daily human lives while tracking, monitoring, recording, transferring, and utilizing various health and biometric data. This study makes its major contribution in providing the basis of understanding of the three factors—IT, Personal, and Social—and the subsequent Attitude, Behavioral intention, and Behavior that affect the self-tracking behavior with the intention of health management.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Constructs and statements of the HITAM-II.

[PDF File (Adobe PDF File), 47KB - ijmr_v3i1e8_app1.pdf]

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Abbreviations

HIT: Health Information Technology
HITAM: Health Information TAM
HITAM-II: Health Information Technology Acceptance Model-II
IT: Information technology
NRF: National Research Foundation of Korea
TAM: Technology Acceptance Model

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