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Contents

Original Papers

Original Paper

Optimizing e-Consultations to Adolescent Medicine Specialists: Qualitative Synthesis of Feedback From User-Centered Design

Jacquelin Rankine[1*], MD, MSc; Deepika Yeramosu[2*], BSc; Loreta Matheo[1], MD; Gina M Sequeira[1,3], MD, MSc; Elizabeth Miller[1], MD, PhD; Kristin N Ray[2], MD, MSc

[1]Division of Adolescent and Young Adult Medicine, Department of Pediatrics, University of Pittsburgh School of Medicine, UPMC Children's Hospital of Pittsburgh, Pittsburgh, PA, United States

[2]Department of Pediatrics, University of Pittsburgh School of Medicine, UPMC Children's Hospital of Pittsburgh, Pittsburgh, PA, United States

[3]Division of Adolescent Medicine, Seattle Children's Hospital, Seattle, WA, United States

[*]these authors contributed equally

Corresponding Author:
Jacquelin Rankine, MD, MSc
Division of Adolescent and Young Adult Medicine, Department of Pediatrics
University of Pittsburgh School of Medicine
UPMC Children's Hospital of Pittsburgh
120 Lytton Avenue
Pittsburgh, PA, 15213
United States
Phone: 1 412 692 7711
Fax: 1 412 692 7532
Email: jacquelin.rankine@chp.edu

Abstract

Background: e-Consultations between primary care physicians and specialists are a valuable means of improving access to specialty care. Adolescents and young adults (AYAs) face unique challenges in accessing limited adolescent medicine specialty care resources, which contributes to delayed or forgone care. e-Consultations between general pediatricians and adolescent medicine specialists may alleviate these barriers to care. However, the optimal application of this model in adolescent medicine requires careful attention to the nuances of AYA care.

Objective: This study aims to qualitatively analyze feedback obtained during the iterative development of an e-consultation system for communication between general pediatricians and adolescent medicine specialists tailored to the specific health care needs of AYAs.

Methods: We conducted an iterative user-centered design and evaluation process in two phases. In the first phase, we created a static e-consultation prototype and storyboards and evaluated them with target users (general pediatricians and adolescent medicine specialists). In the second phase, we incorporated feedback to develop a functional prototype within the electronic health record and again evaluated this with general pediatricians and adolescent medicine specialists. In each phase, general pediatricians and adolescent medicine specialists provided *think-aloud* feedback during the use of the prototypes and semistructured exit interviews, which was qualitatively analyzed to identify perspectives related to the usefulness and usability of the e-consultation system.

Results: Both general pediatricians (n=12) and adolescent medicine specialists (n=12) perceived the usefulness of e-consultations for AYA patients, with more varied perceptions of potential usefulness for generalist and adolescent medicine clinicians. General pediatricians and adolescent medicine specialists discussed ways to maximize the usability of e-consultations for AYAs, primarily by improving efficiency (eg, reducing documentation, emphasizing critical information, using autopopulated data fields, and balancing specificity and efficiency through text prompts) and reducing the potential for errors (eg, prompting a review of autopopulated data fields, requiring physician contact information, and prompting explicit discussion of patient communication and confidentiality expectations). Through iterative design, patient history documentation was streamlined, whereas documentation of communication and confidentiality expectations were enhanced.

Conclusions: Through an iterative user-centered design process, we identified user perspectives to guide the refinement of an e-consultation system based on general pediatrician and adolescent medicine specialist feedback on usefulness and usability related to the care of AYAs. Qualitative analysis of this feedback revealed both opportunities and risks related to confidentiality, communication, and the use of tailored documentation prompts that should be considered in the development and use of e-consultations with AYAs.

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KEYWORDS

referral; consultation; telemedicine; telehealth; adolescents; child health; child health services; confidentiality; access to health care

Introduction

Background

Although general pediatricians manage a variety of adolescent health concerns, referrals to adolescent medicine specialists are common. Common referrals to adolescent medicine specialists include management of menstrual disorders, sexual and reproductive health care, gender-affirming care, and behavioral health care [1]. However, adolescents and young adults (AYAs) experience barriers to completing these referrals and receiving adolescent medicine specialty care. The scarcity of board-certified adolescent medicine specialists is itself a critical barrier to the care of AYAs. The number of adolescent medicine specialists per state ranges from 3.4 adolescent medicine specialists per 100,000 children in Rhode Island to 0 adolescent medicine specialists in 4 states and Puerto Rico [2]. Owing to this lack of adolescent medicine specialists, travel distance is substantial, and appointment availability does not meet demand [3]. As a result, AYAs and their families face significant travel and time burdens, financial costs, and delays in care when seeking adolescent medicine specialty care [4-6], with these barriers falling disproportionately on families with lower socioeconomic status [7]. Even with the rapidly increasing use of live-interactive telemedicine for adolescent medicine specialty care in the context of the COVID-19 pandemic [8], both patient-side barriers (eg, low health literacy and limited internet access) and system-side barriers (eg, inadequate supply of adolescent medicine specialists to meet referral demand) remain [9].

For AYAs referred to adolescent medicine specialists for confidential health concerns, the barriers to attending these visits without the knowledge or assistance of their families may be increased or insurmountable. Confidentiality concerns have been associated with forgone care [10], decreased receipt of sexual and reproductive health services and contraception [11], and decreased screening for sexually transmitted infections among AYAs [12]. Barriers to completed referrals with pediatric subspecialists may lead primary care physicians (PCPs) to seek clinical guidance from subspecialists through alternative routes such as phone calls, text messaging, emails, or in-person *curbside consultations* [13]. These informal methods of consultation are often not accompanied by compensation for clinicians' time or the formal documentation necessary for medical-legal purposes and ongoing care management.

e-Consultations are an alternative strategy for subspecialists to offer clinical guidance to PCPs. In this asynchronous model of telehealth care, a PCP submits patient-specific information to a subspecialist, who later reviews this information and provides recommendations back to the PCP to guide their care [14]. In some cases, patient-specific guidance provided by subspecialists through e-consultations may allow PCPs to manage the patient without requiring an in-person subspecialist visit. In other cases, e-consultations may guide PCPs in evaluation or management while awaiting a subspecialist visit. e-Consultations are now used in many health systems, with evidence suggesting that this form of virtual triage and management increases access to subspecialist expertise and timeliness of appointments for patients who still require in-person subspecialty care [15-17].

Although e-consultations have the potential to increase access to adolescent medicine specialists, the application of this model within adolescent medicine requires careful attention to the nuances of adolescent care. Issues of confidentiality, consent, and communication among PCPs, adolescent medicine specialists, AYAs, and caregivers of AYAs warrant specific focus. In addition, consideration of the optimal information to transfer between PCPs and adolescent medicine specialists [18] and details of workflow, training, and documentation are needed to promote high-quality care while maintaining an efficient workflow for both PCPs and adolescent medicine specialists.

Objectives

In this study, we seek to examine feedback during the iterative development of e-consultations for communication between PCPs and adolescent medicine specialists. Informed by prior studies examining e-consultation features and design [19], we develop an initial prototype and iteratively modify it through cycles of user-centered design. In this manuscript, we share our development process, feedback themes through each design stage, and the documentation templates and workflow developed through this process.

Methods

Study Design

We conducted an iterative user-centered design and evaluation process in two phases. In phase 1, we developed a prototype e-consultation template and workflow based on a literature review and conversations with individuals using e-consultations in other settings, including the Veterans Health Administration and University of Pittsburgh Medical Center. We evaluated the static prototype and workflow storyboards with target users, including general pediatrician PCPs and adolescent medicine specialists. We incorporated feedback from this process to develop a functional prototype within the electronic health record (EHR) and again evaluated this with PCPs and adolescent medicine specialists in phase 2. We performed a qualitative analysis of the feedback obtained through *think-aloud* commentary during the use of the prototypes and semistructured exit interviews to identify perspectives regarding e-consultations for AYA care.

Recruitment

We approached target users via email from an existing research network of primary care practices (Pediatric PittNet) and the Division of Adolescent and Young Adult Medicine of the University of Pittsburgh Medical Center Children's Hospital of Pittsburgh. The Division of Adolescent and Young Adult Medicine is the primary group of adolescent medicine specialists caring for AYAs across 26 counties in Western Pennsylvania as well as portions of Ohio and West Virginia. The general pediatrician PCPs across more than 40 practices affiliated with the Children's Hospital of Pittsburgh span both academic and community practices across 13 counties in Western Pennsylvania. Approximately one-quarter of these practices are in rural counties, and all use a shared EHR, which is also used by the Division of Adolescent and Young Adult Medicine. At the time of this study, no payers in our region paid clinicians for their time conducting store-and-forward provider-to-provider consultations. General pediatrician PCPs and adolescent medicine specialists were eligible for participation, including both academic and community general pediatricians, advanced practice providers, and trainees in fellowship. Clinicians who were not engaged in patient care were excluded from the study. The participants received US $25 gift cards. Participants were purposefully sampled to ensure a balance between PCPs and adolescent medicine specialists and diversity of years of experience and clinical effort. The University of Pittsburgh institutional review board provided ethical approval. We obtained written documentation of informed consent from participants.

Iterative Design Process

Phase 1: Static Prototype

Phase 1 was conducted from July to August 2018. A study team member (DY or KNR) met with each participant in a private office, obtained informed consent, and talked through a series of 22 slides. These slides reviewed the goals of e-consultations, the research process, prototype note templates for both PCPs and adolescent medicine specialists, and storyboards that provided a visual representation of planned workflow and prototype screenshots illustrating the planned process as a clinician worked through the system. We started with these static prototypes because they could be developed with minimal time investment and rapidly adapted in response to feedback. During this phase, data were collected through think-alouds, exit interviews, and web-based surveys. Changes were made to the prototype after every 3 participants to continuously incorporate feedback.

Phase 2: EHR Prototype

After incorporating feedback from phase 1, we developed a functional electronic prototype within the play environment of our EHR (EpicCare). Phase 2 was conducted from July to September 2019. In this phase, participants were asked to complete specific tasks depending on their role (PCP vs adolescent medicine specialist).

During PCP sessions, participants were given 3 vignettes where adolescent medicine specialist advice might be sought related to polycystic ovary syndrome, gender-affirming care, and eating disorders. Participants were asked to prepare mock e-consultations for each vignette within a practice EHR environment. During the first 2 vignettes, PCPs provided think-aloud commentary while completing the task. For the third vignette, participants completed the notes at their usual working pace while their efforts were timed. For the final 3 PCP participants, mock responses created by prior adolescent medicine specialist participants were shared after the prior session components, and the PCPs were asked to *think aloud* as they reviewed and interpreted this mock advice.

During adolescent medicine specialist sessions, participants were given 3 mock e-consultations (1 for each vignette) generated by PCP participants during prior PCP sessions without identifiers of the participating PCP. During the first 2 vignettes, adolescent medicine specialists provided think-aloud commentary while preparing mock responses. For the third vignette, participants completed the mock response at their usual working pace while their efforts were timed.

After completing these tasks, all participants completed semistructured exit interviews and the same web-based survey used in phase 1. Throughout this phase, changes were again continuously made to the EHR prototype in response to feedback.

Data Collection and Analysis

Throughout the iterative user-centered design and evaluation process, feedback was collected from PCPs and adolescent medicine specialists through the processes described above: think-aloud commentary during the use of the prototypes and semistructured exit interviews. During think-alouds, participants were asked to talk through their thoughts as they reviewed the prototypes and were encouraged to comment on possible limitations or undesirable components of the proposed system. The semistructured exit interviews included questions on the perceived usefulness and usability of the e-consultation system.

A study team member (DY or KNR) took written notes during think-alouds and exit interviews, which were deidentified and securely stored. Next, 2 investigators (DY and KNR) analyzed think-aloud and exit interview data using content analysis, informed by elements of the Technology Acceptance Model and usability theory [20,21]. The results were organized around the major overarching themes of the usefulness and usability of e-consultations for AYA care.

After reviewing the prototypes, participants also completed a web-based survey with 31 questions, including demographic questions and items adapted from the Technology Acceptance Model survey [20] and the end user computer satisfaction survey [22]. Demographic data collected in the web-based survey were analyzed with descriptive statistics using Stata 14 (StataCorp). Web-based survey responses from PCPs and adolescent medicine specialists during phases 1 and 2 were compared using the Kruskal-Wallis test to ensure that we did not overly adapt the design to favor one group (PCPs vs adolescent medicine specialists) at the expense of the needs and preferences of the other.

Results

Participants

Participants included 12 general pediatrician PCPs and 12 adolescent medicine specialists (Table 1). Participants included individuals in training (n=6) as well as individuals with more than 20 years of practice (n=9). Participant characteristics were similar in each phase with the exception of years of experience, with more clinicians with more than 21 years in practice in phase 1 (n=7; 6 PCPs and 1 adolescent medicine specialist) than in phase 2 (n=2; 1 PCP and 1 adolescent medicine specialist).

Table 1. Participant characteristics of phase 1 and phase 2.

Characteristics	Phase 1: static prototype (n=12), n (%)	Phase 2: EHR[a] prototype (n=12), n (%)
Clinician type		
PCP[b]	6 (50)	6 (50)
Adolescent medicine specialist	6 (50)	6 (50)
Duration of clinical practice		
Currently in training	2 (17)	4 (33)
0-5 years	2 (17)	4 (33)
6-10 years	1 (8)	0 (0)
11-20 years	0 (0)	2 (17)
>21 years	7 (58)	2 (17)
Clinical time (half-days weekly)		
0-2	3 (25)	4 (33)
3-4	4 (33)	3 (25)
5-6	3 (25)	2 (17)
>7	2 (17)	3 (25)
Gender		
Male	3 (25)	2 (17)
Female	8 (67)	10 (83)
Other or prefer not to answer	1 (8)	0 (0)

[a] EHR: electronic health record.

[b] PCP: primary care physician.

Perceived Usefulness

Regarding the usefulness of e-consultations, PCPs and adolescent medicine specialists perceived potential advantages for patients, including themes of improving access to care, increasing timeliness and convenience of care, reducing travel burden, and enhancing the role of the patient-centered medical home (Table 2).

Table 2. Participant perspectives on the usefulness of e-consultations.

Domain	Primary care themes	Adolescent medicine themes
Relative advantage for patients (vs traditional options)	• Reduces visits (+)[a] • Increases timeliness of care (+) • Increases access for patients with barriers (+) • Increases communication (+) • Improves health care for patients (+)	• Reduces visits (+) • Increases timeliness of care (+) • Increases convenience (+) • Decreases transportation barriers (+) • Keeps care within the medical home (+) • May lead to increased PCP[b] visits in lieu of specialty visits (+/−)[c]
Relative advantage for clinicians (vs traditional options)	• Facilitates communication with a specialist in a more structured way (+) • Value in PCP getting answers for patient and family (+) • Takes a lot of PCP time (−)[d] • Adoption will require adequate payment for time (+/−) • May be better for some clinical scenarios than other (+/−)	• Consult will provide structure and documentation to activities specialists already do (+) • Could use to connect with other specialists or sub-specialists (+) • May help to ensure PCP provides information needed for a consult (+)
Value for generalists versus specialists	• Makes the process easier for specialists but increases work for PCPs (−)	• PCPs may not be comfortable with carrying out adolescent medicine plan (−)
Complexity	• Difficult to anticipate what specialist needs to know (−)	• Difficult to know what PCPs should be expected to include in a consult (−) • Difficult to know what management PCPs are comfortable initiating (−)
Compatibility	• Slightly repetitive of documentation for the visit itself (−)	• Anticipate fitting easily into everyday workflow (+) • Fitting into the workday will depend on the volume (−) • Interoperability issues with other EHRs[e] (−) • Would be ideal if integrated with the scheduling process (+/−)
Learning incentive	• Will lead to less reliance on specialists in the future (+)	• Will help PCPs learn for future patients (+) • May lead to fewer consults in the future (+)
Expected frequency	• Would use on a regular basis (+)	• Definitely anticipate using (+)

[a] Theme perceived as a positive effect of e-consultations.

[b] PCP: primary care physician.

[c] Theme perceived as a positive or negative effect of e-consultations.

[d] Theme perceived as a negative effect of e-consultations.

[e] EHR: electronic health record.

PCP and adolescent medicine specialist perceptions of the advantages of e-consultations for clinicians were more variable. Although adolescent medicine specialists felt that e-consultations would provide structure and documentation to activities that specialists already do, PCPs identified a burden on their time and desired adequate reimbursement in a fee-for-service environment. Similarly, regarding the value for generalists versus specialists, PCPs felt that e-consultations would make the referral process easier for specialists while increasing the workload of PCPs. Regarding the complexity of the process, adolescent medicine specialists expressed concern that PCPs may not be comfortable carrying out their management plans, and both groups noted the complexity of anticipating the knowledge that the other clinician would need. Regarding the compatibility of e-consultations, PCPs raised concerns about duplicating their work, and adolescent medicine specialists expressed varying degrees of concern about incorporating e-consultations into their daily workflow and interoperability with other EHRs. Both PCPs and adolescent medicine specialists noted learning incentives related to increasing PCP knowledge of AYA health concerns and decreasing reliance on specialists for this care in the future. Both groups anticipated the frequent use of e-consultations.

Perceived Usability

Efficiency was a common focus for both PCPs and adolescent medicine specialists, with comments falling into four themes. First, participants recognized the importance of reducing documentation time by avoiding redundancy, minimizing free-text entry, and using drop-down menus (Table 3). Second, they recommended organizational changes to emphasize critical information, including prompting for the specific consult question at the beginning of the templated note. Third, they encouraged maximizing the use of autopopulated data fields. Fourth, they balanced these recommendations for efficient documentation with the need for adequately detailed information. For example, an adolescent medicine specialist recommended using diagnosis-specific templates tailored to referral reason, whereas a PCP worried that too many prompts might be interpreted as guidance to perform history or exam components that may be unnecessary and overly burdensome for specific patients.

Comments related to usability also frequently addressed reducing potential errors within the four themes. First, recommendations to use autopopulated fields to enhance efficiency were tempered with the acknowledgment that autopopulated fields can contain inaccurate or outdated information, leading to recommendations to follow autopopulated data fields with prompts to encourage PCP review and annotation of autopopulated data. Second, the importance of ensuring accurate information for interprofessional communication was emphasized. Third, both PCPs and adolescent medicine specialists advocated for prompts for specific patient and clinical information. These recommendations included prompts for PCPs relevant to the care of AYAs (eg, affirmed name and pronouns), prompts for adolescent medicine specialists to enhance the specificity of their recommendations (eg, exact laboratory test order number), and simple text changes to enhance clarity overall (eg, replacing *follow-up with adolescent* with *follow-up with Adolescent Medicine Clinic*). Fourth, the importance of prompts related to confidentiality was noted both to inform follow-up communication and ensure appropriate confidential documentation within the EHR, if needed.

Comments related to the affective experience of using e-consultations were mixed. Although some users found the amount of data entry to be frustrating and burdensome, others commented that the process was straightforward and clear. Both PCPs and adolescent medicine specialists felt that the e-consultation process was generally easy to learn with minimal training.

Table 3. Participant perspectives on the usability of e-consultations.

Domain and theme	Subtheme
Efficiency	
Reduce documentation time	• Avoid redundant documentation (PCP[a] and AM[b]) • Minimize free text (PCP and AM) • Use drop-down menus when possible (PCP and AM) • Allow the ability to incorporate images (AM)
Organize to prioritize relevant data and questions	• Place question to a specialist upfront to frame the consult (PCP and AM)
Maximize autopopulated data field use	• Pull in existing data fields (eg, family history) to avoid redundant data entry (PCP) • Place free text after relevant autopopulated data to avoid duplicating information (PCP) • Allow objective data to be pulled in and interpreted (eg, BMI percentiles; AM)
Balance efficiency of documentation with the efficiency of the process	• Develop diagnosis-specific templates to enhance efficient data sharing (AM) • Template prompts may be interpreted as a mandate for PCP to obtain information and may increase the burden of the documentation process (PCP)
Freedom from errors	
Minimize potential errors in autopopulated data in EHR[c]	• Autopopulating data fields contain errors and need PCP review (AM and PCP) • Data with a high error rate should be entered rather than pulled in (PCP)
Ensure accurate information for interprofessional communication	• Specialist needs information on how to get in touch with PCP if needed (PCP and AM) • Communicating with PCP by phone is sometimes better than electronically (AM) • PCP would like clarity about which specialist is receiving the consult (PCP)
Maximize clarity of prompts for specific patient and clinical information	• Maximize clarity of the desired outcome of consult (PCP) • Provide specific prompts for key information (eg, preferred language, pronouns; AM) • Maximize clarity of language (AM) • Templates tailored to specific complaints may reduce missing key information (PCP) • Specialist reply templates should use prompts for specific recommendations (eg, lab test order numbers, medication dosing, follow-up interval; PCP and AM)
Maximize clarity of prompts about confidentiality and communication	• Specify parent involvement (or lack thereof) in consultation (AM) • Specify the degree of confidentiality to be maintained (AM and PCP) • Specify whether adolescent, parent, or PCP could be contacted (AM)
Affective experience	
Potential frustration versus straightforward	• Amount of data entry could be frustrating and increase cognitive burden (PCP) • Use blank space and text formatting to increase readability (PCP) • System is straightforward and clear (AM)
Learnability	
Learnable	• System is easy to learn and use; building on familiar design is helpful (PCP) • Recommend focused training in the use of e-consultations (<20 minutes; AM)

[a] PCP: primary care physician.

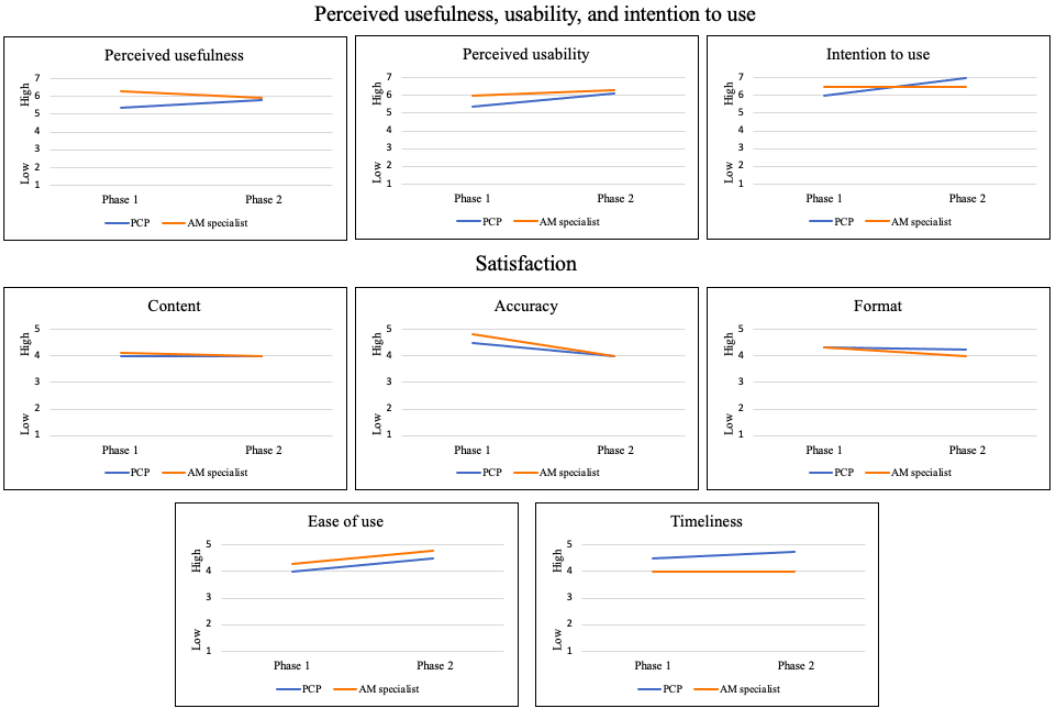
[b] AM: adolescent medicine.

[c] EHR: electronic health record.

Survey Results

During phase 1, PCPs' responses trended lower for perceived usefulness and usability compared with adolescent medicine specialists (*P*=.05; Figure 1). During phase 2, PCPs' perceptions of these domains increased, such that PCPs and adolescent medicine specialists had more similar assessments of e-consultations.

Figure 1. Perceived usefulness, usability, intention to use, and system satisfaction. AM: adolescent medicine; PCP: primary care physician.



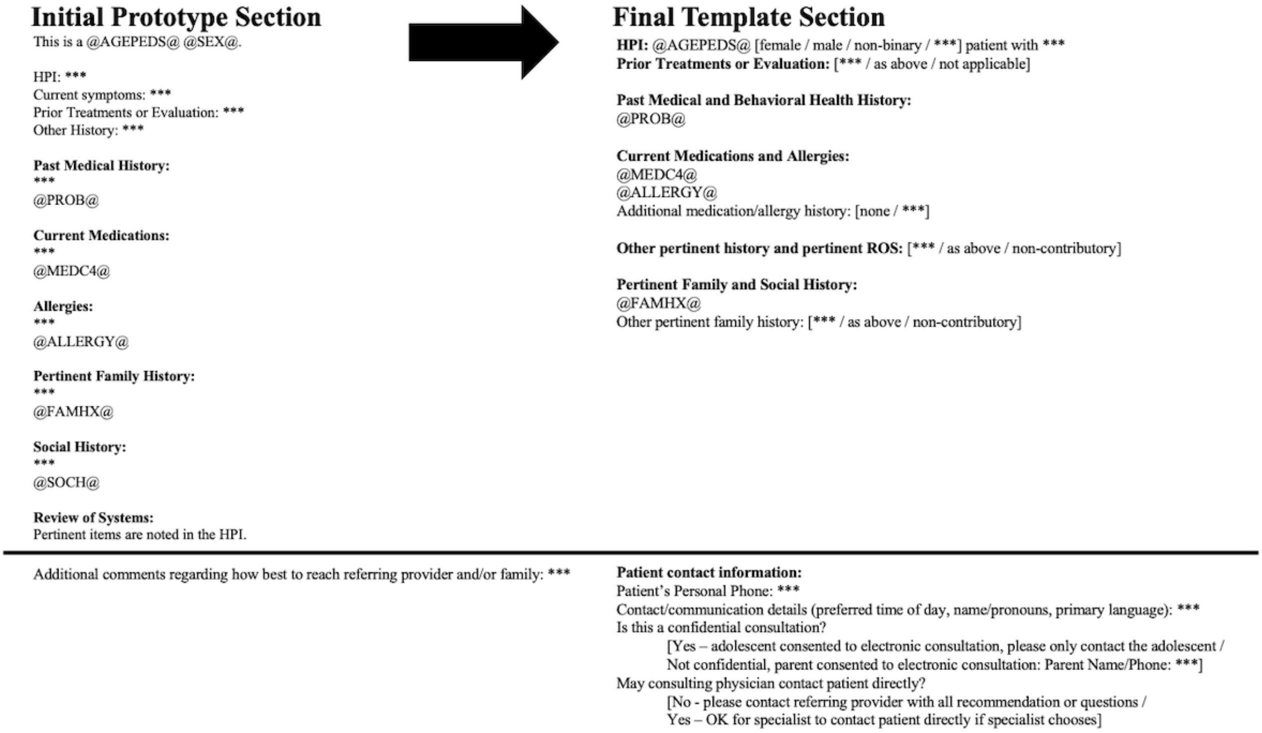
During the timed tasks during phase 2, the median time for PCPs to enter the mock e-consultation was 6 minutes 9 seconds (range 4 minutes 31 seconds-7 minutes 26 seconds). The median time for subspecialists to review and respond to the mock e-consultation was 7 minutes 49 seconds (range 3 minutes 56 seconds-11 minutes 8 seconds).

Iterative Design Changes

During the first phase of development, we made changes based on feedback as participants reviewed the static prototype. For the PCP note template requesting the e-consultation, we moved the consult question for the adolescent medicine specialist to the beginning of the note template, changed the order of items to enhance accuracy and efficiency when autopopulated text was pulled in, and reduced the number of unique prompts across the review of systems, physical exam, family history, and social history fields. Although these portions were streamlined, other specific prompts relevant to the care of AYAs (eg, gender identity, confidentiality, and contact information for patients and families, and PCP) were enhanced. For the adolescent medicine specialist note template responding to the e-consultation, substantially more details were added regarding follow-up recommendations (eg, location, interval, and the specific adolescent medicine specialist to be seen if relevant).

During the second phase of development, we made further changes based on feedback as participants interacted with an EHR prototype (Figures 2 and 3). We added drop-down boxes to most open-ended prompts to allow rapid selection of *as above* if a clinician had already addressed a specific prompt. We consolidated multiple prompts for review of autopopulated text throughout the template into one prompt, which was placed after autopopulated information on past medical history, allergies, and medications, providing a single opportunity to review and add to these automated fields. In addition, prompts were added to pull the objective data with interpretation (eg, BMI percentiles). Furthermore, we clarified the language around contact information and confidentiality expectations for the PCP, adolescent medicine specialist, and patient and included free-text response options to clarify complex privacy concerns if needed (eg, providers may communicate with one parent but not the other). The final note templates are included in their entirety in Multimedia Appendix 1.

Figure 2. Changes in primary care physician e-consultation request note template through the iterative design process.



Initial Prototype Section

This is a @AGEPEDS@ @SEX@.

HPI: ***
Current symptoms: ***
Prior Treatments or Evaluation: ***
Other History: ***

Past Medical History:
***
@PROB@

Current Medications:
***
@MEDC4@

Allergies:
***
@ALLERGY@

Pertinent Family History:
***
@FAMHX@

Social History:
***
@SOCH@

Review of Systems:
Pertinent items are noted in the HPI.

Additional comments regarding how best to reach referring provider and/or family: ***

Final Template Section

HPI: @AGEPEDS@ [female / male / non-binary / ***] patient with ***
Prior Treatments or Evaluation: [*** / as above / not applicable]

Past Medical and Behavioral Health History:
@PROB@

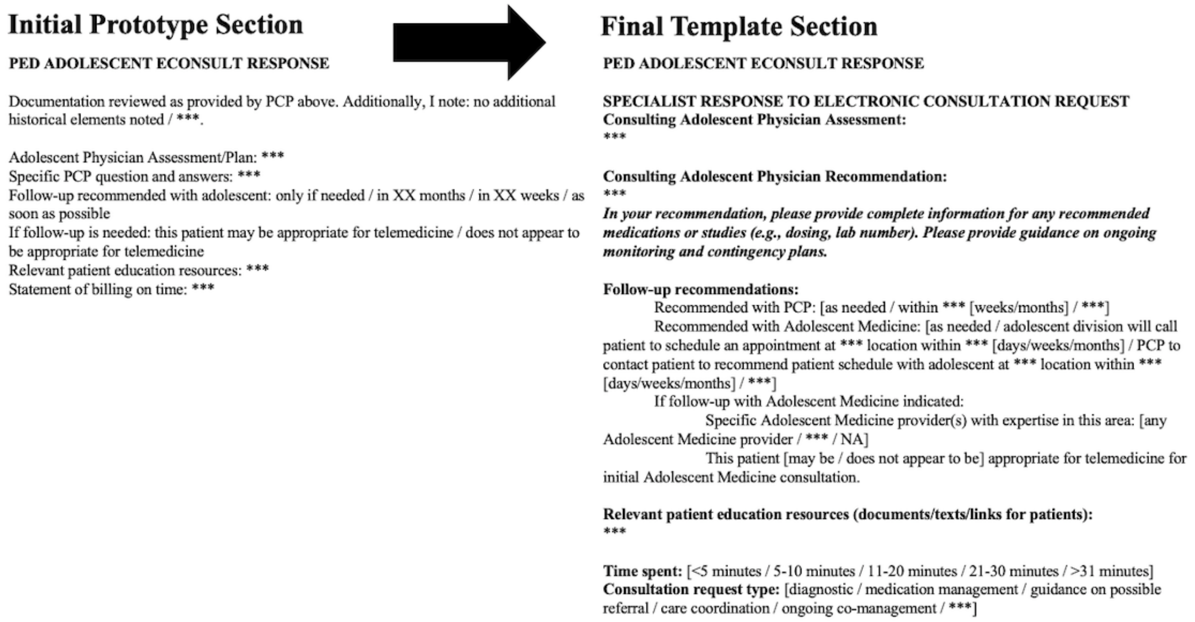
Current Medications and Allergies:
@MEDC4@
@ALLERGY@
Additional medication/allergy history: [none / ***]

Other pertinent history and pertinent ROS: [*** / as above / non-contributory]

Pertinent Family and Social History:
@FAMHX@
Other pertinent family history: [*** / as above / non-contributory]

Patient contact information:
Patient's Personal Phone: ***
Contact/communication details (preferred time of day, name/pronouns, primary language): ***
Is this a confidential consultation?
[Yes – adolescent consented to electronic consultation, please only contact the adolescent / Not confidential, parent consented to electronic consultation: Parent Name/Phone: ***]
May consulting physician contact patient directly?
[No - please contact referring provider with all recommendation or questions / Yes – OK for specialist to contact patient directly if specialist chooses]

Figure 3. Changes in adolescent medicine specialist e-consultation response note template through the iterative design process.



Initial Prototype Section

PED ADOLESCENT ECONSULT RESPONSE

Documentation reviewed as provided by PCP above. Additionally, I note: no additional historical elements noted / ***.

Adolescent Physician Assessment/Plan: ***
Specific PCP question and answers: ***
Follow-up recommended with adolescent: only if needed / in XX months / in XX weeks / as soon as possible
If follow-up is needed: this patient may be appropriate for telemedicine / does not appear to be appropriate for telemedicine
Relevant patient education resources: ***
Statement of billing on time: ***

Final Template Section

PED ADOLESCENT ECONSULT RESPONSE

SPECIALIST RESPONSE TO ELECTRONIC CONSULTATION REQUEST
Consulting Adolescent Physician Assessment:
***

Consulting Adolescent Physician Recommendation:
***
In your recommendation, please provide complete information for any recommended medications or studies (e.g., dosing, lab number). Please provide guidance on ongoing monitoring and contingency plans.

Follow-up recommendations:
Recommended with PCP: [as needed / within *** [weeks/months] / ***]
Recommended with Adolescent Medicine: [as needed / adolescent division will call patient to schedule an appointment at *** location within *** [days/weeks/months] / PCP to contact patient to recommend patient schedule with adolescent at *** location within *** [days/weeks/months] / ***]
If follow-up with Adolescent Medicine indicated:
Specific Adolescent Medicine provider(s) with expertise in this area: [any Adolescent Medicine provider / *** / NA]
This patient [may be / does not appear to be] appropriate for telemedicine for initial Adolescent Medicine consultation.

Relevant patient education resources (documents/texts/links for patients):
***

Time spent: [<5 minutes / 5-10 minutes / 11-20 minutes / 21-30 minutes / >31 minutes]
Consultation request type: [diagnostic / medication management / guidance on possible referral / care coordination / ongoing co-management / ***]

Discussion

Principal Findings

We used a replicable user-centered design process to develop and refine e-consultation templates and processes for general pediatrician consultation with adolescent medicine specialists. We qualitatively analyzed user feedback during two phases of development to guide the revision of our e-consultations and produced a final prototype with similar perceived usefulness and usability among PCPs and adolescent medicine specialists. Our iterative design process and feedback themes may inform the development of similar e-consultation systems in other settings. In particular, by engaging experts in pediatric and adolescent health in our user-centered design process, we identified specific considerations for the use of e-consultations with AYAs to promote safe, equitable, and high-quality care for this population.

Participants identified both opportunities and risks for the use of e-consultations with AYAs related to confidentiality. A major perceived advantage was the potential to enhance access to confidential care for AYAs. AYAs may delay or forgo care because of a lack of knowledge of how or where to obtain services, transportation challenges, and concerns about maintaining confidentiality [23,24]. e-Consultations were perceived as a means to ameliorate these barriers faced by AYAs in traditional primary care to subspecialty referral models by allowing adolescent medicine specialist-guided care of confidential health concerns either without the need for an in-person adolescent medicine visit or with PCP-facilitated handoff to adolescent medicine care. By providing point-of-care education for PCPs during e-consultations, this process may also enhance PCP's ability to deliver care for future confidential health concerns. A perceived threat to confidentiality was the potential for miscommunication between PCPs and adolescent medicine specialists regarding patients' preferences for contact and expectations of confidentiality. To reduce this risk, it was recommended that e-consultations for use with AYAs include prompts to document patients' preferred contact information and explicit expectations surrounding confidentiality. Such prompts could have the additional benefit of encouraging PCPs to discuss laws governing confidential health care for minors and reserve time for private conversations with AYAs during their visits, features of pediatric primary care visits associated with increased disclosure of health concerns that may otherwise be lacking [25]. As laws regarding adolescent confidentiality and consent may be complex and vary among states, those developing e-consultations for AYAs may consider including details of state-specific adolescent privacy regulations to assist PCPs who are unfamiliar. Another perceived threat to confidentiality was unintended caregiver proxy access to e-consultation documentation within the EHR or receipt of an explanation of benefit statements or copays, all of which are previously identified barriers to confidential care for AYAs in general [26,27]. To reduce this risk, those developing e-consultations for use with AYAs should consider local system capacity to restrict the sharing of EHR documentation through patient portals and assess the potential to reduce breach of confidentiality through insurer explanation of benefit statements and copayments. In addition, both PCPs and adolescent medicine specialists who use e-consultations with AYAs should discuss these risks with their AYA patients and examine local options for limiting EHR documentation sharing with caregiver proxies, such as through confidential note types.

Participants further identified opportunities for the use of e-consultations with AYAs to facilitate communication. Overall, participants perceived e-consultations as a beneficial way to enhance communication between clinicians and AYAs and between PCPs and specialists. Both PCPs and adolescent medicine specialists suggested that e-consultations could increase centralized communication from the PCP to their patients, which was seen as promoting high-quality and coordinated care within the patient-centered medical home. e-Consultations were further seen as benefiting AYA health care by facilitating immediate and ongoing communication between PCPs and adolescent medicine specialists in a way not achieved through traditional referral methods [28,29]. The immediate discourse opened through e-consultations was seen as enhancing care by avoiding unnecessary visits to adolescent medicine specialists, identifying when alternative visit types (eg, telemedicine visits) might be appropriate, and triaging the immediacy with which patients should be seen. The ongoing communication facilitated by e-consultations was perceived to both enhance coordination of care and provide valuable opportunities for PCPs to enhance their adolescent health skills, a finding suggested in prior qualitative work and hinted at through a study of referral patterns throughout time [30,31].

AYA-specific e-consultation templates were also seen as a means of enhancing the quality of care for AYAs. Perceived opportunities to improve AYA care delivered by PCPs included placing prompts in PCP templates for patients' names and pronouns—information integration to the sensitive and respectful care of AYAs that may otherwise not be elicited, may not align with EHR documentation, and which AYAs may be reticent to disclose without such signals from providers that they are in a safe space [32]. Condition-specific templates were also identified as an opportunity to ensure that necessary clinical information is transmitted from PCPs to adolescent medicine specialists to allow accurate, timely, and informed recommendations. Although participants saw potential in the ability to specify the information needed for effective collaboration through e-consultation templates, they also acknowledged that excessive documentation might become burdensome and decrease the uptake of e-consultations, a concern raised in prior studies as well [19].

The ability to refine the minimum required documentation to balance efficiency and precision in e-consultations shows the value of iterative user-centered design in this context. Using a multiphase development process including think-alouds, exit interviews, and surveys with representative users, we elicited increasingly specific feedback that facilitated the first broad updates to the content and layout of the e-consultation prototypes and later finer changes to the template language. By engaging users who were both generalists and specialists, we were able to increase the alignment of PCP and adolescent medicine specialist perceptions throughout time through iterative modification with input from both sides. Such user-centered design has the potential to increase the uptake and acceptability of new health information technologies [33] and may be valuable in tailoring existing technologies to promote optimal care of populations with unique health care needs, including AYAs.

Limitations

The user-centered design process outlined here is both a strength and a limitation of this study. Our study included a small number of participants from a single geographic area and practice within a specific clinical context. This allowed the creation of a tailored e-consultation system that may be readily implemented within our local health system but which may lack generalizability or acceptability for other health systems broadly, including those without compatible EHR systems across general pediatric and adolescent medicine specialty practices (although the lessons learned about needed content in these notes could apply to other systems as well). As a result, the themes identified from this development process should be viewed as starting places for conversations in systems other than final recommendations. We also note that the years in practice for PCPs and adolescent medicine specialists varied from phase 1 to phase 2. As this analysis focused on design rather than the implementation of e-consultations, it does not include the evaluation of quality or outcomes of use. Although e-consultations were perceived to have high usefulness and usability during the design process, new concerns may arise during implementation [34,35]. In addition, this study was conducted before dramatic increases in the use of live-interactive telemedicine during the COVID-19 pandemic [8], which may alter the perceived usefulness and intention to use e-consultations in a shifting pediatric care delivery landscape. Finally, we did not include AYAs or caregivers in the design process. Both groups may have additional preferences regarding system design, as evidenced by work with pediatric patients and caregivers [36,37], such that additional work specifically with AYAs and AYA caregivers is warranted.

Conclusions

In conclusion, we used an iterative user-centered design process to develop and refine e-consultations for use by general pediatric PCPs and adolescent medicine specialists. We used qualitative analysis of user feedback elicited during the design process to identify themes relevant to the development and implementation of similar e-consultation systems for use in other health systems or among other patient populations. By engaging experts in the care of children and adolescents in the design process, we identified both opportunities and risks related to confidentiality, communication, and the use of tailored documentation prompts that should be considered in the development and use of e-consultations with AYAs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Final templates for adolescent medicine e-consultation requests and responses.

[DOCX File , 16 KB - humanfactors_v8i3e25568_app1.docx]

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Abbreviations

AYA: adolescent and young adult
EHR: electronic health record
PCP: primary care physician

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Original Paper

MI-PACE Home-Based Cardiac Telerehabilitation Program for Heart Attack Survivors: Usability Study

Eric Y Ding[1], MS; Nathaniel Erskine[2], MD, PhD; Wim Stut[3], PhD; David D McManus[1], BS; Amy Peterson[4], RN, BSN, MS; Ziyue Wang[1], MS; Jorge Escobar Valle[5], MD; Daniella Albuquerque[1], BS; Alvaro Alonso[1], MD; Naomi F Botkin[1], MD; Quinn R Pack[1], MD; David D McManus[1], MD, MSc

[1]Division of Cardiology, Department of Medicine, University of Massachusetts Medical School, Worcester, MA, United States
[2]Department of Anesthesiology, Duke University, Durham, NC, United States
[3]Philips Research, Eindhoven, Netherlands
[4]University of Massachusetts Memorial Marlborough Hospital, Marlborough, MA, United States
[5]MaineHealth Cardiology, Maine Medical Center, Augusta, ME, United States

Corresponding Author:
Eric Y Ding, MS
Division of Cardiology
Department of Medicine
University of Massachusetts Medical School
55 Lake Ave North
Worcester, MA, 01655
United States
Phone: 1 5088561984
Email: eric.ding@umassmed.edu

Abstract

Background: Cardiac rehabilitation programs, consisting of exercise training and disease management interventions, reduce morbidity and mortality after acute myocardial infarction.

Objective: In this pilot study, we aimed to developed and assess the feasibility of delivering a health watch–informed 12-week cardiac telerehabilitation program to acute myocardial infarction survivors who declined to participate in center-based cardiac rehabilitation.

Methods: We enrolled patients hospitalized after acute myocardial infarction at an academic medical center who were eligible for but declined to participate in center-based cardiac rehabilitation. Each participant underwent a baseline exercise stress test. Participants received a health watch, which monitored heart rate and physical activity, and a tablet computer with an app that displayed progress toward accomplishing weekly walking and exercise goals. Results were transmitted to a cardiac rehabilitation nurse via a secure connection. For 12 weeks, participants exercised at home and also participated in weekly phone counseling sessions with the nurse, who provided personalized cardiac rehabilitation solutions and standard cardiac rehabilitation education. We assessed usability of the system, adherence to weekly exercise and walking goals, counseling session attendance, and disease-specific quality of life.

Results: Of 18 participants (age: mean 59 years, SD 7) who completed the 12-week telerehabilitation program, 6 (33%) were women, and 6 (33%) had ST-elevation myocardial infarction. Participants wore the health watch for a median of 12.7 hours (IQR 11.1, 13.8) per day and completed a median of 86% of exercise goals. Participants, on average, walked 121 minutes per week (SD 175) and spent 189 minutes per week (SD 210) in their target exercise heart rate zone. Overall, participants found the system to be highly usable (System Usability Scale score: median 83, IQR 65, 100).

Conclusions: This pilot study established the feasibility of delivering cardiac telerehabilitation at home to acute myocardial infarction survivors via a health watch–based program and telephone counseling sessions. Usability and adherence to health watch use, exercise recommendations, and counseling sessions were high. Further studies are warranted to compare patient outcomes and health care resource utilization between center-based rehabilitation and telerehabilitation.

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KEYWORDS

cardiac rehabilitation; telerehabilitation; health watch; mHealth; exercise

Introduction

Cardiac rehabilitation provides longitudinal cardiopulmonary exercise training with additional disease management interventions to patients with cardiovascular diseases [1,2]. Participation in cardiac rehabilitation is guideline-recommended after many acute cardiovascular events because it can lower cardiovascular mortality, reduce hospital readmissions, and improve quality of life [3,4]. However, many eligible patients never receive referrals for cardiac rehabilitation, and a high proportion of patients who receive referrals never enroll [5-10]. This may be due to numerous factors, such as cost of enrollment, lack of motivation, or inadequate patient education regarding the benefits of cardiac rehabilitation [2]. In a scientific statement from the American Association of Cardiovascular and Pulmonary Rehabilitation, the American Heart Association, and the American College of Cardiology in 2019 [2], it was suggested that less than 1 in 6 patients participated in cardiac rehabilitation after hospitalization for myocardial infarction. Diverse patient, community, health care provider, hospital system, and insurance factors contribute to the persistent underutilization of cardiac rehabilitation [5-7,11]. Typically, outpatients perform cardiac rehabilitation in a dedicated facility under clinician supervision with limited scheduling hours. Difficulties in scheduling, traveling, and financing center-based cardiac rehabilitation help to drive poor enrollment and retention in cardiac rehabilitation [6,12].

Delivery of cardiac rehabilitation using contemporary telecommunication and smart device technologies (cardiac telerehabilitation, ie, tele-CR) may reduce logistical and financial barriers associated with cardiac rehabilitation by facilitating cardiac rehabilitation in the home [13-16]. The ability to perform cardiac rehabilitation at home may increase participation while providing comparable outcomes for patient health-related quality of life, exercise capacity, and mortality [17-21]. Consumers increasingly use internet-connected mobile and wearable devices to monitor fitness [22]; therefore, they may find tele-CR preferable to center-based cardiac rehabilitation. Furthermore, telehealth platforms can also potentially compound and extend the clinical effectiveness of cardiac rehabilitation for patients who have completed ambulatory center-based programs [23].

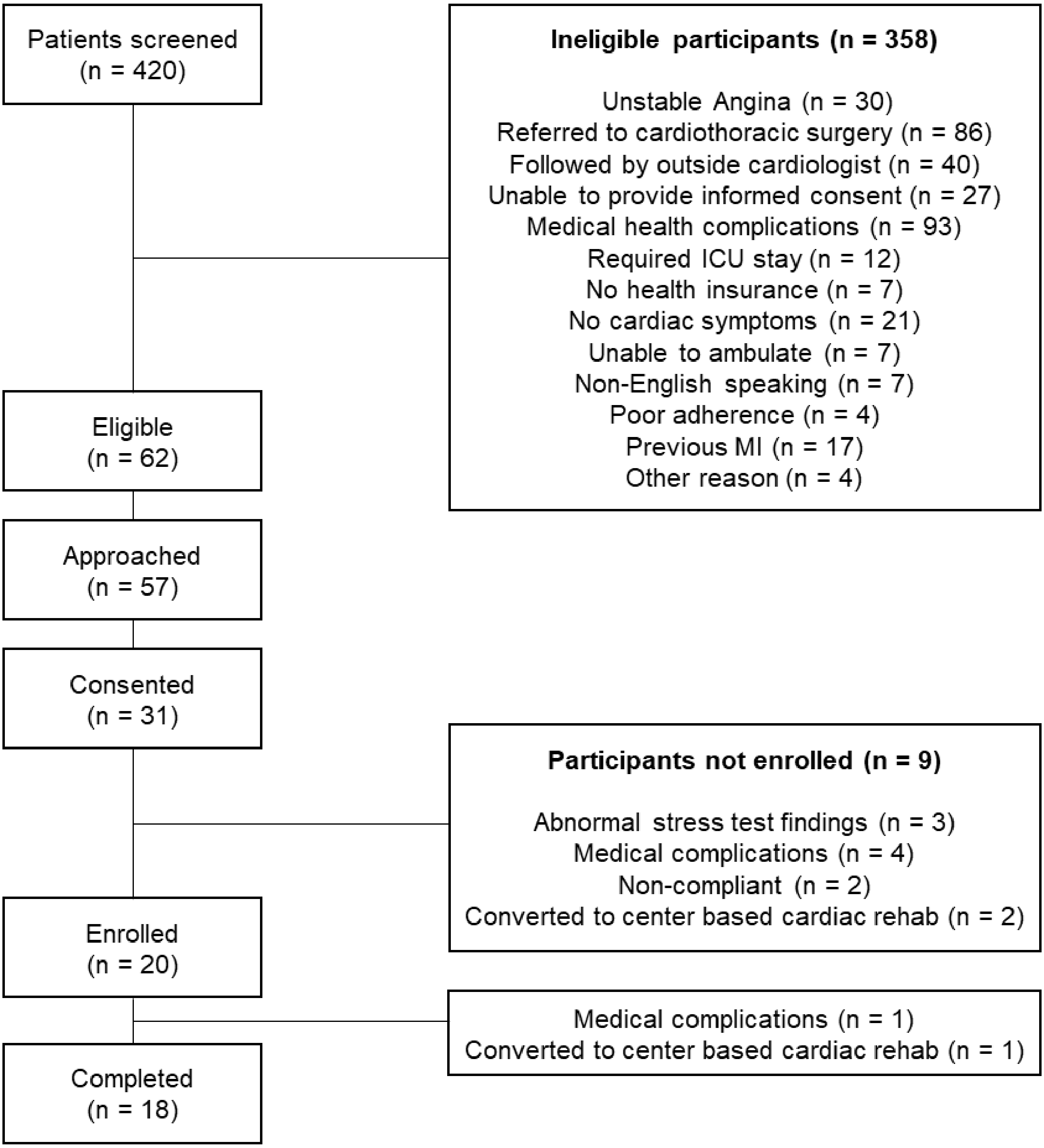
Despite the widespread need for rehabilitation after acute myocardial infarction and technological innovations in this space, wearable device–based rehabilitation solutions are still being studied for evidence to support their adoption and use, though recent developments have significantly advanced this area of research [23-26]. The development of a user-centered platform that is acceptable to patients and can impact key clinical or patient-reported outcomes will likely be a critical component of the clinical adoption of tele-CR [14]. In this study, we examined the usability of and adherence to a nurse-supported 12-week telerehabilitation intervention after acute myocardial infarction for patients who declined to participate in conventional rehabilitation. We conducted exploratory analyses to also examine changes in disease-specific quality of life rehabilitation.

Methods

Study Setting and Sample

All adults who were hospitalized at a single tertiary academic medical center in central Massachusetts for acute myocardial infarction between June and November 2018 were screened for eligibility by trained research assistants using International Classification of Disease Tenth Revision codes, problem lists, laboratory results, and electrocardiogram (ECG) findings, as validated in other studies [27]. Patients between 40 and 80 years, fluent and literate in English, meeting clinical indications for cardiac rehabilitation, and with access to an environment or facilities to perform exercise were eligible for inclusion (Figure 1). Patients who preferred to enroll in conventional center-based cardiac rehabilitation, planned to receive follow-up cardiovascular care outside of our hospital system, were unable to participate in follow-up sessions, had subsequent myocardial infarction, had no health insurance, were unable to provide informed consent, were unable to ambulate, were unable to adhere to study protocols, had unstable angina, had serious medical conditions that precluded study participation (for example, cancer), had no symptoms at the time of their presentation for myocardial infarction, underwent cardiac surgery, and were staying in the intensive care unit were excluded. We only targeted patients who chose to forego traditional, center-based cardiac rehabilitation to provide an alternative cardiac rehabilitation delivery modality; if a patient was deemed appropriate for center-based cardiac rehabilitation by their primary medical team, and agreed to enroll, we opted to avoid interfering with their prescribed management. Research assistants approached potential participants who had acute myocardial infarctions (and their care teams) prior to their discharge. Participants provided written informed consent for study participation and received training on study devices and procedures.

Figure 1. Recruitment flow diagram. MI: myocardial infarction; ICU: intensive care unit.



Study Overview

Each patient obtained a stress test within 4 weeks of screening and enrollment. At an in-person baseline visit, each participant received a watch and tablet, as well as device training. The baseline assessment during their index hospitalization included questions on perceptions of cardiac rehabilitation and disease-specific quality of life. Per standard of care for conventional cardiac rehabilitation, each participant needed to complete a clinically indicated stress test within 4 weeks of hospital discharge to assess safety for exercise and establish target heart rates for rehabilitation activities. A Bruce protocol [28] was followed, and baseline ECG, heart rate, and blood pressure were closely monitored prior to, during, and after exercise. This exercise test is divided into successive stages of increasing intensity, and patients are asked about symptoms throughout. A report is generated upon conclusion of the test and interpreted by medical staff—physician (author DDM) screened all exercise test results for abnormal findings that might place participants at risk from participation in cardiac rehabilitation; participants with concerning results were excluded from the study and referred to follow up with their treating physician. Participants with no abnormal stress test findings attended the in-person training session, during which a trained study staff member provided oral and written instructions for telerehabilitation activities at home.

Components of the Telerehabilitation Program

The MI-PACE tele-CR program included a validated wearable device (Health Watch [29]; Philips Healthcare) that was connected via Bluetooth to an Android tablet computer (Tab 4; Lenovo Group Limited). An app displayed goals and progress for exercise and walking. There was a dashboard for the cardiac rehabilitation nurse to enter the goals and to view the progress of the patients. Counseling and education sessions with the nurse were scheduled weekly over the 12-week study period.

Cardiac Rehabilitation Methods

Research staff instructed participants to complete a set number of walking sessions (light intensity) consisting of bouts of at least 2 minutes, and moderate to vigorous intensity exercise sessions. Rehabilitation counseling sessions were designed by the cardiac rehabilitation nurse and cardiologist (authors AP and DDM, respectively) a priori and were standardized to include components from center-based cardiac rehabilitation programs. Each participant's target heart rate range was set by the cardiac rehabilitation nurse based on the participant's resting and maximum heart rate and performance on the exercise stress test in accordance with conventional cardiac rehabilitation practices [30]. The number and duration of prescribed exercise and walking sessions was determined based on (1) the participant's level of physical activity prior to their acute myocardial infarction, (2) the participant's level of activity after the acute myocardial infarction, (3) exertional chest pain after their cardiac event, (4) orthopedic limitations, and (5) the participant's perceptions of their difficulty achieving exercise target goals. Weekly goals were subject to modification based on the participant's performance the preceding week. Successful completion of goals prompted an increase in the frequency or duration of the sessions, whereas a low completion percentage resulted in maintaining or decreasing the frequency or duration of sessions (with a minimum of 2 walking and 2 exercise sessions per week).

The cardiac rehabilitation nurse reviewed participant data, advised participants on weekly goals, and screened for any issues related to abnormal heart rate. Heart rate zones were modified by the nurse if new medications were prescribed or based upon a treating clinician's advice. Each week, the cardiac rehabilitation nurse contacted the participants at a time deemed preferable by the participant to perform a cardiac rehabilitation counseling session (Multimedia Appendix 1) to review exercise and walking goal completion, check heart rate values, address concerns, and deliver standard cardiac rehabilitation modules on heart disease management (ie, smoking cessation, weight management, stress management). At the end of 12-week program, the study participant returned the health watch and tablet at a study visit and completed an exit interview, which consisted of the baseline assessment components in addition to questions regarding exercise motivation and system usability in the context of the MI-PACE program. The analytical sample for this study comprised participants who completed the full 12-week program. The Philips Internal Committee for Biomedical Experiments and the University of Massachusetts Medical School institutional review board (H00013769) reviewed and approved this study.

Primary Study Outcomes

The primary study outcomes included measures of adherence to components of the cardiac rehabilitation system and its general usability. We examined adherence to the individual component with the following measures: health watch daily wear time in hours, proportion of completed weekly telephone counseling sessions, and proportion of exercise and walking sessions reaching the target duration. Completion of an exercise session was determined based on the number of minutes spent in or above the target exercise heart rate zone. Any exercise time spent below this heart rate zone was not considered cardiac rehabilitation exercise and was not counted toward the exercise goal. Completion of a tele-cardiac rehabilitation session was recorded by the cardiac rehabilitation nurse.

To assess the usability of the MI-PACE system, participants completed the 10-item System Usability Scale (SUS) at the end of the program [31]. Participants rated factors such as complexity, ease of use, and confidence in operating the system on a 5-point Likert-type scale (strongly disagree, disagree, neutral, agree, strongly agree). SUS scores have a range of 0 to 100, with higher scores indicating greater usability. SUS scores of 68 or higher are considered to indicate good usability [32].

Secondary Study Outcomes

We measured participants' daily step counts during the study period. We also determined adherence to wearing the health watch over the course of the study, by operationally defining a day of wear as registering more than 1000 steps and wearing the health watch for more than 2 hours. Participants also completed walking goals distinct from their exercise goals, defined by minutes spent walking in bouts of at least 2 minutes (regardless of them being in the target exercise heart rate zone).

Participants completed the Seattle Angina Questionnaire (SAQ) [33] to assess disease-specific quality of life at baseline and at the end of the study. The SAQ has 5 scales assessing physical limitation, angina stability, angina frequency, treatment satisfaction, and quality of life that are each scored from 0 to 100, with higher scores indicating greater disease-specific quality of life. Expert panels consider changes ≥16.0 points to be clinically meaningful [34].

Clinical Variables

Trained study staff abstracted data on participants' demographic, clinical, treatment, and laboratory characteristics during their index hospitalization from electronic health records—key clinical, electrocardiographic, and laboratory variables (troponin, ECG ST-segment changes, systolic blood pressure, and creatinine levels upon admission, history of renal dysfunction, Killip classification, use of diuretics, and instances of cardiac arrest)—to calculate the Global Registry of Acute Coronary Events (GRACE) risk scores a validated instrument [35], to ascertain severity of acute myocardial infarction and short-term prognosis. Study staff also abstracted baseline ECG information, exercise performance, and presence of symptoms from the stress test performed at study entry.

Statistical Analyses

Baseline demographic and clinical characteristics for participants are presented using percentages for categorical variables, means with standard deviations for continuous variables with normal distributions, and medians with first and third quartile values for continuous variables with skewed distributions. To examine changes in cardiac rehabilitation behaviors over the course of the study, we plotted the weekly median value and interquartile ranges for participants' mean daily health watch wear time, median and interquartile ranges of daily step count, and mean proportion of weekly exercise goals completed.

We compared baseline to end-of-study scores for the SAQ scales using Wilcoxon matched-pair signed-ranks tests due to skewed distributions.

Results

Sample Size and Baseline Characteristics

Overall, study staff screened 420 inpatient admissions for study eligibility, of whom 62 (15%) met eligibility criteria. Of the 62 patients who were eligible, 57 were approached, and 31 (54.4%) consented to participate and completed baseline interviews. Of these 31 individuals, participation in the cardiac telerehabilitation program was deemed to be safe for 20 individuals who successfully completed the baseline stress test (Figure 1). Two participants withdrew prematurely (one due to an unplanned vascular surgery and another because their cardiologist recommended transition to center-based cardiac rehabilitation); the remaining 18 participants (90%) completed the 12-week tele-CR program.

Of participants who completed the 12-week tele-CR program (n=18; age: mean 58 years, SD 7) (Table 1), 6 (33%) were women, 16 (89%) were non-Hispanic White individuals, 6 (33%) had been hospitalized for ST-segment elevation acute myocardial infarction, and the median GRACE score was 92.2 (IQR 82.2, 104.4). Notably, 9 (50%) and 7 (39%) participants reported travel and inadequate time, respectively, as obstacles to participating in center-based cardiac rehabilitation.

Table 1. Baseline characteristics of patients who completed the 12-week telerehabilitation program.

Characteristic	Value (n=18)
Age (years), mean (SD)	58 (7)
Sex, n (%)	
Female	6 (33)
Male	12 (67)
Race and ethnicity, n (%)	
Non-Hispanic White	16 (89)
Middle Eastern	1 (6)
Unspecified	1 (6)
BMI[a] (kg/m^2), median (IQR)	29.1 (27.3, 33.8)
Clinical characteristics[b], n (%)	
Atrial fibrillation or flutter	2 (11)
Chronic kidney disease	4 (22)
Depression	3 (17)
Diabetes	2 (11)
Dyslipidemia	14 (78)
Hypertension	9 (50)
Prior myocardial infarction	0 (0)
Obstructive sleep apnea	2 (11)
Currently smokes	1 (6)
Index hospitalization data	
ST-segment elevation myocardial infarction, n (%)	6 (33)
GRACE[c] risk score, median (IQR)	92.2 (82.2, 104.4)
Maximum troponin level (mg/dL), median (IQR)	3.5 (0.8, 18.7)
Percutaneous coronary intervention, n (%)	14 (78)
Left ventricle ejection fraction (%), mean (SD)	58.8 (9.7)
Baseline cardiac rehabilitation stress test data	
Total exercise time (minutes), mean (SD)	8.4 (3.0)
Metabolic equivalent of task (METs), median (IQR)	10.1 (7.6, 13.4)

[a] BMI: body mass index.

[b] Percentages do not add to 100 because patients may have more than 1 condition.

[c] GRACE: Global Registry of Acute Coronary Events.

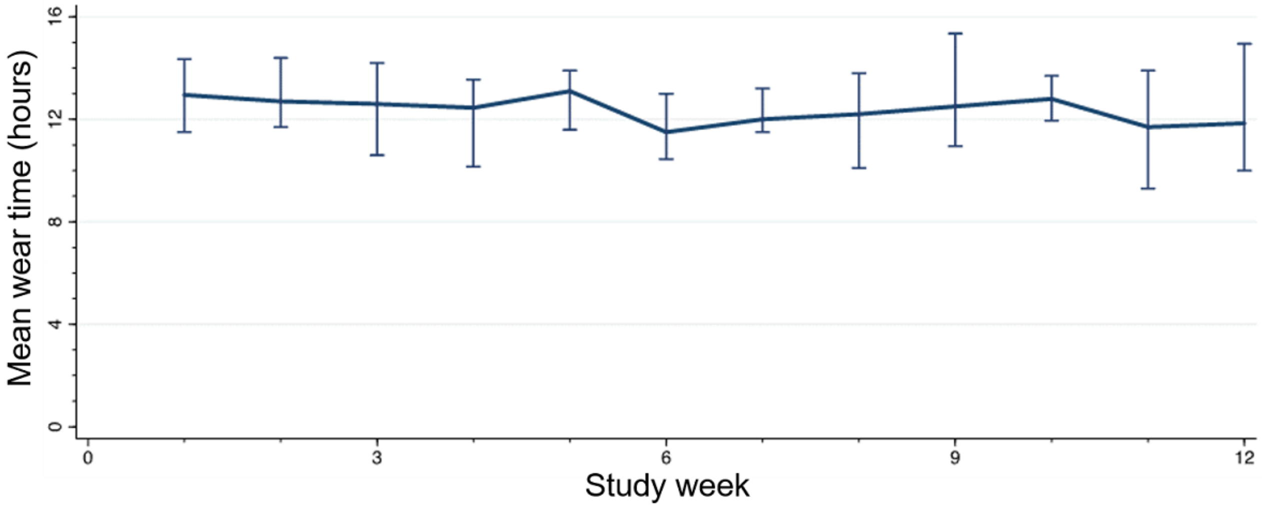
Adherence to Wearing Health Watch

Participants wore the study health watch for a median of 61 (73%) of 84 study days (IQR 35, 78) over the 12-week study period and for a median of 12.7 hours (IQR 11.1, 13.8) per day (Table 2). Daily health watch wear time was consistent over the 12-week study period, with a mean decrease in wear time of 0.06 hours (95% CI −0.15 to 0.02 hours) per week (Figure 2).

Table 2. Adherence metrics to the telerehabilitation program.

Adherence metric	Value
Daily wear time, median (IQR)	12.7 (11.1, 13.8)
Days worn, median (IQR)	61 (35, 78)
Mean percentage of exercise goals met	86.0
Mean percentage of walking goals met	33.6
Mean percentage of phone sessions completed	91.7

Figure 2. Participants' mean daily wear time by study week.



Exercise and Walking

Overall, participants completed a mean of 86% of prescribed exercise goals over the 12-week study period (Table 2). Participants completed a smaller proportion of exercise assignments over time, and there was an average decline of 8% (95% CI 3% to 13%) completion of prescribed exercise goals per additional study week (Figure 3). The overall percentage of completed walking goals for the entire study was 34% (Table 2). Completion of prescribed walking goals remained unchanged over the duration of the study with a mean weekly increase in completion rate of 1% (95% CI −12% to 14%) per additional week. The median of each participant's average daily count was 6023 steps (IQR 3940, 6920). Participants' daily step counts remained steady over the 12-week study period, with an average increase of 15 steps (95% CI −71 to 101) per additional week (Figure 4).

On average, participants walked 121 minutes per week (SD 175); the average number of walking minutes increased by 2.7 minutes per additional study week. On average participants spent 189 minutes per week (SD 210) in their exercise heart rate zone; the average number of exercise minutes decreased by 0.55 minutes per additional study week.

Figure 3. Exercise goals completed by study week.

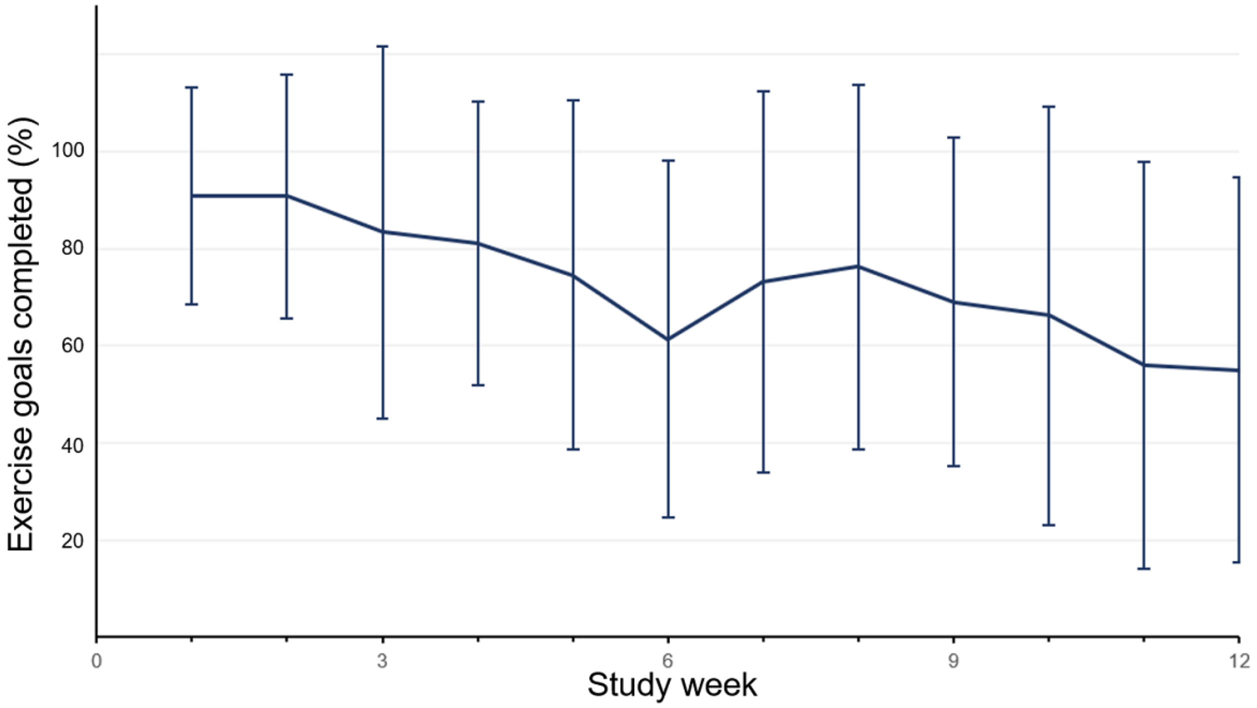
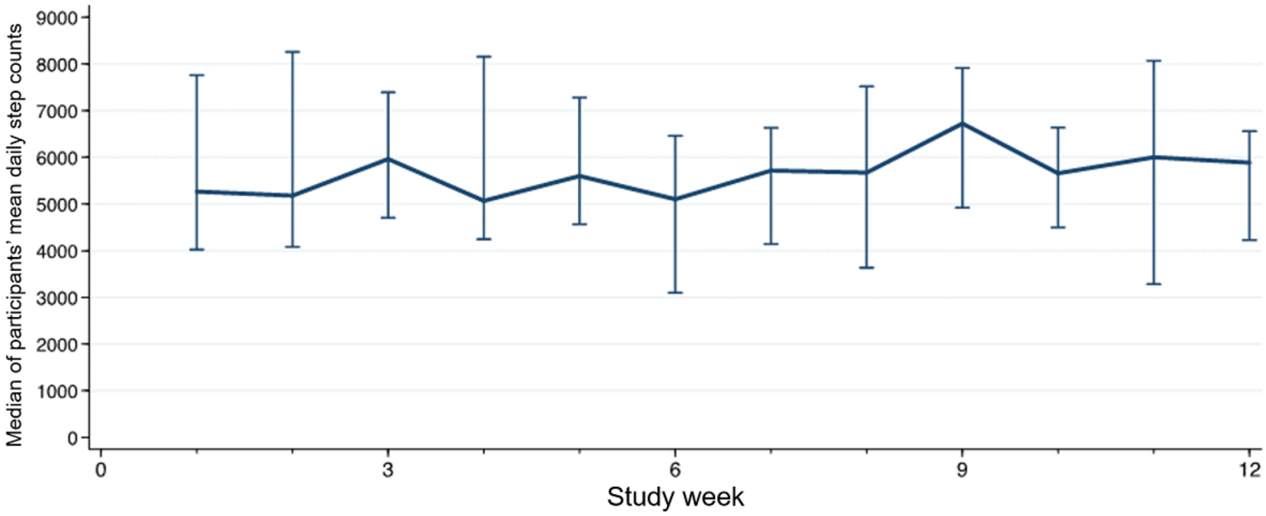


Figure 4. Median daily step count by study week.



Adherence to Tele-CR sessions

The lowest number of telephone counseling sessions attended by a participant was 7 out of 12, and the median number of weekly tele-CR sessions attended was 11, with 8 out of 18 participants attending all 12 sessions.

Health-Related Quality of Life

Quality of life (*P*=.12), self-perception of physical limitation (*P*=.79), angina frequency (*P*=.67), and treatment satisfaction (*P*=.42) scores did not change significantly from baseline to study completion; however, there was a significant improvement in participants' perceptions of their angina stability (baseline: median 50, IQR 41.7, 91.7; after tele-CR: median 100, IQR 50.0, 100; *P*=.003) (Table 3).

Table 3. Seattle Angina Questionnaire Quality of Life scores for survivors of an acute myocardial infarction who completed a 12-week telerehabilitation program (n=18).

Seattle Angina Questionnaire domains[a]	Score, median (IQR)		*P* value
	Baseline	12 weeks	
Physical limitation	98.6 (77.8, 100)	100 (77.8, 100)	.79
Angina stability	50.0 (50.0, 50.0)	100 (50.0, 100)	.003
Angina frequency	90.0 (80.0, 100)	100 (75.0, 100)	.67
Treatment satisfaction	100 (81.3, 100)	100 (90.6, 100)	.42
Quality of life	50.0 (41.7, 91.7)	50.0 (50.0, 91.7)	.12

[a] Each scale has a range from 0 to 100, with higher scores indicating better quality of life.

Usability and Motivation

The median SUS score was 82.5 (IQR 65.0, 90.0). Overall, 82% of participants (14/17) reported that the system motivated them to be physically active, and 82% (14/17) also reported that the system helped them to achieve physical activity recommendations. About a third of participants agreed that, because of the system, they walked and exercised more than they previously had (Table 4).

Table 4. Perception of usability and motivation among survivors of an acute myocardial infarction who completed a 12-week telerehabilitation program.

Items	Participants endorsing (n=18), n (%)		
	Disagree or strongly disagree	Don’t know or neutral	Agree or strongly agree
System usability			
Would use frequently[a]	0 (0)	2 (12)	15 (88)
Found unnecessarily complex[b]	14 (88)	0 (0)	2 (13)
Easy to use[a]	3 (18)	0 (0)	14 (82)
Need technical support[a]	12 (71)	2 (12)	3 (18)
Functions well integrated[a]	4 (24)	1 (6)	12 (71)
Too much inconsistency[a]	8 (47)	0 (0)	9 (53)
People can learn to use quickly[a]	2 (12)	1 (6)	14 (82)
System awkward to use[a]	14 (82)	0 (0)	3 (18)
Self-confidence using system[a]	1 (6)	2 (12)	14 (82)
Need to learn a lot prior to use[b]	13 (81)	1 (6)	2 (13)
Motivation			
The system motivates me to walk and exercise[a]	1 (6)	2 (12)	14 (82)
The system helps me to follow the walking and exercise recommendation[a]	1 (6)	2 (12)	14 (82)
Thanks to the system I walk and exercise more than before[a]	5 (29)	6 (35)	6 (35)

[a] Missing responses (n=1) were not included in the denominator of percentage calculations.

[b] Missing responses (n=2) were not included in the denominator of percentage calculations.

Major Medical and Safety Events

No participants reported injuries or major adverse medical events in connection with their cardiac rehabilitation or study activities. There were no instances of recurrent cardiac events or death among participants over the course of the study.

Discussion

Principal Findings

In this study, we demonstrated that patients hospitalized after acute myocardial infarction who declined to participate in center-based cardiac rehabilitation participated in alternative cardiac telerehabilitation, which comprised a wearable watch, a cardiac rehabilitation app for review of exercise and walking goals, and scheduled telephone sessions with a cardiac rehabilitation nurse, found it to be acceptable. We observed moderately high rates of adherence to exercise recommendations and telephone counseling sessions.

Most indices of disease-specific quality of life remained stable over the 12-week study period; however, perceived angina stability improved. No adverse events were observed among study participants. Participants completing the 12-week cardiac rehabilitation intervention reported the cardiac rehabilitation system to be usable and motivating for physical activity. These results suggest that a nurse-assisted cardiac telerehabilitation program with an internet-connected app and wrist-based wearable device may be an acceptable alternative for patients eligible for but who decline to participate in center-based cardiac rehabilitation.

Participation Adherence

Participants were generally adherent to the tele-CR program. Participants’ health watch wear time and step count averages remained stable throughout the entire 12-week program, which is consistent with findings of other cardiac telerehabilitation studies [4].

The exercise and walking goals were collaboratively set by each patient and the cardiac rehabilitation nurse and thus were individualized. Participants completed a high portion of their exercise goals. We observed a slight decline in adherence to exercise goals over the 12-week study period. These goals are based on achieving heart rate targets, and in combination with the steady step count data, our results may indicate that participants’ exercise intensities slightly declined over time. In particular, when fitness levels improve, the same exercise routine may result in a slightly lower heart rate. Another possible reason for this decrease in exercise goal adherence over the study may be because weekly exercise goals were generally increased if the previous week’s goals were met, and consequently, participants who successfully completed prior weekly exercise recommendations may have found it increasingly difficult to achieve new exercise targets.

The overall percentage of completed walking goals was lower (34%) than that of completed exercise goals (86%), but remained constant over the 12-week study period. We hypothesize that the health watch walking time algorithm, which required that participants walk for 2 continuous minutes (no breaks lasting longer than 10 seconds) in order for the time period to be counted, may have led to underestimation of participants' true walking time. Consistent with this hypothesis, participants in our study reported during their exit survey that interrupted or short walks were not counted toward their walking time. Despite the limitations of the approach used in our study, other activity trackers use similar approaches. For example, Fitbit counts active minutes only after 10 minutes of continuous moderate-to-intense activity [36]. In the future, we may consider lowering the walking time threshold for older adults participating in tele-CR.

Nearly half of the participants completed all 12 tele-CR sessions with the study cardiac rehabilitation nurse, and we observed high adherence to phone sessions throughout the program, though adherence was higher in the first half of the study than that in the second (95% in the first 6 weeks and 87% in the second). Although patient education is a core component of many telerehabilitation protocols [18,26,37], many models tend to utilize technology to implement passive unidirectional communication as opposed to engaging the patient in active education such as (eg, shared decision making in setting goals and assessing their overall needs with respect to their cardiac health). In fact, previous research on tele-CR that used unidirectional patient education concluded that additional telephone support and more intensive coaching would be valuable [38,39]. Our participants nearly unequivocally mentioned support from the cardiac rehabilitation nurse as a highlight of the program and as one of its most important components. The enthusiasm and patience of the cardiac rehabilitation nurse as mentioned by many of the patients is likely to be a major contributor to the high adherence rates to the cardiac rehabilitation nurse sessions.

Usability and Motivation

Participants generally expressed enthusiasm for their experience with the MI-PACE system (SUS score: median 82.5, IQR 65.0, 90.0) and responses on motivation assessments. Recent studies [23,40,41] with tele-CR systems similar to ours reported mean SUS scores of 76 [41], 75 [40] and 65.5 [23], suggesting that tele-CR systems generally show acceptable usability despite the comorbidity and impairment burden of the target population. While the SUS has been validated for use as a complete instrument, examining its individual domains may provide specific insight into different aspects of usability. The item asking about inconsistencies in the system appears to be the only item to generate a wide distribution of responses (Table 4). This heterogeneity in response is likely due to challenges that some participants faced with walking time detection using the health watch; the fact that short and intermittent walks did not contribute to their total walking time discouraged some participants.

Participants overwhelmingly endorsed that the tele-CR system increased their motivation to perform physical activity and helped them with reaching their physical activity targets (82% for both). A much lower proportion of patients reported that the system directly increased their level of physical activity (35%). In this study, participants achieved a high level of physical activity. Participants walked for an average of 121 minutes per week (SD 175) and spending 189 minutes per week (SD 210) in their personal exercise heart rate zone. Participants' average walking time (121 minutes per week) falls below the recommended 150 minutes of weekly moderate-intensity exercise [1], but walking time may have been underestimated by the health watch. Furthermore, the observed average of 189 minutes spent in the exercise heart rate zone is considerably greater than the 75 minutes of vigorous-intensity exercise per week recommended by the American Heart Association, which indicates that participants generally achieved adequately high levels of exercise [42].

Disease-Specific Quality of Life

Angina stability improved significantly (P=.003) in tele-CR participants over the 12-week study period. The lack of statistical significance in other domains (quality of life: P=.12; self-perception of physical limitation: P=.79; angina frequency: P=.67; treatment satisfaction: P=.42) is not surprising in light of the fact that the tele-CR program was not designed to address all facets of clinical care (ie, medical treatment). Significant change in these domains is likely to require longer follow-up. It should also be noted that our study was not sufficiently powered to detect small differences in SAQ (n=18). However, our results are consistent with those of other studies [26,43] demonstrating that the effects of cardiac telerehabilitation on disease-specific and health related quality of life are mixed. For example, though it has been suggested that angina frequency may improve after 6 weeks of cardiac rehabilitation [44], other cohort studies [44,45] show no significant associations between cardiac rehabilitation participation and domains of health related quality of life. Further research is needed to elucidate component factors of cardiac rehabilitation that may contribute to changes in health related quality of life domains to clarify why they are observed in only a subset of studies.

Telerehabilitation and Mobile Health Technology

The use of mobile and wearable technologies for heart rate and activity monitoring has revolutionized many aspects of health care, and cardiac rehabilitation is a promising area for leveraging remote monitoring to improve cardiovascular outcomes. Whereas earlier cardiac telerehabilitation programs focused on web-based portals and providing additional communications channels for patients during the rehabilitation process [17], more recent studies [18,20,21,46] have begun to utilize biosensors in wearable devices to both monitor progress and inform exercise interventions. There appears to be increasing interest in support of leveraging near-continuous biomonitoring from mobile devices to generate real-time feedback in order to individualize recommendations and maximize potential patient benefits in tele-CR. In addition, systematic reviews and meta-analyses have shown the noninferiority of home-based cardiac rehabilitation compared to traditional center-based approaches with respect to virtually all relevant outcomes [17,37], and further studies suggest that costs of tele-CR are at least comparable, if not lower than, those incurred by center-based cardiac rehabilitation [15,18,20].

Very little research, however, has focused on assessing the usability and feasibility of telemonitoring programs in a patient population fraught with a heavy burden of comorbidities (such as a cardiac rehabilitation patient population) or the organizational and systemic challenges in implementing such programs. Involving all stakeholders is important, as they are critical to successfully implement a tele-CR program. Potential differences between the number and quality of health care provider visits delivered through tele-CR versus those delivered through conventional cardiac rehabilitation further emphasize the importance of addressing human factors in tele-CR design processes [47]. Ideally, users or prescribers of the tele-CR system should be involved throughout the process, using a participatory design model, and feedback should be elicited from the patients, their caretakers, health care professionals, and health care company specialists [48]. Recently, a tele-CR intervention whose developers heavily engaged target users in the development process [49] subsequently demonstrated high ease of use (reported by participants) [23], which illustrates the need for stakeholder engagement. Involvement of all stakeholders maximizes the likelihood of designing an end product that is highly usable and addresses the needs of each relevant party to ensure successful clinical application. There is significant value in understanding the nuances surrounding the specific use of devices as well as the myriad of relevant process variables in implementation in tele-CR. This is not only an important step toward the goal of widespread dissemination and adoption of tele-CR, but arguably, a necessary one.

This study contributes to a very sparse knowledge base regarding the usability of, and adherence to, a health watch-based tele-CR program. The intervention and supportive care environment enabled by weekly interactions with a trained cardiac rehabilitation nurse and our findings from the data provided by the wearable device indicate that this specific model of tele-CR may be an acceptable alternative to center-based cardiac rehabilitation as patients overwhelmingly gave high usability ratings for the system.

Implementation Strategy

Design of the study's protocol necessitated careful consideration of implementation strategies in order to ensure its success. The device support provided by study staff throughout the study appears to be an important component of a positive patient experience. While participants were contacted by the study cardiac rehabilitation nurse weekly, the nurse's role did not encompass technical support, and patients generally reported that the availability of study staff for questions regarding the watch and tablet system, both at the initial study visit as well as the duration of their enrollment, had been important to their success in use. This demonstrates the utility of having the necessary support staff to meet patient needs, both in research as well as in clinical practice, with respect to answering technical questions when they arise. One challenge that arose during implementation of this study was the need to streamline patient recruitment while respecting the clinical decisions made by their primary medical teams. Study participation required medical procedures (a stress test) not directly recommended by their medical teams, and thus, that were potentially difficult to integrate into the patient care workflow (and with consequent medical expenditures). Minimizing disruptions to routine patient care and integrating clinical research into existing health care systems is key for the success of similar projects and to ensure patient safety.

Study Strengths and Limitations

The strengths of this study include the use of a population of patients who were eligible for cardiac rehabilitation but who declined center-based rehabilitation, the use of a tele-CR program informed by data from a validated wrist-based wearable device [29], the integration of a remote cardiac rehabilitation nurse to review data and provide standardized and scalable cardiac rehabilitation–specific health education using conventional methods of cardiac rehabilitation counseling, use of validated indices of usability and disease-specific quality of life, and objective monitoring of participants' levels of physical activity after acute myocardial infarction. We acknowledge several limitations: the small sample size, low proportion of eligible to screened patients, and study design that focused on feasibility, adherence, and usability all contribute potential biases that may limit interpretability of the results. Selection bias may have resulted in a population with high baseline physical activity, with participants maintaining, rather than increasing, their physical fitness, which is limits generalizability to other cardiac rehabilitation populations. The study was not powered to identify individual factors associated with cardiac rehabilitation adherence or to determine the effect of cardiac rehabilitation on clinical or patient-reported outcomes (n=18). Additionally, the study cohort was relatively fit at baseline (median MET 10.6), and there may be bias with respect to the potential for activity increase over the course of the 12 weeks. Finally, we did not systematically assess contextual factors related to study implementation or physical fitness postintervention.

Conclusions

Cardiac telerehabilitation with a wearable device for patients after acute myocardial infarction had high usability ratings as well as high rates of adherence to health watch use, exercise recommendations, and telephone counseling sessions, with no associated adverse outcomes reported. Telerehabilitation with wearables may be an alternative for patients who are eligible but unable to participate in center-based cardiac rehabilitation. Additional studies with larger patient samples are warranted to compare patient outcomes and health care resource utilization for center-based rehabilitation to those of telerehabilitation.

Acknowledgments

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Conflicts of Interest

DDM received sponsored research grant support from Bristol-Myers Squibb, Boehringer-Ingelheim, Pfizer, Flexcon, Fitbit, Philips Healthcare, and Biotronik and has received consultancy fees from Bristol-Myers Squibb, Pfizer, Flexcon, Boston Biomedical Associates, and Rose Consulting. WS is an employee of Philips Research.

Multimedia Appendix 1

(A) Health Watch, (B) screenshot of patient-facing PACE app, (C) screenshot of patient list in the provider-facing PACE app, and (D) screenshot of heart rate graph in the provider-facing PACE app.

[DOCX File , 529 KB - humanfactors_v8i3e18130_app1.docx]

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Abbreviations

ECG: electrocardiogram
GRACE: Global Registry of Acute Coronary Events
SAQ: Seattle Angina Questionnaire
SUS: System Usability Scale
tele-CR: cardiac telerehabilitation

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Original Paper

Robotic Pharmacy Implementation and Outcomes in Saudi Arabia: A 21-Month Usability Study

Hisham Momattin[1*], PharmD, MHSA; Shokry Arafa[1*], BSc, RPh; Shahad Momattin[2*]; Rayan Rahal[3*], RPh; James Waterson[4*], MMedEd

[1]Mouwasat Medical Services, Dammam, Saudi Arabia

[2]King Faisal University, Al Hassa, Dammam, Saudi Arabia

[3]Medication Management Solutions, Becton Dickinson Limited, Dubai, United Arab Emirates

[4]Medical Affairs, Medication Management Solutions, Becton Dickinson Limited, Dubai, United Arab Emirates

[*]all authors contributed equally

Corresponding Author:
Hisham Momattin, PharmD, MHSA
Mouwasat Medical Services
Mouwasat Hospital
16 D Street
Dammam, 32263
Saudi Arabia
Phone: 966 9200 04477
Fax: 966 9200 04477
Email: Hisham.Momattin@mouwasat.com

Abstract

Background: We describe the introduction, use, and evaluation of an automation and integration pharmacy development program in a private facility in Saudi Arabia. The project was specifically undertaken to increase throughput, reduce medication dispensing error rates, improve patient satisfaction, and free up pharmacists' time to allow for increased face-to-face consultations with patients.

Objective: We forecasted growth of our outpatient service at 25% per annum over 5- and 10-year horizons and set out to prepare our outpatient pharmacy service to meet this demand. Initial project goals were set as a 50% reduction in the average patient wait time, a 15% increase in patient satisfaction regarding pharmacy wait time and pharmacy services, a 25% increase in pharmacist productivity, and zero dispensing errors. This was expected to be achieved within 10 months of go-live. Realignment of pharmacist activity toward counseling and medication review with patients was a secondary goal, along with the rapid development of a reputation in the served community for patient-centered care.

Methods: Preimplementation data for patient wait time for dispensing of prescribed medications as a specific measure of patient satisfaction was gathered as part of wider ongoing data collection in this field. Pharmacist activity and productivity in terms of patient interaction time were gathered. Reported and discovered dispensing errors per 1000 prescriptions were also aggregated. All preimplementation data was gathered over an 11-month period.

Results: From go-live, data were gathered on the above metrics in 1-month increments. At the 10-month point, there had been a 53% reduction in the average wait time, a 20% increase in patient satisfaction regarding pharmacy wait time, with a 22% increase in overall patient satisfaction regarding pharmacy services, and a 33% increase in pharmacist productivity. A zero dispensing error rate was reported.

Conclusions: The robotic pharmacy solution studied was highly effective, but a robust upstream supply chain is vital to ensure stock levels, particularly when automated filling is planned. The automation solution must also be seamlessly and completely integrated into the facility's software systems for appointments, medication records, and prescription generation in order to garner its full benefits. Overall patient satisfaction with pharmacy services is strongly influenced by wait time and follow-up studies are required to identify how to use this positive effect and make optimal use of *freed-up* pharmacist time. The extra time spent by pharmacists with patients and the opportunity for complete overview of the patient's medication history, which full integration provides, may allow us to address challenging issues such as medication nonadherence. Reduced wait times may also allow for smaller prescription fill volumes, and more frequent outpatient department visits, allowing patients to have increased contact time with pharmacists.

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KEYWORDS

patient satisfaction; automation; integration; medication error; outpatient; medication management; usability; medication dispensing; robotics; pharmacy; medication records; error; record; implementation; outcome

Introduction

Background

An article submitted to the *American Journal of Hospital Pharmacy* in 1967 identified how “outpatient visits are increasing at a rapid rate and administrative adjustments will be needed to manage larger outpatient prescription volumes” [1]. The authors laid out how, “[N]ew methods and procedures must be developed to reduce patient wait time, provide the physician and the pharmacist with information pertinent to drug therapy and increase productivity through the elimination of administrative detail which can be handled better through automation,” and how although “…inpatient pharmacy functions have received a considerable amount of publicity in the literature, little work has been accomplished in this area with regard to outpatient dispensing” [1].

The situation remains similar in 2020. Outpatient visits continue to rise year-on-year, with increasingly complex patients being handled by these departments, and there remains a paucity of literature on the application of automation in outpatients to help handle this increasing workload and to deploy the outpatient pharmacy department’s human resources more effectively. There is also considerable political and financial pressure on health care decision-makers to optimize the utilization of resources and to improve services for patients, while ensuring that any technology that is deployed definitively adds quantifiable health economic value. The size of any initial investment in health technology and automation is inevitably significant and requires substantial decisions to be taken about funding; the need for change; and required re-engineering of a facility’s infrastructure and established hospital and department procedures, policies, and workflows [2].

A reasonable number of studies and meta-analyses related to automation processes for inpatient environments have been conducted; some of these can be extrapolated to the outpatient department but only with the caveat that while the 2 settings share some elements, there are also distinct differences in workflow challenges, safety concerns, service elements, and staffing.

A recent systematic literature review of automated and semiautomated drug distribution systems (DDSes) in acute care hospitals evaluated effectiveness in terms of medication safety, time, and costs of medication management [3]. A general conclusion was that patient safety improved with automation, with a reduction in medication errors in both automated and semiautomated DDS. About 24 studies in the review have explored the impact of DDS in terms of labor time, staffing workload, and changes in work processes; however, only 6 studies have explored the economic outcomes. These studies found that highly centralized systems for dispensing saved more time than decentralized arrangements, and it is also notable that although all the DDSes studied decreased medication errors, many of the systems still incurred prescribing errors. These findings may be attributed to the failure to integrate between prescription and dispensing/administering systems or the reliance upon decentralized systems *knitting together*, rather than ensuring seamless information transfer through a fully integrated system. It is notable that, to assess its ability to reduce administration and dispensing error rates, in a 1-center study of an automatic storage and picking system in a pediatric hospital, a computerized provider order entry (CPOE) system was fully integrated into both the existing manual system for preparing daily unit dose drugs and the automated storage and picking system [4]. The study focused on inpatient unit dosing rather than the dispensing of boxed medications for self-administration, but the metrics of wrong medicine, wrong dosage, and wrong pharmaceutical form can apply equally to inpatient and outpatient dispensing. In this study automation showed an error rate reduction with a risk ratio of 3.52, with wrong medicine and wrong dosage being the most prominent areas of error reduction.

Patients and clinicians are concerned over medication safety but a second priority for patients, particularly outpatients, is the time spent waiting for medications to be dispensed [5]. The most common method of outpatient dispensing is for original-pack medications to be given to the patient rather than unit-dose or blister-packs. This method has advantages for automation, as it requires less fine manipulation of the dispensed medication and allows for a relatively faster throughput and service to the patient [6].

A review of the limited literature focusing directly on outpatient and pharmacy robotics showed the same emphasis on medication safety as with inpatient studies, with an identifiable improvement following automation [7]. Productivity, as measured by prescription filling time, also improved with automation in the reviewed studies with a reduction in the required personnel of between 0.3 and 1.4 full-time employees (FTEs) and increases in items picked per FTE per hour. The review found, however, that despite the decrease in both patients’ wait times and prescription filling time, there was no observable change in staff perception of workload.

With regard to original pack dispensing, a Canadian review of 5 pertinent studies of automation in outpatients found a significant reduction in the relative risk ratio for identified dispensing errors [7]. A recent UK study conducted in the last quarter of 2019 showed that lookalike-soundalike (LASA) errors represented 25.9% of the total of all *human* dispensing errors

[8]. LASA medications is an area where barcode reading by machine would be expected to be potentially error free.

The current literature also provides some indications of how human factors can interact, or fail to interact, with robotics in the dispensing process. During a transitional phase for the introduction of robotics in a community hospital, the average prescription filling time was reduced by 40 seconds per prescription, [9], but the sequencing of technician workflow steps had to be reviewed, and these increased from 17 to 38 seconds, respectively. A more concerning aspect was that workarounds increased from 10% to 36% after the introduction of robotics. We considered this caveat in the present study, particularly in the workflow for prescription to dispensing, and for processes such as inventory and medication labelling. This informed our project plan and, in particular, our plan for integration.

Studies of pharmacy automation generally give an encouraging view of robotics, with the caveat that original pack dispensing via robotic picking can be expected to yield better results in terms of dispensing speed than can unit-dose dispensing. In terms of general automation across the dispensing process, the studies are positive in their reviews of robotic filling of prescriptions and barcode-based medication dispensing, with evidence of reduced error incidence, improved prescription filling time, and completeness of prescriptions.

The Kingdom of Saudi Arabia has been actively engaged in pharmacy automation for a considerable period. There are, however, still *traditional* pharmacies serving communities into which we are introducing automated pharmacies. This gave us an opportunity to make head-to-head comparisons between the 2 systems over an extended period and to gather preimplementation metrics, such as time to filling of prescriptions from the moment a prescription was made or from patient presentation in the case of repeat orders. This addresses a noticeably clear gap in the current literature.

Objectives

We forecasted growth of our outpatient service at 25% per annum over 5- and 10-year horizons and set out to prepare our outpatient pharmacy service to meet this demand. The overall objective of the study that we conducted alongside our project plan to meet this demand was to establish, using an easily reproducible and reliable methodology, the benefits of an automated and integrated pharmacy dispensing solution versus a traditional outpatient pharmacy system through pre- and postimplementation comparisons. Metrics of FTE freed-up time, the time gained or lost in pharmacy tasks, dispensing error rate, patient satisfaction, and patient wait times were assessed in both comparisons. The study also addressed return on investment (ROI) of automation in the outpatient environment, in terms of productivity and avoidance of error.

The study was undertaken in the northeastern region of Saudi Arabia and was intended to help decision-makers in both the private and public sectors to make more fully informed decisions about the adoption of automation generally and, more specifically, the introduction of outpatient pharmacy automated dispensing systems. The possible intangible benefits of outpatient dispensing automation have not been fully assessed in the scientific literature. These include the opportunity to redeploy highly qualified staff away from routine tasks and to direct them toward more constructive engagement with patients.

Methods

Study Design

The study lasted 21 months (September 2018 to June 2020), with a go-live for the automated pharmacy after 11 months (August 2019).

The benefits of an automated and traditional system pre- and postimplementation study is that over the extended period of the study, equally complex patients with diverse issues of infirmity, age, education, pharmaceutical requirements, and health state can be expected to be presented to both systems. A metric of FTE deployment and time gained or lost in pharmacy tasks and in managing each system would therefore be expected to identify how much time for patient counseling and assessment of patient needs is allowed for by each system.

Patient satisfaction in both units was assessed using a standard tool adapted for our facility in a partnership between the pharmacy department and the Press Ganey organization (Textbox 1). The core survey and the questions used have been verified for use in outpatient medical practice [10], and these types of survey are in common use across the United States. The surveys are delivered after each interaction with the outpatient pharmacy via text messaging to smartphones and via email to patients or their carers. The surveys can also be completed on unit-based tablet computers. They are delivered in Arabic and English. Patients are asked to complete a 20-question survey, and although the questions may be altered occasionally for special polling purposes, the core questions related to satisfaction and quality of care, and the 5-point Likert scale (range 1 to 5), remain unchanged, allowing for long-term analysis of trends and assays of the impact of changes in the outpatient pharmacy environment, management, or process on patient satisfaction overall, and for wait time, in particular (ie, three core questions are devoted to this aspect of care).

Data gathered from the facility awaiting implementation indicated a decline in patient satisfaction regarding pharmacy wait time and a decrease in overall patient satisfaction regarding pharmacy services, which was associated with an increasing average wait time, flat pharmacist productivity, and an increase in reported dispensing errors. This provided benchmarks to measure our impact. It also aided with team selection as we identified process variations and choke points hindering improvement (see Figure 1), and we were able to recruit personnel directly involved at these points into the project team. A review of 1 year of preimplementation data is available in the Results section. Our planned outcome indicator metrics were based on preimplementation data.

Textbox 1. Example questions from the patient satisfaction survey used in both units and pre- and postautomation initiation.

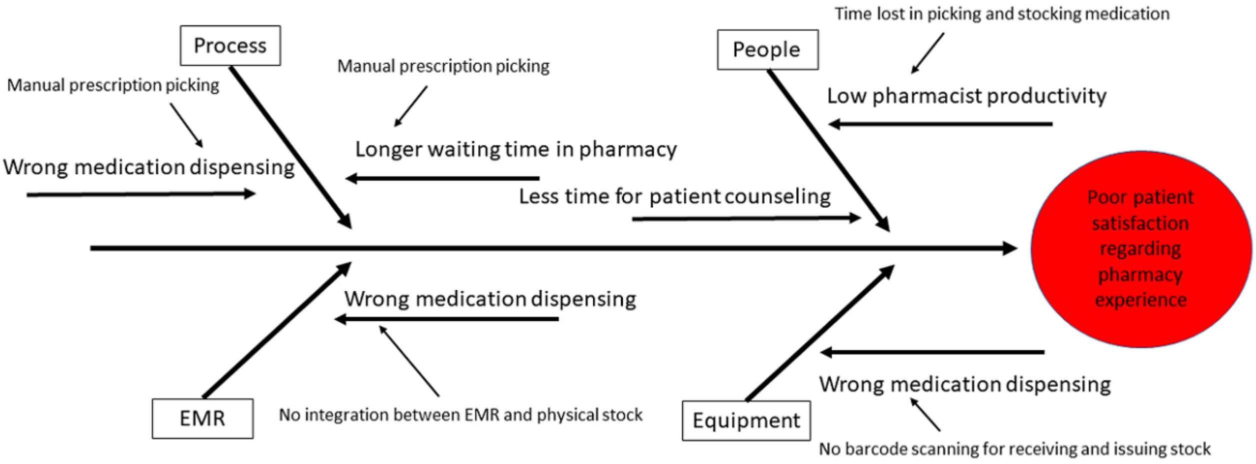
For your visit today you were assisted by a staff member.

Please answer the following questions with that health care provider in mind.

(The survey usually takes about two 2 minutes to complete. Some of the core questions are listed below. For each question, the respondent has the following answer options: “very poor,” “poor,” “fair,” “good,” and “very good”)

- Friendliness and courtesy of the care provider.
- Explanations the care provider gave you about your medications and condition.
- Concern the care provider showed for your questions or worries.
- The amount of time the care provider spent with you.
- Degree to which the care provider talked to you using language you could understand.
- The timeliness of the care provider’s interaction with you.
- The time you had to wait to be called or seen by a care provider.
- The time you had to wait before receiving your medications and being able to leave the hospital.

Figure 1. Identified chokepoints and variances in preimplementation processes. EMR: electronic medical record.



Our initial selection of automation components and systems was guided by a review of the literature. The metrics of technology selection in terms of required storage, picking, and delivery rates was built upon the basics of known pack dispensing rates (2000 articles per day), patient and prescription load per day (1300 patients and 1300 prescriptions), average packs and lines per prescription (10 packs and 10 lines), and lines held (approximately 2000 lines). As noted above, we also forecasted growth of the service at 25% per annum over 5- and 10-year horizons.

The studied outpatient pharmacy operated, at both pre and postimplementation stages, a 24-hour service with peak times between 0900 and 1230 hours and between 1600 and 2200 hours.

Refrigerated items are both stored and dispensed in the department. In terms of storage, we estimated a requirement for 0.67 m^3 with a capacity of 210 packs per fridge.

Our goal was total automation of the processes of stock management; therefore, we investigated systems with fully automatic input, and this was planned to take place during low patient-volume hours at a minimum rate of 1400 packs/hour input.

We intended to use medication manufacturers’ barcodes without relabeling being undertaken in the input process to the robotic pharmacy unit. Relabeling on input may slow the input by as much as 20%, and there are generally restrictions on the dimensions of packs that can be relabeled at the point of entry into the inventory.

HL7 (the interfacing and standard messaging language for transfer of clinical and administrative data between software applications) capability was required to integrate with our existing health information system (HIS) that supports appointments, medication records, and prescription. The integration of the robot pharmacy unit and these systems was achieved via FutureGate Pharmaflow architecture. The VM-Ware for the robotic suite and interface engine is inside the facility's firewall, and VPN access is initiated by our facility if access by vendor engineers is required for remote server maintenance.

Rowa Vmax 160 Hardware (Becton, Dickinson and Company) was selected on the basis of the above criteria for picking and input speed and positive integration attributes. Two machines were purchased, each with dimensions of 7 m length × 1.63 m width × 2.5 m height. Each unit has a capacity for 12,500 medications. The architecture involved 10 dispensing desks, with 10 spiral chutes, fed by 2 unidirectional belts with feed gates, serviced by 1 bidirectional belt feeding from four exit points of the 2 robot picking units.

As discussed above, the overall objective of the study running alongside the implementation was to establish, in a reproducible and reliable manner, baseline data to quantify the impact of robotic automation of a centralized outpatient pharmacy system over a period of 10 months. This was part of a system-wide review of the potential further adoption of pharmacy outpatient automation across the organization. These reviews are concerned with value for money, but this goes beyond simple time-saving and efficiency questions and extends into reduction of medication errors and improved patient safety, improved completeness of prescriptions for each dispensing event, shortening patient wait times, and improving the patient's experience and education level with regard to the medication prescribed.

The pharmacy staffing level in the outpatient department was also roughly equivalent, pre- and postimplementation. See Table 1 for a comparison of the processes in place in pre- and postimplementation.

Process quality indicators and outcome indicators were selected for the study (as described in the Results). These concerned elements pertinent to the process and established criteria, to which we could apply trackers and standards for the implementation and postimplementation periods. These indicators established optimum standards, with ideal values for compliance, with a criterion for each value. Minimum standards were set, as well as transition standards for the implementation and immediate postimplementation periods.

Table 1. Pharmacy attributes pre- and postautomation.

Process	Preautomation traditional outpatient pharmacy	Postautomation outpatient pharmacy
Prescribing	CPOE[a]	CPOE
Medication stock-up and record inputting	Manual	Direct loader to robot storage and barcode reading of expiry dates
Space or volume management	Open shelves with secured lock and key for controlled medications. Unknown packs/m^3	Secured robotic box space calculation and allocation. ~4000 packs/m^3
Medication picking	Manual	Robotic, barcode multi-picking (8 packages maximum per move)
Dispensing method	Original pack	Original pack.
Dispensed items record keeping	Tracking of each item through HIS[b]	Automatic item deduction from stock level
Delivery to point of care	Manual carry	Conveyor belt and spiral chute
Inventory	Twice per year; manual with HIS reconciliation	Automated storage system maintains consistent inventory

[a] CPOE: computerized provider order entry.

[b] HIS: health information system.

Study Procedure

The data recorded for analysis were patient anonymized for hospital number, gender, name, date of birth, or other identifiable material. All employees active in the outpatient unit were informed of the data collection taking place.

Becton, Dickinson and Company (BD) Clinical and BD and FutureGate Global Customer Services were engaged to optimize the automated solution, and the BD Medical Affairs department was requested to undertake a deeper analysis of the data. The Medical Affairs department of BD operates as a distinct arm outside of the commercial operations of the company.

Inclusion and Exclusion Criteria

All formulary items dispensed via the outpatient pharmacy as original pack medications were included in the analysis. Unit-dose medications or blister packs were excluded from the analysis.

Results

During the preimplementation period, the mean number of prescriptions filled per month was 8728.45 (SD 3745.48; minimum 3489; maximum 12,814; median 9544, IQR 2378.75). This value increased during the implementation period to a mean of 13,587.60 (SD 3410.01; minimum 7530; maximum 16,974; median 13,809, IQR 5794), with no change observed for FTE. It was noted that although activity increased significantly in the postimplementation period, the detected error rate also declined rapidly and settled at our target of zero (see Figure 2).

An ongoing review during the implementation of our solution, and of the data aggregated in this period showed that we could start accounting for patient education time (see Tables 2 and 3). This metric had not been gathered in the preimplementation period, as FTEs were constantly focused on picking and dispensing medications and attempting to *keep up* with the patient load. We started to see FTEs taking advantage of the time saved on keep-up tasks, even when this was only 5 minutes per patient, to engage with patients. We placed stretch targets on this time gained of a 30% increase (optimum) with transition targets of 10%-25% increases per patient encounter. How we attempted to guide the activity undertaken with this new *free-time* to increase its benefit, and how we intend to utilize it in the future, for both the pharmacist and the patient is discussed below.

Overall, the study expanded on the findings of the current literature and indicated improved FTE productivity. It also shows the potential for FTE redeployment to more value-added tasks and for further efficiencies.

Overall patient satisfaction was measured pre- and postproject implementation, as it became evident that *freed-up time* was being created by automation for more patient engagement by staff. We wanted to see how much it was valued by patients. Overall patient satisfaction was also clearly and strongly influenced by wait time (see Figure 3).

The question of discovery during implementation also applied to the question of ROI, which we had not initially set out to measure, but substantial productivity improvements drove us to review this in terms of optimization of manpower, optimization of space utilization, reduction of medication error, cost-savings in terms of improvements in patient safety, avoidance of adverse drug events (ADEs), and reduction in medication loss from expired medications. We were able to ascertain a relatively short-term ROI point of 3.5 years (Figure 4).

Figure 2. Pre- and postautomation pharmacy total monthly dispensed items versus near-miss and identified medication errors. "Go-Live" August 2019.

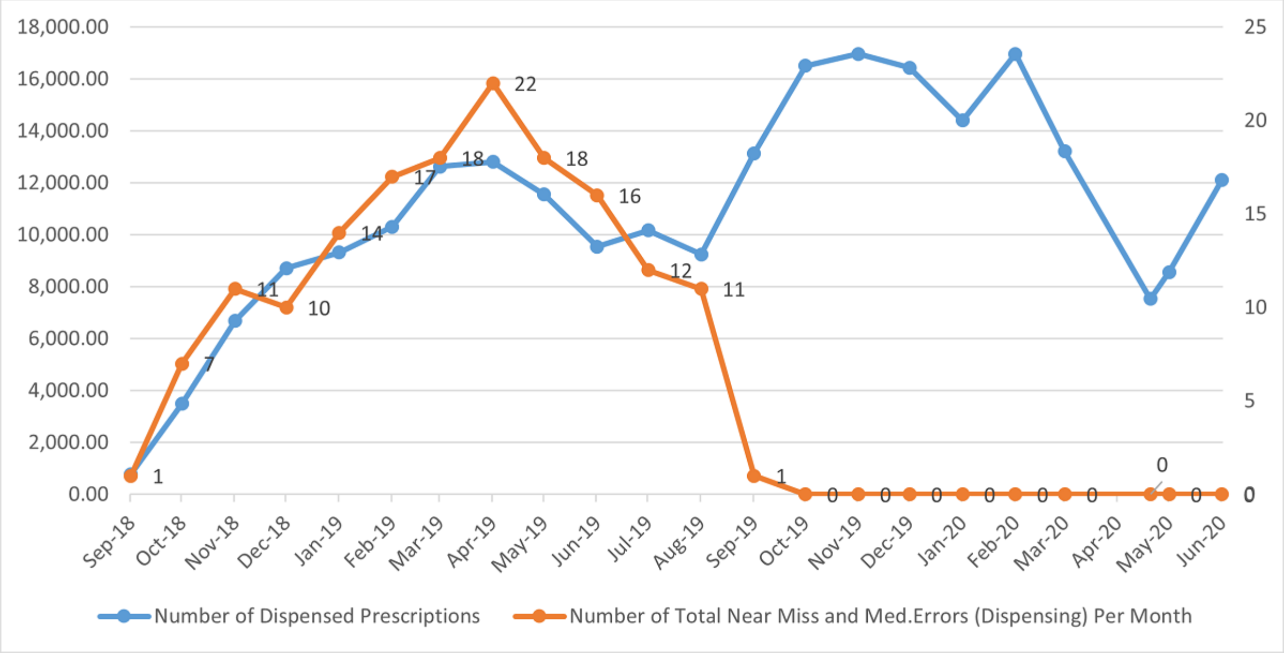


Table 2. Indicator types and outcomes.

Indicator type and description	Achieved metric	Optimum standard	Minimum standard	Transition standard
Process quality				
Staff education on automated processes	100%	100%	90%	80%
Staff education on use of freed up time	100%	100%	90%	80%
Prescriptions filled per month	Meets unit needs	Meets unit needs	Meets unit needs	Meets unit needs
Outcome				
Accuracy of dispensing: error rate per 1000 items dispensed	Zero error	Zero error	Zero error	Zero error
Patient wait time	53% reduction	50% reduction	45% reduction	35% reduction
Patient satisfaction specific to wait time	93% overall	>75% overall	15% increase	10% increase
Pharmacist productivity (daily prescriptions per pharmacist)	33% increase	30% increase	25% increase	10% increase
Overall patient satisfaction	22% increase, 93% overall	20% increase	15% increase	10% increase
Patient education time[a]	Future metric (see discussion)	30% increase	25% increase	10% increase

[a] Metric introduced during implementation phase only.

Table 3. Pre- and postimplementation metrics.

Indicator type and description	Postimplementation metrics			Preimplementation metrics		
	Mean (SD)	Minimum-maximum	Median (IQR)	Mean (SD)	Minimum-Maximum	Median (IQR)
Process quality						
Staff education on automated processes	N/A[a]	N/A	N/A	N/A	N/A	N/A
Staff education on use of *freed up* time	N/A	N/A	N/A	N/A	N/A	N/A
Prescriptions filled per month	13,587.60 (3,410.01)	7530-16,974	13,809 (5794)	8728.45 (3745.48)	(3489-12,814)	9544 (2378.75)
Outcome						
Accuracy of dispensing: error rate per 1000 items dispensed	0.01 (0.02)	0.00-0.08	0 (0)	1.50 (0.26)	(1.15-2.01)	1.53 (0.35)
Patient wait time (min)	7.90 (1.37)	6-11	8.00 (1.5)	15 (5.03)	(5-22)	15.5 (5.5)
Patient satisfaction specific to wait time (%)	89 (0.04)	82-93	90 (7)	58.67 (5.60)	50- 70	59 (5)
Pharmacist productivity (daily prescriptions per pharmacist)	60 (15)	33-74.4	60.98 (20.25)	43.5 (18.66)	(17.39-63.86)	47.57 (25.19)
Overall patient satisfaction (%)	88 (5)	79-93	90 (5.25)	62 (4)	56-68	62 (5.5)
Patient education time[b] (min)	~5	N/A	N/A	N/A	N/A	N/A

[a] N/A: not applicable.

[b] Metric introduced during implementation phase only.

Figure 3. Association between waiting time satisfaction and overall patient satisfaction, automated pharmacy "Go-Live" August 2019.

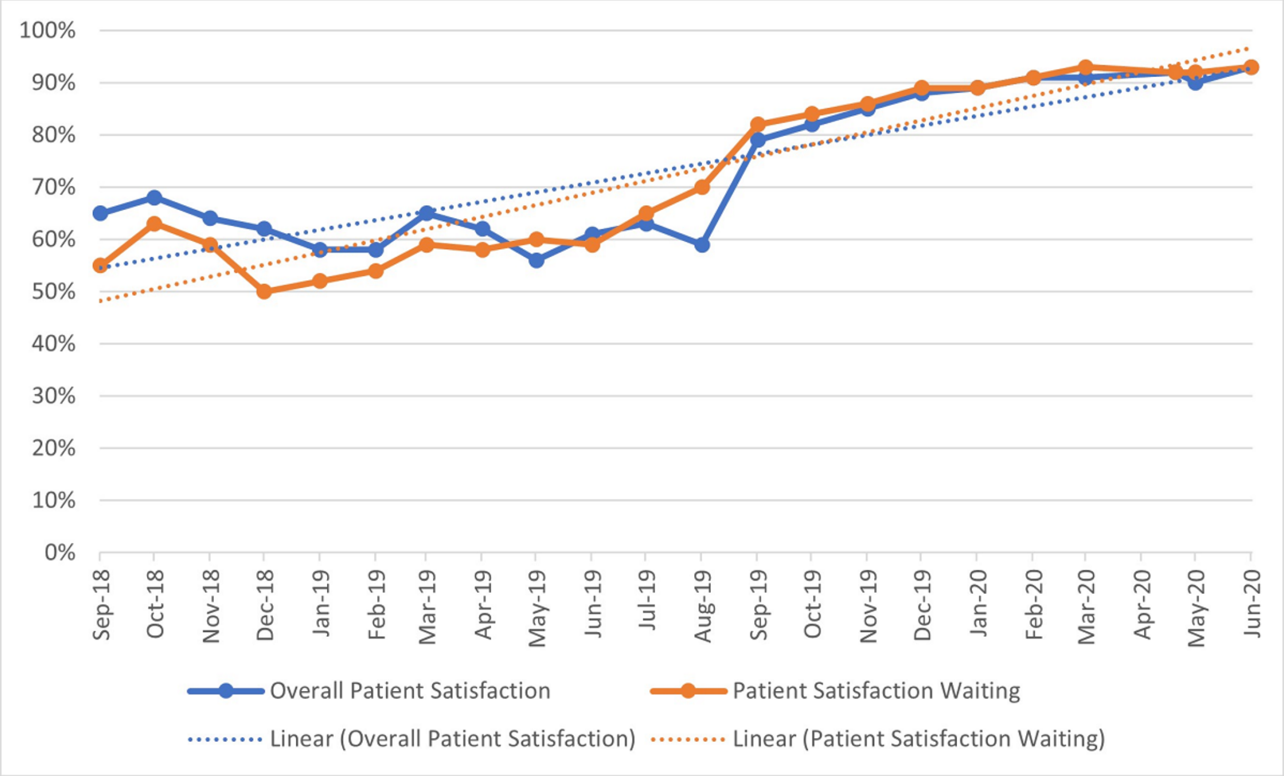
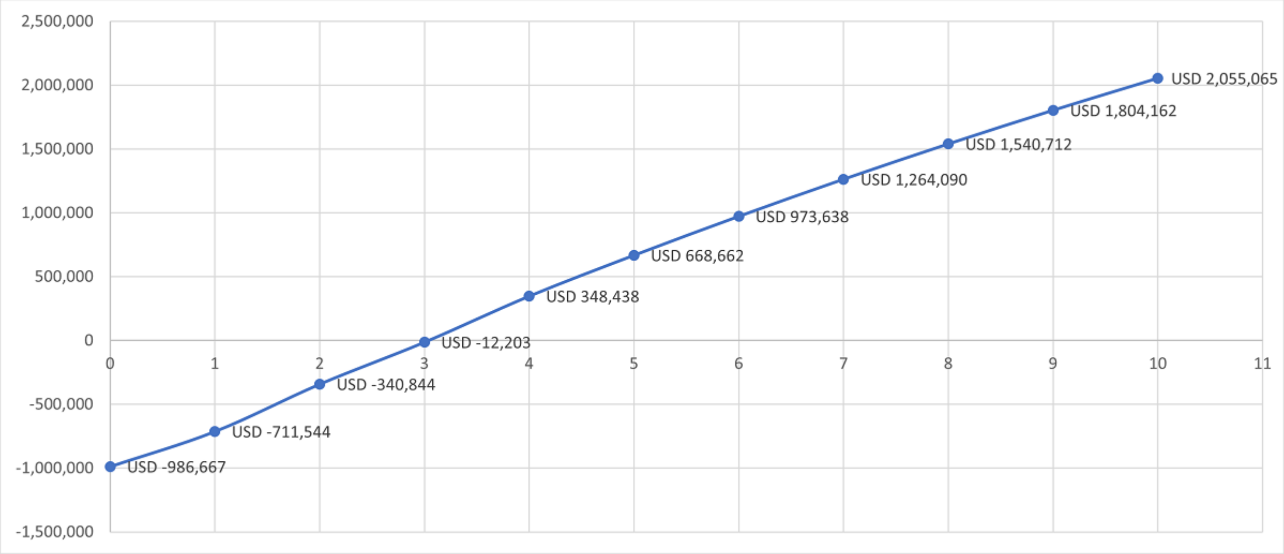


Figure 4. Projected automated-integrated pharmacy return of investment (in USD) with "Tipping Point" at 3.5 years.



Discussion

Principal Findings

Our overall error rate was lower than those reported in other studies [11-13], and we suggest this is also related to the workflow for stocking and dispensing we utilized. Failures of barcode relabeling (ie, omission of labelling) has been cited as one cause of error in robotic dispensing systems [14]. This potential failure was not observed in our workflow because we do not add barcodes to medications and because we use manufacturer product barcodes at stock input and for picking. The risk of dispensing expired stock noted as a *failure mode* [14] can also be mitigated by using original manufacturer medication container barcodes, thereby removing the step of relabeling that introduces the possibility of mislabeling or omission of this information during input to the robotic unit.

Electronic medical record and CPOE integration allows for forecasting of medication demand, and stock held in the robotic unit and availability in the supply chain has also helped us to mitigate the risk of stockouts that may cause incomplete prescription filling or requiring medication substitution. An automated pharmacy solution cannot exist in isolation—the upstream supply chain is vital, particularly when automated filling is planned.

Arguably, our productivity at 33% per FTE was far greater than that reported in other studies of robotic pharmacies directly serving patients; however, these studies have commonly centered on retail pharmacies, with dispensing patient interfaces completely replacing the dispensing pharmacist [15]. Studies with a greater similarity to ours, as discussed above, are limited in the scientific literature.

In acknowledging the limited literature, it is notable that our results are generally in line with many of the previous findings in this field. Positive *user* satisfaction with a centralized automated-dispensing system with a mean score of 5.52 (SD 1.20; maximum: 7) was reported along with a statistically significant drop in dispensing errors from 2.9% to 1.7% (P<.001) in a recent study [11], and a *wrong content* error rate of 0.6%-1.2% recorded in another study [12]. The systems studied were, however, central pharmacies serving diverse inpatient units with automated dispensing cabinets (ADCs) and more traditional ward storage systems, and the ROI estimates given even in the most recent studies are difficult to evaluate against those of the present study, as the system underwent several upgrades over the 8-year study period [11,13]. We were fortunate to have had the same hardware and software from the outset in our automated pharmacy, including the direct loader-to-storage and barcode reading of expiry dates for restocking. An automated pharmacy solution should not be planned or implemented in isolation of its supply needs. We also believe that this automated restocking process was a key reason for the relatively short ROI payoff period of the present study. We may also have benefitted from serving 1 department and 1 community with moderately predictable medication needs and volumes, though with diverse patient subpopulations.

We mapped our dispensing process pre- and postimplementation of the robotic pharmacy (see Figure 1). A similar process-mapping exercise was undertaken in a 2020 French study [13], to more fully uncover the ROI likely to be achieved by implementation of robotic pharmacies. In this study, the FTE costs saved through automation were the most significant gain, followed by stock variation savings [13]. This is entirely similar to our experience, although we arrived at our metrics for the FTE saving through overall productivity per staff count rather than average dispensing time. Our *tipping point* for the ROI at the 3.5-year mark is also similar to that found in this study at 3.75 years [13], and it is comparable to other experiences with medication management automation within facilities (eg, one study on ADCs estimated ROI at 3.8 [minimum: 2.7, maximum: 6.4] years [16]).

Limitations

We recognize the limitations of this study. No blister packs or unit-dose packs were dispensed, and there was no relabeling or splitting of whole pack medications. This may be an issue for units that wish to split or create custom packs, as this would require new barcode labels for each new patient package, which would increase labor and may slow down operations. This may be an issue with limited prescription fills for high-value medications or if units wish to shorten refill times to increase face-time with patients. Furthermore, although we instigated education for staff to assist them in effectively utilizing the *free time* gained from automation, it is more difficult perhaps to effectively assay the productivity of this time. For this purpose, in our projected study of the effectiveness of patient education and medication reconciliation processes by pharmacists, we may be able to show a distinct link between increased (and guided) freedom for pharmacists from clerical tasks taken on by automation and improved patient medication adherence.

In this study, an extensive hospital information system was already in place at the time of the switch to automation. Other units without this level of integration between an existing HIS, the CPOE system, and the appointment system may not achieve similar results. However, in non–peer-reviewed regional publications, there have been reports of traditional versus automated head-to-head studies with no HIS present in either scenario that have still shown commendable metrics on improvement in dispensing time and error reduction in outpatient dispensing [17], with a 28.8% increase in complete orders dispensed and a time reduction approaching 96% for mean total prescription filling time for the automated pharmacy. However, the choke point that remained in both systems was from prescription to the initiation of dispensing, which indicates the importance of CPOE integration.

In terms of the hardware deployed, we have not presented a *standard* discount rate for our infrastructure investment (usually for studies of this sort, we would apply amortization over 10-15 years at a 5% discounted annual rate). Nevertheless, this would have brought the ROI tipping point forward from 3.5 years, and current inflationary pressures (excluding pharmaceuticals) are not exacting.

In this study, overall patient satisfaction increased postautomation. We suggest that this outcome is related to the fact that the *freed-up time* created by automation allowed for more patient engagement by staff and because wait time was being reduced. A 2018 survey [18] conducted in an outpatient pharmacy found a strong relationship between overall patient satisfaction and satisfaction with wait time, but we also noted that the most important predictor of patient satisfaction was the quality and quantity of time spent by pharmacists with patients, and how this time was spent to provide information on the dispensed medications and to resolve patient concerns. In general, current levels of satisfaction with this aspect of patient care have been suggested to be less than optimal, with a study on community pharmacies [19] indicating that only 34% of patients were satisfied with the medication counseling they received at their local center, and only 47.3% of surveyed pharmacists were satisfied with the medication counseling they were able to provide. Both patients and pharmacists identified lack of time as a major reason for these subpar outcomes, and both groups were also strongly positive (88% of patients and 73% of pharmacists) about the development of medication counseling standards to guide counseling sessions. As noted in the limitations of our study, although we have gained *free time* for pharmacists in the outpatient department, we cannot be sure of the effective utilization of this time. We have put training in place (see Table 3), but the above consideration of the quality as well quantity of time spent with patients suggests that a more formal and measurable approach to patient counseling is required, if we are to prove the value of creating free time through automation more fully. Focusing on one particular aspect of medication counseling, such as medication regimen adherence, as an outcome key performance indicator would be a logical approach to this issue. It is possible that with increased face-time between pharmacists and patients and a reduction in inconvenience for the patient in each visit to the outpatient pharmacy, there might be an expectation of improved medication adherence and a reduction in ADEs related to incorrect medication usage by patients [20]. Therefore, in follow-up studies, we intend to extend our work to assaying more exactly how this extra time spent by pharmacists with patients affects medication adherence. Nonadherence is a problem of increasing magnitude that particularly affects those with chronic diseases [21] and symptomless conditions [22]. A major concern is that a drop-off of around 50% can be expected during early stages of a regimen, and that this percentage increases over time [23].

The delivery of educational content to patients has been shown to affect adherence rates [24], but this, of course, takes time and utilizes human resources. Our intention is to use a recognized tool, such as the Morisky-Green-Levine Medication Adherence Scale, to gauge outcomes and to confirm any improvement. We believe that increased time with pharmacists will allow patients to increase their knowledge about their disease and treatment and to better understand their own psychological needs related to regimens. This will lead to improved adherence scores. We also believe that reducing wait times may improve adherence through allowing for smaller prescription fill volumes and more frequent outpatient department visits and, therefore, increased contact time with pharmacists. Pharmacists play a major role in health promotion activities and in providing health education for patients, particularly around their medication regimen [25]. Automation may be the key to freeing them from non–value-added tasks for this vital undertaking, but any automation solution must also be seamlessly and completely integrated into the facility’s appointments, medication records, and prescription software systems for this to be achievable.

Conclusions

The robotic pharmacy solution studied was highly effective, but a robust upstream supply chain is vital to ensure adequate stock levels, particularly when automated filling is planned. The automation solution must also be seamlessly and completely integrated into the facility’s software systems for appointments, medication records, and prescription in order to garner its full benefits.

Overall patient satisfaction with pharmacy services is strongly influenced by wait time, and follow-up studies are required to identify how to use this positive effect and how to make optimal use of the *freed-up* pharmacist time. The extra time spent by pharmacists with patients and the opportunity for complete overview of the patient’s medication history that full integration provides, may allow us to address challenging issues such as medication nonadherence. Reduced wait times may also allow for smaller prescription fill volumes and more frequent outpatient department visits, thereby allowing patients to have increased contact time with pharmacists.

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Conflicts of Interest

RR (Medication Management Solutions) and JW (Medical Affairs Department) are employed at Becton, Dickinson and Company (BD). HM, SA, and SM have no conflicts of interest to declare.

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Abbreviations

ADC: automated dispensing cabinet
ADE: adverse drug event
BD: Becton, Dickinson and Company

CPOE: computerized provider order entry
DDS: drug distribution system
FTE: full-time equivalent
HIS: health information system
LASA: lookalike-soundalike
ROI: return of investment

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Original Paper

Therapists' Experience of Video Consultation in Specialized Mental Health Services During the COVID-19 Pandemic: Qualitative Interview Study

Monika K Gullslett[1], PhD; Eli Kristiansen[1], MA; Etty R Nilsen[2], PhD

[1]Norwegian Center for E-Health Research, University Hospital of North Norway, Tromsø, Norway

[2]School of Business and Economics, University of Tromsø (UiT), Alta, Norway

Corresponding Author:
Monika K Gullslett, PhD
Norwegian Center for E-Health Research
University Hospital of North Norway
Sykehusvn 23
Tromsø, 9019
Norway
Phone: 47 90784208
Email: monika.knudsen.gullslett@ehealthresearch.no

Abstract

Background: As part of political and professional development with increased focus on including service users within mental health services, these services are being transformed. Specifically, they are shifting from institutional to noninstitutional care provision with increased integration of the use of electronic health and digitalization. In the period from March to May 2020, COVID-19 restrictions forced rapid changes in the organization and provision of mental health services through the increased use of digital solutions in therapy.

Objective: The aim of this study was to develop and advance comprehensive knowledge about how therapists experience the use of video consultation (VC). To reach this objective, we evaluated therapists' experiences of using VC in specialized mental health services in the early phase of COVID-19 restrictions. The following questions were explored through interviews: Which opportunities and challenges appeared when using VC during the period of COVID-19 restrictions? In a short-term care pathway, for whom does VC work and for whom does it not work?

Methods: This study employed a qualitative approach based on an abductive strategy and hermeneutic-phenomenological methodology. Therapists and managers in mental health departments in a hospital were interviewed via Skype for Business from March to May 2020, using a thematic interview guide that aimed to encourage reflections on the use of VC during COVID-19 restrictions.

Results: Therapists included in this study experienced advantages in using VC under circumstances that did not permit face-to-face consultations. The continuity that VC offered the service users was seen as a valuable asset. Various negative aspects concerning the therapeutic environment such as lack of safety for the most vulnerable service users and topics deemed unsuitable for VC lowered the therapists' overall impression of the service. The themes that arose in the data analysis have been categorized in the following main topics: (1) VC—"it's better than nothing"; (2) VC affects therapists' work situation—opportunities and challenges in working conditions; and (3) challenges of VC when performing professional assessment and therapy on the screen.

Conclusions: Experiences with VC in a mental health hospital during COVID-19 restrictions indicate that there are overall advantages to using VC when circumstances do not permit face-to-face consultations. Nevertheless, various negative aspects in the use of VC lowered the therapists' overall impression of VC. Further qualitative research is needed, and future studies should focus on service users' experiences, cocreation between different stakeholders, and how to scale up the use of VC while ensuring that the service provided is appropriate, safe, and available.

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KEYWORDS

mental health services; recovery, telemedicine; telepsychiatry; video consultation; COVID-19; coronavirus; therapists' experiences; hospital services

Introduction

Research Context

Mental health service provision in Norway is changing, and there is an increase in noninstitutional care provision for people with long-term mental health problems [1]. One central area of attention is the provision of follow-up care at a distance, including the use of electronic consultations and video consultations (VC) within mental health services in hospitals, which has become more common in recent years [2,3]. Nevertheless, implementation of VC has been slow [4,5]. However, in the period from March to May of 2020, the COVID-19 restrictions enforced a radical change in how health care services were organized. A need to find alternative solutions to face-to-face consultations emerged to enable safe treatment of service users without risk of contagion. The use of VC in different parts of the health care service increased; as such, during the first period of restrictions due to COVID-19, therapists and service users were forced to use technology to communicate, whether or not they had experience with this kind of technology. The pandemic thus became a magnifying glass, revealing both challenges and advantages in the use of VC. This increased use of VC raises questions concerning how the technology may affect both the quality and availability of services in mental health, especially with regard to following up with those in recovery and in need of complex and long-term services.

Reasons for seeking help from mental health services are often based on negative experiences in relationships and difficulties in coping with everyday life. There is a need to tailor digital services to promote recovery and change in service users' mental health state, and to support and improve social relations and coping strategies in the context of everyday life [6,7]. Along the continuum of service provision, VC may be used as part of follow-up care in certain phases of the helping process. In some cases, VC can offer new opportunities for understanding and treating mental health experiences in context. This, in turn, can lead to a greater emphasis on psychosocial approaches, involving service users and carers as active partners in care provision, and refocusing outcomes of services to align with daily life, employment, and other aspects of social inclusion. By contrast, the use of VC may prove challenging for therapists when they seek a comprehensive understanding of the service user's complex situation within their individual context. A final, but equally important, question that has emerged alongside the increased use of VC concerns the impact it has on therapists' work situation [8] and how they cope with the technology in their therapeutic relationships.

Background

Norway's national health and hospital plan [1] emphasizes the goal of realizing a sustainable health care service based on each service user's needs at all levels of the service provided. Both in the meeting between the service user and the therapist, and in the development of the health and care services, the vulnerable voice of the service user must be heard. As part of political and professional development along with an increased focus on including service users within mental health services, services are being transformed; specifically, they are shifting from institutional to noninstitutional care provision with increased use of electronic health (eHealth) and digitalization [1]. Integrating video as a consultation platform is part of the innovation strategy described in Norway's latest national health and hospital plan [1].

The use of VC underscores a shift in the focus of care from treating service users in hospital departments to flexible models within the continuum of care. This change is aimed at increasing the focus on recovery-oriented services [5,9]. Recovery in mental health is a concept that has had a range of definitions over the past several decades [10,11]. The concept is used both to describe an approach and as the process the individual goes through to improve their mental health. These two definitions are interlinked in that recovery as an approach has developed from being described as an individual process [12]; currently, the inclusion of social recovery, and relational and contextual factors are emphasized [13,14]. Being in recovery from severe mental health illness is often a complex process that involves a range of stakeholders, including both professionals and peer support [14-16], and it is often described as a process in which the service user is in the driver's seat for their own recovery to live a self-directed life [11]. In this expanded view of recovery, digital solutions such as VC may have an impact on the process of recovery in numerous ways [9]. The recovery tradition also emphasizes the service user as a human being and not as a diagnosis [10,17]; moreover, in this tradition, the use of language is seen as an important tool to empower individuals with mental health problems, and especially to reduce stigma [18,19]. The term "service user" rather than "patient" is used to refer to people in treatment for mental health problems. "Patient" is a defined role and a theoretical construct closely linked to a medical perspective, and it is a concept used to define, both legally and professionally, an individual receiving any kind of health service.

The use of communication technologies and tools in assessment and therapy in mental health services is not a new phenomenon [4], and there are many different terms used to designate digital treatment, including "telehealth," "telepsychiatry," "telepsychology," "eHealth," "telemedicine," and "video consultations" [4]. In this paper, we use "VC" to refer to an online meeting between a therapist and a service user. There is also a substantial body of research on the use of telehealth in mental care. A recent review of the field of telepsychiatry highlights the use of digital solutions as an effective way to improve access, enhance quality, and provide efficient care [4,20]. VC contributes to the provision of services in the service user's home or other local settings, which may empower the service user, incorporate their voice, and contextualize their mental health problems as part of their everyday life. This promotes the opportunity for the service user to participate in their own recovery process, which is considered important from a recovery perspective [4,7,21,22]. A crisis assessment study on the use of VC in acute mental care in Norway underscores the opportunity to provide continuous follow-up care for people in acute crisis, despite geographical distances and lack of psychiatrists in certain regions [23]. Use of VC between the therapists and the service user strengthened the involvement of the service user during the crisis assessment; specifically, it reduced uncertainty, created shared responsibility for decisions, and functioned as a safety net, even when the use of VC was not required [23-25]. Other recent studies on the use of telecare indicate that follow-up treatment at a distance for people with different diagnoses and backgrounds is effective and safe; these studies included both elderly people with depression and veterans in recovery from posttraumatic stress syndrome [3,26-29]. With regard to the former group, use of VC in therapy with elderly people suggests that VC supports mental health practice, especially as a useful alternative when face-to-face therapy is not possible [30]. Initial skepticism often disappears once the VC is experienced in action; any residual challenges seem to be related to technical problems and a lack of support from staff [31,32].

In general, findings from the above-mentioned studies indicate that the use of VC in treatment may be an efficient way to provide therapy. However, several of these were pilot studies, in which the implementation occurred in a limited area of the service with selected service users and therapists. We know that this kind of approach can lead to self-selection bias, as pilot studies often attract digitally optimistic and mature participants [32]. There can thus be a mismatch between pilot studies and real-world implementation; indeed, when the service has been implemented within the daily operations of a hospital, additional challenges have been revealed [32]. A study on experiences of VC implementation within the everyday operation of a mental health hospital is therefore essential, which will offer new knowledge for the field. Extant research also shows that from the service users' perspective, both lack of face-to-face contact and technical challenges were seen as barriers [8,33], whereas from the health care providers' perspective, physical presence and reading of subtle signs are central in high-quality care [34]. To date, few qualitative studies have dealt with in-depth experiences with the use of VC and recovery in mental health that included both therapists and service users. Given this gap, this study focused on therapists' experiences and addressed the following research questions: Which opportunities and challenges appeared when using VC during the period of COVID-19 restrictions? In a short-term care pathway, for whom does VC work and for whom does it not work?

Case Context

This study was performed at a hospital located in northern Norway, which is a sparsely populated rural area. As the distances between service users and the hospital can be considerable, the hospital has worked to implement technologies for distance communication for decades. The VC system in use during the study period was Skype for Business, which the hospital had been using in this capacity for 3 years. Some of the therapists in the hospital's mental health departments were experienced users of telecare and VC, both in terms of professional collaboration and therapy, with steady use over several years. This characteristic, however, does not apply to all of the therapists in the region. The data extracted from the electronic patient journal (EPJ) system show that the number of consultations in mental health care performed over video has been low, but the use has seen a slow annual increase in recent years. In 2017, 1% of all consultations were performed using video. In 2019, this number increased to 4%, and during the COVID-19 restrictions, the use of VC saw a dramatic increase. On March 12, 2020, Norway completely locked down, which meant that all public institutions—including schools, kindergartens, and offices—closed. During this period (March 15-30, 2020), 72% of all of consultations were performed over video. Owing to a decreasing rate of infection, the restrictions were slowly relaxed in mid-April; however, several restrictions remained in place [35]. Taking local levels of infection into consideration, permission to perform face-to-face consultations (with multiple safeguards in place regarding infection control) was granted. The use of VC thus slowly diminished once again, comprising only 21% of all consultations in the last part of May 2020 (Table 1).

Table 1. Use of video consultations in the hospital.

Period	Performed video consultations, n (%)	Performed face-to-face consultations, n	Total consultations, N
2017	178 (0.7)	27,563	27,741
2018	956 (3.2)	28,569	29,525
2019	1188 (4.1)	28,032	29,220
January 1 to March 15, 2020	341 (5.4)	5984	6325
March 16-30, 2020	352 (72)	139	491
April 2020	718 (58)	524	1242
May 2020	463 (21)	1748	2211

Methods

Research Design

A qualitative, explorative study using in-depth interviews was performed in a mental health hospital. The methodological approach was based in the social sciences, using an abductive strategy that aimed to uncover—and then interpret—knowledge about the social actors in question [36]. This entailed investigating how the therapists experienced, understood, and created a context for using VC in therapeutic meetings with their service users. This perspective worked well with the hermeneutic-phenomenological approach we employed in our analysis; moreover, our choice of research strategy was integrated into the objectives of the study and the research questions under investigation. For the purposes of this study, a hermeneutic-phenomenological perspective meant that the researchers sought an in-depth understanding of the participants' real-world experiences around the use of VC during COVID-19 restrictions [37,38]. Further, the researchers' own hermeneutic position entailed acknowledging that although the data collection and analysis were undertaken with a reflexive and open-minded view, the theoretical approach and researchers' preconceptions would also affect the results.

Interviews

In-depth interviews following a semistructured interview guide were conducted in late March to mid-May 2020, 2 weeks after the COVID-19 restrictions were introduced in Norway. The interviews were conducted on video. The first author (MG) conducted all interviews, and opened each interview by asking the therapist to tell a story about when, how, and why they had implemented VC in their mental health service for the first time. An interview guide was developed beforehand with the aim of mapping the implementation and use of VC from different perspectives; this guide was sent out to all informants prior to the interview. The interview guide was primarily used as a checklist as the interview progressed into more of a conversation. The interviewer was mindful of the fact that conducting interviews in this way may lead to a different information flow than that occurring in a face-to-face meeting, and that while the main objective of the abductive research strategy is to gain in-depth understanding of each participant's perceptions, the use of digital tools may (negatively or positively) affect the process.

Selection and Sample

When the COVID-19 restrictions were implemented, one of the recommendations for mental health workers was to follow up with service users by using VC [39]. A qualitative study had already been planned at the hospital on different aspects regarding the organization and implementation of VC during normal circumstances. When the societal lockdown occurred, we decided to accelerate the process to investigate the therapists' experiences of being rushed into a large-scale implementation of VC in the hospital environment. We sent a request for participation to the management at the hospital on March 20, 2020. The management redistributed the request to everyone in the mental health departments, stating that participation should be given priority.

A total of 14 participants from different disciplines and departments were recruited. The participants worked with adults, adolescents, and children, in addition to performing family therapy; 13 were therapists and 1 was a department head. There was diversity in age, gender, and professional background among the informants: the youngest was 27 and the oldest was 66 years old at the time of the interviews, and there were 3 men and 11 women, 5 of whom had 6 or more years of education, whereas the rest had 3 or more years of experience. In this context, "therapists" is used to denote mental health professionals who are trained to provide treatments in different ways; as such, in this study, the therapists were psychiatrists, psychologists, nurses, and social workers with at least 3 years of university education.

Analysis

All interviews were recorded and transcribed verbatim. The transcriptions were undertaken by a professional firm just after the interviews were completed. To validate the content, the first author read all of the transcriptions and compared them to the recorded interviews. The analysis was performed through a reflexive, open-minded, and abductive process, which enabled an intuitive understanding of the meaning of the text as a whole [36]. Following the initial in-depth reading of the interviews, the content was categorized and grouped together to identify important themes according to the research questions. The themes in the analysis arose through an iterative process of reading and interpreting to identify meaningful units [36-38].

Ethics Approval and Considerations

The study was approved in advance by the ethical committee (PVO) at Helse Nord (project ID 2462). The participants were given both written and verbal information about the study before agreeing to participate. The included informants sent their consent forms via mail to the first author, which were stored without any connection to the gathered data material.

Results

Main Themes

Data were analyzed and categorized with regard to the research questions: Which opportunities and challenges appeared when using VC during the period of COVID-19 restrictions? In a short-term care pathway, for whom does VC work and for whom does it not work? According to the therapists, being forced to initiate the use of VC during COVID-19 restrictions to follow up with service users resulted in both positive and negative experiences. They also expressed an overall perception that the video format offered a necessary opportunity to maintain contact with service users during a challenging and abnormal period. However, several challenges were introduced when the VC was implemented, including the low quality of certain technological aspects, insecurity related to communicating on video, and challenges in managing the service users' reluctance to participate in VC. The themes that arose during data analysis were categorized into three main topics: (1) VC—"it's better than nothing"; (2) VC affects therapists' work situation—opportunities and challenges in working conditions;

and (3) challenges of VC when performing professional assessment and therapy on screen.

VC—“It’s Better Than Nothing”

VC Promotes Continuity and Access to Service

As indicated by the analysis of data extracted from the EPJ system (see Table 1), the use of VC skyrocketed in the period immediately following the introduction of COVID-19 restrictions. This was also noted by one of the therapists interviewed: “I haven’t counted, but I can bet that as many as 85% to 90% of the consultations in the last 2 weeks were on Skype.” Conducting consultations on video allowed the treatment to continue despite the societal lockdown. For some service users, this was valuable; however, the therapists described several service users as reluctant to participate in VC, preferring to wait for the restrictions to ease to continue regular face-to-face treatment instead. From the therapists’ point of view, it was emphasized that VC allowed for closer follow-up and continuity in the treatment of the service users during the COVID-19 lockdown. In some cases, they found it important to encourage service users who were skeptical about the video format to participate in VC to secure continuity and enable follow-up care regarding potentially serious mental health problems. Further, the therapists reported that VC made it easier for service users with social anxiety to take part in consultations, similar to the benefits for users with mobility disabilities or those who worked offshore. They also emphasized how continuity is important when following up with service users with suicidal thoughts; here, a key element is scheduling future appointments to which the service user can look forward, and VC made this possible during the lockdown. Despite these positives, the therapists felt that the quality of the service was affected by the video format. One of the therapists described this challenge as follows:

> *It’s like baking your favorite cake with artificial sweeteners instead of sugar—it will work, and it tastes and looks okay, but there is something missing, it’s not the same quality. However, it’s definitely better than nothing.*

Establishing and Maintaining a Relationship on Video

Initiating a therapeutic relationship on video can be challenging for both the service user and the therapist. The first conversation on video was described as generally consisting of an introduction to the service user’s progress plan, or, in some cases, a risk assessment concerning the severity of the service user’s suicide risk. The latter was found to be especially difficult to achieve on video. Meeting new service users on video could cause insecurity on both sides of the screen and, as one therapist mentioned, although it is always necessary to ensure that confidence and balance are established in the relationship, this is especially important when the initial consultation is on video. Indeed, one of the informants explained that if the therapist feels insecure with the video format, this can affect the power relations between the service user and the therapist. Another therapist felt it was important to provide information to the service user about how to communicate on VC and explain how the pathway of recovery would be addressed on video. Overall, the therapists agreed that it is preferable to meet the service users for the first time face to face to establish a good relationship, and that this would help make future consultations on video less scary and more productive. When employed in consultations with service users they already knew, the therapists felt that video could be a useful tool:

> *Yes, it was a new [service user] and we had not been able to meet physically, so we had the first consultation on Skype. This was a person I knew in advance and [the service user] also knew who I was, so we were not totally strangers to each other. It worked fine.*

It should also be noted that some therapists did experience positive first meetings on video with new service users, although it helped when the therapist and the service user already knew one another. As one of the therapists stated: “I did not complete my education in psychology to meet people on a screen. I want to see them face to face.”

Some of the therapists found VC involving children and adolescents to be particularly challenging, as these service users could experience meeting the therapist on video as frightening in the absence of the natural human comfort and security a face-to-face meeting can provide:

> *Today we had a little 3-year-old who wanted to see us, but then she didn’t dare. “Oh no, I don’t dare,” she said. We had a very good conversation with the parents, but it can be a challenge for youngsters to join.*

Nevertheless, therapists also reported positive experiences, in which children felt safe in the video conversations because the video format allowed them to be in their own home. Some adolescents were quite familiar with the video and internet format, and felt that they could control it—and were more in control when using it—regarding what to choose to display and present on video. However, given the above experiences, some of the therapists were surprised to find that some adolescent service users avoided VC. One possibility to explain this presented was that if it was the service users’ family who wanted them to receive treatment, the service users may have been using reluctance toward VC as an excuse to avoid therapeutic consultations. Nevertheless, the therapists highlighted that just because adolescent service users may be in a digitally mature age group and are used to online communication among themselves on social media, this does not necessarily imply a positive attitude toward VC:

> *I don’t know if it’s about talking to a professional or having some kind of treatment, that makes it difficult? I used to do phone calls, too, but it was hard to get mentally close and open up in the conversation. And maybe when you meet face to face you know better how to get into the right topics, maybe? I do not know.*

With regard to family treatment, several of the therapists raised concerns about using video in consultations, as the focus in this kind of therapy is on creating a relationship with the service user (child) in their own home and monitoring the interaction between the child and the parents. The natural situation is difficult to observe on video, and the therapists feared that important aspects of the children's behaviors were not displayed accurately on screen. The parental guidance consultations, in which only the parents are being guided by the therapist, and the interaction aspect (although beyond the scope of this study) were pointed to by therapists as working well on video.

VC Affects Therapists' Work Situation—Opportunities and Challenges in Working Conditions

Barriers to Effective Communication

On the one hand, working together using video provides an opportunity for closer follow-up and more flexibility in meetings both with service users and with colleagues, including collaborating with providers in other services. On the other hand, therapists also felt that their working conditions were negatively impacted by the video format, and that the communication with the service users changed when it occurred on the screen; as such, they described finding it difficult to make clinical judgments and experienced insecurity regarding the service users' conditions. Several of the therapists revealed that they became exhausted and frustrated when performing VC for an entire workday and that communicating through the screen required a different kind of presence than face-to-face meetings.

> *You get pretty dizzy in your head when you talk to people on Skype. Some conversations last up to, erm, on average, it can last for an hour. But it depends on where you are in the course of treatment. I think you get tired in a different way in, in your head, when you have spent all day on the screen, sitting and talking like that.*

The therapist quoted above had thought it might be easier to conduct consultations on the screen, as not being in the same room could eliminate the potential influence of emotions from the service user. Other therapists also elaborated on the differences between face-to-face and video consultations. One therapist mentioned:

> *If we look at the amount [of VC], it would have been really okay to have some consultations face to face to get variety. When all consultations were on video...well, I don't know how to describe it. It is uncomfortable and it doesn't feel like a good way to work.*

During face-to-face consultations, small breaks often appear naturally during the conversation, and a break while one or the other is thinking feels safe and leads perhaps to a necessary pause in the conversation. In consultations on the screen, these small breaks can feel unnatural. As one therapist noted,

> *The contact feels a little reduced, a little more strained. You sit there staring. It is a deadlocked situation and it is difficult to take breaks. Breaks in the conversation quickly become unpleasant.*

However, another informant pointed out that by working continuously on the screen, more experience with the format was gained, and this led to more natural conversations when using video; this therapist described that a natural approach to working with video developed over time, making it easier to interact in this specific format.

Coping With Technology

Technical problems were reported as severely affecting the quality and safety of VC. One therapist who had experienced a VC in which there were numerous technical problems described the consultation as highly unsuccessful. After the consultation, this therapist felt it necessary to apologize to the service user for the poor quality of the video and the fact that they had been unable to cope with the technology.

> *It's a pretty bad start when you haven't talked to this person before, like the [VC] I mentioned, and we have to give up the consultation for technical problems. We were about to have a first consultation and then we lost 10 to 15 minutes before we found out that it did not work. What impressions are you left with then, [as a service user]? I really wonder how it was for her the first time. I wasn't very happy after that session.*

In retrospect, the therapist regrets not testing the technology before the consultation, saying: "It's our responsibility, isn't it? We offer a type of counseling and then we mess it up or it works badly. It is our responsibility." This therapist was thus left feeling insufficient, that the consultation was unprofessional, and that the VC left both the therapist and the service user feeling negatively about the experience. Distortions in the picture on the screen, disruptions in the sound, losing connection, and other technological interruptions were also felt to have potentially affected the emotional connection and interrupted the flow of a vulnerable conversation. As one therapist explained:

> *Yes, I try, but I don't always know where the problem lies. I am not very good with technology, so…We had a case where we had to do it over the phone. I told the [service user] that she should get help from her partner the next time, and then it worked. While with another [service user] we gave up simply because we couldn't make [the technology] work.*

VC does require a good internet connection, which not all service users and therapists have at home. When technical problems occurred, the therapists told us that their solution was to call the service user via telephone. Some therapists said they tested the technology with other colleagues before conducting the initial conversation with service users. In this way, they avoided unfavorable situations and reduced their fears of using VC. The therapists also found it essential to ensure that the service user had their technology in order and felt comfortable using it. They felt that, as professionals, they had to offer any necessary help:

> *For [service users] who find video technology unfamiliar and difficult to use, they can experience it as a personal failure not to master the technology. They may place the blame for the technical problems on their own incompetence, and not on the different aspects of the technology or system failures.*

One informant explained that if they felt insecure about the technology, they would be fully open about it to the service user to create balance in the relationship. This would also ensure that the service user would not feel like they were to blame for the problems with the technology.

> *Yes, I think it is safe to say it like it is. Maybe also be a bit humble and say that you are not entirely sure of the technology yourself. There may be some connection issues, but we will solve that by calling or doing a trial round first to see if we get it right. Then we can schedule a time for a conversation maybe the next day.*

Lack of Transparency: Not Knowing Who is in the Room

When a service user was in a controlling or abusive relationship, therapists found it challenging to not meet face to face in the office. The therapists explained that it could be difficult to assess with certainty whether the service user could speak openly about how they really felt and was being treated, as the person responsible for the abuse could be in the room with the service user, but off screen. The controlling or abusive partner or parent may also have the opportunity to instruct the service user on what to tell the therapist, and the therapist has no way of knowing whether the service user is being observed during the consultation. As one therapist explained:

> *Her partner has demanded that the conversation take place in a room that he has access to. So, when taking care of [service users] who have manipulative, controlling partners, Skype and telephone represent something I cannot handle. I also have to consider what I say to her [the service user]. If there is something she has told me when we were alone, then I cannot begin the consultation by saying, "The last time, you told me that your partner hit you." He might be sitting right there, you know.*

According to this therapist, for some service users, abuse is embedded in their everyday life, providing a clear limitation regarding what therapists may be comfortable addressing in a VC. This then leads us to the next theme, which is performing therapy on the screen.

Challenges of VC When Performing On-Screen Professional Assessment and Therapy

Suitable and Unsuitable Topics When Using Video

The therapists reported that some conditions and moods were challenging to detect through the video camera, as both body language and other nonvisual impressions disappear. Serious diagnoses and psychological investigations were mentioned as particularly difficult to conduct and discuss over video. Indeed, distrust in the technology and doubt that the VC would progress without disruptions kept many of the therapists from pursuing the most sensitive themes and subjects. They feared that the video connection would break down in the middle of a critical conversation and wanted to avoid having to ask a service user to repeat part of a longitudinal trauma monologue. The most traumatic incidents could be difficult to discuss on video for fear of technical problems or not having control over the service user's environment. Consequently, among other reasons, the therapists did not find video to be a suitable medium for discussing service users' most vulnerable feelings, nor was it easy to find the balance between keeping the therapy moving forward and not digging too deeply into the service users' most vulnerable feelings or traumas. Closing the consultations also represented a potential challenge:

> *I think this is an important aspect, because I have no control after they leave my office. When I meet the person face to face, I have more control over my assessment of what state they are in when they leave.*

One concern shared by several of the therapists centered around the challenge of knowing whether service users were left in an unresolved state and closing the consultation in an appropriate way can be challenging on the screen. A VC can be ended more abruptly than an office visit, by simply pressing the "off" button at the end of the consultation. The therapists feared that ending the conversation too rapidly could be harmful, especially if the consultation had dealt with traumatic subjects. By contrast, avoiding a long journey home by car after an emotional consultation was mentioned as a positive feature with VC, especially for service users with a commute of several hours.

VC as a Filter for Emotions and Health Conditions

Several of the therapists experienced that the video format created distance, which in turn felt like a filter or an obstacle with regard to obtaining relevant information about the service user's condition. According to one therapist:

> *It gets…VC becomes like a filter between us, which, in a way maybe is more apparent on video than normally [face-to-face consultation] (…) The biggest difference is the challenge of simply understanding the nonverbal communication.*

Nonverbal communication that is harder to detect on video might be a glance, a short break from the conversation while looking away, small body movements, jittery fiddling, and similar, almost invisible, movements that although sometimes hard to notice are important for the therapist's assessment of the service user's mental health condition. One therapist described this challenge as follows:

> *I am not sure how to explain it exactly, because it depends on how observant you are. You notice little things. I can listen to and observe a lot when people talk…perceive things.*

This aspect of VC, in which the therapist loses information through the digital filter, was cited as the most challenging and risky part of performing consultations on the screen. One therapist had received a referral stating that a service user had a specific smell; however, because the consultation was performed over video, the therapist lost the opportunity to smell and experience the service user. The therapist explained: "There may be something about cleanliness and, what can I say, if a person does not take care of himself it can be a sign of, for example, depression." With the digital filter in place, there is thus a risk of losing important information regarding certain health conditions, elements, and aspects that may be crucial to the therapist's ability to see the whole picture. In complex situations, VC did not feel like a safe alternative because of this filter and affected the therapists' ability to make clinical judgments about the service users' conditions. Investigating the condition of the service user through the use of standard tools, especially validated schemes to generate diagnoses, was also mentioned as challenging. Indeed, procedures such as these were largely put on hold by therapists until it was possible to meet face-to-face.

Summary of Themes

To summarize the findings, Table 2 includes the main themes and subthemes that emerged in the analysis.

Table 2. Summary of themes and subthemes related to video consultations (VC).

Theme	Subthemes
VC—"it's better than nothing"	VC promotes continuity and access to services; establishing and maintaining relationships on video
VC affects therapists' work situation—opportunities and challenges in working conditions	Coping with technology; lack of transparency—not knowing who is in the room
Challenges of VC when performing professional assessment and therapy on screen	Suitable and unsuitable topics when using video; VC as a filter for emotions and health conditions

Discussion

Principal Findings

In the following, the analytic themes presented in Table 2 will be discussed. The discussion aims to highlight opportunities and challenges in the use of VC in recovery in mental health, assessment, and therapy, and to identify for whom VC worked or did not work in the short-term care pathway from the therapists' perspective.

"It's Better Than Nothing": Video Promotes Continuity and Access to Service

There has been great concern regarding the effect that the COVID-19 restrictions, societal lockdown, and resultant social isolation will have on mental health, particularly with regard to individuals who already have mental health problems or are in a recovery process [40,41]. The use of VC enables access to mental health services, and our findings show that VC does contribute to the overall realization of the continuity and maintenance of the therapist–service user relationship [4,8,20]. Nevertheless, some therapists experienced the initiation of a relationship online to be challenging, and our findings indicate that VC cannot perfectly replace regular face-to-face meetings. This is mainly due to poor clinical quality and technical challenges, as shown in previous research [8,42]. However, from the therapists' perspective in this study, VC was found to help create trust and confidence before the first face-to-face meeting. In some instances, VC can even increase the involvement of the service user and enhance the recovery process, similar to findings in pre-COVID-19 studies [24].

Maintaining the relationship via VC also appears to influence the identity of both the service user and the therapists. For the service user, VC may reinforce the equation of the service user with their diagnosis, which may subsume their humanity entirely in the eyes of another [38]. For the therapists, however, it is also possible that the power balance between the therapists and the service user, and the perception of closeness and distance in their relationship may shift, especially if the therapist reflects on their own insecurity when using VC. Nevertheless, interaction on the screen may also increase the service users' involvement in their own recovery process [8,26]. This may empower the service user if they are confident in coping with the technology, which may in turn further facilitate the recovery process.

Life on the Screen: VC Affects the Therapists' Work Situation

Our findings suggest that the working conditions for therapists can change for the worse when performing VC and might cause more stress in the work situation [43]. The therapists found VC to be more exhausting than face-to-face meetings, as staring into the screen required concentration and demanded a different kind of presence than being together in the same room. As such, the consequences of implementing video technology may, in the long-term, lead to burnout for the therapists, followed by an increase in sick leave [43]. Moreover, challenges may emerge when scaling up the services after a pilot phase [32]; these may include ensuring sufficient time between each consultation on video, and that all therapists are appropriately technologically equipped [44,45]. With regard to the practical aspects of conducting an effective VC, the therapists found it especially problematic when the technology failed or worked poorly. This often interrupted the flow of communication and hampered the therapists' efforts to foster a safe and trusting environment. The therapists expressed concern that the use of VC may be challenging for the service user and lead to a worsening of their situation. Although close relationships and support from the service user's family may be an important part of recovery [19], for others, relationships may negatively influence the recovery process [46,47]. Service users exposed to mental abuse or mistreatment in their home environment may need an alternative to home treatment through video [19]. Similarly, children are often dependent on their parents or next of kin as facilitators when offered consultations on video [48].

Clinical Challenges When Using Video in Consultations

VC seems to be a workable alternative for following up with service users with less severe mental health problems; thus, depending on the service user's specific context and state of mental health, the use of VC may be included in the process where appropriate. The therapists may also speak with the service users about which topics are suitable for VC to determine whether there are topics that should be avoided, including topics that may be too emotional for the service user to cope with without a face-to-face follow-up. Moreover, for a service user who is in personal recovery from severe mental problems, it may be important to be able to choose the topic of conversation, and to know that professional help is available even during a societal lockdown.

VC appears to be less appropriate both for those in need of long-term help and for mapping interactions in social relationships. With regard to the latter, a crucial part of providing mental health services is professional accountability, in which clinical judgment is an important part of mapping the patient's condition to assess their needs and at which level to provide services. In this context, VC can be perceived as a filter that can obscure emotions and make it more difficult to evaluate service users' overall mental conditions [4]. This challenges the quality of the therapists' clinical judgment [49], which is at the core of the therapists' professional practice, and how they see and speak to the patient. The technology itself may make it difficult to provide effective and quality care, which in turn may challenge the relationship between the therapist and service user, and the therapist's ability to follow up with the service user appropriately [50].

The Future of Video Consultations in Mental Health Care

The progression of mental health care requires new ways of providing continuous follow-up in different formats based on changes in the service users' condition and circumstances. A variety of consultation models—face-to-face meetings, video consultations, home care, cocreation meetings, and even in-hospital treatment—may be necessary to provide appropriate care. Based on an analysis of media coverage during the COVID-19 lockdown, Idland [51] argues that although VC will be used as a supplement to face-to-face consultations in the future, most people will still return to face-to-face meetings as soon as possible. The change in the numbers of VCs performed in the hospital under study reflect a similar trend: 74% of the consultations took place via video in the second part of March 2020, followed by a decrease to 21% when the restrictions were eased in May. These numbers (Table 1) are not sufficient to draw conclusions due to the short time period, but they are an indication that can be used for reflection toward the future use of VC in mental health care. The findings clearly indicate that some therapists and service users did not find VC satisfying or safe enough to replace face-to-face consultations in the long run. Further studies are needed to investigate how the use of VC can be perceived as safe and satisfying in normal situations.

Conclusions

The COVID-19 restrictions forced rapid changes in the organization of hospitals and in the treatment of different conditions in the field of mental health. This situation may represent the start of a permanent change in the way mental health services are provided. Indeed, similar changes are already recommended (and sometimes required) by the World Health Organization [52], based on a growing population struggling with mental health problems and increasing challenges regarding how to treat and reach out to those who need help. This study of therapists' experiences with VC in a mental health hospital in Norway during COVID-19 restrictions indicates that there are overall advantages to using VC when circumstances do not permit face-to-face consultations. Although the continuity that VC offers was seen as a valuable asset, the quality of the therapy was considered to be poorer on video than in face-to-face meetings. Various negative aspects related to the therapeutic environment such as lack of safety for the most vulnerable service users and topics unsuitable for VC lowered the therapists' overall impression of the service.

Using VC in therapy may offer opportunities for empowerment by letting the service user select VC as a medium, and may make the service more accessible and available despite physical challenges such as immobility. Access to VC is especially important considering the societal impact of COVID-19. Meeting digitally provides the opportunity to follow up with and take care of the service user's needs. A range of potential advantages appear when transferring parts of the mental health services into digital services and increasing the use of VC, including increased number of service users in treatment, increased satisfaction of both service users and therapists, improved outcomes, destigmatization, and more direct time expenditure on care by the therapists.

Strengths and Limitations of the Study and Issues for Further Research

This study was performed within the context of COVID-19 restrictions, during which the entire department was required to use VC to maintain the treatment of service users in recovery. This allowed access to therapists with both negative and positive perceptions and experiences of digital communication therapy, avoiding the challenge of biased data from digital pioneers. A potential weakness of the study is its reliance on digital interviews. As demonstrated in this study, communicating via video can create a filter and a distance between the actors involved; as such, the information derived from the interviews may have been different if the interviews had been conducted face-to-face.

There is a need for further investigation, including qualitative research, to build solid and evidence-based knowledge that can contribute to developing tailored services for people in recovery and in need of mental health care. Further research should focus on service users' experiences; cocreation between different stakeholders; and how to scale up the use of VC while ensuring that the service provided is appropriate, safe, and available.

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Authors' Contributions

MKG and EK performed the analysis and reflected on the findings together with ERN, who read the most central nodes coded in NVivo. All authors contributed to the writing of the paper's Background and Discussion sections and its revisions.

Conflicts of Interest

None declared.

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Abbreviations

eHealth: electronic health
EPJ: electronic patient journal
VC: video consultation

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Original Paper

Barriers to the Use of Clinical Decision Support for the Evaluation of Pulmonary Embolism: Qualitative Interview Study

Safiya Richardson[1], MD, MPH; Katherine L Dauber-Decker[1], PhD; Thomas McGinn[1], MD, MPH; Douglas P Barnaby[1], MD; Adithya Cattamanchi[2], MD; Renee Pekmezaris[1], PhD

[1]Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Manhasset, NY, United States

[2]Division of Pulmonary and Critical Care Medicine and Partnerships for Research in Implementation Science for Equity (PRISE) Center, University of California San Francisco, San Francisco, CA, United States

Corresponding Author:
Safiya Richardson, MD, MPH
Donald and Barbara Zucker School of Medicine at Hofstra/Northwell
600 Community Drive
Suite 403
Manhasset, NY, 11030
United States
Phone: 1 5166001411
Email: srichard12@northwell.edu

Abstract

Background: Clinicians often disregard potentially beneficial clinical decision support (CDS).

Objective: In this study, we sought to explore the psychological and behavioral barriers to the use of a CDS tool.

Methods: We conducted a qualitative study involving emergency medicine physicians and physician assistants. A semistructured interview guide was created based on the Capability, Opportunity, and Motivation-Behavior model. Interviews focused on the barriers to the use of a CDS tool built based on Wells' criteria for pulmonary embolism to assist clinicians in establishing pretest probability of pulmonary embolism before imaging.

Results: Interviews were conducted with 12 clinicians. Six barriers were identified, including (1) Bayesian reasoning, (2) fear of missing a pulmonary embolism, (3) time pressure or cognitive load, (4) gestalt includes Wells' criteria, (5) missed risk factors, and (6) social pressure.

Conclusions: Clinicians highlighted several important psychological and behavioral barriers to CDS use. Addressing these barriers will be paramount in developing CDS that can meet its potential to transform clinical care.

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KEYWORDS

medical informatics; pulmonary embolism; electronic health records; quality improvement; clinical decision support systems

Introduction

Clinicians often disregard potentially beneficial clinical decision support (CDS) tools. Extensive study of these tools has shown that their use is associated with a morbidity reduction of 10% to 18%, placing CDS at the top of the spectrum of quality improvement interventions [1]. Improvements in quality of care observed with CDS use [2-8] have been significantly limited by consistently low clinician adoption, estimated at 10% [9,10]. CDS based on Wells' criteria for pulmonary embolism [11] serves as an illustration of this phenomenon. Systematic reviews have shown that the use of these criteria decreases ordering of computed tomography (CT) scans by 25% without resulting in additional missed pulmonary emboli (PEs) by clinicians [12]. However, clinicians have requested the removal of CDS tools based on these criteria, even when local efficacy has been demonstrated [13].

A systematic review of 58 studies evaluating barriers to clinician adoption of CDS classified these as "CDS specific, organizational, patient and clinician factors" [14]. CDS-specific factors included those that would improve the ease of tool use (ie, minimal mouse clicks, workflow integration). Organizational factors focused on infrastructure and technical issues (ie, having enough computers). Patient factors focused on clinician perceptions of the impact of CDS on the patient-clinician relationship (ie, CDS diminishes the relationship by distracting the clinician). Clinician factors focused on clinician attitudes toward CDS, including a preference for intuitive thought and perception of CDS as a threat to professional autonomy. Clinician attitudes toward CDS, including psychological and behavioral barriers, are not typically addressed during any stage of CDS development although they represent an important barrier to adoption.

Several important publications have detailed the many challenges to CDS reaching its full potential [15], guiding principles for effective CDS [16] and barriers to guideline concordant care and successful implementation of CDS [17-19]. However, improved understanding of the psychological and behavioral barriers to clinician use of potentially transformative CDS tools would assist developers in creating highly adopted, high-impact tools. We sought to explore these barriers by using a comprehensive behavioral framework to interview users of a CDS tool based on Wells' criteria for pulmonary embolism [20].

Methods

Study Design

We conducted a qualitative study involving emergency medicine physicians (residents and attendings) and physician assistants at two large academic health care facilities in New York. The Northwell Health Institutional Review Board approved this study. Informed consent was obtained for all participants. Participants were recruited by email and presentation at regular faculty meetings. Interviews were conducted between June and September of 2019, and each interview lasted from 30 minutes to 1 hour.

Interview Guide and Behavioral Framework

In-depth interviews focused on the different barriers to use of a CDS tool built based on Wells' criteria for pulmonary embolism to assist clinicians in establishing pretest probability of PE before imaging. A semistructured interview guide was created based on a comprehensive and parsimonious model of behavior—the Capability, Opportunity, Motivation-Behavior (COM-B) model, which specifies that changing behavior requires changing capability, opportunity, and/or motivation [21]. The COM-B model is at the center of a larger behavioral framework—the Behavior Change Wheel. The Behavior Change Wheel was developed from 19 existing behavioral frameworks and includes 9 intervention functions aimed at addressing deficits in one or more of the conditions described by the COM-B model.

CDS Tool

The tool was designed to reduce unnecessary computed tomography pulmonary angiography (CTPA) ordering. Additional details about the design, implementation and evaluation of the tool are available in a previous publication [20]. Emergency clinicians entering any electronic order for the diagnosis of PE (D-dimer, ventilation–perfusion [V/Q] scan, or CTPA) are routed to the tool if they answer "yes" to a dialog box asking, "Are you considering PE?" The tool functions as an expanded order set that allows clinicians to formally calculate pretest probability of PE according to Wells' criteria. For low-risk patients, it only allows clinicians to order D-dimer laboratory testing and for patients with intermediate or high risk of PE, it allows for D-dimer testing, V/Q scan, or CTPA imaging. At any time, the tool can be dismissed by clinicians and then any order can be placed. The tool was developed using adaptive principles in web and health information technology design, which have been detailed in several previous publications [22-25]. The current version of the tool has been active since January 2016 [24]; all study participants had previously used the tool in clinical practice.

Analysis

Thematic saturation was reached after the twelfth interview, with no new insights obtained by the twelfth participant. The COM-B model informed the development of the interview guide, but it was not used to create a priori themes before qualitative analysis. Inductive methods were used to analyze session notes and audio recordings with the COM-B model as a guiding theory. We identified themes using open and then axial coding, and we coded our data accordingly using the qualitative data analysis software NVivo (version 12, released 2018; QSR International Pty Ltd.). Two members (SR and KLD) of the study team, with experience conducting qualitative analysis, coded all sessions. All discrepancies were resolved by consensus.

Results

Interviews were conducted with 5 resident physicians, 5 attending physicians, and 2 physician assistants. Six major barriers to tool use were identified, including (1) Bayesian reasoning, (2) fear of missing a PE, (3) time pressure or cognitive load, (4) gestalt includes Wells' criteria, (5) missed risk factors, and (6) social pressure (Table 1).

Table 1. Themes and representative quotes from qualitative interviews with clinicians.

Theme	Quotes
Bayesian reasoning	• "I don't think [pre-test probability] matters for the CT scan…I've been told if you order a CT, you'll either see it or you won't."
Fear of missing pulmonary embolism	• "…the environment with [quality improvement oversite] and the medical-legal situation, I might argue the threshold to test here is 0%." • "A lot of people say that I'd rather order 10 extra CTs than miss 1 PE…There is a culture of fear of missing." • "…as I've been in practice and I've had law suits and I've seen people have lawsuits…I feel like I tend to irradiate more people than I would have like as a resident…And now I'm like ok radiation, its good stuff."
Time pressure or cognitive load	• "I think that the biggest takeaway that you could take from interviewing ER providers is time, like that's the thing that matters most to us. Time and like ease of use." • "[PERC] feels good…and it's shorter…Wells'…it's longer, it takes a little bit more mental energy to go through."
Gestalt includes Wells' criteria	• "I never use [the clinical decision support tool], I have done the scoring in my head."
Missed risk factors	• "[M]y clinical gestalt has red flags for things that are not on Wells'. …it doesn't have some of the younger woman risk factors like OCPs [oral contraceptive pills] and smoking history."
Social pressure	• "[I]t does happen once in a while that I'll think this person, the patient, can get away with a D-dimer alone but the [physician assistant] or the learner wants to do a CT Scan, and I'm not averse to letting that go through because… sometimes you just need to get talked out of it by getting enough negative ones." • "…I think patient expectations are different. Emergency medicine is becoming like…it's all about customer service. …A lot of things you do because you know your patients are…expecting it."

Clinicians highlighted the belief that the tool was not useful to them because all elements of Wells' criteria for pulmonary embolism were incorporated into their gestalt. The clinical prediction rule is well known and commonly taught during training in emergency medicine. Fear of missing PE was another major theme identified in our analysis. Patient health consequences were rarely mentioned. Clinicians felt that missed PEs were likely to be less clinically significant and unlikely to result in significant harm to patients, but they worried they still might trigger department quality improvement review or legal action. Time pressure was also highlighted as a major barrier to tool use. Although clinicians denied that cognitive load kept them from using the tool, the majority of clinicians spontaneously mentioned their preference for the pulmonary embolism rule-out criteria (PERC) owing to its simplicity. PERC is validated for use in low-risk patients to rule out PE if eight criteria are negative [26].

Additional themes included Bayesian reasoning, missed risk factors, and social pressure. Bayesian reasoning reflected some clinicians not recalling that the posttest probability of PE would be impacted by the pretest probability of PE, predicted by the CDS, regardless of the results of the CT scan. Missed risk factors reflected clinicians' mistrust of the CDS as Wells' criteria for pulmonary embolism do not explicitly include a few known risk factors for PE. Social pressure reflected many clinicians' report that other members of the care team, including the patient and their primary care doctor, could influence their decision to not use or not follow the recommendation of the tool.

Discussion

Principal Findings

In this qualitative study of barriers to the use of CDS for the evaluation of PE, participants reported that the CDS tool was not useful to them despite decades of research validating the efficacy of the clinical prediction rule that served as the basis for the tool and our work showing that tool users at our institution improved their CT scan ordering behaviors [20]. Most clinicians felt that they were able to incorporate the elements of the Wells' criteria for pulmonary embolism into their decision-making without using the tool. The clinical prediction rule, with seven elements, each weighted differently, is complicated enough to make memorization unreliable. There is evidence that clinicians have trouble remembering even simple clinical prediction rules. For example, a study in which clinicians were surveyed about their knowledge of the Ottawa Ankle Rule found that although 89.6% reported using the rule always or most of the time in appropriate circumstances, only 30.9% correctly remembered which four components were part of the rule [27].

Another major barrier to tool use was fear of missing a PE. In a previous study, surveyed emergency medicine clinicians said that about one-fifth of all imaging studies ordered were medically unnecessary [28]. The main perceived contributors were fear of missing a low-probability diagnosis and fear of litigation. Interestingly, although many clinicians in our study reported this as a barrier, only one knew of any emergency medicine clinician who had ever been sued for a missed PE. The great majority of patients in New York who sustain a medical injury because of negligence do not sue [29,30], and evidence of adherence to known clinical practice guidelines can help clinicians avoid liability [31]. More importantly, systematic reviews have shown that the use of the Wells' criteria for pulmonary embolism decreases CT scan ordering by 25% without resulting in additional missed PEs by clinicians [12]. These facts were not unknown to clinicians in our study, and many volunteered similar statements. However, these facts alone were not enough to address this important psychological barrier to tool use.

Psychological and behavioral barriers, such as gestalt includes Wells' criteria and fear of missing PE, as well as time pressure or cognitive load are not easily addressed by educational quality improvement interventions. Emergency medicine clinicians are familiar with and believe the Wells' criteria for pulmonary embolism are useful, as evidenced by a study which surveyed clinicians at our institution [32]. Additionally, the benefits of using the CDS tool, which incorporates these criteria, were reviewed in several academic detailing training sessions for the tool with clinicians before its launch [20]. Additional educational sessions would not be likely to address the sense for physicians that their gestalt adequately considers Wells' criteria for pulmonary embolism without referencing them. This is likely to be the case as well for using educational sessions or traditional CDS to reduce fear of missing PE.

Time pressure or cognitive load may be the most difficult to address and an important barrier to the use of CDS in the emergency department. However, clinicians reported that low utility was the driving factor for dismissal, and not cognitive load or time. They also reported the importance of eliminating even a single extra click and a strong preference for PERC owing to its simplicity; however, unlike the Wells' criteria for pulmonary embolism, it can only be used in low-risk patients. Additionally, emergency medicine may be the clinical specialty with the highest task load and one of the highest cognitive loads [33]. This demanding environment exerts strong pressure on clinicians to find the fastest, safest path forward. In the case of assessment for PE, this often means skipping the CDS and ordering a CTPA—the definitive test to evaluate for PE.

Some of the barriers identified by this study, such as Bayesian reasoning and missed risk factors, might be addressed by simple educational quality improvement interventions. Addressing common knowledge gaps with education—that is, the role of Bayesian reasoning and instances when the rule is not valid—may help to increase adoption rates. A recent study of guideline-discordant CT scans performed to evaluate for PE found that in 39% of these cases, patients had risk factors that were not explicitly incorporated in traditional clinical prediction rules [34]. Building tools with brief instruction manuals may help clarify for clinicians when to use and when not to use these tools. Additionally, although educational quality improvement interventions would be less likely to address barriers such as gestalt includes Wells' criteria, fear of missing PE, and time pressure or cognitive load, there are several behavioral interventions that might move the needle. For example, tool endorsement by key leadership might increase use, by communicating institutional backing for tool use and mitigating the fear of missing PE. Avenues to address the social pressure barrier would need to be informed by further research, for example, by knowledge of study patients and their preferences.

We have shown how a behavioral model can identify novel barriers to the adoption of a CDS tool. Our findings underscore the importance of addressing the psychological and behavioral barriers to CDS use. Although the field stands to benefit greatly from much anticipated advances in computational capabilities—for example, artificial intelligence, including machine learning—these tools are unlikely to meet their potential to transform clinical care until behavioral barriers to their use are adequately described and addressed.

Limitations

Our work has several limitations. All clinicians work in the New York City metropolitan area. Both institutions are academic tertiary care centers. Clinicians outside of this geographical area or working in community hospital settings were not included in this study.

Conclusions

In summary, clinicians highlighted several important psychological and behavioral barriers to CDS use. Addressing these barriers will be paramount in developing CDS that can meet its potential to transform clinical care.

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Conflicts of Interest

None declared.

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Abbreviations

CDS: clinical decision support
COM-B: Capability, Opportunity, and Motivation-Behavior
CT: computed tomography
CTPA: computed tomography pulmonary angiography
PE: pulmonary embolism
PERC: pulmonary embolism rule-out criteria
V/Q: ventilation–perfusion

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Original Paper

Clinician Perspectives on Telemedicine: Observational Cross-sectional Study

Maria Alcocer Alkureishi[1], MD; Zi-Yi Choo[2], BS; Gena Lenti[2], BS; Jason Castaneda[2], BS; Mengqi Zhu[3], MS; Kenneth Nunes[4], MD; George Weyer[3], MD; Julie Oyler[3], MD; Sachin Shah[3,5], MD; Wei Wei Lee[3], MPH, MD

[1]Department of Academic Medicine, University of Chicago, Chicago, IL, United States
[2]Pritzker School of Medicine, Chicago, IL, United States
[3]Department of Medicine, University of Chicago, Chicago, IL, United States
[4]Department of Obstetrics and Gynecology, University of Chicago, Chicago, IL, United States
[5]Department of Pediatrics, University of Chicago, Chicago, IL, United States

Corresponding Author:
Maria Alcocer Alkureishi, MD
Department of Academic Medicine
University of Chicago
5841 S Maryland Av, MC 6082 Rm C124
Chicago, IL, 60637
United States
Phone: 1 773 834 8927
Fax: 1 773 834 5964
Email: malkureishi@peds.bsd.uchicago.edu

Abstract

Background: Since the COVID-19 pandemic onset, telemedicine has increased exponentially across numerous outpatient departments and specialties. Qualitative studies examining clinician telemedicine perspectives during the pandemic identified challenges with physical examination, workflow concerns, burnout, and reduced personal connection with patients. However, these studies only included a relatively small number of physicians or were limited to a single specialty, and few assessed perspectives on integrating trainees into workflows, an important area to address to support the clinical learning environment. As telemedicine use continues, it is necessary to understand a range of clinician perspectives.

Objective: This study aims to survey pediatric and adult medicine clinicians at the University of Chicago Medical Center to understand their telemedicine benefits and barriers, workflow impacts, and training and support needs.

Methods: In July 2020, we conducted an observational cross-sectional study of University of Chicago Medical Center faculty and advanced practice providers in the Department of Medicine (DOM) and Department of Pediatrics (DOP).

Results: The overall response rate was 39% (200/517; DOM: 135/325, 42%; DOP: 65/192, 34%); most respondents were physicians (DOM: 100/135, 74%; DOP: 51/65, 79%). One-third took longer to prepare for (65/200, 33%) and conduct (62/200, 32%) video visits compared to in-person visits. Male clinicians reported conducting a higher percentage of telemedicine visits by video than their female counterparts (P=.02), with no differences in the number of half-days per week providing direct outpatient care or supervising trainees. Further, clinicians who conducted a higher percentage of their telemedicine by video were less likely to feel overwhelmed (P=.02), with no difference in reported burnout. Female clinicians were “more overwhelmed” with video visits compared to males (41/130, 32% vs 12/64, 19%; P=.05). Clinicians 50 years or older were “less overwhelmed” than those younger than 50 years (30/85, 35% vs 23/113, 20%; P=.02). Those who received more video visit training modalities (eg, a document and webinar on technical issues) were less likely to feel overwhelmed by the conversion to video visits (P=.007) or burnt out (P=.009). In addition, those reporting a higher ability to technically navigate a video visit were also less likely to feel overwhelmed by video visits (P=.02) or burnt out (P=.001). The top telemedicine barriers were patient-related: lack of technology access, lack of skill, and reluctance. Training needs to be focused on integrating learners into workflows. Open-ended responses highlighted a need for increased support staff. Overall, more than half “enjoyed conducting video visits” (119/200, 60%) and wanted to continue using video visits in the future (150/200, 75%).

Conclusions: Despite positive telemedicine experiences, more support to facilitate video visits for patients and clinicians is needed. Further, clinicians need additional training on trainee education and integration into workflows. Further work is needed to better understand why gender and age differences exist. In conclusion, interventions to address clinician and patient barriers, and enhance clinician training are needed to support telemedicine's durability.

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KEYWORDS

telemedicine; clinician perspective; patient-centered care; burnout; trainee; outpatient; workflow; virtual health; training; human factors

Introduction

Telemedicine uses electronic communications and software, like video and telephone visits, to deliver remote clinical services to patients [1]. Positive telemedicine outcomes include increased access to care, reduced wait times, improved clinical outcomes, and high patient and clinician satisfaction [2,3]. Despite this, telemedicine is generally less accepted by clinicians compared to patients [4,5], citing concerns over compensation, inadequate training, additional work, and difficulty adapting to technology [5].

Since the COVID-19 pandemic onset, telemedicine has increased exponentially across numerous outpatient departments and specialties [6,7]. Clinicians had to quickly pivot to provide substantial amounts of virtual care, resulting in the need to learn new workflows. In qualitative studies examining clinician telemedicine perspectives in the pandemic's wake, clinicians reported challenges with physical examination, workflow concerns, burnout, and reduced personal connection with patients [8,9]. Although these studies set a baseline for understanding clinician barriers to telemedicine, they only explored perceptions of a relatively small number of physicians [8,10] or were limited to physicians from one specialty [9,11-13]. Furthermore, few studies assessed clinician perspectives on effectively integrating trainees into telemedicine workflows, an important area to address to support the clinical learning environment. As telemedicine maintains its foothold in outpatient medicine throughout and likely beyond the pandemic, it is necessary to understand a broad range of clinician perspectives on its impact on patient care, workflows, and trainee education, particularly since clinicians are more satisfied with telemedicine when they have input and support in its development [3].

Our study aims to survey pediatric and adult medicine clinicians at the University of Chicago Medical Center (UCMC) to understand perspectives on telemedicine benefits and barriers, workflow impacts, and training and support needs. Capturing clinician perceptions in various outpatient departments and specialties is critical to improving the clinician and patient telemedicine experience and to ensuring successful integration and durability of virtual encounters [14].

Methods

Setting and Participants

UCMC is a large urban academic health system and affiliated care network that provides tertiary care in the South Side of Chicago. As background, telemedicine was used for outpatient primary care at UCMC in the Department of Medicine (DOM) and Department of Pediatrics (DOP) whenever possible beginning March 15, 2020, to provide safe and socially distanced care. The total number of UCMC ambulatory visits at this time dropped substantially, with ambulatory visits falling to 23% of visit volumes when compared to the same week in the fiscal year (FY) 2019 [7]. After approximately 6 weeks, however, UCMC ambulatory visit volume had reached 92% of FY 2019 volumes, largely driven by the increase in virtual visits by nearly 1000 of our ambulatory clinicians. Overall, between March 15 and May 31, 2020, UCMC virtual visits increased from 0 to 48,475 visits; 60.5% of total ambulatory visits were virtual, of which 61.2% (n=29,661) were by video and 38.8% (n=18,814) were by telephone [7].

Survey Development

We developed a 54-question survey (Multimedia Appendix 1) to capture clinician perceptions and needs for telemedicine implementation. Questions were based on a literature review of the impact of telemedicine on patient and clinician satisfaction and workflows, and informed by discussions with key UCMC stakeholders and leaders, practicing clinicians, and trainees. The survey consisted of Likert-style and open-ended questions, and assessed key areas including perceptions about benefits and barriers (n=20), workflow impacts (n=5), overall satisfaction (n=4), and training or support needs (n=6). Clinicians who worked with trainees (eg, medical students, residents, or fellows) were asked about their experiences with trainee integration and education (n=7). Open-ended questions (n=4) were included to elicit suggestions not previously asked. This project received a formal Determination of Quality Improvement project status according to UCMC institutional policy and, as such, was not reviewed by an institutional review board.

Survey Distribution

In July 2020, 517 UCMC physicians and advanced practice providers (APPs; eg, advanced practice nurses, clinical nurse specialists, and physicians' assistants) in the DOM (n=325) and DOP (n=192) were invited via email to participate in the survey. The email was sent by UCMC leadership and the study investigators (MAA and WWL). Data was collected and managed using REDcap (v8.9.2; Vanderbilt University) [15]. The survey was open for 6 weeks, with one reminder email at 3 weeks. Individual emails were sent to DOP and DOM chairs and section chiefs at regular intervals, notifying them of their response rate and asking them to encourage clinician participation.

Data Analysis

REDcap data was exported to Stata 16 (Stata Corp) [16] and RStudio (version 3.6.1; RStudio, PBC) [17] for statistical analysis. Quantitative outcomes were summarized by descriptive statistics. Chi-square tests, Fisher exact tests, and *t* tests assessed differences in outcomes among groups of interest. Ordinal logistic regressions examined associations between ordinal outcomes and explanatory variables of interest. Significance was defined as a two-sided *P* value less than .05.

Open-ended question responses were collectively pooled and read. Content analysis identified unique response themes, and representative quotations were identified to build a picture of clinicians' collective experiences and video visit needs [18].

Results

Overview

The overall response rate was 39% (200/517; DOM: 135/325, 42%; DOP: 65/192, 34%). Respondent demographics are displayed in Table 1. The majority of respondents were faculty physicians (DOM: 100/135, 74%; DOP: 51/65, 78.5%), with roughly a quarter of APP respondents (DOM: 35/135, 26%; DOP: 14/65, 21.5%; *P*<.001). Most clinicians were aged 30 to 59 years (154/200, 77%), and 65% (130/200) were female. More female clinicians were also younger (83/130, 64% females <50 years vs 27/64, 42% males; *P*=.006). There were no significant differences by department (DOM vs DOP) or clinician age in terms of the number of half-days per week spent providing direct outpatient care, supervising trainees, or the percentage of telemedicine visits they personally conducted by video in the past week (Table 2). Although there were gender differences, with more male clinicians reporting they conducted a higher percentage of telemedicine visits by video than their female counterparts (*P*=.02), there were no significant differences in number of half-days per week spent providing direct outpatient care or supervising trainees.

Table 1. Clinician information by department.

Variables	Department of Medicine (n=135), n (%)	Department of Pediatrics (n=65), n (%)	*P* value
Clinician position			.77
Physician	100 (74.1)	51 (78.5)	
Advanced practice provider[a]	35 (25.9)	14 (21.5)	
Age (years)			.65
20-29	2 (1.5)	0 (0.0)	
30-39	48 (35.6)	17 (26.2)	
40-49	28 (20.7)	18 (27.7)	
50-59	27 (20.0)	16 (24.6)	
60-69	23 (17.0)	11 (16.9)	
≥70	6 (4.5)	2 (3.1)	
Gender			.49
Female	85 (63.0)	45 (69.2)	
Male	47 (34.8)	17 (26.2)	
Prefer not to say	3 (2.2)	3 (4.6)	
Half-days per week providing direct outpatient care[b]			.07
0-2	56 (41.5)	16 (24.6)	
3-4	44 (32.6)	22 (33.8)	
5-6	24 (17.8)	15 (23.1)	
≥7	11 (8.1)	11 (16.9)	
Telemedicine visits personally conducted by video in the past week?[b] (%)			.09
0-24	38 (28.1)	26 (40.0)	
25-49	33 (24.4)	9 (13.8)	
50-74	32 (23.7)	10 (15.4)	
≥75	32 (23.7)	20 (30.8)	
Number of half-days per week spent supervising trainees[c]			.21
0	69 (51.1)	34 (52.3)	
1-2	51 (37.8)	19 (29.2)	
≥3	14 (10.4)	12 (18.5)	
Types of video visit training received			
Received a document on technical issues	83 (61.5)	47 (72.3)	.18
Webinar on technical issues	47 (34.8)	17 (26.2)	.29
In-person training on technical issues	5 (3.7)	3 (4.6)	.72
Received a document on communication strategies	35 (25.9)	24 (36.9)	.15
Webinar on communication strategies	18 (13.3)	9 (13.8)	>.99
In-person training on communication strategies	1 (0.7)	2 (3.1)	.25
None	25 (18.5)	6 (9.2)	.14
Other	4 (3.0)	3 (4.6)	.68

[a] Examples of advanced practice providers include advanced practice nurses, clinical nurse specialists, and physicians' assistants.

[b] Refers only to visits conducted personally by the clinician and not trainees they supervised.

[c] Trainees include medical students, residents, and fellows.

Table 2. Clinician information by age and gender.

Variables	Female (n=130), n (%)	Male (n=64), n (%)	*P* value	Younger than 50 years (n=113), n (%)	Older than 50 years (n=85), n (%)	*P* value
Half-days per week providing direct outpatient care[a]			.13			.35
0-2	39 (30.0)	30 (46.9)		41 (36.3)	31 (36.5)	
3-4	44 (33.8)	21 (32.8)		38 (33.6)	28 (32.9)	
5-6	33 (25.4)	5 (7.8)		24 (21.2)	14 (16.5)	
≥7	14 (10.8)	8 (12.5)		10 (8.8)	12 (14.1)	
Telemedicine visits personally conducted by video in the past week?[a] **(%)**			.02			.16
0-24	47 (36.2)	15 (23.4)		39 (34.5)	25 (29.4)	
25-49	30 (23.1)	12 (18.8)		24 (21.2)	17 (20.0)	
50-74	28 (21.5)	11 (17.2)		27 (23.9)	14 (16.5)	
≥75	25 (19.2)	26 (40.6)		23 (20.4)	29 (34.1)	
Number of half-days per week spent supervising trainees[b]			.52			.45
0	69 (53.1)	29 (45.3)		63 (55.8)	39 (45.9)	
1-2	43 (33.1)	27 (42.2)		35 (31.0)	35 (41.2)	
≥3	18 (13.8)	8 (12.5)		15 (13.3)	11 (12.9)	
Presence of burnout[c]			.29			.01
Yes	56 (43.1)	22 (34.4)		55 (48.7)	26 (30.6)	
No	74 (56.9)	42 (65.6)		58 (51.3)	59 (69.4)	
Converting in-person visits to video visits has resulted in feeling...			.05			.02
More overwhelmed	41 (31.5)	12 (18.8)		31 (27.4)	24 (28.2)	
Similarly overwhelmed	59 (45.4)	28 (43.8)		59 (52.2)	31 (36.5)	
Less overwhelmed	29 (22.3)	24 (37.5)		23 (20.4)	30 (35.3)	

[a] Refers only to visits conducted personally by the clinician and not trainees they supervised.

[b] Trainees include medical students, residents, and fellows.

[c] As defined by respondents own definition of *burnout*.

Training

Most clinicians received some video visit training on technical issues (DOM: 93/135, 69%; DOP: 51/65, 78%), and fewer received telemedicine communication practice training (DOM: 42/135, 31%; DOP: 27/65, 42%; *P*<.001). There were no differences in training across gender, age, or departments.

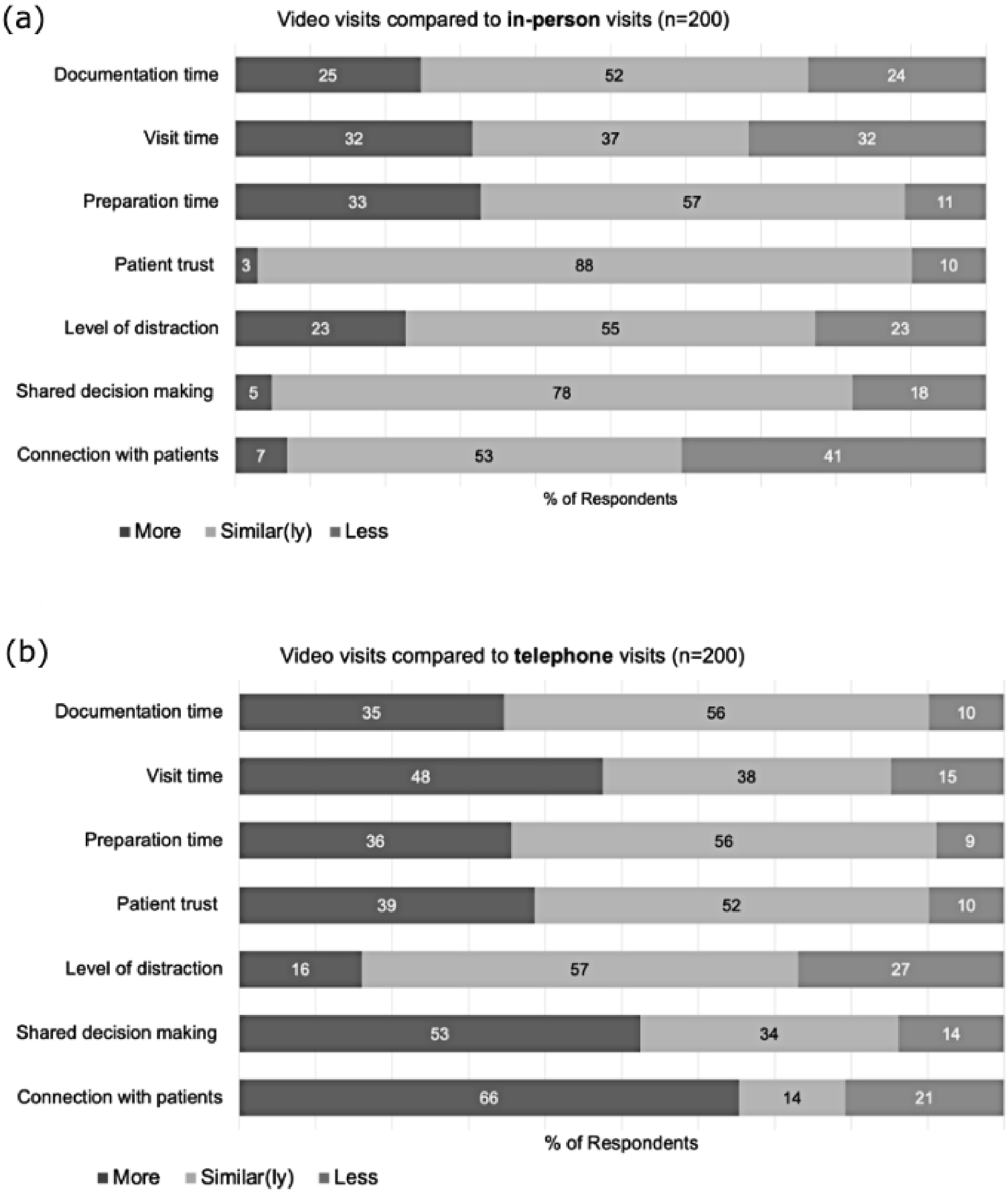
Comparison of Video Visits With In-person and Telephone Visits

Figure 1 demonstrates clinician attitudes and experiences with regard to video, telephone, and in-person visits. Although nearly half of the 200 clinicians reported video visits took a similar amount of time to prepare (n=114, 57%) and document (n=104, 52%) compared to in-person visits, nearly one-third reported video visits took longer to prepare (n=65, 33%), conduct (n=64, 32%), and document (n=49, 25%). Likewise, when comparing video visits with telephone visits, nearly half reported video visits took a similar amount of time to prepare (n=111, 56%) and document (n=111, 56%). However, one-third of clinicians reported video visits took more time to prepare (n=72, 36%), conduct (n=96, 48%), and document (n=69, 35%) than telephone visits. Although there were no differences across gender or age, DOP clinicians were significantly more likely to report that video visits took longer to document compared to in-person visits (DOP: 25/65, 38% vs DOM: 32/135, 24%; *P*=.03) and telephone visits (DOP: 29/65, 45% vs DOM: 40/135, 30%; *P*=.04).

Despite the virtual nature of the visit, most of the 200 clinicians (n=156, 78%) felt they could promote shared decision making during video visits as well as they could in in-person visits. Half (n=106, 53%) felt they could better promote shared decision making during video visits compared to telephone visits. Just over half (n=105, 53%) felt they could personally connect as well or better with patients during video visits compared to in-person visits, with 66% (n=131) reporting they connected better with patients over video than over telephone. Although there were no differences across gender or age, DOP clinicians were more likely to report personal connection (DOM: 79/135, 59%; DOP: 52/65, 80%; *P*=.003), and the ability to share decisions with patients (DOM: 60/135, 44%; DOP: 46/65, 71%; *P*=.01) was better over video compared to telephone. DOP clinicians were also more likely to report that their ability to share decisions with patients was as good or better via video compared to in-person visits (DOM: 105/135, 78%; DOP: 60/65, 92%; *P*=.01).

Just over half of the 200 clinicians reported their level of distraction was similar when comparing video visits to in-person (n=110, 55%) and telephone visits (n=114, 57%). Most (n=176, 88%) felt patient trust in their diagnosis over video was similar compared to in person, whereas about half (n=104, 52%) felt patient trust over video was similar compared to telephone. Just over one-third (n=78, 39%) felt patient trust was better over video compared to telephone. Finally, nearly two-thirds agreed that being able to visualize a patient's home environment (n=120, 60%) and being able to have patient companions join the video visit (n=168, 84%) added valuable insight into their patients' lives. There were no differences across gender, age, or departments in these areas.

Figure 1. Video visit sentiments compared to in-person and telephone visits. Clinicians were asked to rate statements comparing video visits to (a) in-person visits and (b) telephone visits as "more," "similar(ly)," or "less" in various categories (eg, "Video visits take more, similar, or less time to document compared to in-person visits").



Video Visit Barriers

The top three most commonly cited barriers from the 200 clinicians to conducting video visits were not clinician-specific barriers but rather patient related, including patient lack of technical knowledge (n=139, 70%), lack of patient access to necessary technology for a video visit (n=132, 66%), and patient reluctance to have a video visit (n=75, 38%; Table 3). The next most frequently cited barriers were inadequate staff support both during (n=70, 35%) and when scheduling visits (n=68, 34%). There were no differences across gender, age, or departments in visit barriers.

Table 3. Barriers and training needs.

Barriers	DOM[a], n (%)	DOP[b], n (%)
Barriers to conducting video visits (DOM: n=135; DOP: n=65)		
Patient lack of technical knowledge	105 (77.8)	34 (52.3)
Patient access to necessary technology	101 (74.8)	31 (47.7)
Patient reluctance	61 (45.2)	14 (21.5)
Inadequate staff support during visits	48 (35.6)	22 (33.8)
Inadequate scheduling staff support	44 (32.6)	24 (36.9)
Barriers to conducting video visits with residents/fellows (DOM: n=65; DOP: n=31)		
Concerns about integrating them into video visit workflows	34 (52.3)	18 (58.1)
Uncertainty about documentation rules	12 (18.5)	10 (32.3)
Other	14 (21.5)	7 (22.6)
Barriers to conducting video visits with medical students (DOM: n=65; DOP: n=31)		
Concerns about integrating them into video visit workflows	26 (40.0)	10 (32.3)
Uncertainty about documentation rules	15 (23.1)	4 (12.9)
Unsure how to give performance feedback	9 (13.8)	3 (9.7)
Patient reluctance to having medical students involved	9 (13.8)	2 (6.5)
Other	7 (10.8)	5 (16.1)
Training needs (DOM: n=135; DOP: n=65)		
Performing a video visit exam	62 (45.9)	35 (53.8)
Billing aspects	51 (37.8)	31 (47.7)
Technical aspects	52 (38.5)	22 (33.8)
Communication strategies	33 (24.4)	22 (33.8)
Integrating residents/fellows into visit workflows	38 (28.1)	26 (40.0)

[a] DOM: Department of Medicine.

[b] DOP: Department of Pediatrics.

Faculty physicians who precepted trainees (n=96) during telehealth visits cited “concerns about integrating them into video visit workflows” and “uncertainty about documentation rules” as the top two barriers both when working with residents and fellows (n=52, 54% and n=22, 23%, respectively) and medical students (n=36, 38% and n=19, 20%, respectively; Table 3). The next most commonly cited barriers for medical educator clinicians was uncertainty about how to give trainees feedback on their virtual visit performance (residents and fellows: n=15, 16%; medical students: n=12, 13%). Overall, nearly three-quarters of teaching clinicians agreed or strongly agreed that “virtual medicine has made clinical teaching more difficult” (n=69, 72%). This sentiment was further reflected in clinicians’ open-ended responses where some (n=8) reported having little experience with and needing substantially more training to integrate medical students, residents, and fellows into virtual workflows (Textbox 1). There were no differences across gender, age, or departments in trainee barriers.

Textbox 1. Themes and representative quotations of video visit needs.

How can your section/department best support you in the use of video visits?

- Provide clinic staff support to prepare patients for visits
  - “I would like support staff dedicated to virtual visits, so they can interface with patients with expertise.”
  - “Technical support, and working with patients so they are comfortable with video visits.”
- Streamline scheduling processes and video visit workflows
  - “Video visit slots are like clinic slots; allow for enough time for the visit and documentation of the visit.”
  - “Screen the patients who benefit from the video visits, and who should have personal visits at clinic.”

How can your section/department best support your patients in the use of video visits?

- Provide technical support for patients
  - “Provide the support staff to help patients troubleshoot technical issues”
  - “Help them figure out how to access the links and help them troubleshoot so that they are ready to go at the time of their virtual appointment.”
- Provide technology access for patients
  - “Ensure they have access to adequate technology. Some patients don't even have enough cellphone minutes.”
  - “Make them accessible via phone. Most of my patients do not have laptops/tablets and need to use their phone”

What suggestions do you have on how to successfully integrate trainee teaching into telehealth visit workflows?

- Establish learner workflows
  - “We have the trainees begin the call as they would in clinic...then call the attending and ‘present’ the patient and then both join on the call to finish the visit.”
  - “I think it would be good if the trainee and attending could somehow go into a breakout room to discuss the assessment and plan without the patient.”
- Provide teaching training for preceptors
  - “Guide preceptors on how to do this best.”
- Provide more time within telehealth teaching schedules
  - “Give preceptors more time in the schedules to account for the additional time it takes to precept a student.”

Please share additional comments, suggestions, or experiences regarding your video visit experience

- Video visit experiences have been positive, and are useful for many clinicians and patients.
  - “When patients are comfortable with the technology, video visits work very well. In addition, for the most part, patient show rates are significantly higher. I would like to have the opportunity to continue to use telehealth in the future for certain patient visits.”
  - “My patients really like the video visits, however for some frail/elderly patients, it's been both a blessing and a curse.”
- Video visit limitations and utility for certain types of appointments
  - “The inability to perform at least a halfway good physical exam will eventually severely impact patient outcomes and increase cost to the system through increased testing.”
  - “I would support continuing video visits for 1. patients who live far away and are challenged by the distance, 2. patients who have limited resources to come to clinic 3. stable patients who don't need a detailed hands-on examination 4. discussion of a serious condition, or serious decision-making.”

Clinician Experience, Burnout, and Satisfaction

In the survey, participants were asked to self-report their perceived level of burnout. Overall, 81 clinicians reported burnout, with significant differences between departments (DOP: 36/65, 56%; DOM: 45/135, 34%; P=.004) but not by gender (male: 22/64, 34%; female: 56/130, 43%; P=.29). Of note, clinicians younger than 50 years (55/113, 49%) also reported higher levels of burnout compared to those 50 years or older (26/85, 31%; P=.01).

Participants were also asked whether converting in-person visits to video made them feel less, similarly, or more overwhelmed.

Overall, only 28% (n=56) of the 200 clinicians felt more overwhelmed, with nearly half of clinicians (n=90, 45%) feeling similarly and 27% (n=53) feeling less overwhelmed. Notably, a higher proportion of female clinicians (41/130, 32%) than males (12/64, 19%) reported feeling more overwhelmed (P=.05). Although there was no overall difference between clinician age and feeling *more* overwhelmed with video visits, clinicians 50 years or older felt significantly *less* overwhelmed (30/85, 35%) than those younger than 50 years (23/113, 20%; P=.02). Differences in feeling overwhelmed by video visits were not seen across departments.

With respect to training, clinicians who received a greater number of video visit training modalities (eg, a document and webinar on technical issues) were less likely to feel overwhelmed by the conversion to video visits (P=.007) or burnt out (P=.009). Those reporting a higher ability to technically navigate a video visit were also less likely to feel overwhelmed by video visits (P=.02) or burnt out (P=.001). Further, clinicians who conducted a higher percentage of their telemedicine by video were less likely to feel overwhelmed (P=.02); however, there was no difference in reported burnout. There were no gender, age, or departmental differences in training or self-reported ability. Interestingly, there were also no significant differences in feeling burnt out or overwhelmed by the switch to video visits and the number of either personal or supervising teaching attending clinic sessions per week or by the type of virtual visits their trainees had (eg, video or phone).

Overall, more than half of the 200 clinicians (n=119, 60%) enjoyed conducting video visits, and 69% (n=137) reported “the benefits of video visits outweighed the negatives.” Most wanted to continue using video visits (n=150, 75%), which was higher than the fraction of clinicians (n=85, 43%) who wanted to continue using telephone visits (P<.001). There were no differences across gender, age, or department in these areas.

Support and Training Needs

In terms of clinician resources for technical or clinical support during video visits, the largest percentage of the 200 respondents said they had no resource to go to when an issue (technical or process) occurred (n=73, 37%), with the next largest group citing patient service representatives (n=50, 25%) or medical assistants (n=37, 19%) as their primary support resource. The top three video visit training needs reported were guidance on performing an exam (n=97, 49%), billing (n=82, 41%), and technical aspects (n=74, 37%; Table 3). There were no significant differences across gender, age, or department in training needs.

These sentiments were reflected in the open-ended responses (n=42) in Textbox 1. At the departmental level, clinicians (n=14) called for improved staff support before and during video visits. Regarding patient-facing barriers, they also described the need for patient technical support (n=13), while others (n=9) reiterated the need for improved patient technology literacy and access to ensure successful virtual visits. Finally, clinicians shared additional comments regarding their video visit experience. Despite overall positive experiences, clinicians (n=13) commented on video visit challenges such as adjusting to new virtual workflows and the limitations of video visits for certain patient populations and visit types.

Discussion

As virtual visits continue to comprise an important and increasingly prevalent form of health care delivery, it is important to understand the clinician experience and how they perceive video and telephone visits compared to in-person visits. Most clinicians enjoyed conducting video visits and felt that the connection they had with patients was similar to in-person visits. However, it is important to note that one-third of clinicians reported video visits took longer to prepare, conduct, and document compared to in-person visits. Prior to the COVID-19 pandemic, most of our clinicians had never conducted virtual visits. The overnight conversion to telemedicine required rapid adjustments to a new technology and the creation of new workflows. Further, with in-person visits, a medical assistant often starts the visit for the clinician, documenting intake questions and administering screening tools such as depression assessments, gathering background information such as interim hospitalizations and emergency room visits, and verifying information such as their medications, preferred pharmacy, and allergies.

At the start of the transition to telemedicine, most medical assistants were not assisting clinicians with these visit duties, and the burden of that additional workload and documentation fell to clinicians. Having conducted our study, the need to provide clinician visit support in the virtual setting much like that of the in-person setting became clear. Many clinicians stated that they needed more help supporting virtual visits so that patients could be *roomed* just like in a regular visit, and the lack of external visit support may have led to increased clinician burden and therefore increased time to prepare and document virtual visits. Additionally, we found clinicians who had more video visit training and higher self-rated technical knowledge were less likely to feel overwhelmed or burnt out. The longer time needed to prepare and document virtual visits could be due to the need for more training and increased familiarity with technology. As clinicians become more comfortable with virtual visits and new clinical support is implemented, providers should be resurveyed on whether they feel that telehealth visits take more time and what, if any, training needs they continue to have.

Prior to the pandemic, electronic documentation demands on clinicians were already high with clinicians spending more than one half of their workday, nearly 6 hours, interacting with the electronic health record (EHR) during and after clinic hours, 1 to 2 hours of which was during their personal time each night [19], an activity one author aptly termed “pajama time” charting [20]. Even more worrisome is that EHR documentation burden is linked to increases in medical errors, threats to patient safety, inferior documentation quality, job attrition, and clinician burnout [21]. With telemedicine potentially adding to this out-of-visit documentation load and total visit time, it is critical for institutions to recognize that increased demands on clinician time may increase burnout and to proactively develop interventions to promote efficient telemedicine workflows and

EHR efficiency to minimize clinician burden and prioritize wellness.

Despite one-third of clinicians reporting it took longer to prepare, conduct, and document telemedicine visits, we found no significant differences in burnout or feeling overwhelmed by the conversion from in-person to video and clinicians' personal or teaching attending workload. This may be partly due to the fact that our survey period was relatively early on in the course of the pandemic, and although data showing burnout is increasing [22], this may be due to the sustained impacts of the pandemic, and because of our survey time period, these rates may have not yet started to rise to the level that they are at now. There may also be an impact of infection risk during COVID-19 and burnout as a result of clinician anxiety and stress related to either personally contracting COVID-19 or passing it to a family member [23]. The reduced number of in-person visits at the start of the pandemic, which coincided with our study period, could have led to lower rates of burnout since working from home decreased clinician exposure risk and may have reduced infection-related stress and anxiety, thereby outweighing the potential burden of virtual visits themselves.

Further, COVID-19 significantly increased the challenges of work-life balance for clinicians with children [24]. School-aged children transitioned to remote learning, and many day cares and after-school programs closed, creating a sudden need for clinician parents to source childcare. This was a major stressor for many clinician parents, and although nonideal, telemedicine provided a way for clinicians with children to work from home. The ability to provide childcare in light of the pandemic may have led to lower rates of observed burnout.

Additionally, the finding that clinicians who had more video visit training and, perhaps consequently, a higher self-rated technical facility with video visits were less likely to feel overwhelmed or burnt out by transitioning to video visits underscores the importance of clinician familiarity and efficiency with technology as a key driver in their experience. Studies examining EHR use support this finding and suggest that enhanced education and training can improve clinician technical proficiency, self-reported efficiency, and satisfaction, which could eventually have an effect on burnout [25].

We also found that clinicians who conducted a higher percentage of their telemedicine visits by video were less overwhelmed. Although we know this variable refers to the *proportion* of telemedicine visits conducted by video, it is possible that these individuals also conducted a higher *amount* of visits by video by the time they took our survey. Perhaps this group of clinicians had become more adept at conducting video visits and therefore felt less overwhelmed moving their clinics to virtual because of their skill, as previously mentioned. However, it also may be that video visits are for some reason less stressful to conduct compared to telephone visits, perhaps because communication and assessment is easier with the added visual benefit of video. That said, further study in this area is needed.

Additionally, we saw differences between groups in regard to the burden of telemedicine and potential for subsequent burnout. For instance, women reported being more overwhelmed with video visits compared to men. This may be attributed to females conducting a lower percentage of telemedicine visits by video, which was shown to be associated with feeling overwhelmed, as previously mentioned. It is unclear why female clinicians were less likely to conduct video visits despite similar clinical and teaching workloads; however, given female clinicians were younger and thus more junior, they may have opted for fewer video and more telephone sessions. Further, prior to COVID-19, female physicians spent significantly more time on household activities and childcare than their male counterparts, which was likely exacerbated by the closing of schools, day cares, etc during the pandemic [26-28]. There is also evidence that female physicians are more likely to be in frontline clinical positions, less represented in high-level decision making roles [26] and that, overall, female physicians suffered from reduced publishing productivity during COVID-19 compared to male physicians [29]. The cognitive load of new virtual workflows along with these other pandemic-related stressors [30] may provide an explanation for the differences we found in our study between males and females.

Our study also found that older clinicians (>50 years) reported being less overwhelmed than younger clinicians with the addition of video visits to their practice, despite having a similar personal and teaching clinic workload as their younger counterparts, and that younger clinicians had higher burnout at baseline compared to older clinicians. Of note, other studies have similarly found older clinicians generally experienced greater well-being and lower levels of stress compared to younger clinicians during the pandemic [31,32]. Although we had anticipated that older clinicians would potentially be more overwhelmed with the introduction of new technologies to their practice, it may be that, in addition to the diminished childcare responsibilities previously mentioned, older clinicians have greater experience and trust in their diagnostic skill and long-standing relationships with their patient panels, allowing them to more smoothly transition their practice to a virtual setting. Conversely, younger clinicians may have higher rates of burnout due to lack of experience [31] and the need to balance childcare needs in the setting of school and day care closures. These differences underscore the need for health care organizations to understand the various stressors uniquely affecting their clinicians during the pandemic and beyond, and to invest in telemedicine support structures to reduce additional burden placed on clinicians.

Although our surveyed clinicians found they could still promote patient-centered care through virtual visits, we found notable differences between pediatric and adult medicine clinicians in these areas. In particular, pediatric clinicians found telephone visits less beneficial for connecting with and making shared decisions with their patients. Pediatric patients are often not participating verbally in the visit themselves, but rather the child's parent or guardian; therefore, the added benefit of visually observing and connecting with the child through the camera may be more important on the pediatric side. That said, pediatric clinicians reported higher confidence compared to adult clinicians that they could share decision making with their patients over video compared to in-person visits. This reinforces the idea that, although virtual visits are still useful for pediatric patients, video visits may allow for more patient-centered techniques compared to telephone visits.

Although clinicians recognized the need for ongoing training for themselves, the top three telemedicine barriers clinicians encountered were not clinician-centered barriers such as inadequate staff support. Instead, the top three barriers identified were their patient's barriers: access to technology, technical literacy and knowledge, and overall reluctance toward video visits. These findings have several important implications for patient care for telemedicine to be a successful means of providing care for all patients, not only technically savvy or resource-rich patients. Our findings underscore the need to better understand and minimize potential disparities with respect to the digital divide or the gap between persons who have and do not have access to new forms of information technology [33]. An early evaluation of telemedicine visits at UCMC, where Black or African American patients completed significantly fewer video visits but more telephone visits compared to White patients [7], helps further highlight this need. At other institutions, older patients, Black and Hispanic patients, patients with Medicaid insurance, and patients who need an interpreter were also less likely to have a video visit [34,35].

This finding is particularly troubling, as telemedicine was a lifeline for many to access needed clinical care during the pandemic. Telemedicine exposed inequities related to the digital divide for many of our South Side Chicago patients, and in response to this study and the knowledge that our clinician experience and success with telemedicine was critically dependent on our patient's ability to access and use technology, we developed patient-facing materials to help patients prepare for and navigate virtual visits, including high-tech (portal, website, videos, email) and lower-tech (text, phone calls, paper mailing) means. We have also started a qualitative study in response to understand our patients' telemedicine experiences [36] and will use our findings to expand our outreach, identify and develop needed patient resources and interventions to enhance access to technology, and better screen for and promote eHealth literacy. To minimize the digital divide, it is critical for organizations to further explore their patients' telehealth experiences and engage them in helping identify the barriers they face that limit their ability to successfully participate in video visits [37]. In our study, clinicians reported challenges with integrating trainees into telemedicine workflows. Many were uncertain about how to document telemedicine encounters with trainees and how to provide performance feedback. As trainees return to the outpatient setting, it is necessary to address these barriers and to help teaching clinicians define opportunities for trainee education. As new telehealth competencies from the Association of American Medical Colleges emerge [38], clinician educators should focus on how to practically integrate these lessons into learner curriculum and practice. Finally, clinicians self-identified the need for further training and guidance on performing exams on video visits and technical and billing aspects of video visits. Given that over one-third of clinicians did not have a top resource for technical or process issues that arose during video visits, it is important to promote ongoing awareness and support for our many technical resources. In response, we implemented a telemedicine curriculum for medical students, residents, and faculty focusing on helping patients navigate virtual visits while integrating patient-centered care principles and provided faculty with additional training on integrating trainees into virtual workflows in a meaningful and educational manner [39].

There are several important limitations of our study to note. First, our study is limited to one institution, situated in a largely underserved area. To increase generalizability, our survey was cross departmental, including representation from our affiliate care partners who practice in nonacademic and community-based settings. Additionally, it is possible that clinician responses were influenced by the specific telemedicine platform used at UCMC; other organizations may have different experiences based on other platforms. It is important to note, however, that our survey questions broadly targeted aspects of the clinician virtual visit experience without reference to the specific telemedicine platform used. Finally, we did not directly survey patients during this time and all identified barriers, challenges, and perceptions of telemedicine in this study are based solely on the clinician experience. This underscores the need to elicit these perceptions directly from patients to better understand their challenges and perceived benefits of telemedicine.

In conclusion, this is the first study to elicit perspectives on telemedicine from a wide range of faculty from the departments of medicine and pediatrics. Clinicians identified barriers to implementation, challenges to incorporating trainee education, and training needs that should be addressed to improve the telemedicine experience. Overall, it is encouraging that clinicians enjoy video visits and can connect with their patients similarly to in-person visits. However, it is concerning that for a third of clinicians, video visits took longer to prepare, conduct, and document. To support clinician wellness, institutions must more completely understand and support clinician needs. Regarding trainee education, training is needed to help clinician educators successfully integrate students and house staff into virtual workflows, assess learner telemedicine performance, and structure virtual clinic feedback. Most importantly, the top three barriers to successful telemedicine implementation identified by clinicians are patient barriers, highlighting the need to better understand patient perceptions toward video and telephone visits, and proactively address barriers that contribute to the digital divide. It is critical to address each of these needs to support the durability of telemedicine visits as a way to complement and augment the care patients receive in person and to ensure that both clinician and patient experiences are efficient, positive, and patient-centered.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Clinician Survey.
[PDF File (Adobe PDF File), 68 KB - humanfactors_v8i3e29690_app1.pdf]

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Abbreviations

APP: advanced practice provider
DOM: Department of Medicine
DOP: Department of Pediatrics
EHR: electronic health record
FY: fiscal year
UCMC: University of Chicago Medical Center

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Original Paper

User Evaluation of the Swedish Patient Accessible Electronic Health Record: System Usability Scale

Maria Hägglund[1], MSc, PhD; Isabella Scandurra[2], MSc, PhD

[1]Healthcare Sciences and e-Health, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

[2]School of Business, Örebro University, Örebro, Sweden

Corresponding Author:
Maria Hägglund, MSc, PhD
Healthcare Sciences and e-Health
Department of Women's and Children's Health
Uppsala University
Dag Hammarskjölds väg 14B, 1 tr
Uppsala, 752 37
Sweden
Phone: 46 0729999381
Email: maria.hagglund@kbh.uu.se

Abstract

Background: Transparency is increasingly called for in health care, especially, when it comes to patients' access to their electronic health records. In Sweden, the e-service Journalen is a national patient accessible electronic health record (PAEHR), accessible online via the national patient portal. User characteristics and perceived benefits of using a PAEHR influence behavioral intention for use and adoption, but poor usability that increases the effort expectancy can have a negative impact. It is, therefore, of interest to explore how users of the PAEHR Journalen perceive its usability and usefulness.

Objective: The aim of this study was to explore how the users of the Swedish PAEHR experience the usability of the system and to identify differences in these experiences based on the level of transparency of the region.

Methods: A survey study was conducted to elicit opinions and experiences of patients using Journalen. The data were collected from June to October 2016. The questionnaire included questions regarding the usability of the system from the System Usability Scale (SUS). The SUS analysis was the focus of this paper. Analysis was performed on different levels: nationally looking at the whole data set and breaking it down by focusing on 2 different regions to explore differences in experienced usability based on the level of transparency.

Results: During the survey period, 423,141 users logged into Journalen, of which 2587 unique users completed the survey (response rate 0.61%). The total mean score for all respondents to the SUS items was 79.81 (SD 14.25), which corresponds to a system with good usability. To further explore whether the level of transparency in a region would affect the user's experience of the usability of the system, we analyzed the 2 regions with the most respondents: Region Uppsala (the first to launch, with a high level of transparency), and Region Skåne (an early implementer, with a low level of transparency at the time of the survey). Of the participants who responded to at least 1 SUS statement, 520 stated that they had received care in Region Skåne, whereas 331 participants had received care in Region Uppsala. Uppsala's mean SUS score was 80.71 (SD 13.41), compared with Skåne's mean of 79.37 (SD 13.78).

Conclusions: The Swedish national PAEHR Journalen has a reasonably good usability (mean SUS score 79.81, SD 14.25); however, further research into more specific usability areas are needed to ensure usefulness and ease of use in the future. A somewhat higher SUS score for the region with high transparency compared with the region with low transparency could indicate a relationship between the perceived usability of a PAEHR and the level of transparency offered, but further research on the relationship between transparency and usability is required.

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KEYWORDS

usability; system usability scale; evaluation; patient accessible electronic health records; open notes; patient portals

Introduction

Transparency, including the possibility for patients to gain insight into one's own medical information, is increasingly called for in health care, especially, when it comes to patients' access to their electronic health records (EHRs) [1]. Many countries (eg, Finland, France, Norway, Australia, Denmark, Canada, United Kingdom, and Sweden) have, in the past, implemented or are now currently implementing patient accessible electronic health records (PAEHRs) [2]. In some countries, these are local implementations at a specific hospital or region, whereas others have national solutions. Differences in strategies and approaches have affected the uptake and impact, and the implementation progress has, in several countries, been slow due to legal constraints [3,4] and concerns about security and privacy among health care professionals [5-7]. A PAEHR often includes the clinical notes written by different health care professionals, as well as other parts of the EHR (eg, lab results, referrals, and medications).

In the United States, the OpenNotes initiative focuses on providing patients access to their notes, specifically. OpenNotes began as a pilot evaluation project that included 105 volunteer primary care physicians and their 19,000 patients [8,9]. The initiative started in 2010 and has since spread throughout the United States [10]. On April 5, 2021, a new federal rule required US health care providers to allow patients access to all the health information in their EHR [11,12]. This new rule mandates rapid, full access to test results, medication lists, referral information, and clinical notes in electronic formats, by request.

In Sweden, the e-service Journalen is a national PAEHR, accessible online via the national patient portal called 1177.se [13]. The PAEHR service accesses the EHR information from most of the various EHR systems used throughout Swedish health care organizations, via a national health information exchange platform [14,15]. Hence, patients have one access point for all their health record information regardless of (1) how many health care providers they have visited and (2) which EHR system their health care providers use [13]. Since the first Swedish region began providing their inhabitants online access to their health records in 2012, all the other regions have connected to the national infrastructure and the PAEHR Journalen. This was not the case from the beginning, though, and the last of the 21 regions connected only in April 2018. In addition, different regions made different choices about how much of their information would be made available to patients; for example, patients receiving care in one region could gain access to both their lab results and notes, whereas patients receiving care in a different region might only be able to access the notes [13,16].

A growing literature on patients' experiences of accessing their records online reports positive outcomes [10,16]. Patients who read their notes have reported a better understanding of their care plans [10], a sense of greater control over their care [10,16], an improved adherence to medication [17], improved communication with and trust in their clinicians [16,17], and a sense that their care is safer [18].

Despite these benefits, adoption and use can be low [19], and several studies have explored factors that influence adoption [20,21]. User characteristics and perceived benefits of using a PAEHR might influence behavioral intention for use and adoption, but poor usability that increases the effort expectancy can also have an impact. It is, therefore, of interest to further explore how users of the PAEHR Journalen perceive its usability and usefulness; the latter is especially important, considering the differences in the levels of transparency regarding patients' health information in different regions.

In this study, we analyzed data on usability issues from a national survey conducted among patients who use the PAEHR Journalen. A first analysis of the main results from the survey was published in 2018 [16] and contains an overview of the full survey. Here, we focused only on the usability-related questions as well as some demographic data of the participants. At the time of the study (June to October 2016), not all regions allowed patients access to their records through Journalen, and, among those who did, the level of transparency of this information varied [16]. Table 1 represents an overview of what types of clinical content the health care providers had chosen to allow access to at the time of data collection for this study.

The aim of this study was to explore how the users of the Swedish PAEHR experience the usability of the system and to identify differences in these experiences based on the level of transparency regarding patients' health information for the region.

Table 1. Overview of core types of clinical content the health care providers (21 regions and 1 private care provider) had chosen to allow access to at the time of data collection for this study (adapted from [16]).

Care provider	Content provided								
	Medical notes (18/22, 82%)	Diagnoses (15/22, 68%)	Lab results (8/22, 36%)	Medications (7/22, 32%)	Immunizations (7/22, 32%)	Referrals (5/22, 23%)	Access to log lists (3/22, 14%)	Psychiatry notes (2/22, 9%)	Total content available
Blekinge	✓	✓	✓	✓					4
Dalarna	✓					✓			2
Gotland									0
Gävleborg									0
Halland	✓	✓	✓		✓				4
Jämtland/ Härjedalen									0
Jönköping	✓	✓		✓					3
Kalmar	✓	✓	✓	✓					4
Kronoberg	✓	✓						✓	3
Norrbotten	✓			✓	✓				3
Skåne	✓	✓						✓	3
Stockholm	✓	✓	✓						3
Södermanland	✓	✓							2
Uppsala	✓	✓	✓	✓		✓	✓		6
Värmland	✓	✓	✓		✓	✓	✓		6
Västerbotten	✓	✓		✓					3
Västernorrland									0
Västmanland	✓					✓	✓		3
VGR	✓	✓							2
Örebro	✓	✓	✓	✓	✓				5
Östergötland	✓	✓	✓	✓	✓	✓			6
Capio (private care provider)	✓	✓	✓						3

Methods

Study Design

A survey study was conducted to collect opinions and experiences of patients using Journalen. The data were collected from June to October 2016, after ethical approval of the research was granted by the Regional Ethical Review Board in Uppsala, Sweden (EPN 2016/129). Participants were recruited through the national PAEHR Journalen. When patients logged into Journalen, they received a request for voluntary survey participation together with information about the study. Thus, only active users of Journalen were invited to participate.

Data Collection

Survey Preparation

An anonymous questionnaire was designed covering different topic areas with a total of 24 questions in Swedish (see the full questionnaire in [16]), including questions regarding the usability of the system using the System Usability Scale (SUS) [22].

The usability and technical functionality of the electronic questionnaire had not been tested before fielding the questionnaire. However, participants received information about whom to contact in case of technical issues. The SUS has been validated and used in many studies [23].

The collected data were managed by the eHealth service provider Inera AB, in accordance with the Regional Ethical Review Board's approval. The survey data were stored in the same database system as the PAEHR Journalen, meaning that the collected data, including patient IDs, had the same security protection as all patient information handled in the PAEHR. A patient ID was stored during the collection period to ensure that patients had not left duplicate responses. When the collection period was completed, the patient ID was removed and all stored information was anonymized. The anonymized dataset was exported to researchers for analysis.

The System Usability Scale

The SUS [22] is a simple, 5-point Likert scale that provides a global view of subjective assessments of usability, which was developed as a fast and efficient method to collect an overview of the usability of a system [24]. Benefits of the SUS tool include that it is technologically agnostic (ie, it can be used for many different types of information technology systems), that it is quick and easy to use for both participants and researchers, that it provides a single score on a scale that is easy to understand, and that it is cost efficient due to its state of nonpropriety [24]. The SUS consists of 10 statements that were slightly modified and translated to Swedish for this study (Table 2).

Table 2. The System Usability Scale statements[a] and our modifications.

Item	SUS[b] statement	Modified statement	Statement in Swedish
1	I think that I would like to use this system frequently.	I think that I would like to use Journalen regularly.	Jag tror att jag vill använda ”Journalen” regelbundet.
2	I found the system unnecessarily complex.	I found Journalen unnecessarily complex.	Jag anser att ”Journalen” är mer komplicerad än vad den behöver vara.
3	I thought the system was easy to use.	I thought Journalen was easy to use.	Jag anser att ”Journalen” är lätt att använda.
4	I think that I would need the support of a technical person to be able to use this system.	I think that I would need the support of a technical person to be able to use Journalen.	Jag tror att jag skulle behöva personlig teknisk support för att kunna använda ”Journalen.”
5	I found the various functions in this system were well integrated.	I found the various functions in the system were well integrated.	Jag anser att de olika funktionerna i ”Journalen” fungerar väl tillsammans.
6	I thought there was too much inconsistency in this system.	I thought there was too much inconsistency in this system.	Jag anser att det finns många delar i ”Journalen” som inte är konsekventa.
7	I would imagine that most people would learn to use this system very quickly.	I would imagine that most people would learn to use Journalen very quickly.	Jag tror att de flesta skulle kunna lära sig att använda ”Journalen” ganska snabbt.
8	I found the system very cumbersome to use.	I found Journalen very cumbersome to use.	Jag anser att ”Journalen” är besvärlig att använda.
9	I felt very confident using the system.	I felt very confident using Journalen.	Jag känner mig väldigt säker och trygg (på vad jag gör) när jag använder ”Journalen.”
10	I needed to learn a lot of things before I could get going with this system.	I needed to learn a lot things before I could get going with Journalen.	Jag behöver lära mig ganska mycket innan jag kan börja använda ”Journalen.”

[a] Responses were measured with a 5-point Likert scale.

[b] SUS: System Usability Scale.

Data Analysis

Main Analyses

Overall, 2587 patients from 21 regions completed the survey. The number of participants for each region varied. Notably, it was not possible to statistically verify whether the number of participants was at an adequate level to provide more than tentative region-wise and group-wise comparisons. Only completed questionnaires have been analyzed, as the answers were stored in the database only when the participant chose to submit the survey on the last page. However, the SUS items were not mandatory to respond to, and, therefore, the total number of answers for each SUS item varied (Table 3). In addition, 48 participants did not answer any of the SUS items and were excluded from further analysis, leaving 2539 people who answered at least 1 SUS item. Item 1 had the most answers (n=2507), whereas item 6 had the fewest (n=2459). Some free-text comments also indicated that item 6 was difficult to understand for some of the participants.

Rather than excluding questionnaires with missing SUS answers, we have chosen to substitute a neutral (eg, “neither agree nor disagree”) response for the missing items. Since individual items on the SUS score are not necessarily meaningful themselves, this was a feasible approach to make sure that we did not tilt the results to one of the extremes when simply excluding a response.

In this paper, we focused on the SUS questions, which were analyzed according to the SUS method. Questions regarding demographics and perceived usefulness were also included in the analysis (for these questions, we used all survey responses, not excluding those who did not respond to the SUS statements). The analysis was completed on different levels: (1) nationally looking at the whole data set and (2) breaking it down by focusing on 2 different regions to explore differences in experienced usability based on the level of transparency. The 2 different regions were Uppsala (the first to launch, with a high level of transparency), and Skåne (an early implementer, with a low level of transparency at the time of the survey).

Table 3. The number of answers for each System Usability Scale item (N=2539).

Item	Modified SUS[a] item	Total answers
1	I think that I would like to use Journalen regularly.	2507
2	I found Journalen unnecessarily complex.	2476
3	I thought Journalen was easy to use.	2498
4	I think that I would need the support of a technical person to be able to use Journalen.	2471
5	I found the various functions in the system were well integrated.	2481
6	I thought there was too much inconsistency in this system.	2459
7	I would imagine that most people would learn to use Journalen very quickly.	2479
8	I found Journalen very cumbersome to use.	2462
9	I felt very confident using Journalen.	2482
10	I needed to learn a lot things before I could get going with Journalen.	2448

[a] SUS: System Usability Scale.

SUS Analysis

We decided to include all the answers to the SUS items in our calculation, in which participants responded to at least one SUS item, despite some participants not answering all items. We calculated the individual analysis for each participant's SUS score, and the median and mean values for the entire population. The final scores for the SUS can range from 0 to 100, where higher scores indicate better usability. Because the statements alternate between positive and negative, care must be taken when scoring the survey. To calculate the SUS score, each item's score contribution (ranging from 0-4) must be calculated. For items 1, 3, 5, 7, and 9, the score contribution is the scale position minus 1. For items 2, 4, 6, 8, and 10, the contribution is 5 minus the scale position. For participants who missed 1 or more SUS question, we chose to substitute a neutral ("neither agree nor disagree") response for missing items.

The score contributions for each item were then added together and multiplied by 2.5 to achieve the final score [22]. According to Bangor and colleagues' [24] thorough evaluation of the SUS, a system needs to score above 70 to be considered at least passable. Better systems will score in the high 70s to high 80s, and scores over 90 indicate a truly superior system [24]. The authors also argued that any system that scores below 70 would require further usability testing and continued improvement.

We made 3 separate SUS calculations: (1) a calculation of all the individual answers, (2) a calculation of only answers from participants from Uppsala, and (3) a calculation of only answers from participants from Skåne.

Results

During the survey period, 423,141 users logged into Journalen, of which 2587 patients completed the survey (of unique users that logged in, response rate 0.61%). Of all respondents, 62.97% (1629/2587) identified as women and 30.85% (798/2587) as men; 0.39% (10/2587) of respondents chose "other," and 5.80% (150/2587) did not answer this question. According to use statistics provided by Inera AB (the company providing Journalen and the national patient portal [25]), this reflects the gender distribution of the users in general (in 2016, 60% women and 40% men). Of all respondents, 39.81% (1030/2587) stated that they were working or had been working within health care, and 54.54% (1411/2587) stated that they had no professional relation to health care; 5.64% (146/2587) of respondents did not answer this question. Participants had a higher education level than the general population [16]. Among our participants, 60.57% (1487/2455) had higher education, whereas only 42% of the general Swedish population does [26]. We cannot tell whether this is because users of Journalen are well educated or that people with a higher education represent a subgroup of users who are more inclined to answer a survey. Unfortunately, no data on the general education levels of Journalen users exist.

To sum up, the survey results regarding user characteristics on a national level indicate that most participants were women and that the majority had studied at least 3 years of higher education. In addition, results indicate that many users of Journalen were both patients and medical professionals, at various points in their lives.

In Moll and colleagues' [16] overview of the survey results, details of the participants' views of the usefulness and benefits of accessing their health records online are presented in more detail. Overall, patients who answered the survey were positive toward Journalen (Table 4). Participants were asked to rate on a 5-point Likert scale to what extent they agreed to the more general statements, "I think that access to one's medical records online is generally a good reform," and "I think that access to Journalen is good for me." Of all participants, >96% (2454/2541, 96.58% and 2455/2528, 97.11%, for the respective questions) had a positive attitude toward Journalen, answering with either "completely agree" or "partly agree."

Table 4. Participants' attitudes toward patients' access to their medical records online.

Item	Value, n (%)
I think access to one's medical records online is generally a good reform.	2541[a]
Do not agree at all	26 (1.02)
Do not agree	23 (0.91)
Neutral	38 (1.50)
Partly agree	302 (11.89)
Completely agree	2152 (84.69)
I think that access to Journalen is good for me.	2528[a]
Do not agree at all	19 (0.75)
Do not agree	15 (0.59)
Neutral	39 (1.54)
Partly agree	199 (7.87)
Completely agree	2256 (89.24)

[a] Some participants did not answer all questions. Therefore, the total for each variable category differs.

However, a positive attitude toward accessing one's health records does not say much about the usability of the system, and, therefore, we also present the results of the SUS analysis. Results of the analysis of the SUS questions are first described on a national level. Table 5 presents the results of all participants for the SUS items in the survey, including neutral responses replacing missing answers for participants who responded to at least 1 SUS item.

Table 5. Results of the System Usability Scale items for all participants, on a national level (N=2539)[a].

SUS[b] analysis item	Value per 5-point Likert scale response[c], n (%)				
	1	2	3	4	5
I think that I would like to use Journalen regularly.	37 (1.46)	39 (1.54)	182 (7.16)	529 (20.83)	1752 (69.00)
I found Journalen unnecessarily complex.	915 (36.04)	723 (28.48)	577 (22.73)	244 (9.61)	80 (3.15)
I thought Journalen was easy to use.	40 (1.58)	70 (2.76)	285 (11.22)	785 (30.92)	1359 (53.53)
I think that I would need the support of a technical person to be able to use Journalen.	1843 (72.59)	391 (15.40)	205 (8.07)	66 (2.60)	34 (1.33)
I found the various functions in the system were well integrated.	62 (2.44)	171 (6.73)	720 (28.36)	831 (32.73)	755 (29.74)
I thought there was too much inconsistency in this system.	550 (21.66)	466 (18.35)	1120 (44.11)	305 (12.01)	98 (3.86)
I would imagine that most people would learn to use Journalen very quickly.	29 (1.14)	103 (4.06)	355 (13.98)	1140 (44.90)	912 (35.92)
I found Journalen very cumbersome to use.	1587 (62.50)	531 (20.91)	278 (10.95)	96 (3.78)	47 (1.85)
I felt very confident using Journalen.	54 (2.13)	37 (1.46)	275 (10.83)	602 (23.71)	1571 (61.87)
I needed to learn a lot things before I could get going with Journalen.	1790 (70.50)	421 (16.58)	235 (9.26)	64 (2.52)	29 (1.14)

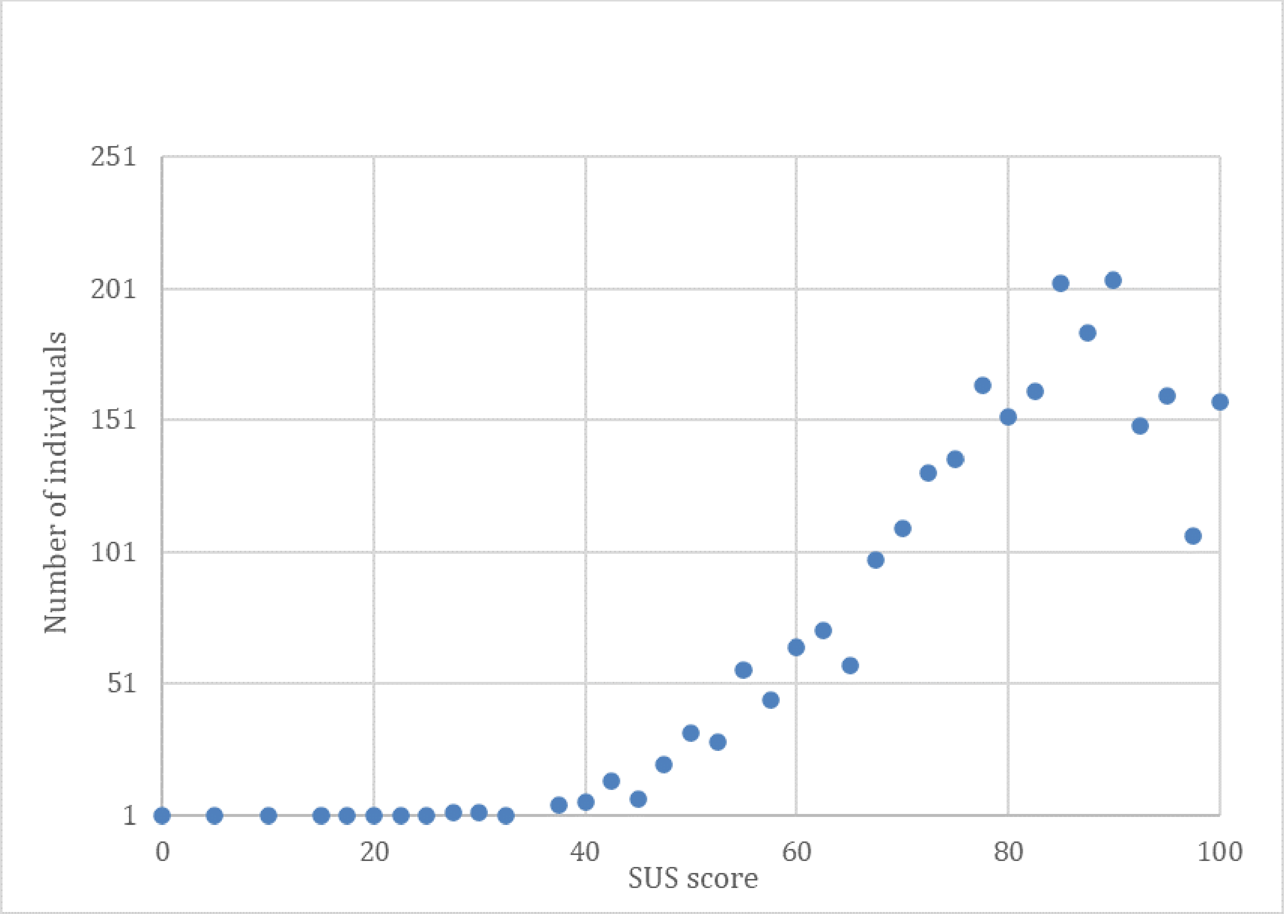
[a] The appropriate number of neutral responses were added to replace missing responses for each item, in order to not skew results due to missing items.

[b] SUS: System Usability Scale.

[c] From 1 ("Do not agree at all") to 5 ("Completely agree").

For all participants, the total mean score for the SUS scale was 79.81 (SD 14.25), which would, according to Bangor and colleagues [24], qualify as a successful system. The median score was 82.5, and the distribution of individual answers is plotted in Figure 1. The scores covered the entire range, from 0 (1 person) to 100 (158 people), but the majority of individuals scored above 60.

Figure 1. Individual System Usability Scale scores. SUS: System Usability Scale.



Each item can have a score contribution between 0 and 4. Most of the items scored above 3; however, 3 questions stood out with score contributions below 3 (Table 6). All 3 questions that score below 3 related to the complexity of the system and whether functions are well integrated in the system.

Table 6. System Usability Scale score contribution of individual items.

SUS[a] analysis item	Score
I think that I would like to use Journalen regularly.	3.54
I found Journalen unnecessarily complex.	2.85
I thought Journalen was easy to use.	3.32
I think that I would need the support of a technical person to be able to use Journalen.	3.55
I found the various functions in the system were well integrated.	2.81
I thought there was too much inconsistency in this system.	2.42
I would imagine that most people would learn to use Journalen very quickly.	3.10
I found Journalen very cumbersome to use.	3.38
I felt very confident using Journalen.	3.42
I needed to learn a lot things before I could get going with Journalen.	3.53

[a] SUS: System Usability Scale.

To further explore whether the level of transparency in a region would affect the user's experience of the usability of the system, we made additional SUS analyses based on the 2 regions with the most participants: Region Uppsala (the first to launch, with a high level of transparency) and Region Skåne (an early implementer, with a low level of transparency at the time of the survey). Overall, 692 participants stated that they had received care in Region Skåne, of which 520 responded to at least 1 SUS item and were included in this analysis. However, 520 participants stated that they had received care in Region Uppsala, of which 331 had responded to at least 1 SUS item. Analysis of Region Skåne responses yielded a final score of 79.37, whereas Uppsala's result was 80.71. The results in mean SUS score were close enough to indicate that no major difference can be seen on the SUS scale based on the level of transparency in the implementation of the PAEHR. A two-tailed *t* test with equal variance yielded a *P* value of .16, indicating that the difference was not statistically significant at the standard 5% significance level.

In addition to the SUS, we also asked a question specifically focused on navigation, more precisely, on the participants' experiences of locating Journalen in the national patient portal. This issue had been brought up as a concern previously; since the national patient portal contains many eHealth services, there were worries that patients might not find Journalen. The majority of the participants (1974/2451, 80.53%) did not have trouble locating the link in the patient portal, whereas 233/2451 (9.51%) expressed difficulty finding Journalen.

Discussion

To summarize, the results indicate that the users of the Swedish PAEHR Journalen rate the service high (79.81) on the System Usability Scale, yet questions relating to consistency and complexity scored lower. Before discussing the results in more detail, we address some methodological limitations of this study.

The System Usability Scale

The SUS does not help identify specific usability issues or provide detailed information on effectiveness or efficiency of the system that is evaluated. For an in-depth usability evaluation, usability testing or other forms of usability evaluations would be necessary. However, to gain an overall understanding of the level of usability of a system, the SUS can be useful [24]. In this study, we chose to use SUS items as parts of a more extensive survey to achieve an overall understanding of the usability of the current version of the Swedish PAEHR Journalen. An SUS score could also be used as a baseline analysis for further evaluations of the PAEHR, particularly, when changes to PAEHR's user interface or content have been implemented.

Limitations of the Survey

The survey distribution may have created a bias in the study, which needs to be considered when interpreting the results. The survey was distributed through the national patient portal and was only accessible once someone logged into Journalen. This was intentional, as the main aim of the study was to explore the experiences of people who had used the e-service. This does, however, mean that only users with the skills and competence to access Journalen were able to answer the survey. If we, instead, had recruited people to represent the entire Swedish population, the results may have been different. In addition, a user who had previously tried using Journalen but did not find it very useful or usable might not have returned at all and would therefore not have found the survey. Hence, our results are likely biased toward more positive users.

In addition, it is not possible to determine whether the participants of our survey are representative of all users of Journalen. As in most survey studies, the participants form a small sample of all possible users, and many more users than those who answered the survey logged into Journalen during the 5 months that the survey was open. We do not know whether the demographic distribution is representative. Our survey participants have a higher education level than the general population, but, unfortunately, we do not know the education levels of all Journalen users. Among our participants, 60.57% (1487/2455) had higher education, whereas only 42% of the general Swedish population does [26]. We cannot tell whether this is because users of Journalen are typically well educated; it may also be that the well-educated users are more likely to answer a survey. An interesting future study would be to explore further whether user education level and eHealth literacy would impact the score on the System Usability Scale.

A high proportion of our participants also had experiences of working in health care. We can only hypothesize as to why this is the case; perhaps health care professionals are more likely to use eHealth services themselves. In future studies, it would also be of interest to see if health care professionals' assessments of the usability of the PAEHR differ from other users, and, if so, how these assessments differ.

Finally, in this study, we have not further analyzed differences in characteristics between users who scored low on the SUS scale and those who scored higher. If we can distinguish characteristics of the low scorers, the needs of these users could be targeted in future redesigns of the PAEHR.

Information Access Through a National Solution

Since the Swedish PAEHR Journalen is built on a national platform, its design and functionality are the same for all users throughout Sweden. However, the clinical content or information that is accessible to patients varies depending on the local regulations in each region. Here, we had an opportunity to explore whether this level of transparency in a region would have an impact on the usability experienced by the end user.

Uppsala (a high transparency area) scored 80.71 and Skåne (a low transparency area) scored 79.37 on the SUS scale, with more than 1-point difference between the 2 groups. This might possibly be due to a lower level of transparency causing frustration among the users in Skåne. However, we cannot answer this question based on these results; many other factors could influence these results.

Conclusions

We conclude that the participants of this survey rated usability of the Swedish national PAEHR Journalen high (scoring 80 on the SUS); however, further research into more specific usability areas is needed to ensure usefulness and ease of use in the future. A somewhat higher SUS score for the region of Uppsala as compared with Skåne could indicate a relationship between the perceived usability of a PAEHR and the level of transparency regarding patients' health information, but these differences in usability could also be related to other regional differences in the implementations of the PAEHR.

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Authors' Contributions

Both authors were involved in the analysis and writing of the paper, while MH took the main responsibility. IS also participated in the design of the study.

Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
PAEHR: patient accessible electronic health record
SUS: System Usability Scale

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Original Paper

Machine Learning–Based Analysis of Encrypted Medical Data in the Cloud: Qualitative Study of Expert Stakeholders' Perspectives

Ala Sarah Alaqra[1], BSc, MSc, Lic, PhD; Bridget Kane[2], CSci, CMIAC, MSc Mgmt, MSc, PhD; Simone Fischer-Hübner[3], MSc, PhD, Habil

[1]Computer Science and Information Systems, Karlstad University, Karlstad, Sweden
[2]Information Systems, Karlstad University Business School, Karlstad, Sweden
[3]Computer Science, Karlstad University, Karlstad, Sweden

Corresponding Author:
Ala Sarah Alaqra, BSc, MSc, Lic, PhD
Computer Science and Information Systems
Karlstad University
Universitetsgatan 2
Karlstad, 65188
Sweden
Phone: 46 054 700 2815
Fax: 46 054 700 2815
Email: as.alaqra@kau.se

Abstract

Background: Third-party cloud-based data analysis applications are proliferating in electronic health (eHealth) because of the expertise offered and their monetary advantage. However, privacy and security are critical concerns when handling sensitive medical data in the cloud. Technical advances based on "crypto magic" in privacy-preserving machine learning (ML) enable data analysis in encrypted form for maintaining confidentiality. Such privacy-enhancing technologies (PETs) could be counterintuitive to relevant stakeholders in eHealth, which could in turn hinder adoption; thus, more attention is needed on human factors for establishing trust and transparency.

Objective: The aim of this study was to analyze eHealth expert stakeholders' perspectives and the perceived tradeoffs in regard to data analysis on encrypted medical data in the cloud, and to derive user requirements for development of a privacy-preserving data analysis tool.

Methods: We used semistructured interviews and report on 14 interviews with individuals having medical, technical, or research expertise in eHealth. We used thematic analysis for analyzing interview data. In addition, we conducted a workshop for eliciting requirements.

Results: Our results show differences in the understanding of and in trusting the technology; caution is advised by technical experts, whereas patient safety assurances are required by medical experts. Themes were identified with general perspectives on data privacy and practices (eg, acceptance of using external services), as well as themes highlighting specific perspectives (eg, data protection drawbacks and concerns of the data analysis on encrypted data). The latter themes result in requiring assurances and conformance testing for trusting tools such as the proposed ML-based tool. Communicating privacy, and utility benefits and tradeoffs with stakeholders is essential for trust. Furthermore, stakeholders and their organizations share accountability of patient data. Finally, stakeholders stressed the importance of informing patients about the privacy of their data.

Conclusions: Understanding the benefits and risks of using eHealth PETs is crucial, and collaboration among diverse stakeholders is essential. Assurances of the tool's privacy, accuracy, and patient safety should be in place for establishing trust of ML-based PETs, especially if used in the cloud.

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KEYWORDS

medical data analysis; encryption; privacy-enhancing technologies; machine learning; stakeholders; tradeoffs; perspectives; eHealth; interviews

Introduction

Background

Technological applications in health care bring many recognized benefits from providing medical help for remote areas [1], or as a means to tackle medical errors and enhance the quality of medical care [2]. The practice of technology in health care is often referred to as electronic health (eHealth) despite the variety of definitions in applications and research [3].

Machine learning (ML), as a subdomain of artificial intelligence (AI), can be defined as allowing the computer (machine) to learn by finding statistical regularities in data and design algorithms accordingly [4]. ML-based eHealth applications have been emerging recently with the promise of great benefits in the area of medical diagnostics [5]. As ML relies on large datasets, data analysis could be outsourced to the cloud for resource preservation and cost-effectiveness [6]. However, additional privacy and security concerns are raised that need to be addressed by legal and technical measures. Moreover, for establishing end-user trust in ML, data security and privacy are eminent factors [7]. In particular, privacy and security challenges are major concerns that need to be addressed when developing new technologies in eHealth [2,8,9]. Privacy-enhancing technologies (PETs) can help to maintain the functionality of a system while technically protecting/improving the privacy of personal data [10,11].

Data Protection and eHealth

From the legal perspective, privacy and security regulations differ around the world; various legislations exist for data protection in different jurisdictions. For example, in Canada, the Personal Information Protection and Electronic Documents Act was issued to protect consumers’ data privacy from private businesses [12]. The General Data Protection Regulation (GDPR) in Europe enforces data protection and privacy [13]. In the United States, the Health Insurance Portability and Accountability Act safeguards the privacy and security for medical data specifically [14]. These examples show the different approaches and scopes to regulate the protection, privacy, and security of medical data, which pose a challenge when specifying data-protection mechanisms, apart from geographical jurisdiction considerations.

In eHealth, there exist several strategies that target data protection using the anonymization and deidentification of health data [15]. One example of deidentifying mechanisms for privacy protection is pseudoanonymization, or pseudonymization, where personally identifying data are replaced with pseudonyms to protect a patient’s privacy [16]. Pseudonymization is used for data processing and analysis purposes, where the identity of patients is not needed, and patients can still be reidentified when data are restored to their prepseudonymized state [16]. Conventional medical data protection measures in eHealth, if any are in place, are often not sufficient. There is a recognized need for better approaches to data protection in the medical context [15], such as by deploying PETs.

Privacy, Security, and Safety Tradeoffs in eHealth

In medical work, the advantage of having records available to several concurrent users over the potential security afforded in a single paper record supports the development of institutional-based electronic health records [17,18]. The contexts where tradeoffs against individual privacy are clear to health care staff include emergency settings, to protect patient safety, or some specific medical contexts. For example, when patient data are being discussed or evaluated between health care professionals, it is part of good communication and practice guidelines that the identity of the person be made known for safety reasons. Communication errors are documented among the leading causes of medical errors [18,19], and the practice of identifying patients correctly helps to reduce medical errors. One would not refer to “the patient in room 53,” “the appendix we had removed yesterday,” or “patient 12345,” for example, because of the potential confusion this could cause that could lead to a medical misadventure. A similar tension among competing interests of protecting privacy, avoiding misleading results, and using data for the public good can be seen in clinical trial data, where protecting patient-level data may compromise the scientific research [20].

However, with the development of cloud and internet services, the risks being taken with respect to preserving private information are not always evident [21]. People have mixed views [22], particularly where medical data are concerned, depending on the context and purpose of use. The existence of the privacy paradox with regard to health-related data is disputed [23]; users do not seem to understand the value of their health data and thus disclose them due to this lack of awareness.

Analysis on Encrypted Data: Use Case

In this qualitative study, we assessed a privacy-preserving tool that allows automated analysis on encrypted medical data in an untrusted cloud environment. Development of the PET is part of the ongoing EU Horizon2020 research project PAPAYA, which stands for PlAtform for PrivAcY preserving data Analytics [24].

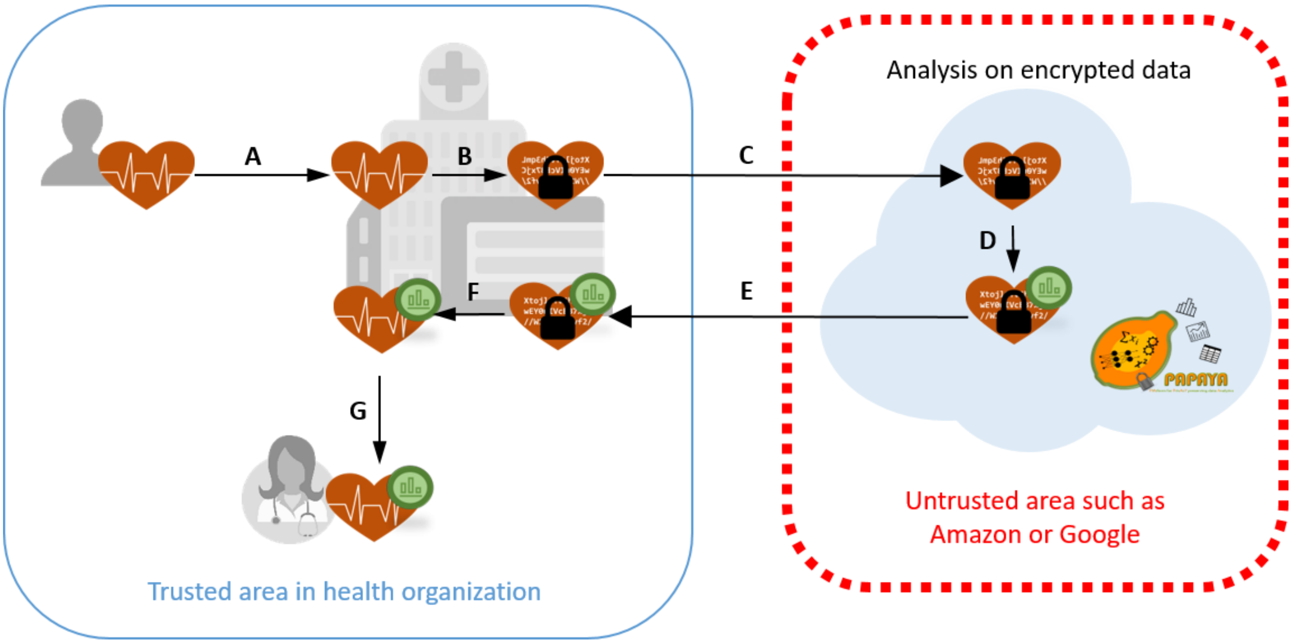
In our interviews, as part of the PAPAYA project, we focused on an eHealth use case related to analysis of electrocardiogram (ECG) data. In the use case scenario, the patient needs to perform cardiac function analysis for a heart-related diagnosis. For this purpose, the patient wears a sensor device that they obtain from a pharmacy to collect their ECG signal data for a period of 24 hours. Upon returning the device to the pharmacy, the data are downloaded and transferred to a medical health platform (Figure 1A), where the ECG signal data are then encrypted (Figure 1B). The encrypted data are then submitted to a data analysis platform running in an untrusted cloud environment (Figure 1C). The data are then automatically analyzed on the PAPAYA platform (Figure 1D). For protecting the patient’s privacy, a privacy-enhancing ML tool (PAPAYA tool) is used on the data analysis platform (PAPAYA platform). Hereafter, we use the acronym PAPAYA to refer to the PAPAYA tool running on the PAPAYA platform. The neural network model used for data classification is executed over encrypted data by utilizing advanced cryptographic schemes such as homomorphic encryption [25] or secure multiparty computation [26-28]. The encrypted automatic analysis report is sent back to the medical health platform (Figure 1E), where it is decrypted (Figure 1F) and then forwarded in plain (ie, unencrypted) form to a cardiologist together with the raw ECG signal data (Figure 1G). The cardiologist then uses both inputs to produce a report on the patient's heart status.

The data analysis tool running on the PAPAYA platform in the cloud has no user interfaces to be used by doctors or patients. However, the analysis report sent to the patient can be displayed via a dedicated dashboard.

Many PETs for protecting and anonymizing medical data or medical data analyses are based on data generalization or adding statistical "noise," and thus a tradeoff between privacy protection and data quality is required. In contrast to these types of PETs, the privacy-preserving tool that is the subject of this study uses cryptographic approaches that do not affect the quality of the analysis result; however, this may not be obvious to stakeholders or users.

Establishing trust is an important component for acceptability and the adoption of technology [29,30], and is especially a challenge for the proposed PET based on "crypto magic," which may be counterintuitive for stakeholders in eHealth. The privacy and security properties of a PET based on analysis of encrypted data in the cloud may not be perceived correctly. Therefore, we focused on human factors and investigated user requirements in terms of measures for establishing trust and transparency for the relevant stakeholders.

Figure 1. Illustration of use case data analysis flow.



Research Objective

The objective of this study was to analyze eHealth stakeholders' perspectives and the perceived tradeoffs concerning data analysis on encrypted medical data in the cloud. Additionally, we aimed to derive user requirements for the upcoming development of the privacy-preserving data analysis tool and its dashboard (ie, the interfaces for viewing data analysis by the cardiologist). Therefore, our research questions were as follows: (1) What are the perspectives, understandings, and privacy concerns regarding the analysis of encrypted medical data in the cloud of eHealth expert stakeholders having medical, technical, and research expertise? (2) What are the user requirements for the development of privacy-preserving data analysis tools based on ML?

A user-centric approach has been advocated to be of importance in the area of privacy and data management [31]. This study explored perspectives from eHealth stakeholders varying in their expertise (medical, technical, and research) involved in medical data analysis. By reporting on the insights of the stakeholders in this study, and identifying requirements, challenges, and perceived tradeoffs, we can contribute to advancing the state of the art of human factors related to the analysis of encrypted medical data in an untrusted environment (cloud). The investigation of human-computer interaction (HCI)-related issues with regard to protecting privacy in ML and the analysis on encrypted data, particularly in health care, is a main novel aspect of this study.

Methods

Design

Since the analysis on encrypted medical data in the cloud is a novel application in the medical area, our user-centered design approach focuses on the user's perspectives and concerns regarding the applicability and acceptability of the given PET. We therefore followed an exploratory approach, using empirical qualitative means for our data collection to understand stakeholders' perspectives and concerns regarding the analysis of encrypted medical data in the cloud. Qualitative methods allow for in-depth investigation of participants' understanding and perspectives, which is crucial when it comes to investigating a concept in its development stages [32].

To investigate the perspectives, understanding, and privacy concerns of expert stakeholders in eHealth of the tool for the privacy-preserving analysis on encrypted medical data, we chose semistructured interviews. To elicit user requirements from the interviews, we conducted a workshop.

Interview Structure

We chose semistructured interviews as our method of investigation, which allows for flexibility while maintaining some key concepts to be covered in the discussion. We interviewed stakeholders who have knowledge related to medical data analysis of the ECG test. The interviews allowed one-on-one conversation with each interviewee to gain their in-depth perspective on the matter. The semistructured form offered the flexibility to investigate parallel subtopics of the different stakeholders' expertise: medical, technical, and research.

In our interviews, we had general questions inquiring about the participant's background and privacy routines, followed by an introduction to the use case and specific questions about the analysis of encrypted ECG data (see Multimedia Appendix 1). Since our participants had diverse expertise, it was relevant for our study to understand the context of their privacy practices and opinions in general before we discussed the specifics of our PET tool.

Recruitment and Sampling

The study consisted of 14 interviews in total with stakeholders of varying expertise. Initially, we targeted medical professionals for our interviews since we were interested in understanding any medical concerns in performing data analysis on encrypted medical data. However, we expanded our recruitment to include those with technical expertise and researchers in the area of eHealth owing to their involvement with medical data processes (as highlighted by initial interviews with medical experts). Our inclusion criteria included being familiar with the ECG test and analysis on medical data. We deliberately did not include any interviewees that were affiliated with the PAPAYA project partners, as this could have introduced a bias. Hence, none of the interviewees had heard about the PAPAYA project prior to the interviews. Eventually, following purposive sampling, we recruited 14 individuals and satisfied our data saturation. Table 1 provides details on the interviewee identifiers with their corresponding expertise (eg, Med1 stands for interviewee #1 with medical expertise). Our interviewees represent a cross-section of experience and specialized knowledge that is typically encountered in medical work. We report the participants' demographics in aggregated form in consideration of our ethical responsibility to preserve participant anonymity.

This study was performed with participants from different countries, age groups, and genders, allowing our sample to be diverse with regard to the inclusion criteria. Using our own professional networks and those of our project partner Media Clinics Italy, we selected experts based on their expertise and knowledge of ECG in Sweden (n=4), Italy (n=2), the United Kingdom (n=2), Ireland (n=4), and Australia (n=2) for purposeful sampling, and recruited the participants via personal invitations for the interview. The 14 interviewees were drawn to investigate any preliminary differences in regulations. The male:female ratio was 5:2. They reported their age in the range of 21-30 (n=2), 41-50 (n=4), 51-60 (n=4), and ≥61 (n=3) years, and one participant chose not to disclose their age group. All participants worked in a public organization either full or part time, apart from one participant who worked in a semigovernmental organization. The experience of the medical professionals varied from 5 years to more than 30 years, whereas the experience of researchers and technical experts varied from 3 years to over 29 years.

Table 1. Interviewee index with their corresponding expertise details.

Interviewee	Expertise	Details
Med1	Medical	Nurse in cardiothoracic care
Med2	Medical	Director of care center, with nursing experience
Res3	Research	Chief information officer in health informatics
MedRes4	Medical+research	Emergency physician with academic posts in medical informatics
Med5	Medical	Family doctor
Med6	Medical	Medical doctor with urology expertise
Res7	Research	Health systems research leader
ResTec8	Research+technical	Professor with computing experience in digital health
MedRes9	Medical+research	Primary physician and professor in informatics and electronic health
MedRes10	Medical+research	Medical doctor and researcher consultant in cardiovascular surgery
Tec11	Technical	Information technology security manager
Res12	Research	Researcher in public health
Med13	Medical	Medical doctor and trainee anesthetist
ResTec14	Research+technical	Researcher in electronic health and cybersecurity

Data Collection

To adhere to the differences in our stakeholders’ expertise, we followed a flexible approach at each interview using a semistructured format. Additionally, since our participants were situated in different locations around the world, we used an online meeting tool for the video call in addition to sharing screens. All interviews were conducted online using the online GotoMeeting tool [33], except for two interviews that were able to be conducted face-to-face. The interviews lasted 30-60 minutes, depending on the expertise of participants (ie, those with technical expertise were able to discuss further technical questions). All interviewees, except for one, consented to their interview being recorded. There were 2-3 interviewers who are privacy and HCI researchers with technical, HCI, and medical expertise present in all interviews, with one leading the interview while the others took notes and added follow-up questions. The data collected are based on the combined notes. In case of conflicts in notes, we included results that were either resolved by our workshops or by referring to the recordings; otherwise, such results were not considered. All interviews, except one, were conducted in English; the exception was an interview that was conducted in Italian in Italy with the aid of translators and collaborators from the project partners.

Interviewees were provided with the consent form and introduction to the study prior to the interview. An interview guide was used by the interviewers, as found in Multimedia Appendix 1. During the interview, participants were given a short introduction followed by introductory questions targeting their background experience, and their understanding of protection needs and the privacy routines practiced in their organizations. The introductory questions allowed us to understand their current situation and better understand their perspectives of the next sections. The use case was then introduced using presentation slides, followed by questions about their perception of privacy and trust, and privacy protection relating to the use case. Media Clinics Italia, our project collaborators who are implementing the use case application, provided us with the presentation slides introducing the use case and the functionality of the PAPAYA platform. The slides include the use case description and correspond mostly to the description that we provide above in the “Analysis on Encrypted Data: Use Case” subsection, presenting the actors and data items involved, as well as a high-level presentation of the use data flow (deconstructed versions of Figure 1). However, no details on the encryption algorithms were provided to the interviewees. Instead, it was only conveyed that the ECG data are analyzed by the PAPAYA platform in encrypted form and that the output in form of the analysis report is also encrypted.

Questions about their trust of the tool and accountability followed showing figures on privacy risk assessment with (Figure 2) and without (Figure 3) using PAPAYA. The provided privacy impact assessment (PIA) was a result of using a PIA tool developed by the French data protection authority Commission Nationale de l'Informatique et des Libertés [34]. Finally, questions regarding informing patients and the level of knowledge needed about the platform were asked.

Between interviews, the three experts met to discuss and analyze the progress of the interviews. Additionally, they discussed whom to recruit next, depending on the expertise needed for the study. Participants continued to be recruited until data saturation was reached in our investigation for each of the expertise groups (medical, technical, and research).

Figure 2. Risk assessment without PAPAYA. PAPAYA: PlAtform for PrivAcY preserving data Analytics.

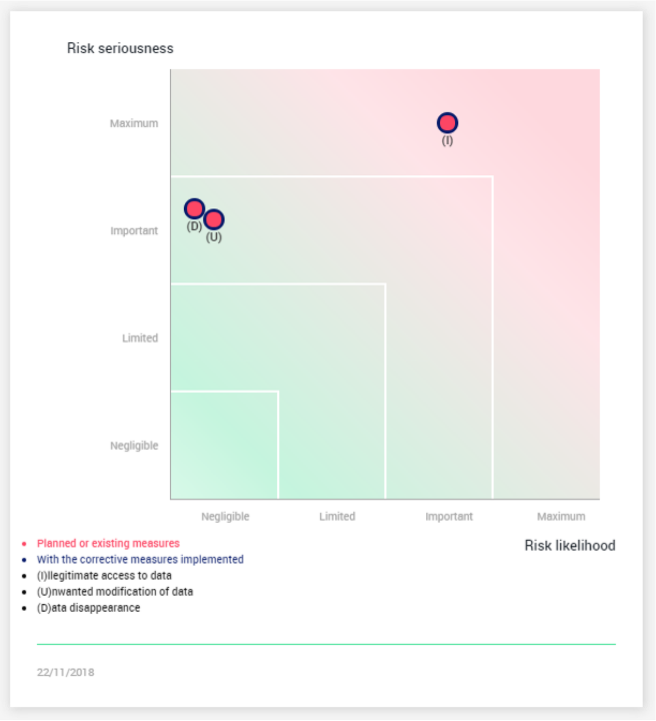
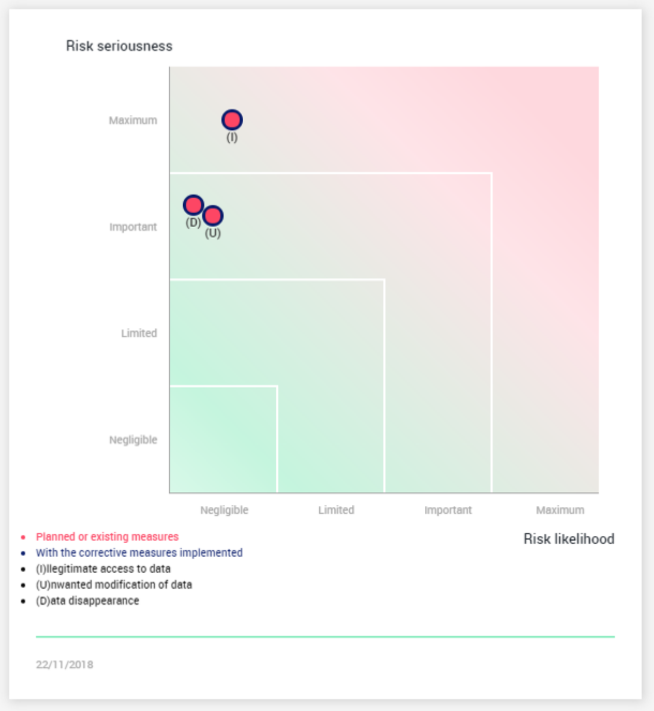


Figure 3. Risk assessment with PAPAYA. PAPAYA: PlAtform for PrivAcY preserving data Analytics.



Data Analysis

We used the data from our interviews for two purposes: the first was to analyze the data to gain an understanding of the participants' perspectives, and the second was to derive user requirements for application implications.

Since our study is qualitative, we have generally looked for patterns and incidents of participants' responses, and then classified our data into categories/themes. We used the structured approach for coding and categorizing our data that falls under the umbrella of the analytical method known as thematic analysis [35,36]. Since thematic analysis is a rather flexible approach [37], we explain our analytical process in detail below.

There were three phases to the data analysis procedure to find patterns and categorize our results into themes. The first phase was to have an agreed-upon results record for each interview. Apart from note-taking during the interviews, the three interviewers independently reviewed the recordings and elaborated on their personal notes (for reliability purposes, added confidence notes on interviewees' responses) they had each taken, using the structure of the interview guide as a template for consistency. They met afterward in a session to discuss the interviews and verify the meanings of the responses; they then merged their notes into an agreed-upon record for each interview. Conflicts and issues that were raised or observed at a particular interview were considered by a further review of the recordings of the interview to double check if there was any omission from the individual interview record. Any discrepancies were reviewed independently with the original digital recording and later rediscussed in a meeting. The second phase involved two rounds of coding of the results to reach an agreement on the codebook. The interviewers independently coded the results record, and discussed the codes together afterward with initial themes and formation of topologies. The third phase involved summarizing and synthesizing the data with the finalized themes. The interviewers met in a session to discuss and evaluate the themes developed and refined in the analysis. Since the interviews were semistructured, the analysis was not purely deductive, since the structure of the interview guide and the questions posed to the interviewees were used in the analysis.

Requirements Elicitation Workshop

To elicit user requirements for addressing our second research question, we conducted a workshop with the three researchers who were taking part in the interviews. The workshop was established to discuss and elicit requirements from the results of the interviews, while taking into consideration legal and technical aspects of the privacy-preserving ML technology. The format of the workshop allowed for metalayered discussion of requirements stated by the interviewees and critique of our results. In addition, the workshop discussion focused on some general implications for both research and practice for future ML applications in eHealth.

Ethical Considerations

The study was reviewed by the ethical advisor of Karlstad University, along with review of the provided interview guide and consent form. The advisor officially confirmed, according to the national regulations, that there are no ethical concerns and no further ethical review was needed by the Institutional Review Board according to the Swedish National Ethics Review Act. Participation in the study was voluntary, and the recording of the session as well as the demographic questions were all optional. No sensitive data were collected, and participants were instructed to not reveal sensitive data (eg, any information related to their own health). They were explicitly instructed at the beginning of the interview that in the case of this happening, the recording would be stopped to remove that part of the interview. The consent form given to interviewees prior to the interviews contained the above information.

Results

Interviews

Overall Themes

We present key results from our thematic analysis of the interviews, categorized in the following subsections. Summary detail on our analysis is provided in Multimedia Appendix 2.

Contextual Protection of ECG Data

When discussing the level needed for protecting ECG data, pseudonymization and encryption were the main approaches mentioned. As emphasized by the interviewees, all patient information is treated in the same way: as private and confidential, and national regulations are taken into consideration. Overall, protection of ECG data in terms of pseudonymization and other current measures is regarded as sufficient depending on the context of where the data are and how they are processed; however, further protection is needed when data are transferred to external processors and especially when using the cloud.

Several participants (Med1, Med2, MedRes4, Med6, Res7) indicated that they do not have the technical expertise to be able to identify what is needed in terms of data protection and encryption; for instance, Med1 stated that it is "…a question for IT (information technology)," Med6 stated that "…would need a computer scientist to answer," and Res7 mentioned "I am not a technical person," and that it is the responsibility of their engineer. They consider the responsibility to be that of the information technology specialists or data analysts. Most participants claimed that privacy can be better protected if the identifying data are kept separately from the signal data (pseudonymized). However, the issue of data integrity was raised if the signals are to be stored separately from the metadata.

A distinction should be made between reading the ECG and interpretation of the result in context. Medical expertise participants expressed the need to review the individual ECG results as well as the medical record when making a diagnosis and treating their patient:

> *On its own an ECG is not worth much…to give an opinion one needs the history, as well as ethnicity and age…you need to know why they are concerned and if they have a family history…[Med1]*

Data privacy measures in clinics usually start with staff induction regarding security and privacy. Health professionals are taught about managing a patient's chart, policies, and guidelines (ie, maintaining the integrity of records). Participants spoke of protecting patient privacy through physical separation in space, locked files, storing data with access control, two-factor authentication (with smart cards in combination with passwords), firewalls, network segmentation, encrypted USB keys, and using secure devices and computers. Electronic access is normally controlled, and all interactions are logged in a file to which the patient can have access. Auditing of interactions is regularly performed. In some cases, security is contracted to an external company (MedRes4).

Participants reported that pseudonymization is considered satisfactory to protect an individual's privacy when performing research using ECG traces without patient-identifying information (Res7, Res12, ResTech14). Guidelines from ethical committees and research approvals are sufficient for research involving medical data.

However, especially in the cases of transferring data outside the organization, participants indicated that pseudonymization does not offer sufficient protection for an individual; the ECG needs to be encrypted if transmitted or stored in the cloud (Res3, Med5, MedRes9, Tech11). Tech11 pointed out that ECG data are stored on the physical ECG machine and are not protected; thus, these data are exposed to "privacy leaks" in case of active adversary attempts, which should be considered. It was also highlighted by Med1, Med2, Res3, Med6, Res12, and Med13 that to maintain the trust of the public, one must ensure protection against privacy breaches of medical data. Two participants referred to prior incidents where data had been leaked when storing at external servers (Med2, MedRes10).

Conditional Sensitivity of ECG Data

The ECG test is considered medical data, having the same status as other medical information, and is thus considered private and confidential. Almost all participants regarded the ECG test results as sensitive, because they constitute medical data and therefore by default are sensitive. Many also referred to the legal regulations as the guide for indicating the sensitivity of medical data.

In the discussion on whether the raw data of the ECG, apart from being medical data, are sensitive, only MedRes4 and MedRes9 stated that ECG data could still be considered sensitive despite pseudonymization, and therefore need protection.

Many participants pointed out that the sensitivity of data also depends on the other information they are combined with, and the additional associations that are made (Med1, Res12, Med13, ResTec14). For example, the very fact that someone had reason to have an ECG is considered private information, as the ECG can demonstrate heart disease. Moreover, it was stated that it can be compromising for a patient if an employer or insurance company learns that they underwent an ECG test. For example, professional athletes could have their career destroyed if they were known to have an abnormal ECG.

Additionally, most participants do not regard the ECG to be as "sensitive" as some other tests. With regard to ECG data, MedRes4 stated that "it is clinical data…all information about the patient is sensitive," and that blood tests, or having it known that one tested, for "having cocaine…is more sensitive." For instance, Med2 ranked the sensitivity of ECG data "on a scale 1 to 10, probably about a 6."

A distinction was made between data that are gathered and given voluntarily by the individual via personal devices and data that are gathered by a health professional (ResTec8, Res3). It was argued that the ECG data, if supplied by the individual, are considered nonsensitive, because these are consumer-contributed data; however, if taken by a medical professional, these data are considered to be sensitive (Res3).

Acceptance of Using External Services

When discussing engaging external services for managing the privacy and security of their data, most regarded it to be impossible to provide a guarantee without any remaining risk to individual privacy. They also accept a tradeoff between risks and benefits, and indicated that some risk might be acceptable if the service is proven to be valuable. Few participants indicated that they would use external services for conducting medical and research trials (Med6), in case of necessity (Res3), or depending on the organization's policy (ResTech8). However, they indicated a need to weigh the pros and cons before making such a move.

Many reported that they already use external services for either outsourcing ECG (Tech11), managing security (Med13, ResTech14), managing computers (Med1), and storage (Med5). Res7 and Med2 reported that they already work with cloud services (such as Amazon), where security and testing are requirements and the use of the cloud service is cautiously accepted, provided that privacy is protected and security is adequately assured by a qualified entity. Med2 added that "working with cloud computing and services, we can't be masters of everything." However, concerns and skepticism were highlighted regarding the lack of trust in cloud services, and several participants (MedRes10, Res12, ResTech14) stated that they prefer using internal mechanisms within their organization. MedRes10 added:

> *if you have a company which doesn't understand why it is important to have patient's secrecy, then actually patient's data can be leaked out…the information we receive at the hospital is important information for companies and if you have a leak at such a source (external), that can be very important for commercial companies.*

Data Protection Drawbacks

Pseudonymization may sometimes be used to avoid sharing sensitive information within a circle, such as when asking for informal advice on a case between colleagues. However, pseudonymization is not very commonly used in clinical practice, except in research contexts, as indicated by the participants (Med6, Res7, ResTech8, MedRes9, and ResTech14) and for lab tests. When discussing data protection, Res3 stated that "data protection does not trump everything…not so black and white"; thus, one needs to weigh the risks and benefits of a technology, effects on safety, and perception by human factors.

For most nontechnical participants, there was a common belief that encryption is being performed by the institution behind the scenes. For example, encrypted email is common within their organization. Encrypted data are better protected than unencrypted data. Encryption is considered important, especially for data that are being transferred between institutions. It was mentioned that encrypted data are considered to be safer than unencrypted data; however, encryption "cannot be trusted 100%" (Res12). Med2, Med5, and ResTech14 expressed concerns about data being encrypted, wherein Med2 and ResTech14 stated that too much encryption has a risk of corrupting data and may result in loss of data integrity.

> *You have to balance the risks with the actual report of the true data,…as a rule of thumb, if we can encrypt without impacting the message in a negative way then it is worth doing…if you start to do a value risk on this, it may be too much encryption…we want the most effective and true result as we can get.* [Med2]

Some incidents were mentioned by Med2 and ResTech14 where data loss occurred due to encryption; cryptographic solutions introduced without proper testing resulted in loss of data. It was highlighted that complete and available data have higher priority in this case.

Concerns of Data Analysis on Encrypted Data

The proposed analysis on encrypted data was well-received by some participants (Med6, Res7, Med13), who believed that they would trust the analysis given proper testing, proofs, and validation studies are provided. Res7 added, "it depends on who did the algorithm behind it…it surely must be tested." Moreover, Med1 and MedRes10 expressed the need for other sources of data in combination to trust the result. The above-mentioned perspectives highlight the *necessities for acceptance* of the proposed technology as expressed by the participants.

However, others expressed strong doubts regarding the algorithm used (ResTech8, ResTech14) and data accuracy resulting from the analysis (Med5). Doubts about the technical possibility were emphasized by MedRes4 and MedRes9. MedRes4 stated, "I didn't know it [analysis of encrypted data] is technically possible...I need to check that out…[encryption is] changing all the time." MedRes9 responded with, "Sorry, sounds like bull**** to me…I don't believe that" regarding the analysis on encrypted data, and added:

> *to analyze ECG while they are being encrypted doesn't make sense… it totally depends on what encryption scheme…You can imagine some simple encryption scheme, might be possible to analyze some aspects… but in the more general sense it's nearly impossible. It's like analyzing a picture which is encrypted, how would you do that?*

Other medical participants remain skeptical that an analysis could be performed on encrypted data and query if only the identifying data are encrypted rather than the raw signal data. Although its proposed use as a screening tool was explained, some medical participants expressed concerns regarding the motivation for using the tool without a cardiologist's guidance, and that this method might be (wrongly) used alone to diagnose a heart disease. Furthermore, Tech11 stated that medical expertise is needed for determining the accuracy of the ECG. By contrast, Res12 stated that technical expertise is needed to answer for the accuracy of the data analysis.

Communicating Privacy and Utility Benefits and Tradeoffs

When discussing trust in the data analysis service, we investigated participants' opinions on providing two different trust statements. The first statement was: "The patient's data will be analyzed in encrypted form so that private data cannot leak to the PAPAYA analytics service; this form of analysis will not negatively impact the data quality." Participants expressed doubts regarding the technological plausibility (MedRes4 and MedRes9) and the encryption (Tech11 and ResTech14). MedRes4 further stated that "would need expert opinion…and contact data-analyst experts."

Participants discussed trust in terms of what is needed, namely the *information* and *reassurances* for trust.

They expressed that trust is dependent on information about the level of protection (Med6), trusting the company of the technology (Med5), or trusting the tool (Res7, Med13). Res12 and ResTech8 expressed the need for more information overall. Specifically, ResTech8 expressed a distrust of the statement:

> *it doesn't tell me anything about how it's going to be encrypted, what other forms of prevention of leakage might occur, what kind of analytics are going to be undertaken…all of those affect my ability to trust and retain privacy…as a statement of fact it is not believable, as a statement of intention it is believable.*

We also inquired about the significance of assurances on trusting the tool. In our interviews, we provided an example of the case where an organization would state that they conducted a PIA. We asked the interviewees the extent to which they would trust PAPAYA if it was stated that this PIA would show a risk reduction for illegitimate access to data from important (Figure 2) to negligible (Figure 3) when using PAPAYA. Some participants (MedRes10, Tec11, Med2) noted the fact that an organization that made the effort to conduct a PIA would generally increase their trust in PAPAYA or that the PIA could be useful to convince decision makers (ResTec14). Med5 considered that the statement was useful and no further information was needed.

However, other participants discussed requests for PIA (privacy and utility benefits) *assurances.* They wanted to have more information about the PIA method (Tec11), how the PIA was conducted (eg, MedRes9 stated, "I would need more detailed descriptions on how they arrive to these measurements…not just presenting them on a diagram"), and about the qualification of the individuals that conducted the PIA (ResTec8) in order to trust the statement. Participants highlighted the need for validation and testing of the tool (Med1, Med2, Res3, MedRes10, Tech11), as well as certifications (Med2, ResTech8, MedTech10, Tech11, ResTech14). Moreover, Res3 highlighted the need for risk assessment, and that tradeoffs between safety and data protection should be addressed; more information should be provided on data quality and costs.

Shared Responsibility for Patient Privacy

When discussing responsibility for patients' privacy, participants indicated that they share responsibility with the organization in this regard (Med1, Res3, MedRes4, Med6, ResTech8, MedRes10, Tech11, Med13). Medical registration depends on observing codes of conduct to protect the patient. However, the institutions employing the professionals (and researchers) have a legal responsibility in most jurisdictions, and accountability rests with the chief operating officer, chairman of the procurement group, or head medical person. In research, the principal investigator is normally the person held accountable for any data breaches (MedRes4, Res7, Res12, ResTech14). Med2 mentioned that "we are bound…by our scope of practice in nursing, with a strong approach to managing patients' confidentiality," and stated that "if it is a data breach from a system perspective, then I think it comes back to the organization." A bigger proportion of responsibility for data protection and security was considered to rest on the organization's security team through technically securing the data; however, nontechnical participants indicated that they do have a say in the applications used and technical infrastructure.

Informing Patients on a Higher Level of Abstraction

The majority of participants do not expect to know in expert detail on how the privacy measures are in place; they want to have sufficient knowledge to be able to explain how the data are used and where they are stored. However, all participants stressed the importance of having information available to all patients. They (Med1, MedRes4, Med5. Med6, Res7, MedRes9, Med13, ResTech14) argued that it is especially important to be able to provide information if people ask for it, by being able to refer to an expert in addition to offering handouts (eg, leaflets).

Informing patients proactively about their rights to privacy and how their data are being protected was perceived as essential by Med2 and MedRes10. However, others suggested that trusting the organization, health systems, and health professionals is sufficient (ResTech8), and trusting that privacy measures are in place has higher priority (Res3). For example, ResTech8 pointed out that according to the national digital health agency,

> *probably 5% would be interested to know and would seek to know…and probably another maybe 10% of patients, if you told them, they would in retrospective be interested in knowing...and the remaining 85% of patients would be uninterested…they would just trust the health system.*

Med5, Med6, and Tech11 indicated that basic knowledge is sufficient to inform patients about the current measures in place to ensure privacy and protection of their data.

Workshop Requirements

Based on our interviews, the following key requirements were elicited relating to perceived tradeoffs and perceptions on informing eHealth stakeholders and patients about the proposed PET (as developed by the PAPAYA project), and its security and privacy protection features for enhancing transparency and promoting trust. Further details on user requirements and legal requirements elicited can be found in our prior work [38]. Notably, the following requirements are not specific to

PAPAYA, but are in fact generalizable to similar PETs for automated data analysis of medical data on a cloud server.

First, eHealth stakeholders will be reluctant to avail of the analytical services in the cloud if they have no confidence that the PET can deliver secure service without loss of quality or data. Therefore, reassurances are required for trusting the proposed PET by providing assurance guarantees confirming that analysis on encrypted data on the privacy-preserving data analytics platform was validated and certified to work as stated to the stakeholders, and making the reports of conformance tests of the platform available. Second, results from a PIA conducted by qualified experts should be presented to all stakeholders for communicating privacy benefits and tradeoffs, comparing the situations when the PET is used or not used. These results should be complemented with information about the PIA evaluation method, process, and qualification of the evaluator. Having information on a PIA available shows that the service provider takes privacy seriously, which can aid users in making decisions on tradeoffs between benefits and privacy risks. Third, stakeholders have indicated the importance of providing information regarding data protection and privacy of their data, and that transparency to patients is crucial. Hence, it is important that medical doctors can address privacy-related questions from the patient side by informing them about privacy protection and data quality guarantees via leaflets or tutorials. Lastly, as suggested by study participants, interested patients should be informed proactively about their rights to privacy and how their data are being protected at the moment when they are requested to provide consent.

Discussion

Principal Findings

To better understand eHealth stakeholders' perspectives, knowledge, and privacy concerns regarding analysis of encrypted medical data in the cloud (our first research question), our results from the interviews brought forth themes that correspond to the general stakeholders' perspectives on data privacy and practices. These themes include (1) *contextual protection of the ECG data*, (2) *conditional sensitivity of ECG data*, and (3) *acceptance of using external services*.

Furthermore, our themes highlight (4) *data protection drawbacks* in general and (5) concerns of *data analysis on encrypted data specific to an ML-based tool*.

Trusting data and the technology is essential, which is achieved by (6) *communicating privacy and utility benefits and tradeoffs*. In addition, accountability is important, and the participants highlighted that there is (7) *a shared responsibility for patient privacy*. Furthermore, when it comes to accessibility of information about the technology used and how data are managed, (8) *informing patients on a higher level of abstraction* was emphasized.

Finally, our workshop derived user requirements for the data analysis on encrypted data in the cloud, which are generalizable to similar ML applications, thereby addressing our second research question (to establish user requirements).

Related Work on Privacy and ECG Data Analysis

Earlier research on remote cardiac monitoring in hospitals or with telemedicine proposed plain processing of the ECG data based on the most common parameters such as cycle length variability (RR intervals) [39,40], whereas more recent work has applied modern techniques based on ML to perform more structured analyses [41]. As might be expected in this type of research, attention tends to be focused on analytical methods to the signal rather than to appreciate the sensitivity of these health data and the concern for privacy. Thus, there is earlier research on the analysis of ECG data without regard for how privacy can be protected. Some more recent studies propose applying encryption to data prior to the data being outsourced for analysis [42]; however, when ML is considered for ECG analysis, attention to privacy diminishes. For example, Kocabas and Soyata [43] applied full homomorphic encryption on ECG data for analysis in a public cloud; however, neither legal privacy nor user requirements were discussed.

We previously reported the PAPAYA arrhythmia detection use case, and legal and user requirements [38]; however, we did not elaborate on the analysis of the eHealth stakeholders' perspectives and the perceived tradeoffs based on the conducted interviews.

Biometric ECG and Data Protection

Previous studies have focused on enhancing the privacy of ECG data using cryptographic schemes [42,44]. However, in this study, we focused on human aspects and involved stakeholders' perspectives on the proposed privacy-preserving solution. A significant outcome of our study is the perception of data sensitivity and data protection by participants. Apart from legal aspects, where the majority of our participants considered medical data sensitive by default (referring to laws on medical data privacy), most expressed the view that the ECG signal is not a personally identifying measurement or biometric, and that pseudonymization should be sufficient. Only two participants (with medical/research expertise) had a different perspective, and argued that the ECG signal is sensitive despite pseudonymization. However, it has been shown that raw ECG signal data are indeed biometric data and thus, even if pseudonymized, they classify as personally identifiable data [45].

Medical data are classified under a special category of data according to Article 9 of the GDPR [46], and thus require special protection. Similarly, participants who regarded ECG data as nonidentifiable data (nonbiometric) still expressed the view that ECG as medical data are sensitive data, and thus require special protection. Therefore, they consider that medical data should be protected in any case, even if it is claimed that the data are anonymized. Hence, the participants are aware of the required protection (eg, as in our use case via encryption), even though the legal and technical reasons for the protection may not be fully understood.

Expertise Differences and Collaboration

Previous studies exploring human factors, perceptions, and trust of PETs show differences in trusting PETs and tools; those with more technical expertise, except for crypto experts, would require more information to trust the tools, which are often based on nonintuitive “crypto magic” operations [47,48]. Similarly in this study, depending on the background of the experts (whether technical or medical), the trust criteria required for this technology differed. Participants with research and technical expertise expressed significant concern for trusting the feasibility of the technology and algorithms, whereas data availability appeared to be more important to the medical experts in general. It is noted that perspectives of participants and their expertise were conflicting when discussing data accuracy: medical experts highlighted the need for technical experts to answer for data accuracy of the tool, whereas technical experts stated that medical opinion on validation is needed. Collaboration among computer scientists and physicians is not new; the focus on different values has been shown to be fruitful [49]. Therefore, there is a clear need for communication and collaboration among different stakeholders with different expertise in eHealth.

Privacy Tradeoffs in eHealth and Trust Assurance for PETs

Previous studies have followed different approaches in dealing with privacy, security and safety tradeoffs, and challenges in eHealth [50-52], including balancing tradeoffs between privacy protection and information utilization in eHealth [51], information accountability [52], or risk mitigation management processes [50].

In our study, when discussing tradeoffs involved in the data analysis tool, functionality, accuracy, and data availability emerged as the main tradeoffs with respect to discussions on privacy and security. It is clear that if security and privacy schemes would hinder the availability of data or corrupt the data, then it is not worth the risk. Trust criteria were key factors in the discussion (eg, trusting the functionality, availability, encryption, organization, or the tool). For instance, having certifications by third parties has been shown to enhance trust [53,54]. Therefore, we argue that in the case of PETs in eHealth, trust assurances should be provided relating to the availability of data so that the safety of patients is ensured.

Trust Assurance for ML

Previous studies have addressed physicians’ perspectives on ML tools and trusting the outcomes, showing that physicians desire to understand the logic of the ML tool in order to trust the results [55-57]. In a more recent study that focused only on clinicians’ perspectives in an ML-based AI system, trust optimization was key in addressing the adoption of the technologies [58]. Challenges for trust in medical AI by the public; the role of credibility of technology companies; as well as the need of transparency, certification, and education for medical AI have all been described [53,54].

With regard to trust in privacy-preserving ML, as the focus of our work, trust issues may arise on the privacy-preserving crypto algorithms concerning functionality, data accuracy, and availability (see above) on top of general trust issues that may already exist in regard to ML. Thus, the requirement for trust assurance for privacy-preserving ML, as stated above based on our finding, is especially relevant.

Education and Information

Challen et al [55] argued that the medical education curriculum should train medical professionals adequately in AI, including ML, along with its advantages, including improvement of quality, and shortfalls such as transparency and liability. Based on our findings, we suggest that such training should also teach medical professionals about PETs for ML to increase their trust, knowledge, and competence for informing interested patients and answering their privacy-related queries.

Support for patients concerning explanations regarding the technologies used, how they might be affected, and informed consent have also been reported to be important for trust, since patients are usually unfamiliar with the technologies used in eHealth and may not be convinced with the benefits of using such technologies [59]. We previously discussed user perceptions and requirements for other types of novel privacy-enhancing eHealth use cases [47], which, in line with this study, showed that even users with more technical expertise also require information about assurance guarantees to trust the claimed privacy-preserving properties of the technology.

For developing usable consent forms that clearly convey the core policy information to all types of users, such technical information should be easily retrievable via clickable links upon demand by interested users rather than the detail shown by default. Therefore, we propose following the suggestion in Article 29 Working Party [60] for using layered privacy notices, which make technical information about privacy protection accessible at lower layers with different layers of details.

Implications and Future Studies

Our work dealing with a privacy-preserving ML tool and its application in the ECG use case has focused on the human aspects from stakeholders’ perspectives on the expert side (medical, technical, and research expertise). Our contribution highlights key areas (themes) and requirements for future applications of the dashboard for the tool as well as user-centered research in eHealth of ML, and especially research on the effectiveness of means for trust assurance (eg, via clear communication, certification of PETs for ML, and education of medical professionals). Although our study focused on the perspectives of eHealth professionals, future studies should also investigate patients’ perspectives and trust criteria for having their data used by new ML-based technologies.

Limitations

Given the relatively small number of participants per category, it is not possible to make definitive claims regarding their countries, gender, or age. However, we have included a diverse sample in our exploration of possible concerns and requirements for the PETs addressed. Additionally, due to our selection criteria of our target group, it was challenging to recruit stakeholders given their demanding professions and limited availability. Further studies could explore if there are general trends to be noted.

Conclusions

Understanding the benefits and risks of using ML-based analysis of encrypted medical data is crucial. Interviewing stakeholders in regard to the data analysis on encrypted data (ML use case) provided empirical data to understand their perspectives, and thus helped to identify key concerns and requirements. The results of our study show that the importance of data protection in eHealth is understood and valued by all stakeholders. Having differences in expertise among our stakeholders with medical, technical, and research backgrounds was significant for analyzing and identifying perceived privacy benefits and tradeoffs in our evaluation. Our results highlight that such differences in backgrounds could also impact the perception and trust in the claim that the data analysis on encrypted data is possible for protecting privacy without compromising data accuracy. Assurance guarantees for the ML-based privacy enhancing tool's privacy, accuracy, and capability to protect patients' safety should be in place for establishing trust in the tool.

To address such perceptions and the correct understanding of tradeoffs, the communication and cooperation of eHealth stakeholders with diverse expertise could help in clarifying questions in regard to the accuracy of the technologies and medical safety of patients. Future research and practice could therefore consider involving a discussion among different stakeholders in the collaborative design and development processes.

Identified trust factors and elicited requirements are not only important for the PAPAYA project but can also be generalized to similar ML-based PETs for automated data analysis of medical data on cloud servers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Guide for semistructured interview with stakeholders for the PAPAYA use case.
[DOCX File , 31 KB - humanfactors_v8i3e21810_app1.docx]

Multimedia Appendix 2
Simplified results from aggregated codes to themes and number of referenced interviews.
[DOCX File , 16 KB - humanfactors_v8i3e21810_app2.docx]

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Abbreviations

AI: artificial intelligence
ECG: electrocardiogram
eHealth: electronic health
GDPR: General Data Protection Regulation
HCI: human-computer interaction
ML: Machine Learning
PAPAYA: PlAtform for PrivAcY preserving data Analytics
PET: privacy-enhancing technology
PIA: privacy impact assessment

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Original Paper

Examining How Internet Users Trust and Access Electronic Health Record Patient Portals: Survey Study

Rong Yin[1], MS; Katherine Law[2], PhD; David Neyens[1,3], PhD, MPH

[1]Department of Industrial Engineering, Clemson University, Clemson, SC, United States
[2]Human Factors and User Experience, Medtronic, Mounds View, MN, United States
[3]Department of Bioengineering, Clemson University, Clemson, SC, United States

Corresponding Author:
David Neyens, PhD, MPH
Department of Industrial Engineering
Clemson University
100 Freeman Hall
Clemson, SC
United States
Phone: 1 8646564719
Email: dneyens@clemson.edu

Abstract

Background: Electronic health record (EHR) patient portals are designed to provide medical health records to patients. Using an EHR portal is expected to contribute to positive health outcomes and facilitate patient-provider communication.

Objective: Our objective was to examine how portal users report using their portals and the factors associated with obtaining health information from the internet. We also examined the desired portal features, factors impacting users' trust in portals, and barriers to using portals.

Methods: An internet-based survey study was conducted using Amazon Mechanical Turk. All the participants were adults in the United States who used patient portals. The survey included questions about how the participants used their portals, what factors acted as barriers to using their portals, and how they used and how much they trusted other web-based health information sources as well as their portals. A logistic regression model was used to examine the factors influencing the participants' trust in their portals. Additionally, the desired features and design characteristics were identified to support the design of future portals.

Results: A total of 394 participants completed the survey. Most of the participants were less than 35 years old (212/394, 53.8%), with 36.3% (143/394) aged between 35 and 55 years, and 9.9% (39/394) aged above 55 years. Women accounted for 48.5% (191/394) of the survey participants. More than 78% (307/394) of the participants reported using portals at least monthly. The most common portal features used were viewing lab results, making appointments, and paying bills. Participants reported some barriers to portal use including data security and limited access to the internet. The results of a logistic regression model used to predict the trust in their portals suggest that those comfortable using their portals (odds ratio [OR] 7.97, 95% CI 1.11-57.32) thought that their portals were easy to use (OR 7.4, 95% CI 1.12-48.84), and frequent internet users (OR 43.72, 95% CI 1.83-1046.43) were more likely to trust their portals. Participants reporting that the portals were important in managing their health (OR 28.13, 95% CI 5.31-148.85) and that their portals were a valuable part of their health care (OR 6.75, 95% CI 1.51-30.11) were also more likely to trust their portals.

Conclusions: There are several factors that impact the trust of EHR patient portal users in their portals. Designing easily usable portals and considering these factors may be the most effective approach to improving trust in patient portals. The desired features and usability of portals are critical factors that contribute to users' trust in EHR portals.

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KEYWORDS

internet; consumer health informatics; patient portal; participatory medicine; electronic health records; logistic model; surveys; questionnaires

Introduction

Patient portals are websites or mobile apps that are designed to help patients access their electronic health records (EHRs), health summaries, pay bills, schedule appointments, and, in some cases, interact with care providers [1]. The use of patient portals has been associated with generating positive health care outcomes in recent studies [2,3]. For example, individuals and families have been shown to be more actively engaged in their health management [4] with better information communication [5]. Using EHR portals may also contribute to increasing the efficiency and effectiveness of health care providers [2].

The US government has been promoting the use of patient portals through federal laws such as the Health Information Technology for Economic and Clinical Health Act of the American Reinvestment and Recovery Act [6], which requires that health providers prove the usefulness of EHRs (defined as using EHRs in a meaningful manner) through a three-stage process [7]. The “meaningful use” of EHR portals is believed to have a positive impact on improving the quality of health care [8]. Government promotion was suggested as one of the major reasons for providers to encourage their patients to register on EHR portals despite the positive benefits of EHR portals [5]. Owing to these requirements, the adoption of EHRs in hospitals increased from 9% in 2008 to 80.5% in 2015 [9].

Although some research has shown a potential correlation between low health literacy and a lower likelihood of using patient portals, the results are inconsistent across studies [10-12]. Meanwhile, vulnerable patients may also require that portals have higher usability (eg, portals that are easy to use) and intensive training may be necessary in such cases [13]. Demographic characteristics such as gender, education, and income have been shown to impact the EHR usage rates [14]. Additionally, other barriers such as the digital divide, and concerns related to privacy and data security have also been shown to impact EHR usage rates [15]. A recent study suggested that the use of EHR portals is still low, although it has been increasing (from 25.6% to 31.4% between 2014 and 2018 according to the data of the Health Information National Trends Survey [14]). Addressing the barriers associated with using portals may not only increase the usage rate of patient portals but may also contribute to improving patients’ trust in their providers, thus encouraging patient-provider communication [16] and potentially improving patient health outcomes. Younger adults and individuals who trust the internet more could have an easier time using patient portals [17]. Additionally, patients who highly trust their health care providers are more likely to use their portals [16]. Generally, most of the trust-related studies about EHR portals focus on the patient-provider relationship [4,18,19]. Few studies have analyzed the patients’ trust in the EHR portals themselves. Studies in similar domains (such as trust in health information websites) have shown the importance of trust in determining which websites to use and how to best use their content [20]. Trust in health websites, such as EHR portals, is an important factor to examine as the internet is not considered a fully reliable source of health information [20,21].

Few studies have focused on the factors that impact patients’ trust in EHR portals. A scoping review [22] of multiple studies recommended that specifying the features of EHR portals for certain primary care patient groups was necessary. Thus, the purpose of our study was to conduct an internet-based survey to examine how current portal users report using their patient portals and the factors impacting their trust in their portals. To better examine how current portal users use and trust their EHR portals, we also examined how they access health information and trust those information sources, and what design features of these patient portals are preferable for continued use.

Methods

Survey Design

Our internet-based survey was designed using Qualtrics and distributed using Amazon Mechanical Turk. Amazon Mechanical Turk is a widely used [23] internet-based tool to recruit people to perform virtual tasks such as survey participation and content moderation. Many participants can be recruited efficiently using Amazon Mechanical Turk [24]. The data obtained using Amazon Mechanical Turk have been considered reliable [25-27] and more representative of the general population [28] than the data obtained from convenience samples (eg, college students) and generally represent diverse backgrounds [29].

The survey (see Multimedia Appendix 1) was designed with specific questions for patient portal users, and a slightly different version of the survey was used if participants reported that they were not current portal users. We included a wide variety of questions in the survey to assess the perceptions of participants on patient portals, how they are accessed and used, difficulties in using patient portals (eg, data safety and security and difficulty in understanding information presented in the portal), and what features are desired in these portals. The survey also contained questions about seeking, accessing, and trusting health information from other sources. We included specific questions to evaluate how much portal users trust their current portals. Participants were asked to respond to a 5-point Likert scale (ranging from “strongly agree” to “strongly disagree”) to the following statement: “I trust the current EHR portals that I am using.”

None of the questions required mandatory responses and we also included options such as “Do not know” or “Prefer not to answer” for some questions, as appropriate. We also included free response options for some questions. Two quality check questions were included in the survey to ensure that the participants were answering the questions carefully rather than randomly choosing an answer (eg, we asked the participants to choose “yes” for a subitem of a question and asked them to select “strong agree” for another question). We removed the responses of the participants who did not answer the quality check questions correctly.

Participants

The participants were required to be residents living in the United States aged over 18 years. We recruited 500 participants to participate in the survey. After removing the participants (46 participants) who failed to answer our quality check question in the survey and those who were not EHR portal users (60 participants), we included 394 participants in this analysis, who were current portal users. This study was identified as a research activity involving human subjects that met exemption criteria under the Code of Federal Regulations (CFR), namely 45 CFR 46 and 21 CFR 56 by the Clemson University Institutional Review Board, as the survey was anonymous, and no identifiable data were collected. The data were collected in January 2020. Each participant received US $1 as compensation for completing the survey using Amazon Mechanical Turk.

Data Analysis

Simple statistics were used to describe the survey population along with several different parameters. In our data analysis, some of the subjective rating questions that used 5-point Likert scale options were converted to binary answers. For example, the Likert scale options of “agree” and “strongly agree” were combined into a single category that was compared to all other Likert scale responses. Logistic regression was used to explore what factors impacted portal users’ trust in their portals. We used the stepwise Akaike Information Criterion (AIC) selection method [30] to identify the best fit model. We performed an automated AIC forward stepwise selection procedure using the StepAIC function in the Modern Applied Statistics with S package in R (version 4.0.2). This function automatically adds variables into a model such that the AIC is lower with the additional variable than without it. This function identifies the variable set that produces a model with the lowest AIC value among all the possible variables. We included 13 explanatory variables in the final model after applying this AIC selection method. We set α=.05 as the level of statistical significance. The data analysis was conducted using R (R Foundation for Statistical Computing).

Results

Descriptive Statistics

Demographics

Approximately half of the participants (212/394, 53.8%) were younger (less than 35 years old), followed by 36.3% (143/394) that were middle-aged (35-55 years old), and 9.9% (39/394) that were older (over 55 years old), as observed in Table 1. Female portal users accounted for 48.5% (191/394) of our participants. Almost all the participants (372/394, 94.4%) reported being employed and most (372/394, 94.4%) of the participants reported being covered by a health insurance plan. Additionally, 72.6% (286/394) of our participants had their most recent health care appointment within the last 6 months.

Overall, 23.9% (94/394) of the participants reported using EHR portals weekly or more frequently, whereas 46.7% (184/394) reported having used their portals monthly and 29.4% (116/394) of the participants reported using their portals only yearly or less often. Furthermore, 48.7% (192/394) of the participants reported sending messages through the EHR portals to their care providers annually or more frequently. Meanwhile, 54.3% (214/394) of the participants reported receiving messages through the EHR portals from their care providers at least annually.

Table 1. Characteristics of participants who are current portal users (N=394).

Characteristic	Participants, n (%)
Age	
Younger adults (<35 years)	212 (53.8)
Middle-aged adults (from 35 to 55 years)	143 (36.3)
Older adults (>55 years)	39 (9.9)
Gender	
Male	203 (51.5)
Female	191 (48.5)
Education	
Educated to high-school level or lower	38 (9.6)
Some college or graduate education	356 (90.4)
Income	
Less than US $52,000	222 (56.3)
More than US $52,000	172 (43.7)
Marital status	
Married	251 (63.7)
Not married	143 (36.3)
Employment status	
Employed	372 (94.4)
Unemployed	12 (3)
Retired	10 (2.5)
Internet use frequency	
At least daily	368 (93.4)
Less than daily	26 (6.6)
Insurance status	
Insured	372 (94.4)
Uninsured	22 (5.6)
Last health care appointment	
Less than 6 months	286 (72.6)
More than 6 months	108 (27.4)
Portal use frequency	
Weekly or more frequently	94 (23.9)
Monthly	184 (46.7)
Yearly or less	116 (29.4)
Message exchange	
Send messages to providers annually or more frequently	192 (48.7)
Received messages from providers annually or more frequently	214 (54.3)

Participants' Views of Their Portals

Most of the participants (300/394, 76.1%) consider their portals as a valuable part of their health care, with 93.4% (368/394) of the participants believing that their portals were easy to use. Overall, 76.6% (302/394) of the participants reported that they believed using portals had become habitual in managing their health. Additionally, most of the participants (366/394, 92.9%) reported trusting their portals, and 90.4% (356/394) of the participants reported believing that their portals were important in managing their health. Furthermore, 93.4% (368/394) of the participants thought that it was important to have a record of past health information (eg, visit history, lab results, and appointments) on their EHR portals. A total of 92.4% (364/394) of the participants reported that they were comfortable with their portals.

Portal Features Used by Participants

The participants could choose multiple answers that fit their conditions. There were primarily 10 features that were used by portal users, as shown in Table 2. The most frequently used features of portals were “view lab results” (229/394, 58.1%), “make/check appointments” (215/394, 54.6%), and “view/pay bills” (201/394, 51%). Approximately half of the participants (195/394, 49.5%) reported using portals to check their visit history. Meanwhile, 33.3% (131/394) of the participants reported using their portals to contact their health providers, and 27.4% (108/394) of the participants reported having requested prescription refills through portals. Only a few participants had used other features including educational materials (54/394, 13.7%), immunization reports (41/394, 10.4%), and review allergies and alerts (33/394, 8.4%).

Table 2. Portal features used by participants (N=394).

Portal feature	Participants, n (%)
View lab results	229 (58.1)
Make and check appointments	215 (54.6)
View and pay bills	201 (51)
Check my visit history	195 (49.5)
Contact my health providers	131 (33.3)
Prescription refill request	108 (27.4)
Medications	83 (21.1)
Educational materials	54 (13.7)
Immunizations	41 (10.4)
Document and review allergies and alerts	33 (8.4)

Factors Leading to Difficulty in Using Portals

The survey included questions about what design features or factors led to difficulty in using patient portals. The most frequently reported factors that made portals difficult to use were concerns about data safety and security (136/394, 34.5%), as indicated in Table 3. Some (111/394, 28.2%) participants reported limited access to the internet as a factor that led to difficulty in using portals. Irrelevant messages (88/394, 22.3%) and being unable to view enough patient information (81/394, 20.6%) were the other two leading factors that made portals difficult to use. As common issues with most web-based products, spam and too many messages (55/394, 14%) and lost passwords (51/394, 12.9%) were also noted to result in difficulties. Difficulty in understanding the health information on their patient portals was reported by 11.7% (46/394) of the participants, whereas only 3.3% (13/394) of the participants reported that they did not trust the information displayed on the patient portals. Additionally, 7.6% (30/394) of the participants reported preferring to use other websites (eg, WebMD, Wikipedia, and Google) rather than their portals.

Table 3. Factors causing difficulty in using portals as reported by participants (N=394).

Factor	Participants, n (%)
Concerns about my data safety and security	136 (34.5)
Limited access to the internet	111 (28.2)
Messages that are not relevant to me	88 (22.3)
Unable to view enough patient information	81 (20.6)
Spam and too many messages	55 (14)
Lost password	51 (12.9)
Difficult to understand the information in portals	46 (11.7)
Preference for other websites instead (eg, WebMD, Wikipedia, and Google)	30 (7.6)
Not trusting the information displayed	13 (3.3)

Sources of Health Information

The participants were asked whether they had ever used other online information sources to obtain health information, and they could choose multiple answers. As seen in Table 4, most participants (331/394, 84%) reported having used WebMD for health information. Internet-based medical articles were used by 76.4% (301/394) of the participants and Wikipedia was used by 68% (268/394). More than half of the participants (221/394, 56.1%) reported having used health blogs to obtain health information. Approximately half of the participants reported using government and hospital websites to obtain health information. Meanwhile, some of the participants also reported using social media platforms such as Facebook (128/394, 32.5%), Twitter (106/394, 26.9%), and Instagram (98/394, 24.9%) to access health information.

Table 4. Online information sources that participants used to obtain health information (N=394).

Source	Participants, n (%)
WebMD	331 (84)
Internet-based medical articles	301 (76.4)
Wikipedia	268 (68)
Health blogs	221 (56.1)
Government websites	200 (50.8)
Hospital websites	200 (50.8)
Facebook	128 (32.5)
Twitter	106 (26.9)
Instagram	98 (24.9)

Across several internet-based sources of health information, WebMD and medical articles were reported as the most frequently trusted health information sources, with 79.2% (312/394) and 77.9% (307/394) of our respondents reported trusting WebMD and internet-based medical articles, respectively, as observed in Table 5. Hospital system websites and government websites were also highly trusted, with 75.6% (298/394) and 68.3% (269/394) of the participants trusting the sources, respectively. Although 68.3% of the participants used Wikipedia for health information, only 59.1% (233/394) trusted it. Health blogs were also trusted by more than half of the participants (215/394, 54.6%). Other social media platforms such as Facebook (108/394, 27.4%), Twitter (99/394, 25.1%), and Instagram (99/394, 25.1%) were trusted by fewer participants than the other information sources.

Table 5. Internet-based sources of health information sources that participants reported trusting (N=394).

Source	Participants, n (%)
WebMD	312 (79.2)
Medical articles	307 (77.9)
Hospital websites	298 (75.6)
Government websites	269 (68.3)
Wikipedia	233 (59.1)
Health blogs	215 (54.6)
Facebook	108 (27.4)
Twitter	99 (25.1)
Instagram	99 (25.1)

Information Presentation Method

The participants were asked to identify their preferences for the presentation of health educational materials and could choose multiple answers. Most of the participants (250/394, 63.5%) believed that videos were the most effective way to present health educational materials, followed by texts (196/394, 49.8%), photographs (126/394, 32%), and diagrams or charts (105/394, 26.7%).

Accessing EHR Patient Portals

Approximately half of the participants (184/394, 46.7%) reported using their EHR portals monthly, 23.1% (91/394) reported using EHR portals on a yearly basis, and 19% (75/394) used their portals weekly. Meanwhile, daily portal usage was reported by 4.8% (19/394) of the participants. Only 6.4% (25/394) of the participants reported using their patient portals only once.

In terms of how the participants accessed their portal, most participants (305/394, 77.4%) used their portals through home computers (the participants could select more than one option). The other two common EHR portal access approaches were mobile devices (118/394, 28.9%) and work computers (95/394, 24.1%). Very few participants reported using EHR portals through public computers such as library computers (14/394, 3.6%) and school computers (4/394, 1%).

Contacting Health Providers With Questions

We assessed how many participants used secure messaging through their portals to contact their health care providers. The participants reported that "messages through portals" constituted the most (156/394, 39.6%) used method to contact their health care providers. Another widely reported method for contacting their health care providers was through telephone (146/394, 37.1%). Meanwhile, only 12.9% (51/394) and 9.9% (39/394) of our participants, respectively, reported using email or scheduling an in-person visit when they had health-related questions for their health providers.

Predicting Users' Trust in the EHR Patient Portal

We built a logistic regression model to predict the EHR portal users' trust in their patient portals, as shown in Table 6. Compared to others, participants who were frequent internet users (ie, used the internet at least daily) were significantly more likely to trust their portals (odds ratio [OR] 43.72, 95% CI 1.83-1046.43). Participants who were comfortable using their EHR portals were more likely to trust the portals that they were currently using (OR 7.97, 95% CI 1.11-57.32). Participants who believed their portal was important in terms of managing their health (OR 28.13, 95% CI 5.31-148.85) or who believed that their EHR portal was a valuable part of their health care (OR 6.75, 95% CI 1.51-30.11) were more likely to trust their portals. Participants who used Wikipedia (OR 12.87, 95% CI 2.23-74.26) or social media platforms (such as Facebook, Twitter, and Instagram; OR 4.44, 95% CI 1.14-17.24) for obtaining health information were also more likely to trust their EHR portals. Meanwhile, the participants' trust in some web-based health information sources was positively related to the trust in their portals. Participants who trusted WebMD (OR 3.98, 95% CI 1.11-14.32) or government websites (OR 7.73, 95% CI 1.92-31.19) to obtain health information were also more likely to trust their EHR portals. Some factors that led users to believe that their portals were difficult to use were negatively associated with the participants' trust in their portals. Participants who believed that they received irrelevant messages (spam or too many messages) through their portals were less likely to trust their portals (OR 0.05, 95% CI 0.005-0.61). In contrast, participants who found their portals easy to use were more likely to trust their portals (OR 7.4, 95% CI 1.12-48.84).

Table 6. Logistic regression model to predict users' trust in electronic health record portals.

Factor	Estimate	SE	Z value	*P* value	Odds ratio (95% CI)
Intercept	–12.21	2.54	–4.81	<.001	—[a]
Comfortable in using my EHR[b] portal	2.08	1.01	2.06	.04	7.97 (1.11-57.32)
EHR portal is important in managing my health	3.34	0.85	3.92	<.001	28.13 (5.31-148.95)
Used Wikipedia for health information	2.56	0.89	2.86	.004	12.87 (2.23-74.26)
Trust WebMD to get health information	1.38	0.65	2.12	.03	3.98 (1.11-14.32)
Spam made my portal hard to use	–2.94	1.25	–2.36	.02	0.05 (0.005-0.61)
Trust government websites	2.05	0.71	2.88	.004	7.73 (1.92-31.19)
EHR portal is a valuable part of my health care	1.91	0.76	2.50	.01	6.75 (1.51-30.11)
Hard to understand information in my portal	–2.03	1.10	–1.84	.07	NS[c]
Irrelevant message made my portal hard to use	–1.02	0.82	–1.24	.22	NS
Frequent internet users (daily use)	3.78	1.62	2.33	.02	43.72 (1.83-1046.43)
Used social media to get health information	1.49	0.69	2.16	.03	4.44 (1.14-17.24)
It is easy to use my EHR portal	2.00	0.96	2.08	.04	7.40 (1.12-48.84)
Older adults	–1.62	1.17	–1.39	.17	NS
Model statistics parameters					
Likelihood ratio test result –2 log likelihood, x^2 (*df*)	–84.64 (14)	N/A[d]	N/A	N/A	N/A
Model *P* value	<.001	N/A	N/A	N/A	N/A
χ^2 (*df*)	117.396 (13)	N/A	N/A	N/A	N/A
AIC[e]	112.64	N/A	N/A	N/A	N/A

[a] Not available.

[b] EHR: electronic health record.

[c] NS: no statistically significant differences found at α=.05.

[d] N/A: not applicable.

[e] AIC: Akaike Information Criterion.

Features That Would Encourage Future Portal Use

In addition to assessing the participants' evaluation of their current patient portals, the participants were also asked about features (or potential features) that would encourage them to use their portals more. This question had 29 options that we provided based on the features identified in the literature or features that may potentially fit within an EHR patient portal (eg, mental health self-assessment). Participants were also able to include additional features that were not listed, and these might lead them to use their EHR portal more. The participants were able to select unlimited potential portal features that might encourage them to use the system more. Among all the features, more than one-third of the participants agreed that they would use their portals more if the portals included real-time chats with physicians, safe and secure messaging, and prevention and follow-up reminders, as observed in Table 7. Other features including real-time virtual appointments, lab results, and appointment requests were also important factors that might lead to increased portal use.

Table 7. Electronic health record patient portal features that participants reported wanting (N=394).

Factor	Participants, n (%)
Real-time chat with physicians	154 (39.1)
Safe and secure messaging	151 (38.3)
Reminders: preventive and follow-up	135 (34.3)
Real-time virtual appointment	126 (32)
Lab results	124 (31.5)
Appointment requests	121 (30.7)
Access materials (eg, lab reports, bills, or educational materials)	119 (30.2)
Prescription refill requests	119 (30.2)
Appointment reminders	103 (26.1)
Billing	99 (25.1)
Diagnostic test results	90 (22.8)
Insurance information	80 (20.3)
Patient-specific educational materials and web resources	77 (19.5)
Wellness and preventive care	74 (18.8)
Medications	66 (16.8)
Appointment log	65 (16.5)
Exercise information	65 (16.5)
Virtual therapy	64 (16.2)
Mental health resources and education	59 (15)
Mental health self-assessment	52 (13.2)
Immunizations	48 (12.2)
Problems lists	47 (11.9)
Calorie calculator and diet manager	44 (11.2)
Smart watch or Fitbit data entry	42 (10.7)
Public health information	40 (10.2)
Self-monitoring data entry	38 (9.6)
Allergies and alerts	32 (8.1)
Sexual health information	28 (7.1)

Discussion

Principal Findings

This study sought to investigate how individuals accessed health information and their EHR patient portals as well as identify barriers and facilitators for portal use. We conducted an internet-based survey that asked EHR portal users about their behaviors associated with portal usage, as well as their opinions about portal usage and about current and potential features of EHR portals. In general, most participants reported that their patient portals were valuable and that they trusted their portals.

Our results suggest that many factors contribute to users' trust in EHR portals. The usage and trust associated with some other internet-based health information sources were also found significant in predicting the likelihood of patients trusting the portals. In contrast, spam, irrelevant messages, and difficult-to-understand information within the portals were identified as factors that could lead to a decrease in the likelihood of users trusting EHR portals. Thus, there are ways to design and manage future EHR systems that support patients to develop trust in their EHR portals. For example, when it is necessary to refer to a piece of educational health information (such as the definition, detection, and symptoms of hypertension) in EHR portals, referring to a trusted information source such as WebMD may potentially increase users' trust in EHR portals. This is consistent with the research findings indicating that health care providers, the internet, and government health agencies are the three most trusted health information sources [31]. One study suggested that approximately one-third of the patients reported having difficulties in finding health information and concerns about the information quality [31]. Thus, providing necessary health information within EHRs has its potential value, and choosing a trusted health information source as a reference is vital in designing a trustworthy EHR. Ensuring that the EHR portals are easy to use and have easy-to-understand information may contribute to increased trust in these portals [32]. It is critical that users trust their EHR patient portals as well as the information and instructions contained in these portals; otherwise, the systems may not be valuable to the patients [33]. Moreover, patient trust in eHealth features including health websites is an important factor leading to crucial patient outcomes [34,35]. Identifying the factors and groups that have high trust and those who do not trust EHR patient portals can lead to better designed systems for users and increased trust in the EHR portals, which can eventually improve the use of EHR portals [32].

Generally, our sample of portal users included more younger and middle-aged adults, which is consistent with the population of EHR portal users in other survey studies [36,37]. We did not detect gender differences in the survey participants across our analyses. However, other studies have shown gender differences in terms of the access and use of EHR portals [37]. The use of EHR patient portals among more specific gender and age groups for specific diseases should be examined to reveal the specific user needs and characteristics, such as individuals having multiple chronic conditions who may need closer monitoring on their EHR portal [38]. Not everyone reported having access to fast and reliable internet connections, and there are populations of potential EHR portals users who were not represented in our survey sample. Thus, our survey participants reflect users with access to the internet and may not represent all the potential users of EHR portals.

Several studies have proposed improving self-health management through mobile health apps [39], and the integration of mobile apps with computer-based EHRs has been demonstrated [33,40]. Future studies should examine the factors related to internet characteristics in different locations (eg, home, public, or work) or on different platforms (eg, mobile, tablet, or computer). Designing EHR patient portals with effective displays for computers and mobiles may make the design of EHR portals more complex and introduce additional usability issues. Furthermore, our study suggests that most EHR users used their portals infrequently, such as monthly. Thus, the design of EHR portals needs to support easy learning and the ability to retain the knowledge about how to engage with the system.

Consistent with a previous study [41], data security concerns and limited internet access are the most frequent barriers that our participants reported as related to perceiving portals to be difficult to use, which was followed by irrelevant messages and being unable to view enough patient information. Future EHR portals designers should pay special attention to address security concerns, avoid irrelevant messages such as advertising messages, and provide comprehensive health information.

It has been shown that older adults have many potential barriers in using EHR portals such as limited health literacy, limited access to health technology, and preference for in-person communication [42,43]. Limited access to the internet and limited ability to use computer-based EHR technology were reported as some of the major barriers for elderly people to use EHR portals [41]. However, modern health technology features such as EHR portals may potentially provide significant benefits for specific groups of people with specific clinical needs. For example, there may be substantial benefits for the elderly, who may need to track their health records more frequently owing to multiple complex health conditions [43,44]. It is necessary for future research studies to specifically target groups of patient portal users (eg, older individuals and individuals with specific health conditions) and nonusers. A recent study suggests that some interventions (eg, an intervention that used one-on-one training on EHRs [45]) could improve EHR portal usage among vulnerable populations [46]. Future studies may examine EHR portal usage among different age groups with different internet accessibility levels, as well as interventions to promote the use of EHR portals.

Although secure messaging through EHR portals is believed to have a positive impact on patient-provider communication [47], the overall message communication between portal users and health providers was reported as infrequent in our study (less than half of the participants send messages through portals annually or more frequently, although slightly more participants received messages through portals). The communication through portals between patients and providers did not replace traditional communication approaches such as email, telephone, or text messaging. We could see that emerging methods like text messaging through EHR portals and traditional methods like telephone calls are commonly used when our participants had questions for their health care providers. Although health care providers believe that the use of EHR portals can positively impact information delivery and improve patient-provider communication according to a recent study [44], EHR portals are still not widely used for communication, and there are several opportunities to improve messaging features.

In general, there is no comprehensive understanding of how users feel about their patient portals and what factors are associated with their usage. Our study suggested that viewing lab results, checking appointments, and paying bills are the most commonly used portal features and the specifics of how these functions are designed and implemented is an important direction for future research. The features that are widely used and valued are the core features of patient portals. There are other features that participants want to use or those that would lead them to use their portals more often. For example, the ability to engage in real-time chats with care providers is an uncommon feature for most EHR portals, but our study demonstrated that is a highly valued and desired feature. This feature could help patients connect to their clinicians without always requiring an office visit, which would help reduce the burden on clinics while also providing individualized care. Additionally, reducing clinical visits when not necessary is critical during periods with highly infectious diseases (eg, COVID-19 or the annual flu season). Under the special situation of the COVID-19 pandemic, minimizing unnecessary in-person visits and conducting remote discussions are particularly valuable [48-50]. Based on the results of this study, these features may further encourage the use of EHR systems and help patients remain connected to their health care providers. Another web-based communication feature, namely safe and secure messaging, was also highly ranked by EHR portal users. In fact, among the top 10 desired features in our results, 4 were related to documentation (eg, lab results and billing), 3 to communication with health care providers, and 3 to appointments and scheduling such as appointment reminders and requests. Thus, there is value in continuing to develop tools for internet-based communication between EHR portal users and their care providers.

Our study was conducted within the United States, and thus the results are most relevant within the US health system. Although there are some features that are more universal and may apply to health systems across the world, some specific features related to billing are specific to the United States. Further, only 60 nonusers participated in the survey, and thus we did not include nonusers in the analysis. A separate study with a larger sample size of nonusers that examines the specific barriers for nonusers and their perspectives on EHR portals will contribute to the literature.

Our study also examined the methods that the survey participants reported preferring for the presentation of educational health information. Most of the participants preferred videos, which topped the other methods of information presentation. Written text (or using words) was ranked second and was viewed as a better way than photographs or diagrams and charts. Future studies should evaluate these preferences and determine how best to present information in multimodal strategies. Additionally, as videos were reported as the most preferred information presentation method, future research should examine what types of health information can be presented in the video format. Future research should also examine how video presentation impacts the comprehension of health information, considering how the design of video presentations may facilitate the information exchange process and improve communication efficiency. Videos have been shown to be effective for online education and do not require reading abilities and facilitate repeated viewing for comprehension; they may support different learning styles and lead to better learning outcomes [51,52].

Against the backdrop of the COVID-19 pandemic, the close monitoring of patients' health conditions in a virtual or web-based modality is important for public health. For example, employers may require regular negative COVID-19 test results for in-person work, and thus, more people may be accessing and engaging with their EHR patient portal to access these test results. Therefore, frequent, safe, and easy access to their test results (eg, lab results section) is a critical design feature for the use of EHR patient portals. Special attention should be paid to design these features to satisfy the user needs and expectations; thus, future research should examine how to design and implement these types of features and specific features that are important for future portal users.

Conclusion

This study examined the use of EHR portals by internet users. Our study provides insights into some desired features and factors that lead to users trusting their EHR patient portals. Additionally, we identified some of the frequently encountered barriers to using EHR patient portals. It should be noted that the survey was administered prior to the COVID-19 pandemic, and thus, it may not reflect current trends in the availability and use of internet-based health information and virtual health care appointments. In conclusion, designing effective and easily usable EHR portals may be the most effective approach to improving users' trust in the portals. The features and interface design of EHR portals are critical factors that contribute to increasing users' trust in EHR portals. Future work should evaluate how to most effectively design these features to extend the benefits of using EHR patient portals for monitoring health.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey on electronic health record patient portals created for and used in this study.

[DOCX File , 37 KB - humanfactors_v8i3e28501_app1.docx]

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Abbreviations

AIC: Akaike Information Criterion
CFR: Code of Federal Regulations
EHR: electronic health record
OR: odds ratio

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Original Paper

Usability of a Co-designed eHealth Prototype for Caregivers: Combination Study of Three Frameworks

Melanie Tremblay[1], MA; Karine Latulippe[1], PhD; Manon Guay[2,3], PhD; Véronique Provencher[2,3], PhD; Anick Giguère[4,5], PhD; Valérie Poulin[6,7], PhD; Véronique Dubé[8,9], PhD; Dominique Giroux[4,10], PhD

[1]Department of Teaching and Learning Studies, Université Laval, Québec, QC, Canada

[2]School of Rehabilitation, Université de Sherbrooke, Sherbrooke, QC, Canada

[3]Center of Research on Aging, Centre intégré universitaire de santé et de services sociaux de l'Estrie, Centre hospitalier universitaire de Sherbrooke, Sherbrooke, QC, Canada

[4]Center of Excellence on Aging Quebec, Québec, QC, Canada

[5]Department of Family Medicine and Emergency Medicine, Université Laval, Québec, QC, Canada

[6]Université du Québec in Trois-Rivières, Trois-Rivières, QC, Canada

[7]Interdisciplinary Center for Research in Rehabilitation and Social Integration, Université Laval, Québec, QC, Canada

[8]Research Centre of the University Hospital of Montreal, Montreal, QC, Canada

[9]School of Social Work and Criminology, Université Laval, Québec, QC, Canada

[10]Department of Rehabilitation, Université Laval, Québec, QC, Canada

Corresponding Author:
Melanie Tremblay, MA
Department of Teaching and Learning Studies
Université Laval
2325 Rue de l'Université
Québec, QC, G1V 0A6
Canada
Phone: 1 (418) 656 2131
Email: melanie.tremblay.50@ulaval.ca

Abstract

Background: Co-design (or the participation of users) has shown great potential in the eHealth domain, demonstrating positive results. Nevertheless, the co-design approach cannot guarantee the usability of the system designed, and usability assessment is a complex analysis to perform, as evaluation criteria will differ depending on the usability framework (or set of criteria) used. ISO (International Organization for Standardization) on usability (ISO 9241-210), Nielsen heuristic, and Garrett element of user experience inform different yet complementary aspects of usability.

Objective: This study aims to assess the usability and user experience of a co-design prototype by combining 3 complementary frameworks.

Methods: To help caregivers provide care for functionally impaired older people, an eHealth tool was co-designed with caregivers, health and social service professionals, and community workers assisting caregivers. The prototype was a website that aims to support the help-seeking process for caregivers (finding resources) and allow service providers to advertise their services (offering resources). We chose an exploratory study method to assess usability in terms of each objective. The first step was to assess users' first impressions of the website. The second was a task scenario with a think-aloud protocol. The final step was a semistructured interview. All steps were performed individually (with a moderator) in a single session. The data were analyzed using 3 frameworks.

Results: A total of 10 participants were recruited, 5 for each objective of the website. We were able to identify several usability problems, most of which were located in the *information design* and *interface design* dimensions (Garrett framework). Problems in both dimensions were mainly coded as *effectiveness* and *efficiency* (ISO framework) and *error prevention* and *match between the systemand the real world* (Nielsen heuristic).

Conclusions: Our study provided a novel contribution about usability analysis by combining the 3 different models to classify the problems found. This combination provided a holistic understanding of the usability improvements needed. It can also be used to analyze other eHealth products.

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KEYWORDS

usability evaluation; co-design; research methods; caregivers; service providers; product objectives

Introduction

Background

eHealth is becoming increasingly important to support people in taking care of their own health and that of their loved ones. In 2019, more than 90% of Canadians had access to the internet and 50% reported having access to at least one web-based health service [1]. The COVID-19 pandemic has amplified its use. eHealth is notably one of the solutions that can support caregivers in the daily tasks required to care for an older person at home [2]. Guay et al [3] suggest that internet-based interventions can have positive effects on the psychological well-being of caregivers of older persons. Irani et al [4] reported that people with chronic diseases and their caregivers were satisfied with the use of the technology. However, some faced technical challenges, whereas others were concerned about the technology's lack of a personalized approach. Moreover, caregivers of functionally dependent older persons are often older themselves. In 2012, in Québec (Canada), 41% of caregivers were aged over 55 years [5]. A digital divide related to age and education [6], which are both determining factors of internet use [7], still remains. Concerns can, therefore, be raised about the acceptability of eHealth solutions within this group of users, as many factors influence older people's acceptance of technology, such as privacy implications and usability factors [8].

In response to this issue, there is a growing interest in the co-design approach [9]. In this approach, researchers, designers, and participants are cocreating with users, who are considered experts of their experience and play a large role in knowledge development, idea generation, and concept development [10]. Authors have reported that the participation of different actors in a co-design project allowed a better understanding of each other's perspective and reality [9,11]. As co-designers, caregivers and older adults can share their concerns and expectations about the technology in a democratic process, which might increase the fit between their needs and the system developed. However, the co-design approach cannot guarantee the usability and user experience (UX) of the designed system.

Usability and UX Evaluation

Usability Definition

Usability is the "functional relationships between people and the products and systems they use" [12]. It is also defined as the "extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [13]. Users do not want a difficult or uncomfortable experience in their interaction with the system, but usability requires more than just the users' desire for it [14]. To achieve usability of the system, we need to evaluate it and adjust the design to address the problems found. Usability assessment is a complex analysis to perform, as evaluation criteria will differ depending on the usability framework (or set of criteria) used.

The International Organization for Standardization Framework

The ISO (International Organization for Standardization) usability framework (ISO 9241-210) is a framework accepted worldwide [13] to assess usability in general. The criteria of this framework are all part of the ISO's definition of usability: *effectiveness*, *efficiency*, *satisfaction,* and *context of use*. The *specified users,specified goals*, and *context of use* are a combination of the situated aspects of the interaction with the system: who are the users, what do they want to achieve with the system, and in which context (at home or at work, on their phone or on their computer, etc)? All these factors need to be considered when assessing the usability of a system. *Effectiveness* is the *accuracy and completeness with which users achieve specified goals*. Are users able to achieve the task? *Efficiency* refers to the *resources used in relation to the results achieved*. How long and how easy was it to accomplish the task? *Satisfaction* is defined as the "extent to which the user's physical, cognitive and emotional responses that result from the use of a system, product or service meet the user's needs and expectations" [13]. Did users appreciate their interaction with the system while performing the task?

This framework allows a general picture of usability but cannot provide specific insights into what is needed to achieve better results. How can we fix a problem related to effectiveness? The Nielsen heuristic framework (1995) provides more details on what the system should do to meet the ISO criteria.

The Nielsen 10 Usability Heuristics Framework

Heuristics describe an approach to problem solving whereby people will rely on a limited number of principles to reduce the complexity of a task by *predicting values to simpler judgmental operations* [15]. Heuristics are helpful in predicting the reaction of users interacting with a system. The Nielsen framework (1995) listed 10 heuristics to consider while assessing or trying to achieve usability:

1. *Visibility of system status:* "The design should always keep users informed about what is going on, through appropriate feedback within a reasonable amount of time."
2. *Match between the system and the real world:* "The design should speak the user's language. Use words, phrases, and concepts familiar to the user, rather than internal jargon. Follow real-world conventions, making information appear in a natural and logical order."
3. *User control and freedom:* "Users often perform actions by mistake. They need a clearly marked 'emergency exit' to leave the unwanted action without having to go through an extended process."
4. *Consistency and standards:* "Users should not have to wonder whether different words, situations, or actions mean

the same thing. [Words, situations, and actions should] follow platform and industry conventions."

5. *Error prevention:* "Good error messages are important, but the best designs carefully prevent problems from occurring in the first place. Either eliminate error-prone conditions or check for them, and present users with a confirmation option before they commit to the action."
6. *Recognition rather than recall:* "Minimize the user's memory load by making elements, actions, and options visible. The user should not have to remember information from one part of the interface to another. Information required to use the design (e.g. field labels or menu items) should be visible or easily retrievable when needed."
7. *Flexibility and efficiency of use:* "Shortcuts, hidden from novice users, may speed up the interaction for the expert user, such that the design can cater to both inexperienced and experienced users. [The system should] allow users to tailor frequent actions."
8. *Esthetic and minimalist design:* "Interfaces should not contain information which is irrelevant or rarely needed. Every extra unit of information in an interface competes with the relevant units of information and diminishes their relative visibility."
9. *Help users recognize, diagnose, and recover from errors:* "Error messages should be expressed in plain language (no error codes), precisely indicate the problem, and constructively suggest a solution."
10. *Help and documentation:* "It's best if the system doesn't need any additional explanation. However, it may be necessary to provide documentation to help users understand how to complete their tasks [16]."

Refer to the NNGroup website [16] for a detailed description, with examples of each heuristic. These heuristics are guidelines for achieving *effectiveness*, *efficiency*, and *satisfaction*. They focus on the task goals. However, users' goals are not always task oriented (do-goals) [17]. Other goals, such as be-goals, will affect their experience with technology [18]. Users are not just users. They are also human beings with feelings. The UX shifts the focus from the product to feelings while users interact with the technology [19].

Garrett Framework: The Elements of UX

The elements of UX framework [20] proposes 5 dimensions to describe UX design: strategy, scope, structure, skeleton, and surface. Each dimension has distinctive elements (Textbox 1).

Each framework provides a different understanding of how a product can get closer to what users really want. These frameworks inform different yet complementary aspects of usability and UX.

Textbox 1. The elements of user experience and their description.

Dimension, Elements, and Description

- Strategy
  - Product objectives: what are the business goals or other specific goals the product is aiming for?
  - User needs: who are the target users and what do they want?
- Scope
  - Functional specifications: what functionalities are required to address user needs and product objectives?
  - Content requirements: what content is required to address user needs and product objectives?
- Structure
  - Interaction design: how does the system behave in response to the users' actions?
  - Information architecture: what is the structural arrangement and distribution of information throughout the system?
- Skeleton
  - Information design: how is the information presented to facilitate understanding?
  - Interface design: how are the interface elements organized on the page to enable users to interact with the system?
  - Navigation design: what elements allow the user to access the different sections of the information architecture?
- Surface
  - Sensory design: what sensory (vision, touch, etc) experience is created by the product?

Objective

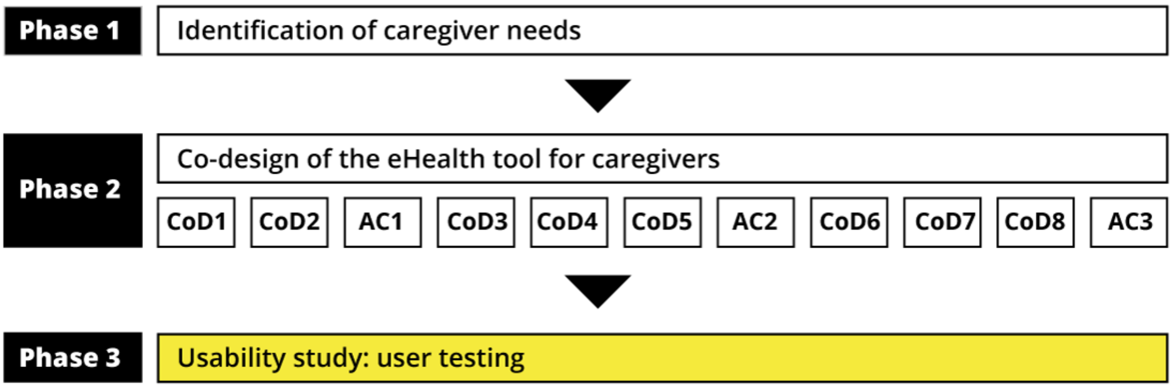
The objective of this study is to assess the usability and UX of an early version co-designed prototype to support the help-seeking process of caregivers of functionally dependent older persons. Trying to gather as much information as possible on potential improvements, we want to explore the contribution of the 3 frameworks presented: the ISO [13], Nielsen usability heuristics [16], and Garrett elements of UX [20].

Methods

Context of the Study

On the basis of the potential value of the co-design approach in the eHealth domain, we first co-designed an eHealth prototype to support the help-seeking process of caregivers of functionally dependent older persons (Figure 1). The co-design phase of the study (phase 2) included 8 co-design sessions and 3 advisory committee meetings held in 11 of the 16 administrative regions of the province of Québec from May 2017 to June 2018.

Figure 1. Context of the study. Ac: advisory committee session; CoD: co-design session.



The research project protocol of the entire study can be found in the paper by Latulippe et al [21], and results on user needs, requirements, and overall process and design decisions are presented in 3 papers [22-24]. A total of 74 co-designers were recruited, including 30 caregivers, 26 community workers, and 18 health professionals. Advisory committee meetings were held in plenary and co-design sessions were held in both plenary and subgroup workshops and included different types of activities depending on the objectives of the session.

The eHealth prototype developed was a website with 2 main objectives: helping caregivers to find resources (with a search tool and a questionnaire to help identify the needs) and allowing service providers to offer their services. The prototype is currently hosted on a private server.

Explorative Usability and UX Assessment

We chose an exploratory study method to assess usability, as the prototype was in its first version [25,26]. Changes were made to phase 3 of the initial protocol to gather more appropriate knowledge about usability and UX, considering the state of the prototype [21]. These changes include the addition of users' first impressions, the accuracy of the methods used to perform the think-aloud method, and the use of a semistructured interview rather than a standardized questionnaire.

Recruitment

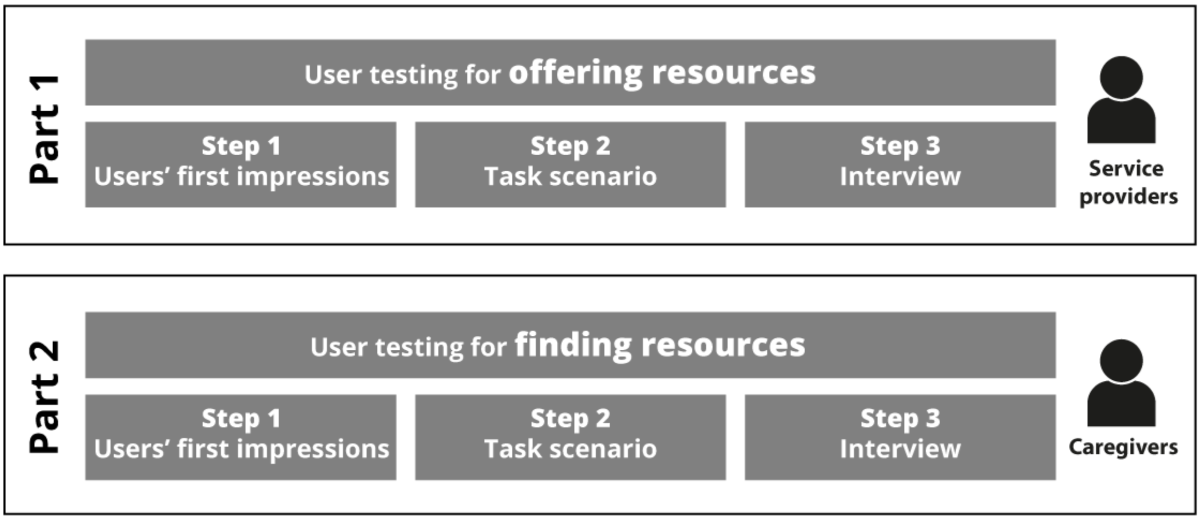
Participant recruitment included recruiting for the 2 objectives of the website (offering and finding resources for caregivers). Two researchers (KL and MC) completed the recruitment and data collection. All participants were recruited from a single region of Québec for feasibility reasons. The first inclusion criterion was potential users of the website. We contacted service providers via telephone and email. Service providers helped to recruit caregivers within their organization. One inclusion criterion for service providers was to provide services to caregivers of functionally dependent older persons. One inclusion criterion for caregivers was to provide assistance on a regular basis (at least once a week) to a person aged 65 years or older. Participating in phase 2 (co-design of the tool) was not an inclusion criterion for recruitment in the usability study (phase 3), but it was also not an exclusion criterion. As the objective of this study was exploratory and we were testing with an early version of the prototype, we targeted 10 users, including service providers and caregivers. We wanted an equal representation of participants for each objective of the website. Faulkner [27] revealed that the average percentage of problem areas found in 100 trials of 5 users found 85% (38/45), ranging from 55% (25/45) to nearly 100% (45/45), whereas groups of 10 found 95% (43/45) of the problems.

Data Collection

Global Process

As the prototype was in the early stages of development, the database did not contain any resources except the *test* resource entered by researchers during the programming of the prototype. Thus, we completed data collection in 2 parts through individual user testing, including 3 steps each (Figure 2). For the first part, we evaluated usability and UX for the *offering resources* objective. Participants contributed to adding some resources in the database in which caregivers would eventually search. For the second part, we evaluated usability and UX for the *finding resources* objective with caregivers. We collected data in French, the main language used in Québec.

Figure 2. Study methodology.



We completed the 3 steps of each part in a single session of 30-45 minutes with each participant. All sessions were videotaped. We conducted tests at the workplace for service providers and at home (or in a community center) for caregivers. Moderators used either a portable PC with a webcam and the Open Broadcast Studio (The OBS Project) [28] or the participant's own computer, a camera or an iPad, and an audio recorder. Open Broadcast Studio is a free open-source software that allows the recording of multiple sources of data simultaneously. The webcam captures the participants' reaction. The integrated audio captor records participants' verbalization, and the desktop or browser windows are captured as another source.

Step 1: Users' First Impressions

We used the 5-second test (5ST) to gather the first impression of users. This involved a display of the home page for 5 seconds, followed by questions [29,30]. The 5ST technique was used to gather information about general eye-catching attributes of the home page and provided general first impressions. After the 5 second display, we asked participant, "Can you tell me what you remember seeing?" To collect more detailed information about the perception of the utility for each user subgroup, we added a second display of the home page without a time limit. Participants were then asked to express their perceived usefulness, "As a [caregiver or service provider], what do you think you could do with this website?"

Step 2: Task Scenarios

The second step included task scenarios [25] with a coaching think-aloud protocol [31]. The task scenarios represented several tasks that the user would typically perform with this website and put them in context [25]. Scenarios differed depending on the targeted subgroup. Each scenario included a practice task to familiarize participants with the think-aloud protocol, followed by 5 assessed tasks. We selected the tasks based on what each subgroup of users would typically want to do with the website and on specific interactions that the research team wanted to assess (Textbox 2). In accordance with the *coaching think-aloud* protocol, moderators worked with participants during task performance. When the participant stopped talking during the task, the moderator repeated the instruction, *keep thinking aloud, please*. When a participant struggled with a task, the moderator provided some guidance.

Textbox 2. Task scenarios and related questions.

Part 1: Offering Resources

- Find resources
    - “You want to find resources for a caregiver you interact with. How would you proceed?”
- Create a profile
    - “You want to create a profile for your organization. How would you proceed? Please create a complete profile.”
- Add an activity
    - “You want to add an activity offered by your organization. How would you proceed?”
- Add a document
    - “You want to add an information document presenting details of your organization’s services. How would you proceed?”

Part 2: Finding Resources

- Identifying their own needs
    - “You are tired and you need help but you do not know exactly what you are looking for. What would you do?”
- Finding a resource in their region
    - “You want to find a support group in your region. How would you proceed?”
- Adding a search result to their favorites
    - “You want to keep the name of an organization to go back to it more quickly. How would you proceed?”
- Finding a document
    - “You want a document suggesting strategies for bathing assistance. How would you proceed?”

Step 3: Semistructured Interview

We created an interview guide based on validated usability questionnaires [32-35]. We created our own interview guide because validated questionnaires have limited applicability and are not suited to all systems [36]. We also wanted to address the specific objectives of the usability evaluation and UX of our prototype, such as problems faced during task performance [25]. We included 8 questions, with probing questions adapted to our designed prototype in the interview guide to answer more specifically to our study objectives (Textbox 3).

Textbox 3. Questions for the semistructured interview.

Questions

1. “When you were [task], I noticed [negative attitude, discomfort, difficulties, time to perform tasks]. Can you tell me why you had [negative attitude, discomfort, difficulties, time to perform tasks]?”
2. “Is the website easy to use?”

   Probing question: “What seems complicated to you?”
3. “Is the organization of the website logical and optimal?”

   Probing question: “What is inconsistent in the website’s organization?”
4. “Did you find information easily?”

   Probing question: “Which information did you not find easily?”
5. “When navigating on the website, is it easy to know where you are?”

   Probing question: “When were you not able to know where you were?”
6. “Generally speaking, are you satisfied with this website?”
7. “Do you feel comfortable using this website?”
8. “Would you like to use this website for your tasks?”

To collect sociodemographic data, participants were asked questions about their age, profession, education level, and profession. We also asked 3 multiple-choice questions to assess participants' perceptions of their technology profiles (Textbox 4).

Textbox 4. Sociodemographic data collection.

Multiple-Choice Questions and Their Answer Choices

- Frequency of internet use
    - Several times a day
    - Several times a week
    - About once a week
    - About once a month
    - Never
- Ability to find information on the internet
    - Always
    - Most of the time
    - Occasionally
    - Rarely
- Comfort level with technology in general
    - Rate from 1 to 10 (1 being very uncomfortable and 10 being very comfortable)

Data Analysis

One researcher (corresponding author) performed the data analysis. We conducted qualitative data analysis in Microsoft Excel using the video recordings of each session. For the first (user impression) and third (semistructured interviews) steps, we conducted an inductive thematic analysis [37]. All participant verbalizations (answers) were transcribed, and some answers were translated by the author for publication purposes. We numbered each answer and collected a list of 5 data items for each (Textbox 5). We used the filter functionality to group and analyze the data.

For the second step (task scenarios), we conducted a deductive analysis [37] based on each criterion of the 3 frameworks [13,16,20]. We entered participant observations and verbalizations for each task. We numbered each problem found during the tasks and registered details for 12 items, each being a column in the Microsoft Excel spreadsheet. Textbox 5 presents a list of the items collected for each step.

For step 2, we first coded each problem according to one criterion of each framework. We then combined the coding for all frameworks using the pivot table functionality. We selected the Garrett [20] criteria to organize the identified heuristic [16] of each problem in the rows field and crossed them with ISO categories [13] in the columns field in the Microsoft Excel spreadsheet.

The study received ethical approval from the *Comité d'éthique de la recherche sectoriel santé des populations et première ligne* (2016-2017-10 MP). Informed consent was obtained from each participant, who also received a nominal compensation of Can $20 (US $16.45).

Textbox 5. List of data items collected.

Items Collected at Each Step

- Step 1 (first impression) and step 3 (semistructured interview)
    - Data input number
    - Participant ID
    - Participant category (service provider or caregiver)
    - Source of data (question)
    - Data (transcript)

- Step 2 (task scenarios)
    - Data input number
    - Participant ID
    - Participant category (service provider or caregiver)
    - Source of data (observation, verbalization, or both)
    - Data (transcript or description of observation)
    - Problem identified
    - Task
    - Source of error
    - Potential solution
    - International Organization for Standardization category
    - Heuristic category
    - Garrett category

Results

Participants' Demographics

We recruited a total of 10 participants: 4 caregivers and 6 service providers. We conducted 5 user tests for each phase (part 1: offering resources and part 2: finding resources; Table 1). One service provider participated as if she were a caregiver (phase 2). She represented what could happen in a real-context setting: a service provider helping a caregiver.

Table 1. Participants' sociodemographic data (N=10).

Sociodemographic items	Offering resources (n=5)	Finding resources (n=5)
Gender, n (%)		
Women	3 (60)	4 (80)
Men	2 (40)	1 (20)
Age (years), mean (SD; range)	53.4 (13.4; 42-75)	71.2 (7.8; 58-78)
Education level, n (%)		
College	2 (40)	N/A[a]
Bachelor's degree	1 (20)	4 (80)
Master's degree	1 (20)	N/A
Doctorate	1 (20)	1 (20)
Frequency of internet use, n (%)		
Several times a day	1 (20)	1 (20)
Several times a week	3 (60)	4 (80)
About once a week	1 (20)	0 (0)
Capacity to find information on the internet, n (%)		
Always	1 (20)	2 (40)
Most of the time	4 (80)	3 (60)
Comfort level with technology in general from 1 to 10, mean (SD; range)	7.9 (1.02; 6-9)	7 (0.70; 6-8)

[a] N/A: not applicable.

Step 1: Users' First Impressions

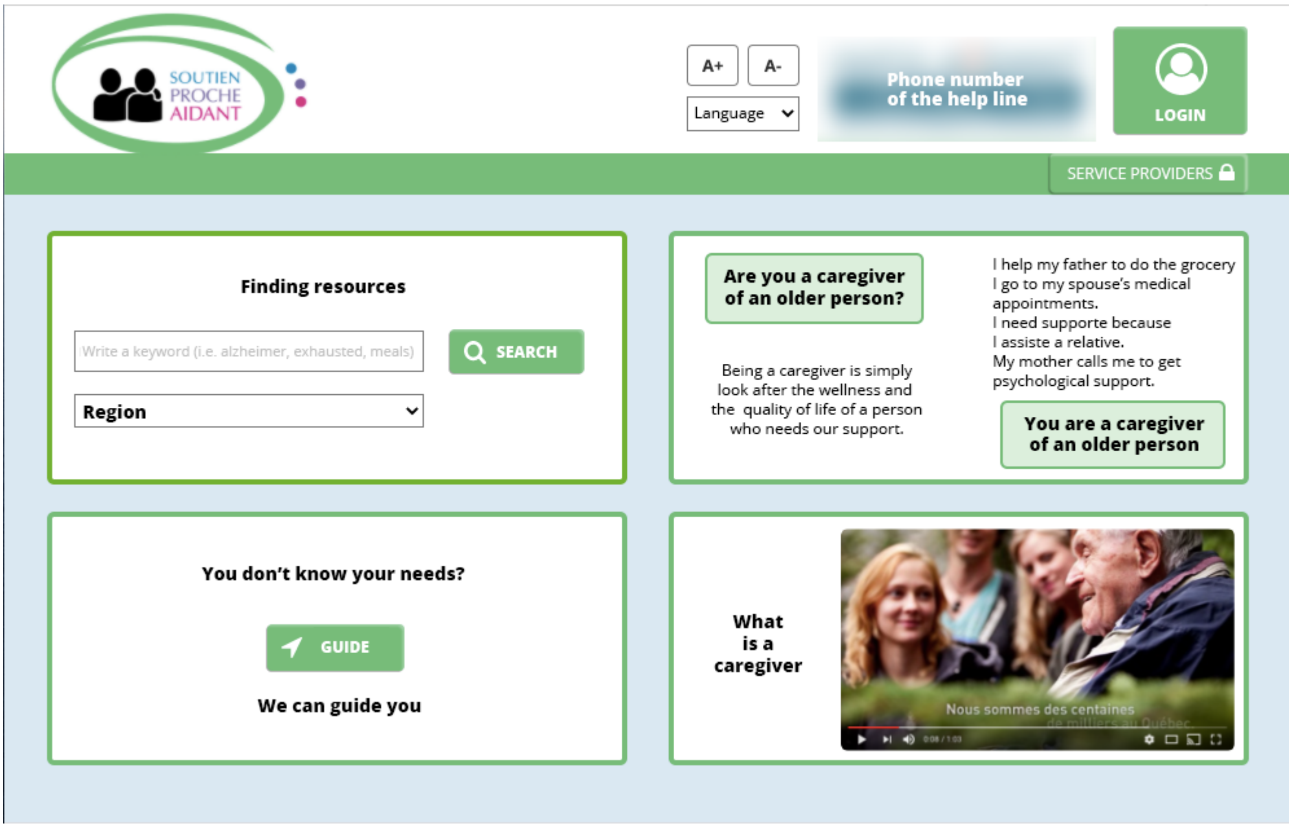
Table 2 presents the results (emerging categories) for the 5ST of the home page. Elements most commonly identified by participants were located in the top-right section of the page (n=10).

Table 2. Participants' first impressions of the home page (5-second test; n=10).

Interface section	Caregivers mentions (n=5), n (%)	Service providers mentions (n=5), n (%)
Header (9 mentions)		
The phone number of the helpline for caregivers	1 (20)	3 (60)
The name of the website	0 (0)	1 (20)
The log-in (to access the user profile)	1 (20)	2 (40)
Caregivers support (logo)	0 (0)	1 (20)
Top left (7 mentions)		
A search tool	2 (40)	2 (40)
Finding resources	2 (40)	1 (20)
Top right (10 mentions)		
The definition of a caregiver	3 (60)	0 (0)
The question, "are you a caregiver for an elderly person?"	2 (40)	2 (40)
Examples of what is a caregiver	0 (0)	2 (40)
Caregiver of an older person	0 (0)	1 (20)

The top left section, where the search tool is located, was among the elements that were perceived less frequently. It was perceived by 7 participants, with only 4 participants mentioning the search tool, which corresponds to the *finding resources objective*. Figure 3 shows the home page displayed to the participants.

Figure 3. Home page display.



Being a caregiver is simply look after the wellness and the quality of life of a person who needs our support.

I help my father to do the grocery
I go to my spouse's medical appointments.
I need supporte because I assiste a relative.
My mother calls me to get psychological support.

After the 5ST, for the second home page display (without a time limit), all service providers answered that they thought the website was for *finding resources to refer or help caregivers*. One service provider also mentioned the requirement of registering its organization. All caregivers answered that they could search or find resources or service providers; 2 of them insisted on the fact that they could find respite resources.

Step 2: Task Scenarios

Summary

We identified 151 problems with the task scenarios, which were classified according to the categories of the 3 frameworks. Some participants were not able to perform all the tasks because of programming errors. When problems were programming errors, they were classified as N/A (not applicable) in each category. This was also done if the focus on the task seemed to interfere with the participant's perception, for example, if the participant did not see an item they were asked about (the phone number of the helpline for caregivers) because the focus was not on that item but on the task (finding a resource in their region). In those cases, we did not classify the problems, as the task could have affected the interpretation of a category. Most problems (49/151, 32.5%) occurred during the creation of a profile for service providers. The other tasks with a considerable number of problems for service providers were *finding resources* (18/151, 11.9%) and *adding an activity* (10/151, 6.6%). For caregivers, 11.3% (17/151) of problems occurred during the task *finding a resource in their region* and 8.6% (13/151) of problems during the task *identifying their own needs*. The following sections provide a description of these problems.

ISO Classification

Table 3 presents findings related to the ISO usability framework. The table presents the number of problems in each category, an example for each with data input number, participant ID, and the transcript or description of the observation. Service providers are identified as SP# and caregivers as C#. It also presents the task where the problems occurred and the type of problem.

Table 3. Problems with the website, classified according to the International Organization for Standardization framework.

Usability criteria (ISO[a] 9241-210)	Problems, n (%)	Task (example)	Verbalization or observation (example)	Problem detected (example)
Effectiveness		Finding a resource in their region	"So, I will go to Find resources, I will search for the region first" [#23, C1]	The participant writes nothing in the search bar before clicking on the search button
Total (n=151)	68 (45)			
SP[b] (n=68)	50 (73.5)			
Caregiver (n=68)	18 (26.5)			
Efficiency		Creating a profile	"It is really annoying to have to scroll. I don't know if I can just write it, how does it work? it is not simple." [#6, SP1]	Too much scrolling to choose the city
Total (n=151)	49 (32.5)			
SP (n=49)	31 (63.3)			
Caregiver (n=49)	18 (36.7)			
Satisfaction		Finding a resource in their region	Participant is using the advanced research functionality; "No, it isn't the right solution, there are no options!" [#83, C2]	The participant is looking for the word *activity* in the advanced research
Total (n=151)	18 (11.9)			
SP (n=18)	9 (50)			
Caregiver (n=18)	9 (50)			
Context of use		Creating a profile	Participant is clicking on the log-in (the one for the caregiver) and then clicks on creating a profile. The participant receives an error message. [#88, SP4]	The participant did not see the access dedicated to service providers
Total (n=151)	4 (2.6)			
SP (n=4)	4 (100)			
N/A[c] (n=151)	12 (7.9)	Question asked after finding a resource in their region	"Did you see the phone number for the help line?" [#21, C1, interviewer]; "I was focusing on the resource, I would have seen it after." [participant]	The participant did not see the phone number (focus on the task)

[a] ISO: International Organization for Standardization.

[b] SP: service provider.

[c] N/A: not applicable.

Almost half of the problems (68/151, 45%) were classified as *effectiveness* and occurred mainly for service providers during part 1 (50/68, 74%). A total of 32.5% (49/151) were classified as *efficiency*, again mostly by service providers (31/49, 63%). A few problems (18/151, 11.9%) were related to *satisfaction*. Four problems were classified as *context of use*. These problems were identified by a single participant, and most of them (3/4, 75%) could be explained by the fact that this participant was visually impaired. The problems coded as *context of use* included the following: (1) the participant tried to connect or create a profile using the caregiver access instead of the service provider access, (2) insufficient color contrast, (3) and the size of user interface elements.

Nielsen Heuristic Classification

Regarding the classification using Nielsen heuristics, *match between the system and the real world* was the most important heuristic principle identified, representing 19.9% (30/151) of problems (Table 4). This heuristic was mostly identified for problems arising for service providers (21/30, 70%) when performing the *create a profile* task (12/30, 40%). Other frequently mentioned usability principles included *help and documentation* (25/151, 16.6%), *user control and freedom* (22/151, 14.6%), *error prevention* (21/151, 13.9%), and *recognition rather than recall* (18/151, 11.9%), all of which were again mostly for service providers during the *create a profile* task.

Table 4. Classification of problems according to Nielsen heuristics.

Heuristic principle	Problems, n (%)	Task (example)	Verbalization or observation (example)	Problem detected (example)
Match between the system and the real world		Create a profile	At the end of the task, the interviewer is pointing on the screen to the access for service providers. The participant says, “It’s locked!” [#108, SP5]	The lock icon is perceived as an item locked on the screen
Total (n=151)	30 (19.9)			
SP[a] (n=30)	21 (70)			
Caregiver (n=30)	9 (30)			
Help and documentation		Create a profile	“What is my username? What was asked before to connect, my email address?” [#7, SP1]	The participant enters their email in the field for the website instead of the email field
Total (n=151)	25 (16.6)			
SP (n=25)	19 (76)			
Caregiver (n=25)	6 (24)			
User control and freedom		Create a profile	“I have a video of a caregiver online on my website.” [#16, SP1]	There is no option to add a hyperlink to a video, only to upload one
Total (n=151)	22 (14.6)			
SP (n=22)	13 (59.1)			
Caregiver (n=22)	9 (40.9)			
Error prevention		Create a profile	The participant clicks on the log-in instead of the create a profile button (#48, SP3)	The create a profile button is beneath the connection button
Total (n=151)	21 (13.9)			
SP (n=21)	14 (66.7)			
Caregiver (n=21)	7 (33.3)			
Recognition rather than recall		Add a research result in their favorites	“I could add it in the favourite of my browser...Here I don’t know what to do” [#135, C3]	The favorite button is not appearing when the user is not connected
Total (n=151)	18 (11.9)			
SP (n=18)	11 (61.1)			
Caregiver (n=18)	7 (38.9)			
Visibility of system status		Find a resource in their region	She is clicking on the search button and nothing seems to happen (#147, C4)	The system is not providing information about the action performed
Total (n=151)	8 (5.3)			
SP (n=8)	5 (62.5)			
Caregiver (n=8)	3 (37.5)			
Esthetic and minimalist design		Find resources	“And here you have the XYZ Volunteer Center...Three times!” [#25, SP2]	The same research result is appearing 3 times
Total (n=151)	6 (3.9)			
SP (n=6)	3 (50)			
Caregiver (n=6)	3 (50)			
Help users recognize, diagnose, and recover from errors		Add a document	An error message appears: “I assume it is because I did not upload a document?” [#39, SP2]	The upload of a document failed
Total (n=151)	4 (2.6)			
SP (n=4)	3 (75)			

Heuristic principle	Problems, n (%)	Task (example)	Verbalization or observation (example)	Problem detected (example)
Caregiver (n=4)	1 (25)			
Consistency and standards		Create a profile	The participant did not enter the postal code or the region of the city. (#53, SP3)	The input fields for the postal code and region are located beside the other input field, on the right side, rather than below them
Total (n=151)	2 (1.3)			
SP (n=2)	2 (100)			
Flexibility and efficiency of use		Add an activity	"If the activity added appears below, it is a bit annoying. We don't know if it worked or not." [#36, SP2]	The added activity is located under the field for adding an activity
Total (n=151)	2 (1.3)			
SP (n=2)	2 (100)			
N/A[b] (n=151)	13 (8.6)	Find a resource in their region	The participant clicks on support group, but nothing happens. (#139, C3)	Link is not working (programming error)

[a] SP: service provider.

[b] N/A: not applicable.

Garrett Elements of UX Classification

Table 5 presents the results of the analysis using the Garrett framework. Most of the problems (113/151, 75.8%) were classified in the *skeleton plane*, especially in the *interface design* (54/151, 35.8%) and *information design* (50/151, 33.1%) dimensions. For *interface design*, 65% (35/54) of problems occurred for service providers, mostly to *create a profile* (20/54, 37%). For *information design*, 80% (40/50) of problems occurred for service providers, mostly to *create a profile* (24/50, 48%). Only one problem was categorized in the *user needs* category, and it was also classified for *context of use* in the ISO categorization. This problem reflects an accessibility problem for visually impaired users, meaning that the prototype did not address the specific needs of visually impaired users.

Table 5. Classification of problems with Garrett elements of user experience.

Plane and user experience element	Problems, n (%)	Task (example)	Verbalization or observation (example)	Problem detected (example)
Strategy				
Product objectives	0 (0)	N/A[a]	N/A	N/A
User needs		Finding resources	Even if the user is not able to see the entire page at once, she is still able to find the item on the screen, such as the search button. (#86, SP4)	The website is not offering options for visually impaired people
Total (n=151)	1 (0.7)			
SP[b] (n=1)	1 (100)			
Scope				
Functional requirements	0 (0)	N/A	N/A	N/A
Content requirements	0 (0)	N/A	N/A	N/A
Structure				
Interaction design		Finding a resource in their region	"I can ask a question, can't I?" [#82, C2]	The participant would like to ask a question instead of using the search engine
Total (n=151)	19 (12.5)			
SP (n=19)	11 (57.9)			
Caregiver (n=19)	8 (42.1)			
Information architecture	0 (0)	N/A	N/A	N/A
Skeleton				
Information design		Creating a profile	"What does 24-h surveillance mean? It's not clear." [#112, SP5]	The wording is not understood
Total (n=151)	50 (33.1)			
SP (n=50)	40 (80)			
Caregiver (n=50)	10 (20)			
Interface design		Finding a resource in their region	The participant clicks on the description of a support group and nothing happens. (#77, C2)	Only the title is clickable
Total (n=151)	54 (35.8)			
SP (n=54)	35 (64.8)			
Caregiver (n=54)	19 (35.2)			
Navigation design		Finding a resource in their region	The participant and the interviewer are retyping the initial website address to return to the home page. (#65, C1)	The return to the home page with the logo is not understood
Total (n=151)	9 (6)			
SP (n=9)	3 (33.3)			
Caregiver (n=9)	6 (66.7)			
Surface				
Sensory design		Finding a document	"What we are trying to do is to colour code the organization in blue, the activities in pink, and the document in purple. You didn't notice the colour coding?" [#84, C2, interviewer]; "Not at all! I don't see the point." [C2]	The participant did not notice the change of color depending on the type of result
Total (n=151)	6 (3.9)			
SP (n=6)	4 (66.7)			

Plane and user experience element	Problems, n (%)	Task (example)	Verbalization or observation (example)	Problem detected (example)
Caregiver (n=6)	2 (33.3)			
N/A				
No classification (n=151)	12 (7.9)	Finding a resource in their region	The participant is entering information in the advance research engine without looking at the results first. (#129, C3)	Due to a programming error, results are not showing besides the advance research box, but below it

[a] N/A: not applicable.

[b] SP: service provider.

Combining the Frameworks

Combining all 3 frameworks of analysis provides a comprehensive picture of the identified problems. Multimedia Appendix 1 presents the problems in terms of the dimension of the Garrett framework and the category of ISO usability criteria. The combination also identifies the Nielsen heuristic usability guideline the problem does not address. This table indicates that for *interface design*, problems were mainly identified for *effectiveness* (22/54, 41%) and efficiency (24/54, 44%), with several problems of *error prevention* (ie, when trying to connect to their profile). Problems are also found for *effectiveness* (19/50, 38%) and *efficiency* (25/50, 50%) in *information design*, concerning especially the *match between the systemand the real world*, mostly for service providers during the creation of their profile and the *help and documentation* (eg, caregiver was looking for the word *Respite* and did not think of entering it in the search engine). The combination of frameworks allows a better understanding of usability problems and provides greater insight into the improvements needed. The numbers in the cells indicate the number of problems at the intersection of the row and the column.

Step 3: Semistructured Interview

Overview

This section presents the questions and translations of the transcripts, including answers to each question. Service providers are identified as SP [#] and caregivers as C [#]. Question 1 was asked during task performance, and the results were included at that point.

Question 2

The second question was as follows: “Is the website easy to use?”—Seven participants answered this question. Answers varied among participants: 3 answered “yes” (SP4, C1, and C5), 1 specifying that it was easy to understand and that the screen was not overloaded (C1). Two answers seemed ambivalent:

> *We find resources when it [website] works properly. If I am looking for an organization but I don’t know the organizations...Finding resources, I don’t know the resources, it is not clear.* [SP1]
>
> *Middle. Knowing if it [the search] worked or not. But visually it’s quite easy, not overloaded. It is easy to search.* [C3]

One participant answered negatively:

> *It makes me feel incompetent. I can’t immediately find what I’m looking for.* [SP5]

Question 3

The third question was: “Is the organization of the website logical and optimal?”—Seven participants answered this question. Two were positive:

> *Personally, I think it’s OK. I will sit with the caregiver and find resources.* [C5]
>
> *Oh yes! We have a lot to learn. If I had it, I would learn a lot!* [C4]

Three participants said it was clear, but not optimal (SP4, SP5, and C3). Similarly, 2 participants mentioned it could be better (SP2), 1 commenting on the information: “For me, information needs to be precise, I don’t want to get lost in things that will take time” [C2].

Question 4

Next, the following question was asked to six participants: “Did you find information easily?”—Only 1 answer was fully positive: “Yes, indeed. It should have info for each organization” [C1].

Other answers were more mitigated: “Yes and no. For now, there is not a lot in it” [SP4], with some commenting on the fact that they needed the interviewer to complete the task (C3 and C4). Two were negative:

> *Not really. I was not able to get results.* [SP2]
>
> *It was too long.* [C2]

One participant commented on the information he was not able to find easily:

> *I expected to arrive directly in the activities, because now, I have to go through the list before getting to the activities. Especially because it is presented...In the list, the organizations were first, then the activities and after the documents. There should be some logic to it.* [C1]

Question 5

The fifth question was as follows: “When navigating on the website, is it easy to know where you are?”—All participants who answered this question (n=8) said they were mostly able to figure out where they were. Three participants answered “yes” (SP2, SP4, and C5); one answered “Quite easily” [C2];

and another answered "Yes, I think" [C4]. Other answers were ambivalent, with participants providing some explanation:

> *The first time no, but after yes.* [C3]
>
> *It's because we could not see the rest. I knew where I was in the section I could reach.* [SP1]
>
> *I knew where I was in the website. But, when I clicked here [browser Back button], I expected to go back to the page I was before, but it brings me back to the beginning.* [C1]

Question 6

The following question was answered by only 1 participant: "Generally speaking, are you satisfied with this website?"

> *More or less. Contrasts should be adjusted for older and colour-blind people.* [SP4]

Question 7

The following question was: **"**Do you feel comfortable using this website?"—Two of those who answered this question (n=4) answered "yes" (SP4 and C3). One specified that she would use it with a digital tablet (C2). Another (SP2) mentioned that he would be somewhat comfortable using it, even with the current problems. He was referring to one of the programming problems.

Question 8

For the last question: "Would you like to use this website for your tasks?"—Again, 2 (of a total of 3) participants answered simply "yes" (SP4 and C3). One participant indicated that he would use it with caregivers:

> *Of course, I would use it! I would use it with the caregiver to help him develop his ability to find information with this tool.* [SP6]

Discussion

Principal Findings

This study aims to assess the usability and UX of the 2 objectives of an early co-designed prototype. Findings from step 1 (users' first impressions) indicate that participants were able to identify the 2 main objectives of the website. Moreover, even if participants were ambivalent regarding information retrieval, (answers from question 3 during step 3) and the ease of use of the website (answers for question 2 during step 3), they were still comfortable and interested in using the website (answers from questions 5 to 7 during step 3). On the other hand, results from the task scenarios (step 2) tend to indicate that there were more usability problems for the *offering resources* objective, especially when service providers were trying to create their profile. However, this was not the website's main objective, as the co-design study first aimed to conceive an eHealth tool to support the help-seeking process of caregivers. The second objective (*offering resources*) emerged early during the co-design process, that is, during the identification of functional and content requirements [23]. As mentioned by Luck [38], in participatory design research, knowledge is constructed through practice, and one cannot entirely foresee the direction of the experiment. This was the case, for example, for the co-design study by Tironi [39], in which new knowledge about the ontological perspective of users forced the redefinition of the initial protocol.

Required Improvements on Accessibility

A second finding relates to accessibility. Accessibility "means removing barriers that might prevent someone from using something, regardless of their access needs" [40]. Accessibility problems were found during task scenarios (step 2) for 1 service provider. Due to a visual impairment, this participant was unable to see the entire page at once. The participant was using a special device to enlarge the interface on the screen. Even if it is uncommon to identify *context of use* as a usability category (other studies generally use the effectiveness, efficiency, satisfaction triad), we chose to include it in our study to see whether we would be able to classify problems in that category, and we were able to do so. The special needs of this participant were not addressed. We recognize that no participant with a visual impairment was included during the co-design process [22]. To maximize the potential of addressing all user needs, participants with special needs should have been included in the co-design process. As mentioned by Cahill [41], co-design or participatory action research is precisely an appropriate method for *including excluded perspectives* and challenging typical knowledge production. From a social justice perspective, other co-design studies should include users with impairments, as special techniques to co-design with them are offered in the literature [42,43].

Combination of Frameworks

The combination of the 3 frameworks was a novel contribution. It has broadened the perspective and enhanced the strength of our study. As pointed out by Lacerda and von Wangenheim [44] in their systematic literature review, current usability models have many problems (lack of information on the intended use, data collection instruments, and assessment process), leading researchers to seek other sources or combine different models and methods. In our study, the use of the ISO framework was particularly helpful in revealing an important accessibility issue. The use of the Garrett framework was decisive in identifying the dimensions in which the problem was located. Nielsen heuristics helped us to understand how to improve the website in further iterations of the prototype. Each framework provided useful insights to understand the usability and UX of our prototype. However, the combination of the analyses of all 3 frameworks was even more informative. For example, we were able to identify that most problems were located in the *interface* and *information design* and were *effectiveness* problems (users being unable to complete the task) or *efficiency* problems (the level of difficulty in performing the task). Moreover, we were able to get a better idea of how to address the problems, knowing which heuristics they were not addressing, which were often the *match between the system and the real world* and *help and documentation*.

Challenges and Limitations

This study has some limitations. First, scenarios were created by the research team and imposed on the participants. This may have affected the results, as the focus was on the task and might have hindered access to other useful information. Second, the data were analyzed by only 1 expert or researcher. The results were presented to the research team, who agreed on the big picture without determining proper intercoder agreement. Third, programming errors interfered with some tasks, which may have led to the loss of useful information on usability. These problems were identified as programming errors, but the participants were not able to perform the task. If it had been possible to perform the task, other usability problems might have been identified for the task. During the analysis, we also realized that there was a possible mapping issue between the different categories of the frameworks. For example, “The participant did not see the phone number” could have been identified as either *effectiveness* or *efficiency*. The interpretation relies on what the analyst was focusing on. It could be coded as *effectiveness* if we consider that the user needs to call the phone number, and it could be coded as *efficiency* if the phone number is one method (among several) to access information. Thus, the combination of the 3 conceptual frameworks does not bring a mutually exclusive categorization, but it reduces the risk of blind spots. Regardless of the category, we were still able to identify that the phone number was not perceived and needed more emphasis.

Other limitations were related to the study participants. First, the participants had a high level of education, as most had a university degree (n=8). Although this might represent the population of service providers, it is not representative of the caregiver population. In Québec, only 27.6% of caregivers had a university degree [45]. The second limitation was the age gap between the *offering resources* group and the *finding resources* group. Age is a determining factor in the use of internet products [7]. However, the *finding resources* group was mostly caregivers of functionally dependent older persons. Statistics indicate that these caregivers are often older themselves [5], which could explain the gap. The third limitation was the number of participants. Although we had 10 users, all of them were not testing exactly the same pages. Five users were testing each objective of the website. Nevertheless, looking at the results, we still consider that most of the problems seemed to emerge during this usability and UX assessment, without an absolute confirmation on the saturation of problems. As this study was exploratory and targeted an early version of the website, we are confident that we have collected sufficient information to improve the prototype.

Our results are transferable to a very limited extent to other eHealth systems. They are indeed related to a specific interactive product (website) dedicated to specific users (caregivers and service providers). Nevertheless, our analysis proposition combining the ISO [13], Nielsen heuristic [16], and elements of UX [20] is highly applicable to the usability or UX evaluation of other eHealth systems.

Conclusions

This study provided improvement possibilities for a prototype co-designed with caregivers and service providers. We were able to identify several usability and UX problems. The 3 frameworks used for the analysis allowed us to understand the nature of the problem (ISO) [13] and the dimension where it lies (elements of UX) [20], as well as provide potential problem-solving solutions based on the predicted judgmental operations (Nielsen heuristics) [16]. Thus, we will continue the co-design process to address those problems by recruiting service providers and caregivers to co-design a new version of the prototype. Our analytical method, based on the 3 conceptual frameworks and their combination, broadened the perspective of the problems encountered. This combination of frameworks for usability and UX analysis is a novel contribution that is transferable to other eHealth systems, which contributes to the advancement of knowledge in the eHealth community.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Synthesis of results combining the 3 analysis frameworks.
[PDF File (Adobe PDF File), 59 KB - humanfactors_v8i3e26532_app1.pdf]

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Abbreviations

5ST: 5-second test
ISO: International Organization for Standardization
UX: user experience

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Original Paper

The Role of Computer Skills in Personal Health Record Adoption Among Patients With Heart Disease: Multidimensional Evaluation of Users Versus Nonusers

Martina A Clarke[1,2], MSHI, PhD; Ann L Fruhling[1], MBA, PhD; Elizabeth L Lyden[3], MSc; Alvin E Tarrell[1], MSc; Tamara L Bernard[2], RN, BSN, MPH; John R Windle[2], MD

[1]School of Interdisciplinary Informatics, College of Information Science and Technology, University of Nebraska Omaha, Omaha, NE, United States
[2]Division of Cardiovascular Medicine, Department of Internal Medicine, University of Nebraska Medical Center, Omaha, NE, United States
[3]Department of Biostatistics, College of Public Health, University of Nebraska Medical Center, Omaha, NE, United States

Corresponding Author:
Martina A Clarke, MSHI, PhD
School of Interdisciplinary Informatics
College of Information Science and Technology
University of Nebraska Omaha
6001 Dodge Street
Omaha, NE, 68182-0116
United States
Phone: 1 402 554 2801
Email: martinaclarke@unomaha.edu

Abstract

Background: In the era of precision medicine, it is critical for health communication efforts to prioritize personal health record (PHR) adoption.

Objective: The objective of this study was to describe the characteristics of patients with heart disease that choose to adopt a PHR.

Methods: A total of 79 patients with chronic cardiovascular disease participated in this study: 48 PHR users and 31 nonusers. They completed 5 surveys related to their choice to use or not use the PHR: demographics, patient activation, medication adherence, health literacy, and computer self-efficacy (CSE).

Results: There was a significant difference between users and nonusers in the sociodemographic measure education (P=.04). There was no significant difference between users and nonusers in other sociodemographic measures: age (P=.20), sex (P=.35), ethnicity (P=.43), race (P=.42), and employment (P=.63). There was a significant difference between PHR users and PHR nonusers in CSE (P=.006).

Conclusions: In this study, we demonstrate that sociodemographic characteristics were not an important factor in patients' use of their PHR, except for education. This study had a small sample size and may not have been large enough to detect differences between groups. Our results did demonstrate that there is a difference between PHR users and nonusers related to their CSE. This work suggests that incorporating CSE into the design of PHRs is critical. The design of patient-facing tools must take into account patients' preferences and abilities when developing effective user-friendly health information technologies.

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KEYWORDS

patient portal; communication; patients; precision medicine; health literacy

Introduction

Precision Medicine in Cardiovascular Disease

The Precision Medicine Initiative is a nationwide initiative that was launched in 2015 to transform the United States health care delivery from a "one-size-fits-all" approach to one that takes into account individual variability in genes, environment, and lifestyle when providing patients with treatment and prevention strategies [1]. The primary goal of precision medicine is to provide optimized medical care and outcomes for each patient.

Benefits of precision medicine include increased prediction capabilities to determine which treatments work best for particular patients; better insight into the underlying mechanisms by which multiple diseases occur; enhanced methods for preventing, diagnosing, and treating a variety of illnesses; and improved electronic health records (EHRs) integration in clinical care, which promotes easier access to health data [2].

Management of life-threatening illnesses and chronic diseases has been progressing toward precision medicine for many years [3]. There has been exceptional precision medicine advancement related to cardiovascular disease (CVD) [4-8], which aids in the transformation of the management practice for CVD. Despite these advancements, CVD still ranks as one of the leading causes of death in the United States [9]. CVD contributes US $320 billion to health care costs annually. This includes the cost of health care services, medicines, and lost productivity due to death. This cost is projected to increase to US $818 billion by 2030 [10]. In addition to focusing on preventive measures to reduce the incidence of CVD, improving current patients' management of this disease will reduce the CVD's economic cost on the health care system. Although targeted therapies related to cardiovascular medicine are less developed than in other specialties, such as oncology, these therapies have been acknowledged as a practical next step in patient-centered CVD treatments [4]. Patient-centered care relies heavily on patients becoming more involved in their health and wellness in order to achieve the optimal benefits from the health care system. Effective communication between health care providers and patients is necessary for health promotion efforts to be successful. New strategies, such as the personal health record (PHR), have been implemented to enhance the effectiveness of health information communication between patients and their providers.

Patient Portal Use

The Medicare and Medicaid EHR Incentive Programs advocate for patients to be involved in their health care. The PHR allows patients to electronically view their health information, after-visit summaries, credible educational materials, and reconcile their medication list [11]. PHR use should improve patient–provider communication, self-management of chronic illnesses, and medication adherence [12,13]. However, a data brief from the Office of the National Coordinator for Health Information Technology reported that although more than 90% of health care organizations offer patient portal access, less than 25% of patients actually use it [14]. Another study by Powell and Deroche [15] found that 35% of patients with a chronic disease have never used their patient portal. Patients with a chronic illness play an important role in their health improvement because chronic illnesses require continuous self-management efforts [16-19]. A study by Henry et al [20] found that providing educational information in patient portals can improve chronic disease self-management. Patients managing a chronic illness must be involved in and knowledgeable about their health. Patients who are engaged in their care are more inclined to follow treatment plans and manage their health [14,21,22].

Precision medicine offers promising improvements to health care. However, for this potential to materialize, it is necessary to involve patients in the process. In addition to generating targeted therapies, precision medicine will also generate complex risk and benefit information that will be hard to interpret for low-literacy populations [23]. Adoption of precision medicine in CVD will require patients to interact with complex results in their PHR. A literature review by Wynn et al [24] found that a patient's health literacy impacts his/her ability to understand precision medicine materials; therefore, providing patient-facing materials that are understandable to all health literacy levels must be a priority when designing health information technology (HIT) tools.

Educational gaps in precision medicine exist for patients, which requires interventions to be implemented to improve knowledge, awareness, and attitude on how precision medicine will be incorporated into the patient experience and the PHR [25]. For patients to receive the most value from their PHR, the information presented within must be written at a level comprehensible to a lay audience so that they have the ability to act on the information received [26-30]. Research is needed to determine appropriate data display, visual aids, and understandable language that will foster adoption of the PHR; however, evidence remains limited in this area [24,31]. Previous research has focused on patient portal use among patients with multiple chronic illnesses, but none have focused solely on patients with CVD.

Objective

The promotion of technology-assisted disease self-management is increasing as PHRs continue to be adopted by health care organizations. Therefore, the objective of this study is to describe the characteristics of patients with heart disease who choose to adopt PHRs. Sociodemographic and propensity characteristics were explored among PHR users and non-PHR users.

Methods

Study Design

This study involved multiple, previously validated surveys completed by cardiovascular medicine patients affiliated with the University of Nebraska Medical Center (UNMC). This survey was administered between August 2015 and June 2019. UNMC's Institutional Review Board approved this study as an expedited research project.

Organizational Setting

UNMC is an academic medical center whose clinical partner is Nebraska Medicine. The Division of Cardiovascular Medicine operates 3 clinics with over 28,000 annual patient visits. The team includes experts in general cardiology and a team of leading subspecialists in areas such as cardiac electrophysiology, interventional cardiology, structural heart disease, diagnostic cardiovascular imaging, congenital heart disease, advanced heart failure, mechanical circulatory support, and heart transplants. A nonprofit organization, Healthcare Information and Management Systems Society, rated UNMC with Stage 7 of the Electronic Medical Record (EMR) Adoption Model in

2016 [32]. A Stage 7 rating is awarded to hospitals and clinics with a fully integrated EHR that transports data using Continuity of Care Documents, utilizes data warehousing to assess clinical data, and demonstrates summary data continuity for all hospital services [33]. The PHR offered at UNMC is Epic (Verona) MyChart, a tethered PHR, and was available to patients at the beginning of 2014.

Recruitment

For our study, we recruited patients who received care at the UNMC's Heart and Vascular Center. When eligible patients were identified, a nurse coordinator contacted patients via a telephone call. The recruitment phone call introduced the voluntary nature of the study, and explained what the patient's participation in study would entail. Data collection sessions were scheduled and conducted in a clinic or adjacent conference room. Whenever feasible, the data collection session was linked to patients' scheduled appointment for convenience. This method of connecting the data collection session with patients' upcoming clinic visit was especially appealing to busier young and middle-aged adults. Participants were not compensated for their participation.

Participants

Overall, recruitment response was positive. A total of 95 patients were screened for participation in this research project. Of those, 16 declined while 79 accepted and participated in the research. Eligible participants were current patients of UNMC, scheduled for a clinic visit follow-up, 19 years old and older, and able to give consent. Use of the PHR was not a screening criterion. PHR users were defined as research patients who signed up for Nebraska Medicine's Epic MyChart and sending at least one message prior to enrollment in this research project. Of the 79 who participated in the research there were 48 users and 31 non-users of the PHR.

Data Collection

Each data collection session lasted 15-30 minutes. After consent was obtained, the survey was administered. Sociodemographic data were collected followed by administration of 5 survey tools: the Computer Self-Efficacy (CSE) Survey, the Health Literacy Survey, the Medication Adherence Survey (MAS), and the Patient Activation Measure (PAM). These battery of surveys measure the patient's comfort using computers, their general medical knowledge, their likelihood of taking prescribed medications, and their engagement in their care.

Measures

Computer Self-Efficacy

The CSE questionnaire is a 10-item survey that utilizes an 11-point Likert scale, and asks the patients their confidence in completing a task under a variety of scenarios, such as when given step-by-step instructions, utilizing on-call user help, or initial training in getting started. Scores for each question range between 0 and 10, with the total score then being between 0 and 100. The CSE has long been used to assess users' belief that they can successfully interact with a computer system. Based on social psychology, self-efficacy has been found to influence the users' behavior related to their use of the system [34].

Health Literacy Survey

The Health Literacy Survey is a 3-item survey that measures patients' adequacy in understanding health information. Developed and validated by Chew et al [35,36], the Health Literacy Scale works well in a busy clinical environment. Health literacy and PAMs are both correlated with health outcomes, however Smith et al [37] noted a poor correlation between the 2 measures and argued that both should be targeted to improve patient safety and engagement.

Medication Adherence Survey

MAS is an 8-item patient survey that provides reliable predictions of patient medication compliance [38]. MAS has a strong correlation with clinical outcomes in patients with hypertension and other conditions [39]. Patients with greater knowledge, attitude, satisfaction, and coping skills were more likely to have high medication adherence, whereas those stressed or requiring a complex medication scheme were less likely to be adherent [40].

Patient Activation Measure

The PAM (Insignia Health) is a 13-item survey using a 4-point Likert scale. It is a robust and well-validated assessment tool developed by Hibbard and colleagues [41] to measure the level of patients' engagement in their health. The PAM scale reflects a developmental model of activation. Activation appears to involve 4 stages: (1) believing the patient role is important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying the course even under stress.

Data Analysis

Survey data were recorded and stored in a secure database and analyzed using SAS 9.4 (SAS Institute) in conjunction with a biostatistician (EL). The data were summarized using descriptive statistics which included counts and percentages, means, SDs, medians, and interquartile ranges. Patient characteristics were compared between PHR users and non-users using the Fisher exact test for categorical data and the 2-sample unpaired *t* test for continuous data. The 2-sample *t* test was used to compare the composite scores for the survey instruments between the groups. Missing data were handled using pairwise deletion (available-case analysis). In other words, results were reported for the nonmissing values for each variable analyzed. All tests were 2-sided and a *P* value of <.05 was considered statistically significant.

Results

Table 1 shows the demographics of patients with CVD that participated in this study. Responses are classified according to PHR users (48 participants) and PHR nonusers (31 participants). There was a significant difference between users and nonusers in the sociodemographic measure education (*P*=.04). There was no significant difference between users and nonusers in the sociodemographic measures age (*P*=.17), sex

(*P*=.35), ethnicity (*P*=.43), race (*P*=.42), and employment (*P*=.75).

There was a significant difference (*P*=.006) between PHR users and PHR nonusers in CSE (Table 2).

Figure 1 shows the mean CSE scores by survey items for PHR users and nonusers. Both users and nonusers reported being less able to complete a task using a computer software application if they had never used a computer application like it before.

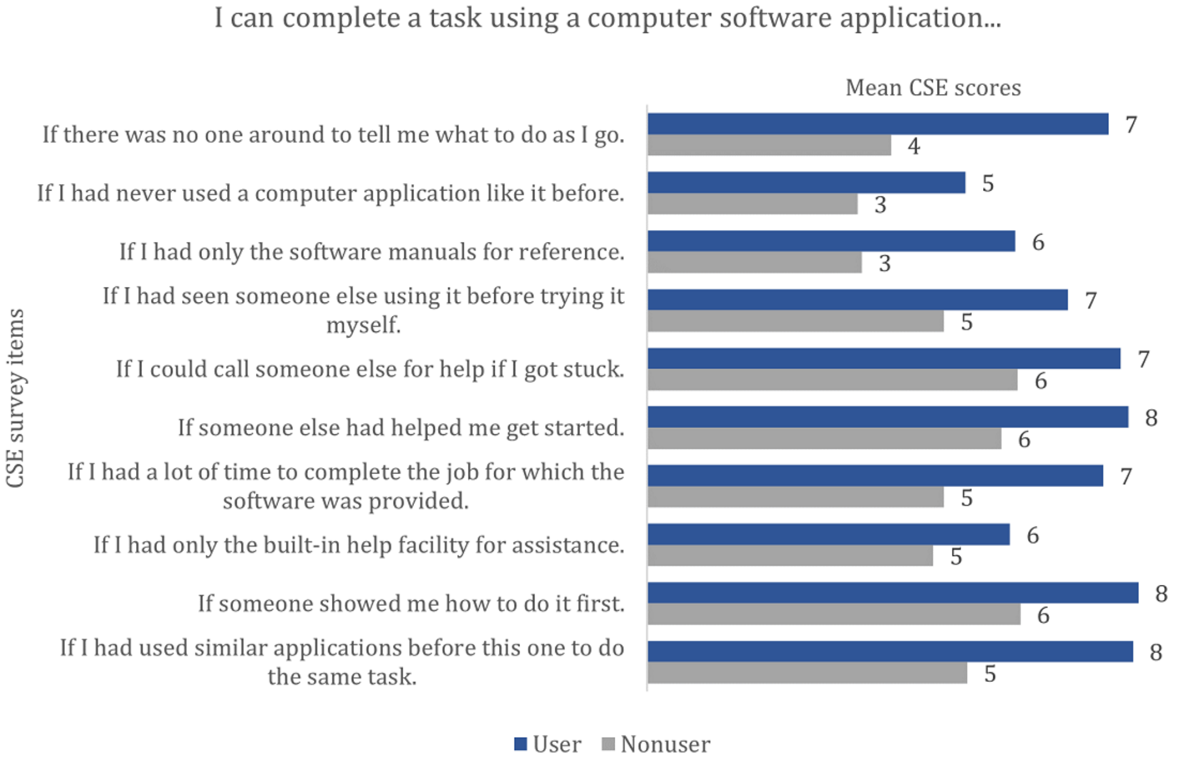
Table 1. Distribution of population characteristics categorized by PHR users and PHR nonusers (N=79).

Demographics	Nonuser (n=31)	User (n=48)	*P* value
Age (years), mean	63	57	.20
Sex, n (%)			.36
Male	18 (58)	22 (46)	
Female	13 (42)	26 (54)	
Education, n (%)			.04
Some high school	3 (10)	1 (2)	
High-school graduate/general educational diploma	9 (29)	9 (19)	
Some college/associate degree	10 (32)	17 (35)	
College graduate	8 (26)	9 (19)	
Postsecondary education	1 (3)	12 (25)	
Ethnicity, n (%)			.43
Hispanic/Latino	4 (13)	7 (15)	
Not Hispanic or Latino	27 (87)	41 (85)	
Race, n (%)			.42
American Indian/Alaskan Native	1 (3)	0 (0)	
Black/African American	6 (19)	6 (13)	
White	24 (77)	42 (88)	
Employment, n (%)			.63
Employed	11 (35)	19 (40)	
Unemployed	20 (65)	29 (60)	

Table 2. Characteristics of PHR users and PHR nonusers.

Characteristics	Nonuser			User			
	N	Mean (SD)	Median (IQR)	N	Mean (SD)	Median (IQR)	*P* value
Computer Self-Efficacy	30	46.23 (34)	45.5 (65)	48	66.58 (28.95)	73.50 (45.50)	.006
Health Literacy	31	8.42 (29)	8 (2)	48	8.25 (1.3)	8 (2)	.72
Medication Adherence	15	6.87 (1.25)	7 (2.25)	23	6.28 (1.4)	7 (1.25)	.20
Patient Activation	31	64.34 (17.8)	55.62 (21.6)	48	67.45 (18)	67.82 (21.1)	.50
Patient Activation Level	31	2.61 (1.05)	3 (2)	48	3 (0.9)	3 (1)	.08

Figure 1. Mean CSE scores by survey items for PHR users and nonusers. Scores range from 0 to 10. CSE: computer self-efficacy; PHR: personal health record.



Discussion

Principal Findings

Overview

Our results show a significant difference between PHR users and PHR nonusers' education (*P*=.04) and CSE (*P*=.006). This study adds to the ongoing discussion about the adoption of PHRs with a focus on patients with CVD. However, these results cannot be generalized to patients with an acute illness because of the different care required from chronic diseases. Although chronic disease is a major health care issue in the United States, the health care system is slow to re-adjust from an acute care focus to a system that addresses the complexities of chronic disease [42]. The use of HIT, such as PHRs, can support the management of chronic diseases. There is a lack of studies that look at PHR adoption among patients with heart disease. Patients with heart disease are an important group to study because CVD is a complex chronic disease and is one of the leading causes of death in the United States. Heart disease and stroke account for almost 801,000 deaths annually, costing US $316 billion in health care expenditures and lost productivity annually [43]. CSE plays a role in PHR acceptance and use. Previous literature on PHR adoption shows a difference between race and ethnicity in PHR use. Multiple studies found that Black and Hispanic patients were less likely to use a PHR as well as individuals with Medicare or Medicaid insurance [44-49]. Most of those studies recruited based on specific demographics as dependent not independent variables. Our results suggest that awareness of these disparities may have bolstered strategies focused on the demographics with lower usage rates in an effort to increase adoption [50]. A deeper analysis is needed to validate these results.

CSE's Role in PHR Use

Our results demonstrate a difference between PHR users and nonusers in CSE, but not in other measured scales. CSE is significantly influenced by one's computer knowledge and previous computer experience [51]. Having prior computer knowledge before using a PHR would increase CSE scores and likelihood of PHR use. Patients are more open to trying a PHR because they are familiar with how computer applications work.

Patient Activation Was Not a Factor in PHR Adoption

Another interesting finding is that patient activation was not a factor in PHR adoption. Previous studies have shown an association between PHR use and improved levels of patient activation [52-54]. Patients who are engaged in their care are less likely to adopt the PHR if they also have low self-efficacy. Our results implicate that patient's comfort using technology plays a more important role in PHR use than patient activation.

Recommendations

It is important to address the challenges in using HIT for patients with lower literacy levels [55]. It is critical that the PHR's display be tailored to the comprehension abilities of individuals with low computer literacy. Further, technological support should be made available when possible. Future research should examine the feasibility of computerized adaptive tests as screening tools to identify patients' literacy skills [56,57]. Future research should also compare characteristics of patients receiving acute care versus chronic care in terms of their PHR adoption and use. Understanding these differences will assist in developing targeted interventions to improve PHR use.

Limitations

This study was limited to patients with cardiology issues; therefore, this study needs to be reproduced in other practice settings because of the specific information needs of the different specialties [58,59]. Recruitment came from a single academic medical center and the results need to be validated in multiple academic centers. This study had a small sample size and may not have been large enough to detect differences between groups. There may be specific patient characteristics that were not measured in this cohort that may have an effect on patients' PHR usage.

Conclusions

CSE played a role in whether or not a patient would be a PHR user. Design of patient-facing tools must take into account patients' preferences and abilities when developing effective user-friendly HIT tools [60]. Providing tools designed for the "average patient" will result in isolation of patients that do not fit into the "average" mold. Future research should explore the PHR features most used by patients with cardiology issues to understand how to prioritize functionality. Future HIT tools should be developed to overcome gaps in CSE. PHRs have the promise of improving chronic disease management and increasing patient engagement. Optimizing the PHR to support its intended users will provide the momentum needed to increase patient engagement in their care [61-63].

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Conflicts of Interest

None declared.

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Abbreviations

CSE: computer self-efficacy
CVD: cardiovascular disease
EHR: electronic health record
EMR: Electronic Medical Record
HIT: health information technologies
MAS: Medication Adherence Survey
PAM: Patient Activation Measure
PHR: personal health record
UNMC: University of Nebraska Medical Center

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Original Paper

Designing Consumer Health Information Technology to Support Biform and Articulation Work: A Qualitative Study of Diet and Nutrition Management as Patient Work

Courtney C Rogers[1], MPH; Thomas J Moutinho Jr[2], PhD; Xiaoyue Liu[3], PhD, RN; Rupa S Valdez[1,4], PhD

[1]Department of Engineering Systems and Environment, University of Virginia, Charlottesville, VA, United States
[2]Department of Biomedical Engineering, University of Virginia, Charlottesville, VA, United States
[3]School of Nursing, University of Virginia, Charlottesville, VA, United States
[4]Department of Public Health Sciences, University of Virginia, Charlottesville, VA, United States

Corresponding Author:
Rupa S Valdez, PhD
Department of Public Health Sciences
University of Virginia
PO Box 800717
Hospital West Complex
Charlottesville, VA, 22908
United States
Phone: 1 434 982 2510
Email: rsv9d@virginia.edu

Abstract

Background: Diet and nutrition management is an integral component of Crohn disease (CD) management. This type of management is highly variable and individualized and, thus, requires personalized approaches. Consumer health information technology (CHIT) designed to support CD management has typically supported this task as everyday life work and, not necessarily, as illness work. Moreover, CHIT has rarely supported the ways in which diet and nutrition management requires coordination between multiple forms of patient work.

Objective: The purpose of this study was to investigate diet and nutrition management as biform work, identify components of articulation work, and provide guidance on how to design CHIT to support this work.

Methods: We performed a qualitative study in which we recruited participants from CD-related Facebook pages and groups.

Results: Semistructured interviews with 21 individuals showed that diet and nutrition management strategies were highly individualized and variable. Four themes emerged from the data, emphasizing the interactions of diet and nutrition with physical, emotional, information, and technology-enabled management.

Conclusions: This study shows that the extent to which diet and nutrition management is biform work fluctuates over time and that articulation work can be continuous and unplanned. The design guidance specifies the need for patient-facing technologies to support interactions among diet and nutrition and other management activities such as medication intake, stress reduction, and information seeking, as well as to respond to the ways in which diet and nutrition management needs change over time.

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KEYWORDS

Crohn disease; inflammatory bowel diseases; chronic disease; self-management; consumer health information technology; qualitative research; user-centered design; patient work; context; articulation work; diet; nutrition

Introduction

Crohn disease (CD), a type of Inflammatory Bowel Disease (IBD), affects approximately 3 million people in the United States [1]. Several factors may contribute to the occurrence of CD, including genetics, environment, and diet [2], but a mechanistic understanding of the disease etiology is unknown [3,4]. CD causes life-disrupting symptoms such as excessive diarrhea, depression, and malnutrition [5] that occur in states of disease remission and inflammatory flare-ups. With no current cure, individuals with CD are tasked with managing their condition, including coordinating complex procedures and regimens [6,7]. As with many chronic conditions, management can include performing multiple tasks and developing skills such as remembering to take medications on time, scheduling appointments, tracking symptoms, seeking social support, and managing nutrition and diet [8].

Though diet and nutrition have not been implicated in causing CD, certain foods can trigger an inflammatory flare-up or exacerbate symptoms for those with CD [9,10]. Moreover, individuals with CD have an increased risk of malnutrition and micronutrient deficiencies [11-14], which are contributing factors to disease morbidity [14-16]. While more research is needed, the current scientific and anecdotal evidence is reason enough for individuals with CD to take diet and nutrition seriously. However, there is no consensus on nutritional or dietary guidelines or a standard nutritional assessment method, making diet- and nutrition-based management challenging [17]. Furthermore, there are limited resources for managing a specific dietary regimen at home [18]. One self-management strategy is to identify and eliminate foods that intensify symptoms [17], typically by adopting an elimination diet and food journaling [19]. Adherence to these methods is demanding, due to social pressures to eat at restaurants, stigma associated with food journaling, difficulty entering reliable dietary information, and difficulty maintaining the habit of journaling [19]. Additionally, stress related to managing cumbersome daily activities, including nutrition management, can contribute to the occurrence of CD symptoms [20] and affect social and emotional well-being [21]. Even without the demands of these activities, adopting an elimination diet may not be successful at mitigating CD symptoms, as there is variability within one's own metabolism and microbiome over time [4,22]. Therefore, it is increasingly important to develop personalized approaches to diet and nutrition for individuals with CD [23].

Consumer health information technology (CHIT) could address challenges with diet and nutrition management of CD. However, CHIT developed for diet and nutrition purposes only partially addresses the needs of CD management, as features need to be more nuanced to capture the complexities surrounding diet and nutrition. Although tools have been developed for CD, specifically, and IBD, more generally, the apps do not offer robust features for tracking diet and nutrition. Current popular IBD-related apps (eg, GI [Gastrointestinal] Monitor, GI Buddy, and MyCrohnsAndColitisTeam) offer logging capabilities, trend reports, and community forums. These apps lack an integration of features, including those that monitor behaviors and disease states, track diet and nutrition, facilitate connections with providers, develop social networks, provide psychological tools, and provide accurate medical information. As a result, currently available apps lack features to deliver personalized diet and nutrition guidance, integrate this guidance into the broader context of daily CD management, and adapt management activities across a lifespan [24]. Overall, tools tend to treat diet and nutrition management as isolated from other components of management. For CHIT to be a more meaningful part of diet and nutrition management for individuals with CD, its design must be informed by a deeper understanding of these complexities and interactions.

The shortcomings of CHIT designed for CD management may be viewed through the lens of Corbin and Strauss's [6] theoretical framework of the illness trajectory. In this framework, 3 lines of work are described: (1) illness work (eg, managing medication, scheduling appointments, or tracking symptoms), (2) everyday life work (eg, bathing, eating, or doing laundry), and (3) biographical work (ie, major life events and identity formation). These lines of work often occur in tandem, mutually shape each other, and require coordination known as articulation work [6]. Articulation work is often needed to manage interactions between different tasks [6]; however, CHIT for this condition is often not designed to capture and support interactions between and within the lines of work and, therefore, minimizes the importance of these interactions. Furthermore, CHIT generally supports diet and nutrition management as a generalized, everyday routine, rather than a complex disease management task specific to those living with CD. However, the division between illness work and everyday life work does not necessarily hold for work that has overlapping components such as diet and nutrition management. It is clear that this work is a critical component of illness work, in addition to everyday life work, for individuals living with CD. During times of remission, the overlap between illness and everyday life work may be minimal. However, in times of flare-ups, the overlap could be considerable, with little to no distinction, since every meal requires consideration of the effects it could have on the condition. We refer to patient work [6,25,26] exhibiting these highly overlapping, dual characteristics as biform work. As such, CHIT design for diet and nutrition management for individuals with CD may be understood through the theoretical concepts of biform work and articulation work to explicate and support overlap and interactions, respectively. Therefore, in this study, we aimed to gain a more comprehensive view from a patient perspective of diet and nutrition management through this lens and to provide guidance for how CHIT can be designed to support this work.

Methods

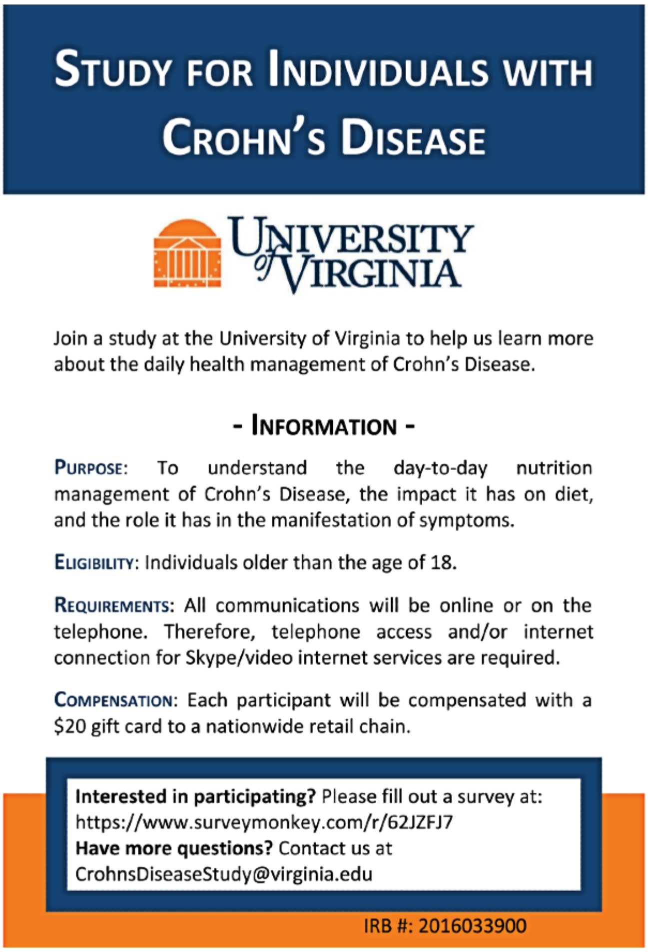
Sample

Eligible participants were over 18 years of age, diagnosed with CD, and US residents. Once eligibility was confirmed, a convenience sampling strategy was used to contact individuals to participate in the study.

Recruitment

Participants were recruited from the online social media platform Facebook [27]. The keyword "Crohn's disease" was used to search for pages and groups that support individuals with CD. Administrators of both public and private groups were contacted prior to posting information about the study. Posts were directly submitted to pages for approval. Administrators from 9 CD groups and 11 CD pages agreed to the request. We also posted on our personal Facebook profiles. These posts contained a flyer that included information about the study purpose, a link to the recruitment survey on Survey Monkey, and compensation information (Figure 1). The recruitment survey contained questions about basic demographic information (ie, age and gender) and contact information. Compensation was a $20 gift card to a nation-wide retail chain. The recruitment survey was closed after 54 responses were received. Respondents who provided valid information and met eligibility criteria were contacted for an interview. If the respondent did not reply within 24 hours, a follow-up message was sent. Those who did not respond after 2 attempts were not contacted again.

Figure 1. Study recruitment flyer.



Study for Individuals with Crohn’s Disease

University of Virginia

Join a study at the University of Virginia to help us learn more about the daily health management of Crohn’s Disease.

\- Information -

Purpose: To understand the day-to-day nutrition management of Crohn’s Disease, the impact it has on diet, and the role it has in the manifestation of symptoms.

Eligibility: Individuals older than the age of 18.

Requirements: All communications will be online or on the telephone. Therefore, telephone access and/or internet connection for Skype/video internet services are required.

Compensation: Each participant will be compensated with a $20 gift card to a nationwide retail chain.

Interested in participating? Please fill out a survey at: https://www.surveymonkey.com/r/62JZFJ7
Have more questions? Contact us at CrohnsDiseaseStudy@virginia.edu

IRB #: 2016033900

Data Collection

Data collection took place from October 2016 to February 2018 in 2 phases. Data saturation [28,29] was reached after the second phase of interviews. Interviews were semistructured, lasted approximately 45 minutes, and took place over the phone or on a video-chat platform. We used an interview guide consisting of 15 questions and additional probes. Topics included diet and nutrition management, how diet and nutrition management relate to other aspects of CD management, and experience with existing management tools. The interview guide was not grounded in a particular framework, in order to gain direct information from participants [30]. An informed consent script was read to all participants at the beginning of the interview, and oral consent was audio recorded. Interviews were audio recorded with permission from the participant. Audio recordings were stored in a secured University of Virginia Box account and were deleted from the initial recording device once uploaded.

Data Analysis

All interview recordings were transcribed. Data were analyzed using QSR NVIVO 11.3, through a conventional content analysis process informed by Hsieh and Shannon [30]. We gained an initial impression of the data and then iteratively drew themes. After analyzing the first 2 transcripts individually, 4 team members determined the preliminary codebook through consensus building [31,32]. The preliminary codebook was reviewed by the senior author (RSV). The next 6 transcripts were divided between the first 3 authors. Then, we came together and decided on the second version of the codebook with input from RSV. The remaining transcripts were analyzed by the first author, and any changes to the codebook were reviewed by RSV. We engaged in simultaneous coding when a participant’s statement was reflective of more than 1 code [31]. This coding framework was used to analyze the remaining data. A final codebook was created to define each theme and subtheme.

Ethics Approval

This study was approved by the University of Virginia Social and Behavioral Sciences institutional review board.

Results

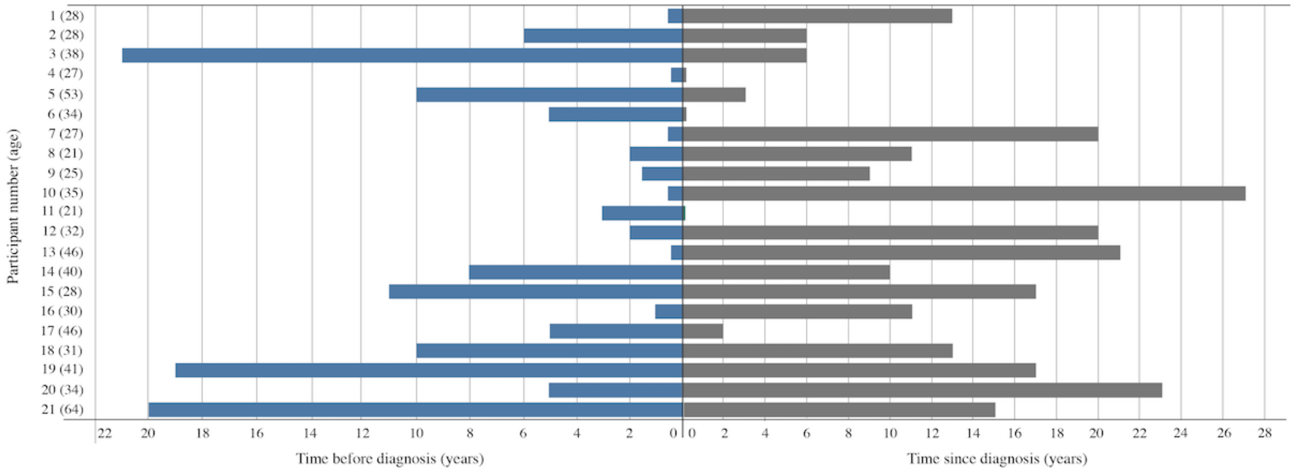
Sample Characteristics

In total, 54 individuals filled out the survey, and, of those, 3 (6%) did not provide sufficient contact information, 27 (50%) did not respond to the follow-up, 3 (6%) were unable to interview due to medical complications, and 21 (39%) were successfully enrolled. Of the 21 participants, 16 (76%) were female, and the average age was 35 years (Table 1). Participants reported living with an official diagnosis of CD for an average of 12 years and felt that they had CD for 6 years, on average, before their official diagnosis (Figure 2).

Table 1. Participant demographic data (N = 21).

Characteristic	Participants, n (%)
Age (years)	
20-29	8 (38)
30-39	7 (33)
40-49	4 (19)
50-59	1 (5)
60-69	1 (5)
Gender	
Male	5 (24)
Female	16 (76)

Figure 2. Participant experience with self-management of Crohn disease.



Themes

Overview of Themes

Qualitative content analysis yielded 4 overarching themes (Table 2). The themes were oriented around diet and nutrition management as biform work and highlight the articulation work required for CD management. The first 3 themes characterize 3 dimensions of diet and nutrition management, while the fourth theme is orthogonal to the first 3, addressing how tools are used for management.

Table 2. Themes and categories identified based on interview analysis.

Theme and subthemes	Definition
Physical management	Relationship between diet and nutrition and symptoms of CD[a]
Management of medication	Relationship between diet and nutrition and prescription drugs
Management of remission	Relationship between diet and nutrition and periods with reduced symptoms
Management of flare-ups	Relationship between diet and nutrition and periods of increased symptoms
Emotional management	Relationship between diet and nutrition and the psychological aspects of living with CD
Management of social relationships	Relationship between diet and nutrition and forming and maintaining connections with people
Management of routines	Relationship between diet and nutrition and daily tasks
Management of stress	Relationship between diet and nutrition and experiences of mental and emotional strain
Information management	Relationship between diet and nutrition and information gathering
Management of information from health care professionals	Experiences with seeking and obtaining advice about diet and nutrition from trained providers
Management of information from text sources	Experiences with seeking and obtaining advice about diet and nutrition from books, websites, and other written materials
Management of information from social networks	Experiences with seeking and obtaining advice about diet and nutrition from online and offline connections
Technology-enabled management	Experience using CD management tools for diet and nutrition
Management experiences using existing tools	Experiences with using technologies to facilitate activities related to diet and nutrition
Management needs not met by existing tools	Experiences with lack of usefulness and usability of available technologies related to diet and nutrition

[a] CD: Crohn disease.

Theme 1: Physical Management

Participants discussed the following components of physical management: (1) management of medication, (2) remission, and (3) flare-ups.

Management of Medication

Some participants indicated that CD medications positively impact the need for dietary management:

> *I would say that [the medication] was so good…[that diet] was more of a minor fact that I would forget—not forget that I had a disease, but [I] would live my life more normally.* [Participant #7]

In other cases, the participants expressed combining medications and dietary management to control and limit flare-ups:

> *I am on Remicade, and I believe that a diet is very important, and what you eat can try to treat it from the natural side.* [Participant #8]

One participant with an ostomy bag had trouble with absorbing medications after eating:

> *[A]bout an hour after I eat, I'm passing whatever through the ostomy—...medication, pills...* [Participant #12]

Management of Remission

When in remission, participants mentioned some consistencies in the foods they tolerate. Participants that committed a restricted diet to memory took several years to develop their diet through trial-and-error processes using food journaling. Many participants did not plan meals and primarily cooked meals at home to control ingredients used. Often, each individual discussed a lack of variation in their diet:

> *I lead a pretty boring life. I pretty much eat the same thing for breakfast, same thing for lunch. I don't vary my dinners all that much.* [Participant #13]

Even with a fixed diet, participants experienced inconsistencies in the foods they could eat:

> *[Spinach] is fine one day. Then, 2 days later, if I were to eat the same amount of spinach, it's like, "Oh, holy hell," my bag [is] blown off. There's green everywhere, and it's just a nightmare.* [Participant #10]

Management of Flare-ups

Management activities during remission periods were variable across participants but were more consistent across participants during flare-ups. All participants identified certain foods that tend to cause gastrointestinal distress and increase the risk of a flare-up. The exact type of food varied across participants and for each individual over time. All individuals talked about changing their diet during a flare-up. The majority of participants mentioned eating easily digestible foods such as broths when flare-ups were particularly bad and caused concerns about fluid loss:

> *Is it gonna be [a flare-up] that runs off of bone broth and crackers, or is it gonna be a full "can't eat*

> *anything and I'm gonna get dehydrated"[one]?* [Participant #19]

Theme 2: Emotional Management

Participants identified multiple dimensions of managing the psychological aspects of living with CD, including management of social relationships, routines, and stress.

Management of Social Relationships

Many participants expressed that their unique dietary requirements prevented them from engaging in social activities. An inability to engage in social activities often strained relationships:

> *When it is bad,…I can't leave the house, I can't make plans, I've lost friendships with people.* [Participant #3]

As food is often an integral part of social activities, participants shared feelings of stigmatization when they declined invitations:

> *The view that I get is probably like, "Oh, she's snobby. She doesn't wanna come out to eat." I feel that's the stigma they put on me...* [Participant #34]

If participants did dine out as a social activity, they experienced feelings of sadness in recognizing the foods they can no longer eat. In one case, a participant noted the effect this feeling had on a relationship:

> *[W]hen I look at a menu, it's like, "Oh, I can't have that. I can't have that." It's not a great way of making the other person happy to be around you when you're depressed that you can't eat cheese.* [Participant #18]

Management of Routines

Since diet and nutritional management of CD is highly individualized, several participants felt frustrated with using trial-and-error methods to devise routines to follow. Food and eating were sources of tension for participants in their management routines:

> *I could probably say I am afraid of [food]. It sounds really weird…that you are so afraid of food.* [Participant #5]

When there were deviations in routine, participants experienced increased difficulties with managing diet and nutrition:

> *Trying to travel with a diet is very difficult...Everything's set around food...You go to the kid's functions, you go to [visit] other family—anything—everything's food oriented.* [Participant #17]

Some participants discussed the financial strains of incorporating diet and nutrition into their routines:

> *I don't want [my family] to have to go out of [their] way to pay more for food, just so that I can possibly eat it.* [Participant #11]

Management of Stress

Participants stated that increased stress from everyday life exacerbated their symptoms and, in turn, affected their diet and nutrition:

> *[S]tress is a major trigger with this disease...If it's emotional, if it's traumatic, if it's work related, the stress will affect the disease.* [Participant #19]

In one case, the uncertain nature of diet and nutrition as well as of the disease in general was a source of daily stress:

> *I guess just not knowing when the symptoms are gonna pop up—it's very difficult when you're dating or at school or working...Stress definitely triggers it and makes me sicker.* [Participant #18]

To manage the stress levels and the mental health impacts of CD, several participants sought professional assistance:

> *I'm in therapy...I've always had chronic depression because of the Crohn's. We go over stress levels and all that stuff.* [Participant #12]

Theme 3: Information Management

Participants reported gathering information from health care professionals, text sources, and social networks.

Management of Information from Health Care Professionals

There was a consensus among participants that it is rare to gather useful information about diet and nutrition management of CD from health care professionals. One participant noted about a physician:

> *The doctor has never even said anything [about nutritional needs]. That would be another very helpful thing for people with CD to find the right food to help their body.* [Participant #5]

Moreover, some participants were frustrated with the advice given by dieticians, as it was often not CD-specific:

> *I spoke with a dietician a few years ago, and they literally quoted the [Food and Drug Administration] guidelines. I'm looking at them, [and I'm] like, "I have Crohn's. I thought you were a dietician for Crohn's."* [Participant #17]

Management of Information From Text Sources

Most participants cited gathering information from internet searches as well as professional and nonprofessional websites:

> *[I] did a lot of internet researches. There's the Crohn's & Colitis Foundation that I've got a lot of information on.* [Participant #16]

Though the internet was the most frequented for information, some participants favored books for diet and nutrition information:

> *I love books, so I will pick the library first, over the internet.* [Participant #19]

Management of Information from Social Networks

Though participants received and sought information from health care providers and text sources, they discussed information from social networks more at length. Participants noted using anecdotal information from online and offline social network members to identify foods that may or may not contribute to the risk of a flare-up. For instance, a participant explained:

> *I'm [in] a support group on Facebook and a lot of [them] say, "I don't eat leafy greens, so I couldn't tell you what they do to me." That's what everybody says.* [Participant #14]

Participants tended to glean information and support from family members and close friends in their social network. In several cases, family members were involved in managing diet-based decisions, because they had CD, were respected by the participant, or were professionally trained in nutrition. However, they were not the participant's formal health care provider:

> *My dad, he also has Crohn's as well as my brother, who also has Crohn's...[W]e can all relate to the issue that we're experiencing.* [Participant #18]

Information about recipes, meal planning, and living with a restricted diet was also found by participants on social media:

> *I use Instagram a lot, because a lot of people post things there, especially, recipes or ideas or things that work for them, kind of similar to the forums we talked about earlier.* [Participant #3]

Social media activity varied among participants, where some were active in posting and others preferred to only read the posts in pages and groups.

Theme 4: Technology-Enabled Management

Participants reported using various tools for CD management and described their experiences using these tools, critiquing aspects that were not useful and noting limitations in usability.

Management Experience Using Existing Tools

Participants expressed a range of perspectives on available tools. A few participants identified benefits of food diaries immediately after a diagnosis of CD to help figure out an initial effective diet. One noted that:

> *For 7 or 8 months, I kept a food journal with any symptoms I might be having...[T]hat really helped me know what I can and can't eat.* [Participant #2]

Other participants found food diaries time consuming, difficult to keep up with, and, often, hard to gather valuable information from, due to the inconsistent nature of diet and nutrition:

> *I tried to [track my diet], but I am really bad about that. Even keeping track of that, you still don't know, because you could eat something and you feel fine with it. And, next time you eat it, you feel terrible.* [Participant #1]

Although there are tools available for tracking diet and nutritional content, participants reported not using these tools for prolonged periods due to their limitations. One limitation noted by participants was that these available tools were not designed for CD management and, thus, were not perceived as useful:

> *I probably would [use a tool] if I had something that I liked. And, trust me, if there was something out there that I thought was amazing, I would have found it.* [Participant #3]

Participants tried using a range of apps such as FitBit, MyFitnessPal, and MyPlate; however, one participant noted:

> *[I found myself] going back to pencil and paper and writing things down.* [Participant #21]

This was because of difficulties navigating app interfaces. Overall, participants reported a lack of usefulness and usability of currently available technology designed to track diet and nutrition.

Management Needs Not Met by Existing Tools

The cohort interviewed had limited prolonged engagement with CHIT, due, in part, to the lack of CD-specific tools available. However, participants wanted to engage more with CHIT, and they discussed features that integrate various aspects of illness and everyday life work. First, several participants stated that a tool to improve locating and accessing bathrooms would be helpful, particularly, during flare-ups:

> *I think [it would be helpful] if somebody were to develop an app with the technology...[that] would tell you what gas stations or what stores are nearby...[and] have a public restroom...and how accessible are those bathrooms—a single stall, or is it a multi-stall?* [Participant #10]

Notably, many of the participants voiced a desire to have better connections with other individuals with CD in their local area:

> *I actually have been seeking out these support groups. Some Facebook group that I'm on for Crohn's, they give out a roll call, trying to find out where everyone is living...Someone just connected me with—to an in-person support group—...I will likely end up joining that.* [Participant #18]

Participants were interested in automated features and tracking trends related to behavioral factors such as diet and nutrition and disease states:

> *A statistical analysis to find out how am I doing—[a]n app—would be great, or, a beautiful spreadsheet just [for] trends, that would be great.* [Participant #19]

Participants expressed a desire for integrated app features or the ability to synchronize data from multiple apps:

> *It looks like [recent apps designed for individuals with IBD] track food—...I didn't really wanna separate [the functions]. That way, if I wanted to look back, it wouldn't be in 2 places. I've already got My Plate activated with my food for my history now.* [Participant #17]

More specifically, a few participants stated that they would appreciate connections to health care providers:

> *I think it would be really great if my doctor was connected to [an app], somehow—[if] the information got sent over,...so they had access to how I'm [doing]...* [Participant #20]

Discussion

Principal Results

Qualitative content analysis revealed 4 themes: physical, emotional, informational, and technology-enabled management. Across participants, diet and nutrition management was an integral part of both illness and everyday life work. However, the extent to which diet and nutrition management could be considered as biform work varied, not only by participant but also over time. Participants usually attempted to manage their diet during remission to prevent flare-ups. For some participants, the use of medication reduced—or, in some cases, eliminated—the need to manage diet and nutrition as illness work. Illness work was also reduced via relying on a consistent diet. During flare-ups, the need for diet and nutrition management as illness work was imperative, as each participant reported maintaining a list of "safe foods" that they rely on. Participants discussed the centrality of stress in CD management, as it tended to exacerbate symptoms, in turn, causing an increased need to manage diet and nutrition as illness work. For many participants, stress stemmed from frustrations with their limited diets and subsequent difficulties developing and maintaining social relationships. As information from professionals was often insufficient, participants relied mainly on social networks to learn about the dietary aspects of CD management. Obtaining and seeking information about diet and nutrition management was often illness work, as participants typically used this information to avoid or ease disease symptoms. Lastly, statements about articulation work were pervasive throughout the interviews. Tasks such as taking medication and eating needed to be coordinated to avoid adverse outcomes. In other cases, tasks were inextricably linked, such as managing stress along with diet and nutrition. For some participants, stress was caused by the diet-restrictive nature of CD, in turn, affecting disease severity and subsequently increasing the need to manage diet and nutrition.

Participants identified the need for complex and integrated functionalities for CHIT to support diet and nutrition management, as there are varying degrees of overlap between illness and everyday life work. Coordination is also required between and within lines of work. The need to manage diet and nutrition as illness work fluctuated over time for participants; however, CHIT rarely responded to oscillations in times of remission and flare-ups, as participants predominantly noted these using general apps designed to track physical activity and calorie expenditures. Moreover, available tools did not support information management as illness work, since participants sought information about diet and nutrition mostly from social networks. For those that used management tools, many reported paper-based food journaling as cumbersome illness work. Additionally, a majority experienced limitations related to usefulness and usability in available tools to meet these needs. Altogether, participants desired features that are more responsive to the realities of living with CD and the interconnected nature of this condition. These desired features included automated diet and nutrition tracking, facilitated social connections, a public restroom finder, analytics, information-sharing with health care professionals, and integration with other apps that are already part of their daily workflow.

Elaboration on Theoretical Concepts

Even though we initially proposed the concept of biform work, the results from this study show that this concept is not necessarily fixed with regard to diet and nutrition management for people living with CD. There were instances where this type of management was both illness and everyday life work and also instances where it largely became everyday life work. Even if diet and nutrition management existed in a state of everyday life work, psychological factors often could trigger a flare-up for participants and, consequently, increase the illness work–related characteristics. Though not the focus of this study, there may be an opportunity to explore these psychological factors more deeply, as diet and nutrition management could also be a component of biographical work. Thus, this type of management could exist as multiform work, meaning that there could be overlap between everyday life, illness, and biographical work. The concept of diet and nutrition management as multiform work could be meaningful in other conditions such as obesity and anorexia. In such conditions, the need to manage diet and nutrition can be illness and everyday life work, in addition to biographical work, as relationships with food can contribute to self-identity [33-36]. By examining when and how diet and nutrition management can exist as multiple lines of work, a more holistic perspective can be elucidated, and, as a result, interventions can be developed to be more responsive to the multifaceted realities of diet and nutrition management of many chronic conditions.

Since the extent to which diet and nutrition management existed as biform work varied among the participants and over time, the reported need for articulation work between and among other management tasks varied as well. Articulation work was needed for task coordination, aligning with the original conceptualization of this type of work [6]. The understanding of articulation work in the context of chronic disease management has generally remained the same, focusing on organizing, delegating, scheduling, and regimenting consistent tasks [37-41]. However, for the participants in this study, articulation work was not so linear, as management needs typically were in flux and could change instantaneously. Also, management tasks, in some cases, mutually shaped each other and, by their nature, could not be regimented. For example, stress from daily life events triggered increases in symptoms and subsequent increases in management tasks. This kind of stress can be unpredictable and, for example, could stem from an impromptu invitation to a social gathering. As such, there is a need to expand on the understanding of articulation work, so that interventions can better attend to the interconnected nature of diet and nutrition management and other management tasks.

Comparison With Previous Literature and Implications for Design

Interactions between the first 3 themes yielded several insights into how future patient-facing technologies can be developed to support diet and nutrition management as biform work, when needed, and facilitate articulation work. The fourth theme informs potential features and functionalities of these technologies.

The first theme demonstrated the articulation work needed to manage diet and nutrition and medication. The interconnected nature of these factors is supported by the scientific evidence, as both food and medications have been shown to affect the composition of the gut microbiome [42,43] and, thus, inflammation in the intestine [44]. As early research demonstrates the individualized and variable nature of diet and nutrition's association with CD [42], general dietary guidelines may not be appropriate, and individualized guidance may need to be developed. Currently, CHIT designed specifically for CD does not support this type of articulation work, as the majority of tools do not make connections between medication and food intake [45,46]. To assist with this work, technology that leverages pattern detection through machine learning [47] could be designed to facilitate the identification of individualized diet and nutrition guidance by capturing and coordinating food and medication intake and monitoring symptoms. Although several participants discussed the difficulties of food journaling, others found that smartphone barcode scanning features, such as the one in the MyFitnessPal app [48], made it easier to track food intake. Moreover, the addition of nutrient content information in food databases within an app could help to mitigate malnutrition by tracking both macronutrients and micronutrients, which has shown to be important in CD management [14,49]. This capability is not readily available in the MyFitnessPal app [11] or other apps with barcode scanning functionality. Incorporating these features into technology could address barriers in capturing food intake [19]. Additionally, machine learning at both the individual and aggregate level could be used to identify both safe and irritating foods and automate meal planning by identifying acceptable ingredients and substitutions, reducing the work required and increasing the utility of technology that facilitates food journaling [9,10]. Lastly, customized features that adapt to individual needs over time could support the fluctuations in diet and nutrition management as biform work. For example, if medication has eliminated the need for an individual to manage diet and nutrition as illness work, a user could then hide the food journaling feature and rely on the symptom tracker to reopen this feature if a flare-up is imminent.

The second theme shows that for the participants in this study, psychological factors also had an effect on the extent to which diet and nutrition needed to be managed as biform work. Participants described how diet and nutrition can affect social well-being and mental health, in turn, affecting disease states and requiring more articulation work. This finding supports the evidence that individuals with food restrictions have reduced social and emotional well-being [21], experience increased levels of stress and anxiety [50], and experience stress that, in turn, affects disease severity [20]. Moreover, this study provides further evidence that the processes of diet and nutrition management, not only disease severity and illness perceptions, are a source of stress [51]. Though a few apps designed to support diet and nutrition management for individuals with CD allow for mood tracking [45,46], these features are still nascent and neither include capabilities to track social engagements nor are adaptive to the extent to which these factors exist as biform work. Patient-facing technology could assist in monitoring and reducing stress and promoting social well-being by supporting biform work when needed and elucidating interactions among diet and nutrition, social engagement, and stress. Mobile sensing can identify increased stress levels [52,53] to facilitate activities [54] such as providing meditation guidance or prompting a connection to a health care provider [55]. By monitoring stress levels, these data can be analyzed along with diet and nutrition, medication, and symptom data. Machine learning could be applied to explore the relationships between these factors to further refine a food irritant profile and identify patterns in flare-ups. This profile could be used to identify restaurants and specific menu items that align with a user's restrictions, which could reduce the psychological burdens participants expressed they experience when attending social activities. Additionally, these data can be synthesized with location and calendar data, which could help to predict stressful events based on past data related to daily activities and stress. Location and calendar data could also be cross-referenced with data available on public restrooms [56], to automatically have a restroom option available to the user, reducing stress in urgent situations. As some apps have started to integrate behavioral insights [46], these features could be expanded by using predictive analytics to identify when flare-ups are about to occur and provide recommendations for foods that are least likely to initiate or exacerbate a flare-up and preemptively suggest users cancel activities. By tracking a wide range of contextual factors beyond food intake, there is an opportunity to explore why participants experienced inconsistencies with fixed diets. Though there are apps that are providing support to track a broad range of variables, these apps aim to provide data to health care providers to improve clinical care, rather than to support individuals with CD in performing biform and articulation work [46].

As discussed in the third theme, participants sought and obtained diet and nutrition information from health care providers, text sources, and social networks. Similar to this study, one study documented that individuals with IBD wanted to know more about dietary management to reduce flare-ups and noted limitations in dietary advice offered by health care providers [57]. Additionally, seeking health information on social media is increasing in prevalence [58,59]. Available apps offer a range of education materials, and some allow connections to health care providers [60-62]. A few apps offer social networking functions [45,46], which increases the articulation work needed to find and integrate information into disease management strategies. To limit articulation work, technology could help promote online relationships among individuals with CD by suggesting connections based on similar food profiles to share recipes and general diet and nutrition information. Furthermore, those who have similar types of daily routines could be connected to share diet and nutrition management techniques to reduce the illness component of biform work. Additionally, features that connect individuals to health care providers could be expanded to facilitate appointment reminders and scheduling, to promote clinical management, as this has been shown to be a key component of long-term management of CD [63,64]. The collection and sharing of the patient-generated health data with providers could also support clinical care of patients with CD

[65-68]. Lastly, the aggregation of these data across users, such as those in the IBD Partners research network [69], can be used to collect the amount of data needed to develop personal nutrition guidance through machine learning [70], deliver precision medicine [71-73], and promote citizen-science in health care [74]. However, it is important to note that there are uncertainties surrounding the amount and variety of data required to build and validate predictive models, as studies range from using the n of 1 study design [75] to including hundreds [76] or thousands of participants [77].

Limitations

Although this study provided several insights about diet and nutrition management for CD, it also had a few limitations. Since we asked participants to describe CD management over time, the data could be subject to recall bias. However, the participants were not asked to recount certain details about events but, rather, asked to reflect on the most salient points of diet and nutrition management and their overall experience with CD. By recruiting on social media, the sample inherently was comfortable using technology, and, thus, this study did not allow for an understanding of the needs of those with limited technology experience. However, use of this sampling strategy could be beneficial, as the participants could identify challenges with the technology that did not necessarily stem from general inexperience or discomfort using technology. Additionally, apps that partially address some of the needs identified may have been developed since the study was conducted. However, our discussion section acknowledges these apps when they are relevant to a need that was articulated by participants. Lastly, the CHIT guidance provided centers around tracking symptoms to improve outcomes. It has been shown that monitoring biomarkers may be a more effective indicator of disease progression than tracking symptoms alone [64]. Nonetheless, symptom management is an important part of an integrated approach for managing CD and has been shown to be effective in improving the quality of life for individuals with CD [78-80].

Conclusions and Future Directions

Our interviews with individuals with CD reflected 4 main themes, illustrating the fluctuating biform nature of diet and nutrition management as well as the continuous and, in some cases, spontaneous articulation work needed to manage complex interactions between diet and nutrition and other aspects of life with CD. The participants in this study experienced numerous challenges with diet and nutrition management and use of existing technologies to support management activities. Future work should focus on other chronic conditions that require diet and nutrition management to supplement the understanding of biform work, explore the concept of multiform work, and expand on the definition of articulation work. Methods such as journaling could help to capture the nuances and complexities of daily diet and nutrition management. This study also provided descriptive and prescriptive design guidance [81] for CHIT designed to support the holistic and variable experience of diet and nutrition management for individuals with CD. Subsequent research should focus on using this guidance as a foundation for original designs or to redesign technologies for this purpose. Refinement of the proposed design guidance through an iterative participatory design process is essential for the development of interventions that will benefit individuals with CD and promote long-term engagement [82].

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Conflicts of Interest

None declared.

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Abbreviations

CD: Crohn disease
CHIT: consumer health information technology
IBD: inflammatory bowel disease

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Original Paper

Implications of Age on Social Media Utilization in Health Care Practice Development: Cross-sectional Survey Study

Harrison Marsh[1], MBA; Mhd Hasan Almekdash[1], MA, MS, PhD; Stephen Rossettie[1], MBA; Albin John[1], MBA; Kassie Pelham[1,2], MS; Brent Magers[1,2], MHA, FACHE, FHFMA

[1]Texas Tech University Health Sciences Center, Lubbock, TX, United States

[2]Texas Tech Physicians Group, Lubbock, TX, United States

Corresponding Author:
Harrison Marsh, MBA
Texas Tech University Health Sciences Center
3601 Fourth Street Stop 6238
Lubbock, TX, 79430
United States
Phone: 1 713 304 1033
Email: harrison.marsh@ttuhsc.edu

Abstract

Background: Medical practices, which are businesses through which one or more physicians treat patients, have likely not yet taken full advantage of the reach of social media. This study analyzed data collected using an anonymous survey to assess the potential utilization of large, established social media platforms in health care. The survey collected data from a diverse population of health care professional students, faculty, and physicians affiliated with the Texas Tech University Health Sciences Center (TTUHSC). This study provides significant, actionable data to more efficiently implement a social media strategy focused on age to help developing private practices and outpatient clinics from the perspective of those with experience in the field of medicine.

Objective: This cross-sectional, exploratory, descriptive study aims to explore the most effective strategies to use social media based on patient age to bring further success to a medical practice.

Methods: Data were gathered from an anonymous, peer-validated Qualtrics survey created by the corresponding authors based on the recommendations from a panel of experts including executive leadership at TTUHSC. The survey used a variety of question styles to measure differences between social media platforms, including frequency of use, current and future implications in medicine, and comfort in a health care setting. The sample population included students, interns, faculty, and physicians affiliated with the TTUHSC located throughout West Texas.

Results: The anonymous survey included 673 individuals from several different age groups predetermined at the beginning of the study. There were 154 respondents aged between 18 and 25 years, 171 aged between 26 and 35 years, 133 aged between 36 and 45 years, 104 aged between 46 and 55 years, and 111 aged between 56 and 89 years. The sample population also has a variety of educational achievements. The respondents were grouped based on the highest level of education attained, and this included 23.5% (n=158) of respondents who earned a high school diploma, 42% (n=283) who earned a bachelor’s degree, 17.1% (n=115) who earned a master’s degree, and 17.4% (n=117) who earned a doctorate degree.

Conclusions: As social media continues to gain momentum, efficient utilization of the available platforms can help medical practices achieve larger patient populations and deliver more personalized care. However, privacy and security concerns should be considered while using social media in health care settings. Although this study demonstrated overwhelming interest in using social media in the medical field across all age groups, adoption willingness appears to be higher in younger respondents than in older respondents. Facebook was the most widely accepted social media platform in health care settings among all age groups. Nonetheless, other social media platforms could potentially be used more effectively depending on the age range of the targeted patient population.

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KEYWORDS

social media; health care; age; medical practice development; patient acquisition; health care delivery; patient education; target patient population

Introduction

Background

Nearly half of the world's population now uses social media (approximately 3.5 billion). According to the Pew Research Center, in 2005, only 5% of American adults used at least one of these platforms. However, by 2011, that share had risen to 50% of all Americans, and in 2019, 72% of Americans reported using one of the social media platforms [1]. Considering the rapid growth and vast use, there is no doubt that social media can be used to bring further success to the medical field. The difficulty is how to best optimize this tool among varying patient populations [2,3]. Several medical institutions and private practices now broadcast recurring podcasts, YouTube videos, and other forms of social media [4]. For example, in 2019, the Texas Tech Physicians implemented paid Facebook advertising targeting current and prospective patients in West Texas to attract interest to the physicians and improve general health care screening in the area. This initiative drove a growth of over 500% in their web-based following. However, two obstacles prevent the consistent optimization of these tools. First, the direct and indirect benefits of social media are yet to be measured. Second, the best methods to capitalize on social media for new or growing medical practices are yet to be completely explored. Having seen the success of social media use in already-established groups such as Texas Tech Physicians, it is very likely that physicians interested in attempting to open a new private medical practice would also benefit from social media implementation to establish a good reputation, especially during the early stages of the practice [5]. The information and conclusions gathered from this research could greatly benefit anyone trying to improve the patient acquisition, patient satisfaction, or overall health care delivery of a medical practice [6].

Several direct benefits of using social media in health care have been identified, including increased interactions with patients, increased information accessibility, further tailored information, improved peer, social, and emotional support, increased public health surveillance, and greater potential to influence health policy [7,8]. With the rapid development and improvement of social media platforms, these benefits are only the beginning of the potential improvements that could be made through social media utilization [9]. The questions that remain are as follows: what forms of social media would lead to the greatest success, what percentage of patients from different backgrounds would social media utilization likely benefit, and what indirect benefits could arise from proper utilization of these platforms.

Objectives

Some of the challenges of social media utilization in medical practice have already been identified as quality, reliability, confidentiality, and privacy concerns [7,10,11]. However, social media has made improvements in these areas of concern such that the current benefits may outweigh the risks [12]. Although these apprehensions with social media utilization should still be addressed in further studies, this study will focus more on the opportunities of efficient social media use in the health care setting by focusing on differences in social media utilization and preference based on age.

Methods

Study Design and Sample

This was a cross-sectional survey design, exploratory, and descriptive investigation. The Institutional Review Boards at Lubbock and Odessa approved this protocol and waived the requirement for informed consent.

The possible benefits of social media utilization were measured through data gathered from an anonymous survey evaluating different perspectives of faculty, staff, and students of all backgrounds, ages, and education levels affiliated with the Texas Tech University Health Sciences Center (TTUHSC). Thus, information such as health care discipline and campus location were not captured. The total number of complete responses analyzed was 673. These participants' perspectives are particularly valuable, as all of those who took the survey had significant exposure to how health care systems function through their diverse experiences with TTUHSC. The TTUHSC includes the School of Medicine, School of Nursing, School of Health Professions, and School of Pharmacy spread across campuses in Lubbock, Amarillo, Dallas, El Paso, Midland, and Odessa. However, no participants outside the TTUHSC system or under the age of 18 years were included in this study. The survey measured overall social media utilization among different age groups, occupations, and education levels, along with interest in social media directed toward health care. The survey also assessed what forms of social media use would be most beneficial in facilitating the success and growth of a developing medical practice. The data collected works in conjunction with an extensive review of published literature to show the demand for social media utilization in health care, while providing a perspective from a unique population of health care faculty and students affiliated with health sciences centers in West Texas.

Respondents had 2 weeks to respond to the survey. The survey included 12 questions in a variety of formats that took 3 to 5 minutes to complete. The survey was distributed by email to an automatically generated, random list of approximately 5000 people affiliated with each TTUHSC campus. This survey was conducted by self-selection (to limit bias, respondents did not know the topic of the survey until after beginning it) and was optional, so no follow-up was carried out.

The population was chosen based on a unique and potentially valuable perspective on how social media can be implemented successfully in a health care setting from those who have had experience in the field. These data were then analyzed by age to gain insight into how opinions on social media changed based on different levels of experience in their health care careers as well as different stages of life. The value of our data is focused on providing a more focused analysis of data based on those with experience in the health care field. We hope this additional insight will provide benefits to those attempting to implement or improve social media utilization to contribute to the development of their health care practice.

Measures and Data Collection

The survey assesses social media use in general as well as the current and prospective implications of social media use in health care across different platform options. The social media platforms assessed were Facebook, Instagram, Twitter, LinkedIn, and YouTube. Differences in use across social media platforms were measured by requiring respondents to choose from six options assessing use frequency. The options included *I do not use this platform*, *I use this platform monthly*, *I use this platform weekly*, *I use this platform daily*, *I use this platform hourly*, or *I use this platform more than once per day*. These responses were scaled from 0 to 5 and are presented in Table 1. The comfort level of respondents with different social media platforms being used in a health care setting was measured through comparison by asking respondents to rank the different social media platforms from most comfortable to least comfortable with each platform being used in health care. The responses were scaled from 1 to 7 and are presented in Table 2. In addition, a variety of subjective questions were included to better understand the amount of social media use and the preference of such use among respondents in a health care setting. Respondents were also asked about concerns that they may have with integrating social media into their health care experience. All collected responses were assessed in groups defined by age.

Responses were defined by age prospectively, using the internal TTUHSC data. Age ranges were based on stages of life or career: 18 to 25 years, students; 26 to 35 years, interns or early career; 36 to 45 years, rapid career advancement; 46 to 55 years, peak career attainment; and 56 to 65+ years, career maturity. Ages over 65 years were included as anyone with an active TTUHSC email would not yet be retired and continuing in the same career stage.

Age often helps distinguish patient populations of different health care practices (ie, pediatrics vs geriatrics). Aging is also a well-established risk factor for the development of multiple chronic diseases, including cardiovascular disease, stroke, cancer, osteoarthritis, and dementia [13]. Other variables, such as occupation and education, require nuanced social media strategies that are less advantageous than a strategy tailored to age groups. However, occupational and educational data-based social media strategies may benefit from further studies.

Table 1. Social media platform use (rated using a 0-5 scale, where 0 indicates “I do not use social media” and 5 indicates “I use the platform hourly or more than 12 times a day”) by age groups.

Social media platform	18-25 years, median (IQR)	26-35 years, median (IQR)	36-45 years, median (IQR)	46-55 years, median (IQR)	56-89 years, median (IQR)	*P* value[a]
Facebook	2 (2-3)	2 (2-3)	2 (2-2)	2 (2-3)	2 (1-3)	.06
Instagram	2 (1-2)	2 (1-3)	2 (0-4)	2 (0-3)	0 (0-3)	<.001
Twitter	1.5 (0-2)	0 (0-1)	0 (0-2)	0 (0-4)	0 (0-0.25)	<.001
LinkedIn	0 (0-5)	0 (0-5)	2 (0-5)	3 (0-5)	2 (0-5)	.12
YouTube	3 (2-4.25)	3 (2-4)	4 (2-4)	4 (2-4)	4 (2-5)	.61

[a] All *P* values were obtained from the independent samples Kruskal-Wallis test.

Table 2. Social media platforms that the participants are most comfortable using (ranked from 1-7, where 1 indicates the least comfortable using and 7 indicates the most comfortable using) in a health care setting by age groups.

Social media platform	18-25 years, median (IQR)	26-35 years, median (IQR)	36-45 years, median (IQR)	46-55 years, median (IQR)	56-89 years, median (IQR)	*P* value[a]
Facebook	6 (5-7)	6 (5-7)	7 (5-7)	6 (5-7)	6 (4-7)	.47
Instagram	5 (4-6)	5 (4-6)	5 (4-6)	5 (4-6)	4 (3-6)	<.001
Twitter	4 (3-5)	4 (3-5)	4 (3-5)	4 (2.5-5)	3.5 (2-4.75)	.02
LinkedIn	3 (3-5)	4 (3-5)	4 (3-5)	4 (3-6)	4.5 (3-6)	.009
YouTube	5 (4-6)	5 (4-6)	5 (3-6)	5 (3.5-6)	5 (3.25-6)	.02

[a] All *P* values were obtained from the independent samples Kruskal-Wallis test.

Data Analysis

The data were summarized using descriptive statistics such as median (IQR) and frequency (percentage) as appropriate, depending on the level of measurement of the examined variables. A chi-square test was conducted to determine statistically significant differences in categorical variables across different age groups. The Kruskal-Wallis H test was conducted to determine the statistically significant differences in ordinal level variables across different age categories. The Dunn post hoc test adjusted with Bonferroni correction was performed for pairwise comparisons. As the Kruskal-Wallis H test compares mean ranks among groups on the examined variables, the mean ranks of groups that showed statistically significant differences were reported in addition to the medians and IQRs. Statistical significance was set at $P<.05$. All analyses were performed using the IBM SPSS software, version 25.

Results

General Study Population Results

A total of 5000 surveys were distributed, and there were a total of 811 responses. Due to some incomplete responses, the total usable responses were 13.46% (673/5000). Data show that 72.7% (489/673) of the sample population had concerns with social media use in health care due to lack of privacy or communication security, whereas only 4% (27/673) showed no concerns at all.

Results of Categorical Variables Across Age Groups

Table 3 summarizes our findings from four of the most telling questions that were asked in our survey. The first of these research questions (Q8) was used to assess the current influence of health care professionals on social media by asking respondents whether they had ever followed a professional social media account of an independent physician or medical practice. Across all respondents, 48.4% (326/673) answered “yes,” 12.8% (86/673) answered “no, but I would like to if that was an option,” leaving only 38.8% (261/673) of respondents who had never intended to follow a health care professional. There was a statistically significant association between age groups and the above response ($\chi^2_8=82.6$; $P<.001$; Table 3). This difference between age groups was most apparent in respondents aged 56-89 years, of which the majority (81/111, 73%) indicated that they would generally not follow a professional social media account of an independent physician or medical practice.

The next research question (Q10) was used to gauge the utility of a doctor with an updated LinkedIn account to share his or her achievements and educational or professional history. A total of 76.4% (514/673) of respondents indicated that they would find it beneficial if their physician had a public LinkedIn account. However, as in the first question, chi-square tests of the respondents’ answers were significantly different by age ($\chi^2_8=40.2$; $P<.001$; Table 3).

The following question (Q11) was used to garner patient interest in following or using social media for personal medical use, such as scheduling appointments. Three responses were included, as shown in Table 3, with responses differing by the degree of interest shown in using social media for this purpose. In total, 56.3% (379/673) of respondents said that they would follow a social media page that allows them to schedule appointments and contact their nurse or doctor directly to ask questions. However, only 43.7% (294/673) of respondents preferred this over a traditional web page. As with the previous research questions, these responses also differed significantly by age ($\chi^2_8=19.8$; $P=.01$). Respondents aged 56-89 years were significantly different when compared with all other ages, with 59.5% (66/111) of them indicating that they would not even follow the page (Table 3).

The final question shown in Table 3 (Q12) was used to assess the degree to which social media could be used to improve the likelihood of patients scheduling recommended screening tests. The responses, based on four selections ranging from no benefit to large improvement, showed that 46.8% (315/673) of the survey population would be more likely to schedule critical screening tests after seeing an educational social media post that provides links that would allow them to schedule an appointment. As with the other questions, however, chi-square analysis ($\chi^2_8=50.1$; $P<.001$) revealed that these responses varied significantly by age. The likelihood decreased with increasing age of the sample population. Only 24.3% (27/111) of those aged over 55 years were more likely to schedule an appointment.

Table 3. Differences in categorical variables across categories of age groups.

Survey questions	18-25 years (n=154), n (%)	26-35 years (n=171), n (%)	36-45 years (n=133), n (%)	46-55 years (n=104), n (%)	56-89 years (n=111), n (%)	*P* value[a]
Q8. Have you ever followed a professional (not personal) social media account of an independent physician or medical practice?						<.001
Yes	77 (50)	98 (57.3)	76 (57.1)	52 (50)	23 (20.7)	
No	43 (27.9)	52 (30.4)	41 (30.8)	44 (42.3)	81 (73)	
No, but I would like to if that was an option	34 (22.1)	21 (12.3)	16 (12)	8 (7.7)	7 (6.3)	
Q10. Would you find it beneficial from a patient's perspective for your doctor to have an updated, public LinkedIn account that would allow you to have more access to his or her professional history, achievements, and education?						<.001
Yes, this would help me develop confidence in my physician and add credibility to the guidance he or she gives me	71 (46.1)	86 (50.3)	62 (46.6)	44 (42.3)	44 (39.6)	
Yes, but probably would not check it anyway	68 (44.2)	46 (26.9)	40 (30.1)	28 (26.9)	25 (22.5)	
No, I do not think that would be useful or beneficial	15 (9.7)	39 (22.8)	31 (23.3)	32 (30.8)	42 (37.8)	
Q11. As a patient would you be inclined to follow and use a social media page (Instagram, Facebook, etc) to contact your nurse or doctor directly to get medical questions answered, schedule appointments, and get updates? Would this be more convenient than using a conventional web page?						.01
Absolutely, this would be convenient	58 (37.7)	62 (36.3)	52 (39.1)	34 (32.7)	27 (24.3)	
I would follow the social media account but probably never take advantage	40 (25.9)	42 (24.5)	22 (16.5)	24 (23.1)	18 (16.2)	
I would not be interested in the social media account and would just use a regular website for the information I need	56 (36.3)	67 (39.2)	59 (44.4)	46 (44.2)	66 (59.5)	
Q12. Would you be more likely to schedule critical screening tests such as mammograms or colonoscopies if you saw an educational post on social media explaining the importance of them and providing a convenient link that would allow you to directly schedule an appointment?						<.001
Yes, this would help me remember to get important preventive testing	86 (55.9)	90 (52.6)	64 (48.1)	48 (46.2)	27 (24.3)	
This would be beneficial and educational, but I probably would not be inclined to schedule an appointment through the post	51 (33.1)	49 (28.7)	36 (27.1)	33 (31.7)	37 (33.3)	
If I saw the post, I would not pay much attention to it	10 (6.5)	16 (9.4)	16 (12)	4 (3.8)	17 (15.3)	
This would not benefit me	7 (4.5)	16 (9.4)	17 (12.8)	19 (18.3)	30 (27)	

[a] All the *P* values are obtained from the Pearson chi-square test.

Social Media Use by Age

The Kruskal-Wallis test was conducted to determine the differences in social media platform use (rated using a 0-5 scale, where 0 indicates *I do not use social media* and 5 indicates *I use the platform hourly more than 12 times a day*) across different age groups. Statistically significant differences were found among different-aged Instagram users (*P*<.001) and Twitter users (*P*<.001; Table 1). Post hoc tests for use of Instagram revealed that the use differed significantly between the age groups 56-89 years (median 0, IQR 0-3) and 18-25 years (median 2, IQR 1-2; mean ranks, respectively, 217-316; *P*=.03), 56-89 years (median 0, IQR 0-3) and 26-35 years (median 2, IQR 1-3; mean ranks, respectively, 217-313; *P*<.001), 56-89 years (median 0, IQR 0-3) and 36-45 years (median 2, IQR 0-4; mean ranks, respectively, 217-311; *P*=.001), and 56-89 years (median 0, IQR 0-3) and 46-55 years (median 2, IQR 0-3; mean ranks, respectively, 217-314; *P*=.02), but the use did not differ between any other age group combination. As for the use of Twitter, the post hoc test showed that there was a significant difference between age groups 56-89 years (median 0, IQR 0-2.5) and 18-25 years (median 1.5, IQR 0-2; mean ranks, respectively, 255-319; *P*=.16), 56-89 years (median 0, IQR 0-2.5) and 46-55 years (median 0, IQR 0-4; mean ranks, respectively, 255-322; *P*=.03), 26-35 years (median 0, IQR 0-1) and 18-25 years (median 1.5, IQR 0-2; mean ranks, respectively, 257-318; *P*=.002), 26-35 years (median 0, IQR 0-1) and 46-55 years (median 0, IQR 0-4; mean ranks, respectively, 257-322; *P*=.009), and 36-45 years (median 0, IQR 0-2) and 18-25 years (median 1.5, IQR 0-2; mean ranks, respectively, 258-319; *P*=.04), but the use did not differ between any other age group combination.

Of the survey population, 76.8% (517/673) claimed to follow a form of social media that regularly posts something educational related to the medical field. Facebook was the most frequently used social media platform and was considered most acceptable for use in a health care setting across all ages surveyed. A total of 58.8% (396/673) of the sample population checked Facebook multiple times a day, and the use varied with each social media platform (Multimedia Appendix 1).

Social Media Comfort in Health Care by Age

The Kruskal-Wallis test was also conducted to determine the significant differences in social media platforms that the participants are most comfortable using (ranked from 1-7, where 1 indicates the least comfortable using and 7 indicates the most comfortable using) in a health care setting that differed by age groups. Across various categories of age, except for *Facebook*, the participants' responses varied significantly by age group for Instagram (*P*<.001), Twitter (*P*=.02), LinkedIn (*P*=.009), and YouTube (*P*=.02) in a health care setting (Table 2). A post hoc test showed that there was a statistically significant difference in Instagram use in a health care setting between age groups 56-89 years (median 4, IQR 3-6) and 18-25 years (median 5, IQR 4-6; mean ranks, respectively, 253-346; *P*=.001) and between age groups 46-55 years (median 5, IQR 4-6) and 18-25 years (median 5, IQR 4-6; mean ranks, respectively, 270-346; *P*=.008), but the use did not differ between any other age group combination. As for comfort using Twitter, the post hoc analysis revealed a statistically significant difference between age groups 56-89 years (median 3.5, IQR 2-4.7) and 18-25 years (median 4, IQR 3-5; mean ranks, respectively, 259-332; *P*=.02), but the use did not differ between any other age group combination. For LinkedIn, there was a statistically significant difference between age groups 56-89 years (median 4.5, IQR 3-6) and 18-25 years (median 3, IQR 3-5; mean ranks, respectively, 334-261; *P*=.02) and age groups 46-55 years (median 4, IQR 3-6) and 18-25 years (median 3, IQR 3-5; mean ranks, respectively, 325-260; *P*=.04), but the use did not differ between any other age group combination. Finally, for YouTube, the post hoc test revealed a statistically significant difference between age groups 36-45 years (median 5, IQR 3-6) and 26-35 years (median 5, IQR 4-6; mean ranks, respectively, 262-333; *P*=.006), but the use did not differ between any other age group combination.

Discussion

Principal Findings

The growing interest and influence of social media in the general public undoubtedly poses the following question [1]: why is this not being more heavily used in health care? The current explanation is that the apprehensions toward social media stem from quality, reliability, confidentiality, and privacy concerns [7]. More specifically, the most common contributors to individual and institutional fear against the use of social media in medicine and health care may include the potential violation of ethical standards, patient privacy, confidentiality, and the misrepresentation of information. According to our survey, the greatest concerns were lack of privacy (258/673, 38.3%) and communication security (231/673, 34.3%). Despite these concerns, a strong social media presence can be used to fortify a positive reputation as a medical practice. It can also be an effective way to educate the followers on important medical topics, which in turn could lead to further patient acquisition. Along with educating patients, another possible improvement to a developing medical practice is increased patient satisfaction through possibilities such as improved patient adherence [14]. The possible implications of efficient utilization of social media will continue to grow over time, but many developing medical practices that have not yet started to take advantage of these opportunities are possibly missing out on significant improvements in several areas.

Despite the concerns expressed with social media use in the medical field, the vast majority of respondents showed strong interest in greater social media involvement in health care. The results were relatively consistent between respondents aged 18-55 years, but those aged over 55 years appear to express a change in outlook on social media involvement in health care. The majority of the data's significant findings were from the abrupt change in the opinion of the older respondents. The trend showed a steady decrease in the interest of social media utilization in health care, as each age group increased until a steep drop was found after 55 years of age (Table 3). For example, about 46.8% (315/673) of respondents indicated that they would be more likely to schedule critical screening tests after seeing an educational social media post that provides a link that would allow them to schedule an appointment. However, the likelihood decreased with increasing age of the sample population, and less than 24.3% (27/111) of those aged over 55 years were more likely to schedule an appointment (Table 3; *P*<.001). Another finding separating the opinion of those aged over 55 years was when asked if respondents followed a professional (not personal) social media account of an independent physician or medical practice. About 48.4% (326/673) of the respondents indicated that they did. However, when analyzed by age, the majority (81/111, 73.2%) of respondents aged 56-89 years indicated that they would not follow a professional social media account of an independent physician or medical practice (Table 3; *P*<.001). Finally, 56.3% (379/673) of respondents indicated that they would follow a social media page that allows them to schedule appointments and contact their nurse or doctor directly to ask a question. However, only 43.7% (294/673) of respondents would prefer this over a traditional web page, and respondents aged 56-89 years were significantly different from the other groups, with 59.5% (66/111) indicating that they would not even follow the page (*P*=.009; Table 3). The majority of respondents within all age groups expressed that it would be beneficial from a patient's perspective to have a doctor with a public, updated LinkedIn account, allowing more details on their professional history. However, this was expressed more conclusively among younger respondents aged between 18 and 25 years (71/154, 46.1%) than among older respondents aged between 56 and 89 years (44/111, 39.6%; Table 3).

It could be valuable to consider how often each platform is being checked and by what demographic. Although it is likely that health care providers are more prone to follow social media regarding education in health care, these data still provide value because they show that the majority of health care professionals of all ages (the survey population had a relatively even distribution of ages) find value in social media. The data also allow us to further analyze which social media platforms are preferred for medical-related content by health care professionals of different age groups.

Facebook and Instagram are the platforms most often checked multiple times a day, where YouTube appears to be a weekly habit and LinkedIn monthly. The majority of respondents did not use Twitter, but those that used Twitter checked it frequently (Multimedia Appendix 1). The survey data measured which social media platforms could be most successful in a health care setting by comparing differences in use and comfort in a health care setting among different age groups. Facebook was the most frequently used social media platform and was considered most acceptable for use in a health care setting across all ages (Multimedia Appendix 1). However, statistically significant differences in age groups were found between respondents' use of both Instagram and Twitter. There were no significant differences between the 18 to 55 years age group, but the 56 to 89 years age group used Instagram significantly less than each of the other age groups (Table 1). The 56-89 years age group recorded a median of 0, meaning no use at all, whereas all other age groups reported significantly different use. The 18 to 25 years (*P*=.03), 26 to 35 years (*P*<.001), 36 to 45 years (*P*=.001), and 46 to 55 years (*P*=.02) age groups all recorded a median of 2, indicating almost daily use. Twitter also showed a similar variation in use by age. The 56 to 89 years age group reported infrequent to no use of Twitter at all, with a median of 0, which was significantly less than the 18 to 25 years age group that reported monthly to weekly use (median 1.5; *P*=.16). Twitter showed that the 46 to 55 years age group also differed significantly, with more frequent use than the 56 to 89 years age group (*P*=.03). However, the 46 to 55 years age group recorded a significantly less frequent use of Twitter when compared with the 26 to 35 years age group (*P*=.009; Table 1). Clearly, certain social media platforms such as Instagram and Twitter are more favorably adopted among younger populations. Understanding these differences could be vital to the implementation of successful and efficient strategies to use social media in a developing health care practice.

Considering the reservations to increased social media in the medical field that have been expressed, understanding the different levels of comfort for each social media platform in a health care setting could have a significant impact on the success of social media utilization. Levels of comfort among different social media platforms showed similar significant differences between age groups. The 56 to 89 years age group expressed significantly less comfort with the utilization of Instagram in health care (median 4) when compared with the 18 to 25 years age group (median 5; *P*=.001). The 46 to 55 years age group also recorded less comfort with Instagram in health care when compared with the 18 to 25 years age group (*P*=.008; Table 2). It is important to consider this decrease in comfort with increasing age for any social media utilization plan involving Instagram in health care. Twitter also showed a significant difference in comfort level using the platform in a health care setting when comparing the 56 to 89 years age group with the 18 to 25 years age group. The older populations (aged 56-89 years) showed significantly less comfort with Twitter's use in health care (median 3.5) compared with those aged 18 to 25 years (median 4; *P*=.02; Table 2). As such, these platforms may be less useful for physicians in geriatric care than those in specialties with younger patients. For example, pediatric practices may benefit from these platforms, as the appointments are generally scheduled by parents that may fall in surveyed ages between 18 and 46 years. Interestingly, not all social media platforms showed decreased comfort with utilization in the health care setting in the older age groups. LinkedIn actually followed the opposite trend. The 56 to 89 years age group showed significantly more comfort with LinkedIn utilization in the health care setting (median 4.5) when compared with the 18 to 25 years age group (median 3; *P*=.02). The 46 to 55 years age group also showed significantly more comfort with LinkedIn in a health care setting (median 4) when compared with the 18 to 25 years age group (median 3; *P*=.04). These data show that LinkedIn could be a valuable tool for a medical practice wanting to appeal to an older patient population when implementing a social media utilization plan.

With these data in mind, it is reasonable to conclude that younger respondents tend to be more active and comfortable on social media, so the platforms they most commonly use will be checked on a more frequent basis. This should be considered when targeting specific demographics for educational videos or patient acquisition. For example, two platforms that were not included in the survey data that serve younger demographics are Snapchat and TikTok. Snapchat is most frequently used by people aged between 13 and 29 years, with 69% of 13- to 17-year-olds using the app and 62% of 18- to 29-year-olds using the app. Snapchat reached 210 million daily users in the fourth quarter of 2019. For this reason, Snapchat may not be the best option for health care–related use and was not included in the survey, but it would be worth considering in the future if it retains its current user base. The platform TikTok gained significant popularity after beginning this research and was not included in the survey data. However, it has since become a major platform with rapid growth and could be a strong tool in a future health care social media program. Although more data would need to be collected on its effectiveness in the health care setting, TikTok may be a strong option because its 800 million active users spend an average of 52 minutes per day on the app worldwide. Only 41% of the users were aged between 16 and 24 years, so there are many over the age of 25 years. The higher the active user base, the more likely a health care practice will be able to reach or target specific patient populations. Different social media platforms may be used in different ways to accomplish their objectives, but the intrinsic value of social media is the ability to reach a larger and diverse audience.

If a health care organization was trying to improve patient acquisition or reach a broader audience, the survey data suggest that optimization of social media programs requires consideration of patient demographics, especially targeting the platform type and time and use of each platform based on age. The styles of social media utilization with the first and second most interest among survey respondents were posts that address important medical topics each month with short weekly educational videos from a physician specializing in that particular area and live social media question and answer sessions, respectively. Despite the overwhelming amount of data suggesting that social media could be an excellent resource in the health care industry, some data indicate that there are significant concerns that may prevent efficient adoption. The majority of respondents across all age groups reported that they would not take advantage of a social media page that facilitated direct communication to receive answers to medical questions, schedule appointments, or receive general updates (Table 3). Further research is needed to better understand the possible impact of the concerns related to privacy and security of communication on the ease of general patient adoption of social media in the health care industry. Those interested in more generalizable demographics could repeat this survey with a larger sample population, including people with occupations in a variety of industries across various geographic locations in the United States. This could provide valuable insights into the most effective social media utilization in health care for different target populations. Although the future applications and growth in popularity of patients using social media to seek out medical guidance are currently unknown, the data from this survey and other available data suggest that social media utilization has room to grow and may play a more prominent role in health care. The younger generations who spend significant amounts of time each day on social media will eventually be responsible for the majority of health care spending, which could allow social media to be a powerful tool for many medical practices in the future.

Limitations and Future Research

This study included participants with higher education and experience in the Texas health care industry; however, this presents limitations due to the lack of geographical location and occupational diversity among all respondents. Further studies would benefit from including more respondents who are not affiliated with the health care system and respondents from a broader geographical distribution to improve generalizability and further understand how the public would react to increased social media utilization in the medical field. Furthermore, the survey was optional and was sent to anyone with a ttuhsc.edu email. Although this enabled a large sample size, this study design allows for self-selection, which may create a bias in the responses.

Although some challenges of health care utilization have already been identified, it would be helpful to expand on these challenges in further studies, especially addressing misinformation spread through social media in the health care field. In addition, an attempt to understand the higher use preference of LinkedIn by older age groups could help shed more light on this reverse trend compared with other social media platforms, and we recommend this as an area of future study.

Conclusions

As social media continues to grow, efficient utilization of the available platforms can help a medical practice reach out to a broader population and deliver personalized care. Although the data collected in this study demonstrated an overwhelming interest in using social media in the medical field across all age groups, adoption willingness appears to be higher in younger respondents than in older respondents. Facebook is the most widely accepted social media platform for health care applications. However, other social media platforms, such as Instagram, may be better tools for targeting younger generations. Medical practices should use social media pages to present content that is timely, relevant, and written in a clear language familiar to the target audience.

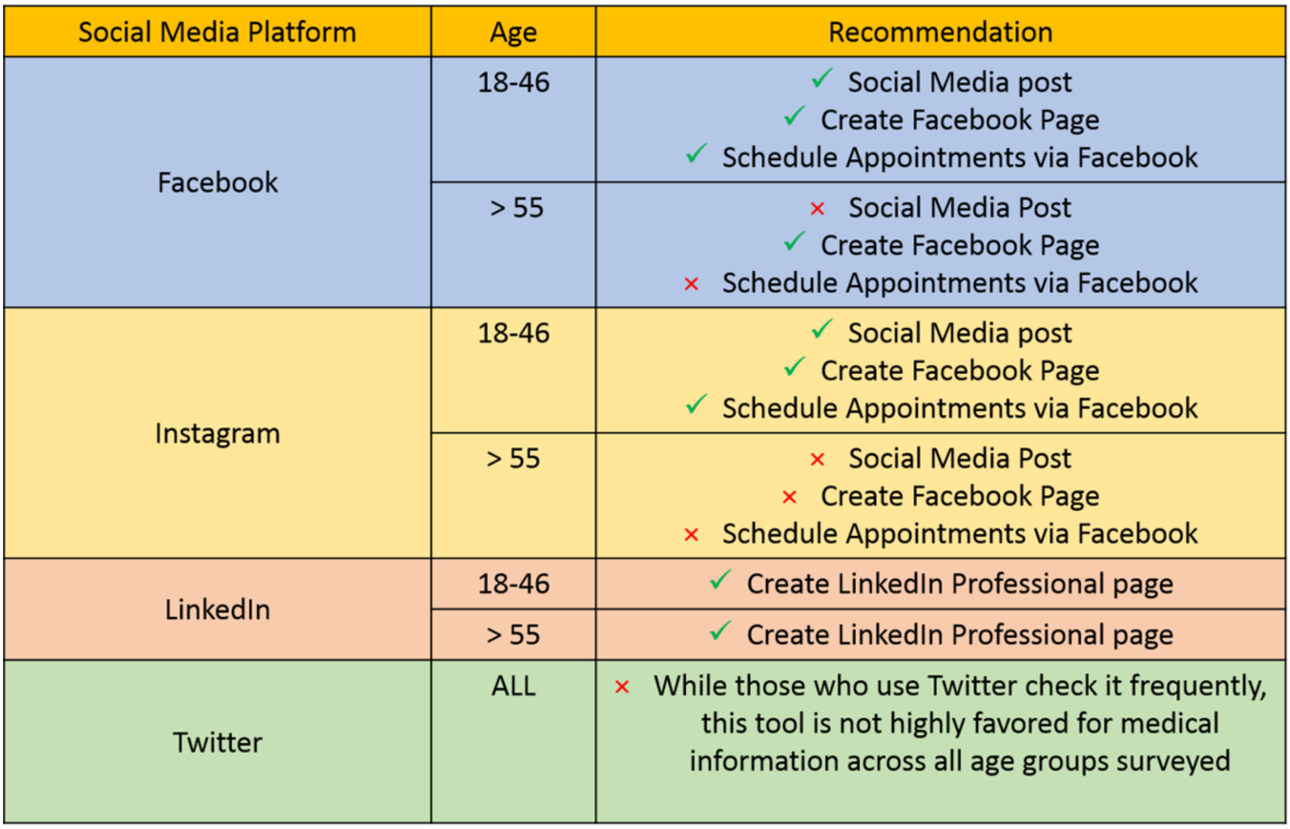
Furthermore, physicians are encouraged to have updated LinkedIn profiles to gain the attention of more potential patients and to increase patients' confidence in their physicians. Respondents aged over 55 years seem to be less receptive to following health care–related social media pages and are particularly less receptive to using social media over a traditional web page. However, based on the majority of survey responses, there is great interest in the availability of educational health care videos on social media, access to health care providers, and appointment scheduling via hyperlinks. It is plausible that using social media in these ways could lead a medical practice to an increase in patient acquisition and improved health care delivery. There are significant concerns related to information accuracy, privacy, and security that need to be addressed to improve outcomes from social media use in the medical field. However, the current benefits and future possibilities of social media utilization make it a powerful and strategic option for medical practices to adopt.

Recommendations

On the basis of our data, we recommend that all physicians have an updated LinkedIn account, which could improve the patient-physician relationship as well as ensure patients' confidence in their physician, among all patients aged over 18 years (Table 3; Figure 1).

Growing medical practices that are implementing a social media utilization plan should focus on patient age when targeting different patient populations. Stratifying by patient age showed more significant associations in our data and is likely more accessible information than factors such as occupation and education when implementing a social media outreach plan in a health care setting. As all age groups were more comfortable with Facebook in a health care setting and checked Facebook most frequently (Multimedia Appendix 1; Figure 1), it would likely be the most effective platform when targeting patient populations with a broad age range (18-89 years). Facebook supplemented with LinkedIn could be more effective when targeting patient populations aged over 46 years. Instagram along with Facebook could be effective in targeting patients aged under 46 years. As most medical practices have patients of all ages, our research supports a multifaceted approach that includes multiple social media platforms uniquely used to target different age groups (Figure 1).

Figure 1. Recommendations for social media strategies in health care based on age.



Social Media Platform	Age	Recommendation
Facebook	18-46	✓ Social Media post ✓ Create Facebook Page ✓ Schedule Appointments via Facebook
	> 55	× Social Media Post ✓ Create Facebook Page × Schedule Appointments via Facebook
Instagram	18-46	✓ Social Media post ✓ Create Facebook Page ✓ Schedule Appointments via Facebook
	> 55	× Social Media Post × Create Facebook Page × Schedule Appointments via Facebook
LinkedIn	18-46	✓ Create LinkedIn Professional page
	> 55	✓ Create LinkedIn Professional page
Twitter	ALL	× While those who use Twitter check it frequently, this tool is not highly favored for medical information across all age groups surveyed

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Current usage of social media among different age groups.

[DOCX File , 25 KB - humanfactors_v8i3e27528_app1.docx]

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Abbreviations

TTUHSC: Texas Tech University Health Sciences Center

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Factors Affecting Portal Usage Among Chronically Ill Patients During the COVID-19 Pandemic in the Netherlands: Cross-sectional Study

Qingxia Kong[1], BSc, MSc, PhD; Danique Riedewald[1], BSc, MSc; Marjan Askari[2], BSc, MSc, PhD

[1]Rotterdam School of Management, Erasmus University, Rotterdam, Netherlands

[2]Erasmus School of Health Policy & Management, Erasmus University, Rotterdam, Netherlands

Corresponding Author:
Qingxia Kong, BSc, MSc, PhD
Rotterdam School of Management
Erasmus University
Burgemeester Oudlaan 50
Rotterdam, 3062 PA
Netherlands
Phone: 31 10 408 2277
Fax: 31 10 408 9014
Email: q.kong@rsm.nl

Abstract

Background: The COVID-19 pandemic has impacted the capacity of the regular health care system, which is reflected in limited access to nonurgent care for patients who are chronically ill in the Dutch health care system. Nevertheless, many of them still depend on health care assistance to manage their illnesses. Patient portals are used to provide continued health care (remotely) and offer self-management tools during COVID-19 and potentially after. However, little is known about the factors influencing portal use and users' satisfaction among patients who are chronically ill during the COVID-19 pandemic.

Objective: This study aims to examine predictors of patient portal use among patients who are chronically ill, the willingness to recommend the portal to others, and the likelihood of future use among portal nonusers.

Methods: An online self-administered questionnaire was distributed among patients who are chronically ill via social media in May 2020. The questionnaire consisted of four parts: (1) demographics including age and hours of daily internet use; (2) physical health status including COVID-19 infection, perceived level of control, and hospital visits; (3) mental health status including depression and life satisfaction; and (4) portal use including response waiting time and awareness. Descriptive, correlation, univariate, and multivariate analyses were conducted to identify factors that affect portal use, users' willingness to recommend, and nonusers' likelihood of future portal use.

Results: A total of 652 patients responded, and 461 valid questionnaires were included. Among the 461 patients, 67% (n=307) were identified as patient portal users. Of the nonusers, 55% (85/154) reported not being aware of the existence of a patient portal at their hospital. Significant predictors of portal use include level of control (*P*=.04), hospital visit time (*P*=.03), depression scale (*P*=.03), and status of life satisfaction (*P*=.02). Among portal users, waiting time to get a response via the portal (*P*<.001) and maximum acceptable waiting time (*P*<.001) were the strongest predictors for willingness to recommend the portal; among nonusers, the model predicted that those who were not aware of patient portals (*P*<.001) and were willing to wait moderately long (*P*<.001) were most likely to use the portal in the future.

Conclusions: This study provides insights into factors that influence portal use and willingness to recommend, based on which health care providers can improve the adoption of patient portals and their services. It suggests that health care providers should leverage efficient operations management to improve responsiveness and reduce waiting time to enhance user satisfaction and willingness to recommend use. Health care organizations need to increase portal awareness among nonusers and train their patients to increase both use and longer adoption of patient portals. Factors including depression and life satisfaction can influence portal use; therefore, future studies on determinants of portal use and nonuse in this specific population are needed.

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KEYWORDS

COVID-19; pandemic; digital technology; eHealth; patient portals; chronically ill patients; portal responsiveness; portal awareness

Introduction

On January 30, 2020, COVID-19 was officially declared a pandemic by the World Health Organization [1]. As a result of the virus outbreak, the Netherlands, along with other countries, announced a lockdown. This lockdown, called an *intelligent lockdown*, entailed that people were encouraged (not forced) to stay inside as much as possible, social gatherings with more than three people were prohibited, and many (nonessential) businesses were temporarily closed [2]. The primary purpose of this *intelligent lockdown* was to prevent peak loads of patients requiring intensive care [3]. The pandemic's consequences were a massive burden on the Dutch health care system, particularly in the initial period of the outbreak (March 2020). Intensive care units were struggling with allocating their capacity, causing patients to be distributed over various hospitals throughout the Netherlands [4]. Meanwhile, regular health care was disrupted due to the COVID-19 outbreak. To alleviate the pressure of health care professionals and to prevent them and nonurgent patients from infecting each other [5], nonurgent patients' appointments were canceled, postponed, or moved online [6,7]. Several experts and health care professionals subsequently proposed eHealth as a solution for the continuation of care for patients who are chronically ill [8,9].

According to a study supported by the Dutch government, approximately 5.3 million Dutch patients have one or more chronic illnesses. This number is expected to rise to 7 million by 2030 [10]. In Europe, about 70% to 80% of the total health care budget is spent on treating and preventing chronic disease [11], which indicates that chronic illness is a common issue with an enormous financial burden. Two critical elements of chronic care are frequent contact with their care providers and self-management (eg, adapting to their condition and learning to deal with their disease) [12]. Therefore, some still rely on regular nonurgent health care and need assistance during the COVID-19 pandemic to keep their illness under control. Limited access to care, in addition to the fear of contracting the virus, getting sick, or even passing away, could potentially lead to diminished (perceived) physical and mental health outcomes for this group of patients [13,14]. Indeed, previous studies have shown that people with chronic diseases are more prone to anxiety and depression than those without [15,16]. Although care for patients with COVID-19 requires the most attention during this crisis, it is crucial to continue to provide patients who are chronically ill the care they need, including offering self-management tools, monitoring, controlling, and disease treatment. It will ultimately reduce the risk of emergency care and hospital admission, and prevent long-term complications in these patients [17].

During the COVID-19 pandemic, eHealth has been suggested as a valuable solution to provide care to patients who are chronically ill, enabling self-management of chronic conditions and providing care remotely and safely [18,19]. The Dutch government has compiled a subsidy program (VIPP) to accelerate the implementation of eHealth solutions in specialized medical care organizations throughout the country [20]. By 2019, 60 out of 73 Dutch hospitals offered an eHealth solution [21]. The solution is essentially a platform called a *patient portal*. In these patient portals, patients are, among other things, able to investigate their electronic health records, directly message their health care practitioner, and view their laboratory results along with personal details. Each hospital was allowed to decide on the functionalities implemented in its patient portal. Despite the VIPP implementation, several reports provide evidence on the lack of patient engagement, reflected in a large portion of nonusers [22].

Therefore, it is crucial to understand which factors influence portal use for patients who are chronically ill, users' satisfaction, and nonusers' likelihood of future use to promote the adoption of patient portals and retain current users. A retrospective cohort study among the adult patient population found that those who are younger, are White, have commercial insurance, and have higher annual income are more likely to be portal users [23]. Another cross-sectional survey also found that age and income are significant predictors of portal adoption [24]. A cross-sectional survey among adult patients of a university hospital revealed that being chronically ill and having higher eHealth literacy were the best predictors for portal use [22]. However, it remains unknown which factors influence portal use among the patient group of interest—patients who are chronically ill—and, in particular, whether and how perceived physical and mental health conditions play a role during the COVID-19 pandemic. Besides, several papers published after the outbreak of COVID-19 studied patient satisfaction on patient portals or telehealth [25]. However, those studies are mainly descriptive (ie, they survey how many patients are satisfied with their experience rather than predicting or investigating the causal relationship). This study contributes to understanding which factors predicted portal use, portal users' satisfaction, and portal nonusers' likelihood of future adoption among patients who are chronically ill during the COVID-19 pandemic.

The research questions of this study are what factors affect patient portal use among patients who are chronically ill during the COVID-19 pandemic in the Netherlands and what factors affect portal users' willingness to recommend and nonusers' likelihood of using patient portals during the COVID-19 pandemic in the Netherlands?

Methods

Study Design and Procedure

A cross-sectional study was designed using an online self-administered questionnaire (the survey is available upon request). The survey was written in English and then translated into Dutch and verified by a person proficient in Dutch. The questionnaire was distributed throughout several Facebook groups aimed at (peer) support and providing information for patients who are chronically ill in May 2020.

After displaying the introduction of the questionnaire, informed consent was obtained electronically, before actual enrollment. It was explicitly stated that participation was voluntary, and participants could withdraw at any time without any consequences. Moreover, complete anonymity of the response was ensured.

During the period of data collection, the number of Dutch people who tested positive for COVID-19 exceeded 40,000, over 11,000 people were hospitalized, and almost 6000 deaths related to COVID-19 had been reported in a population of 17 million inhabitants [26]. When distributing the questionnaire, the national *intelligent lockdown* had been active for approximately 1.5 months. As compensation for the time spent on the survey, online gift codes were distributed through a raffle. To ensure good quality responses, some survey items were programmed to be restricted in range so that incorrect inputs were not allowed.

This study followed the Institutional Review Board (IRB) for the Protection of Human Subjects Guidelines. All procedures in this study were approved by the IRB (2020/04/24-61392qko) prior to its initiation.

Participants

Since the study focused on patient portals as implemented by Dutch hospitals, the targeted population for our study was patients who are chronically ill and residing in the Netherlands. Inclusion criteria were as follows: patients aged between 18 and 65 years, having at least one chronic illness, and having spent more than 2 minutes completing the questionnaire. Questionnaires that were not completed were removed from the final data set.

Measures

Demographic Characteristics

Demographic variables included participant's gender (male, female, or other), age, highest educational level completed, main occupation, yearly income, chronic illness or illnesses, hours of daily internet use, and portal use (yes or no).

Physical Health Status and Hospital Visits

Physical health status was assessed using four categories: (1) COVID-19 status, (2) level of control over chronic illness, (3) lifestyle and exercise, and (4) perceived health. COVID-19 status was assessed by inquiring about the prevalence of any COVID-19 symptoms over the last 2 weeks (yes, no, or unsure), COVID-19 testing (yes or no), and COVID-19 infection (yes, no, or unsure). Level of control over chronic illness was assessed using a single 5-point item, asking people to rate their current level of control over their chronic illness (totally in control to not at all in control). Lifestyle was assessed using a common measure of lifestyle and activity [27,28]. Exercise was measured by the frequency of exercise in the last 2 weeks. Perceived health was measured using the Self-Rated Health measure, a widely used, single-item measure of self-perceived health status [29]. The item consisted of one question ("In general, would you say your health is:") with five answer options between 1 (excellent) and 5 (poor) [30]. Finally, patients' frequency of hospital visits and their durations were also measured.

Mental Health

Mental health was assessed using questions about both depression severity and life satisfaction. Depression severity was measured using the Patient Health Questionnaire 9 assessment scale, which is generally used to aid clinicians in diagnosing, monitoring, and treating depressive symptoms and their severity [31]. Patients score nine different items on a scale of 0 (not at all) to 3 (nearly every day). The scores are then summed up to achieve a final score, which can be assessed by the clinician or researcher over a few cut-off categories. The categories are 0 to 4, 5 to 9, 10 to 14, 15 to 19, and 20 to 27, in sequence of increasing depression severity [32]. General well-being was assessed by examining participants' satisfaction with life, using the Satisfaction with Life Scale [33]. The tool allows participants to self-report their opinions regarding the satisfaction they experience with their own lives. The scale contains five items, and participants report their answers over a 7-point Likert scale (1, strongly disagree, to 7, strongly agree). After the assessment, scores are summed up to arrive at a final score. The outcomes are categorized as 5 to 9 (extremely dissatisfied), 10 to 14 (dissatisfied), 15 to 19 (slightly dissatisfied), 20 (neutral), 21 to 25 (slightly satisfied), 26 to 30 (satisfied), and 31 to 35 (extremely satisfied).

Patient Portal Use

Participants were identified as portal users if they selected *yes* to the question "Have you ever used a patient portal?" Among portal users, their portal use was assessed by frequency of use, time duration of use, and waiting time. The time of use measures the average duration each time a patient uses a portal, and frequency of use indicates how often a patient uses a portal. They are two dimensions of patient engagement with the portal. Furthermore, the waiting time from sending a request until receiving a reply was recorded. For patient portal users (ie, people who have used a portal before), their usual and maximum acceptable waiting time was asked. In contrast, for nonusers, only the maximum acceptable waiting time was recorded. Lastly, portal users' willingness to recommend the portal to others—a strong indicator of customer loyalty and predictor for growth [34]—was measured by a single question: "Would you recommend the patient portal to others?" Portal nonusers were asked to input a percentage value (from 0 to 100) to answer the question "What is your likelihood of using such a portal?" to measure their likelihood of future portal use.

Data Analysis

Descriptive analysis was performed to gain insight into the patient population, portal users, and nonusers regarding their demographics, physical health status, hospital visits, and mental health status. Additionally, chi-square tests (for categorical variables) and Welch *t* tests (for numerical variables) were performed to compare the characteristics between portal users and nonusers. Next, univariate analyses were performed for the dependent variable (portal use) to detect its possible predictors. Variables with $P<.20$ in the univariate regression were consequently included in the multiple regression analysis after considering the correlation between variables (using statistical analysis and expert opinion). A stepwise backward elimination was then applied to reduce the number of independent variables and obtain the final multiple regression model. This approach allowed thorough exploration and testing of possible predictors to arrive at a final model [35]. Similar procedures were applied to the other two dependent variables (willingness to recommend among portal users and likelihood of use among portal nonusers) to get the final multiple regression models. All analyses were performed using RStudio (version 4.0.2; RStudio, PBC).

Results

Descriptive Analysis

A total of 652 respondents started the questionnaire, whereby 461 respondents completed it successfully. Only completed questionnaires were used in the final data set for analysis. Of all the participants, 307 (66.6%) reported to have used a patient portal, and 154 (33.4%) reported that they had not used a patient portal until the moment the survey was conducted.

Demographics of all participants, portal users, and nonusers are displayed in Table 1. From our sample (N=461), 94 (20.4%) were male, 365 (79.2%) were female, and 2 (0.4%) individuals identified as other. The mean age of the sample was 42.9 (SD 13.0) years. The number of participants that reported having a single chronic disease was 302 (65.5%), and 159 (34.5%) reported having multiple chronic diseases. Significant differences were noted in the mean age (*P*=.008) and main occupations (*P*=.03) between portal users and nonusers.

Table 2 displays the physical health status, hospital visits, and mental health status of all participants, portal users, and nonusers. The majority of the 461 patients reported to have their illness “a little bit” (n=113, 24.5%) to “moderately in control” (n=229, 49.7%), 66 (14.3%) reported to have total control, and 46 (10.0%) reported to have no control over their illness at all. Furthermore, few patients (n=30, 6.5%) reported that their perceived health was very good or excellent, while the majority reported good (n=127, 27.6%), fair (n=177, 38.4%), or poor (n=127, 27.6%) perceived health. Moreover, the majority of respondents reported spending 0.5 hours to 1 hour (n=151, 32.8%) and 1 hour to 2 hours (n=166, 36.0%) each time they visit a hospital (including travel time); 70 (15.2%) respondents spent less than half an hour, while only 19 (4.1%) spent more than 3 hours. Furthermore, only 18 (3.9%) participants reported having or having had COVID-19, 130 (28.2%) were uncertain, and 313 (67.9%) reported that they never had COVID-19. About mental health, most participants reported having no (n=172, 37.3%) to mild forms of (n=158, 34.3%) depression, while only 9.8% (n=45) reported having moderately severe or severe depression. Relative to life satisfaction, 146 (31.7%) and 117 (25.4%) of the participants were satisfied and slightly satisfied with their lives, respectively. Moreover, 27 (5.9%) and 28 (6.1%) were extremely satisfied and extremely dissatisfied with their lives, respectively. Among the measured characteristics, level of control (*P*=.005), average time of hospital visits (*P*=.04), depression (*P*=.02), and life satisfaction (*P*=.005) were significantly different between portal users and nonusers.

Table 1. Demographics of all the participants, portal nonusers, and users during the COVID-19 pandemic in the Dutch population of patients who are chronically ill.

Demographics	Total (N=461)	Nonusers (n=154)	Users (n=307)	*P* value
Gender, n (%)				.60
Female	365 (79.2)	122 (79.2)	243 (79.2)	
Male	94 (20.4)	32 (20.8)	62 (20.2)	
Other	2 (0.4)	0 (0.0)	2 (0.7)	
Age (years), mean (SD)	42.9 (13.0)	45.1 (12.5)	41.8 (13.1)	.008
Highest education, n (%)				.06
Primary school	13 (2.8)	8 (5.2)	5 (1.6)	
Secondary/high school	82 (17.8)	29 (18.8)	53 (17.3)	
MBO[a,b] completed	201 (43.6)	73 (47.4)	128 (41.7)	
HBO[c,d] or university degree	155 (33.6)	41 (26.6)	114 (37.1)	
Graduate degree	10 (2.2)	3 (1.9)	7 (2.3)	
Main occupation, n (%)				.03
Self-employed	45 (9.8)	11 (7.1)	34 (11.1)	
Employee	242 (52.5)	73 (47.4)	169 (55.0)	
Student	35 (7.6)	9 (5.8)	26 (8.5)	
Unemployed	117 (25.4)	50 (32.5)	67 (21.8)	
Retired	22 (4.8)	11 (7.1)	11 (3.6)	
Yearly income (€[e]), n (%)				.29
0-20,000	171 (37.1)	61 (39.6)	110 (35.8)	
20,001-30,000	103 (22.3)	38 (24.7)	65 (21.2)	
30,001-40,000	120 (26.0)	39 (25.3)	81 (26.4)	
≥40,001	67 (14.5)	16 (10.4)	51 (16.6)	
Chronic illness, n (%)				.52
Single chronic illness	302 (65.5)	104 (33.9)	198 (64.5)	
Multiple chronic illnesses	159 (34.5)	50 (16.3)	109 (35.5)	
Daily internet use (hours), mean (SD)	5.7 (4.3)	5.4 (4.4)	5.8 (4.3)	.60

[a] MBO: Middelbaar beroepsonderwijs.

[b] English translation: secondary vocational education. It is oriented toward vocational training and is equivalent to a junior college education.

[c] HBO: Hoger beroepsonderwijs.

[d] English translation: higher professional education. It is oriented toward higher learning and professional training, and is the equivalent to a college education in the United States.

[e] A currency exchange rate of €1=US $1.18 is applicable.

Table 2. Physical health status, hospital visits, and mental health status of all the participants, portal nonusers, and users during the COVID-19 pandemic in the Dutch population of patients who are chronically ill.

Variables	Total (N=461), n (%)	Nonusers (n=154), n (%)	Users (n=307), n (%)	*P* value
COVID-19 infection				.72
Yes	18 (3.9)	101 (65.6)	212 (69.1)	
Not sure	130 (28.2)	46 (29.9)	84 (27.4)	
No	313 (67.9)	7 (4.5)	11 (3.6)	
Level of control				.005
Totally	66 (14.3)	28 (18.2)	38 (12.4)	
Moderately	229 (49.7)	63 (40.9)	166 (54.1)	
A little bit	113 (24.5)	41 (26.6)	72 (23.5)	
Not at all	46 (10.0)	16 (10.4)	30 (9.8)	
I don’t know	7 (1.5)	6 (3.9)	1 (0.3)	
Perceived health (SRH[a])				.31
Excellent	4 (0.9)	2 (1.3)	2 (0.7)	
Very good	26 (5.6)	8 (5.2)	18 (5.9)	
Good	127 (27.5)	36 (23.4)	91 (29.6)	
Fair	177 (38.4)	57 (37.0)	120 (39.1)	
Poor	127 (27.5)	51 (33.1)	76 (24.8)	
Average time of hospital visit (hours)				.04
<0.5	70 (15.2)	32 (20.8)	38 12.4)	
0.5-1	151 (32.8)	42 (27.3)	109 (35.5)	
1-2	166 (36.0)	56 (36.4)	110 (35.8)	
2-3	55 (11.9)	21 (13.6)	34 (11.1)	
>3	19 (4.1)	3 (1.9)	16 (5.2)	
Depression (PHQ-9[b])				.02
None	172 (37.3)	56 (36.4)	116 (37.8)	
Mild	158 (34.3)	49 (31.8)	109 (35.5)	
Moderate	86 (18.7)	25 (16.2)	61 (19.9)	
Moderately severe	33 (7.2)	15 (9.7)	18 (5.9)	
Severe	12 (2.6)	9 (5.8)	3 (1.0)	
Life satisfaction				.005
Extremely satisfied	27 (5.9)	6 (3.9)	21 (6.8)	
Satisfied	146 (31.7)	44 (28.6)	102 (33.2)	
Slightly satisfied	117 (25.4)	28 (18.2)	89 (29.0)	
Neutral	21 (4.6)	10 (6.5)	11 (3.6)	
Slightly dissatisfied	70 (15.2)	27 (17.5)	43 (14.0)	
Dissatisfied	52 (11.3)	24 (15.6)	28 (9.1)	
Extremely dissatisfied	28 (6.1)	15 (9.7)	13 (4.2)	

[a] SRH: Self-Rated Health.

[b] PHQ-9: Patient Health Questionnaire 9.

Table 3 reports the frequency of portal use before and after the lockdown. An increase in the frequency of portal use has been observed after the lockdown as compared to before, whereby the relative difference was 500%, 221.1%, and 8.3% in daily, weekly, and monthly use, respectively. After the lockdown, 67 (21.8%) reported daily to weekly use, and 106 (34.5%) have used the patient portal monthly. Among all the portal users, the most common use times were “5 minutes or less” (n=121, 39.4%) and “5-10 minute” (n=124, 40.4%), while 62 (20.2%) of them reported using the portals for more than 10 minutes.

In relation to the maximum acceptable waiting time, nonusers reported a lower maximum acceptable waiting time than users. Among the users, 78 (28.4%) reported a longer actual waiting time than they deem acceptable. Finally, among portal users, 257 (83.7%) would likely recommend portals to others, and among nonusers, the average likelihood of future use (ranging from 0% to 100%) was 53.6% (SD 33.3%).

Table 3. Descriptive of patient portal use before and after lockdown (n=307).[a]

Portal use	Frequency of use before lockdown, n	Frequency of use after initiation of lockdown, n	Relative difference (%)
(Almost) daily	1	6	500
Weekly	19	61	221.1
Monthly	56	106	89.3
Less than monthly	231	134	–42.0

[a] Relative comparison between periods translated according to relative frequency of use (period before the intelligent lockdown had a much larger timespan than the period after initiation of the intelligent lockdown and thus included portal nonusers).

Multiple Regression Analysis

To investigate which combinations of the different predictors could best explain the variance in portal use versus nonuse and portal users’ willingness to recommend and portal nonusers’ likelihood of future use, three separate regression models were constructed after performing univariate regression analysis and considering possible correlations. In the first analysis (model 1), a logistic regression was performed to investigate the association between portal use and the included variables after the first steps, which were age, hospital visit time, level of control, depression, and life satisfaction. In the second analysis (model 2), a logistic regression was performed to study the relationship between portal users’ willingness to recommend and the variables average number of hours spent on the internet daily, the frequency of portal use after the COVID-19 lockdown in March 2020, waiting time for portal response, and maximum acceptable time to wait. In the third analysis (model 3), a multiple regression analysis was conducted between portal nonusers’ likelihood of use and age, income, maximum acceptable waiting time, and their awareness of patient portals’ existence as candidate variables. The results of the regression analysis are displayed in Table 4.

Regression results of model 1 showed that shorter hospital visit times (“less than half an hour”) predict less portal use (β=–.725; *P*=.03) compared to longer visit times. Compared to “totally under control,” moderate level of control predicts a higher chance (β=.629; *P*=.04*)* of portal use. Two mental health conditions were shown to significantly affect participants’ portal use. Participants with severe depression (β=–1.652; *P*=.03) and life dissatisfaction or extreme life dissatisfaction (β=–.844; *P*=.02) were found to be less likely to use patient portals. Furthermore, age demonstrates a small yet nonsignificant impact on portal use, whereby older age negatively affects portal use (β=–.015; *P*=.08).

Among portal users, the logistic regression results from model 2 showed that actual waiting time and maximum acceptable waiting time were the strongest predictors of users’ willingness to recommend. Participants whose average waiting time was between 1 to 2 days (β=–2.081; *P*<.001) or greater than 2 days (β=–1.784; *P*<.001) were less likely to recommend the portal system to others, compared to those who received responses via portal systems within 24 hours. Participants who reported a moderate maximum waiting time (1-2 days) were more likely to recommend portal systems (β=2.292; *P*<.001).

For portal nonusers (model 3), awareness of the portal existence was the strongest predictor besides maximum acceptable waiting time. Among nonusers, 85 (55.2%) reported being unaware of the existence of a patient portal at their hospital. Participants that were unaware of the existence of portal systems were 25.9% (*P*<.001) more likely to use portal systems, compared to those that already knew of their existence before the time of the survey. Participants who had a moderate maximum acceptable waiting time (12-24 hours) were 21.2% (*P*<.001) more likely to use portal systems in the future. Furthermore, middle income class participants (€30,001 [US $35,440.20] to €40,000 [US $47,252.00]) were 15.3% (*P*=.01) more likely to use portal systems compared to low income class participants (<€20,001 [US $23,627.20]), and older-aged participants also showed a slightly lower likelihood (β=–.003; *P*=.10*)* of use.

Table 4. Results of the multiple regression model, indicating the significant predictors.

Variables	Model 1 portal use (all participants)		Model 2 recommendation (portal users)		Model 3 likelihood of using (portal nonusers)	
	Estimates	*P* value	Estimates	*P* value	Estimates	*P* value
Intercept	1.513	.004	0.685	.10	0.579	<.001
Age	–0.015	.08	N/A[a]	N/A	–0.003	.10
Income (€[b]; reference: 0-20,000)						
20,001-30,000	N/A	N/A	N/A	N/A	–0.00938	.88
30,001-40,000	N/A	N/A	N/A	N/A	0.153	.01
≥40,001	N/A	N/A	N/A	N/A	0.054	.51
Daily internet hours	N/A	N/A	0.093	.07	N/A	N/A
Hospital visit time (hours; reference: 0.5-1)						
<0.5	–0.725	.03	N/A	N/A	N/A	N/A
1-2	–0.246	.35	N/A	N/A	N/A	N/A
2-3	–0.548	.12	N/A	N/A	N/A	N/A
>3	0.613	.37	N/A	N/A	N/A	N/A
Level of control (reference: totally)						
Moderately	0.629	.04	N/A	N/A	N/A	N/A
Little bit	0.328	.36	N/A	N/A	N/A	N/A
Not at all	0.823	.08	N/A	N/A	N/A	N/A
I don’t know	–1.825	.11	N/A	N/A	N/A	N/A
Depression scale (reference: mild)						
None	–0.147	.58	N/A	N/A	N/A	N/A
Moderate	0.259	.43	N/A	N/A	N/A	N/A
Moderately severe	–0.321	.45	N/A	N/A	N/A	N/A
Severe	–1.652	.03	N/A	N/A	N/A	N/A
Life satisfaction scale (reference: satisfied or more)						
Slightly satisfied	0.116	.69	N/A	N/A	N/A	N/A
Neutral	–1.009	.05	N/A	N/A	N/A	N/A
Slightly dissatisfied	–0.589	.08	N/A	N/A	N/A	N/A
Dissatisfied or less	–0.844	.02	N/A	N/A	N/A	N/A
Portal use COVID-19 (reference: daily)						
Weekly or more	N/A	N/A	1.269	.11	N/A	N/A
3-5 times	N/A	N/A	2.050	.06.	N/A	N/A
1-2 times	N/A	N/A	0.124	.74	N/A	N/A
Waiting time (reference: less than 24 hours)						
1-2 days	N/A	N/A	–2.081	<.001	N/A	N/A
>2 days	N/A	N/A	–1.784	<.001	N/A	N/A
Never tried	N/A	N/A	–0.911	.16	N/A	N/A
No possibility	N/A	N/A	–0.681	.35	N/A	N/A
Maximum acceptable waiting time (reference: <12 hours)						
12-24 hours	N/A	N/A	1.187	.006	0.212	<.001
1-2 days	N/A	N/A	2.292	<.001	0.192	.006
>2 days	N/A	N/A	1.502	.03	0.181	.05

Variables	Model 1 portal use (all participants)		Model 2 recommendation (portal users)		Model 3 likelihood of using (portal nonusers)	
	Estimates	*P* value	Estimates	*P* value	Estimates	*P* value
Awareness (reference: yes)	N/A	N/A	N/A	N/A	0.259	<.001
Participants, n	461	N/A	307	N/A	154	N/A
Akaike information criterion	570.87	N/A	246.96	N/A	N/A	N/A
R^2	N/A	N/A	N/A	N/A	0.3554	N/A
Adjusted R^2	N/A	N/A	N/A	N/A	0.2904	N/A

[a] N/A: not applicable.

[b] A currency exchange rate of €1=US $1.18 is applicable.

Discussion

Main Findings and Comparison With Other Studies

Although the societal and health impacts of the COVID-19 pandemic have been present for nearly a year, there is no evidence on factors that affect patient portal adoption among patients who are chronically ill during the COVID-19 pandemic. Moreover, little research has been done on what influences users' willingness to recommend and nonusers' likelihood of using patient portals during the COVID-19 pandemic. Our findings portray some interesting insights for portal service providers and health care professionals.

In the participant population under study, we found that almost 67% (307/461) of participants were portal users, which is much higher than for general patient populations reported [36-38]. For example, Griffin et al [36] found in their study that 83.4% of patients were nonusers of the UNC Chart patient portal among a general patient population. It could be attributed to the difference in the study population and the impact of the COVID-19 pandemic. Ancker et al [39] found that patients with chronic illness were more likely to use a patient portal. Table 3 shows that both the number of portal users and frequency of use have increased significantly after the lockdown initiation in spring 2020. We found that participants whose level of control was moderate had a higher likelihood of using portal systems than participants with total control. This may be attributed to participants' perception whereby they deem a portal as unnecessary when their health is well managed and under control.

Besides, we found that participants with shorter visit times to a hospital have a reduced likelihood of portal use compared to those with longer visit times. As reported in many other studies [40-42], savings on travel time and cost are among the major benefits of eHealth. This result suggests that the convenience of physical visits most likely reduces remote visits using patient portals. Furthermore, participants with severe depression and lower life satisfaction tend to use patient portals less. Mental health problems likely deter patients from using portal systems. This result coincides with the observation that patients with chronic anxiety and depression are less likely to be intense eHealth users [37]. Future studies should focus on determinates of portal use and nonuse in this specific population.

Our results show that older age may negatively affect portal use. It is in line with a recent study in the older population on the intention to use medical applications. Feelings of having control, service availability, perceived ease of use and usefulness, and attitude toward the medical application affect the intention to use in older adults, which may be attributed to anxiety triggered by technology use, lack of privacy, or trust [43]. Another study also argues that this is probably because older people often lack the infrastructure, knowledge, and skills needed to use eHealth programs [44]. Future studies are required to investigate determinants of portal use and nonuse in the older adult population.

Willingness to recommend patient portal systems was also investigated. No less than 83.7% reported willingness to recommend the portal to family and friends, which suggests that most users were satisfied and loyal with their hospital's patient portal system [34]. The average waiting time to receive a response was a strong predictor for users' positive experience using portal systems. Approximately 29% of patients reported receiving responses within 2 hours of a request, which is considered rapid. Numerous studies in the appointment scheduling area have shown the importance of managing waiting time in health care management [45-47]. Marketing research has shown that waiting time is a crucial determinant of customer satisfaction and loyalty [48]. Nonusers seem to expect faster response rates from patient portals than users. Palawatta [49] demonstrated that if nonusers perceive the response rate is longer than their perceived acceptable waiting time, they will feel less satisfied and, therefore, less inclined to try the portal system. Users, if they experience disconfirmation in waiting time and maximum acceptable waiting time, are likely to be less satisfied and therefore less likely to remain committed to using the portal system. These are essential insights for health care practitioners and managers to leverage operational efficiencies such as appointment scheduling and resource allocation.

Among the nonuser group, the majority (85/154, 55%) reported not being aware of a patient portal system at their hospital. Awareness of portal systems was found to be the largest predictor for future use in our study. It seems that many patients do not use portals partly due to unawareness of their existence. This result is in line with Griffin et al [36], who found that patients often did not use patient portals simply because they were unaware of their existence. This result suggests that enhancing the awareness of portal systems is the first step for health care organizations to take to increase portal use.

Limitations and Future Research

There are some limitations bound to this study. First, the survey is cross-sectional, making it impossible to make causal claims, limiting the study to predictions only. Furthermore, the study relies on self-reported data on portal use. This is because when the study was implemented, we did not have access to the actual use data, such as log data of portal users. Besides, this survey focused on both portal users and nonusers to study factors that influence portal use and future use of nonusers. This, for example, cannot be replicated by merely approaching the actual users. However, it would be more insightful to use real use data (eg, log data retrieved from the portal) to establish the length and frequency of use. We suggest this as a future study when access to portal data is possible.

Second, the study invited participants via social media (Facebook peer support group) to complete the self-administered questionnaire. On one hand, sampling from Facebook support groups has apparent benefits, such as convenience and its focus on the targeted population. On the other hand, it also has a few known biases [50,51]. For example, Facebook excludes people who have a lower eHealth literacy, one important predictor of portal use among adult patients [22]. Besides, not everybody uses Facebook, especially older people. Although this problem is partly compensated by focusing on the age group 18 to 65 years, our results might overestimate the proportion of portal users among the total population. This partly explains why the ratio of portal users is higher than reported in many other studies. Little is known about the characteristics of people who do not use technology and why they do not use the portal. We suggest that future studies should focus on older people and people with less eHealth literacy.

Moreover, more females than males participated in this study. According to Smith [52], females are more likely to respond to (online) surveys than males. The authors proposed different reasons that could be grounded to this observation, including behavioral differences between males and females in relation to the internet or inherent internal feelings. Another study [53] found similar results (70% female response).

Finally, it is important to see which functionalities users use and the respective frequency to understand the perceived value of these functionalities to patients. This will potentially improve the frequency of use and tailoring portal systems according to the needs of patient. Future research could build on our results, aimed at further investigation of the use dimension of patient portals.

Conclusion

Individuals that have spent less time on physical hospital visits, whose health is moderately under control or with severe depression or lower life satisfaction are less likely to use patient portal systems. Among users, short waiting time was the most important predictor for satisfaction of portal use, and among nonusers, awareness was the most important predictor of future portal system use. These findings provide insights for health care providers on how to promote patient portal use and improve user satisfaction.

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Conflicts of Interest

None declared.

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Abbreviations

IRB: Institutional Review Board

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Original Paper

Independent Use of a Home-Based Telemonitoring App by Older Patients With Multimorbidity and Mild Cognitive Impairment: Qualitative Study

Madlen Scheibe[1], Dr rer medic, Dipl-Soz; Caroline Lang[1], Dipl-Berufspäd, MPH; Diana Druschke[1], Dipl-Psych; Katrin Arnold[1], Dipl-Soz; Edwin Luntz[1], Dipl-Soz; Jochen Schmitt[1], MD, MPH; Vjera Holthoff-Detto[2,3], MD

[1]Center for Evidence-Based Healthcare, University Hospital Carl Gustav Carus and Carl Gustav Carus Faculty of Medicine, Technische Universität Dresden, Dresden, Germany

[2]Department of Psychiatry, Psychotherapy and Psychosomatics, Alexianer Hospital Hedwigshöhe, St Hedwig Hospital Berlin, Berlin, Germany

[3]Carl Gustav Carus Faculty of Medicine, Technische Universität Dresden, Dresden, Germany

Corresponding Author:
Madlen Scheibe, Dr rer medic, Dipl-Soz
Center for Evidence-Based Healthcare
University Hospital Carl Gustav Carus and Carl Gustav Carus Faculty of Medicine
Technische Universität Dresden
Fetscherstraße 74
Dresden, 01307
Germany
Phone: 49 351 458 2815
Email: Madlen.Scheibe@ukdd.de

Abstract

Background: The management of multimorbidity is complex and patients have a high burden of disease. When symptoms of dementia also appear, it becomes even more difficult for patients to cope with their everyday lives and manage their diseases. Home-based telemonitoring may support older patients with multimorbidity and mild cognitive impairment (MCI) in their regular monitoring and self-management. However, to date, there has been no investigation into whether patients with MCI are able to operate a telemonitoring app independently to manage their own diseases. This question has become even more important during the current COVID-19 pandemic to maintain high-quality medical care for this patient group.

Objective: We examined the following research questions: (1) How do patients with MCI assess the usability of the telemonitoring app? (2) How do patients with MCI assess the range of functions offered by the telemonitoring app? (3) Was there an additional benefit for the patients with MCI in using the telemonitoring app? (4) Were patients with MCI able to use the telemonitoring app independently and without restrictions? (5) To what extent does previous experience with smartphones, tablets, or computers influence the perceived ease of use of the telemonitoring app?

Methods: We performed a formative evaluation of a telemonitoring app. Therefore, we carried out a qualitative study and conducted guided interviews. All interviews were audio-recorded, transcribed verbatim, and analyzed using the Mayring method of structured content analysis.

Results: Twelve patients (8 women, 4 men) were interviewed; they had an average age of 78.7 years (SD 5.6) and an average Mini-Mental State Examination score of 24.5 (SD 1.6). The interviews lasted between 17 and 75 minutes (mean 41.8 minutes, SD 19.4). Nine patients reported that the telemonitoring app was easy to use. All respondents assessed the range of functions as good or adequate. Desired functionalities mainly included more innovative and varied educational material, better fit of the telemonitoring app for specific needs of patients with MCI, and a more individually tailored content. Ten of the 12 patients stated that the telemonitoring app had an additional benefit for them. Most frequently reported benefits included increased feeling of security, appreciation of regular monitoring of vital parameters, and increased independence due to telemonitoring. Eight patients were able to operate the app independently. Participants found the app easy to use regardless of whether they had prior experience with smartphones, tablets, or computers.

Conclusions: The majority of examined patients with MCI were capable of operating the telemonitoring app independently. Crucial components in attaining independent use were comprehensive personal support from the start of use and appropriate design features. This study provides initial evidence that patients with MCI could increasingly be considered as a relevant user group of telemonitoring apps.

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KEYWORDS

telemedicine; aged; multimorbidity; dementia; patient acceptance of health care; health care quality, access, and evaluation; qualitative research

Introduction

Background

Multimorbidity, defined as the simultaneous occurrence of at least two chronic diseases, is a characteristic of the health situation of older people and is common among those in high-income countries [1]. In 2019, more than 58% of adults aged 65 years or over were suffering from multimorbidity in Organisation for Economic Cooperation and Development (OECD) countries and this figure reached up to 70% or more in Germany [2]. The management of multimorbidity is often complex, and patients face several challenges in terms of understanding and self-managing the conditions and medication, regularly monitoring several clinically relevant vital parameters, and coordinating multiple medical services [3,4]. Multimorbidity is also associated with polypharmacy, including the risk of adverse drug events, a decline in physical functioning, or increased health care utilization such as emergency admissions [5-9]. This often results in decreased quality of life, including psychological distress [1,5,9]. Moreover, mental illnesses such as anxiety and depression are more common in patients with multimorbidity [3]. When symptoms of dementia also appear, it becomes even more difficult for patients to cope with their usual and independent tasks in daily life and manage their own diseases [3]. Additionally, symptoms of dementia act as risk multipliers across all age and morbidity strata, leading to worse health outcomes [10]. It is estimated that in 2019, nearly 20 million people had dementia in OECD countries. This number will more than double by 2050 if current developments continue [2]. Mild cognitive impairment (MCI) represents a preclinical, transitional stage between healthy aging and dementia. MCI has been shown to affect 10%-15% of the population 65 years and older. Each year, 10%-15% of people with amnestic MCI progress to Alzheimer disease compared to only 1%–2% of the healthy older generation [11].

Telemonitoring can play an important role in coping, compensating, and supporting cognition [12,13]. Regular home-based telemonitoring may support older patients with multimorbidity and MCI in their self-management and regular home monitoring of clinically relevant vital parameters. Furthermore, telemonitoring may help patients to feel more secure, remain longer and independently in their familiar home environment, and increase overall quality of life. At the same time, telemonitoring helps to relieve the burden on formal and informal caregivers [12-16].

There are already a large number of telemonitoring apps available for different kinds of chronic diseases, with corresponding usability and acceptance evaluations that have been summarized in several systematic reviews [17-20]. However, the number of existing studies and evaluations on telemonitoring apps focusing on multimorbidity is currently limited [21-23]. Another issue that has not yet been investigated is whether patients with MCI are able to use a telemonitoring app independently, and how they assess usability and acceptance. This target group is considerably large and so too is the associated potential for improved care. Therefore, the aim of this study was to help close this research gap.

Within our study, "usability" was defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" [24], whereas user acceptance was defined as the "attitude towards a particular situation" [25].

The question of whether patients concurrently suffering from multiple chronic diseases and MCI would be able to use telemonitoring apps has become even more important in recent months due to the COVID-19 pandemic. Telemonitoring apps can be of great value, especially for vulnerable patient groups such as the chronically ill, as patient care was only possible to a limited extent during the lockdown. For example, outpatient visits were cancelled or postponed, and the availability of in-person support services was reduced [26,27]. In addition, especially in such isolation situations, people with chronic illness depend on close health care to prevent serious complications or even death resulting from those complications [28-30]. The health care system needs to respond to the needs of patients suffering from chronic noncommunicable diseases, which are the majority of conditions [31]. Disease-tailored and easy-to-use home-based telemonitoring solutions could be a suitable measure to continue the care for chronically ill patients while maintaining the legally required social distance, and to give them the secure feeling of being well cared for [28,29,32].

Study Aims and Research Questions

This study was part of the feasibility study "Autonomy despite multimorbidity in Saxony through patient empowerment, holistic care for older people with networking of all regional institutions and service providers" (ATMoSPHAERE) performed between October 2015 and June 2019. The main aim of the study was the iterative development of a technology-based information and communication platform enabling an intersectoral networking of treating physicians in practices, nurses, therapists, social services, and patients with multimorbidity and their caregivers. The comprehensive study design has already been reported elsewhere [33,34]. Within the study, a telemonitoring app for patients was developed (see Description of the Telemonitoring App in the Methods section). The aim of this study was to perform a formative evaluation of the telemonitoring app from the perspective of older patients with multimorbidity suffering from MCI.

In detail, we examined the following research questions by means of a qualitative study: (1) How do patients with MCI assess the usability of the telemonitoring app? (2) How do patients with MCI assess the range of functions offered by the telemonitoring app? (3) Was there an additional benefit for the patients with MCI in using the telemonitoring app? (4) Were patients with MCI able to use the telemonitoring app independently and without restrictions? (5) To what extent does previous experience with smartphones, tablets, or computers influence the perceived ease of use of the telemonitoring app?

Overall, our formative evaluation had two aims. The first aim was to examine the usability of the app and possibilities of independent use to evaluate its perceived ease of use. The second aim was to evaluate the content and the additional benefits resulting from the use of the telemonitoring app to assess its perceived additional benefits. Both evaluation issues were equally relevant for an adequate evaluation to develop an individually tailored telemonitoring app.

Methods

Study Design

We opted for a formative evaluation to assess a telemonitoring app that was under development while performing this study. Patient feedback from the interviews provided important aspects for the further iterative development process of the telemonitoring app in line with the needs of the target group [35-37].

When planning the substudy, we had to consider what could be expected of this target group. We had to make sure that the formative evaluation would not lead to excessive demands over and above those caused by actual usage of the telemonitoring app. Keeping this in mind, we decided to apply only one iteration stage and chose the qualitative method of guided interviews for this target group.

We opted to use personal interviews instead of questionnaires since we expected a certain degree of insecurity and restraint toward the research topic among the participants due to a possible lack of previous experience [38]. We used this method as it was particularly advantageous for our vulnerable patient group. This method enabled a personal conversation, thus facilitating a relationship of trust to be established; if necessary, one could explain something again or, in case of ambiguities, one could specifically ask for more information. Additionally, this approach enabled us to adapt the interview guideline flexibly according to the participants and their individual characteristics (eg, health status, individual burden of disease, life situation), and their previous experience in handling tablets, smartphones, or telemedicine solutions [39-41]. At the same time, the use of an interview guideline enables comparisons between the interviews and also prevents storytelling from digressing too far [40,42,43].

Recruitment of General Practitioners and Study Patients

Potential general practitioners were partners within a network of accredited academic teaching practices. Their practices were located in the city of Dresden, Germany, with approximately 560,000 inhabitants. Interested general practitioners were recruited in network meetings. They were informed about the study and signed a declaration of consent form.

Study patients were recruited by the general practitioners. Study nurses screened patients by applying the validated measuring instruments Mini-Mental State Examination (MMSE; assessment based on [44], German version [45]) and the Clock-Drawing Test [46] to assess cognition, as well as the Timed Up & Go test [47] to assess the mobility of potential study patients. The crucial factor for study inclusion was the degree of cognitive impairment, which was assessed by an MMSE score of 20-26 at the baseline assessment. Patients who were found to be eligible and met the inclusion criteria (Textbox 1) were informed by their general practitioner about the study and received written information. After patients decided to participate, they signed a declaration of consent form. Patients could withdraw their consent at any time.

Study patients were asked about their readiness for a personal interview after using the telemonitoring app for at least 2 months. After the study patients agreed to be interviewed, a researcher informed them about the interview details. Participants were included regardless of whether or not they had prior experience with the use of smartphones, tablets, or computers.

Textbox 1. Study inclusion and exclusion criteria.

Inclusion criteria

- Age ≥65 years
- Multimorbidity (presence of at least two chronic diseases)
- Mild cognitive impairment defined by a Mini-Mental State Examination (MMSE) score between 20 and 26 or mild dementia according to International Classification of Diseases (ICD)-10
- Capable of understanding patient information and consenting to the study
- Independent operation of television via remote control and/or computer/laptop three or more times per week
- Unimpaired hearing
- Sufficient motoric and sensory speech ability
- Sufficient eyesight to follow a television program easily

Exclusion criteria

- Missing capacity of consent
- Unable to speak German fluently
- Moderate to severe dementia defined by an MMSE score <20 or according to ICD-10
- Motoric impairment (Timed-Up & Go test ≥30 seconds in initial measurement, 20-29 seconds in two repeated measurements)
- Severe psychiatric comorbidities (eg, schizophrenic psychoses, addictions)
- Currently participating in a comparable telemonitoring program or participation within the last 12 months

Description of the Telemonitoring App

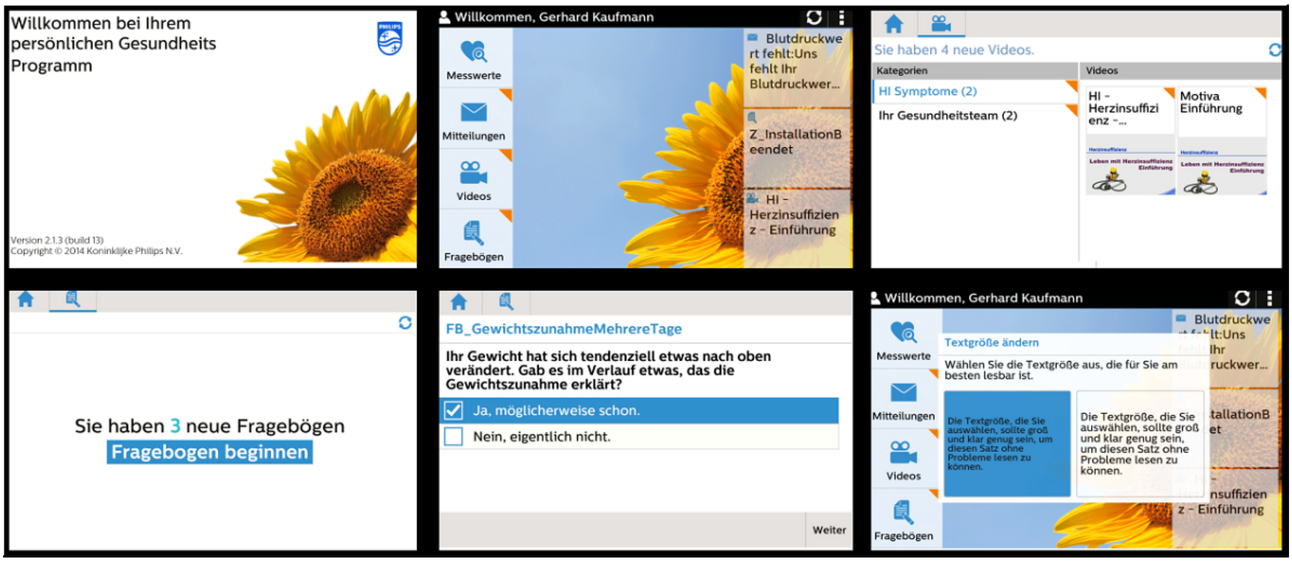
The telemonitoring app was provided by the technical project partner Philips Medical Systems GmbH (hereafter Philips) and consisted of the telemonitoring software Motiva, the telemonitoring hardware in the form of a tablet (ASUS ZenPad 7.0 or Samsung Tab 4), as well as a Bluetooth-enabled sphygmomanometer. Figure 1 shows images of the telemonitoring app's user interface.

After study inclusion, study patients were instructed at home on the use of the hardware and software by a technician from the German Red Cross. In addition, they received a user manual where essential functions were explained in an easy-to-understand way.

Table 1 provides an overview of the functionalities offered by the telemonitoring app and the corresponding tasks that patients were responsible for performing according to the general practitioner's treatment regime.

All collected patient data were transferred to the ATMoSPHAERE platform and could be viewed by the responsible general practitioner (Figure 2).

Figure 1. Screenshots of the user interface of the telemonitoring app.



Willkommen bei Ihrem persönlichen Gesundheits Programm

Version 2.1.3 (build 13)
Copyright © 2014 Koninklijke Philips N.V.

Willkommen, Gerhard Kaufmann

Blutdruckwert fehlt:Uns fehlt Ihr Blutdruckwer...

Z_InstallationBeendet

HI - Herzinsuffizienz - Einführung

Sie haben 4 neue Videos.

Sie haben 3 neue Fragebögen

FB_GewichtszunahmeMehrereTage

Ihr Gewicht hat sich tendenziell etwas nach oben verändert. Gab es im Verlauf etwas, das die Gewichtszunahme erklärt?

☑ Ja, möglicherweise schon.

☐ Nein, eigentlich nicht.

Willkommen, Gerhard Kaufmann

Textgröße ändern

Wählen Sie die Textgröße aus, die für Sie am besten lesbar ist.

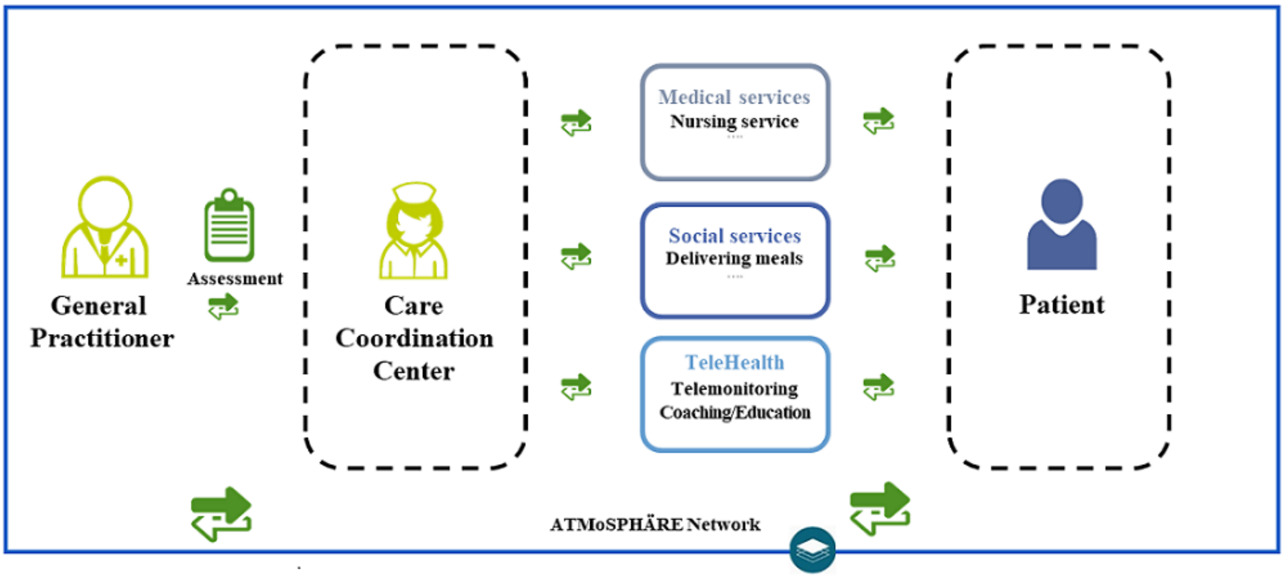
Die Textgröße, die Sie auswählen, sollte groß und klar genug sein, um diesen Satz ohne Probleme lesen zu können.

Die Textgröße, die Sie auswählen, sollte groß und klar genug sein, um diesen Satz ohne Probleme lesen zu können.

Table 1. Overview of functionalities of the telemonitoring app and patient tasks to be performed.

Functionalities offered by the telemonitoring app	Patient tasks to be performed
Measurement of vital data with provided measuring devices at predefined times according to the general practitioner’s treatment regime; data are automatically transmitted to the tablet and to a German Red Cross care coordination center for intervention necessity assessment	Once per week: measurement of blood pressure and heart frequency
Continuous weekday monitoring of measured vital data values by case and care managers at the care coordination center; these managers contact patients in case of exceeding vital data values for possible therapeutic intervention (thresholds predefined by general practitioner)	Completing intervention questionnaires providing information about the reasons for deviation to the case and care managers to derive possible therapeutic interventions
Overview of measured vital data and vital data charts	Not applicable
Regular provision of patient questionnaires	Once at the beginning: completing a questionnaire on general health conditions Once per week: Completing questionnaires on treatment modifications, medication adherence, sleeping habits, pain, alcohol and tobacco consumption, and the disease-specific health status (eg, chronic heart failure and type 2 diabetes) Depending on individual needs: completing additional questionnaires sent by the case and care managers (eg, on the topics of nutrition and depression)
Provision of educational and training material, particularly instructional videos for individual chronic diseases	Not applicable
Receiving messages from the case and care managers (eg, reminder of measurement or answering questionnaires, video recommendations, or congratulations on milestones)	Not applicable

Figure 2. ATMoSPHAERE network including the telemonitoring app. ATMoSPHAERE: Autonomy despite multimorbidity in Saxony through patient empowerment, holistic care for older people with networking of all regional institutions and service providers.



Theoretical Framework and Interview Guideline

As a basis for the guided interviews, we developed a uniform guideline with open-ended questions (see Multimedia Appendix 1). A specially created set of usability criteria and comprehensive overview of acceptance factors with explicit regard to the requirements of older people concerning telemedicine apps has previously been developed and published by one of the authors of this study [38,48,49], which has been used in several studies to evaluate telemonitoring apps for older people [50-53]. These criteria served as the theoretical framework for guideline development. Guideline development and formulation of interview questions also were established following guidelines from the relevant methods literature [39,54,55].

Data Collection

The patient interviews were conducted between June 2016 and December 2017. Continuous study inclusion facilitated the interviewing of new study participants throughout the study period. All study patients received the same telemonitoring equipment (tablet, sphygmomanometer). To enable comparisons among patients, all interviews were based on the same interview guideline. All patients opted for a face-to-face-interview at their homes. All interviews were audio-recorded.

Data Evaluation

All interviews were transcribed verbatim. The transcripts then served as the foundation upon which consecutive data analysis was performed. All interviews were analyzed applying the method of structured content analysis developed by Mayring [56]. This is the central content analysis technique and allows for an association between the deductive and inductive creation of categories [56,57]. The analytical focus was on designing a system of categories and subcategories, as well as their characteristics [56], which in turn served as structural dimensions.

Coding started with the development of an initial deductive category system derived from the questions in the interview guideline, discussed and agreed upon within the research team (DD, KA, MS, EL). Two analyzing researchers (EL, MS) coded two interviews independently to further develop the category system. These researchers differed in age and gender to allow for diversity of perspectives in the context of data analysis. This was then discussed by the entire research team and consolidated. The consolidated category system was then used by two researchers (EL, MS) as the basis for coding all interviews. During analysis, the coders independently specified, modified, or removed categories based on the text material. Missing but relevant categories were added inductively based on the transcripts. This process was continued until saturation of the category system was reached (ie, no new categories emerged) [57].

The inductive development of categories was carried out as follows. Based on the textual material in the transcripts, units of meaning formed the units of analysis. Relevant content of the units of meaning was paraphrased to generate a category label. In accordance with recommendations from the methodological literature, a low level of abstraction was initially selected for the generation of category labels [56]. It was scaled down in the course of analysis and further review of the text material. Subsequently, the abstraction level of the different categories was harmonized to reach a final uniform abstraction level of the category system. Finally, the assignment of individual text sections to the respective categories was reviewed again by the entire research team. Differences in coding were discussed and resolved by consent. If necessary, text segments were recoded accordingly.

Our approach complied with the principles of openness and investigator triangulation within qualitative research [40,54]. For data analysis, the software MAXQDA (MAXQDA Plus 12 portable) was used.

The chosen method allowed us to individually adapt the interview guideline to the actual interview and to the aspects presented as relevant by the participants. In turn, this resulted in interviews where we were not able to ask all possible questions, patients did not answer questions even after the question was repeated, or where the participants themselves added new aspects.

Ethics Approval

The ethics committee at Technische Universität Dresden (approval number EK 1012016) approved the study.

Results

Patient Characteristics and Interview Duration

Of the 19 participants that met the inclusion criteria of our study, 12 agreed to be interviewed. To achieve the greatest heterogeneity possible within our study sample, we interviewed all 12 patients. The interviews lasted between 17 and 75 minutes (mean 41.8 minutes, SD 19.4). Table 2 shows the patient characteristics of the selected cohort.

Ten study patients used an Asus ZenPad 7.0 tablet and two study patients used a Samsung Tab 4.

Table 2. Characteristics of the interviewed patients and the average result of the Mini-Mental State Examination (MMSE) (N=12).

Patient characteristics	Sample value
Gender, n (%)	
Male	4 (33)
Female	8 (67)
Age category (years), n (%)	
65-74	2 (17)
75-85	9 (75)
≥86	1 (8)
Age (years), mean (SD)	78.7 (5.6)
Marital status, n (%)	
Single/widowed	6 (50)
Married/cohabitation	6 (50)
Number of comorbidities, n (%)	
2-8	7 (58)
≥9	5 (42)
Comorbidity, n (%)	
Essential (primary) hypertension	10 (83)
Type 2 diabetes mellitus	5 (42)
Chronic ischemic heart disease	4 (33)
MMSE score, mean (SD)	24.5 (1.6)

Assessment of Usability by Patients With MCI

Usability of the Telemonitoring App

With respect to experience during the initial phase of use, 7 of 10 patients reported that the telemonitoring app was difficult to understand at the beginning. Six of 11 patients reported a feeling of insecurity.

> *Well, in the beginning I was also doubtful: Can you do it or not or are you doing something wrong? And I was just told, if you entered something wrong, you can always do it again.* [Patient 47]
>
> *Well, I first had to fumble a bit with the thing. I have just a normal phone here. [...] Now it's fine.* [Patient 214]

After talking about the initial phase, we asked patients to describe the current usage situation. We observed a clearly positive development. Nine of the 12 patients reported that the telemonitoring app was easy to use at this time: "I find it easy to use. At the beginning [...] I was also anxious." [Patient 47].

After being asked about difficulties in using the telemonitoring app, one patient answered: "Well, actually nothing more. But the first time, I hadn't really gotten into it. But that was a long time ago." [Patient 214].

With respect to individual usability aspects of the telemonitoring app, 7 of 10 patients understood the presentation of the contents of the telemonitoring app well (ie, the used figures and language). Seven of nine patients rated the used symbols as easy to understand.

The questions which are written in the blue box are clear. And then there's "Start" or "Back" if I saidsomething wrong. [Patient 37]

> *Yes, that's all explained in the manual, yes. It's a nice red triangle, you practically have to press on it and you just need to read it properly.* [Patient 47]

The size of images and illustrations (8/8), the font size (12/12), as well as the color contrast (10/10) were rated as perfectly appropriate by all patients who answered these questions within the interviews.

As another aspect of usability, the effort to make inputs was perceived to be less burdensome by almost all patients (10/11). Seven of 11 patients pointed out that this was made possible due to the automated transmission of vital data from the measuring device to the tablet. Six of seven patients rated the menu navigation as simply structured and easily comprehensible.

Tablet Usability

When examining the usability of a telemonitoring app, it is also worth considering the ease of use of the corresponding hardware in terms of the tablets.

Nine of 10 patients expressed that the tablet was easy to use. However, the patients reported functional problems with the hardware. The very slow startup of the tablet, including difficulties in finding an internet connection (7/9), and the arbitrary change of the device into flight mode, including difficulties in transferring the measured vital data to the ATMoSPHAERE platform (4/9), were most frequently mentioned. Three of nine patients reported difficulties in operating the On/Off switch and the same number were bothered by a low battery life or long charging time of the tablet. These functional issues had a negative impact on the overall satisfaction with the telemonitoring app provided, with only six of nine participants having reported being very satisfied or rather satisfied.

Interviewer*: So, on the whole, would you say it's fun to use that or rather not so much fun?*

Patient 225*: If it worked right, I would enjoy it […].*

Interviewer*: Yes, but as it is now?*

Patient 225*: [...] I always approach it with a bit of mixed feelings.*

Range of Functions of the Telemonitoring App

Six patients assessed the telemonitoring app's range of functions and all rated it is as good or adequate. They also named desired functionalities to be included in the app. Three items were most frequently mentioned. The first item involved provision of more innovative and varied educational materials:

> *Yes, but that's always the same, isn't it? [...] It is always the same there. The woman, I don't know her name and blood sugar and stuff. That's something that gets on my nerves* [Patient 214]

The second item was related to a better fit of the telemonitoring app to the specific needs of patients with MCI:

> *The only thing I have, that really concerns me is my short-term memory. And that is not being treated here. [...] I wish it were, because many people feel that way. [...] And then also about the operating instructions, you could get something every 2 months or 3 months short, a small article, on one page, that's enough: "We'll tell you again about the operating instructions."* [Patient 245]
>
> *Support for dementia development is not in here, is it? But I still hope that maybe at some point it will be further developed, that maybe some suggestions will be implemented.* [Patient 55]

The third item was related to having more individually tailored contents of the telemonitoring app in terms of more individualized questionnaires and response categories or by considering additional diseases within the range of functions:

> *A huge number of food suggestions and so on. But then, maybe other things that would be more interesting. They cannot be queried. I don't know. You can't write anything in it by yourself.* [Patient 245]

Additional Benefits, Negative Effects, and Changes in Everyday Life of Patients With MCI

Additional Benefits of the Telemonitoring App

Ten of the 12 patients stated that the telemonitoring app has an individual additional benefit for them. Eight of the 12 patients stated that they have an increased feeling of security owing to the regular transmission of vital data, and the knowledge that case and care managers are checking their values and will contact them in case of exceeding critical values. Patients reported: "They'll take care of me" [Patient 225] and "[...] one is monitored and that is not wrong in my opinion" [Patient 179]. The fact that some of the interviewees did not have supporting family members in the direct neighborhood reinforced that feeling.

Five of the 12 patients regularly measured their blood pressure only since having started using the telemonitoring app and appreciated that kind of monitoring: "Well, you either just do it or you forget and here, I do it" [Patient 214].

Four of the 12 patients rated as positive the possibility of being able to monitor blood pressure independently of the general practitioner's visit according to their individual needs/feelings. According to one patient, this leads to "[…] independence because you know it's your blood pressure, everything is fine. And you can just go. […] in the beginning someone always had to go shopping with me" [Patient 47].

Furthermore, the following aspects were positively rated by the interviewed patients: the availability of more health-related data as an improved basis for general practitioners' treatment decisions, an individualized overview of the development of vital parameters, and the perception of the telemonitoring app as a welcome change to everyday life.

Negative Effects of Using the Telemonitoring App

Aside from the additional benefit of telemonitoring app use, which was central for the majority of interviewed patients, 2 of the 12 patients also reported negative effects in using the telemonitoring app. The study-related, more frequent measurement of vital data led to uncertainty, because patients could not properly classify fluctuating values due to their lack of expertise. Patients were aware that case and care managers from the German Red Cross intervened in instances of exceeding values, but even slight fluctuations seemed to lead to uncertainty. In addition, differences in the values between the devices used in the study and patients' own measurement devices were reported to be disturbing.

Changes in Everyday Life From Using the Telemonitoring App

We also asked the participants to what extent their everyday life has changed due to the use of the telemonitoring app. Six of nine patients reported that study participation and regular measurements did not represent any significant changes: "[…] you accept this early in the morning, this 5-minute thing in no way makes it difficult" [Patient 179]. Three of nine patients stated that the telemonitoring app even simplified their everyday life. They rated the effort to use it as very little and its integration into everyday life as simple.

Ability of Patients With MCI to Use the Telemonitoring App Independently

Almost all patients (10/11) had received further support after their initial introduction to the telemonitoring app at home. Most commonly (8/11), they received telephone support from the case and care managers at the German Red Cross or got help directly from Philips, or a German Red Cross technician visited patients at their home in the case of serious problems. Four of 11 patients stated that they had used the user manual, which had been given to them at the beginning of use. Besides the support by project staff, family members assisted patients in using the telemonitoring app. For 3 of 11 patients, the partner/spouse and for 4 of 11 patients, other family members such as children and grandchildren played an important role in handling the app. In some cases, patients were not using the telemonitoring app themselves: Patient 55 (supported by daughter), Patient 61 (supported by wife), as well as Patient 68 and Patient 99 (supported by husbands). Patient 68 and Patient 99 showed the lowest MMSE scores (22) within the study population; Patient 55 showed an MMSE score of 26 and Patient 61 had a score of 25. Patients 61 and 68 each had a supporting spouse; these spouses had been included in the overall study (but not in this substudy) and had each achieved a higher MMSE value themselves. This might be the main reason that these supporting spouses took care of the transmission of vital data and other aspects of study participation.

The other eight patients were able to operate the telemonitoring app independently, in spite of their MCI.

Influence of Previous Experience With Smartphones, Tablets, or PCs on Perceived Ease of Use of the Telemonitoring App

Three of the 12 patients reported previous experience with a computer but not with a smartphone or a tablet. One patient stated previous experience with a smartphone/tablet but not with a computer. Two patients had already used both a computer and a smartphone/tablet. Two patients had never used a computer, smartphone, or tablet before. Four patients did not comment on this question.

In the context of evaluation, we considered separately to what extent people without prior experience might have had greater difficulties in using the telemonitoring app. The participants found the app easy to use regardless of whether or not they had prior experience, and there were no clear differences in the assessment of the individual usability aspects examined. Only one of the 12 patients, who already had previous experience with a smartphone, found the telemonitoring app difficult to use.

Discussion

Main Findings

To our knowledge, our study is the first to investigate whether patients with MCI are able to operate an app for monitoring their multiple chronic diseases, and how they evaluate its usability and additional benefits for their everyday life.

As one main result, we were able to show that the majority of examined patients with MCI were capable of operating a telemonitoring app independently. However, we also found the following framework conditions and features of the telemonitoring app to be crucial preconditions for independent telemonitoring by patients with MCI, resulting in high perceived ease-of-use: personal support and design features.

All patients, with one exception, received further support after their initial introduction to the telemonitoring app at their home. Most commonly, they received telephone support from the case and care managers at the German Red Cross or directly from Philips, or a German Red Cross technician visited the patients at home in the case of major problems. Thus, a personal introduction and the availability of constant and familiar contact persons are important in decreasing the perceived effort of use and increasing acceptance among this target group. Our previous studies with older patients suffering from chronic diseases also found this to be a key acceptance factor [38,49]. These factors have already been assessed as crucial in the “Senior Technology Acceptance & Adoption Model (STAM)” [58] and by Schmid et al [59]. Furthermore, the availability of constant and familiar contact people also reduces the fear that using technology may result in loss of human contact [12].

Perceived ease of use and perceived additional benefit are the main impact factors on user acceptance within various well-known technology acceptance models [58,60,61]. The following design features of the telemonitoring app examined resulted in high usability, and therefore in high perceived ease of use, for patients with MCI: (1) use of understandable semantics (eg, no foreign language words or technical terms that are not generally understandable); (2) use of easily understandable outputs and displays; (3) easily understandable and self-explanatory menu structures; (4) easily understandable navigation to the desired content of the telemonitoring app; (5) sufficient sizes of fonts and illustrations; (6) sufficient color contrast; (7) low input effort through automatic transmission of blood pressure values; and (8) clearly understandable feedback from the platform on (incorrect) input.

The telemonitoring app examined largely met the criteria that earlier studies have shown to be crucial for a high level of usability for older users [12,38,48,49,59]. This in turn led to higher user adherence [62]. However, usability was partly restricted by functional problems of the hardware that resulted in patient dissatisfaction. These reliability problems can result in a lack of trust and less extensive use or even end of use [34,63,64]. Hardware robustness and a stable internet connection are two key requirements for enabling the use of a telemonitoring app. Both have been highlighted as crucial issues in many studies [53,65,66]. If both requirements are not met, independent operation and use of support services are significantly more difficult or even not possible. Vulnerable individuals, especially those with cognitive impairment, could become worried by experienced difficulties. This can lead to the fact that otherwise useful telemonitoring apps may not be beneficial for these patients. Additionally, a fundamentally high usability of the telemonitoring app and permanently available contact persons for technical questions are crucial to relieve the burden on informal caregivers. For older patients with MCI, these people are often the first point of contact for questions and usage problems, and difficulties would thus put them under additional strain [67,68].

As another main result, our study revealed that the participants found the telemonitoring app easy to use regardless of whether or not they had previous experience with the use of smartphones, tablets, or computers; this presupposes that the telemonitoring app has the relevant design features mentioned above and that personal support is continuously available on weekdays.

However, our study results also discovered that some of the patients hardly ever worked with the app themselves, and their relatives predominantly operated the app instead. In future studies, patients experiencing difficulty could possibly operate the telemonitoring app together with their spouses or other relatives living close by. This could contribute to a feeling of security and support for both sides. However, the use of the telemonitoring app can be problematic for patients who live alone and do not receive any support from other individuals. Therefore, future research should examine how a telemonitoring app with personal support should be designed and function to enable independent usage by this vulnerable target group. In this context, future telemonitoring apps should be developed in close cooperation with patients with MCI to consider their needs and perspectives comprehensively. This kind of codesigning has also been emphasized as a central requirement for a high degree of usability and user acceptance within several studies [14,69-72]. In addition, greater patient involvement can lead to empowering effects among this patient group [70,71].

The majority of patients with MCI perceived the telemonitoring of their state of health as beneficial. Most frequently, the patients reported an increased feeling of security. Other studies have also shown this aspect as a significant benefit of telemonitoring app usage by older patients [73,74]. In addition, the possibility of being able to measure blood pressure independently of a general practitioner visit led to more autonomy and independence according to the opinion of four study patients. Several studies have shown autonomy of patients to be a positive outcome of telemedicine interventions, as indicated in a recent review by Kruse et al [75]. This effect is especially valuable for multimorbid, older patients with MCI who are facing several challenges in terms of understanding and self-managing their health conditions [8,9]. The management of multimorbidity is often complex, and patients face several challenges in terms of understanding and self-managing the conditions and medication, regular monitoring of several clinically relevant vital parameters, and coordinating multiple medical services [3,4].

Our study also showed that patients with MCI desired greater consideration of individual characteristics within the telemonitoring app. They explicitly asked for more individualized questionnaires and response categories. They also stated that additional diseases should be considered in the development of the telemonitoring app. Other studies also verified an individually adjustable and modular content of the app to be crucial for increasing perceived usefulness among the highly heterogeneous older population with chronic illnesses [38,48,49,59,69,73,76]. The challenge for the app development process is to enable customization and guarantee high usability at the same time. The consideration of artificial intelligence or self-learning approaches could be useful in this matter.

This study was a formative evaluation as part of an iterative development process. The telemonitoring was further developed in accordance with the feedback from the interviews. In the course of the project, patients were also able to use Fresh Minder apps for memory training [77]. Moreover, additional questionnaires and care plans (eg, for pain, dizziness, sleep, and activity) were developed and implemented, and offers for potentially helpful social and nursing services were added.

With regard to coping with the effects of the COVID-19 pandemic, our results have shown that telemonitoring of older patients with multimorbidity and MCI is feasible. Studies have also shown that the pandemic has changed health care toward increased acceptance and utilization of telemedicine by both patients and providers [29,32]. Furthermore, telemonitoring can help to reduce fears, insecurities, and the feeling of social isolation among those affected [29], which also plays an important role in coping with the COVID-19 pandemic.

Implications for Future Research

Telemedicine solutions for patients with MCI had already focused on the following topics, which have been systematically reviewed by Lorenz et al [13]: preservation or improvement of memory performance [78,79], app-based memory training [77,80], preservation of fitness and agility [81], preservation of an independent way of life [82], and provision of information about dementia [79]. All of these topics focused exclusively on patients with cognitive impairment. Future research should focus more on influencing factors enabling patients with multimorbidity and MCI to take an active and participatory role within their treatment process by using telemonitoring apps. Furthermore, research is needed to examine up to which severity stage of dementia patients are able to use a telemonitoring app. Therefore, more qualitative and quantitative studies are required to explore this topic in further detail.

Future studies should be performed in a controlled design. It would be expedient to investigate whether and how telemonitoring itself, and the increased feeling of security and independence, affect the number of general practitioner visits, vital parameters, disease progression, medication adherence, emergency admissions or admissions to nursing homes, quality of life, depression, or empowerment. Furthermore, a health economic evaluation would be useful to examine whether the use of such a telemonitoring app can lead to better care at the same costs or with cost savings.

Implications for Practice

Our study provides initial evidence for the usage of a telemonitoring app by individuals with MCI. We showed that patients with multimorbidity and MCI can be considered as a target group for the use of telemonitoring apps if the above-mentioned conditions are met. For general practitioners and other health professionals, it is important to carefully select which patients are suitable for using such technology and to intensively discuss this option with the patients. Any existing concerns can also be addressed in this context. The patient's needs and own perceptions, including in the sense of self-selection, are essential requirements for successful use. For individuals with various preexisting chronic conditions, it is essential to carefully determine whether such an app offers effective support. Basically, such apps must fit into the individual treatment pathway and should not represent an additional burden for either the patient or the physician. In this context, it should be taken into account whether relatives are available or whether the patient lives alone and how this might affect use of the telemonitoring app. In addition, the general practitioner or health care professional and the patient should regularly assess and jointly decide whether or not such an app remains suitable.

Overall, the COVID-19 pandemic has caused a rethinking of many issues, which may lead to greater receptiveness among this patient group and treating physicians for such apps.

Strengths and Limitations

This study was carried out as part of the ATMoSPHAERE project, which ended in June 2019 and focused on older patients with MCI. To our knowledge, our study was the first to investigate whether patients with MCI are able to operate a telemonitoring app for managing symptoms of their multiple chronic diseases. We were able to show that the majority of examined patients with MCI were capable of operating a telemonitoring app independently. With regard to ensuring adequate care for multimorbid, chronically ill patients with MCI during the COVID-19 pandemic, this result is highly valuable. Furthermore, our results on relevant acceptance and usability factors of such a telemonitoring app provide important information for the design and implementation of future home-based telemedicine solutions. Our study design and results can be used as a starting point for quantitative studies in this field with a larger sample size and a controlled study design.

In addition to its strengths, our study also has limitations. The recruitment of patients from this vulnerable group was difficult because of concerns regarding their own abilities to operate a telemonitoring app; hence, the occurrence of a selection bias cannot be excluded. Moreover, some patients from this cohort dropped out of the overall study before the qualitative study started due to technical difficulties with the telemonitoring app examined. Finally, we included all 12 patients who met the inclusion criteria and agreed to be interviewed to achieve the greatest heterogeneity possible within our study sample. During the interview series, we noticed that the patients' responses were repeated toward the end and we reached saturation concerning the topics addressed in the interviews with our available sample. However, it cannot be excluded that the inclusion of further patients with MCI would have opened other relevant topics. When interviewing study participants, there is always the possibility that their answers are influenced by social desirability, which in turn could lead to biased results. To tackle this issue, we opted for an open interview setting, gave the participants the chance to ask questions, and kept the number of people present during the interview to a minimum. In addition, recall bias can exist, particularly in the case of interviewing patients with MCI. Some patients did not adhere to the interview topics and talked about aspects subjectively perceived to be relevant. Hence, some questions remained unanswered or may have been answered inadequately (response bias). However, our study design and results provide a valuable basis for future studies with a larger sample size.

Conclusions

When continuous personal support was available right from the start of use and when the app was tailored in a needs- and disease-specific design, ensuring high perceived ease of use, the majority of examined patients with MCI were capable of operating the telemonitoring app independently. Hence, this study provides initial evidence that older patients with multimorbidity and MCI could increasingly be considered as a relevant user group for telemonitoring apps and should be involved as codesigners in their development. Future studies should investigate this issue further with a larger sample of patients with MCI.

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Authors' Contributions

The overall study and the presented substudy focusing on patients with MCI were conceived and designed by VH, JS, DD, and MS. VH was in charge of the overall direction and planning of the study. CL supported the recruitment of general practitioners and study patients. The interview guideline was initially developed by MS, and discussed and consented to by the entire research team (all authors). The interviews were conducted by KA, DD, and MS. Data evaluation was carried out by MS, EL, DD, and KA. MS wrote the manuscript with considerable input from CL. All authors reviewed and commented on the final manuscript.

Conflicts of Interest

None declared. Unrelated to this project, JS received institutional funding from Sanofi, Novartis, ALK, and Pfizer for investigator-initiated research, and acted as a consultant for Lilly, Novartis, and Sanofi.

Multimedia Appendix 1
Interview guideline.
[PDF File (Adobe PDF File), 575 KB - humanfactors_v8i3e27156_app1.pdf]

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Abbreviations

ATMoSPHAERE: Autonomy despite multimorbidity in Saxony through patient empowerment, holistic care for older people with networking of all regional institutions and service providers
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
OECD: Organisation for Economic Co-operation and Development

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Original Paper

Applying Mobile Technology to Sustain Physical Activity After Completion of Cardiac Rehabilitation: Acceptability Study

Abdelaziz Elnaggar[1], MBBS, MPH; Julia von Oppenfeld[2], BA; Mary A Whooley[2,3,4], MD; Stephanie Merek[2], MPH; Linda G Park[1,2], MS, FNP-BC, PhD

[1]Department of Community Health Systems, School of Nursing, University of California San Francisco, San Francisco, CA, United States
[2]Veterans Affairs Medical Center, San Francisco, CA, United States
[3]Department of Medicine, University of California San Francisco, San Francisco, CA, United States
[4]Department of Epidemiology & Biostatistics, University of California San Francisco, San Francisco, CA, United States

Corresponding Author:
Linda G Park, MS, FNP-BC, PhD
Department of Community Health Systems
School of Nursing
University of California San Francisco
2 Koret Way
Room 531A
San Francisco, CA, 94143-0610
United States
Phone: 1 415 502 6616
Email: linda.park@ucsf.edu

Abstract

Background: Many patients do not meet the recommended levels of physical activity after completing a cardiac rehabilitation (CR) program. Wearable activity trackers and mobile phone apps are promising potential self-management tools for maintaining physical activity after CR completion.

Objective: This study aims to evaluate the acceptability of a wearable device, mobile app, and push messages to facilitate physical activity following CR completion.

Methods: We used semistructured interviews to assess the acceptability of various mobile technologies after participation in a pilot randomized controlled trial. Intervention patients in the randomized controlled trial wore the Fitbit Charge 2, used the Movn mobile app, and received push messages on cardiovascular disease prevention and physical activity for over 2 months. We asked 26 intervention group participants for feedback about their experience with the technology and conducted semistructured individual interviews with 7 representative participants. We used thematic analysis to create the main themes from individual interviews.

Results: Our sample included participants with a mean age of 66.7 (SD 8.6) years; 23% (6/26) were female. Overall, there were varying levels of satisfaction with different technology components. There were 7 participants who completed the satisfaction questionnaires and participated in the interviews. The Fitbit and Movn mobile app received high satisfaction scores of 4.86 and 4.5, respectively, whereas push messages had a score of 3.14 out of 5. We identified four main themes through the interviews: technology use increased motivation to be physically active, technology use served as a reminder to be physically active, recommendations for technology to improve user experience, and desire for personal feedback.

Conclusions: By applying a wearable activity tracker, mobile phone app, and push messages, our study showed strong potential for the adoption of new technologies by older adults to maintain physical activity after CR completion. Future research should include a larger sample over a longer period using a mixed methods approach to assess the efficacy of technology use for promoting long-term physical activity behavior in older adults.

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KEYWORDS

physical activity; cardiac rehabilitation; digital health; mobile app; wearable device, mHealth; mobile phone

Introduction

Background

After a major cardiac event, such as myocardial infarction or coronary revascularization, the current class 1A recommendation is to refer patients to cardiac rehabilitation (CR) [1-3]. CR is an important evidence-based exercise and secondary prevention program that reduces mortality and secondary events after cardiac events with the goal of continuing physical activity in patients after program completion [4-7]. However, many studies have shown that patients fail to maintain physical activity after completing CR and often return to a sedentary lifestyle [8,9]. Therefore, more targeted interventions are needed to promote physical activity maintenance after CR completion.

As smartphone ownership increases across age groups [10], mobile health (mHealth) technologies, including text messages or mobile apps, have emerged as a promising interactive intervention to promote self-management of behaviors, such as physical activity [11,12]. Mobile apps coupled with wearable activity trackers are useful tools for the self-management of physical activity. Self-management is achieved through instant visual feedback delivered by the mobile app and stored data on patterns (eg, weekly trends in physical activity) [13,14].

mHealth interventions have shown a range of positive behavioral changes, including increasing self-monitoring and self-care, as well as facilitating peer and social support [15,16]. In addition, mHealth has been used to induce behavioral changes to target self-management of chronic conditions. Physical activity has been one of the main uses of mHealth [17-19] with the advent of wearable devices, however, there is high variability in engagement with health apps (ie, several times a day to once a month). Little is known about the acceptability of these interventions in older populations after completing CR [13,14,20]. To better understand how to maintain behavioral changes after CR, we ascertained patient preferences and experiences after using various mHealth technologies for 2 months following CR completion.

Objective

The primary aim of this study is to assess the acceptability of using mHealth tools (ie, wearable activity trackers, mobile phone apps, and push through messages) to promote physical activity after completion of CR among older adults. This paper presents a secondary study focused on acceptability that was conducted as part of the primary Mobile4Heart study, a pilot randomized controlled trial (RCT) [21].

Methods

Overview and Study Design

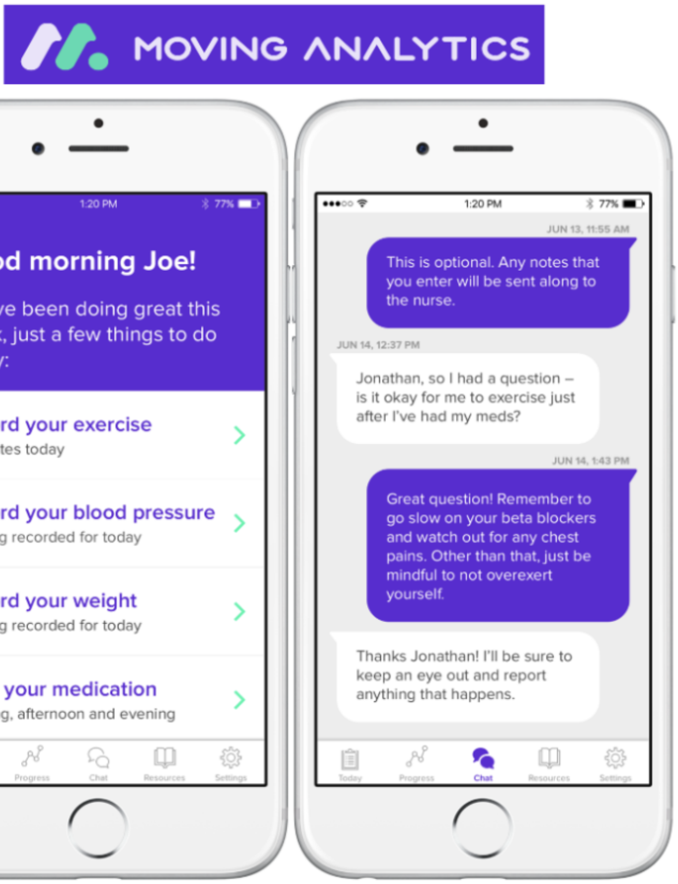
The parent Mobile4Heart study was a pilot RCT that evaluated group differences in physical activity and exercise capacity after 2 months of using digital health technologies; the results are presented in a separate publication [21]. The 2-month duration was based on the pilot nature of the RCT. Participants in the intervention group were provided with (1) a Fitbit Charge 2 to record their step counts, (2) the Moving Analytics Movn mobile app, which is a smartphone app designed specifically as a telemonitoring tool for CR patients (Figure 1), and (3) push through messages on cardiovascular disease prevention and physical activity delivered through the app. The individuals from the intervention arm of the Mobile4Heart RCT were asked to participate in evaluating the intervention presented in this paper.

This study presents a secondary study using two separate approaches to examine acceptability. We asked the intervention group participants to provide feedback about their experience with the technology (n=26) and conducted semistructured individual interviews with 7 representative participants. During the individual interviews, we used a semistructured interview guide that included a quantitative scale on satisfaction with the different technology components that allowed for an open-ended approach to ask and respond to questions for more substantial feedback on their responses (Multimedia Appendix 1).

We used thematic analysis with an emphasis on the acceptability of the technology. The interviews were transcribed verbatim, and 2 trained researchers independently reviewed and coded the interview transcripts and applied deductive codes developed from the interview guide domains. Through an iterative process and constant comparative approach, we finalized the coding scheme, refined themes, and identified patterns and relationships among the qualitative data.

Mobile4Heart was approved by the institutional review board at the medical center for recruitment as well as by the academic institution that sponsored the study (ClinicalTrials.gov NCT03446313).

Figure 1. Movn mobile app screen displays.



Good morning Joe!

You've been doing great this week, just a few things to do today:

Record your exercise
0 minutes today

Record your blood pressure
Nothing recorded for today

Record your weight
Nothing recorded for today

Take your medication
Morning, afternoon and evening

JUN 13, 11:55 AM
This is optional. Any notes that you enter will be sent along to the nurse.

JUN 14, 12:37 PM
Jonathan, so I had a question – is it okay for me to exercise just after I've had my meds?

JUN 14, 1:43 PM
Great question! Remember to go slow on your beta blockers and watch out for any chest pains. Other than that, just be mindful to not overexert yourself.

Thanks Jonathan! I'll be sure to keep an eye out and report anything that happens.

Participants and Setting

Participants were enrolled from 3 community CR centers in Northern California between February 2018 and January 2019. Eligibility criteria for participation included the ability to speak English, age >18 years, and actively participating in CR because of a previous cardiac event that qualified the patient for CR. After meeting the primary inclusion criteria, participants were screened for cognitive impairment using the Mini-Cog test [22-24]. Exclusion criteria included inability to access a smartphone and unstable clinical conditions (eg, unstable arrhythmias, uncontrolled hypertension, active infection, and second- or third-degree heart block).

Recruitment and Procedures

Overview

Full procedure details related to the Mobile4Heart study have been published elsewhere [25]. Briefly, enrollment occurred by meeting participants within 2 weeks after completion of CR, and participation started immediately after the first baseline meeting. All participants provided written informed consent before participation. Sociodemographic characteristics and self-reported physical activity were collected. For this study, all intervention participants were asked about their general experience with the three digital intervention technologies using open-ended questions at the completion of the intervention period. In addition, a convenience sample of 7 individuals participated in semistructured individual interviews that lasted between 45 and 60 minutes, with the completion of a questionnaire about their experiences using the mHealth technologies (Multimedia Appendix 2). We sought to include a representative sample of individuals with varying levels of engagement with the intervention. The interviews were designed to address the perceptions and experiences of participants with the three technologies used for the intervention, facilitators and barriers of use, the impact of these interventions on their future physical activity, and suggestions for improving these interventions. All interviews were conducted in person in a private conference room at the medical center. Participants first completed a Likert scale questionnaire. The interviewer then used open-ended questions to prompt additional inputs based on the responses from the questionnaire. Furthermore, 2 study staff members conducted the interviews, including the principal investigator. The interviews were audio and digitally recorded and transcribed verbatim as raw data for analysis. All participants received separate compensation for participation in the clinical trial, but the 7 participants who completed the interviews received an additional US $25 gift card as compensation for their time.

Mobile Phone App

The study staff downloaded the Moving Analytics (Movn) and Fitbit mobile apps on their smartphones (Figure 1). Generic emails and study participation numbers were generated by the study staff to register participants on both apps to protect participants' data. Both apps were synced wirelessly with the participants' mobile phones to view step count and physical activity data. In addition, Fitbit data were also synced to Fitabase [26], which is a comprehensive data management platform designed to store Fitbit data in cloud format. The study staff demonstrated both apps to participants and asked them to navigate through both apps. The study staff ensured that the participants were comfortable using the basic functions and features of the Fitbit device and Movn app. The Fitbit device tracked step count and some aerobic exercises such as running and using an elliptical machine; however, only step count was used to measure physical activity in this study. The Movn app was used to track daily weight, blood pressure, heart rate, and medication use and allowed participants to record any physical activity not captured by the Fitbit device (eg, swimming or weightlifting). In addition, the Movn app allowed participants to report any cardiovascular symptoms. The study staff triaged all participants' symptom entries once a day. If a participant recorded shortness of breath or chest pain, a message prompted participants to immediately call 911 through a button on the app.

Wearable Activity Tracker

Participants were provided with the Fitbit Charge 2 to wear upon enrollment during all waking hours for the 2-month study period. Participants were instructed to remove the device when showering and swimming, as the devices were not waterproof. The study staff assisted participants with the basic functions and features of both the device and the app, which included syncing the device with the mobile app and charging the device. Fitbit Charge 2 is a medium-sized wrist-worn activity tracking device that collects real time data about physical activity with a small monitor that provides instant visual feedback to the user. Fitbit devices use a 3-axis accelerometer to translate movement into digital measurements of body movements, frequency, duration, and intensity, and pattern of movement to determine the number of steps taken and distance traveled [27]. In addition, it measures energy expenditure (calories burned) and sleep quality. However, only step count data were collected for this study. This device was chosen for the following reasons: (1) convenience to the participants as it required charging only once every 5 days, (2) data storage for up to 7 days on the device, and once synced with Fitabase, the research team was able to view participants' performance, (3) the ability to create generic accounts without breaching participants' privacy, if desired, and (4) the relatively low cost of the device.

Push Through Messages

On the basis of the American Heart Association Simple 7 principles [28], a bank of messages was created that included suggestions on promoting participants to engage in physical activity, healthy nutritional habits, and medication tracking (Multimedia Appendix 1). Some of these messages were one-way; however, most of the messages were two-way, which allowed participants to respond to ensure their active engagement. Through the Movn app, the study staff sent these push through messages three times per week on random weekdays between 9 AM and 6 PM, providing positive feedback and additional motivation for physical activity. This feature also allowed the study staff to craft a personalized text for each participant. Thus, this created an additional communication channel between the study staff and participants to follow up on their progression and to answer any technical questions.

Data Analysis

The 7 participants who participated in the semistructured interviews were asked to rate their satisfaction regarding the different technologies used in the study on a 1- to 5-point Likert scale (5 being the highest). The scores from the satisfaction survey were presented quantitatively as means. For the interviews, 2 study staff independently coded and analyzed the transcripts using thematic analysis to identify themes and subthemes. Through an iterative process and constant comparative approach, we finalized the coding scheme, refined themes, and identified patterns and relationships among the qualitative data. We discussed the findings after independent coding was completed, and the principal investigator resolved any inconsistencies or discrepancies. Emerging codes from the interviews were used to identify the themes of participants' acceptability of the wearable device, push through messages, and smartphone apps.

Results

Participant Characteristics

A total of 32 participants from the intervention arm of the Mobile4Heart study were eligible to provide feedback on the intervention. Out of the 32 participants, 6 intervention patients were excluded for the following reasons: 1 participant was lost to follow-up, 1 was diagnosed with terminal cancer, 3 failed primary screening, and 1 had a broken toe and was unable to finish the study (Multimedia Appendix 3 shows the CONSORT [Consolidated Standards of Reporting Trials] diagram). Baseline characteristics of the enrolled patients are shown in Table 1. The mean age of participants was 66.7 years (SD 8.6). There were 77% (20/26) male participants and 23% (6/26) female participants, and 73% (19/26) self-identified as White individuals.

Table 1. Baseline sociodemographic data (N=26).

Characteristics	All intervention participants (n=26)	Questionnaires and interview participants (n=7)
Age (years), mean (SD)	66.7 (8.6)	64.4 (7.7)
Female, n (%)	6 (23)	2 (29)
Race or ethnicity, n (%)		
Hispanic, Latino, or Latina	1 (4)	0 (0)
White	19 (73)	5 (71)
Married, n (%)	23 (88)	7 (100)
Employed, n (%)	10 (38)	2 (29)
College graduate, n (%)	18 (69)	6 (86)
Causes for enrollment in cardiac rehabilitation, n (%)		
Ischemic heart disease (no)	19 (73)	4 (57)
Heart failure (no)	4 (15)	2 (29)
Valvular heart disease (no)	2 (8)	1 (14)
Structural heart disease (no)	1 (4)	N/A[a]

[a] N/A: not applicable.

Findings

Overview

There were overall high satisfaction scores for the Fitbit wearable device and Movn mobile app but lower satisfaction scores with the push through messaging feature, as shown in Multimedia Appendix 4.

Participants' feedback and interviews about their experiences with digital technology yielded four major themes (Textbox 1). Two themes focused broadly on positive experiences with these interventions, whereas the other two themes focused on the limitations and needed improvements.

Textbox 1. Cited themes from qualitative interviews.

Themes

- Technology use increased motivation for physical activity
- Technology use served as a reminder to remain physically active
- Recommendations for technology to improve user experience
- Desire for personal feedback

Theme 1: Technology Use Increased Motivation to Be Physically Active

There was a general consensus among all participants that digital technology has robust potential to promote physical activity as it provides a sense of continuity to CR by providing motivation. Using various digital technologies was a key facilitator for increasing motivation. The mean age of the participants was approximately 64 years (SD 7.7), and the general consensus among these older adults was that both apps provided a user-friendly layout:

> *...it made me feel as if it was an extension of CR.*

Participants reported wearing the device on the wrist was a motivational intervention by itself. In addition, daily step feedback through the device as well as the app provided a sense of commitment to complete the daily target for step counts. Participants enjoyed the Fitbit features and functions that enabled them to self-monitor and obtain insight on the distance walked through the number of steps:

> *Motivated me to walk more and reach the 10,000 steps goal.*

This provided a sense of enjoyment in tracking the number of steps and distance walked throughout the day. When one of the participants was asked if the use of technology helped him stay motivated, his response was as follows:

> *Absolutely! Very necessary for insight.*

In addition, the vibrating function of the device when the daily step goal was reached provided additional enforcement of positive physical activity behavior:

> *Furthered commitment to exercise, incentivized to do better.*

Both the Movn and Fitbit apps provided visual feedback about the progress of each participant by viewing weekly steps in a chart review. Many participants highlighted the ease of use and interpretation of the data through both apps:

> *...and for someone with limited knowledge in technology like me, Fitbit was encouraging for me to keep moving.*

Participants emphasized the ability to not only reflect on their daily steps' progression through charts on their step counts but also to set a new personal target to achieve every day. This allowed an increase in participants' awareness of their physical activity levels and the progress they achieved. In addition, some participants enjoyed the other features within both apps about heart rate and sleeping performance, which provided some information about their overall physical activity performance as well as their recovery:

> *Feedback about different health aspects like sleeping and food intake are information to know about myself.*

Participants commented on the benefit of receiving push through messages from the study staff through the app throughout the week at random times as a motivational tool to remain physically active, knowing that the study staff is updated with their physical activity status:

> *Just the fact knowing you guys [study staff] are watching my numbers motivated me to walk more.*

In addition, the messages incentivized some participants to perform different exercises other than walking or running. Participants commented that these messages provided some physical activity hints and motivations to set a new personal goal:

> *The messages gave me some hints and good advice, like stretching.*

Theme 2: Technology Use Served as a Reminder to Be Physically Active

Participants' comments about the use of technology were mainly for increasing motivation and a reminder to maintain physical activity. They also enjoyed the Fitbit features and functions that enabled them to self-monitor and obtain insight on the distance walked through the number of steps. The visual display of the device was a sufficient reminder for some participants to remain active. In addition, the device had a vibrating function as a reminder to move in case of inactivity for over 2 hours:

> *The device gives a nudge every while, which is a good reminder to go out and walk.*

Participants attributed their self-awareness of their physical activity through immediate feedback about the number of steps walked during the day as a contributing factor to their behavioral change:

> *Yes, it was a visual reminder, allows me to track something while I'm walking.*

The Movn app also sent a notification reminder around the end of the day to submit any additional workout activities that were not captured throughout the day by the Fitbit device, which had an additional reinforcement effect. Furthermore, the app provided a platform for participants to upload different health measures, such as blood pressure and glucose. These measures were not recorded for this study, but participants commented that it was a convenient tool to track all their measurements in one place. The Movn app also enabled participants to report any cardiac symptoms related to their condition, which would alert the study staff instantly and was triaged by a health professional daily:

> *Push notification [from the app] throughout the day was helpful to remind me to remain active.*

Although patients were instructed to use the Fitbit wearable device to track step counts and the Fitbit app to download steps, some participants chose to explore the other features on the Fitbit mobile app as well. Some of them mentioned enjoying the social interaction feature in the Fitbit app, which was the requested feature of the Movn app to interact with their CR peers. Both apps provided different notification reminders throughout the day.

Theme 3: Recommendations for Technology to Improve User Experience

A number of obstacles and barriers were reported by the participants regarding each type of intervention technology, with some suggestions for development and improvement. A common theme was the complaint about the Fitbit device being only water-resistant (not waterproof), which limited the physical activities that could be captured by the wearable device.

In addition, an important comment that may be relevant for many middle-aged to older adults was regarding the size of the text on the wearable device's screen. Having an accompanying website portal is helpful in providing another way to view data, as Fitbit already provides:

> *...needs larger print on device. Too small, can't read that thing.*

The limited sensitivity of the heart rate sensor was spotted by multiple participants, as the device takes a few minutes to detect a consistent heart rate change during the workout; therefore, some exercises such as weightlifting or yoga were not accurately recorded:

> *The heart rate monitor takes about 10 minutes to capture actual heart rate change while working-out.*
>
> *Doesn't capture different activities I do in the gym, like weightlifting.*

The Movn app showed the progress of each participant over time; however, this feature was only accessible to the research staff, not the participant:

> *...I stopped using it. I would check the other app (Fitbit) instead because I wanted to see my progress.*

Push through messages were sent through the mobile app and were viewable as a notification message on the participant's phone. Most of the participants did not report any technical issues with the push through messages, presumably because they were accustomed to viewing text messages on their phones. However, some participants reported an inability to read the messages at the beginning of the study as the notification feature was disabled on their phones.

Overall, there were varying levels of acceptance of the Fitbit device; some participants chose to keep the Fitbit (n=8) at the end of the study, whereas others returned them in lieu of US

$100 in gift card incentives (n=12). Some sought to purchase more advanced tracking devices (n=2), whereas others already owned a wearable device (n=4).

Theme 4: Desire for Personal Feedback

A number of technical challenges and difficulties were reported by the participants regarding each app. Some participants reported that the inability to adjust the targeted number of steps per day because of physical challenges, such as osteoarthritis, was frustrating:

> *...my knees hurt; I can't walk 10,000 steps!*

Some participants had some barriers with the Movn app features. These were related to the lack of knowledge and understanding about how to use the app, limited number of physical activity progression charts, and insufficient individual feedback or goal setting for each participant:

> *[Need] more communication, more hand-holding for less tech-savvy people like me.*
>
> *Doesn't give feedback, doesn't provide me with any chart about my progress.*
>
> *I can't set my own goals, want to see progress graphs for a longer duration.*

Although the Movn app had different educational materials related to cardiovascular disease health, many participants mentioned the need for additional general health and nutritional advice within the app itself:

> *Would like some nutritional guidance and more health details, like food calories and fat burning.*

Although push through messages from the study staff to the participants through the Movn app were appreciated by many participants, there was consistent feedback from the majority of participants about the need for more personalized messages. Many participants felt that the messages were automated and not customized for each participant's physical activity step counts and personal goals. Subsequently, some participants lost interest in responding to the two-way messages, as they were either too obvious or not personalized:

> *The texts need to be more personal with some interaction.*
>
> *The messages were not helpful, nor motivating. Need more specific input and interaction.*
>
> *It was too obvious; I didn't know what to respond to you.*

Discussion

Principal Findings

In this study, we evaluated patients' perceptions of the acceptability of mHealth interventions to improve physical activity maintenance after completing a CR program. In general, participants found the Fitbit devices easy to use and useful to self-monitor activity and progress on a daily basis. They also reported the ability to use mobile phone apps to track their physical activity progress, which consequently maintains and improves their physical fitness. The push through messages had an additional motivational effect as a reminder to remain active. These three interventions increased participants' awareness and self-management of their activity levels. Participants' long-term use of these technologies remains encouraging as some participants chose to keep the Fitbit at the end of the study. Some chose to purchase tracking devices that were more advanced or already owned a wearable device. Some of the participants who returned the devices preferred not to wear an activity tracking device on their wrist.

We also sought to assess the acceptability of mobile apps among an older population. Although we did not instruct participants to use the Fitbit app except to download their step counts, many chose to explore and subsequently use the Fitbit app. The use of the Fitbit app and Movn app was not equal for all participants, and toward the end of the study period, many participants reported using one app while rarely using the other. This highlights that although participants liked tracking their physical activity, entering their additional workout data into the app was cumbersome to some of them. Many participants expressed their desire for a device that captured all workouts that synchronized automatically with their phones without having to manually enter their workout data. In previous studies that used Fitbit devices with a coaching app, researchers found that participants frequently used both the Fitbit app and the intervention app, but several preferred the features and usability of the Fitbit app [29]. Several researchers have addressed this issue by integrating the features of commercially available apps with a second app and pulling data from one app into the other, hence making the intervention more convenient for participants by using only one app [30-32].

Another important objective of this acceptability study was to determine the impact of push through messages on increasing physical activity. The push messages had the lowest satisfaction scores compared with the other technologies, indicating that improvement is needed in this area. The interviews elucidated the need for more personalized and tailored messages that responded to the physical activity that the participants were engaging in. Some responded negatively and ignored the messages when they thought they were automated. This lack of personalization could potentially harm the relationship between the participant and future clinical providers if expectations are not clearly explained upfront (ie, automated vs personalized or a combination). We provided a combination of messages delivered from our bank of messages and personalized messages. On the contrary, other participants reported having a feeling of assurance that the study staff actively monitored their progression, which helped reinforce the participants' sense of commitment to remain physically active. This finding is consistent with other studies that consider text message interventions to be effective for improving physical activity and significantly increasing the number of steps per day after the intervention [33]. Using all these interventions together provided insights into how this older population could engage with mobile technology to maintain long-term physical activity after CR. As individual needs should be of primary importance, especially when using health-related apps [34-36], tailoring push through messages could easily supplement an intervention that deploys an activity tracking device.

Comparison With Prior Work

There is currently a dearth of research examining the acceptability of mHealth technologies by older adults after the completion of CR. However, results from several studies indicate that mobile phone apps and text messages are viewed favorably by this age population with important facilitators of ongoing use, such as ease of use and rapid accessibility [37-41]. The findings of this study were similar to those of other studies, particularly the ease of navigating through mobile phone apps [37,40]. However, some participants expressed difficulties with the Fitbit device, including charging issues, limited use because of the need to take the device off while showering, and the device's inability to capture different types of physical activity and sports. Other challenges involved a lack of understanding of the various features of both apps, suggesting the need for technology training geared toward this age group regarding app style and layout [42-45].

Previous studies have indicated that data security and privacy may be barriers to participant engagement with mobile interventions, particularly with regard to older adults [46,47]. In addition, there are concerns among this group regarding the lack of regulatory oversight [48]. In this study, however, we found that participants expected to share their data on the app as they were aware that the research team at the other end was monitoring their progress and actively interacting with them, which motivated them to keep using the app compared with machine-operated apps [49]. This willingness to engage with the technology and confidence in the research or clinical team has the potential to increase participant commitment to an active lifestyle, as the presence or absence of patient trust affects health outcomes and adherence [50-52]. Many commercially available mHealth apps have substandard privacy and security protection for users [53-55]. It is imperative that researchers vet the apps used in mHealth interventions to maintain this trust. In addition, clearly explaining and demonstrating security settings to participants may help alleviate safety and privacy concerns encountered in future research.

Some participants expressed their interest in sharing their daily steps progression with other participants they met in their CR program to create a sense of friendly competition with each other. Researchers found that users of a social networking app reported that social comparison motivated physical activity, particularly when compared with higher performers [56]. This highlights the need for further research on the benefits of social engagement with peer participants and peer-to-peer support. Adding a social component to future interventions may help with accountability and decrease barriers to physical activity. Providing a supportive web-based community for users to share tips, encouragement, and even engage in small contests with other users could add to the overall participant experience and increase commitment to physical activity after CR.

Limitations and Strengths

Several limitations of our pilot study should be noted. We had a small sample size with 7 interviews; however, we believe we achieved data saturation on our topic of acceptability with technology to promote physical activity after CR. Our sample mostly comprised White individuals and men who owned smartphones; thus, our findings have limited representation of other diverse racial groups and women. In addition, we recruited all participants from a single institution in Northern California; therefore, our sample may not represent a broader and older population. Although this study provides insight into the initial experience of older adults using mobile technology over 2 months, long-term behavioral changes are unknown.

Despite these limitations, our study provides important insights into the integration of technology-supported care for patients who often fail to maintain regular physical activity after CR and relapse to a sedentary lifestyle that predisposes them to a secondary cardiac event. Our study confirmed previous research that supports the potential impact of a system that provides reminders and motivation to promote self-care behaviors [57,58]. Wearing the activity tracking device provided repeated reminders by showing the number of steps while also nudging the participant to walk after 2 hours of inactivity. In addition, the two-way push through messages provided by the study staff provided additional active reminders. The impact of this combination of tools was shown to be promising in promoting more step counts among intervention patients compared with the control group in our parent study [21], whereas this study provided the acceptability data.

Conclusions

Our mHealth intervention shows high acceptability of mHealth technologies to promote physical activity among older adults after CR. Participants' expectations for using mHealth technology included tracking several health metrics, monitoring personal progress, and personalized communication with the research staff. These results provide promising preliminary groundwork for a community-based physical activity program after CR that is supported by secure mHealth technology to provide personalized feedback and social support.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Push through messages bank.

[DOCX File , 246 KB - humanfactors_v8i3e25356_app1.docx]

Multimedia Appendix 2

Interview question and satisfaction scale.

[DOCX File , 528 KB - humanfactors_v8i3e25356_app2.docx]

Multimedia Appendix 3

CONSORT (Consolidated Standards of Reporting Trials) diagram of Mobile4Heart participants.

[PDF File (Adobe PDF File), 291 KB - humanfactors_v8i3e25356_app3.pdf]

Multimedia Appendix 4

Satisfaction scores with technology use in 7 participants.

[PDF File (Adobe PDF File), 54 KB - humanfactors_v8i3e25356_app4.pdf]

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
CR: cardiac rehabilitation
mHealth: mobile health
RCT: randomized controlled trial

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Original Paper

US Physicians’ Perspective on the Sudden Shift to Telehealth: Survey Study

Bhavneet Walia[1], DPhil; Anshu Shridhar[2], MD; Pratap Arasu[2], MD; Gursimar Kaur Singh[1], BSc

[1]Department of Public Health, Syracuse University, Syracuse, NY, United States

[2]Division of Cardiology, Syracuse Veteran Affairs Medical Center, Syracuse, NY, United States

Corresponding Author:
Bhavneet Walia, DPhil
Department of Public Health
Syracuse University
430B Barclay
Syracuse, NY, 13244
United States
Phone: 1 3154433930
Email: bwalia@syr.edu

Abstract

Background: Given the sudden shift to telemedicine during the early COVID-19 pandemic, we conducted a survey of practicing physicians’ experience with telehealth during the prepandemic and early pandemic periods. Our survey estimates that most patient visits in the United States during the early COVID-19 pandemic period were conducted via telehealth. Given this magnitude and the potential benefits and challenges of telehealth for the US health care system, in this paper, we obtain, summarize, and analyze telehealth views and experiences of US-based practicing-physicians.

Objective: The aim of this study was to examine the extent of shift toward telehealth training and care provision during the early pandemic from the US-based practicing physicians’ perspective. We also sought to determine the short- and long-term implications of this shift on the quality, access, and mode of US health care delivery.

Methods: We conducted a purposive, snowball-sampled survey of US practicing-physicians. A total of 148 physician completed the survey. Data were collected from July 17, 2020, through September 4, 2020.

Results: Sample training intensity scaled 21-fold during the early pandemic period, and patient-care visits conducted via telehealth increased, on average, from 13.1% directly before the pandemic to 59.7% during the early pandemic period. Surveyed physician respondents reported that telehealth patient visits and face-to-face patient visits are comparable in quality. The difference was not statistically significant based on a nonparametric sign test (P=.11). Moreover, physicians feel that telehealth care should continue to play a larger role (44.9% of total visits) in postpandemic health care in the United States. Our survey findings suggest a high market concentration in telehealth software, which is a market structural characteristic that may have implications on the cost and access of telehealth. The results varied markedly by physician employer type.

Conclusions: During the shift toward telehealth, there has been a considerable discovery among physicians regarding US telehealth physicians. Physicians are now better prepared to undertake telehealth care from a training perspective. They are favorable toward a permanently expanded telehealth role, with potential for enhanced health care access, and the realization of enhanced access may depend on market structural characteristics of telehealth software platforms.

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KEYWORDS

physician survey; US telehealth training; US telehealth care; COVID-19; pandemic; snowball sampling; health care access; health care quality; telehealth; telemedicine; survey; physician; perspective; recommendation; policy; public health; implication; quality; access

Introduction

Background

The sudden onset of the COVID-19 pandemic in the United States has provided a test of the US health care delivery infrastructure. As first responders, US health care professionals are navigating a two-pronged challenge not observed in the country since the 1918 H1N1 outbreak—a devastating pandemic that caused at least 50 million deaths globally and was a predecessor to the currently prevalent strains of swine flu. Namely, US health care professionals are treating a largely unknown and deadly virus, while also continuing to practice most other regular functions of medicine during a pandemic. In many cases, technological applications, specifically telehealth, have been drawn on heavily to aid frontline medical professionals in navigating this challenge.

Telehealth represents a potentially cost-effective method to deliver certain types of eligible care, both during and following the pandemic, provided that the underlying technology is able to limit the natural drawbacks of remote care. A primary objective of telehealth is to provide enhanced "access to safe, effective, and appropriate care when and where [patients]. need it, and that providers can [do] more good for more people" [1]. Despite the early recognition of telehealth benefits, US telehealth visits did not scale until many years later. In 2005, there were an estimated 206 telehealth visits in the United States (0.02 per 1000 visits) [2]. By 2017, the estimated number of visits had scaled to 202,374 (6.57 per 1000 visits) [2]. During this growth period, the 2009 American Recovery and Reinvestment Act provisioned $155 billion to US health care toward telehealth-related initiatives such as Health Information for Economic and Clinical Health (HITECH). Despite this rapid growth, data suggest that US telehealth was "still uncommon by 2017" [2], and telemedicine training (eg, in medical school) remained scarce during this period [3-5]. Indeed, physicians reported "considerable interest in, but limited use of, telehealth services" during prepandemic times [6]. Recent infodemiological research suggests that public interest in telehealth was positively correlated to COVID-19 infection rates and that the United States may lack telecommunication infrastructure to meet a growing demand for telehealth [7,8]. More generally, several studies suggest a general rise in telehealth use during recent years [9-13].

Research Questions and Scope

This study utilizes a large sample US physician survey to characterize changes in the US telehealth use, scale, and training during the COVID-19 pandemic. We also seek to determine the level of physician experience and satisfaction with present telehealth technology platforms and training, as well as diversity of platforms used. Of primary concern, these research questions will help us understand (1) the benefits and challenges of the current telehealth technology, training, and practices; (2) whether physicians believe that recent scaling of US telehealth will sustain in the postpandemic era; (3) whether physicians wish for recent scaling of US telehealth to sustain in the postpandemic period; and (4) how to build more effective telehealth technology infrastructure and practices. Surveyed physicians were asked their *perspectives* regarding telehealth systems used, *helpful andchallenging* aspects of these systems, and the *overall efficacy of telehealth delivery* compared with *in-person care* for different classes of nonemergency treatments.

We also asked respondents' *recommendations* for changing the current telehealth systems used vis-à-vis technological features or health care delivery protocol, as well as their vision of the role and scope of telehealth in health care, both during the pandemic and beyond. Beyond this primary research focus, survey responses will provide an estimate as to the diversity of telehealth platforms used across a large sample of physicians. If the telehealth software market features high market concentration among software platform providers, this could cause upward pressure on the price of provisioning telehealth, and potential cost savings from telehealth may not be realized due to market structural factors [14]. The overall effect of telehealth on health care consumer price is indeterminate. For example, telehealth features cost-saving elements that will also be discussed.

Motivation for Research Design and Research Question Summary

Physician surveys play a vital role toward characterizing health care system inputs and outcomes [15-19], as do systematic reviews of physician survey data [20]. Survey methods have been used broadly to characterize the generally low rate and specialized nature of telehealth adoption (eg, for rural populations) prior to the COVID-19 pandemic [6,21,22]. To a lesser extent, studies have considered the role and scope of telehealth during and after the pandemic [14].

This study seeks to extend the available literature by considering US-based practicing physicians' views and training and by using characteristics with respect to telehealth expansion during the early COVID-19 pandemic. In doing so, we seek to characterize the implications, benefits, and challenges of this expansion from the perspective of interest, with implications for later-pandemic and postpandemic telehealth provision.

Methods

Survey Design

This study presents the first large sample physician survey on telehealth following the onset of the COVID-19 pandemic. We surveyed practicing clinical physicians across the United States regarding their telehealth use and training before and during the pandemic. The survey instrument was constructed by authoring physicians based on their professional experience. The main exclusion criteria for the survey were (1) nonphysician, (2) nonpracticing physician, or (3) physician practicing outside the United States. To obtain a broad, national perspective, we collected surveys from 148 practicing US physicians through snowball sampling and allocated a US $10 e-gift card to each respondent. The snowball sampling methodology was purposive, seeking feedback from US physicians currently using telehealth software. We collected data from July 17, 2020, through September 4, 2020 (ie, for almost 2 months and ending at approximately the half-year point of the US pandemic period).

Characteristics of Survey Respondents

We divided respondents' employing organizations into four categories: (1) hospital or larger corporate organization, (2) solo or group practice, (3) government (federal) hospital, and (4) academic hospital. According to the physician respondents, an average of 70% of their patients travelled less than 25 miles for their visit, 18.5% traveled between 25 and 50 miles, and 11.5% traveled more than 50 miles for their visit prior to the pandemic. These values (unweighted means) represent physician *estimates* and are subject to factors such as physician recall and physician knowledge of patient whereabouts. Patients may sometimes choose physicians based on factors such as proximity to work. Furthermore, 28.3% of the patients were aged 51-70 years old, making this the most common age category, and 13.6% of the patients were less than 18 years old, making this the least-represented age category. Patient gender distribution was balanced, with 49.4% female, 48.7% male, and the rest identifying as other. Physicians reported an estimated average payer-mix among patients as 29.2% Medicaid, 31.8% Medicare, 25.5% private health insurance, 10.7% as veterans administrative care, and 2.8% as other.

Ethical Approval

Data were collected from an anonymous Qualtrics survey that was generated by the authors. The survey was approved by the Syracuse University Institutional Review Board as an ethical research instrument.

Results

Training Rates: Overall and by Respondent Characteristic

Survey results on telehealth training vary substantially by physicians' employer type. Table 1 summarizes the pervasiveness of telehealth training by employer, before and during the pandemic.

Participating physicians report that, on average, their access to telehealth training increased during the early pandemic period as compared to the prepandemic period. The training rate increased in 4 of 5 employer categories (in some instances, it increased dramatically), and it was constant at a high rate in the fifth category. Government hospitals had substantially higher sampled training rates before the pandemic, whereas there was a high degree of convergence in training rates across employers during the pandemic. Sampled physicians report more telehealth training hours during the early pandemic period than during the entire prepandemic period of their respective careers. The average training time increased from 1.33 hours (80 minutes) before the pandemic to 1.67 hours (100 minutes) since the onset of the pandemic.

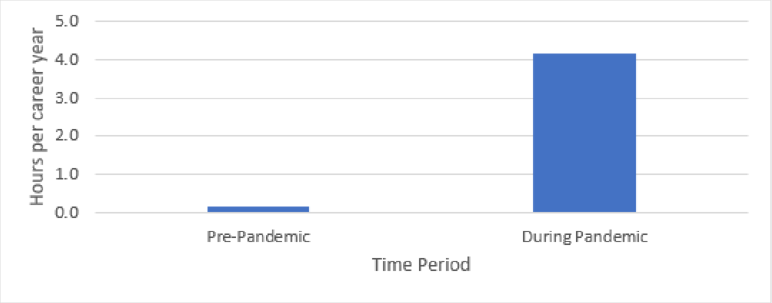
Although the general level of the US physician telehealth system training remains fairly modest, these results suggest an abrupt intensification of training during the early pandemic months, which in turn suggests an abrupt shift in the health care system needs and delivery modes with the onset of the pandemic. Figure 1 demonstrates average telehealth training intensities—prorated on a per career year basis—before and during the pandemic period, respectively, where the typical survey respondent had a career length of 8.1 years prior to the pandemic and 0.4 years from beginning of the pandemic to the time of survey (8.5 total career years on average).

Figure 1 shows the extent of shift in telehealth training during the early pandemic period. Sampled physicians reported an average of 0.2 hours of telehealth training per career year before the pandemic and 4.2 hours per career year during the early pandemic period, a 21-fold scaling of training intensity during the latter period.

Table 1. Telehealth training coverage by employer type, before and during the COVID-19 pandemic.

Employer type	Telehealth training before the pandemic, n (%)	Additional or first-time telehealth training since the pandemic began, n (%)	Relative increase in training
Hospital or large corporate organization	38 (53.6)	56 (78.6)	Yes
Solo or group practice	10 (27.6)	19 (51.7)	Yes
Government (federal) hospital	11 (80)	11 (80)	Balanced
Academic hospital	12 (43.5)	22 (82.6)	Yes
Other	0 (0)	1 (100)	Yes

Figure 1. Telehealth training intensity in hours per career year.



Characteristics of Telehealth Software Used

Regarding telehealth software used, 66.9% (99/148) of the respondents used CloudVisit Telemedicine, 25% (37/148) used Doximity Dialer, and 3.4% (5/148) used Chiron Health. Six other telehealth software were mentioned as the primary software used, where each featured <1% market concentration. This finding suggests a high sample market concentration among telehealth software in the US health care system. The Herfindahl-Hirschman Index (HHI) of market concentration for this sample is approximately 5171. An HHI value of 10,000 reflects pure monopolistic provision, an HHI value between 0 and 1500 indicates competitive provision according to the US Department of Justice, and an HHI value above 2500 indicates a highly concentrated market. These sample results indicate a high level of market concentration in US telehealth software; any limitations of the few leading software platforms will affect physician-patient telehealth interactions at near-market scale. Moreover, market concentration can have profound upward pressure on the price that the software consumer pays and can erode any potential cost savings from telehealth to the health care system and health care consumers. This sample result is consistent with the market concentration characteristics of both software and health care markets.

Questions regarding the general quality of nonemergency telehealth care compared to face-to-face care show that the quality of telehealth was perceived as worse by a plurality of physician respondents (50/148, 33.8%), equal in quality by 31.1% (46/148), slightly better by 14.2% (21/148), much better by 14.2% (21/148), and much worse by 6.7% (10/148) physician respondents. Thus, slightly more sampled physicians reported a quality drop-off rather than a quality gain from telehealth.

Eligible Visit Types and Intensity of Telehealth Use During the Early COVID-19 Pandemic

Given the challenges and risks of face-to-face visits during the pandemic, physicians are relying more heavily upon telehealth visits. In the prepandemic period, sampled physicians conducted an average of 13.1% of visits via telehealth compared to 59.7% during the pandemic (unweighted means reported). Moreover, Moore et al’s [6] finding that physicians reported “considerable interest in, but limited use of, telehealth services” during prepandemic times is corroborated by our survey data. As several types of visits are not eligible for telehealth delivery, 59.7% of telehealth visits represent an aggressive deployment of telehealth delivery. Physicians have converted approximately 25.9% of telehealth visits into face-to-face visits during the pandemic, down from 32.4% before the pandemic. This finding suggests that, during the pandemic, physicians were using telehealth as a more effective filter in identifying needed face-to-face follow-up visits; patients not needing face-to-face follow-up are more often relegated to telehealth follow-up or no follow-up.

Currently, patient reluctance and internet accessibility represent limiting factors for telehealth provision. On average, physicians reported that 26.6% of the patients are reluctant to participate in telehealth, whereas 29% lack connectivity to conduct a telehealth visit. A description as to the regions served by surveyed physicians may provide context with respect to patient reluctance. The sample represents physicians practicing in 25 US states and 1 US territory, where the sampled physicians serve in all CDC National Center for Health Statistics (NCHS) Urban-Rural Classification categories, including large metro (36/148, 24.3%), large fringe metro (9/148, 6%), medium metro (43/148, 29.1%), small metro (45/148, 30.4%), micropolitan (10/148, 6.8%), and noncore or rural (5/148, 3.4%) areas.

Telehealth Visit Duration During the Early COVID-19 Pandemic

Of the 148 physicians surveyed, 84 (56.8%) reported allocating the same average time duration to a telehealth visit as to a face-to-face visit; 4 (2.7%), spending substantially less time; 36 (24.3%), slightly less time; 16 (10.8%), slightly more time; and 8 (5.4%), substantially more time. Telehealth does not appear to be substantially distorting the time-of-visit distribution. Overall, more respondents reported allocating less time (40/148, 27%) than more time (24/148, 16.2%) to telehealth visits.

Characteristics of Physician Views Toward Telehealth

With regard to the postpandemic period, respondents feel that they could deliver approximately 44.9% of patient visits via telehealth. This represents more than three times the reported prepandemic delivery rate for these physicians and only a moderate decrease from the pandemic delivery rate.

Many surveyed physicians (49/148, 33.1%) felt that telehealth delivery decreases the value of their clinical skills, consistent with a capital-labor substitution view of the technology. Loss of patient-physician relationship under telehealth expansion was also a moderately observed response (51/148, 34.5%). It is potentially important to note that patient-physician relationship development may not always be productive in terms of health care. For example, the literature shows that individuals can experience performance decrements as the perceived stakes associated with a task rise [23-25], and that this phenomenon affects surgeons [26]. A surgeon performing a risky surgery may feel more stake-associated pressure if they have formed a relationship with the patient.

According to survey respondents, the five most major challenges faced while providing telehealth during the COVID-19 pandemic are (1) limitations on physician’s ability to deliver certain types of health care by the very nature of telehealth (ie, regardless of level of telehealth development), (2) inadequate telehealth technology, (3) lack of organizational support for telehealth, (4) inadequacies in reimbursement for visit, and (5) prior inadequate physician telehealth training. These results were based on a single question in the survey with categorical response options, as well as a “write-in” reply box. The most common policy recommendations regarding improvements in telehealth delivery were (1) malpractice protection for telehealth, (2) clarity regarding reimbursement policies, (3) training to use technology more efficiently, and (4) policies regarding duration per episode of care. One respondent commented that video-conferencing use, as required by some private insurances, caused problems because many patients were not equipped for videoconferencing.

Discussion

Present and Future Use of Telehealth

The results of our physician-respondent survey suggest that the COVID-19 pandemic motivated a substantial shift toward telehealth training and care provision in the United States. Our results further suggest discovery as to the potential and value of telehealth care such that physicians perceive comparable quality of care under telehealth provision compared to a face-to-face visit. Given this discovery, physicians foresee a heavily expanded role of telehealth provision even in the post-pandemic period. However, a moderately high percentage of physician respondents also report both innate and soluble limitations of telehealth technology, as well as a loss of perceived value of their skills under telehealth expansion. Most physicians from different practices and specialties see value in continuing with telehealth provided that a few elements of telehealth provision improve—telehealth technology development, adequate training of physicians and administrative staff, clear reimbursement policies (ie, insurance policies), and clarity on malpractice regulation being the chief elements.

From estimates of patient reluctance and internet accessibility, as reported in the results section, let us conservatively estimate that 30% of the patients have at least one of these limiting characteristics. These limiting factors alone would place a cap on the capacity of telehealth delivery at 70% of visits. Visit eligibility would further decrease this soft cap, such that the survey-estimated pandemic telehealth visit rate (59.7%) represents something close to the present capacity load for telehealth delivery.

Given that physicians feel telehealth care should continue to play a larger role (44.9% of visits) in the postpandemic US health care, we conclude that there was substantial discovery with respect to viability of telehealth during the pandemic period that may not have occurred otherwise. In this respect, the pandemic has been something of a natural experiment for telehealth viability. This also suggests that technological adoption in health care exhibits characteristics of path-dependence or dependence on the occurrence or nonoccurrence of exogenous circumstances rather than being purely a process of optimal decision-making by well-informed firms. Indeed, health care industry policies and practices have been shown to exhibit path dependence [20-22,27-30].

Market concentration is a frequent issue in software markets given that software units can be scaled at essentially zero marginal cost to the seller, and software consumers are often "locked in" after learning a given system. Moreover, we observe high rates of market concentration in health care markets generally, with more than 90% of health care markets characterized as highly concentrated or super-concentrated according to HHI [18]. Telehealth software, which represents a *software* market within the *health care* industry, appears to be no exception. Telehealth software companies sometimes promote further concentration. An article from InTouchHealth, a subsidiary of Teladoc Health, states, "Telehealth would be nearly impossible unless every healthcare provider is using the same system" [1]. This statement represents the monopoly provision of telehealth platforms (eg, via a winner-take-all standards war) as an important condition toward sustained telehealth use by the health care industry. Shachar et al [7] Identified telehealth market regulation as a primary concern with respect to the postpandemic scale and the overall effect of telehealth [7].

Telehealth and US Health Care Outcomes

The three core objectives of the 2010 US Patient Protection and Affordable Care Act relate to (1) increasing access to health care, chiefly through expanded Medicaid enrollment for the working poor; (2) a higher quality of care through improved medical and market decisions; and (3) reducing cost and patient risk via improved efficiency and higher rates of insured individuals [31]. Our survey results suggest that telehealth provision is largely consistent with these goals. Telehealth has increased access to nonemergency health care during the pandemic and can continue to provide improved access to rural patients and many patients who have difficulties reaching a medical facility in the postpandemic period. Telehealth could reduce the cost of care delivery, as well as the price paid by patients [32] by streamlining some of the logistical hurdles to physicians and patients during face-to-face visits. Furthermore, the survey results suggest that patients often travel long distances for a face-to-face visit. In many cases, this travel time allocation imposes loss of work time and other opportunity costs for the patient that might be minimized through the scaling of telehealth for eligible visits. However, the outcome along this dimension is potentially dependent on market structural and regulatory issues [7]. Survey responses indicate that, on average, the physician-perceived average quality of care remained roughly the same with telehealth expansion. Moreover, telehealth has been popular during the pandemic primarily because it reduces the risk of infection during health care delivery, wherein this risk reduction is an important component of health care quality.

Takeaways and Future Directions

This study presents a large sample physician survey on telehealth following the onset of the COVID-19 pandemic. The picture that emerges from this physician survey is that the scaling of telehealth can provide the US health care system with increased flexibility, access, and potential health care cost benefits. We acknowledge some study limitations. This was a physician survey and did not capture patients' views. Further research is therefore needed to determine the benefits and challenges of telehealth expansion from the patients' perspective. Furthermore, additional research can subcategorize areas of eligible treatment that are more amenable to telehealth expansion in terms of benefits yielded. The survey represents physician responses from 25 US states and 1 US territory. The advantages of the present sample notwithstanding, estimates might have been improved had it been possible to obtain survey responses from physicians in every US state and territory. Moreover, the sample was taken cross-sectionally and does not feature the benefits of a longitudinal survey. More generally, voluntary survey data is subject to recall bias and selection bias, and snowball sampling may lead to sample points that are clustered according to employer or social network. The study also does not address complementary means to improve telehealth infrastructure such as administrative operationalization and clinical care reorganization [33]. Indeed, scaling one's software capabilities alone will not fully support continued growth in telehealth. Owing to space and scope limitations, such analyses will be considered in future research.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
HHI: Herfindahl-Hirschman Index
HITECH: Health Information for Economic and Clinical Health
NCHS: National Center for Health Statistics

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Original Paper

Access, Use, and Patient-Reported Experiences of Emergency Care During the COVID-19 Pandemic: Population-Based Survey

Jodi Gray[1], MPH; Andrew Partington[1], BCom, BHlthSc (Hons); Jonathan Karnon[1], PhD

[1]Flinders Health and Medical Research Institute, College of Medicine and Public Health, Flinders University, Bedford Park, Australia

Corresponding Author:
Jonathan Karnon, PhD
Flinders Health and Medical Research Institute
College of Medicine and Public Health
Flinders University
Level 2 Health Sciences Building
Sturt Road
Bedford Park, 5042
Australia
Phone: 61 8 7421 9821
Email: jonathan.karnon@flinders.edu.au

Abstract

Background: An increase in the number of people presenting to emergency departments (EDs) is contributing to ED overcrowding. In the early stages of the COVID-19 pandemic, there was a significant reduction in the number of ED presentations in Australia, creating an opportunity to learn from patients' experiences of alternative management options.

Objective: The aim of this study is to report on the use and experience of health services by Australian adults experiencing a health issue during the COVID-19 pandemic for which they would have presented at an ED prior to the pandemic.

Methods: An online survey was conducted in May 2020. Reported health issues were categorized using an existing classification system. Data collected included demographics, care pathways, levels of concern at times of health issue and survey completion, and patient-reported experiences with care.

Results: A total of 1289 eligible respondents completed the survey. Almost 25% (309/1289) of respondents avoided an ED presentation, of which 58% (179/309) used an alternative form of health care and 42% (130/309) self-managed. Respondents making face-to-face or telehealth appointments with their general practitioner (GP) reported high levels of ED avoidance (135/286, 47%) and mostly positive experiences of care provided by GPs. A high proportion of those who self-managed reported high levels of concern at the time of completing the survey (42/130, 32%).

Conclusions: Telehealth consultations with GPs may be a more promotable alternative to the ED beyond the COVID-19 pandemic, providing easier access to a doctor with access to patients' medical histories than an appointment for a face-to-face consultation. GP telehealth consultations may also address barriers to accessing health care for those with potentially the greatest need. The reported use and positive experiences with GP telehealth appointments should inform further research on their appropriateness as an alternative to the ED.

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KEYWORDS

ED avoidance; emergency department avoidance; telehealth; COVID-19; access; usage; experience; patient-reported; emergency department; survey; telemedicine; barrier

Introduction

There are increasing numbers of presentations to Australian public hospital emergency departments (EDs); in 2018/2019, there was a 4.2% increase in annual ED presentations to 8.4 million [1]. Morley et al [2] report increases in low-acuity ED presentations as one of the main input-based drivers of ED crowding. In Australia, almost 90% of GP consultations are fully subsidized by the government [3], but there is no fee for Australian residents who present at the ED of public hospitals. This likely facilitates low-acuity ED presentations. A recent Australian study in which general practitioners (GPs) held a regular GP consultation with patients immediately after a decision to discharge to home from the ED concluded that 20% to 40% of all ED presentations could potentially be diverted to primary care [4].

In the early stages of the COVID-19 pandemic, there was a significant reduction in the number of ED presentations in Australia [5], at least in part due to perceived infection risk in the ED. As a result of the pandemic, the Australian government introduced funding for GP telehealth consultations, which accounted for over 20% of GP consultations in 2020 [3]. The Australasian College for Emergency Medicine notes that "[t]here are many lessons to be learned from the response to COVID-19," including responses relating to the management of health events for which individuals would have attended an ED prior to the pandemic [6].

While some reductions in ED presentations during the pandemic may be attributable to reductions in acute events due to social distancing and lockdown orders, it is unknown how many patients requiring care have sought alternative, non-ED care, and how many have experienced inappropriate care or even harm by avoiding the ED [7]. Worldwide, many have reported on the reduction in ED presentations observed during the COVID-19 pandemic [7-10]; however we found no studies that specifically explored whether patients sought out other health care services as an alternative to the ED and their experiences with those services. There has been some reporting of concurrent changes in health service utilization. For example, in the United Kingdom, the reduction in ED attendance during the COVID-19 pandemic has occurred alongside an increase in the number of ambulance callouts with treatment at the scene rather than transport to hospital; an increase in the number of calls to the NHS telephone helpline (NHS 111) but with fewer callers referred to an ED; and a reduction in the number of GP appointments despite the use of telehealth services where possible [7,11].

Evaluations of patient [12] and practitioner [13] experiences with expanded telehealth during the COVID-19 pandemic (eg, in general practice, allied health, and specialist care) have been largely positive; however, none have specifically looked at telehealth for ED avoidance during this pandemic period.

We report findings from a survey—undertaken during the early stages of the COVID-19 pandemic—of Australian adults who reported experiencing a health issue for which they would previously have presented at an ED. The survey data describe respondent characteristics, health issues experienced, care pathways accessed, and respondents' experiences with care received. The aim of the survey was to identify potential lessons from the response to the pandemic to inform further research to improve emergency care in Australia.

Methods

Overview

An online survey (Multimedia Appendix 1) was designed to collect information on health-seeking behavior through people's use of services during the early stages of the COVID-19 pandemic in Australia. Potential participants were asked to complete the survey if they had experienced a health issue for which they considered attending a hospital ED within the last four weeks. An additional survey question sought confirmation that respondents would have attended an ED for this issue prior to the pandemic. This paper follows the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) checklist for the reporting of online surveys [14].

Survey Design and Implementation

The survey instrument was designed by the authors, and the separate components of the survey were developed in turn. Existing classification systems for health issues were reviewed [15], but a free-text response was selected to reduce respondent burden with respect to health literacy and response times, with the aim of categorizing responses for analysis.

A total of four broad care pathways were defined:

1. Attended the ED as their first option
2. Attended the ED after contacting another (non-ED) health care provider first
3. Only contacted another (non-ED) health care provider
4. Self-managed (ie, did not seek any form of health care)

Respondents who contacted another health care provider were asked for further details. Likert scales were used to assess levels of concern at the times of the health event and the survey, as well as general health.

The 10-item Generic Short Patient Experiences Questionnaire (GS-PEQ) [16] was used to assess respondents' experiences with care provided. Given the need to keep online surveys short and concise, a short-form patient-reported experience measures questionnaire was required. The GS-PEQ is based on the validated and reliable Nordic Patient Experiences Questionnaire (NORPEQ) [17] and other validated instruments used within the Norwegian health system [16]. The GS-PEQ assesses patient experiences using 10 questions with Likert scale responses.

The full survey underwent two rounds of online piloting with colleagues at Flinders University, followed by online piloting on May 5, 2020, with 53 panel provider respondents.

The survey was implemented online (Qualtrics [18]) during May 2020. Survey respondents were recruited via an International Organization for Standardization–accredited panel provider from May 5-14, 2020 (Dynata [19]), which enabled the recruitment of a large nationally representative sample within a short time period. A weblink to the survey was sent to all individuals registered with the provider, with the estimated time to complete the survey, but no information on the survey content. The weblink displayed the participant information sheet. Following this, potential respondents were asked for consent to participate before completing the screening question (Multimedia Appendix 1, page 1). The panel provider rewards respondents for completing surveys based on a structured incentive scheme that accounts for survey characteristics such as length and complexity.

Further recruitment was conducted from May 7-28, 2020, using Twitter and paid advertisements on Facebook (Multimedia Appendix 2). This allowed us to increase the number of young (18 to 24 years) female respondents, making the respondent sample more reflective of the Australian population of ED attenders (Multimedia Appendix 3) [1]. No incentives for survey completion were offered to Twitter or Facebook respondents.

Survey Analysis

Incomplete and inconsistent survey responses were excluded from the analysis. This included where the respondent gave no answer describing the health issue, indicated they attended for a normal hospital admission (ie, not an ED attendance), or said they attended only a non-ED provider but when asked which provider, they indicated they attended the ED.

Free-text descriptions of the health issue were categorized into Berendsen Russell et al’s 17 presenting problem categories [15]. Descriptions with insufficient detail and categories with small numbers were merged into an “other” category, leaving nine categories for reporting (cardiovascular, gastrointestinal, infection, injury, mental health, musculoskeletal, neurology, respiratory, and other).

Descriptive statistics were undertaken in R (version 3.3.3; R Foundation for Statistical Computing) [20] on the following: respondent characteristics, reported health conditions, and level of concern at the time of the reported event for different care choices; changes in level of concern between the time of the event and the time of completing the survey for different starting levels of concern and care choices; and respondent-reported experiences (GS-PEQ) for patients receiving face-to-face and telehealth GP appointments.

The distributions of responses for different care choices are presented (eg, the proportion of respondents in each age group category that presented to an ED first). Confidence intervals and *P* values are not presented to avoid the perception of p-hacking [21], as well as because the reported comparisons should be interpreted as descriptive and hypothesis generating, not as inferential and hypothesis testing.

Ethics Approval and Funding

The project was approved by the Flinders University Social and Behavioural Research Ethics Committee (project number 8652).

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Results

Survey Respondents

A total of 10,754 potential respondents viewed the information sheet for the survey; of these, 10,019 (93%) consented to participate, and 1920 (18%) consented and met the eligibility criteria (Table 1). Of the eligible respondents, 264 were excluded as their surveys were incomplete or inconsistent and 367 were excluded as the respondent stated that they would not have chosen to attend the ED for the stated health issue prior to the COVID-19 pandemic. Of the resulting final 1289 (12%) respondents, most were recruited through the panel provider (1104/1289, 86%; Multimedia Appendix 3).

Figure 1 displays the characteristics of all respondents and respondents by care choice. The eligible survey respondents were representative of the gender and geographical location of Australians who presented at an ED in 2018-2019, though the age distribution was different [1]. Primarily, the survey included smaller proportions of respondents aged 75 years and older and aged between 18 and 24 years, and a larger proportion of those aged between 25 and 44 years (Multimedia Appendix 3). A total of 15 respondents were missing demographic characteristic data and are excluded from percentage calculations.

Table 1. Respondent recruitment.

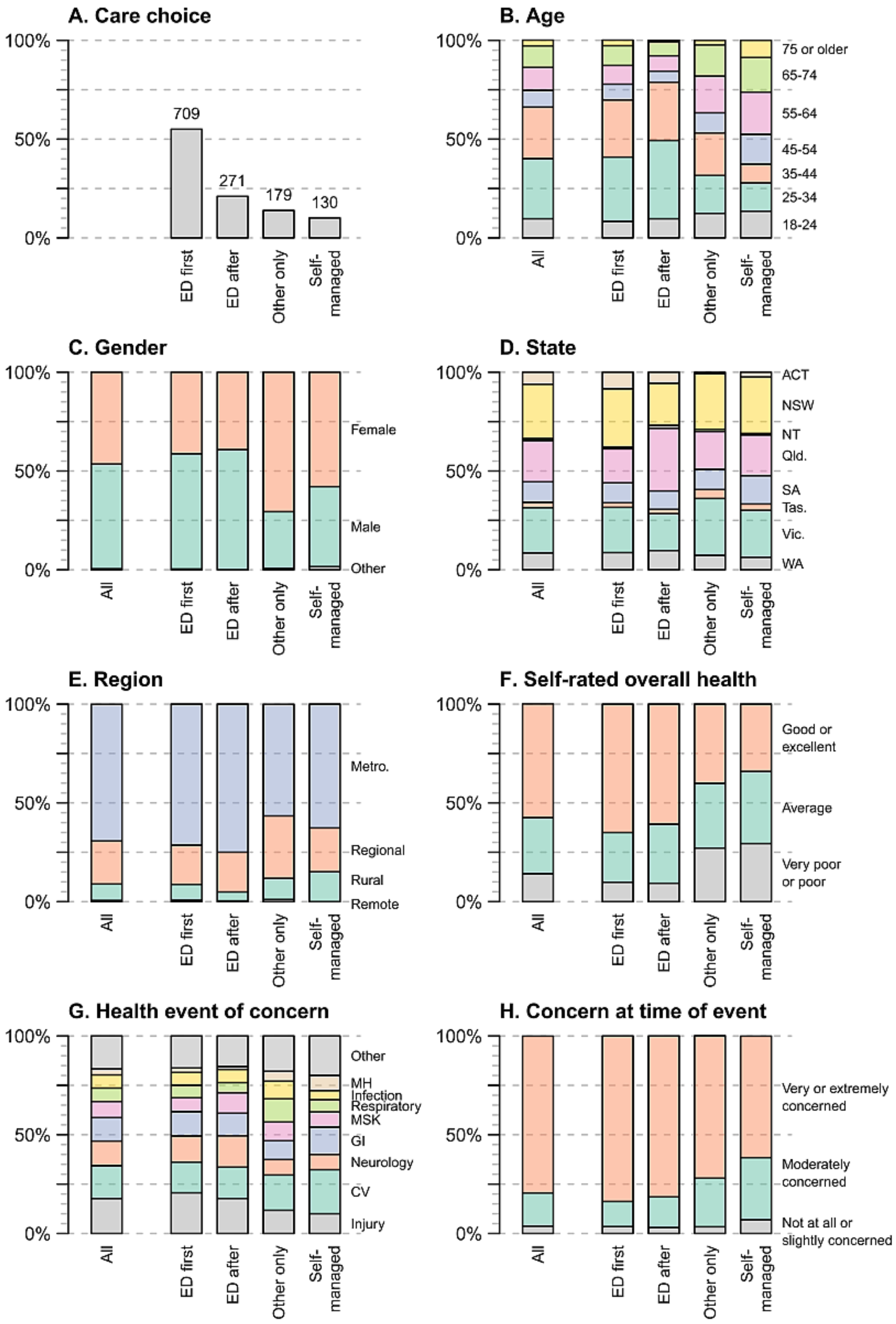
Recruitment steps	Panel provider, n (%)	Facebook and Twitter, n (%)	Total, n (%)
Viewed information sheet	10,386 (100)	368 (100)	10,754 (100)
Did not consent to participate[a]	730 (7.0)	5 (1.4)	735 (6.8)
Did not meet screening criteria[a]	8086 (77.9)	13 (3.5)	8099 (75.3)
Eligible (ie, consented and met screening criteria[a])	1570 (15.1)	350 (95.1)	1920 (17.9)
Excluded from analysis[b,c]	466 (29.7)	165 (47.1)	631 (32.9)
Included in analysis[c]	1104 (70.3)	185 (52.9)	1289 (67.1)

[a] Percentage calculated using the number who viewed the information sheet as the denominator.

[b] Responses were excluded from the analysis if the survey answers were incomplete or inconsistent, or the respondent would not have chosen to attend the ED for the stated health issue prior to the COVID-19 pandemic. Examples of incomplete and inconsistent survey responses include when the respondent gave no answer describing the health issue, indicated they attended for a normal hospital admission (ie, not an ED attendance), or indicated they attended only a non-ED provider but when asked which provider, they indicated they attended the ED).

[c] Percentage calculated using the number eligible as the denominator.

Figure 1. Respondent characteristics. Characteristics of all respondents included in the analysis and for respondents by care choice. Panels show data by (A) care choice, (B) age, (C) gender, (D) state, (E) region, (F) self-rated overall health, (G) health event of concern, and (H) concern at time of event. ACT: Australian Capital Territory; CV: cardiovascular; ED: emergency department; GI: gastrointestinal; MH: mental health; MSK: musculoskeletal; NSW: New South Wales; NT: Northern Territory; Qld.: Queensland; SA: South Australia; Tas.: Tasmania; Vic.: Victoria; WA: Western Australia.



Respondents resided in all states and territories of Australia and across metropolitan (882/1274, 69%) and nonmetropolitan areas (392/1274, 31%). More than half of respondents rated their health as good or excellent (733/1274, 58%). The most common health events reported by respondents were categorized as an injury (228/1274, 18%), cardiovascular conditions (214/1274, 17%), neurological conditions (161/1274, 13%), or gastrointestinal conditions (153/1274, 12%; see Multimedia Appendix 4 for further details and health event subcategories).

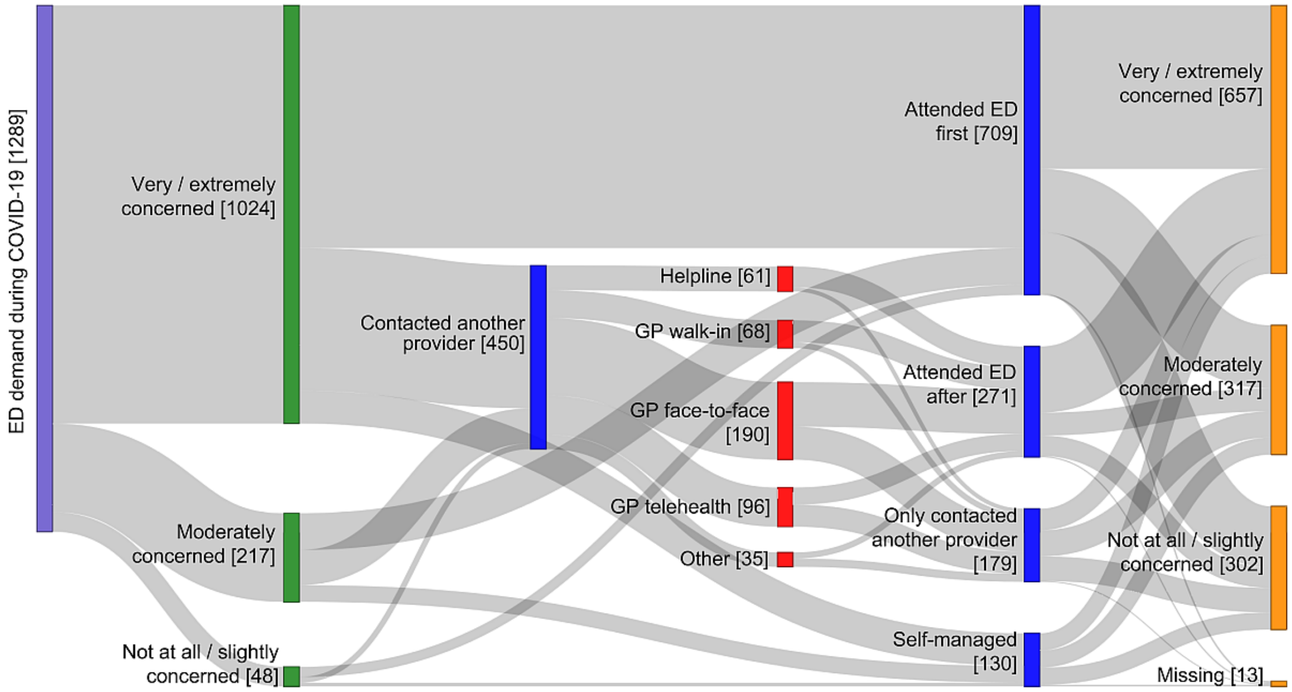
Care Choices

More than half of the respondents attended an ED as their first option (709/1289, 55%; Figure 1A; Figure 2; interactive version of Figure 2 in Multimedia Appendix 5). The remaining respondents delayed or completely avoided the ED: 21% (271/1289) reported attending an ED after contacting another health care provider, 14% (179/1289) only contacted another health care provider and did not attend an ED, and 10% (130/1289) self-managed their condition without contacting any provider.

A range of health care providers (Figure 2; Multimedia Appendix 5) were contacted by the respondents who either delayed attending the ED (contacted another provider first) or avoided attending the ED (only contacted another provider). Health care services used by these respondents were predominantly face-to-face GP appointments (190/450, 42%), telehealth appointments with GPs (96/450, 21%), attendance at GP walk-in clinics (68/450, 15%), and phoning a helpline (61/450, 14%). Other providers respondents contacted (35/450, 8%) included specialists (eg, their nephrologist, cardiologist, psychiatrist), allied health providers (eg, physiotherapist, dentist), pharmacists, or an ambulance service.

Of the respondents who contacted a helpline, 84% (51/61) went on to attend an ED, as did 79% (54/68) of respondents who attended a GP walk-in clinic. Fewer of the respondents who attended a face-to-face appointment with a GP (109/190, 57%) or a telehealth appointment with a GP (42/96, 44%) went on to attend the ED.

Figure 2. Respondents' levels of concern and care choices. Sankey figure mapping respondents' level of concern at the time of the health event (green bars), their care choices (blue and red bars), and level of concern at the time of completing the survey (orange bars). An interactive version of this figure is available in Multimedia Appendix 5. ED: emergency department; GP: general practitioner.



Care Choices and Demographics

A younger cohort either attended the ED first or attended the ED after seeing another provider (72% of ED attenders were aged under 45 years, 701/971 [9 missing]), while 41% of those who avoided the ED or self-managed their health condition were aged 55 years or over (125/303 [6 missing]). A higher proportion of male respondents (410/675, 61%) compared to female respondents (290/593, 49%) reported attending the ED first. With some exceptions, the use of different health care types was fairly consistent across all states and geographic areas. Self-rated overall health (not related to the health issue of concern) was reported as good or excellent by more of those who attended the ED first (456/703 [6 missing], 65%) or attended the ED after contacting another provider (163/268 [3 missing], 61%), compared to those who avoided ED attendance (contacted another provider: 71/177 [2 missing], 40%; self-managed: 43/126 [4 missing], 34%).

There was some variation in care choices across health conditions. Injury was the most frequently reported health condition for those attending the ED (ED first: 146/709, 21%; ED after contacting another provider: 48/271, 18%), while cardiovascular conditions were most frequently reported for those only contacting another provider (32/179, 18%) or self-managing (29/130, 22%).

Care Choices and Level of Concern

The majority of respondents (1024/1289, 79%) reported being very or extremely concerned at the time of the health event (Figure 1H; Figure 2; Multimedia Appendix 5; Multimedia Appendix 6). Of those who attended the ED first, 84% (594/709) were very or extremely concerned at the time of the event, compared to 82% (221/271) of those who attended the ED after contacting another health care provider, 72% (129/179) of those who contacted another provider only, and 62% (80/130) of those who self-managed.

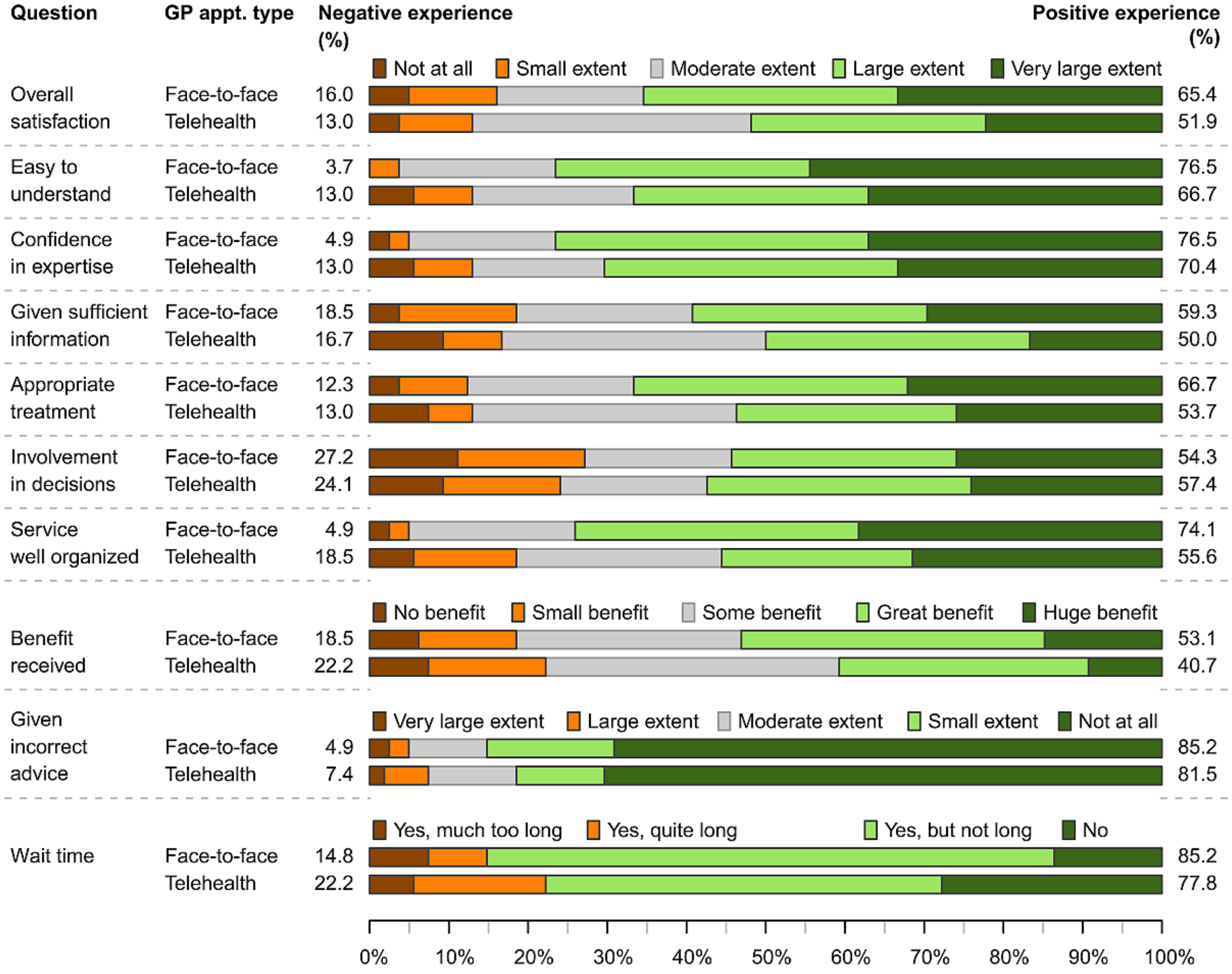
A large number of respondents (607/1276 [13 missing], 48%) started and remained “very or extremely concerned” about the health issue (Multimedia Appendix 6). This sustained high level of concern was observed most prominently among those who either attended the ED as their first choice (373/705 [4 missing], 53% of this group) or went to the ED after having contacted another provider (152/268 [3 missing], 57%), compared to 27% (47/177 [2 missing]) of those who only contacted another provider and 28% (35/126 [4 missing]) of those who self-managed. Increased levels of concern were reported by 5% (58/1276 [13 missing]) of respondents overall, with the proportion highest for those who self-managed their health condition (8/126 [4 missing], 6%).

Care Choices and Patient-Reported Experiences

From the GS-PEQ, overall satisfaction with the non-ED health care service was similar for respondents who went on to attend the ED (154/271 satisfied, 57%) and those who only contacted another provider (106/179 satisfied, 59%), as were the levels of overall dissatisfaction (later attended ED: 33/271 dissatisfied, 12%; another provider only: 25/179 dissatisfied, 14%).

For those who only contacted another health care provider, Figure 3 reports patients' experiences with care for those who accessed a GP via a telehealth appointment (54/179) and those who attended a face-to-face appointment with a GP (81/179). Examining overall satisfaction, telehealth respondents reported being satisfied (28/54, 52%) at a lower frequency than participants attending a face-to-face appointment (53/81, 65%). For almost all components of care, a larger proportion of the respondents attending face-to-face appointments reported positive experiences with the care provided compared to telehealth respondents. Negative experiences were more frequently reported for telehealth compared to face-to-face for ease of understanding (telehealth: 7/54, 13%; face-to-face: 3/81, 4%), confidence in the provider's expertise (telehealth: 7/54, 13%; face-to-face: 4/81, 5%), whether the health service was well organized (telehealth: 10/54, 19%; face-to-face: 4/81, 5%), and waiting times (telehealth: 12/54, 22%; face-to-face: 12/81, 15%).

Figure 3. Patient experiences with care for those who only contacted another provider (GP face-to-face and GP telehealth appointments). The 10-item Generic Short Patient Experiences Questionnaire uses Likert scales to assess patient experiences with the non-ED care received. Negative experience (dissatisfied) includes the two most negative responses. Positive experience (satisfied) includes the two most positive responses. The wait time question used a 4-point Likert scale, while all other questions used a 5-point Likert scale. ED: emergency department; GP: general practitioner.



Respondents Who Self-managed

The 10% of respondents (130/1289) who reported that they did not seek any form of health care may be of particular concern. These are respondents who would previously have presented at an ED, but due to the COVID-19 pandemic, they self-managed their health issue. Compared to respondents reporting alternative care choices, these respondents were more than twice as likely to be older than 65 years of age (self-managed 33/126 [4 missing], 26% versus sought any care 143/1148 [11 missing], 12%), report very poor or poor general health (37/126 [4 missing], 29% versus 142/1147 [11 missing], 12%), and live in a rural area/small town (19/126 [4 missing], 15% versus 87/1148 [11 missing], 7.6%).

Respondents not seeking care were also more likely to be female (73/126 [4 missing], 58% versus 520/1148 [11 missing], 45%), and to report mental health (10/130, 7.7% versus 29/1159, 2.5%) or cardiovascular (29/130, 22% versus 185/1159, 16%) conditions of concern.

Over 60% of self-managed respondents (80/130) reported being very or extremely concerned at the time of the reported health event, with 33% (42/126 [4 missing]) reporting being very or extremely concerned about their stated health issue at the time of survey completion, and an additional 33% (42/126 [4 missing]) reporting being moderately concerned at the time of survey completion.

Discussion

Principal Findings

This paper has reported findings from a large survey undertaken in May 2020 of 1289 adult Australians who reported experiencing a health issue in the last four weeks, for which they would have attended a hospital ED prior to the COVID-19 pandemic.

Overall, 35% (450/1289) of respondents contacted another health care provider, of whom 60% (271/450) went on to present at an ED. This means 14% of all respondents (179/1289) sought health care from an alternative source to the ED and avoided presenting at an ED. The avoidance of an ED presentation to the date at which the survey was completed, combined with low levels of dissatisfaction with the health care received suggests around 1 in 7 patients with a perceived need for emergency care can be cared for satisfactorily outside of an ED.

Among survey respondents who contacted another provider, 79% contacted a GP (354/450), with an ED presentation avoided by 43% and 56% of respondents who contacted a GP for a face-to-face (81/190) or telehealth (54/96) consultation, respectively. The avoidance of an ED presentation by around half of all patients making a booked GP consultation implies more scope to promote the use of GP consultations as an alternative to presenting at an ED. However, the effectiveness of campaigns to promote use of primary care as an alternative to EDs may be limited by accessibility barriers and funding incentives that may promote ED attendance [2,22]. The ongoing availability of GP consultations via telehealth may provide an effective and attractive alternative to ED presentations, especially if bulk billed. Bulk-billed GP telehealth consultations mean that patients do not need to travel to an ED department and experience long waiting times in the ED, while still providing a consultation with a medically trained doctor that is free at the point of care for patients. Face-to-face GP consultations require travel and that may tip the balance toward an ED presentation. Another alternative is a telephone helpline, such as Healthdirect [23], but this was rarely reported in survey responses, and of those who did use a helpline, 84% (51/61) subsequently presented to the ED. In comparison to a helpline service, GP telehealth consultations are with doctors who can provide definitive medical advice, and long waiting times on the phone are avoided because an appointment time is made.

While further research is required to assess the acceptability and appropriateness of GP telehealth consultations as an alternative to ED presentations, preliminary evidence suggests telehealth has become an acceptable and viable method of providing a broad range of health care services. A survey of Australian patients who accessed telehealth services during the COVID-19 pandemic found 62% reported their experience as “as good as” or “better than” face-to-face appointments, with many reporting that continuing telehealth services would be useful postpandemic [12]. Clinicians across general practice, allied health, and specialist services have described how changes to managerial and medical culture, combined with changes to funding of telehealth during the pandemic, have legitimized telehealth services, increasing confidence in and acceptance of this technology [13].

A finding of concern is that 10% of respondents (130/1289) did not seek any form of health care, with high reported rates of concern about their stated health issue at the time of survey completion. Self-management was more common in older individuals and those with poor or very poor general health—groups at heightened risk of COVID-19 severe illness. The introduction of government funding for GP telehealth consultations was designed to provide concerned patients with a safe method of receiving health care during the pandemic, but the finding that 1 in 10 individuals with potentially urgent health care needs chose to self-manage their health condition suggests barriers to the use of telehealth should be further explored and addressed. Isautier et al [12] found 1.4% (19/1369) of their survey participants were unable to access telehealth services during the pandemic. Reasons included that their GP or health care professional did not provide telehealth services, appointments were not available when required, the patient did not have internet access, or the patient felt the process was too complicated.

Limitations

The recruitment of survey respondents via an online survey resulted in the underrepresentation of persons in the youngest and oldest age categories: 3% (37/1274) and 10% (123/1274) of survey respondents were aged 75 years or older and 18 to 24 years, respectively, compared to 16.0% and 16.3% of people presenting at Australian EDs in 2018-2019, respectively (Multimedia Appendix 3) [1]. These differences should be taken into account when interpreting the survey findings; for example, the underrepresentation of older respondents may have underestimated the true proportion of people who avoided presenting at an ED, and in particular, those who did not seek health care. The benefits of using an online survey include the collection of data from a large sample (in this case, 1289 eligible respondents).

The nature of the survey data collected, in particular, the reliance on self-reported health conditions and the lack of a validated measure of urgency means that the application of inferential statistical analyses was not appropriate. Self-reported surveys are a valid source of data to describe the demographic characteristics of adults who experienced events for which they would have attended an ED prior to the COVID-19 pandemic and a general classification of the associated health problem. Self-report is also appropriate for describing patients' experience of alternative forms of health care. We propose that the data are sufficient to inform hypotheses to be addressed by further research.

Building on the findings of the survey reported in this paper, further research might focus on defining, facilitating, and promoting the use of GP services for a range of conditions as an alternative to the ED. Such research might focus on musculoskeletal, respiratory, and cardiovascular conditions, which were most commonly reported by respondents who received health care while avoiding the ED. Facilitation options include incentives for bulk billing for "ED avoidance" consultations, while promotional activities might aim to improve health literacy using stories describing the experiences of people who avoided the ED during the COVID-19 pandemic, as well as the promotion of telehealth as a more convenient alternative to presenting at an ED.

The other key focus for further research that has been highlighted by the survey findings is the cohort of individuals who perceived a need for emergency care, but did not seek health care from any provider. Barriers and facilitators to accessing health care by this group should be investigated, with a particular focus on GP telehealth consultations, for which funding was introduced to facilitate better access. Such research can inform improved access to health care in times of public health emergencies as well as in "normal" times, as the pandemic is likely to have exacerbated an existing access issue [24].

Conclusions

The reported survey of adult Australians who experienced a health issue for which an ED presentation would have been made prior to the COVID-19 pandemic provides insights into the effects of the COVID-19 pandemic on the demand and use of health care in Australia. The survey has provided evidence of positive experiences with alternatives to the ED, including telehealth consultations with GPs. It has also identified a cohort of generally older people with poorer general health for whom health system responses to support access to health care during the pandemic may have been insufficient. These findings provide a starting point for further research that should inform important policy responses that build on and respond to the effects of the COVID-19 pandemic on the health system.

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Authors' Contributions

All authors contributed to the study conception, study design, and survey design. Online data collection was organized by JK. Data analysis was performed by JG, with input from JK and AP. The first draft of the manuscript was written by JG. All authors commented on and contributed substantially to all versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey tool.
[PDF File (Adobe PDF File), 322 KB - humanfactors_v8i3e30878_app1.pdf]

Multimedia Appendix 2
Survey advertisements used for social media.
[PDF File (Adobe PDF File), 186 KB - humanfactors_v8i3e30878_app2.pdf]

Multimedia Appendix 3
Respondent characteristics for additional groups.
[PDF File (Adobe PDF File), 101 KB - humanfactors_v8i3e30878_app3.pdf]

Multimedia Appendix 4
Detailed coding of problem description using Berendsen Russell's categories and subcategories.
[PDF File (Adobe PDF File), 166 KB - humanfactors_v8i3e30878_app4.pdf]

Multimedia Appendix 5
Interactive version of Figure 2. Respondents' levels of concern and care choices.
[ZIP File (Zip Archive), 123 KB - humanfactors_v8i3e30878_app5.zip]

Multimedia Appendix 6
Sankey plots of level of concern at the time of the health event and level of concern at time of completing the survey by health care choice.
[PDF File (Adobe PDF File), 188 KB - humanfactors_v8i3e30878_app6.pdf]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
ED: emergency department
GP: general practitioner
GS-PEQ: Generic Short Patient Experiences Questionnaire
NORPEQ: Nordic Patient Experiences Questionnaire

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130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org