Review

How the Use of a Patient-Accessible Health Record Contributes to Patient-Centered Care: Scoping Review

Janine Benjamins[1,2], MD; Annemien Haveman-Nies[2,3], PhD; Marian Gunnink[1], MD; Annemieke Goudkuil[1], MSc; Emely de Vet[2], PhD

[1]Icare JGZ, Meppel, Netherlands

[2]Chairgroup Consumption & Healthy Lifestyles, Wageningen University, Wageningen, Netherlands

[3]GGD NOG, Warnsveld, Netherlands

Corresponding Author:
Janine Benjamins, MD
Icare JGZ
Blankenstein 550
Meppel, 7943 PH
Netherlands
Phone: 31 612329494
Email: j.benjamins@cjgnoordveluwe.nl

Abstract

Background: Worldwide, patient-centered care is becoming a widely used concept in medical practice, getting more and more attention because of its proven ability to improve quality of care and reduce costs. Although several studies show that patient-accessible electronic health records (PAEHRs) influence certain aspects of patient-centered care, the possible contribution of PAEHR implementation to patient-centered care as a comprehensive concept has not, to our knowledge, been structurally evaluated to date.

Objective: The objective of this study is to review whether and how the use of PAEHRs contributes to patient-centered care both in general and among specific population groups.

Methods: We followed PRISMA Extension for Scoping Reviews reporting guidelines. We identified literature in 5 databases, using the terms “patient-accessible medical records,” “patient experiences,” and “professional experiences” as key concepts. A total of 49 articles were included and analyzed with a charting code list containing 10 elements of patient-centered care.

Results: Studies were diverse in design, country of origin, functionalities of the investigated PAEHR, and target population. Participants in all studies were adults. Most studies reported positive influence of PAEHR use on patient-centered care; patient accessible health records were appreciated for their opportunity to empower patients, inform patients about their health, and involve patients in their own care. There were mixed results for the extent to which PAEHRs affected the relation between patients and clinicians. Professionals and patients in mental health care held opposing views concerning the impact of transparency, where professionals appeared more worried about potential negative impact of PAEHRs on the patient-clinician relationship. Their worries seemed to be influenced by a reluctant attitude toward patient-centered care. Disadvantaged groups appeared to have less access to and make less use of patient-accessible records than the average population but experienced more benefits than the average population when they actually used PAEHRs.

Conclusions: The review indicates that PAEHRs bear the potential to positively contribute to patient-centered care. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centered attitude need to be addressed. Potentially significant benefits for disadvantaged groups will be achieved only through easily accessible and user-friendly PAEHRs.

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KEYWORDS

personal health records; patient portals; patient-centered care; patient-accessible records

Introduction

In the last 30 years, patient-centeredness has grown worldwide in relevance in health care policy, practice, and research. In 1987, Harvey Picker developed the Pickers' Principles of Patient Centered Care [1]. Thereafter, patient-centered care gained increasing prominence in the US when the Institute of Medicine advocated for patient-centered care as a cornerstone of health care quality [2]. In 2015, the World Health Organization stated that patient-centered care should become the standard for health care systems all over the world [3].

Key factors in patient-centered care are responsiveness to the patients' individual needs and preferences, and partnership between care providers and patients in decision making [4-7]. Patients are acknowledged as unique human beings with needs and preferences that have to be taken into account when clinical decisions are made. Ideally, patients as well as their family members or caregivers are involved in making these decisions. This requires clear information and communication with patients.

Patient-centered care has been gaining importance because of its proven ability to increase the quality of care, with lower health care utilization as a beneficial side effect [3,8-13]. The growing importance and development of the concept in different countries has led to a diversity in models, definitions, and terminology. For this review, we used an integrative model by Scholl et al [5], integrating more than 400 definitions and models into a new and comprehensible model for patient-centered care.

In the Netherlands, patient-centered care has also taken center stage in the discussion about quality of care, especially in care for youth [14]. To contribute to patient-centered care, three organizations for preventive youth health care and youth social services in the North Veluwe region developed a PAEHR system [14]. The assumption that the use of PAEHRs contributes to patient-centered care, however, has not yet been sufficiently proven.

Several reviewers investigated effects of PAEHRs by reporting on a variety of outcomes related to patient health, quality of care, or patient satisfaction [15-23]. The aspects of patient-centered care that have been mentioned are, for instance, empowerment of patients, trust in care providers, and the clinician-patient relationship. For these aspects, both beneficial [15-19] and unfavorable or even harmful consequences of the use of a PAEHR [19-23] to patient-centered care have been reported. Some studies report that disadvantaged groups might benefit less from the use of PAEHRs than others, as their access to and use of PAEHRs is lower than average [19,20,22,23]. To date, we know of no published review that structurally evaluates the possible contribution of PAEHRs to patient-centered care as a comprehensive concept. Performing such a review would enable us to explore whether PAEHRs could serve as a tool to strengthen this value-based health care model.

Since the relationship between the use of PAEHRs and the broad concept of patient-centered care has, to date, received limited attention in reviews, a broad overview of recent literature is required, with inclusion of different study designs. With such a broad perspective, a scoping review is more suitable than a systematic review, as scoping reviews aim to broadly summarize and synthesize evidence instead of finding answers to circumscript questions and including only specified study designs. A scoping review can be helpful to provide direction to future research and search for gaps in knowledge [24,25]. The objective of this review is to provide an overview of recent literature about experiences of patients and professionals with the use of PAEHRs and to investigate whether and how the use of PAEHRs contributes to patient-centered care, both in general and among specific population groups.

Methods

Search Strategy and Inclusion Criteria

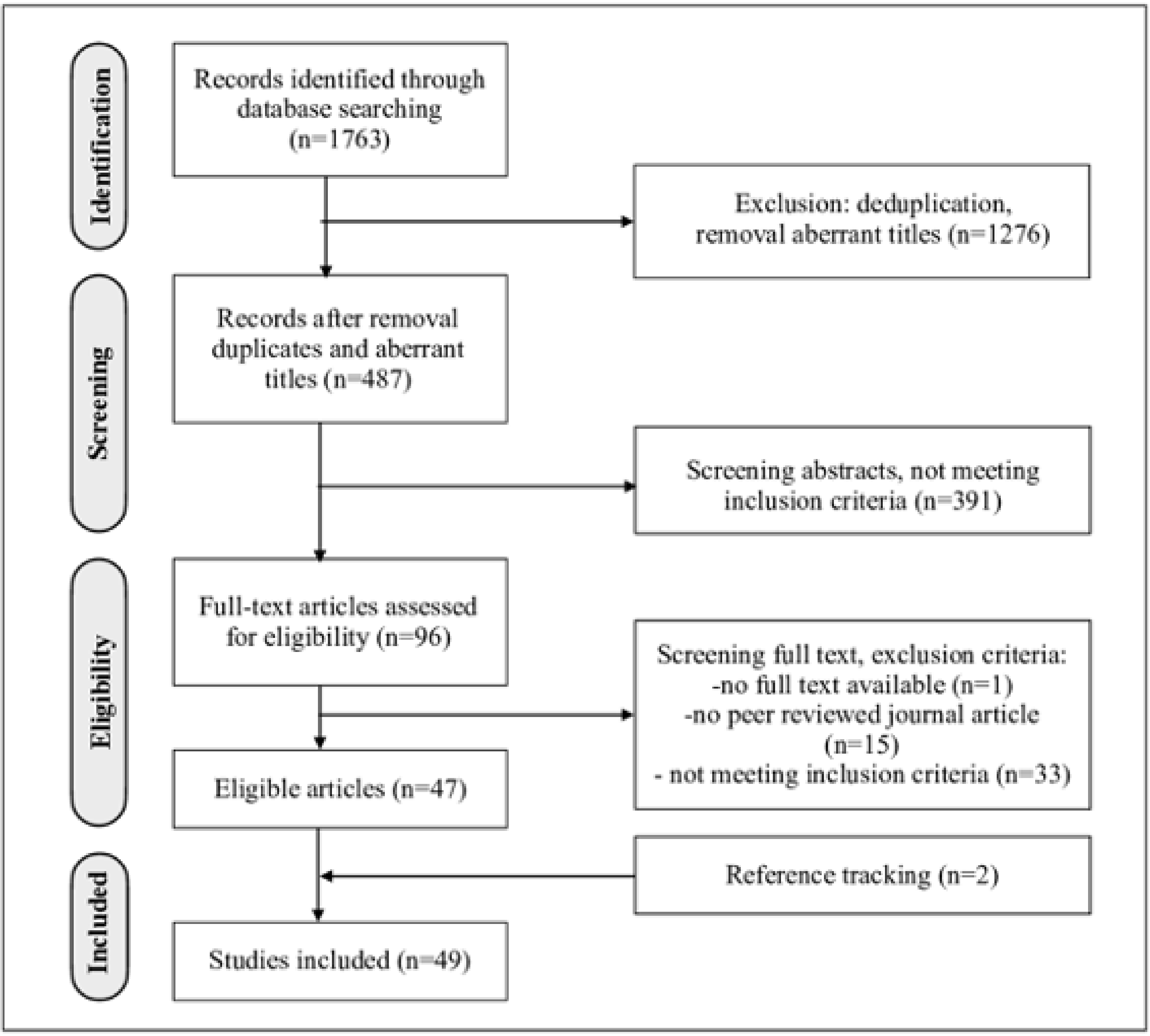
Design and reporting of this scoping review were in line with the framework for scoping reviews by Arksey and O'Malley [24-26], which was further developed by other authors, finally leading to the PRISMA Extension for Scoping Reviews guideline and checklist [27,28]. Multimedia Appendix 1 contains the completed PRISMA checklist for this review. The a priori review protocol has not been registered. Key concepts used in the search were "patient-accessible medical records," "patient experiences," and "professional experiences." Table 1 contains the full electronic search string for the Scopus database. The search was limited to papers written in English or Dutch, being languages all authors understand, and to studies published between January 2000 and April 2019. This period was chosen because, in a first quick search, most articles about PAEHRs appeared to originate from 2000 or more recently. Five databases were searched: (1) Pubmed, (2) Medline, (3) Scopus, (4) Socindex, and (5) Psychinfo. The final search was run on April 9, 2019. Search records were uploaded to Endnote X8 to facilitate the article selection process.

Searches, deduplication, and first screening of titles were performed by SJB. In total, 1763 articles were found and screened for eligibility (Figure 1). Aberrant titles were removed, and abstracts of remaining articles were independently screened by different individuals (SJB, MG, and AG), in line with the scoping nature of the review. We included research articles from peer reviewed journals for which full text could be retrieved. The articles were based on original research data. They addressed "experiences" of professionals or patients/clients using a PAEHR. Articles were screened in 3 rounds. After every round, different interpretations were discussed between all three screening authors to come to a unanimous decision. If necessary, the inclusion criteria were adapted before the next round to ensure uniform selection. SJB screened the remaining full text articles on inclusion criteria. To exclude articles from predatory journals, every journal was checked against the JournalGuide whitelist [29]. The selection process was finalized by reference tracking; all references of selected articles were checked with the inclusion criteria and added when eligible.

Table 1. Full search string for Scopus, split into three key concepts.

Key concepts	Search string per concept
Patient-accessible	("Patient" OR "Patients" OR "client" OR "clients") AND ("access" OR "online access" OR "accessible") AND ("record" OR "records" OR "file" OR "files")
Medical records	AND "Personal health records" OR "Health Record, Personal" OR "Personal Health Record" OR "Record, personal health" OR "personal health records" OR "Personal Health information" OR "Health Information, Personal" OR "Information, Personal Health" OR "Personal Medical Records" OR "Medical Record, Personal" OR "Medical Records, Personal" OR "Personal Medical Record" OR "Record, Personal Medical" OR "Records, Personal Medical" OR "patient portals" OR "Patient Web Portal" OR "Portal, Patient Web" OR "Portals, Patient Web" OR "Web Portal, Patient" OR "Web Portals, Patient" OR "Patient Internet Portals" OR "Internet Portal, Patient" OR "Internet Portals, Patient" OR "Patient Internet Portal" OR "Portal, Patient Internet" OR "Portals, Patient Internet" OR "Patient Web Portals" OR "Patient Portal" OR "Portal, Patient" OR "Open Notes" OR "Electronic health records"
Patient experiences AND physician experiences	AND "patient experiences" OR "physician experiences" OR "experiences" OR "experiences, patient" OR "experiences, patients" OR "experiences, physician" OR "experiences, physicians" OR "experiences, professional" OR "professional experiences" OR "outcome assessment (health care)" OR "benefit" OR "satisfaction" OR "patient outcomes"

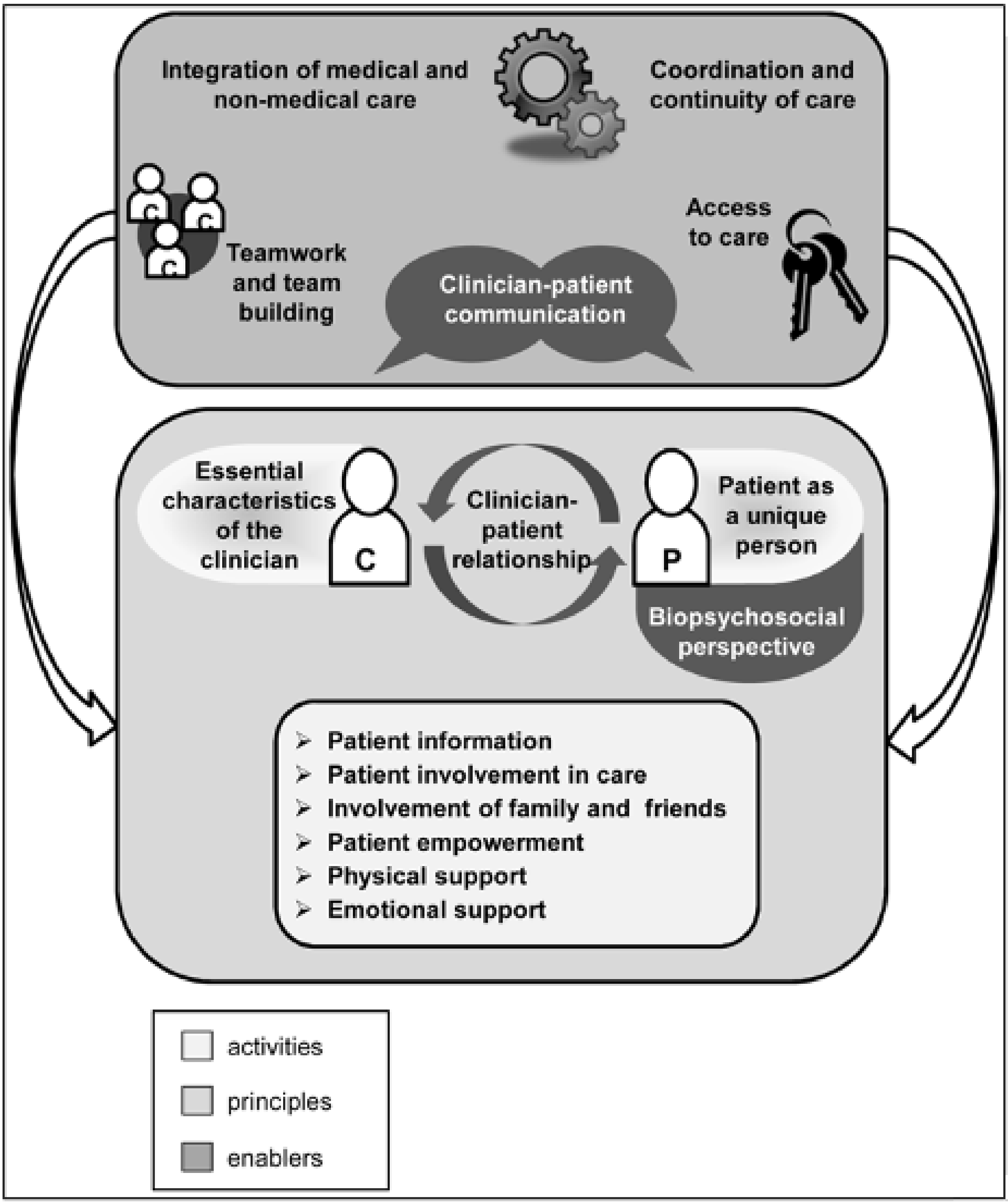
Figure 1. Flow diagram of article selection.



Data Analysis

Through discussion SJB, AH, and EV came to a charting code list (see Multimedia Appendix 2). The list contained codes for general article information, study methods, description of the investigated PAEHR, and 10 dimensions of patient-centered care. The dimensions of patient-centered care were derived from a model, developed by Scholl et al (Figure 2) [5]. This model distinguishes 15 dimensions in 3 groups: (1) principles, (2) enablers, and (3) activities. The principles represent the essential factors of a patient-centered attitude in professionals. The principles and the enablers, which are organizational conditions for patient-centeredness, lay the foundation for the last group, the activities. These are actions and measures by which patient-centered behavior becomes visible. Assuming that use of PAEHRs would affect the "activities" from the model, possibly affect the "enablers," and not affect the "principles," we included all 5 enablers and 4 activities. We did not include the activities "physical support" and "emotional support," since we expected not to find any relation with the use of PAEHRs. From the principles, only clinician-patient relationship was included, because we considered this dimension a dynamic one that could be influenced by use of a PAEHR. A separate charting code was created for differences among population groups, since former research suggests that disadvantaged groups might benefit less from the use of PAEHRs than others [19,20,22,23]. The charting process was done by SJB and discussed afterward with the other authors. All charted data were aggregated through group discussion with all co-authors.

Figure 2. Model of Patient-centered Care, by Scholl et al (2014).



Results

Overview

In total, 49 eligible articles were included [21,30-77]. Multimedia Appendix 3 presents a brief summary of the articles, with characteristics of each study, functionalities of the studied PAEHR, and reported elements of patient-centered care. Multimedia Appendix 4 provides an overview of all outcomes. In this appendix, the articles were divided into 3 study design groups to facilitate the analysis. The largest group (n=34) consists of descriptive studies, both qualitative and quantitative [21,32-35,37-43,45,47-51,53,55,56,58,59,62,63,65,69-73, 75-77]. The other 2 groups contain pre-post-test comparative studies [21,40,60,61, 70,71,75,76] and studies comparing intervention and control groups [30,31,36,44,46,47,52, 54,57,64,66-68,74]. The results of 7 mixed methods studies were divided and categorized according to the groups they best matched with [21,40,47,70,71,75,76].

Most articles (n=29) originated from the US [21,30,32-40,42,44-46,49,50,54-58,60,63,66,69,74,76,77]. Clustered in 5-year periods, 3 articles originated from 2000-2004 [34,40,66], 3 from 2005-2009 [43,67,68], 15 from 2010-2014 [21,33,47,49,54,55,58,59,64,69,71,73-75,77], and 28 from 2014-2019 [30-32,35-39,41,42,44-46,48,50-53,56,57,60-63, 65,70,72,76]. Duration of experience with a PAEHR varied from 1.5 to 48 months. Population sizes were also diverse, ranging from 9 in a qualitative study [41] to several thousand in an Open Notes survey study (n=29,191) [56]. Finally, the population demographics varied; most studies included a broad range of patients (eg, patients in hospitals [30,34,60,72,76] or in primary care [21,32,42-46,48,49,54,57,58,63]). Other studies focused on specific patient groups, like cancer patients [30,37,50,59,62,75], cardiac patients [40,66,74], chronically ill patients [31,64,71], HIV-positive patients [36,57], psychiatric patients [35,39,70], gynecologic patients [67,68,73], and veterans [35,36,39,55,56,69,77]. Ten studies investigated experiences of both patients and their care providers [21,32,34,40,51,57,58,60,70,72]. Four studies focused on professionals only [38,41,61,65]. Respondents in all studies were adults, mostly of no specific age group. Three studies surveyed parents of pediatric patients [33,37,51].

Apart from record-access, the most common functionalities of the PAEHRs were "electronic messaging" [33,36,37, 40,51,55,56,64-66,68-70,72,74,76] and the possibility to add or edit health information [31,34,54-56,58,62,65,70,72,74,75]. Six studies investigated a so-called active PAEHR that sent patients "personalized health messages" [31,34,58,63,67,68]. Other functionalities were "give feedback on health information"[62,65], "download information to share with others"[30,42,58], "grant direct access to others" [55,62,76,77], and administrative tasks like "scheduling appointments" [30,51,59], "paying bills" [30], and "requesting medication refill" [30,72].

One patient-accessible record was paper-based and consisted of a briefcase with all medical information, which was updated after every visit to the clinic [47]. Two PAEHRs were electronic but not available online [43,73]. One was a USB-stick containing all medical information, which was revised during every visit to the clinic [73]. The other was a kiosk in the clinic's waiting room, where patients could access all medical info during their visit [43]. In one study, 9 physicians were interviewed about their experiences with PAEHRs in general [30].

Dimensions of Patient Centeredness

The outcomes for the 10 coded dimensions of patient-centered care have been summarized in Table 2. In 34 of the studies at least 3 of these dimensions were explored. None of the studies mentioned the dimensions "integration of medical and non-medical care" and "teamwork". The following paragraphs describe the outcomes for each dimension of patient-centered care. When describing outcomes, we use the term "effect" both for experienced effects as well as for objective results from comparative studies.

Table 2. Summary of results for dimensions of patient-centered care. This table represents, for every explored dimension of patient-centered care, whether reported outcomes point in a positive or negative direction. “Negative” in a pre-post comparative design means “less positive than expected.” In a pre-post or intervention-control design, the term “neutral” refers to the outcome “no difference” or “no significant difference.”

Dimension	Number of studies, n	Descriptive studies, reference number		Comparative studies, reference number		
		Positive	Negative	Positive	Neutral	Negative
Information	40	[21,32-34,37-43,45,47-51,53,55,56,58,59,62,63,65,69-72,75-77]	N/A[a]	[30,31,36][b]; [44,46,47,76]	[60,67]	[61]
Involvement in care	33	[32,34,37,38,40-43,47-51,55,56,59,62,63,65,69,71,75,77]	N/A	[36,54][b]; [44]	[30,46,64,67,74]	[60,61]
Empowerment	23	[21,33,39,42,45,47,48,50,56,58,63,70,76]	N/A	[46,59,60,66]; [76][b]	[36,40,61,68,70,71,75]	N/A
Communication	22	[33,34,37,40,41,45,47,48,51,53,55,58,59,62,63,65,70,71,76,77]	N/A	[76]	[57,66]	N/A
Involvement of family and friends	14	[42,45,47,49,51,55,59,62,69,71,73,76]; [70][c]	[70][c]	[57]	N/A	N/A
Clinician-patient relationship	22	[21,32,35,38-43,45,50,59,62,63,65,71,72]	[41][c]	[44,74]	[57]	[60,61]
Access to care	5	[42,45,49,62,63]	N/A	N/A	N/A	N/A
Coordination / continuity of care	3	[40,58,76]	N/A	N/A	N/A	N/A
Integration medical / nonmedical	0	N/A	N/A	N/A	N/A	N/A
Teamwork	0	N/A	N/A	N/A	N/A	N/A

[a] N/A: not applicable.

[b] Significant effect.

[c] Both positive and negative aspects reported.

Information

Forty studies investigated if and in what way patients felt more informed about their health after use of a PAEHR. We distinguished 3 different topics: (1) what patients valued in reading records, (2) emotional consequences, and (3) understandability. Seven descriptive studies examined reasons for reading medical records [32,43,45,56,62,75,76]. Patients valued reading their record because they wanted to know about their health or because they wanted to be sure they understood what the doctor said or because they were curious. Patients valued reading their records most because it improved understanding of health issues [21,34,39,45-47,50,53,56,60,61,65,69,71,75-77], helped to prepare for next visits [21,56,59,61-63,65,71,75,76], and helped to remember the care plan [21,40,42,43,45,46,49,50,56,61,76]. Reading also helped patients to follow treatment recommendations [33,39,41]. Six studies compared the difference in health knowledge between intervention and control groups [30,31,36,44,47,67]. One study found a significantly higher “self-health management knowledge score” among PAEHR adopters than among nonadopters ($P<.01$) [30]. Another study found that the intervention group was significantly better informed than the control group about their latest blood measurement levels, including date, time, and trend changes, and about normal lab values ($P<.001$) [31]. A third study found that HealtheVet users were able to correctly identify their CD4 counts significantly more often (Fisher exact test=.048) and their viral load (Fisher exact test=.003) than nonusers [36]. The other studies found no significant difference [44,47,67]. Two pre-post studies compared expectations with experiences [61,76]. After a period of PAEHR use, one of the studies reported better understanding of care plans among patients than expected (OR=1.39) [76]. In the other study, however, interviewed psychiatrists reported less improvement than expected in the extent to which patients understood their medical conditions or remembered their care plans [61].

Reading their records also provided patients with reassurance [33]. In 4 qualitative studies, patients said that transparency reduced anxiety and stress [33,45,56,62]. They experienced waiting for news as more stressful than reading notes by themselves. One patient said: “It is easier to break down at home where you are surrounded by family, than at the doctor’s office” [62]. If reading records caused stress, this was in most cases related to new diagnoses which had not yet been discussed with the professional [33]. Stress was also caused if health care professionals trivialized a patient’s problem in the record [39]. Less than 10% of patients often or always experienced worries or confusion after reading their record [21,39,56,57,76]. Three intervention-control studies found no significant difference in anxiety levels or reported worries between users and nonusers [47,52,57].

Six studies investigated if patients understood everything they read and how they felt they did not understand [34,40,50,58,62,77]. Some patients said they would appreciate built-in-definitions and less jargon. On the other hand, one patient added: “I would rather have the doctors just write what they write and me work to understand it, than them writing it for me and leaving something out that I would like to know" [40]. Moreover, although patients found some medical terminology too difficult, they managed to find explanations on the internet [58,62].

Involvement in Care

Thirty-two studies described the impact of use of PAEHRs on involvement in care. Twenty-three descriptive studies described involvement of patients in their care as a benefit of using a PAEHRs [32,34,37,38,40-43,47-51,55,56,59,62,63,65,69,71,75,77]. Clinicians in one study said that using a PAEHR resulted in a "power shift" towards patients. Some of them saw this as a "move towards patient-centered care, creating better opportunities for collaboration with patients" [38]. In intervention-control studies, the 13-question Patient Activation Measurement (PAM-13) Questionnaire was most commonly used to measure involvement of patients in their care. Two intervention-control studies found a significantly higher PAM-score in the user groups [36,54]. One study reported a mean PAM-13 score of 47 points in the intervention group versus 45 points in the control group (P=.0014) [54], whereas the other study reported a mean PAM-13 score of 72.5 in the intervention group versus a mean of 63.49 in the control group (P=.03) [36]. Three studies found no significant effect on activation score or decision making [64,67,74]. One study, comparing different user subgroups, reported that less educated patients and non-White patients were more likely to report that reading visit notes was extremely important to engaging in their care than more educated and White patients [46]. In the 2 pre-post comparisons, the observation that patients were "feeling more in control" was slightly lower than expected [60,61].

Five studies investigated if patient involvement would result in patients finding and correcting errors in their record [45,60,62,65,76]. One descriptive study reported that 6 patients in a group of 15 had found errors but had not requested correction [62]. One study investigated a PAEHR with a feedback option [45]. Patients valued this feedback option because it helped them to correct errors. Two descriptive studies reported that physicians felt that use of PAEHRs could prevent medical errors and that the PAEHRs were used by patients as a means to check for accuracy [65,76]. In one pre-post study, patients found less errors than expected, although errors were found and corrected; in a group of 50 patients, 3 patients reported finding errors in medication, 2 patients found errors in radiology test reports, and 1 patient found an error in a laboratory test report [60].

Involvement of Family and Friends

Fourteen studies investigated whether and how family and friends were involved in care through use of PAEHRs. Thirteen descriptive studies reported that patients shared health information with relatives, friends, and health professionals [42,45,47,49,51,55,59,62,69-71,73,76]. Patients said they shared information to answer questions of family and friends and to keep them informed. Sharing information also helped to discuss their disease with relatives or caregivers. The percentage of patients who actually shared notes with others differed among studies, from 15% to 67%. One descriptive study among patients with a bipolar disorder reported that 23% of the 39 respondents considered access to family caregivers preferable, whereas 25% thought it would be harmful [70]. One study, comparing HIV-positive patients with other patients in primary care, found that HIV-positive patients were more likely than other primary care patients to share or discuss visit notes with others, both friends and professionals [57]. In one mixed-methods study, caregivers especially valued the ability for a patient to share information with them, because this enabled them to view notes of visits which they had not been able to attend [76].

Empowerment

In 13 descriptive studies, patients mentioned that they felt more in control of their health or that they could take better care of their own health due to reading their record [21,33,39,42,45,47,48,50,56,58,63,70,76]. In one study, patients appreciated the possibility to share a print-out of their record with another doctor [59]. Patients also said that their role became more active [45]. They experienced more ownership of their own health status [63]. Three control-intervention studies reported no significant difference in empowerment between intervention and control groups [36,66,68]. In 7 pre-post studies, 6 studies found no significant effect on empowerment scores [40,60,61,70,71,75]. The 7th study reported that patients were more confident in their ability to manage their health information (OR 2.14, 95% CI 1.59-2.89) and their care (OR 1.48, 95% CI 1.14-1.93) [76].

Communication

Twenty descriptive studies investigated the effect on communication between patient and health care professional and reported an improvement [33,34,37,40,41,45,47,48,51,53,55,58,59,62,63,65,70,71,76,77]. Communication became easier because of the PAEHRs, and interaction improved [34,58]. The ability to view health information improved the level of communication during subsequent visits and made it possible to communicate "on a more level playing field" with health care professionals [41,51]. The use of a PAEHR also removed barriers, for instance, "because you can ask 'stupid' questions that you wouldn't pick up the phone for" [33]. Two intervention-control studies reported on communication and found no significant differences between intervention and control groups [57,66]. One pre-post study reported that caregivers appreciated the possibility to view notes of visits they could not attend, because it improved their communication with care providers [76].

Seven descriptive studies investigated the influence of PAEHR use on time investment, 5 of them reporting no difference [21,32,40,58,62,65,72]. One study reported that some professionals needed more time to edit or explain notes. However, they framed this as "better documentation, a good thing" [21]. In one study, a professional said that it was improving efficiency: "finally something to save me time!" [58]. One intervention-control study reported that professionals received more messages per patient, but nonetheless did not feel a perceptible change in workload [66]. Four pre-post studies investigated expectations of more time investment, but none demonstrated an increased time investment [21,40,60,61].

Clinician-Patient Relationship

Seventeen descriptive studies reported on the clinician-patient relationship [21,32,35,38-43,45,50,59,62,63,65,71,72]. Patients reported that they were feeling better about their doctors after reading their records [32,39]. They appreciated their doctors' expertise more and experienced a more equal relationship [40,41,43,45,62,64,65,72]. They valued the level of transparency, especially when notes were written respectfully [35,43,50,59]. Respectfully written notes contributed to their feelings of trust [35,71]. As a result, they felt heard and cared for [45]. Three intervention-control studies and 1 pre-post study reported on the professional-client relationship and found no significant differences [44,57,74]. Two other pre-post studies, however, found that the experienced increase of trust in physicians was less than expected, both from a patient and a professional perspective [60,61].

Related to the fear of damaging a therapeutic relationship, some professionals expected that they would report differently if they knew patients could be reading their visit notes. A psychiatrist in one study said: "Sometimes a disbalance occurs, patients 'directing their care' and dictating their doctors how to write their notes" [41]. These psychiatrists also feared that transparency of records could damage the therapeutic relationship, especially when notes revealed subjective impressions. Four pre-post intervention studies investigated if clinicians reported differently about sensitive subjects. Professionals appeared to report less differently than they had expected [21,57,58,61].

Access to Care

An access to care dimension was mentioned in 5 qualitative studies [42,45,49,62,63]. Patients experienced that the PAEHRs gave easy and quick access to health information [42,45,62]. Rapid access was perceived to be advantageous in emergency situations [49]. One study also mentioned that immediacy of secure messaging cultivated a sense of ease of access [63].

Coordination and Continuity

In 2 qualitative studies [40,58] continuity and coordination of care came up. Patients mentioned the benefit of being able to bring their health information along to another care provider and to take care of their own medication when they are out of town.

Differences Among Population Groups

Since former research suggests that different population groups do not profit equally from the use of PAEHRs [19,20,22,23], we searched for differences in our review. Seven studies compared the composition of the studied population with national demographic data. They reported that PAEHR users were more likely to be White and higher educated than nonusers [30,35,36,39,40,44,45]. Four studies investigated experiences of different ethnic and socioeconomic groups [32,45,46,49]. One descriptive study found that women, older patients, and high frequency users found reading notes very important to engaging in their care [45]. Another descriptive study reported that older, lower educated, retired, and unemployed patients, as well as patients with a poor self-reported health and participants in other studies were more willing to share visit notes with others [49]. A third descriptive study found that disadvantaged groups such as the elderly, non-White patients, less educated patients, or patients with poor self-reported health, reported more often than others that use of a PAEHR made them feel better about their doctors [32]. One intervention-control study focused on the importance of PAEHRs to non-White and less educated patients [46]. Both non-White and less educated patients reported more often than White and higher educated patients that the PAEHRs helped them to understand and remember care plans, feel informed, and make decisions concerning their own care. Both non-White patients and less educated patients found reading notes extremely important to engaging in their care.

Discussion

Summary

This review investigates whether and how the use of PAEHRs contributes to patient-centered care, both in general and among specific patient groups. Overall, the articles in this review support the assumption that patient-accessible records contribute to patient-centered care. In all 34 descriptive studies, a positive effect is reported for different dimensions. One descriptive study reported a possible negative effect of PAEHRs on the "therapeutic relationship." Five out of 22 pre-post or intervention-control studies reported significant positive effects related to the dimensions "information," "involvement of patients," or "empowerment." No significant negative effects were reported.

The studies in this review included adults only. Four studies found that, in particular, disadvantaged groups experienced PAEHR-related benefits [32,45,46,49].

Dimensions of Patient-Centered Care

As we expected, the effect on the different "activities" in the Scholl et al model [5] was described most often. Although some effects on "enablers" are reported, only two of the "enablers" are mentioned: (1) access to care [42,45,49,62,63] and (2) coordination/continuity of care [40,58,76]. A complicating factor in the analysis was the varied use of dimensions and their definitions. For instance, whereas Scholl et al [5] distinguished "information," "involvement in care," and "empowerment" as different dimensions, some studies included "involvement" and "knowledge/information" in questionnaires about "empowerment" [5,40,68,71].

Furthermore, we found topics in our review that were not described by Scholl et al [5]. One topic was that patients contributed to patient safety by finding and correcting errors in their records [45,60,62,65,76]. After discussing this topic, we added the subject to "involvement in care," arguing that patients showed their involvement in care by checking their record for errors. In a recent article by Zeh et al [78], however, patient safety was added to the Scholl et al model [5] as a new dimension based on a Delphi study among patients. Patients regarded patient safety as an important dimension of patient-centered care.

Both negative and positive effects were reported for the dimension "patient-clinician relationship." In particular, professionals in mental health care expressed concerns that the transparency of PAEHRs would damage the patient-clinician relationship [38,61]. This is in line with results from other studies. In a recent Norwegian study [79], professionals in mental health care report significantly more often than their colleagues in somatic care that they change their way of writing when using PAEHRs. They also discuss significantly more often than their colleagues in somatic care whether patients should be denied access to their record. Dobscha et al [80] reported that only half of the mental health professionals they queried (107/198) considered sharing mental health Open Notes with patients a good idea, while most of them (174/205) supported the idea in general to share medical notes with patients.

In opposition to professionals, mental health care patients in our review felt that transparency in a PAEHR strengthened the patient-clinician relationship, given that sensitive information was reported in a respectful way [35,38]. The fact that professionals see this differently could be caused by traditional role expectations “in which the patient is viewed as someone to ‘protect’ and for whom the clinician is responsible” [38]. These role expectations are at odds with the patient-centered care principle of “equal partnership between client and professional” and might cause the reluctance toward the use of transparent PAEHRs.

In line with this assumption, another study emphasizes the importance of a patient-centered attitude by offering specific recommendations for mental health professionals to strengthen the therapeutic alliance in the context of patient-accessible records [35]. These recommendations focus on the “principle” dimensions from the Scholl et al model [5]. The findings in these studies strengthen the assumption in the Scholl et al model that the “activity” dimensions only become visible if the “principles” of patient-centered care, reflected in a patient-centered attitude, have been embraced by professionals.

Differences Among Population Groups

Previous research suggests that disadvantaged groups might profit less from the introduction of PAEHRs than others because they make less use of PAEHRs [19,20,22,23]. In our review, 7 studies reported that users of PAEHRs were more likely to be White and higher educated than nonusers [30,35,36,39,40,44,45], probably due to different access abilities [36]. Surprisingly, 4 other studies found that disadvantaged groups experienced heightened benefits from the use of PAEHRs [32,45,46,49]. An explanation for this benefit could be the value of rereading information that cannot be absorbed all at once. Moreover, Bell et al [32] state that non-White patients are said to distrust White medical professionals, not expecting them to respect their cultural values. Reading transparent records would prove otherwise and might help these patients to trust their doctors more [32]. These findings show that disadvantaged groups benefit from the use of PAEHRs, once they have found their way into the system. This emphasizes the importance in designing and implementing PAEHRs that are easily accessible in order to include disadvantaged groups.

Practical Implications

Our review shows that the use of PAEHRs could enhance patient-centered care, but the effects can be influenced by factors on professional and patient levels. On a professional level, adoption of the principles of patient centered care appears to be crucial for a positive impact of the use of PAEHRs on the patient-clinician relationship. On the patient level, easy access and user-friendliness is important to secure access for all demographics and to facilitate the PAEHR-related benefits that disadvantaged groups might experience.

Strengths and Limitations

One of the strengths of this scoping review is that we included all types of designs and we did not focus on “patient-centered care-specific” search terms. As a result, we created a broad overview on the topic. Subsequently, the analysis was guided by the use of selected dimensions of patient-centered care from Scholl et al [5], which helped us to organize and interpret the information and added strength to the review. On the other hand, the fact that the analysis was conducted in separate dimensions made it more difficult to explore interaction and dependence between the dimensions and to draw conclusions about the impact of PAEHRs on patient-centered care as a whole.

Another strength is the combination of searches from 5 different databases, from both a medical and a social perspective.

A limitation of this review is that, by specifying only “physicians” in our search terms and not “nurses,” “nurse practitioners,” or nonmedical professionals, we could have missed some articles that were relevant to the subject.

One more limitation of this review is that we included articles in only English and Dutch and no unpublished data or grey literature. For example, no articles from Estonia or Japan could be included, although both countries are very active in eHealth and the government of Estonia has implemented a PAEHR system that is being used for every citizen of the country.

The strength of the conclusions in this review also depends on the quality of the individual studies. Therefore, we conducted a global quality check, where aspects of study design and population were assessed. Although a thorough quality appraisal is not common in scoping reviews, a more detailed quality check could have added strength to the review. The global check indicated that, on average, study results could have been biased because of population selection, as virtually all studies included only native speakers and most of the studies made use of convenience sampling.

Conclusions

This review indicates that PAEHRs bear potential to positively contribute to patient-centered care. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centred attitude need to be addressed. Potentially high benefits for disadvantaged groups will be achieved only through easily accessible and user-friendly PAEHRs.

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Authors' Contributions

JB, AH, and EV participated in the conception and design of the review. JB, AG, and MG performed the search and elimination of titles/abstracts. All authors contributed to the analysis and interpretation of the data. JB and AH lead the drafting of the manuscript, and EV, AG, and MG contributed to critical revisions of the manuscript. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Completed PRISMA-ScR Checklist.
[PDF File (Adobe PDF File), 499 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Coding list, used for analysis.
[XLSX File (Microsoft Excel File), 11 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Study characteristics, PAEHR functionalities and dimensions of Patient Centered Care.
[XLSX File (Microsoft Excel File), 84 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Analysis of outcomes.
[XLSX File (Microsoft Excel File), 33 KB-Multimedia Appendix 4]

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Abbreviations

PAEHR: patient accessible health records
PAM-13: 13-question Patient Activation Measurement

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Original Paper

Rapid COVID-19 Screening Based on Self-Reported Symptoms: Psychometric Assessment and Validation of the EPICOVID19 Short Diagnostic Scale

Luca Bastiani[1], PhD; Loredana Fortunato[1], MSc; Stefania Pieroni[1], MSc; Fabrizio Bianchi[1], PhD; Fulvio Adorni[2], MPH; Federica Prinelli[2], PhD; Andrea Giacomelli[3], MD; Gabriele Pagani[3], MD; Stefania Maggi[4], PhD; Caterina Trevisan[5], MD; Marianna Noale[2], MSc; Nithiya Jesuthasan[2], MPH; Aleksandra Sojic[2], PhD; Carla Pettenati[2], MD; Massimo Andreoni[6], MD; Raffaele Antonelli Incalzi[7], MD; Massimo Galli[3], MD; Sabrina Molinaro[1], PhD

[1]Institute of Clinical Physiology, National Research Council, Pisa, Italy
[2]Institute of Biomedical Technologies, National Research Council, Milano, Italy
[3]Infectious Diseases Unit, Department of Biomedical and Clinical Sciences Luigi Sacco, Università di Milano, Milano, Italy
[4]Institute of Neuroscience, Aging Branch, National Research Council, Padova, Italy
[5]Geriatric Unit, Department of Medicine, University of Padova, Padova, Italy
[6]Infectious Diseases Clinic, Department of System Medicine, Tor Vergata University of Rome, Rome, Italy
[7]Unit of Geriatrics, Department of Medicine, Biomedical Campus of Rome, Rome, Italy

Corresponding Author:
Sabrina Molinaro, PhD
Institute of Clinical Physiology
National Research Council
Via Moruzzi 1 Pisa
Pisa, 56127
Italy
Phone: 39 0503152094
Email: sabrina.molinaro@ifc.cnr.it

Abstract

Background: Confirmed COVID-19 cases have been registered in more than 200 countries, and as of July 28, 2020, over 16 million cases have been reported to the World Health Organization. This study was conducted during the epidemic peak of COVID-19 in Italy. The early identification of individuals with suspected COVID-19 is critical in immediately quarantining such individuals. Although surveys are widely used for identifying COVID-19 cases, outcomes, and associated risks, no validated epidemiological tool exists for surveying SARS-CoV-2 infection in the general population.

Objective: We evaluated the capability of self-reported symptoms in discriminating COVID-19 to identify individuals who need to undergo instrumental measurements. We defined and validated a method for identifying a cutoff score.

Methods: Our study is phase II of the EPICOVID19 Italian national survey, which launched in April 2020 and included a convenience sample of 201,121 adults who completed the EPICOVID19 questionnaire. The Phase II questionnaire, which focused on the results of nasopharyngeal swab (NPS) and serological tests, was mailed to all subjects who previously underwent NPS tests.

Results: Of 2703 subjects who completed the Phase II questionnaire, 694 (25.7%) were NPS positive. Of the 472 subjects who underwent the immunoglobulin G (IgG) test and 421 who underwent the immunoglobulin M test, 22.9% (108/472) and 11.6% (49/421) tested positive, respectively. Compared to NPS-negative subjects, NPS-positive subjects had a higher incidence of fever (421/694, 60.7% vs 391/2009, 19.5%; *P*<.001), loss of taste and smell (365/694, 52.6% vs 239/2009, 11.9%; *P*<.001), and cough (352/694, 50.7% vs 580/2009, 28.9%; *P*<.001). With regard to subjects who underwent serological tests, IgG-positive subjects had a higher incidence of fever (65/108, 60.2% vs 43/364, 11.8%; *P*<.001) and pain in muscles/bones/joints (73/108, 67.6% vs 71/364, 19.5%; *P*<.001) than IgG-negative subjects. An analysis of self-reported COVID-19 symptom items revealed a 1-factor solution, the EPICOVID19 diagnostic scale. The following optimal scores were identified: 1.03 for respiratory problems, 1.07 for chest pain, 0.97 for loss of taste and smell 0.97, and 1.05 for tachycardia (ie, heart palpitations). These were the most important symptoms. For adults aged 18-84 years, the cutoff score was 2.56 (sensitivity: 76.56%; specificity: 68.24%) for NPS-positive subjects and 2.59 (sensitivity: 80.37%; specificity: 80.17%) for IgG-positive subjects. For subjects aged ≥60 years, the cutoff score was 1.28, and accuracy based on the presence of IgG antibodies improved (sensitivity: 88.00%; specificity: 89.58%).

Conclusions: We developed a short diagnostic scale to detect subjects with symptoms that were potentially associated with COVID-19 from a wide population. Our results support the potential of self-reported symptoms in identifying individuals who require immediate clinical evaluations. Although these results come from the Italian pandemic period, this short diagnostic scale could be optimized and tested as a screening tool for future similar pandemics.

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KEYWORDS

COVID-19; screening; diagnostic scale; validation; assessment; diagnostic; symptom; survey; algorithm

Introduction

SARS-CoV-2 has led to a global pandemic; on July 28, 2020, over 16 million cases and 650,805 deaths across more than 200 countries were reported by the World Health Organization and Johns Hopkins Center for Health Security [1,2]. Italy was the first European country to be hit hard by the COVID-19 epidemic. It was also the European country with the highest number of COVID-19 deaths recorded (ie, 24,780 as of April 27, 2020) [3]. Besides the immediate human toll, the readily acknowledged and potentially long-lasting effects of the pandemic on global economies, politics, health, and privacy policies at many levels has extended beyond the development of vaccines and treatments. The rapid spread of the COVID-19 disease and its seemingly high degree of variability in its presentation among individuals has led to a level of clinical and scientific focus that has not been previously seen. This focus has encompassed both traditionally reviewed and preprint publications and resources. Collaborative groups are being formed at the local, regional, national, and international levels to address patient data collection, aggregation, and analysis in ways that may change the way research is carried out in the future [4]. To ensure that these efforts are both effective and productive, data must be evaluated in a way that is suitable for their inclusion in these activities, while still recognizing that what we understand about COVID-19 is much less than what we do not understand [5].

Due to the far-reaching scope of the pandemic, we are already confronting (1) the need to implement individual testing at a level far above current capacities to optimize individual treatment, assess disease spread, and anticipate potential strains on health care resources and personnel [6]; (2) the need for improvements in available tests, such as nasopharyngeal swab (NPS) and antibody detection tests, (ie, improvements in accuracy, specificity, and sensitivity) to enable the reliable evaluation and interpretation of data for use in clinical care and policy decisions [7]; and (3) the need to harmonize clinical observations and definitions to support the development of guidelines and prognostic and diagnostic indicators, and to develop a comprehensive understanding of COVID-19 and critical factors that can help differentiate between different patient susceptibilities, presentations of the disease, and responses to treatment [8,9].

The use of web-based surveys can greatly enhance access to broader populations in a cost-effective manner, optimize screening for individuals who may need immediate care, and provide an approach for achieving item 3 in the previous paragraph. A cross-sectional national survey, EPICOVID19, was launched on April 13, 2020 and received more than 200,000 responses [10]. The survey, which represents phase I of this study, was promoted through social media (ie, Facebook, Twitter, Instagram, and WhatsApp), press releases, internet pages, local radio and television stations, and institutional websites that called upon volunteers to contact the study website. The inclusion criteria were as follows: age of >18 years; access to a mobile phone, computer, or tablet with internet connectivity; and on-line consent to participate in this study.

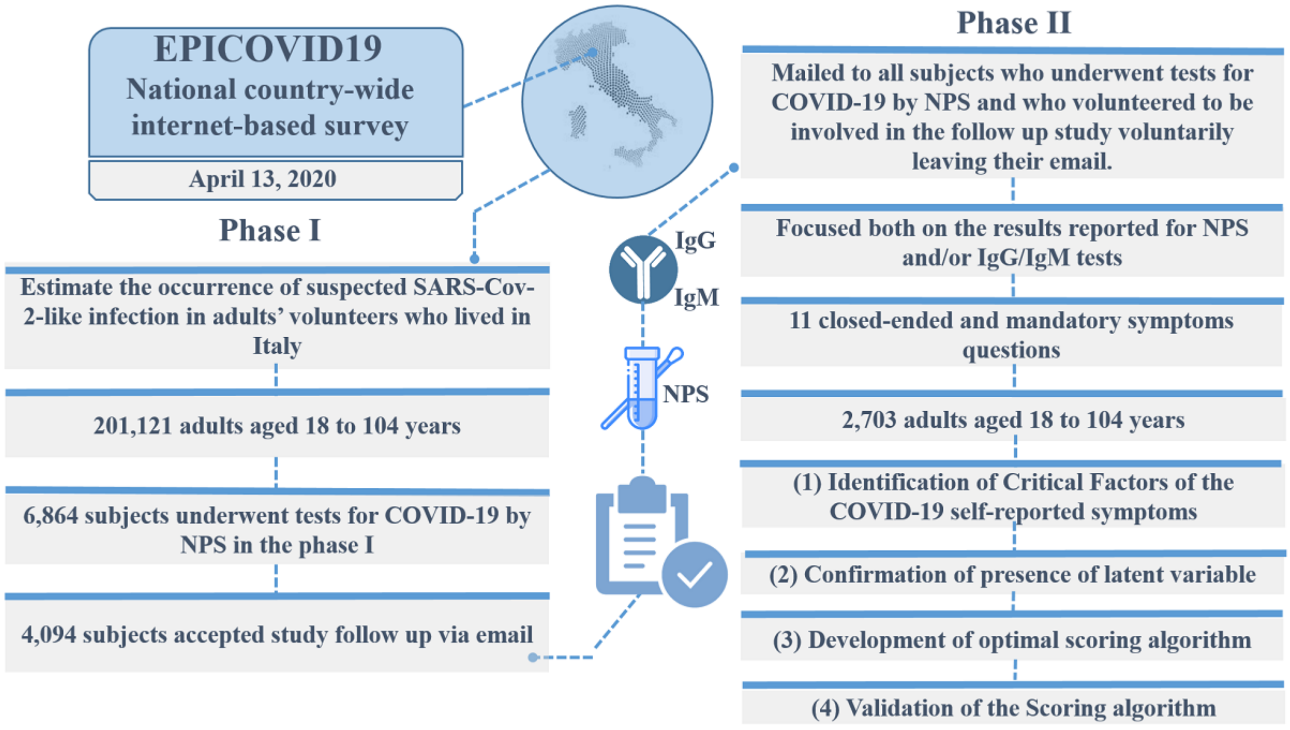
This study was conducted during the epidemic peak of COVID-19 in Italy. The aim of our study was to assess the capability of the self-reported symptoms collected through the EPICOVID19 questionnaire in discriminating COVID-19 among symptomatic subjects, in order to identify individuals with suspected COVID-19 who need to undergo instrumental measurements and clinical examinations (ie, phase II of the EPICOVID19 study). The final objectives were proposing a method for the development of a total score for the self-reported symptoms in the EPICOVID19 questionnaire, and validating the scoring method based on molecular and serological clinical diagnosis data.

Methods

Study Design and Participants

Our study is phase II of the EPICOVID19 Italian national survey [9] (pages 1-8 in Multimedia Appendix 1), which launched in April 2020 and included a convenience sample of 201,121 adults who completed the EPICOVID19 questionnaire. Figure 1 shows the overview of the EPICOVID19 2-phase study. The Phase I questionnaire investigated 6 areas through 38 questions. The 6 areas were as follows: (1) sociodemographic characteristics, (2) clinical evaluation, (3) personal characteristics and health status, (4) housing conditions, (5) lifestyle, and (6) behaviors after the lockdown.

Figure 1. Overview of the EPICOVID19 2-phase study. IgG: immunoglobulin G; IgM: immunoglobulin M; NPS: nasopharyngeal swab.



The Phase II questionnaire was mailed to all subjects who underwent NPS testing for COVID-19 and volunteered to be involved in the follow-up study in their phase I response. Phase II focused on the results of NPS and serological immunoglobulin G (IgG)/immunoglobulin M (IgM) tests and self-reported symptoms, with the aim of better identifying both symptomatic and asymptomatic SARS-CoV-2 infection cases [10].

Phase II was implemented by using an open-source statistical survey framework, LimeSurvey (version 3.17). This is a PHP (Hypertext Preprocessor)–based framework that is distributed under the GNU General Public License.

In phase II, responses to 11 questions were required. These questions covered the administration of the NPS and serological tests and the time that elapsed between observed/reported symptoms and clinical examination (ie, NPS and IgG/IgM tests) (pages 1-8 in Multimedia Appendix 1).

Of the 6864 subjects who underwent NPS testing for COVID-19 in phase I, 4094 subjects were invited by email to complete the Phase II questionnaires via the internet. Of these 4094 subjects, 38 could not participate because their email invitations were not delivered due to various issues (eg, wrong email address, full mailbox, host or domain name not found, etc), 101 refused to provide consent, and 1252 received the email, but did not proceed to complete the questionnaire.

The web-based survey included questions with close-ended answers in order to facilitate questionnaire compilation and avoid errors in digitizing answer values. At the end of the Italian lockdown period on May 2, 2020, the survey was closed and all collected data were exported for analysis with statistical tools. The base data for the statistical analysis was structured as a table that contained 1 row for each survey participant and as many columns as the collected responses. The questionnaire is available in pages 1-16 in Multimedia Appendix 1.

A total of 2703 subjects (response rate: 66%) completed the Phase II survey. After considering the 6864 subjects who underwent the NPS test in the Phase I survey, we compared the characteristics of 2703 respondents and 4161 nonrespondents. Respondents and nonrespondents to the Phase II survey appeared similar with respect to gender, age, the perception of their own health, and self-reported comorbidities. The details of the comparison between these 2 groups of subjects are included in page 9 in Multimedia Appendix 1. The resulting data of the 2703 subjects who completed the Phase II questionnaire were linked to the self-reported symptom results of the Phase I EPICOVID19 questionnaire, which included questions on the presence of 11 symptoms.

Statistical Analysis

We analyzed the self-reported symptoms that were collected in the survey to define a method for calculating a total score and validate the scoring method for serological and molecular clinical diagnoses. This was done by using 4 standard questionnaire validation steps.

The first step was the identification of critical factors. We determined the factorial structure of the COVID-19 self-reported symptom items via exploratory factor analysis (EFA), followed by confirmatory factor analysis (CFA). EFA and parallel analysis were performed to evaluate the performance of specific symptoms (ie, loadings) and define the number of factors underlying these loadings.

The second step was the confirmation of the presence of latent variables. We carried out CFA via structural equation modelling to confirm the presence of 1 latent variable (ie, factor) underlying the 11 symptoms that were chosen to identify

COVID-19. Several goodness-of-fit criteria were used, as follows: (1) standardized root mean square residual (SRSR); (2) root mean square error of approximation (RMSEA), which could not be >0.10; (3) comparative fit index (CFI); and (4) Tucker-Lewis index (TLI), which could not be <0.90.

The third step was the development of an optimal scoring algorithm. We developed an optimal scoring algorithm via homogeneity analysis by means of alternating least squares (HOMALS) and multiple correspondence analysis (MCA). Through the HOMALS procedure, we replaced specific dichotomous responses (ie, Yes/No) with categorical quantifications; the resulting score was the sum of the subject's symptom responses after they were recoded based on category quantifications.

The fourth step was the validation of the scoring algorithm. We validated the score by using an external objective criterion that was based on receiver operating characteristics analysis, in order to evaluate the performance of COVID-19 symptom scores in distinguishing symptomatic individuals in the complete sample (ie, participants aged between 18 and 84 years) and 2 specific age groups (ie, participants aged <60 years and ≥60 years). Since we aimed to discriminate COVID-19 cases, we calculated the sensitivity, specificity, and Youden index with the following 2 reference standards: (1) subjects who tested positive in the NPS tests versus subjects who tested negative in the NPS test, and (2) subjects who tested positive in the serological IgG tests versus subjects who tested negative in the IgG test. The overall predictive performance was evaluated via area under the curve (AUC) analysis.

All statistical analyses were carried out using R software (version 3.6.3), IBM SPSS 23 (IBM Corp), and Stata Statistical Software (Release 15; StataCorp LLC). The details of the performed statistical analyses are reported in pages 10-12 in Multimedia Appendix 1.

Ethical Approval

The Phase II EPICOVID19 study was approved by the Ethical Committee of the Istituto Nazionale per le Malattie Infettive, Institute for Research, Hospitalization and Healthcare Lazzaro Spallanzani as an amendment of the EPICOVID19 epidemiological study (approval number 93 in the trial register). Data transfer was safeguarded by means of password protection and encryption/decryption policies. All data were handled and stored in accordance with the European General Data Protection Regulation 2016/679 [11]. Informed consent details were accessible on the home page of the platform, and participants were asked to review these details before starting the Phase II questionnaire. The home page explained the purpose of the study, which data were to be collected, and how data were stored.

Subjects' email addresses were the personal data provided on a voluntary basis in phase I. In our study, email addresses were only used to (1) send email invitations for participating in the Phase II survey and (2) link the information related to NPS and IgG/IgM test results to the information on symptoms collected during the phase I survey. In the participation mail, subjects were able to participate by clicking on the provided link to the survey, not participate by ignoring the invitation, communicate with the authors by using the provided study-specific email address, and request the deletion of their email address from the database.

Results

Study Design and Participants

The characteristics and NPS, IgG, and IgM results of the 2703 subjects, which were supplied by those who completed the Phase II survey, are shown in Table 1. The sample predominantly consisted of women (1841/2703, 68.1%), and the average age was 49 years (SD 15.0 years) and 52 years (SD 14.1 years) for women and men, respectively. Of the 2703 respondents, 151 (5.6%) had a low educational status, 837 (31%) had a medium educational status, and 1715 (63.4%) had a high educational status. The most reported chronic condition by participants was hypertension (361/2703, 13.4%), followed by immune system diseases (266/2703, 9.8%), and depression and anxiety diseases (194/2703, 7.2%). The least frequently reported chronic symptoms were liver (21/2703, 0.8%) and kidney (22/2703, 0.8%) diseases. All the details are reported in page 13 in Multimedia Appendix 1.

Statistical Analysis

Of the 2703 subjects, 694 (25.7%) tested positive in the NPS test. Of these 694, 84 (12.1%) were asymptomatic. With regard to the subgroup of subjects who underwent serological testing, 472 underwent the IgG test and 421 underwent the IgM test, and 22.9% (108/472) and 11.6% (49/421) tested positive, respectively. Of the 108 IgG-positive subjects, 1 (0.9%) was asymptomatic. Of the 49 IgM-positive subjects, 5 (10.2%) were asymptomatic. With regard to NPS-positive subjects, the average number of days between initial symptoms and the day of swab execution was 9.3 days (SD 9.4 days; median 7 days, IQR 3-7 days). With regard to IgG-positive subjects, the average number of days between initial symptoms and the day of serological test execution was 36.1 days (SD 15.1 days; median 36.5 days, IQR 28-47 days). With regard to IgM-positive subjects, the average number of days from initial symptoms to the day of serological test execution was 26.1 days (SD 17.9 days; median 28 days, IQR 4-40 days). The incidence rate of the 11 symptoms reported by the 3 groups (ie, the NPS, IgG, IgM test groups) was similar between men and women. In the NPS-positive group, women only had a higher incidence of sore throat and cold and tachycardia (ie, heart palpitations) than men. In the IgG-positive group, men only had a higher incidence of headaches than women. In the IgM-positive group, women had a lower incidence of symptoms related to conjunctivitis than men.

The frequency of symptoms among NPS-positive subjects (Table 1) ranged from low rates of observation (eg, tachycardia [ie, heart palpitations]: 120/694, 17.3%; conjunctivitis: 111/694, 16%) to high rates of observation (eg, fever: 421/694, 60.7%; olfactory and taste disorders: 365/694, 52.6%). For all symptoms apart from headache, the incidence rates were significantly higher in NPS-positive subjects than in NPS-negative subjects (*P*<.001). With regard to the subgroup of individuals who underwent serological tests, the symptoms with a high incidence among subjects who tested positive were fever (IgG-positive group: 65/108, 60.2%; IgM-positive group: 28/49, 57.1%) and pain in muscles, bones, and joints (IgG-positive group: 73/108, 67.6%; IgM-positive group: 27/49, 55.1%). In the IgG serological test group, no significant difference was observed in the incidence of sore throat and cold symptoms (*P*=.23) between IgG-positive and IgG-negative subjects. The incidence of respiratory difficulty (*P*=.35), chest pain (*P*=.35), and gastrointestinal symptoms (*P*=.08) did not significantly differ between IgM-positive and IgM-negative subjects.

Table 1. Self-reported characteristics that were obtained from the Phase II survey and analyzed by using SARS-CoV-2 infection test results (N=2703).[a]

Variable	SARS-CoV-2 tests								
	Nasopharyngeal swab test, n=2703			Immunoglobulin G antibody test, n=472			Immunoglobulin M antibody test, n=421		
	Tested positive	Tested negative	*P* value	Tested positive	Tested negative	*P* value	Tested positive	Tested negative	*P* value
Number, n (%)	694 (25.7)	2009 (74.3)	N/A[b]	108 (22.9)	364 (77.1)	N/A	49 (11.6)	372 (88.4)	N/A
Women, n (%)	440 (63.4)	1401 (69.7)	.001	61 (56.5)	258 (70.9)	.005	25 (51)	260 (69.9)	.008
Age (years), mean (SD)	55.5 (18.06)	47.55 (12.81)	<.001	48.8 (11.74)	45.5 (11.49)	.009	50.6 (10.56)	45.8 (11.69)	.008
Answered questions on symptoms, n (%)									
Fever with a temperature of >37.5°C for at least 3 consecutive days	421 (60.7)	391 (19.5)	<.001	65 (60.2)	43 (11.8)	<.001	28 (57.1)	68 (18.3)	<.001
Cough	352 (50.7)	580 (28.9)	<.001	63 (58.3)	76 (20.9)	<.001	26 (53.1)	95 (25.5)	<.001
Sore throat and cold	232 (33.4)	756 (37.6)	.048	46 (42.6)	132 (36.3)	.233	16 (32.7)	135 (36.3)	.62
Headache	313 (45.1)	703 (35)	<.001	61 (56.5)	96 (26.4)	<.001	23 (46.9)	117 (31.5)	.03
Pain in muscles, bones, and joints	360 (51.9)	572 (28.5)	<.001	73 (67.6)	71 (19.5)	<.001	27 (55.1)	98 (26.3)	<.001
Loss of taste and smell	365 (52.6)	239 (11.9)	<.001	66 (61.1)	29 (8)	<.001	21 (42.9)	55 (14.8)	<.001
Respiratory difficulty (ie, sense of breathlessness at rest)	179 (25.8)	249 (12.4)	<.001	21 (19.4)	28 (7.7)	<.001	7 (14.3)	37 (9.9)	.35
Chest pain (ie, sternum pain)	136 (19.6)	251 (12.5)	<.001	26 (24.1)	25 (6.9)	<.001	7 (14.3)	37 (9.9)	.35
Tachycardia (ie, heart palpitations)	120 (17.3)	237 (11.8)	<.001	24 (22.2)	27 (7.4)	<.001	10 (20.4)	31 (8.3)	.007
Gastrointestinal complaints (ie, diarrhea, nausea, and vomiting)	289 (41.6)	452 (22.5)	<.001	54 (50)	65 (17.9)	<.001	17 (34.7)	87 (23.4)	.08
Conjunctivitis (ie, red eyes)	111 (16)	221 (11)	<.001	24 (22.2)	35 (9.6)	.001	11 (22.4)	40 (10.8)	.02

[a] Mean (SD) was used for continuous variables, which were analyzed with an independent 2-tailed *t* test, and n (%) was used for categorical variables, which were analyzed with a Chi-square test.

[b] N/A: not applicable.

The EFA, which involved the principal-component factors and Horn parallel analysis methods, pointed out 1 factor. Eigenvalues, descriptive indices, and goodness-of-fit indices for the cumulative percentage of explained data variability obtained through EFA are displayed in Table 2. Principal-component factors analysis only highlighted 1 factor with an 89.9% proportion of explained variability, while the Horn parallel analysis identified 2 factors with eigenvalues of >1.0 and a 49.8% and 10.3% proportion of explained variability, respectively.

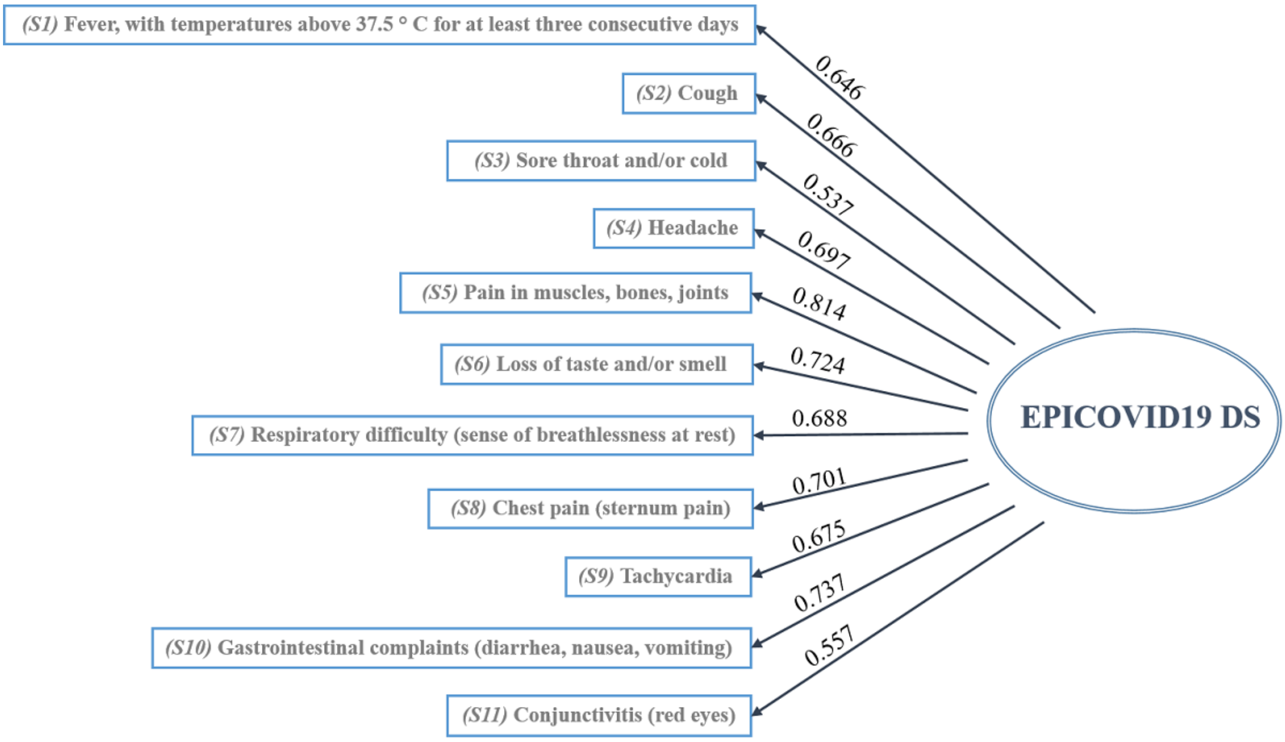
Table 2. Descriptive and goodness-of-fit dimensionality indices from the exploratory factor analysis of the 11 EPICOVID19 symptoms reported by 2703 subjects, based on the principal-component factors and Horn parallel analysis methods with an eigenvalue of >1.

Factor	Exploratory factor analysis					
	Principal-component factors analysis			Horn parallel analysis		
	Eigenvalue	Proportion of explained variability	Cumulative explained variability	Eigenvalue	Proportion of explained variability	Cumulative explained variability
1	5.00	89.9%	89.9%	5.48	49.8	49.8%
2	N/A[a]	N/A	N/A	1.14	10.3	60.1%

[a]N/A: not applicable.

Based on a priori determined cutoff value, a factor loading of >0.35 was maintained. The factor loading rule of the 1-factor solution extracted from the principal-component factors analysis is available in page 13 in Multimedia Appendix 1. The dimensionality indices of the 1-factor solution, which had a high cumulative and proportion of explained variability (89.9%), confirmed the presence of 1 latent variable underlying COVID-19 symptom items. Therefore, we defined the 1-factor solution as the EPICOVID19 diagnostic scale (EPICOVID19 DS). Based on our CFA results, we confirmed that the latent construct was unidimensional and determined how the variables contributed to the EPICOVID19 DS. Figure 2 shows the values of the standardized factor loadings for the 1-factor model. The magnitude of each factor loading value was >0.4, which indicated the importance of the corresponding item to the EPICOVID19 DS. For example, pain in muscles, bones, and joints was the most important variable, with a factor loading value of 0.814. The other variables with an optimal specific validity index were respiratory difficulty (sense of breathlessness at rest: 0.688; loss of taste and smell: 0.724) and gastrointestinal complaints, with item-factor correlations of 0.737. The lowest values were observed for the sore throat and cold and conjunctivitis items, which had a specific validity index of 0.537 and 0.557, respectively. The goodness of fit (ie, SMSR and RMSEA) of the EPICOVID19 DS was acceptable, because 2 indices were <0.10 (SMSR 0.072; RMSEA 0.052; CFI 0.977; TLI 0.971). We computed CFA indices to measure the internal validity of the model (page 14 in Multimedia Appendix 1).

Figure 2. Standardized factor loading values of the 1-factor model, EPICVOID19 DS. The goodness-of-fit indices are as follows: a standardized root mean square residual of 0.072, root mean square error of approximation of 0.052, comparative fit index of 0.977, and Tucker-Lewis index of 0.971. EPICOVID19 DS: EPICOVID19 diagnostic scale.



Given the successful unidimensionality testing of the EPICOVID19 DS, optimal scaling was performed. The proposed optimal score was extracted from the HOMALS procedure (ie, single-factor measurement), and for each subject, the computed optimal score was obtained by summing the category quantifications of the screening questionnaire item responses. Cronbach (α=0.88) and Greenacre (statistic=78%) indices confirmed the unidimensionality found in the EFA and CFA. The HOMALS optimal category quantifications of the EPICOVID19 symptom variables are summarized in Table 3, which has columns for the binary options (ie, Yes/No) and rows for the different symptoms. The HOMALS category quantifications were scaled so that the score obtained from the sum of responses would range from 0 (ie, if a subject answered "No" to all the symptoms) to 10 (ie, if a subject answered "Yes" to all the symptoms). These values are shown in the last column of Table 3. An example of a resulting score calculation is as follows: if the subject response pattern with respect to symptoms is "Yes, No, Yes, No, No, Yes, Yes, No, No, No, Yes," the corresponding recoded response pattern is 0.80, 0, 0.64, 0, 0, 0.97, 1.03, 0, 0, 0, 0.88, and the subject's optimal score would be calculated as 0.8 + 0 + 0.64 + 0 + 0 + 0.97 + 1.03 + 0 + 0 + 0 + 0.88 = 4.2.

Table 3. Multiple correspondence analysis optimal weights for the recoding of the EPICOVID19 diagnostic scale.

Symptoms	HOMALS[a] category quantifications		Recoded HOMALS category quantifications	
	No	Yes	No	Yes
Fever with a temperature of >37.5°C for at least 3 consecutive days	−0.362	0.8421	0	0.80
Cough	−0.426	0.810	0	0.81
Sore throat and/or cold	−0.358	0.622	0	0.64
Headache	−0.470	0.780	0	0.83
Pain in muscles, bones, and joints	−0.505	0.959	0	0.97
Loss of taste and/or smell	−0.326	1.133	0	0.97
Respiratory difficulty (ie, sense of breathlessness at rest)	−0.246	1.305	0	1.03
Chest pain (ie, sternum pain)	−0.232	1.388	0	1.07
Tachycardia (ie, heart palpitations)	−0.209	1.374	0	1.05
Gastrointestinal complaints (ie, diarrhea, nausea, and vomiting)	−0.393	1.042	0	0.95
Conjunctivitis (ie, red eyes)	−0.164	1.170	0	0.88

[a] HOMALS: homogeneity analysis by means of alternating least squares.

There was no significant difference in the mean EPICOVID19 DS score between men (mean 2.34, SD 2.2) and women (mean 2.49, SD 2.4) (*P*=.14). A low negative correlation between the scores and ages of the participants was found (ρ=−0.126; *P*<.001). Of the 2703 subjects, 1738 (64.3%) reported no preexisting diseases, 684 (25.3%) only had 1 chronic condition, while the remaining 281 (10.4%) declared ≥2 conditions. Significant differences in the mean EPICOVID19 DS score were observed between participants who did not report any disease (mean 2.26, SD 2.3) and those with at least 1 preexisting condition (mean 2.75, SD 2.4) (*P*<.001). Based on our analysis of the mean EPICOVID19 DS score among healthy subjects and subjects with 1 chronic condition, we observed significant differences between healthy subjects and subjects with lung diseases (healthy subjects: mean 2.40, SD 2.3; subjects with lung diseases: mean 3.10, SD 2.5; *P*<.001), healthy subjects and subjects with immune system diseases (healthy subjects: mean 2.39, SD 2.3; subjects with immune system diseases: mean 2.91, SD 2.4; *P*<.001), and healthy subjects and subjects with depression and anxiety diseases (healthy subjects: mean 2.42, SD 2.4; subjects with depression and anxiety: mean 2.79, SD 2.6; *P*=.036). For the other chronic conditions (ie, heart disease: *P*=.22; hypertension: *P*=.59; kidney disease: *P*=.45; tumor: *P*=.13; metabolic disease: *P*=.52; liver disease: *P*=.64), no significant differences in mean EPICOVID19 DS score were found.

The screening properties of the EPICOVID19 DS were compared to those of COVID-19–positive molecular and serological tests. These are shown in Table 4. The best Youden index value was observed for EPICOVID19 DS, with respect to subjects diagnosed with COVID-19 via NPS testing. A good trade-off between sensitivity and specificity was observed (sensitivity: 76.56%; specificity: 68.24%; AUC 77.5, 95% CI 75.6-79.4). The cutoff score obtained was 2.56. The sensitivity and specificity of the EPICOVID19 DS improved when compared to those of COVID-19–positive IgG antibody test (sensitivity: 80.37%; specificity: 80.17%; AUC 86.0, 95% CI 82.3-89.5). The cutoff value obtained (2.59) was similar to that of the NPS-positive test. The positive and negative predictive values for the IgG-positive serological test (positive predictive value [PPV]: 54.43%; negative predictive value [NPV]: 93.27%) were higher than those of the NPS test (PPV: 42.26%; NPV: 90.55%). We observed a poor performance with regard to IgM test results, so these are not presented in Table 4.

Table 4. Sensitivity and specificity of the EPICOVID19 diagnostic scale compared to those of positive COVID-19 molecular and serological diagnoses (ie, for subjects aged 18-84 years).

Statistic	SARS-CoV-2 tests	
	Nasopharyngeal swab test (n=2703), value (95% CI)[a,b]	Immunoglobulin G antibody test (n=472), value (95% CI)[c,d]
Sensitivity, %	76.56 (72.99-79.87)	80.37 (71.58-87.42)
Specificity, %	68.24 (66.16-70.28)	80.17 (75.69-84.14)
Positive likelihood ratio	2.41 (2.23-2.61)	4.05 (3.23-5.08)
Negative likelihood ratio	0.34 (0.30-0.40)	0.24 (0.17-0.36)
COVID-19–positive tests, %	23.29 (21.68-24.96)	22.77 (19.05-26.83)
Positive predictive value, %	42.26 (40.38-44.17)	54.43 (48.77-59.98)
Negative predictive value, %	90.55 (89.23-91.74)	93.27 (90.40-95.33)
Accuracy, %	70.18 (68.39-71.93)	80.21 (76.32-83.72)

[a] There were 694 NPS-positive subjects.

[b] The cutoff value for the nasopharyngeal swab test was 2.59.

[c] There were 108 immunoglobulin G-positive patients.

[d] The cutoff value for the immunoglobulin G antibody test was 2.56.

When the EPICOVID19 DS scoring algorithm was applied to specific age groups, the sensitivity and specificity of the IgG-positive antibody test (sensitivity: 88.00%; specificity: 89.58%; AUC 93.10, 95% CI 86.0-99.5) improved greatly among subjects aged ≥60 years, and the obtained cutoff value (1.28) was lower than the cutoff value for the subjects aged <60 years (2.71; sensitivity: 88.00%; specificity: 89.58%; AUC 93.10, 95% CI 86.0-99.5). The PPV and NPV of the IgG test were higher for subjects aged ≥60 years (PPV: 81.48%; NPV: 93.48%) than those for subjects aged <60 years (PPV: 51.52%; NPV: 94.38%). Furthermore, we observed the same performance in the NPS test between the specific age groups (ie, aged ≥60 years and aged <60 years), with respect to the overall sample (ie, aged 18-84 years). The details of the screening properties of the EPICOVID19 DS compared to those of COVID-19–positive molecular and serological tests for specific age groups are reported in page 16 in Multimedia Appendix 1.

Discussion

Our focus was on developing a tool composed of simple questions related to COVID-19 symptomatology for the identification of subjects who are more likely to be infected with SARS-CoV-2 in the general population. We validated the EPICOVID19 DS with a sample of voluntary subjects based on serological and molecular clinical diagnoses. The optimal score, which was computed for 2703 adults aged 18-84 years, discriminated symptomatic individuals. Before calculating the score, we performed both exploratory and confirmatory factor analyses to determine the number of factors/dimensions underlying the questionnaire. The results of these analyses supported the 1-factor model and the unidimensionality of the EPICOVID19 questionnaire. The magnitude of all factor loading values was satisfactory, and the highest factor loading values were observed for respiratory difficulty, chest pain, tachycardia (ie, heart palpitations), and loss of taste and smell. Furthermore, gastrointestinal complaint items appeared to be the most essential features of the EPICOVID19 DS. The high value for chest pain can also be explained by the fact that several patients reported it, possibly because of tracheal pain caused by pneumonia [12,13]. Several clinical studies on hospitalized patients have shown that, at the onset of COVID-19, patients frequently show typical symptoms of viral pneumonia [3]. Symptoms that are less common, but still reported by a substantial number of patients, are nasal congestion, sore throat, gastrointestinal complaints, and olfactory and taste disorders [14-16]. Subjects have often reported gastrointestinal complaints as concurrent symptoms instead of isolated symptoms of SARS-CoV-2 infection [17]. The lowest factor loading values were observed for sore throat and cold and conjunctivitis. These lower values may be related to the fact that conjunctivitis and cold are not the most frequent symptoms of COVID-19 [18]. In line with other recent studies [19,20], the features we encountered in this study showed various aspects of the definition for COVID-19 diagnosis. Cough, loss of taste and smell, and respiratory difficulty are among the most reported symptoms in previous studies, and they corresponded to the items that were the most important to our score [12,16,21,22].

The clinical presentation of COVID-19 varies, and discrepancies may exist between symptoms and the disease. A recent meta-analysis of the symptoms of 50,000 patients with COVID-19 found that fever and cough were the most common symptoms (incidence: 89.1% and 72.2%, respectively) [23], and a separate study on hospitalized subjects has suggested that respiratory distress has been reported in the most critical cases of COVID-19 [24]. With the aim of supporting medical decision making, predicted models have been developed for detecting people in the general population who are at risk of being admitted to hospital and diagnosing COVID-19 in patients with related symptoms. However, the results presented in a recent systematic review on such models describe poor research performance and a high risk of bias [25].

Based on our HOMALS, we proposed a scoring methodology for developing an improved scale. Therefore, we provided a numerical weight value (ie, optimal quantification) that represents the importance of the binary response categories (ie, Yes/No) for each question in the EPICOVID19 DS. As a result, the various binary items of the 11 questions in the EPICOVID19 DS contributed to the overall score, albeit with different weights. This produced an improved scale (ie, 0-10) that reflects the importance of each symptom. Thus, respiratory problems and chest pain were the most important symptoms, with a score of 1.03 and 1.07, respectively. The other symptoms that had an important contribution to the total score were gastrointestinal complaints (0.95), loss of taste and smell (0.97), and tachycardia (ie, heart palpitations) (1.05). Subsequently, we computed the sensitivity and specificity of EPICOVID19 DS compared to those of COVID-19–positive serological and molecular tests. For NPS-positive subjects, the cutoff score was 2.56, with a sensitivity of 76.56% and specificity of 68.24%. For IgG-positive subjects, the cutoff score was 2.59, and sensitivity, specificity, PPV, and NPV with respect to NPS-positive tests substantially improved (sensitivity: 80.37%; specificity: 80.17%; PPV: 54.43%; NPV: 93.27%). When the EPICOVID19 DS scoring algorithm was tested on subjects aged ≥60 years, the accuracy of IgG-positive antibody tests improved (sensitivity 88.00%; specificity 89.58%; AUC 93.10, 95% CI 86.0-99.5; PPV: 81.48%; NPV IgG 93.48%), and the threshold of detection (1.28) was lower than that of subjects aged <60 years.

Our data are consistent with the findings reported in previous studies. In mid-May 2020, the European all-cause mortality monitoring system showed that all-cause mortality was above the expected rate in several European countries (ie, Belgium, France, Malta, and Spain), including Italy [26], mainly for people aged ≥60 years. People aged ≥60 years are more vulnerable to SARS-CoV-2 infection, and those with preexisting medical conditions are particularly at risk. Several best practices for older people and their families have been recommended by the World Health Organization, Centers for Disease Control and Prevention, geriatricians, and infectious diseases specialists [27]. The sensitivity and specificity of serological and molecular diagnostic tests for COVID-19 have not been fully elucidated, but several studies have suggested that sensitivity could be as low as 80% [28,29]. This raises concerns of high false-negative rates, which could result in an increase in infection spread among the community. There is no absolute answer for the sensitivity and specificity of COVID-19 diagnostic tests, because to determine their accuracy, they must be compared with a gold-standard test, which does not currently exist. By considering estimates for sensitivity and specificity, PPVs and NPVs can be calculated based on disease prevalence and the rate of illness in the population. However, there is considerable uncertainty with regard to the prevalence of COVID-19 [30]. Statistically, it has been assumed that PPVs vary widely and range between 30-50% in areas with a low COVID-19 prevalence, as stated in a recent US study on COVID-19 [31].

Early recognition screening and rapid diagnosis are essential for preventing transmission and providing supportive care in a timely manner. Nevertheless, screening is different from further, more detailed diagnostic test assessments. This is of particular relevance, as resources for full testing remain limited, and optimizing the use of such resources is critical. The EPICOVID19 DS can be used as a preliminary assessment that attempts to detect subjects with symptoms that are potentially associated with COVID-19 among a wide population. The EPICOVID19 DS does not enable clinical interviews for determining complete symptomatic profiles and needs, but it does identify those who may warrant further assessment. Therefore, it would be advantageous to use the EPICOVID19 DS for screening in primary care settings, so that general practitioners can avoid people with suspected COVID-19 in primary care offices whenever possible [32]. The EPICOVID19 DS can also be used as an initial screening tool before patients are managed remotely via telephone or video consultations [33]. Additionally, the EPICOVID19 DS can be applied to the general population. Once a score is assigned to each symptom, the EPICOVID19 DS can allow for different cutoff values to be set, based on the subjects involved and the gold standards used (ie, NPS tests, serological tests, clinical evaluation by clinicians, etc).

It should be noted that since it is plausible to expect a lower prevalence rate in the general population than the 22.77% in this study, the probability of NPVs would increase beyond the current 93.27%. Consequently, the probability of progressing to COVID-19 for subjects who test negative (ie, 1 − NPV) would be less than the current 6.7%. Furthermore, although the identified symptoms in this study are not specific to COVID-19, they have been reported as valid references for a population setting, because they are frequently reported by patients with COVID-19. In a nonpandemic scenario, it is likely that these symptoms could be assessed with different weights because of their aspecificity, which would configure the EPICOVID19 DS as a valid diagnostic support tool for pandemic situations. Moreover, health authorities are still unable to use classic tests to monitor the spread of SARS-CoV-2 infection, and allowing the circulation of unsuspecting individuals with COVID-19 could represent a risk for the spread of the infection. The validation of an instrument that can easily identify a suspected COVID-19 case by attributing a score to each symptom related to COVID-19 can be of great importance in facilitating the containment of the epidemic. Our proposed cutoff score seems worthy of validation for use in broader populations to confirm its clinimetric properties. In the event of its validation, our cutoff score might be useful in selecting people who require serological and molecular diagnostic tests for COVID-19.

The availability and accessibility of diagnostic tests for the SARS-CoV-2 coronavirus have proven to be key in containing the COVID-19 pandemic. The early identification of subjects who test positive for COVID-19 (ie, via molecular and serological tests) among people with specific symptoms or people who are at risk is crucial for limiting the spread of the infection. The tool we validated responds to the need for readily identifying a suspected COVID-19 case, by attributing a score to each symptom related to COVID-19. Although our validation was satisfactory, our proposed cutoff score seems worthy of further testing in larger populations in order to confirm its clinimetric properties and usefulness in selecting people who require serological and molecular diagnostic tests for COVID-19.

Although the EPICOVID19 DS tool can be used as a public health prevention instrument, directing subjects to a self-assessment tool without warning may trigger panic, alarm, and concern among the screened population. Furthermore, the limitations of our study must be considered. First, participation in this study was voluntary, and the sample was not representative of the general population. This means that potential selection biases must be taken into consideration. Second, data were collected from a highly educated, young-adult convenience population sample with low multimorbidity. This was a result of the phase I EPICOVID19 study [10], and such a sample is expected in studies that involve a web-based questionnaire that is promoted via email invitation. Third, in the context of a pandemic, our survey might have interested people who had no opportunity to report symptoms to clinicians. Moreover, the effect of recall bias cannot be excluded among the participants who tested positive for COVID-19 or presented with symptoms related to SARS-COV2 infection. The fourth limitation of our study is the small sample size in the analysis of the 2 age groups (ie, subjects aged <60 and ≥60 years). Given these limitations, the adoption of the EPICOVID19 DS should be considered with caution. The procedures outlined for the development of the EPICOVID19 DS can be applied iteratively as new data is collected, to continue the refinement of this potentially valuable clinical decision support tool.

In conclusion, the proposed EPICOVID19 DS seems worthy of further testing in different scenarios and populations to achieve a comprehensive understanding of its clinimetric properties for both low-prevalence and high-prevalence COVID-19 settings, and its aptitude for capturing disease severity data. This will allow us to define the boundaries of its use and identify optimal indicators to assist clinicians with the early recognition of COVID-19.

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Authors' Contributions

SM, LB, FA, and FP were responsible for the study concept and design. LB, LF, and SP were responsible for the literature search. FA, LF, and SP were responsible for the acquisition of data. LB, FA, FB, FP, and SM were responsible for the analysis and interpretation of data. LB, LF, SM, SP, and FB were responsible for drafting the manuscript. MG, AG, RAI, CP, MA, and GP were responsible for critically revising the manuscript for important intellectual content. LB and SM were responsible for statistical analysis. GP, SM, CT, MN, NJ, AS, CP, and MA critically revised the manuscript for important intellectual content. All authors participated in data interpretation. All authors read and approved the final version of the manuscript. The corresponding author, SM, attests that all listed authors meet authorship criteria and that no others who meet the criteria have been omitted.

Conflicts of Interest

AG received consultancy fees from Mylan and educational support from Gilead.

Multimedia Appendix 1

Phase I EPICOVID19 questionnaire, Phase 2 Valid Symptoms Section of the EPICOVID19 questionnaire, and statistical appendix.
[DOCX File , 79 KB-Multimedia Appendix 1]

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Abbreviations

AUC: area under the curve
CFA: confirmatory factor analysis
CFI: comparative fit index
EFA: exploratory factor analysis
EPICOVID19 DS: EPICOVID19 diagnostic scale
HOMALS: homogeneity analysis by means of alternating least squares
IgG: immunoglobulin G
IgM: immunoglobulin M
NPS: nasopharyngeal swab
NPV: negative predictive value
PHP: hypertext preprocessor
PPV: positive predictive value
RMSEA: root mean square error of approximation
SRSR: standardized root mean square residual
TLI: Tucker-Lewis index

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Review

How the Use of a Patient-Accessible Health Record Contributes to Patient-Centered Care: Scoping Review

Janine Benjamins[1,2], MD; Annemien Haveman-Nies[2,3], PhD; Marian Gunnink[1], MD; Annemieke Goudkuil[1], MSc; Emely de Vet[2], PhD

[1]Icare JGZ, Meppel, Netherlands

[2]Chairgroup Consumption & Healthy Lifestyles, Wageningen University, Wageningen, Netherlands

[3]GGD NOG, Warnsveld, Netherlands

Corresponding Author:
Janine Benjamins, MD
Icare JGZ
Blankenstein 550
Meppel, 7943 PH
Netherlands
Phone: 31 612329494
Email: j.benjamins@cjgnoordveluwe.nl

Abstract

Background: Worldwide, patient-centered care is becoming a widely used concept in medical practice, getting more and more attention because of its proven ability to improve quality of care and reduce costs. Although several studies show that patient-accessible electronic health records (PAEHRs) influence certain aspects of patient-centered care, the possible contribution of PAEHR implementation to patient-centered care as a comprehensive concept has not, to our knowledge, been structurally evaluated to date.

Objective: The objective of this study is to review whether and how the use of PAEHRs contributes to patient-centered care both in general and among specific population groups.

Methods: We followed PRISMA Extension for Scoping Reviews reporting guidelines. We identified literature in 5 databases, using the terms “patient-accessible medical records,” “patient experiences,” and “professional experiences” as key concepts. A total of 49 articles were included and analyzed with a charting code list containing 10 elements of patient-centered care.

Results: Studies were diverse in design, country of origin, functionalities of the investigated PAEHR, and target population. Participants in all studies were adults. Most studies reported positive influence of PAEHR use on patient-centered care; patient accessible health records were appreciated for their opportunity to empower patients, inform patients about their health, and involve patients in their own care. There were mixed results for the extent to which PAEHRs affected the relation between patients and clinicians. Professionals and patients in mental health care held opposing views concerning the impact of transparency, where professionals appeared more worried about potential negative impact of PAEHRs on the patient-clinician relationship. Their worries seemed to be influenced by a reluctant attitude toward patient-centered care. Disadvantaged groups appeared to have less access to and make less use of patient-accessible records than the average population but experienced more benefits than the average population when they actually used PAEHRs.

Conclusions: The review indicates that PAEHRs bear the potential to positively contribute to patient-centered care. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centered attitude need to be addressed. Potentially significant benefits for disadvantaged groups will be achieved only through easily accessible and user-friendly PAEHRs.

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KEYWORDS

personal health records; patient portals; patient-centered care; patient-accessible records

Introduction

In the last 30 years, patient-centeredness has grown worldwide in relevance in health care policy, practice, and research. In 1987, Harvey Picker developed the Pickers' Principles of Patient Centered Care [1]. Thereafter, patient-centered care gained increasing prominence in the US when the Institute of Medicine advocated for patient-centered care as a cornerstone of health care quality [2]. In 2015, the World Health Organization stated that patient-centered care should become the standard for health care systems all over the world [3].

Key factors in patient-centered care are responsiveness to the patients' individual needs and preferences, and partnership between care providers and patients in decision making [4-7]. Patients are acknowledged as unique human beings with needs and preferences that have to be taken into account when clinical decisions are made. Ideally, patients as well as their family members or caregivers are involved in making these decisions. This requires clear information and communication with patients.

Patient-centered care has been gaining importance because of its proven ability to increase the quality of care, with lower health care utilization as a beneficial side effect [3,8-13]. The growing importance and development of the concept in different countries has led to a diversity in models, definitions, and terminology. For this review, we used an integrative model by Scholl et al [5], integrating more than 400 definitions and models into a new and comprehensible model for patient-centered care.

In the Netherlands, patient-centered care has also taken center stage in the discussion about quality of care, especially in care for youth [14]. To contribute to patient-centered care, three organizations for preventive youth health care and youth social services in the North Veluwe region developed a PAEHR system [14]. The assumption that the use of PAEHRs contributes to patient-centered care, however, has not yet been sufficiently proven.

Several reviewers investigated effects of PAEHRs by reporting on a variety of outcomes related to patient health, quality of care, or patient satisfaction [15-23]. The aspects of patient-centered care that have been mentioned are, for instance, empowerment of patients, trust in care providers, and the clinician-patient relationship. For these aspects, both beneficial [15-19] and unfavorable or even harmful consequences of the use of a PAEHR [19-23] to patient-centered care have been reported. Some studies report that disadvantaged groups might benefit less from the use of PAEHRs than others, as their access to and use of PAEHRs is lower than average [19,20,22,23]. To date, we know of no published review that structurally evaluates the possible contribution of PAEHRs to patient-centered care as a comprehensive concept. Performing such a review would enable us to explore whether PAEHRs could serve as a tool to strengthen this value-based health care model.

Since the relationship between the use of PAEHRs and the broad concept of patient-centered care has, to date, received limited attention in reviews, a broad overview of recent literature is required, with inclusion of different study designs. With such a broad perspective, a scoping review is more suitable than a systematic review, as scoping reviews aim to broadly summarize and synthesize evidence instead of finding answers to circumscript questions and including only specified study designs. A scoping review can be helpful to provide direction to future research and search for gaps in knowledge [24,25]. The objective of this review is to provide an overview of recent literature about experiences of patients and professionals with the use of PAEHRs and to investigate whether and how the use of PAEHRs contributes to patient-centered care, both in general and among specific population groups.

Methods

Search Strategy and Inclusion Criteria

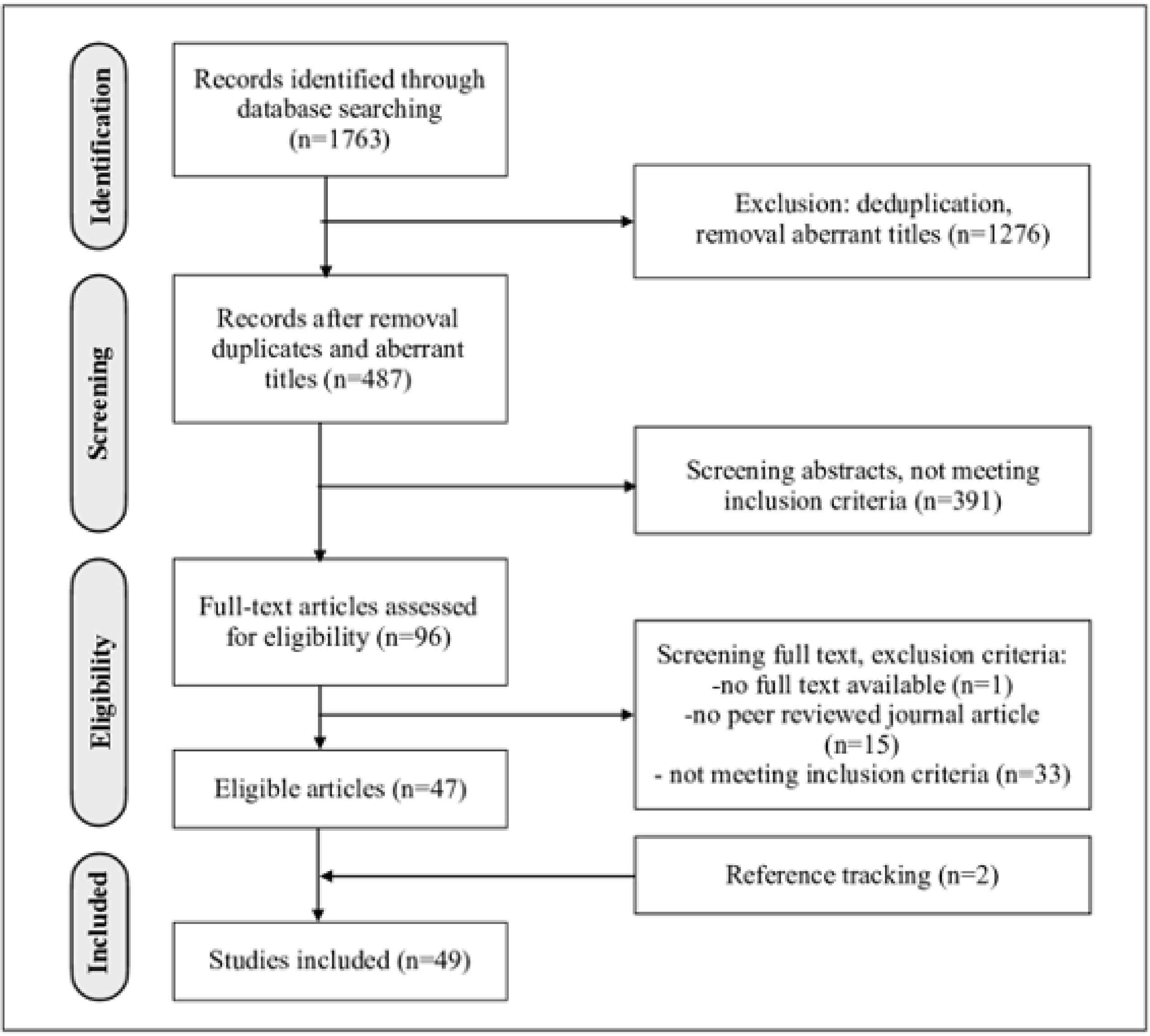
Design and reporting of this scoping review were in line with the framework for scoping reviews by Arksey and O'Malley [24-26], which was further developed by other authors, finally leading to the PRISMA Extension for Scoping Reviews guideline and checklist [27,28]. Multimedia Appendix 1 contains the completed PRISMA checklist for this review. The a priori review protocol has not been registered. Key concepts used in the search were "patient-accessible medical records," "patient experiences," and "professional experiences." Table 1 contains the full electronic search string for the Scopus database. The search was limited to papers written in English or Dutch, being languages all authors understand, and to studies published between January 2000 and April 2019. This period was chosen because, in a first quick search, most articles about PAEHRs appeared to originate from 2000 or more recently. Five databases were searched: (1) Pubmed, (2) Medline, (3) Scopus, (4) Socindex, and (5) Psychinfo. The final search was run on April 9, 2019. Search records were uploaded to Endnote X8 to facilitate the article selection process.

Searches, deduplication, and first screening of titles were performed by SJB. In total, 1763 articles were found and screened for eligibility (Figure 1). Aberrant titles were removed, and abstracts of remaining articles were independently screened by different individuals (SJB, MG, and AG), in line with the scoping nature of the review. We included research articles from peer reviewed journals for which full text could be retrieved. The articles were based on original research data. They addressed "experiences" of professionals or patients/clients using a PAEHR. Articles were screened in 3 rounds. After every round, different interpretations were discussed between all three screening authors to come to a unanimous decision. If necessary, the inclusion criteria were adapted before the next round to ensure uniform selection. SJB screened the remaining full text articles on inclusion criteria. To exclude articles from predatory journals, every journal was checked against the JournalGuide whitelist [29]. The selection process was finalized by reference tracking; all references of selected articles were checked with the inclusion criteria and added when eligible.

Table 1. Full search string for Scopus, split into three key concepts.

Key concepts	Search string per concept
Patient-accessible	(“Patient” OR “Patients” OR “client” OR “clients”) AND (“access” OR “online access” OR “accessible”) AND (“record” OR “records” OR “file” OR “files”)
Medical records	AND “Personal health records” OR “Health Record, Personal” OR “Personal Health Record” OR “Record, personal health” OR “personal health records” OR “Personal Health information” OR “Health Information, Personal” OR “Information, Personal Health” OR “Personal Medical Records” OR “Medical Record, Personal” OR “Medical Records, Personal” OR “Personal Medical Record” OR “Record, Personal Medical” OR “Records, Personal Medical” OR “patient portals” OR “Patient Web Portal” OR “Portal, Patient Web” OR “Portals, Patient Web” OR “Web Portal, Patient” OR “Web Portals, Patient” OR “Patient Internet Portals” OR “Internet Portal, Patient” OR “Internet Portals, Patient” OR “Patient Internet Portal” OR “Portal, Patient Internet” OR “Portals, Patient Internet” OR “Patient Web Portals” OR “Patient Portal” OR “Portal, Patient” OR “Open Notes” OR “Electronic health records”
Patient experiences AND physician experiences	AND “patient experiences” OR “physician experiences” OR “experiences” OR “experiences, patient” OR “experiences, patients” OR “experiences, physician” OR “experiences, physicians” OR “experiences, professional” OR “professional experiences” OR “outcome assessment (health care)” OR “benefit” OR “satisfaction” OR “patient outcomes”

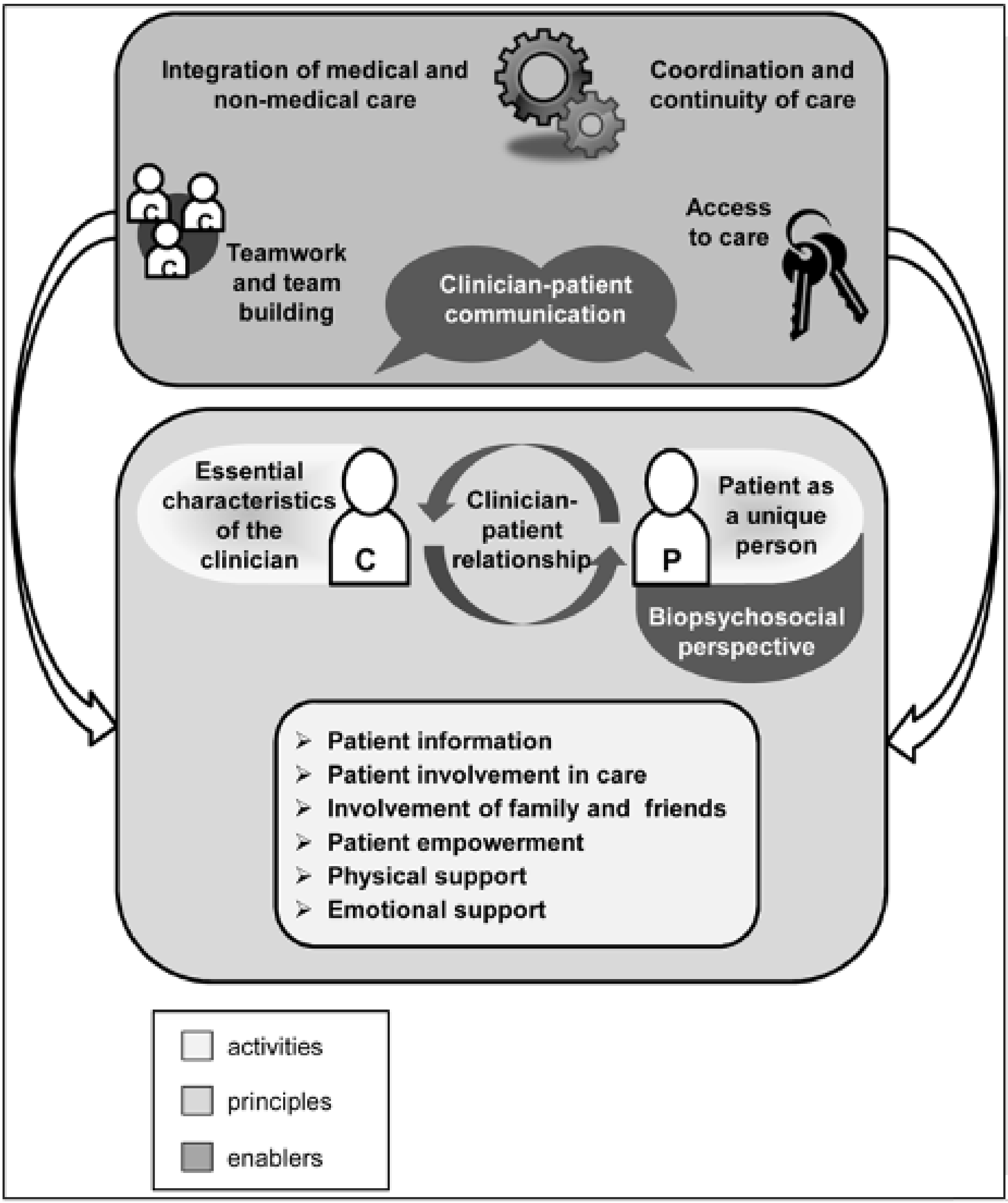
Figure 1. Flow diagram of article selection.



Data Analysis

Through discussion SJB, AH, and EV came to a charting code list (see Multimedia Appendix 2). The list contained codes for general article information, study methods, description of the investigated PAEHR, and 10 dimensions of patient-centered care. The dimensions of patient-centered care were derived from a model, developed by Scholl et al (Figure 2) [5]. This model distinguishes 15 dimensions in 3 groups: (1) principles, (2) enablers, and (3) activities. The principles represent the essential factors of a patient-centered attitude in professionals. The principles and the enablers, which are organizational conditions for patient-centeredness, lay the foundation for the last group, the activities. These are actions and measures by which patient-centered behavior becomes visible. Assuming that use of PAEHRs would affect the "activities" from the model, possibly affect the "enablers," and not affect the "principles," we included all 5 enablers and 4 activities. We did not include the activities "physical support" and "emotional support," since we expected not to find any relation with the use of PAEHRs. From the principles, only clinician-patient relationship was included, because we considered this dimension a dynamic one that could be influenced by use of a PAEHR. A separate charting code was created for differences among population groups, since former research suggests that disadvantaged groups might benefit less from the use of PAEHRs than others [19,20,22,23]. The charting process was done by SJB and discussed afterward with the other authors. All charted data were aggregated through group discussion with all co-authors.

Figure 2. Model of Patient-centered Care, by Scholl et al (2014).



Results

Overview

In total, 49 eligible articles were included [21,30-77]. Multimedia Appendix 3 presents a brief summary of the articles, with characteristics of each study, functionalities of the studied PAEHR, and reported elements of patient-centered care. Multimedia Appendix 4 provides an overview of all outcomes. In this appendix, the articles were divided into 3 study design groups to facilitate the analysis. The largest group (n=34) consists of descriptive studies, both qualitative and quantitative [21,32-35,37-43,45,47-51,53,55,56,58,59,62,63,65,69-73,75-77]. The other 2 groups contain pre-post-test comparative studies [21,40,60,61, 70,71,75,76] and studies comparing intervention and control groups [30,31,36,44,46,47,52,54,57,64,66-68,74]. The results of 7 mixed methods studies were divided and categorized according to the groups they best matched with [21,40,47,70,71,75,76].

Most articles (n=29) originated from the US [21,30,32-40,42,44-46,49,50,54-58,60,63,66,69,74,76,77]. Clustered in 5-year periods, 3 articles originated from 2000-2004 [34,40,66], 3 from 2005-2009 [43,67,68], 15 from 2010-2014 [21,33,47,49,54,55,58,59,64,69,71,73-75,77], and 28 from 2014-2019 [30-32,35-39,41,42,44-46,48,50-53,56,57,60-63,65,70,72,76]. Duration of experience with a PAEHR varied from 1.5 to 48 months. Population sizes were also diverse, ranging from 9 in a qualitative study [41] to several thousand in an Open Notes survey study (n=29,191) [56]. Finally, the population demographics varied; most studies included a broad range of patients (eg, patients in hospitals [30,34,60,72,76] or in primary care [21,32,42-46,48,49,54,57,58,63]). Other studies focused on specific patient groups, like cancer patients [30,37,50,59,62,75], cardiac patients [40,66,74], chronically ill patients [31,64,71], HIV-positive patients [36,57], psychiatric patients [35,39,70], gynecologic patients [67,68,73], and veterans [35,36,39,55,56,69,77]. Ten studies investigated experiences of both patients and their care providers [21,32,34,40,51,57,58,60,70,72]. Four studies focused on professionals only [38,41,61,65]. Respondents in all studies were adults, mostly of no specific age group. Three studies surveyed parents of pediatric patients [33,37,51].

Apart from record-access, the most common functionalities of the PAEHRs were “electronic messaging” [33,36,37,40,51,55,56,64-66,68-70,72,74,76] and the possibility to add or edit health information [31,34,54-56,58,62,65,70,72,74,75]. Six studies investigated a so-called active PAEHR that sent patients “personalized health messages” [31,34,58,63,67,68]. Other functionalities were “give feedback on health information”[62,65], “download information to share with others”[30,42,58], “grant direct access to others” [55,62,76,77], and administrative tasks like “scheduling appointments” [30,51,59], “paying bills” [30], and “requesting medication refill” [30,72].

One patient-accessible record was paper-based and consisted of a briefcase with all medical information, which was updated after every visit to the clinic [47]. Two PAEHRs were electronic but not available online [43,73]. One was a USB-stick containing all medical information, which was revised during every visit to the clinic [73]. The other was a kiosk in the clinic’s waiting room, where patients could access all medical info during their visit [43]. In one study, 9 physicians were interviewed about their experiences with PAEHRs in general [30].

Dimensions of Patient Centeredness

The outcomes for the 10 coded dimensions of patient-centered care have been summarized in Table 2. In 34 of the studies at least 3 of these dimensions were explored. None of the studies mentioned the dimensions “integration of medical and non-medical care” and “teamwork”. The following paragraphs describe the outcomes for each dimension of patient-centered care. When describing outcomes, we use the term “effect” both for experienced effects as well as for objective results from comparative studies.

Table 2. Summary of results for dimensions of patient-centered care. This table represents, for every explored dimension of patient-centered care, whether reported outcomes point in a positive or negative direction. “Negative” in a pre-post comparative design means “less positive than expected.” In a pre-post or intervention-control design, the term “neutral” refers to the outcome “no difference” or “no significant difference.”

Dimension	Number of studies, n	Descriptive studies, reference number		Comparative studies, reference number		
		Positive	Negative	Positive	Neutral	Negative
Information	40	[21,32-34,37-43,45,47-51,53,55,56,58,59,62,63,65,69-72,75-77]	N/A[a]	[30,31,36][b]; [44,46,47,76]	[60,67]	[61]
Involvement in care	33	[32,34,37,38,40-43,47-51,55,56,59,62,63,65,69,71,75,77]	N/A	[36,54][b]; [44]	[30,46,64,67,74]	[60,61]
Empowerment	23	[21,33,39,42,45,47,48,50,56,58,63,70,76]	N/A	[46,59,60,66]; [76][b]	[36,40,61,68,70,71,75]	N/A
Communication	22	[33,34,37,40,41,45,47,48,51,53,55,58,59,62,63,65,70,71,76,77]	N/A	[76]	[57,66]	N/A
Involvement of family and friends	14	[42,45,47,49,51,55,59,62,69,71,73,76]; [70][c]	[70][c]	[57]	N/A	N/A
Clinician-patient relationship	22	[21,32,35,38-43,45,50,59,62,63,65,71,72]	[41][c]	[44,74]	[57]	[60,61]
Access to care	5	[42,45,49,62,63]	N/A	N/A	N/A	N/A
Coordination / continuity of care	3	[40,58,76]	N/A	N/A	N/A	N/A
Integration medical / nonmedical	0	N/A	N/A	N/A	N/A	N/A
Teamwork	0	N/A	N/A	N/A	N/A	N/A

[a] N/A: not applicable.

[b] Significant effect.

[c] Both positive and negative aspects reported.

Information

Forty studies investigated if and in what way patients felt more informed about their health after use of a PAEHR. We distinguished 3 different topics: (1) what patients valued in reading records, (2) emotional consequences, and (3) understandability. Seven descriptive studies examined reasons for reading medical records [32,43,45,56,62,75,76]. Patients valued reading their record because they wanted to know about their health or because they wanted to be sure they understood what the doctor said or because they were curious. Patients valued reading their records most because it improved understanding of health issues [21,34,39,45-47,50,53,56,60,61,65,69,71,75-77], helped to prepare for next visits [21,56,59,61-63,65,71,75,76], and helped to remember the care plan [21,40,42,43,45,46,49,50,56,61,76]. Reading also helped patients to follow treatment recommendations [33,39,41]. Six studies compared the difference in health knowledge between intervention and control groups [30,31,36,44,47,67]. One study found a significantly higher “self-health management knowledge score” among PAEHR adopters than among nonadopters (*P*<.01) [30]. Another study found that the intervention group was significantly better informed than the control group about their latest blood measurement levels, including date, time, and trend changes, and about normal lab values (*P*<.001) [31]. A third study found that HealtheVet users were able to correctly identify their CD4 counts significantly more often (Fisher exact test=.048) and their viral load (Fisher exact test=.003) than nonusers [36]. The other studies found no significant difference [44,47,67]. Two pre-post studies compared expectations with experiences [61,76]. After a period of PAEHR use, one of the studies reported better understanding of care plans among patients than expected (OR=1.39) [76]. In the other study, however, interviewed psychiatrists reported less improvement than expected in the extent to which patients understood their medical conditions or remembered their care plans [61].

Reading their records also provided patients with reassurance [33]. In 4 qualitative studies, patients said that transparency reduced anxiety and stress [33,45,56,62]. They experienced waiting for news as more stressful than reading notes by themselves. One patient said: “It is easier to break down at home where you are surrounded by family, than at the doctor’s office” [62]. If reading records caused stress, this was in most cases related to new diagnoses which had not yet been discussed with the professional [33]. Stress was also caused if health care professionals trivialized a patient’s problem in the record [39]. Less than 10% of patients often or always experienced worries or confusion after reading their record [21,39,56,57,76]. Three intervention-control studies found no significant difference in anxiety levels or reported worries between users and nonusers [47,52,57].

Six studies investigated if patients understood everything they read and how they felt they did not understand [34,40,50,58,62,77]. Some patients said they would appreciate built-in-definitions and less jargon. On the other hand, one patient added: “I would rather have the doctors just write what they write and me work to understand it, than them writing it for me and leaving something out that I would like to know" [40]. Moreover, although patients found some medical terminology too difficult, they managed to find explanations on the internet [58,62].

Involvement in Care

Thirty-two studies described the impact of use of PAEHRs on involvement in care. Twenty-three descriptive studies described involvement of patients in their care as a benefit of using a PAEHRs [32,34,37,38,40-43,47-51,55,56,59,62,63,65,69,71,75,77]. Clinicians in one study said that using a PAEHR resulted in a "power shift" towards patients. Some of them saw this as a "move towards patient-centered care, creating better opportunities for collaboration with patients" [38]. In intervention-control studies, the 13-question Patient Activation Measurement (PAM-13) Questionnaire was most commonly used to measure involvement of patients in their care. Two intervention-control studies found a significantly higher PAM-score in the user groups [36,54]. One study reported a mean PAM-13 score of 47 points in the intervention group versus 45 points in the control group (P=.0014) [54], whereas the other study reported a mean PAM-13 score of 72.5 in the intervention group versus a mean of 63.49 in the control group (P=.03) [36]. Three studies found no significant effect on activation score or decision making [64,67,74]. One study, comparing different user subgroups, reported that less educated patients and non-White patients were more likely to report that reading visit notes was extremely important to engaging in their care than more educated and White patients [46]. In the 2 pre-post comparisons, the observation that patients were "feeling more in control" was slightly lower than expected [60,61].

Five studies investigated if patient involvement would result in patients finding and correcting errors in their record [45,60,62,65,76]. One descriptive study reported that 6 patients in a group of 15 had found errors but had not requested correction [62]. One study investigated a PAEHR with a feedback option [45]. Patients valued this feedback option because it helped them to correct errors. Two descriptive studies reported that physicians felt that use of PAEHRs could prevent medical errors and that the PAEHRs were used by patients as a means to check for accuracy [65,76]. In one pre-post study, patients found less errors than expected, although errors were found and corrected; in a group of 50 patients, 3 patients reported finding errors in medication, 2 patients found errors in radiology test reports, and 1 patient found an error in a laboratory test report [60].

Involvement of Family and Friends

Fourteen studies investigated whether and how family and friends were involved in care through use of PAEHRs. Thirteen descriptive studies reported that patients shared health information with relatives, friends, and health professionals [42,45,47,49,51,55,59,62,69-71,73,76]. Patients said they shared information to answer questions of family and friends and to keep them informed. Sharing information also helped to discuss their disease with relatives or caregivers. The percentage of patients who actually shared notes with others differed among studies, from 15% to 67%. One descriptive study among patients with a bipolar disorder reported that 23% of the 39 respondents considered access to family caregivers preferable, whereas 25% thought it would be harmful [70]. One study, comparing HIV-positive patients with other patients in primary care, found that HIV-positive patients were more likely than other primary care patients to share or discuss visit notes with others, both friends and professionals [57]. In one mixed-methods study, caregivers especially valued the ability for a patient to share information with them, because this enabled them to view notes of visits which they had not been able to attend [76].

Empowerment

In 13 descriptive studies, patients mentioned that they felt more in control of their health or that they could take better care of their own health due to reading their record [21,33,39,42,45,47,48,50,56,58,63,70,76]. In one study, patients appreciated the possibility to share a print-out of their record with another doctor [59]. Patients also said that their role became more active [45]. They experienced more ownership of their own health status [63]. Three control-intervention studies reported no significant difference in empowerment between intervention and control groups [36,66,68]. In 7 pre-post studies, 6 studies found no significant effect on empowerment scores [40,60,61,70,71,75]. The 7th study reported that patients were more confident in their ability to manage their health information (OR 2.14, 95% CI 1.59-2.89) and their care (OR 1.48, 95% CI 1.14-1.93) [76].

Communication

Twenty descriptive studies investigated the effect on communication between patient and health care professional and reported an improvement [33,34,37,40,41,45,47,48,51,53,55,58,59,62,63,65,70,71,76,77]. Communication became easier because of the PAEHRs, and interaction improved [34,58]. The ability to view health information improved the level of communication during subsequent visits and made it possible to communicate "on a more level playing field" with health care professionals [41,51]. The use of a PAEHR also removed barriers, for instance, "because you can ask 'stupid' questions that you wouldn't pick up the phone for" [33]. Two intervention-control studies reported on communication and found no significant differences between intervention and control groups [57,66]. One pre-post study reported that caregivers appreciated the possibility to view notes of visits they could not attend, because it improved their communication with care providers [76].

Seven descriptive studies investigated the influence of PAEHR use on time investment, 5 of them reporting no difference [21,32,40,58,62,65,72]. One study reported that some professionals needed more time to edit or explain notes. However, they framed this as "better documentation, a good thing" [21]. In one study, a professional said that it was improving efficiency: "finally something to save me time!" [58]. One intervention-control study reported that professionals received more messages per patient, but nonetheless did not feel a perceptible change in workload [66]. Four pre-post studies investigated expectations of more time investment, but none demonstrated an increased time investment [21,40,60,61].

Clinician-Patient Relationship

Seventeen descriptive studies reported on the clinician-patient relationship [21,32,35,38-43,45,50,59,62,63,65,71,72]. Patients reported that they were feeling better about their doctors after reading their records [32,39]. They appreciated their doctors' expertise more and experienced a more equal relationship [40,41,43,45,62,64,65,72]. They valued the level of transparency, especially when notes were written respectfully [35,43,50,59]. Respectfully written notes contributed to their feelings of trust [35,71]. As a result, they felt heard and cared for [45]. Three intervention-control studies and 1 pre-post study reported on the professional-client relationship and found no significant differences [44,57,74]. Two other pre-post studies, however, found that the experienced increase of trust in physicians was less than expected, both from a patient and a professional perspective [60,61].

Related to the fear of damaging a therapeutic relationship, some professionals expected that they would report differently if they knew patients could be reading their visit notes. A psychiatrist in one study said: "Sometimes a disbalance occurs, patients 'directing their care' and dictating their doctors how to write their notes" [41]. These psychiatrists also feared that transparency of records could damage the therapeutic relationship, especially when notes revealed subjective impressions. Four pre-post intervention studies investigated if clinicians reported differently about sensitive subjects. Professionals appeared to report less differently than they had expected [21,57,58,61].

Access to Care

An access to care dimension was mentioned in 5 qualitative studies [42,45,49,62,63]. Patients experienced that the PAEHRs gave easy and quick access to health information [42,45,62]. Rapid access was perceived to be advantageous in emergency situations [49]. One study also mentioned that immediacy of secure messaging cultivated a sense of ease of access [63].

Coordination and Continuity

In 2 qualitative studies [40,58] continuity and coordination of care came up. Patients mentioned the benefit of being able to bring their health information along to another care provider and to take care of their own medication when they are out of town.

Differences Among Population Groups

Since former research suggests that different population groups do not profit equally from the use of PAEHRs [19,20,22,23], we searched for differences in our review. Seven studies compared the composition of the studied population with national demographic data. They reported that PAEHR users were more likely to be White and higher educated than nonusers [30,35,36,39,40,44,45]. Four studies investigated experiences of different ethnic and socioeconomic groups [32,45,46,49]. One descriptive study found that women, older patients, and high frequency users found reading notes very important to engaging in their care [45]. Another descriptive study reported that older, lower educated, retired, and unemployed patients, as well as patients with a poor self-reported health and participants in other studies were more willing to share visit notes with others [49]. A third descriptive study found that disadvantaged groups such as the elderly, non-White patients, less educated patients, or patients with poor self-reported health, reported more often than others that use of a PAEHR made them feel better about their doctors [32]. One intervention-control study focused on the importance of PAEHRs to non-White and less educated patients [46]. Both non-White and less educated patients reported more often than White and higher educated patients that the PAEHRs helped them to understand and remember care plans, feel informed, and make decisions concerning their own care. Both non-White patients and less educated patients found reading notes extremely important to engaging in their care.

Discussion

Summary

This review investigates whether and how the use of PAEHRs contributes to patient-centered care, both in general and among specific patient groups. Overall, the articles in this review support the assumption that patient-accessible records contribute to patient-centered care. In all 34 descriptive studies, a positive effect is reported for different dimensions. One descriptive study reported a possible negative effect of PAEHRs on the "therapeutic relationship." Five out of 22 pre-post or intervention-control studies reported significant positive effects related to the dimensions "information," "involvement of patients," or "empowerment." No significant negative effects were reported.

The studies in this review included adults only. Four studies found that, in particular, disadvantaged groups experienced PAEHR-related benefits [32,45,46,49].

Dimensions of Patient-Centered Care

As we expected, the effect on the different "activities" in the Scholl et al model [5] was described most often. Although some effects on "enablers" are reported, only two of the "enablers" are mentioned: (1) access to care [42,45,49,62,63] and (2) coordination/continuity of care [40,58,76]. A complicating factor in the analysis was the varied use of dimensions and their definitions. For instance, whereas Scholl et al [5] distinguished "information," "involvement in care," and "empowerment" as different dimensions, some studies included "involvement" and "knowledge/information" in questionnaires about "empowerment" [5,40,68,71].

Furthermore, we found topics in our review that were not described by Scholl et al [5]. One topic was that patients contributed to patient safety by finding and correcting errors in their records [45,60,62,65,76]. After discussing this topic, we added the subject to "involvement in care," arguing that patients showed their involvement in care by checking their record for errors. In a recent article by Zeh et al [78], however, patient safety was added to the Scholl et al model [5] as a new dimension based on a Delphi study among patients. Patients regarded patient safety as an important dimension of patient-centered care.

Both negative and positive effects were reported for the dimension "patient-clinician relationship." In particular, professionals in mental health care expressed concerns that the transparency of PAEHRs would damage the patient-clinician relationship [38,61]. This is in line with results from other studies. In a recent Norwegian study [79], professionals in mental health care report significantly more often than their colleagues in somatic care that they change their way of writing when using PAEHRs. They also discuss significantly more often than their colleagues in somatic care whether patients should be denied access to their record. Dobscha et al [80] reported that only half of the mental health professionals they queried (107/198) considered sharing mental health Open Notes with patients a good idea, while most of them (174/205) supported the idea in general to share medical notes with patients.

In opposition to professionals, mental health care patients in our review felt that transparency in a PAEHR strengthened the patient-clinician relationship, given that sensitive information was reported in a respectful way [35,38]. The fact that professionals see this differently could be caused by traditional role expectations “in which the patient is viewed as someone to ‘protect’ and for whom the clinician is responsible” [38]. These role expectations are at odds with the patient-centered care principle of “equal partnership between client and professional” and might cause the reluctance toward the use of transparent PAEHRs.

In line with this assumption, another study emphasizes the importance of a patient-centered attitude by offering specific recommendations for mental health professionals to strengthen the therapeutic alliance in the context of patient-accessible records [35]. These recommendations focus on the “principle” dimensions from the Scholl et al model [5]. The findings in these studies strengthen the assumption in the Scholl et al model that the “activity” dimensions only become visible if the “principles” of patient-centered care, reflected in a patient-centered attitude, have been embraced by professionals.

Differences Among Population Groups

Previous research suggests that disadvantaged groups might profit less from the introduction of PAEHRs than others because they make less use of PAEHRs [19,20,22,23]. In our review, 7 studies reported that users of PAEHRs were more likely to be White and higher educated than nonusers [30,35,36,39,40,44,45], probably due to different access abilities [36]. Surprisingly, 4 other studies found that disadvantaged groups experienced heightened benefits from the use of PAEHRs [32,45,46,49]. An explanation for this benefit could be the value of rereading information that cannot be absorbed all at once. Moreover, Bell et al [32] state that non-White patients are said to distrust White medical professionals, not expecting them to respect their cultural values. Reading transparent records would prove otherwise and might help these patients to trust their doctors more [32]. These findings show that disadvantaged groups benefit from the use of PAEHRs, once they have found their way into the system. This emphasizes the importance in designing and implementing PAEHRs that are easily accessible in order to include disadvantaged groups.

Practical Implications

Our review shows that the use of PAEHRs could enhance patient-centered care, but the effects can be influenced by factors on professional and patient levels. On a professional level, adoption of the principles of patient centered care appears to be crucial for a positive impact of the use of PAEHRs on the patient-clinician relationship. On the patient level, easy access and user-friendliness is important to secure access for all demographics and to facilitate the PAEHR-related benefits that disadvantaged groups might experience.

Strengths and Limitations

One of the strengths of this scoping review is that we included all types of designs and we did not focus on “patient-centered care-specific” search terms. As a result, we created a broad overview on the topic. Subsequently, the analysis was guided by the use of selected dimensions of patient-centered care from Scholl et al [5], which helped us to organize and interpret the information and added strength to the review. On the other hand, the fact that the analysis was conducted in separate dimensions made it more difficult to explore interaction and dependence between the dimensions and to draw conclusions about the impact of PAEHRs on patient-centered care as a whole.

Another strength is the combination of searches from 5 different databases, from both a medical and a social perspective.

A limitation of this review is that, by specifying only “physicians” in our search terms and not “nurses,” “nurse practitioners,” or nonmedical professionals, we could have missed some articles that were relevant to the subject.

One more limitation of this review is that we included articles in only English and Dutch and no unpublished data or grey literature. For example, no articles from Estonia or Japan could be included, although both countries are very active in eHealth and the government of Estonia has implemented a PAEHR system that is being used for every citizen of the country.

The strength of the conclusions in this review also depends on the quality of the individual studies. Therefore, we conducted a global quality check, where aspects of study design and population were assessed. Although a thorough quality appraisal is not common in scoping reviews, a more detailed quality check could have added strength to the review. The global check indicated that, on average, study results could have been biased because of population selection, as virtually all studies included only native speakers and most of the studies made use of convenience sampling.

Conclusions

This review indicates that PAEHRs bear potential to positively contribute to patient-centered care. However, concerns from professionals about the impact of transparency on the patient-clinician relationship as well as the importance of a patient-centred attitude need to be addressed. Potentially high benefits for disadvantaged groups will be achieved only through easily accessible and user-friendly PAEHRs.

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Authors' Contributions

JB, AH, and EV participated in the conception and design of the review. JB, AG, and MG performed the search and elimination of titles/abstracts. All authors contributed to the analysis and interpretation of the data. JB and AH lead the drafting of the manuscript, and EV, AG, and MG contributed to critical revisions of the manuscript. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Completed PRISMA-ScR Checklist.
[PDF File (Adobe PDF File), 499 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Coding list, used for analysis.
[XLSX File (Microsoft Excel File), 11 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Study characteristics, PAEHR functionalities and dimensions of Patient Centered Care.
[XLSX File (Microsoft Excel File), 84 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Analysis of outcomes.
[XLSX File (Microsoft Excel File), 33 KB-Multimedia Appendix 4]

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Abbreviations

PAEHR: patient accessible health records
PAM-13: 13-question Patient Activation Measurement

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Original Paper

Lifelog Data-Based Prediction Model of Digital Health Care App Customer Churn: Retrospective Observational Study

Hongwook Kwon[1], MS; Ho Heon Kim[1], MS; Jaeil An[1], MS; Jae-Ho Lee[2,3], MD, PhD; Yu Rang Park[1], PhD

[1]Department of Biomedical Systems Informatics, College of Medicine, Yonsei University, Seoul, Republic of Korea
[2]Department of Information Medicine, Asan Medical Center, College of Medicine, University of Ulsan, Seoul, Republic of Korea
[3]Department of Emergency Medicine, Asan Medical Center, College of Medicine, University of Ulsan, Seoul, Republic of Korea

Corresponding Author:
Yu Rang Park, PhD
Department of Biomedical Systems Informatics
College of Medicine
Yonsei University
50-1 Yonsei-ro
Seodaemun-gu
Seoul, 03722
Republic of Korea
Phone: 82 2 2228 2493
Email: yurangpark@yuhs.ac

Abstract

Background: Customer churn is the rate at which customers stop doing business with an entity. In the field of digital health care, user churn prediction is important not only in terms of company revenue but also for improving the health of users. Churn prediction has been previously studied, but most studies applied time-invariant model structures and used structured data. However, additional unstructured data have become available; therefore, it has become essential to process daily time-series log data for churn predictions.

Objective: We aimed to apply a recurrent neural network structure to accept time-series patterns using lifelog data and text message data to predict the churn of digital health care users.

Methods: This study was based on the use data of a digital health care app that provides interactive messages with human coaches regarding food, exercise, and weight logs. Among the users in Korea who enrolled between January 1, 2017 and January 1, 2019, we defined churn users according to the following criteria: users who received a refund before the paid program ended and users who received a refund 7 days after the trial period. We used long short-term memory with a masking layer to receive sequence data with different lengths. We also performed topic modeling to vectorize text messages. To interpret the contributions of each variable to model predictions, we used integrated gradients, which is an attribution method.

Results: A total of 1868 eligible users were included in this study. The final performance of churn prediction was an F1 score of 0.89; that score decreased by 0.12 when the data of the final week were excluded (F1 score 0.77). Additionally, when text data were included, the mean predicted performance increased by approximately 0.085 at every time point. Steps per day had the largest contribution (0.1085). Among the topic variables, poor habits (eg, drinking alcohol, overeating, and late-night eating) showed the largest contribution (0.0875).

Conclusions: The model with a recurrent neural network architecture that used log data and message data demonstrated high performance for churn classification. Additionally, the analysis of the contribution of the variables is expected to help identify signs of user churn in advance and improve the adherence in digital health care.

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KEYWORDS

churn prediction; digital health care; life-log data; topic modeling; recurrent neural network; deep learning interpretation; attribution method; integrated gradients; digital health; prediction; model; data; app; observational; time-series; neural network

Introduction

Customer churn prediction is one of the most important concerns for almost every company. If customers leave, then sales are reduced, and new customers are needed to replace the previous ones [1]. However, the cost of attracting new customers is 5- to 10-times higher than the cost of retaining customers [2]; therefore, it is much more effective to predict potential churn and prevent these customers from leaving by utilizing promotions or marketing.

Digital health care refers to public health services ranging from simple weight management to professional medicine using mobile devices [3]. With smartphone use becoming more common, the digital health care industry is growing, and numerous health-related apps have been launched [4]. This has provided many people with convenient access to digital health care; however, for them to achieve actual improvements in health, they need to use the apps consistently [5,6]. Therefore, the prediction of churn and the retention of digital health care service customers have significant implications for companies and for users.

Because of the importance of predicting customer churn, studies [7,8] have been performed. However, these studies have generally been conducted using statistical methods and time-insensitive machine learning techniques (eg, decision tree, logistic regression, or support vector machine) [7], by which some information can be lost during the preprocessing sequence [8]. Therefore, a model structure that can accept time-series patterns is necessary.

Many studies have used structured information about customers, which is generally stored in customer relationship management databases [9]. However, more customer text data are becoming available, such as online posts and messages, and it is known that analyzing text data improves predictive performance in customer churn problems [10,11].

We aimed to apply a recurrent neural network structure to leverage time-series patterns in user lifelog data and text message data to predict user churn for digital health care apps. We also aimed to examine the impact of time-series data on model performance and whether the presence of text data affects the performance of churn prediction.

Methods

Health Care App

This study was conducted using data from Noom (Noom Inc), a global digital health care app that provides lifestyle-related functions, such as food logs, exercise logs, weight logs, in-app group activities, and in-app articles. Users are encouraged to log their food intake, exercise every day, and record their weight every week [12]. Users of this digital health care service can also send messages to personal coaches to ask questions about dietary intake, exercise, mindset, or program descriptions. Personal coaches offer feedback to users, in the form of praise, emotional support, encouragement, and validation, based on the user's entries [12].

Study Design

This study predicted customer churn based on lifelog data provided during the customer’s use period. Both paid and free services are available in this digital health care app, and the study defined customers who were refunded for their paid services as churn users.

We received anonymized and unidentified payment information and log data from the company for Korean users only. User data were randomly selected among users who had service payment records between January 1, 2017 and January 1, 2019. Users can select a program lasting 4, 8, 16, or 24 weeks; we limited our analysis to the 16-week program because the largest number of customers chose this period. Additionally, the service use period of the program varied depending on the date of payment and whether the users churned; therefore, we used only log data corresponding to each user’s paid service period for analysis.

Because the proportion of customers who request a refund is generally very small compared with the proportion of total users, the same ratio of retained users was extracted to match the number of churn users to address the problem of data imbalance associated with machine learning [13]. First, users who cancelled their subscriptions, with the refund date recorded, were selected. If their refund occurred after the end of the 16-week program, users were considered retained users and were excluded from the churn user group. The paid program includes a trial period lasting 7 days; during that time, users can request a refund after the initial payment. Therefore, users who received refunds during the trial period were excluded from the churn group because data for fewer than 7 days are insufficient for analysis reliability and generalization. Finally, 934 users were included as the churn group, and 934 retained customers were randomly selected for inclusion as the retained group; the 2 groups were equally matched with respect to gender [14].

This study was approved by the institutional review board (2017-1253) of the Asan Medical Center. The need for informed consent was waived because this study used routinely collected log data that were anonymously managed at all stages, including during data cleaning and statistical analyses.

Model Structure

The overall predictive model structure was designed to include both time-variant and time-invariant inputs. Inputs that occur over time include lifelog data such as step records, daily weight measurement records, diet intake records, and user text messages. Inputs that were considered constant included age, sex, initial BMI, or target BMI of each user (Figure 1).

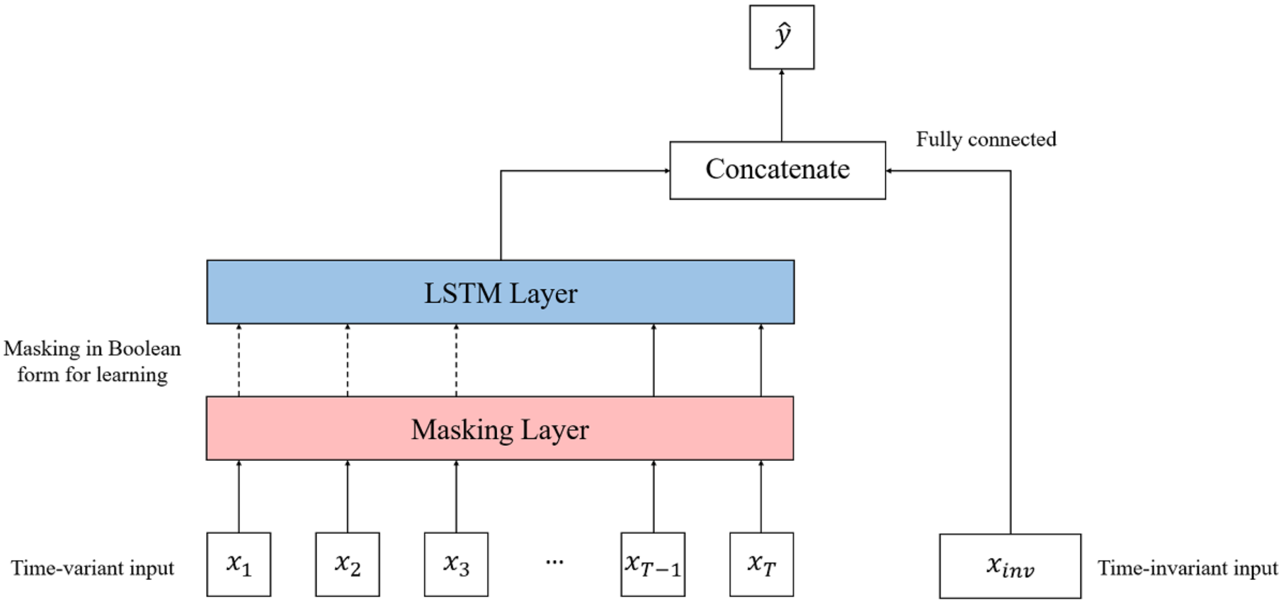
The time-variant node used a long short-term memory structure, which belongs to the recurrent neural network family and is good for processing time-series data. Long short-term memory was developed to solve the vanishing gradient problem that can occur when training a basic recurrent neural network [15,16]. Long short-term memory has a memory cell that contains a node with a self-connected recurrent edge of a fixed weight, thereby ensuring that the gradient can exist over long time steps without vanishing or exploding [17].

Long short-term memory, as in other recurrent neural network-based models, should have the same sequence length input for time; therefore, the time steps of every sample need to be adjusted to ensure that they are the same. The period of service use was constant for retained users; however, for those in the churn group, the period of service varied depending on the time of departure of the user. Therefore, zero padding was used to lengthen the service period data of the churn group to 16 weeks.

One possible critical problem is that the day data of churn users are padded with zeros. Another is that the actual existing data of churn users are relatively short compared with the data of the retained users. If our algorithms notice that part of the sequence is padded with zeros (ie, in the case of churn users), then the problem of leaking the actual labels occurs. A masking layer was added to keep the model unaware of the length of the input sequence. The masking layer produces a Boolean-type tensor for learning whether to use certain values or to ignore them in downstream tasks, and it is used to handle time-series data of different lengths [18].

After padding and masking, time-variant inputs were processed in the long short-term memory layer and the outputs of the layer were concatenated with the time-invariant inputs. Finally, binary classification of the churn was performed.

Figure 1. Overall model architecture. LSTM: long short-term memory.



Text Message Preprocessing

The Noom app provides a function for users and coaches to communicate with each other through text messages. The messages that users receive from coaches can vary depending on their assigned coach; therefore, only messages sent by users were included in this study. User intentions can be more directly inferred from text messages than from log data. To input text message data in the model, the messages were vectorized. Although there are many advanced word-level and sentence-level embedding techniques, topic modeling with latent Dirichlet allocation was used in this study.

Topic modeling assumes each document is a set of random topics and probabilistically presents the importance of the topics and words in the document [19]. Latent Dirichlet allocation was used to estimate the probability that a word corresponds to a particular topic and the probability that a particular topic exists to find the topics in each unstructured document [20]. After topic modeling, each topic name was labeled as intended by the researcher (ie, the name of the topic is not determined by any criteria, but rather by discretion), taking into account the distribution of words corresponding to each topic. Topic modeling has the advantage of easy implementation and intuitive interpretation by examining the proportion of topics in sentences. For each text message, topic modeling was conducted to demonstrate the distribution of the topic proportion of each message. Additionally, since one person could send multiple messages during 1 day, the means of topic vectors was calculated to check the overall topic of the day, and the maximum of the vectors was taken to ensure that important topics that do not appear frequently were not diluted in the average.

Although topic modeling is popular because it is simple to use and easy to understand, there is a limitation: researchers must determine the optimal number of topics present in the documents [21]. This is not a serious problem if the exact number of topics is known, but it is very difficult to select the optimal number of topics without prior knowledge. To solve this problem, the optimal number of topics was determined using the coherence score, which calculates the similarity between the words included in the topic and calculates whether the topic consists of words that have semantic similarity [22].

Interpretation Method

Identifying signs of churn in advance is extremely important for a company; however, because of its nested nonlinear structure, most deep learning models, including our model, are black boxes that, despite their good performance, do not provide information regarding the basis of the predictions [23]. To compensate for this uninterpretability, integrated gradients, which are part of an attribution method, were applied.

Attribution methods produce explanations of an analytic model by assigning an attribution value (relevance or contribution) to each input feature [24]. We used integrated gradients—a final prediction is calculated by multiplication of each variable and coefficient, and the output of the model is also a product of inputs and gradients in the deep learning structure, similar to linear regression [25]. The integrated gradients method was designed to improve the simple gradient approach, which does not satisfy implementation invariance (ie, the attributions are always identical for 2 functionally equivalent networks). Integrated gradients attempt to capture the effects of nonlinearities by computing the gradient along a line between the input data and given reference baseline data [26]. The integrated gradient of the dimension *i* is defined as follows:

$$IntegratedGradients_i(x) ::= (x_i - x'_i) \times \int_{\alpha=0}^{1} \frac{\partial F(x' + \alpha \times (x - x'))}{\partial x_i} d\alpha$$

where

$$F: R^n \rightarrow [0,1],$$

which represents a deep neural network function; $x \in R^n$ represents the input; and $x' \in R^n$ represents the baseline data (eg, zero-embedding vector for text neural network) [27]. Using this method, we can examine the effect of each variable on the final output of the model; to explain the effect of each variable on the model, we investigated the average value of the integrated gradients for each variable.

Model Evaluation

During the model performance evaluation, we compared the performance from 2 perspectives: (1) how the performance of the model changes as data close to the point of churn (or retention) is determined at the last date, with some daily data excluded sequentially from the end of the period and (2) the performance differences in the model depending on the data regarding the presence of the text message vectors at every time point. Classification accuracy, F1 score, and area under the receiver operating characteristic curve were calculated.

This study was implemented with Python programming language (version 3.6.8). Data preprocessing procedures related to topic modeling were implemented using the gensim package (version 3.8.3). All neural network modeling including long short-term memory and masking layer were implemented using TensorFlow (version 1.14.0) and Keras (version 2.3.1).

Results

Baseline Characteristics

A total of 1868 eligible users (934 churn and 934 retained), were included in this study. The churn and retained groups showed no statistical differences in gender (*P*>.999) and age (*P*=.20). Both groups comprised mostly women (both groups 825/934, 88.3%), and the mean age was approximately 31 years. The initial BMI and target BMI were calculated based on the height, initial weight, and weight targeted by service use, and both showed no statistically significant differences (*P*=.41 and *P*=.19, respectively). Statistically significant differences were found for the total service period (*P*<.001) and the number of input days for meals (*P*<.001), messages (*P*<.001), walking (*P*<.001), and weight tables (*P*<.001), which are time-variant log data (Table 1).

Table 1. Demographic characteristics.

Variables	Churn users (n=934)	Retained users (n=934)	*P* value
Gender, n (%)			>.999
Female	825 (88.3)	825 (88.3)	
Male	109 (11.7)	109 (11.7)	
Age (years), mean (SD)	31.3 (7.1)	31.7 (7.9)	.20
Initial BMI, kg/m^2, mean (SD)	25.2 (4.1)	25.1 (3.8)	.41
Target BMI, kg/m^2, mean (SD)	22.0 (3.6)	21.8 (3.4)	.19
Total number of days of service use, mean (SD)	43.9 (31.3)	112.0 (N/A[a])	<.001
Meal input days	24.0 (23.2)	53.8 (35.8)	<.001
Message sent days	11.8 (11.1)	22.3 (16.9)	<.001
Walk days	40.3 (29.5)	82.9 (32.9)	<.001
Weigh-in days	9.2 (11.4)	20.6 (19.9)	<.001

[a] N/A: not applicable.

Topic Modeling

The value of coherence according to the number of topics is shown in Figure 2. The scores steadily increased for up to 9 topics (0.6469); then, they repeatedly fluctuated and did not show much further increase. Therefore, the optimal number of topics was determined to be 9.

The results—the weighted proportion of the top 10 words—of topic modeling with 9 topics are shown in Table 2.

Figure 2. Coherence score by the number of topics.

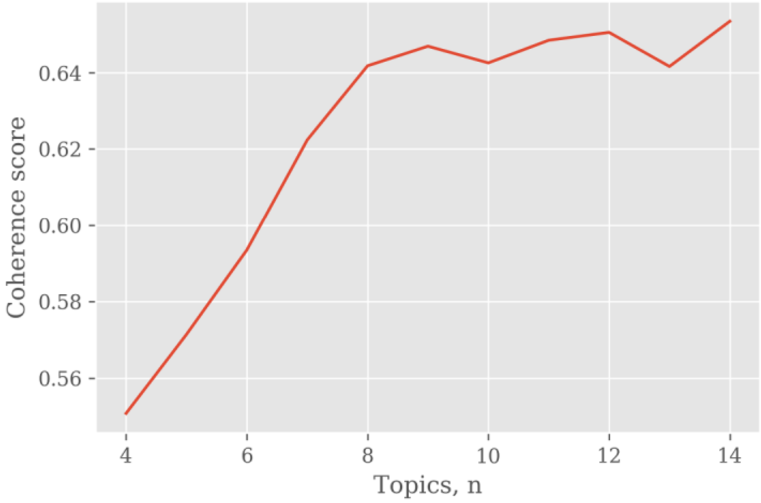


Table 2. Topic modeling results using a combination of the top 10 keywords and weight.

Top 10	Topic								
	Food plan	Schedule	Dining plan	Bad habit	Weight management	Daily life	Dietary intake	General exercise	Coaching
Rank 1									
Keyword	Dinner	Today	Record	Water	Weekend	Time	Thought	Exercise	Thanks
Weight	0.079	0.163	0.088	0.042	0.068	0.085	0.067	0.282	0.114
Rank 2									
Keyword	Today	Yesterday	Tomorrow	Alcohol	Weight	Morning	Effort	Muscle	Diet
Weight	0.032	0.065	0.05	0.036	0.065	0.074	0.052	0.021	0.032
Rank 3									
Keyword	Meal	Next	Hello	Weirdness	Coach	Dinner	Control	Squat	Health
Weight	0.031	0.027	0.028	0.035	0.064	0.059	0.051	0.02	0.026
Rank 4									
Keyword	Snack	Saturday	Day	Weight	Goal	Lunch	Calorie	Stretching	Preparation
Weight	0.03	0.025	0.028	0.026	0.052	0.05	0.049	0.02	0.026
Rank 5									
Keyword	Promise	Start	Travel	Binge	Weight reduction	Meal	Food	Home	Coach
Weight	0.03	0.024	0.023	0.025	0.037	0.04	0.044	0.017	0.023
Rank 6									
Keyword	This time	Mission	Meal	Late-night meal	Height	Leave work	Diet	Aerobic	Stress
Weight	0.028	0.023	0.02	0.017	0.036	0.02	0.043	0.013	0.022
Rank 7									
Keyword	Home	Coach	Menu	Mind	Now	Company	Maximum	Gym	Body
Weight	0.025	0.021	0.018	0.015	0.02	0.018	0.016	0.012	0.021
Rank 8									
Keyword	Plan	Sunday	Eat out	Stamina	This time	Home	Intake	Feeling	Finish
Weight	0.025	0.02	0.017	0.014	0.017	0.016	0.014	0.012	0.021
Rank 9									
Keyword	Weekend	Action	Business dinner	Night	Hello	Possible	Fat	Week	Concern
Weight	0.025	0.02	0.015	0.014	0.016	0.015	0.013	0.012	0.02
Rank 10									
Keyword	Salad	This time	Person	Input	Management	Go to work	Meal	Start	Habit
Weight	0.021	0.02	0.014	0.014	0.016	0.012	0.013	0.011	0.02

Model Performance

The results shown in Table 3 show the classification accuracy, F1 score, and area under the receiver operating characteristic curve for the same test data when (1) some daily data were excluded sequentially from the end of the period and (2) with or without the text message vectors at every time point.

The results showed that the performance gradually increased as more data included the latter time. There was a performance difference of approximately 0.12 (F1 score, with text vector) when the whole-period data were included compared to when the last week data were excluded. The classification performance was generally better if text was included at almost all time points. When text data were included, the predicted performance increased by a mean of approximately 0.085 (F1 score), at every time point.

Table 3. Performance comparison.

Data period and text inclusion	Accuracy	F1 score	AUROC[a]
Excluding the last week			
Without text vector	0.70	0.68	0.70
With text vector	0.78	0.77	0.77
Excluding the last 5 days			
Without text vector	0.70	0.68	0.71
With text vector	0.79	0.78	0.78
Excluding the last 3 days			
Without text vector	0.71	0.70	0.72
With text vector	0.80	0.79	0.80
Including full duration data			
Without text vector	0.83	0.83	0.82
With text vector	0.89	0.89	0.89

[a] AUROC: area under the receiver operating characteristic curve.

Model Interpretation

According to the results, the contribution of the *steps per day* variable, which denotes that the number of daily steps collected automatically, not those input by the user, was larger than the contributions of the other variables (0.1085). This was followed by *afternoon snack cal* (calorie intake from snacks during the afternoon) at 0.0999 and *receive sent ratio* (ratio of the received messages to the sent messages) at 0.0967.

Among the top 20 variables, there were 12 variables related to text messages, 6 variables related to meals, 1 variable related to walking, and 1 variable related to weight. Among the 9 topic vectors, *topic bad habit max*, which corresponds to poor lifestyle patterns (such as drinking alcohol, overeating, and late-night eating) showed the highest contribution (0.0875) (Figure 3).

To verify the contribution of each variable to the churn prediction model over time, the contribution of the variables corresponding to each time over 112 days (for the 16-week program) is expressed in line plots in Figures 4 and 5 (using force_plot [28]). Overall, the contributions of the variables appeared larger as they approached the later time points of churned and retained users.

Because the model in this study outputs the probability of churn, the graph increased to make the probability of churn high for churn users and low for retained users to decrease the probability of churn. Box plots show the contribution of the variable on each date. For example, when we check each graph of the last day's churn and retained users showing the largest contributions, *steps per day* showed the greatest value, as seen for the overall variable contribution (Figure 6). Although several topic variables appeared for both churn and retained users, such as *bad habit*–related and *coaching*-related variables, the impact of each variable on the predicted performance was in the opposite direction.

To determine if the high contributing variables also showed differences in actual values between the 2 groups (churn and retained users), we checked the actual values of the *steps per day* variable, which had the greatest contribution in Figure 3. For retained users, the graph showed the entire 112 days; however, for churn users, the service use period varied depending on the user; therefore, the data were selected at varying intervals suitable for each user's start and end dates. Comparisons of actual values showed that the churn group had maintained a relatively constant value or that the value decreased slightly from the initial date to the last date of service use (from 4774.02 to 4532.35). However, the value of the retained group had a tendency to continue to decrease by half (from 5048.37 to 2485.48) starting from a value at the time of initial service use that was similar to that of the churn group (Figure 6).

Figure 3. Average impact on model output of each variable.

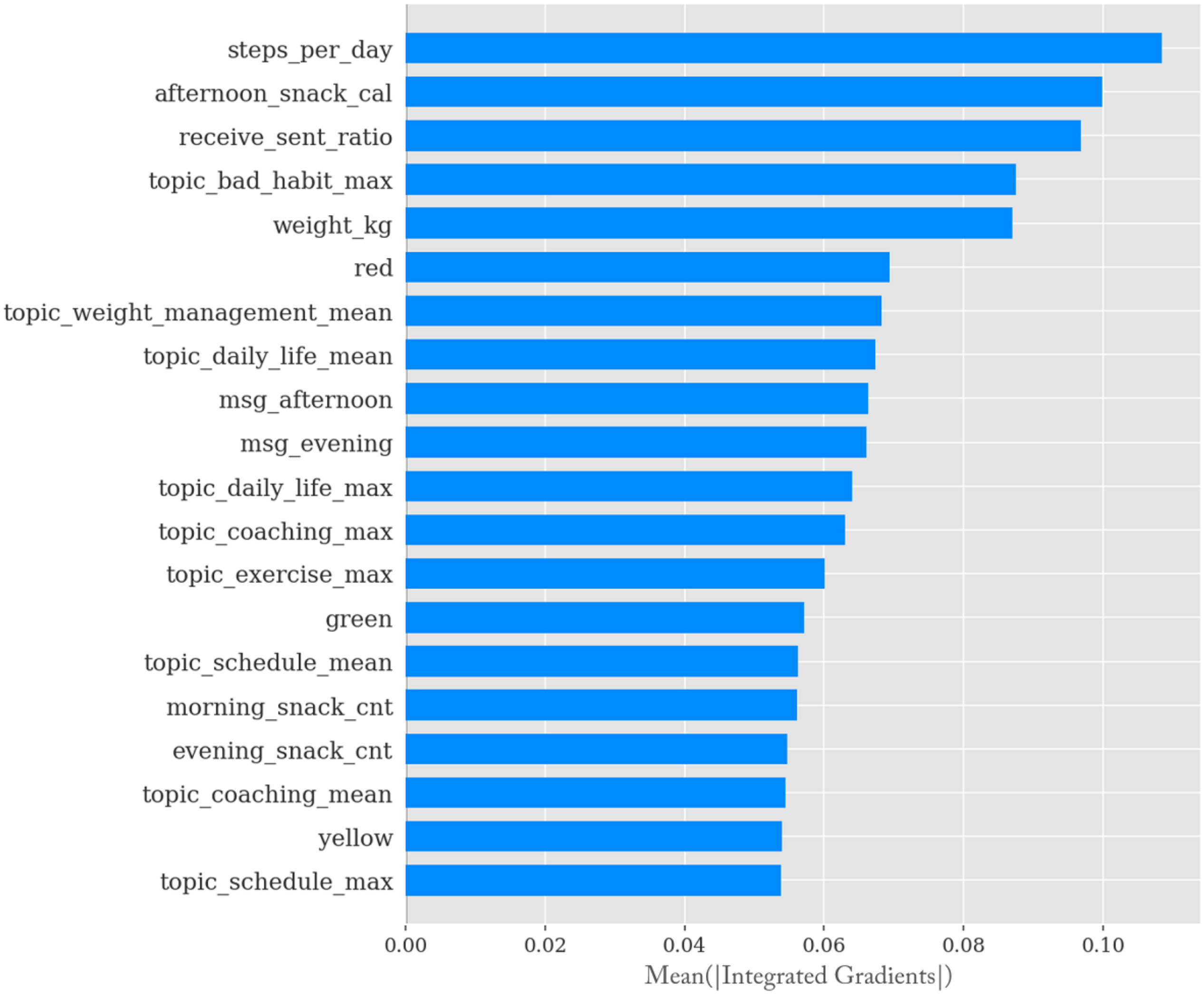


Figure 4. Churn users' daily average contribution of variables over time (above, line plot) and contributions of each variable on the last day (below, bar plot).

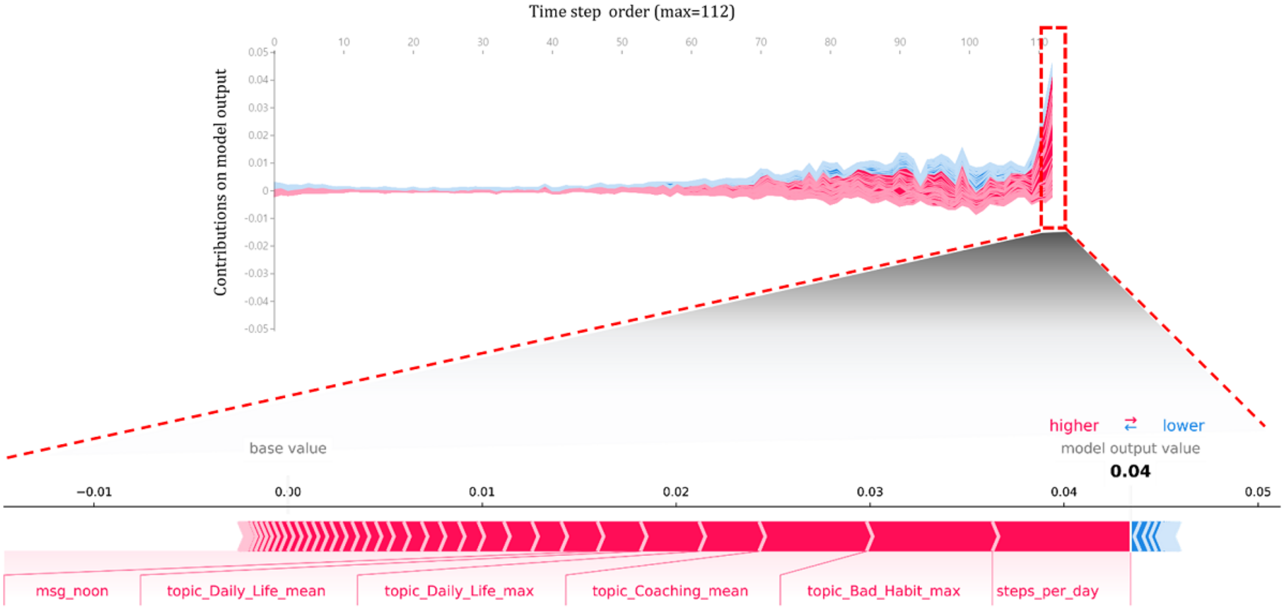


Figure 5. Retained users' daily average contribution of variables over time (above, line plot) and contributions of each variable on the last day (below, bar plot).

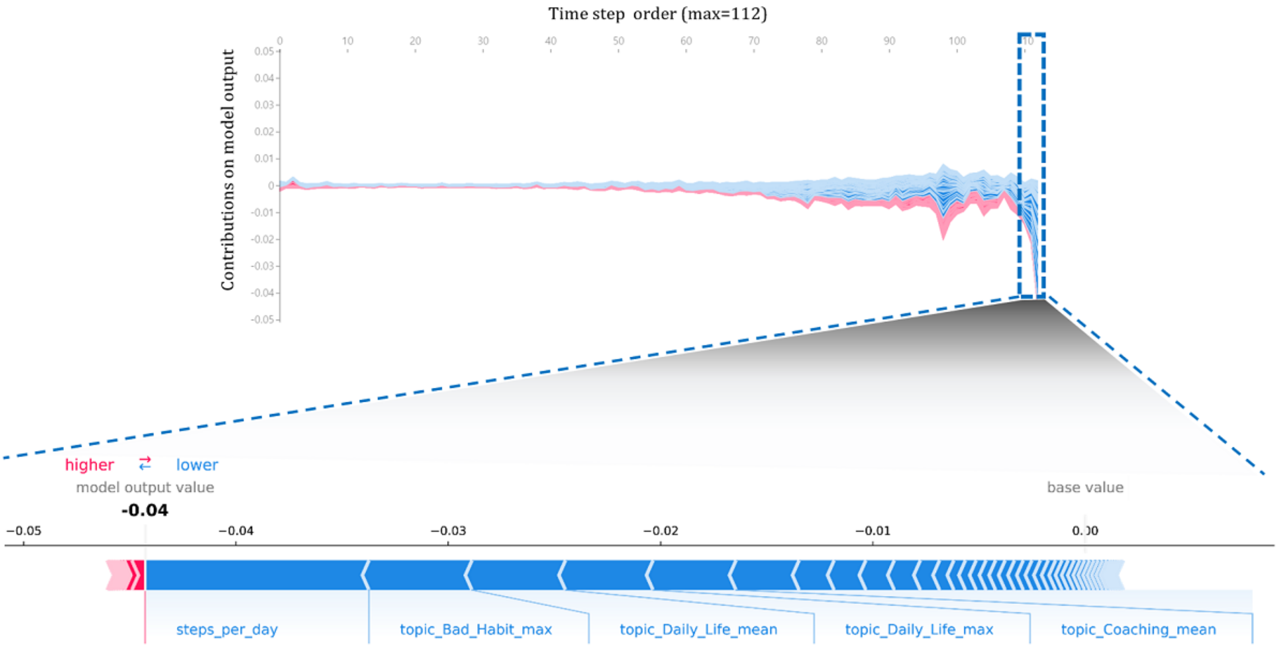
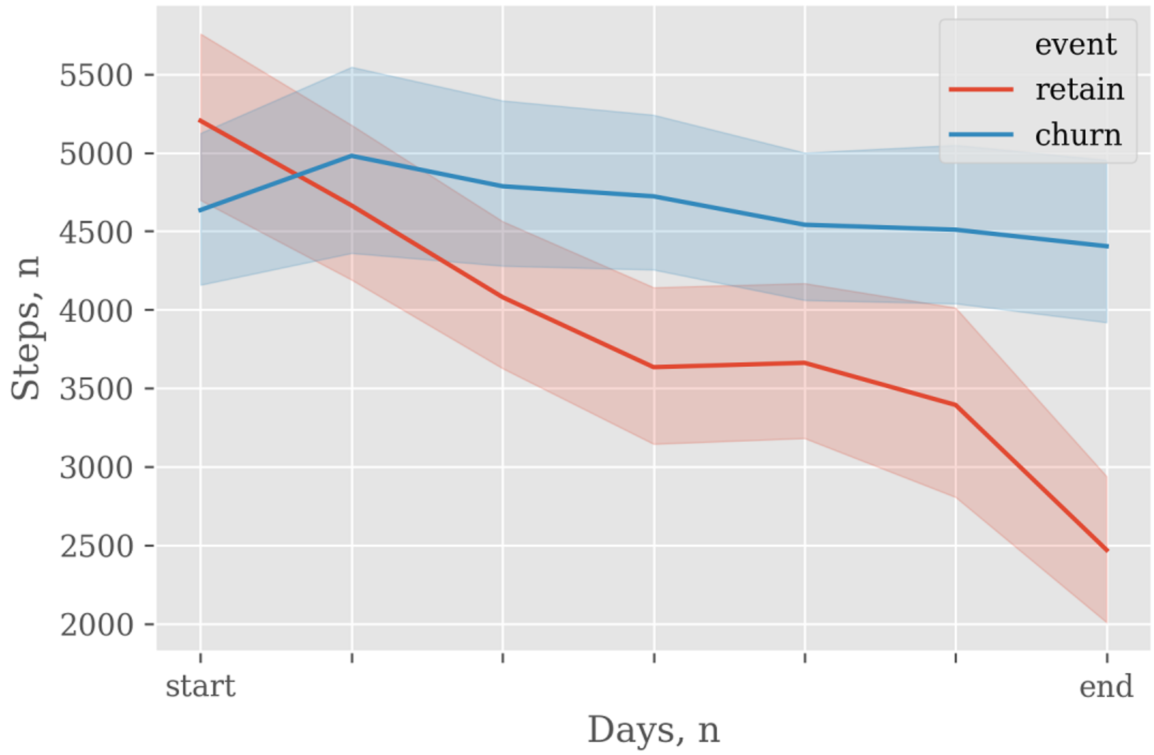


Figure 6. Changes in the mean number of steps_per_day from start to end.



Discussion

Principal Findings

First, as evidenced by the model performance comparisons, for the end time-point, when there were more data, the predictive performance increased for churn and retained users. This could also be seen during the interpretation stage: the closer the end point, the higher the contribution of variables. A previous study [7] compressed the time-series data to input them in models that do not receive time-series patterns. Even in studies [29,30] using a model that could receive time-series data as input, data were lost when inputs were reduced (ie, data cut-off) in order to match the input shape of the models. In these cases, the performance of the model may be relatively poor because it does not reflect the fact that as the end of the period is approached, there is a greater difference between the churn and retained groups [31,32]. However, in our study, by including all the data for different durations of service use by each customer, our model was able to identify churn or retained patterns of the entire time period of service use, thereby improving the predictive performance. The ability to use data of different time lengths allows for the consideration of significant characteristics of the last moment and the immediate training and prediction of churn using only the data collected at that time without waiting for a certain period of time to collect data of equal lengths from all users. This makes it possible to promptly find users who are expected to churn. Therefore, companies can focus on such users and intervene, possibly improving user adherence to their mobile app. Because the steady use of mobile health care apps is closely related to improvements in the users' health [33,34], increasing adherence is crucial to enhance satisfaction with the mobile app and for practical health promotion. Therefore, churn predictions with different lengths of data are important not only for companies but also for users.

Second, including text data can also provide better predictive performance. Because of the growing amount of unstructured customer data that can be collected both inside and outside a company, companies are studying unstructured data [35,36]. In particular, textual information can serve as important information for predicting churn [10]. Nevertheless, companies still struggle with extracting meaningful information from text [37]. In our study, we were able to increase the performance of churn prediction using vectors of messages sent by users as input to the model. We created message vectors through topic modeling to understand which specific topics affected the churn prediction by checking the contribution of each topic vector. For example, the topic that had the greatest impact on churn prediction was *bad habit topic* (eg, drinking alcohol, overeating, and late-night eating, which is known to have a negative influence on weight and health [38]). In other words, mentioning and conversing about these bad habits can also affect the churn of digital health care apps. With knowledge of this beforehand, companies can take measures to encourage the user not to churn by identifying and resolving the user's problems or complaints. Therefore, adding text data not only increases the predictive performance of the churn predictive model but also enhances interpretability by providing intuitive understanding. Companies that want to identify signs of user churn in advance should consider collecting and analyzing unstructured data that directly project customers' thoughts.

Limitations

This study was conducted, using data from churn users until the day before the churn occurred and data for the entire service period of the retained users, as a proof of concept study. However, this assumption may not be appropriate in the real world because the company may not know when the customers will leave. Nevertheless, the probability distribution of the predictions for retained users tended to change the final prediction from churn to retention. In other words, the sensitivity of the churn user data are high; therefore, from the company's point of view, the possibility of missing the churn user can be reduced. However, for practical forecasting by real-world companies, further studies of variations in probability of churn over time are needed. This study was retrospective. It used past records of mobile app users to identify signals of churn and identify the churn users. Because our analysis was retrospective, there was a constraint on its effectiveness for prospective data. Therefore, it is necessary to study whether early interventions for groups expected to be churn users provide more clinical indicators.

Conclusion

We used a model with recurrent neural network architecture that used user log data and text data to determine the churn of digital health care users. Our analysis of variables is expected to help identify signs of user churn in advance and improve adherence in the field of digital health care.

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Conflicts of Interest

None declared.

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Original Paper

Uptake of Proactively Offered Online and Telephone Support Services Targeting Multiple Health Risk Behaviors Among Vocational Education Students: Process Evaluation of a Cluster Randomized Controlled Trial

Prince Atorkey[1,2,3,4], BSc, MPhil; Christine Paul[1,3,4], PhD; Billie Bonevski[1,3], PhD; John Wiggers[1,2,3,4], PhD; Aimee Mitchell[1,2], BPsych (Hons); Emma Byrnes[1,3], BSocSc (Hons); Christophe Lecathelinais[1,2,3], DESS; Flora Tzelepis[1,2,3,4], PhD

[1]School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, Newcastle, Australia
[2]Hunter New England Population Health, Hunter New England Local Health District, Newcastle, Australia
[3]Hunter Medical Research Institute, University of Newcastle, Newcastle, Australia
[4]Priority Research Centre for Health Behaviour, Faculty of Health and Medicine, University of Newcastle, Newcastle, Australia

Corresponding Author:
Prince Atorkey, BSc, MPhil
School of Medicine and Public Health
Faculty of Health and Medicine
University of Newcastle
University Drive
Callaghan
Newcastle, 2308
Australia
Phone: 61 0249246565
Fax: 61 0249246490
Email: prince.atorkey@uon.edu.au

Abstract

Background: A high proportion of vocational education students smoke tobacco, have inadequate nutrition (ie, low fruit and vegetable intake), drink alcohol at risky levels, or are physically inactive. The extent to which vocational education students will sign up for proactively offered online and telephone support services for multiple health risk behaviors is unknown.

Objective: The aim of this study is to examine the uptake of proactively offered online and telephone support services for smoking, nutrition, alcohol consumption, and physical activity risk behaviors, individually and in combination, among vocational education students in the Technical and Further Education (TAFE) setting. The characteristics associated with the uptake of online or telephone services for smoking, nutrition, alcohol consumption, and physical activity risk behaviors were also examined.

Methods: Vocational education students enrolled in a TAFE class in New South Wales, Australia, which ran for 6 months or more, were recruited to participate in a cluster randomized controlled trial from May 2018 to May 2019. In the intervention arm, participants who did not meet the Australian health guidelines for each of the smoking, nutrition, alcohol consumption, and physical activity risk behaviors were provided electronic feedback and proactively offered online and telephone support services. Uptake of support was measured by whether participants signed up for the online and telephone services they were offered.

Results: Vocational education students (N=551; mean age 25.7 years, SD 11.1; 310/551, 56.3% male) were recruited into the intervention arm. Uptake of the proactive offer of either online or telephone services was 14.5% (59/406) for fruit and vegetables, 12.7% (29/228) for physical activity, 6.8% (13/191) for smoking, and 5.5% (18/327) for alcohol use. Uptake of any online or telephone service for at least two health behaviors was 5.8% (22/377). Participants who were employed (odds ratio [OR] 0.10, 95% CI 0.01-0.72) and reported not being anxious (OR 0.11, 95% CI 0.02-0.71) had smaller odds of signing up for online or telephone services for smoking, whereas participants who reported not being depressed had greater odds (OR 10.25, 95% CI 1.30-80.67). Participants who intended to change their physical activity in the next 30 days had greater odds (OR 4.01, 95% CI 1.33-12.07) of signing up for online or telephone services for physical activity. Employed participants had smaller odds (OR 0.18, 95% CI 0.06-0.56) of signing up for support services for at least two behaviors.

Conclusions: Although the uptake of proactively offered online and telephone support services is low, these rates appear to be higher than the self-initiated use of some of these services in the general population. Scaling up the proactive offer of online and telephone services may produce beneficial health outcomes.

Trial Registration: Australian New Zealand Clinical Trials Registry: ACTRN12618000723280; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=375001.

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KEYWORDS

uptake; proactive offer; online support services; telephone support services; multiple health risk behaviors; vocational education students

Introduction

Vocational Education Settings and Multiple Health Risk Behaviors

Vocational education settings are mandated to offer education programs that equip students with technical qualifications that prepare them for specific occupations such as carpentry, hairdressing, plumbing, floristry, automotive engineering, and welding [1]. A high proportion of vocational education students compared with university students report tobacco smoking, poor nutrition, risky alcohol consumption, and physical inactivity [2,3]. For instance, in an Australian study, 35% of vocational education students reported smoking tobacco daily, 96% did not consume at least five serves of vegetables daily, 50% did not meet the recommended daily fruit consumption of at least two servings, 49% consumed alcohol at risky levels, 88% were physically inactive, and 98% engaged in multiple health risk behaviors [2]. It is important to target smoking, nutrition, alcohol consumption, and physical activity health risk behaviors because they are associated with an increased risk of chronic diseases and death [4]. The risk of chronic disease and mortality is higher when one engages in multiple smoking, nutrition, alcohol consumption, and physical activity risk behaviors [4,5]. Vocational education settings are predominately made up of young adults [2]; therefore, offering interventions that target these risk behaviors at an early age could reduce chronic diseases, mortality, and health care costs.

Smoking, nutrition, alcohol consumption, and physical activity health risk behaviors have been found to co-occur or cluster together in vocational education students [6-8]. For example, a study with community college students identified 3 clusters: *active, binge-drinkers with poor dietary intake*; *nonactive, moderate-smokers and nondrinkers with poor dietary intake*; and *moderately active, nonsmokers and nondrinkers with poor dietary intake* [7]. This highlights the importance of taking a holistic approach to behavioral interventions and targeting multiple health risk behaviors collectively. Transfer theory [9] also suggests that the advantages of addressing multiple health risk behaviors include that the knowledge and experiences acquired to successfully modify one behavior can be applied to change other health behaviors [10]. Given the rates of smoking, nutrition, alcohol consumption, and physical activity risk behaviors among vocational education students, and that such behaviors tend to cluster together, connecting this population to services that provide effective support to modify these health behaviors has the potential to improve health outcomes in this population.

Effectiveness of Online and Telephone Support Services in Modifying Health Risk Behaviors

Online and telephone interventions are effective in reducing smoking [11,12], improving nutrition [13,14], reducing alcohol consumption [15], increasing physical activity [13,14], and modifying multiple health risk behaviors [13,16], and they provide a means for changing these behaviors among vocational education students. Advantages of telephone and online interventions include privacy and reduction in stigma [17-19], avoidance of travel time and cost [20], potential to reach a large number of people [21,22], ability to reach individuals who may not seek support [23], and capacity to provide support when it is needed most [19].

In the United States and Australia, for example, evidence-based online and telephone interventions designed to modify health risk behaviors are available to the general population at no cost to users [24-26]. Online interventions available for the general population in Australia include QuitCoach (smoking) [27], Tertiary Health Research Intervention Via Email (THRIVE; alcohol) [28], Healthy Eating Quiz (fruit and vegetable consumption), and 10,000 steps (physical activity) programs [29]. Telephone services available to the Australian general population include Quitline (smoking) [30], Alcohol Drug Information Service (ADIS; alcohol), and Get Healthy Information and Coaching Service (GHICS; fruit and vegetable consumption and physical activity) [31]. Despite the efficacy of online and telephone support services in improving health risk behaviors, the uptake of such services is low [32,33]. For example, only 3% to 4% of smokers in Australia and the United States use the Quitline [32]. Less than 1% of adults in New South Wales, Australia, who are overweight and obese call the GHICS to receive support to increase their fruit and vegetable consumption and physical activity [34]. Only 0.3% of smokers reported using an internet-based intervention in an attempt to quit smoking in the past year [35]. Furthermore, when the figures provided in an Australian study were divided by the total Australian population aged 16 years and older [36] with access to the online service, only 0.4% were found to use the Healthy Eating Quiz [37].

The low rates of use of online and telephone support services may partially be due to the passive recruitment approaches (eg, mass media campaigns) used by these services, which generally rely on individuals to initiate contact with the service providers themselves [38]. Alternatively, proactive recruitment involves service providers initiating contact with the individual to offer support services and has been found to increase the uptake of such services [22,39-42]. For instance, 52% of smokers who were proactively offered Quitline telephone support accepted it [30], and 23% of people who were proactively offered the GHICS accepted it [43]. McClure et al [44] reported that 7% of smokers who were proactively invited to use an internet-based intervention (ie, Project Quit) accepted and visited the website and 4% signed up to use the service.

Factors Associated With Uptake of Support Services

Sociodemographic characteristics are associated with whether people will sign up to use online or telephone interventions. Skov-Ettrup et al [22] found that participants who spent 11 years or more in school compared with those who spent shorter periods in school were less likely to use telephone counseling to quit smoking. Furthermore, participants aged 18 to 39 years were more likely to sign up for an internet-based intervention targeting smoking than those aged 40 years or more [22]. A study conducted in Hong Kong also found that being employed and belonging to a middle-income family was significantly associated with accepting to use a telephone service to quit smoking [45]. Furthermore, Schneider et al [41] found that Dutch adults who were younger, male, highly educated, employed, and were in a relationship were more likely to express interest in the proactively offered online intervention targeting multiple lifestyle behaviors.

Existing studies on the uptake of online and telephone services and factors associated with uptake focus only on the general population or university students [22,45]. Only one study examined the uptake of online support services for multiple health risk behaviors [41], whereas the other studies focused on a single health risk behavior only (eg, smoking) [22,32,44,45]. Despite their high rates of smoking, nutrition, alcohol consumption, and physical activity risk behaviors, it is unknown whether vocational education students will sign up for proactively offered online and/or telephone support to modify one or more of these behaviors. Furthermore, whether the sociodemographic and psychological characteristics of vocational education students are associated with signing up for online and telephone support services is unexplored. Although no previous research has examined whether psychological characteristics are associated with uptake of online and telephone support services targeting multiple health risk behaviors, mental health issues have been found to co-occur or cluster with health risk behaviors [6,46]. Therefore, it is important to examine whether those with symptoms of psychological distress (ie, anxiety and depression) will sign up for support services targeting their health risk behaviors.

Objectives

The aims of this study are to examine the following among vocational education students in the Technical and Further Education (TAFE) setting:

1. Uptake of proactively offered online and telephone support services for each smoking, nutrition, alcohol consumption, and physical activity risk behavior and multiple health behaviors (ie, at least two behaviors).
2. Sociodemographic and psychological characteristics associated with the uptake of online and telephone support services for each smoking, nutrition, alcohol consumption, and physical activity risk behavior and multiple health behaviors (ie, at least two behaviors).

Methods

Study Design and Setting

The data used in this study were gathered from May 2018 to May 2019 as part of a cluster randomized controlled trial examining the effectiveness of electronic feedback and online and telephone support services targeting multiple health risk behaviors among vocational education students. Of the 14 TAFE campuses, 8 campuses were randomized to the intervention group and 6 campuses to the control group. The control campuses received no intervention. The data from all 8 intervention campuses, which were located in the Hunter, Upper Hunter, and Central Coast regions of New South Wales, Australia, are included in this paper. Vocational education students who attended these 8 intervention campuses were proactively offered online and telephone support services for those behaviors where they did not meet Australian health guidelines. The University of Newcastle Human Research Ethics Committee granted ethics approval for this study. Written approval was also provided by the Chief Education and Training Officer from TAFE New South Wales to conduct this research. The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12618000723280).

Participants

Participants were eligible to participate if they were aged 16 years and above and enrolled in a TAFE class that ran for 6 months or more. Participants were excluded if they met the recommended health guidelines for all smoking, nutrition, alcohol consumption, and physical activity risk behaviors and were not able to read or write English.

Procedure

The TAFE service coordinator on each campus identified all eligible classes that ran for 6 months or more and approached the head teachers of the department followed by the teachers of the classes to obtain approval to attend those classes. In those classes where the head teacher and teacher granted approval, TAFE students were given an information letter in class about the research 1 week before data collection. On the day of data collection, members of the research team attended the class to administer the online survey. First, a verbal explanation of the study was provided to the class by a researcher, and interested students were given a computer tablet to complete the online questionnaire. Informed consent was obtained online on the first page before the online survey questions. Interested students selected that they would like to participate in the trial before the survey questions appeared on screen.

Intervention

Electronic Feedback

For each smoking, nutrition, alcohol consumption, and physical activity health risk behavior, if a participant did not meet the Australian health guidelines, information appeared on the computer tablet, specifying that they did not meet the recommended guidelines, and information was provided about effective behavior change strategies. Table 1 presents the Australian health guidelines for each risk behavior and the electronic feedback provided to those who did not meet the recommended guidelines for each behavior.

Table 1. Australian health guidelines and electronic feedback for each smoking, nutrition, alcohol consumption, and physical activity risk behavior.

Health risk behaviors	Australian health guidelines	Electronic feedback
Smoking tobacco	No smoking of cigarettes or tobacco products [47].	• Australian guidelines recommend that not smoking any cigarettes and not using any tobacco improves your health. • Quitting smoking can produce immediate and long-term benefits to your health. • Quitting smoking can take a few attempts so it is important to keep trying. Strategies that can help you quit include web-based and telephone programs, getting your doctor's advice and support, and using nicotine replacement therapies. • We are offering free help to smokers who would like to stop smoking or would consider stopping in the future.
Nutrition (fruit and vegetable intake)	Eat 2 or more serves of fruit each day and 5 or more serves of vegetables each day [48].	• Australian guidelines recommend that adults should eat at least two serves of fruit each day and at least five serves of vegetables each day. Eating healthy can improve your overall health. Strategies that can help you increase your fruit and vegetable intake include web-based and telephone programs, speaking to a dietitian, and getting advice from your doctor. • We are offering free help to people who do not eat enough fruit or vegetables and may like assistance to increase the amount of fruit and vegetables they eat.
Alcohol intake	No more than 2 standard alcoholic drinks per day (to reduce life-time disease risk) and no more than 4 standard alcoholic drinks on one occasion (to reduce the risk of injury and acute problems) [49].	• Australian guidelines recommend that adults should drink no more than 2 standard drinks of alcohol on one day and no more than 4 standard drinks on one occasion to reduce the risk of alcohol-related harm. • Reducing the amount of alcohol you drink can have immediate and long-term benefits to your health. Strategies that can help you reduce your alcohol intake include web-based and telephone programs and getting your doctor's advice and support. • We are offering free help to people who drink more alcohol than recommended and may like assistance to reduce the amount of alcohol they drink.
Physical activity	Do at least 150 to 300 minutes of moderate physical activity or at least 75 to 150 minutes of vigorous physical activity each week [50].	• Australian guidelines recommend that adults do 150 to 300 minutes of moderate physical activity or 75 to 150 minutes of vigorous physical activity each week. Increasing your physical activity can improve your overall health. Strategies that can help you increase your physical activity include web-based and telephone programs, regular times to do physical activity, and participating in sports. • We are offering free help to people who do not do enough physical activity and may like assistance to increase their physical activity.

Proactive Offer of Online and Telephone Services

After the electronic feedback had appeared for each smoking, nutrition, alcohol consumption, and physical activity risk behavior where the participant did not meet Australian health guidelines, both online and telephone services were offered. The online and telephone services were QuitCoach and Quitline for smoking, Healthy Eating Quiz and GHICS for fruit and vegetable consumption, THRIVE and ADIS for risky alcohol consumption, and 10,000 steps and GHICS for physical activity. These support services were chosen because they are existing programs available to the general population in New South Wales for free, and previous studies have demonstrated their effectiveness [27,31,37,51-53]. Participants who agreed to use the online support services were asked to provide their email or mobile phone details. The hyperlinks of the online programs were sent to them. Participants who agreed to sign up for telephone support services were asked to provide their contact details (home and/or mobile phone number) so that the telephone services could contact them.

Measures

Uptake of Proactively Offered Online and Telephone Services

Uptake was measured by participants indicating *yes* they would like to use the specified service and providing the relevant contact details (ie, phone number and/or email address). Uptake referred to signing up to use the services offered.

Sociodemographic Characteristics

Age, sex, country of birth, Aboriginal and Torres Strait Islander identity, highest level of education completed, marital status, employment status, and postcode of residence were collected.

BMI

Participants were asked to self-report their height in centimeters and weight in kilograms. Conversion tables were displayed in the questionnaire to help participants if they required assistance converting their height from feet and inches into centimeters or their weight from stone into kilograms. Participants' BMI scores were calculated and categorized as underweight (BMI<18.5 kg/m^2), healthy weight (BMI 18.5-24.9 kg/m^2), overweight (BMI 25-29.9 kg/m^2), and obese (BMI≥30 kg/m^2).

Anxiety and Depression

The Patient Health Questionnaire-4 (PHQ-4) is a reliable and valid measure that was used to measure anxiety and depression [54]. The PHQ-4 asks, *Over the last 2 weeks, how often have you been bothered by the following problems?* The 2 questions used to measure depression were (1) *Little interest or pleasure in doing things* and (2) *Feeling down, depressed or hopeless*. The 2 items used to measure anxiety were (1) *Feeling nervous, anxious or on edge* and (2) *Not being able to stop or control worrying*. Response options were as follows: not at all (0), several days (1), more than half the days (2), and nearly every day (3) [54]. Scores on both the anxiety and depression scale were dichotomized into yes (ie, those with a total score ≥3 for anxiety or depression) and no (ie, those with a total score <3 for anxiety or depression).

Intention to Change

Participants' intentions to change the behaviors for which they did not meet Australian guidelines were assessed by asking what best described their intentions regarding (1) quitting smoking, (2) reducing alcohol consumption, (3) increasing daily fruit intake, (4) increasing daily vegetable intake, and (5) increasing weekly physical activity. The response options were as follows: will quit (for smoking) or reduce (for alcohol) or increase (for fruit, vegetables, and physical activity) in the next 30 days; will quit (for smoking) or reduce (for alcohol) or increase (for fruit, vegetables, and physical activity) in the next 6 months; may quit (for smoking) or reduce (for alcohol) or increase (for fruit, vegetables, and physical activity) in the future, but not in the next 6 months; never expect to quit (for smoking) or reduce (for alcohol) or increase (for fruit, vegetables, and physical activity); and do not know.

Statistical Analysis

All analyses were performed using SAS version 9.3 (SAS Institute Inc). Frequencies and percentages were used to describe categorical data (ie, sociodemographic characteristics, BMI, and psychological characteristics). Mean and standard deviation were used to describe the continuous data (ie, age of respondents) in the demographics table. The uptake of proactively offered online and telephone support services was described using frequencies and percentages. Four multiple logistic regression models were used to examine whether sociodemographic characteristics, psychological characteristics, and intention to change were associated with signing up for telephone or online services for each smoking, nutrition, alcohol consumption, and physical activity risk behavior. BMI was also included in the regression models for nutrition and physical activity that examined the characteristics associated with signing up for telephone or online support services for these behaviors. A fifth logistic regression model was used to identify whether sociodemographic factors, psychological characteristics, and intention to change were associated with signing up for telephone or online support services for multiple health risk behaviors (ie, at least two risky behaviors).

Results

Participants' Characteristics

Overall, 551 participants had at least one health risk behavior and were offered both online and telephone support services. Table 2 shows the sociodemographic characteristics, BMI, and psychological characteristics of the sample.

Table 2. Sociodemographic, BMI, psychological characteristics, and vocational education courses of the sample (N=551).

Characteristic	Value
Gender, n (%)	
Male	310 (56.3)
Female	228 (41.4)
Other	13 (2.4)
Age, years, mean (SD)	25.7 (11.1)
Country of birth, n (%)	
Australia	509 (92.4)
Other	42 (7.6)
Highest level of education completed, n (%)	
High school or less	388 (70.4)
TAFE[a] or university	163 (29.6)
Marital status, n (%)	
Never married	345 (62.6)
Married or living with partner	166 (30.1)
Divorced or separated or widowed	40 (7.3)
Employment status, n (%)	
Employed	432 (78.4)
Unemployed	119 (21.6)
Aboriginal and Torres Strait Islander, n (%)	
Yes	72 (13.1)
No	479 (86.9)
Residence [b] , n (%)	
Urban	331 (64.4)
Rural	183 (35.6)
BMI status [c] , n (%)	
Underweight	21 (4.0)
Healthy weight	241 (45.6)
Overweight	147 (27.8)
Obese	119 (22.5)
Depression, n (%)	
Yes	131 (23.8)
No	420 (76.2)
Anxiety, n (%)	
Yes	163 (29.6)
No	388 (70.4)
Vocational education course, n (%)	
Automotive mechanic	165 (29.9)
Community service or mental health	56 (10.2)
Floristry	49 (8.9)
Fabrication and welding	38 (6.9)
Hairdressing	37 (6.7)

Characteristic	Value
Mechanical engineering	34 (6.9)
Animal studies or veterinary nursing	33 (6.0)
Arts	23 (4.2)
Dental nursing	22 (4.0)
Electrotechnology	21 (3.8)
Protective coating	19 (3.5)
Programming	15 (2.7)
Baking	13 (2.4)
Mobile plant technology	12 (2.2)
Photography	7 (1.2)
Commercial cookery	5 (0.9)
Business administration	2 (0.4)

[a] TAFE: Technical and Further Education.

[b] Data missing for residence, n=37.

[c] Data missing for BMI, n=23.

Uptake of Proactively Offered Online and Telephone Support Services

Table 3 outlines the uptake of online and telephone support services for each smoking, nutrition, alcohol consumption, and physical activity risk behavior as well as for multiple health risk behaviors. Among those who smoked tobacco, 6.8% (13/191) and 2.6% (5/191) signed up to use QuitCoach and Quitline, respectively, to help them quit smoking, whereas 6.8% (13/191) signed up to use either Quitline or QuitCoach. For participants not meeting the recommended guidelines for fruit and vegetable intake, 14.3% (58/406) and 3.9% (16/406) signed up to use the Healthy Eating Quiz and GHICS, respectively, to improve their fruit and vegetable intake. A total of 14.5% (59/406) signed up for either the Healthy Eating Quiz or GHICS. Of those who were offered online and telephone services to reduce their alcohol consumption, 5.5% (18/327) signed up for THRIVE and 0.9% (3/327) signed up for ADIS, with 5.5% (18/327) signing up for either ADIS or THRIVE. Among those who did not meet the physical activity guidelines, 11.4% (26/228) signed up for 10,000 steps and 7.0% (16/228) signed up for GHICS to improve their physical activity; 12.7% (29/228) signed up for either 10,000 steps or GHICS to modify their physical activity.

Table 3. Uptake of proactively offered online and telephone support services (N=551).

Health risk behaviors and online and telephone interventions	Eligible students offered the support services, n	Signed up to support services, n (%)
Smoking		
Quitline (telephone)	191	5 (2.6)
QuitCoach (online)	191	13 (6.8)
Quitline or QuitCoach	191	13 (6.8)
Inadequate fruit and vegetable consumption		
Get Healthy Information and Coaching Service (telephone)	406	16 (3.9)
Healthy Eating Quiz (online)	406	58 (14.3)
Healthy Eating Quiz or Get Healthy Information and Coaching Service	406	59 (14.5)
Risky alcohol consumption		
ADIS[a] (telephone)	327	3 (0.9)
THRIVE[b] (online)	327	18 (5.5)
THRIVE or ADIS	327	18 (5.5)
Physical inactivity		
Get Healthy Information and Coaching Service (telephone)	228	16 (7.0)
10,000 steps (online)	228	26 (11.4)
10,000 steps or Get Healthy Information and Coaching Service	228	29 (12.7)
Uptake of support services for multiple behaviors		
Uptake of telephone services for multiple behaviors (eg, GHICS[c] and ADIS)	377	8 (2.1)
Uptake of online services for multiple behaviors (eg, THRIVE and Healthy Eating Quiz)	377	21 (5.6)
Uptake of any service (online or telephone) for at least two health behaviors (eg, THRIVE for alcohol and GHICS for physical activity)	377	22 (5.8)

[a] ADIS: Alcohol Drug Information Service.

[b] THRIVE: Tertiary Health Research Intervention Via Email.

[c] GHICS: Get Healthy Information and Coaching Service.

Of the participants who engaged in multiple health risk behaviors, 5.6% (21/377) signed up for online support services for multiple behaviors and 2.1% (8/377) signed up for telephone services for multiple behaviors. For participants with multiple health risk behaviors, 5.8% (22/377) signed up for either telephone or online services for at least two health behaviors.

Characteristics Associated With the Uptake of Proactively Offered Telephone or Online Support Services for Health Risk Behaviors

The characteristics associated with the uptake of proactively offered telephone or online support services for smoking and alcohol consumption (Table 4), nutrition and physical activity (Table 5), and at least two health risk behaviors (Table 6) have been presented.

Table 4. Characteristics associated with uptake of telephone or online support services for smoking and alcohol consumption.

Characteristics	Uptake of QuitCoach or Quitline (smoking)			Uptake of THRIVE[a] or ADIS[b] (alcohol)		
	n (%)	Odds ratio (95% CI)	*P* value	n (%)	Odds ratio (95% CI)	*P* value
Gender			.30			.17
Male	8 (6.4)	Ref[c]		13 (6.2)	Ref	
Female	5 (8.3)	0.33 (0.04-2.65)		5 (4.6)	0.38 (0.10-1.51)	
Age (years)			.64			.49
16-39	11 (6.4)	0.55 (0.04-6.93)		15 (5.2)	0.50 (0.07-3.63)	
>40	2 (18.2)	Ref		3 (13.6)	Ref	.
Highest level of education completed			.72			.63
High school or less	9 (5.8)	0.72 (0.12-4.20)		14 (5.5)	1.41 (0.34-5.80)	
University or TAFE[d]	4 (10.8)	Ref		4 (5.7)	Ref	
Marital status			.77			.42
Never married	8 (6.1)	0.70 (0.14-3.56)		9 (4.1)	0.64 (0.21-1.97)	
Divorced or separated or widowed	2 (13.3)	1.75 (0.13-23.00)		3(15.0)	2.14 (0.32-14.58)	
Married or living with partner	3 (6.7)	Ref		6 (7.0)	Ref	
Employment			.02			.68
Employed	8 (4.8)	0.10 (0.01-0.72)		14 (5.0)	0.72 (0.15-3.37)	
Unemployed	5 (20.0)	Ref		4 (8.2)	Ref	
Residence			.07			.86
Urban	6 (5.8)	0.23 (0.05-1.15)		12 (6.4)	1.10 (0.37-3.29)	
Rural	7 (9.7)	Ref		6 (5.1)	Ref	
Depression			.03			.57
Yes	2 (3.3)	Ref		3 (3.8)	Ref	
No	11(8.4)	10.25 (1.30-80.67)		15 (6.1)	1.53 (0.35-6.75)	
Anxiety			.02			.43
Yes	6 (9.0)	Ref		5 (4.9)	Ref	
No	7 (5.7)	0.11 (0.02-0.71)		13 (5.8)	0.59 (0.16-2.22)	
Aboriginal or Torres Strait Islander			.28			.34
Yes	2 (5.6)	0.34 (0.05-2.39)		1 (2.4)	0.35 (0.04-3.05)	
No	11 (7.1)	Ref		17 (6.0)	Ref	
Intention to change			.08			.13
No intention to change in 6 months or did not know	5 (3.7)	Ref		12 (4.3)	Ref	
Intention to change in 30 days	4 (16.0)	5.46 (1.11-26.97)		4 (13.8)	3.01 (0.76-11.95)	
Intention to change in 6 months	4 (12.5)	3.96 (0.77-20.27)		2 (11.8)	3.63 (0.67-19.62)	

[a] THRIVE: Tertiary Health Research Intervention Via Email.

[b] ADIS: Alcohol and Drug Information Services.

[c] Ref: Reference category

[d] TAFE: Technical and Further Education.

Table 5. Characteristics associated with the uptake of telephone or online support services for nutrition and physical inactivity.

Characteristics	Uptake of Healthy Eating Quiz or GHICS[a] (fruit and vegetables)			Uptake of 10,000 steps or GHICS (physical activity)		
	n (%)	Odds ratio (95% CI)	*P* value	n (%)	Odds ratio (95% CI)	*P* value
Gender			.60			.34
Male	25 (10.9)	Ref[b]		6 (6.1)	Ref	
Female	33 (20.0)	1.22 (0.58-2.56)		22 (17.7)	1.80 (0.54-6.05)	
Age (years)			.78			.72
16-39	48 (14.1)	1.15 (0.42-3.15)		18 (10.0)	0.78 (0.20-3.02)	
>40	11 (22.5)	Ref		11 (25.6)	Ref	
Highest level of education completed			.42			.76
High school or less	34 (11.9)	0.75 (0.38-1.50)		13 (9.1)	0.85 (0.30-2.39)	
University or TAFE[c]	25 (20.7)	Ref		16 (18.8)	Ref	
Marital status			.65			.56
Never married	31 (12.3)	0.79 (0.37-1.67)		13 (10.2)	1.00 (0.31-3.22)	
Divorced or separated or widowed	4 (11.8)	0.60 (0.17-2.11)		5 (25.0)	2.31 (0.49-10.90)	
Married or living with partner	24 (20.0)	Ref		11 (13.7)	Ref	
Employment			.07			.11
Employed	33 (10.5)	0.48 (0.22-1.05)		10 (6.5)	0.42 (0.14-1.24)	
Unemployed	26 (28.6)	Ref		19 (25.3)	Ref	
Residence			.17			.65
Urban	45 (18.5)	1.65 (0.81-3.38)		21 (14.3)	1.29 (0.44-3.80)	
Rural	13 (9.6)	Ref	.	7 (10.3)	Ref	
Depression			.20			.36
Yes	18 (17.7)	Ref		10 (15.9)	Ref	
No	41 (13.5)	0.58 (0.26-1.32)		19 (11.5)	0.57 (0.17-1.90)	
Anxiety			.29			.90
Yes	19 (16.2)	Ref		13 (16.3)	Ref	
No	40 (13.8)	1.58 (0.68-3.64)		16 (10.8)	1.08 (0.32-3.62)	
Aboriginal or Torres Strait Islander			.19			.29
Yes	5 (10.0)	0.43 (0.12-1.52)		3 (10.0)	0.41 (0.08-2.13)	
No	54 (15.2)	Ref		26 (13.1)	Ref	
BMI status			.23			.13
Overweight	11 (10.5)	0.60 (0.25-1.42)		9 (16.1)	3.43 (1.01-11.65)	
Obesity	20 (23.3)	1.39 (0.65-2.97)		12 (21.1)	2.34 (0.68-8.01)	
Healthy weight or underweight	26 (13.2)	Ref		7 (7.1)	Ref	
Intention to change			.25			.04
No intention to change in 6 months or did not know	25 (11.5)	Ref		7 (6.4)	Ref	
Intention to change in 30 days	23 (20.2)	1.76 (0.87-3.56)		15 (24.2)	4.01 (1.33-12.07)	
Intention to change in 6 months	10 (14.1)	1.57 (0.67-3.66)		7 (12.3)	1.57 (0.42-5.86)	

[a] GHICS: Get Healthy Information and Coaching Service.

[b] Ref: Reference category

[c] TAFE: Technical and Further Education.

Table 6. Characteristics associated with the uptake of telephone or online support services for multiple health risk behaviors.

Characteristics	Uptake of any service for multiple health risk behaviors		
	n (%)	Odds ratio (95% CI)	*P* value
Gender			.74
Male	7 (3.2)	Ref[a]	
Female	14 (9.4)	1.22 (0.38-3.86)	
Age (years)			.75
16-39	16 (5.0)	1.25 (0.32-4.94)	
>40	6 (15.4)	Ref	
Highest level of education completed			.69
High school or less	12 (4.4)	0.81 (0.29-2.27)	
University or TAFE[b]	10 (9.9)	Ref	
Marital status			.24
Never married	9 (3.9)	0.47 (0.15-1.45)	
Divorced or separated or widowed	4 (13.3)	1.69 (0.37-7.69)	
Married or living with partner	9 (8.0)	Ref	
Employment			.003
Employed	8 (2.7)	0.18 (0.06-0.56)	
Unemployed	14 (18.2)	Ref	
Residence			.85
Urban	16 (7.2)	0.89 (0.29-2.79)	
Rural	6 (4.7)	Ref	
Depression			.13
Yes	10 (10.2)	Ref	
No	12 (4.3)	0.41 (0.13-1.30)	
Anxiety			.94
Yes	10 (8.5)	Ref	
No	12 (4.6)	1.04 (0.31-3.50)	
Aboriginal or Torres Strait Islander			.54
Yes	3 (5.7)	0.60 (0.12-2.98)	
No	19 (5.9)	Ref	
Intention to change at least two behaviors			.49
No intention to change at least two behaviors	14 (5.1)	Ref	
Intention to change at least two behaviors	8 (8.0)	1.43 (0.52-3.93)	

[a] Ref: Reference category.

[b] TAFE: Technical and Further Education.

Characteristics Associated With Signing Up for QuitCoach or Quitline for Smoking and for THRIVE or ADIS for Alcohol Consumption

After adjusting for the covariates, vocational education students who reported not being depressed had greater odds (odds ratio [OR] 10.25, 95% CI 1.30-80.67) of signing up for QuitCoach or Quitline than those who were depressed. Those who were employed (OR 0.10, 95% CI 0.01-0.72) or reported not being anxious (OR 0.11, 95% CI 0.02-0.71) had smaller odds of signing up for QuitCoach or Quitline.

None of the characteristics were associated with signing up for THRIVE or ADIS to modify alcohol consumption after adjusting for the covariates.

Characteristics Associated With Signing Up for Healthy Eating Quiz or GHICS for Fruit and Vegetable

Intake and for 10,000 Steps or GHICS for Physical Activity

After adjusting for the covariates, none of the factors were associated with signing up for the Healthy Eating Quiz or GHICS for fruit and vegetable consumption.

After adjusting for the covariates, vocational education students who intended to increase their physical activity within 30 days had greater odds (OR 4.01, 95% CI 1.33-12.07) of signing up for 10,000 steps or the GHICS than those who did not intend to change in 6 months or did not know if they intended to change.

Characteristics Associated With Signing Up for Services for Multiple Health Risk Behaviors

Among vocational education students who engaged in multiple health risk behaviors, those who were employed had significantly smaller odds (OR 0.18, 95% CI 0.06-0.56) of signing up for support services for at least two behaviors than those who were unemployed after adjusting for the covariates.

Discussion

Principal Findings

This study examined the uptake of proactively offered online and telephone support services targeting smoking, nutrition, alcohol consumption, and physical activity risk behaviors and multiple health risk behaviors among vocational education students. More than half of the participants were men. Given that most health behavior studies have an overrepresentation of women, this study, in contrast, presents findings where men are well represented and can be reached via TAFE [55]. The findings revealed that the uptake of online and telephone services that targeted smoking, inadequate fruit and vegetable consumption, risky alcohol consumption, and physical inactivity was low among vocational education students. We also found that less than 10% of vocational education students who engaged in multiple health risk behaviors signed up for online or telephone support services to modify at least two health risk behaviors. Vocational education students who were employed and those who did not have symptoms of anxiety were less likely to sign up for support services targeting smoking. Vocational education students who reported no symptoms of depression were more likely to sign up for support services targeting smoking. Vocational education students who intended to change their physical activity in the next 30 days were more likely to sign up for physical activity support services than those who did not intend to change in 6 months or did not know. Finally, vocational education students who were employed were less likely to sign up for support services for at least two health risk behaviors.

Comparison With Prior Work

Uptake of proactively offered telephone support for smoking was relatively low in our study (2.6%) compared with an Australian study that proactively offered telephone support to smokers in the general population (52%) [30] and compared with 82.9% in a study conducted in Hong Kong [45] and 74% in a Denmark study [22]. Differences in the characteristics of the populations in these 3 studies compared with the younger group in this study may provide some explanation for the lower uptake of proactively offered telephone support in vocational education students than in the general population. For example, younger adults may feel that they will not experience health consequences of smoking in the near future and, consequently, may be less likely to wish to quit smoking than their older counterparts. Furthermore, women may be more likely to sign up for support services than men [22,56], and this may in part account for the higher uptake of smoking telephone services reported in previous studies [22,30,45]. Uptake of proactively offered online support (QuitCoach) targeting smoking in our study (6.8%) was similar to that reported by McClure et al [44] in their study (7%). The study by Skov-Ettrup et al [22] reported a higher uptake (69%) of internet intervention for smoking compared with our study. Although the uptake of telephone support for smoking cessation was low (2.6%) among vocational education students, it is comparable with the proportion of smokers in the general population that use the Quitline in Australia (4%) [32] and in the United States (3.5%) [33]. There were no direct age or socioeconomic status comparable data on uptake in these 2 studies. There are a number of potential reasons for the low uptake of smoking services among vocational education students. First, vocational education students may not wish to quit smoking and may believe there are advantages to smoking that override any negative consequences. Second, they may perceive that they are not addicted to cigarettes and feel that they could quit smoking unassisted if they wanted to. Third, they may be part of a social network where their peers smoke tobacco and may feel that they need to continue to smoke to feel socially accepted by their peers. Additional reasons may include their lack of readiness to change their health risk behaviors, perceived inappropriateness of the services they were offered, their preference to change by themselves, and a belief that the support services they were offered would not help them [57].

Compared with the less than 1% of adults in New South Wales who are overweight and obese and who reported using the GHICS [34], our study achieved higher rates (7.0% for physical inactivity and 3.9% for fruit and vegetables) of signing up for this service. However, the rates of vocational education students signing up for this service were lower compared with what was reported in the study by Wolfenden et al [58], in which 23% of New South Wales residents aged 18 years and above in the general community agreed to allow their details to be forwarded to the GHICS when they were proactively called. Furthermore, our study reported a higher (14.3%) rate of signing up for the Healthy Eating Quiz for fruit and vegetables compared with the study where only 0.4% of people aged 16 years and above signed up to use the Healthy Eating Quiz [37]. There is no existing research that has examined the uptake of proactively offered online and telephone support services targeting risky alcohol consumption; therefore, no comparisons can be made with this study.

Although the uptake of support services was low across the health risk behaviors, vocational education students appeared to prefer online support services (5.5%-14.3%) to telephone services (0.9%-7.0%) targeting each behavior and multiple health risk behaviors. This is not surprising given that the TAFE setting is mostly composed of young adults, who are more likely to use the internet [59] and prefer online support services [60]. The convenience of being able to access online programs when they wished to rather than scheduling a particular time to speak with an advisor may also explain why vocational education students preferred online programs to telephone services. In addition, in vocational education students, the uptake of any support services targeting nutrition and physical activity (12.7%-14.5%) appeared higher than that of services for smoking and alcohol (5.5%-6.8%). Possible explanations include that for physical activity and fruit and vegetable consumption, the goal is to increase healthy behaviors, whereas changes to smoking and alcohol consumption involve stopping risky behaviors. Vocational education students may smoke tobacco or drink alcohol to help them cope with stress, depression, or anxiety [61], during social gatherings including work functions with colleagues [62,63], or to feel socially accepted and to improve self-confidence [62,63]. As a result, vocational education students may be less likely to sign up for services to change smoking and alcohol behaviors than nutrition and physical activity behaviors.

Those who were employed had smaller odds of signing up for support services (ie, Quitline or QuitCoach) for smoking and for services for at least two health risk behaviors. This is in contrast with the study by Mak et al [45], which examined the factors that influenced parents who smoke to participate in a proactive telephone intervention for smoking, and the study by Schneider et al [41], which reported that participants who were employed were more likely to participate in an online intervention targeting multiple lifestyle behaviors [41]. Students who worked may have felt that they had less time compared with students who did not work and did not want to sign up for support services they could not commit the time to. We also found that participants who reported not being depressed were more likely to sign up for support services that targeted smoking, whereas those who were not anxious were less likely to sign up for online or telephone support services for smoking. Previous research has found a relationship between smoking cessation and improved mental health [64]. Vocational education students who are smokers and experiencing symptoms of anxiety may thus feel more compelled to sign up for smoking support services not only to quit smoking but also to improve their mental health [64]. Smoking cessation interventions should therefore not only focus on the physical addiction of smoking but also consider the psychological needs of service users to offer coping strategies that may be useful not only for quitting smoking but also for reducing anxiety and psychological distress. Vocational education students who intended to increase their physical activity in 30 days were more likely to sign up for 10,000 steps or the GHICS compared with those who did not intend to increase their physical activity in the next 6 months or did not know if they would change. Intention to change was associated with the uptake of physical activity services but not with the uptake of smoking, nutrition, and alcohol support services. These results suggest that smoking, nutrition, and alcohol support services should be offered to all vocational education students who do not meet the recommended guidelines, irrespective of their intention to change. Physical activity services may benefit from targeting their messaging and recruitment efforts to those intending to increase their physical activity in 30 days. Interventions that target health risk behaviors should therefore consider how to promote their services to vocational education students who do not meet the recommended guidelines for each behavior and how to incorporate strategies to motivate vocational education students to sign up for support services.

Our study offered existing online and telephone services to vocational education students. Although some services such as the GHICS targeted multiple behaviors (ie, fruit and vegetable intake and physical activity), others such as the Quitline focused on one behavior (ie, smoking). There is no telephone service in Australia that addresses all smoking, nutrition, alcohol consumption, and physical activity risk behaviors collectively. Given that smoking, nutrition, alcohol consumption, and physical activity risk behaviors cluster together in vocational education students [6-8] and that transfer theory [10] suggests that modifying one health risk behavior can lead to changes in other behaviors, future studies may wish to offer vocational education students interventions in a form where all smoking, nutrition, alcohol consumption, and physical activity risk behaviors can be addressed by the same service simultaneously.

Limitations

This study had some limitations. First, to be eligible to participate in this study, which was part of a cluster randomized controlled trial, vocational education students needed to be enrolled in a class that ran for at least six months. Therefore, these findings may not be generalizable to vocational education students enrolled in courses that run for less than 6 months. Second, vocational education classes were recruited from the Hunter, Upper Hunter, and Central Coast areas of New South Wales and may not be representative of all vocational education campuses across Australia or internationally.

Conclusions

Although most vocational education students who were offered online and telephone support services did not sign up for these, the uptake rates for some of the support services appear to be higher than self-initiated uptake in the general population. Scaling up the proactive offer of online and telephone services may produce beneficial health outcomes. Proactively offering support services to vocational education students is sustainable via a system whereby students receive electronic feedback about health risk behaviors and referral to existing online and telephone services as part of the standard vocational education enrollment procedure and via student services. The use of existing online and telephone services is an important strength that supports the sustainability of such an intervention in a vocational education setting.

The findings from this study also suggest that vocational education students prefer online support services to telephone services that target smoking, nutrition, alcohol consumption, physical activity and multiple health risk behaviors. Uptake of support services for nutrition and physical activity also appeared higher than that for smoking and alcohol health risk behaviors. This provides important information for developing health interventions for vocational education students in terms of the mode of delivering interventions to vocational education students and the behaviors they prioritize to change. Future studies should also explore what vocational education students perceive to be the barriers that hinder their uptake of online and telephone support services targeting multiple health risk behaviors and what strategies they would be more likely to use.

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Conflicts of Interest

None declared.

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Abbreviations

ADIS: Alcohol and Drug Information Services
GHICS: Get Healthy Information and Coaching Service
NHMRC: National Health and Medical Research Council
OR: odds ratio
PHQ-4: Patient Health Questionnaire-4
TAFE: technical and further education
THRIVE: Tertiary Health Research Intervention Via Email

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Original Paper

Perceived Factors Influencing the Public Intention to Use E-Consultation: Analysis of Web-Based Survey Data

Miaojie Qi, MD; Jiyu Cui, MPA; Xing Li, MPA; Youli Han, PhD

School of Public Health, Capital Medical University, Beijing, China

Corresponding Author:
Youli Han, PhD
School of Public Health
Capital Medical University
No10 Xitoutiao Youanmenwai Fengtai District
Beijing, 100069
China
Phone: 86 13520451080
Email: hanyouli@ccmu.edu.cn

Abstract

Background: Unbalanced distribution of medical resources is becoming a major challenge, particularly in the selection of doctors. e-Consultation could provide patients with more choices of doctors and break the constraints of time and space. However, the acceptance of e-consultation is still poor and the mechanism of adoption is unclear.

Objective: The aim of this study was to identify the factors influencing the public intention to use e-consultation and explore the effect path of the factors and behavior intention.

Methods: The hypotheses of our research model were developed based on the technology acceptance model and perceived risk theory. A web-based survey was conducted by an electronic questionnaire collection platform; this survey that consisted of a 29-item questionnaire with 5-point Likert scales was completed by 934 respondents. Structural equation modeling was used to analyze the data. Item evaluation and reliability, validity, path loading, goodness of fit, and multiple group analysis were used to check the moderation effects.

Results: The standardized factor loadings of the items were between 0.551 and 0.873. The composite reliability of 9 constructs ranged from 0.706 to 0.840. The average variance extracted ranged from 0.387 to 0.640. The fitness indices showed that the collected data fitted well with the research model. Perceived usefulness was the strongest positive factor effecting behavior intention (β=.399, *P*<.001). Perceived ease of use had a positive effect on behavior intention but it was not statistically significant (β=.117, *P*=.07) and it had a positive effect on perceived usefulness (β=.537, *P*<.001). Perceived risk could be well explained by financial risk (β=.972, *P*<.001), privacy risk (β=.774, *P*<.001), social risk (β=.871, *P*<.001), time risk (β=.894, *P*<0.001), and psychological risk (β=.774, *P*<.001). Perceived risk had negative effects on perceived usefulness (β=–.375, *P*<.001) and behavior intention (β=–.297, *P*<.001). Personal innovativeness had a positive influence on perceived ease of use (β=.241, *P*<.001) and a slight effect on behavior intention (β=.124, *P*=.001). Age (χ^2_{58}=133.5, *P*<.001) and usage experience (χ^2_{58}=82.5, *P*=.02) had a slight moderation effect on the paths.

Conclusions: Perceived usefulness and perceived risk have significant effects on public intention to use e-consultation. Therefore, platform and manufacturer must improve the function of e-consultation, which will promote the public intention to use e-consultation fundamentally. In order to control the perceived risk of public, government should play an important role in enforcing management of e-consultation markets and approving corresponding medical insurance policies. Besides, personal innovativeness had an effect on behavior intention. Moreover, the paths of factors had some heterogeneity among people with different characteristics. Therefore, it is necessary to adjust the strategies to fit more groups better.

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KEYWORDS

China; e-consultation; perceived risk; surveys and questionnaires; technology acceptance model

Introduction

Background

In China, patients can directly go to tertiary referral hospitals to consult doctors, as primary care physicians do not have sufficient capacity to deal with complex diseases, which results in overloading of tertiary hospitals and increase in the unmet demands of patients [1,2]. With the outbreak of the COVID-19 pandemic, this overwhelming situation is becoming more prominent. e-Consultation provides a new way to solve this challenging situation between doctors and patients. e-Consultation—an innovative way to address the growing medical demand—allows users to overcome the barriers of space and time to have more possibilities of choosing doctors from the whole country, and it is becoming more widespread nowadays. e-Consultation can be classified into 2 types: inter-physician consultation and inter-patient-and-physician consultation [3]. In this study, we focused on the e-consultation between patients and health care providers and we did not involve telecare, telemonitor, and other eHealth. Specifically, users do not need to consult doctors in person and can obtain medical advice asynchronously after uploading personal illness information on the internet through video and text messaging to doctors [4,5].

Compared with face-to-face consultation, e-consultation has some natural advantages and unavoidable limitations. Specially, users only use words, pictures, and videos to communicate with doctors and are unable to receive a medical examination. Therefore, e-consultation is only used on nonurgent minor ailments now [6]. However, according to 2020 World Health Statistics, most patients develop common and chronic diseases, which means that e-consultation could meet great medical demands. In addition to medical advice on diagnosis and treatment regimen, e-consultation could provide patients with timelier and more convenient care [7,8], reduce cost for patients [7,9,10], and improve equitable access for underserved patients and to specialist care [11,12]. For the health system, e-consultation could improve the efficiency of referrals and face-to-face consultation [13-17] and improve the quality of health care [13,18]. Therefore, e-consultation might be a potential solution for major challenges that our health care system faces today [12]. However, many patients are unwilling to use e-consultation even if their illnesses are not serious because they prefer to see doctors in person [19]. A study showed that the average workload of doctors providing web-based health care services was 0.38 patients in China [20] and the situation that people lack awareness of e-consultation exists in a developed country too [21]. For the large part, users are unwilling to believe in the judgments of the doctors in web-based health care services without seeing doctors and without undergoing a medical examination [22]. Our previous survey also found that patients with prior experience of using e-consultation went to the hospital later for the same disease because they wanted to check if the judgement of the doctors providing web-based health care services was accurate. There are great risks perceived by patients if they follow the e-consultation judgement completely. Therefore, many people stated that with the help of their primary care providers, they can use e-consultation better in order to avoid mistakes [23].

As mentioned above, there are many researches focused on the clinical and socioeconomic effects of e-consultation, but these researches have not explored the process or the acceptance of e-consultation or the barriers and the promoters of e-consultation [24]. The content of e-consultation is significantly different from the other functions of eHealth; therefore, we cannot simply apply the usage mechanism of eHealth into e-consultation. This study can fill this gap effectively. The acceptance of e-consultation is a matter of accepting medical information technology, and the technology acceptance model (TAM) explains the acceptance behavior of information communication technology for individuals well [25]. However, our preliminary research and field investigation showed that perceived risk was a significant factor influencing usage behavior, which was reported in many studies as well. However, perceived risk is always taken as a simple dimension in prior researches, which lead to the lack of specific and accurate guiding effects on reality. This research aims to further decompose the perceived risk dimension comprehensively. Therefore, combining TAM and perceived risk, we reconstructed a new model to explore the acceptance mechanism of e-consultation, and we hope this research would help governments and providers make effective and efficient intervention strategies.

Theoretical Background

TAM

The TAM was proposed by Davis based on the previous theories. TAM focuses on an individual's intention to accept information technology. In TAM, perceived usefulness is defined as the extent to which people believe apps would help them perform their job better. Perceived ease of use is defined as the extent to which people believe using apps would be free of effort. Perceived usefulness and perceived ease of use are the 2 main elements that have influence on the intention to use, and sufficient intention leads to actual usage behavior [25]. TAM has been successfully adapted in many eHealth [26], mobile health [27], mobile management systems [28,29], and web-based medical websites [30].

Perceived Risk Theories

A lot of researches show that perceived risk is a key factor that influences people to use medical innovations [28,31-33]. In the medical field, the public always makes medical decisions uncertainly due to information asymmetry, especially when using some emerging medical products and functions. e-Consultation has not really realized the maturity of technology and the stability of the service mode, which aggravates the uncertainty. As shown in the research that even if patients reported satisfaction and acceptance of e-consultation, they did not express strong interests in participating in this interaction because of medical responsibility and accuracy of disease description [34]. Therefore, we take perceived risk as one of the core dimensions of this study and integrate it with TAM.

Originally, perceived risk illustrates the mechanism of people for accepting new brands in the commercial market. It is a sense of uncertainty caused by consumers' inability to predict the outcome of their purchases. The components of perceived risk includes performance risk, physical risk, financial risk, social risk, and psychological risk [35]. With the development of the perceived risk theory, more components are added into the construct, including time risk [36] and privacy risk [37]. Perceived risk theory holds the view that people try to minimize the perceived risk of behavior rather than to maximize the perceived benefit when making consumption decisions [38]. In our study, performance risk is defined as the possibility of e-consultation not performing as it is designed [35,39]. Physical risk is the chances that e-consultation could result in delays in treatment or in misdiagnoses [35]. We can find that delaying treatment or a misdiagnosis means performing out of control; therefore, we just need to keep one factor between performance risk and physical risk. Financial risk and time risk refer to the possibility that users may face loss of money and time when using e-consultation [35,39]. Social risk is the chances that the use of e-consultation would affect the way others think of the users [35,39]. Psychological risk is the chance that e-consultation would not fit in well with users' self-image or self-concept [35,39]. Privacy risk is the potential loss of control over personal information [35,39].

Personal Innovativeness

Personal innovativeness is defined as the degree to which a person is relatively willing to adopt e-consultation in this study [40]. The relationship between technology and the degree of receptiveness to innovation determines how quickly a person adopts information and communications technology [41]. Personal innovativeness can explain the individual differences in their perception of e-consultation advantages and risks. Individuals with higher innovativeness prefer change and tend to gather more information of the technical products. The positive attitude of the innovator toward products would be promoted by the increased interaction with products, which makes them pay more attention to the advantages of technical products and not worry about products working in the designed way [42]. This viewpoint has also been tested in several researches of mobile health adoption [27,43].

Research Model and Hypotheses

The public can choose any registered doctor on the e-consultation platform with a limited cost. The platforms provide users with all kind of hospital departments with different service levels from different regions. Thus, the public have more access for better consultation services. Through e-consultation, users can receive valuable suggestions easily and quickly. After obtaining enough suggestions, they are able to make and follow health decisions better. These functions of e-consultation are attractive to the users. Besides, if it is easy to learn how to use e-consultation, it means that the public will accept e-consultation easier without much effort. Thus, we propose the following hypotheses based on TAM:

Hypothesis 1: Perceived usefulness will influence behavior intention positively.

Hypothesis 2: Perceived ease of use will influence behavior intention positively.

Hypothesis 3: Perceived ease of use will influence perceived usefulness positively.

If e-consultation provides incorrect suggestions, users would be delayed in accepting correct treatment or they may receive wrong treatment. Loss of performance means a loss of health. Unlike the common consumer behavior, performance risk and physical risk are always perceived by the public together. Therefore, physical risk could be absorbed into performance risk. In the TAM, perceived usefulness reflects the functions of e-consultation as well. High levels of risk perceived by people means that they have a suspicion on the usefulness of e-consultation. Therefore, it is unnecessary to integrate performance risk and physical risk into the model again. Besides, since e-consultation needs users to submit symptoms, medical records, and other personal information, the operation of e-consultation would be a new challenge for the user. Thus, we propose the following hypotheses:

Hypothesis 4a: Financial risk is a component of perceived risk of using e-consultation.

Hypothesis 4b: Privacy risk is a component of perceived risk of using e-consultation.

Hypothesis 4c: Social risk is a component of perceived risk of using e-consultation.

Hypothesis 4d: Time risk is a component of perceived risk of using e-consultation.

Hypothesis 4e: Psychological risk is a component of perceived risk of using e-consultation.

Hypothesis 5: Perceived risk will influence perceived usefulness negatively.

Hypothesis 6: Perceived risk will influence perceived ease of use negatively.

Hypothesis 7: Perceived risk will influence behavior intention negatively.

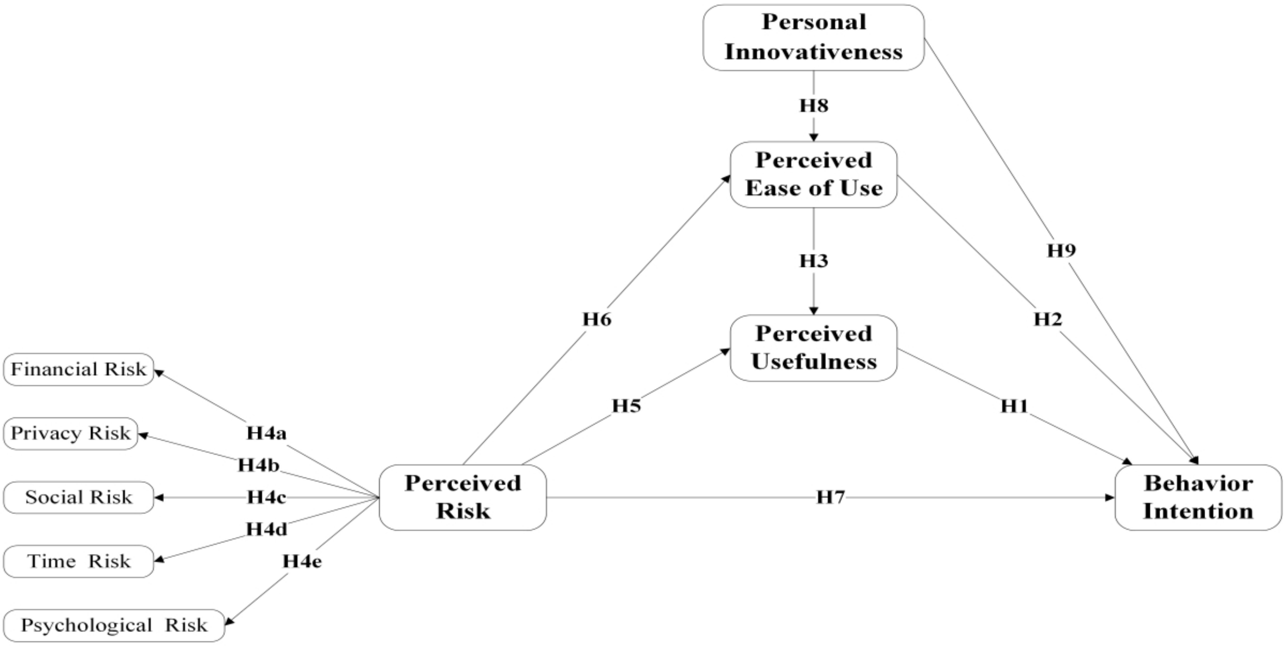
e-Consultation as a combination of information technology and medical services subverts the traditional concept of consultation. Therefore, if people have better innovativeness, they are willing to adopt all kinds of new information technology, including e-consultation. Some other researches show that personal innovativeness also has a direct effect on perceived ease of use. Because people with high level of innovativeness have richer experience in using emerging products, they would think the operation of e-consultation is less difficult. Thus, we propose the following hypotheses:

Hypothesis 8: Personal innovativeness will influence perceived ease of use positively.

Hypothesis 9: Personal innovativeness will influence behavior intention positively.

Overall, the research model is showed in Figure 1.

Figure 1. Research model based on the technology acceptance model and perceived risk theory. Personal innovativeness had effects on behavior intention and perceived ease of use. H: hypothesis.



Aim of This Study

The objective of this study was to investigate people’s actual usage of e-consultation and their characteristics. Moreover, based on the TAM integrating with perceived risk and personal innovativeness theory, a questionnaire survey was used to explore the relationships and paths of the factors that influence people’s intention to use e-consultation.

Methods

Study Design

All survey items were adopted from previous studies related to eHealth and health information technology. The first version of the questionnaire was directly translated from English to Chinese by a group of researchers. Items were reasonably changed to adapt to the e-consultation. Then, the second version of the questionnaire was completed after 2 rounds of experts’ discussions on the first questionnaire. The experts consisted of 2 college professors, 7 staffs from an eHealth company, and 7 doctors with e-consultation using experience. Some items were added or removed or replaced according to the suggestions of experts. The third modification of the questionnaire was completed after a preliminary survey of 222 students majoring in health management from Capital Medical University. Some items were removed or changed to ensure the reliability and validity of the questionnaire. In the end, back translation was performed from Chinese to English by another qualified translator. The final items (Table 1, [44-46]) were measured with a 5-point Likert scale ranging from “strongly disagree” (1) to “strongly agree” (5). The final questionnaire consisted of 2 parts. The first part was the demographic information of the respondents. The second part, which includes the items for constructs, was designed to measure the respondents’ perception on each item.

Table 1. Measurement items of the constructs.

Construct	Item
PU[a] [25,44,45]	
PU1	Using e-consultation would make it easier to consult a specialist or a certified doctor.
PU2	Using e-consultation enables me to understand my disease and treatment recommendation more quickly.
PU3	Using e-consultation facilitates complete communication with doctor.
PU4	Using e-consultation enables me to know more about disease prevention and management.
PU5	Using e-consultation enables me to make better treatment-related decisions.
PU6	I find it easy to obtain information on e-consultation.
PEU[b] [25,44,45]	
PEU1	Learning to use e-consultation is easy for me.
PEU2	In e-consultation, my doctor talks to me clearly and helps me understand my situation appropriately.
PEU3	Using e-consultation would not require much mental effort.
PEU4	It is easy for me to become skillful at using e-consultation.
FR[c] [31,35,39]	
FR1	e-Consultation is not effective and is a waste of money.
FR2	e-Consultation may make me spend extra money in case of a misdiagnosis, leading to delayed correct treatment.
FR3	Using e-consultation may lead to potential fraud.
PRR[d] [35,39]	
PRR1	After using e-consultation, my personal information may be leaked.
PRR2	After using e-consultation, my personal information may be used without my knowledge.
PRR3	After using e-consultation, my illness information may be found by others around me.
SR[e] [31,35,39]	
SR1	If I use e-consultation, it would negatively affect the way others think of me.
SR2	If I use e-consultation, my friends and relatives would think less highly of me.
TR[f] [31,39]	
TR1	e-Consultation may be a waste of time because it is not effective.
TR2	e-Consultation may be a waste of time because of wrong diagnoses or treatments.
PSR[g] [31,35,39]	
PSR1	e-Consultation is not my traditional way to consult doctors, which would lead to psychological issues
PSR2	I am unable to communicate with doctors face-to-face thereby leading to psychological issues
PSR3	I am worried that I cannot describe my disease symptoms correctly when using e-consultation.
PI[h] [40,45,46]	
PI1	I often follow new information technologies with interest.
PI2	If I hear about a new information technology, I would look for ways to experiment with it.
PI3	Among my peers, I am usually the first to try out new information technologies.
BI[i] [25]	
BI1	I intend to use e-consultation.
BI2	I intend to use more e-consultation.
BI3	I predict that I will use e-consultation.

[a] PU: perceived usefulness.

[b] PEU: perceived ease of use.

[c] FR: financial risk.

[d] PRR: privacy risk.

[e] SR: social risk.

[f] TR: time risk.

[g] PSR: psychological risk.

[h] PI: personal innovativeness.

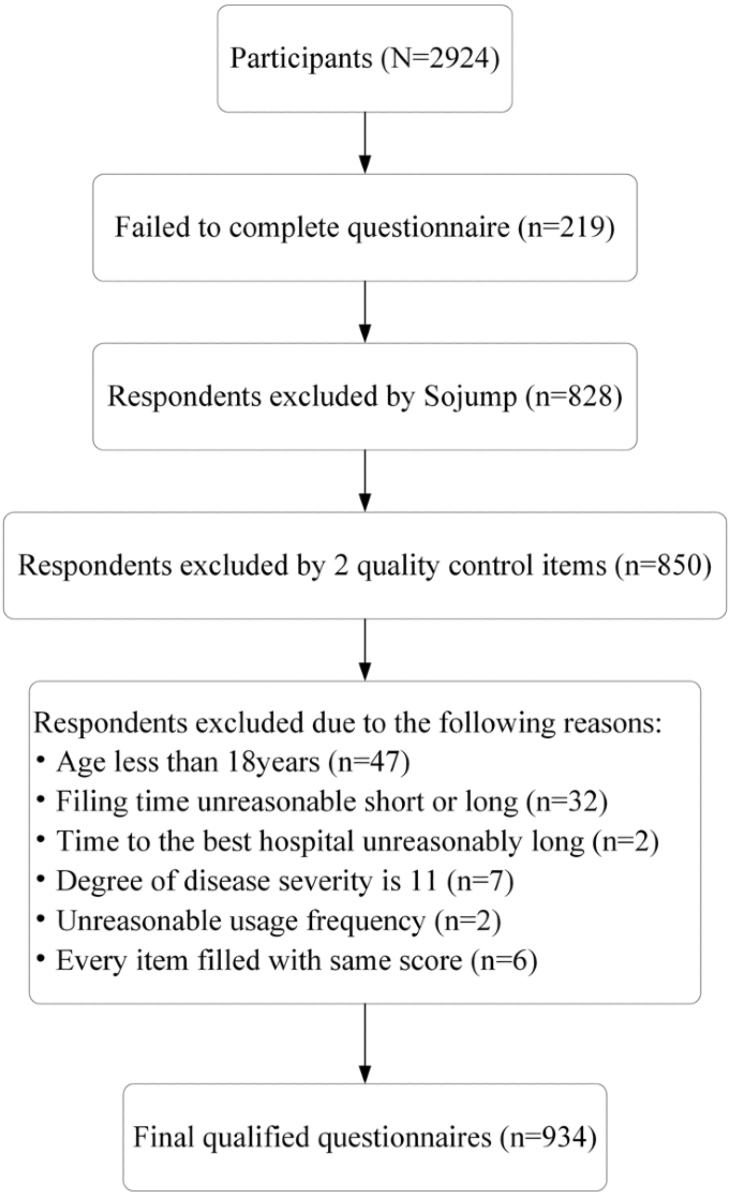
[i] BI: behavior intention.

Data Collection

With the development of information technology, internet protocol restriction, and real-name system, the data quality of web-based surveys meets the requirements of scientific researches. As mentioned above, the users of e-consultation are mainly concentrated in young and middle-aged groups, and the middle-aged group is more willing to accept web-based questionnaires. Therefore, a web-based survey was conducted by Sojump in this research. Sojump is an e-survey company [47], which has 2.6 million samples with all kinds of social demographic characteristics, and unqualified objects can be excluded based on the purpose of the study. The questionnaire was announced on Sojiangwang [48] until the required population was reached. The Sojiangwang is a platform belonging to Sojump, in which all kinds of people can register in. The Sojiangwang asks every registrant to upload the real identity information and audit the identity information. In this platform, the registrant can see all the questionnaires when they meet the included standard of the questionnaires. All different questionnaires would be named with a unified format: “questionnaire + number.” In order to ensure the quality of the survey, Sojump uses a series of logical and common sense items to eliminate the halfhearted respondents, and 828 respondents were excluded by this way in our study. Besides, we also designed 2 items to screen the poor-quality questionnaires. The first item listed in the demographic information survey is “e-Consultation could provide surgical and pathological examination services” and the respondents were asked to choose “disagree.” The second item listed in the construct is “Now, e-consultation could provide diagnosis and treatment for all kind of diseases” and the respondents were asked to choose “strongly disagree.”

At the beginning of the electronic questionnaire, the following information was given first: the purpose of the questionnaire, information and instructions regarding the questionnaire, assurance of proper handling of personal information, and the name of the research institution. The questionnaire link provided on the website (Sojiangwang) could not be copied. After users filled in the questionnaire through the link, the link was removed from the list and could not be used repeatedly. We have reported the results of this survey following the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) checklist, which can be found in Multimedia Appendix 1. The data were collected from March 30, 2020 to April 4, 2020. A total of 2924 participants were involved in this survey, and 934 respondents’ questionnaires reached the inclusion criteria of the survey (Figure 2). This study was approved by the ethics committee of the Capital Medical University (number Z2019SY017).

Figure 2. Sampling procedure.



As shown in Table 2, female respondents were more than male respondents. Most respondents were between 18 and 45 years of age (861/934, 92.2%). The education level of the respondents was good because only 21.7% (203/934) of the respondents had a lower level of education than bachelor's degree. Most respondents were from the more developed eastern region (559/934, 59.9%) and urban region (797/934, 85.4%). The level of income and the access to medical resources were relatively average. Approximately 67.5% (630/934) of the respondents had used e-consultation, of which 80.1% (505/630) had used e-consultation 5 times or less last year. The aims of using e-consultation include helping themselves (352/630, 55.9%) and others (278/630, 44.1%). Both serious and minor diseases could be the subject of e-consultation.

Table 2. Geographical characteristics of the respondents (N=934).

Characteristics	n (%), Value
Gender	
Male	379 (40.6)
Female	555 (59.4)
Age (years)	
18-25	239 (25.6)
26-35	463 (49.6)
36-45	159 (17.0)
>46	73 (7.8)
Education	
Middle school or lower	13 (1.4)
High school	52 (5.6)
Three-year college	138 (14.7)
Bachelor	660 (70.7)
Master or higher	71 (7.6)
Residence	
Rural	137 (14.6)
Urban	797 (85.4)
Location	
Eastern	559 (59.9)
Midregion	164 (17.5)
Western	152 (16.2)
Northern	59 (6.3)
Average annual income (¥, US $1=¥6.475)	
0-10,000	297 (31.8)
11,000-20,000	348 (37.3)
21,000-30,000	174 (18.6)
>30,000	115 (12.3)
Time to the best hospital in district and county (minutes)[a]	
1-10	281 (30.1)
11-20	289 (30.9)
21-30	227 (24.3)
>30	137 (14.7)
Usage experience	
Used	630 (67.5)
Unused	304 (32.5)
Usage frequency last year	
0-2	215 (34.1)
3-5	290 (46.0)
>5	125 (19.9)
Use e-consultation for whom	
Myself	352 (55.9)
Others	278 (44.1)

Characteristics	n (%), Value
Disease severity[b]	
1-5	337 (53.5)
6-10	293 (46.5)

[a] Measures the accessibility of high quality medical resources.

[b] Users themselves assessed the severity of last disease consulted by e-consultation using a 5-point Likert scale ranging from “strongly not serious” (1) to “strongly serious” (10).

Data Analysis

SPSS 20.0 (IBM Corp) was used to analyze the descriptive statistics of respondents’ demographic characteristics and the Cronbach α of the constructs. Amos 24.0 (IBM Corp) was used to evaluate items, measurements, and structural models. Confirmatory factor analysis of the measurement model was used to evaluate the structural model’s path effects, significance, goodness of fit, and moderation effects. Composite reliability and average variance extracted were adopted to evaluate construct reliability and validity.

Results

Measurement Model Testing

The results of reliability and validity are shown in Table 3. The composite reliability, Cronbach α of construct, was greater than the recommended value of .7, and except for financial risk, perceived usefulness, and perceived ease of use, the average variance extracted of constructs was higher than 0.5 [49]. In order to assure the availability of the model, we excluded the low loading items (PU3, PU4) to construct model 2 for testing the result of model 1. We found that although the average variance extracted was promoted a little in model 2, the model fit indices had no substantial improvement (Table 3). Further, the path effects had no substantive difference between model 1 and model 2. Besides, some researches showed that all factors fulfilled a weak or strong validity because factor loadings were statistically significant and the coefficients of path were substantial [50]. Therefore, it was reasonable to accept the results of model 1. As shown in Table 4, the collected data fit well with the research model [51]. The χ^2/df (1111.9/363) of model 1 was 3.1 and was lower than 5. The root mean square error of approximation was 0.047 and was lower than 0.05. The goodness of fit index, comparative fit index, normed fit index, Tucker-Lewis index, and incremental fit index were greater than 0.9 and the adjusted goodness of fit index was 0.9.

Table 3. Item loading and validity.

Construct/Item	Factor loading		Cronbach α		Composite reliability		Average variance extracted	
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2
PU[a]			.754	.740	0.790	0.740	0.387	0.416
PU1	0.664	0.665						
PU2	0.652	0.651						
PU3	0.577	—[b]						
PU4	0.551	—						
PU5	0.640	0.639						
PU6	0.640	0.625						
PEU[c]			.743	.743	0.747	0.748	0.425	0.426
PEU1	0.623	0.629						
PEU2	0.665	0.658						
PEU3	0.645	0.646						
PEU4	0.673	0.676						
FR[d]			.744	.744	0.745	0.745	0.495	0.494
FR1	0.648	0.647						
FR2	0.734	0.734						
FR3	0.725	0.725						
PRR[e]			.829	.829	0.840	0.840	0.640	0.640
PRR1	0.867	0.867						
PRR2	0.873	0.874						
PRR3	0.638	0.637						
SR[f]			.702	.702	0.706	0.706	0.547	0.547
SR1	0.789	0.789						
SR2	0.687	0.687						
TR[g]			.761	.761	0.761	0.761	0.614	0.614
TR1	0.786	0.786						
TR2	0.781	0.781						
PSR[h]			.754	.754	0.768	0.768	0.529	0.529
PSR1	0.813	0.813						
PSR2	0.766	0.765						
PSR3	0.583	0.583						
PI[i]			.745	.745	0.753	0.753	0.509	0.509
PI1	0.575	0.575						
PI2	0.792	0.792						
PI3	0.754	0.754						
BI[j]			.790	.790	0.789	0.789	0.556	0.556
BI1	0.768	0.768						
BI2	0.768	0.768						
BI3	0.698	0.697						

[a] PU: perceived usefulness.

[b] Not available.

[c] PEU: perceived ease of use.

[d] FR: financial risk.

[e] PRR: privacy risk.

[f] SR: social risk.

[g] TR: time risk.

[h] PSR: psychological risk.

[i] PI: personal innovativeness.

[j] BI: behavior intention.

Table 4. Research model fit.

Fit index	Value (χ^2/df)	GFI[a]	AGFI[b]	RMSEA[c]	CFI[d]	NFI[e]	TLI[f]	IFI[g]
Recommended value	<5	>0.9	>0.9	<0.05	>0.9	>0.9	>0.9	>0.9
Value in model 1	3.1 (1111.9/363)	0.917	0.900	0.047	0.932	0.903	0.924	0.933
Value in model 2	3.2 (1002.4/310)	0.919	0.901	0.049	0.934	0.907	0.925	0.934

[a] GFI: goodness of fit index.

[b] AGFI: adjusted goodness of fit index.

[c] RMSEA: root mean square error of approximation.

[d] CFI: comparative fit index.

[e] NFI: normed fit index.

[f] TLI: Tucker-Lewis index.

[g] IFI: incremental fit index.

Structural Model Testing

The judgments of hypotheses based on the SEM results are shown in Table 5. The judgments of model 1 and model 2 exhibited the same results and the standardized factor loadings of path were very closed. Perceived ease of use had no statistically significant effect on behavior intention (β=.117, *P*=.07; β1=.104, *P*=.13). Perceived usefulness had a positive effect on behavior intention (β=.399, *P*<.001; β1=.431, *P*<.001) and was the strongest positive factor of behavior intention. Perceived ease of use had a positive effect on perceived usefulness (β=.537, *P*<.001; β1=.530, *P*<.001). Perceived risk could be well explained by financial risk (β=.972, *P*<.001; β1=.973, *P*<.001), privacy risk (β=.774, *P*<.001; β1=.774, *P*<.001), social risk (β=.871, *P*<.001; β1=.870, *P*<.001), time risk (β=.894, *P*<.001; β1=.894, *P*<.001), and psychological risk (β=.774, *P*<.001; β1=.774, *P*<.001). Among the components, the effect of financial risk was the strongest and that of social risk was the weakest. Perceived risk had negative effects on perceived usefulness (β=–.375, *P*<.001; β1=–.399, *P*<.001) and behavior intention (β=–.297, *P*<.001; β1=–.275, *P*<.001). Personal innovativeness had a positive influence on perceived ease of use (β=.241, *P*<.001; β1=.242, *P*<.001). Compared with other factors, personal innovativeness had a slight effect on behavior intention (β=.124, *P*=.001; β1=.123, *P*=.001).

Table 5. Results of hypothesis testing.

Hypothesis	Path	β[a]	*P* value	Judgement of model 1	β1[b]	*P* value	Judgement of model 2
H1	PU[c]→BI	.399	<.001	Accepted	.431	<.001	Accepted
H2	PEU[d]→BI	.117	.07	Rejected	.104	.13	Rejected
H3	PEU→PU	.537	<.001	Accepted	.530	<.001	Accepted
H4a	PR[e]→FR[f]	.972	<.001	Accepted	.973	<.001	Accepted
H4b	PR→PRR[g]	.774	<.001	Accepted	.774	<.001	Accepted
H4c	PR→SR[h]	.537	<.001	Accepted	.536	<.001	Accepted
H4d	PR→TR[i]	.894	<.001	Accepted	.894	<.001	Accepted
H4e	PR→PSR[j]	.871	<.001	Accepted	.870	<.001	Accepted
H5	PR→PU	–.375	<.001	Accepted	–.399	<.001	Accepted
H6	PR→PEU	–.491	<.001	Accepted	–.488	<.001	Accepted
H7	PR→BI	–.297	<.001	Accepted	–.275	<.001	Accepted
H8	PI[k]→PEU	.241	<.001	Accepted	.242	<.001	Accepted
H9	PI→BI[l]	.124	.001	Accepted	.123	.001	Accepted

[a] β: standardized factor loading of model 1.

[b] β1: standardized factor loading of model 2.

[c] PU: perceived usefulness.

[d] PEU: perceived ease of use.

[e] PR: perceived risk.

[f] FR: financial risk.

[g] PRR: privacy risk.

[h] SR: social risk.

[i] TR: time risk.

[j] PSR: psychological risk.

[k] PI: personal innovativeness.

[l] BI: behavior intention.

Moderation Effect Testing

We further tested the moderating effects of geographical characteristics by multiple-group analysis [52,53]. In order to simplify the data analysis, the total sample was reclassified into 2 subgroups (Table 6). First, to screen the factors with moderation effects from characteristics, we constrained the measurement weights, structural weights, structural covariances, structural residua, and measurement residua of the subgroup model to construct parameter constraints models. If the results of the constraints model and the unconstrained model were significantly different, it indicated that the paths between subgroups are the factors that might have a moderation effect. As showed in Table 6, age (χ^2_{58}=133.5, P<.001), income (χ^2_{58}=85.6, P=.01), and usage experience (χ^2_{58}=82.5, P=.02) might have moderation effects.

Table 6. Dichotomous geographical characteristics of the respondents (N=934).

Characteristics	n (%), Value	χ^2 (*df*)	*P* value
Gender		43.3 (58)	.93
Male	379 (40.6)		
Female	555 (59.4)		
Age (years)		133.5 (58)	<.001
18-30	464 (49.7)		
>30	470 (50.3)		
Education		25.7 (58)	>.99
Three-year college or lower	203 (21.7)		
Bachelor or high	731 (78.3)		
Residence		47.8 (58)	.83
Rural	137 (14.6)		
Urban	797 (85.4)		
Location		38.2 (58)	.98
Eastern	559 (59.9)		
Not eastern	375 (40.1)		
Income (¥, US $ 1 =¥6.475)		85.6 (58)	.01
0-10,000	297 (31.8)		
>10,000	637 (68.2)		
Time to the best hospital (minutes)		35.7 (58)	.99
1-20	570 (61.0)		
>21	364 (39.0)		
Usage experience		82.5 (58)	.02
Used	630 (67.5)		
Unused	304 (32.5)		
Usage frequency last year		49.4 (58)	.78
0-2	215 (34.1)		
>2	415 (65.9)		
Use e-consultation for whom		44.1 (58)	.91
Myself	352 (55.9)		
Others	278 (44.1)		
Disease severity		70.5 (58)	.13
1-5	337 (53.5)		
6-10	293 (46.5)		

Second, we estimated the path loadings and the critical ratios for differences of each subgroup (Table 7). If the absolute value of the critical ratio was lower than 1.96, there would be a significant difference between the paths of the 2 subgroups. Compared with the older subgroup (β_{age2}=.235, *P*=.02), it is estimated that perceived usefulness has more positive effect on behavior intention in the younger subgroup (β_{age1}=.537, *P*<.001). The path loading of hypothesis 9 was not significant in the older subgroup (β_{age1}=.054, *P*=.34). Income had no significant moderation influence on the research model. Besides, the usage experience only had some influence on path coefficient. It is shown that the path loading of perceived ease of use to behavior intention has a significant difference, but the coefficients were very close ($\beta_{experience1}$=.532; $\beta_{experience2}$=.534). The path loading of personal innovativeness to perceived ease of use in the used group ($\beta_{experience1}$=.149, *P*=.008) was lower than that of the unused group ($\beta_{experience1}$=.327, *P*<.001). We found that there was no substantial difference in the usage mechanism whether or not the public used e-consultation.

Table 7. Multiple group analysis.

Hypothesis (H)	β_{age1}[a]	β_{age2}[b]	CR[c]	$\beta_{income1}$[d]	$\beta_{income2}$[e]	CR	$\beta_{experience1}$[f]	$\beta_{experience2}$[g]	CR
H1	.537***	.235 (.022)	–2.221**	.346***	.432***	0.203	.498***	.345***	0.02
H2	.09 (.328)	.172 (.057)	0.556	.115 (.251)	.111 (.193)	–0.030	.045 (.630)	.137 (.162)	0.629
H3	.464***	.587***	1.025	.554***	.538***	0.571	.532***	.534***	–2.043**
H4a	.957***	.987***	—[h]	.942***	.980***	—	.980***	.944***	—
H4b	.741***	.795***	–0.226	.754***	.766***	–1.338	.769***	.688***	0.364
H4c	.442***	.630***	0.511	.515***	.512***	–1.729	.557***	.376***	0.625
H4d	.847***	.943***	–0.694	.800***	.932***	–1.507	.874***	.851***	1.087
H4e	.842***	.899***	–1.274	.821***	.880***	–1.632	.880***	.745***	0.787
H5	–.391***	–.367***	–0.294	–.297***	–.390***	–0.252	–.393***	–.314***	0.306
H6	–.534***	–.456***	0.022	–.408***	–.501***	0.538	–.490***	–.318***	–0.513
H7	–.221 (.004)	–.371***	–1.704	–.323***	–.272***	1.386	–.247***	–.255 (.001)	–1.193
H8	.203 (.002)	.284***	1.831	.258 (.002)	.229***	–0.704	.149 (.008)	.327***	2.785**
H9	.054 (.344)	.186***	2.159**	.197 (.004)	.097 (.039)	–1.47	.125 (.016)	.127 (.063)	0.594

[a] β_{age1}: standardized factor loading of age from 18 years to 30 years.

[b] β_{age2}: standardized factor loading of age over 30 years.

[c] CR: critical ratios for differences.

[d] $\beta_{income1}$: standardized factor loading of income below ¥100,000 per year; US $1=¥6.475.

[e] $\beta_{income2}$: standardized factor loading of income over ¥100,000 per year.

[f] $\beta_{experience1}$: standardized factor loading of the used.

[g] $\beta_{experience1}$: standardized factor loading of the unused.

[h] Not available due to fixed parameter.

**P<.05.

***P<.001.

Discussion

Principal Results

Our study found that perceived usefulness is one of the most important determinants of individuals' intention to use e-consultation, which is similar to that reported in most related studies on the acceptance of information communication technology [27,29,30]. Even in subgroups with different characteristics, the direction and significance of path loading were not changed. Our results indicate that promoting the function of e-consultation is a key to attract the public to use it because the higher perceived usefulness means the public have more trust in the ability and integrity of doctors and platforms [24]. Compared with face-to-face consultation, e-consultation could only be used to diagnose common and chronic diseases lacking necessary medical examinations and the supporting treatment system, but the text suggestions from the specialists are still important for the public. In particular, in some special cases (eg, COVID-19 pandemic), e-consultation could not only achieve the goal of public isolation but also meet the patients' demand of medical services. Although e-consultation cannot be a complete substitute for face-to-face consultations, it may serve as an entry level consultation after integrated into the face-to-face consultation [54]. In addition to the service ability of e-consultation, technical difficulties, including substandard signal construction, virtual device, and video equipment, would significantly weaken people's evaluation on the usefulness of e-consultation [55]. Therefore, while improving the functionality, providers should also pay attention to improve the facilitation condition of e-consultation.

Different from the related researches, our research shows that perceived ease of use has no effect on the behavior intention but it has a strong effect on perceived usefulness. Normally, since the information communication technology products are used in the professional field, learning to use these products is a challenge for users. However, e-consultation just needs users to interact with doctors on the internet by using a personal computer or a smartphone. With the popularity of smartphones in China and worldwide [56], it is reasonable to believe that the public can easily learn how to operate e-consultation; therefore, the ease of use no longer plays a role in the promotion. As shown in a survey of 947 respondents, less than 20% of the people think that the reason they do not use e-consultation is that they are not skillful enough to complete the operation [57]. Another possible explanation is related to the characteristics of the respondents. Perceived ease of use comprises ease of operation, understanding, and expression. In our survey, most of the respondents had high educational backgrounds and were young, which leads to a stronger understanding ability, thereby leading to no significant relationship between perceived ease of use and behavior intention.

Personal innovativeness has a direct effect on perceived ease of use and behavior intention, which is consistent with the findings of a previous study [45]. Although more and more high-tech products are emerging, the public are always keen to try the popular products rather than the new ones. Therefore, it is essential to strengthen the publicity of e-consultation for the public. Of course, formatting innovativeness is a complex and long process [58]; therefore, finding the innovative individual might be a better choice. In the promotion of e-consultation, e-consultation providers should offer advanced services for the innovative and stable services for the common.

Perceived risk has a significantly negative effect on behavior intention. Because of health issues, the public would take risks more seriously and perform risk aversion [59]. Uncertainty and information asymmetry are typical features of medical services, which always leads patients with common diseases to fail in selecting the most effective services (primary health care). They would prefer to go to a tertiary hospital for the minimization of medical risk instead of the maximization of utility [60]. Different from other results that risk influence intention [29,38] or attitude [37] directly, our results show that perceived risk weakens not only behavior intention but also perceived usefulness and perceived ease of use directly. It shows that if we do not control the risk of e-consultation, even if e-consultation could provide services for more diseases, the public would reduce the evaluation and the intention of e-consultation. In addition, perceived usefulness contains performance risk and physical risk and perceived ease of use reflects the risk of operation. It indicates that performance risk, physical risk, and operation risk are components of perceived risk, which is consistent with the theoretical hypothesis and our previous surveys. However, perceived ease of use has no effect on behavior intention. Therefore, we need to take note that ease of operation may not promote the usage intention, but the difficulty of operation may reduce the intention.

There are many studies on the barriers in e-consultation, but these only explored the objective and external factors, for example, signal coverage, equipment, and characteristics of the patients. Even if some qualitative studies ask users' subjective evaluation, the final results are not comprehensive [61]. Our study made up for some gaps in these researches and found that among the other components, financial risk and time risk were the most considered by people. In China, the e-consultation platforms provide free and paid consultation services for users. The choices of doctors and number of questions would be limited in the free services and the cost of paid services cannot be submitted to medical insurance. Therefore, if e-consultation is not effective, the cost and time of using e-consultation will be wasted altogether. Compared with the indirect costs [62] saved by e-consultation, the opportunity cost of e-consultation is more valued by the public. Besides, not all patients believed that e-consultations could play the role in reducing the time to access specialists' advice [63]. Therefore, it is important to strengthen the connection between e-consultation and offline treatment and include the cost of e-consultation into the medical insurance system. These are the 2 keys to promote e-consultation use.

Many studies have found that the key barriers of using e-consultation for patients are privacy concerns and security of their data [5,19,64]. The path of perceived risk and privacy risk showed that providers should strengthen the construction of e-consultation information systems. Privacy disclosure has been a big problem in the medical field [65,66]. Users worry about not only the illegal disclosure but also the exposure to their family members with some special diseases such as mental illness [67]. We should appeal to the government to make related laws and strengthen the supervision of the operation of the e-consultation platform, and then, the public would upload their personal medical information during e-consultation.

e-Consultation, a new consultation model, has been in China for less than 20 years, and the public have little detailed knowledge about it; therefore, the public cannot get used to this kind of non–face-to-face consultation quickly, which has aroused the public's attention to psychological risk. Besides, body language is often accompanied by patients' expression, but the text-based e-consultation cannot reveal the body language, which can easily cause anxiety about the incomplete expression for patients [68]. Real-time video calls could alleviate this problem to some extent, but it is not applicable to all patients because of limitations in different video equipment. Of course, since the public with general health literacy are often unable to describe the uncommon disease symptoms and feelings correctly [69], they would worry about their medical behavior in e-consultation. Therefore, it would be necessary to improve the public's health literacy to decrease the psychological risk. In fact, the lack of people's health literacy is a long-standing problem and it is difficult to be overcome completely [70]. We need to cooperate with certain auxiliary ways to assist the public to use e-consultation, among which keeping a special receptionist [71] may be a good solution.

Although social risk is only a minor component of perceived risk, we need to improve the awareness of e-consultation among the public to help them understand it correctly. As mentioned above, the public know less about e-consultation; therefore, there is no effective consensus on e-consultation in the society. Some researches show that the most prominent reason for nonuse of e-consultation is that the public are not aware of the existence of the service [56,71]. With the improvement of awareness, the public would think it is a reasonable choice to use e-consultation and would not make negative assessments on it.

Our results show that personal innovativeness has an effect on behavior intention for the older population but has no effect for the younger population. A study on users not using e-consultation also showed that age had a moderation effect on behavior intention [57]. We think that for the young, especially between the ages from 18 years to 30 years in our study, their innovativeness generally has a high level; therefore, the path loading of personal innovativeness and behavior intention are not significant. Besides, perceived usefulness has less effect on the behavior intention for the older, because with the increase in age, patients place more emphasis on service attitude and medical process and not just utility [72]. Compared with the age factor, the usage experience has only a slight moderation effect on the usage mechanism. The effect direction of the paths is not changed, which indicates that the mechanisms of factors are consistent between the used and unused. Of course, we can also find that personal innovativeness has more effect on the perceived ease of use for the unused. Therefore, raising the innovativeness of the unused might achieve better effect during the promotion of e-consultation.

Limitations

Our data was collected by a web-based survey; therefore, some selection bias was unavoidable. First, this study showed that 67.5% (630/934) of the respondents were experienced in using e-consultation; however, the usage rate of the students was only 25.7% in our previous survey. These data show that our respondents use mobile devices or computers more frequently. Thus, a higher awareness of e-consultation was observed among these respondents. Second, most respondents came from urban areas (797/934, 85.4%). They might be less willing to use e-consultation because it is easier for them to receive high quality medical resources in the cities. Third, the average age of the respondents was 31 years in our study and 78.3% (731/934) of the respondents had higher education degrees than bachelor’s degree; therefore, our sample may have less medical demand and usage of e-consultation [56]. Besides, the young sample would influence the moderation effect of age. Although it is a better way to survey more people with usage experience through web-based surveys, it is not suitable for all people such as the older adults or the undereducated. Therefore, further offline population-based surveys are necessary, which could be a household survey of residents for small samples with cluster-stratified sampling. In addition, our survey meets the requirements of health care consultations during the COVID-19 pandemic, wherein the public had to stay at home, which might make people have a high intention to use e-consultation.

Conclusions

Our research focuses on the positive and negative factors that influence the public acceptance of e-consultation and supports the use of TAM and perceived risk in explaining public intention to use e-consultation. We found that perceived usefulness and perceived risk are the most important determinants effecting people’s intention to use e-consultation. Therefore, platforms and manufacturers must improve the function of e-consultation, which will promote the public intention to use it fundamentally. Further, to control the perceived risk of public, government should play an important role in enforcing management of e-consultation markets and approving corresponding medical insurance policies. Besides, we found that personal innovativeness has an effect on behavior intention and the path of factors has differences among people with different characteristics to some degree. Therefore, it is necessary to adjust the strategies to adapt to different groups.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Checklist for Reporting Results of Internet E-Surveys.
[DOCX File , 22 KB-Multimedia Appendix 1]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
TAM: technology acceptance model

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Original Paper

Patients’ Perspectives About Factors Affecting Their Use of Electronic Personal Health Records in England: Qualitative Analysis

Alaa Abd-Alrazaq[1], BSc, MSc, PhD; Zeineb Safi[1], BSc, MSc; Bridgette M Bewick[2], BA, MA, PhD; Mowafa Househ[1], BCom, MEng, PhD; Peter H Gardner[3,4], BSc, MSc, PhD

[1]Division of Information and Computing Technology, College of Science and Engineering, Hamad Bin Khalifa University, Doha, Qatar
[2]Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, United Kingdom
[3]School of Pharmacy and Medical Sciences, University of Bradford, Bradford, United Kingdom
[4]Wolfson Centre for Applied Health Research, Bradford, United Kingdom

Corresponding Author:
Alaa Abd-Alrazaq, BSc, MSc, PhD
Division of Information and Computing Technology
College of Science and Engineering
Hamad Bin Khalifa University
LAS Building,
Education city
Doha, RD5256
Qatar
Phone: 974 55708549
Email: alaa_alzoubi88@yahoo.com

Abstract

Background: General practices (GPs) in England have recently introduced a nationwide electronic personal health record (ePHR) system called Patient Online or GP online services, which allows patients to view parts of their medical records, book appointments, and request prescription refills. Although this system is free of charge, its adoption rates are low. To improve patients’ adoption and implementation success of the system, it is important to understand the factors affecting their use of the system.

Objective: The aim of this study is to explore patients’ perspectives of factors affecting their use of ePHRs in England.

Methods: A cross-sectional survey was carried out between August 21 and September 26, 2017. A questionnaire was used in this survey to collect mainly quantitative data through closed-ended questions in addition to qualitative data through an open-ended question. A convenience sample was recruited in 4 GPs in West Yorkshire, England. Given that the quantitative data were analyzed in a previous study, we analyzed the qualitative data using thematic analysis.

Results: Of the 800 eligible patients invited to participate in the survey, 624 (78.0%) returned a fully completed questionnaire. Of those returned questionnaires, the open-ended question was answered by 136/624 (21.8%) participants. A total of 2 meta-themes emerged from participants’ responses. The first meta-theme comprises 5 themes about why patients do not use Patient Online: concerns about using Patient Online, lack of awareness of Patient Online, challenges regarding internet and computers, perceived characteristics of nonusers, and preference for personal contact. The second meta-theme contains 1 theme about why patients use Patient Online: encouraging features of Patient Online.

Conclusions: The challenges and concerns that impede the use of Patient Online seem to be of greater importance than the facilitators that encourage its use. There are practical considerations that, if incorporated into the system, are likely to improve its adoption rate: Patient Online should be useful, easy to use, secure, and easy to access. Different channels should be used to increase the awareness of the system, and GPs should ease registration with the system and provide manuals, training sessions, and technical support. More research is needed to assess the effect of the new factors found in this study (eg, lack of trust, difficulty registering with Patient Online) and factors affecting the continuing use of the system.

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KEYWORDS

electronic personal health records; tethered personal health records; patient portal; patient online; technology acceptance; technology adoption; qualitative research; mobile phone

Introduction

Background

Over the past 2 decades, there has been a rapid and widespread diffusion of electronic personal health records (ePHRs) in health care institutes [1]. The Markle Foundation defines ePHRs as web-based portals that enable users to access their medical records stored by their health care providers [2]. Other services can be added to ePHRs, such as booking appointments, requesting referrals, messaging health care providers, requesting medication refills, and educational materials [3,4]. Several benefits may be gained from using ePHRs, such as empowering patients [5,6], increasing their adherence to medication [7,8], improving their self-management [8,9], enhancing patient-provider relationships and communications [10,11], decreasing adverse events and allergic reactions [11,12], and avoiding duplicated tests [11,12].

General practices (GPs) in England started implementing ePHRs in 2003 when patients were enabled to access their full records through kiosks installed in some GPs. These kiosks allow patients to check their demographic information, consultations, test results, letters, and allergies [13].

In 2007, the National Health Service (NHS) offered patients in England access to their Summary Care Records (SCR) through HealthSpace [14-16]. HealthSpace is a secure web-based personal health record that has several functions: booking or canceling hospital appointments, recording and charting health indicators (eg, vital signs, weight, peak flow), calendar with email reminders, NHS address book, links to educational sources, secure messaging, and access to the SCR [15,17]. The SCR is a summary of key health information (allergies, adverse reactions, current medications, and main diagnoses) extracted from patient electronic medical records held by their general practitioners, and it is stored centrally and accessible by authorized NHS staff in urgent situations [14,16]. Because of the low adoption rate and technical issues, HealthSpace was shut down in December 2012 [18].

In 2015, the NHS implemented ePHRs under a program called Patient Online or GP online services, which enables users to book appointments, request prescription refills, and access coded information in their medical records such as demographics, medications, allergies, test results, problems list, immunizations, and medical and surgical procedures [19]. Currently, it is the largest ePHR in England, given that it has been implemented in more than 99% of GPs [19]. As the system is provided by different companies, it is called by different names such as Patient Access, Patient Services, The Waiting Room, and SystemOnline [19]. GP online services have been introduced in the United Kingdom at a time when funding for the NHS is under pressure. Given the context of austerity, individual practices have limited resources to support the rollout of GP online services.

Research Problem and Aim

Despite the potential benefits of ePHRs, their adoption rate in England was only 28% by the end of June 2019 [20]. Identifying the factors affecting patients' use of ePHRs is important to improve patients' adoption and the implementation success of ePHRs [21-25]. A systematic review of 97 studies found that factors affecting patients' use of ePHRs in England have not been examined, and there is a lack of qualitative studies (8%) in this topic [26]. Accordingly, this study aimed to explore patients' perspectives of factors affecting their use of ePHRs (Patient Online) in England.

Methods

Data Collection

A cross-sectional survey was conducted between August 21 and September 26, 2017. In this study, a self-administered questionnaire was used to collect quantitative data through closed-ended questions and qualitative data through an open-ended question (Multimedia Appendix 1). The qualitative data provide the focus of this study. Note that the findings from the quantitative analysis of the survey data were presented in a previous paper [27]. The survey gained health research authority approval before starting data collection (The Research Ethics Committee reference number: 17/SC/0323).

Sample

A convenience sample of patients was recruited from 4 GPs in West Yorkshire, England. Patients were eligible to participate if they (1) lived in England and were registered at 1 of the 4 GPs, (2) were aged 18 years or older, and (3) had not used Patient Online before (nonusers).

Analysis

The qualitative data were analyzed using thematic analysis. Given the exploratory nature of this study, an inductive approach was used to generate themes directly from the data [28]. The analysis was performed following the steps proposed by Braun and Clarke [29]: (1) familiarizing with the data through scrutinizing and rescrutinizing the transcript; (2) coding data systematically; (3) generating subthemes and themes from codes; (4) checking the fit of those themes and subthemes to the original utterances and drawing an initial thematic map; (5) refining and regrouping some inappropriate codes and generating meta-themes from the themes for more granular grouping; and finally, (6) defining and naming subthemes, themes, and meta-themes. We followed the guidelines of Braun and Clarke, as these are considered the most systematic guide for conducting thematic analysis to date [30,31]. The analysis was carried out by the first author (AA), and the validity of codes and themes was checked by another author (BB). AA and BB discussed codes and themes. Where AA and BB had differing views on the code labels and/or thematic content, these discrepancies were resolved through discussion. In all cases, agreement was reached between AA and BB. Microsoft Excel was used to manage the analysis process.

Results

Collected Data

Out of the 800 eligible patients invited to participate in the survey, 624 (78%) participants completed the questionnaire. Of those participants, 136 (21.8%) answered the open-ended question. The 136 comments contained 221 utterances. A comment refers to the whole text written by a participant as a reply to our question, whereas an utterance refers to a part of the comment that has one idea or thought. In total, 3 of the 221 utterances were excluded because 2 utterances were illegible and the meaning of 1 utterance was not discernible. The final number of utterances included in the thematic analyses was 218. The excluded utterances were all part of longer comments, and for that reason, the final number of comments remained 136. Subsection 3.1 summarizes the characteristics of the respondents, and Subsection 3.2 presents the findings of the thematic analysis.

Participants' Characteristics

Table 1 summarizes the characteristics of the participants who answered the open-ended question and those who did not. Those who responded to the question had a mean age of 43.7 years (SD 18.3). More female participants answered the question than male participants (80/136, 58.8% were females). The majority of the respondents had a White ethnicity (107/136, 78.7%), had an income of less than US $40,000 per year (95/136, 69.8%), and had access to the internet (112/136, 82.4%). In terms of education, 39.7% (54/136) of the respondents had a bachelor's degree or higher.

Table 1. Characteristics of respondents (n=136).

Characteristics	Value, n (%)
Age (years), mean (SD)	43.7 (18.3)
18-24	19 (14.0)
25-34	35 (25.7)
35-44	23 (16.9)
45-54	20 (14.7)
55-64	17 (12.5)
65-74	12 (8.8)
≥75	10 (7.4)
Sex	
Male	56 (41.2)
Female	80 (58.8)
Ethnicity	
White	107 (78.7)
Asian	14 (10.3)
Black	6 (4.4)
Mixed	7 (5.1)
Others	2 (1.5)
Income (US $)	
<20,000	55 (40.4)
20,000-29,999	24 (17.6)
30,000-39,999	16 (11.8)
40,000-49,999	9 (6.6)
50,000-59,999	6 (4.4)
60,000 or more	5 (3.8)
Prefer not to say	21 (15.4)
Education	
Up to secondary school	13 (9.6)
Secondary school	31 (22.8)
College/Diploma	38 (27.9)
Bachelor’s degree	38 (27.9)
Master’s degree	10 (7.4)
Doctoral degree	6 (4.4)
Internet access	
Yes	112 (82.4)
No	24 (17.6)

Findings of Thematic Analysis

In total, 2 meta-themes were generated as a result of the thematic analysis. The first meta-theme consists of 5 themes and relates to utterances explaining why patients do not use Patient Online (Figure 1). The second meta-theme pertains to utterances about why patients use Patient Online, and it contains 1 theme: encouraging features of Patient Online. The following sections contain more details about all 6 themes.

Figure 1. Thematic map. GP: general practice.

Theme 1: Concerns About Using Patient Online

The first theme, concerns about using Patient Online, is made up of 7 subthemes: (1) concerns about privacy and security, (2) difficulty accessing Patient Online, (3) difficulty using Patient Online, (4) lack of trust in Patient Online, (5) difficulty registering, (6) technical concerns, and (7) the inability of Patient Online to save money and time (Figure 1).

The security and privacy of Patient Online was a major concern for respondents. Their concerns were attributed to the recent NHS hack attacks, worries that their data will be accessed by third parties, and uncertainty about the security measures of Patient Online:

> *I believe that Patient Online has/ will have too many privacy issues, look what happened when the NHS was hacked.* [Participant #9]
>
> *Only concern is confidentiality of System One as I am aware CIA [Central Intelligence Agency] are now using the system.* [Participant #30]

The second subtheme shows that difficulty accessing (logging in) the system can be a barrier to its use. The main reasons given for difficulty accessing Patient Online were the inability to find its URL link and forgetting passwords and log-in details:

> *I tried to use the system but I can never find the correct link...* [Participant #120]
>
> *...I always forget my password.* [Participant #35]

The third subtheme was generated from comments about difficulty using Patient Online. Although the previous subtheme reflects patients' concerns about logging on to Patient Online, this subtheme represents their worries about using the system after logging in to it (ie, ordering prescriptions, managing appointments, checking their records). According to some respondents, these concerns are exacerbated when nobody can help in using the system:

> *I don't know if this would be easy to use.* [Participant #5]

> *If people experience a difficulty and do not know where to find help, or who to ask, they may give up trying.* [Participant #49]

The fourth subtheme indicates that some patients did not trust Patient Online to do what they want it to do. They doubted that an appointment would actually be booked for them if they booked via Patient Online:

> *...I don't trust the service.* [Participant #9]

> *...I am not sure I would entirely trust it...* [Participant #123]

Concerns with difficulty registering with Patient Online were brought together to form the fifth subtheme. These concerns were attributed to the fact that they have to visit the practice in person with their ID to be able to register to use the system. To ease the registration process, a respondent suggested that the registration to Patient Online becomes part of the patient registration in practice:

> *You also have to make a trip to the surgery with ID to be able to use the service.* [Participant #28]

> *I think more effort should be made to encourage patients to sign up for this, and the process should be more streamlined-perhaps done as a matter of course when registering.* [Participant #7]

The sixth subtheme encompasses utterances that show concern regarding the technical difficulties of Patient Online. Technical issues here refer to technical errors that people believe they will face when using Patient Online:

> *Technology goes wrong and does not tell you why.* [Participant #58]

The last subtheme brought together utterances from some respondents who were worried about the inability of Patient Online to save money and time. This is reflected in the utterances of the seventh subtheme, that is, respondents, especially those who live near the practice doubted that using Patient Online saves money and time:

> *In my experience many of these things do not end up saving people's time and money. So I don't think I'll be using this except infrequently.* [Participant #38]

> *It would not save travel costs because I live next to it.* [Participant #85]

Theme 2: Issues About Awareness of Patient Online

The utterances in this theme suggest that if respondents had more knowledge or awareness about Patient Online, they would use it. This theme consists of 2 subthemes: lack of awareness of Patient Online and advertising about Patient Online. In the first subtheme, the respondents stated that the lack of knowledge about the system's presence, what it is about, how to use, and how to access it was the main reason for not using it:

> *To be honest, I've never heard of Patient Online before and that may be why people haven't used it.* [Participant #88]

> *Not been shown what it is about and how to use it.* [Participant #80]

In the second subtheme, several respondents attributed their lack of awareness of Patient Online to the lack of advertisement about it. For this reason, they acknowledged the essential role of the publicity of Patient Online in increasing people's awareness of it:

> *It is not openly advertised in the surgery that Patient Online is available.* [Participant #28]

> *...may not be enough advertisement.* [Participant #62]

Theme 3: Challenges Regarding Internet and Computers

The third theme refers to issues regarding prerequisites for using Patient Online (ie, a computer and internet access). Respondents identified 3 challenges regarding the internet and computers, which form the 3 subthemes within this theme. The first challenge is the lack of internet or computer access. Many respondents attributed the nonuse of Patient Online to not having internet or computer access:

> *Those who don't have access to the internet may not use it.* [Participant #57]

Although many respondents have access to the internet and computers, they have limited skills in using them, and this is the second challenge:

> *I can't use a computer so I can't use Patient Online.* [Participant #2]

The third challenge is the lack of use of internet or computers. This subtheme indicates that some users may have access to computers and internet and the required skills but do not frequently use them:

> *I do not use computers of any kind.* [Participant #75]

Theme 4: Perceived Characteristics of Nonusers

The fourth theme was generated from utterances about who is less likely to use Patient Online. The 3 main characteristics of nonusers were related to age, use of GP services, and income. These characteristics formed 3 subthemes, in addition to an extra subtheme that encompasses infrequently reported characteristics.

Age was the most commonly reported characteristic of nonusers. Respondents suspected the ability of older people to use Patient Online for different reasons: lack of computer and internet skills, lack of internet access, lack of awareness of how to use the system, lack of confidence in using it, lack of technology use, and their preference for face-to-face contact:

> *Elderly people may have no understanding or knowledge of how to use a computer or the internet.* [Participant #69]

> *Older people may not use it as they don't have access to internet or know how to use services.* [Participant #116]

In the second subtheme, respondents attributed the nonuse of the system to lack of use of GP services in general, such as consultations and medications:

> *I've never used it as it's rare that I attend the surgery and I'm not on any medication.* [Participant #132]

Low income formed the third subtheme. Respondents stated that people need enough income to have internet access or get training to be able to use computers and the internet:

> *I do not have enough income/benefits...* [Participant #20]

The last subtheme encompasses characteristics of other people who are more likely to be nonusers of Patient Online and those who live near the practice, illiterate people, people who cannot read in English, and people who forget to use Patient Online:

> *I would use Patient Online more often if I lived further away from the surgery.* [Participant #15]

> *I am not good at reading or spelling so online would not be good for me.* [Participant #70]

Theme 5: Preferring Personal Contact

Preferring personal contact was identified as the main justification for not using Patient Online. Patients prefer personal contact because they think it is more reliable, easier, provides an instant reply, and is important in urgent conditions:

> *It is more reliable to speak to someone directly about their medical records rather than using online.* [Participant #29]

> *Picking up the phone and speaking to someone is easier.* [Participant #135]

Theme 6: Encouraging Features of Patient Online

Within this theme, respondents identified features of Patient Online that may encourage them to use the system. One of the main features of Patient Online is that it is useful for different people, such as students, people with mobility needs, people who cannot reach the practice, and busy people:

> *I feel that it would be particularly useful for students.* [Participant #63]

Another feature mentioned by respondents is ease of access. Some respondents thought that Patient Online could be more accessible if it was a mobile app. It is noteworthy that mobile apps were not available for accessing GP online services at the time of data collection. Later, patients have been enabled to access GP online services via a mobile app called NHS App [32]:

> *A mobile application would be more accessible...* [Participant #95]

Respondents reported other features of Patient Online, which may encourage people to use it, namely, secure, quick, user-friendly interface, convenient, and less stressful:

> *If it is secure and fast then people will use it, I suppose.* [Participant #68]

> *If the interface is not user-friendly people might not be encouraged to use Patient Online.* [Participant #82]

Discussion

Principal Findings

The aim of this study is to explore why patients in England choose to use ePHRs. Participants identified one leading cause that encouraged them to use Patient Online, which relates to its features being useful, easy to access, secure, quick, user-friendly interface, convenient, and less stressful. However, patients identified many reasons for not using Patient Online, which were categorized into 5 themes: concerns about using Patient Online, lack of awareness of Patient Online, challenges regarding internet and computers, perceived characteristics of nonusers, and preference for personal contact.

In the first theme, concerns about using Patient Online, the most prominent reason for not using Patient Online was privacy and security concerns. This may be attributed to the fact that ePHRs typically contain personal and sensitive information, and patients have previously been shown to be concerned about the accessibility of these data [33]. The hack attacks that happened to the NHS 4 months before data collection may have exacerbated these concerns in this sample. This finding is consistent with the results of the quantitative data in the original study [27], where perceived privacy and security significantly affected patients' intention to use Patient Online. This factor was also found in other quantitative studies [33-36] and qualitative studies [37-43].

Participants also raised their concerns about difficulty logging on to Patient Online because of losing its URL and forgetting passwords and log-in details. This issue posed a challenge for patients because they were given new complex passwords and usernames to access Patient Online. Although passwords can be changed through the system, usernames are fixed. This effect of difficulty accessing the system has also been demonstrated in several studies [41,44,45].

Other worries were reported about difficulty using Patient Online, especially when there is no one to help. This may be attributed to the fact that patients need adequate computer and internet skills to use Patient Online. They may also need to access it without any help from others to protect their privacy. This factor was also found in quantitative analysis in the original study [27], where effort expectancy (ie, ease of use) and behavioral intentions were significantly associated. Furthermore, numerous quantitative and qualitative studies have shown similar findings regarding this factor [37,38,40,41,45-47].

Participants expressed their concerns about the difficulty they experienced registering with Patient Online. Indeed, it could be argued that the process of registration with Patient Online is less flexible than several systems (eg, MyChart, PatientSite, My Health Manager, My Health at Vanderbilt), where patients can register with the system using email, websites, or phone and with no need to visit the practice. To the best of our knowledge, this factor was not found in previous studies. This may be because of the ease of registration with other systems.

The inability of Patient Online to save money and time was a concern for some participants, especially those who live near the practice. This concern may have made patients feel that Patient Online is not useful for them. Thus, this factor is related to perceived usefulness, which was the most influential factor according to the quantitative analysis in the original study [27]. The effect of this factor was also demonstrated by quantitative studies [46-49] and other qualitative studies [37,40,41,45,50].

Finally, 2 further concerns in this group were raised by participants, a lack of trust in Patient Online to book appointments or request medication refills and the technical issues that some patients reported when using Patient Online. To the best of our knowledge, neither of these factors have been reported in previous studies.

In the second theme, lack of awareness of different aspects of Patient Online was an influential factor in not using the system. Lack of advertising about Patient Online was the main reason for this lack of awareness. Although 3 of the 4 GPs had advertisements about Patient Online visibly displayed on screens or brochures in the waiting room during the study, some patients still reported a lack of awareness of the system. This factor was in line with the findings of previous quantitative studies [51,52] and qualitative studies [37,41,45,53].

With regard to the third theme, 3 challenges related to computers and the internet were identified. The first is the lack of internet or computer access. This factor was represented by the construct *facilitating condition* in the quantitative analysis, and it was found to significantly affect the actual use of Patient Online [27]. Furthermore, previous studies have shown a significant deleterious effect of a lack of internet [54-59] and computer access [38,46,52,57].

The limited skills in using the internet or computers was the second challenge in this group. This challenge may have produced reports that patients found Patient Online difficult to use. Hence, this factor is related to perceived ease of use (ie, effort expectancy), which was the most influential factor according to the quantitative analysis in the original study [19]. Numerous studies have supported this effect of computer literacy [38,40,41,53,60] and internet literacy [61,62].

The last challenge was the lack of using internet or computers. This challenge may also be related to perceived ease of use, as those who rarely use computers and the internet may perceive the system difficult to use. Several previous studies showed similar findings regarding the effect of lack of computer use [43,46,62] and internet use on the adoption of ePHRs [39,43,54,63-65].

Regarding the fourth theme, participants determined the following characteristics of nonusers of Patient Online, which were consistent with findings of previous studies: older people [61,66-69], who rarely use GP services [55,66,68,70,71], who have low income [46,52,72,73], who live near the practice [70], and who have lower literacy levels [46,52,72,73].

In the last theme, participants justified their nonuse of the system by indicating their preference for personal contact with their GP. This was attributed to the perceived advantages of personal contact over the system. This factor was found in other studies [40,51,52].

Strengths

This study enabled us to explore new factors that were not examined by the quantitative part of the study (eg, lack of awareness) and previous studies (eg, lack of trust). Furthermore, this study allowed us, to some extent, to support and explain some relationships proposed in the quantitative study (eg, performance expectancy, perceived privacy, security).

To the best of our knowledge, this study had the largest sample size in comparison with all qualitative studies on this topic. This allowed us to explore a wide range of patients’ perspectives on the adoption of ePHRs.

Limitations

This study collected data from 4 GPs implementing the same ePHR (ie, SystemOnline), which may limit the generalizability of this study to other practices implementing other ePHRs (ie, Patient Access, Patient Services, The Waiting Room, Engage Consult, and Evergreen Life/i-Patient). However, it should be noted that all these systems provide the same services to the patients (ie, booking appointments, requesting prescription refills, and viewing health records), and no participant had used any of them before. As a result, the participants in this study were unlikely to have made comparisons between the different systems.

Although the qualitative data collected by an open-ended question helped in exploring factors affecting patients’ use of Patient Online, such data may not be equivalent to qualitative data collected by interviews or focus groups. Thus, we could not deeply understand the adoption process of Patient Online. However, this qualitative analysis did not aim to understand in depth the phenomenon of interest; rather, it aimed only to help in identifying other factors not included in the model and explaining the findings of the quantitative study. As answering the open-ended question was voluntary, there may be an element of self-selection.

As the open-ended question was put after closed-ended questions, participants’ answers to the open-ended question may be influenced by this order. This order was based on researchers’ recommendations that questionnaires should start with the most interesting and easy-to-answer questions, and open-ended and demographic questions should be presented at the end of the questionnaire [74-76].

Practical Implications

We believe that adoption of GP online services will significantly increase in the future, given that many factors identified in this study will be automatically and considerably mitigated by time. Specifically, the proportion of patients who are more comfortable with the use of computers, smartphones, electronic systems, and the internet will increase in the future given their increased spread over the world. Thus, these services may be desired and expected by patients. However, developers, marketers, and GPs still play a crucial role in increasing the adoption of GP online services.

During system development, patients should be involved in the process to identify the features that make the system useful and easy to use. Some participants pointed out that the system will be useful when it allows them to book walk-in appointments, communicate with their doctors, and select the required doctor. As Patient Online currently enables patients to choose the required doctor, developers should consider adding these services, which are provided by many ePHRs (eg, MyChart, MyHealtheVet, Patient Gateway) [46,66,77]. Furthermore, users of such systems should be informed and reassured about the different security measures that are in place (eg, strong firewalls, encouragement to use complex and long passwords), and it should be made clear that the provision of GP online services is strictly controlled by legislation to safeguard personal data. To ease logging on to the system, developers should develop a system that allows patients to access it through their fingerprints or face recognitions, instead of using complex usernames and passwords. It is noteworthy that the NHS App, which has been recently developed, is the only system that enables patients to access GP online services using fingerprints or face recognitions [32].

To increase the awareness of the system, its functionality, and its benefits, marketers should improve their publicity through different channels, such as public media (eg, television, radio, newspapers, magazines), social media (eg, Facebook, Twitter, YouTube), emails, mails, automated messages on the practices' telephone system, and advertisements in general public areas (eg, shopping centers, health care settings, highway streets, universities). Face-to-face communication is considered as one of the most effective channels in marketing to persuade potential adopters to adopt an innovation [78,79]. Thus, all staff in practice (eg, physicians, nurses, receptionists) should offer the system to patients during their visits. GP staff may not be keen on publicizing online services because of a lack of incentives and time. Therefore, consideration should be given to providing incentives and resources for GPs to increase patients' awareness of GP online services.

Although patients have been recently enabled to sign up in the GP online services without visiting their surgeries through only the NHS App [80], they still need to visit their surgeries in person to register to use GP online services provided by other systems (eg, SystemOnline, Patient Access). To ease signing up in these systems, GPs should allow patients to register on web or through phone and make the signing up procedure a part of patient registration in the practice. GPs may enhance patients' perceptions of usefulness, ease of use of the system, and their trust in it by helping them in using a beta version of the system through a computer in a waiting room. GPs should provide online assistance, technical support, manuals, and training to allow patients to solve any technical issues that face them when using the system, thereby decreasing their technical concerns. GPs should collaborate with other parties (eg, Patient Online providers and government bodies) to provide computers and/or internet access at affordable prices for those who do not have them and cannot afford them. Given that many UK GPs report being overstretched and limited funding has been provided to support the rollout of GP online services, consideration should be given to providing incentive programs (eg, Meaningful Use policy as issued by the US government). Incentive programs could be used to encourage GPs to publicize their online services and encourage patients to use them.

Recommendations for Future Research

As this study could not provide a deep understanding of the adoption process of Patient Online, a deeper understanding of the adoption of online services could be gained through further qualitative work using interviews or focus groups. Several factors were revealed in this analysis but were not part of the conceptual model in the quantitative study, namely, awareness of Patient Online, lack of trust in the system, difficulty registering, disability, lack of use of GP services, and distance to the GPs. Future studies should consider adding these factors to the model and quantitatively examine them. Finally, more research is needed to identify the factors affecting the continuing use, as long-term viability and eventual success of information technology count on its continuing use more than initial use [81-83].

Conclusions

This research explored patients' perspectives regarding factors influencing their use of Patient Online. We found about 20 factors grouped into 6 themes. The findings of this study supported the findings of the quantitative study (eg, performance expectancy, effort expectancy, perceived privacy). This study found new factors that were not examined by the quantitative part of the study (eg, lack of awareness) and previous studies (eg, lack of trust).

The challenges and concerns that impede the use of Patient Online seem to be greater than the facilitators that encourage its use. To foster use, several practical implications were suggested: Patient Online should be useful, easy to use, secure, and easy to access; different channels should be used to increase the awareness of the system; and GPs should ease registration with the system and provide manuals, training sessions, and technical support. More research is needed to quantitatively assess the effect of the new factors found in this study (eg, lack of trust, difficulty registering with Patient Online) and factors affecting continuing use of the system.

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Authors' Contributions

AA and PG developed the protocol. AA collected the data. AA analyzed the data under BB's guidance and supervision. AA and ZS drafted the manuscript, and it was revised critically for important intellectual content by all authors. All authors approved the manuscript for publication and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.
[DOCX File , 70 KB-Multimedia Appendix 1]

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Abbreviations

ePHR: electronic personal health record
GP: general practice
NHS: National Health Service
SCR: summary care record

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Original Paper

Patients’ Perspectives About Factors Affecting Their Use of Electronic Personal Health Records in England: Qualitative Analysis

Alaa Abd-Alrazaq[1], BSc, MSc, PhD; Zeineb Safi[1], BSc, MSc; Bridgette M Bewick[2], BA, MA, PhD; Mowafa Househ[1], BCom, MEng, PhD; Peter H Gardner[3,4], BSc, MSc, PhD

[1]Division of Information and Computing Technology, College of Science and Engineering, Hamad Bin Khalifa University, Doha, Qatar
[2]Leeds Institute of Health Sciences, School of Medicine, University of Leeds, Leeds, United Kingdom
[3]School of Pharmacy and Medical Sciences, University of Bradford, Bradford, United Kingdom
[4]Wolfson Centre for Applied Health Research, Bradford, United Kingdom

Corresponding Author:
Alaa Abd-Alrazaq, BSc, MSc, PhD
Division of Information and Computing Technology
College of Science and Engineering
Hamad Bin Khalifa University
LAS Building,
Education city
Doha, RD5256
Qatar
Phone: 974 55708549
Email: alaa_alzoubi88@yahoo.com

Abstract

Background: General practices (GPs) in England have recently introduced a nationwide electronic personal health record (ePHR) system called Patient Online or GP online services, which allows patients to view parts of their medical records, book appointments, and request prescription refills. Although this system is free of charge, its adoption rates are low. To improve patients’ adoption and implementation success of the system, it is important to understand the factors affecting their use of the system.

Objective: The aim of this study is to explore patients’ perspectives of factors affecting their use of ePHRs in England.

Methods: A cross-sectional survey was carried out between August 21 and September 26, 2017. A questionnaire was used in this survey to collect mainly quantitative data through closed-ended questions in addition to qualitative data through an open-ended question. A convenience sample was recruited in 4 GPs in West Yorkshire, England. Given that the quantitative data were analyzed in a previous study, we analyzed the qualitative data using thematic analysis.

Results: Of the 800 eligible patients invited to participate in the survey, 624 (78.0%) returned a fully completed questionnaire. Of those returned questionnaires, the open-ended question was answered by 136/624 (21.8%) participants. A total of 2 meta-themes emerged from participants’ responses. The first meta-theme comprises 5 themes about why patients do not use Patient Online: concerns about using Patient Online, lack of awareness of Patient Online, challenges regarding internet and computers, perceived characteristics of nonusers, and preference for personal contact. The second meta-theme contains 1 theme about why patients use Patient Online: encouraging features of Patient Online.

Conclusions: The challenges and concerns that impede the use of Patient Online seem to be of greater importance than the facilitators that encourage its use. There are practical considerations that, if incorporated into the system, are likely to improve its adoption rate: Patient Online should be useful, easy to use, secure, and easy to access. Different channels should be used to increase the awareness of the system, and GPs should ease registration with the system and provide manuals, training sessions, and technical support. More research is needed to assess the effect of the new factors found in this study (eg, lack of trust, difficulty registering with Patient Online) and factors affecting the continuing use of the system.

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KEYWORDS

electronic personal health records; tethered personal health records; patient portal; patient online; technology acceptance; technology adoption; qualitative research; mobile phone

Introduction

Background

Over the past 2 decades, there has been a rapid and widespread diffusion of electronic personal health records (ePHRs) in health care institutes [1]. The Markle Foundation defines ePHRs as web-based portals that enable users to access their medical records stored by their health care providers [2]. Other services can be added to ePHRs, such as booking appointments, requesting referrals, messaging health care providers, requesting medication refills, and educational materials [3,4]. Several benefits may be gained from using ePHRs, such as empowering patients [5,6], increasing their adherence to medication [7,8], improving their self-management [8,9], enhancing patient-provider relationships and communications [10,11], decreasing adverse events and allergic reactions [11,12], and avoiding duplicated tests [11,12].

General practices (GPs) in England started implementing ePHRs in 2003 when patients were enabled to access their full records through kiosks installed in some GPs. These kiosks allow patients to check their demographic information, consultations, test results, letters, and allergies [13].

In 2007, the National Health Service (NHS) offered patients in England access to their Summary Care Records (SCR) through HealthSpace [14-16]. HealthSpace is a secure web-based personal health record that has several functions: booking or canceling hospital appointments, recording and charting health indicators (eg, vital signs, weight, peak flow), calendar with email reminders, NHS address book, links to educational sources, secure messaging, and access to the SCR [15,17]. The SCR is a summary of key health information (allergies, adverse reactions, current medications, and main diagnoses) extracted from patient electronic medical records held by their general practitioners, and it is stored centrally and accessible by authorized NHS staff in urgent situations [14,16]. Because of the low adoption rate and technical issues, HealthSpace was shut down in December 2012 [18].

In 2015, the NHS implemented ePHRs under a program called Patient Online or GP online services, which enables users to book appointments, request prescription refills, and access coded information in their medical records such as demographics, medications, allergies, test results, problems list, immunizations, and medical and surgical procedures [19]. Currently, it is the largest ePHR in England, given that it has been implemented in more than 99% of GPs [19]. As the system is provided by different companies, it is called by different names such as Patient Access, Patient Services, The Waiting Room, and SystemOnline [19]. GP online services have been introduced in the United Kingdom at a time when funding for the NHS is under pressure. Given the context of austerity, individual practices have limited resources to support the rollout of GP online services.

Research Problem and Aim

Despite the potential benefits of ePHRs, their adoption rate in England was only 28% by the end of June 2019 [20]. Identifying the factors affecting patients' use of ePHRs is important to improve patients' adoption and the implementation success of ePHRs [21-25]. A systematic review of 97 studies found that factors affecting patients' use of ePHRs in England have not been examined, and there is a lack of qualitative studies (8%) in this topic [26]. Accordingly, this study aimed to explore patients' perspectives of factors affecting their use of ePHRs (Patient Online) in England.

Methods

Data Collection

A cross-sectional survey was conducted between August 21 and September 26, 2017. In this study, a self-administered questionnaire was used to collect quantitative data through closed-ended questions and qualitative data through an open-ended question (Multimedia Appendix 1). The qualitative data provide the focus of this study. Note that the findings from the quantitative analysis of the survey data were presented in a previous paper [27]. The survey gained health research authority approval before starting data collection (The Research Ethics Committee reference number: 17/SC/0323).

Sample

A convenience sample of patients was recruited from 4 GPs in West Yorkshire, England. Patients were eligible to participate if they (1) lived in England and were registered at 1 of the 4 GPs, (2) were aged 18 years or older, and (3) had not used Patient Online before (nonusers).

Analysis

The qualitative data were analyzed using thematic analysis. Given the exploratory nature of this study, an inductive approach was used to generate themes directly from the data [28]. The analysis was performed following the steps proposed by Braun and Clarke [29]: (1) familiarizing with the data through scrutinizing and rescrutinizing the transcript; (2) coding data systematically; (3) generating subthemes and themes from codes; (4) checking the fit of those themes and subthemes to the original utterances and drawing an initial thematic map; (5) refining and regrouping some inappropriate codes and generating meta-themes from the themes for more granular grouping; and finally, (6) defining and naming subthemes, themes, and meta-themes. We followed the guidelines of Braun and Clarke, as these are considered the most systematic guide for conducting thematic analysis to date [30,31]. The analysis was carried out by the first author (AA), and the validity of codes and themes was checked by another author (BB). AA and BB discussed codes and themes. Where AA and BB had differing views on the code labels and/or thematic content, these discrepancies were resolved through discussion. In all cases, agreement was reached between AA and BB. Microsoft Excel was used to manage the analysis process.

Results

Collected Data

Out of the 800 eligible patients invited to participate in the survey, 624 (78%) participants completed the questionnaire. Of those participants, 136 (21.8%) answered the open-ended question. The 136 comments contained 221 utterances. A comment refers to the whole text written by a participant as a reply to our question, whereas an utterance refers to a part of the comment that has one idea or thought. In total, 3 of the 221 utterances were excluded because 2 utterances were illegible and the meaning of 1 utterance was not discernible. The final number of utterances included in the thematic analyses was 218. The excluded utterances were all part of longer comments, and for that reason, the final number of comments remained 136. Subsection 3.1 summarizes the characteristics of the respondents, and Subsection 3.2 presents the findings of the thematic analysis.

Participants' Characteristics

Table 1 summarizes the characteristics of the participants who answered the open-ended question and those who did not. Those who responded to the question had a mean age of 43.7 years (SD 18.3). More female participants answered the question than male participants (80/136, 58.8% were females). The majority of the respondents had a White ethnicity (107/136, 78.7%), had an income of less than US $40,000 per year (95/136, 69.8%), and had access to the internet (112/136, 82.4%). In terms of education, 39.7% (54/136) of the respondents had a bachelor's degree or higher.

Table 1. Characteristics of respondents (n=136).

Characteristics	Value, n (%)
Age (years), mean (SD)	43.7 (18.3)
18-24	19 (14.0)
25-34	35 (25.7)
35-44	23 (16.9)
45-54	20 (14.7)
55-64	17 (12.5)
65-74	12 (8.8)
≥75	10 (7.4)
Sex	
Male	56 (41.2)
Female	80 (58.8)
Ethnicity	
White	107 (78.7)
Asian	14 (10.3)
Black	6 (4.4)
Mixed	7 (5.1)
Others	2 (1.5)
Income (US $)	
<20,000	55 (40.4)
20,000-29,999	24 (17.6)
30,000-39,999	16 (11.8)
40,000-49,999	9 (6.6)
50,000-59,999	6 (4.4)
60,000 or more	5 (3.8)
Prefer not to say	21 (15.4)
Education	
Up to secondary school	13 (9.6)
Secondary school	31 (22.8)
College/Diploma	38 (27.9)
Bachelor’s degree	38 (27.9)
Master’s degree	10 (7.4)
Doctoral degree	6 (4.4)
Internet access	
Yes	112 (82.4)
No	24 (17.6)

Findings of Thematic Analysis

In total, 2 meta-themes were generated as a result of the thematic analysis. The first meta-theme consists of 5 themes and relates to utterances explaining why patients do not use Patient Online (Figure 1). The second meta-theme pertains to utterances about why patients use Patient Online, and it contains 1 theme: encouraging features of Patient Online. The following sections contain more details about all 6 themes.

Figure 1. Thematic map. GP: general practice.

Theme 1: Concerns About Using Patient Online

The first theme, concerns about using Patient Online, is made up of 7 subthemes: (1) concerns about privacy and security, (2) difficulty accessing Patient Online, (3) difficulty using Patient Online, (4) lack of trust in Patient Online, (5) difficulty registering, (6) technical concerns, and (7) the inability of Patient Online to save money and time (Figure 1).

The security and privacy of Patient Online was a major concern for respondents. Their concerns were attributed to the recent NHS hack attacks, worries that their data will be accessed by third parties, and uncertainty about the security measures of Patient Online:

> *I believe that Patient Online has/ will have too many privacy issues, look what happened when the NHS was hacked.* [Participant #9]
>
> *Only concern is confidentiality of System One as I am aware CIA [Central Intelligence Agency] are now using the system.* [Participant #30]

The second subtheme shows that difficulty accessing (logging in) the system can be a barrier to its use. The main reasons given for difficulty accessing Patient Online were the inability to find its URL link and forgetting passwords and log-in details:

> *I tried to use the system but I can never find the correct link...* [Participant #120]
>
> *...I always forget my password.* [Participant #35]

The third subtheme was generated from comments about difficulty using Patient Online. Although the previous subtheme reflects patients' concerns about logging on to Patient Online, this subtheme represents their worries about using the system after logging in to it (ie, ordering prescriptions, managing appointments, checking their records). According to some respondents, these concerns are exacerbated when nobody can help in using the system:

> *I don't know if this would be easy to use.* [Participant #5]

> *If people experience a difficulty and do not know where to find help, or who to ask, they may give up trying.* [Participant #49]

The fourth subtheme indicates that some patients did not trust Patient Online to do what they want it to do. They doubted that an appointment would actually be booked for them if they booked via Patient Online:

> *...I don't trust the service.* [Participant #9]

> *...I am not sure I would entirely trust it...* [Participant #123]

Concerns with difficulty registering with Patient Online were brought together to form the fifth subtheme. These concerns were attributed to the fact that they have to visit the practice in person with their ID to be able to register to use the system. To ease the registration process, a respondent suggested that the registration to Patient Online becomes part of the patient registration in practice:

> *You also have to make a trip to the surgery with ID to be able to use the service.* [Participant #28]

> *I think more effort should be made to encourage patients to sign up for this, and the process should be more streamlined-perhaps done as a matter of course when registering.* [Participant #7]

The sixth subtheme encompasses utterances that show concern regarding the technical difficulties of Patient Online. Technical issues here refer to technical errors that people believe they will face when using Patient Online:

> *Technology goes wrong and does not tell you why.* [Participant #58]

The last subtheme brought together utterances from some respondents who were worried about the inability of Patient Online to save money and time. This is reflected in the utterances of the seventh subtheme, that is, respondents, especially those who live near the practice doubted that using Patient Online saves money and time:

> *In my experience many of these things do not end up saving people's time and money. So I don't think I'll be using this except infrequently.* [Participant #38]

> *It would not save travel costs because I live next to it.* [Participant #85]

Theme 2: Issues About Awareness of Patient Online

The utterances in this theme suggest that if respondents had more knowledge or awareness about Patient Online, they would use it. This theme consists of 2 subthemes: lack of awareness of Patient Online and advertising about Patient Online. In the first subtheme, the respondents stated that the lack of knowledge about the system's presence, what it is about, how to use, and how to access it was the main reason for not using it:

> *To be honest, I've never heard of Patient Online before and that may be why people haven't used it.* [Participant #88]

> *Not been shown what it is about and how to use it.* [Participant #80]

In the second subtheme, several respondents attributed their lack of awareness of Patient Online to the lack of advertisement about it. For this reason, they acknowledged the essential role of the publicity of Patient Online in increasing people's awareness of it:

> *It is not openly advertised in the surgery that Patient Online is available.* [Participant #28]

> *...may not be enough advertisement.* [Participant #62]

Theme 3: Challenges Regarding Internet and Computers

The third theme refers to issues regarding prerequisites for using Patient Online (ie, a computer and internet access). Respondents identified 3 challenges regarding the internet and computers, which form the 3 subthemes within this theme. The first challenge is the lack of internet or computer access. Many respondents attributed the nonuse of Patient Online to not having internet or computer access:

> *Those who don't have access to the internet may not use it.* [Participant #57]

Although many respondents have access to the internet and computers, they have limited skills in using them, and this is the second challenge:

> *I can't use a computer so I can't use Patient Online.* [Participant #2]

The third challenge is the lack of use of internet or computers. This subtheme indicates that some users may have access to computers and internet and the required skills but do not frequently use them:

> *I do not use computers of any kind.* [Participant #75]

Theme 4: Perceived Characteristics of Nonusers

The fourth theme was generated from utterances about who is less likely to use Patient Online. The 3 main characteristics of nonusers were related to age, use of GP services, and income. These characteristics formed 3 subthemes, in addition to an extra subtheme that encompasses infrequently reported characteristics.

Age was the most commonly reported characteristic of nonusers. Respondents suspected the ability of older people to use Patient Online for different reasons: lack of computer and internet skills, lack of internet access, lack of awareness of how to use the system, lack of confidence in using it, lack of technology use, and their preference for face-to-face contact:

> *Elderly people may have no understanding or knowledge of how to use a computer or the internet.* [Participant #69]

> *Older people may not use it as they don't have access to internet or know how to use services.* [Participant #116]

In the second subtheme, respondents attributed the nonuse of the system to lack of use of GP services in general, such as consultations and medications:

> *I've never used it as it's rare that I attend the surgery and I'm not on any medication.* [Participant #132]

Low income formed the third subtheme. Respondents stated that people need enough income to have internet access or get training to be able to use computers and the internet:

> *I do not have enough income/benefits...* [Participant #20]

The last subtheme encompasses characteristics of other people who are more likely to be nonusers of Patient Online and those who live near the practice, illiterate people, people who cannot read in English, and people who forget to use Patient Online:

> *I would use Patient Online more often if I lived further away from the surgery.* [Participant #15]
>
> *I am not good at reading or spelling so online would not be good for me.* [Participant #70]

Theme 5: Preferring Personal Contact

Preferring personal contact was identified as the main justification for not using Patient Online. Patients prefer personal contact because they think it is more reliable, easier, provides an instant reply, and is important in urgent conditions:

> *It is more reliable to speak to someone directly about their medical records rather than using online.* [Participant #29]
>
> *Picking up the phone and speaking to someone is easier.* [Participant #135]

Theme 6: Encouraging Features of Patient Online

Within this theme, respondents identified features of Patient Online that may encourage them to use the system. One of the main features of Patient Online is that it is useful for different people, such as students, people with mobility needs, people who cannot reach the practice, and busy people:

> *I feel that it would be particularly useful for students.* [Participant #63]

Another feature mentioned by respondents is ease of access. Some respondents thought that Patient Online could be more accessible if it was a mobile app. It is noteworthy that mobile apps were not available for accessing GP online services at the time of data collection. Later, patients have been enabled to access GP online services via a mobile app called NHS App [32]:

> *A mobile application would be more accessible...* [Participant #95]

Respondents reported other features of Patient Online, which may encourage people to use it, namely, secure, quick, user-friendly interface, convenient, and less stressful:

> *If it is secure and fast then people will use it, I suppose.* [Participant #68]
>
> *If the interface is not user-friendly people might not be encouraged to use Patient Online.* [Participant #82]

Discussion

Principal Findings

The aim of this study is to explore why patients in England choose to use ePHRs. Participants identified one leading cause that encouraged them to use Patient Online, which relates to its features being useful, easy to access, secure, quick, user-friendly interface, convenient, and less stressful. However, patients identified many reasons for not using Patient Online, which were categorized into 5 themes: concerns about using Patient Online, lack of awareness of Patient Online, challenges regarding internet and computers, perceived characteristics of nonusers, and preference for personal contact.

In the first theme, concerns about using Patient Online, the most prominent reason for not using Patient Online was privacy and security concerns. This may be attributed to the fact that ePHRs typically contain personal and sensitive information, and patients have previously been shown to be concerned about the accessibility of these data [33]. The hack attacks that happened to the NHS 4 months before data collection may have exacerbated these concerns in this sample. This finding is consistent with the results of the quantitative data in the original study [27], where perceived privacy and security significantly affected patients' intention to use Patient Online. This factor was also found in other quantitative studies [33-36] and qualitative studies [37-43].

Participants also raised their concerns about difficulty logging on to Patient Online because of losing its URL and forgetting passwords and log-in details. This issue posed a challenge for patients because they were given new complex passwords and usernames to access Patient Online. Although passwords can be changed through the system, usernames are fixed. This effect of difficulty accessing the system has also been demonstrated in several studies [41,44,45].

Other worries were reported about difficulty using Patient Online, especially when there is no one to help. This may be attributed to the fact that patients need adequate computer and internet skills to use Patient Online. They may also need to access it without any help from others to protect their privacy. This factor was also found in quantitative analysis in the original study [27], where effort expectancy (ie, ease of use) and behavioral intentions were significantly associated. Furthermore, numerous quantitative and qualitative studies have shown similar findings regarding this factor [37,38,40,41,45-47].

Participants expressed their concerns about the difficulty they experienced registering with Patient Online. Indeed, it could be argued that the process of registration with Patient Online is less flexible than several systems (eg, MyChart, PatientSite, My Health Manager, My Health at Vanderbilt), where patients can register with the system using email, websites, or phone and with no need to visit the practice. To the best of our knowledge, this factor was not found in previous studies. This may be because of the ease of registration with other systems.

The inability of Patient Online to save money and time was a concern for some participants, especially those who live near the practice. This concern may have made patients feel that Patient Online is not useful for them. Thus, this factor is related to perceived usefulness, which was the most influential factor according to the quantitative analysis in the original study [27]. The effect of this factor was also demonstrated by quantitative studies [46-49] and other qualitative studies [37,40,41,45,50].

Finally, 2 further concerns in this group were raised by participants, a lack of trust in Patient Online to book appointments or request medication refills and the technical issues that some patients reported when using Patient Online. To the best of our knowledge, neither of these factors have been reported in previous studies.

In the second theme, lack of awareness of different aspects of Patient Online was an influential factor in not using the system. Lack of advertising about Patient Online was the main reason for this lack of awareness. Although 3 of the 4 GPs had advertisements about Patient Online visibly displayed on screens or brochures in the waiting room during the study, some patients still reported a lack of awareness of the system. This factor was in line with the findings of previous quantitative studies [51,52] and qualitative studies [37,41,45,53].

With regard to the third theme, 3 challenges related to computers and the internet were identified. The first is the lack of internet or computer access. This factor was represented by the construct *facilitating condition* in the quantitative analysis, and it was found to significantly affect the actual use of Patient Online [27]. Furthermore, previous studies have shown a significant deleterious effect of a lack of internet [54-59] and computer access [38,46,52,57].

The limited skills in using the internet or computers was the second challenge in this group. This challenge may have produced reports that patients found Patient Online difficult to use. Hence, this factor is related to perceived ease of use (ie, effort expectancy), which was the most influential factor according to the quantitative analysis in the original study [19]. Numerous studies have supported this effect of computer literacy [38,40,41,53,60] and internet literacy [61,62].

The last challenge was the lack of using internet or computers. This challenge may also be related to perceived ease of use, as those who rarely use computers and the internet may perceive the system difficult to use. Several previous studies showed similar findings regarding the effect of lack of computer use [43,46,62] and internet use on the adoption of ePHRs [39,43,54,63-65].

Regarding the fourth theme, participants determined the following characteristics of nonusers of Patient Online, which were consistent with findings of previous studies: older people [61,66-69], who rarely use GP services [55,66,68,70,71], who have low income [46,52,72,73], who live near the practice [70], and who have lower literacy levels [46,52,72,73].

In the last theme, participants justified their nonuse of the system by indicating their preference for personal contact with their GP. This was attributed to the perceived advantages of personal contact over the system. This factor was found in other studies [40,51,52].

Strengths

This study enabled us to explore new factors that were not examined by the quantitative part of the study (eg, lack of awareness) and previous studies (eg, lack of trust). Furthermore, this study allowed us, to some extent, to support and explain some relationships proposed in the quantitative study (eg, performance expectancy, perceived privacy, security).

To the best of our knowledge, this study had the largest sample size in comparison with all qualitative studies on this topic. This allowed us to explore a wide range of patients' perspectives on the adoption of ePHRs.

Limitations

This study collected data from 4 GPs implementing the same ePHR (ie, SystemOnline), which may limit the generalizability of this study to other practices implementing other ePHRs (ie, Patient Access, Patient Services, The Waiting Room, Engage Consult, and Evergreen Life/i-Patient). However, it should be noted that all these systems provide the same services to the patients (ie, booking appointments, requesting prescription refills, and viewing health records), and no participant had used any of them before. As a result, the participants in this study were unlikely to have made comparisons between the different systems.

Although the qualitative data collected by an open-ended question helped in exploring factors affecting patients' use of Patient Online, such data may not be equivalent to qualitative data collected by interviews or focus groups. Thus, we could not deeply understand the adoption process of Patient Online. However, this qualitative analysis did not aim to understand in depth the phenomenon of interest; rather, it aimed only to help in identifying other factors not included in the model and explaining the findings of the quantitative study. As answering the open-ended question was voluntary, there may be an element of self-selection.

As the open-ended question was put after closed-ended questions, participants' answers to the open-ended question may be influenced by this order. This order was based on researchers' recommendations that questionnaires should start with the most interesting and easy-to-answer questions, and open-ended and demographic questions should be presented at the end of the questionnaire [74-76].

Practical Implications

We believe that adoption of GP online services will significantly increase in the future, given that many factors identified in this study will be automatically and considerably mitigated by time. Specifically, the proportion of patients who are more comfortable with the use of computers, smartphones, electronic systems, and the internet will increase in the future given their increased spread over the world. Thus, these services may be desired and expected by patients. However, developers, marketers, and GPs still play a crucial role in increasing the adoption of GP online services.

During system development, patients should be involved in the process to identify the features that make the system useful and easy to use. Some participants pointed out that the system will be useful when it allows them to book walk-in appointments, communicate with their doctors, and select the required doctor. As Patient Online currently enables patients to choose the required doctor, developers should consider adding these services, which are provided by many ePHRs (eg, MyChart, MyHealtheVet, Patient Gateway) [46,66,77]. Furthermore, users of such systems should be informed and reassured about the different security measures that are in place (eg, strong firewalls, encouragement to use complex and long passwords), and it should be made clear that the provision of GP online services is strictly controlled by legislation to safeguard personal data. To ease logging on to the system, developers should develop a system that allows patients to access it through their fingerprints or face recognitions, instead of using complex usernames and passwords. It is noteworthy that the NHS App, which has been recently developed, is the only system that enables patients to access GP online services using fingerprints or face recognitions [32].

To increase the awareness of the system, its functionality, and its benefits, marketers should improve their publicity through different channels, such as public media (eg, television, radio, newspapers, magazines), social media (eg, Facebook, Twitter, YouTube), emails, mails, automated messages on the practices' telephone system, and advertisements in general public areas (eg, shopping centers, health care settings, highway streets, universities). Face-to-face communication is considered as one of the most effective channels in marketing to persuade potential adopters to adopt an innovation [78,79]. Thus, all staff in practice (eg, physicians, nurses, receptionists) should offer the system to patients during their visits. GP staff may not be keen on publicizing online services because of a lack of incentives and time. Therefore, consideration should be given to providing incentives and resources for GPs to increase patients' awareness of GP online services.

Although patients have been recently enabled to sign up in the GP online services without visiting their surgeries through only the NHS App [80], they still need to visit their surgeries in person to register to use GP online services provided by other systems (eg, SystemOnline, Patient Access). To ease signing up in these systems, GPs should allow patients to register on web or through phone and make the signing up procedure a part of patient registration in the practice. GPs may enhance patients' perceptions of usefulness, ease of use of the system, and their trust in it by helping them in using a beta version of the system through a computer in a waiting room. GPs should provide online assistance, technical support, manuals, and training to allow patients to solve any technical issues that face them when using the system, thereby decreasing their technical concerns. GPs should collaborate with other parties (eg, Patient Online providers and government bodies) to provide computers and/or internet access at affordable prices for those who do not have them and cannot afford them. Given that many UK GPs report being overstretched and limited funding has been provided to support the rollout of GP online services, consideration should be given to providing incentive programs (eg, Meaningful Use policy as issued by the US government). Incentive programs could be used to encourage GPs to publicize their online services and encourage patients to use them.

Recommendations for Future Research

As this study could not provide a deep understanding of the adoption process of Patient Online, a deeper understanding of the adoption of online services could be gained through further qualitative work using interviews or focus groups. Several factors were revealed in this analysis but were not part of the conceptual model in the quantitative study, namely, awareness of Patient Online, lack of trust in the system, difficulty registering, disability, lack of use of GP services, and distance to the GPs. Future studies should consider adding these factors to the model and quantitatively examine them. Finally, more research is needed to identify the factors affecting the continuing use, as long-term viability and eventual success of information technology count on its continuing use more than initial use [81-83].

Conclusions

This research explored patients' perspectives regarding factors influencing their use of Patient Online. We found about 20 factors grouped into 6 themes. The findings of this study supported the findings of the quantitative study (eg, performance expectancy, effort expectancy, perceived privacy). This study found new factors that were not examined by the quantitative part of the study (eg, lack of awareness) and previous studies (eg, lack of trust).

The challenges and concerns that impede the use of Patient Online seem to be greater than the facilitators that encourage its use. To foster use, several practical implications were suggested: Patient Online should be useful, easy to use, secure, and easy to access; different channels should be used to increase the awareness of the system; and GPs should ease registration with the system and provide manuals, training sessions, and technical support. More research is needed to quantitatively assess the effect of the new factors found in this study (eg, lack of trust, difficulty registering with Patient Online) and factors affecting continuing use of the system.

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Authors' Contributions

AA and PG developed the protocol. AA collected the data. AA analyzed the data under BB’s guidance and supervision. AA and ZS drafted the manuscript, and it was revised critically for important intellectual content by all authors. All authors approved the manuscript for publication and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.
[DOCX File , 70 KB-Multimedia Appendix 1]

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Abbreviations

ePHR: electronic personal health record
GP: general practice
NHS: National Health Service
SCR: summary care record

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Original Paper

Patient Perspectives on Health Data Privacy and Implications for Adverse Drug Event Documentation and Communication: Qualitative Study

Serena S Small[1,2*], MA; Corinne M Hohl[1,2,3*], MHSc, FRCPC, MD; Ellen Balka[1,4*], PhD

[1]Centre for Clinical Epidemiology & Evaluation, Vancouver Coastal Health Research Institute, Vancouver, BC, Canada
[2]Department of Emergency Medicine, University of British Columbia, Vancouver, BC, Canada
[3]Emergency Department, Vancouver General Hospital, Vancouver, BC, Canada
[4]School of Communication, Simon Fraser University, Burnaby, BC, Canada
*all authors contributed equally

Corresponding Author:
Serena S Small, MA
Centre for Clinical Epidemiology & Evaluation
Vancouver Coastal Health Research Institute
710-828 W 10th Ave
Vancouver, BC, V5Z1M9
Canada
Phone: 1 6048754111 ext 55219
Email: serena.small@ubc.ca

Abstract

Background: Adverse drug events are unintended and harmful effects of medication use. Using existing information and communication technologies (ICTs) to increase information sharing about adverse drug events may improve patient care but can introduce concerns about data privacy.

Objective: This study aims to examine the views of patients and their caregivers about data protection when using ICTs to communicate adverse drug event information to improve patient safety.

Methods: We conducted an exploratory qualitative study. A total of 4 focus groups were held among patients who had experienced or were at risk of experiencing an adverse drug event, their family members, and their caregivers. We recruited participants through multiple avenues and iteratively analyzed the data using situational analysis.

Results: Of the 47 participants recruited, 28 attended our focus groups. We identified 3 primary themes. First, participants felt that improved information sharing about adverse drug events within their circle of care would likely improve care. Second, participants were concerned about data handling and inappropriate access but believed that the benefits of information sharing outweighed the risks of privacy breaches. Finally, participants were more concerned about data privacy in the context of stigmatized health conditions.

Conclusions: Current conditions for maintaining health data privacy are consistent with participants' preferences, despite the fact that health data are susceptible to breaches and mismanagement. Information sharing that increases patient safety may justify potential privacy risks. Greater attention to patient concerns and the effect of social and contextual concerns in the design and implementation of health information technologies may increase patient confidence in the privacy of their information.

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KEYWORDS

health information technology; adverse drug events; privacy of patient data

Introduction

Background

Adverse drug events are unintended and harmful outcomes of medication use and a leading cause of emergency department visits and unplanned hospital admissions [1-4]. More than 30% of patients presenting to hospitals with adverse drug events are affected by repeat events that occur because care providers unintentionally re-expose patients to medications that previously caused harm [5]. A lack of effective automated processes to communicate adverse drug event information between health providers and across locations of care contributes to the recurrence of these events.

Poor communication about adverse drug events reflects broader fragmentation and siloed information in health. Recent initiatives at the provincial and federal levels of the government in Canada aim to address these communication gaps. In Ontario, the Digital First for Health Strategy intends to increase the availability of patient records for frontline clinicians and reduce barriers to integration [6]. British Columbia's Digital Health Strategy seeks to modernize the health system through integration, improved care delivery, and data accessibility for clinicians and patients [7]. This includes increasing access to clinical information through end-to-end medication management using existing clinical information systems [8]. Enabling PharmaNet, British Columbia's medication dispensing database, to receive and transmit adverse drug event information may support such an undertaking.

Objectives

Enhanced communication about adverse drug events may improve patient safety but can also reveal sensitive diagnoses to a broader range of clinicians than those currently aware of them. This could introduce privacy concerns for patients, particularly among those living with stigmatized illnesses. We examined patients' perceptions about the need to share information about adverse drug events to optimize patient safety while maintaining data privacy.

Methods

Study Design

We conducted a qualitative study to explore patients' perceptions of information privacy and sharing in the context of developing software to facilitate adverse drug event documentation and communication. Research ethics boards of the University of British Columbia and Simon Fraser University reviewed and approved the protocol. All participants provided written informed consent.

Study Setting and Sample

Our target study population included adults (≥19 years) who had lived experience with or were at risk of an adverse drug event and family members and caregivers of patients who had experienced an adverse drug event. All participants lived in the Vancouver area or Whistler, British Columbia, between September 2016 and May 2017. We excluded patients who were living in long-term care facilities, did not manage their own medications, were receiving palliative care, were from out of province, or did not speak English. If we approached a patient who was excluded based on the above criteria, we attempted to recruit a family member or caregiver for participation, if they were present during recruitment.

Recruitment

We used multiple sampling strategies to recruit patients who had lived experience with an adverse drug event or who were at risk of an adverse drug event because of their age (≥65 years) or exposure to polypharmacy and the family members and caregivers of patients who had experienced an adverse drug event. We recruited in person, through posters, and through web-based advertisements.

From September to November 2016, we recruited those who were experiencing or who were at risk of experiencing an adverse drug event. Emergency department pharmacists recruited a convenience sample of patients presenting to the emergency department of Vancouver General Hospital, a tertiary care hospital in Vancouver, Canada, when completing medication reviews. We placed posters in high-traffic areas in the emergency department and at a hospital-based research center to encourage patients and their family members to contact the research team if they were interested in participating. We also sought to recruit members of the general population by posting web-based advertisements on Kijiji and Craigslist and by snowball sampling from personal connections. In recruitment advertisements, we stated that we were seeking patient opinions on having information about their medication-related problems shared among care providers. Our intent was to reach a broader range of individuals who met our target sample criteria, including those that may not have had direct contact with the acute care setting at the time of the focus groups.

From February to May 2017, we recruited individuals with stigmatized illnesses (HIV and/or substance use disorder) by placing posters at a clinic that provides care to HIV-positive women. We hypothesized that these patients may have specific privacy concerns and also because HIV medications are currently not documented in the provincial medication dispensing database, PharmaNet, in part because of privacy concerns at the time of PharmaNet's implementation [9].

Among those recruited through snowball sampling from personal connections, there was an established relationship between the researchers and participants before the study. For all others, beyond contact for recruitment purposes, there was no prior established relationship.

Data Collection

The focus groups followed a semistructured discussion guide developed collaboratively by the research team to address themes relevant to adverse drug event information sharing (Multimedia Appendix 1). The principal investigator (EB) and a research assistant (SS) with expertise in qualitative research created the first draft. Other members of the research team then revised and edited the discussion guide to offer different disciplinary perspectives.

Key themes addressed in the discussion guide were experiences with adverse drug events, knowledge of information-sharing practices, and attitudes about data privacy and privacy policy. We allowed participants to engage in open dialog and ask questions beyond the discussion guide and identify and discuss new concepts that we had not considered.

We held focus groups in a research office at the Vancouver General Hospital. The principal investigator (EB), a female social scientist with extensive experience in qualitative methods, led the focus groups, and a research assistant (SS) attended to take notes. At the beginning of each group, we introduced the researchers present and provided a brief definition of adverse drug events, including examples, providing rationale for the groups. Recruitment materials informed prospective participants that we sought to gather opinions to guide the development of a system to support sharing of information about adverse drug events among health care providers. We reiterated this at the time of the focus groups.

We gathered additional information about the participants, including demographic information, using a short debriefing survey at the conclusion of each focus group (Multimedia Appendix 2). We audio recorded the focus groups, which were then transcribed by a research assistant (SS).

Data Analysis

We coded and analyzed transcriptions using *NVivo 11* qualitative data analysis software (QSR International, version 11, 2015). We created a provisional coding frame to reflect the thematic structure and discussion guide questions. The structure of the coding frame organized participant comments conceptually along the following themes: data privacy, information sharing, awareness of privacy policy, policy preferences, experience with adverse drug events, and recommendations. We (SS and EB) iteratively coded and analyzed the data using situational analysis, a theoretical and methodological approach that examines contextual, relational, and discursive elements in the data through the concurrent creation of memos and mapping exercises [10].

Results

Focus Groups and Participant Characteristics

Of the 47 participants we recruited, 28 attended a focus group. Each focus group had 5 to 8 participants (Table 1). A total of 20 participants (20/28, 71%) were in groups A, B, and C. Of these participants, 65% (13/20) were aged above 65 years and at risk of an adverse drug event, 25% (5/20) were from the general population, and 10% (2/20) were caregivers or family members of patients with adverse drug events. Group D consisted of 8 women (8/28, 29%) recruited from a clinic serving HIV-positive women.

Table 1. Focus group composition (N=28).

Group ID	Participants, n (%)
A	8 (29)
B	7 (25)
C	5 (18)
D	8 (29)

Each focus group lasted for 120 min. Most participants (25/28, 89%) completed the debriefing survey (Table 2). Most participants were female and aged above 51 years. Many participants had lived experiences with an adverse drug event, knew someone else who had, or both. Most participants had completed at least some postsecondary education.

Table 2. Participants' characteristics (N=28).

Variable	Participants, n (%)
Gender	
Male	6 (21)
Female	19 (68)
No response	3 (11)
Age (years)	
<20	0 (0)
20-35	2 (7)
36-50	5 (18)
51-65	10 (36)
>66	8 (29)
No response	3 (11)
Experience with adverse drug events	
Yes, have lived experienced with an adverse drug event	3 (11)
Know someone who has experience with an adverse drug event	7 (25)
Both lived experience and know others who have experienced an adverse drug event	6 (21)
No, have not experienced an adverse drug event	6 (21)
Unsure	3 (11)
No response	3 (11)
Highest level of education	
Some high school	3 (11)
Completed high school	3 (11)
Some postsecondary	7 (25)
Completed college or university	7 (25)
Some graduate school	2 (7)
Master's degree	1 (4)
Doctoral degree	1 (4)
No response	4 (14)

Primary Themes

We identified 3 primary themes about information sharing and privacy in the context of adverse drug event communication. Participant quotes to support each theme are presented in the corresponding textboxes, which are representative of the findings for each theme.

Participants Believed Enhanced Information Sharing Among Clinicians Would Improve Care

Experiences With Informational Discontinuity of Care

Many participants described experiences with fragmented information sharing (Textbox 1). In some cases, participants experienced negative outcomes as a result of poor information sharing. Participant 1, for example, described how their father-in-law's experience with poor communication of an adverse drug event affected his long-term health, resulted in unnecessary costs, and emotionally affected the patient and his family. Several participants noted that in the absence of effective information-sharing processes, they took responsibility for information sharing themselves.

Textbox 1. Participant quotes about experiences with informational discontinuity of care.

- "I don't think there's a lot of communication between the doctors. Say you have a GP, you have a rheumatologist, you have an HIV specialist – you tell one doctor one thing and they say, 'oh I didn't know that, when did that start?'…So you gotta follow up yourself because he can't…they get so busy, or they forget, or they don't care or whatever." [Participant 25, group D]
- "I have been to [the] emergency department with an adverse reaction twice, and it's very busy. The doctors who see you don't have time to write your discharge report up in time for you to take a copy away with you…I would like to have further information and would like to be able to pass it on to my GP." [Participant 11, group B]
- "I think in my father-in-law's case, [the lack of information sharing] cost our system more money…there were more doctors involved…there was more angst involved…my father-in-law's condition plummeted. And there were more people involved, there was more testing done, ambulance was called ten times." [Participant 1, group A]
- "I don't think it's very well shared. If it is, it's pretty piecemeal." [Participant 3, group A]
- "I've just always heard that adverse effects are supposed to be reported…but I never had any confidence that they were." [Participant 8, group A]
- "I have learned that in many cases, the people to whom I go for one medical event or another don't always share the information." [Participant 12, group B]
- "My family doctor gets everything, but I particularly have to make a point of asking for copies to be sent to a couple of my specialist physicians." [Participant 11, group B]

Benefits of Better Communication

Participants felt that better communication between providers in their circle of care would have a positive effect on health outcomes and could improve their experience with the health system, including improved disease and medication management (Textbox 2). They suggested that communication would lessen the recall burden for patients and their families and that broader information sharing would support clinical decision making, especially in situations in which a patient would be unable to communicate or recall the required information.

Textbox 2. Participant quotes describing the benefits of better communication.

- "And then…someone who is elderly, who may have dementia, who doesn't have someone advocating for [them] – that information needs to be shared so that somebody can make sure that they're making good decisions around their health care and prescription medications." [Participant 1, group A]
- "[My father-in-law's] health would have been maintained at a higher level for a longer period of time, had the information been shared more regularly." [Participant 1, group A]
- "Yes, the more [my care providers] know [about my] medications…the better they're taking care of me." [Participant 27, group D]
- "When my mother was admitted and all they need is her care card number…all the information [is] there already, so it's a lot easier for us." [Participant 19, group C]
- "You'd think that the more information that your caregivers have…the better off you're going to be if you have a problem or if you're unconscious or whatever." [Participant 20, group C]
- "I think the more we share the information, it's a huge financial benefit…both the emotional and financial side." [Participant 7, group A]
- "…We have the language barriers, we have culture barriers, we have all of those things to deal with and it makes things very, very difficult, so another reason for having this information [available] to so many people." [Participant 3, group A]
- "My view is that I am less concerned about privacy, and more concerned about people [caring] for me having the information that they need." [Participant 8, group A]

Most Participants Preferred Electronic Information Sharing

Many participants supported the use of health information technologies to share adverse drug events and medication information (Textbox 3). Participants viewed electronic communication as quick, easy, and environmentally sustainable while also reducing the risk of lost or misplaced files. Although recognizing these advantages, participants were concerned about data security threats (eg, hackers) and system failure (eg, because of an earthquake). As a result, participants felt that clinicians should not rely exclusively on electronic information sharing and storage. Participants suggested backups to electronic information sharing, including telephone-based communications between clinicians, and electronic or paper-based backups.

Textbox 3. Participant quotes about electronic information sharing.

- “I personally would want it electronically, just because with the technology age nowadays it’s…the easiest method and the quickest method to transfer information…also it’s more eco-friendly than having all these pieces of paper that might get lost…” [Participant 18, group C]
- “I think I’d want it electronic because it is simpler, and mounds of more paper aren’t necessary…or needed.” [Participant 16, group C]
- “All I’ve gotta say is: is there an app for that?” [Participant 3, group A]
- “I don’t think we should lose the ability to ever…pick up the phone, because there are quick emergency situations that can save a life…but generally I think that electronically is the most practical.” [Participant 7, group A]
- “I’m in favour [of] electronically, but with ensured back up because you could lose everything.” [Participant 8, group A]
- “Digital is my first choice.” [Participant 14, group B]
- “There’s been breaches with confidential medical files when it comes to computers.” [Participant 21, group D]
- “I would want it electronically and [on] paper because…we live in an earthquake zone.” [Participant 17, group C]

Participants Were Concerned With Data Handling and Inappropriate Access

Participants Believed Professional Roles Should Determine Access Permissions

Participants focused on the different professional groups that would access their health information rather than the information systems that would mediate information sharing (Textbox 4).

Role-based access was a recurrent theme, and participants discussed whether access to information was pertinent to every clinical role. For example, group A agreed that pharmacists needed access to patient information but debated whether pharmacy assistants also did. Similarly, participants in groups A and D questioned whether care providers in long-term care facilities (eg, care aides) or allied health professionals (eg, physiotherapists) required full access to medical information or if they had adequate training to manage confidentiality.

Textbox 4. Participant quotes about role-based access.

- “I would say it would be ok for [my information to be shared] as long as it’s…the doctor... Say…someone on a team…like maybe a social worker of something, they might be valuable on the team, but the medication part would have absolutely nothing to do with them. So, they shouldn’t be having access to that information because they can’t do anything about it.” [Participant 21, group D]
- “When it comes to doctors and nurses…they share. But if…the definition of ‘care team’ is broader than that, then I would need to know who they were and what they were doing [with my information.]” [Participant 17, group C]
- “[Care aides are] usually wonderful people, but they don’t have the information…on how to deal with the ethics of private information. This is my experience with my mother. But yeah, it would depend who it was. I mean my physio doesn’t need to know, right?” [Participant 17, group C]
- “It’s more of a question of what is their education, what is their guidelines…Like a pharmacist…keeps everything confidential. Does the assistant?” [Participant 7, group A]
- “Maybe…the key is who gets the information [is] anybody that has to do with the prescription.” [Participant 3, group A]
- “You run into a whole hornet’s nest when you’re talking about other people getting that information, like for example insurance companies.” [Participant 12, group B]
- “[The doctors] always have [medical] students in their office, right? They come in with the doctors…So the [medical student has] your information, they’ve got everything in that conversation…And where does it go from there?” [Participant 25, group D]
- “I was just going to say that all the medical and allied health, secondary health professions, have confidentiality and privacy as a really major, serious part of their curriculum…It’s as secure as it can be given people.” [Participant 8, group A]

Participants Perceived Internal and External Threats to Their Information in Medical Facilities

Participants believed that data stored electronically in medical facilities were unlikely to be secure (Textbox 5). When asked whether they were aware of any breaches of medical information, a small number of participants said yes. At least one breach was mentioned in each group. Several said that they had heard of both clinical and administrative staff mishandling data, including improper disposal, private conversations in public spaces, and inappropriate access of records. Participants had also heard of external threats, including hacking and breaches of Canadian data by American companies; however, none had been firsthand victims of data breaches in medical facilities. Despite this awareness, most agreed that hearing about breaches did not affect their willingness to share their health data. One participant summarized this sentiment by stating that they thought the benefits of information sharing exceeded the risks of privacy breaches.

Textbox 5. Participant quotes about data security.

- “I think if someone really wanted to get [my medical information] they could get it…People within the office [of] the hospital, if they wanted to get access to it, I think they could get it. Even if they don’t have…official approvals. And, data hacking is advancing.” [Participant 17, group C]
- “I never thought of it as being that confidential…It’s on a computer and in your pharmacy, and there’s a zillion people [that] have access to it. I just accept the system the way it is.” [Participant 20, group C]
- “[Information is] only as secure as the individuals handling it.” [Participant 3, group A]
- “I don’t think pharmacies are very secure.” [Participant 15, group B]
- “There’s a lot of hackers out there that can get access to [your information].” [Participant 25, group D]
- “There’s faxes that have…gone to the wrong fax number, so there’s a breach of confidentiality there.” [Participant 21, group D]
- “And where the breaches occur are chatting down the hallway, nurses chatting in the elevator, people in the cafeteria…” [Participant 8, group A]
- “I’ve heard of…an operator throwing some CDs or…storage device in the garbage and then somebody went in the garbage and pulled it out, and there’s half a million records on there.” [Participant 3, group B]
- “I mean, there have been serious privacy breaches on record with the provincial government specifically.” [Participant 15, group B]
- “A whole stack of personal information and somebody just dumped it out in the back lane somewhere.” [Participant 14, group B]

Privacy Concerns Are Amplified When Considering Stigma and Potential Discrimination

Discussions about stigma and discrimination around health data emerged in most groups (Textbox 6). Many felt that sharing information about stigmatized illnesses, which could occur if an adverse drug event to HIV medication was recorded, should occur only within a patient’s circle of care, which is consistent with current data privacy standards. Among participants in group D (who live with stigmatized illnesses), concerns about the effects of stigma and discrimination were amplified. Previous experience with the health system that had reduced complex lived experiences with negative labels colored this group’s perception of the system. There was a relationship between trust, willingness to share health information, and stigma. One participant, for example, commented that they might withhold medical information if they did not trust their care provider or had concerns about where their information was going and who could access it. Although we sought to understand information-sharing preferences in clinical settings, several participants mentioned unprompted that their sensitive medical information should not be shared with colleagues or employers. Participants suggested ways to reduce stigma, including educating clinicians and providing information for patients during care encounters.

Textbox 6. Participant quotes about stigma and discrimination.

- “When [a care provider] comes in and [is] talking about someone’s health, you just don’t outright say ‘hey how’d you get that?’ That’s really disrespectful to a person whether they have diabetes, cancer, HIV, or Hep C, or whatever their medical situation is.” [Participant 21, group D]
- “So, depending on who’s accessing that information…that’s where stigma, discrimination comes in, because [the patient] could…end up being judged from the medication they’re on because [the care provider] knows what those medications are used for.” [Participant 21, group D]
- “I remember all the stigma around cancer when I was a child. It was like the ‘c-word’. You didn’t even call it cancer. And it’s great to see the shift now…It would be lovely if we could get that way with stuff like mental health, Hep C, HIV. You know, there’s definitely more awareness out there but unfortunately there’s…the ignorance.” [Participant 21, group D]
- “I’ll tell you right now, the honest truth about the Downtown Eastside is [care providers] don’t care about you. You’re just a number, you’re just an addict, you’re just a prostitute, you’re just a drunk…You’re not a human being…You’re just shuffled through, seen by whoever’s there [at the clinic] …They don’t [have] your files.” [Participant 28, group D]
- “There was the case of the woman refused entry into the US because she was on anti-depressants.” [Participant 17, group C]
- “I have a mental illness…if I’m a danger to myself or to others, and I’m not taking my meds…then yes, my diagnosis along with my meds need to be passed on to somebody…if I’m stable, then just my medication [information should be shared].” [Participant 4, group A]
- “You know, [doctors] want you to tell them everything…but I don’t want to tell you [doctors] this part, because I don’t trust you guys.” [Participant 25, group D]
- “I just feel…the students…or the…residents, they need to be better educated on…bedside manners.” [Participant 21, group D]
- “I do see more often that…the confidentiality blurbs are out there more often when you’re signing things, [saying] this is how we protect information. That never used to be out there, so I think there is more awareness out there, but I think it needs to continue, like even…ramp it up. And not [allow] people [to] get…complacent about it.” [Participant 21, group D]

Discussion

Principal Findings

We explored patients' perceptions about information privacy and sharing in the context of developing a health information technology that will enable electronic documentation and automated communication of adverse drug event information between providers and across care settings. Most participants supported improved information sharing about adverse drug events, expected technologies, and clinicians to protect their privacy and understood that a lack of information sharing could pose a greater risk to their safety than potential threats to privacy. In the following sections, we explore how existing organizational and institutional measures to protect data privacy are consistent with participant expectations.

Privacy legislation provides a framework for data management. In British Columbia, the Freedom of Information and Protection of Privacy Act (FIPPA) governs the collection, use, and dissemination of personal information by public entities, including health authorities and hospitals. Under FIPPA, public entities must enact and enforce security measures to prevent unauthorized collection, use, access, disclosure, and disposal of personal information. Public entities such as hospitals and clinics must notify individuals that their information is being collected and used but do not require patient consent to share patient information with other members of the care team [11]. Our study participants' privacy preferences were consistent with these legislative requirements: participants were favorable toward information sharing among clinicians but were wary of giving access to those outside their circle of care (eg, an insurance company) or among those within the circle of care for whom information about an adverse drug event is irrelevant to their role (eg, a physiotherapist). A system that supports adverse drug event data sharing among a patient's circle of care must minimize the barriers to effective communication and should not require additional patient consent.

Improvement in communication about adverse drug events may be achieved by leveraging existing health information technologies, such as PharmaNet. PharmaNet employs numerous data management safeguards, including physical security (eg, limited access to equipment), operating system security (eg, user access keys), network security (eg, firewall), and screen security (eg, only certain items viewable based on each user's security profile) [12]. It also adheres to the principles of role-based access, wherein different user groups have different access permissions, which was strongly preferred among participants. In addition, individuals can find out when their record is accessed and those with further privacy concerns can add a password to their PharmaNet profile, allowing them to determine who can or cannot view their profile. This is valuable for individuals living with stigmatized illnesses.

Despite the privacy measures implemented in health information technologies, security under real-world conditions is more volatile. Breaches of health data have been a recurrent focus of media attention and critique, including incidents involving PharmaNet. In 2014, for example, approximately 1600 profiles were compromised by an unknown, unauthorized individual using a doctor's account [13]. In 2017, more than 20,000 profiles were breached [14]. These breaches exemplify our participants' concerns and demonstrate the challenge of managing the risks associated with privacy breaches while ensuring that data are accessible in the interest of patient care. Following these events and other privacy concerns, the provincial Ministry of Health introduced a new project to support user management for PharmaNet, which will streamline access approval when implemented [15].

In addition to legislative frameworks, concerns about handling sensitive health information can be addressed in the design of systems by implementing role-based access functionality, building complex password requirements, and regularly auditing use and users. Participants' concerns regarding threats to data security among staff in medical facilities can be addressed through other nontechnical approaches. Implementation should incorporate education that addresses safe information handling, including proper methods of sharing data and disposing of paper records, and strategies for maintaining the security of log-in credentials. These measures may increase clinicians' ability to maintain the security of information in their custody while increasing patients' confidence in the privacy of their information and in the efficacy of information sharing in health.

Limitations

Sample composition is the primary limitation of this study. Participant self-selection and recruitment from an urban area may have introduced selection bias. More women participated than men. Participants in rural regions, men, and those with other health trajectories or access points within the health system may have different experiences in the health sector that are not reflected. As such, our findings may not translate to other regions, populations, and health conditions. In addition, we did not screen participants who volunteered via classified websites (n=5) to determine whether they met the defined sample criteria (ie, at risk of or experienced an adverse drug event or a family member or caregiver). Therefore, we cannot verify whether all responses are representative of these sample criteria.

Conclusions

Participants were generally supportive of enhanced informational continuity of care about adverse drug events to facilitate care delivery. The belief that enhanced information sharing would improve care and that a lack of information sharing poses safety risks indicates patient support for broader use of information and communication technologies (ICTs) in health. Privacy considerations were important to participants but largely in the context of the human actors handling the data rather than the electronic systems that mediate information transfer. Fears about stigma and discrimination were prominent drivers, particularly among patients who had experienced stigmatization. Our findings suggest the need to consider the ways that social and contextual factors (eg, living with a stigmatized illness) that affect patient privacy can be addressed at both the human and technical levels in the design and implementation of ICTs in health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Discussion guide.
[DOCX File , 21 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Follow-up survey.
[DOCX File , 20 KB-Multimedia Appendix 2]

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Abbreviations

FIPPA: Freedom of Information and Protection of Privacy Act
ICT: information and communication technology

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Review

Implementation of Telehealth Services to Assess, Monitor, and Treat Neurodevelopmental Disorders: Systematic Review

Althea Z Valentine[1], BSc, MSc, PhD; Sophie S Hall[2], PhD; Emma Young[3], MSc; Beverley J Brown[1], PhD; Madeleine J Groom[1], PhD; Chris Hollis[1,4,5], PhD; Charlotte L Hall[1], PhD

[1]Institute of Mental Health, School of Medicine, Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom

[2]Department of Neuroscience, Psychology and Behaviour, University of Leicester, Centre for Medicine, Leicester, United Kingdom

[3]Nottinghamshire Healthcare National Health Service Foundation Trust, Library and Knowledge Services, Duncan Macmillan House Staff Library, Nottingham, United Kingdom

[4]National Institute for Health Research MindTech MedTech Co-operative, Institute of Mental Health, School of Medicine, Division of Psychiatry and Applied Psychology, University of Nottingham, Nottingham, United Kingdom

[5]Department of Child and Adolescent Psychiatry, Queen's Medical Centre, Nottingham, United Kingdom

Corresponding Author:
Althea Z Valentine, BSc, MSc, PhD
Institute of Mental Health
School of Medicine, Division of Psychiatry and Applied Psychology
University of Nottingham
Triumph Road
Nottingham, NG7 2TU
United Kingdom
Phone: 44 01157484249
Email: althea.valentine@nottingham.ac.uk

Abstract

Background: In response to COVID-19, there has been increasing momentum in telehealth development and delivery. To assess the anticipated exponential growth in telehealth, it is important to accurately capture how telehealth has been used in specific mental health fields prior to the pandemic.

Objective: This systematic review aimed to highlight how telehealth has been used with clinical samples in the neurodevelopmental field, including patients with neurodevelopmental disorders (NDDs), their families, and health care professionals. To identify which technologies show the greatest potential for implementation into health services, we evaluated technologies for effectiveness, economic impact, and readiness for clinical adoption.

Methods: A systematic search of literature was undertaken in April 2018 and updated until December 2019, by using the Medline, Web of Science, Scopus, CINAHL Plus, EMBASE, and PsycInfo databases. Extracted data included the type of technology, how the technology was used (ie, assessment, treatment, and monitoring), participant characteristics, reported outcomes and authors' views on clinical effectiveness, user impact (ie, feasibility and acceptability), economic impact, and readiness for clinic adoption. A quality review of the research was performed in accordance with the Oxford Centre for Evidence-Based Medicine Levels of Evidence.

Results: A total of 42 studies met the inclusion criteria. These studies included participants and family members with autism spectrum disorders (21/42, 50%), attention deficit hyperactivity disorders (8/42, 19%), attention deficit hyperactivity or autism spectrum disorders (3/42, 7%), communication disorders (7/42, 17%), and tic disorders (2/42, 5%). The focus of most studies (33/42, 79%) was on treatment, rather than assessment (4/42, 10%) or monitoring (5/42, 12%). Telehealth services demonstrated promise for being clinically effective, predominantly in relation to diagnosing and monitoring NDDs. In terms of NDD treatment, telehealth services were usually equivalent to control groups. There was some evidence of positive user and economic impacts, including increased service delivery efficiency (eg, increased treatment availability and decreased waiting times). However, these factors were not widely recorded across the studies. Telehealth was demonstrated to be cost-effective in the few studies that considered cost-effectiveness. Study quality varied, as many studies had small sample sizes and inadequate control groups. Of the 42 studies, only 11 (26%) were randomized controlled trials, 12 (29%) were case studies or case series, 6 (14%) were qualitative studies, and 5 (12%) were noncomparative trials.

Conclusions: Telehealth has the potential to increase treatment availability, decrease diagnosis waiting times, and aid in NDD monitoring. Further research with more robust and adequately powered study designs that consider cost-effectiveness and increased efficiency is needed. This systematic review highlights the extent of telehealth technology use prior to the COVID-19 pandemic and the movement for investing in remote access to treatments.

Trial Registration: PROSPERO International Prospective Register of Systematic Reviews CRD42018091156; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42018091156

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KEYWORDS

neurodevelopmental disorders; technology; telehealth; review; COVID-19; implement; effective; mental health

Introduction

Background

Neurodevelopmental disorders (NDDs) are lifelong disorders that typically develop during the early stages of child development and have a high frequency of co-occurrence [1,2]. In this systematic review, NDDs are defined in accordance with the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition criteria [3], and include autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), intellectual disability, communication disorders, specific learning disorder, motor disorders, stereotypical movement disorder, and tic disorders. Young people with NDDs have been identified as particularly vulnerable to the mental health impacts of COVID-19, due to changes in support and routine and increased isolation and loneliness [4,5].

Prior to the COVID-19 pandemic, telehealth interventions were attracting interest as effective options for improving mental health provision in overstretched health services. The COVID-19 pandemic has increased the demand for effective mental health support, and the growing need to offer easy-to-access remote service availability [4,6,7] has substantially increased telehealth use [8]. It is therefore essential that we not only identify which existing telehealth technologies show the greatest efficacy for use with individuals with NDDs, but also capture the state of the existing evidence base in order to evaluate the inevitable growth of this field.

Prior Work

There is no universally agreed upon definition for telehealth [9]. In this systematic review, we use the term “telehealth” to encompass telemedicine, telemental health, and telepsychiatry.

In a systematic review of the use of telehealth services for communication disorders, Molini-Avejonas and colleagues [10] found that over 85% (88/103) of telehealth studies reported the advantages that telehealth has over nontelehealth approaches. For example, Molini-Avejonas and colleagues [10] reported that telehealth is typically viewed favorably by users and health care practitioners, as telehealth helps to reduce geographical barriers and possibly save time during consultations and travel. However, barriers to telehealth implementation have been identified. These barriers relate to training, technology issues, and acceptance by both health care practitioners and patients [10]. Indeed, a study that explored the views of health care practitioners (ie, neurologists) toward digital devices in clinical practice found that while the majority (95%) of the 405 participants used computers regularly at work, less than half (43.5%) used a tablet [11]. This suggests that one of the barriers to the uptake of technology may be acceptance from health care professionals.

Sutherland and colleagues [12] have also updated a systematic review [13] of telehealth literature on participants with ASD. During 2010-2016, 14 studies with a total of 284 ASD participants assessed telehealth services, including assessments, interventions, functional behavioral analyses, and language therapy. These studies included a variety of controls, including comparisons between telehealth and face-to-face sessions (6/14, 43%), online learning with and without telehealth sessions (6/14, 43%), and telehealth services that provided no intervention and those that provided treatment as usual (2/14, 14%). Although these studies varied in quality, telehealth services were comparable to face-to-face services and better than control/comparison groups in experimental studies. Another systematic review found that telehealth systems have been used to deliver education to parents and support the diagnosis and treatment of ASD [14].

In terms of ADHD, only 1 systematic review has focused on the use of telehealth. This review found 11 articles, which all reported data from 3 trials that were conducted in 2007-2017 [15]. The majority (10/11, 91%) of studies used a sample of children. Telehealth was viewed favorably, as it was well accepted by health care professionals and users and shown to provide improved outcomes, such as reduced symptomology and improved functioning. However, the authors concluded that further research was necessary to assess the usefulness of telehealth in health care delivery [15]. This review highlighted a lack of research on using telehealth to replace usual treatment rather than augment usual treatment, and a lack of studies that consider the assessment, diagnosis, and treatment of adults with ADHD.

Although condition-specific systematic reviews have been conducted, no single review has assessed the use of telehealth across people with different NDDs. This is important, given the prevalence of NDD comorbidities. Many previous reviews have also been limited to trials. Although trials are important, user feedback, economic impact, and readiness for clinical adoption are important for rapidly developing policies for implementing telehealth services after the COVID-19 pandemic.

The Goal of This Study

The aim of this systematic review was to highlight how telehealth has been used, prior to the COVID-19 pandemic, with clinical samples within the neurodevelopmental field, including patients with NDD, their families, and health care professionals. In light of the post-COVID-19 pandemic call for implementing the rapid adoption of telehealth into clinical practice [16], this systematic review focused on studies that reported on the clinical/service effectiveness, economic impact, and user impact (ie, feasibility/acceptability) of telehealth to aid in assessment, diagnosis, monitoring, and treatment. This review serves to identify potentially effective telehealth technologies for use with patients with NDDs and document the evidence base prior to the anticipated rapid expansion of telehealth in the neurodevelopmental field.

Methods

Study Design

This systematic review was part of a larger review [17], which assessed all technology that has been used for NDDs. The protocol for our main review was registered with PROSPERO (CRD42018091156). Given the vast number of obtained papers that related to telehealth, it was most appropriate to present these in a stand-alone article. The literature search was undertaken in accordance with the recommended principles in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [18].

Search Strategy

A systematic search of literature was undertaken by an information specialist (EY) using the following databases: Medline, Web of Science, Scopus, CINAHL Plus, EMBASE, and PsycInfo. Searches were also performed in the Cochrane Library, Journal of Medical Internet Research, Institute of Electrical and Electronics Engineers, and Association for Computing Machinery Digital Library databases. The search included all terms that related to NDDs and telehealth, including controlled vocabulary headings such as “Intellectual Disability,” “Mentally Disabled Persons,” “Learning disorders,” “Developmental Disabilities,” “Neurodevelopmental Disorders,” and “Telemedicine.” Keywords and synonyms that related to all NDDs, including “ASD,” “ADHD,” “Tic Disorders,” “Communication and Language Disorders,” “Learning Disorders,” and “Learning Disabilities,” were also used for the search. Terms that related to telehealth included keywords, such as “tele care,” “tele coaching,” “telecomm,” “teleconference,” “teleconsultation,” “telehealth,” and “telemanagement,” as well as terms that related to teletherapy, telepractice, and eHealth. As this study was part of a wider search of all technologies, additional terms that related to various technologies, such as mobile apps, video games, virtual reality, and robotics, were also included. However, the results of the search for these terms are presented in another study [17]. A copy of the Medline search strategy is included in Multimedia Appendix 1. Endnote software (Clarivate) and Microsoft Excel were used to manage the data. The initial search was restricted to published, peer-reviewed, academic papers written in English, and was conducted in March/April 2018 and recently updated in July 2020 to cover the period of January 2014 to December 2019. The World Health Organization has acknowledged December 2019 as the month that the first case of COVID-19 was officially recorded [19].

PICOS (population, intervention, comparison, outcome, study design) guidelines were used to define the inclusion criteria. With regard to population, we included studies that involved people with NDDs or parents, carers, or health care professionals who worked with people with NDDs. With regard to intervention, we included studies that clinically used telehealth equipment in the assessment, diagnosis, monitoring, or treatment of NDDs. No restrictions on comparisons were put in place for literature. With regard to outcomes, included studies were to have at least 1 outcome of interest from clinical effectiveness, economic impact, and user impact. Based on the National Institute of Clinical Excellence glossary, the following terms were referred to in the search: (1) “clinical effectiveness,” which refers to how beneficial telehealth was in terms of assessment, monitoring, or treatment compared to usual care, a control group, or another type of care; (2) “economic impact,” which refers to the evaluation of service delivery efficiencies (eg, whether an intervention reduces clinician time), as well as any economic evaluation (eg, cost-effectiveness or costs and benefits evaluations) of telehealth; and (3) “user impact,” which refers to the feasibility of using telehealth in terms of technical feasibility (ie, how simple or difficult it was to use telehealth services) and the administrative infrastructure (ie, how the technology fits within an organization). Usability impact also covered design factors that affect the user experience and users’ acceptability of the technology (ie, users’ willingness to attend and engage with the technology). With regard to study types, we excluded systematic reviews and meta-analyses.

Studies on telehealth were restricted to those that used synchronous (ie, real-time) remote clinical care in relation to the diagnosis, monitoring, or treatment of an NDD. Although studies that involved both audio and video communication were included, studies that provided care via only a telephone were excluded. Studies were also excluded if they used asynchronous (ie, nonreal-time) data, including email communications between patients and health care practitioners, physiological data (eg, electroencephalogram data) that were remotely interpreted, and data regarding telehealth services that were delivered solely in educational/employment settings, such as schools or vocational training centers. In addition, studies were excluded if they did not involve an NDD clinical sample or if they focused on lifestyle interventions (eg, obesity management rather than NDD treatment).

Data Extraction and Quality Assessment

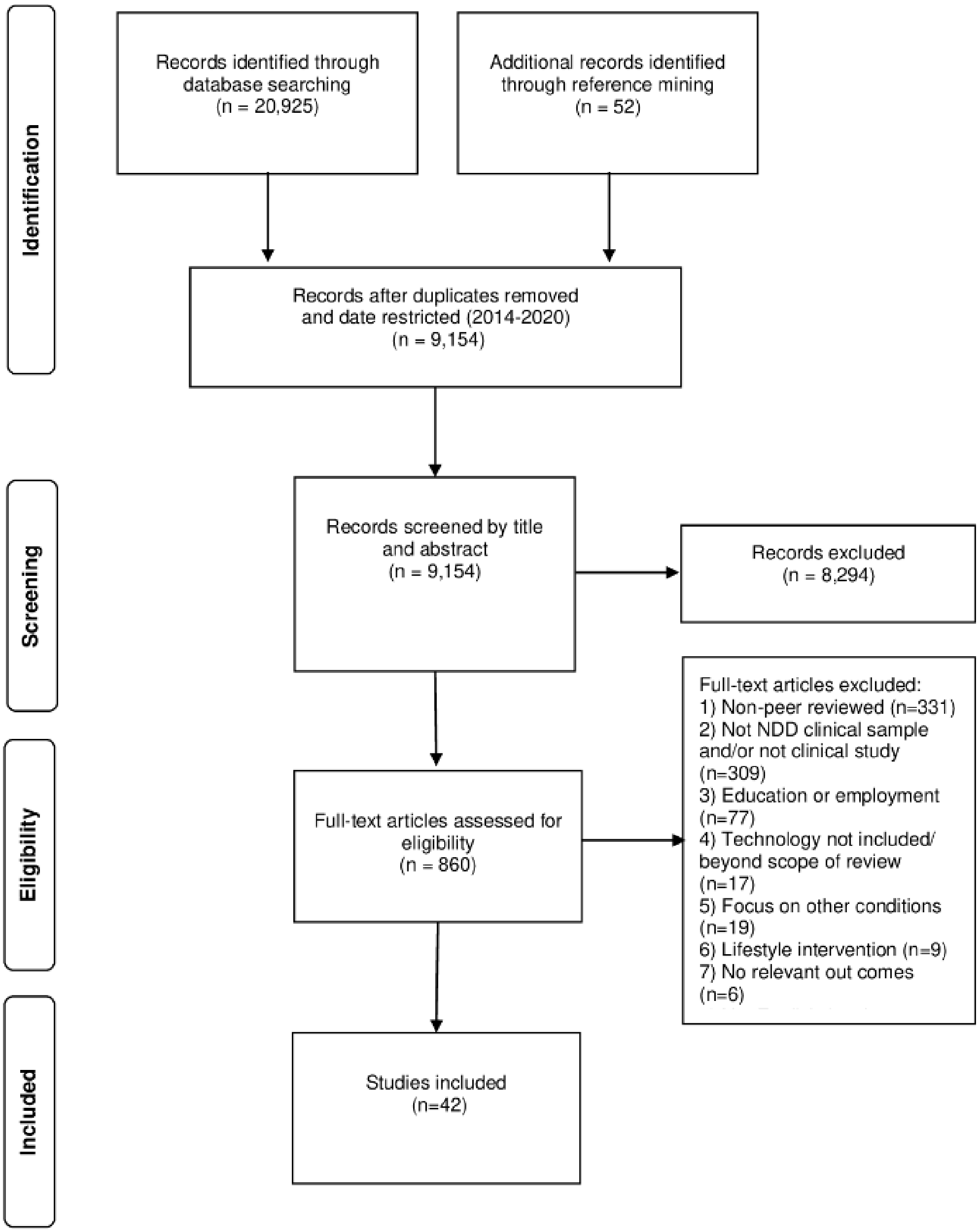
Titles and abstracts were reviewed for initial screening, and excluded papers were further independently screened. Two authors (AZV and CLH) independently reviewed full texts and extracted data by using an Excel database. Extracted data included authors and the year of publication; brief summaries of the study design, including the type of telehealth used and study methods; how the technology was used (ie, assessment, treatment, or monitoring); and information on participant samples, including the number of participants in a sample, health condition, gender, population type (ie, parent, clinician, or children/young people populations), and age (ie, if children were studied). The relevant outcomes that related to the authors' views on clinical effectiveness, user impact, economic impact, and readiness for clinic adoption were also noted. Results were synthesized in tabulated form (Multimedia Appendix 2).

A quality review of the research was also conducted. Papers were appraised by 3 authors (CLH, SSH, and BJB) based on the Oxford Centre for Evidence-Based Medicine Levels of Evidence. Each paper was rated with a score of 1-5; randomized controlled trials (RCTs) were typically ranked high (score=1) and qualitative papers/judgments were typically ranked low (score=5). Throughout the paper, this score is referred to as a quality rating (QR) [20]. Disagreements were resolved through discussion.

Results

The process of identifying and selecting studies is outlined in a flow diagram (Figure 1), and a summary of the included papers is presented in Multimedia Appendix 2.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2009 flow diagram depicting the study selection process.



Study Characteristics

A total of 42 studies met the inclusion criteria. The greatest number of studies were conducted on ASD (22/42, 52%) and ADHD (8/42, 19%). Studies on communication disorders (7/42, 17%), and tic disorders (2/42, 5%) were the least represented. Additionally, 3 (7%) studies used a sample of participants with ADHD, ASD, or both. Of the 42 papers, 23 (55%) reported a wide range of additional diagnoses, such as another coexisting NDD (10/23, 43%), oppositional defiant disorder (7/23, 30%), and anxiety (4/23, 17%), and 19 (45%) studies did not report any comorbidities. Most studies (29/42, 69%) reported data from children's parents/carers. Of these 29 studies, 22 (76%) included children aged <7 years, 3 (10%) included adult telehealth service users, and 7 (30%) documented the perspective of health care professionals. Approximately half (20/42, 48%) of all papers reported on data from a male or predominantly male sample. However, in parent/carer studies, the primary caregiver was more likely to be female. Most studies were conducted in the United States (27/42, 64%), Australasia (7/42, 17%) and Europe (6/42, 14%). Studies typically focused on treatment (33/42, 79%), rather than monitoring (5/42, 12%) or assessment (4/42, 10%).

Outcomes of interest

Assessment

Summary of Assessment Papers

We found 4 papers that focused on the assessment of NDDs. Of these 4 papers, 3 (75%) used telehealth to remotely diagnose ASD [21-23] and 1 (25%) assessed the objective measurement of hyperactivity in patients diagnosed with ADHD [24]. All ASD studies involved parents and children under 6 years of age. The ADHD study involved children and young people aged 6-16 years. All studies had ≤65 participants (range 17-65; Multimedia Appendix 2). Of the 4 papers, 3 (75%) had a QR of 2 [22] or 3 [23,24], and 1 (25%) [21] had the lowest QR of 5.

Clinical Effectiveness

The Wehrmann and Müller [24] pilot non-RCT used webcam footage to create a video-activity score to measure physical activity as an objective assessment of hyperactivity in children with suspected ADHD. The video-activity score did not show criterion validity with clinicians’ or parents’ hyperactivity ratings.

The findings from the ASD studies were more favorable. Reese and colleagues [22], who reported preliminary RCT findings on which families were assigned to in-clinic or telehealth evaluations, found that families could be coached to complete ASD assessment activities with young children via videoconferencing and clinicians could make accurate diagnoses remotely. Similarly, Juarez et al [21] reported on 2 studies, of which 1 compared a telediagnosis to a face-to-face assessment. This study demonstrated that, compared to gold-standard tools, remote ASD diagnostic consultations resulted in clinicians correctly diagnosing 78.9% (15/19) of children. No children were inaccurately diagnosed with ASD. Stainbrook and colleagues [23] investigated referrals before and after the introduction of a telehealth service. They found that implementing a diagnostic consultation service for ASD, in partnership with an early intervention service, increased referrals for diagnostic evaluation and the likelihood of families attending appointments. Following referral, 56 (89%) of the 63 families chose to receive further appointments via telehealth services rather than face-to-face services, and families with complex problems were the most likely to access clinic services.

User Impact, Feasibility, and Acceptability

In a second qualitative feasibility study, Juarez and colleagues [21] reported positive user feedback from both health care professionals and families. Families from rural areas reported geographical and time barriers to accessing traditional health care. These barriers were reduced with remote diagnoses, leading to high levels of satisfaction. Stainbrook and colleagues [23] found that families were more likely to attend telehealth appointments. Following referral, 56 (89%) of the 63 families chose to receive appointments via telehealth services rather than face-to-face services, and families with complex problems were the most likely to access clinic services.

Service Delivery Efficiencies and Economic Impact

Stainbrook and colleagues [23] were the only authors to document service delivery efficiencies. They reported that implementing a telehealth service reduced the time to diagnosis by 11-12 months.

Readiness for Clinic Adoption

Despite the effectiveness and positive user impact of telehealth in the assessment of ASD, the studies all had a small sample size. Of the 3 ASD papers, 1 (33%) did not report on suitability for implementation [23] and 2 (67%) stated that further research is necessary [21,22]. The ADHD assessment paper [24] reported negative findings and concluded that telehealth assessments for ADHD were not suitable for implementation. As such, prior to the COVID-19 pandemic, there were no telehealth technologies that were reported to be efficacious in assessing NDDs and suitable for immediate adoption in practice.

Monitoring

Summary of Monitoring Papers

We found 5 articles that reported on a sample of children with ADHD and their families. All papers were based on the CATTS (Children’s ADHD Telemental Health Treatment Study) [25]. We found an RCT that assessed the effectiveness of a telehealth service for children with ADHD, which included pharmacological treatment monitoring and caregiver behavior training/psychoeducation. The RCT study compared families who received augmented treatment as usual, which involved only 1 telehealth consultation, to families who received 6 telehealth sessions, which were conducted approximately 1 month apart. The papers were generally highly rated (QR=2), and the main study was an RCT. Secondary papers looked at caregiver outcomes [26,27] and health care professionals’ decisions on medication changes [28]. The remaining paper received a low QR (QR=5) because of the qualitative nature of the report, which focused on caregiver satisfaction and engagement, and health care professional fidelity [29]. Although not all studies were directly related to monitoring, they were collated together to allow the reader to understand that data were from multiple articles that related to the same trial. We found 4 studies that were based on the main trial’s dataset, which included 223 families of children with ADHD aged 5-12 years and their carers [25]. The remaining study [27] involved a subsample of 37 participants.

Clinical Effectiveness

Overall, both methods of telehealth delivery resulted in reductions in ADHD and oppositional defiant disorder behaviors and improvements in role performance and impairment, with the telehealth model generally resulting in better outcomes [25] and better parental mental health [26] than face-to-face models.

In a feasibility trial of a subsample of families, Tse and colleagues [27] assessed the outcomes from baseline to 25 weeks and found similar outcomes for child ADHD behaviors. However, they also found that parents who used telehealth services had considerably less improvement in caregiver strain and empowerment than those who received face-to-face training.

User Impact, Feasibility, and Acceptability

High levels of engagement and satisfaction were reported by parents [27,29]. Rockhill et al [28] reported that fidelity was not impacted by telehealth delivery. The authors argued that telehealth provides added value in terms of increasing treat-to-target goals and offering support to health care professionals.

Service Delivery Efficiencies and Economic Impact

Service delivery efficiencies and economic impact were not reported in any monitoring papers.

Readiness for Clinic Adoption

Myers and colleagues [25] provided clinical guidance regarding the use of telehealth in treating children with ADHD, and the results from the RCT were promising. Further research is recommended in the development of the CATTS trial, including research that involves the greater use of teachers in interventions and objective school outcome measures, such as the completion of homework and behavioral observations, to further validate the tool. Tse and colleagues [27] concluded that telehealth delivery was promising in terms of readiness for clinic adoption, but telehealth for caregivers' distress needed further study, including the investigation of the best delivery modality. Future research on the cost benefits of telehealth models of care for ADHD was also recommended. These findings indicated promise in the implementation of technologies for monitoring ADHD.

Treatment

We found 33 papers that reported on the use of telehealth technologies to treat NDDs. The majority of the papers focused on ASD (18/33, 55%). Other reported conditions were ADHD with or without ASD (5/33, 15%), communication disorders (7/33, 21%), tic disorders (2/33, 6%) and learning disabilities (1/33, 3%). Due to the volume of treatment papers, each condition will be considered in turn.

ASD

Summary of ASD Treatment Papers

In terms of ASD, 1 paper presented a case report of a 16-year-old male with Asperger syndrome, social isolation, and depression. Clarke [30] reported that communicating via telehealth allowed a clinician to develop a relationship with a young person who was later able to attend a clinic in person and reconnect with his family. The remaining papers (17/18, 94%) focused on some aspect of parent training. Of these 17 papers, 6 (35%) reported on providing telehealth-delivered functional analysis and communication training to parents [31-36], and 1 (6%) reported on using telehealth-delivered functional analysis to train a health care professional [37]. These studies mainly consisted of case studies or case series (6/7, 86%) that used a multiple baseline experimental design and had a QR of 3 [35] or 4 [31,32,34,36,37]. Another paper (1/7, 14%) reexamined 2 nonresponding participants' data from an RCT (QR=4) [33].

We found 4 studies on 4 programs that incorporated self-directed online learning with remote therapy, support, or coaching [38-41]. These included studies on ImPACT Online Communication Training [38,39], which evaluated the feasibility (QR=4) and clinical efficacy (QR=3) of the ImPACT Online program in addressing social communication development, and a noncomparative feasibility study (QR=4) on OASIS ABA (Online and Applied System for Intervention Skills Applied Behavior Analysis)–based parent training [40]. Another program, which involved reciprocal imitation training, was used in a single-subject multiple-baseline design study (QR=4) [41].

In a noncomparative trial that gathered data from before and after intervention (QR=4), Little and colleagues [42] studied occupational-based coaching via telehealth for increasing positive interactions and everyday routines. This included an evaluation of acceptability/cost [43] and a linked qualitative (QR=5) appraisal of parents' perceptions [44]. The remaining programs were the Sunny Starts parent training program for increasing sociocommunicative behavior, which was used in a case series with multiple baseline experimental data (QR=4) [45]; the RUBI-PT (Research Unit on Behavioral Interventions-Parent Training) program, which was developed by the Research Unit on Behavioral Interventions Autism Network and targeted behaviors such as aggression and tantrums in children with ASD; benchmarking, which was used in a trial that compared the data of new services to data from previously published clinical trials (QR= 4) to evaluate effectiveness (eg, reduction in disruptive behavior), feasibility, and acceptability [46]; and parent coaching with a focus on educating parents about effective approaches for children with ASD (eg, social narratives and visual schedules), which was used in a qualitative paper (QR=5) [47].

Clinical Effectiveness

The majority of the ASD papers reported that treatment was clinically effective in improving caregiver knowledge, caregiver competence, and child participation (6/18, 33%) [38-42,45], increasing communication responses (2/18, 11%) [34,45], and reducing problem behaviors (5/18, 28%) [31,32,35-37]. We found 1 (5%) paper [33] that discussed 2 young children with ASD who underwent functional communication training, but this was unsuccessful in reducing problem behaviors. The authors suggested that although not all patients can be treated via telehealth, if sessions are recorded, watching the recordings can lead to the identification of the reason why treatment was not successful. Ingersoll and colleagues [39] noted that both online self-directed training and therapist-assisted, parent-mediated telehealth intervention led to improvements in fidelity, self-efficacy, stress, and parents' perceptions of their child, and that families who received therapist coaching and support gained improved social skills.

User Impact, Feasibility, and Acceptability

High levels of engagement and satisfaction were reported by parents [40,43,46]. However, difficulties surrounding failing technology and incomplete personal interaction were also documented [44,47]. Ingersoll and colleagues [38] found that parental engagement and satisfaction were similar for both self-directed and therapist-assisted methods of telehealth delivery. However, having a therapist increased engagement and led to higher rates of telehealth service completion. Parents often engaged with the program (ie, without therapist support) outside of traditional working hours, which allowed for greater flexibility than in face-to-face coaching.

In a qualitative study, Ashburner et al [47] explored the perceived advantages and disadvantages of a follow-up early intervention service that was delivered via remote technology, by comparing the service to previous face-to-face services. Content analysis showed that parents, service providers, and the ASD specialist perceived remote technologies to be helpful in upskilling parents/service providers and enabling families to access support from home. However, all study participants agreed that remote technology should be used to augment, rather than replace, face-to-face contact, which is similar to the findings reported by Little et al [43].

The use of telehealth for training health care professionals was also shown to be a promising way of providing support to practitioners in the field, which led to the greater implementation of target strategies [37].

Service Delivery Efficiencies and Economic Impact

Suess and colleagues [32] reported on telehealth service delivery efficiencies and argued that in some cases, brief, efficient telehealth appointments bypasses the need for further in-clinic support and allows for quicker treatment initiation. Several authors [40,41,47] suggested that telehealth has the potential to increase access to ASD services (ie, particularly in remote areas) and reduce costs, time, and travel. Lingren et al [35] compared the costs of therapy for caregivers of children with ASD between different telehealth models, including in-home telehealth, regional clinic telehealth, and in-home, face-to-face telehealth models. The costs were lowest for the in-home telehealth model, but the in-home and in-home, face-to-face telehealth models were substantially less costly than the costs for face-to-face in-home therapy. Similarly, in a study that involved a 12-week telehealth intervention for families with a child with ASD, the authors reported that the costs for both outpatient and in-home care models were approximately 2.6 times more expensive than the costs for telehealth models [43].

ADHD

Summary of ADHD Treatment Papers

We found 5 treatment papers from the ADHD sample that included patients with ADHD and patients with ASD. The highest quality paper (ie, a small RCT with a QR of 2) compared patients who underwent internet-based cognitive behavioral therapy based on the InFocus program (ie, with/without therapist support) to those in the waitlist control [48]. The other papers were of much lower in quality. We found 1 experimental pilot study (QR=5) that used a nonrandomized pre-post intervention study design to assess the feasibility and acceptability of a parenting group training program delivered via telehealth [49]. Additionally, Sehlin and colleagues [50] provided qualitative data (QR=5) for a study that involved a face-to-face meeting that was followed by 8 weeks of internet-based chat sessions for providing coaching and support. Another qualitative paper (QR=5) conducted implementation interviews with health care professionals after providing coaching and support at 3 trial sites in Sweden [51]. The final paper used a multiple descriptive case design (QR=4) to assess caregiver perspectives in a sample of 10 caregivers of young people with ADHD or ASD who took part in an internet-based intervention [52].

Clinical Effectiveness

In general, clinical effectiveness was unclear or not reported (3/5, 60%) [50-52], and all studies were limited by small sample sizes (range 7-45). We found 2 group therapy telehealth programs that showed great promise. A study [48] found that an internet-based cognitive behavioral therapy telehealth treatment program, which included weekly online group therapy sessions for adults with ADHD, was no more clinically effective than unsupported self-help alone. However, people in both programs faired better than those in the waiting list controls. The second group therapy program showed a trend of improvement in child ADHD symptoms following a group parenting intervention, but the program was not adequately powered [49].

User Impact, Feasibility, and Acceptability

Sehlin et al [50] found that although remote coaching was perceived favorably by participants, difficulties surrounded failing technology and incomplete personal interaction were reported. Shah and colleagues [49] also reported that clinicians experienced difficulties with internet connections and found it hard to read body language and expressions, as faces were sometimes out of focus during video appointments. They also reported that patients experienced disturbances from other family members, and that the inability to role play during telehealth appointments was problematic. However, parents were at ease and relaxed during telehealth appointments.

Gillberg and Wentz [51] assessed professionals' perceptions on internet-based support and coaching and the barriers and facilitators to implementation. Facilitators of positive perceptions included improved access, equality distribution, and the delivery/quality of health care services. Reported barriers included the design of the intervention, technical issues, attitudes of staff, organizational culture and structure, and work division and resource allocation.

Service Delivery Efficiencies and Economic Impact

Most studies (4/5, 80%) did not report the economic impact. However, cost-savings in terms of time and travel were noted in 1 (20%) study [49].

Other NNDs (ie, Communication Disorders, Tic Disorders, and Learning Disabilities)

Summary of Other Treatment Papers

Treatment programs for communication disorders (eg, stuttering) were evaluated in 7 papers. A noncomparative trial (QR=4) investigated the Camperdown Program, which was used to reduce stuttering in adolescents [53]. The remaining papers assessed the Lidcombe program for preschoolers. With regard to the Lidcombe program, we found 1 RCT (QR=2) that compared telehealth care delivery to in-clinic, face-to-face care delivery [54], and 1 study (QR=2) that involved a quantitative evaluation of parent satisfaction ratings [55]. We found 1 paper (QR=4) that involved a noncomparative trial that assessed reductions in stuttering severity and frequency, as well as satisfaction with telehealth delivery [56]. The remaining papers all had the lowest quality rating (QR=5). We found 2 papers that discussed clinical insights from health care professionals who were involved in telehealth treatment delivery for patients with stuttering [57,58]. We also found a descriptive-analytic study of satisfaction with telehealth treatment for stuttering [59]. Furthermore, we found 2 papers on a pilot open-case series (QR=4) [60] and an RCT that used a waiting list control for the assessment and treatment of chronic tic disorders (QR=2) [61]. The final paper (QR=5) provided an account of a telehealth service that was delivered at a large-scale regional service level [62].

Clinical Effectiveness

In terms of the Lidcombe program, the Phase I [56] trial demonstrated the efficacy of remotely delivering the program to families with a preschool child who stutters. However, the results of a main parallel, open-plan, noninferiority RCT trial [54] showed that it was not clear whether webcam treatment was noninferior to standard treatment in the short term. Carey and colleagues [53] conducted a Phase II clinical trial that examined adolescents' responsiveness to the webcam-delivered Camperdown program, and found that adolescents experienced substantially reduced stuttering in terms of both frequency and severity, although relapse was a problem.

User Impact, Feasibility, and Acceptability

High levels of engagement and satisfaction were reported by parents/carers [53,60,61]. The use of telehealth to train health care professionals was shown to be a promising way of providing support to practitioners in the field [58]. Jahromi and Ahmadian [59] explored satisfaction in telespeech therapy among 30 Iranian patients aged ≥14 years. The authors reported that satisfaction with the therapy was high, but the low internet speed in the country was a major challenge for half the participants, as they could not maintain eye contact with the therapist due to the distorted image transmission. Similarly, another study reported that difficulties arose with regard to completing certain aspects of treatment due to limited web camera viewing ranges and audio/visual difficulties [61].

The feasibility of delivering both the Lidcombe and Camperdown programs via telehealth methods was documented, and parents were generally satisfied [53,54,56]. However, Bridgman and colleagues [57] highlighted that individual adjustments were required to tailor the treatment process to families' needs in order to maximize outcomes. Ferdinands and Bridgman [55] examined parent satisfaction and stuttering severity at baseline and during the 9-month/18-month follow up, and found that increased parental satisfaction was generally, but not always, linked with the severity of stuttering. This demonstrates the need to provide treatment at the family level when monitoring children with communication disorders. There was no considerable difference in parent satisfaction between clinic and telehealth care delivery.

Ricketts et al [60,61] conducted pilot studies that explored the feasibility of assessing tic severity over voice over internet protocol (VoIP), which allows users to make and receive calls via an internet connection. They compared the feasibility, acceptability, and efficacy of VoIP-delivered therapy for tic disorders to those of a waitlist control. They found a decrease in tic severity that was similar to the decrease identified in the original Cognitive Behavioral Intervention for Tics trial [63] and greater than that of the waitlist control [61].

Service Delivery Efficiencies and Economic Impact

Merrill et al [62] provided an overview of Ohio's Telepsychiatry Project for Intellectual Disability, which provides specialized mental health services to rural communities. This paper documented telehealth from a service delivery perspective. Although no specific figures were given, the report indicated that the service improved access to care, reduced emergency department visits/hospitalizations, and resulted in cost savings, including reduced travel expenses, medical expenses, and support costs. Similar cost savings were reported in other studies [54,59].

Readiness for Clinic Adoption

Of the 33 treatment papers, 5 (15%) deemed telehealth to be suitable for clinic adoption, either as an adjunct to current practices or on its own [30,47,50,59,62]. Furthermore, 24 (73%) papers noted that telehealth required further research before being implemented into clinical practice. The remaining papers were unclear/did not report on readiness for clinic adoption. Prior to the COVID-19 pandemic, the delivery of interventions via telehealth for parents of children with ASD, young people and adults who stutter, and adults with intellectual disability were thought to be suitable for clinic adoption. For young people who struggle with attending appointments, therapy conducted via VoIP was recommended. In addition, coaching and support via a chat program was recommended as an adjunct to usual treatment for young people and adults with ADHD/ASD.

Discussion

Principal Results

The purpose of this systematic review was to examine the evidence base for the clinical use of technology within the neurodevelopmental field prior to the COVID-19 pandemic, to identify possible telehealth technologies that can be considered for wide-spread implementation and document the current state of the evidence base prior to the anticipated rapid development in this field.

Assessment

Telehealth has been used to assess small samples of people with ASD, and telehealth shows promise for clinical adoption. In terms of economic impact, there are potential cost savings and service efficiencies, but the evidence base is limited. The ADHD assessment tool is not clinically effective, and there has been no evidence for the assessment of other NDDs at present.

Monitoring

As identified in a previous review by Spencer and colleagues [15], all studies that used telehealth for monitoring were for monitoring ADHD, and all studies were from the same trial (ie, the CATTS [25]), which had promising results for acceptability and effectiveness. Telehealth monitoring seems to be an approach that should be considered for clinic adoption.

Treatment

Telehealth has been used to treat a range of NDDs. However, the majority of conditions fall under ASD, and treatment has mainly focused on parent training interventions. These interventions have shown some evidence of clinical efficacy, such as improving caregiver knowledge, competence, and child participation, and reducing problem behaviors. Even when telehealth is not clinically effective, the recording of sessions can help health care professionals identify why the treatment did not work [33]. Treatments for communication disorders have also focused on parent intervention programs, which have shown some evidence of clinical efficacy and no difference in parent satisfaction between remote delivery and face-to-face delivery. Despite the fact that previous literature has suggested that the evidence for using telehealth to manage communication disorders is substantial [10], our review did not reveal a large number of papers that involved communication disorders, as more papers focused on ASD. Furthermore, our findings on effectiveness were mixed; the lack of an adequate control group was a limiting factor in several studies [53].

We found little evidence for the delivery of parenting interventions for ADHD. However, it is possible that the search terms used in this review limited access to such papers. Telehealth services for young people and adult service users tended to focus on the remote delivery of coaching, support, and therapy. The 1 case study of a young person with ASD who received online therapy had a promising outcome. People with ASD may particularly benefit from using technology to overcome communication difficulties, as this involves fewer social pressures than face-to-face therapy [64].

Cognitive-behavioral strategies have been used for both ADHD and tic disorders, and mixed clinical efficacies have been reported. There is a larger body of evidence for using behavioral and cognitive-behavioral treatments for tic disorders than evidence for using such treatments for ADHD, but further research is necessary for both disorders. There was limited evidence for using telehealth as a means of providing training to health care professionals. However, barriers to this approach, including the design of the intervention, technical issues, attitudes of staff, organizational culture and structure, and work division and resource allocation, were widely reported.

In summary, there is a much larger body of evidence for the efficacy of providing remotely delivered interventions to parents and children than evidence for providing such interventions to young people and adult service users. There is also a small body of evidence for using telehealth to train health care professionals. Generally, the user impact for all participants was positive. There was very little research on economic impact. Overall, the evidence base is of variable quality.

Key Implementation Issues

This systematic review highlighted key implementation issues for using telehealth services. The number of telehealth technologies that are ready to be implemented in practice is limited, as most studies stated that further research is necessary before such technologies are acceptable for clinical adoption. Service providers should consider both service users' opinions on such technology and the evidence base when choosing whether to implement telehealth technology into clinical practice. If families view telehealth technology as an adjunct to usual treatment, cost savings may not be achieved.

The telehealth delivery of treatments may have benefits. In some studies, allowing users to access treatment at convenient times and providing personalized treatment led to greater treatment engagement and completion. Families were more at ease and relaxed when participating in telehealth treatment. The need to personalize treatment to individuals and families was apparent across several studies. This is particularly important, as disruptions by other family members can occur. There is limited evidence for service delivery efficiencies. Implementation difficulties included failing technology, audio and visual problems, and difficulties in making eye contact. These were particularly problematic in countries with low internet speeds. In line with previous reviews, several studies have reported that health care professionals found reading body language and facial expressions difficult due to distorted images [10,65].

Directions for Future Research

This systematic review reveals that there is a lack of research that assesses the use of telehealth in aiding the diagnosis of a wide range of NDDs, and that the current focus is on autism. In general, cost-effectiveness and possible service efficiencies are underinvestigated, but they are an important consideration for real-world implementation. Future research should focus on developing guidelines and blueprints for how to best integrate telehealth care into clinical practice [66].

Limitations

The limitations of this study must be taken into account when interpreting the findings. As the search yielded a much greater number of papers than anticipated, the search was limited to the previous 5 years. This was a deviation from the initial protocol. However, it can be argued that this method allows for a more effective analysis of current technology and precludes the inclusion of outdated technology. Furthermore, limiting the search to published academic papers may have exacerbated the risk of bias, as authors were not contacted for unpublished work due to the volume of published papers obtained. This is a limitation of our study, and further reviews should explore unpublished data, especially data from conference papers, as these provided a vast amount of possibly relevant data. However, conference papers were excluded from this systematic review due to time constraints.

The majority of studies were conducted in high-income countries, thereby limiting the generalizability of our findings. It is likely that there would be intercountry variations in barriers to implementing new technology into existing health care systems. Although these barriers are typically considered outside the remit of standard reporting for trials, an understanding of these barriers is important if these technologies are to be routinely implemented.

The majority of data were of mid- to low-quality, and our findings should be interpreted with caution. This was generally because of small sample sizes and the high number of qualitative/reflexive study designs. However, RCTs are time-consuming and do not always lend themselves to real-world evaluations.

Conclusions

Our literature search highlighted that, prior to the COVID-19 pandemic, there was promising evidence for the use of telehealth in clinical practice, in relation to NDDs. Telehealth technologies were more frequently used to support the treatment and monitoring of NDDs; there was less evidence for their use in supporting the assessment of NDDs. The main focus of telehealth in the neurodevelopmental field was on ASD and ADHD, which are two of the most commonly occurring NDDs. There was evidence of good clinical outcomes and cost savings for health care providers. However, further research is required to substantiate this evidence. With the growing need to provide easy access to remotely delivered clinical support for enabling the wide-spread reach of health care and reducing the risk of spreading infectious diseases, it is essential that real-world evaluations for implementation and cost-effectiveness are conducted.

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Authors' Contributions

CLH designed the study and wrote the protocol; MJG and CH provided feedback on the protocol. EY and AZV conducted the literature searches. AZV, CLH, BJB, and SSH reviewed the abstracts and titles for inclusion. AZV and CLH extracted the data. CLH and BJB completed the risk of bias assessment. AZV wrote the first draft of the manuscript with support from CLH and SSH. CLH supervised the process with support from CH. All authors contributed to and approved the final manuscript

Conflicts of Interest

CH acknowledges the financial support of the National Institute of Health Research Nottingham Biomedical Research Centre and National Institute of Health Research MindTech MedTech Co-operative. All other authors declare that they have no conflicts of interest.

Multimedia Appendix 1

Sample search for 1 database (ie, Medline).
[DOC File , 44 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Summary of included studies.
[DOC File , 139 KB-Multimedia Appendix 2]

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Abbreviations

ADHD: attention deficit hyperactivity disorder
ASD: autism spectrum disorder
CATTS: Children’s ADHD Telemental Health Treatment Study
NDD: neurodevelopmental disorder

OASIS ABA: Online and Applied System for Intervention Skills Applied Behavior Analysis
PICOS: population, intervention, comparison, outcome, study design
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QR: quality rating
RCT: randomized controlled trial
RUBI-PT: Research Unit on Behavioral Interventions-Parent Training
VoIP: voice over internet protocol

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Original Paper

Digital Health Literacy and Web-Based Information-Seeking Behaviors of University Students in Germany During the COVID-19 Pandemic: Cross-sectional Survey Study

Kevin Dadaczynski[1,2*], MSc, PhD; Orkan Okan[3*], PhD; Melanie Messer[4], PhD; Angela Y M Leung[5], BN, MHA, PhD; Rafaela Rosário[6], MSc, PhD; Emily Darlington[7], MPH, MSc, PhD; Katharina Rathmann[1], PhD

[1]Department of Nursing and Health Sciences, Fulda University of Applied Sciences, Fulda, Germany

[2]Centre for Applied Health Science, Leuphana University Lueneburg, Lueneburg, Germany

[3]Interdisciplinary Centre for Health Literacy Research, Faculty of Educational Science, Bielefeld University, Bielefeld, Germany

[4]Section "External Lecturer", APOLLON University of Applied Sciences, Bremen, Germany

[5]Centre for Gerontological Nursing, World Health Organization Collaborating Centre for Community Health Services, School of Nursing, Hong Kong Polytechnic University, Hong Kong SAR, Hong Kong, China

[6]School of Nursing, University of Minho, Braga, Portugal

[7]Health Systemic Process EA 4129 Research Unit (P2S), University of Lyon, University Claude Bernard of Lyon 1, Lyon, France

[*]these authors contributed equally

Corresponding Author:
Kevin Dadaczynski, MSc, PhD
Department of Nursing and Health Sciences
Fulda University of Applied Sciences
Leipziger Sraße 123
Fulda, 36037
Germany
Phone: 49 661 9640 6073
Email: kevin.dadaczynski@pg.hs-fulda.de

Abstract

Background: Digital communication technologies are playing an important role in the health communication strategies of governments and public health authorities during the COVID-19 pandemic. The internet and social media have become important sources of health-related information on COVID-19 and on protective behaviors. In addition, the COVID-19 infodemic is spreading faster than the coronavirus itself, which interferes with governmental health-related communication efforts. This jeopardizes national public health containment strategies. Therefore, digital health literacy is a key competence to navigate web-based COVID-19–related information and service environments.

Objective: This study aimed to investigate university students' digital health literacy and web-based information-seeking behaviors during the early stages of the COVID-19 pandemic in Germany.

Methods: A cross-sectional study among 14,916 university students aged ≥18 years from 130 universities across all 16 federal states of Germany was conducted using a web-based survey. Along with sociodemographic characteristics (sex, age, subjective social status), the measures included five subscales from the Digital Health Literacy Instrument (DHLI), which was adapted to the specific context of the COVID-19 pandemic. Web-based information-seeking behavior was investigated by examining the web-based sources used by university students and the topics that the students searched for in connection with COVID-19. Data were analyzed using univariate and bivariate analyses.

Results: Across digital health literacy dimensions, the greatest difficulties could be found for assessing the reliability of health-related information (5964/14,103, 42.3%) and the ability to determine whether the information was written with a commercial interest (5489/14,097, 38.9%). Moreover, the respondents indicated that they most frequently have problems finding the information they are looking for (4282/14,098, 30.4%). When stratified according to sociodemographic characteristics, significant differences were found, with female university students reporting a lower DHLI for the dimensions of "information searching" and "evaluating reliability." Search engines, news portals, and websites of public bodies were most often used by the respondents as sources to search for information on COVID-19 and related issues. Female students were found to use social media and health portals more frequently, while male students used Wikipedia and other web-based encyclopedias as well as YouTube more often. The use of social media was associated with a low ability to critically evaluate information, while the opposite was observed for the use of public websites.

Conclusions: Although digital health literacy is well developed in university students, a significant proportion of students still face difficulties with certain abilities to evaluate information. There is a need to strengthen the digital health literacy capacities of university students using tailored interventions. Improving the quality of health-related information on the internet is also key.

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KEYWORDS

digital health; literacy; infodemic; health information; behaviour; coronavirus; COVID-19; university student; student; infodemiology

Introduction

Shortly after the outbreak of SARS-CoV-2 and the associated disease, COVID-19, were first reported [1], it was declared a pandemic [2,3] by the World Health Organization. When the first case of COVID-19 was reported in Germany on January 27, 2020, the government responded immediately by launching an unprecedented nationwide emergency response plan that focused on four pillars: prevention, detection, containment, and treatment [4]. In addition to the National Pandemic Plan [5] and to health care and medical interventions [4], the government endorsed a public health communication strategy that was supported by all health agencies and public health bodies on national and local levels [6-9]. This communication strategy involved public broadcasting agencies, which launched web-based media campaigns, including daily nationwide podcasts. The underlying objective of this approach was to provide citizens with the necessary information on COVID-19 and how it affected people's health [4,10-13]. Within a short period of time, a massive amount of web-based health-related information on COVID-19 became available on issues such as protective behaviors, preventive measures, treatment options, dashboard statistics, the latest scientific insights, and various safety recommendations [14-16]. It has now become clear that this pandemic has been accompanied by an "infodemic"—an overabundance of valid and invalid health information on COVID-19 [17,18]. By means of digital communication technologies, especially the internet and social media, the COVID-19 infodemic is spreading faster than the coronavirus itself, which interferes with governmental health communication efforts and jeopardizes national public health containment strategies.

Altogether, this situation creates a complex information environment that requires people to be able to access, navigate, understand, use, and critically evaluate information and services in ways that support healthy and protective behaviors in the time of the COVID-19 pandemic. Therefore, health literacy, which is the ability to find, understand, and evaluate health information and apply it in daily decision-making and health behavior [19], is of utmost importance during the current pandemic [14]. Digital health literacy applies this understanding of health literacy to digital contexts and environments [20], and it has become a core competence and necessity for navigating web-based information and health service environments within the realm of the COVID-19 pandemic and the associated infodemic [21]. However, in Germany, it has been shown that more than half of the population has limited health literacy; therefore, people report difficulties in dealing with health-related information [22]. A recent study conducted in Germany on health literacy in relation to information regarding COVID-19 resulted in similar findings [23]. People particularly have difficulty assessing the trustworthiness of media information on COVID-19 and its associated health problems. In addition, people with limited health literacy are more likely to be confused due to the massive amounts of information available in the media and on the internet [23]. Information is a carrier of important health knowledge to contain the virus and empower citizens to demonstrate health literacy [16,24]; the pandemic has placed increased demand on the general population to find information relevant to them and critically reflect on this information, as well as to transfer information into their everyday life and practices.

This issue is particularly critical for university students, who consist of a significant proportion of young adults in Germany. University students comprise the population that primarily uses digital technologies and web-based health information [25,26]. Although it can be noted that students have not been the primary focus of research since the beginning of the pandemic, a recent study with over 5400 medical students from Vietnam revealed that higher levels of health literacy were associated with less fear of COVID-19 [27]. Therefore, health literacy is a critical intervention target, especially since fear is one of the toxic outcomes that result from an infodemic [17,28]. The aim of this study is to investigate the digital health literacy and web-based information-seeking behaviors among university students in Germany during the first wave of the COVID-19 pandemic, particularly during university closures. This study is informed by the conceptual model of health literacy as presented by Sørensen and colleagues [19] and the model of digital health literacy as proposed by van der Vaart and Drossaert [20]. The assumptions in both models are that personal and environmental determinants influence an individual's capacity regarding various dimensions of personal information management, which include informing health decisions and behaviors that are beneficial for health. Our study focuses on personal and environmental determinants, personal information management, and behavioral aspects. In this context, the following research questions were addressed:

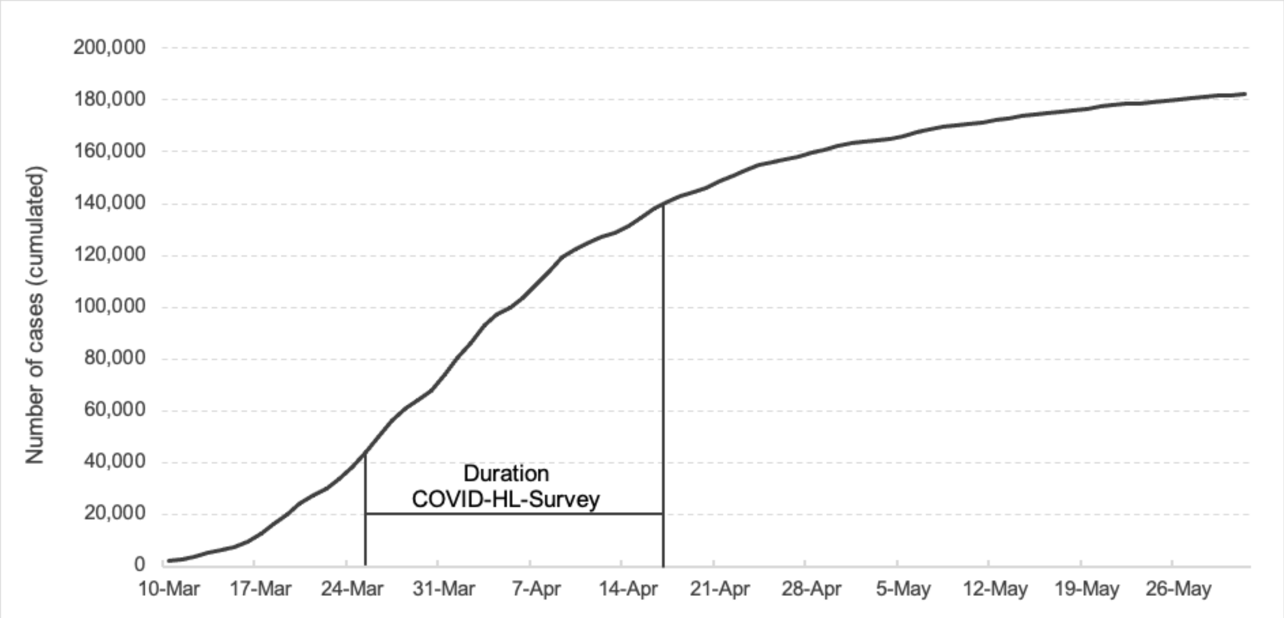
- What are the levels of COVID-19–related digital health literacy in German university students stratified by social, economic, and geographical indicators?
- Which sources of web-based information are used and which topics are searched for in the context of COVID-19 by German university students?
- Can differences be identified between students with regard to health literacy, the sources used for information searching, and the topics addressed in relation to COVID-19?

Methods

Study Design and Participants

A national cross-sectional web-based survey was conducted including a nonrandomized sample (convenience sample) of German university students. To address as many university students as possible, all private and state universities (ie, 392 universities containing 2.9 million students [29]) were invited to participate in the study by email. A reminder was sent two weeks after the survey started. The presidencies of all the universities and the deaneries of all faculties were contacted and asked to forward an invitation letter to their students. University students enrolled at a private or state university were eligible to participate in this study. To increase the homogeneity of the sample, respondents were initially asked to indicate their current status. Those who indicated that they were not currently enrolled as students at a German university were excluded from the data set (n=245). The duration of the study was 3 weeks, and it took place from March 25 to April 17, 2020. Within the 3 weeks during which the survey was implemented, the number of confirmed COVID-19 cases in Germany increased from 44,175 to 141,016 (Figure 1 [30]). The survey was administered electronically using the Enterprise Feedback Suite survey tool (Questback) [31]. Participation was voluntary, and anonymity was ensured. Upon entering the web-based survey site, participants were presented with information regarding the background and the aims of the study. After checking a consent box at the bottom of the page, participants were directed to the questionnaire. Our study was approved by the Bielefeld University ethics committee (No. EUB 2020-053).

Figure 1. Confirmed cumulative cases of COVID-19 in Germany from March to May 2020 (source: RKI COVID-19 Dashboard [30]).



Measures

Sociodemographic information included sex (male, female, diverse), age, study course (bachelor's degree, master's degree, other), and subjective social status (SSS). Age was measured in absolute numbers, and based on an analysis of the distribution, four categories were created (≤20 years, 21-23 years, 24-26 years, and ≥27 years). Social status was assessed using the German version of the MacArthur Scale, which includes a ladder with 10 steps [32]. Respondents were asked to position themselves at the step that best reflected their status in the social hierarchy, with higher values indicating a higher social status. According to previous studies, respondents were categorized into three groups: low SSS (1-4), medium SSS (5-7), and high SSS (8-10) [33].

Digital health literacy was evaluated using five of the seven subscales from the validated Digital Health Literacy Instrument (DHLI) [20], each including three items to be answered on a 4-point scale (eg, 1, very difficult; 4, very easy). The DHLI was adapted to the context of the COVID-19 pandemic (eg, "When you search the Internet for information on the coronavirus or related topics, how easy or difficult is it for you to…"). The five subscales include (1) searching the web for information on COVID-19, (2) adding self-generated content on COVID-19, (3) evaluating the reliability of COVID-19–related information, (4) determining personal relevance of COVID-19–related information, and (5) protecting privacy on the internet. The internal consistency (Cronbach α) of the first four subscales was acceptable to good (.70<α<.83). Due to low reliability (α=.46), scaling was omitted for the protecting privacy subscale.

The section about web-based information-seeking behaviors focused on the sources that were used to receive web-based health information about COVID-19 and related topics. The respondents were presented with a 10-item list of different web-based sources (eg, search engines, websites of public health bodies, government agencies, and social media providers), in which the frequency of their use could be rated on a 5-point scale (0, don't know; 4, often) [34]. Students were also asked to indicate the specific topics they searched for in the context of COVID-19. The assessment was based on a self-developed list of 9 topics (eg, current spread of COVID-19, symptoms of COVID-19, measures to protect against infection, dealing with psychological stress caused by the COVID-19 pandemic), using yes or no answers.

An overview of all items and scales used for this paper can be found in Multimedia Appendix 1. The entire questionnaire is available on request from the first authors.

Statistical Analysis

To control for the selection bias caused by a convenience sampling procedure, we used weighting to adjust the sample distribution to the characteristics of the general population of German university students. Based on the data provided by the Federal Statistical Office via the GENESIS database [35], the data could be weighted for gender and desired study degree. In the first step, all data on digital health literacy and information-seeking behavior were analyzed descriptively. Subsequently, bivariate analyses were conducted by cross-tabulating the two levels of digital health literacy (limited vs sufficient) with sociodemographic characteristics using chi-square tests. For this purpose, all DHLI subscales (except “protecting privacy”) were dichotomized using median splits. Due to the low internal consistency for the dimension “protecting privacy” and the fact that two subscales from the original DHLI instrument were not used, we also refrained from calculating an overall mean value, as done by Van der Vaart and Drossaert [20]. For all analyses, *P* values <.05 were considered statistically significant. However, due to the large sample size, the strength of the association was determined using the Cramer index (Cramer V). The Cramer V is a normalized version of the chi square statistic test for nominal scaled variables. According to Cohen [36], the strength of each association was interpreted as an effect size measure using the following conventions: ≥0.1 (small), ≥0.3 (medium), ≥0.5 (large). In further analyses, chi-square tests were also performed for the levels of digital health literacy and the topics searched for with regard to COVID-19. Finally, to analyze differences between the levels of digital health literacy and the sources used to search for COVID-19–related information, *t* tests for independent samples were conducted. Cohen *d* was used as an effect size measure by applying the following conventions: ≥0.2 (small), ≥0.5 (medium), ≥0.8 (large) [36].

Results

After further plausibility checks and adjustment for incorrect data, the data set contained complete questionnaires from 14,916 participants aged between 18 and 72 years (mean age: 24.3). Students from 130 universities and all 16 federal states participated (see Table 1). In terms of geographical coverage (see Figure 2), most respondents were from the west of Germany (6355/14,833, 42.8%), followed by students from the south (3694/14,833, 24.9), and almost equally from the north (2307/14,833, 15.6%) and the east (2476/14,833, 16.7%).

Table 1. Characteristics of the study participants (N=14,916; values are weighted).

Characteristic	Value, n (%)		
	Total	Male (n=7687, 51.5%)	Female (n=7229, 48.5%)
Age (years; n=14,897)			
≤20	2640 (17.7)	1342 (17.5)	1298 (18.0)
21-23	5495 (36.9)	2586 (33.7)	2909 (40.3)
24-26	3567 (23.9)	1923 (25.0)	1643 (22.8)
≥27	3195 (21.4)	1827 (23.8)	1369 (19.0)
Study course (n=14,916)			
Bachelor’s degree	10,351 (69.4)	5463 (71.1)	4887 (67.6)
Master’s degree	2796 (18.7)	1460 (19.0)	1337 (18.5)
Other (eg, PhD)	1769 (11.9)	764 (9.9)	1005 (13.9)
Subjective social status (n=14,913)			
Low	2575 (17.3)	1408 (18.3)	1168 (16.2)
Middle	10,090 (67.7)	4974 (64.7)	5116 (70.8)
High	2247 (15.1)	1303 (17.0)	945 (13.1)

Figure 2. Geographical distribution of the study sample (N=14,916). BB: Brandenburg; BE: Berlin; BW: Baden-Wuerttemberg, BY: Bavaria; HB: Bremen; HE: Hesse; HH: Hamburg; MV: Mecklenburg-Western Pomerania; NI: Lower Saxony; NW: North Rhine-Westphalia; RP: Rhineland-Palatinate; SH: Schleswig-Holstein; SL=Saarland; SN: Saxony; ST: Saxony Anhalt; TH: Thuringia.

In comparison with the whole population of German university students via the GENESIS database, some deviations could be observed. While students from Baden-Wuerttemberg (12.7% vs 4.5%) and North Rhine-Westphalia (27.5% vs 12.4%) were underrepresented in our study, our sample includes significantly more students from Bavaria (14.0% vs 20.4%) and Hesse (9.4% vs 21.7%). The gender distribution was almost balanced, with 51.5% male university students (7687/14,916) and 48.5% female students (7229/14,913). Regarding SSS, more than two-thirds of respondents reported a middle SSS (10,090/14,913, 67.7%), while 17.3% (2575/14,916) reported a low SSS and 15.1% (2247/14,913) reported a high SSS (mean SSS 6.0, SD 1.54).

Figures 3 to 7 show the different dimensions of digital health literacy and the percentages of student scoring. Within the “information search” subscale, university students indicated that they most frequently had problems finding the information they were looking for (4282/14,098, 30.4%), while the use of suitable words and search queries caused less difficulty (1644/14,101, 11.7%). Regarding the dimension of “adding self-generated content,” respondents reported the most difficulties in expressing their own opinion, in expressing thoughts or feelings in writing (3975/13,754, 28.9%), and in writing a message in a way that is understandable for others (4661/13,752, 33.9%). Across all dimensions, the greatest difficulties could be found in assessing the reliability of health-related information (5964/14,103, 42.3%) and the ability to determine whether the information was written with commercial interest (5489/14,097, 38.9%). The use of the found information for one’s own health-related decisions (eg, regarding protective measures, 2443/14,079, 14.4%) and the application of this information in daily life caused difficulties for approximately one-fifth of the respondents (2812/14,067, 20.0%). Finally, some heterogeneity could also be found in the items relating to the dimension of “protecting privacy.” Although approximately 35% of the respondents experienced difficulties to judge who could read messages posted on the web (4768/13,589, 35.1%), only 6.7% stated that they sometimes or often shared private information on the web (914/13,715).

Figure 3. Responses to questions in the Digital Health Literacy Instrument subscale “information search” (n=14,098 to n=14,110), %.

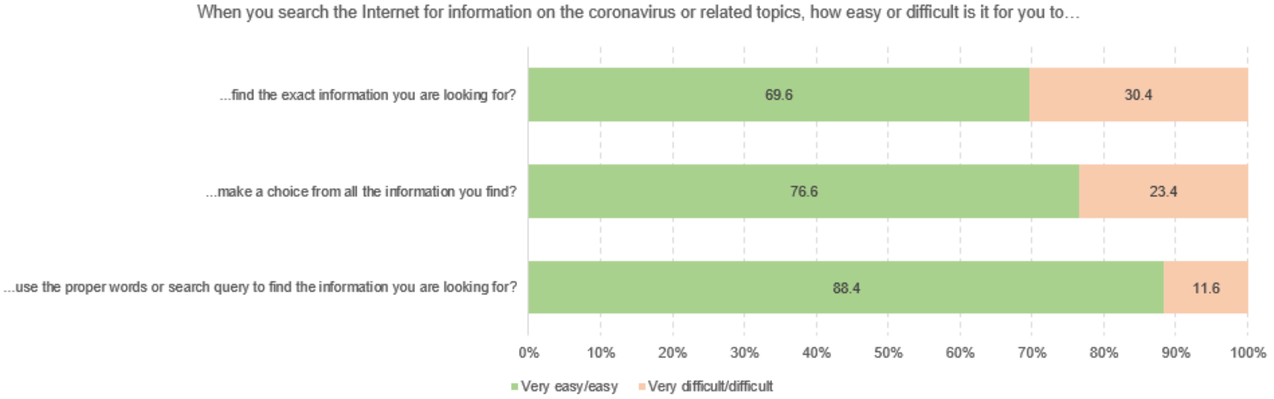


Figure 4. Responses to questions in the Digital Health Literacy Instrument subscale “adding self-generated content” (n=13,721 to n=13,754), %.

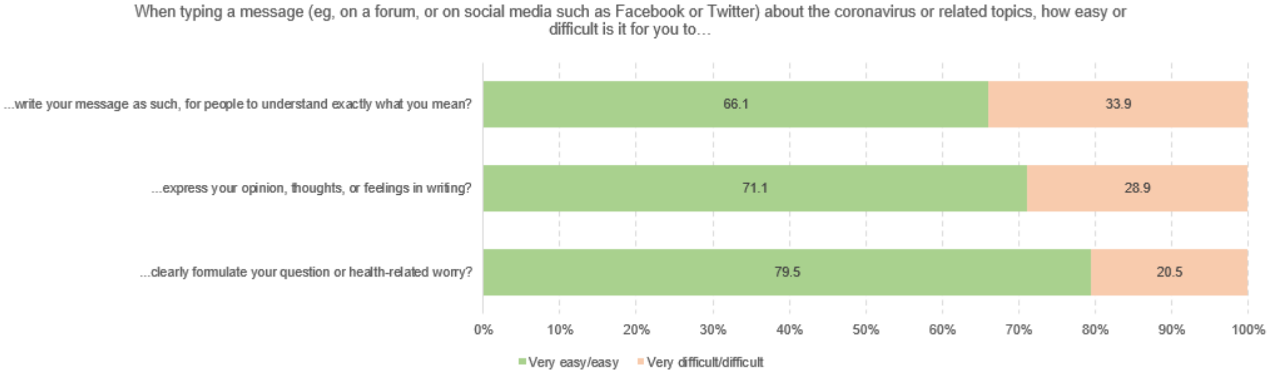


Figure 5. Responses to questions in the Digital Health Literacy Instrument subscale “evaluating reliability” (n=14,081 to n=14,103), %.

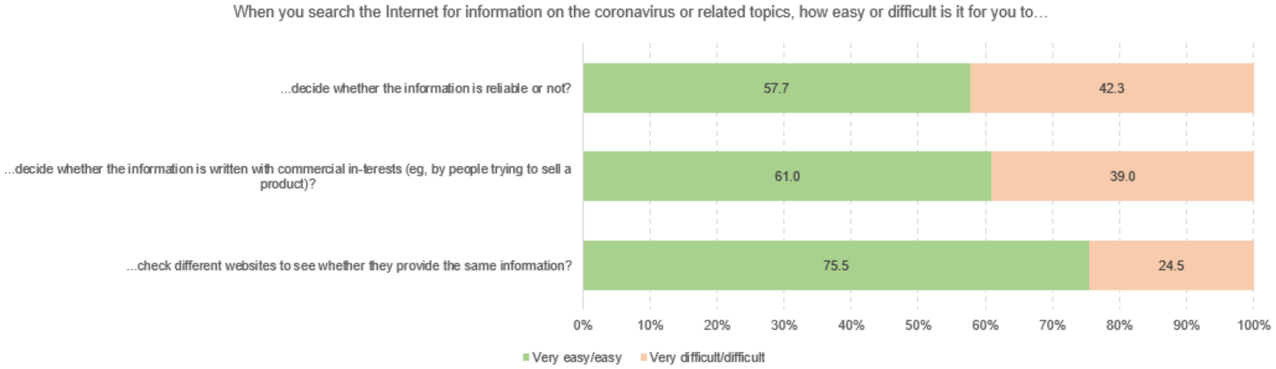


Figure 6. Responses to questions in the Digital Health Literacy Instrument subscale “determining relevance” (n=14,076 to n=14,092), %.

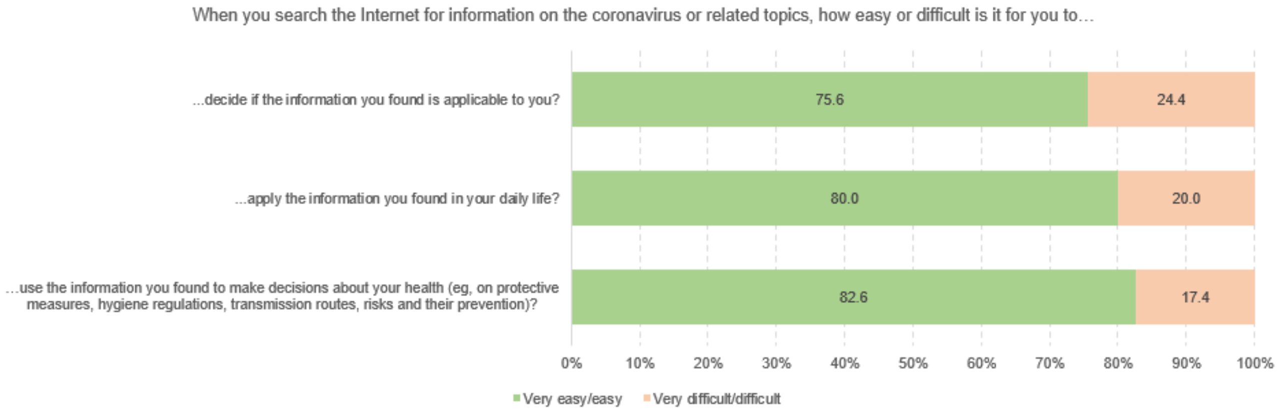


Figure 7. Responses to questions in the Digital Health Literacy Instrument subscale “protecting privacy” (n=13,589 to n=13,715), %.

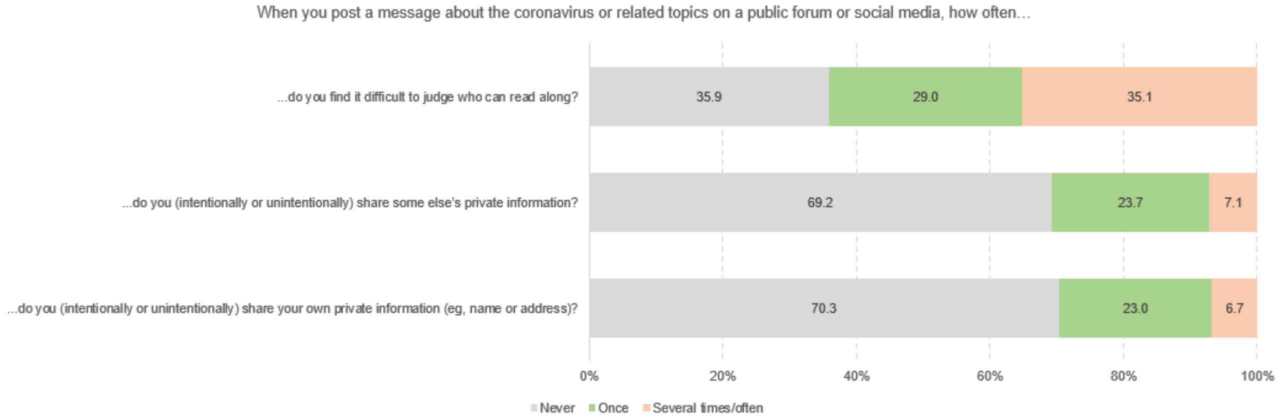


Table 2 and Table 3 show the digital health literacy levels of the respondents, stratified by sociodemographic and geographic characteristics. Concerning gender, significant differences were found, with female university students showing lower digital health literacy across all subscales. However, taking the strength of the association (*V*) into account, small effect sizes could be identified only for the dimensions “information searching” (male: 2087/7219, 28.9%, female: 2711/6865, 39.5%, χ^2_1=175.37, *P*<.001, *V*=0.11) and “evaluating reliability” (male: 2156/5994, 36.0%, female: 2660/5630, 47.2%, χ^2_1=152.16, *P*<.001, *V*=0.11). All other differences were below the threshold for small effects and were hence considered trivial. When considering differentiation by age group, in all subscales, a slight tendency of increasing level of digital health literacy with increasing age was observed. However, these significant differences proved to be trivial when calculating effect sizes. The same was observed for study course, SSS, and geographical distribution. Slight differences between the groups were observed; however, the differences remained below the threshold for small effects.

Table 2. Digital health literacy levels of university students for the subscales of “information search” and “adding self-generated content” according to their sociodemographic and geographic characteristics.

Characteristic	Information search					Adding self-generated content				
	Limited, n (%)	Sufficient, n (%)	χ^2 (*df*)	*P*	V	Limited, n (%)	Sufficient, n (%)	χ^2 (*df*)	*P*	V
Gender			175.37 (1)	<.001	0.11			29.77 (1)	<.001	0.05
Male	2087 (28.9)	5132 (71.1)				2687 (38.7)	4255 (61.3)			
Female	2711 (39.5)	4154 (60.5)				2913 (43.3)	3815 (56.7)			
Age (years)			17.77 (3)	<.001	0.04			78.38 (3)	<.001	0.08
≤20	868 (35.3)	1593 (64.7)				1091 (45.7)	1295 (54.3)			
21-23	1841 (35.5)	3340 (64.5)				2174 (43.0)	2883 (57.0)			
24-26	1139 (33.6)	2250 (66.4)				1307 (39.8)	1975 (60.2)			
≥27	948 (31.2)	2088 (68.8)				1020 (34.8)	1909 (65.2)			
Study course			26.17 (2)	<.001	0.04			98.48 (2)	<.001	0.08
Bachelor’s degree	3431 (35.4)	6253 (64.6)				5339 (56.6)	4087 (43.4)			
Master’s degree	848 (31.5)	1845 (68.5)				1577 (61.2)	1001 (38.8)			
Other (eg, PhD)	519 (30.4)	1188 (69.6)				1153 (69.2)	513 (30.8)			
Subjective social status			11.84 (2)	.003	0.03			29.64 (2)	<.001	0.05
Low	831 (34.5)	1580 (65.5)				1010 (43.1)	1335 (56.9)			
Middle	3310 (34.7)	6233 (65.3)				3853 (41.6)	5409 (58.4)			
High	655 (30.8)	1471 (69.2)				735 (35.7)	1325 (64.3)			
Geographic location			39.15 (3)	<.001	0.05			39.28 (3)	<.001	0.05
North	686 (31.6)	1484 (68.4)				857 (40.6)	1255 (59.4)			
East	786 (33.5)	1561 (66.5)				582 (37.7)	1406 (62.3)			
West	1962 (32.7)	4036 (67.3)				2325 (39.9)	3508 (60.1)			
South	1338 (38.3)	2154 (61.7)				1539 (45.3)	1858 (54.7)			
Total	4798 (34.1)	9286 (65.9)				5600 (41.0)	8069 (59.0)			

Table 3. Digital health literacy levels of university students for the subscales of “evaluating reliability” and “determining relevance” according to their sociodemographic and geographic characteristics.

Characteristic	Evaluating reliability					Determining relevance				
	Limited, n (%)	Sufficient, n (%)	χ^2 (*df*)	*P*	V	Limited, n (%)	Sufficient, n (%)	χ^2 (*df*)	*P*	V
Gender			152.16 (1)	<.001	0.11			38.10 (1)	<.001	0.05
Male	2156 (36.0)	3838 (64.0)				2387 (33.2)	4799 (66.8)			
Female	2660 (47.2)	2970 (52.8)				2617 (38.2)	4232 (61.8)			
Age (years)			35.04 (3)	<.001	0.05			9.78 (3)	.02	0.03
≤20	864 (42.5)	1169 (57.5)				874 (35.7)	1571 (64.3)			
21-23	1825 (43.5)	2373 (56.5)				1859 (36.0)	3308 (64.0)			
24-26	1179 (42.3)	1611 (57.7)				1252 (37.1)	2124 (62.9)			
≥27	945 (36.5)	1645 (63.5)				1013 (33.4)	2017 (66.6)			
Study course			23.75 (2)	<.001	0.05			9.94 (2)	.007	0.03
Bachelor’s degree	3434 (42.9)	4565 (57.1)				3513 (36.4)	6137 (63.6)			
Master’s degree	846 (38.1)	1373 (61.9)				935 (34.8)	1749 (65.2)			
Other (eg, PhD)	536 (38.1)	870 (61.9)				555 (32.6)	1146 (67.4)			
Subjective social status			18.69 (2)	<.001	0.04			30.11 (2)	<.001	0.05
Low	890 (44.0)	1133 (56.0)				928 (38.6)	1475 (61.4)			
Middle	3258 (41.7)	4553 (58.3)				3421 (36.0)	6091 (64.0)			
High	665 (37.2)	1121 (62.8)				655 (30.9)	1462 (69.1)			
Geographic location			41.08 (3)	<.001	0.06			10.43 (3)	.015	0.03
North	674 (38.0)	1101 (62.0)				731 (33.8)	1433 (66.2)			
East	763 (39.1)	1187 (60.9)				855 (36.6)	1482 (63.4)			
West	2017 (40.8)	2921 (59.2)				2086 (34.9)	3897 (65.1)			
South	1339 (46.2)	1558 (53.8)				1300 (37.4)	2176 (62.6)			
Total	4816 (41.4)	6808 (58.6)				5004 (35.7)	9032 (64.3)			

Search engines, news portals, and websites of public bodies were most often used by the respondents as sources to search for and find information on COVID-19 and related issues (see Figure 8 and Figure 9). These sources were followed by social media platforms such as Facebook, Instagram, and Twitter, or video portals such as YouTube, with 37.6% of respondents (5302/14,092) stating that they used these media sometimes or frequently. In contrast, health-related blogs or web-based guides were used much less frequently. When stratified by sociodemographic characteristics, relevant differences could only be observed for gender. Female students were found to use social media ($t_{13,921}$=–19.09, *P*<.001, *d*=–0.32) and health portals ($t_{13,463}$=–14.42, *P*<.001, *d*=–0.24) more frequently than male students. In contrast, Wikipedia and other web-based encyclopedias ($t_{14,051}$=19.19, *P*<.001, *d*=0.32), as well as YouTube ($t_{14,054}$=18.13, *P*<.001, *d*=0.30), were more often used by male students. Regarding the topics, respondents stated that they most frequently searched for information on the current spread of SARS-CoV-2 (12,648/14,114, 89.6%) and associated restrictions (12,126/14,114, 85.9%), recommendations and assessments regarding the situation (10,975/14,114, 77.8%), and the symptoms of COVID-19 (10,089/14,114, 71.5%). Although significantly less often, one-fifth of the university students stated that they looked for information on how to cope with psychological stress caused by the COVID-19 situation (2921/14,114, 20.7%). When differentiated by sociodemographic variables, gender differences could be found, as male students searched significantly more often for information on economic and social consequences of the COVID-19 pandemic (male: 4943/7237, 68.3%, female: 3817/6878, 55.5%, χ^2_1=245.62, *P*<.001, *V*=.13).

Figure 8. Internet search queries related to COVID-19 (n=14,111), %.

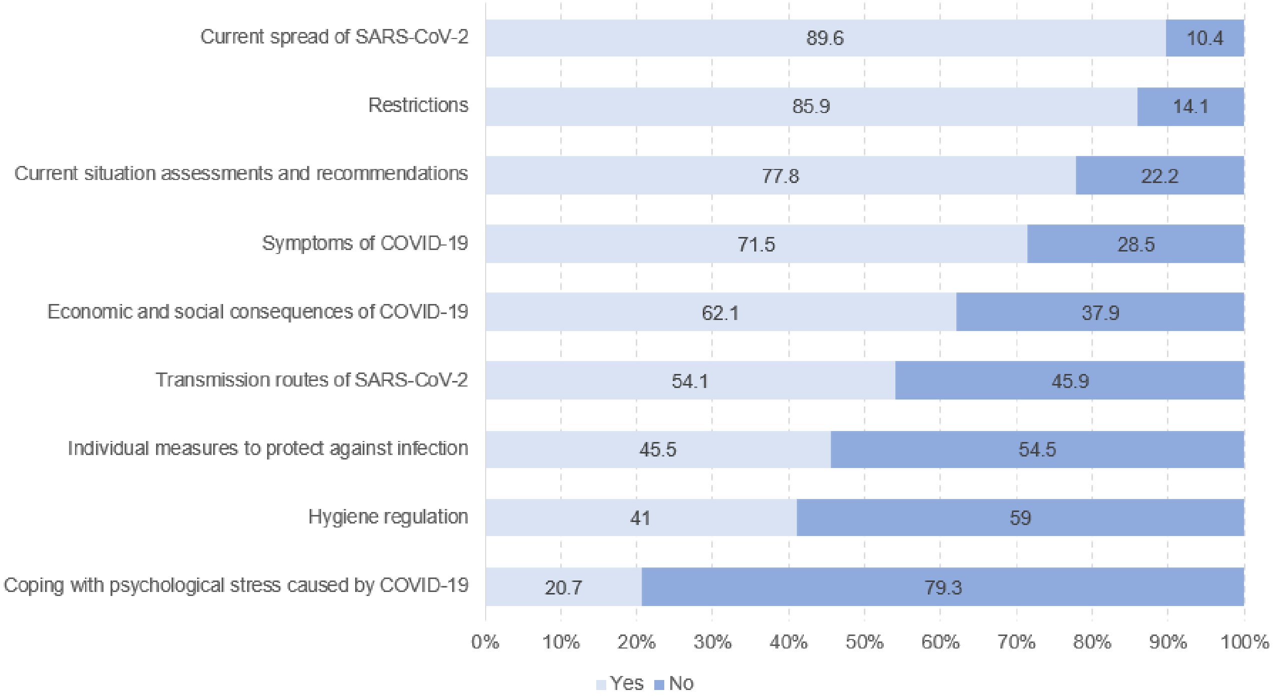
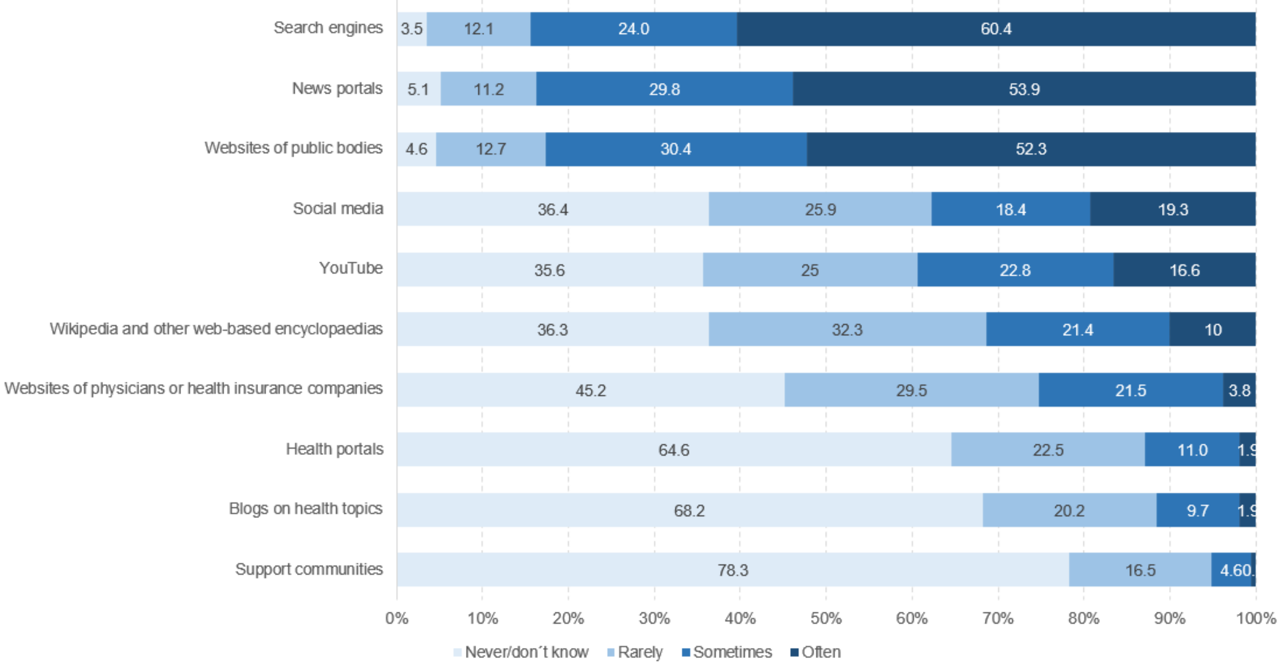


Figure 9. Frequency of use of internet sources for web-based health information seeking (n=14,012 to n=14,094), %.



Finally, digital health literacy was stratified according to web-based information-seeking behavior. No relevant differences could be found for the topics that students searched for. Regarding the sources used for the search and the handling of health-related information, significant and relevant differences emerged for the DHLI subscale "evaluating reliability." Respondents with sufficient digital health literacy in that dimension reported using the websites of public bodies (eg, Robert Koch Institute) more frequently (t_{9344}=19.44, *P*<.001, *d*=0.37). The opposite could be observed for social media (Facebook, Instagram, Twitter) ($t_{10,019}$=–14.29, *P*<.001, *d*=–0.27) and support communities (t_{9028}=–12.06, *P*<.001, *d*=–0.23), which were more frequently used by respondents who reported more difficulties in evaluating the reliability of information (see Table 4 and Table 5).

Table 4. Sources used for COVID-19 information search stratified by digital health literacy level for the “information search” and “adding self-generated content” subscales.

Item	Information search				Adding self-generated content			
	Limited, mean (SD)	Sufficient, mean (SD)	*P*	*d*	Limited, mean (SD)	Sufficient, mean (SD)	*P*	*d*
Search engines (eg, Google, Bing, Yahoo!)	3.44 (0.79)	3.40 (0.85)	.003	–0.05	3.43 (0.82)	3.42 (0.83)	.21	N/A[a]
Websites of public bodies (eg, Robert Koch Institute)	3.20 (0.88)	3.36 (0.85)	<.001	0.18	3.24 (0.87)	3.35 (0.85)	<.001	0.12
Wikipedia and other web-based encyclopedias	1.99 (0.96)	2.08 (0.99)	<.001	0.09	2.03 (0.98)	2.07 (0.98)	.005	0.05
Social media (eg, Facebook, Instagram, Twitter)	2.31 (1.14)	2.15 (1.12)	<.001	–0.14	2.29 (1.14)	2.17 (1.12)	<.001	–0.10
YouTube	2.19 (1.09)	2.21 (1.10)	.22	N/A	2.25 (1.10)	2.18 (1.09)	<.001	–0.07
Blogs on health topics	1.47 (0.74)	1.44 (0.75)	.056	N/A	1.46 (0.74)	1.45 (0.75)	.35	N/A
Support- communities	1.30 (0.59)	1.26 (0.56)	<.001	–0.08	1.30 (0.59)	1.27 (0.56)	.002	–0.05
Health portals	1.53 (0.77)	1.49 (0.76)	.004	–0.05	1.51 (0.77)	1.51 (0.77)	.80	N/A
Websites of physicians or health insurance companies	1.84 (0.89)	1.84 (0.89)	.72	N/A	1.82 (0.88)	1.86 (0.91)	.005	0.05
News portals (eg, newspapers, television)	3.30 (0.86)	3.34 (0.87)	.03	.04	3.32 (0.86)	3.32 (0.87)	.75	N/A

[a] N/A: not applicable due to lack of significance.

Table 5. Sources used for COVID-19 information search stratified by digital health literacy level for the “evaluating reliability” and “determining relevance” subscales.

Item	Evaluating reliability				Determining relevance			
	Limited, mean (SD)	Sufficient, mean (SD)	*P*	*d*	Limited, mean (SD)	Sufficient, mean (SD)	*P*	*d*
Search engines (eg, Google, Bing, Yahoo!)	3.49 (0.79)	3.36 (0.86)	<.001	–0.15	3.43 (0.82)	3.41 (0.84)	.07	N/A[a]
Websites of public bodies (eg, Robert Koch Institute)	3.13 (0.92)	3.45 (0.79)	<.001	0.37	3.22 (0.89)	3.35 (0.84)	<.001	0.16
Wikipedia and other web-based encyclopedias	2.03 (0.98)	2.08 (1.00)	.008	0.05	2.02 (0.97)	2.06 (0.99)	.01	0.04
Social media (eg, Facebook, Instagram, Twitter)	2.38 (1.15)	2.07 (1.10)	<.001	–0.27	2.28 (1.14)	2.16 (1.12)	<.001	–0.10
YouTube	2.24 (1.12)	2.17 (1.09)	.001	–0.06	2.22 (1.10)	2.19 (1.09)	.20	N/A
Blogs on health topics	1.49 (0.76)	1.42 (0.74)	<.001	–0.10	1.46 (0.74)	1.45 (0.75)	.37	N/A
Support-communities	1.36 (0.64)	1.22 (0.53)	<.001	–0.23	1.31 (0.61)	1.25 (0.55)	<.001	–0.10
Health portals	1.56 (0.80)	1.47 (0.74)	<.001	–0.12	1.52 (0.78)	1.49 (0.76)	.02	–0.04
Websites of physicians or health insurance companies	1.81 (0.88)	1.87 (0.91)	.001	0.05	1.82 (0.88)	1.85 (0.90)	.09	N/A
News portals (eg, newspapers, television)	3.30 (0.87)	3.33 (0.87)	.04	0.04	3.33 (0.84)	3.32 (0.88)	.32	N/A

[a] N/A: not applicable due to lack of significance.

Discussion

To our knowledge, this study is the first to investigate the digital health literacy and information-seeking behaviors in university students during the COVID-19 outbreak in Germany. Nationwide and overall, university students show high levels of digital health literacy. However, one-third of all students (4282/14,098, 30.4%) reported having problems finding the correct information on a particular health-related topic. Also, almost half of all students (5964/14,103, 42.3%) had problems evaluating the reliability of web-based information, which includes difficulties in identifying commercial interests behind the information presented in the news (5489/14,097, 38.9%). Moreover, the greatest challenges were related to assessing the reliability of COVID-19–related information and to judging whether commercial interests were attached to this information. Female students reported more difficulties in searching and evaluating web-based COVID-19–related information than male students.

Although digital health literacy levels were sufficient in a large proportion of the respondents, the results must be viewed in a more differentiated way. Germany applied a very successful health communication strategy [4] based on easily understandable and easy-to-use health information regarding COVID-19 (eg, washing hands, physical distancing, wearing masks), which was of low complexity compared to other health or disease information [23]. The communication mode was primarily push-based, directing information toward people through all media and communication channels. In comparison, for noncrisis communication, people must supply themselves with information (pull communication) to a greater extent, which requires active searching for information and hence requires strong health literacy. The way in which communication was altered (push vs pull) could explain the lack of differences in digital health literacy levels in relation to socioeconomic status, which are usually found in health literacy studies [22,37]. In addition, our study reports on the state of students' digital health literacy levels during the early stages of the so-called first wave of the pandemic, at a time when adherence to policies of measures to protect against COVID-19 was high. However, this could change in the current second wave, when people lose trust in official sources and the support for compliance with official recommendations diminishes. Declining support of public measures can already be observed in Germany. Demonstrations against restrictions are taking place, and people are demanding a return to prepandemic conditions and the reopening of the economy, all of which manifests through a refusal to apply the recommended protective measures (eg, no physical distancing, no face masks) [38].

Data protection and security is also an important issue in the context of digitalization and of the digital transformation of society. Using digital health services and communicating about health topics on the internet and on social media requires particular communication technologies to ensure user safety and user-friendliness. Our findings indicate that one-third of all students (4768/13,589, 35.1%) reported problems judging whether a third party can read their messages posted on the web. Studies on web-based data protection in the German population showed that 72% of respondents doubted the safety of the personal data they shared on the internet [39]. Moreover, 55% even believed that they had no control over what happens to their web-based data [40]. Despite its importance, we were required to exclude the subdimension "protecting privacy" from further bivariate analyses due to low reliability. When introducing the original DHLI, van der Vaart and Drossaert [20] also reported an unsatisfactory Cronbach alpha for this subscale (α=.57). Although this supports the validity of our study findings, it also suggests a need for further refinement (eg, by reformulating the item "…do you find it difficult to judge who can read along?“ to "…do you find it difficult to judge how the security of your private information is secured by the media provider?" to emphasize the role of protective measures taken by the media provider).

The most preferred sources to look for web-based health- and COVID-19–related information among students included search engines, news portals, and websites of public bodies, followed by social media and video portals. Favorite search topics were the current spread of COVID-19 (12,648/14,114, 89.6%), restrictions (12126/14,114, 85.9%), recommendations and risk assessments (10,975/14,114, 77.8%), and COVID-19 symptoms (10089/14,114, 71.5%). Similarly to earlier studies on population health literacy, which focus on both generic health literacy [22,41] and health literacy in relation to COVID-19 [15,23], making a judgment about the reliability of COVID-19–related information in the media and identifying potential commercial interests represent the most difficult tasks. There is also a significant positive association between having sufficient levels of digital health literacy and accessing more trustworthy and thus more reliable web-based health content. Students with higher levels of digital health literacy in the dimension of "evaluating information reliability" accessed the official websites of public bodies and agencies more often and turned less often to sources such as support communities, including forums, and social media compared to students with lower competencies in this dimension. While the ability to seek information and to produce and provide information did not show any significant differences across digital health literacy levels, students with higher abilities to determine the personal relevance of the information they obtained show similar patterns to those shown for the subscale "evaluating reliability."

Interestingly, only one-fifth of students (2921/14,114, 20.7%) reported having searched for information related to psychological stress and the consequences of the COVID-19 pandemic on mental health. This finding is surprising, as other studies show that the COVID-19 pandemic has enormous effects on mental health [42,43], and an infodemic can trigger an epidemic of fear and anxiety [28]. On the other hand, it should be emphasized that this survey was conducted at the beginning of the first wave of the pandemic and that psychological problems became more important as the pandemic progressed. Therefore, reliable and trustworthy (mental) health information is key in this situation for citizens to act upon information and knowledge provided by governments, health authorities, and scientists, and thereby to help slow the spread of COVID-19 [14,16,44-47]. In this context, infodemiology becomes important to better understand communication patterns, information routes and content, and how they affect behaviors, attitudes, and health status [28]. Citizen behavior, however, must be facilitated by adequate government actions and policies that provide not only health information but also health, social, and economic services for citizens to cope with the situation [14]. The impact of the ongoing COVID-19 infodemic places an additional burden on web-based health information seekers. This threat amplifies the negative effects of low digital health literacy. In their representative survey of COVID-19–related health literacy during the pandemic, Okan and colleagues [23] found that 56% of the German population felt confused about the vast amount of information regarding COVID-19. Women, younger age groups, and families with children younger than 18 years in their household are significantly more affected. At the same time, people with lower income and who reside in federal states of the former East Germany were found to feel less informed than their counterparts. This ongoing study highlights that the infodemic must be acknowledged "as a meta-risk in its own right" that aggravates the current situation [23]. Therefore, this infodemic requires particular attention during the COVID-19 emergency, which includes public policy strategies aiming to address the toxic spread of misinformation and disinformation about SARS-CoV-2 and COVID-19 [14,15,23]. Moreover, producers, providers, and suppliers of health information must ensure that information is evidence-based and adheres to health literacy principles, including barrier-free and easy access, user-friendliness and ease of understanding, cultural appropriateness, and relevance for everyday public use [21,23]. Social media platforms should also counteract the spread of misinformation and disinformation about COVID-19. The fight against misinformation and disinformation should become an important issue in public policy [17,18]. As proposed by Gunter Eysenbach, the four pillars to fight an infodemic include (1) infoveillance (the monitoring of information), (2) strengthening health literacy and digital health literacy in the population, (3) applying constant knowledge refinement (eg, fact checking), and (4) adequate knowledge transfer and minimizing political and commercial influence on health information [45]. This is supported by the World Health Organization within their infodemic management framework, which suggests six policy recommendations to manage infodemics during an emergency such as the COVID-19 pandemic [46]. These recommendations include (1) basing interventions and messages on the latest evidence, (2) applying knowledge transfer and making health information easy to understand, (3) collaborating with communities to better understand their information needs, (4) analyzing information impact and cooperating with social media platforms, information suppliers, and civil society, (5) informing these actions by reliable information and adapt action based on the respective and latest narratives, and (6) further improving infodemic management by all means necessary and also through interdisciplinary research collaboration [46]. Skills to navigate digital information environments were already crucial before the COVID-19 pandemic to mitigate the effects of digital inequalities [47,48]. These skills have become even more essential during the pandemic, as the importance and use of communication technologies and media have changed massively since the outbreak of COVID-19 [14,16,45,48,49].

The most important finding of the stratified analyses is that among students with limited digital health literacy, female students reported having more problems finding the correct information and evaluating the reliability of COVID-19–related information. In Germany, women often have more care responsibilities and are generally more engaged with health issues than men [23], and they are also more active in searching the internet for health information [49,50]. This may lead them to be more critical vis-à-vis health information on COVID-19, as they have a more sensible awareness that not all information is reliable. In addition to this, a recent study showed that women are much more worried about the sheer amount of COVID-19–related information on the internet [23]. They were more concerned when they had children ≤18 years of age. Many young women are faced with difficulties and challenges when they search for and evaluate health information, especially because there is so much conflicting information on COVID-19 available on the web.

To sum up, the findings from this study raise concern and have important implications for public health. First, problems related to access to accurate and situation-specific information in the context of a public health emergency may lead to the use of invalid information, which is unhelpful or even detrimental to the causes of slowing infection rates and sustaining a successful infectious disease strategy. Second, when students access disinformation or false information and they have difficulty making judgments about the correctness of the information, they will most likely not identify that information for what it is (eg, "fake news," commercial messaging). In turn, using the wrong information can again cause harm and impede engagement in effective health behaviors. Third, feeling safe in the digital world, especially when seeking health-related information and interacting with others about health concerns, is a critical issue. Many students expressed uncertainties regarding the safety of personal information shared on the web. These findings suggest the need to implement health education measures to strengthen students' health literacy capacities. In addition, there is a need for more accurate public health information platforms to provide timely and evidence-based information with a view to inform individual behavior and system-level responses. Studies on health literacy in Germany conducted in 2011 [37], 2013 [41,50], and 2014 [22,41] have shown that half of the adult population, including both younger and older adults, have limited health literacy. In response, health literacy policy initiatives were launched, such as the science and civil society–led German National Action Plan on Health Literacy [51] and the Alliance for Health Literacy [52], which is led by the federal Ministry of Health. These initiatives focus on strengthening population health literacy, starting in early childhood and at school, to enable children to grow into health-literate adults. However, little progress has been made since then, and a health education curriculum that addresses health literacy is still lacking in Germany. Furthermore, people with lower education in Germany have more often lower levels of health literacy [22,37]. If students, who belong to a population group with higher education, already have difficulties with their digital health literacy, it can be assumed that people with less education are also vulnerable to having lower levels of health literacy and associated information tasks, such as finding, understanding, and evaluating COVID-19–related information on the web.

Our study has several limitations. The sample, although weighted, is not representative of all university students in Germany. We may have missed many students who use the internet less frequently and those who may have been troubled due to university closures and associated changes to their lives. The implications may not be transferable to other populations and age groups in Germany. Additionally, students in Germany are privileged in terms of educational achievement and therefore in terms of socioeconomic status compared to people seeking a tertiary education with non–degree level requirements. This survey was conducted in the early days of the first wave of the pandemic, when adherence was high; this could explain the finding that students perceived information tasks to be easy to undertake and therefore reported high levels of digital health literacy. This may not be the case in a second phase, after enduring lengthy restrictions on everyday and university life activities and rapidly emerging conflicting information on COVID-19, all of which could make judgment much more difficult. Due to the effects of the COVID-19 pandemic on physical contact and face-to-face meeting, we had to use a web-based survey in adherence to German COVID-19 policies, whereas the developers of the original questionnaire, van der Vaart and Drossaert [20], highlighted that the application of a web-based questionnaire may exclude people with weak digital competencies. Therefore, a potential bias in our sample is that it may have excluded students who use the internet to a lesser extent or those with lower digital competencies. Nevertheless, due to web-based activities related to their studies (eg, access to e-learning and university communication platforms) and given that most German universities provide their services via web-based systems, students in Germany in general represent a proportion of the population who have more intersections with the digital world, inevitably use the internet more often, and have a higher affinity to using web-based media content.

Our findings show that overall, the level of digital health literacy in relation to dealing with web-based COVID-19–related information was high. However, a significant proportion of university students still face difficulties with certain abilities to deal with information, such as finding the right information and evaluating its reliability. There is a need to strengthen the digital health literacy capacities of university students, particularly female students, using tailored interventions. Actions must also include the design of interventions to increase the quality of health information on the internet, to implement fact-checking strategies in web-based and social media, and to increase the health literacy of people who produce, supply, and provide health information and services on the web. For example, universities can provide courses on digital health literacy and health information to their staff and students and can also disseminate reliable news on COVID-19 through their web-based channels. Raising awareness among universities and education administrators might aid the emergency response, and it could also increase the health literacy responsiveness of organizations and students. The benefit of the COVID-HL survey is that it provides first-time knowledge that could help decision-makers develop policies and programs that foster healthy and protective behaviors, plan for preventive measures, and promote adherence to COVID-19 policies, on the basis of students' needs in terms of digital health literacy. Digital health literacy will empower university students and all other population groups to take greater control in the prevention and spread of COVID-19, which in turn is likely to lead to better health outcomes.

Authors' Contributions

KD and OO contributed equally and prepared the first draft of the manuscript. MM, AYML, RR, ED, and KR provided feedback on the first draft. KD, OO, and KR designed and conducted the survey. MM, AYML, RR, ED, and KR helped with the analyses and contributed to data interpretation. All authors contributed to writing and revising the manuscript and approved the final version for submission.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Overview of scales and items.

[DOCX File , 97 KB-Multimedia Appendix 1]

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Abbreviations

DHLI: Digital Health Literacy Instrument
SSS: subjective social status

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Original Paper

Application of In-Home Monitoring Data to Transition Decisions in Continuing Care Retirement Communities: Usability Study

Katherine Wild[1], PhD; Nicole Sharma[1], BA; Nora Mattek[1], MPH; Jason Karlawish[2,3,4], MD; Thomas Riley[1], BA; Jeffrey Kaye[1,5], MD

[1]Department of Neurology, Oregon Center for Aging and Technology, Oregon Health and Science University, Portland, OR, United States
[2]Department of Medicine, University of Pennsylvania, Philadelphia, PA, United States
[3]Department of Medical Ethics and Health Policy, University of Pennsylvania, Philadelphia, PA, United States
[4]Department of Neurology, University of Pennsylvania, Philadelphia, PA, United States
[5]Department of Biomedical Engineering, Oregon Center for Aging and Technology, Oregon Health and Science University, Portland, OR, United States

Corresponding Author:
Katherine Wild, PhD
Department of Neurology
Oregon Center for Aging and Technology
Oregon Health and Science University
Portland, OR
United States
Phone: 1 503 494 6975
Email: wildk@ohsu.edu

Abstract

Background: Continuous in-home monitoring of older adults can provide rich and sensitive data capturing subtle behavioral and cognitive changes. Our previous work has identified multiple metrics that describe meaningful trends in daily activities over time. The continuous, multidomain nature of this technology may also serve to inform caregivers of the need for higher levels of care to maintain the health and safety of at-risk older adults. Accordingly, care decisions can be based on objective, systematically assessed real-time data.

Objective: This study deployed a suite of in-home monitoring technologies to detect changing levels of care needs in residents of independent living units in 7 retirement communities and to assess the efficacy of computer-based tools in informing decisions regarding care transitions.

Methods: Continuous activity data were presented via an interactive, web-based tool to the staff identified in each facility who were involved in decisions regarding transitions in care among residents. Comparisons were planned between outcomes for residents whose data were shared and those whose data were not made available to the staff. Staff use of the data dashboard was monitored throughout the study, and exit interviews with the staff were conducted to explicate staff interaction with the data platform. Residents were sent weekly self-report questionnaires to document any health- or care-related changes.

Results: During the study period, 30 of the 95 residents (32%) reported at least one incidence of new or increased provision of care; 6 residents made a permanent move to a higher level of care within their communities. Despite initial enthusiasm and an iterative process of refinement of measures and modes of data presentation based on staff input, actual inspection and therefore the use of resident data were well below expectation. In total, 11 of the 25 staff participants (44%) logged in to the activity dashboard throughout the study. Survey data and in-depth interviews provided insight into the mismatch between intended and actual use.

Conclusions: Most continuous in-home monitoring technology acceptance models focus on perceived usefulness and ease of use and equate the intent to use technology with actual use. Our experience suggests otherwise. We found that multiple intervening variables exist between perceived usefulness, intent to use, and actual use. Ethical, institutional, and social factors are considered in their roles as determinants of use.

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KEYWORDS

technology; remote sensing technology; care transition

Introduction

Although factors associated with older adults' moves to residential facilities have been well described [1-4], our understanding of the reasons for changes in the level of care in persons who live in continuing care retirement communities (CCRCs) is limited. However, there appears to be some overlap with transitions from independent community living. Increased confusion, loss of mobility, medication nonadherence, and reduced socialization have been identified as predictors of movement to higher levels of care in a CCRC [5-8].

A delay in identification of increased dependence or inability to perform routine self-care activities can result in costly and potentially dangerous outcomes for at-risk residents. Typically, decisions about care needs and transitions in the levels of care for older adults living in CCRCs rely on communication and coordination among professional staff members. Ideally, these decisions are based on the evaluations of relevant health and behavioral changes. As Couture et al [9] have argued, the decision-making process is best accomplished by input from all stakeholders across health care professions as well as from family members and the residents themselves. Georgiou et al [10] identified barriers to optimal communication in residential care facilities, which may have a negative impact on the provision of quality care related to efficient and timely transitions to different levels of care. Another challenge to judicious care transitions is the relative inability to detect changes in a resident's care needs before an acute event occurs.

It has been noted that policies and procedures may not be suitable for efficient and timely information transfer. Kelsey et al [5] reported that policies for transfer from one level of care to another vary across facilities, ranging from a multidisciplinary team approach to decision making by a facility manager or administrator. They recommend that future research attention be paid to the ultimate appropriateness of resident transfers to higher levels of care. In the long term, codification of procedures and identification of factors contributing to moves within a residential community can serve to reduce resistance and misunderstanding and may have the potential to enhance safety and prolong independence in at-risk older adults.

A lack of formalized protocols or objective behavioral markers to guide the process may contribute to the uncertainty and divergent views associated with the determination of residents' needs for transition from independent to more assisted living within a continuing care setting. One way to compile objective, systematically assessed activity data is through continuous monitoring technologies. Demiris and Thompson [11] have cited the value of in-home activity monitoring technologies in delivering large, individually anchored data sets that are *useful, meaningful, and actionable*.

Systems that improve our ability to unobtrusively monitor important health changes because of chronic disease and aging could allow timely intervention that prevents avoidable loss of independence. Continuous collection of health and activity information in the home can enable early identification of clinically significant changes. Our experience in examining the feasibility of deploying a comprehensive, ubiquitous sensing platform in the homes of older adults has been reported previously [12,13]. ORCATECH (Oregon Center for Aging & Technology) research has demonstrated the sensitivity of unobtrusive in-home technology to detect early changes in medication management capacity [14,15], patterns of mobility [16-18], nighttime sleep behaviors [19], computer use [20,21], and driving [22]. Such technologies can provide important information in guiding decisions regarding increased care needs. We aimed to test the hypothesis that providing objective and continuous data from home-based technologies to the care teams in retirement communities will result in fewer transitions to higher levels of care through early identification of behavioral or activity changes that lead to increased in-home assistance.

In this paper, we report on the results of Ambient Independence Measures for Guiding Care Transitions (AIMS), a study that provided designated staff at 7 continuing care residential communities with access to an automated, continuous data monitoring platform via a web-based dashboard that collected residents' behavioral and physiological sensor-based independence metrics. Owing to low use of data by the staff, the trial was not able to adequately evaluate the primary hypothesis that providing these data will result in fewer transitions to higher levels of care and increase in-home assistance because of early identification of potential problems. We describe the procedures implemented to maintain staff engagement and consider the challenges of new technology adoption in residential facilities. Using exit interviews with the staff, we examined the reasons for the low use of the data to recommend how studies of home monitoring of health and activity can be improved.

Methods

Overview

Before initiating the trial, focus group sessions were conducted with care transition teams at the participating retirement communities to better understand their routine process of making decisions about when residents need to transition to a higher level of care and to receive feedback on the proposed AIMS data provision interface. Their recommendations were incorporated into the final dashboard interface where feasible. Residents were then monitored for 3 years, with behavior and activity data supplied to identified staff for half the study residents.

Recruitment

Older Adult Participants

Individuals were recruited from existing registries of volunteers for research residing in one of 7 retirement communities in the Portland metropolitan area and during presentations given at these communities about the project. These residential facilities participated in previous and ongoing research about technology and aging. Demographic data were collected at the time of enrollment in this study or other ORCATECH studies. Participants were aged 75 years or older, independently living in an apartment that was larger than one room, living alone, not demented, and of average health for their age (ie, without a medical illness that would limit physical participation or possibly lead to death over the next 36 months). As part of their participation in this study, the residents agreed to have their in-home activity data shared with their facility staff and were required to have internet service and to be computer users. The cohort was allocated to having the staff view their in-home activity via the web-based dashboard versus no viewing, using simple randomization (computer-generated assignment) at a 1:1 ratio, with an enrollment goal of 50 residents per group. The observation period for the study was 3 years.

Resident participants were instructed to live their lives without any specific health or activity intervention. They replied once a week to an email that directly queried them regarding health or activity change (mood, pain, loneliness, falls, hospital visits, visitors, and limited activity due to health) as well as the need for new or additional care.

Staff Participants

A total of 25 staff members at these facilities were self-identified as participants in decision making around residents' transitions in levels of care. They were recruited to this study during regularly scheduled staff meetings. Staff were aged between 21 and 66 years (mean 39.6, SD 10.4 years) and were employed at their present facility for an average of 10 years (range 2 weeks to 16 years). Staff levels of education ranged from high school graduate to master's degree; a majority (17/25, 68%) had obtained at least a college degree. Their job titles varied and included directors, nurses, social workers, and resident care coordinators.

Monitoring Platform

The details of the home technology system have been described previously [12,13]. In brief, sensors and other in-home technologies are deployed to continuously monitor daily activities. In response to specific queries from the research team regarding the dashboard content and interface, the staff made multiple concrete suggestions on all aspects, ranging from how to better navigate the site to changing the symbols used to represent alerts for changes in activity status. On the basis of the input from the care teams, a study protocol was finalized, which focused on home-based sensors and devices whose data were perceived as indicating that major functions had changed and thus could influence independent living decisions. The selected metrics included mobility, physiological health, nighttime behaviors, medication adherence, socialization, cognitive function, and self-reported health changes via a web-based weekly health form (Table 1).

Table 1. Ambient Independence Measures for Guiding Care Transitions study metrics and devices.

Core functions	Measures	Sensors or devices used
Physical capacity and mobility	Total daily activity, number of room transitions, typing speed, time out of home	PIR[a] motion sensors and contact sensors, computer use metrics (eg, keyboard trigrams)
Walking speed	Median weekly walking speed from multiple daily walks	PIR motion sensor line
Sleep and nighttime behavior	Time of awakening in the morning, time spent in bed at night, wake after sleep onset, times up at night, sleep latency	PIR motion sensors
Physiologic health	Daily BMI, morning pulse	Bioimpedance scale
Medication adherence	Percentage of doses missed in a 7-day period relative to prescribed schedule	MedTracker electronic pillbox
Socialization and engagement	Time out of home, time alone, phone call patterns, online computer activity (email and social networking sites)	PIR motion sensors, contact sensors, personal computer, phone monitors
Cognitive function	Time to complete online tasks, mouse movements, prospective memory for medication	Personal computer or tablet, MedTracker
Health and life events	Online self-report: emergency room, doctor, hospital visits, home visitors, mood, pain, loneliness, falls, injuries, change in home space, home assistance received, change in medications	Personal computer or tablet

[a]PIR: passive infrared.

Resident homes were installed with a sensor platform consisting of passive infrared motion and contact sensors, MedTrackers, weight scales, and software to capture all metrics as well as residents' computer use. A web-based reporting tool was developed to track these data, identify outlying data and trends, and provide staff with access to views of these data on a variety of timescales in a dashboard format that was available to the participating facilities' care transition teams. Figure 1 presents an example of a dashboard data summary for a single resident across various metrics over time. The dashboard interface was designed to be interactive, allowing for the manipulation of time scale, activity, and residents of interest. It also provided alerts to the staff for behaviors and activities that fell outside the range of normal for any particular resident. The basic approach for alerts was to develop a baseline model of typical measures for each individual over multiple weeks and monitor these measures on a regular basis (eg, weekly) for trends away from the norm. Alerts were embedded in data summaries for individual behaviors and activities. Figure 2 depicts a sample resident's summary graphic, where outlying behaviors are represented by an alert (!) and green checkmarks indicate the usual behavior *for that resident.*

Figure 1. Sample dashboard display (screenshot) of continuously assessed in-home activity metrics in Ambient Independence Measures for Guiding Care Transitions (AIMS) residents. The display, showing data at the individual level, can be customized by the user to show higher-level summaries, single metrics, numerical detail, and different windows of time. In this custom view, multiple metrics are displayed (eg, time out of home, physiologic measures, sleep measures, bathroom trips). The gray shading indicates preset ranges.

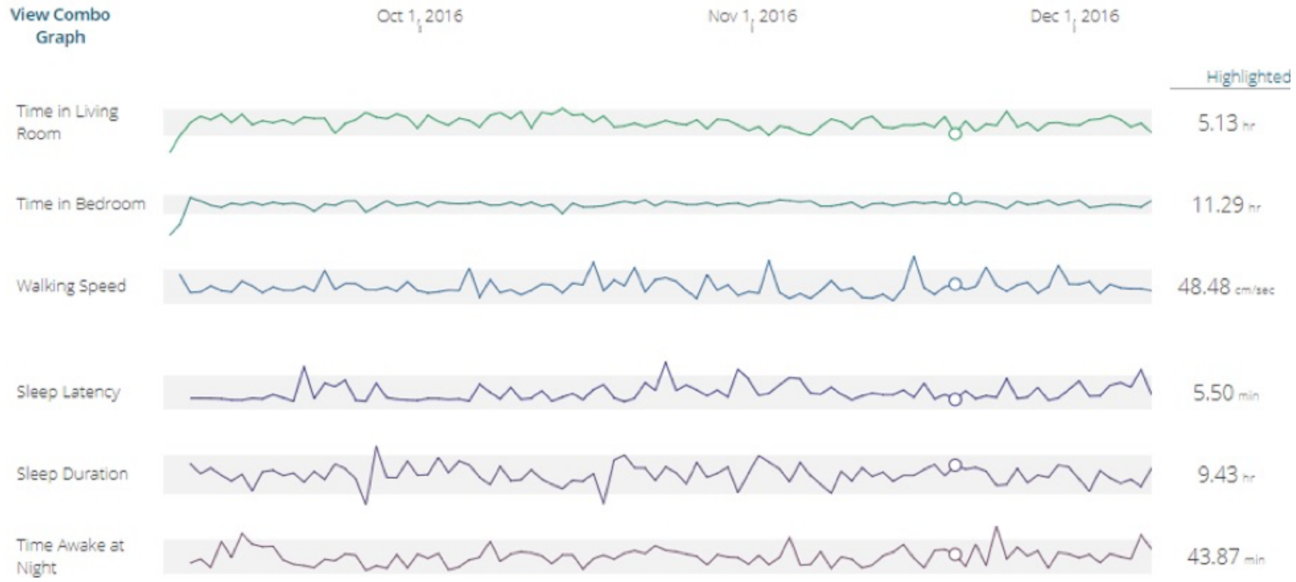

Figure 2. Sample dashboard display of residents' summary data. Exclamation points indicate departure from the usual level of behavior or activity for each resident (Temperature and Carbon Dioxide refer to environmental metrics and were not included in this study).

Resident Summary

Sort By Name	Weight	Walking Speed	Medication Adherence	Phone Duration	Temperature	Carbon Dioxide	Room Transitions	Gross Activity	Self Report
Subject 339	✓	✓	✓	✓	✓	✓	✓	✓	✓
Subject 1226	✓	✓	✓	!	✓	✓	✓	!	✓
Subject 1138	!	!	✓	✓	✓	✓	!	✓	✓
Subject 1222	✓	✓	✓	!	✓	!	!	!	✓
Subject 1127	✓	!	✓	✓	!	✓	✓	!	✓
Subject 1149	✓	!	✓	✓	✓	✓	✓	✓	✓
Subject 880	!	✓	✓	✓	✓	✓	✓	✓	✓

Staff Training and Engagement

Facility staff who had been identified as part of the transition assessment team and were willing to participate in the study were scheduled for 1-hour training sessions by AIMS study staff. Each staff member also received a printed dashboard user guide with detailed instructions on the use of the dashboard and its functionalities in terms of resident activity categories, data summaries, and useful comparisons across activities and time frames. Contact information for additional help was included, and technicians returned to sites to provide additional training as needed. During the study period, minimal additional training was requested; our technician made 2 additional visits to facilities and provided occasional help by telephone. These data are not tabulated.

To maintain engagement with the project, we mailed quarterly newsletters to residents and staff participants (Figure 3).

Newsletters contained study updates regarding recruitment and participation, illustrative dashboard screenshots and data summaries, and *fun facts* based on data collected. For example, one newsletter presented data summarizing the sleep habits of participating residents. Newsletters to staff were accompanied by nominal gift cards to express appreciation.

Figure 3. Sample page from the quarterly newsletter mailed to Ambient Independence Measures for Guiding Care Transitions (AIMS) study participants and staff. Study enrollment at the time of this newsletter was 89 residents and 20 staff.

ORCATECH
SENSING LIFE KINETICS

AIMS STUDY QUARTERLY OVERVIEW

FEBRUARY 2016 – ISSUE 1

AIMS STUDY PARTICIPANTS AT A GLANCE

89 resident participants

- **80% are female**
- **Average age is 87 years**
- **Average education is 16 years**

These participants reside in one of seven CCRCs taking part in our study.

20 CCRC staff participants

- **90% female**
- **Average age is 41.1 years**
- **Average years at CCRC is 5.5**
- **Average years in their field is 11.4**

YOUR SLEEP HABITS

24% of you get up before 6:30am

17% of you go to bed after 11pm

The average AIMs participant sleeps for **9 hours and 2 minutes** each night.

WHAT IS THE AIMS STUDY?

The purpose of the Ambient Independence Measures for Guiding Care Transitions (AIMs) study is to determine how the information we gather from ORCATECH's in-home technology can provide retirement community staff more information about the health of their residents.

Sometimes it's not clear that someone could use additional help until they have a bad fall or other incident, and then it may be too late to avoid having to move to assisted living or nursing care. We hope our technology may eventually help residents receive assistance earlier so these situations can be avoided.

WHAT HAVE WE LEARNED SO FAR?

Since we are just finishing up enrolling participants, we've mostly learned about YOU!

How many online weekly forms have study participants completed?

- 96% of study participants completed at least 1 health form during December 2015 with an average of 3.24 forms per person for the month.
- Over 1400 online weekly health forms have been completed by our study participants between February and October 2015!

Look forward to more data updates in our next issue!

Data Collection and Analysis

For the duration of the study, dashboard access metrics were tracked, including the number of log-ins, average time spent on each dashboard page, and number of page views by each staff member.

Staff were emailed monthly surveys querying their use of the AIMS dashboard. They were asked whether they had looked at the dashboard in the last month and whether the dashboard was used in discussions about any residents. If they reported not having used the dashboard, they were asked to provide a reason. All surveys ended with an open request for feedback about the web-based activity dashboard. Midway through the study, in an effort to reengage, staff participants were sent a new survey with sample data illustrating acute and subtle changes in the behavior of one study resident. The staff responded to questions regarding the management of alerts and subsequent actions. For example, they were asked to identify preferred methods for the transmission of event reports, whether by dashboard alerts, emails, or other formats. Possible time frames for alerts, follow-up actions, and data interpretations were also probed.

At the end of the 36-month data collection period of the study, interviews with staff participants were held at 2 facilities jointly by 2 authors (KW and J Kaye) to discuss actual dashboard use among staff, study-related workload, and any other factors related to their use of the dashboard over the course of the study. The interviews were open ended and intended to elucidate barriers and opportunities for improving staff engagement in future studies (Multimedia Appendix 1).

Descriptive data for participating residents were collected at baseline. The rest of the data presented here were collected via web-based surveys and in-person interviews. Owing to small numbers, quantitative analyses of staff responses were not deemed appropriate.

Human Subjects' Protections

The protocol was approved by the Oregon Health & Science University Institutional Review Board (IRB#9944). Written informed consent was obtained from all participants before their inclusion in the study. The older adult residents did not receive compensation for study participation; the staff received nominal gift cards with newsletter mailings.

Results

Participants

A total of 95 older adult residents from 7 residential facilities in the Portland, Oregon, metro area were recruited and enrolled into the AIMS cohort (Table 2). They were 80% (76/95) female, with a mean age of 86.4 years (range 70-105 years) and Mini-Mental State Examination score of 28.7 (range 21-30). Overall, 10 participants had a Clinical Dementia Rating score of 0.5, consistent with mild cognitive impairment. Between enrollment and the data collection period, 4 participants withdrew; of the remaining 91 participants, 44 were assigned to the *viewable data* group and 47 to the *nonviewable data* group.

During data collection from December 2014 to December 2017, 6% (6/95) AIMS participants made a permanent move from independent living to assisted living or to a health care center. In addition, 32% (30/95) participants answered “yes” at least once to the weekly question regarding new care provision. The most commonly reported forms of assistance were medication management (n=22) and help with bathing, dressing, and grooming (n=19). Most of the additional assistance was provided by facility staff (n=20), whereas a minority received assistance from family or privately hired caregivers.

Table 2. Baseline demographic and clinical characteristics (N=95).

Variable	Value
Age (years), mean (SD)	86.4 (7.4)
Female, n (%)	76 (80)
Education (years), mean (SD)	15.9 (2.4)
Mini-Mental State Examination, mean (SD)	28.7 (1.6)
Cognitively impaired, n (%)	10 (11)
Geriatric Depression Scale, mean (SD)	1.1 (1.9)
Functional Assessment Questionnaire, mean (SD)	1.0 (3.3)
Cumulative Illness Rating Scale, mean (SD)	20.6 (2.6)

Staff Engagement

During the 3 years of study, 11 of the 25 consented staff members logged in at least once to the activity dashboard (Table 3). All facilities were represented by at least one staff member. The number of unique log-ins to the dashboard per facility ranged from 1 to 9. Staff *page views*, that is, the number of pages of data looked at per staff member, ranged from 4 to 211 over the duration of data collection. It is clear that some staff were more engaged than others; at facility #7, 1 of 5 participating staff members logged in during the course of the study, but that staff member had 211 page views. In the 4 facilities where more than one staff member viewed the dashboard, there was consistent overlap in the residents viewed. For example, in one facility, 2 staff members viewed the same 3 residents’ data. Some residents merited multiple page views. Of the 6 residents who actually transitioned to a higher level of care during the study period, 4 had been randomly assigned to the group where monitored data were shared with staff; only 2 of these transitioned residents’ data were viewed by the staff before their transitions.

Monthly surveys were discontinued because of a low response rate. Across the 5 monthly email surveys, a total of 81 invitations to respond were sent to the staff. A total of 25 completed surveys were returned. Of the 25 surveys, in 12 instances, staff members indicated that they had looked at the web-based AIMS dashboard in the past month. Survey responses of those who had not used the dashboard in the past month (n=13) indicated that they forgot to use the dashboard (7/13, 54%), they did not need to use it because of their role in the organization (4/13, 30%), or they were unable to get onto the dashboard system because they forgot their password (2/13, 15%). Of the 12 instances where the staff indicated they had looked at the web-based AIMS dashboard, none had used the information from the dashboard as a part of a discussion about a resident they viewed.

Of the 25 eligible staff participants, 5 responded to the midstudy survey, which included sample data designed to reengage staff participants, emailed in January 2017. They generally endorsed a preference for controlling the frequency of initial alerts and follow-up reminders. Although 4 of the 5 respondents judged alerts to acute changes to be useful, only 2 respondents felt the same for alerts regarding subtle changes or trends. In open text, they explained that subtle changes in behavior were not likely to affect the overall function or well-being and were not *acute enough* to warrant their involvement. One respondent elaborated:

> *There is a fine line between monitoring someone’s independent lives and knowing when to interfere for safety reasons...It is hard to know when to involve a care team without being too Orwellian. I would likely wait a month and then have a bit more data to take to a team meeting to assess the subtle changes collectively.*

At the end of the data collection period, 6 staff participants at 2 facilities were interviewed by 2 authors (KW and J Kaye). Interviews ranged from 1 to 1.5 hours. Feedback regarding barriers to the use of the AIMS dashboard and the data presented fell into 2 general categories.

Table 3. Staff engagement with the data dashboard.

Site	Number of participants consented	Dashboard use		
		Total number of participants logged	Total number of unique log-ins	Total page views
1	5	2	3	121
2	3	2	6	57
3	2	2	2	51
4	3	2	9	88
5	4	1	1	17
6	3	1	2	40
7	5	1	4	211

Practical Issues and Barriers

Technical difficulties with the use of dashboard at the beginning of the study proved to be dissuasive for some staff members:

> *We had difficulty logging into the system in the beginning.*

The infrequency of use exacerbated the log-in challenges because of continued unfamiliarity with the system. Furthermore, multiple staff noted that once they did access the site, the residents of interest to them in terms of changing care needs were not always study participants (because a minority of the residents they were overseeing were in the study at their site), making it less likely that they would re-enter the site. At the same time, the staff felt inundated by data in general and lacked the time to adequately review and interpret dashboard metrics. More than one staff commented that the study required a designated staff member to monitor data. Alternatively, one staff member suggested that if alerts were triaged to appropriate staff, they would all receive fewer irrelevant emails and alerts. Another staff member added that it would be critical for the system's effectiveness that staff only receive alerts relevant to their position, "then if you get an alert you know it was meant for you." The frequency of alerts and potential false alarms were naturally of concern in relation to time management for already overextended care providers.

Other feedback related to specific behaviors was monitored by the AIMS project. Despite initial enthusiasm about the areas of interest (eg, sleep, medication adherence, socialization), the staff subsequently recognized additional behaviors as more relevant to their decision making, such as disruptive behaviors or missing meals or appointments. At the same time, others appreciated receiving *real-time data* on metrics such as weight and sleep duration. They did acknowledge that although the residents were excited to be part of a research program, the staff felt they needed more experience with possible outcomes to see the benefits of behavior monitoring. In general, the staff struggled with the challenge of responding to acute events versus detecting trends and patterns of behavioral decline and determining how to integrate such monitoring into their daily schedules. Ultimately, some saw these data as potentially helpful in developing a model for transition, allowing them to be more proactive and less reactive.

Professional Bias and Ethical Concerns

One interviewee acknowledged that she had biases from the beginning, in that her training as a counselor led her to be more intuitive than data driven in her decision making. Others noted their strong inclination to use the data as objective support for their own subjective perceptions of care needs.

A second concern was related to the inherent conflict between resident autonomy and safety. Multiple staff members voiced this sentiment, citing the necessary compromise between letting a resident "do what they want" even if that were to include risky behavior. However, the installation of monitoring technology raised the issue of risk management for some, in that knowledge of potentially unsafe behavior would require a decision regarding the appropriate staff response. Patient autonomy and privacy were referenced in a question posed by a director of nursing services: "How paternalistic do you want your environment to be?" An intrinsic tension between residents' desire for control and their general willingness to share monitoring data was reflected in staff efforts to provide optimal care while respecting self-determination.

Discussion

Principal Findings

We report the results of developing and implementing an automated, continuous data monitoring platform that presented CCRC residents' daily activity data on a regular basis to professional staff charged with decisions about care transitions. Our goal was to assess whether these activity metrics meaningfully contributed to this decision-making process and to test their contribution by examining in a randomized controlled trial framework whether those metrics might inform decisions regarding transitions to higher levels of care by providing early and actionable data on changes in behavior and activity.

During the 3 years of study monitoring, only 6 participants transitioned to a higher level of residential care. This number was lower than anticipated and may reflect a growing trend toward engaging additional in-home assistance instead. A total of 30 participants reported needing new in-home assistance during the study, ranging from medication management to assistance with bathing. The low rate of transitions may have contributed to the underutilization of the monitoring data dashboard by facility care staff.

Although initial acceptance of the project was enthusiastic, with the staff in 7 facilities committing to regular utilization of the data dashboard, this enthusiasm failed to carry over into implementation. The staff used the dashboard sporadically, and those who did identified several limitations to use, ranging from technology challenges to ethical concerns.

Comparisons With Previous Work

Previous work on the adoption of technology by health care professionals has used various iterations of the Technology Acceptance Model (TAM) [23]. This model postulates that the intention to use technology is predicated on attitudes that are mediated by the perceived attributes of the technology. The two most important attributes in explaining acceptance and use of technology have been proposed to be perceived usefulness and perceived ease of use [24]. Modified technology acceptance models have added subjective norms and facilitator conditions as determinants of intent to use [25].

Although all models have been shown to have some explanatory power, research applications have typically incorporated *behavioral intention to use* rather than actual use. Few studies include measures of actual technology use, relying instead on measures of behavioral intent. Our experience in this project suggests that despite perceived usefulness at baseline and attempts to accommodate users' needs to achieve perceived ease of use, actual technology use can still be lower than predicted by indicators of intent to use.

TAMs have been applied to the identification of barriers to adoption by health care providers. Organizational factors such as administrative leadership and support, including additional time allotment and clear incentives, adequate resources for training and ongoing technical support, and organizational planning for implementation have been cited as important barriers [26-29]. Technical impediments include malfunctioning or unreliable equipment and devices and lack of coordination or complementarity with existing procedures. Failure to include potential end users in the design and planning of technology applications has also been cited as an impediment to adoption [27,30]. In addition, the ability of users to exert control over the technology's behavior has been cited as an important motivator in the adoption of a new technology [31]. Sabrowski and Kollak [32] describe the *domestication* of technology as a process whereby the system or device is integrated and adapted to the user's needs and environment. They postulate that until care professionals view a technology as integral to an improvement in the delivery of care, they will be resistant to adoption. Finally, human factors connected to attitudes and previous experiences with technology can have enormous influence. Lack of knowledge or familiarity with a device or system can diminish both perceived usefulness and ease of use. Furthermore, for health care providers seeking to maximize the quality of life for a medically fragile population, concerns about loss of human contact can foster negative attitudes toward technology. Savenstedt et al [33] identified themes elicited from interviews with professional caregivers of older adults. Technology applications were seen as both an aid and a threat to not only humane care but also to their roles as caregivers. They cited the loss of immediate contact and involvement with their care recipients as a potential consequence of technology applications. The authors suggest that these inherent conflicts foster resistance to change despite outward acceptance.

Limitations and Lessons Learned

We found sporadic adoption of a new monitoring technology by professional staff. Despite initial enthusiasm and ongoing efforts to engage the participating staff in 7 residential care communities, the goal of this study, that is, to analyze the impact of technology-based data on decision making around transitions in care, was not achieved. Previous research has described organizational, personal, and technological characteristics and contexts that may facilitate or impede the adoption of health technologies [29,34-37]. Feedback from our staff participants was consistent with these barriers to technology use.

Organizational Barriers to Use

Organizational factors such as clearly communicated expectations and possible study outcomes, continuous monitoring of technical support needs of the staff, and recognition of time commitments may have been inadequately addressed. A consistent recommendation has been the early inclusion of end users in design and implementation. Although our initial focus groups elicited some preferences and priorities, a longer run-in iterative process might have reduced the gap between our efforts at participatory design and the reality of the final implementation. Although some staff members recommend identifying a *champion* or *super-user* at each facility to provide onsite, continuous support and motivation to engage with the platform [37], we found few staff members who self-identified as such. Other organizational factors, although beyond the scope of this project, should be considered moving forward. A unified commitment to the implementation of new technologies by the administration, staff, and residents is required and must include the provision of adequate time for staff education and training, recognition of professional autonomy, and ongoing identification of potential barriers.

Personal and Professional Barriers to Use

Personal and professional traits related to technology adoption include experience with technology, peer attitudes, staff engagement, and professional satisfaction [29,34]. Although initial training was provided to all staff in dashboard use and features, additional active ongoing technical support might have increased engagement. Perceived usefulness may have been diminished because of lack of concordance between resident research participants and particular residents of interest (who were not monitored in the study) to the transition teams.

The staff expressed ethical concerns related to the quality of care and privacy. Previously, unexamined conflicted attitudes toward monitoring technology surfaced only after actual engagement with the system. A more detailed discussion of the implications and possible outcomes of staff participation in a continuous monitoring study before implementation might have mitigated ethical apprehensions. An increase in staff workload or change in procedure, without adequate motivation and explanation, cannot be expected to be enthusiastically adopted. In the future, identification of intrinsic and extrinsic motivators, adequate and sustained training, and a realistic understanding of the goals of the study must be an integral part of research in technology adoption.

Technical Barriers to Use

Finally, issues with the technology itself may have presented barriers to implementation. Technical issues such as failed passwords and initial platform malfunctions, while infrequent, led to some early negative interactions, which proved to be difficult to overcome. In addition to the initial discussion of needs with end users, further refinement of the platform might have enhanced sustained participation. However, the refinement of protocols must be balanced with the time and resources needed to implement a program, acknowledging that staff turnover can attenuate involvement over time.

The original premise of our intervention was that a less obtrusive, information-on-demand approach would be least disruptive to workflows. However, at least initially, sending notifications of changes in resident behavior rather than relying on the staff to engage and retrieve data from a novel and unfamiliar source might have increased their understanding of the utility of the technology and its relevance to their daily practice. Providing actionable, customized information on residents at risk would demonstrate the potential benefits of continuous monitoring over standard procedures regarding transitions in care.

Conclusions

The limitations of previous work describing the intent to use technology without the inclusion of actual use as the final outcome are demonstrated by our findings. Initial enthusiasm and support for in-home, continuous monitoring of activity and behavior was established among the staff of 7 continuing care residential communities. Nevertheless, multiple factors, whether technical, personal, or institutional, intervened between intent and use. Future research examining technology adoption cannot ignore this crucial outcome measure if widespread acceptance and implementation of health care technologies are to be advanced. Finally, and perhaps most importantly, future work should examine whether a culture change toward proactive intervention to prevent or safely delay unwanted care transitions, rather than using technology for emergency response and acute situational management, will achieve wider use of technologies across residential care communities and related settings.

Conflicts of Interest

None declared.

Multimedia Appendix 1

End of study discussion guide.
[DOCX File , 13 KB-Multimedia Appendix 1]

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Abbreviations

AIMS: Ambient Independence Measures for Guiding Care Transitions
CCRC: continuing care retirement community
TAM: Technology Acceptance Model
ORCATECH: Oregon Center for Aging & Technology

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