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A Web-Based Application for Complex Health Care Populations: User-Centered Design Approach

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Abstract

Background: Although eHealth technology makes it possible to improve the management of complex health care systems and follow up on chronic patients, it is not without challenges, thus requiring the development of efficient programs and graphic user interface (GUI) features. Similar information technology tools are crucial, as health care populations are going to have to endure social distancing measures in the forthcoming months and years.

Objective: This study aims to provide adequate and personalized support to complex health care populations by developing a specific web-based mobile app. The app is designed around the patient and adapted to specific groups, for example, people with complex or rare diseases, autism, or disabilities (especially among children) as well as Alzheimer or senile dementia. The app’s core features include the collection, labeling, analysis, and sorting of clinical data. Furthermore, it authorizes a network of people around the patient to securely access the data contained in his or her electronic health record.

Methods: The application was designed according to the paradigms of patient-centered care and user-centered design (UCD). It considers the patient as the main empowered and motivating factor in the management of his or her well-being. Implementation was informed through a family needs and technology perception assessment. We used 3 interdisciplinary focus groups and 2 assessment surveys to study the contexts of app use, subpopulation management, and preferred functions. Finally, we developed an observational study involving 116 enrolled patients and 253 system users, followed by 2 feedback surveys to evaluate the performance and impact of the app.

Results: In the validated general GUI, we developed 10 user profiles with different privacy settings. We tested 81 functions and studied a modular structure based on disease or medical area. This allowed us to identify replicable methods to be applied to module design. The observational study not only showed good family and community engagement but also revealed some limitations that need to be addressed. In total, 42 of 51 (82\%) patients described themselves as satisfied or very satisfied. Health care providers reported facilitated communication with colleagues and the need to support data quality.

Conclusions: The experimented solution addressed some of the health system challenges mentioned by the World Health Organization: usability appears to be significantly improved when the GUI is designed according to patients’ UCD mental models and when new media and medical literacy are promoted. This makes it possible to maximize the impact of eHealth products, thereby overcoming some crucial gaps reported in the literature. Two main features seemed to have potential benefit compared with other eHealth products: the modeling, within the app, of both the formal and informal health care support networks and the modular structure allowing for comorbidity management, both of which require further implementation.
Background

The improvement in health services and the quality of health treatment and social care has led to a significant increase in survival (and quality of life) among adults and children with chronic complex diseases and high health care needs [1].

According to the World Health Organization (WHO), over a billion people have some form of disability, whereas 110 to 190 million adults have significant difficulty functioning. An estimated 39% of the Italian population is affected by some chronic disease, with increasing disability rates. Currently, more than 3 million people in Italy are disabled. These patients are characterized by multiple morbidities, requiring the use of a range of services and a technology-enhanced care model [1-4].

eHealth may help such patients manage multiple clinical encounters and large amounts of clinical information generated from various sources. Indeed, patients report a highly frequent use of information and communications technology (ICT) to search for health information, communicate with health care providers (HCPs), track medical information and medications, and assist in decision making regarding treatment [5]. Notably, patients attempt to use ICT tools for self-management, as they expect to benefit from eHealth and enhance control over their own disease [6].

Extant research suggests that eHealth tools supporting patient-HCP interaction, patient self-management, and HCP-HCP interactions (through electronic health record integration) are of great benefit to patients [7,8]. These benefits may increase further, as the COVID-19 crisis has triggered additional demand for remote care models and systems. Previous studies have pointed out a number of critical issues concerning complex health care populations, since these include different subpopulations that pose specific medical and organizational challenges for the design of public service provision. These issues include the accurate assessment of the levels of services and needs, implementation of services and resources tailored to specific needs, coordination and integration of family-centered care planning, promotion of health systems based on patient or family self-management, and the redefinition of models of multidisciplinary team care [5,9,10].

According to the 2012-2020 eHealth Action Plan, in 2011, the Italian Public Administration promoted a high-communication health care project and a citizen’s Electronic Health Dossier (Fascicolo Sanitario Elettronico) [8,11], but the project encountered difficulties in getting under way and proved difficult to implement. The few ongoing initiatives have not received positive feedback from users due to usability problems and the low digital literacy of both HCPs and families [12].

Objectives

In this context, the ABILITA2 Project (Italian: Sviluppo di un Applicativo per terminali mobILI dedicato a popolazioni ad aTTA complessità Assistenziale; English: Development of a web-based Mobile Application for complex healthcare populations) takes advantage of ICT and its eHealth applications, exploiting the patient-centered care approach. When addressing the abovementioned issues, it adapts the service to different subpopulations, providing models that can be replicated in the future [13].

To meet the requirement of interdisciplinarity, the ABILITA2 consortium includes a partnership between ICT companies (Informapro Srl, Logica Informatica Srl, and Mediamed Interactive Srl) and medical and research centers (Ospedale Pediatrico Bambino Gesù - Rome and Consultorio Pediatrico ASL Rieti) as well as patient associations related to the medical areas of Alzheimer disease, autism, artificial nutrition, and rare pediatric diseases.

The project’s general objective was to provide adequate and personalized support to complex health care populations by developing a specific web-based app, Abilita, designed around the patient and customizable for specific groups, notably people with complex or rare diseases (eg, genetic syndromes, patients requiring parenteral nutrition), autism or disabilities (especially among children), and Alzheimer or senile dementia. The core features of the app allow for the collection, labeling, analysis, and sorting of clinical data. Furthermore, it authorizes a network of people around the patient to securely access the data contained in his or her electronic health record.

The study’s specific objectives are as follows:

- Assess levels of service and patient needs, testing assessment procedures and tools, especially for pediatric and older adult groups who are less considered in the eHealth market.
- Promote patient self-management and co-responsibility as the basis for a suitable and user-friendly web application. The emphasis is on patient empowerment (understanding of his or her role, acquisition of sufficient knowledge to be able to engage with HCPs, patient skills, and the availability of a facilitating environment [14,15]).
- Enhance and innovate the coordination between professionals and caregivers, specifically exploring the potential of a collaborative network operating on the patient’s behalf, which is built by the patient based on his or her individual needs and institutional contacts.
- Make the most of a proximity support network, which includes informal relationships with relatives, friends, and key figures in the territory, which is a crucial health care management factor [16,17].
- Encourage families or communities to play an active role and, at the same time, ensure quality of data, care, and
assistance by using GUI modeling of proper actions per profile according to the level of skill and motivation.

• Assess the app’s performance and impact.

Methods

Assessment and Design Process

The project adopted a user-centered design (UCD) approach in graphic user interfaces (GUIs) and considered users’ point of view and needs as central. The difference from other methods is that UCD meets the needs and desires of users rather than forcing them to change their behavior to meet the product settings [18]. Since the designers considered the user to be the patient (or parent/caregiver), an interdisciplinary analysis was needed to assess needs and then model actions, logic paths, questions, and answers within the interface. To do so, clinical and medical competence needs to be flanked by skills in computer sciences and database management, communication or new media sciences, psychology, and sociology [13]. The study used a number of focus groups based on a general inductive approach. The results of these focus groups were then further investigated through anonymous questionnaires [19]. The focus groups met monthly with 90- to 120-min sessions to analyze the different issues raised by the study.

Focus group A assessed patients’ needs and scenarios of use. It included patients (n=4), health care workers (n=2), psychologists (n=1), researchers in communication sciences (n=1), and software developers (n=1). All participants were part of the project network and discussed the experience of patients and caregivers with ICT products and possible scenarios using the Abilita app. Finally, a web-based questionnaire (Q1) was developed for the purpose of studying the main features, habits, needs, and digital and medical literacy of patients and families. Q1 was sent to a selected sample of patient associations (presidents and expert members in steering groups): Alzheimer Uniti Roma ONLUS, Associazione Nazionale Genitori Soggetti Autistici (ANGSA) Lazio Onlus, Associazione italiana sulla nutrizione Artificiale Domiciliare “Un filo per la Vita,” Associazione Prader Willi Lazio, Associazione Italiana delezione cromosoma 22 Onlus. The 20 anonymous responses were collected in June 2018; and the statistics of multiple-choice items and summaries of open-answer items were contained in a project report in September 2018 [20,21].

Focus group B, consisting of HCPs (n=4), psychologists (n=1), privacy officers (n=1), and software developers (n=2), was devoted to the general GUI design. The outcomes of the assessment of patient needs were translated into design challenges. The discussion raised a number of research questions, including the problem of low HCP motivation or time and the need to consider the patient as the main subject motivated to use the app. It is also necessary to task the patient or caregiver with data entry and updating health records and adding user profiles to the app (to model both institutional and informal patient support networks). Additional issues concerned the powers of individual user profiles (reading or writing of sections of the data set), the need to ensure health data quality, even when not directly entered by HCPs, and to predict real-world data entered by the patient and his or her proximity network. We used paper prototyping throughout the process that led to the user requirements document delivered in November 2018 for all identified user profiles (patient, parent or tutor, caregiver, family member, doctor, nurse, structure manager, social operator, temporary, and emergency).

In designing the health record, we tried to identify possible user behaviors, which led to additional questions: what does a particular population require and how can the interface structure be customized for specific pathologies to meet patient needs and coordination requirements? Data and pages are not equally relevant for all subpopulations, and preferred content, information, and functionalities differ across groups. In this respect, the general GUI of Abilita could be made more powerful by customizing content and database structure, with a view to create GUIs for more specific medical areas (the Abilita modules).

Focus group C was set up to assess this potential. It included presidents and steering group members from patient associations (n=4), psychologists (n=1), communication sciences researchers (n=1), and software developers (n=1). The discussion addressed the specific needs of the subpopulations involved in the study, after which we administered a mandatory questionnaire (Q2) to test the usefulness and effectiveness of feasible implementations. Q2 was sent out through email to a selected sample of national and regional patient associations; the 15 anonymous responses were then collected into a database highlighting the main aspects or attention points for GUI customization and the preferred functions that could be identified.

Observational Study, Feedback, and Validation

After the development of the prototype, we performed an observational study to evaluate its application in terms of its functionality, versatility, responsiveness to patients or families’ needs, user-friendliness, and rate of acceptance. We designed the study in line with international Good Clinical Practice criteria and obtained approval from the ethics committees of the medical centers involved (document protocols 1589_OPBG_2018 and 2474/CE Lazio1).

A total of 116 of the 130 (89.2%) patients invited to participate in the study were included, as they (or their families) possessed the required computer skills. They were recruited in the Rome area and in the Province of Rieti, a setting marked by a variety of health needs and increased geographic isolation due to the 2016 earthquake. During the 6-month study period (January-June 2019), the patients authorized additional user profiles to access their data, namely 32 HCPs, 97 parents, 5 family members, and 3 caregivers, for a total of 253 app users. We then analyzed individual user accesses to explore the actual use of the app. Frontal, telephone, and web-based tutoring sessions helped the patient participants (or their parents if the patient was aged under 16 years) to complete the registration and browse the app upon uploading their personal data. In June 2019, we developed a voluntary web application feedback questionnaire for patients (Q3) with indicators for evaluating usefulness or satisfaction, privacy, and security impact. We identified usability and effectiveness, while task managers tested
the app’s compliance with general recommendations and technical functionality. A link to the questionnaire was sent by email (we avoided multiple responses by limiting survey access to a single instance), and we received 51 anonymous responses in July 2019; the statistics on multiple-choice items and summaries of open-answer items were reported in a project report in September 2019.

In July 2019, we conducted 23 semistructured individual interviews with 10 doctors and 13 nurses to explore the app’s usefulness in the follow-up of chronic patients, its usability, and other features of the HCP interface (questionnaire Q4).

Table 1 summarizes the different data collection stages of the research.

<table>
<thead>
<tr>
<th>Data collection process</th>
<th>Description</th>
<th>Access and recruitment criteria</th>
<th>Collected data and period</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group A</td>
<td>8 participants (4 members of the patients’ associations or caregivers, 2 HCPs\textsuperscript{a}, 1 software programmer, and 1 psychologist); 1 facilitator (researcher in communication sciences)</td>
<td>Members of the project network, experienced in the management of 5 medical areas (autism spectrum disorders, 22q11.2 deletion syndrome, Alzheimer disease, Prader-Willi syndrome, chronic intestinal failure)</td>
<td>Eight 2-hour meetings in the period, April-May 2018</td>
<td>Definition of main aspects and attention points to be tested on a larger sample of respondents through the questionnaire Q1; definition of scenarios of use</td>
</tr>
<tr>
<td>Questionnaire Q1</td>
<td>62 items mostly in a multiple-choice format and with partial adaptive questioning</td>
<td>A web questionnaire mandatory for a restricted sample of national and regional patient association members (closed mandatory survey [21])</td>
<td>20 anonymous responses collected in May 2018</td>
<td>Project report</td>
</tr>
<tr>
<td>Focus group B</td>
<td>8 participants (2 software programmers, 2 doctors, 2 nurses, 1 psychologist, and 1 privacy officer); 1 facilitator (researcher in communication sciences)</td>
<td>Members of the project network, experienced in eHealth and GUI\textsuperscript{b} design processes</td>
<td>Fifteen 2-hour meetings in the period, June-November 2018</td>
<td>User requirement document for all the identified user profiles</td>
</tr>
<tr>
<td>Focus group C</td>
<td>6 participants (4 members of the patients’ associations, 1 software programmer, and 1 psychologist); 1 facilitator (researcher in communication sciences)</td>
<td>Members of the project network, experienced in the management of 5 medical areas (autism spectrum disorders, 22q11.2 deletion syndrome, Alzheimer disease, Prader-Willi syndrome, chronic intestinal failure)</td>
<td>Five 2-hour meetings in the period, December 2018-January 2019</td>
<td>Definition of main aspects and attention points to be tested on a larger sample of respondents through the questionnaire Q2</td>
</tr>
<tr>
<td>Questionnaire Q2</td>
<td>7 items mostly in an open-answer format</td>
<td>Text file sent by email to a selected sample of national and regional patient association members (closed mandatory survey [21])</td>
<td>15 anonymous responses collected in January 2019</td>
<td>Database with main aspects and attention points for customization of the GUI</td>
</tr>
<tr>
<td>Observational study</td>
<td>Use of the Abilita app in real-world settings by patients, families, HCPs, and communities</td>
<td>We invited 130 patients of the project medical centers to participate (Provinces of Rome and Rieti); 116 accepted the invitation and were recruited</td>
<td>253 system users in the period January-June 2019 (116 patients, 32 HCPs, 97 parents, 5 other family members, and 3 caregivers)</td>
<td>Report on statistics of use in real-world settings exported by the system administrators</td>
</tr>
<tr>
<td>Questionnaire Q3</td>
<td>36 items mostly in a multiple-choice format (16 defined by a Likert scale score) and with partial adaptive questioning</td>
<td>A web questionnaire; we invited the 116 patients involved in the observational study and obtained 51 responses (closed voluntary survey [21])</td>
<td>51 responses collected in July 2019</td>
<td>Project report</td>
</tr>
<tr>
<td>Questionnaire Q4</td>
<td>17 items (16 defined by a Likert scale score and 1 open-answer item)</td>
<td>Face-to-face interviews; we invited the 32 HCPs involved in the observational study; 23 accepted</td>
<td>23 responses collected in July 2019</td>
<td>Project report</td>
</tr>
</tbody>
</table>

\textsuperscript{a}HCP: health care provider.

\textsuperscript{b}GUI: graphic user interface.
Results

Assessment and Design Process

Q1 clarified the overall context of the study. The age at first diagnosis for complex health care diseases ranged from 0 to 5 years for the majority of cases and from 65 to 80 years in the remaining cases. All patients were not autonomous and had at least one caregiver. Their digital skills were at a basic or medium level, with limited experience with the use of IT tools to communicate with social and (private or public) health care services. Patients or caregivers displayed significant awareness of their medical areas. They were able to name the diagnosis in technical terms, describe the main elements of the disorder or disease (causes, severity, symptomatology, correlations with other disorders, and risk factors), mention the pharmacological therapies with precision, describe recommended daily treatments and activities (diets, sport), and recognize changes in symptoms (especially aspects to be monitored and reported to health care personnel). The most frequently used documents were treatment plans, reports of visits or exams, and prescriptions. Most patients reported to a health care unit devoted to their specific disorder or disease and scheduled follow-up visits every 6 months on average. In this context, potential clients believed that Abilita could successfully respond to the following requirements:

- Provision of tools and resources to manage emergency situations (average score of 8.2 on a 0-10 scale, SD 1.6).
- Collection and storage of health care documents and digital contents (average score of 7.7 on a 0-10 scale, SD 3.0).
- Remote communication with authorized health care personnel (average score of 7.6 on a 0-10 scale, SD 2.1).

Focus group A identified the Online Help function as a central tool for the app, as it served multiple goals: it accompanies the user in browsing the sections even when he or she has low digital or medical literacy, and it acts as an intermediary between the different users operating within a patient’s personal folder.

Focus group B confirmed the main areas of the GUI (menu items) as follows: Home page; Help; My data; My network; Search; My story; Organizer; Notifications; Personal profile; Info room; Emergency card. The Online Help, personalized as a female avatar named Lisa, interacts with the user by written and/or audiovisual messages. The app also features a medical glossary explaining technical terms and jargon. When users first access the app, Lisa provides advice and recommendations on how to start, suggests the sections to be prioritized, and offers easily accessible demos of app functions. In subsequent usage, Lisa highlights unread notifications, scheduled appointments, and missing information in the Emergency card when relevant (Figure 1).

The my data area is the medical and administrative record and comprises 2 sections: general outline and clinical data and documents (Figure 2). The sections include importance or severity labels that ensure the record’s organization and facilitate access to the most relevant data. Key information on the type of disease, therapy, particular care needs, and specific conditions is easily available. Thanks to the validation function, HCPs can validate data entered by patients or caregivers.

Figure 1. Home page–shortcuts to the main areas and welcome or follow-up message from Lisa.
In the area *my network*, the patient or the parent or legal tutor can create a personalized collaborative network of care support (eg, doctors, nurses, parents, friends, neighbors, domestic helpers, babysitters and tutors, teachers, etc). Each member of the network is assigned a separate profile with authorization to access some or all of the personal data. Furthermore, the patient may authorize all health care facilities, thereby enabling all HCP personnel to read and update their medical records. The app also makes available temporary or emergency authorization facilities as well as the blanket withdrawal of all permissions. In the *search* area, it is possible to carry out simple or advanced database searches sorted by data subject or by authorized person (highly recommended by HCPs to facilitate access to relevant information). *My story* hosts a personal diary where users can note clinical data as well as daily experiences, relevant episodes or therapeutic adherence (*Multimedia Appendix 1*). Actions in the app are always traceable, which allow reconstruction of the author and the date of changes and data validation. *Figure 3* summarizes the results of the design process, the relationship between the design and objectives of the research (as discussed in the focus groups) and privacy policy.

In keeping with the privacy policy, the patient is the sole owner and controller of his or her data and the only person able to decide who may treat them and under what conditions, which meets both General Data Protection Regulation requirements and recommendations concerning patient empowerment [22,23]. All sensitive data and interactions between the client (web-based application or emergency mobile app) and the server are encrypted.
The results of focus group C confirm that the GUI’s disease specificity crucially improves app usability and patient engagement. The relevance of the data set and the perception of utility by families and communities increases when the app is customized based on the specific needs of a subpopulation. In particular, we studied subpopulation management for the following medical areas: autism spectrum disorders, 22q11.2 deletion syndrome, Alzheimer disease, Prader-Willi syndrome, and chronic intestinal failure. The main gaps were centered around the coordination of social and health care services (mostly during follow-up) as well as family support. As a result, the design of the *Abilita modules* for each medical area includes specific GUI features: personalization of the content and structure of the medical data set, contents of the *info room* (information about the disease), and functions of the *organizer* and *notifications* as well as recommendations and priority highlights from Lisa. More specifically, the study foregrounded the following elements:

- Each subpopulation would like to have a personalized page in the *clinical data* subsection.
- Different diseases and ages need differentiated administrative forms.
- The agenda and remind functions could be implemented for specific situations and connected with local networks.
- Users consider it important that data for clinical research at different levels be available.
- Users consider the latest disease-specific documents and recommendations important, such as the Integrated Care Pathway or best clinical practices.

### Table 2. Statistics of use of the study population (N=116).

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males, n (%)</td>
<td>67 (57.8)</td>
</tr>
<tr>
<td>Age (years), n (%)</td>
<td></td>
</tr>
<tr>
<td>0-10</td>
<td>67 (57.8)</td>
</tr>
<tr>
<td>10-20</td>
<td>28 (24.1)</td>
</tr>
<tr>
<td>&gt;20</td>
<td>21 (18.1)</td>
</tr>
<tr>
<td>Accesses by patients (n=623), mean (SD)</td>
<td>5.4 (2.3)</td>
</tr>
<tr>
<td>Authorizations by patients, n</td>
<td>207</td>
</tr>
<tr>
<td>Entered documents, n</td>
<td>868</td>
</tr>
<tr>
<td>Entered clinic visits, n</td>
<td>307</td>
</tr>
<tr>
<td>Entered exams, n</td>
<td>271</td>
</tr>
<tr>
<td>Entered diagnoses, n</td>
<td>155</td>
</tr>
<tr>
<td>Entered vaccines, n</td>
<td>348</td>
</tr>
<tr>
<td>Entered inputs on importance or severity, n</td>
<td>1040</td>
</tr>
<tr>
<td>Authorized parents, n</td>
<td>97</td>
</tr>
<tr>
<td>Other authorized family members, n</td>
<td>5</td>
</tr>
<tr>
<td>Authorized caregivers, n</td>
<td>3</td>
</tr>
<tr>
<td>Authorized HCPs*, n</td>
<td>32</td>
</tr>
</tbody>
</table>

*aHCP: health care provider.*
Table 3. Answers to questions 1-16, expressed in percentage of Likert scale scores.

<table>
<thead>
<tr>
<th>Question No.</th>
<th>Question</th>
<th>Scores, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Is Abilita useful for the orderly archiving of medical documents?</td>
<td>1 (2) 6 (12) 44 (86)</td>
</tr>
<tr>
<td>2</td>
<td>Is Abilita useful for the orderly archiving of documents concerning care and assistance?</td>
<td>2 (4) 6 (12) 43 (84)</td>
</tr>
<tr>
<td>3</td>
<td>Is Abilita useful for remembering the renewal of some clinical evaluations?</td>
<td>0 (0) 10 (20) 41 (80)</td>
</tr>
<tr>
<td>4</td>
<td>Is Abilita useful to having your medical history under control everywhere?</td>
<td>1 (2) 2 (4) 48 (94)</td>
</tr>
<tr>
<td>5</td>
<td>Does Abilita allow you to monitor some medical parameters when recommended by the HCPs?</td>
<td>2 (4) 7 (14) 42 (82)</td>
</tr>
<tr>
<td>6</td>
<td>Is Abilita useful for recording daily self-measurements (eg, blood pressure)?</td>
<td>10 (20) 9 (18) 32 (62)</td>
</tr>
<tr>
<td>7</td>
<td>Does Abilita allow you to share information on healthcare or psycho-educational assistance with various professionals?</td>
<td>3 (6) 8 (16) 40 (78)</td>
</tr>
<tr>
<td>8</td>
<td>Does Abilita allow you to receive relevant information in a health emergency away from home?</td>
<td>0 (0) 6 (12) 45 (88)</td>
</tr>
<tr>
<td>9</td>
<td>Does Abilita allow you to share health information with HCPs without bringing your complete medical chart with you?</td>
<td>0 (0) 3 (6) 48 (94)</td>
</tr>
<tr>
<td>10</td>
<td>Does Abilita help you adhere to drug therapy regimens (with reminders) and track what has actually been taken?</td>
<td>6 (12) 10 (20) 35 (68)</td>
</tr>
<tr>
<td>11</td>
<td>Does Abilita help you remember which medical devices to buy or order?</td>
<td>6 (12) 14 (27) 31 (61)</td>
</tr>
<tr>
<td>12</td>
<td>Does Abilita help you remember administrative deadlines for requesting disability status or for other socio-healthcare procedures?</td>
<td>5 (10) 13 (25) 33 (65)</td>
</tr>
<tr>
<td>13</td>
<td>Does Abilita help you to find a document in your archive quickly using advanced search functions?</td>
<td>3 (6) 8 (16) 40 (68)</td>
</tr>
<tr>
<td>14</td>
<td>Does Abilita provide useful information about bureaucratic aspects, scientific research or treatments?</td>
<td>2 (4) 14 (27) 35 (69)</td>
</tr>
</tbody>
</table>
Questions 17 and 18 asked users about the areas they would like to see enhanced: the answers covered all the areas suggested, with no specific option prevailing significantly, and the same applies to what functions should be integrated (question 18). Interestingly, the option *ability to set preferred tabs or activities to create shortcuts for most used functions* obtained 37% (19/51) of the responses, suggesting that customization is the best strategy. No relevant issues arose regarding privacy and security (questions 19-20): 57% (29/51) of users had no general problems, 65% (33/51) had no problems entering and classifying data, only 23% (12/51) had problems but overcame them with the Lisa online help or with practice (questions 21-30).

Other open and unstructured optional questions (31-36) yielded good feedback concerning the Lisa web-based help, with 47% (24/51) suggesting further implementation of this tool. Patients and caregivers urged informing family doctors and pediatricians about the app to maximize dissemination. The answers on scientific research and on PDTAs (diagnostic-therapeutic assistance pathways) highlight *Abilita*’s potential for data collection subject to privacy consent, for reconstructing analogies in groups of patients affected by the same disease or disorder, and for patient associations to pursue their institutional goals. In addition, *Abilita*’s effectiveness in facilitating relationships or communication with HCPs and local facilities was positively evaluated, preferably with the support of the region. Furthermore, participants considered that the main strengths of the project were *knowledge of one’s own medical history with a click* and the overall philosophy behind the app (*Multimedia Appendix 3*).

Q4, which included 17 predefined questions and addressed 23 HCPs, produced average positive scores of 72% (4 or 5) in the first 16 items defined by a Likert scale score (*Multimedia Appendix 4*). In the last open-answer item, asking strengths or weaknesses of the project, the following aspects were highlighted:

- The availability of reports and alerts facilitated communication among HCPs and accelerated diagnostic and care paths.
- Users appreciated the involvement of patients or parents in the data entry of documents, lab results, and parameters, although 6 respondents raised concern about quality.
- Overall, 39% (9/23) of respondents encountered general problems in using *Abilita*, especially in the first weeks, and asked that Online Help tools be implemented.
- Users appreciated the importance or severity labels.

### Discussion

#### Principal Findings

The project used needs assessment to establish the contexts to interface with, showing a prevalence of non–self-sufficient patients—typically infants and older adults—diagnosed at an average age of 0 to 5 or 65 to 80 years and mainly supported by health care units specifically devoted to the disorder or disease, for whom follow-up visits are scheduled on average every 6 months. Basic digital skills and good levels of medical literacy of families were identified as starting points of the design.

A sample of 116 patients participated in the observational study. Each patient authorized an average of 1.8 persons to access his or her data, typically parents and family members, doctors, nurses, and psychologists, with the additional involvement of the communities of other institutions and informal environments, for a total of 253 system users. In approximately 35% of cases, data entry was performed by the patients or their parents from the beginning.

Questionnaire Q3 yielded positive patient feedback on the utility of the app to address some health system challenges mentioned as relevant by WHO [24] and on themes such as delayed reporting of events (WHO challenge 1.2), communication roadblocks, lack of access to information or data, insufficient utilization of data and information (WHO challenges 1.4-1.6), insufficient continuity of care, inadequate supportive supervision (WHO challenges 3.5-3.6), low adherence to treatments, and loss of follow-up (WHO challenges 5.2-5.4).

We received no direct evidence on other challenges mentioned by WHO, such as low health worker motivation (3.4), geographic inaccessibility (5.2), insufficient patient engagement (8.1), or absence of community feedback mechanisms (8.3). Some useful indications do emerge in the interpretation of the answers to the same questionnaire Q3. The app promoted communication and team management among HCPs, health care bodies, and families (question 34) and, in addition, increased end user confidence in their own capacity to provide up-to-date, readily searchable, and clear medical information (question 36). According to answers to questions 33 and 35, *Abilita* can contribute to scientific research and PDTA definition (diagnostic-therapeutic assistance pathways), thereby addressing the lack of population denominator (challenge 1.1) —that is, once used by a larger sample of patients in the same medical area, it can become a tool for further assessment of subpopulation management.

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<table>
<thead>
<tr>
<th>Question No.</th>
<th>Question</th>
<th>Scores, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.</td>
<td>Can <em>Abilita</em> support HCPs in drawing up a treatment plan and help you follow it?</td>
<td>2 (4)</td>
</tr>
<tr>
<td>16.</td>
<td>Overall were you satisfied with the trial run of <em>Abilita</em>?</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

*aHCP: health care provider.*
The general choices of the GUI design revealed some advantages:

- The GUI is designed around the patient, who is modeled as the main empowered and motivating actor of the actions necessary to maintain and update the medical record.
- Users are constantly supported by the Online Help (avatar Lisa), thus addressing medical and digital literacy issues and patient’s commitment in terms of his or her specific role, the main problems that arise while using many ICT products.
- Coordination and management needs can be modeled as pathways and actions recommended by Lisa within the app; they are also addressed by targeted functions (search, calendar, and notification areas).
- Real-world data can be traced and collected to then be reused to advance research on the management of complex chronic conditions.

The issue of data quality, indeed highlighted by 6 of the respondents to the HCP survey, was addressed in the project through the track changes and validation functions. It is worth noting that patients and families are increasingly being required to participate in health monitoring, through daily self-measurement and recording of symptoms or in questionnaires, for diseases such as diabetes, and most recently in the COVID-19 pandemic [25,26]. eHealth market engagement strategies—especially in light of the new patient co-responsibility paradigm—are based on flexibility and customization, with a user-friendly design that makes it possible to communicate with or forward information or data to HCPs [27]. In its adoption of these strategies, Abilita is in line with a reframed relationship between active citizens and professionals and is intended as a social innovator in the development of a smart community model with the involvement of the proximity network—the app’s core feature.

Although informal or territorial networks were not fully exploited by the users during the observational study, as suggested by the number of authorized user profiles (Table 2), we can hypothesize that this was influenced by the study’s short duration and the characteristics of the patients involved, mainly children and teenagers. The lockdown period in Italy and Europe revealed the need to innovate public health systems precisely in this direction, linking them to local support networks (through new professional figures such as community nurses) and moving toward an integrated vision of health care. The role of volunteering and associations in providing support to self-isolated and vulnerable persons has also been highlighted [28,29]. In this context, specific design choices may require further refinement, considering, for example, the addition of other user profiles such as territory medicine physician or volunteer.

The modular structure of Abilita allows for the personalization of data sets and functions. It also facilitates far-sighted and sustainable investments owing to the partnership’s commercial initiatives, which are aimed at developing new modules (optimal feedback has already been received from relevant stakeholders) and intercepting specific target audiences interested in them. Most importantly, this structure allows the patient to choose one or more application modules in the case of different pathologies. In this way, Abilita has added the value of comorbidity management that is crucial to complex health care populations.

Usability appears to be significantly improved when the GUI is designed according to patients’ mental models and when new media and medical literacy are promoted. Following this principle, the assessment of specific subpopulation needs and the development of personalized GUIs for specific medical areas appears important. Procedures to assess patients’ needs were successfully experimented and a replicable methodology was defined.

Limitations

This analysis was limited by the low number of enrolled subjects and its short duration. Data collected during the study period and answers to questionnaire Q3 refer mainly to pediatric populations; more evidence is needed about older adult patients’ feedback. In fact, only one quarter of them were adults or seniors, but the app was designed and particularly valid for non-self-sufficient subjects, both children and older adults.

The strategy of modular implementation appears to be the best one, but no module has yet been developed and tested. A complete comparison with other available apps, mainly focused on a single disease, will be relevant once the corresponding modules are developed. Specific GUI design choices need to be refined. Nevertheless, the study shows the versatility of this approach for complex health care populations.

Conclusions

eHealth technology allows better management of complex health care aspects in the follow-up of chronic complex disease patients, but translating the UCD into GUI features of an eHealth app is a difficult task. The decision to use patient self-management and co-responsibility as the basis for an eHealth information system seems to have been successful in enhancing the probability of matching the needs of the target population. Moreover, usability appears to be significantly improved when the GUI is designed according to patients’ UCD mental models and when new media and medical literacy are promoted. Its potential applications in an era of greater sociosanitary distancing are certainly of particular interest.

Possible lines of exploitation are as follows:

- Design and develop new Abilita modules dedicated to specific clinical areas with particular care needs (not least with automatic data download and information managed by the patient’s clinical facility of reference).
- Make Abilita an integral part of the automatic distribution of data and dissemination of procedures in the public sector (The Italian National Health Care system is structured by regional area, with disease-specific health care facilities that may be very distant from users).
- Strengthen and expand Abilita and the patient association network to share information and solutions to the various problems faced by caregivers on a daily basis.
- Simplify usability as much as possible with the possible introduction of voice command shortcuts.
Acknowledgments
The authors thank all the patients and families who agreed to participate in this study. They also thank Dr Alberto E Tozzi for his useful and timely suggestions.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Screenshots and description of the Italian graphic user interface.

[PDF File (Adobe PDF File), 877 KB - humanfactors_v8i1e18587_app1.pdf]

Multimedia Appendix 2
Tested Abilita functions.

[PDF File (Adobe PDF File), 424 KB - humanfactors_v8i1e18587_app2.pdf]

Multimedia Appendix 3
Feedback questionnaire—patients.

[PDF File (Adobe PDF File), 2061 KB - humanfactors_v8i1e18587_app3.pdf]

Multimedia Appendix 4
Feedback questionnaire—health care providers.

[PDF File (Adobe PDF File), 281 KB - humanfactors_v8i1e18587_app4.pdf]

References


Abbreviations

GU: graphic user interface
HCP: health care provider
ICT: information and communications technology
UCD: user-centered design
WHO: World Health Organization
Procedures of User-Centered Usability Assessment for Digital Solutions: Scoping Review of Reviews Reporting on Digital Solutions Relevant for Older Adults

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Abstract

Background: The assessment of usability is a complex process that involves several steps and procedures. It is important to standardize the evaluation and reporting of usability procedures across studies to guide researchers, facilitate comparisons across studies, and promote high-quality usability studies. The first step to standardizing is to have an overview of how usability study procedures are reported across the literature.

Objective: This scoping review of reviews aims to synthesize the procedures reported for the different steps of the process of conducting a user-centered usability assessment of digital solutions relevant for older adults and to identify potential gaps in the present reporting of procedures. The secondary aim is to identify any principles or frameworks guiding this assessment in view of a standardized approach.

Methods: This is a scoping review of reviews. A 5-stage scoping review methodology was used to identify and describe relevant literature published between 2009 and 2020 as follows: identify the research question, identify relevant studies, select studies for review, chart data from selected literature, and summarize and report results. The research was conducted on 5 electronic databases: PubMed, ACM Digital Library, IEEE, Scopus, and Web of Science. Reviews that met the inclusion criteria (reporting on user-centered usability evaluation procedures for any digital solution that could be relevant for older adults and were published in English) were identified, and data were extracted for further analysis regarding study evaluators, study participants, methods and techniques, tasks, and test environment.

Results: A total of 3958 articles were identified. After a detailed screening, 20 reviews matched the eligibility criteria. The characteristics of the study evaluators and participants and task procedures were only briefly and differently reported. The methods and techniques used for the assessment of usability are the topics that were most commonly and comprehensively reported in the reviews, whereas the test environment was seldom and poorly characterized.

Conclusions: A lack of a detailed description of several steps of the process of assessing usability and no evidence on good practices of performing it suggests that there is a need for a consensus framework on the assessment of user-centered usability evaluation. Such a consensus would inform researchers and allow standardization of procedures, which are likely to result in improved study quality and reporting, increased sensitivity of the usability assessment, and improved comparability across studies.
and digital solutions. Our findings also highlight the need to investigate whether different ways of assessing usability are more sensitive than others. These findings need to be considered in light of review limitations.

**Introduction**

**Background**

Digital solutions, defined as any set of technologies, systems, and mobile apps that are available on a digital device such as an iPad, a laptop, or a smartphone [1], have become popular in different areas, namely to optimize and personalize health care provision [2], to promote healthy lifestyles (eg, physical activity) [3,4], to minimize loneliness and social exclusion by promoting social, religious, civic, and political participation [5-7], or to improve safety, independence, and confidence [2].

The accelerated aging of the population imposes several challenges on the health care and social systems. Owing to the higher rates of disease and morbidity [8,9], digital solutions have been noted as a valid contributor to help reach a high number of individuals at lower costs [10]. However, developing digital solutions adjusted to older adults presents specific challenges related to age and disease, such as loss of visual and hearing acuity or changes in fine motricity. These need to be considered so that the technology matches the users' needs and characteristics and, ultimately, its use results in an added value in daily life [11,12]. To guarantee that a digital solution is fully adjusted to its users, a robust evaluation process must be considered [13]. One of the key attributes of digital solutions that require careful attention and evaluation is usability.

Usability is part of the user experience, that is, the total usage phenomenon [14], and is defined as the measure by which a product can be used by specific users to achieve specific goals with effectiveness, efficiency, and satisfaction in a specific context of use [15]. Efficacy refers to the degree of accuracy and completeness with which users achieve certain goals in a given environment, efficiency is related to the accuracy and completeness of the goals achieved with regard to the resources used, and satisfaction is defined as the comfort and acceptance on the use of a system [15]. Furthermore, the level of usability obtained depends on the specific circumstances in which the product is used and the usage context includes users, tasks, equipment (hardware and software), and the physical and social environment, as all of these factors can influence the usability of digital solutions [15]. In other words, usability is the ability of a product to be understood, learned, used, and attractive to the user, when used under specific conditions. This definition reinforces the idea that a product has no intrinsic usability and only the ability to be used under specific conditions [16]. Good usability allows reducing task execution times, errors, or learning times; improves user satisfaction; and leads to improved product acceptability, increased user satisfaction, and improved product reliability [17].

Usability evaluation is an important part of the overall development of user interaction mechanisms, which consists of interactive cycles of design, prototyping, and validation [18]. Ideally, usability evaluation must be present at all development stages and must be iterative to enable a continuous evolution of the quality of the product or service. The literature describes several models, methods, and techniques to ensure that usability issues are considered during the development process. The selection of these models, methods, and techniques depends on the development stage of digital solutions and available resources [19]. Certain models of usability assessment rely on usability experts, whereas others rely on end users (user-centered usability assessment). The former are known as the analytical models [20] and involve the inspection of the digital solution by experts to assess the various aspects of user interaction against an established set of principles of interface design and usability [21,22]. The latter refer to the empirical models [20] and involve having the perspective of users and are key to highly usable digital solutions by ensuring that the digital solutions meet the users’ needs and requirements, that is, they are adapted to the body and mind of their user in a given context [23]. This perspective is gathered using different methods (eg, test and inquiry) and techniques (eg, interviews, think-aloud, and observation), which are usually combined [24]. Both models are essential in the development process of digital solutions and provide complementary information [25]. This review focuses on the users’ assessment of usability.

Usability assessment involving users is a complex task, and the use of only one method (eg, test or inquiry) may not be comprehensive enough to thoroughly consider all relevant issues associated with a given product or service [19]. In addition, different methods have different strengths and weaknesses and provide information on different aspects of the digital solution [19]. Nevertheless, it is important to standardize the evaluation and reporting of usability procedures across studies. This will guide researchers, facilitate comparisons across studies, promote high-quality usability studies, which would be more likely to identify usability problems, and provide relevant data that contribute to highly usable solutions. The first step to standardizing is to provide an overview of how user-centered usability evaluation procedures are reported in the literature.

**Objective**

This scoping review of reviews aims to synthesize the procedures used or reported for the different steps of the process of conducting a user-centered usability assessment of digital solutions relevant for older adults and identify potential gaps in the present reporting of procedures. The secondary aim is to identify the principles guiding this assessment.
Methods

Study Design
This study followed the 5-stage scoping review methodology defined by Levac et al [26] based on the framework previously developed by Arskey and O’Malley [27]. The stages include (1) identification of the research question, (2) identification of relevant studies, (3) selection of relevant studies, (4) charting the data, and (5) collating, summarizing, and reporting the results of the review. A scoping review of the literature aims to map key concepts, summarize a range of evidence, especially in complex fields, and identify gaps in the existing literature. It allows for broader perspectives in comparison with systematic reviews [26,27] and, therefore, was the appropriate approach for this study, in which we aimed to cover a broad range of usability evaluation procedures and identify gaps to direct future research.

Identification of the Research Question
The research question provides a roadmap for the subsequent stages of the review. It was defined based on the analysis of the literature in the field of usability evaluation of digital solutions and the expertise of the research team, that is, during our previous work in the field of usability evaluation, we identified a lack of consensus in the academic literature regarding the instruments, protocols, and methodologies used for assessing usability across a range of digital solutions (eg, websites, assistive technology, augmented reality). Therefore, to have a more in-depth knowledge of the practices and procedures used, the following research question was defined: What are the current practices for the user-centered assessment of the usability of digital solutions (eg, procedures instruments) relevant (ie, that could be used and have value) for the older adult population? This broad question was subdivided into 5 research questions: (1) What are the characteristics of study evaluators reported in user-centered usability studies for digital solutions relevant to older adults? (2) What are the characteristics of study participants reported in user-centered usability studies for digital solutions relevant to older adults? (3) How are the tasks used for user-centered usability studies for digital solutions relevant to older adults? (4) What are the methods and techniques used in user-centered usability studies for digital solutions relevant to older adults? and (5) Where (ie, the environment) do user-centered usability evaluations take place?

Identification of Relevant Studies
The search expression usability OR user experience was used in the electronic search carried out in PubMed, ACM Digital Library, IEEE, Scopus, and Web of Science. The search expression did not include older adults as we did not want to limit the inclusion of reviews to those specifically mentioning older adults. Databases were searched for English language reviews published between January 1, 2009, and January 23, 2020. The limit of 2009 was established, as 2007 was the year the ambient assisted living joint programme was launched by the European Commission, which is a transnational funding program exclusively focused on the research and development of digital solutions directed at older adults [28]. Therefore, we searched for reviews from 2009 onward that covered the primary studies published after 2007.

Selection of Relevant Studies
All references were imported into Mendeley software (Elsevier, North-Holland) through which duplicates were removed. The first 300 abstracts were screened by 3 reviewers (HC, AS, and NR). Differences in judgment were used to refine the inclusion and exclusion criteria and were discussed until consensus was reached. This first phase of screening also served to build a common understanding of the inclusion and exclusion criteria. Screening of the remaining abstracts was performed by 1 reviewer (HC). Similarly, the first 10 full articles were screened by 2 reviewers (HC and AS), and differences in judgment were discussed until consensus was reached. If consensus was difficult to attain, a third reviewer who is a senior reviewer and an expert on usability (NR) was consulted. The remaining full papers were independently screened by one of these 3 reviewers.

To be included in this scoping review, studies had to report on user-centered usability procedures or methods of evaluation for any type of digital solution that could be relevant for older adults and that was (1) published in English; (2) a review, either systematic, scoping, or narrative review; (3) addressing and synthesizing evidence on any of the steps or methodologies used for usability assessment; and (4) addressing usability in general or for a specific digital solution that was considered relevant (this was a subjective judgment made by the authors of the review) to older adults or those caring for older adults, such as informal caregivers, family members, or health care professionals.

Studies were excluded if they (1) were grossly unrelated to the study topic (eg, chemistry field); (2) targeted children or younger age groups (eg, digital solutions for children with diabetes); (3) addressed usability for nondigital solutions (eg, buildings) or digital solutions assessed as not of interest for older adults or those caring for them (eg, moodle and eLearning solutions); and (4) addressed usability of digital solutions for caregivers of older adults, but only those studies that did not involve interaction or feedback with older persons or those caring for them were included.

Charting the Data and Collating, Summarizing, and Reporting the Results
The data extraction tool was developed using an iterative team process. The preliminary data extraction categories were derived from our research questions. The following data were extracted from each review: authors, year of publication, purpose/aim of the study, and the number of studies included in the review. Further extraction, analysis, and reporting of results were guided by the framework proposed by Ellsworth et al [29] for reporting usability evaluations, and the following operational definitions were used for this review:

1. Study evaluators, that is, the individuals who conducted the usability evaluation.

2. Participants, that is, the individuals who were asked to evaluate the usability of a product or service.
3. Tasks, that is, the activities that participants were asked to perform when evaluating the usability of a product or service.

4. Methods and techniques: methods refer to the set of techniques used to perform formative user-centered usability evaluation of a certain type at any stage of the product or service development. Usability evaluation techniques refer to a set of procedures used to perform a usability evaluation and collect data of a certain type. For this review, methods and techniques of usability evaluation were categorized and defined as presented in Table 1 (adapted from Martins et al [30]). Usability assessment usually requires the combination of more than one method, can be conducted remotely (ie, evaluators are separated in space from users) or in the presence of the participants, and can be synchronous (ie, occur at the time of the participants’ interaction with the system) or asynchronous [30].

5. The test environment, that is, the environment where the evaluation of usability takes place: (1) laboratory or controlled conditions, usually a transversal assessment, or (2) in a real context, that is, the usability assessment is carried out in the same context and circumstances where the end product or service is expected to be used, which is usually a longitudinal assessment. Details on the characteristics of each of these components of the usability assessment were extracted.

Table 1. Methods of user-centered usability evaluation.

<table>
<thead>
<tr>
<th>Method and definition and technique for data collection</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Test:</strong> involves observing users while they perform predefined tasks and consists of collecting mostly quantitative data; the test is centered on the interaction of the user with the technology</td>
<td>Evaluated by recording elements related to the execution of a particular task (eg, execution time, success or failure, number of errors, eye-tracking, and automated usability evaluation or logfiles or web usage analysis or app-use generated data or sensor data)</td>
</tr>
<tr>
<td><strong>Performance evaluation</strong></td>
<td></td>
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<tr>
<td><strong>Observation</strong></td>
<td>Attentive visualization and systematic recording of a particular phenomenon, including people, artifacts, environments, behaviors, and interactions. Observation can be direct, when the researcher is present during the task execution, or indirect, when the task is observed through other means such as video recording</td>
</tr>
<tr>
<td><strong>Think-aloud</strong></td>
<td>Users are invited to talk about what they see, do, think, or feel as they interact with the system or service</td>
</tr>
<tr>
<td><strong>Inquiry:</strong> provide valuable, subjective, and usually qualitative information on the users’ opinions and expectations</td>
<td></td>
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<tr>
<td><strong>Focus groups</strong></td>
<td>Involves a small number of people in an informal discussion</td>
</tr>
<tr>
<td><strong>Interviews</strong></td>
<td>Involves a one-to-one interaction to gather opinions, attitudes, perceptions, and experiences</td>
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<tr>
<td><strong>Scales/questionnaires</strong></td>
<td>Collects data on characteristics, thoughts, feelings, perceptions, behaviors, or attitudes, measuring either one (scale) or several (questionnaire) dimensions of usability. It is important to distinguish whether instruments were validated</td>
</tr>
<tr>
<td><strong>Diary studies</strong></td>
<td>Users record events related to their experience in the context of daily activity and later share them with the evaluators</td>
</tr>
<tr>
<td><strong>Card sorting</strong></td>
<td>It involves participants using logic while sorting content or cards into categories or groups that make sense to them, given the information they are provided with</td>
</tr>
</tbody>
</table>

**Results**

**Overview**
The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram for this scoping review is presented in Figure 1. A total of 3958 articles were identified from the 5 electronic databases. Of these, 1298 were eliminated because they were duplicates or did not have the author’s name. The remaining 2660 records were screened based on title and abstract and 2509 were excluded because they were not reviews (66/2660, 2.48%) or were out of scope (2443/2660, 91.8%). A total of 151 full texts were read for further analysis. Of these, 115 manuscripts were excluded because they were not related to usability, 3 articles were not found, and 13 reported on the assessment of usability by experts. Therefore, 20 reviews were included in this scoping review of the reviews. Of these, 19 were systematic reviews and one was a narrative review. Table 2 presents the main characteristics of the included reviews (study, purpose, and number of included studies).
Figure 1. Flow diagram showing study identification and selection for the present review.

- Records identified through database searching (n=3958)
- Records after duplicates removed (n=2660)
- Records screened by title and abstract (n=2660)
- Full-text articles assessed for eligibility (n=151)
- Reviews included (n=20)
- Records excluded (n=2509) with reasons:
  - Not reviews (n=66)
  - Out of scope (n=2443)
- Records excluded (n=131) with reasons:
  - Out of scope (n=115)
  - Expert-based assessment usability (n=13)
  - Not found (n=3)
### Table 2. General characteristics of included reviews.

<table>
<thead>
<tr>
<th>Study</th>
<th>Purpose of the review</th>
<th>Number of studies included in the review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ellsworth et al (2017) [29]</td>
<td>Review methods employed for usability testing on electronic health records</td>
<td>120</td>
</tr>
<tr>
<td>Allison et al (2019) [31]</td>
<td>Review methodologies and techniques to evaluate websites; provide a framework of the appropriate website attributes that could be applied to any future website evaluations</td>
<td>69</td>
</tr>
<tr>
<td>Azad-Khaneghah et al (2020) [32]</td>
<td>Review the rating scales used to evaluate usability and quality of mobile health applications</td>
<td>87</td>
</tr>
<tr>
<td>Baharuddin et al (2013) [33]</td>
<td>Propose a set of usability dimensions that should be considered for designing and evaluating mobile applications</td>
<td>Not referred</td>
</tr>
<tr>
<td>Bastien (2010) [34]</td>
<td>List test procedures and define and develop tools to help conduct user tests</td>
<td>Not referred (narrative review)</td>
</tr>
<tr>
<td>Bhattar et al (2013) [35]</td>
<td>List the most commonly applied usability evaluation methods and related emerging trends</td>
<td>30</td>
</tr>
<tr>
<td>Cavalcanti et al (2018) [36]</td>
<td>Understand which methods and user assessment approaches are commonly used in motor rehabilitation studies that use augmented reality applications</td>
<td>32</td>
</tr>
<tr>
<td>Fernandez et al (2012) [37]</td>
<td>Analyze the usability evaluation methods that have proven to be the most effective in the web domain</td>
<td>18</td>
</tr>
<tr>
<td>Fernandez et al (2011) [38]</td>
<td>Analyze the usability evaluation methods that have been employed to evaluate web applications over the last 14 years</td>
<td>206</td>
</tr>
<tr>
<td>Fu et al (2017) [39]</td>
<td>Assess the usability of diabetes mobile apps developed for adults with type 2 diabetes</td>
<td>7</td>
</tr>
<tr>
<td>Hussain et al (2014) [40]</td>
<td>Review the relevant and appropriate usability dimensions and measurements for banking applications</td>
<td>49</td>
</tr>
<tr>
<td>Inal et al (2020) [41]</td>
<td>Analyze how usability is being addressed and measured in mobile health interventions for mental health problems</td>
<td>42</td>
</tr>
<tr>
<td>Klaassen et al (2016) [42]</td>
<td>Analyze if usability methods are equally employed for different end-user groups and applications</td>
<td>127</td>
</tr>
<tr>
<td>Lim et al (2019) [43]</td>
<td>Identify, study, and analyze existing usability metrics, methods, techniques, and areas in mobile augmented reality learning</td>
<td>72</td>
</tr>
<tr>
<td>Narasimha et al (2017) [44]</td>
<td>Analyzing the characteristics of usability-related studies conducted using geriatric participants and the subsequent usability challenges identified</td>
<td>16</td>
</tr>
<tr>
<td>Shah and Chiiew (2019) [45]</td>
<td>Identify, analyze, and synthesize the usability features and assessment approaches of pain management mobile applications targeted at the evaluation studies</td>
<td>27</td>
</tr>
<tr>
<td>Simor et al (2016) [46]</td>
<td>Analyze usability evaluation methods used for gesture-based games, considering devices with the motion-sensing capability</td>
<td>10</td>
</tr>
<tr>
<td>Sousa and Lopez (2017) [47]</td>
<td>Identify psychometrically tested questionnaires that measure the usability of eHealth tools</td>
<td>35</td>
</tr>
<tr>
<td>Yen and Bakken (2012) [48]</td>
<td>Review and categorize health information technology usability study methods, and to provide practical guidance on health information technology usability evaluation</td>
<td>346</td>
</tr>
</tbody>
</table>

**Study Evaluators**

Only 4 out of the 20 (20%) [29,36,37,46] included reviews briefly mentioned any characteristic of the evaluators' profile. One of the reviews [36] reported that one of the 32 articles included mentioned that the person who performed the usability assessment was a blind evaluator. One review stated that several studies (exact numbers not provided) used graduate students as both evaluators to perform usability inspections and participants in experimental sessions (eg, think-aloud protocol, remote user
testing) [37], whereas another review [46] reported that usability evaluations were conducted by researchers. In a review by Ellsworth et al [29], 29% (35/120) of the included articles presented the description of the study evaluators responsible for designing and carrying out the usability evaluation, but the characteristics reported in primary studies were not provided.

**Participants**

Half of the reviews included in this scoping review did not refer to the characteristics of the participants included in the primary studies reviewed. Of the reviews, 50% (10/20) reviews that reported on any of the participants’ characteristics, 4 reported mean age or age range [36,41,46,49], 4 reported the gender of participants [36,41,44,46], 8 reported the sample size [35,36,39,41,42,46,47,49], and 7 reported on other characteristics of participants by describing them as healthy participants or as having a specific clinical condition [36,37,39,41,44,46,49]. Nevertheless, 20% (4/20) reviews that reported the age of the participants also reported that not all primary studies detailed such information. Other characteristics of participants mentioned were being healthy, having a specific clinical condition, belonging to a specific occupational group (health care providers or students), and previous experience with mobile devices. **Multimedia Appendix 1** presents a description of the information provided within the included reviews.

**Tasks**

Only 2 of the 20 (10%) included reviews referred to the tasks that participants were asked to perform for the usability evaluation [46,49]. Simor et al [46] conducted a usability evaluation for gesture-based games and reported that the games and, consequently, the usability evaluation of each study had different aims, target populations, interfaces, and details, but in the majority of the studies, the protocol used was presented. Zapata et al [49] performed a systematic review on mobile health apps and reported that 17 of the 22 primary studies included reported the number of tasks performed by the users. The number of tasks ranged between 1 and 25.

**Methods and Techniques**

Of the 20 systematic reviews included, only 3 (15%) [33,40,41] did not refer to the methods and techniques of usability used. Among the inquiry methods, the questionnaires/scales (15/20, 75%) and interviews (12/20, 60%) were most commonly reported. Among the test methods, the techniques of performance (9/20, 45%) and think-aloud were the most commonly reported (6/20, 30%; **Table 3**). Of the 20 reviews, 6 (30%) reported on combinations of techniques mentioning a total of 22 different combinations of 4, 3, or 2 techniques. Most combinations include at least one technique from each method, which indicates that a multimethod approach was used (**Table 4**). Among scales/questionnaires, which constitute the technique most often reported, the most common usability assessment scales were the System Usability Scale [29,32,41-43,46,47] and the Post-Study System Usability Questionnaire [41,42,46,47]. The other scales/questionnaires include the Questionnaire for User Interaction Satisfaction [29,42,47], the Software Usability Measurement Inventory [32,42], the Usefulness, Satisfaction, and Ease of use Questionnaire [32,41], the Computer System Usability Questionnaire [32,47], the After-Scenario Questionnaire [46,47], the Perceived Useful and Ease of Use [32], the IsoMetrics usability inventory [32], the Health Information Technology Usability Evaluation Scale [32], the user Mobile Application Rating Scale [32]; the IBM ease of use [42], and the ISO 9241–11 Questionnaire [43]. In addition, several reviews have reported the use of nonvalidated questionnaires [32,41,43,46]. One review reported that 26% of the included studies used a remote assessment of usability, where participants are in an uncontrolled environment [31].
Table 3. Detailed techniques used for usability evaluation.

<table>
<thead>
<tr>
<th>Study</th>
<th>Test</th>
<th>Observation (n=3)</th>
<th>Performance evaluation (n=9)</th>
<th>Think-aloud (n=6)</th>
<th>Focus group (n=3)</th>
<th>Interview (n=12)</th>
<th>Scales or questionnaires (n=15)</th>
<th>Diary studies (n=1)</th>
<th>Card sorting (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bastien (2010) [34]</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Ellsworth et al (2017) [29]</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Fernandez et al (2012) [37]</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Fernandez et al (2011) [38]</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Klaassen et al (2016) [42]</td>
<td>✓</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Sousa and Lopez (2017) [47]</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Yen and Bakken (2012) [48]</td>
<td>—</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td></td>
</tr>
</tbody>
</table>

*aReported in the review.

bNot reported.
Table 4. Detailed description of the combination of techniques used for usability assessment.

<table>
<thead>
<tr>
<th>Techniques</th>
<th>Study</th>
<th>Multimethod</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation + performance evaluation + think-aloud + scale/questionnaire</td>
<td>Cavalcanti et al (2018) [36]</td>
<td>✓</td>
</tr>
<tr>
<td></td>
<td>Fu et al (2017) [39]</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Inal et al (2020) [41]</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Shah &amp; Chiew (2019) [45]</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Simor et al (2016) [46]</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Zapata et al (2015) [49]</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + performance evaluation + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + scale/questionnaire + interview + diary studies</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + think-aloud + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + performance evaluation + think-aloud + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + scale/questionnaire + focus group</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + scale/questionnaire + observation</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + observation</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Think-aloud + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Think-aloud + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Scale/questionnaire + interview + focus group</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + scale/questionnaire + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + scale/questionnaire</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Observation + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + observation</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Performance evaluation + scale/questionnaire</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Think-aloud + scale/questionnaire</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Think-aloud + interview</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Scale/questionnaire + interview + focus group</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Scale/questionnaire + diary studies</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>Interview + focus group</td>
<td>N/A</td>
<td>✓</td>
</tr>
</tbody>
</table>

*aReported in the review.  
\[N/A\]: not applicable.
Educational or digital literacy levels are likely to influence how the degree of similarity between the sample and the target end users. Insufficient for the reader to make a judgment regarding the reported across reviews were age and sex. However, these seem to exist on what should be reported. The methods and techniques used for the assessment of user-centered usability are the topics most commonly and comprehensively reported in the reviews, whereas the test environment is seldom and poorly characterized. Despite our aim of searching for reviews reporting on digital solutions relevant for older adults, only one of the included reviews specifically targeted older adults. This suggests that studies using older adults are scarce and that the findings of this scoping review also apply to usability studies with adults.

Our findings are in line with the review of Ellsworth et al [29], who reported that several of the included studies described the participants, but not the individual who conducted the usability assessment (study evaluator). The level of expertise and domain experience, whether the study evaluator is external to the team developing the product or service being assessed or, on the contrary, is part of the team and potentially has a conflict of interest when assessing usability, are examples of aspects that have the potential to influence the results of the usability assessment. Therefore, these should be reported by the authors. Most of the techniques are complex procedures of usability assessment; some of these depend on the interaction between the participant and the study evaluator and, therefore, require experience and knowledge to be assessed effectively.

The characteristics of the study participants most commonly reported across reviews were age and sex. However, these seem insufficient for the reader to make a judgment regarding the degree of similarity between the sample and the target end users. Educational or digital literacy levels are likely to influence how the participant perceives the usability of the system. For example, different subgroups of older adults may perceive the usability of the same system differently [46]. Therefore, a detailed characterization of physical, emotional, cognitive, and digital skills is needed for an appropriate interpretation of the results of the usability evaluation in certain subgroups of older adults. Furthermore, a detailed characterization of health conditions might also be relevant [46]. These aspects will also inform whether the sample used is representative of the end users. The use of nonrepresentative users and, therefore, the failure to consider their needs and preferences may result in products with low usability [36]. In general, the sample sizes are small, and no rationale for the size of the sample is provided. The appropriate sample size for usability studies is a matter of debate, with some authors arguing that 4 or 5 participants are enough to identify approximately 80%-85% of usability problems [50-52], whereas others report that with these numbers of participants only 35% of usability problems are determined [53]. The type of interfaces, the tasks performed by the participants, the context of use, and the state of technology development may explain the differences between studies [34]. Furthermore, it is worth noting the definition of usability as the measure by which a product can be used by specific users to achieve specific goals with effectiveness, efficiency, and satisfaction [15]. Conceivably, small sample sizes may be enough to detect usability problems but may be insufficient to have a broader view of usability more in line with the present definition.

Only 2 reviews reported on the tasks that participants were asked to perform to assess the usability of the product or service [46,49], and both concluded that, in general, studies reported on the protocol of the tasks used. Tasks vary depending on several factors, such as study aims, target population, interfaces, methods, and techniques used for usability assessment [46]. Nevertheless, the definition or selection of tasks that participants should perform should mirror the future use of the product or service [34,40]. No principles were found to guide the selection of tasks. For example, should there be a minimum set of tasks to be performed, should tasks require single or multiple steps, or should there be a minimum amount of time that each participant needs to spend using the product or service are illustrative examples of issues that are not clear.

The methods and techniques used for the assessment of usability have been consistently reported, and most reviews have found that a combination of methods and/or techniques are usually performed, in line with recommendations [19]. Different methods and techniques have different strengths and limitations [46] and, therefore, their combination is more likely to provide a comprehensive view of usability problems [19]. For example, scales and questionnaires are easy to use and useful for gathering self-reported data about the user’s perception but might have limited value informing on which aspects of the system need to be targeted for improvement [29,54]. Scales and questionnaires should be valid, but a few reviews have reported the use of scales and questionnaires that are unlikely to have been validated. Although there might be reasons to develop or adapt a scale/questionnaire, this process must be followed by evidence of its validity [41]. Interviews and observations are recommended when the number of participants is small because...
both generate high amounts of data that are time-consuming to analyze. Nevertheless, interviews can be useful to understand the reasoning of the user when facing a problem, and observation gives an insight into the moment when a problem occurs [46]. It is argued that think-aloud protocols may result in the loss of focus on the tasks being performed, whereas user performance is an easy assessment, particularly in cases where the system automatically records the performance indicators, but might provide limited information if used alone [46]. The most frequent multimethod combination described in the literature is the test and inquiry method combination; however, we found no information in the included reviews regarding which combination of techniques is the most sensitive and whether this could vary depending on the development stage of the product or service being evaluated. Furthermore, the combination of techniques should allow for the assessment of effectiveness, efficiency, and satisfaction, as these are all part of usability.

Only 2 reviews reported on the test environment, but both referred that most included studies reported usability testing to have been conducted in the real context. Nevertheless, we found no indication of how long the usability assessment should be conducted, that is, how long the participants should be allowed to use the product or service before assessing it, and whether conducting the usability assessment in a real context means that the product or service was used in the circumstances that it is expected to be used.

**Recommendations and Future Research**

The conducting of rigorous experiments on user-centered usability is likely to result in increased sensitivity for these experiments, that is, an increased ability to detect usability issues. Developing a consensus framework is likely to improve the quality of studies on usability evaluation and respective reporting, improve comparability of usability results across studies, provide digital solutions helping consumers and producers to identify the best products, improve the efficiency of the process of usability evaluation and facilitate further research on the impact of usability on other outcomes, such health-related outcomes. **Textbox 1** presents a list of parameters that we believe should be considered when planning and reporting user-centered usability studies. These parameters provide guidance while also being flexible to accommodate study differences regarding aspects such as study participants or the digital solution being assessed. At present, we are working on a Delphi-study aiming to establish an international consensus on user-centered usability evaluation procedures.

**Textbox 1.** A proposed guide of aspects to consider when designing and reporting a user-centered usability evaluation study.

<table>
<thead>
<tr>
<th>Study evaluator:</th>
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</tr>
</thead>
<tbody>
<tr>
<td>• Provide a rationale for sample size</td>
<td></td>
</tr>
<tr>
<td>• Experience with usability evaluation with users (if none, plan training)</td>
<td></td>
</tr>
<tr>
<td>• Establish clear inclusion and exclusion criteria (age, gender, educational level, and academic background)</td>
<td></td>
</tr>
<tr>
<td>• Clarify whether internal or external to product development</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide a rationale for sample size</td>
<td></td>
</tr>
<tr>
<td>• Define clear inclusion and exclusion criteria</td>
<td></td>
</tr>
<tr>
<td>• Define sampling methods (probability/nonprobability) and setting of recruitment</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Methods and techniques:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide a rationale for the combination of methods and techniques</td>
<td></td>
</tr>
<tr>
<td>• Define equipment needed</td>
<td></td>
</tr>
<tr>
<td>• Select valid and reliable instruments of assessment</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Task:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Define the number</td>
<td></td>
</tr>
<tr>
<td>• Provide a detailed description of tasks</td>
<td></td>
</tr>
<tr>
<td>• Develop a participant script</td>
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</table>

<table>
<thead>
<tr>
<th>Test environment/equipment:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Identify and justify the choice (lab test or field test or both; remote test or face to face)</td>
<td></td>
</tr>
<tr>
<td>• Identify facilities and material needed</td>
<td></td>
</tr>
<tr>
<td>• Ensure the existence of an observation room and recording room</td>
<td></td>
</tr>
<tr>
<td>• Ensure the proper functioning of all equipment necessary for the test evaluation</td>
<td></td>
</tr>
</tbody>
</table>
Limitations of This Scoping Review

Some limitations are directly related to the typology of this review, such as the absence of assessment of the quality of the included reviews and the quantitative summary of findings [55]. Usability is also a topic on which a large number of publications are published as conference proceedings, and such publications were not specifically searched (selection bias). Nevertheless, it is likely that by including mostly reviews published in journals that these are more comprehensive, as conference proceedings tend to have lower word counts for included papers. Abstracts and full-text screening were performed first by 3 and 2 authors, respectively, and after a common understanding was built, only 1 reviewer screened the remaining abstracts and full papers. Although we believe that this did not have a major impact on the results, having only 1 person screening for inclusion might have increased the possibility of error and of not including a potentially relevant study. The judgment made to decide whether a manuscript was on a product or technology that could be of use for older adults was a subjective judgment made by the authors and could have biased the results toward the field of health. Finally, no cross-checking of the primary studies included in each review was made and, therefore, the same primary studies could have been included in more than one review.

In summary, we found a lack of a detailed description of several steps of the process of assessing the usability of digital solutions and no evidence on good practices. These findings suggest the need for a consensus framework on the assessment of usability that informs researchers and allows standardization of procedures. Furthermore, it highlights the need to investigate whether different techniques of assessing usability are more sensitive than others to detect usability issues.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary details of participant profile and sample size (sometimes percentages do not add up to 100%, as only partial information was provided in the review).

References

5. Gilson A, Dodds D, Kaur A, Potteiger M, Li JH. Using computer tablets to improve moods for older adults with dementia and interactions with their caregivers: pilot intervention study. JMIR Form Res 2019 Sep 3;3(3):e14530 [FREE Full text] [doi: 10.2196/14530] [Medline: 31482847]


The Use of Telehealth Technology to Support Health Coaching for Older Adults: Literature Review

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2Center for Outcome Research, Houston Methodist, Houston, TX, United States
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4Department of Psychological and Brain Sciences, Texas A&M University, College Station, TX, United States

Abstract

Background: Health coaching is an intervention process for driving behavior change through goal-setting, education, encouragement, and feedback on health-related behaviors. Telehealth systems that include health coaching and remote monitoring are making inroads in managing chronic conditions and may be especially suited for older populations.

Objective: This literature review aimed to investigate the current status of health coaching interventions incorporating telehealth technology and the associated effectiveness of this intervention to deliver health care with an emphasis on older adults (aged 65 and older).

Methods: A literature review was conducted to identify the research conducted on health coaching combined with remote monitoring for delivering health care to older adults. The Ovid MEDLINE and CINAHL databases were queried using a combination of relevant search terms (including middle aged, aged, older adult, elderly, health coaching, and wellness coaching). The search retrieved 196 papers published from January 2010 to September 2019 in English. Following a systematic review process, the titles and abstracts of the papers retrieved were screened for applicability to health coaching for older adults to define a subset for further review. Papers were excluded if the studied population did not include older adults. The full text of the 42 papers in this subset was then reviewed, and 13 papers related to health coaching combined with remote monitoring for older adults were included in this review.

Results: Of the 13 studies reviewed, 10 found coaching supported by telehealth technology to provide effective outcomes. Effectiveness outcomes assessed in the studies included hospital admissions/re-admissions, mortality, hemoglobin A1c (HbA1c) level, body weight, blood pressure, physical activity level, fatigue, quality of life, and user acceptance of the coaching program and technology.

Conclusions: Telehealth systems that include health coaching have been implemented in older populations as a viable intervention method for managing chronic conditions with mixed results. Health coaching combined with telehealth may be an effective solution for providing health care to older adults. However, health coaching is predominantly performed by human coaches with limited use of technology to augment or replace the human coach. The opportunity exists to expand health coaching to include automated coaching.

(JMIR Hum Factors 2021;8(1):e23796) doi:10.2196/23796

KEYWORDS

telemedicine; remote sensing technology; health coaching; decision support systems; clinical; older adults
Introduction

Overview of Chronic Diseases

Chronic diseases are health-related conditions that require ongoing medical attention or limit one’s daily activities [1]. These conditions are common among older adults and were the leading causes of death among older adults (aged 65 and older) in the United States in 2017 [2]. Chronic disease management within the world’s aging population is creating a burden on the health care industry [3]. For example, the average medical expenditures in the United States within this older population were 2.6 times the national average and accounted for over one-third of medical spending in 2010 [4]. A subsequent survey by the Kaiser Family Foundation found that older adults (age 55 and over) in the United States accounted for 56% of all health care spending in 2016 but made up only 29% of the population [5].

The Census Bureau projects that the US population aged 65 or older will grow from 49 million in 2016 to 95 million by 2060 [6]. Ninety percent of these older adults prefer to age in place, or remain in their homes as they grow older [7] which could also mitigate health care costs for this population compared to the cost of assisted living communities. Aging in place allows them to better maintain contact with friends and family, but this preference presents a challenge for determining what health-related technology is needed to help meet this desire [8]. Telehealth may be one way to effectively manage chronic diseases among older adults while also enabling them to live at home, especially with a number of opportunities available to assist aging in place through advancements in smart sensing technology [9]. Furthermore, the COVID-19 pandemic has also shown the necessity of understanding the efficacy of telehealth systems, as these systems may be the only mode of non-emergency health care delivery for vulnerable populations in a pandemic situation [10]. However, despite the increased access to telehealth technologies, implementation strategies that do not address self-management of one’s health care have led to disappointing findings, such as the failure to reduce re-admissions in individuals with heart failure [11,12].

While telehealth has enabled virtual visits with health care professionals, the self-management capabilities of telehealth require special attention to patient engagement and behavior change methods to improve active participation. Health coaching has gained widespread use in the past few years. Two recent systematic reviews found health coaching to be somewhat effective for adults with chronic conditions [13,14]. Kivelä et al [13] found health coaching to be effective for the patient’s physiological, behavioral, and psychological status, specifically, improvements in weight management, physical activity, physical health, and mental health. Oliveira et al [14] found health coaching to be effective in increasing the level of physical activity in older adults but found no significant improvement in quality of life, mobility, or mood. Neither of these studies evaluated health coaching combined with remote monitoring. The goal of our review was to investigate the current status of health coaching interventions that incorporate telehealth remote monitoring technology and the associated effectiveness of this intervention with an emphasis on older adults.

Background

Telehealth is an all-encompassing term for clinical and nonclinical remote health care services and is defined by the Center for Connected Health Policy as “a collection of means or methods for enhancing health care, public health and health education delivery and support using telecommunications technologies” [15]. For the purpose of this literature review, telehealth includes telemedicine, remote patient monitoring (RPM), remote activity monitoring (RAM), decision support systems (DSSs), and health coaching systems.

Telemedicine is the use of telecommunication technology to allow health care workers to provide clinical services (eg, medical therapy) to patients remotely [16]. Telemedicine is useful for providing clinical services to patients in sparsely populated areas or places remotely located from a health care facility [17].

RPM is the use of electronic devices and telecommunication technology to monitor and transmit patient physiological or metabolic parameters to a digital database that can be accessed by authorized users [18]. RPM usually involves Bluetooth-enabled or internet-connected devices that automatically transmit monitored parameters. RPM can also include electronic wellness questionnaires that elicit information concerning the patient’s well-being and health status.

RAM is the use of electronic devices to provide remote monitoring of a person’s mobility or activities of daily living (ADLs) [19]. ADLs can be remotely monitored using motion detection devices installed in a person’s residence or a wearable device, such as a smart watch, that detects, records, and transmits movement activity. Another form of ADL monitoring is medication adherence monitored remotely via automated pillboxes. Automated pillboxes are used to organize medications, provide reminders to take medications, and provide information to clinicians via telehealth regarding medication use [20].

DSSs are electronic (computerized) systems which evaluate data collected via remote monitoring and transform the data into useful information regarding the patient’s health and wellness [21]. The DSS makes clinical or behavioral recommendations based on an evaluation of the monitored data. An example of a recommendation is a reminder to the patient to take his/her medication if an automated pillbox senses the person has not taken their medication that day. If the medication is still not taken after some delay, the DSS can notify the health care providers or health coaching system. The DSS can also initiate an emergency notification to 911 if certain threshold values of monitored parameters are exceeded.

Health coaching systems are defined as “patient-centered processes that are based upon behavior change theory” and include goal setting, education, encouragement, and feedback on health-related behaviors [14]. Disease management, by contrast, focuses on the specific disease(s) instead of the patient’s behavior [22]. Health coaching programs provide health-related information, recommendations, or encouragement to the patient on a routine or as-needed basis to help drive
behavior changes [21]. Forms of health coaching include encouragement, feedback, health care suggestions, periodic health tips, or short educational presentations based on an analysis of the patient’s health status and monitored data. An example of a coaching message is sleep management advice if the patient is not sleeping well. The health coaching system can be manual (human health coach only), partially automated, or fully automated using artificial intelligence and machine learning to generate health coaching messages to the patient.

**Methods**

A literature review was chosen for this study to identify the research conducted on the current state and effectiveness of health coaching combined with remote monitoring (RPM or RAM) and any knowledge gaps that warrant further research. This review was specifically focused on health coaching combined with telehealth to deliver health care with an emphasis on older adults. The Ovid MEDLINE and CINAHL databases were queried to first retrieve papers related to health or wellness coaching for populations that included older adults and to then narrow the results to those studies that included some form of remote monitoring. Given the rapid pace with which telehealth is advancing, results from 2010 or later were chosen for this search to focus on relatively current research. The full electronic search strategy was [(MH “Middle Aged”) OR (MH “Aged+”) OR AB (older adult* or elder* or aged) OR TI (older adult* or elder* or aged)] AND [AB ((health or wellness) n1 coaching) OR TI ((health or wellness) n1 coaching)]. The search criteria included articles published from January 2010 to September 5, 2019 (date of search) in English. Keywords included those related to older populations (aged, elder, and older adult) and coaching (health or wellness coaching). This combination of search terms retrieved 225 papers relevant to health coaching. The review of these papers was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Figure 1) [23]. After deleting duplicates, 196 papers were included for an abstract review and screening. These abstracts were reviewed for studies that discussed health coaching for populations that included older adults (aged 65 and older) combined with some form of remote monitoring. The abstract screening yielded 42 articles for full-text review, of which 13 articles were identified that met the eligibility criteria (health coaching, remote monitoring, and older adults). Studies were excluded from our review if older populations (aged 65 and over) were not included, if the study did not include remote monitoring (RPM or RAM), or if the study did not include some form of coaching intervention. Subsequent to the review, 2 additional studies were identified [24,25] which provided the results for the ACTIVATE Trial [26] included in the original search. The results of the literature review were charted based on the following criteria: description of the coaching intervention, type of remote monitoring, study type, size of the study population, length of the study, condition monitored, and the outcomes.
Results

The results of the literature review are summarized in Table 1. All 13 studies were published between 2014 and 2019. Four studies were randomized controlled trials that ranged from 83 to 1437 participants [12,26-28]. One study was a quasi-experiment (nonrandomized cohort study) with 144 participants [29]. Six studies were pilot trials that ranged from 6 to 33 participants [21,30-34]. There was 1 qualitative interview of 10 health care workers [35] and 1 user acceptance study with 11 participants [36]. The main goal of each of these studies was to evaluate the effectiveness of health coaching. Our review focused on the effectiveness of health coaching (human coach versus automated coaching system) combined with remote monitoring technology (RAM and RPM) for older adults.
Table 1. Summary of results from the literature review.

<table>
<thead>
<tr>
<th>Study</th>
<th>Coaching intervention</th>
<th>Type of remote monitoring</th>
<th>Study type</th>
<th>Sample size, n</th>
<th>Study duration</th>
<th>Condition monitored</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>[12]</td>
<td>Human coach and telephone calls</td>
<td>RPM&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Randomized control trial</td>
<td>1437</td>
<td>26 weeks</td>
<td>Chronic heart failure</td>
<td>Re-admissions (N&lt;sup&gt;e&lt;/sup&gt;), mortality (N), and quality of life (Y&lt;sup&gt;f&lt;/sup&gt;)</td>
</tr>
<tr>
<td>[27]</td>
<td>Human coach and telephone calls</td>
<td>RAM&lt;sup&gt;c&lt;/sup&gt; and RPM</td>
<td>Randomized control trial</td>
<td>595</td>
<td>1 year</td>
<td>Chronic heart failure, diabetes</td>
<td>Blood pressure (N), body weight (N), and quality of life (N)</td>
</tr>
<tr>
<td>[26]</td>
<td>Human coach and telephone calls</td>
<td>RAM</td>
<td>Randomized control trial</td>
<td>83</td>
<td>12 weeks</td>
<td>Cancer</td>
<td>Physical activity (Y) and sedentary behavior (Y)</td>
</tr>
<tr>
<td>[28]</td>
<td>Human coach, telephone calls, and mobile app</td>
<td>RAM and RPM</td>
<td>Randomized control trial</td>
<td>131</td>
<td>26 weeks</td>
<td>Diabetes</td>
<td>HbA&lt;sub&gt;1c&lt;/sub&gt;&lt;sup&gt;d&lt;/sup&gt; level (N), body weight (Y), and quality of life (N)</td>
</tr>
<tr>
<td>[29]</td>
<td>Human coach, telephone calls, SMS text messages, online training, and social networking</td>
<td>RAM and RPM</td>
<td>Quasi-experiment</td>
<td>144</td>
<td>1 year</td>
<td>Diabetes</td>
<td>HbA&lt;sub&gt;1c&lt;/sub&gt; (Y) and body weight (Y)</td>
</tr>
<tr>
<td>[30]</td>
<td>Human coach, DSS&lt;sup&gt;a&lt;/sup&gt;, telephone calls, and exercise videos</td>
<td>RAM and RPM</td>
<td>Pilot study</td>
<td>12</td>
<td>8 weeks</td>
<td>Chronic obstructive pulmonary disease</td>
<td>Program adherence (Y) and patient satisfaction (Y)</td>
</tr>
<tr>
<td>[31]</td>
<td>Human coach, telephone calls, and SMS text messages</td>
<td>RAM</td>
<td>Pilot study</td>
<td>24</td>
<td>4 weeks</td>
<td>Cancer</td>
<td>Physical activity (Y) and fatigue (Y)</td>
</tr>
<tr>
<td>[32]</td>
<td>Human coach, DSS, exercise videos, and SMS text messages</td>
<td>RAM</td>
<td>Pilot study</td>
<td>6</td>
<td>2-6 weeks</td>
<td>General health</td>
<td>Yes</td>
</tr>
<tr>
<td>[21]</td>
<td>Human coach, DSS, exercise videos, SMS text messages</td>
<td>RAM and RPM</td>
<td>Pilot study</td>
<td>33</td>
<td>Various</td>
<td>General health</td>
<td>Behavior change (I&lt;sup&gt;g&lt;/sup&gt;)</td>
</tr>
<tr>
<td>[33]</td>
<td>Human coach, telephone calls, and mobile app</td>
<td>RAM and RPM</td>
<td>Pilot study</td>
<td>21</td>
<td>26 weeks</td>
<td>Diabetes</td>
<td>HbA&lt;sub&gt;1c&lt;/sub&gt; level (Y) and body weight (Y)</td>
</tr>
<tr>
<td>[34]</td>
<td>Automated coach, DSS, SMS text messages, and mobile app</td>
<td>RAM</td>
<td>Pilot study</td>
<td>27</td>
<td>26 weeks</td>
<td>Diabetes</td>
<td>HbA&lt;sub&gt;1c&lt;/sub&gt; level (Y) and activity level (Y)</td>
</tr>
<tr>
<td>[35]</td>
<td>Human coach and SMS text messages</td>
<td>RAM</td>
<td>Qualitative interview</td>
<td>10</td>
<td>N/A&lt;sup&gt;d&lt;/sup&gt;</td>
<td>General health</td>
<td>Inconclusive</td>
</tr>
<tr>
<td>[36]</td>
<td>Human coach, telephone calls, and mobile app</td>
<td>RAM and RPM</td>
<td>User acceptance study</td>
<td>11</td>
<td>26 weeks</td>
<td>Diabetes</td>
<td>User acceptance (Y)</td>
</tr>
</tbody>
</table>

<sup>a</sup>DSS: decision support system.
<sup>b</sup>RPM: remote patient monitoring.
<sup>c</sup>RAM: remote activity monitoring
<sup>d</sup>N/A: not applicable.
<sup>e</sup>N: not effective.
<sup>f</sup>Y: effective.
<sup>g</sup>I: inconclusive.
<sup>h</sup>HbA<sub>1c</sub>: hemoglobin A<sub>1c</sub>.

The predominate type of health coaching was via a human coach (12/13 studies) [12,21,26-33,35,36], whereas an automated health coaching system was employed in only 1 study [34].
interventional contact based on remote monitoring results [12,21,28,32]. Four studies employed the use of a DSS to augment or assist the health coach [21,30,32,34]. The DSSs included software programs that generated trends and alerts for the health coach based on the remotely monitored data [30], artificial intelligence systems that evaluated the remotely monitored data and provided recommendations to the health coach [21,32], and a fully automated system that monitored physical activity and provided tailored feedback to the patient based on the monitored results [34]. Four studies employed the use of a mobile app for remote monitoring [28,33,34,36]. RAM was the most common type of telehealth technology employed (12 studies) [21,26-30,33,36]. Communication with the patient was via telephone only (7 studies) [12,26-28,30,33,36], SMS text messages only (4 studies) [21,32,34,35], or telephone and SMS text messages (2 studies) [29,31]. Study durations ranged from 2 weeks to 1 year with 6 studies lasting 26 weeks or longer. The conditions monitored included diabetes (6 studies) [27,29-33,34,36] cancer (2 studies) [26,31], chronic heart failure (2 studies) [12,27], chronic obstructive pulmonary disease (1 study) [30], and overall general health (3 studies) [21,32,35].

Effectiveness outcomes assessed included hospital admissions/re-admissions, mortality, hemoglobin A1c (HbA1c) level, body weight, blood pressure, physical activity level, fatigue, quality of life, and user acceptance of the coaching program and technology. Of the 13 studies reviewed, 10 found coaching supported by telehealth technology to be effective in at least one of the outcomes assessed in the studies [12,26,28-34,36]. As much as 5 of the 6 studies that monitored diabetes found health coaching plus remote monitoring to be effective particularly for physical activity level and body weight [28,29,33,34,36]. Neither of the 2 studies that monitored chronic heart failure found health coaching plus remote monitoring to be effective [12,27] except for improving one’s quality of life in one of the studies [12]. Both studies that monitored patients with cancer found health coaching plus remote monitoring to be effective at improving the patient’s physical activity level [26,31]. Only 1 [32] of the 3 studies that monitored general health [21,32,35] found health coaching plus remote monitoring to be effective. In summary, the results indicate that health coaching plus remote monitoring can be effective at improving a patient’s physical activity level, HbA1c values, and in reducing body weight.

Discussion

Principal Findings

Health coaching that incorporates telehealth technologies has been implemented in older populations with mixed results. As much as 10 of the 13 studies reviewed found this method of health coaching to provide effective outcomes [12,26,28-34,36]. This literature review identified several gaps that warrant discussion or additional research.

Human Versus Automated Coach

One of the more prominent findings identified in this review was the dependence on a human to provide health coaching and interaction with the patient. As much as 12 of the 13 studies reviewed included a human coach [12,21,26-33,35,36], and thus the outcomes were probably heavily reliant on a human in the process. Four of the studies did include health coaching systems that incorporated the use of a DSS [21,30,32,34]; however, only 1 study completely replaced the human coach with a DSS [34].

The health coaching system in the Yom-Tov et al’s pilot study [34] was fully automated in that neither the patient nor the health coach had to manually enter data or actions into the DSS or remote monitoring system after the patient’s activity goals were established. A smartphone app recorded the patient’s physical activity and transmitted the data to the DSS. A tailored daily feedback SMS text message was sent to each participant to encourage exercise. An algorithm determined the message to be sent based on whether the patient reached his/her activity goal the previous day. The study found that customizing or changing the daily message based on the actual physical activity performed was effective at getting the patient to increase daily activity whereas a constant daily reminder message was not effective. The use of a DSS to augment or replace human coaching indicates there is some movement toward augmenting the human coach with DSS technology. A benefit of using a DSS combined with remote monitoring is the ability to provide 24/7 continuous monitoring and intervention which may not be possible with a human coach. Although costs were not assessed in these studies, it is surmised that lessening the amount of direct human involvement in the coaching process should reduce overall cost. Additional studies should be performed with the focus of comparing the clinical and cost-effectiveness of the following 3 forms of health coaching: (1) human health coach only, (2) health coaching performed by a DSS only, and (3) a hybrid model of health coaching by a human coach augmented by a DSS.

Telephone Versus Electronic Media Communications

Another finding identified in this review was the heavy reliance on the use of a telephone to communicate with patients. Nine of the studies used a telephone for delivering coaching with mixed effectiveness results (2 of these studies augmented telephone communications with SMS text messages) [12,26-31,33,36]. The other 4 studies used DSS messages, SMS text messages, or video messages in lieu of telephone calls, also with mixed effectiveness results [21,32,34,35]. These results indicate that coaching effectiveness may not be dependent on the method of communication with the patient. Additional studies should be performed to evaluate the effectiveness and acceptance of using electronic media to communicate with the patient instead of live telephone calls.

Use of Smartphone Apps

Four studies included the use of a smartphone app as part of the integrated telehealth solution [28,33,34,36] with positive results for 3 of these studies [33,34,36]. Only one of these studies specifically evaluated the acceptance of smartphone app technology by the patients [36]. A recent qualitative study interviewed 12 community-dwelling older adults (aged 65-78) and found that older adults were, in general, satisfied with using technology to help monitor and manage their health on a daily basis (albeit amid some fears that technology would replace...
human contact) [37]. Thus, there appears to be an opportunity to expand the use of technology, such as smartphone apps, as part of a telehealth system for older adults.

### Coachability of Patients

Although not explicitly evaluated in the studies, it is probable that the results of these studies were dependent on the willingness of the patient to accept health coaching. Some of the studies evaluated the willingness of the patient to accept health coaching as part of the inclusion criteria while other studies only included patients who expressed an interest in the study. Thus, it can be assumed that most of the studies were biased toward those patients who are coachable. An opportunity exists to explore the effectiveness of health coaching using telehealth technology for patients who are not coachable.

### Limitations

This literature review was focused on studies that included older adults (aged 65 and older) in the population assessed. Studies that excluded older adults were not included in our review, so the results should not be extrapolated to general populations. Most of the coaching interventions reviewed in this study included a human coach who provided feedback to participants via telephone calls. This type of coaching depends on the effort of the human coach to provide an adequate type of coaching to the participant which may or may not include all aspects of a robust coaching program (goal setting, education, encouragement, and feedback on health-related behaviors). In addition, the studies reviewed did not attempt to assess the capability of a human coach versus an automated health coaching system to effect behavior change. Additional research is needed to make this assessment. There was only 1 fully automated coaching intervention study found in our review, so no conclusion can be drawn regarding the effectiveness of automated health coaching interventions. Additional research is needed in the area of automated health coaching. The search criteria for this review focused first on health and wellness coaching that was then further filtered on remote monitoring as an element of the coaching. Several other studies of telehealth might have included coaching but not as a focus of the study.

### Conclusions

Four inter-related issues face the health care industry: (1) the increasing numbers and percentage of older adults, (2) chronic disease management among this older population, (3) the desire of older adults to age in place, and (4) the cost of health care for older adults. Health coaching combined with telehealth technology has been shown to provide effective outcomes in 10 of 13 studies reviewed. Four studies included the use of a DSS to augment or replace the health coach with positive results. However, insufficient evidence of automated health coaching was found in our review to draw a conclusion regarding the efficacy of automated coaching. Although not assessed in these studies, the inclusion of automation in the health coaching process has the potential to reduce overall health care costs for older adults. The benefits of health coaching combined with telehealth are evident and should be further explored.

### Future Directions

One of the more prominent findings identified in this review was the dependence on a human to provide health coaching and interaction with the patient. Thus, the outcomes were probably heavily reliant on a human in the process. Future studies need to assess the capability of automated coaching systems versus human coaches to affect health behavior changes. Another prominent finding was the use of live telephone calls to provide coaching to the patient. Future studies should be performed to evaluate the effectiveness and acceptance of using electronic media to communicate with the patient. The studies reviewed did not specifically evaluate coachability or the willingness of the patient to accept health coaching. An opportunity exists to explore the effectiveness of health coaching using telehealth technology for patients who are not coachable. This discrepancy should be investigated by including quality of life measures in future studies of coaching systems. As sensors for RPM and RAM become more advanced and affordable, much more data will be available to monitor and evaluate. With advances in big data analytics, DSSs will be better informed and able to identify interventions when necessary. Based on the results of this review, additional studies should be conducted of the expanded use of health coaching and DSSs as part of the health care solution for older adults. In addition, cost-effectiveness of health coaching combined with telehealth needs to be assessed against human-only health coaching methods. The results of these studies would inform the future direction of health coaching.

### Acknowledgments

The lead author of this literature review (CM) is a qualified veteran who receives funding (tuition and fees) from the Texas Veterans Commission through the Hazlewood Act. There is no involvement by the Texas Veterans Commission in the review and approval of this study.

### Conflicts of Interest

None declared.

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Abbreviations

ADL: activity of daily living
DSS: decision support system
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RAM: remote activity monitoring
RPM: remote patient monitoring
The Use of Telehealth Technology to Support Health Coaching for Older Adults: Literature Review

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Please cite as:
Markert C, Sasangohar F, Mortazavi BJ, Fields S
The Use of Telehealth Technology to Support Health Coaching for Older Adults: Literature Review
JMIR Hum Factors 2021;8(1):e23796
URL: http://humanfactors.jmir.org/2021/1/e23796/
doi:10.2196/23796
PMID:33512222

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Perceptual Gaps Between Clinicians and Technologists on Health Information Technology-Related Errors in Hospitals: Observational Study

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Abstract

Background: Health information technology (HIT) has been widely adopted in hospital settings, contributing to improved patient safety. However, many types of medical errors attributable to information technology (IT) have negatively impacted patient safety. The continued occurrence of many errors is a reminder that HIT software testing and validation is not adequate in ensuring errorless software functioning within the health care organization.

Objective: This pilot study aims to classify technology-related medical errors in a hospital setting using an expanded version of the sociotechnical framework to understand the significant differences in the perceptions of clinical and technology stakeholders regarding the potential causes of these errors. The paper also provides some recommendations to prevent future errors.

Methods: Medical errors were collected from previous studies identified in leading health databases. From the main list, we selected errors that occurred in hospital settings. Semistructured interviews with 5 medical and 6 IT professionals were conducted to map the events on different dimensions of the expanded sociotechnical framework.

Results: Of the 2319 identified publications, 36 were included in the review. Of the 67 errors collected, 12 occurred in hospital settings. The classification showed the “gulf” that exists between IT and medical professionals in their perspectives on the underlying causes of medical errors. IT experts consider technology as the source of most errors and suggest solutions that are mostly technical. However, clinicians assigned the source of errors within the people, process, and contextual dimensions. For example, for the error “Copied and pasted charting in the wrong window: Before, you could not easily get into someone else’s chart accidentally...because you would have to pull the chart and open it,” medical experts highlighted contextual issues, including the number of patients a health care provider sees in a short time frame, unfamiliarity with a new electronic medical record system, nurse transitions around the time of error, and confusion due to patients having the same name. They emphasized process controls, including failure modes, as a potential fix. Technology experts, in contrast, discussed the lack of notification, poor user interface, and lack of end-user training as critical factors for this error.

Conclusions: Knowledge of the dimensions of the sociotechnical framework and their interplay with other dimensions can guide the choice of ways to address medical errors. These findings lead us to conclude that designers need not only a high degree of HIT know-how but also a strong understanding of the medical processes and contextual factors. Although software development teams have historically included clinicians as business analysts or subject matter experts to bridge the gap, development teams will be better served by more immersive exposure to clinical environments, leading to better software design and implementation, and ultimately to enhanced patient safety.

(JMIR Hum Factors 2021;8(1):e21884) doi:10.2196/21884

http://humanfactors.jmir.org/2021/1/e21884/
KEYWORDS
patient safety; medical errors; health information technology; sociotechnical framework; patient harm

Introduction

Background

The widespread use of information technology (IT) has contributed to improved patient safety in the hospital setting [1-5]. However, many different kinds of medical errors attributable to the use of IT in health care have negatively impacted patient safety [6,7]. The number of patients who experience adverse events is estimated to be 40% of all patients who visit primary and ambulatory care [8]. These safety events may lead to an extended hospital stay, additional side effects, or distress and in some cases death. In addition to the loss of life and health impairment, the consequences of adverse events include increased financial costs to patients and the society at large [9].

In hospital settings, several benefits, including health care delivery improvement and reduction in medication errors, have been attained through the use of health information technology (HIT) [3]. However, new patient safety errors attributable to the use of HIT continue to be a significant issue [7]. For example, according to a recent study [10], in Pennsylvania alone, a total of 889 medication error reports listed HIT as a factor contributing to events submitted to the Pennsylvania Patient Safety Authority in the first 6 months of 2016. The study also shows that dose omission, wrong dosage, and extra dosage were the most commonly reported events. The most common HIT systems implicated in the events were the computerized prescriber order entry system, the pharmacy system, and the electronic medication administration record. Several government agencies and academic and clinical practitioner committees have been concerned about the unintended consequences of introducing IT in clinical environments. Several articles [9-11] report such adverse patient safety events related to HIT and emphasize the need for more cohesive HIT development processes to reduce the gulf of evaluation between medical and IT teams.

This pilot study seeks to classify patient safety events in hospital settings and to understand the differing perspectives of HIT designers and users concerning the potential causal factors of technology-related medical errors. In addition, the study suggests prescriptive measures to prevent recurrences of errors. Understanding the perspectives of both medical and IT stakeholders could help resolve the root causes of medical errors. The proposed classification could be used in facilitating medical and technology stakeholders in working together and working through different perspectives on the causes of HIT-related errors to identify likely solutions and ultimately design better HIT artifacts. To better understand the significant differences, we selected from our list of errors collected through the literature review, 12 archetype errors that occurred in a clinical setting, and examined them using the lens of sociotechnical theory from both clinical and IT systems perspectives. In the next section, we introduce the sociotechnical framework and present the proposed error classification. Following this, the Methods section details data collection and analysis. Subsequently, the results and discussion are presented before the Conclusions section.

Sociotechnical Framework

The sociotechnical theory posits that organizational performance depends on the interactions between social and technical factors, grouped into 4 pillars: technology, process, people, and environment [12]. Prior research suggests that developing applications that cater to end-user needs requires designers and developers to understand the workflow structures, organizational culture, and environment in which these systems will operate [13]. Hence, patient safety improvement is contingent on the joint optimization of social and technical factors in the hospital setting.

This paper creates a more detailed taxonomy by adding subcomponents of the 4 central pillars to the sociotechnical framework [12,13]. The expanded taxonomy allows for a better classification of errors and the development of more precise solutions. Furthermore, we classify the errors in terms of the causes based on the feedback of medical experts and IT professionals. Using the results of this classification process, we provide more in-depth insights into the significant differences in medical and clinical staff members’ and IT professionals’ perceptions regarding these errors and offer a prescription to mitigate them.

Several studies have used the sociotechnical framework to examine several aspects of HIT implementation and use, including human-computer interaction [14], the impact of policy, infrastructure, and people on the quality of health information [15], ergonomic and macroergonomic aspects of health technologies [16-20], risk assessment of electronic medical record safety [18], and usability factors [14,18]. The sociotechnical framework has also been used to classify patient safety events [21-23]. However, these studies have classified errors on the sociotechnical framework’s high-level dimensions on which errors map the most (Table 1 shows a comparison of the 3 published papers closest to our efforts and details how this study is different). The sociotechnical framework suggests that multiple forces from multiple dimensions (and different hierarchical levels of a particular dimension) are at work when errors occur [24]. As patient safety events occur in a complex environment, there is a need for a classification that considers the impacts of multiple dimensions of the framework on each patient safety event’s occurrence. Table 1 provides a summary differentiating the studies closest to the work in this paper. These studies were included because the authors used the sociotechnical framework to classify medical errors [21,23] or HIT-related sentinel events [22].

http://humanfactors.jmir.org/2021/1/e21884/
Medical error classifications have been developed using other approaches. The System Theoretic Accidents Models and Process framework has been used to classify medical errors in 3 broad categories: feedback, control action, and knowledge errors [25]. The Human Factors Classification Framework [26] has been adapted to health care to classify medical errors in 5 categories: decision errors, skill-based errors, perceptual errors, routine violations, and exceptional violations [27,28]. Other studies have developed taxonomies without the use of a particular framework [29-31]. Prior studies have not applied the sociotechnical framework on medical errors with the intent of exploring the root causes and potential avenues through which the errors can be fixed. Furthermore, the dimensions of sociotechnical frameworks described in the extant research literature have not considered the emergence of new technologies such as cloud computing, n-tier architectures, and new management paradigms, including DevOps and microservices architecture. We adapted and extended the sociotechnical framework with additional dimensions that reflect new trends in IT. A group of expert researchers in information systems and sociotechnical theory reviewed this model [32]. Feedback from these experts was incorporated to refine the classification model, which is presented in Figure 1.

<table>
<thead>
<tr>
<th>Studies (references)</th>
<th>Methodologies for error classification</th>
<th>Errors classified in 1 high-level dimension only—fitting one dimension excludes others</th>
<th>Errors classified in one dimension and its subdimensions only—fitting one dimension excludes others</th>
<th>Errors classified in multiple high-level dimensions</th>
<th>Classification based on multiple dimensions and their subcomponents</th>
<th>One error at a time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety huddles to proactively identify and address electronic health record safety [21]</td>
<td>✓^a</td>
<td>✓</td>
<td>_^b</td>
<td>✓</td>
<td>✓</td>
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</tr>
<tr>
<td>Contribution of sociotechnical factors to health information technology–related sentinel events [22]</td>
<td>✓</td>
<td>_</td>
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<tr>
<td>Exploring the sociotechnical intersection of patient safety and electronic health record implementation [23]</td>
<td>✓</td>
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<tr>
<td>This study</td>
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<td>✓</td>
<td>✓</td>
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<td>✓</td>
</tr>
</tbody>
</table>

^aMethodology applicable to the study.

^bMethodology not applicable to the study.
Proposed Classification

Sociotechnical theory emphasizes the interplay of the social and technical aspects of adopting and using technology [17,18,33]. The theory hinges on four basic constructs (technology, people, process, and environment) and the interaction between these constructs. In the expanded version of the sociotechnical framework, we detail the components of the technology dimension to include the IT infrastructure, which in turn comprises hardware, software, and apps. These also include emerging technologies, such as cloud computing, the internet of things, mobile apps, and the use of artificial intelligence, predictive and prescriptive analytics, and robotics. The technology dimension can also be partitioned based on the type of use, broadly classified as either administrative (including administrative IT and resource scheduling) or clinical. The need to investigate at this level of detail stems from the fact that the type of interaction varies based on the interacting...
subcomponents. Furthermore, the app layers can be viewed as comprising the user interface, middleware (including the logic layer), backend (including the logic layer), and data.

The process dimension includes administrative and clinical workflows. Administrative workflows related to IT include the collection, storage, processing, and presentation of information for more effective resource management, such as clinical and IT staff management, operating room scheduling, risk and safety management, billing and facility management, and inventory management to ensure the business management of the hospitals. The subdimensions of IT processes are software development, HIT implementation and maintenance, and training and support. Clinical processes include patient record management, clinical pathways, patient bed assignment, and physician notes. Some processes are both clinical and administrative; these include the inventory management of drugs and clinical supplies, surgery room and equipment scheduling, and patient discharge management. Processes in health care settings allow all stakeholders to perform tasks in a predetermined manner to obtain successful outcomes [24,34,35]. Patient safety errors manifest when there is a misalignment between the elements of IT and clinical processes.

The people dimension includes patients, clinical staff, and administrative staff. People interact with each other and with the technology available to them. The hospital employee space consists of providers with different competencies and clinical authorities and administrative staff with priorities that are often very different from those of clinical providers. Several examples are worth mentioning here. First, clinical staff members prioritize patients’ clinical health, whereas IT personnel are more concerned with the processes involved in health care. Inconsistencies in their priorities often lead to errors. As people interact with the entire work system, a mismatch between people and any other components increases the risk of harm to patients. Human errors are also a threat to patient safety [36]. Therefore, it is essential to build user interfaces and systems that consider the priorities and goals of the different types of users of the system, and these goals go beyond the purely functional and technical requirements of the job.

The environment consists of the care setting (eg, ambulatory, emergency, and in-patient), regulatory (eg, compliance, privacy, and security related), and culture. Culture stems from management style, organizational policy, and other systemic factors. Furthermore, different types of employees prioritize different goals, and conflicts in achieving these goals are often manifest in the building, implementation, and functioning of systems. Patients receiving services are external to the health care organization. To ensure more effective health care service provisioning, patient participation in the process is very important. In some areas, tasks must be performed by patients away from the health care organization. Contextual environments and skills to perform the required tasks differ from those of health care providers [33,35]. Regulations can also have a constraining effect on the error-free functioning of all subsystems. A thorough classification of patient safety events should consider specific areas of interaction between the environment dimension and all other dimensions. We use this expanded classification model to understand the gap in the mental models of clinical staff and technology professionals regarding the root cause of errors and how they should be addressed. We articulate our research design in the next section.

Methods

Research Design

The research design is comprised of 2 significant steps: developing a shortlisted set of IT-related patient safety issues and the classification of the root causes of medical errors with the sociotechnical lens using expert interviews. Figure 2 depicts the flow of the study.

Error Collection Using Literature Review

In this study, we first developed an extended sociotechnical framework that includes a finer level of granularity. Next, we systematically reviewed the literature on patient safety and medical errors from Ovid-MEDLINE, Embase, and Web of Science, which are leading medical databases in addition to Google Scholar. The systematic review process shown in Figure 2 aligns with commonly used steps of the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)
guidelines [37], as depicted by several exemplar papers [38-40]. The searches were performed using the following search terms: (“Patient Safety” OR “Medical”) AND (“issue” OR “error”) AND (“health information technology” OR “information technology”). Initially, the title, abstract, and index terms were used to screen published journal papers, conference papers, proceedings, case studies, and book chapters. We also used ancestral search to locate potentially relevant articles. Subsequently, the shortlisted papers were reviewed entirely. Two reviewers performed the screening independently. The reviewers met regularly to discuss the inclusion of the studies. A third reviewer was consulted when there was a discrepancy. Interrater reliability indicated a high agreement (Cohen \( \kappa \) value of 0.95).

Inclusion criteria included studies that addressed patient safety by identifying specific issues that occurred in health care settings and linked these errors to HIT. Furthermore, we excluded studies that were not available as the full text in the final search; were not in English; or were reports, abstracts only, letters, or commentaries.

**Expert Interviews**

An invitation email to participate in the study was sent to the alumni of the University at Buffalo. The email contained the eligibility criteria consisting of \( \geq \)5 years of HIT experience and at least 1 IT-related professional certification. A separate invitation email mentioning the selection criteria was sent to medical experts through the Office of Business Coordination at the University at Buffalo. A minimum experience of 5 years working as a medical doctor or as a registered nurse was required to qualify for the interview. All participants who responded met the selection criteria and were included in the study.

To better understand the perspectives of different stakeholders, we conducted multiple semistructured interviews [41] with different stakeholders, namely 6 IT and 5 medical experts to map the errors on the different dimensions of the expanded sociotechnical framework. Experts could map an error on multiple (or on all) subdomains of the sociotechnical framework to show the different sociotechnical factors that could contribute to the error. The purpose of accounting for the different perspectives was to understand how each group understood the predicates of the problem and allow us to reflect on how best the error could be addressed. Interviews were selected based on their domain experience, education, and industry certifications. The IT experts, who were recruited from the alumni list of the State University of New York at Buffalo, were software development professionals with a master’s degree and IT professional certifications, such as the certified scrum master, the health level 7 control specialists, and the project management professional certifications. The minimum work experience cutoff for IT experts was 5 years for HIT in addition to possessing at least one IT-related professional certification.

IT experts who were interviewed had extensive IT experience (mean 10.33, SD 1.11 years) with significant HIT experience (mean 8.83, SD 2.03 years; Multimedia Appendix 1 uploaded as a supplementary file for brief profiles of IT interviewees). The medical experts interviewed were physicians and registered nurses with broad primary care experience from working with multiple health care institutions across the United States and Canada. They are all currently working with hospitals and institutions affiliated with the university at Buffalo (Multimedia Appendix 2). Medical experts had a mean experience of 16.6 (SD 7.33) years. The minimum and maximum numbers of years of HIT experience for IT experts were 5 and 12, respectively. The work experience of medical experts varied from 8 to 27 years. The questionnaire and interview process are detailed in Multimedia Appendix 3. Experts were asked to provide their opinions on why the selected errors (Multimedia Appendix 4 [42-48]) occurred and how the errors could be prevented. The extensive experience of both IT and medical experts in their respective domains qualifies them to map medical errors on the sociotechnical framework. The study was approved in November 2019 (IRB# STUDY00003838).

**Results**

**Search Results**

The literature search resulted in 344 articles, 141 of which were duplicates. After removing articles based on their content, we retained 36 articles [10,28,42-47,49-76] that met the 2 criteria set for the study. We then extracted 67 unique patient safety events from the articles in which 12 specific issues related to IT use in the hospital setting were shortlisted. The process followed the PRISMA methodology [37] as detailed in Figure 3. The remaining errors occurred outside a health care setting and were excluded from the study. The error description includes the error context in the literature review format commonly known as problems, interventions, comparisons, and outcomes model [37]. The articles describing the errors contained a clear purpose, literature review, research methodology, results, and conclusions.
Study Characteristics and Error Classification

In this study, experts categorized errors based on their opinion of where the source of the error lies. Experts were provided with the definitions of the elements of the framework and were informed that an error could result from multiple sources. They were asked to map each error at the lowest level of one or multiple dimensions of the sociotechnical framework. The authors then interacted with the experts to understand the reasons behind their mapping selection. The interactions included questions related to suggestions on the best way to address the problems and prevent them from occurring. In line with extant literature on data analysis in qualitative research coding [77,78], expert interviews were subsequently deconstructed into keywords and phrases and then grouped into ideas and concepts. The output of the analysis is summarized in the “key observations” below, for example, in Error 1: “Copied and pasted charting in the wrong window: Before, you could not easily get into someone else's chart accidentally...because you would have to pull the chart and open it.”

Medical experts highlighted several contextual issues, such as the number of patients a health care provider is set to see in a short time frame, unfamiliarity with a new electronic medical record system, nurse transitions around the time of the error, and confusion due to patients having the same name. They emphasized process controls, including failure modes, as a potential fix. The technology experts discussed the lack of notification, poor user interface, and lack of end-user training as critical factors in this error. Error 2: “Incompatible data standards across multiple mobile applications led to the missing of vital data fields, which led to information loss.”

Like the first sample, medical experts attributed this error to system software–related interoperability issues. They also highlighted several changes in the International Classification of Diseases (ICD) during the transition from ICD 9 to ICD 10 as an example of a situation that could lead to errors.
Technology experts, however, emphasized data formats, data transfer protocols, and service-orientated architecture as potential causes of errors.

Although we have detailed 2 instances here, the experts reviewed all 12 errors and identified the most likely set of possible dimensions to which the errors could be attributed. The sample errors used in the study are presented in Multimedia Appendix 2, and the results of analyzing these data are presented in Table 2, followed by several key observations.
### Table 2. Classification by medical and IT experts.

<table>
<thead>
<tr>
<th>Errors</th>
<th>Classification by medical experts</th>
<th>Classification by IT&lt;sup&gt;a&lt;/sup&gt; experts</th>
</tr>
</thead>
</table>
| Nurse was supposed to enter a prescription for Amoxicillin 250 mg PO q8h×7 days (21 dispensed). However, the nurse failed to change the default dosage amount and dispensed too much medication (30 dispensed) | - UI-clinical app implementation and maintenance  
- Clinical staff  
- Training                                                                                                                                                                                                                              | - UI-clinical app software development  
- Clinical staff                                                                                                                                                                           |
| Copied and pasted charting in the wrong window: “Before, you could not easily get into someone else’s chart accidentally…because you would have to pull the chart and open it” | - Clinical staff  
- Clinical app  
- Training                                                                                                                                                                                                                             | - Clinical staff  
- In-patient                                                                                                                                                                                                                                   |
| In general practice ward, the doctor consulted a patient with another patient's records and prescribed medications according to the wrong records. The patient died the same day of taking it. No further details were available | - Clinical staff  
- Clinical UI  
- Clinical middleware                                                                                                                                                                                                                          | - Clinical UI  
- Implementation and maintenance  
- Staff-admin (IT)                                                                                                                                                                                                                              |
| The receptionist intended to alert the general practitioner via the practice software about a patient with chest pain but instead sent the message to himself. The patient later died from a myocardial infarction | - UI-patient pathways  
- Clinical staff                                                                                                                                                                                                                          | - UI-clinical app software development  
- Training and support  
- Patient pathways                                                                                                                                                                                                                             |
| A patient received only half of their usual quantity of blood pressure medication because a repeat prescription for the medication did not transfer to a new software system when the patient's historical records were migrated. Because they did not have enough medication the patient tried to stretch out the old dose by taking the medication on alternate days. The patient had a stroke but made a full recovery. | - Software-systems  
- Patient pathways  
- Patient  
- Culture                                                                                                                                                                                                                                               | - Data-clinical  
- Software development  
- Staff-admin (operations)  
- Culture                                                                                                                                                                                                                                             |
| A child had a full body x-ray. Some of the images went missing from the archival system where they were digitized. The x-ray was repeated to acquire the missing images, re-exposing the child to high levels of radiation | - Software-systems  
- Patient pathways                                                                                                                                                                                                                          | - Data-clinical                                                                                                                                                                                                                                      |
| A compound in high demand such as Rifampicin was not listed in the computerized physician order entry system. The consequence was that the physician could not order rifampicin. | - Data-clinical  
- Ancillary  
- In-patient  
- Culture                                                                                                                                                                                                                                              | - Data-clinical  
- Software development  
- Staff-admin (operations)  
- Culture                                                                                                                                                                                                                                             |
| When an update is made to the frequency field on an existing prescription, the frequency schedule ID is not simultaneously updated on new orders sent to the pharmacy via (application) | - Software-development  
- Clinical people  
- Software-systems                                                                                                                                                                                                                             | - Data-clinical  
- Staff-admin (IT)  
- Software-systems                                                                                                                                                                                                                            |
| Monitoring and Eavesdropping on Patient Vital Signs by hacking into the packet transfer from an internet of things device to the central system | - Middleware  
- Maintenance  
- People-staff (operations)  
- Compliance  
- Security                                                                                                                                                                                                                                        | - System software  
- Data-clinical  
- Software development  
- Compliance  
- Security                                                                                                                                                                                                                                           |
| Vulnerabilities of the hospital’s IOT devices were exploited to initiate a denial-of-service attack to bring down hospital’s servers which disrupted normal functioning | - Hardware  
- Software  
- IT implementation  
- Compliance  
- Security                                                                                                                                                                                                                                           | - Compliance  
- Security                                                                                                                                                                                                                                         |
| Use of portable devices that are not password protected makes the patient record vulnerable to the invasion of privacy | - Data-clinical  
- Software-development  
- Maintenance  
- Compliance  
- Privacy                                                                                                                                                                                                                                          | - System software  
- Software-development  
- Security                                                                                                                                                                                                                                           |
| Incompatible data standards across multiple mobile applications led to the missing of vital data fields which led to information loss | - Software-systems  
- Software-development                                                                                                                                                                                                                       | - Data-clinical                                                                                                                                                                                                                                       |

<sup>a</sup>IT: information technology.  
<sup>b</sup>UI: user interface.
Discussion

Principal Findings

Some of the crucial observations include (1) The identified potential sources of the errors and solution areas differed considerably between clinicians and IT specialists; (2) both groups identified multiple factors as potential causes of the errors; (3) the clinicians often focused on postproduction (eg, implementation, maintenance, training, context, and the way the application is used) issues as causal factors; (4) IT experts focused on software functionality, software development, and technical implementation issues as causal factors; (5) on most occasions when IT experts identified an issue as a “data” problem, clinicians seemed to think that the problem lay elsewhere, including the software system, software development, or patient pathways; (6) both groups seem to be congruent with the issues of compliance and security; and (7) IT experts rarely identified clinical pathways or workflows as an issue.

The classification of the identified medical errors using the framework is presented in Table 2. The continued occurrence of many errors is a reminder that current HIT software testing and validation do not seem adequate in terms of ensuring the functioning of the software within the health care organization. The attribution of the errors to different aspects of the sociotechnical framework by clinicians and IT professionals informs us that technologists and clinicians generally differ in their perspectives on factors that impact IT-related safety events. Software experts are often not acclimatized to the environment in which HIT software and tools are used, which could be a cause to the problem.

Although IT and medical experts’ perceptions are similar in security and privacy, IT specialists often tend to assume that the issues are either software or hardware or user interface related. In contrast, clinicians tend to consider environmental, contextual, and process factors as contributors to patient safety events. The benefit of such a classification suggests that designers and developers who fix the errors consider the artifact’s environment and the people using the artifact. A key realization is that such errors will continue to occur if health IT system developers do not fully grasp the importance of technology functioning in an environment of care delivery where the patient needs are paramount.

A careful review of the IT experts’ classification of errors highlights the view that IT experts consider technology as the source of most errors and suggest solutions that are mostly technical. The IT experts highlighted the software systems and development as the top 2 sources of most errors. Similarly, the suggestions of potential fixes mostly revolve around the software. However, a common refrain that accompanied their answers was, “The doctor should double-check…” In contrast, clinicians tended to assign the source of errors within the people, process, and contextual (environmental) dimensions for the most part.

The difference in perspective could be explained by the fact that clinicians tend to deal with the system after implementation. In contrast, IT experts tend to look at the same problem from an IT development perspective. For example, for “Error 1,” for which IT experts were asked how they would prevent a doctor from using the wrong chart when he had multiple charts open, the answer was always to restrict access to 1 open chart at a time. However, clinicians prefer having multiple windows open so that they can quickly consult with multiple patients in different rooms without having to close out and reopen a chart. For them, the issue is, “How easy is it for a physician to realize the mistake,” and “Physicians should still be able to open multiple charts.” The differing perspectives between designers and developers of the technology and its users can contribute to medical errors.

The development teams of clinical applications typically include clinicians who provide domain expertise. However, our study indicates that this may not be sufficient as IT experts do not fully grasp the clinical environment and how workloads and other patient-related variabilities impact the use of the software. Therefore, as a future investigation, we suggest that software companies immerse developers in clinical environments for a short period, so that the understanding of the environment is built into their psyche and translates into a more robust design.

HIT systems can be made less error prone if programmers and systems developers understand the health care organization’s operating environment. Current systems do not have fail-safe mechanisms that could prevent some of the errors. For example, consider the documented error, “the nurse was supposed to enter a prescription...the nurse failed to change the default amount and dispensed too much medication”; from a software perspective, better checks and warnings can be developed. In this specific instance, a system challenge asking the nurse to review the dosing amount could have prevented the problem. From a process perspective, nurses could be trained to reexamine the dosage. Creating a poka-yoke (like a check-off box for dose amount) would force nurses to check the dosing before refilling the prescriptions. As the clinical experts and IT experts suggested slightly different predicates for the error, a solution that addresses the issue from both technical and from a process and workforce training perspective would provide multiple layers of defense against such failures. The different views expressed by IT and clinical experts can be used to create technical and process solutions so that there is a more robust defense against these types of errors.

Limitations and Future Studies

The results of this study should be interpreted cautiously, as there are several limitations to this study. The first shortcoming is related to the smaller number of participants interviewed in this study. Only 11 interviews comprising 5 medical providers and 6 HIT professionals were conducted. Therefore, this study should be considered a pilot study suggesting the differences in the mental models of the clinical and technical staff, which potentially leads to ineffective systems analysis and ultimately manifests as errors in practice. In addition, both IT and medical experts have, for the most part, acquired their education and expertise at affiliated institutions in the Northeast of the United States. Future studies should examine the hypothesis that medical experts are more likely to attribute medical errors to...
contextual factors, whereas IT experts on technical factors use
a nationally representative sample.

Second, we shortlisted 12 unique errors that occurred in a
hospital setting; the findings of this study cannot be generalized
beyond that context. Furthermore, we extracted the errors used
in this study from articles written in the English language. Future
studies could examine errors that occurred in medical homes,
patients’ homes, or other nonhospital settings or include studies
written in other languages.

Third, the study did not examine errors that were discovered
by HIT users before the occurrence of a patient safety event. Future
studies should examine near-miss errors to determine
their potential root causes and fixes using the lens of sociotechnical theory.

Conclusions
This study classifies medical errors gathered from extant
literature based on an expanded sociotechnical framework.
Interviews from health care and IT experts reveal differing
perspectives on why medical errors occur in clinical settings. Health care experts were more likely to attribute the source of
an error to the implementation and use of an IT tool, whereas
IT experts were likely to identify software design and functionality as causal factors of medical errors. From the results
of this study, we offer several error-prevention prescriptions
that can be tested in future research. First, IT experts should
observe the functioning of HIT postimplementation and collect
metrics related to its impact on (1) physician consultation time,
(2) physician efficiency, (3) patient-physician relationship, (4)
training needs, and (5) how the software fits into the workflow
and culture of the organization. Software developers should be
trained to be sensitive to the provider and patient needs because
their lack of exposure to postproduction issues and usage contexts leads to the development of applications that do not
cater to all user situations. Understanding these situations may
lead to building software constraints and improved user training.
Although software development teams have historically included
clinicians as business analysts or subject matter experts to bridge
the gap, development teams will be better served by more
immersive training and exposure to clinical environments,
leading to better software design and software implementation
strategies.

Authors' Contributions
TN, PM, R Sharman, R Singh contributed equally.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Interviewees—information technology experts.
[DOCX File, 15 KB - humanfactors_v8i1e21884_app1.docx]

Multimedia Appendix 2
Interviewees—medical experts.
[DOCX File, 13 KB - humanfactors_v8i1e21884_app2.docx]

Multimedia Appendix 3
Interview process and questionnaire.
[DOCX File, 13 KB - humanfactors_v8i1e21884_app3.docx]

Multimedia Appendix 4
List of errors.
[XLSX File (Microsoft Excel File), 11 KB - humanfactors_v8i1e21884_app4.xlsx]

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The Relationship Between Individual Coping and the Need to Have and Seek Health Information Among Older Adults: Exploratory Mixed Methods Study

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Abstract

Background: The need to have and seek information shapes the context of computing systems. When it comes to health, individual coping influences human behavior. Therefore, the relationship between individual coping and the need to have and seek health information plays a crucial role in the development of digital health systems.

Objective: This study aims to examine the relationship between individual coping and the need to have and seek health information among older adults.

Methods: Questionnaires and semistructured interviews investigated the health information need (HIN) and health information–seeking behavior (HISB) in relation to the individual coping strategies of 26 older Germans.

Results: The mean age of the interviewed group was 71 years (SD 7). Quantitatively, a trend was found for a negative correlation between the avoidance-oriented coping and HIN ($r_s = -0.37895$; bias-corrected and accelerated bootstrap 95% BCa CI $-0.730$ to $0.092$; $P = .05$). The qualitative results supported this finding. For some participants, information and exchange was part of dealing with their health situation, whereas others wanted to learn as little as possible to avoid a decline in their health status. The older adults acquired, collected, and exchanged paper-based health data to augment clinical information sources and support information exchange with professionals.

Conclusions: Individual coping strategies are relevant for the design of digital health systems. They can support older adults in coping with their health situation, although it remains unclear how systems must be designed for people with an avoidance coping strategy to achieve the same acceptance.

(JMIR Hum Factors 2021;8(1):e15858) doi:10.2196/15858

KEYWORDS
health; information science; systems analysis; eHealth; engineering; gerontology; information technology; mobile phone

Introduction

Background

Due to demographic changes and the underlying aging society, the number of people in need of help and care increases. At the same time, however, the number of nursing staff decreases and a gap emerges that can hardly be closed by the care provided by family members alone [1]. To address this problem, experts place great hope in health digitalization. Digital health systems offer an opportunity to support and maintain the independence and self-responsibility of older people; they enable professional health services to be made more effective and family members to be relieved [2]. Therefore, an analysis of the use context is necessary and is the subject of this study.
Cognition, knowledge, and personal experiences of the user [3,4]; the working environment; and the user’s task are a few of the standard variables considered when investigating the context of information systems. However, this context can also be described by the target group’s health information need (HIN) and health information-seeking behavior (HISB) [5-9]. HISB denotes the search for health information resulting from a perceived HIN to reach a certain goal [10]. When seeking information, a user applies different sources of information that might be analogous, such as a print medium (e.g., the newspaper) or a digital medium such as the internet or a smartphone app [11,12]. In fact, the HIN of older adults showed a relationship with the use of health information seeking [13]. Here, it appeared that older adults, who require more information about their health, engage more with mobile devices such as smartwatches or mobile health apps installed on tablet PCs. However, the influences on HIN seem to be manifold.

In the health care context, where an illness often relates to a stressful situation, individual coping strategies can have an influence on patients’ HISB [14-16]. In particular, the model of information-seeking behavior by Wilsons and Walsh [17] illustrates that actions or a series of actions taken to approach an unpleasant or stressful situation include or are related to HISB. For example, people who want to avoid coping with their illness feel more overwhelmed by illness-related information and less if provided by an information presentation that fits their coping strategy. Not surprisingly, van Zuuren and Wolfs [18] found that HISB is highly related to task- and problem-oriented coping strategies and that some people even perceive the information itself as a threat similar to the illness. Lower socioeconomic status, poor health, low media attentiveness, and high affective components of information seeking were associated with overload. The strongest predictors were education level and cognitive aspects of information seeking, which indicates that health information literacy skills strongly predict the overload [19].

Research Questions

The incidence of disease increases during the course of life. In older adults, illnesses occur more frequently from the age of 50 years. Older adults thus represent an important audience for digital health systems. Although previous work described their information needs and behavior quantitatively, qualitative descriptions and relationships with individual coping are lacking. As individual coping has a particularly strong influence on a person’s behavior in the context of an illness, the following research questions (RQs) investigate the information needs (RQ 1) and information seeking (RQ 2) of older adults and their relation to individual coping (RQ 3) in a qualitative and quantitative manner: RQ 1: Which HINs do older adults have?, RQ 2: How do older adults acquire the needed health information?, RQ 3: How does the coping of older adults relate to their HINs and HISB?

Methods

Study Design

To answer the previously mentioned RQs, a mixed methods field study was conducted [20]. Qualitative interviews allow respondents to talk at some depth, choosing their own words to describe their HIN and HISB. Questionnaires then quantitatively measured HIN, HISB, and individual coping (Coping Inventory of Stressful Situations [CISS]).

Participants

The sample consisted of 26 older adults living in the German state of North Rhine-Westphalia. A total of 18 interviewees also answered the questionnaires. Moreover, 8 participants answered the questionnaires only, as they refused to be interviewed directly. A total of 3 interview recordings (ID01, ID11, and ID12) were lost because of recording issues. A total of 33% (5/15) of the interviewed participants who answered the questionnaire were male and 67% (10/15) were female. The mean age of the interviewed group was 71 years (SD 7). The participants had a rather varied level of education: 14 had completed secondary modern school (Volksschule/Hauptschule in German). Five of these had subsequently undergone vocational training (Berufsausbildung). A total of 3 participants attended secondary school (Realschule) and high school (Gymnasium), whereas only 1 participant had a university degree (Hochschulabschluss). Participants ID04 and ID05 were a couple and interviewed together.

All 26 participants were born in Germany. Participants were primarily office employees and craftsmen. In total, 8 of the participants who were interviewed and answered the questionnaires had a leadership position, whereas 7 did not have a leadership position. A total of 54% (14/26) were living at home with their partner, wife, or husband. The other 31% (8/26) lived alone at home, and 15% (4/26) lived at retirement homes (Table 1).
Table 1. Demographics (N=26).

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Educational level</th>
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Procedure

The interviews were conducted and the questionnaires were answered during the interviewers’ visit to the participants’ homes. During the visit, the inquiry procedure took up to 1.5 hours and started with an introduction, followed by acquiring informed consent and answering demographic questions. Subsequently, a semistructured interview was conducted, which was followed by different structured questionnaires and, finally, by the assessment of individual coping strategies via the CISS.

Interview Guideline

The qualitative interview guideline was based on the study by Warner et al [21] (Multimedia Appendix 1), who investigated nonoccupational information needs using a framework that focused on the essential components of information needs and behaviors—the user, the needs, the sources of information, and the tools and solutions users apply—and on the interaction effects between these variables. Their tool was pretested with data from a cross-sectional and large random sample. It was adapted to the domain of personal health and shortened to the version included in Multimedia Appendix 1.

Initially, participants were queried on their required health information. Subsequently, they were asked about the information they needed during the last week or month regarding their personal health or health in general, vital data, medication prevention, treatment, and additional topics that occurred to the participants. In section 2 of the interview, participants had to rank the mentioned information needs and describe the frequency and time of occurrence of the question or the problem they had and the sources they already used, planned to use, or failed to use. In cases where no information sources were acquired, participants were asked to describe which sources they thought might have the necessary information.

Sociodemographic Questionnaire

With this questionnaire, we queried not only standard but also theoretically relevant parameters such as age, educational achievements, professional background and available
information sources, cultural background, and current living conditions (Multimedia Appendix 1).

**CISS**

The CISS is a 48-item instrument used to measure 3 basic coping strategies, with 16 items per scale: task-oriented (T), emotion-oriented (E), and avoidance (A) [22,23]. Items are scored on a 5-point Likert scale (1=not at all to 5=very much). Higher scores indicate greater use of that particular coping strategy. To exclude the interviewee’s fatigue as an external factor, we decided to apply the paper-and-pencil MHS QuikScore with 21 items.

**Information Need Questionnaire**

In addition to the open, semistructured interview, the need for information and the behavior were queried using a specially created, theory-based questionnaire [17]. The need for information is implicitly taken into account by the question of satisfaction with the available health information, which the participants were able to answer using a 5-point Likert scale (1=applicable, 2=rather applicable, 3=partially, 4=rather not applicable, and 5=not applicable). The corresponding questionnaire can be found in Multimedia Appendix 1.

**Qualitative Data Analysis**

Theoretical thematic analysis inspired by the 6-step recursive process by Braun and Clarke was used to analyze the qualitative interview data. The main advantages of thematic analysis lie in its flexibility, usefulness, and easy access to researchers who are new to qualitative research [24]. Transcripts were analyzed thematically. Thematic analysis is characterized by an essentialist, analyst-driven, and semantic approach, which means that the coding process was done in relation to the RQs, preresearched concepts of HIN and HISB, and thus, with regard to particular areas of interest. Progression from a semantic level to a level of interpretation gave rise to broader meanings and implications. With respect to the HIN and HISB topics, we systematically coded with the help of Dedoose software (University of California, Los Angeles). There were no qualitative questions on individual coping during the interviews. Individual coping was quantitatively measured using a questionnaire (CISS). The relationship between HIN and HISB and coping was analyzed by quantitatively grouping participants into the coping groups, as described in the following section, and then qualitatively describing the HIN and HISB groups.

**Quantitative Analysis**

To investigate the influence of individual coping strategies on HIN and HISB of older adults, we built CISS-type clusters based on the 3 CISS dimensions: task-oriented coping (T), emotion-oriented coping (E), and avoidance-oriented coping (A). When a participant’s score of each of the 3 was higher than the mean of all participants on the same dimension, this dimension labeled the dimension type. This resulted in 6 CISS types—T, E, A, TE (task-emotion oriented coping), TA (task-avoidance oriented coping), and TEA (task-emotion-avoidance oriented coping)—based on which we compared the questionnaire results on information need and seeking behavior (Wilson Questionnaire given in Multimedia Appendix 1).

The descriptive analysis of the questionnaire data was carried out using Dedoose software (University of California, Los Angeles). The statistical software SPSS (IBM Corp) version 24 was used to calculate the chi-square test results attaining the relationship of HIN, HISB, and CISS subscales. The CISS groups were compared qualitatively within the framework of a mixed methods analysis. An overview of the qualitative and quantitative measures and the analysis with respect to the independent variables is depicted in Table 2.

<table>
<thead>
<tr>
<th>Measurement and analysis type</th>
<th>HIN a</th>
<th>HISB b</th>
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<td>N/A</td>
<td>Thematic analysis of groups</td>
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aHIN: health information need.
bHISB: health information–seeking behavior.
cQUAL: qualitative.
dN/A: not applicable.
eQUAN: quantitative.

**Results**

**HIN Interview Data**

In total, 3 groups of information need emerged from the thematic analysis. The participants themselves indicated the level of HIN either directly or indirectly, for example, by naming a lot of information needs. A total of 2 independent qualitative analysts assigned them to the corresponding category. In cases where different assignments were made, the decision was discussed and then a unanimous decision was made. The following groups emerged from the analysis: (1) participants with no or low information need, (2) participants with moderate information need, and (3) participants with high information need.
addition to the intensity of information need, a thematic analysis also revealed these different topics:

1. Need concerning communication with doctors
2. Need concerning information with thematic prevention/precaution (including questions on nutrition and sports)
3. Need for information about medication
4. Need for health-related costs and their generation
5. Need concerning information about vital data and health parameters
6. Need for better exchange between health-related actors and institutions
7. Need for information about health insurance company
8. Need for age-related possibilities for obtaining information
9. Isolated further requirements for information that could not be classified.

In the following sections, the information needs for each of the 3 groups formed, broken down by topic, are presented.

**Group 1: No or Low HIN**

This group includes ID03, ID04, ID08, ID14, and ID16. ID04 and ID16 indicated that they had no need for or did not comment on health-related information. ID14 supported the statements of ID15, but otherwise did not express its own HIN (ID15 expressed moderate HIN in topic 2). Cancer screening was an important issue for ID03. In addition, ID03 had no current HIN at the time of the interview because the participant was generally satisfied with the information transfer of his own doctors and presented it as honest, open, and to the point. The HIN of ID08 depended on their own health situation. As this was satisfactory at the time of the interview, the participant had no particular HIN. However, the question of good prevention measures is interesting for ID08. ID08 also spoke of an experience in which her doctor was unable to answer all health-related questions. She then added information from the internet to the information she received. Both ID03 and ID08 were satisfied with their health situation and showed a need for prevention/precaution (topic 2).

**Group 2: Moderate HIN**

This group includes ID05, ID06, ID10, ID15, and ID18. All interview partners, except for ID10, addressed (topic 1) a need for communication with doctors. Thus, ID05 stated that she is generally satisfied with the transfer of information between the doctor and herself. In this context, it was perceived as negative that doctors do not have or cannot take enough time for the treatment, thus leading to treatment insufficiency. ID05 commented on the medication prescription as follows:

> Before that, the doctors wrote down what the heart desires. They didn’t bother at all, I think.

However, ID05 trusted the doctors. ID06 was very satisfied with the medical expertise, the related organization, and accessibility of the information she encountered. This covered the largest part of ID06’s HIN. Doctor appointments were dutifully documented by ID06:

> This is very important for me. I always write down in my notebook how often I go to the doctor.

It was important for ID06 that the information comes from a doctor and that the information is bundled with this doctor. ID15 was generally satisfied with the information he gets on health-related questions:

> Well, information in general has never been withheld from me when I have asked for it [both at the doctor’s office and on the internet].

Access to information was given for ID15, even if it was sometimes problematic to obtain it because of a lack of exchange between doctors. In contrast, like ID05, ID18 considered the doctors’ lack of time to be a problem:

> The doctors only have three minutes’ time. How is he supposed to explain [the meaning of the diagnosis: Morbus Sudeck] to me in three minutes.

Due to the lack of time, information could not be transmitted sufficiently, which led to a compensatory measure in the form of information generation via the internet. Generally, ID18 was satisfied with the information about her health available to her. ID18 often relied on her own perception. In comparison with its sensation, ID18 ranked the quantity of information to be secondary.

ID05, ID06, ID18, and ID10, in particular, expressed an HIN on the topic of prevention/precaution (including questions on nutrition and sports; topic 2). For ID06, precaution was a very important issue, and ID18 stated that there is a need for further information. ID05, however, would have liked to get information on diet advice. ID10’s HIN focused on sports activities. For example, ID10 needed instructions for his regular sports training sequences, which he has received from video recordings on a DVD. He had a need for daily alternating sports exercises and would have liked to know how far he can increase and vary his training. In this context, ID10 had an HIN to determine his sporting progress, too:

> How has body fat percentage developed over time, for example?

For ID05, ID06, and ID18, there was an HIN (topic 3) about the medication. ID06, in particular, focused on the interaction of medication. For ID06, the main trust in their own doctors was reflected in the way they deal with medication:

> You don’t even want to know what can be there. We rely on the doctors.

Nevertheless, ID06 would have liked further information on medication and the reliability of medication effects, which is contradictory.

Furthermore, ID06, ID15, and ID18 had a (topic 4) need for health-related costs and how costs arise. ID15 would have liked to have more information about how hospitals and doctors bill patients. For ID18, the bills for clinical examinations and treatments were not transparent and comprehensible, which was why ID18 would have liked more information on this topic:

> I do not understand the billing process, it is not comprehensible at all how they do it.

ID06 was dissatisfied with the information received regarding health insurance coverage.

https://humanfactors.jmir.org/2021/1/e15858

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(page number not for citation purposes)
ID15 expressed the need for a better exchange between health-related actors and institutions (topic 6). Thus, ID15 was dissatisfied with the information flow between doctors and believed that the views of the doctors were not sufficiently congruent. For him, this was reflected in the diagnoses that were made. The fact that doctors make different diagnoses based on the same facts ensures that the information becomes more unreliable. ID15 would have liked to see more clarity, accuracy, and congruency from doctors. Besides, he was dissatisfied with the limited and inaccurate information flow from doctors and hospitals to their patients. He mentioned the example of a planned operation that was to be performed on him:

> It was already three o’clock in the afternoon, when I was supposed to be picked up and I was still lying in the bed with my hospital gown open in the back. I thought I’d get going now. And I had not received the information.

According to his own statement, after receiving no information, he checked out himself.

Moreover, ID15 would have liked more information on (topic 7) health insurance companies. Overall, ID15 was satisfied with the information he received from his health insurance company on the scope of services provided there. Accordingly, he would not consider it to be a problem that health information is being stored on his health insurance card if it was accessible to doctors, thus facilitating the exchange of information. ID15 found it interesting to know which information is stored in the health insurance card and which personal information can be viewed there.

ID18, however, had a need for age-appropriate means of obtaining information (topic 8). This was reflected in the desire for better guidance on the internet to obtain the desired information more quickly. Thematically interesting for ID18 were, among other things, hints for self-help groups to get reports of their experiences.

ID05 concluded by commenting on isolated further needs for information (topic 9). An HIN was defined here in terms of the limited and inaccurate information flow from doctors and hospitals to their patients. He mentioned the example of a fraud during a coffee trip:

> Yes, we were once badly fooled. We were on a coffee trip there and they sold us a product. [...] There were also people who said “yes, we did that too” and afterwards we found out that they mix people among the coffee trip participants who belong to them. Afterwards, you’re always smarter.

**Group 3: High HIN**

The group with high HIN encompassed ID02, ID07, ID09, ID13, and ID17. ID02, ID07, and ID17 had (topic 1) a need for communication with doctors. ID02 had the desire for more transparency in medical examinations. He was bothered by the fact that information only came when it was requested. In contrast, ID17 had a basic need for information regarding his or her health situation:

> And I am someone, I said from the beginning, who wants to know what I have. I want to know how I have to handle it.

For her, this handling of information was part of their information behavior. Furthermore, the personal relationship with the doctor was important for ID17, who was also the most important information source for her.

ID07, however, reported a recent experience that has had a lasting influence:

> [My daughter] who is 27 weeks pregnant, will have twins, and her gynecologist said that she has to go to her family doctor. The family doctor said that the leukocytes were too high. And he, who then sent her home, said, “I’ll check it out” and talked to her on the machine this morning and told her “yes, her gynecologist would get in touch with her next week.”

ID07 believed that doctors often lack the feeling for the context or the empathy for the patients’ situation. She firmly believes that patients, especially her own daughter, have to put up with long waiting times and are informed relatively late about their own symptoms.

ID07 described the idea of the doctors’ lack of empathy with the fact that doctors often have no intuition for someone not wanting further information. She talked about a procedure in which the flow of information led to her feeling nervous and restless:

> That already strained me with what they said. “We’ll saw your bone through there,” and so on.

She also described a third incident that had a lasting impact on her information needs. ID07 was much younger, and although she was still breastfeeding, this could have been dangerous for the child, as her treating physician had prescribed cortisone (Cortisone is a pregnane [21-carbon] steroid hormone. It is one of the main hormones released by the adrenal gland in response to stress). ID07 described the idea of the doctors’ lack of empathy with the fact that doctors often have no intuition for someone not wanting further information. She talked about a procedure in which the flow of information led to her feeling nervous and restless:

> That already strained me with what they said. “We’ll saw your bone through there,” and so on.

The described incidents led ID07 to the statement that she is not a doctor’s friend and that she critically questions the information provided by them. Accordingly, she wanted several expert opinions on a diagnosis:

> Yes, and he sees that I have a child and does not ask me if I am breastfeeding or something like that, but prescribes me a cortisone medicine. You can’t do that. That goes into the blood and then into the child.

The described incidents led ID07 to the statement that she is not a doctor’s friend and that she critically questions the information provided by them. Accordingly, she wanted several expert opinions on a diagnosis:

> Somewhat, I always have the feeling that I am missing information, because I say “yes okay, then I go to the next doctor. I’ll ask his opinion about that. Or I’ll ask a third doctor about this.” That is, with one piece of information, I am therefore probably not so satisfied. Probably this will not be enough for me, then I would need a little bit more.

Overall, the desire for credible doctors prevailed at ID07, as did the desire for self-determination:
You are sent from one doctor to another and don’t have much of a choice to say: “But I’m going to see another doctor.”

ID02 and ID03 commented on (topic 2) the HIN on prevention/precaution (including questions on nutrition and sports). ID02 had an in-depth interest in cancer screening. ID13, in this regard, had an HIN on pain causes and management, as she was currently in pain. In connection with this, ID13 had an HIN that deals with muscle activity and performance. She was interested in how you can plan your daily activities meaningfully in that context.

ID13 and ID17 had (topic 3) an HIN about the medication. Thus, ID13 had an HIN on the effects and intake of medication. ID13 consolidated her own doctors to obtain information. ID17 showed a need for transparent communication in the field of medication. She found it difficult that she had to act as an information source when she visits a new doctor and had to inform him about the medication she was taking. ID02 and ID13 showed a need for (topic 4) health-related costs and their generation. For ID13, medical bills and the handling of costs by doctors and health insurance companies were mentioned as interesting points. ID02 was interested in questions that dealt with the composition of treatment costs. For example, ID02 stated that the flow of information between doctors and the patient on this subject was impersonal and inaccurate. For him, it was important to be able to understand the costs.

ID02, ID07, ID13, and ID17 commented on (topic 5) an HIN on vital data and health parameters. Thus, ID02 had the desire for direct clarification of available health data, for example, measured values. ID17 showed an HIN on health-related parameters and values and their personal significance. ID17 would have liked assistance in interpreting health-related data, as described in the first case of her pregnant daughter. ID13 indicated that vital signs were generally not very important to her. Blood pressure was excluded from this, even if ID13 stated that she was able to assess it well on the basis of body sensation:

I consider it very important, but I don’t need to measure it, I can tell you by heart what it is like. [...] My blood pressure is always 140 over 80 with medication intake. [...] As soon as the lower value rises, I feel as if I really wanted to squabbles.

ID17 had a basic HIN; however, ID17 did not want to be reminded of her illness every day. This included, for example, the daily wearing of a measuring device, which she considered to be very stressful for her. Her wish for information and the desire not to be constantly reminded of her illness was somewhat of a dilemma.

ID02 and ID07 had a (topic 6) need for better exchange between health-related actors and institutions. For ID07, the flow of information between doctors and patients in this field was impersonal and inaccurate. She assumed that these processes were carried out by a third party, for example, a secretary, and that the attending physician was not even informed about the costs involved. In ID07’s view, this matter was also an incomplete communication between doctors, which annoyed her personally.

On (topic 7) an HIN about health insurance companies, ID07 stated that it is a difficult matter on which she would have liked to have more information. In addition, ID13 stated that, according to her, health insurance companies work against, not with and for, patients, which leads to the exclusion of patients:

Something could come from the insurance company to make life easier for you... So that they’ll be more active in approaching people.

ID13 also expressed her opinion on (topic 8) the need for age-related means of finding information and would have liked to have easier access to it. The background was that, according to her statement, many older people do not have internet access.

Finally, ID07 and ID17 (topic 9) indicated isolated needs for further information. In ID07, it represented a desire for self-determination:

You are sent from one doctor to another and don’t have much of a choice to say: I’m going to see another doctor.

This led to an HIN about the availability of alternative doctors and a need for general information about doctors before a doctor becomes a patient. ID17 focused on the social environment and the HIN for relief measures. The reason for this need was her own heart disease manifested in the form of several heart attacks. According to patient ID09, there was an HIN for follow-up and preparation in addition to the discussion with the doctor. The doctor was considered to be the most important source of information for personal health information; however, ID09 felt that this is missing because of time pressure of the physician, lack of interest in the patient by the physician, or the fact that the physician does not take patients seriously:

They don’t take you for full [...] I didn’t understand at all what he said to me [...] I’ve written down the words (technical terms/unintelligible words), and I’m going to the family so a family member can translate them for me.

For an appropriate exchange of information about health information, ID09 required the fulfillment of emotional and interpersonal needs by the physician as a prerequisite for exchanging information in a personal conversation. If a doctor did not comply, the need for information was covered by another source of information. Most importantly, she saw a difference between the specialists and the family doctor.

HIN Questionnaire Data

The descriptive results of the questionnaire data revealed that the information needs of older adults were quite low: 46% (12/26) of the sample were satisfied or rather satisfied 12% (3/26), 8% (2/26) were rather dissatisfied with the available health information, and 35% (9/26) were partly dissatisfied. HIN is indicated by the satisfaction with the information at hand. Information need was thus measured by how applicable participants considered the statement “I am satisfied with the information I have available on health/my health.”

Information-Seeking Behavior Interview Data

A total of 9 participants showed diverse tools that they already used to record, keep, and exchange information regarding their
health. Accordingly, Figure 1 documents pictures and screenshots. These artifacts included descriptions of surgical procedures; examination results of imaging procedures; tables with results of laboratory tests; folders with personal disease histories (prescriptions, diagnoses, findings, etc); handwritten medication overviews and appointment reminders; and personal diaries with medical data such as blood pressure, pain perception, and behavior.

Some participants clearly showed either an active (ID08, ID10, ID17, and ID18) or a passive (ID08, ID10, ID17, and ID18) information behavior. In contrast, ID06, ID07, ID13, and ID15 represented a mixture of active and passive information behaviors and were classified according to the statement into 1 of the 2 groups. ID03, ID04, and ID16 did not state anything about their information behavior. Participants with active information behavior most frequently conducted research on health issues (prevention) and searched for information about diagnoses and (risk of) examinations. Another important point describing active search was to actively exchange health-related information with the social environment and actively asking doctors (in the form of calls or personal conversations) if uncertainties or questions prevailed.

Participants with passive information behavior required a reminder to go to medical checkups instead of actively remembering or investigating information about it. Their passive information search behavior was reflected in the intake of medication. Here, the doctor played an active role in providing information on the effect and intake and giving further advice on the medication. Passive participants perceived information from the social environment instead of actively using information systems such as the internet to find information. The passive information retrieval process started by observing one’s own symptoms before consulting a doctor. Some participants with passive information search behavior perceived health information as less desirable and irritating for some patients.

Figure 1. Participant’s documentation of health-related information on paper and digital media.

Information-Seeking Behavior Questionnaire Data

Answers to the questions on information-seeking behavior showed that the largest part of the sample (7/26, 27%) used health information to change their health behavior. A total of 23% (6/26) used it to complement professional information either as preparation for a conversation or in addition to it (Table 3).

The results suggest that older adults use 2 to 3 sources to find relevant health information. On the basis of all valid answers, 15% (4/26) use 1 information source, 31% (8/26) use 2 sources, 35% (9/26) use 3 sources, 12% (3/26) use 4 sources, and 8% (2/26) use 5 different sources. All participants find health information on television shows. Here, 85% (22/26) of participants mentioned the German television show Visite (reports on medical topics). Other sources include newspapers and magazines (eg, Apothekenrundschau, a magazine distributed free of charge in German pharmacies) and the radio. On the basis of all valid answers, 73% (19/26) indicated that their information sources deliver the information they need, whereas 12% (3/26) said that using their information sources does not lead to the information they want. The other 12% (3/26) indicated that their information sources partly deliver the information they need. The majority of participants (20/26, 77%) were willing to share health-related information with other people. Only 19% (5/26) were unwilling to do so. The following table depicts more about how participants characterized their information acquisition (Table 4).
Table 3. Percentages of the different purposes older adults use health information for (N=26).

<table>
<thead>
<tr>
<th>Use</th>
<th>Participants, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generate knowledge</td>
<td>4 (16)</td>
</tr>
<tr>
<td>Change health-related behavior</td>
<td>7 (27)</td>
</tr>
<tr>
<td>Complement doctors’ information</td>
<td>6 (22)</td>
</tr>
<tr>
<td>Making health decisions</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Treatment</td>
<td>4 (17)</td>
</tr>
<tr>
<td>Exchange experiences</td>
<td>3 (11)</td>
</tr>
</tbody>
</table>

Table 4. Information-seeking behavior of the sample (N=26).

<table>
<thead>
<tr>
<th>CISS&lt;sup&gt;a&lt;/sup&gt;-item</th>
<th>Valid answers, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I am actively seeking information about (my) health.”</td>
<td>Applicable 6 (33)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 2 (11)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 4 (22)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 0</td>
</tr>
<tr>
<td></td>
<td>Not applicable 6 (33)</td>
</tr>
<tr>
<td></td>
<td>Missing 8 (30)</td>
</tr>
<tr>
<td>“I am looking for information about health or my health rather casually.”</td>
<td>Applicable 5 (29)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 1 (6)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 1 (6)</td>
</tr>
<tr>
<td></td>
<td>Not applicable 11 (61)</td>
</tr>
<tr>
<td></td>
<td>Missing 8 (30)</td>
</tr>
<tr>
<td>“I am consciously looking for information about (my) health.”</td>
<td>Applicable 8 (44)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 1 (6)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 1 (6)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 2 (11)</td>
</tr>
<tr>
<td></td>
<td>Not applicable 6 (33)</td>
</tr>
<tr>
<td></td>
<td>Missing 8 (30)</td>
</tr>
<tr>
<td>“I am passively looking for information about (my) health.”</td>
<td>Applicable 7 (39)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 3 (17)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not applicable 8 (44)</td>
</tr>
<tr>
<td></td>
<td>Missing 8 (30)</td>
</tr>
<tr>
<td>“I am permanently looking for information about (my) health.”</td>
<td>Applicable 2 (39)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 1 (6)</td>
</tr>
<tr>
<td></td>
<td>Not applicable 15 (83)</td>
</tr>
<tr>
<td></td>
<td>Missing 8 (30)</td>
</tr>
<tr>
<td>“I am a curious person.”</td>
<td>Applicable 16 (64)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 4 (16)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 3 (12)</td>
</tr>
<tr>
<td></td>
<td>Rather not applicable 0 (0)</td>
</tr>
<tr>
<td></td>
<td>Not applicable 2 (8)</td>
</tr>
<tr>
<td></td>
<td>Missing 1 (4)</td>
</tr>
<tr>
<td>“I am willing to take risks.”</td>
<td>Applicable 7 (28)</td>
</tr>
<tr>
<td></td>
<td>Rather applicable 3 (12)</td>
</tr>
<tr>
<td></td>
<td>Partially applicable 4 (16)</td>
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<tr>
<td></td>
<td>Rather not applicable 3 (12)</td>
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<tr>
<td></td>
<td>Not applicable 8 (32)</td>
</tr>
<tr>
<td></td>
<td>Missing 1 (4)</td>
</tr>
</tbody>
</table>

<sup>a</sup>CIS: Coping Inventory of Stressful Situations.

The Influence of Coping Strategies on HIN and HISB Interview Data

Task-Oriented Coping Strategy

The information needs of the participants (n=5) from the group with task-oriented coping behavior (T group) are clear and varied. For example, they include the exchange of information between health actors, transparent information on doctors and health insurance billing, and even nonexistent information needs. Thus, one assumption is that T group members are more interested in additional process-relevant organizational information. Information about one’s own health is only needed and exchanged when complaints or symptoms occur. A clear diagnosis, cause, and precaution (e.g., cancer precaution) and an exchange of experiences are desired. In addition, participant ID08 stated that information needs are primarily “dependent on the health situation, and therefore are currently low.”

Across the entire group, doctors are viewed as the most important source of information, even if the experiences were not always good. The information behavior concerning one’s own health is symptom-/illness-related and focused on the doctor. The internet is often mentioned but is critically viewed as a means of obtaining health information. For ID02, the lack of knowledge about a technology constitutes a hurdle for technology use, so that “as far as health is concerned, I don’t go there (comment: the internet) because I don’t know how it works and I can’t use it.” ID18’s statement that “A technical system doesn’t replace the doctor. I mean, it can inform me, but the internet can’t treat me” reflects again the strong reliance on the doctor and shows that information is tied to treatment and action in general.

Avoidance-Oriented Coping Strategy

Only 1 female interviewee was assigned to the group with a pure avoidance-oriented coping strategy. The need for information of the interview partners with an avoidance-oriented coping strategy is comparatively low and relates to drug intake and effect. The doctor stands at the center of information retrieval. He/she has the patients’ complete confidence, and information provided by him/her is not questioned or controlled. Great uncertainty and fear of all other sources exists because of fear of fraud or being taken advantage of, which results from personal experience. The doctor initiates any kind of information behavior. There is no individual drive to gain information. General and personal health information is obtained from a small number of information sources.

Task- and Avoidance-Oriented Coping Strategy

Only 1 female interviewee was assigned to this group. Her need for information is similar to the needs of group A: she seeks exclusive information about occurring diseases or complaints that are completely provided by doctors. Similarly, the search for information behavior is only active in the case of complaints and then directed solely at doctors. Information available on television is randomly included in the current personal situation. There is high distrust of all sources of information not related to doctors.

https://humanfactors.jmir.org/2021/1/e15858

JMIR Hum Factors 2021 | vol. 8 | iss. 1 | e15858 | p.62
(page number not for citation purposes)
**Task- and Emotional-Oriented Coping Strategy**

Each participant in the TE group demonstrated a high need for information. Compared with the participant in group A, this includes just as much diversity, but in the TE group, it focuses much more on the individual than on the indirectly related organizational processes. Moreover, compared with group A, interest is not linked to a disease or symptom but is generally present. To obtain health-related information and data, fitness trackers, blood pressure monitors, and digital training instructions are used to document and independently influence one’s own health. Doctors are mentioned as the most important source, but “the different diagnoses which one receives from doctors to one and the same symptom show...that one should remain critical toward doctors” (ID14). In no other group is supplementing medical information with active, personal information gathering so self-evident: “I always in-form myself in advance before I go to the doctor.” Additionally, it is no wonder that, compared with other groups, emotional states play a major role here: “A personal relationship (to the doctor) is very important” stated ID17 and described trust to be an important factor by stating that “I find it pleasant when you can see the person directly, look him in the eye. That creates trust.”

**Task-, Emotion-, and Avoidance-Oriented Coping Strategy**

Of the 3 interview participants in the TEA group, only 1 woman gave detailed answers to the interview questions. As with the participant in group A, doctors are viewed as responsible for providing information about the participant’s health. However, ID07 stated:

> those (doctors) unfortunately often lack the feeling for the context. They lack empathy for the situation of uncertainty in which the patient finds himself.

Here, the method of information transfer is primarily criticized, which does not take sufficient stock of the patient’s emotional world: “You feel dispatched and inadequately treated” (ID07). Unlike the TE group and similar to the T and A groups, the required information includes diagnoses and medication information and help to interpret laboratory findings and treatment methods. These are obtained without exception from personal sources of information such as the doctor or pharmacist or, in exceptional cases, from a medically trained relative. The remaining male interviewees of the TEA group indicated that they did not want to know about health or their personal health. The mixed methods analysis of normalized code frequencies in the separate CISS groups supports the preceding qualitative view. The results should be viewed against the background of the group size (A: n=2, T: n=7, TE: n=9, TA: n=2, and TEA: n=4). Codes concerning information behavior most frequently occurred in the TE group.

In short, it can be stated that qualitative interviews suggest an HIN influenced by individual coping strategies. This matches the results of international researchers and theoretical models [15,17,19,21]. Particularly noticeable in the quantitative analysis of the qualitative data was the influence of the avoidance-oriented coping strategy (group A). People who applied the avoidance strategy entirely or partly had a descriptively much lower HIN. This seems to be intrinsically motivated because satisfaction with the doctor was not necessarily accompanied by an increased HIN. The TE group was the most open to technology use and the collection and interaction of and with its own health-related data. Further investigations could serve to identify factors that explain this observation beyond coping strategies.

**The Influence of Coping Strategies on HIN Questionnaire Data**

The score of participants’ satisfaction with information at hand (ie, information need; $D(26)=0.294$; $P<.001$) is significantly different from normality. The numerical scores of each dimension were as follows: task-oriented coping $D(25)=0.158$, $P=.11$; emotion-oriented coping $D(25)=0.114$, $P=.25$; and avoidance-oriented coping $D(24)=0.193$, $P=.80$. The bootstrapping method and bivariate correlation models were applied to investigate the relationship between the scores of individual coping strategies and information need.

Bias-corrected and accelerated bootstrap 95% CIs (95%, BCa CI) are reported in square brackets. No relationship was found between information need and the task-oriented coping strategy score ($r_s=-0.056$, 95% BCa CI $-0.469$ to 0.445; $P=.79$). In addition, no correlation was found between information need and the emotion-oriented coping strategy score ($r_s=-0.149$, 95% BCa CI $-0.532$ to 0.260; $P=.49$). However, a trend was found for a negative correlation between the avoidance-oriented scale and information need ($r_s=-0.378$, 95% BCa CI $-0.730$ to 0.092; $P=.05$). The more strongly a person is characterized by an avoidance-oriented coping strategy, the lower is the person’s health-related information need (Figure 2).
The Influence of Coping Strategies on HISB Questionnaire Data

Emotion-oriented coping has a negative relationship with the perceived success of an information source ($r_s = -0.607$, 95% BCa CI −0.876 to −0.139; $P = .20$). The more people rely on the emotion-oriented coping strategy, the lower they rated the success of the information they received from the sources they used. The casualness with which a person looks for health-related information is positively related to the success of an information source ($r_s = -0.620$, 95% BCa CI 0.302 to 0.884; $P = .01$). The more casually a person searches, the higher the person rates the source in terms of success. The consciousness with which a person conducts the information search is positively correlated with the person’s activity level in the search ($r_s = 0.929$, 95% BCa CI 0.839 to 0.982; $P < .001$). The more consciously a person searches, the more active will be the search. The consciousness with which a person conducts the information search is positively correlated with the avoidance-oriented coping strategy ($r_s = 0.561$, t 95% BCa CI 0.056 to 0.889; $P = .03$). The more consciously a person searches for health-related information, the higher the scale value of the avoidance-oriented coping strategy is.

Discussion

Principal Findings

This study on HINs and HISBs of older adults investigated the general context of data visualizations in a group of 18 adults aged between 50 and 91 years. Interviews on the topic of HINs and HISBs were conducted, transcribed, coded, and qualitatively analyzed. Questionnaires on social demographics and coping strategies served as a basis for comparing qualitative and quantitative results. Essentially, the results indicate a heterogeneous need for information on the part of older people, where one part of the population needs and desires the exchange of personal health data and the other part adopts an attitude of avoidance. There is a need to deal with one’s own health data as a supplement to professional and medical sources of information.

Discussion of RQs

The first RQ to be answered in this regard was RQ 1: Which HINs do older adults have? The results indicate that the health-related information needs of the older people surveyed are not homogeneous. More than half of the participants were satisfied with the information available. According to the definition by Case et al [15], this corresponds to a low need for information. The majority of the interviewees justified the need for health information by stating that they had no health complaints. Another reason provided by the participants in this
group was the unsubstantiated assumption that the acquisition and examination of information about one’s own health can lead to the triggering of diseases or an increase in the current pain. This statement is contradictory because a need for preventive, relevant information was often formulated at the same time. This contradiction can point to a need for a more detailed consideration of individual types of health-related information. This study examined the general need for information and revealed that different types of health-related information appear to have different effects on patients and their behavior. In addition to the group that has little or no need for information, there is also a group who makes intensive efforts to gain information about their health. For these people, it is not enough to know what is necessary; rather, they use additional sources of information such as the internet or television to supplement the information they receive from their doctors. For these individuals, information acquisition is considered part of their coping strategy. Only if these patients are sufficiently informed about their illness, do they consider themselves able to make decisions and communicate with doctors.

It was particularly surprising that half of all respondents already collected health data on paper and were using computers. These included notes listing the type and quantity of medication patients carry in their wallets to provide a basis for decision making. Furthermore, doctors had made laboratory results and examination values available to the patients in tabular printouts. Older people had disease histories meticulously collected in folders consisting of examination results, x-rays, medication instructions, and accounts together with detailed visualizations of surgical procedures. Occasionally, participants documented blood pressure, sports activities, and symptoms in a digital form or wrote pain diaries to draw conclusions about causes and adapt their health-related behavior accordingly. The interviewees were among the generation that did not grow up with digital technology. It can, therefore, be assumed that the described number of people digitally documenting their health will increase even further with the growing number of digital natives. Here, it is necessary to investigate whether and to what extent the group of information avoiders will play a role in digital health systems that visualize personal health data.

Results regarding health information relevant to older people indicate that more information is needed concerning preventive measures and everyday healthy behavior. Most importantly, there was a lack of a decision-making basis for one’s own behavior. This conclusion is supported by the information regarding the objectives pursued with the collected information. About one-third of the participants stated that they wanted to change their own health behavior according to the information they had collected. The need for information coming directly from the doctor and more intensive communication between doctors and patients reveals the fundamental importance of doctors for older patients. Despite the doctors’ position as the most trustworthy source of information, older people see their lack of time as a barrier to having their information needs met. Most importantly, current billing structures do not allow, for example, detailed clarification of medical terms from the treating physician or receipt of more treatment and diagnosis-specific information from the doctor. Even if digital health systems have the potential to compensate for the doctors’ aforementioned lack of time, the doctors’ acceptance of digital health systems would require a clear billing concept for services provided digitally.

With regard to RQ 2, How do older adults acquire needed health information?, the results indicate that health issues and symptoms initiate the information search. Furthermore, if the principal information source—the doctor—does not provide enough information, search activities are initiated. This is in line with the model of information-seeking behavior by Wilson, which states that the failure of one source to provide information motivates search activities. Older adults’ information behavior can thus be considered occasional. Occasional searching could be an alternative explanation for the heterogeneous need for general information. The health status of participants was not explicitly investigated and needs to be considered in future studies on this topic. Furthermore, when it comes to health, the results suggest that the most frequently used and most trustworthy information source is the doctor. These results are consistent with those of age-independent studies. In particular, the older adults attribute medical competence only to the doctor; therefore, they put the decision about a treatment completely in the hands of the doctor. At the same time, similar to the results of the study by Geuter and Weber [7], trust is perceived as a particularly important determinant that arises from personal contact with the treating physician. In addition to the professional competence of the source, the influence of emotional factors on the search for information becomes evident. Besides doctors, television and even the internet are sources of information.

With regard to RQ 3, How does the coping of older adults relate to their HINs/HISB?, it can be stated that the qualitative and quantitative results indicate an influence of coping strategy on HIN and HISB. An avoidance-oriented coping behavior especially leads to a lower information need. Assuming that a lower information need results in avoiding information search with technology, avoidance-oriented coping behavior can be considered as a hurdle for health technology and health data visualization use. Further investigations on system design with regard to coping strategies are needed.

Limitations
The main limitation of this study is its ecological validity. Its cross-sectional design provides insights into HISBs of older adults for a single point in time. Although it closes the research gap of investigating how the specific population of older adults requires information, questions on HINs with respect to ongoing health conditions remain unanswered. As with many studies on the need for health and patient information, the subjective character of this study might be subject to social desirability. Older adults, in particular, often feel the need to conclude from the questions what might be expected from them to adjust their answers accordingly. Future studies on HIN would benefit from controlling this variable. Ecological validity could be improved by investigations within a natural setting, meaning that data from patients’ providers or search engines could be analyzed to triangulate subjective data using objective observational data, interaction, and logfiles.
Furthermore, the study was conducted with participants from Aachen, Germany. Germany’s socioeconomic parameters such as health care, average monthly income, life expectancy, education level, and density of dental care provision match those of other European Union (EU) member countries. Consequently, the data collected should be comparable with those of most of the other EU members, but HINs differ in countries with different economic or cultural backgrounds. At the same time, the results should be subjected to a generalization against the background of sample size and the procedure for acquiring participants.

Another factor that may have influenced the results of the study is that the patients interviewed may have a different understanding of terms in relation to the queried criteria than initially assumed. Against the background of this study, it seems quite probable that the criteria asked for, such as the health-related information need, for example, could be understood differently than initially assumed. The patients only answered and assessed these questions on a personal level. In addition, the study participants felt that the question regarding their satisfaction with the information available to them was in part an evaluation of their physician because they understood their physician to be responsible for communicating this information. Their relationship and experience with their physician is thus an influencing factor.

Conclusions

The results regarding the general need for information identify the need for older people to gain insight into personal health data and to use this as a basis and addition to medical information provided by physicians. This motivates successive investigations on age-differentiated, ergonomic considerations of the visualization of personal health data. However, it should be noted that not every older adult wishes to independently analyze his/her own health data. When provided with health-related data, participants most importantly require support to interpret the data and assess their significance for their personal situation. As the daily use of health-related data puts the disease first, a visualization of data with a direct reference to the disease carries the risk of reduced acceptance, adherence, and use of the corresponding system. In contrast, the need for behavior-changing and preventive measures suggests that data visualizations that allow for conclusions about personal behavior and its correlation with symptoms might positively influence these factors. One unresolved issue in this regard is the extent to which data visualization can increase the motivation of the patient to change a behavior.

This study focused on the need for health information to examine the broad context of digital health systems. Empirical evidence for a correlation between health-related information needs and data visualization/use of technology is lacking and needs to be investigated, especially for the group of older adults. There is also little empirical knowledge about the importance of trust in connection with the visualization of personal health data. Although investigations on factors that influence or generate trust in the data might also be especially relevant for the health care domain, it is still unclear how trust develops in the context of health-related decision making and how corresponding processes proceed or if data visualizations might even increase the user’s acceptance of a digital health system.

Finally, it remains to be clarified whether there is a difference between the information needs of chronically ill and acutely ill people or whether differences in HIN arise predominantly according to observed symptoms or life and care experience. Particularly vulnerable groups (those with Parkinson disease, Alzheimer disease, etc.) must be taken into account.

Implications for Technology Development

The following implications for technology developments were derived from presented results:

1. Digital health technology might be more accepted if its use is recommended and accompanied by the physician.
2. The occurrence of personal symptoms and diagnoses might trigger individual information search behavior.
3. The physician should provide information on illness and medication more effectively, whereas the patient provides information on health-related parameters to the diagnostic process most effectively.
4. Digital systems that can support the patient in everyday documentation of symptoms and complaints to support the diagnostic processes of doctors are required.
5. Patients need support in documenting symptoms and complaints.
6. Cooperation and data exchange of all actors involved in diagnosis and treatment simplifies this for the patient.
7. Comprehensibility and competence of the information source is a key requirement of the patient and should therefore be considered in system development.
8. Adaptive systems for coping strategies are required to address the nonhomogeneous health-related information needs of older adults; therefore, digital health systems must enable patients and users to assess the trustworthiness of information and develop trust.
9. Older adults require diverse types of health-related information and use different methods to acquire information. The planning and development of digital health systems should combine and harmonize different sources of information. Not only user groups with their skills and abilities but also the characteristics of the information sources should be taken into account to effectively coordinate their interaction.
10. Communication strategies implemented in the system that put health rather than illness in the foreground foster acceptance and adherence.

Regarding the design recommendations, it must be considered that these will have to be validated before being actually applicable to system design.
Acknowledgments
This publication is part of the TECH4AGE research project funded by the Federal Ministry of Education and Research, under grant no. 16SV7111) and promoted by Verein Deutscher Ingenieure Innovation+Technik GmbH.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Questionnaires.
[PDF File (Adobe PDF File), 183 KB - humanfactors_v8i1e15858_app1.pdf ]

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URL: https://humanfactors.jmir.org/2021/1/e15858
doi:10.2196/15858
PMID:33522973

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Abstract

Background: As the COVID-19 pandemic has become a major public health threat worldwide, it is critical to understand what factors affect individual engagement in protective actions. Because of its authoritarian political system and state-owned media system, how Chinese individuals engaged in protective actions against COVID-19 might be different compared to other countries.

Objective: The purpose of this study is to examine how the source of information about COVID-19, Chinese individuals’ risk perception of COVID-19 (ie, perceived severity and perceived susceptibility), and their efficacy appraisal in controlling COVID-19 (ie, response efficacy and self-efficacy) affected their engagement in protective actions. Additionally, this study aims to investigate whether there is any difference in these relationships throughout the duration of this pandemic.

Methods: A six-wave repeated cross-sectional survey (N=1942) was conducted in six major cities in China between February 7 and April 23, 2020. Participants’ reliance on expert versus inexpert sources for information about COVID-19, their perceived severity of and susceptibility to COVID-19, their response efficacy and self-efficacy, and their engagement in protective actions (staying at home, wearing a face mask, and washing hands) were measured. Demographic variables (sex, age, income, education, and city of residence), knowledge of COVID-19, and self-rated health condition were controlled.

Results: Reliance on expert sources did not become the major factor that motivated these actions until wave 3, and the negative effect of inexpert sources on these actions was limited to wave 2. Perceived severity encouraged some protective behaviors but its effect varied depending on the specific behavior. In addition, perceived severity exhibited a stronger effect on these behaviors compared to perceived susceptibility. The positive effect of response efficacy was only significant at waves 1 and 2, and limited to certain behaviors.

Conclusions: Chinese individuals’ engagement in protective behaviors might not entirely be their autonomous decision but a result of compliance with executive orders. After the early outbreak, expert sources started to facilitate protective behaviors, suggesting that it might take time to develop trust in these sources. The facilitating effect of perceived severity lasted throughout the duration of the pandemic, but that of response efficacy was limited to the early stage.

(JMIR Hum Factors 2021;8(1):e23232) doi:10.2196/23232

KEYWORDS
information source; perceived severity; perceived susceptibility; response efficacy; self-efficacy; health information; protective behavior; COVID-19; protection; behavior; risk; perception; prediction
Introduction

Background

Having spread to 188 countries and regions [1], COVID-19 has become a serious public health threat worldwide. As of October 16, 2020, COVID-19 has caused over 38 million cases and nearly 1,100,000 deaths [1]. China is the first country where COVID-19 was discovered. As early as December 2019, COVID-19 was found in Wuhan, China [2]. The number of confirmed cases and deaths in China grew rapidly in January but started to decline in late February [3]. As of October 16, 2020, China reported 90,899 cases including 4739 deaths [1].

Despite scientific efforts, much about COVID-19 still remains uncertain, such as its origin and mutation [4]. Thus, given its high levels of risks, individuals are encouraged to take protective actions [5,6]. The extant research has explicated how individuals’ engagement in protective behavior against COVID-19 varied depending on their knowledge, fear, risk perception, morality, and internet use [7-12].

However, empirical evidence in China is still scarce. The authoritarian political system in China reduced resistance to the government’s executive orders such as locking down cities and placing citizens under quarantine [13], which controlled the spread of the pandemic [3]. In addition, the state ownership of media in China enables the government to provide large-scale health education and campaigns consistently, which might have facilitated engagement in protective actions. Thus, investigations on what factors affected Chinese individuals’ engagement in protective actions against COVID-19 may provide additional knowledge on the potential influence of a unique sociocultural environment on health behavior.

However, to the best of our knowledge, only one study was conducted on how Chinese individuals performed protective actions against COVID-19 [12]. Furthermore, that study is a one-time cross-sectional investigation at the early stage of the outbreak [12]. As it remains unknown when the pandemic might end, it is critical to examine how factors related to taking preventive measures against COVID-19 might change across different stages of its outbreak. Therefore, this study employs a repeated cross-sectional approach to address this limitation. Specifically, built on the extended parallel process model (EPPM) [13], this study aims to test the theory by examining how individuals’ risk perception of COVID-19 and their efficacy appraisal in controlling COVID-19 might affect their engagement in protective actions. Moreover, we seek to add to the extant research by investigating the role that one’s reliance on different sources for information about COVID-19 plays in performing these protective actions. Although we built our study on EPPM, other theoretical work such as the protection motivation theory [14], the health belief model [15], and the risk perception attitude framework [16] also considered variables in EPPM and made similar predictions.

EPPM

EPPM contends that whether individuals engage in protective behaviors depends on their risk perception and efficacy appraisal [17]. Risk perception is usually conceptualized as the sum of average of perceived severity and perceived susceptibility [18]. Perceived severity refers to one’s perception of the adversity of consequences if individuals do not engage in recommended actions, whereas perceived susceptibility is conceptualized as the likelihood that one is subject to the given health threat [18-20]. Additionally, efficacy appraisal is conceptualized as the sum of response efficacy and self-efficacy [18]. Response efficacy refers to the extent to which individuals think recommended protective actions can manage the given threat effectively, whereas self-efficacy is conceptualized as individuals’ confidence in performing those recommended acts [17,18].

The original research on EPPM posits that whether risk perception may facilitate engagement in protective actions depends on the level of efficacy appraisal [17,21]. Specifically, risk perception can only motivate individuals to perform protective actions at high levels of efficacy appraisal, whereas this positive relationship is absent at low levels of efficacy appraisal [17,21]. However, subsequent work demonstrated that risk perception can drive protective actions without high efficacy appraisal [22] because the innate aversion to loss prompts individuals to avoid potential risks by taking preventive measures [23]. Therefore, higher levels of perceived severity and perceived susceptibility may be associated with heightened motivation to perform protective actions [22,24-28].

In addition, individuals reporting high levels of response efficacy are more driven to engage in behaviors that can minimize the threat [26,29,30] because this confidence is often correlated with enhanced levels of hope [31]. Moreover, individuals reporting high levels of self-efficacy are more likely to follow the recommended acts because they tend to think it is less challenging to perform those behaviors [32]. Taken together, we predict that response efficacy and self-efficacy in controlling COVID-19 should exhibit positive relationships with engagement in protective behaviors.

Information Sources About COVID-19

Individuals equipped with accurate health information are usually more motivated to engage in health behaviors [9]. However, the volume of rumors about COVID-19 makes individuals vulnerable to health misinformation [33]. One factor that could potentially affect the credibility of information is its source. We categorized information sources into expert versus inexpert sources. Expert sources are conceptualized as individuals with medical expertise and organizations with professional gatekeepers that can screen information before it is published. These expert sources include expert media, government administrations, expert health organizations, and medical experts. The gatekeeping theory contends that gatekeepers, or people screening the information in these organizations, can enhance the accuracy of information [34]. Additionally, the heuristic-systematic model suggests that the public is inclined to trust the information provided through these sources because of its authority and thereby more motivated to follow the recommendations that these sources offer [35]. By contrast, inexpert sources are those lacking expertise background or professional gatekeepers, namely celebrities, social media influencers, and social contacts that are not doctors. Therefore,
individuals relying on expert versus inexpert sources for information about COVID-19 may demonstrate different patterns of protective behaviors. Given these differences, we predicted that individuals relying on expert sources for information about COVID-19 should be more driven to engage in protective actions whereas reliance on inexpert sources should be related to engagement in protective actions negatively. As mentioned earlier, a repeated cross-sectional investigation will be employed. Hence, an additional question is whether these relationships changed throughout the duration of this study. Three protective actions were assessed: staying at home, wearing a face mask, and washing hands.

**Methods**

**Overview**

A six-wave repeated cross-sectional survey was conducted between February 7 and April 23, 2020, in collaboration with a large company that provides sampling services in China. Every other week, an online survey was distributed to a convenience sample of residents in six major cities in China. These cities were Beijing, Shanghai, Guangzhou, and Shenzhen, which are the four largest cities in China, as well as Wuhan, where the first COVID-19 cases were discovered [2], and Hangzhou, another city among the cities with the most reported cases [36].

Our survey started on February 7, 2020. Although cases were first found in Wuhan in late December 2019, the Chinese government did not inform the public that COVID-19 could be transmitted between humans until January 20 [37]. On January 23, Wuhan was locked down [38], which started a series of executive orders on travel bans and wearing face mask [13]. We did not start our research until February 7 because January 24 was the Lunar New Year’s Eve, which started a weeklong holiday. Therefore, we could not start our study until early February.

The data collection of wave 1 lasted from February 7-14, 2020. The second wave started on February 20 because most businesses in China restarted by late February and early March [39]. Thus, we wanted to investigate how the resumption of business might have affected our proposed relationships. Given the time difference between these two waves, we decided to collect our data every other week.

The lift of the lockdown in Wuhan on April 7, 2020, signaled the progress of pandemic control [40]. We collected the last wave (April 16-23) of data after April 7 to examine whether the lift of Wuhan’s lockdown might have changed our participants’ responses.

**Sample**

Table 1 presents the characteristics of the final sample in each wave. We matched the education and age of our sample to the national population. The most recent national census available to the public shows that around 14% of Chinese people received an associate’s degree or higher [41]. We also used this census to calculate the proportion of age strata in our sample: aged 18-30 years (19%), 31-45 years (26%), and 46 years and older (55%). However, this quota of education and age did not always match our sample characteristics in all waves.

Across all waves, there was no significant difference in biological sex ($\chi^2_5=5.56, P=.35$) and city of residence ($\chi^2_25=6.99, P>.99$). However, our participants differed significantly between waves in their age ($F_{5,901.48}=5.75, P<.001$; one assumption of one-way variance of analysis is the homogeneity of variances in the dependent variable; however, this assumption was violated when age was compared across waves, so Welch was used to compare differences between waves), education ($\chi^2_5=27.49, P<.001$), and income ($\chi^2_5=44.88, P<.001$).
### Table 1. Sample characteristics across waves.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Wave 1 (n=321)</th>
<th>Wave 2 (n=319)</th>
<th>Wave 3 (n=315)</th>
<th>Wave 4 (n=343)</th>
<th>Wave 5 (n=329)</th>
<th>Wave 6 (n=315)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>154 (48)</td>
<td>164 (51.4)</td>
<td>141 (44.8)</td>
<td>157 (45.8)</td>
<td>153 (46.5)</td>
<td>163 (51.7)</td>
</tr>
<tr>
<td>Female</td>
<td>167 (52)</td>
<td>155 (48.6)</td>
<td>174 (55.2)</td>
<td>186 (54.2)</td>
<td>176 (53.5)</td>
<td>152 (48.3)</td>
</tr>
<tr>
<td><strong>Age (years), n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>55 (17.1)</td>
<td>64 (20.1)</td>
<td>63 (20)</td>
<td>84 (24.5)</td>
<td>74 (22.5)</td>
<td>60 (19)</td>
</tr>
<tr>
<td>31-45</td>
<td>97 (30.2)</td>
<td>82 (25.7)</td>
<td>87 (27.6)</td>
<td>110 (32.1)</td>
<td>86 (26.1)</td>
<td>80 (25.4)</td>
</tr>
<tr>
<td>≥46</td>
<td>169 (52.6)</td>
<td>173 (54.2)</td>
<td>165 (52.4)</td>
<td>149 (43.4)</td>
<td>169 (51.4)</td>
<td>175 (55.6)</td>
</tr>
<tr>
<td><strong>Education, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle school or lower</td>
<td>38 (11.8)</td>
<td>21 (6.6)</td>
<td>24 (7.6)</td>
<td>10 (2.9)</td>
<td>23 (7)</td>
<td>50 (15.9)</td>
</tr>
<tr>
<td>High school</td>
<td>234 (72.9)</td>
<td>252 (79)</td>
<td>249 (79)</td>
<td>265 (77.3)</td>
<td>250 (76)</td>
<td>222 (70.5)</td>
</tr>
<tr>
<td>Associate’s degree or higher</td>
<td>49 (15.3)</td>
<td>46 (14.4)</td>
<td>42 (13.3)</td>
<td>68 (19.8)</td>
<td>56 (17)</td>
<td>43 (13.7)</td>
</tr>
<tr>
<td><strong>Household monthly income (US $)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤$500, n (%)</td>
<td>15 (4.7)</td>
<td>9 (2.8)</td>
<td>14 (4.4)</td>
<td>7 (2)</td>
<td>14 (4.3)</td>
<td>25 (7.9)</td>
</tr>
<tr>
<td>$501-$714.29, n (%)</td>
<td>31 (9.7)</td>
<td>29 (9.1)</td>
<td>22 (7)</td>
<td>25 (7.3)</td>
<td>21 (6.4)</td>
<td>36 (11.4)</td>
</tr>
<tr>
<td>$714.3-$1142.86, n (%)</td>
<td>55 (17.1)</td>
<td>41 (12.9)</td>
<td>48 (15.2)</td>
<td>55 (16)</td>
<td>49 (14.9)</td>
<td>75 (23.8)</td>
</tr>
<tr>
<td>$1142.87-$1785.71, n (%)</td>
<td>81 (25.2)</td>
<td>95 (29.8)</td>
<td>87 (27.6)</td>
<td>93 (27.1)</td>
<td>93 (28.3)</td>
<td>89 (28.3)</td>
</tr>
<tr>
<td>$1785.72-$5500, n (%)</td>
<td>113 (35.2)</td>
<td>126 (39.5)</td>
<td>128 (40.6)</td>
<td>138 (40.2)</td>
<td>130 (39.5)</td>
<td>79 (25.1)</td>
</tr>
<tr>
<td>$5500.01-$11,928.57, n (%)</td>
<td>20 (6.2)</td>
<td>9 (2.8)</td>
<td>9 (2.9)</td>
<td>16 (4.7)</td>
<td>16 (4.9)</td>
<td>8 (2.5)</td>
</tr>
<tr>
<td>≥$11,928.58, n (%)</td>
<td>6 (1.9)</td>
<td>10 (0.31)</td>
<td>7 (2.2)</td>
<td>9 (2.6)</td>
<td>6 (1.8)</td>
<td>3 (1)</td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td>4.03 (1.32)</td>
<td>4.15 (1.23)</td>
<td>4.1 (1.24)</td>
<td>4.21 (1.19)</td>
<td>4.14 (1.24)</td>
<td>3.63 (1.31)</td>
</tr>
<tr>
<td><strong>City of residence, n (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Beijing</td>
<td>55 (17.1)</td>
<td>53 (16.6)</td>
<td>52 (16.5)</td>
<td>59 (17.2)</td>
<td>52 (15.8)</td>
<td>51 (16.2)</td>
</tr>
<tr>
<td>Shanghai</td>
<td>54 (16.8)</td>
<td>53 (16.6)</td>
<td>51 (16.2)</td>
<td>58 (16.9)</td>
<td>52 (15.8)</td>
<td>52 (16.5)</td>
</tr>
<tr>
<td>Guangzhou</td>
<td>53 (16.5)</td>
<td>53 (16.6)</td>
<td>54 (17.1)</td>
<td>71 (20.7)</td>
<td>54 (16.4)</td>
<td>50 (15.9)</td>
</tr>
<tr>
<td>Shenzhen</td>
<td>53 (16.5)</td>
<td>51 (16)</td>
<td>53 (16.8)</td>
<td>51 (14.9)</td>
<td>64 (19.5)</td>
<td>53 (16.8)</td>
</tr>
<tr>
<td>Wuhan</td>
<td>52 (16.2)</td>
<td>53 (16.6)</td>
<td>52 (16.5)</td>
<td>50 (14.6)</td>
<td>53 (16.1)</td>
<td>53 (16.8)</td>
</tr>
<tr>
<td>Hangzhou</td>
<td>54 (16.8)</td>
<td>56 (17.6)</td>
<td>53 (16.6)</td>
<td>54 (15.7)</td>
<td>54 (16.4)</td>
<td>56 (17.8)</td>
</tr>
</tbody>
</table>

**Measures**

Table 2 presents the reliability and descriptive statistics of independent and dependent variables in this study. Reliance on expert sources was measured by asking participants to indicate the extent to which their major source of information about COVID-19 was government health departments, government administrations, official media, medical institutes, medical experts, family and friends who are doctors, or the World Health Organization and other health organizations outside China (1=strongly disagree, 7=strongly agree). Reliance on inexpert sources was assessed by the same question except that the sources were replaced with celebrities, social media influencers, family and friends who are not doctors, and other social contacts who are not doctors. The reliability of these two variables at all waves reached .7 or above, except for reliance on inexpert sources, which was .66 at wave 4.

Gore and Bracken’s [42] 7-point Likert scale (1=strongly disagree, 7=strongly agree) was adapted to measure perceived severity, perceived susceptibility, response efficacy, and self-efficacy in controlling COVID-19. Specifically, perceived severity was measured with three questions (“COVID-19 is a very serious disease/will pose a severe threat to my health/will pose a severe threat to others’ safety”), and perceived susceptibility was measured with two items (“My chance to get COVID-19 is high” and “I can get COVID-19 from others”). Response efficacy was assessed with two items (“modern medical knowledge can control COVID-19” and “COVID-19 can be cured as long as one follows doctors’ recommendations”), and self-efficacy was assessed with three items (“I can follow the recommended acts to protect myself from COVID-19,” “I have no difficulty in performing those protective behaviors that the government recommended,” “I can master how to perform recommended actions”). The reliability of these three variables reached .7 or above across all waves except for self-efficacy, which was .69 at wave 2.
Table 2. Cronbach alpha, means, and SDs of major variables.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>Wave 4</th>
<th>Wave 5</th>
<th>Wave 6</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>α</td>
<td>Mean (SD)</td>
<td>α</td>
<td>Mean (SD)</td>
<td>α</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Expert sources</td>
<td>.78</td>
<td>5.41 (0.85)</td>
<td>.79</td>
<td>5.61 (0.79)</td>
<td>.73</td>
<td>5.61 (0.68)</td>
</tr>
<tr>
<td>Inexpert sources</td>
<td>.70</td>
<td>4.00 (1.04)</td>
<td>.75</td>
<td>3.95 (1.04)</td>
<td>.75</td>
<td>3.84 (1.03)</td>
</tr>
<tr>
<td>Perceived severity</td>
<td>.80</td>
<td>6.09 (1.03)</td>
<td>.83</td>
<td>6.26 (0.99)</td>
<td>.78</td>
<td>6.10 (1.00)</td>
</tr>
<tr>
<td>Perceived susceptibility</td>
<td>.72</td>
<td>4.24 (1.56)</td>
<td>.73</td>
<td>4.30 (1.63)</td>
<td>.79</td>
<td>3.92 (1.59)</td>
</tr>
<tr>
<td>Response efficacy</td>
<td>.70</td>
<td>5.42 (1.18)</td>
<td>.80</td>
<td>5.28 (1.33)</td>
<td>.72</td>
<td>5.39 (1.17)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.77</td>
<td>5.89 (0.95)</td>
<td>.69</td>
<td>5.86 (0.90)</td>
<td>.71</td>
<td>5.83 (0.87)</td>
</tr>
<tr>
<td>Staying at home</td>
<td>N/Aa</td>
<td>4.10 (1.00)</td>
<td>N/A</td>
<td>4.15 (0.99)</td>
<td>N/A</td>
<td>3.99 (0.96)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>N/A</td>
<td>4.75 (0.89)</td>
<td>N/A</td>
<td>4.78 (0.81)</td>
<td>N/A</td>
<td>4.79 (0.78)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>N/A</td>
<td>4.72 (0.81)</td>
<td>N/A</td>
<td>4.80 (0.57)</td>
<td>N/A</td>
<td>4.75 (0.64)</td>
</tr>
</tbody>
</table>

aN/A: not applicable.

Personal engagement in protective measures was assessed through three 5-point Likert questions. Participants were asked how often they went out during the past 7 days (1=never, 2=once or twice, 3=three or four times, 4=five or six times, 5=seven times or more). We reverse coded participants’ response to this question, so the large number indicates staying at home more often. We also asked participants how often they wore a face mask and washed their hands during the past 7 days (1=never, 2=rarely, 3=sometimes, 4=often, 5=all the time). Again, larger numbers indicate higher frequency of wearing a face mask and washing hands.

Control variables were biological sex, age, education (recoded as 1=middle school or lower, 2=high school, 3=associate’s degree or higher), household monthly income, city of residence, self-rated health condition (1=very unhealthy, 5=very healthy), and knowledge. Knowledge was measured with 17 questions on the transmission of COVID-19, its medication, vulnerable population, and prevention methods. Participants received one point whenever they made a correct option. This made the maximum score 42 points.

Data Analysis

We employed the Kruskal-Wallis H test to examine if there was any difference between engagement in the three protective behaviors and if the level of engagement in these behaviors differed across time. In addition, we conducted repeated ordinal regression through SPSS 25 (IBM Corp) to test our predictions. At each wave, the dependent variables were entered into the model separately, along with control variables and independent variables. This analysis was repeated six times. Log odds ratios (ORs) and ORs along with their 95% CIs were reported to indicate the relationship between two variables.

The ordinal regression results are shown in the tables in the next section. Given the volume of these findings, results were presented separately with different sets of independent variables. Yet, ordinal regression was conducted with all independent variables listed in the tables.

Results

Engagement in Protective Behaviors

Table 3 presents results of the comparisons between engagement in three protective behaviors. Significant differences were found in staying at home across all waves ($\chi^2=110.01, P<.001$). However, no significant differences were found in wearing a face mask ($\chi^2=8.07, P=.15$) and washing hands ($\chi^2=10.81, P=.06$) across time. In addition, across all six waves, we found significant differences consistently in the level of engagement in all three behaviors (Table 3).
Table 3. Differences in engagement in three protective behaviors across time.

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>Wave 4</th>
<th>Wave 5</th>
<th>Wave 6</th>
<th>Chi-square (df)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staying at home, mean</td>
<td>4.10</td>
<td>4.15</td>
<td>3.99</td>
<td>3.76</td>
<td>3.60</td>
<td>3.57</td>
<td>110.01 (5)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Wearing a face mask, mean</td>
<td>4.75</td>
<td>4.78</td>
<td>4.79</td>
<td>4.81</td>
<td>4.80</td>
<td>4.70</td>
<td>8.07 (5)</td>
<td>.15</td>
</tr>
<tr>
<td>Washing hands, mean</td>
<td>4.72</td>
<td>4.80</td>
<td>4.75</td>
<td>4.70</td>
<td>4.74</td>
<td>4.68</td>
<td>10.81 (5)</td>
<td>.06</td>
</tr>
</tbody>
</table>

#### The Effects of Perceived Severity and Perceived Susceptibility

Table 4 presents how perceived severity and perceived susceptibility predicted engagement in the three protective behaviors across time. Perceived severity of COVID-19 predicted staying at home positively at waves 2 and 6 (Table 4). Individuals perceiving COVID-19 as more severe were more likely to wear a face mask at waves 1 and 5 (Table 4). The effect of perceived severity on washing hands was significant at waves 2, 4, 5, and 6 (Table 4). Conversely, perceived susceptibility to COVID-19 only predicted staying at home at waves 1 and 3, and both relationships were negative (Table 4). The effects of perceived susceptibility on wearing a face mask and washing hands were not significant.
Table 4. The effects of perceived severity and perceived susceptibility on engagement in protective behaviors across time.

<table>
<thead>
<tr>
<th>Time and protective behaviors</th>
<th>Perceived severity</th>
<th>Perceived susceptibility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Log OR* (95% CI)</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Wave 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.80 (0.69 to 0.93)</td>
<td>0.69 (0.66 to 1.06)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.46 (0.05 to 0.87)*</td>
<td>1.59 (1.06 to 2.39)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.31 (-0.04 to 0.66)</td>
<td>1.36 (0.96 to 1.93)</td>
</tr>
<tr>
<td>Wave 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.75 (0.53 to 1.04)</td>
<td>1.00 (1.02 to 2.17)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.86 (0.69 to 1.07)</td>
<td>1.69 (1.22 to 2.35)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.85 (0.68 to 1.06)</td>
<td>0.89 (0.70 to 1.12)</td>
</tr>
<tr>
<td>Wave 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.86 (0.69 to 1.07)</td>
<td>1.06 (0.70 to 1.60)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.93 (0.73 to 1.16)</td>
<td>0.05 (-0.36 to 0.47)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.90 (0.67 to 1.31)</td>
<td>1.36 (0.96 to 1.93)</td>
</tr>
<tr>
<td>Wave 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.94 (0.72 to 1.36)</td>
<td>0.86 (0.68 to 1.06)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.92 (0.67 to 1.25)</td>
<td>1.41 (0.92 to 2.17)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.85 (0.68 to 1.06)</td>
<td>1.00 (1.02 to 2.17)</td>
</tr>
<tr>
<td>Wave 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.91 (0.86 to 1.06)</td>
<td>1.12 (0.87 to 1.43)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.99 (0.87 to 1.18)</td>
<td>0.55 (0.12 to 0.98)*</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.90 (0.73 to 1.19)</td>
<td>0.37 (0.10 to 0.64)**</td>
</tr>
<tr>
<td>Wave 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>1.13 (0.87 to 1.43)</td>
<td>0.11 (-0.14 to 0.36)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.90 (0.73 to 1.16)</td>
<td>0.04 (-0.37 to 0.45)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.95 (0.69 to 1.31)</td>
<td>0.37 (0.10 to 0.64)**</td>
</tr>
</tbody>
</table>

*OR: odds ratio.

**P<.05.

The Effects of Response Efficacy and Self-Efficacy

Table 5 shows how response efficacy and self-efficacy affected engagement in protective actions across time. At wave 1, response efficacy predicted staying at home and washing hands positively (Table 5). After wave 1, its effect on protective behaviors became weak. Individuals who reported higher levels of response efficacy were more likely to stay at home at wave 2 and wash hands at wave 4 (Table 5). Response efficacy was not significantly associated with wearing a face mask at any time. Self-efficacy did not predict any protective behavior at any time.
Table 5. The effects of response efficacy and self-efficacy on engagement in protective behaviors across time.

<table>
<thead>
<tr>
<th>Time and protective behaviors</th>
<th>Response efficacy</th>
<th>Self-efficacy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Log OR* (95% CI)</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Wave 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.30 (0.08 to 0.52)**</td>
<td>1.35 (1.08 to 1.68)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>−0.01 (−0.42 to 0.41)</td>
<td>0.93 (0.69 to 1.27)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.36 (0.04 to 0.68)*</td>
<td>1.43 (1.04 to 1.97)</td>
</tr>
<tr>
<td>Wave 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.31 (0.11 to 0.50)**</td>
<td>1.36 (1.11 to 1.66)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.05 (−0.36 to 0.46)</td>
<td>1.05 (0.70 to 1.59)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.01 (−0.30 to 0.32)</td>
<td>1.01 (0.74 to 1.38)</td>
</tr>
<tr>
<td>Wave 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.08 (−0.13 to 0.28)</td>
<td>1.08 (0.88 to 1.32)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>−0.07 (−0.48 to 0.35)</td>
<td>0.94 (0.62 to 1.42)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>−0.14 (−0.43 to 0.15)</td>
<td>0.87 (0.65 to 1.17)</td>
</tr>
<tr>
<td>Wave 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>−0.09 (−0.27 to 0.08)</td>
<td>0.91 (0.77 to 1.09)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.25 (−0.09 to 0.58)</td>
<td>1.28 (0.92 to 1.79)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.26 (0.01 to 0.51)*</td>
<td>1.30 (1.01 to 1.66)</td>
</tr>
<tr>
<td>Wave 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.18 (−0.04 to 0.39)</td>
<td>1.19 (0.96 to 1.48)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.15 (−0.27 to 0.58)</td>
<td>1.17 (0.76 to 1.78)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.02 (−0.29 to 0.33)</td>
<td>1.02 (0.75 to 1.39)</td>
</tr>
<tr>
<td>Wave 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.03 (−0.20 to 0.25)</td>
<td>1.03 (0.82 to 1.28)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>−0.13 (−0.52 to 0.27)</td>
<td>0.88 (0.59 to 1.31)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>−0.09 (−0.40 to 0.23)</td>
<td>0.92 (0.67 to 1.25)</td>
</tr>
</tbody>
</table>

*OR: odds ratio.  
*P<.05.  
**P<.01.

The Effects of Reliance on Expert Versus Inexpert Sources

Table 6 demonstrates how individuals’ reliance on expert versus inexpert sources for information about COVID-19 might affect their engagement in the three protective actions across time. Reliance on expert sources did not predict engagement in any protective behaviors at wave 1, and only predicted wearing a face mask at wave 2 (Table 6). Starting from wave 3, the facilitating effect of expert sources became more prominent. Specifically, reliance on expert sources predicted staying at home positively at waves 3 and 4 (Table 6). In addition to wave 2, individuals relying on expert sources for information about COVID-19 were more likely to wear a face mask at waves 4, 5, and 6 (Table 6). The relationship between reliance on expert sources and washing hands was significant at waves 3, 4, 5, and 6 (Table 6).

The effect of reliance on inexpert sources on protective behaviors was more limited. Reliance on inexpert sources exhibited a negative effect on staying at home at wave 2 (Table 6). Individuals relying on inexpert sources were less likely to wear a face mask at wave 2 and wash hands at wave 5 (Table 6).
### Table 6. The effects of reliance on expert versus inexpert sources on engagement in protective behaviors across time.

<table>
<thead>
<tr>
<th>Time and protective behaviors</th>
<th>Expert sources</th>
<th>Inexpert sources</th>
<th>Expert sources</th>
<th>Inexpert sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Log OR(^a) (95% CI)</td>
<td>OR (95% CI)</td>
<td>Log OR (95% CI)</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td><strong>Wave 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.06 (–0.25 to 0.37)</td>
<td>1.06 (0.78 to 1.45)</td>
<td>0.04 (–0.18 to 0.25)</td>
<td>1.04 (0.84 to 1.28)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>–0.06 (–0.71 to 0.60)</td>
<td>0.94 (0.49 to 1.81)</td>
<td>–0.22 (–0.66 to 0.22)</td>
<td>0.80 (0.52 to 1.24)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.33 (–0.16 to 0.82)</td>
<td>1.39 (0.85 to 2.28)</td>
<td>–0.34 (–0.72 to 0.05)</td>
<td>0.71 (0.49 to 1.05)</td>
</tr>
<tr>
<td><strong>Wave 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.34 (–0.01 to 0.69)</td>
<td>1.40 (0.99 to 1.99)</td>
<td>–0.25 (–0.49 to –0.02) (^*)</td>
<td>0.78 (0.62 to 0.99)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.68 (0.01 to 1.34) (^*)</td>
<td>1.97 (1.01 to 3.83)</td>
<td>–0.50 (–0.97 to –0.03) (^*)</td>
<td>0.61 (0.38 to 0.97)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.39 (–0.13 to 0.92)</td>
<td>1.48 (0.87 to 2.51)</td>
<td>–0.27 (–0.65 to 0.12)</td>
<td>0.77 (0.52 to 1.12)</td>
</tr>
<tr>
<td><strong>Wave 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.50 (0.11 to 0.89) (^*)</td>
<td>1.64 (1.11 to 2.42)</td>
<td>–0.20 (–0.43 to 0.03)</td>
<td>0.83 (0.65 to 1.03)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.64 (–0.12 to 1.40)</td>
<td>1.89 (0.89 to 4.05)</td>
<td>–0.06 (–0.48 to 0.36)</td>
<td>0.94 (0.62 to 1.43)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.76 (0.21 to 1.30) (^**)</td>
<td>2.13 (1.23 to 3.68)</td>
<td>–0.15 (–0.48 to 0.17)</td>
<td>0.86 (0.62 to 1.19)</td>
</tr>
<tr>
<td><strong>Wave 4</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.49 (0.17 to 0.82) (^**)</td>
<td>1.64 (1.18 to 2.27)</td>
<td>–0.10 (–0.34 to 0.14)</td>
<td>0.91 (0.71 to 1.15)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.82 (0.20 to 1.44) (^*)</td>
<td>2.26 (1.22 to 4.22)</td>
<td>–0.34 (–0.89 to 0.20)</td>
<td>0.71 (0.41 to 1.23)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.96 (0.50 to 1.42) (^***)</td>
<td>2.61 (1.65 to 4.12)</td>
<td>–0.04 (–0.39 to 0.31)</td>
<td>0.96 (0.68 to 1.36)</td>
</tr>
<tr>
<td><strong>Wave 5</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.01 (–0.34 to 0.35)</td>
<td>1.01 (0.71 to 1.42)</td>
<td>–0.08 (–0.30 to 0.14)</td>
<td>0.92 (0.74 to 1.15)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.64 (0.09 to 1.20) (^*)</td>
<td>1.90 (1.09 to 3.30)</td>
<td>–0.35 (–0.80 to 0.11)</td>
<td>0.71 (0.45 to 1.11)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.59 (0.13 to 1.05) (^*)</td>
<td>1.80 (1.14 to 2.85)</td>
<td>–0.37 (–0.71 to –0.03) (^*)</td>
<td>0.69 (0.49 to 0.97)</td>
</tr>
<tr>
<td><strong>Wave 6</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying at home</td>
<td>0.08 (–0.30 to 0.46)</td>
<td>1.08 (0.74 to 1.58)</td>
<td>–0.22 (–0.44 to 0.003)</td>
<td>0.80 (0.64 to 1.00)</td>
</tr>
<tr>
<td>Wearing a face mask</td>
<td>0.64 (0.09 to 1.19) (^*)</td>
<td>1.90 (1.10 to 3.28)</td>
<td>–0.19 (–0.54 to 0.16)</td>
<td>0.83 (0.58 to 1.17)</td>
</tr>
<tr>
<td>Washing hands</td>
<td>0.74 (0.27 to 1.22) (^**)</td>
<td>2.10 (1.31 to 3.39)</td>
<td>–0.05 (–0.34 to 0.24)</td>
<td>0.95 (0.71 to 1.28)</td>
</tr>
</tbody>
</table>

\(^a\)OR: odds ratio.  

\(^*\)P < .05.  

\(^**\)P < .01.  

\(^***\)P < .001.

### The Effects of Control Variables

Knowledge did not predict staying at home at any time. Individuals equipped with more knowledge were more likely to wear a face mask at wave 3 (OR 1.14, 95% CI 1.05-1.25; P < .01). The relationship between knowledge and washing hands was only significant and positive at wave 3 (OR 1.14, 95% CI 1.05-1.25; P < .01). The relationship between knowledge and washing hands was only significant and positive at wave 3 (OR 1.09, 95% CI 1.02-1.17; P < .05) and wave 6 (OR 1.08, 95% CI 1.01-1.15; P < .05).

The self-rated health condition predicted wearing a face mask (OR 2.21, 95% CI 1.27-3.85; P < .01) and washing hands positively at wave 4 (OR 1.63, 95% CI 1.10-2.41; P < .05). At wave 6, the relationship between self-rated health condition and staying at home was positive (OR 1.43, 95% CI 1.02-2.00; P < .05).

Income predicted staying at home negatively at wave 3 (OR 0.77, 95% CI 0.64-0.93; P < .01), wave 4 (OR 0.81, 95% CI 0.67-0.97; P < .05), and wave 6 (OR 0.83, 95% CI 0.69-1.00; P < .01). Individuals with a greater household monthly income were more likely to wear a face mask at wave 1 (OR 1.67, 95% CI 1.19-2.35; P < .01), wave 2 (OR 1.49, 95% CI 1.02-2.17; P < .05), wave 4 (OR 1.47, 95% CI 1.00-2.16; P < .05), and wave 6 (OR 1.43, 95% CI 1.08-1.89; P < .05). The relationship between income and washing hands was positive at wave 1 (OR 1.37, 95% CI 1.04-1.79; P < .05) and wave 4 (OR 1.37, 95% CI 1.06-1.77; P < .05).

Compared to women, men washed hands less often at wave 4 (OR 0.38, 95% CI 0.20-0.72; P < .01), wave 5 (OR 0.43, 95% CI 0.23-0.80; P < .01), and wave 6 (OR 0.50, 95% CI 0.28-0.92; P < .05). Age predicted washing hands positively at wave 1 (OR 1.04, 95% CI 1.01-1.08; P < .05), wave 4 (OR 1.06, 95% CI 1.02-1.09; P < .01), and wave 6 (OR 1.04, 95% CI 1.00-1.07; P < .05). At wave 4, participants with a high school degree
washed hands less often than those with an associate’s degree or above (OR 0.36, 95% CI 0.15-0.89; P<.05).

When it comes to city differences, residents in Wuhan, where COVID-19 cases were first discovered, were used as the reference group. No significant difference was found in wearing a face mask and washing hands across all waves, except that residents in Beijing reported to wear a face mask more often than those in Wuhan (OR 9.69, 95% CI 1.09-86.38; P<.05). However, residents in Wuhan stayed at home more often than those in the other cities at most times, as Tables 7 and 8 shows.

### Table 7. City differences in staying at home waves 1, 2, and 3 (Wuhan was used as the reference group).

<table>
<thead>
<tr>
<th>City</th>
<th>Wave 1 (Log OR, 95% CI)</th>
<th>Wave 2 (Log OR, 95% CI)</th>
<th>Wave 3 (Log OR, 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beijing</td>
<td>–0.62 (–1.38 to 0.13)</td>
<td>0.54 (0.25 to 1.14)</td>
<td>0.17 (0.08 to 0.39)</td>
</tr>
<tr>
<td>Shanghai</td>
<td>–0.99 (–1.75 to –0.22)*</td>
<td>0.37 (0.17 to 0.80)</td>
<td>0.18 (0.08 to 0.40)</td>
</tr>
<tr>
<td>Guangzhou</td>
<td>–0.87 (–1.62 to –0.11)*</td>
<td>0.42 (0.20 to 0.89)</td>
<td>0.17 (0.08 to 0.40)</td>
</tr>
<tr>
<td>Shenzhen</td>
<td>–0.15 (–1.93 to –0.36)**</td>
<td>0.32 (0.15 to 0.70)</td>
<td>0.21 (0.09 to 0.47)</td>
</tr>
<tr>
<td>Hangzhou</td>
<td>–1.01 (–1.77 to –0.25)**</td>
<td>0.37 (0.17 to 0.78)</td>
<td>0.27 (0.11 to 0.62)</td>
</tr>
</tbody>
</table>

*OR: odds ratio.  
*P<.05.  
**P<.01.  
***P<.001.

### Table 8. City differences in staying at home waves 4, 5, and 6 (Wuhan was used as the reference group).

<table>
<thead>
<tr>
<th>City</th>
<th>Wave 4 (Log OR, 95% CI)</th>
<th>Wave 5 (Log OR, 95% CI)</th>
<th>Wave 6 (Log OR, 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beijing</td>
<td>–1.26 (–2.02 to –0.51)**</td>
<td>0.28 (0.13 to 0.60)</td>
<td>0.87 (0.41 to 1.84)</td>
</tr>
<tr>
<td>Shanghai</td>
<td>–1.35 (–2.11 to –0.58)**</td>
<td>0.26 (0.12 to 0.56)</td>
<td>0.53 (0.25 to 1.15)</td>
</tr>
<tr>
<td>Guangzhou</td>
<td>–1.35 (–2.07 to –0.64)**</td>
<td>0.26 (0.13 to 0.53)</td>
<td>0.28 (0.13 to 0.59)</td>
</tr>
<tr>
<td>Shenzhen</td>
<td>–1.25 (–2.02 to –0.48)**</td>
<td>0.29 (0.13 to 0.62)</td>
<td>0.48 (0.24 to 0.99)</td>
</tr>
<tr>
<td>Hangzhou</td>
<td>–1.75 (–2.52 to –0.98)**</td>
<td>0.17 (0.08 to 0.38)</td>
<td>0.36 (0.17 to 0.74)</td>
</tr>
</tbody>
</table>

*OR: odds ratio.  
*P<.05.  
**P<.01.  
***P<.001.

### Summary

Despite inconsistencies, some patterns still emerged. First, reliance on expert sources encouraged protective behaviors, but this effect did not emerge until wave 3 and was stronger on wearing a face mask and washing hands. Second, the discouraging effect of reliance on inexpert sources was limited to wave 2 except that it predicted washing hands negatively at wave 5. In addition, perceived severity exhibited a stronger effect on protective behaviors than perceived susceptibility. Furthermore, self-efficacy was not associated with engaging in protective behaviors, whereas the effect of response efficacy was limited to waves 1 and 2. Among all control variables, the effect of knowledge was limited, whereas the city of residence exhibited a stronger effect on staying at home.

### Discussion

#### Principal Findings

The COVID-19 pandemic triggered research on what factors affected individuals’ engagement in protective behaviors [7-12]. This study is built upon EPPM, a theoretical framework that explains how risk perception and efficacy appraisal might affect individuals’ engagement in protective behaviors [13]. In addition, given the volume of misinformation about preventive measures against COVID-19 [33], we extended EPPM and the...
extant research on protective actions against COVID-19 by recognizing the value of accurate information and considering Chinese individuals’ reliance on expert versus inexpert information sources. Further, differences across time and between three target behaviors were also revealed. The patterns of our findings previously summarized provide important implications on health education and suggest the intertwined relationship between one’s health behavior and the sociocultural system where these individuals reside.

First, we found that perceived severity could encourage protective behaviors, but their effects were not consistent and different depending on the specific behavior. Taken as a whole, perceived severity predicted washing hands positively at waves 2, 4, 5, and 6, more consistently than wearing a face mask (waves 1 and 5) and staying at home (waves 2 and 6). The inconsistency might be related to the executive orders that the Chinese government issued, which forced individuals to wear a face mask in public and placed them in quarantine [13]. Therefore, in this study, wearing a face mask and staying at home were not entirely autonomous decisions but more because of compliance with the executive orders. However, washing hands was not required, and it was impossible to ensure that everyone washed their hands as recommended. Thus, how often individuals washed their hands was likely derived from their evaluation of the risk.

Surprisingly, perceived susceptibility predicted staying at home negatively at waves 1 and 3. The post hoc analysis found that at both waves the common predictor of perceived susceptibility was self-rated health condition (wave 1: OR 0.72, 95% CI 0.56-0.92; P<.05; wave 3: OR 0.65, 95% CI 0.50-0.86; P<.01), and older participants reported a worse health condition (wave 1: OR 0.97, 95% CI 0.95-0.99; P<.01; wave 3: OR 0.95, 95% CI 0.93-0.97; P<.001). Therefore, among older participants, there might be a gap between risk perception and behavior. Although they realized that they could be subject to COVID-19, they still went out. This suggests that health education for seniors should focus on bridging the perception-behavior gap.

Overall, the effect of perceived susceptibility on protective behaviors was minimal. However, the impact of perceived susceptibility should not be dismissed. For example, protection motivation theory contends that human behavior is a function of the perceived severity of the threat, perceived susceptibility to the threat, and response efficacy, and no behavior is performed if any of these predictors are zero [14]. Although more empirical evidence is needed to understand whether health education in China during the pandemic lacks information on susceptibility, this result suggested that subsequent education should highlight the chance that certain populations are vulnerable to the pandemic.

In addition to risk perceptions, our results showed that response efficacy only predicted staying at home at waves 1 and 2, and washing hands at wave 1. Hence, at the early stage of the outbreak, individuals engaged in preventive measures because perhaps they believed these actions were effective to protect them against the given threat. This suggests that practitioners may want to adjust the emphasis of health education as time passes. Specifically, elevating response efficacy of the target audience may be important at the early stage of the outbreak.

By contrast, self-efficacy did not predict any protective behavior at any time. One possible reason is that our measure of self-efficacy addressed overall confidence in performing preventive measures instead of specific preventive actions. However, there might be differences in the level of difficulty in performing these three protective behaviors. Thus, our measure might not have assessed this subtle difference.

It is important to note that EPPM research tends to test the aggregate effects of perceived severity and perceived susceptibility as well as response efficacy and self-efficacy on protective behaviors [18,21,22,42,43]. However, we demonstrated the separate effects of these variables, and we found their distinct effects. This suggests that perceived severity versus perceived susceptibility (response efficacy vs self-efficacy) may be essentially different, which needs further study.

In addition to testing EPPM, our results demonstrated how reliance on expert versus inexpert sources might affect Chinese individuals’ engagement in protective actions. Our findings reveal that the positive effect of expert sources did not emerge until wave 3 when most businesses restarted [39]. The post hoc analysis found that, controlling for knowledge, self-rated health condition, and demographic variables, reliance on expert sources at wave 1 was significantly lower than all other waves (wave 2: OR 2.26, 95% CI 1.72-2.98; P<.001; wave 3: OR 1.56, 95% CI 1.19-2.04; P<.01; wave 4: OR 1.75, 95% CI 1.34-2.29; P<.001; wave 5: OR 1.54, 95% CI 1.17-2.02; P<.01; wave 6: OR 1.57, 95% CI 1.20-2.06; P<.01). One explanation is that it took time for the Chinese public to develop trust in these expert sources and follow the messages that these sources delivered. Expert sources in China, such as official media and health departments, are under strict control by the Chinese government, which was blamed for their failure to provide timely responses to COVID-19 during its early outbreak. This might have affected Chinese individuals’ trust in these expert sources given their close connection with the government. However, the aggressive actions that the government took controlled the spread of the pandemic and made the number of cases start to decline in late February 2020 [3,13]. Therefore, at wave 3, which started in early March, Chinese individuals might have gained more trust in these expert sources, making them more willing to comply with the recommendations that these sources offered. This suggests that individuals’ trust in information sources may exhibit a critical impact on their health behavior. Furthermore, this finding suggests that the conventional approach to persuading the public to engage in protective behaviors during the pandemic, which centers on knowledge provision, may not be effective. A more important mission might be to help the public develop trust in the community of public health practitioners including those working for the government. Therefore, a perspective of public relations is needed in future research and practices on health education.

In contrast, reliance on inexpert sources did not affect protective behaviors most of the time, except that these sources discouraged preventive measures at wave 2. This shows that
our participants might have realized the risks of inexpert sources in information provision, so they did not follow this information. Although these findings are promising, information literacy should still be a focus of future health education and campaigns, especially those vulnerable to health misinformation, such as seniors and less educated individuals.

Additionally, the significant effect of reliance on inexpert sources was limited to wave 2. One possible explanation is that the public interest changed as time passed. In January and February 2020, the public may have been concerned about how to control and treat COVID-19. However, the restart of businesses might have signaled that the pandemic was under control. By then, individuals may have been more concerned about economic recession and recovery. Hence, after wave 2, the focus of the information exchanged between inexpert sources might have changed, which made reliance on these sources not significantly related to taking preventive measures.

Finally, the effects of several control variables warrant discussion. The impact of knowledge on protective behaviors was limited, and residents in Wuhan stayed at home more than participants in other cities at most times. These two findings can be explained by the influence of executive orders. The lockdown of Wuhan lasted more than 2 months, so naturally, participants from Wuhan stayed at home more. Additionally, the limited influence of knowledge suggests that Chinese individuals’ engagement in protective behaviors might not be a result of their autonomous decisions but compliance with executive orders. Although this approach to behavior change controlled the spread of COVID-19 in China [3,13], the duration of its effect is questionable, which future research needs to investigate.

Limitations and Future Research

These findings must be interpreted with several caveats. First, the cross-sectional nature of this study makes it impossible to build causal relationships between variables. Second, our study uses self-reported data. This method relies on participants’ memory and can be subject to social desirability.

In addition, as previously explained, Chinese individuals performed these protective actions partly because of their compliance with strict law enforcement and executive orders issued by China’s government. This might explain why our participants’ responses to questions measuring their engagement in protective behaviors were skewed. Furthermore, this might affect the validity of responses that our participants provided. Hence, social desirability must be considered when results are interpreted.

Although we matched the age and the education level of our sample to the national population in China, the generalizability of our sample may still be a limitation. Moreover, the proportions of education and age did not match the national population at all waves. The significant differences in education, income, and age between waves might have introduced additional variances and affected the validity of our results.

This study was conducted in China during the COVID-19 pandemic. This particular timing and geographic location might limit the generalizability of our results. Cross-cultural comparisons and longitudinal observations can be valuable directions for future research.

Our measures of self-efficacy and knowledge could also affect the validity of our findings. As mentioned earlier, the measure of self-efficacy did not specify the preventive behavior. Moreover, we self-created our scale of knowledge based on relevant information from the media. Established measures based on a manual provided by health departments would be more valid.

It is important to note that our definition of risk perception was limited to cognitive appraisal, which may dismiss the effect of affective responses. Future inquiries are needed to understand how cognitive and affective appraisals of risks may affect individuals’ engagement in protective behaviors during the pandemic.

Finally, as argued earlier, whether Chinese individuals engaged in protective behavior might partly be a result of strict executive orders. Thus, Chinese individuals’ attitude toward the political system may play a part in their engagement in protective behaviors against COVID-19. This implication may also apply in other countries such as the United States, where pandemic control has been politicalized [44,45]. Therefore, future research may need to examine how variables such as political interest and political orientation may affect one’s health behavior.

Conclusion

This study provides empirical evidence on what affected Chinese individuals’ engagement in protective behaviors against COVID-19 between February and April 2020. Given the authoritarian political system in the media, Chinese individuals’ engagement in protective behavior might not be an entirely autonomous decision but a result of compliance with executive orders. Our findings demonstrate that expert sources did not encourage protective behaviors until the early stage passed, suggesting that it might take time to develop trust in expert sources. Therefore, the effect of health education may depend on information as well as the relationship between practitioners and the public. This suggests that a perspective of public relations should be considered in future research. In addition, perceived severity could motivate some protective measures, but its effect differed depending on the specific behavior. Furthermore, the facilitating effect of perceived severity lasted throughout the duration of the pandemic but that of response efficacy was limited to the early stage. Hence, practitioners may want to adjust the emphasis of health campaigns depending on the stage of the pandemic.

Acknowledgments

This work was supported by the Department of Education in Guangdong Province under grant 2019SFKC06.
Conflicts of Interest

None declared.

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Abbreviations

**EPPM**: extended parallel process model

**OR**: odds ratio