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e-Learning for the elderly on drug utilization: A pilot study

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Abstract

This study explores the attitudes of elderly people to the use of electronic educational technology (e-learning) on drug utilization, with particular emphasis on the layout, usability, content, and level of knowledge in the tool. e-Learning modules were evaluated by a group of elderly people (aged ≥65 years, n = 16) via a questionnaire comprising closed and open-ended questions. Both qualitative and quantitative analyses of the responses showed mostly positive reviews. The results indicate that the e-learning modules are a suitable tool for distributing information and education and that they can be managed by elderly individuals who are familiar with computers, allowing them to learn more about medication use.

Keywords

aged, computer-assisted instruction, drug utilization, education, e-learning

Introduction

Medication is an important part of health care, contributing to an improved quality of life for many elderly people. In Sweden, most people aged 70–79 years use one or more medicines regularly, while about half of those aged 80–89 years use five or more medicines regularly.[1] The elderly often have complex problems associated with age-related changes in pharmacokinetics and pharmacodynamics, multi-morbidity resulting in increased sensitivity to drugs, and a greater risk of adverse drug reactions.[2] Special attention should therefore be given to the treatment of elderly people with

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medications. Drug-related problems cause unnecessary suffering in this age group and are associated with high costs to society.[3]

The Swedish Council on Health Technology Assessment in Health Care and the Swedish National Board of Health and Welfare have stated that improvements are required in the prescription of medications for the elderly and in the use of medication by the elderly, and that education and information are one factor that could contribute to this.[2,3]

The proportion of elderly individuals in the Swedish population has increased during recent decades and will continue to increase.[4] Many elderly people in Sweden have access to the Internet at home and use computers. According to Statistics Sweden, 87 percent of Swedish men and women in the age range 65–74 years had home access to the Internet during 2014.[5] Age and education correlate with usage of the Internet; the older old (≥78 years) use the Internet the least.[6] In the future, however, it is anticipated that older people will use the Internet and computers to a greater extent.[7]

In the United States, a national campaign to provide information for the elderly and their caregivers has been introduced. It consists of web-based information, useful links, and slide shows about the use of medications by older adults. The website is titled Medication Use Safety Training (MUST) for Seniors, and the site was developed by the National Council on Patient Information and Education, Maryland, USA. The website encourages individuals to learn more about specific areas that interest them.[8] Alternative outlets for web-based information are electronic educational technology (e-learning) or multimedia education.

Several projects underway in Sweden have the goal of educating elderly people about medical treatment and related areas through e-learning and face-to-face meetings. The project “Awareness about medicines” (Koll på Läkemedel) is a collaboration between two pensioners’ associations (the Swedish Pensioners Association (Svenska pensionärsförbundet seniorerna (SPF)) and the Swedish National Pensioners’ Organisation (Pensionärernas riksorganisation (PRO))) and the Swedish national pharmaceuticals company (Apoteket AB) which allows older people to learn more about appropriate medical treatment.[9] The project “Feeling well with or without medicines” (Må bra—med eller utan läkemedel) focuses on the health and welfare of the elderly and is a collaboration among 10 municipalities in Sweden. This project uses face-to-face group meetings about different themes in the area of health and medication.[10]

e-Learning sites about medication use that are designed for and adapted to the specific needs and requirements of the elderly are not very common. However, a study in elderly people (≥65 years) in Korea showed that self-efficacy and knowledge about the safe use of medication were greater in those who used interactive e-learning techniques plus an information booklet than in those who only received the information booklet or no information at all.[11] Self-efficacy and knowledge about drug interactions were also better in a group with access to e-learning than in a control group without access to e-learning.[12]

Many studies involving e-learning and multimedia have included participants of all ages, without being restricted to the elderly.[13] Positive results have been seen in this respect in studies of web-based interventions for patients with diabetes, HIV, or hypertension.[14–16] e-Learning about medications seems to be more effective than usual care or no education at all, but further research is needed to increase confidence about the effects of different interventions, including e-learning, for educating patients about prescribed and over-the-counter medications.[13] e-Learning has been found to increase knowledge of heart failure treatment more than traditional teaching alone.[17] More extended studies are required in order to evaluate the retention of the new knowledge over time, although another study in patients with heart failure found that interactive e-learning was superior to traditional face-to-face education with respect to treatment knowledge after both 1 and 6 months.[18]

Available education methods about medication for the elderly often entail face-to-face meetings in groups, which can be a problem for the elderly because of mobility problems, illnesses, lack of transportation, and scheduled meetings at times that do not suit. The advantages of web-based education methods are that it is easier to keep them up-to-date than written information and they are cost effective. However, it is acknowledged that some elderly people do not have access to the Internet at home,[5] which would tend to exclude these individuals from participating.

The purpose of this study was to explore the attitudes of elderly people to the e-learning modules in the field of drug utilization, with particular emphasis on layout, usability, relevance, and level of knowledge of the content.

Methods

This study evaluated e-learning modules that had been designed and adapted for use by the elderly. Initially, a prototype was developed, evaluated, and validated by a small test group. A revised version of the prototype was then evaluated by asking a group of elderly people to fill out a questionnaire.

The regional ethical board in Linköping, Sweden, approved the study (no. 2012/351-31).

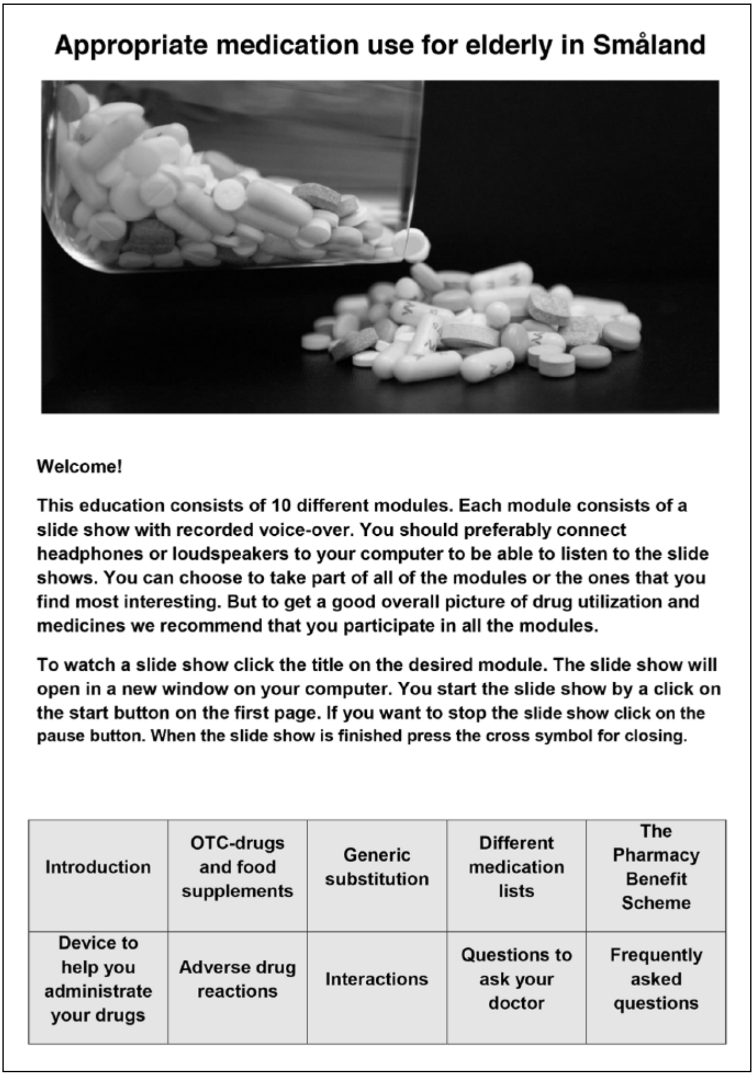
Intervention and e-learning modules

The topics to be included in the modules were selected in collaboration with pharmacists by screening questions that were frequently asked by elderly patients in hospital wards or when visiting their pharmacy. The following topics were selected: Introduction, Over-the-counter medication and food supplements, Generic substitution, Different medication lists, The Pharmacy Benefit Scheme, Devices to help you administrate your drugs, Adverse drug reactions, Interactions, Questions to ask your doctor, and Frequently asked questions.

During the development of the e-learning modules, a participatory design was used; user representatives have been involved from the start both in the design process and in the evaluation process. The main focus in working with the user representatives was subjective satisfaction, which refers to how pleasant it is to use the system.[19] The choice of tool and design of the e-learning modules focused on simplicity and accessibility. It was assumed that the target group of elderly would not have a high level of digital skills and could have impaired hearing or vision. The e-learning modules were designed based on these assumptions, taking into account the size of the text, adequate color contrasts, and the addition of audio. The audio was added to ease participation for those with problems associated with reading text on the screen. Guidelines from the Swedish Association for the Visually Impaired were used to help design the layout in the e-learning modules.[20]

The first version was developed in Power Point (Microsoft, Redmond). This version consisted of slide shows about drugs and drug utilization, with informative text and pictures. In the next version, Slide Rocket (ClearSlide, San Francisco) was used to produce the presentations. WordPress (General Public License) was used to publish the final version of the material on the Internet, with the focus on appearance, web standards, and usability. The website housing the e-learning modules included a short presentation of the research project itself, an introduction on how to use the education tool and some useful links, as well as links to the slide show modules. Figure 1 shows a representative page from the website.

The use of the Internet allowed flexible learning, that is, participants were able to choose the time and place that suited them, and to repeat the lesson as required. Thus, this tool requires access to a computer and the Internet.



Appropriate medication use for elderly in Småland

Welcome!

This education consists of 10 different modules. Each module consists of a slide show with recorded voice-over. You should preferably connect headphones or loudspeakers to your computer to be able to listen to the slide shows. You can choose to take part of all of the modules or the ones that you find most interesting. But to get a good overall picture of drug utilization and medicines we recommend that you participate in all the modules.

To watch a slide show click the title on the desired module. The slide show will open in a new window on your computer. You start the slide show by a click on the start button on the first page. If you want to stop the slide show click on the pause button. When the slide show is finished press the cross symbol for closing.

Introduction	OTC-drugs and food supplements	Generic substitution	Different medication lists	The Pharmacy Benefit Scheme
Device to help you administrate your drugs	Adverse drug reactions	Interactions	Questions to ask your doctor	Frequently asked questions

Figure 1. A sample page from the e-learning website.

The three County Councils in the southeast of Sweden were contacted to ensure that no interfering interventions were addressed to the target group (elderly people aged ≥65 years; approximately 760,000 inhabitants).

Initial evaluation

After being published on the Internet, the e-learning modules were evaluated during a test period (February to March 2013) by four people (two men and two women) in the age range of 64–71 years. This test group evaluated the modules with a focus on usability, appearance, and relevance. Thereafter, experts ($n = 5$) in pharmacy, e-learning, health informatics, web design, and drug informatics also reviewed the content. Representatives from two pensioners' associations also expressed their opinions on the content of the modules during the test period. The collected opinions were evaluated and included as appropriate in the e-learning modules.

Final evaluation

The revised e-learning modules were evaluated during the period from April to June 2013. Most of the participants (10/16) were using the modules at a center where they had access to computers. The researcher was present during the session and could observe that the participants actually used the modules. The remaining participants (6/16) used the modules on their own without superintendence. After studying the modules, the participants were asked to fill in a questionnaire on the content, layout, and level of knowledge of the modules, and on their computer skills and background data. Informed consent was obtained from the participants.

The participants were asked to fill in the questionnaire within 2 weeks of agreeing to participate in the study. However, illness, journeys, and changes of residency meant that the questionnaires were actually completed between 2 and 5 weeks from the date of inclusion.

Participants

The test group of elderly people was recruited from three sites: a patient association, a pensioners' association, and a primary care center. A project member contacted the elderly individuals in person and asked them whether they would like to participate in the study. The same approach was used at all three sites. The inclusion criteria were as follows: age ≥65 years and access to a computer and the Internet. Exclusion criteria were as follows: low vision, impaired hearing, poor understanding of the Swedish language, and cognitive impairment.

The use of an age of ≥65 years to define the term elderly was based on the general definition of elderly in literature from the Swedish National Board of Health and Welfare.[2]

Questionnaire

The questionnaire comprised 23 questions, including open-ended questions and questions on the participant's background. A six-point Likert-type rating scale with each point labeled was used, where 1 represented "do not agree" and 6 represented "fully agree." A "no opinion/do not know" option was also available so that the participants did not have to answer any question they were uncomfortable with.[21]

During the initial stage, the questionnaire was evaluated with respect to content validity and face validity.[22] The initial test group were instructed to evaluate the appropriateness and relevance of the questions (i.e. content validity), and the appearance of the questionnaire in terms of readability by looking at formatting, layout, and clarity of wording (i.e. face validity).[23] Some small changes were made at this stage to the original version of the questionnaire.

Quantitative analysis

The results of the questionnaires were analyzed using frequency analysis on an ordinal scale. In order to enhance the readability of the results the six-point scale was collapsed to three categories when analyzed: disagree (1–2), neutral (3–4), and agree (5–6).

Qualitative analysis

The open-ended questions were analyzed by qualitative content analysis in line with the conceptual framework developed by Krippendorff.[24] The manifest content in the open-ended questions was

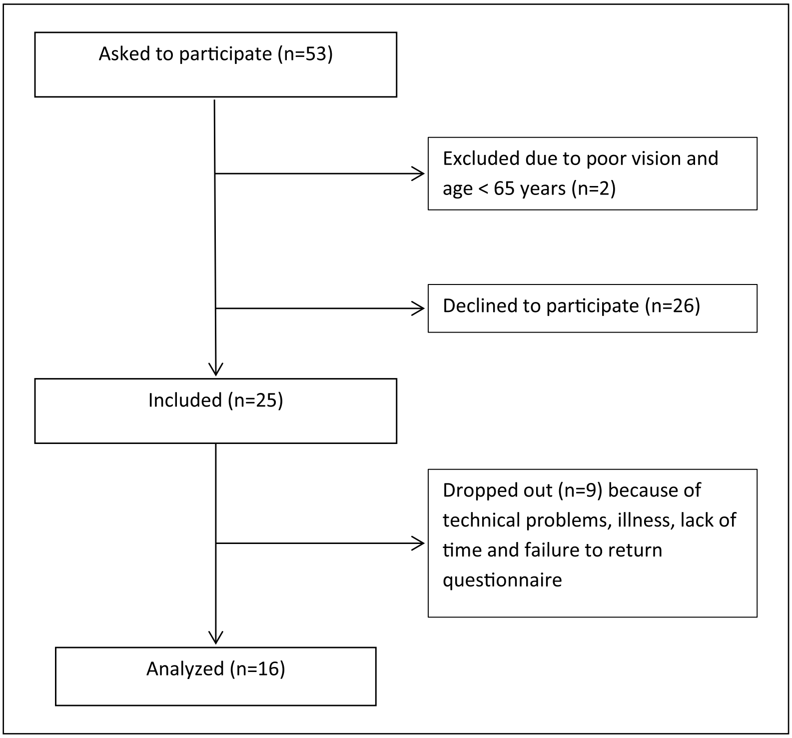


Figure 2. Flow diagram showing the participants in the study.

analyzed with an inductive approach which contained open coding followed by categorization and abstraction. The categories were stated with citations from the participants.[25]

The entire text from each participant in response to the open-ended questions was regarded as a meaning unit from which codes and categories were constructed. The definitions of the text units (meaning units, codes, and categories) were defined according to Graneheim and Lundman.[26]

After reading the text twice, the first author carried out the initial analysis and constructed meaning units, codes, and categories. Subsequently, the first and second authors read the text and discussed the coding and analysis decisions in analytical sessions to reach consensus. Finally, the fifth author checked the adequacy of the complete analysis.

Results

Study participants

A total of 53 elderly people were invited to participate in the study. Of these, 16 (3 males and 13 females) completed the education modules and the questionnaire, corresponding to a response rate of 30 percent. A participant flow diagram is presented in Figure 2.

The age distribution among the respondents was as follows: three aged 66–70 years, five aged 71–75 years, five aged 76–80 years, one aged 81–85 years, and two aged 86–90 years. The mean age among the men was 79 years and among the women was 75 years. The highest levels of education among the respondents were as follows: seven left after primary school, six left after high school, two achieved college degrees, and one attended another education facility. The median

Table 1. Summary of responses from participants (n = 16) showing the frequency and proportion of agreement (on a six-point Likert-type rating scale) with 12 statements concerning the web-based education tool, where 1–2 represents "disagree," 3–4 represents "neutral," and 5–6 represents "agree."

Questions from the evaluation questionnaire	Disagree (1–2)	Neutral (3–4)	Agree (5–6)
1. I think that the appearance of the text is easy to read	0	2 (13%)	13 (81%)
2. I think that it is easy to hear the information as spoken	0	3 (19%)	12 (75%)
3. I think that the images in the training material are simple and easy to understand	0	1 (6%)	14 (88%)
4. I think that the training material is too long	8 (50%)	6 (38%)	1 (6%)
5. I think that it is easy to start the training material by using the initial link	0	4 (25%)	11 (69%)
6. I think that it is easy to close the different modules in the training material	0	4 (25%)	11 (69%)
7. I think that it is easy to navigate through the different modules in the training material	0	4 (25%)	10 (63%)
8. I think that the start page is clear and easily understood	0	3 (19%)	11 (69%)
9. I think that it is easy to follow the links in the training material	0	2 (13%)	13 (81%)
10. I think that the content of the training material is essential to me	0	3 (19%)	11 (69%)
11. I think that the information in the training material is easy to understand	0	3 (19%)	12 (75%)
12. I think that the level of knowledge in the training material is too high	10 (63%)	3 (19%)	2 (13%)

Questions 1–6, 9, and 11–12: one non-responder; questions 7–8 and 10: two non-responders.

level of education was equal between the men and the women. Nine of the 16 participants did their banking on the Internet, while seven did not.

Although they were not required to provide the information, some of the invited 53 elderly reported their reasons for not participating in the study: lack of access to a computer and the Internet, illness, lack of computer experience, lack of time, and no requirement for further information or education about drugs.

Quantitative analysis

Layout. The responses from the completed questionnaires are summarized in Table 1. A majority (81%) of the respondents agreed that the text was easy to read, 75 percent agreed that they could hear the information clearly, and 88 percent agreed that the images were easy to understand. The participants had different points of view in the question concerning the length of the information: half of the respondents disagreed that the education course was too time consuming.

Usability. The attitudes concerning the usability of the link to open the education site varied among the participants. A majority (69%) agreed that the link was easy to use, 63 percent agreed that it was easy to navigate through the different modules, 69 percent agreed that the start page was easy to understand, and 81 percent of the respondents agreed that it was easy to follow the links in the education.

Content and level of knowledge. A majority (75%) of the respondents agreed that the information was easy to understand and 69 percent agreed that the training material was essential to them. A

Table 2. Summary of the responses from the participants (n = 16) is divided into two groups based on age: Group 1 and Group 2.

Questions from the evaluation questionnaire	Group 1, ≤75 years (n = 8)			Group 2, >75 years (n = 8)		
	Disagree (1–2)	Neutral (3–4)	Agree (5–6)	Disagree (1–2)	Neutral (3–4)	Agree (5–6)
1. I think that the appearance of the text is easy to read	0	0	8	0	2	5
2. I think that it is easy to hear the information as spoken	0	0	8	0	3	4
3. I think that the images in the training material are simple and easy to understand	0	0	8	0	1	6
4. I think that the training material is too long	6	2	0	2	4	1
5. I think that it is easy to start the training material by using the initial link	0	1	7	0	3	4
6. I think that it is easy to close the different modules in the training material	0	0	8	0	4	3
7. I think that it is easy to navigate through the different modules in the training material	0	1	7	0	3	3
8. I think that the start page is clear and easily understood	0	0	7	0	3	4
9. I think that it is easy to follow the links in the training material	0	0	8	0	2	5
10. I think that the content of the training material is essential to me	0	1	7	0	2	4
11. I think that the information in the training material is easy to understand	0	0	8	0	3	4
12. I think that the level of knowledge in the training material is too high	6	1	1	4	2	1

The table shows the frequency (on a six-point Likert-type rating scale). Questions 1–6, 9, and 11–12: one non-responder; questions 7–8 and 10: two non-responders.

majority (63%) disagreed that the level of knowledge was too high. None of the participants answered “no opinion” to any of the questions in the questionnaire.

Analysis by age. To visualize the responses in relation to age, the respondents were divided into two groups based on age Group 1, ≤75 years (n = 8, range: 66–74 years) and Group 2, >75 years (n = 8, range: 76–89 years). The responses from the questionnaires are summarized in Table 2. There were minor differences in the responses between the two groups. There was a slight tendency that the degree of agreement was lower among Group 2, but due to the low number of participants, this was not statistically tested.

Qualitative analysis

Six categories were used to describe the participants’ opinions of the web-based education tool from the questionnaire’s open-ended questions (Table 3): (1) layout and structure, (2) content and relevance, (3) distribution channels, (4) self-confidence, (5) drug-related problems, and (6) suggested improvements. The categories self-confidence and drug-related problems were from the

Table 3. Five open-ended questions in the evaluation questionnaire.

Open-ended questions
I regard the following as good in the training material
I regard the following as less good in the training material
I regard the following as deficiencies in the training material
My suggestions to improve the training material are
Other views

Table 4. Example of open-ended question analysis.

Meaning units	Codes	Category
Quite time-consuming and repetitive. Replication of what already been told in some cases	Time-consuming Repetitive	Suggested improvements
A feeling of increased security about my medicines. Dare to ask questions to pharmacy and health care staff. Knowledge is never wrong.	More secure Dare to ask questions	Self-confidence

participants' personal experiences and beliefs, and the other categories were related to technical issues in the e-learning modules. See Table 4 for an analytical overview.

Layout and structure. The participants regarded the appearance of the website as good. Likewise, they regarded it positive to be able to take in the information at their own pace, and that it was easier to understand than receiving only verbal information.

The participants proposed traditional lectures followed by group discussions as an alternative to the web-based information:

> Easier to understand the information on your own than verbal information only. (Participant 8)

Content and relevance. The participants regarded the topics on the site as relevant. The topics most appreciated were according to the open-ended questions the Pharmacy Benefit Scheme (the Swedish Government subsidizes prescription drugs for residents of Sweden), drug interactions, and medication lists. One participant regarded the information as a good way of supplementing, asking questions about medications at the pharmacy or at the doctor's office. The participants regarded the content of the modules as good or okay:

> Everything felt good and relevant. I saved the information to be able to look at it again. (Participant 4)

> I did not lack anything on the education site. (Participant 21)

Several participants wanted more information regarding specific medicines; in particular, they wanted more details and information on how they interact with other medicines:

> I would like more information about specific medicines on the education site. (Participant 4)

> The education site lacked details about what drugs you can combine or not combine. (Participant 15)

Distribution channels. One participant suggested using a TV commercial as an alternative for distributing some of the information currently on the education site. The lack of access to computers among the elderly was seen as a problem with the web-based education site:

> All the telephone numbers that are mentioned on the education site, as well as the information about the Pharmacy Benefit Scheme, would be great as a commercial on TV. Many of the elderly don't have access to a computer. (Participant 21)

Self-confidence. Some participants reported a feeling of increased security about medication and increased self-confidence when asking questions about drugs and drug treatment:

> A feeling of increased security about my medicines. Dare to ask questions to pharmacy and health care staff. (Participant 24)

Drug-related problems. The participants felt that the research about the elderly and medications was good and that knowledge can help to avoid many mistakes and misunderstandings:

> The elderly might be a little reserved and not ask questions. Many mistakes and misunderstandings could be corrected with more knowledge. (Participant 24)

Suggested improvements. Some participants regarded the education tool as rather time consuming and repetitive. The opinions varied on the voice options used in the education tool:

> Quite time consuming and repetitive. Replication of what we've already been told in some cases. (Participant 3)

Discussion

We found that the prototype of the e-learning modules has the potential to be a useful tool for distributing information about medications to the elderly. Overall, the participants found the education process positive; nevertheless, there were comments about deficiencies in the layout, content, and method of distribution. The group varied in their preference for web-based information or traditional information.

In general, a lack of experience with computers could prevent elderly patients from participating in web-based education. Lack of access to a computer was a common problem among the people who were asked to participate and was a reason for not participating in the study for some. However, many of the participants were happy to be able to access information on the Internet at their own pace. These results are in line with earlier research.[27] Other participants preferred to access the information from traditional lectures and group discussions.

Most agreed that the content was essential for them. These results were an indication that the choice of topics was accurate and that these topics should be included in ongoing work on the education modules. Opinions about the length of the information varied among the participants. Because of this, it was difficult to judge whether it was too extensive. It is hard to develop an education unit that is short but also contains detailed, rich information. Different individuals seem to have different requirements, and all education modules cannot be expected to suit everyone.

There were comments concerning the necessity to include detailed information about medicines and drug interactions in the e-learning modules. However, at this stage, it is not feasible to include information about specific medicines because of the wide variety of medicines used by the elderly. In the future, it might be possible to direct the information toward specific target groups of patients with specific diagnoses.

When the participants were divided into two groups based on their age, there were minor differences in the responses between the groups (Table 2). Actually, there was a slight tendency that the degree of agreement was lower among Group 2, but due to the low number of participants, this was not statistically tested. If the number of participants had been larger, a statistical difference might have been proven.

In that case, a plausible explanation to the difference between the groups might be that the participants in Group 1 were more experienced with computers than Group 2.

It is also possible that Group 2 experienced age-related hearing loss and vision impairment to a greater extent than Group 1, which could affect the ability to acquire the information in the e-learning modules. Furthermore, there seemed to be an age-related difference in understanding the information. In the statement concerning whether the information was easy to understand, the younger group had a higher degree of agreement.

It is important that this type of software should be flexible and user-friendly. In this study, the participants were able to select any module according to their own interests, in any order. This was seen as a way of individualizing the e-learning modules for each user. This method of individualization means that the information is suitable for many different target groups.

The elderly participants managed the e-learning modules well, which indicates that this could be a useful tool for informing and educating the elderly. In the future, the proportion of elderly in the population will increase and each individual will probably take more responsibility for their own health. It is important to be able to find and understand accurate health information.

Previous research shows that the oldest people (defined as ≥78 years of age) use the Internet the least.[6] A study from the United States suggests that older adults need to increase their general computer expertise. It is possible that this will be less of a problem when Internet users currently in their 50s and early 60s become older. The current generation of Internet-connected adults is unlikely to abandon their Internet use and is actually more likely to develop their computer expertise in the future.[7]

Before the participants were included, we did not ask them about their current understanding and knowledge of medication use, which probably contributed to the different opinions about the prototype e-learning modules. If we had had that information, it might have been easier to find appropriate module subjects and levels of knowledge to satisfy the participants. It might have been preferable to include more participants, but we found the data to be sufficient based on the purpose which was to evaluate the modules in a pilot test.

The unequal distribution of men and women among the participants was an issue and might have biased the results. However, the mean age was quite similar between the two groups (men and women), as well as the level of education. It would have been preferable to include more men to achieve an even gender distribution. The results cannot be extrapolated to larger groups, in which opinions would presumably vary even more. The participants completed the study in 2–5 weeks. This variation in times for completing the questionnaires is thought not to have affected the results, but this cannot be excluded.

The elderly people who agreed to participate in our study were probably those with an interest in drugs and medical treatment who wanted to learn more. They probably already had good knowledge of the area prior to the education course, which limits the generalizability of the results.

This study used an inductive approach in the content analysis. Inductive content analysis is recommended when there are no previous studies dealing with the phenomenon or when knowledge is fragmented.[25] Trustworthiness is important in content analysis. Intercoder reliability (ICR) is required when more than one researcher is involved in the deductive analysis process. However, it has been suggested that in inductive content analysis, trustworthiness should be checked in the way that one researcher is responsible for the analysis and that other researchers carefully follow-up on the analysis process and categorization.[28] The analysis in this study was performed according to these suggestions. According to S. Elo and H. Kyngäs, authentic citations have been used to increase the trustworthiness of the analysis.[25]

Based on our findings, the e-learning modules have been further developed: revision of structure and content, optimization of layout, and revision of the voice recordings. In an ongoing randomized controlled trial (RCT) study with a larger study population, the purpose is to investigate whether the optimized e-learning modules on medication really contribute to increased knowledge, that is, improved performance, perceived knowledge, and self- confidence about medicines, as well as general beliefs about medicines among the elderly. Nothing of this was investigated in the pilot study.

Conclusion

The results indicate that e-learning modules are a suitable tool for distributing information that can be managed by elderly individuals with access to a computer. The benefits of the course reported by the participants included increased knowledge and increased self-confidence about drug utilization, as well as the possibility of absorbing the information at their own pace.

Practice implications

e-Learning modules about medication utilization could be a useful tool for educating and informing elderly patients who are familiar with computers. e-Learning provides a flexible education option for the elderly to use at their own pace.

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The development and application of a protocol for the writing, assessing, and validating of a corpus of relationship-focused text messages for new and expecting fathers

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Abstract

In developed countries, antenatal education aims to reduce difficulties that mothers and fathers experience during transition to parenthood. However, fathers are often distracted from preparing themselves by the attention given to preparing and supporting mothers. Developments in digital communication present alternative means of supporting fathers at this time. Studies, across a range of health concerns, have reported successful outcomes from text-based interventions. Text messaging, focusing on the issues that cause paternal distress at this time, could provide timely, targeted, and effective support to fathers in their transition to parenthood. This study aimed to develop a corpus of messages that could be sent to new fathers during pregnancy and in the months after birth. Messages were intended to support new dads in caring for their own physical and mental health, nurturing strong relationships with their child, and developing strong parenting partnerships. The process employed in message development was similar to that previously employed in developing messages for people who had experienced a cardiac event. A corpus of messages and linked information focusing on fathers' relationships with their children, partners, and themselves were initially developed by a core group. The corpus was then culled, refined, and expanded by a larger, more diverse, group of experts ($n = 46$), including parents, academics, and practitioners. The iterative, consultative process used in this study proved to be a functional way of developing and refining a large corpus of timed messages, and linked information, which could be sent to new fathers during their transition to fatherhood.

Keywords

assistive technologies, ehealth, healthcare service innovation and IT, mobile health, pervasive technologies, fathering, parenting

Introduction

For many fathers, the first year of parenting is often marked by psychological distress, as they grapple with social isolation and emerging difficulties in their relationships with their partners, their new children, and with themselves.[1] The distress that fathers experience at this time has

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implications for the fathers themselves, their partner's emotional well-being, and for the social and emotional well-being of their children.[2,3] In developed countries, antenatal education is expected to ameliorate or reduce these difficulties by preparing both mothers and fathers for their transition to parenthood.[4] However, services provided to parents at this time, such as face-to-face and online classes, tend to focus their curriculum on preparing for the birth. Fathers are often distracted from considering their own preparation for parenting by focusing on their role as a support person for their partner and by a lack of insight into the challenges that they are likely to face in the coming months.[5–7]

Fathers may be better prepared for their transition to parenthood by being provided with information on key issues such as infant development, crying and settling, role and relationship changes, managing psychological distress, and understanding how to provide effective support for their partners.[8] To adequately and consistently address the needs of fathers, it may be more effective to deliver this information and support directly to them, outside of forums preparing their partners for childbirth, at time when the information is relevant, and in a manner that fits with their needs.

Fathers form a hard to reach populations due to a range of factors such as the persistence of gendered parenting roles and responsibilities, the lack of support that men experience in the workplace for their fathering role, the gendered expectations of providers, and the expectations of men themselves.[5,9] Although these and other barriers have remained unsatisfactorily stable over time, there is now a substantial body of evidence describing how they can be taken into account when providing men with family-related services.[10–12] Recommendations for father inclusive practice include factors such as matching service times to men's availability by running services after hours, hiring more male staff, and reducing the feminisation of service delivery by neutralising décor, displaying posters and pictures that include male imagery, and having reading material available that is better suited to men waiting for appointments. However, attempts to apply the above recommendations in practice are often ad hoc while practice change requires considerable effort and support. It is also evident that results are often discouraging and that practitioners, particularly those in child and maternal services, often revert to a maternal orientation when the opportunity arises.[13]

The emergence of mobile communication technologies that enable the delivery of affordable, convenient, personalised, and engaging health information directly to men provides an opportunity to avoid many of the barriers to father inclusion by dissociating service delivery from the constraints of clinical environments.[14,15] The development of text-based services could therefore provide an effective means for consistently supporting large numbers of new dads during their transition to parenthood. The widespread uptake of mobile phones in western economies now means that text messaging offers a potentially important tool to communicate with fathers during the perinatal period. Text messaging has been successfully employed in programmes focusing on weight reduction, diabetes management, medication compliance, and peer support in mental health programmes.[16] Text messaging has also been shown to be effective in engaging a population of homeless men, known to be extremely hard to reach, with support services.[17] However, there are currently no reports on the use of text-based messaging systems to support fathers during their transition to parenthood. In developing a text-based intervention for this group of men, it is important to carefully consider the key purpose, or strategic aim, of the messages that new dads would receive.

During their transition to parenthood, fathers are developing a new, parenting relationship with his partner along with an attachment relationship with their child.[18] Many fathers experience high levels of distress as they struggle to adjust to these new and changing relationships which can be compounded by a sense of isolation from previous social networks and altered levels of intimacy in their relationship with their partner.[18] Although fathers may be compensated for the loss of connection that they experience by an emerging relationship with their new child, the formation of strong father–child attachments is often slower to develop in intensity than that which occurs between mothers and their babies.[19] The current project aimed to develop a corpus of supportive text messages that can promote the father–child bond, support and enhance a father's relationship with his partner, and help fathers to better monitor and manage their own mental health.

There were opportunities to apply learnings from projects that previously developed health-related text messages and reported on the processes used in their message development. Text4baby, a US project employing technology to provide health information to new mothers, used expert opinion, a literature review, and maternal focus groups to develop topic areas before working with federal agencies and experts to develop message content for a corpus of over 240 messages.[20] Redfern et al.[21] took a more staged and consultative approach to the drafting of messages designed to support lifestyle change in people with cardiovascular disease. After developing an initial corpus of messages from clinical experience, Redfern et al.'s messages were validated by academics and clinicians and then by potential users who gave their thoughts on a draft corpus of messages. Redfern et al. then used this feedback to refine and expand their body of messages before trialling them in a clinical cohort.

This article reports on the methods used to develop large group of relationship-focused messages that address fathers' needs at specific points on a timeline spanning 12 weeks gestation to 24 weeks after the birth.

Methods

A corpus of messages ($N=129$), including 27 messages developed during a related pilot study,[22] was constructed by the investigators using readily available web-based sources of information from reliable sites, and both clinical and academic expertise in the areas child development, father self-care, infant attachment, and coparenting relationships. These messages were designed to address relationship factors that were likely to occur between the father and his partner, his child, and himself during his transition to parenthood.

A reference group ($N=46$) was formed to review the messages. The reference group comprised health professionals, academics, and representatives from non-government organisations providing family services. All participants in this group had demonstrated a strong interest in the transition to fathering through their clinical work, publications, and presentations. Most of the members were currently working in Australia, but there was also representation from Europe ($n=3$) and North America ($n=4$).

For the purposes of review, messages were divided into nine subcategories: feeding support, drug and alcohol, family violence, father–infant care, father–infant relationship, parenting partnership, partner care, child safety, and father self-care. Members were each asked to nominate two of these subcategories where they had expertise. Each member was then sent a selection of messages, with most receiving 15 messages, from their nominated areas of interest, and asked to provide feedback for each message, on 5-point Likert-type scales ranging from 0 (strongly disagree) to 5 (strongly agree). Questions about each message explored; the importance of the issue addressed in the message, the clarity and readability of the message, and the acceptability of the message to fathers. Members were also asked to provide an opinion on whether or not the available evidence supported the intention to send the message to new dads and if there were any other messages that they thought should be included in the corpus. A time limit was set at 3 weeks, for each member to respond, and a reminder was emailed after 2 weeks.

A protocol was drafted to interpret and judge reference group responses to the Likert-type questions during the questionnaire development phase.[23] Mean scores equal or below 3 on 'importance

Table 1. Means of reviewer feedback on items.

	Importance (*M*)	Readability (*M*)	Acceptability (*M*)	N[a]	*p***
Feeding support	4.53	4.16	4.04	4	0.144
Drug and alcohol	4.72	4.45	4.0	3	0.207
Family violence	4.34	3.44	3.68	6	0.197
Father–infant care	3.89	3.93	3.78	34	0.122
Father–infant relationship	4.59	4.26	4.27	29	0.001****
Parenting partnership	4.42	3.82	3.89	23	0.362
Partner care	4.77	4.41	4.3	8	0.012***
Child safety	4.32	4.01	4.26	8	0.600
Self-care	4.65	4.28	4.25	11	0.005****
Total	4.36	4.04	4.02	127	

[a] Number of messages related to category.
**Paired *T* test (2 tailed) – difference between item means and total means.
***$p < 0.05$.
****$p < 0.01$.

of the message' resulted in the message being discarded. Mean score equal or below 3 on 'clarity' resulted in the message being substantially reworded or discarded if that could not be achieved. A mean score below or equal to 3.5 on 'acceptability' resulted in the message being discarded. The decision to nominate a higher cut-off for the acceptability question was due to concern about distributing messages with the potential to contribute to paternal distress.

Following this stage of the review process, links to webpages, from highly relevant, evidence-based, government, and not-for-profit sources, were added to many of the texts ($N=57$). The updated corpus of messages ($N=127$) were then allocated to positions on a timeline from 12 weeks gestation to 24 weeks postnatal and the entire timed cohort was circulated to the reference group for their consideration. For this final stage of the review process, all members of the reference group were asked to provide feedback on areas of concern regarding either messages or links. Feedback from this phase of the process was then reviewed by a small working party and the corpus of messages was finalised.

Results

In the first round, where reviewers ($N=46$) were asked to critique approximately 15 items each, 772 message reviews were provided by 94 per cent ($N=43$) of the reference group; three reviewers did not respond within the allocated time period. Most items were reviewed by several members of the reference group ($M=7.0$, range = 2–14, $SD=2.75$). Nine items received only two reviews and these were in the area of father–infant care, where only a limited number of members expressed a sense of interest/expertise.

Reviewers generally rated all messages very highly (see Table 1). Four items, which did not meet the predetermined cut-off levels, were removed, for example: 'When tired or distressed, some parents think their child is trying to upset them. I really do prefer it when you are calm' was deleted from the corpus due to concerns about both clarity and acceptability. However, another two items about teething the introduction of solids were added to the corpus following reviewer suggestions. These additional items were considered to address important issues that had been previously overlooked. Despite the generally positive nature of the critiques, 109/127 (86%) messages were reworded in response to suggestions, for example: 'I will learn to love your face and I will try to copy your facial movements? I will do this from a very early age' was changed to 'I will learn to love your face and I will try to copy things that you do with your face from a very early age'. In another example: 'Lots of food in and poops out. It's normal for newborn babies to poo many times a day' was redrafted to read 'Lots of food in and poops out. Newborn babies often poo many times a day. Sometimes we don't. How am I doing dad?'

The greatest area of disagreement arose around four messages related to breastfeeding, which were also items that attracted the largest number of reviews ($M=9.5$). Concern about these items centred on a tension between either encouraging fathers to promote breastfeeding or to support their partner's choices. These tensions were resolved by adjusting messages to carefully address these concerns; such as the following message, scheduled to arrive 20 weeks before delivery, which was changed from 'Breastfeeding. Good for baby, good for Mum, and good for the wallet. Let her know if you want this for your family' to 'Breastfeeding. Great for baby, good for Mum, and easy on the wallet. If mum wants to breastfeed then let her know you want this for your family'. A later message, scheduled to arrive after the baby was born, was changed from 'If Mum is struggling with breastfeeding you can find ways to support her and encourage her to keep going' to 'If breastfeeding isn't working out or isn't right for mum that's OK. Babies thrive on the love they get from their parents. You could remind mum of this'.

There were a number of other changes across the corpus of messages. One important change, as a result of reviewer recommendations, was to have as many messages as possible expressed as if they were coming from the child, either in utero or after birth. In other cases, the reviewers made small but important suggestions which improved both clarity and accuracy, for example … 'The nurses will want to take some blood from baby's foot to test for gene or blood disorders. Best to find out early. [Link to website included]' was changed to 'The nurses will want to take some blood from my foot to test for rare medical conditions. Best to find out early dad. [Link to website included]'. Although many of the changes that were made, as a result of this process, were subtle they made important contributions to accuracy, clarity, and readability of messages ($M=5.86$ years of education, $SD=2.32$) across the corpus.[24]

Feedback from reviewers was generally very positive but there were some item groups – father–infant relationship, partner care, and self-care – that rated significantly higher than the mean of all groups (see Table 1). Items on father–infant care averaged the lowest scores on reviewer feedback, but the mean of these scores was not significantly different to the group mean.

When the revised corpus of messages, including links, was circulated to the entire reference group, with instruction to provide feedback on areas of concern regarding messages or links, 14 members of the reference group provided feedback. This was the first time that members of the group were able to see the entire corpus of messages. Feedback on this final round of reviews included only minor comments resulting in modest changes to some messages. No messages were deleted as a result of this phase in the process and only two links were redirected.

Discussion

The consultative processes employed in these phases of the project achieved the aims of developing, fine tuning, and validating a corpus of messages that could be confidently sent to new fathers during their transition to parenthood. The review process made a major contribution to the clarity of the messages through both suggestions from reviewers to make messages clearer, and the advice that reviewers gave on how messages could be better constructed. This consultative process therefore resulted in substantial refinement of messages across the corpus. The outcomes achieved through this process gave investigators confidence that messages in the corpus were likely to be important, clear, readable, and acceptable to new fathers.

A previous systematic review in the area of text message development has noted the importance of detailed documentation of the processes associated with message development in order to understand mechanisms of behaviour change.[15,25] The use of the present process to expand and validate a corpus of messages adds to the literature in this field by replicating components of the process that Redfern et al.[21] applied to message development in a different context. This study found that the process was readily understood by members of the reference group and enabled them to focus their involvement to their areas of speciality. This study found the current process workable in the context of relationship-focused message development targeted at new fathers. The process has contributed to the validity of the corpus of messages by generating evidence of expert support, however; the acceptability of the messages and the effect that they have on fathers in their transition to parenthood is yet to be explored.

Limitations

Although efforts were made to form a reference group with adequate experience from a broad range of disciplinary perspectives, the quality of this group could have been enhanced by deliberately including more consumer representation. It was fortunate that many members were parents or grandparents themselves and that some of these were parents, both mothers and fathers, of younger children. The initial process of message development could also have been enhanced with a more deliberate, and therefore replicable, approach to the review of available information. Future projects on text development could develop clear and repeatable processes for the review of both the formal and informal sources of information used in the development of an initial corpus of messages.

Conclusion

The processes employed in recruiting a multidisciplinary reference group, having the group members identify their areas of interest, and seeking their feedback on a reasonably small group of messages proved to be an effective way to develop and validate a corpus of relationship-focused text messages for new fathers. The consultative process employed to refine and validate the corpus of text messages, which could be sent to new dads during their transition to fatherhood, contributed to the quality and range of messages while also providing confidence in the accuracy, readability, and acceptability of items. The messages developed through this process form the first corpus of relationship-focused text messages designed to support new fathers during their transition to parenthood.

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Consumer-led health-related online sources and their impact on consumers: An integrative review of the literature

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Abstract

The aim of the review was to describe consumer-led health-related online sources and their impact on consumers. The review was carried out as an integrative literature review. Quantisation and qualitative content analysis were used as the analysis method. The most common method used by the included studies was qualitative content analysis. This review identified the consumer-led health-related online sources used between 2009 and 2016 as health-related online communities, health-related social networking sites and health-related rating websites. These sources had an impact on peer support; empowerment; health literacy; physical, mental and emotional wellbeing; illness management; and relationships between healthcare organisations and consumers. The knowledge of the existence of the health-related online sources provides healthcare organisations with an opportunity to listen to their consumers' 'voice'. The sources make healthcare consumers more competent actors in relation to healthcare, and the knowledge of them is a valuable resource for healthcare organisations. Additionally, these health-related online sources might create an opportunity to reduce the need for drifting among the healthcare services. Healthcare policymakers and organisations could benefit from having a strategy of increasing their health-related online sources.

Keywords

consumer, healthcare, integrative review, Internet, online source

Introduction

The Internet has become the major resource of information relating to health,[1,2] and its use by healthcare consumers is expected to increase.[3] The Internet, with its ubiquitous nature and potential anonymity,[4] has fascinated millions of healthcare consumers who access it every day to find health-related information.[5,6] The channels that the healthcare consumers use, either for obtaining or sharing health-related information, are, in this review, called health-related online sources. In

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this review, the sources are assumed to be consumer-led, which here means that they are not offered by healthcare organisations. For the Internet user searching for health-related information, this review uses the term consumer, which has replaced the term patient.[7] Health policymakers have begun to recognise the potential of the Internet as a source of consumers' experiences,[4] and, in the United Kingdom's National Health Service (NHS) Future Forum Report on Information,[8] have actually talked about 'a new culture of transparency and public voice being fuelled by the digital revolution'.

Studies have revealed the need for combining healthcare and the Internet in order to produce better services.[9–11] Previous studies have addressed this idea from four key viewpoints. The first observed health-related online sources through the lenses of marketing and was, therefore, interested in how the marketing of health services can benefit from online sources and consumers' experiences.[12,13] The second viewpoint was related to health science, which, in most cases, focused on how successful interventions, tools and guidelines using the Internet[11,14] were. The third viewpoint covered misleading and unverifiable information.[15,16] The fourth viewpoint was technological, which primarily examined the development of health-related online sources for the purposes of healthcare.[17] Despite the increased research interest in the use of the Internet in the healthcare context, research into health-related online sources seems to be limited: quite little is known about their impact.[4,6]

The aim of this study is to describe the consumer-led health-related online sources and their impact on consumers. The research questions are as follows:

1. How have health-related online sources been studied in the past?
2. What kind of consumer-led health-related online sources have been accessed between 2009 and 2013?
3. What kinds of impact of health-related online sources have been explored by previous studies?

The use of health-related online sources, drifting among them and the implications

Internet usage differs between countries and across continents. For example, mainstream culture might create certain attitudes towards Internet use, thereby reducing it among a certain part of the population. Also, access to the Internet varies and is most often bound to the development of the country.[18] Users of the Internet, compared to non-users, tend to be more educated and have better earnings; their mean age is 45.8 years.[19–21] Several studies have reported health-related Internet usage to be more common among women.[19,20] The Norwegian study carried out by Wangberg et al.[3] found no significant differences between genders' health-related Internet use. This review uses characteristics of Internet users that could be applied to the Scandinavian population, where Internet use is very high. The Scandinavian countries all have similar health-related Internet usage. According to Norwegian, Swedish and Finnish studies, nearly 70 per cent of Scandinavian people have used the Internet to find illness, nutrient or other health-related information,[3,22,23]). Using the Internet for these purposes is, in this review, understood to mean using health-related online sources; the channels offering such information are referred to as health-related online sources. When healthcare consumers offer these sources, these sources are, in this review, understood to be consumer-led.

The relationship between healthcare consumers and the Internet is to be expected, since learning more about a disease and interacting with others in a similar situation are the major coping strategies used by the consumer.[9] Ye[24] found that people without a family history of cancer were half as likely to participate in online health activities. Healthcare consumers as users of the Internet play different roles: patients, caregivers and family members coping with the illnesses of others in the household.[1] It has been claimed that online consumers do not want to be treated as stereotypical patients with a specific condition.[25] Thus, one of the main ways in which healthcare consumers are asserting their individuality is through the Internet and online sources. The Internet offers a way to question healthcare providers and professionals;[26] search for information relating to second opinions, complementary or alternative medicines; and learn about specific diagnoses.[20] The Internet increases the consumers' ability to influence their healthcare.[9] The information taken from the Internet seems to be highly appreciated,[20,27] since as much as 60 per cent of consumers looking for information on the Internet considered the information found to be as good as, or better than, the information received from a doctor.[20]

Healthcare consumers' feedback is posted on the Internet for the whole world to see,[28] and thus, it offers scientists, society and end-users the chance to learn what their consumers have to say. In addition, in most Scandinavian countries, healthcare is in crisis caused by an ageing population and failing economies.[29] The Internet has been seen as society's chance to secure good patient-centred care, since the major benefit of the Internet is its ubiquitous nature. Thus, it can be easily applied in healthcare environments to solve modern challenges.[28] Ultimately, the evaluation and usage of health-related online sources is a job for end-users, for whom these online sources can provide an opportunity to produce services that are of high quality, driven by experience-based knowledge, to increase the safety of consumers and to help healthcare administrations to find innovative ways[30] of using such health-related online sources for development.

Methods and materials

The review was carried out as an integrative literature review with a qualitative content analysis being used as an analysis method. The integrative review method was chosen for this review since it is especially useful and applicable in areas where there is only a little pre-existing knowledge and where the issues are complex and require more detailed exploration. Literature searches were conducted in accordance with guidelines relating to literature reviews.[31]

The data were collected using well-known healthcare and administration databases: CINAHL, Business Source Complete (EBSCO), ABI/INFORM complete and PsycINFO (Table 1). To make sure that information retrieval was relevant, a librarian was consulted to determine the appropriate search strategy for this area of research. The information retrieval was carried out by using relevant words for the phenomenon, including their combinations and synonyms, and by finally undertaking test searches in the selected databases. The search for some terms was limited to the title of the article in order to deal with the volume of results. The inclusion and exclusion criteria for the studies were determined at the beginning of the process.

In this review, a manual search was carried out using the journals that appeared to include good and relevant studies after the database search. The journals scrutinised were: *The Journal of Medical Internet Research*, *Telemedicine and e-Health*, and *Patient Education and Counseling*. While researching *The Journal of Medical Internet Research* using its official webpages, one good article was found from a journal called *Medicine 2.0*, and it was included. The previous year range of 2009–2016 was also valid for this search. In total, the number of articles found was 954, which reduced to 464 after duplicates were removed using Refworks.

Following the information retrieval, the studies' titles and abstracts were screened by the primary author. If no abstract existed, or a decision on inclusion could not be made from the abstract alone, the whole text was analysed. In the second screening, the studies' complete texts were screened and, prior to inclusion, their quality was appraised by two independent researchers using their own criteria for quantitative, qualitative and mixed-methods studies. Suitable critical appraisal

Table 1. Search strategy.

Keywords	Database	Results
ti(internet OR online OR web* OR virtual* OR 'network* site') AND (consumer* OR patient* OR user*) AND ti(health* OR 'health care' OR 'health service*')	CINAHL	446
	EBSCO	110
	ABI/INFORM Complete	95
	PsycINFO	251 (not included after 2013)
Manual search	*Journal of Medical Internet Research* (including the article from the Medicine 2.0)	49
	Telemedicine and e-Health	1
	Patient Education and Counseling	2
Total		**954**
Total after duplicates removed		**464**
Inclusion and exclusion criteria	(1) Peer reviewed original scientific articles, (2) published between 2009 and 2016 in the electronic databases, (3) in English, Swedish or Finnish, (4) full text available through the Library of the University of Oulu, (5) focused primarily on consumer-led health-related online sources, (6) were found to be of good quality according to a critical appraisal tool and (7) were undertaken in a context of developed countries having similar Internet usage to Scandinavia. The studies (1) exploring the population whose ability to use Internet due to illness differed from the mainstream were excluded.	

tools were found from the list by the Sansom Institute[32] and modified forms of the following tools were applied: McMaster Critical Review Form (for quantitative studies), Critical Appraisal Skills Programme (CASP) screening tool for qualitative studies and Evaluation Tool for Mixed-Methods Studies. Since there is no specific threshold to determine whether a study is of sufficient quality,[33] the studies were included if they met a minimum of 50 per cent of the addressed criteria or were otherwise felt to be of sufficient quality. If there were any disagreements over the quality, they were resolved through discussions and further reading of the full text until a consensus was reached.

Finally, 26 studies were chosen. The studies were analysed by using qualitative content analysis in which the aim is to understand the contents of the text and search for the essential themes in the studies.[34] In addition, quantisation was used while addressing the first research question. After reading and understanding the content of the studies, the following topics were produced for addressing the second research question: health-related online communities, health-related rating webpages and health-related social networking sites (Table 2). The following impacts were found that addressed the third research question: peer support, empowerment, health literacy, physical, mental and emotional wellbeing, illness management and relationships between healthcare organisations and consumers.

The research methods used and the branches of sciences covered in studies exploring health-related online sources and their impact on consumers

Of the 26 studies selected for this review (Table 2), 13 were carried out using qualitative methods, seven using quantitative methods and six using a mixture of both. The sources of the information

Table 2. Studies exploring health-related online sources and their impacts.

The author(s) and the journal	The aim of the study	*First Research Question*: Data and Methods	Country	Conclusions	*Second research question*: Online sources	*Third research question*: Impact
Informatics for Health and Social Care[35]	To examine and compare cancer-related conversations in online forums hosted by Canadian and American associations for retired people.	There were 125/1817 (6.8%) Canadian cancer-based discussions and 70/892 (7.8%) American-based cancer-based discussions. A content analysis was carried out.	Canada, United States	Online discussion forum associations may serve as an important channel for information about cancer prevention and screening, treatment and care support, and healthcare advice for seniors.	Health-related online communities	Health literacy
Dolce (2011) *Oncology Nursing Forum*[36]	To describe the experiences of cancer survivors with healthcare providers in the context of the Internet as a source of health information.	Online cancer communities hosted by the Association of Cancer Online Resources. Purposive sample of 488 cancer survivors, with varying cancer types and survivorship stages, and caregivers. Secondary data analysis using Krippendorff's thematic clustering technique of qualitative analysis.	United States	Through online health information and resources, concealed failures in healthcare relationships were revealed and cancer survivors and caregivers were empowered to influence and control care decisions.		Empowerment Health literacy Physical mental and emotional wellbeing Relationship between healthcare organisations and consumers
Patient Education and Counseling[37]	To investigate perceptions of online support group (OSG) users in both empowerment and communication with their health professionals.	246 participants across 33 chronic illness OSGs completed an online questionnaire. Data were explored using descriptive statistics, frequencies and correlations and analysed using both multiple and binary logistic regression.	United Kingdom	OSGs have the potential to produce empowerment outcomes for those who choose to use them. Furthermore, users report a positive reaction to information found online from their health professionals.		Empowerment
Journal of Medical Internet Research[38]	To predict that the effects of OSG participation would partly depend on patients' ability to cope with thoughts and emotions regarding the illness.	184 Dutch breast cancer patients filled out a questionnaire, of whom 163 were visiting an online peer-support community. Z scores and correlations.	Netherlands	Breast cancer patients' ability to cope with emotions and thoughts regarding the illness influence the relationship between OSGs participation and psychological wellbeing.		Physical, mental and emotional wellbeing
Journal of Medical Internet Research[39]	To extend cross-sectional findings by tracking patients over an extended period of time to further assess individual emotional coping differences.	A total of 133 Dutch patients with breast cancer filled out a baseline questionnaire (T0) and a follow-up (T1, 6 months later). ANOVAs.	Netherlands	Participating frequently online was especially helpful for patients who approach their emotions less actively; their emotional wellbeing increased over time.		Physical, mental and emotional wellbeing
Patient Education and Counseling[40]	To examine the perceived value and types of social support that characterise the discussion of women who participate in postpartum depression online discussion groups.	A directed content analysis was used to examine 512 messages posted on a postpartum depression OSG over six month.	Canada	OSGs provide women experiencing postpartum depression a safe place to connect with others and receive information, encouragement and hope.		Health literacy

(Continued)

Table 2. (Continued)

The author(s) and the journal	The aim of the study	*First Research Question*: Data and Methods	Country	Conclusions	*Second research question*: Online sources	*Third research question*: Impact
Journal of Medical Internet Research[41]	To understand how Web-based discussion forums influence maternal health literacy.	The sample included 11 Norwegian women who participated in open Web-based discussion forums when experiencing PGP in pregnancy. The data were collected using synchronous qualitative email interviews and were analysed using thematic analysis.	Norway	The popularity of Web-based discussion forums among pregnant women suggests that this group needs additional sources of information and support to complement traditional consultations with health professionals.		Peer support Empowerment Health literacy
Diabetes Spectrum[42]	To identify what key stakeholder groups most value about the Reality Check online community and to contribute the experiences from this long-running and self-sustaining online programme to the growing field of peer-support research.	42 patients participated in six focus groups and responded to seven questions raised by the facilitator. Thematic analysis.	Australia	The online community provides a wide range of support that is distinct from what can be received from clinical care. In addition, the online community increases its users' ability to manage their illness.		Peer support Illness management
Information Technology & People[43]	To examine how participation in an online health community (OHC) provides direct benefits in the form of information utility and social support and an indirect influence on perceptions of patient empowerment.	A multi-method approach involving interviews with moderators of 18 OHCs and a field survey of 153 OHC participants.	United States	OHC participation leads to direct benefits in the form of information utility and social support. That information utility also helps to shape perceptions of patient empowerment among community participants.		Peer support Empowerment
Communications of Association for Information Systems[44]	To contrast community members' support behaviour and companionship activities in two large healthcare virtual support communities.	Combines both qualitative and quantitative methods. The target community is an online cancer support community. In total 2,009 messages and 317 members.	United States	Findings suggest that increasing online avenues for, and encouragement for companionship activities in, any virtual support community could increase participation in support exchange, leading to improved health outcomes.		Peer-support Physical, mental and emotional wellbeing
Kordzadeh et al.[45] Communications of Association for Information Systems	To examine user participation at the individual and group (thread) levels.	2,176 threads initiated by 130 users and 1,947 messages exchanged between these users and their peers. OLS regression and ANOVAs.	United States	Results support short-term reciprocity, but refute the positive relationship associated with long-term reciprocity.		Peer support Health literacy

Table 2. (Continued)

The author(s) and the journal	The aim of the study	*First Research Question*: Data and Methods	Country	Conclusions	*Second research question*: Online sources	*Third research question*: Impact
Australian Marketing Journal[46]	To explore the impact of OSGs on the doctor–patient relationship.	Combination of survey, interview and content analysis. 93 responses were received and the response rate was 4 per cent.	Australia	The traditional asymmetric relationship between patient and doctor is challenged by a new form of educated, empowered health consumer who is able to work in partnership with medical service providers.		Empowerment Health literacy
Journal of Medical Internet Research[47]	To examine the impact of a well-respected UK-based online support forum for carers of people with dementia.	8 participants were interviewed about their experiences of using the forum. Mixed methods.	United Kingdom	Many of the reported experiences and benefits are unique to online peer support.		Peer support Health literacy Physical, mental and emotional wellbeing Illness management
Patient Education and Counseling[48]	To explore how individuals use OHC content in clinical discussions and how HCPs react to it.	In-person and virtual focus groups with patients/caregivers who visited OHCs (n = 89). Thematic response analysis.	United States	Individuals do not use OHCs to circumvent HCPs but instead to gather more in-depth information.		Illness management Relationship between healthcare organisations and consumers
Journal of Medical Internet Research[49]	To examine the presence of therapeutic affordances as perceived by women who use endometriosis OSGs.	Sixty-nine women participated in a Web-based interview exploring OSG use. Responses were analysed using inductive thematic analysis.	United Kingdom, United States	The Self-Presentation, Connection, Exploration, Narration, and Adaptation (SCENA) model reveals a range of positive aspects that may benefit members, particularly in relation to reassurance and coping.	(also included health-related social networking site)	Peer support Empowerment Health literacy Physical, mental and emotional wellbeing Illness management
Health Communication[50]	To examine self-efficacy within the computer-mediated communication (CMC) of four OHCs.	Online ethnography and discourse analysis (n = 8,231).	United States	Three themes follow: sharing disease experience, suffering from disease symptoms, and asking for help.		Peer support Empowerment Illness management
Journal of Service Management[51]	To seek to identify the motivators of activities in OHCs and examine their specific and unique effects.	Six focal OHC members and their recent posts (n = 81) and related threads (893 posts from 265 members). Netnographic study.	United States	Social identity drives patients' value co-creation activities.		Peer-support
Epilepsy & Behaviour[52]	To describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes.	An online survey completed by 1323 participants from selected chronic disease groups. Various SPSS (IBM SPSS statistics) analyses.	United States	The members of the community reported a range of benefits and felt these might be related to the extent of site use.		Empowerment Health literacy Physical, mental and emotional wellbeing Illness management Relationship between healthcare organisations and consumers

(Continued)

Table 2. (Continued)

The author(s) and the journal	The aim of the study	*First Research Question*: Data and Methods	Country	Conclusions	*Second research question*: Online sources	*Third research question*: Impact
Journal of Medical Internet Research[53]	To gather feedback on the perceived benefits from use of our online service by people with epilepsy.	An online survey completed by 221 patients with epilepsy. Various SPPS analyses.	United States	Perceived benefits included: finding another patient experiencing the same symptoms (59%), gaining a better understanding of seizures (58%) and learning more about symptoms or treatments (55%). The controlled sharing of health data may have the potential to improve disease self-management.		Peer support Empowerment Illness management Relationship between healthcare organisations and consumers
Journal of Service Marketing[54]	To present data that demonstrate the construction of tacit knowledge within OHCs and how consumers exercise their 'voice' within complex professional services.	Textual data were collected and analysed from the forum retrospectively from an 11-month period, entailing contributions from 252 participants. Content analysis using a simple 'discourse analysis'.	United Kingdom	Forum participants negotiate their understanding in the context of their personal experience.		Empowerment
Journal of Medical Internet Research[55]	To explore differences in peer support received by lurkers and posters in online breast cancer communities. Also, the effects of such support on both groups' mental health were examined.	An exploratory, descriptive, cross-sectional web-based survey of 253 members of four Japanese online breast cancer communities. Various SPPS analyses.	Japan	The participation in online communities – even as a lurker – may be beneficial to breast cancer patients' mental health.		Peer support Physical, mental and emotional wellbeing
Social Science and Medicine[56]	To examine comments made on the sites from the perspective of reflexivity in modern society. How are patients positioned by the websites and how do they position themselves when writing a review of received care?	A discourse analysis of four of the six sites under study, including patient reviews of institutions and professionals (n = 450). Supplementary data from interviews with stakeholders related to the Dutch sites (n = 15) is also used.	United States, United Kingdom, Netherlands	The focus on reflexivity in healthcare means that not only must institutions be more transparent about their performance but also patients are expected to be more transparent about their choices as well.	Health-related rating websites	Empowerment Relationship between healthcare organisations and consumers
Informatics in Primary care[57]	To evaluate and describe online reviews of healthcare providers.	Analysed 16703 ratings of 6101 providers. Multivariate analysis and logistic regression analysis, and text analyses of narrative commentary (n = 15952). Mixed methods.	United States	Online ratings were largely positive.		Illness management

Table 2. (Continued)

The author(s) and the journal	The aim of the study	*First Research Question*: Data and Methods	Country	Conclusions	*Second research question*: Online sources	*Third research question*: Impact
Medicine 2.0[58]	To explore the motivations and challenges faced by the patients who share videos about their health and experiences on YouTube.	Analysis of the videos created by 4 patients about their self-reported motivations and challenges they face as YouTube users.	Spain Norway	The main reason for making videos was to bridge the gap between traditional health information about their diseases and everyday life. The first consequence of sharing their life on YouTube was a loss of privacy. However they also experienced the positive effects of exploring their feelings, being part of a large community of peers, and helping each other to deal with a chronic condition.	Health-related social networking sites	Peer support Health literacy Physical, mental and emotional wellbeing Illness management
Journal of Medical Internet Research[59]	To explore the potential benefits and dangers of a social networking service (SNS) for depression, based on a concurrent triangulation design of mixed-methods strategy, including qualitative content analysis and social network analysis.	A cross-sectional Internet survey of 105 participants, which involved the collection of SNS log files and a questionnaire, was conducted in an SNS for people with self-reported depressive tendencies. Mixed-method strategy.	Japan	An SNS for people with depressive tendencies provides various opportunities to obtain support that meets users' needs. It is recommended that participants do not use SNSs when they feel that the SNS is not user-selectable, when they receive egocentric comments, when friends have a negative assessment of the SNS, or when they have additional psychological issues.		Peer support Empowerment Health literacy Physical, mental and emotional wellbeing
De la Torre-Díez et al.[60] *Telemedicine and e-HEALTH*	To characterise the purpose and use of Facebook and Twitter groups concerning colorectal cancer, breast cancer and diabetes.	A content analysis of 216 breast cancer groups, 171 colorectal cancer groups and 527 diabetes groups on Facebook and Twitter.	Spain	Social networks are a useful tool for supporting patients suffering from diseases.		Health literacy

PGP: pelvic girdle pain; OLS: ordinary least squares; ANOVA: analysis of variance; HCP: healthcare professionals.

were most often healthcare consumers but caregivers were also included in a few studies. By caregiver, studies meant either healthcare professionals or relatives of a patient suffering from a specific illness. Research data were most often collected either through observation or using surveys but a few studies used interviews, and one study was carried out as secondary analysis. The most popular method was observation, which was most often used in the context of health-related online sources. Some studies used more than one data collection method with online surveys often being used. The studies were carried out in the following countries: United States, United Kingdom, Netherlands, Canada, Norway, Japan, Australia and Spain. Some of the studies covered more than one country, but the most commonly researched countries were United States, United Kingdom and Netherlands. Also, the Spanish study and the other Spanish–Norwegian study examined English-speaking sources.

Most of the data were processed using different types of analytical methods, which produced descriptive information. The qualitative studies were most often analysed using content analysis, but also discourse analysis, text analysis, thematic analysis, social network analysis and video analysis were carried out. The quantitative methods used in analysing data were statistical analysis methods, of which the most popular were Chi-Square, Kruskal–Wallis, Student's T-test, correlations, logistic regression and ANOVAs.

The health-related online sources were explored from the viewpoint of health science, medicine, psychology, economics and informatics. One of the studies clearly combined two branches of science, while several other studies were less clear on their combinations of scientific fields. The combination of sciences used most often was nursing or medicine combined with informatics.

Consumer-led health-related online sources

Online communities (Figure 1) consist of large, geographically dispersed groups of healthcare consumers who may or may not know each other, but share a common interest.[43] Some of the online communities were distinctive groups only representing one illness, but some of them, such as PatientsLikeMe, included several different forums for several different illnesses.

Health-related online communities were usually used and developed by people with similar health experiences.[40,42,43,55] Their purpose was usually to increase knowledge among the healthcare consumers with particular illnesses.[52] The users of the online communities adopted different kinds of roles among the groups: they were either active posters or lurkers[55] and, in some cases, users of the groups became experts (Dolce, 2009). Health-related online communities may contain social networking and rating possibilities.[46]

Social networking sites are Internet-based Web 2.0 applications that allow online social networks to be created where individuals are able to share interests and activities.[59] The included studies referenced three different social network sites that included content related to health: Facebook,[49,60] Twitter[60] and YouTube.[58] One of the studies did not specify the services used, but did reference MySpace. Health-related social networking sites gave similar types of support as health-related online communities[58,60] but they also included several disjunctive features. Social networking sites are different from the other online communities, since they allow the users to be made visible to their social networks.[60] Shoebotham and Coulson[49] noted that compared to health-related online communities, consumers expressed more concerns over privacy when using social networking sites. Social networking sites do not allow anonymous profiles unlike health-related online communities. While communities are most often targeted at healthcare consumers with specific illnesses, health-related social networking sites also involve the mainstream population for purposes such as raising illness awareness,[58] fundraising, advancing disease prevention or fighting against the diseases.[60]

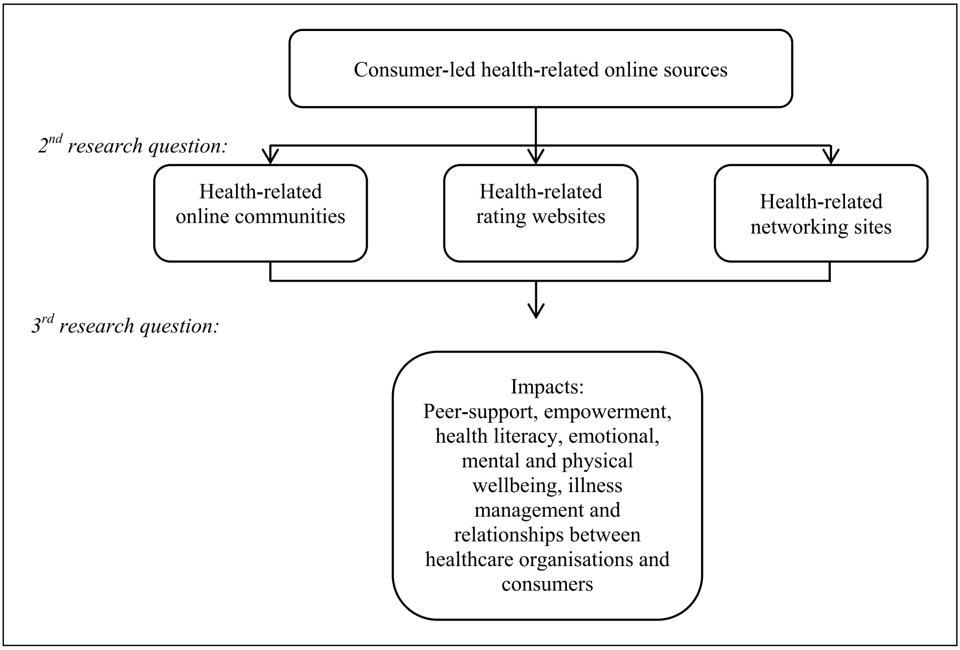

Figure 1. A synthesis figure for research questions 2 and 3.

Healthcare rating websites offer a consumer the chance to rate their medical providers.[57] They presented a different kind of viewpoint in comparison to the health-related online communities and social networking sites. On the rating websites, healthcare consumers did not share information about their illness but they evaluated the functionality of the healthcare organisations or physicians.[56,57] On these sites, healthcare consumers reported their experiences of institutions, professionals, medication or treatments and could be asked to rate different aspects of the care, such as communication, hygiene or accessibility.[56]

The impact of the health-related online sources

All three of the consumer-led health-related online sources mentioned earlier aspire to increase the level of health-related information.[53,56,58] Some of them evaluate illness-related information, while others may evaluate the information related to healthcare providers or professionals. They all have an impact on the person with the specific illness as well as society and healthcare in general, but they have different types of users and different ways of disseminating information.[57,60] The primary impacts seen in studies exploring health-related online sources are peer support; empowerment; health literacy; physical, mental and emotional wellbeing; illness management; and relationship between healthcare organisations and consumers.

In most of the cases, health-related online sources enabled peer support. Seeking a connection with others with the same medical condition is one coping strategy, with the resulting process being termed ‘peer support’.[42] Healthcare consumers were able to find another person with similar symptoms through online sources. This made it possible to make new friends and share experiences, thus helping consumers to understand what it was like to have specific treatments for their condition.[49–51,53,59] Sharing stories related to their illnesses made some consumers realise that other users of the online sources were in a worse situation than they were, which made some of them feel positive about their own situation.[47] In some cases, online sources were not merely used for the purpose of peer support but also for deeper companionship.[44] Sometimes consumers took on the role of helper or adviser to others since they felt they had a lot of experience to share.[41,46,49] Several studies showed that health-related online sources created a strong feeling of belonging even becoming family-like, which again had positive impacts on emotional and physical wellbeing.[49,51] Zhao et al.[51] noted that when consumers strongly identify with their health-related online source, they are more willing to co-create value with peers through sharing. Although peer support was most often seen as a positive impactor, Shoebotham and Coulson[49] noted that a small part of the consumers found arguments and preoccupation had negative impacts.

Empowerment is still poorly defined within literature,[61] but according to some views, an empowered healthcare consumer has been seen as a part of a more productive relationship with their healthcare professional.[62] According to this review, empowerment included different kinds of features, which were usually combined with the fact that the consumer is better informed about the disease.[37,46,50,54] Being better informed enabled, for example, better knowledge of treatments, and the health-related online sources better prepared a consumer for consultations since they knew what questions to ask and felt more informed about the symptoms.[37,49,52] In addition, empowered consumers were able to question, persuade and even coerce healthcare professionals.[41,63] Furthermore, they even took on roles similar to those of health educators and government agencies responsible for public health.[56]

According to Gómez-Zúñiga et al.,[58] health-related online sources were created because of a lack of information and, thus, one of their goals was to increase health literacy. Health literacy embodies the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that advance and maintain good health.[35] According to Kordzadeh et al.,[45] the primary goal of healthcare consumers is to seek health-related information, rather than socialising with peers. It was shown that health-related online sources made it possible to learn more about diagnoses, illnesses and treatments.[48,52,59] Healthcare consumers learned about the latest treatments and were able to access the best available research through health-related online sources (Dolce, 2009). Many healthcare consumers commented that they were able to find information that had not been provided by medical professionals.[41,49] Some of the healthcare consumers turned to online sources since they did not know where else they could get information.[47] These sources also developed the expertise of consumers, since, in some cases, users of the health-related online sources took the role of mentors or 'patient experts'.[40,46,58] The consumers said that even the healthcare professionals reported the growing level of expertise among consumers and noted that they were reaching higher levels of expertise than the professionals themselves (Dolce, 2009). Health-related online sources were also a way of sharing health literacy among other people.[46,58,60]

Health-related online sources had an impact on physical, mental and emotional wellbeing (e.g. Dolce, 2009).[44,48,52] Studies showed that being a member of a health-related online source may cause a reduction in behaviour that is harmful to their illness.[52,59] For example, membership of a particular health-related online support group decreased HIV patients' risky behaviour and helped them decide to start taking antiretroviral drugs.[52] Online sources might also reduce the feeling of loneliness, help accept the condition and, through narration, impact positively on mental wellbeing.[47,49] According to Setoyama et al.,[55] who researched active posters and lurkers in Japanese online groups, a poster who received emotional support in online communities felt less anxious. Lurkers also experienced positive effects on their mental health. Also Batenburg and Das[39] noted that participating frequently online was especially helpful for healthcare consumers who approach their emotions less actively. In addition, the relationship between online sources and wellbeing might be influenced by individual differences in coping styles.[38] In one case, health-related online support groups were even seen as 'life-saving' during cancer survival (Dolce, 2009). Takahashi et al.[59] noticed that negative and egocentric comments were seen mostly as a psychological issue that might be bad for emotional or physical wellbeing.[49,58,59] Finally, Gómez-Zúñiga et al.[58] reported that those persons sharing health-related information on YouTube noted that loss of their privacy was a negative impact on their wellbeing, while the people behind the health-related online sources became targets of unwanted marketing.

Most of the consumers using health-related online sources agreed that the sites improved their ability to manage their own or their relative's illness, that is, cope with problems in their lives.[47,48,52,58] Consumers also reported that meeting other consumers made them feel less self-conscious about their condition, that the online source made them feel more in control of their condition and, finally, that the online source enhanced their quality of life.[49,53] Health-related online sources enabled more effective illness-related decision-making, since the majority of healthcare consumers found that online information had a significant influence on their decision-making.[57] In some cases, patients managed their illness themselves having self-diagnosed it (Dolce, 2009) or asking for help with the medicines from other healthcare consumers instead of healthcare professionals.[50]

In some studies, health-related online sources seemed to have an impact on the relationship between a healthcare organisation and its consumers (e.g. Dolce, 2009).[46,56] Health-related online sources have been seen as a consumer's opportunity to make healthcare organisation or public health more transparent. One of the main purposes of rating websites is to increase the transparency of a healthcare organisation's policies and practices, making it respond to publicly broadcast concerns and complaints.[56] Dissatisfaction with healthcare providers may be one reason to start using health-related online sources.[48] Also, stories about diagnostic failures are shared on health-related online sources (Dolce, 2009) and, in some cases, discussions on those sites has brought about a change of doctor,[52,53] or a demand to see another specialist.[53] Although some healthcare consumers are unhappy with their healthcare professional, many studies found that health-related online sources may also provide a better relationship between caregivers and healthcare consumers.[53,56] According to Wicks et al.,[53] healthcare consumers reported receiving better care from healthcare professional after starting to use health-related online sources. On the other hand, Rupert et al.[48] found cases where healthcare providers reacted negatively when the consumer mentioned online source usage. Finally, using the sources has a developmental impact on healthcare since it may make healthcare consumers more capable of evaluating the medical expertise and professional capabilities of a healthcare professional and, additionally, it may improve the quality of the care they receive.[56]

Discussion and conclusion

The aim of this research was to describe consumer-led health-related online sources and their impact on consumers. The number of scientific articles over the last 5 years describing research into health-related online sources has been rapidly increasing. At the same time, the impacts of online health sources on their users have also been explored, but there is a need to explore this area more effectively and deeper.

The main research approach used in the articles explored was qualitative. The predominant use of qualitative research could be because the phenomenon of health-related online sources is relatively new and qualitative research is flexible, capable of adjusting to new information.[64] In addition, there may only be a little quantitative data from the field, since there may be a lack of suitable standard measures and interpreting the data using those measures might be challenging. Identifying the data collection method was found to be complicated for some studies, as they did not strictly obey the basic rules of any of the data collection methods because the data were derived from the Internet. It should be noted that, as a research environment, the Internet can be considered a new type.

When undertaking Internet research, the use of complementary data analysing methods might be useful. Since it has been argued that online sources are a way for a consumer to voice their opinions,[54] using analysis methods such as discourse or text analysis might offer significant results. Using these methods might be especially useful for research into rating websites or communities, which possibly include a great deal of data encapsulated in colourful speech, complex writing styles and interwoven contexts. Also, newer methods such as networking analysis and video analysis should be used more. One observation was that researching the combination of the Internet and healthcare is multidisciplinary. It may even be that a new branch of science, which combines informatics and healthcare, is about to be born.

As Setoyama et al.[55] and this review noted, research involving non-English speaking countries is limited. In this review, most of the studies explored countries where English was the primary language. The studies from English-speaking countries were most likely found because of the English language inclusion criteria. On the other hand, it should be noted that English-speaking sources may also include consumers from non-English speaking countries.[52]

In this review, three different kinds of health-related online sources were investigated as determined by the content analysis: health-related online communities, health-related rating websites and health-related social networking sites. These types of online sources were identified in research by Ziebland and Wyke,[4] who categorised some of the well-known health-related online sources. In addition, they found general health information sites and blogs, which were not found in this review. The lack of health information sites might be explained by the year range used by this study since, as a phenomenon, these kinds of sites are not new and are thus already a lot researched. While searching data, some articles described traditional health information sites, but they were not included since they did not include information of these sites' impacts. Thus, it can be asked, are the impacts of health information sites investigated enough? Usually, they were only explored from the viewpoint of secure and trustworthy information content. The lack of blogs and healthcare applications was surprising. There are plenty of blogs related to health[4] but the information retrieval did not include any articles that had researched just blogs and their impacts. Are blogs actually investigated or are they such a new phenomenon that they are still not found in searches? Unlike this review, Ziebland and Wyke[4] categorised PatientsLikeMe as a consumer review/reputation site, whereas this review saw it used more as a illness-related community, unlike the rating websites which included little or no illness information. It should also be noted that there are many different names for the different sources so, for example, online communities may also be called forums or groups. Therefore, there needs to be standard terms applied to health-related online sources.

The primary impacts found in the studies exploring consumer-led health-related online sources, as noted in this review, are empowerment; health literacy; physical, mental and emotional wellbeing; relationship between healthcare organisations and consumers; illness management; and peer support. The studies carried out by Ziebland and Wyke[4] and Barak et al.[65] supported the impacts found. As Ziebland and Wyke[4] found, so this study also found both negative and positive impacts. The negative impacts were that consumers felt that health-related online sources may create psychological issues through negative and egocentric comments and, in addition, they inflicted a loss of privacy. It is important to note that losing privacy occurs only in those cases where the consumer agrees to publish information under his or her own name. Usually, privacy site will offer the chance for a consumer to remain anonymous.[4,47]

Healthcare organisations need to also take information related to negative impacts into account when developing services related to online sources. However, negative impacts have been little researched in comparison to positive ones,[66] possibly because previous studies only focused on positive impacts. However, the absence of evidence for negative impacts does not mean they do not exist. Thus, exploring the negative impacts is also important, especially in cases where they might cause great harm or risks to the health of the healthcare consumer or to others.[66] Also, those impacts seen in a positive light might have a hidden dark side. Healthcare professionals are concerned that health-related online sources might become too trusted.[5] They believe that Internet information can often lead to consumers' becoming confused, distressed or misinformed and result in harmful self-diagnosis or self-treatment.[67] Is it safe for non-healthcare educated consumers, who have comprehensive access to all health literature provided on the Internet, to start diagnosing themselves or others?[68] Earlier studies have a disagreement over whether the healthcare consumers inform the healthcare professionals about the information picked from the Internet. The studies in this review showed that the use of online sources improved the relationship between the consumer and the healthcare professional.[46,52,56] However, some studies found that consumers preferred to hide Internet-based information from their healthcare professionals.[5,20]

In contrast to this review, Bartlett and Coulson[37] saw empowerment as a hyponym, causing further impacts such as health literacy and peer support. This review did not find that, but it is notable that empowerment was the most common emergent impact in the included studies[46,49,50] and it was often used in a context which implied that other things were caused by it. Thus, it can be questioned whether the empowerment is, as Bartlett and Coulson[37] predicted, a major impact of health-related online sources that enables the other impacts or, as Bartlett and Coulson[37] called, 'empowerment outcomes'. On the other hand, Johnston et al.,[43] whose main interest was empowerment as well, considered empowerment as a consequence of social support (cf. peer support). What is the relationship between impacts? Are some of them major impacts causing minor impacts?

Given that health-related online sources, in most cases, made healthcare consumers more competent actors and more aware of health issues, these sources may reduce consumers' drifting among the healthcare services. If almost 70 per cent of Scandinavians use the Internet to improve or maintain their health[3,22,23]), should also healthcare professionals, administrators and policymakers take advantage of this development? Healthcare consumers share their experience-based knowledge across the sources, in the process becoming experts or consultants whose knowledge might even be better than that of the healthcare professionals (Dolce, 2009). At present, the information exchange occurs between healthcare consumers and consumer-led health-related online sources. The recommendation based on the results of this review is that healthcare organisations should become a part of this behaviour by providing health-related online sources as a part of their corporate strategy. By doing this, healthcare organisations can become a part of this bidirectional information exchange, in which an organisation provides care for its consumers through trustworthy and safe information. According to Vennik et al.,[69] some healthcare consumers felt that the risk of getting untrustworthy information from the Internet could be reduced by getting the healthcare provider to participate in the conversation. In return, the organisation would receive valuable experience-based information from the consumers and possibly save resources. This is similar to the strategy of the site PatientsLikeMe – which is not only used inter alia for patient communication but also for providing data about the real-world nature of disease to help researchers, pharmaceutical companies, regulators, providers and non-profit organisations develop more effective products and care.[70] Finally, the Internet, with its health-related online sources and ubiquitous nature, could offer a cost-effective base for low-threshold services by providing anonymity and 24 h-a-day access.

As a whole, the use of online sources satisfied healthcare consumers' needs for a sense of community and emotional support,[49,51] as well as in terms of peer support.[47,50] Healthcare organisations could use this information when developing services in times of scarcer resources towards providing more effective healthcare services. Studies show that this is also what patients would like. This kind of development work is even more justified when the information available via online sources is of low quality,[16] in the situation when consumers primarily search for deeper information via online resources.[48] This kind of development would challenge the traditional way of working in healthcare[41] and shift the usual relationship between patient and professionals into more of a partnership.[46] So the big question is, are healthcare organisations and professionals ready for this size of change in their activities?

Our conclusions are as follows:

1. The predominant use of qualitative methods might be explained as the phenomenon of online sources is a relatively new one and the need for greater information is required. Also, research into consumer-led health-related online sources is largely limited to the English-speaking population. It could be essential to develop standard measurements when obtaining quantitative data from online sources. These measures could be developed in a way that takes account of the differences (e.g. culture, age or illness) between consumers.
2. The knowledge of the existence of the sources provides healthcare organisations with an opportunity to listen to their consumers' 'voice'. More research from the field of consumer-led health-related online sources is required, with it being important to define them and actively note new ones.
3. Healthcare consumers, as the users of consumer-led health-related online sources, are more competent and connected actors in regards to healthcare, even becoming experts who are capable of managing their illness. Their knowledge is a valuable resource for healthcare providers and policymakers that could be used more to develop better care.
4. Consumer-led health-related online sources have several positive impacts that might reduce the need for drifting among healthcare services and might save healthcare organisations' resources, should such companies incorporate these sites into their own corporate strategy. By doing this, an organisation could create a bidirectional channel with healthcare consumers, along which the healthcare organisation itself could transfer care and trustworthy information to its consumers. In return, consumers would offer their experience-based knowledge to the organisation. The Internet might be useful in producing low-threshold services. The Internet could provide the solution to many of the current problems with healthcare.

For future studies, the following subjects would be of interest to research: more detailed information about health-related online sources and their positive and negative impacts, the organisational viewpoint of online sources, and the use of health-related online sources among the non-English speaking population. In the future, research should analyse data collected from the Internet more effectively.

Limitations

An integrative literature review has the following limitations. As is the case with most literature reviews, there remains the possibility that some relevant articles may have been overlooked, particularly if studies did not mention specific online sources. Additionally, choosing the correct search terms for the retrieval of information may have been unsuccessful and using electronic databases may have introduced errors because of differences between different databases. Only peer-reviewed studies were included and thus relevant studies classified as grey literature might have been excluded. Finally, the researcher's lack of fluency in certain languages may have resulted in the exclusion of potential studies (n = 32). Undertaking a literature review does not raise any ethical questions, since it analyses previously completed research and no participants in that research are ever contacted.[71]

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Pervasive mobile healthcare systems for chronic disease monitoring

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Abstract

Pervasive mobile healthcare system has the potential to improve healthcare and the quality of life of chronic disease patients through continuous monitoring. Recently, many articles related to pervasive mobile healthcare system focusing on health monitoring using wireless technologies have been published. The main aim of this review is to evaluate the state-of-the-art pervasive mobile healthcare systems to identify major technical requirements and design challenges associated with the realization of a pervasive mobile healthcare system. A systematic literature review was conducted over IEEE Xplore Digital Library to evaluate 20 pervasive mobile healthcare systems out of 683 articles from 2011 to 2016. The classification of the pervasive mobile healthcare systems and other important factors are discussed. Potential opportunities and challenges are pointed out for the further deployment of effective pervasive mobile healthcare systems. This article helps researchers in health informatics to have a holistic view toward understanding pervasive mobile healthcare systems and points out new technological trends and design challenges that researchers have to consider when designing such systems for better adoption, usability, and seamless integration.

Keywords

body sensors, chronic disease monitoring, communication protocols, mobile computing, pervasive healthcare system

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Introduction

Modern societies are plagued with the continuous rising of fundamental health challenges, such as chronic diseases and a lack of medical professionals.[1,2] The proliferation of chronic diseases is now a serious social issue in the world. The World Health Organization (WHO) report on non-communicable diseases (NCD) shows that chronic conditions are still a global phenomenon and prominent cause of death among the population. NCD deaths are projected to increase from 38 million in 2012 to 52 million by 2030, and are currently responsible for 82 percent of deaths.[3] Very often, failure to manage chronic diseases results in lower quality of life, increased economic burden, and social problems.[4,5] There is an increasingly high need for cost-effective healthcare services that can be provided to everyone, everywhere, and anytime ubiquitously to support and monitor patients and to avoid expensive hospital-based care.[6]

Pervasive healthcare (PH) is a new discipline involving the use of ubiquitous computing technology to provide emergency and preventive healthcare services.[6] It is an emerging area with the widespread plethora of health sensors, communication protocols, and intelligent context-aware applications.[7] PH systems aim in pro-active detection of significant vitals of patients, ensuring preventive care and continuous monitoring solutions, thereby improving both system reliability and efficiency.[8] There is growing evidence that the benefits and importance of PH are worth the effort and are beyond argument.[9,10] The major benefits include its pervasive and assistive technology nature, self-management of conditions, remote monitoring, high-quality health assessment and medical service, and a significant reduction in escalating the cost of healthcare. Besides all these benefits, the patients can lead a normal life at their own convenience.[9,11] Nowadays, most PH systems are making use of mobile technologies due to their high accessibility and various inbuilt sensors. There has been an exponential rise in PMHSs and their potential to alleviate the burden of health issues. Many works have been done till now, but there is still a high need to conduct a state-of-the-art review of PMHSs to investigate recent trends in PMHSs and derive current opportunities and challenges for future expansion of this emerging research area.

The remainder of this article is structured as follows: In section “Research methods”, a research methodology is presented based on Kitchenham’s guidelines to plan, conduct, and report the review. Section “Planning the review” presents the planning phase used to extract potential articles from IEEE Xplore Digital Library and points out the data sources, search terms, inclusion, and exclusion criteria. Section “Conducting the review” lists down the main steps that are used to conduct the review. Section “Reporting the review” presents the analysis of the publications exhibiting the inclusion criteria and reports the results by (1) classifying the 20 systems that were reviewed and (2) discussing the general results for each PMHS. Section “Discussion” discusses the 20 PMHSs at different levels in terms of node level, network level and human level. Section “Open research challenges” focuses on the potential research challenges and opportunities. Finally, section “Conclusion” concludes the article.

Research methods

In this article, a systematic literature review is conducted by identifying, evaluating, and interpreting all available research relevant to the topic area “Pervasive Mobile Healthcare Systems for Chronic Disease Monitoring.” The systematic review is undertaken to summarize existing evidence of the benefits and limitations of the study, to identify gaps and open challenges in order to suggest new directions for future research, and to provide a foundation for new research work. The systematic review is carried out in three phases according to the guidelines proposed by Kitchenham,[12] namely (1) Planning the review (2) Conducting the review, and (3) Reporting the review which are discussed further in section “Planning the review.”

Planning the review

In order to plan the review, a pre-defined protocol is used to determine an appropriate strategy to undertake the review, which consists of (1) the data sources to be searched (including databases, specific journals, and conference proceedings), (2) the search terms, and (3) the inclusion and exclusion criteria considered in the review.

Data sources

With the advance and prevalence of pervasive health, the number of publications related to PMHSs has risen significantly since the past few years. After exploring some databases to conduct searches, highest relevance of indexed papers was found mainly in IEEE Xplore Digital Library. Therefore, the IEEE Xplore Digital Library was selected for this particular review as it is more appropriate for PMHS-oriented topics.

Search terms

Articles were found via computerized search of the topic areas. In order to select typical PMHS and at the same time narrow down the selected publications in a reasonable range, the search term ((pervasive health system) AND (mobile) AND (chronic disease)) was used. The search was limited to the last 5 years, namely between 2011 and 2016. A detailed illustration of methodology for extracting articles is followed. The last update was on 12 March 2016.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were used to select and accept the published articles to review the state-of-the-art PMHSs for monitoring chronic diseases.

To be included in the review, a system had to exhibit the following characteristics:

- Use of mobile phone and wireless infrastructure as an intervention,
- Support for chronic disease monitoring,
- Use of biosensors,
- Articles published from 2011 to 2016.

Systems excluded from the review exhibited any of the following characteristics:

- Articles that describe systems that do not contribute original research;
- Articles that describe systems where the sole purpose is to educate the patient about the disease;
- Articles that describe systems without an English-language user interface;
- In the form of book chapters, guest editorials, unpublished working papers, master's and doctoral dissertations, and article summaries

Conducting the review

The review was conducted according to the planning phase. Moreover, Mendeley was used for document management, and Excel was used for data extraction and analysis.

Selection process

The selection process follows the multistage process based on Kitchenham's guidelines. Initially, key terms were searched in the data source whereby a total of 683 non-duplicated articles were retrieved. After exclusion of the articles based on the title, abstracts, and full texts, only 33 articles remained. Finally, after the exclusions based on papers exhibiting only the inclusion criteria, the systematic review resulted in 20 unique relevant solutions.

Data analysis

The results of the data analysis are reported in section "Selection process." The results highlight the key features and requirements and identify research gaps of the 20 systems that were reviewed with the aim of identifying critical factors to improve the adoption, usability, and seamless integration of PHMSs in the patients' life and in the context of the larger patient-centric healthcare system. The first section of the result classifies the 20 PMHSs into four major categories of monitoring, namely (1) self-monitoring, (2) assisted monitoring, (3) supervised monitoring, and (4) continuous monitoring. The second section includes the general results which comprise detailed analysis of the (1) target audience, (2) sensor types, (3) contextual information/parameters monitored, (4) architecture of PMHSs, (5) communication protocols, (6) incentives and motivations, and (7) decision-making techniques.

Reporting the review

The state-of-the-art PMHSs for monitoring of chronic diseases that have been reported in the literature were investigated. After analysis of the selected articles, the PMHSs were grouped into four main categories. The following section presents the results and classifies the PMHSs.

Classification of PMHSs

Depending on the use, complexity of the system, and whether intervention of health professionals is required, PHMSs are often classified into four main categories, namely self-monitoring, assisted monitoring, supervised monitoring, and continuous monitoring. The 20 PMHSs are discusses further in the section below.

Self-monitoring. Self-monitoring usually makes use of technologies that can support the shift from managing illness to maintaining wellness through preventive care. Technologies for self-monitoring usually include an integration of both invasive and non-invasive sensors, mobile applications that enable patients to gather, monitor, and manage their own personal health. Self-monitoring of diseases do not involve external caregiver but is rather focused on self-care, self-discipline, and self-confidence of patients. The self-monitoring systems mainly consist of a wireless body area network (WBAN) and a mobile unit (MU). The WBAN typically consists of a collection of low power, miniaturized, invasive, or non-invasive, lightweight devices with wireless communication capabilities that operate in the proximity of the human body to collect the patient's physiological and contextual parameters. These sensors' data are wirelessly transmitted to the MU which store, process, and analyses the physiological data in order to notify the patient through a user-friendly and interactive graphical or audio interface. In the systems reviewed (n = 20), the MU was either a smartphone (19) or a personal digital assistant (PDA, 1). Typical diseases that are usually self-monitored (Figure 1) are chronic obstructive pulmonary disease (COPD) and sleep apnea. The self-monitoring systems and the different criteria are presented in Table 1.

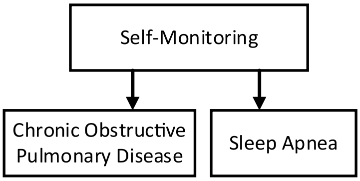

Figure 1. Self-monitoring diseases.

Hofer et al.[13] propose a personal health system platform which uses Vital Sign Monitor1 (VSM1), a wearable medical sensor, to continuously monitor vital signs such as heartbeat, skin temperature, and movement/activity of patients with COPD. These sensor data are sent to an Android smartphone that acts as a data collector and are ultimately sent to an observation storage by means of interoperability standards. Compressed sensing techniques are also used to efficiently acquire and reconstruct each signal. Similarly, Juen et al.[14] developed a middleware software which runs on stand-alone smartphones with sensor chips similar to medical accelerometers to automatically detect the gait speed during natural walking to predict natural walking speed and distance during a 6-min walk test (6MWT) which is standard assessment for COPD and congestive heart failure. Thanuja and Balakrishnan[15] propose a sleep apnea monitoring system in smartphone using the matrix laboratory (MATLAB) tool. Electrocardiogram (ECG) sensors are used to record the heart activities and process the ECG signals to monitor obstructive sleep apnea episodes. The final output is then sent to Android mobile phone for alert.

Although some of the systems connect to a remote server to store and process the vital signs to notify the patients, they do not involve the interactions of healthcare professionals.

Assisted monitoring. Assisted-monitoring systems go beyond self-monitoring systems whereby the patients can request the assistance of an external health professional through SMS, phone calls, emails, and audio alarm in case of emergency. These systems usually consist of a WBAN, an MU, and a remote server. Most of the systems reviewed that provide assisted monitoring are focused on patients with asthma, risks of fall, cardiac disease, and any other chronic diseases (Figure 2).

Al-Dowaihi et al.[16] propose a prototype system whereby asthma's patients can self-monitor and manage their health condition accurately, as well as informing the health professionals in case of emergency. The patients make use of a peak flow meter to measure the degree of obstruction in the airways, and these data are then sent to an Android mobile phone through Bluetooth. Then, the patient's data are sent to the web portal. The medical staff perform daily check-ups and the health professionals monitor all the patients' history, triggers, symptoms, and medications, and take appropriate actions.

Horta et al.[17] propose a system specifically for elderly patients suffering from the risks of fall. This system consists of three modules, namely (1) fall detection, (2) data processing and visualization of information from sensors, and (3) communication through web services with medical staff and external database storage. The built-in smartphone accelerometers detect the daily movements' accelerations in order to detect user fall. The wearable body sensors (ECG, respiration, electrodermal activity (EDA), blood volume pulse, and electromyography) collect vital parameters and fall detection data that are sent to the smartphone through Bluetooth for biofeedback monitoring. The smartphone then sends the patient's data to the web services that can alarm the medical staff.

Liu et al.[18] developed a novel family-based long-term healthcare monitoring system called "HealthKiosk" that provides rich contextual information and alerting mechanisms for any chronic conditions of elderly, children, and young fitness trainers. People suffering from any chronic disease can use their installed biomedical sensors (e.g. glucose meter, blood pressure, etc.) to take measurements. Then, the sensed data are sent to a small server or smartphone via existing communication

Table 1. Self-monitoring systems.

Cite	Description	Targeted audience	Parameters and devices	Communication protocols
Hofer et al.[13]	An interoperable personal health system To monitor and compress signals in chronic obstructive pulmonary disease	Pulmonary patients	Tier1: SpO2, HR, BT, BP, ECG,PA Tier2: smartphone Tier3: server	Bluetooth, HTTPs, WAN
Juen et al.[14]	A natural walking monitor for pulmonary patients using mobile phones	Pulmonary patients	Tier1: PA, HR, SpO2 Tier2: Android smartphone Tier3: -	Bluetooth, Internet
Thanuja and Balakrishnan[15]	Real-time sleep apnea monitor using ECG	Sleep apnea patients	Tier1: ECG Tier2: Android smartphone Tier3: -	GSM/UMTS

BT: body temperature; BP: blood pressure; ECG: electrocardiogram; GSM: global system for mobile communication; HR: heart rate; HTTP: Hypertext Transfer Protocol; PA: pulmonary artery; UMTS: Universal Mobile Telecommunication Service; WAN: wide area network.

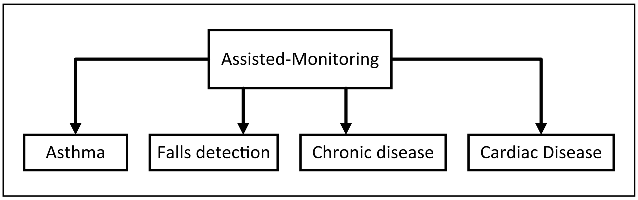

Figure 2. Assisted-monitoring diseases.

networks like 3G, Wi-Fi, and Bluetooth. Afterward, the integrated data are sent to a backend support system where the clinical decision-supporting system processes the medical data and detects any deterioration to generate alert and invoke intervention of health professionals if needed.

The WellPhone presented by Moser and Melliar-Smith[19] is used as a personal health monitoring device which interfaces various health monitoring devices, such as blood pressure monitor, body weight scale, pulse oximeter, blood glucose meter, and accelerometer to the smartphone, and collects physiological data from those devices. This device provides feedback to the patients who are suffering from any chronic diseases by means of visualization and speech interaction, and alerts a health professional if needed.

SHARON is a novel tension-free mobile application system with implantable cardio defibrillator system and sensor mechanisms developed by Kumar and Ganesan.[20] It is specifically focused on people with cardiac diseases and uses built-in smartphone stethoscope. Alerts are triggered when patients reach critical level and an alarm is eventually initiated to be sent to the patients' family members. The system also fixes appointment in the nearest hospital zone if necessary.

To summarize, these assisted-monitoring systems allow the patients to request the assistance of an external caregiver in case of emergency to whom only the data are forwarded (Table 2).

Table 2. Assisted-monitoring systems.

Cite	Description	Targeted audience	Parameters and devices	Communication protocols
Al-Dowaihi et al.[16]	Self-monitoring of people with asthma	Asthma patients	Tier1: peak flow meter Tier2: Android smartphone Tier3: server	Bluetooth, Internet
Horta et al.[17]	A mobile health application for falls detection and biofeedback monitoring	Elderly/falls detection	Tier1: PA, ECG, EMG, BVP, EDA, respiratory Tier2: smartphone Tier3: server	Bluetooth, Internet, Wi-Fi, HTTP
Liu et al.[18]	A family-based connected healthcare system for long-term monitoring	Chronic patients	Tier1: BP, HR Tier2: smartphone Tier3:	3G, Wi-Fi, Bluetooth, WAN, HTTP
Moser and Melliar-Smith[19]	A smartphone used as a personal health monitoring device	Chronic patients	Tier1: BP, weight, HR, SpO2, blood Glucose, PA Tier2: smartphone Tier3: -	Bluetooth
Kumar and Ganesan[20]	New mobile-based health application to cater the well-being of heart	People with cardiac disease	Tier1: ECG, SpO2 Tier2: PDA, PC, smartphone with stethoscope microphone, Tier3: server	Internet, GSM

BT: body temperature; BP: blood pressure; BVP: blood volume pulse; ECG: electrocardiogram; EDA: electrodermal activity; EMG: electromyography; GSM: global system for mobile communication; HR: heart rate; HTTP: Hypertext Transfer Protocol; PA: pulmonary artery; PDA: personal digital assistant; UMTS: Universal Mobile Telecommunication Service; WAN: wide area network.

Supervised monitoring. Supervised monitoring goes a level beyond assisted monitoring whereby the health professionals not only intervene in case of emergency but instead all the physiological data are periodically sent and stored remotely for doctors, family, and friends to access the current and the past conditions of the patients or to configure the wireless body sensors remotely using a conventional web browser. Most of the systems are related to continuously monitor the health parameters of people suffering from cardiac diseases, hypertension, and any other chronic diseases (Figure 3), and they also include a component to manage emergency situations.

The system proposed by Nawka et al.[21] is either patient-driven or doctor-driven in case of emergencies, service-oriented, and provides a user-friendly interface for health management. It is based on ISO/IEEE11073 (X73) family of standards supporting high-quality medical sensors and uses the existing communication protocol for faster and reliable access to data. JavaScript Object Notation (JSON), a lightweight text-based open standard, is also used to represent data that are transferred between the system and remote server through the Hypertext Transfer Protocol (HTTP). The health professionals are connected to the remote server, and once the data are received, they perform their clinical diagnosis and transmit diagnostic reports with e-prescriptions back to the patients over HTTP.

Triantafyllidis et al.'s[22] system is based on unobtrusive vital signs monitoring through a non-invasive multisensing sensor, service-oriented architecture to handle any communication issues,

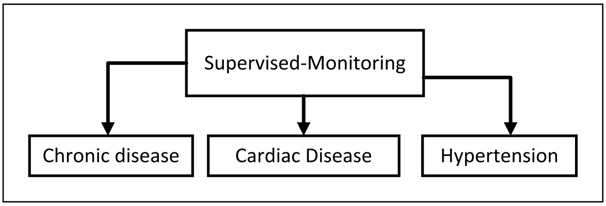

Figure 3. Supervised-monitoring diseases.

and popular social service such as micro-blogging to share and discuss the recorded information within the patient's community.

Rotariu et al.[23] propose a remote blood pressure and heart rate monitoring system for continuous long-time patient monitoring as a part of a diagnostic procedure. The patients can seek assisted healthcare if they are suffering from a chronic condition or supervised healthcare during recovery from any severe condition or surgical procedure. The system uses low-powered devices suitable for battery operation and high-peak performance. The PDA receives the blood pressure and heart rate values from the attached wireless blood pressure and heart rate monitor and sends alarms to the users (patient's physician, healthcare specialist, ambulance center, or hospital) when these values exceed the preset limits. The PDA also communicates periodically to the central monitoring server through the Internet by using Wi-Fi or global system for mobile communication (GSM)/General Packet Radio Service (GPRS).

To summarize, in such systems (Table 3), once any abnormality is detected in the patient's vital signs and behavioral patterns, a warning message is sent immediately to the health professional's mobile phone in order to initiate the appropriate actions. A web-based interface is also used to synchronize data with the smartphone, to process and present data on a real-time basis so as to ensure a complete data analysis, precise health management, and on-time remote assistance for the patients by doctors and nurses.

Continuous monitoring. Continuous-monitoring systems not only include all the functionalities of self-monitoring, assisted monitoring, and supervised monitoring but also comprise of a shared approach between the patient and health professionals. Such systems collect and analyze physiological signs on a real-time basis using intelligent techniques which correlate data from multiple sensors in order to offer real-time assistance or preventive actions to the patients. These systems are devised specially for people suffering from stress, cognitive impairment, dementia, or Alzheimer who require real-time continuous monitoring and assistance (Figure 4).

Abbate et al.[29] proposed MIMS, a minimally invasive monitoring sensor, that provides comprehensive and customizable health monitoring services, especially to elderly patients suffering from cognitive impairment, risks of falls, dementia, and Alzheimer's disease. MIMS offers active and passive 24×7 monitoring of patients' physical activities and vital signs. The sensed data are analyzed preceding potential emergency events using advanced intelligent systems in order to predict them quickly.

Duarte et al.[30] developed a mechanism for indoor patient monitoring for medical purposes which rely on real-time continuous sensing algorithm to determine the location of a patient inside his or her home at each moment. Medical specialists continuously monitor the daily activities of patients and detect changes in the patients' behavior that could be interpreted as early signs of any health-related issue.

Table 3. Supervised-monitoring systems.

Cite	Description	Targeted audience	Parameters and devices	Communication protocols
Ramesh et al.[24]	A mobile software for health professionals to monitor remote patients	Chronic patients	Tier1: ECG, BP Tier2: smartphone Tier3: server	2/3G, Bluetooth, Internet, GSM/ Wi-Fi
Postolache et al.[25]	Enabling telecare assessment with pervasive sensing and Android OS smartphone	Chronic patients	Tier1: PA, HR, SpO2 Tier2: Android Smartphone Tier3: Server	Bluetooth, Internet, Wi-Fi, UMTS
Nawka et al.[21]	A scalable and extensible smartphone-based healthcare system to provide real-time continuous monitoring of health conditions of individuals	Chronic patients	Tier1: ECG, BP, BT, weight, glucometer HR, SpO2 Tier2: Android wmartphone Tier3: server	HTTP, Bluetooth, UART, USB, WiFi, Zigbee
Jiménez and Torres[26]	An IoT-aware healthcare monitoring system	Chronic patients	Tier1: HR Tier2: smartphone Tier3: server	Bluetooth, Internet, XMPP
Triantafyllidis et al.[27]	Personalized sensor-based system for pervasive healthcare monitoring	Chronic patients	Tier1: HR, BR, BT, BP, PA Tier2: smartphone Tier3: -	Bluetooth, HTTP, Internet, web services
Triantafyllidis et al.[28]	Supporting heart failure patients through personalized mobile health monitoring	People with cardiac disease	Tier1: BP, HR, SpO2, weight, PA Tier2: Android Smartphone Tier3: Server	Bluetooth, HTTP, 3G/4G, TSL
Triantafyllidis et al.[22]	A pervasive health system integrating patient monitoring, status logging, and social sharing	People with hypertension	Tier1: HR, PA, BT, BR Tier2: smartphone Tier3: server	HTTP, Bluetooth, Internet, wireless
Rotariu et al.[23]	A remote blood pressure and heart rate monitoring system	People with hypertension	Tier1: BP, HR Tier2: PDA Tier3: server	Wi-Fi, Internet GSM/GPRS, SimpliciTi

BT: body temperature; BP: blood pressure; ECG: electrocardiogram; GSM: global system for mobile communication; HR: heart rate; HTTP: Hypertext Transfer Protocol; PA: pulmonary artery; PDA: personal digital assistant; UMTS: Universal Mobile Telecommunication Service; WAN: wide area network; XMPP: Extensible Messaging and Presence Protocol.

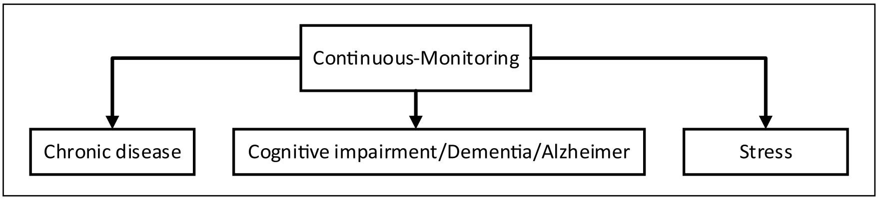

Figure 4. Continuous-monitoring diseases.

Table 4. Continuous-monitoring systems.

Cite	Description	Targeted audience	Parameters and devices	Communication protocols
Abbate et al.[29]	A minimally invasive monitoring sensor platform for active and passive monitoring of human movements and physiological signals	Cognitive impairment/ dementia/ Alzheimer	Tier1: PA, EEG, REM Tier2: smartphone/ laptop/PDA Tier3: server	IEEE 802.15.4, Zigbee, Internet Bluetooth, cellular network
Duarte et al.[30]	Novel solution for indoor patient monitoring for medical purposes	Chronic patients	Tier1: PA Tier2: Android smartphone Tier3: –	Wi-Fi, Internet
Majeed et al.[31]	Mobile healthcare system to reduce the distance between the patient and the healthcare center for long-term nursing care	Chronic patients	Tier1: HR Tier2: Android smartphone Tier3: server	GSM, GPS, Wi-Fi, Internet
Zhang et al.[32]	A mobile and remote stress monitoring, alleviation and management system	People with anxiety	Tier1: ECG, HR, PA Tier2: smartphone Tier3: server	Bluetooth, 3G, Wi-Fi

ECG: electrocardiogram; EEG: electroencephalograph; GSM: global system for mobile communication; GPM, gross potential market; HR: heart rate; PA: pulmonary artery; REM; PDA: personal digital assistant.

Majeed et al.[31] proposed a mobile monitoring healthcare system for the chronic patients who need long-term nursing care and thereby decreases the need for patients to go to the hospital visits or stay. The system senses the patients' physiological parameters, monitors the patient status, and ultimately notifies center and records the patients' details that can be accessed by the physician from anywhere and anytime.

Zhang et al.[32] presented deStress, a mobile and remote stress monitoring system that monitors and manages stress. Patients' psychological stress data are collected, analyzed, and shared with healthcare professionals. Moreover, a feedback approach is presented that is based on adaptive respiration to set the ideal personalized respiration parameters and consequently adjust the patient respiration frequency to alleviate the stress.

To summarize (Table 4), these continuous-monitoring systems use intelligent algorithms in order to provide continuous and ubiquitous information flow between the patients and healthcare professionals. These systems provide both real-time interventions in response to critical event alerts and also provide preventive customized feedback.

General results

The following section evaluates the 20 existing PMHSs and most of them are targeted toward chronic and elderly patients suffering from diseases. Most systems are developed on either wireless local area network or wireless personal area network. The PMHSs use various sensor devices and mobile phones to capture or transmit the physiological data. In order to transmit the data, common communication protocols, such as Wi-Fi, Bluetooth, Internet, 2G/3G/4G, and ZigBee, are used. Most systems are developed on architectures like client–server, web-based, or stand-alone. The

Table 5. User-oriented and manufacturer-oriented requirements.

Requirements	Description	User/manufacturer
Value	Must add value to the user's quality of life	User-oriented
Safety	Must be biocompatible, unobtrusive, and safety-tolerant to prevent harm to the user	User-oriented
Security	Must consist of security measures such as user authentication to percent unauthorized access and manipulation	User-oriented
Privacy	Sensor design needs to be unobtrusive to keep medical conditions discrete. Moreover, sensors must be able to protect sensitive information about patient through encryption techniques	User-oriented
Compatibility	Must be able to seamlessly integrate and interoperate with other sensor nodes or networks through proper standardization of communication protocols and data storage	User-oriented
Ease of use	Need to be miniature, unobtrusive, ergonomic, easy to wear, and stylish	User-oriented
Regulatory processes	Federal Communications Commission (FCC) certification and United States Food and Drug Administration (FDA) approval to get products to market	Manufacturer-oriented

user acceptance is usually influenced by specific motivations and incentives, and different decision-making techniques are used for intelligent decision making. The different aspects of the systems such as the target audience, the sensor types used, the types of architectures of the PMHSs, the communication protocols to transfer information, contextual information/parameters monitored, incentives and motivation triggers, and decision-making techniques in different PMHSs are presented and discussed.

Target audience. PMHSs are developed for a target audience of chronic or elderly patients suffering from illnesses like COPD, cardiac diseases, asthma, sleep apnea, hypertension, stress, cognitive impairment, dementia, Alzheimer's, risks of fall, and many other chronic conditions. These PMHSs are mostly convenient to patients who prefer home and out-patient care rather than hospitalization. Many other patients are geared toward these systems since they can easily tap into patient-centric healthcare services whereby healthcare professionals can assist them in the diagnosis and treatment of their conditions and consequently adding value to their life. In fact, Boulos et al.[33] highlighted that the higher adoption rate of smartphones by elder people and patients with chronic disease will depend on cost, usability, awareness, and the type of technology.

Sensor types. Sensor nodes are usually composed of either on-body or implantable nodes. All sensor nodes are equipped with wireless transceiver unit, mini processor, and energy supply device like battery. They sense, collect, and process various physiological vital signs of patients. These sensed data are then forwarded to an access point using a wireless interface. Widespread sensors' adoption and diffusion depend on several factors[34] involving both the user and the manufacturer as shown in Table 5. Common sensor nodes used in setting up PMHSs are accelerometer, glucometer, blood pressure, respiration, ECG, electroencephalograph (EEG), electromyography (EMG), electrooculography (EOG), pulse oximeter, and body temperature.

Contextual information/parameters monitored. Wireless sensor devices are used to continuously collect and transmit the physiological vital signs so as to monitor health of patients and offer timely intervention and healthcare services. Out of the 20 studies that were analyzed (Table 6), most of them used accelerometers or mobile phone in-built accelerometers to measure the physical activity, heartbeat, and respiration of the individuals.[14,19,32]

Pulse oximeters are also commonly used to monitor heart rate, ECG, and blood oxygen level.[14,19,21,28] Height[18] and weight[18,19,21,28] sensors are used to measure the height and weight of individuals. Thermometers are also used in the measurement of body temperatures.[21] A peak flow meter is used to measure the degree of obstruction in the airways, especially in asthmatic patients.[16] Blood pressure monitors are used to collect readings of the blood pressure[18,19,21,24,27,28] and heart rate[23] of the patients. A blood glucose meter is essential to monitor the blood glucose level of patients.[19,21]

VSM1 is a wristwatch-type wearable medical device that is placed on the patients' upper arm. It has sensors in direct contact with the skin and continuously monitors vital signs such as heartbeat, skin temperature, and movement/activity for patients suffering from COPD.[13] Smart wrist-worn devices are also used to sense photoplethysmography (PPG), heart rate, blood oxygen level, and physical activity for chronic patients.[25]

Zephyr BioHarness is a wearable multi-sensing device that monitors heart rate, activity, posture, respiration rate, and skin temperature[22,27] for chronic and hypertensive patients. The Bioplux system base-station is a device that consists of a big range of health sensors, such as the accelerometer, ECG, electromyography (EMG), blood volume pulse (BVP), EDA, and respiration sensor that collects the patients' signals to detect risks of falls.[17]

Jiménez and Torres[26] used CC2451 sensortag to gather vital data about temperature, humidity, pressure, accelerometer, gyroscope, magnetometer, and smart sensor type chest strap belt to monitor the heart rate of patients.

Abbate et al.[29] use the Shimmer sensor to monitor body movements of patients, and Enobio sensor that senses rapid eye movement (REM) signals to monitor sleep stages and senses EEG signals to monitor brain activity during sleep for patients suffering from cognitive impairment, dementia, or Alzheimer's.

To summarize, it is of paramount importance that all the sensed contextual information or parameters meet the standards of quality of information (QoI) and which is ultimately essential for fast, reliable, timely decisions, and user acceptance.

Communication protocols. Sensor data from existing PMHSs are currently being communicated to the access point using various communication protocols such as 2G/3G, 3G/4G, Bluetooth, Wi-Fi, and GSM/Universal Mobile Telecommunication Service (UMTS), IEEE 802.15.4, ZigBee, UBS, and GPRS. Sensor data are often transferred to the remote station using Internet or Simple Object Access Protocol (SOAP) over HTTP. Since the PMHSs involve many biosensors, interactions with mobile phone, remote, and web servers, it is very important to consider the qualitative aspect of the communication protocol. The connectivity should be stable and without interference during any exchange of information so that the systems are efficient and performant.

Architecture of PMHS. The commonly used architectures to develop PMHSs are client-–server, web-based, or stand-alone. Systems using a client–server or web-based share the same type of architecture and usually consist of three Tiers, namely Tier 1 (WBAN), Tier 2 (Access Point—AP), and Tier 3 (Remote Server). Tier 1 refers to the wireless communication between body sensor nodes and AP, Tier 2 is used to transfer the sensors data to the remote server using appropriate communication protocols, and Tier 3 refers to the remote server that provides just-in-time monitoring

Table 6. Sensors and parameters monitored.

Cite	Sensors/parameters monitored
Hofer et al.[13]	VSM1: monitor vital signs like, for example, heartbeat, skin temperature, or physical activity
Juen et al.[14]	Mobile phones with accelerometer complemented with MoveSense (a sensing middleware that overcome firmware limitations in current smartphones converting them into medical quality monitors): monitor physical activity, heart rate Nonin Onyx II 9560 Bluetooth Pulse Oximeter: monitor heart rate and blood oxygen level
Thanuja and Balakrishnan[15]	ECG sensor: ECG signal collection
Al-Dowaihi et al.[16]	Peak flow meter: measure the degree of obstruction in the airways
Horta et al.[17]	Bioplux system base-station: collects signals from the sensors (accelerometer, electrocardiogram (ECG), electromyography (EMG), blood volume pulse (BVP), electrodermal activity (EDA), and respiration sensor)
Liu et al.[18]	Height, weight sensor, and blood pressure sensor: collect height, weight, and blood pressure measurements
Moser and Melliar-Smith[19]	Blood pressure monitor: record blood pressure readings Body weight scale: measurement of an individual's weight Pulse oximeter: measures the pulse rate and the blood oxygen saturation level of the individual Blood glucose meter: monitoring of blood glucose Accelerometer: record the level of physical activity, heartbeat and respiration of the individual
Kumar and Ganesan[20]	Mobile phone with a stethoscope comprising Sharon sensor: Record medical information of patients
Ramesh et al.[24]	Wireless body sensors: sense ECG and blood pressure
Postolache et al.[25]	Smart wrist-worn device: sense photoplethysmography (PPG), heart rate, blood oxygen level, and physical activity
Jiménez and Torres[26]	CC2451 sensortag: gather ambient data (temperature, humidity, pressure, accelerometer, gyroscope, and magnetometer) Smart sensor type chest strap belt: sense heart rate
Triantafyllidis et al.[28]	Blood pressure and heart rate monitor: measure blood pressure Weighing scales: measure weight Pulse oximeter: measure oxygen saturation Bio-patch: continuous measurement of heart rate and activity
Nawka et al.[21]	Pulse oximeter: measure heart rate Blood pressure monitor: record blood pressure readings Thermometer: measure body temperature Weighing scale: measure weight Glucose meter: monitor blood glucose
Triantafyllidis et al.[27]	Zephyr BioHarness (wearable multi-sensing device): monitor heart rate, activity, posture, respiration rate, and skin temperature Blood pressure monitor: record blood pressure readings Weight scales: measure weight
Triantafyllidis et al.[22]	Zephyr BioHarness (wearable multi-sensing device): monitor heart rate, activity, posture, respiration rate, and skin temperature
Rotariu et al.[23]	A&D UA-767PC blood pressure monitor: measure blood pressure and pulse rate

(Continued)

Table 6. (Continued)

Cite	Sensors/parameters monitored
Abbate et al.[29]	Shimmer sensor: monitor body movements Enobio sensor: sense rapid eye movement signals to monitor sleep stages and sense electroencephalograph (EEG) signals to monitor brain activity during sleep
Duarte et al.[30]	Sensor embedded in smartphone: monitor the location of a patient
Majeed et al.[31]	Sensor embedded in smartphone: record biosignals from the patient
Zhang et al.[32]	Wearable stress monitor consisting of two sensors: (1) pulsometer to monitor PPG signal and (2) tri-axial accelerometer to measure acceleration signal

of received data. Stand-alone architectures use the mobile phone as both the sensor and AP. While designing the architecture of the PMHSs, several design challenges are taken into consideration (Table 7) to improve the adoption of such systems.

Motivations and incentives. With the advancement and prevalence of PH applications, user acceptance has become a pertinent criterion that needs to be met besides the proper functioning of the system. Very few research focus on user acceptability and important factors that persuade people to accept and use health monitoring systems.[35]

According to the study of Aflaki et al.,[35] user acceptance is dependent on intrinsic motivations and extrinsic incentives. As depicted in Figure 5, intrinsic motivations are any activity that excite people to do something for the sake of enjoyment of the activity itself, whereas extrinsic incentives are external factors which are designed to influence behavior of people. Therefore, when intrinsic motivations match extrinsic incentives, that is, if what motivates people from inside matches facilities and supports provided externally, the system acceptance will be greater.

Motivations and incentives for self-monitoring systems. Table 8 shows that in self-monitoring systems, both intrinsic motivations and extrinsic incentive factors that influence patients' behaviors are well-being programs whereby the patients self-monitor their health parameters to ensure a preventive lifestyle and early diagnosis to help them stay healthy and preserve their well-being.

Motivations and incentives for assisted-monitoring systems. Table 9 shows that in assisted-monitoring systems, intrinsic motivations factors that influence patients' behaviors are related to their well-being, such as awareness of their health conditions,[16,17,19] well-being of their hearts,[20] and of the treatment[16–19] they receive based on the diseases they are suffering from. Most extrinsic incentives factors are related to well-being programs[16,18,19] and health services for a free/reduced price.

Motivations and incentives for supervised-monitoring systems. Table 10 shows that in supervised-monitoring systems, both intrinsic motivations and extrinsic incentives factors that influence patients' behaviors are related to the treatment they are receiving for the diseases they are suffering from and the real-time health services they are provided with.[21–27] In Triantafyllidis et al.'s[22] system, the intrinsic motivation and extrinsic incentives are linked with social sharing where the patients can discuss their symptoms and health conditions with their relatives and community network for better health support.

Table 7. Design challenges considered.

Cite	Design challenges considered
Hofer et al.[13]	Performance, security, and interoperability constraints were considered while designing the system. Performance was boosted through lossy compression techniques, security was addressed to secure resources, and interoperability was increased by reusing the mobile app with different server side implementations and using HL7 message format.
Juen et al.[14]	Accuracy constraint was considered by lowering the error rates while predicting the walk distance.
Thanuja and Balakrishnan[15]	Accuracy and less computation time constraint have been considered to increase the efficiency of the system to analyze the ECG signal using MATLAB tool.
Al-Dowaihi et al.[16]	Efficiency and accuracy aspects have been considered to monitor and record asthma symptoms.
Horta et al.[17]	The flexibility and robustness of the hardware used have been taken into account to allow system reliability.
Liu et al.[18]	Performance criteria have been considered by comparing to st pf* case studies. The aspect of usability has taken into account by providing a user-friendly interface to patients.
Moser and Melliar-Smith[19]	Security and privacy aspects have been considered by using security standards like National Institute of Standards and Technology (NIST) and Health Insurance Portability and Accountability Act (HIPAA) to maintain privacy and confidentiality of patients.
Kumar and Ganesan[20]	Security management of the system has been considered by involving embedding, identification and rights validation for all users.
Ramesh et al.[24]	Security aspects have been considered by using SQLite database to ensure confidentiality.
Postolache et al.[25]	The system architecture focuses on sensitivity, repeatability, and robustness to accurately predict health risk factors.
Jiménez and Torres[26]	The aspect of extensibility during runtime was considered while designing the system by using low-cost wireless sensors and already existent Internet of things technology as communication platform.
Triantafyllidis et al.[28]	Usability and user satisfaction constraints have been considered when designing the system to ensure wide acceptance of the system.
Nawka et al.[21]	Interoperability and scalability aspects have been considered for remote monitoring of patients who seek professional and regular healthcare. The system is developed using IEEE 11073-20601 standard which provides real-time plug-and-play interoperability and its' abstraction layers are customized. The aspect of usability has taken into account by providing a user-friendly interface to patients.
Triantafyllidis et al.[27]	Usability and privacy aspect was considered while designing the system to promote a sense of security and reassurance to the patients.
Triantafyllidis et al.[22]	Security and privacy aspect was considered via protocols such as OAuth.
Rotariu et al.[23]	Cost minimization, extensibility, and reliability have been considered by using devices with low power consumption and effective Internet network infrastructure.
Abbate et al.[29]	The system focuses on optimizing the information derived from sensor networks to support the dynamic information needs of a broad spectrum of intelligent sensor-enabled applications.

*Performance criteria have been considered by comparing two set of case studies. The aspect of usability has taken into account by providing a user-friendly interface to patients.

(Continued)

Table 7. (Continued)

Cite	Design challenges considered
Duarte et al.[30]	Performance and applicability of the system were implemented and analyzed for wider user acceptance.
Majeed et al.[31]	The system architecture aims at minimizing the need for additional attached sensors and minimizing the use of the network.
Zhang et al.[32]	(1) Terminal versatility, (2) reliable data transmission and storage, (3) high sensor data quality and validation, (4) wearability and battery life, and (5) algorithms efficiency and computational inexpensiveness were considered by (a) using only one wearable physiological sensor to increase the user comfortableness, (b) building a cloud system for stress data management, (c) designing an efficient stress monitoring algorithm to quickly monitor the stress level, (d) increasing the battery life, and (e) implementing a GUI on smart phone platforms to improve the user experiences.

ECG: electrocardiogram; GUI: graphical user interface; MATLAB: matrix laboratory.

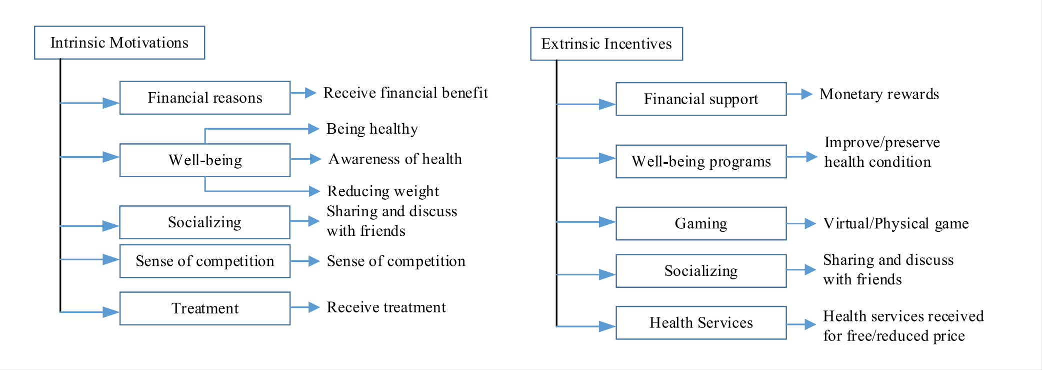

Figure 5. Intrinsic motivations and extrinsic incentives.

Table 8. Incentives and motivations for self-monitoring systems.

Cite	Motivations	Incentives	Techniques used
Hofer et al.[13]	Well-being: health condition's awareness	Well-being: alerting, support activities, analytical and diagnostic support	Mobile application with personalized messages
Juen et al.[14]	Well-being: health condition's awareness Health services: patients get the opportunity to conduct a widely used medically accepted test outside a medical clinic	Well-being	Using smartphone instead of fitness devices
Thanuja and Balakrishnan[15]	Well-being: Health condition's awareness	Well-being	Using MATLAB simulator for analyzing the sleep time ECG instead of ECG machine. Enable self-diagnosis

ECG: electrocardiogram; MATLAB: matrix laboratory.

Table 9. Incentives and motivations for assisted-monitoring systems.

Cite	Motivations	Incentives	Techniques used
Al-Dowaihi et al.[16]	Well-being Treatment	Well-being programs	Subjects were compliant with monitoring their asthma using their mobile phone
Horta et al.[17]	Well-being Treatment—Improve patient safety	Health Services	Mobile devices are used to display information graphically to users
Liu et al.[18]	Treatment	Well-being programs	Provide rich contextual information and alerting mechanisms to patients
Moser and Melliar-Smith[19]	Well-being Treatment	Well-being programs	Provides feedback to the patient by means of visualization and speech interaction, and alerts a health professional in case of emergency
Kumar and Ganesan[20]	Well-being of hearts	Well-being programs	Patient received daily reminder messages

Table 10. Incentives and motivations for supervised-monitoring systems.

Cite	Motivations	Incentives	Techniques used
Ramesh et al.[24]	Treatment	Health services	A warning message is sent to the health professional in case of emergency. Doctors, family, and friends to view and manage the current and the past conditions of the patient
Postolache et al.[25]	Treatment	Health services	Remote assistance of the patients by doctors and nurses
Nawka et al.[21]	Treatment	Health services	Continuous monitoring of health conditions of patients seeking professional healthcare through mobile phone
Jiménez and Torres[26]	Treatment	Health services	Send alerts in real time to patients' relatives or medical doctors that an elderly patient has experienced a problem that could need medical attention or hospitalization
Triantafyllidis et al.[27]	Treatment	Health services	Easy to use and useful system using smartphone where health professionals monitor the patient condition and configure monitoring plans in an individualized manner
Triantafyllidis et al.[28]	Treatment	Health services	A personalized mobile-based home monitoring system aiming to support heart failure patients in daily self-monitoring of their condition whereby healthcare professionals review patient's status remotely in real time. Detailed instructions accompanied with animated videos are displayed to assist patients.
Triantafyllidis et al.[22]	Treatment Socializing	Health services Socializing	Health monitoring through wearable sensors and alert generation, patient status logging, and social sharing within a networked community

Table 11. Incentives and motivations for continuous-monitoring systems.

Cite	Motivations	Incentives	Techniques used
Abbate et al.[29]	Treatment	Well-being programs	Use of a graphical user interface (GUI) that allows the patients to interact with the sensor devices and perform self-diagnosis and checkup. The caregivers receive alerts if a fall happens.
Duarte et al.[30]	Treatment	Well-being programs	The healthcare professionals can detect changes in the behavior of the patient that can be interpreted as early signs of any health-related issue.
Majeed et al.[31]	Treatment	Well-being programs	Patients can benefit from indoor and outdoor monitoring at home and decrease the need to go to the hospital.
Zhang et al.[32]	Treatment	Well-being programs	Patients with anxiety can easily monitor, manage, and alleviate their stress with the collaboration of health care professionals.

Motivations and incentives for continuous-monitoring systems. Table 11 shows that in continuous-monitoring systems, intrinsic motivations that influence patients are the treatment they receive and extrinsic incentives factors are related to their well-being whereby patients benefit from the two-way approach between patients and health professionals so that they receive a real-time continuous monitoring healthcare service and just-in-time intervention.

Decision-making techniques. Data mining and machine learning techniques such as Decision Trees, Artificial Neural Networks (ANN), Fuzzy Logic, Hidden Markov Model (HMM), Support Vector Machine (SVM), Bayesian Classifiers, Bayesian Networks, and clustering techniques like k Nearest Neighbor (kNN) and k-Means are usually used in many research for intelligent decision making.[36]

Abbate et al.[29] used the machine learning techniques, such as the Support Vector Machine (SVM), Bayesian networks, and reinforced learning, to develop an intelligent gathering module in the event classification algorithms. Juen et al.[14] used the Gaussian Process Regression (GPR) model for treadmill walking, a three-layer ANN using the genetic algorithm to minimize the mean square error and an SVM with Fisher's linear kernel and an epsilon of 0.01 in the insensitive loss function. The HMM is used as a print proposed methodology in the research proposed by Kumar and Ganesan[20] and is compared with histogram recognition technique to evaluate the number of successful health transactions based on various timing intervals for sample training set.

Other data mining techniques such as dynamic assignment techniques have been used by Majeed et al.[31] to design and tune multimedia and also to ensure high-speed data transfer. Moreover, Liu et al.[18] proposed a lightweight process engine which runs a simple data processing logic and defines reusable data operations. The processing logic is composed of an aggregation operation to aggregate any received data, a transform operation to transform the combined data in a certain format, and a security operation for encryptions.

Discussion

In this section, the challenges of the 20 PMHSs are evaluated at different levels, such as node, network, and human-centric. Node-level challenges are related with the sensors' design and energy consumption without violating their unobtrusiveness. Network-level challenges are related with data collection and transmission without violating the security and privacy. Finally, the human-centric challenges are related to (1) the degree of system acceptance, (2) sensitivity, and (3) mobility of sensors whereby a patient can access high-quality medical services anywhere and anytime, (4) standardization, and (5) interoperability.

Node-level challenges

Sensor technology. Despite the fact that there is a plethora of sensors, there is still a need for data integration models to be used in PMHSs so that one device can be used to monitor a patient for multiple conditions.[29] The sensor design is a key factor to improve PMHSs' performance. Common sensors used are accelerometer, ECG, EEG, pulse oximeter, blood pressure, body temperature, respiration rate, and so on. Most patients also prefer wearable sensors over implantable sensors due to their high cost and the need of chirurgical operation.

Efficiency/power consumption. One of the biggest challenges and problems is energy consumption of sensor devices used in PMHSs. This has a high impact on the acceptance and compliance level of PMHSs. Low power consumption remains an important characteristic of wireless devices.[23] In Ramesh et al.,[24] power consumption is estimated and then the energy is optimized to increase the battery life of smartphone by 6 h. Other systems[18] make use of RESTful design to collect data which reduce the power requirements on sensors, leading them to be more portable and energy efficient. Compressive sensing techniques are also used to reduce energy consumption.[13] Despite the use of low-power wireless devices, robust energy techniques and intelligent algorithms are still needed to sustain extensive power consumption during persistent communications.[22] Low-power monitoring sensors will attain importance as PMHSs evolve. Moreover, the energy techniques and other dynamic algorithms should be explored for greening the PMHSs.[24]

Network-level challenges

Effective methods for data collection. Using optimized techniques for high QoI during data collection in PMHSs is crucial for correct diagnosis of the patients. Advanced signal processing algorithms associated with vital signs assessment are used for efficient data collection.[25] However, optimization of QoI for data collection in sensor networks remains to be further explored. In addition, time stamping and ordering of events, synchronization of different sensors are open problems for study and research.

Reliable transfer of data. Reliable data transmission is a key factor in PMHSs. Delayed sensor data can lead to incorrect diagnosis, inappropriate treatments, and untimely decisions. In Triantafyllidis et al.,[27] sensor-specific APIs are used to transmit encapsulated sensor data in the response message to ensure reliable data transfer. Dynamic publish/subscribe mechanisms are used to ensure messaging reliability by publishing and discovering data automatically at runtime.[13] Moreover, low transmission power and small-sized antennae of wireless sensor devices usually result in reduced signal-to-noise ratios that consequently increase the bit error rate and reduce the reliable coverage area. Reliable data transfer should be investigated since it is still a challenge for PMHSs.

Security. Ensuring security during data collection and transmission from sensors to access point and from access point to remote server is highly critical for successful design and acceptance of PMHSs. Some systems[19,21] have been using encrypted Bluetooth wireless communication, cellular telephony communication, and encrypted Internet communication to ensure data security and prevent possible data tampering or hijacking. To reinforce the need of secure PMHSs, security standards like National Institute of Standards and Technology (NIST) and Health Insurance Portability and Accountability Act (HIPAA) need to be followed. Moreover, very few systems are using encrypted or cryptography techniques to protect the data, so there is still a high need for such techniques to be developed and enhanced.[29] In Triantafyllidis et al.,[22] protocols such as OAuth are used to ensure authentication. Other web-based PHMSs[13,18] also make use of REST services to ensure authentication and authorization of users to login the system.

Privacy. Several studies have converged to the point that ensuring data privacy of patients is of vital significance in PMHSs.[21,29] The physiological signal-based authentication method is proposed in Moser and Melliar-Smith[19] to ensure privacy of patients. In Triantafyllidis et al.,[22] protocols such as OAuth are used to maintain privacy. Status alert messages are also used to notify physicians about patients.[27] Secure connection over an encrypted channel is established with the Server.[21] Very often, inadequate privacy protection consequently reduces the patients' willingness to adopt PMHSs. Thus, privacy-preserving mechanisms should be developed for acceptance of PMHSs and to ensure data integrity.

Human–centric challenges

Technology acceptance. The technology acceptance of users is especially important for successful adoption of PMHSs. Triantafyllidis et al.[22,27] surveyed the level of user-friendliness of their PMHSs with a limited number of subjects. Yet, it is crucial to explore the usability of the system with different groups of users since each user has a different kind of interaction with the system. Proper technical support and training are very essential to ensure broader acceptance of PMHSs, especially by elder patients and those with low technology literacy. Moreover, very few systems focus on the user-friendliness and natural interfaces with immediate response capabilities, and thus, there is a high need to perform more studies to assess the technology acceptance of PMHSs.

Sensitivity of sensors. The sensitivity of the sensor devices can be affected due to various environmental conditions, thereby reducing the sensitivity of wearable sensors or increasing the need of recalibration. Despite many systems are using sensors in the PMHSs, few of them happen to mention the importance of sensitivity. Yet, more exploration is needed in this aspect in terms of self-calibration algorithm, and sensitivity enhancement algorithm.

Mobility. Proper communication network is important to ensure that patients are connected anytime and anywhere with other devices, data centers, and healthcare centers.[31] The use of mobile devices, tablets, smartwatches, and sensors are important for mobility, especially during prolonged period.[15,17,29,30] PMHSs can provide additional support to patients and promote mobility through unobstructed, ubiquitous, and continuous monitoring.[25] In Abbate et al.,[29] multi-hop and ad hoc sensor networks are used to promote mobility.

Standardization. Nowadays, the development and adoption of standardization are becoming fundamental in all PMHSs so that these systems can operate in a multidisciplinary environment and be technology independent of their vendors. In Nawka et al.,[21] Jiménez and Torres[26] and Abbate et al.,[29] open standards such as IEEE802.15.4-based ZigBee are used to ensure low-cost and low-power short-range wireless communication networks. It is crucial that open architectures are adopted so that sensor node services are easily integrated with the existing medical services infrastructure.

Interoperability. A seamless flow of information among heterogeneous sensors over a network is of utmost importance for more accessible systems. To ensure interoperability, standard data format and protocols can be used. Continua Design Guidelines (CDG) are used by Hofer et al.,[13] to some extent, due to hardware limitations. Medical Markup Language (MML) and Health Level Seven International (HL7) are used to define representations for physiological measurements.[13,19] Different software and protocols are also used to address the issue of interoperability.[29] In Hofer et al.[13] and Nawka et al.[21] IEEE 11073-20601 specification has been used to provide interoperability between various health sensors. Thus, the propagating use of standards is crucial to address the aspect of interoperability in PHMSs.

Open research challenges

PMHSs have immense opportunities for monitoring chronic diseases, but at the same time, such systems give rise to several challenges. These systems are very critical and complex since they demand high dependability, reliability, security, and privacy for successful adoption and acceptability. Due to these complexities, many research challenges are still open. The challenges are discussed in the section below and are categorized under the node-level, network-level, and human-centric level.

Node-level challenges

Sensor technology. In PMHSs, wearable sensor devices are battery powered, and there are always design challenges from the hardware and software constraints arising from the form factor, lightweight, cost-effectiveness, energy efficiency, unobtrusiveness, sensing reliability, sensing and transmission coverage, and safety requirements for daily continuous health monitoring. So it is of high importance to consider safety and sustainability requirements while designing the sensors.

Efficiency/power consumption. Moreover, in order to address the issue of limited power resources, energy harvesting, an alternative to power sensor nodes, can be used to convert the ambient energy into electrical energy for optimized lifetime and performance.[37] Optimization algorithm using particle swarm optimization (PSO) can also be further explored and applied to a certain extent to address wireless sensor network issues such as optimal deployment, node localization, clustering, and data aggregation.[38] However, it is still crucial to evaluate the optimized algorithms using PSO for different network density.[39] Also, PSO usually needs a significant amount of memory for processing and is not very suitable for high-speed real-time applications.[40]

Network-level challenges

QoI. Another challenge lies on the network level. Ensuring QoI during data collection, data processing, and data delivery in PHMSs is a major challenge as guaranteeing QoI in PHMSs is hardly possible. PMHSs need to satisfy the degree of confidence of QoI through various quality dimensions such as timeliness, accuracy, reliability, completeness, relevancy, usability, and confidentiality, so that relevant and timely decisions can be taken by patients and medical experts. Higher QoI in PMHSs will allow capture of regular measurements, thus promoting better day-to-day healthcare follow-ups through reliable diagnostics, monitoring, and clinical guidance. Thus, it is a huge challenge to ensure that the most significant data can always be delivered in a real-time manner due to frequent deep fading and packets loss.

Prathap et al.[41] highlight the importance of on-time and reliable data delivery at the network level. Moreover, several quality of service (QoS) parameters such as end-to-end packet delays, packet delivery ratio, average energy consumption per packet, and routing overhead for variable source traffic loads and wireless link bit error rates are considered in order to ensure high QoI. In order to improve the QoS, the study discusses about the commonly used routing algorithms, namely (1) energy-efficient differentiated directed diffusion mechanism (EDDD), (2) multiconstrained QoS multipath (MCMP), (3) multipath multi-speed protocol (MMSPEED), and (4) LOCALized Multi-Objective (LOCALMOR). EDDD is energy efficient but neither scalable nor adaptive. Moreover, the algorithms, MCMP and MMSPEED, consider link delay and reliability as routing decision parameters but not energy efficient. LOCALMOR achieves the on-time and reliable data delivery but it is not scalable.

Despite all the research being conducted, the challenge is still to design an effective routing protocol that uses a dynamic mechanism to automatically detect sensors in the network that remain static for long periods of time for data aggregation and propagation as a single transmission.

Security and privacy. Moreover, security and privacy constraints are an indispensable component that should be met for widespread adoption of PHMSs. Very often, authentication and data integrity are difficult tasks in limited resources of medical sensors. Fundamental security specifications, such as data confidentiality, integrity, availability, accountability, storage, and access control, are of paramount importance and are key challenges when implementing PMHSs.[42] Therefore, advanced algorithms, authentication protocol, encryption methods, and efficient cryptography methods should be further developed to prevent data tampering, hijacking, or any other attacks.[43] Other techniques like secure software protocols for routing and data aggregation can be implemented.

Human–centric challenges

Another major challenge often faced by PMHSs are human-centric issues. Since the PMHSs are usually used to target various aged groups with different diseases, it is essential that both technology-naive and technology-averse patients are able to use the PMHSs with ease. Concerning the sensitivity and mobility of sensors, it is equally important that users are seamlessly connected to the wireless network and they can move around freely anywhere and anytime despite any environmental conditions.[6] Novel link quality metrics and handover mechanisms should be further developed to ensure that sensor nodes are seamlessly connected to the access points.[44] Although Technology Acceptance models are available, user acceptance patterns should be further investigated, evaluated, and verified for PMHSs adoption.[45] Despite many PMHSs are on the shelf, extending the network lifetime in such systems remains one of the greatest challenges since wireless sensor devices are unable to operate for long time due to their limited power resources. Therefore, further research can be done with regard to energy harvesting to address the issue of energy consumption.[46] Moreover, reduction of motion artifact, low-power design, on-node processing, and distributed interference in wireless networks still need to be addressed to enhance the usability and functions of these devices for practical use.

The emerging deployment of PMHSs is triggering a worldwide paradigm shift from reactive to preventative healthcare whereby design considerations play a very important role in addressing the challenges outlined. These systems offer a variety of exciting opportunities from a healthcare perspective, such as encouraging self-healthcare, assisted healthcare, supervised healthcare, and continuous monitoring.

Conclusion

This article presented a review of state-of-the-art PMHSs that are widely used in medical applications, with particular focus on issues and challenges related to PMHSs. Given the fact that PMHSs are been introduced at an exponential rate to provide smart healthcare to different patients, researchers have started to explore technological solutions to enhance the provision of healthcare in a way which complements existing services. In this article, 20 PMHSs from 2011 to 2016 are evaluated to improve patients' quality of life, and various prominent issues are outlined for design considerations during PHMSs development. A more significant data set from different medical informatics libraries (100 papers over a period of 10 years) can be considered as future work, and other criteria such as user acceptance, adoption, and QoI can be extensively considered. From the results, it is seen that common diseases such as COPD, heart diseases, asthma, sleep apnea, hypertension, stress, cognitive impairment, dementia, Alzheimer's, risks of fall, and many other chronic conditions are monitored mainly for elderly or chronic patients. Moreover, client–server and web-based architecture appears to be the most common choice for the use of PMHSs. The systems make use of various wireless communication protocols to transfer sensor data from sensor devices to access points and also to remote servers. Various sensor devices are used in order to collect the vital physiological signs of the patient for disease monitoring. However, as pointed out, there are a number of challenges that remain to be tackled at the sensor level, network level, and human level. There are still many future works to be done to achieve a perfect compromise among all the design considerations when developing PMHSs. Despite all these challenges, a paradigm shift in healthcare delivery model from doctor-centric to patient-centric, from acute reactive to continuous preventive, and from sampling to monitoring is noticed in the trend. The confluence of PMHSs development can lead to exponential advantages in the healthcare sector mainly in continuous monitoring applications. In the near future, the evolution of PMHSs can significantly improve the health conditions and lifetime expectation for various patients. The current challenges faced when designing PMHSs were outlined, and the main areas that researchers should investigate further for successful deployment, adoption, and seamless integration of PMHSs in patients' life were discussed.

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The Penn State Heart Assistant: A pilot study of a web-based intervention to improve self-care of heart failure patients

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Abstract

The Penn State Heart Assistant, a web-based, tablet computer-accessed, secure application was developed to conduct a proof of concept test, targeting patient self-care activities of heart failure patients including daily medication adherence, weight monitoring, and aerobic activity. Patients ($n = 12$) used the tablet computer-accessed program for 30 days—recording their information and viewing a short educational video. Linear random coefficient models assessed the relationship between weight and time and exercise and time. Good medication adherence (66% reporting taking 75% of prescribed medications) was reported. Group compliance over 30 days for weight and exercise was 84 percent. No persistent weight gain over 30 days, and some indication of weight loss (slope of weight vs time was negative (−0.17; p value = 0.002)), as well as increased exercise (slope of exercise vs time was positive (0.08; p value = 0.04)) was observed. This study suggests that mobile technology is feasible, acceptable, and has potential for cost-effective opportunities to manage heart failure patients safely at home.

Keywords

chronic heart failure, mobile devices, patient education, patient motivation for self-care, remote patient monitoring

Introduction

Heart failure (HF) is a major public health concern, responsible for high rates of hospitalization and re-hospitalization.[1] It is the most common reason for hospital admission in the United States and Europe for patients over the age of 65 years, and is also associated with the highest rate of readmission compared to all other medical and surgical causes of hospitalization.[2,3] Nearly, 25 percent of patients discharged with a primary diagnosis of HF are readmitted within 30 days.[4] In addition to the morbidity of repeat hospitalizations, the cost of hospitalizations is high.[5] In 2012, the total economic burden in the United States from HF was estimated at US$31 billion, with US$21 billion coming directly from medical expenses and 80 percent of that from the cost of hospitalization.[2,6,7] Accordingly, there is a strong motivation both clinically and economically to improve HF patient outcomes.

Generally, hospital readmission is driven by disease progression and inadequate self-care.[8] HF self-care involves patient adherence to the treatment plan (such as medication and exercise recommendations) and careful monitoring of changes in weight.[9] HF programs which include frequent provider contact have demonstrated reduction in re-hospitalization rates and even improve mortality.[10,11] Such programs, however, are expensive, not widely available and typically do not provide long-term care.[12] A major reason for the limited access to these programs is the need for time-consuming one-on-one interventions from highly trained personnel to educate HF patients, motivate them to engage in self-care, and monitor them regularly. Moreover, the benefits of current self-care programs are not generally sustained over time.[10,11]

Mobile technology provides an opportunity to improve both the efficiency and quality of HF management in cost-effective ways.[13] Both the World Health Organization[14] and the American Heart Association[15] are focused on understanding the impact of mobile technology on health, but also on using these new technologies to transform healthcare. Specifically, technology promises the opportunity to “remotely” provide patients with consistent education, motivation to become engaged in their own self-care, and assistance in monitoring on a regular basis.

There have been a number of large, rigorous, technology clinical trials in HF management.[16–19] However, a series of recent systematic reviews[13,20–22] reveal great variability in type of technology (i.e. telephone, email, text, web portal); timing (i.e. frequency of contact, whether at set times or as needed); interface (i.e. automated, live or mixed); uni-directional or bi-directional transfer of health information; and content. Patient outcomes in these studies generally involve mortality,[13] hospital readmission,[23] or both.[19,24] To date, the potential mechanisms, such as self-care, driving these patient outcomes in HF have rarely been examined.

Two studies, similar to our own, bear closer examination. Lyngå[25] qualitatively assessed patients' responses to a telephone-based, weight monitoring randomized control trial (RCT). In a sample of older adults (n = 20; age range: 61–86) with New York Heart Association (NYHA) class II-IV HF, the patients reported that knowing they were being monitored activated them to engage in their own care. In a recently completed clinical trial, Better Effectiveness After Transition-Heart Failure (BEAT-HF), Ong et al.[18] tested a telephone coaching and telemonitoring intervention which focused on self-care education and daily monitoring via a wireless transmission pod. This large (n = 1437), 2-arm, multicenter trial resulted in no significant differences between the intervention and control group in 30-day readmission rates or 180-day mortality rates. Two significant study limitations noted by the investigators were lack of integration of the trial into the clinical practice sites caring for the patients and uneven protocol adherence rates. However, they did not report patient responses to the intervention itself, so the impact of monitoring on patient activation is not known. In general, processes and behaviors around patient motivation and activation are currently understudied in HF self-care technology intervention studies despite being identified as a key concept in chronic illness self-care.[25,26] Taken together, these two studies suggest a need for better understanding the role that the patient and the potential to enhance motivation to engage in self-care when using technology plays in common HF outcomes.

Cognizant of the technological/utilization challenges identified in past HF technology studies, in the present study we used an easy to use wireless computer tablet. This type of technology is widely available, affordable, and easy for patients to use. Accordingly, we anticipated that this would enhance both the ease of use and uptake of the program.The purpose of this study then was to conduct a proof of concept test of a custom, web-based, secure application delivered via tablet computer to improve HF patient self-care. The specific goals of the intervention were to *educate* the patient through an educational video session, *motivate* the patient to become involved in their self-care by providing feedback on their progress, and allow them to *self-monitor* their condition, in the form of graphs of their weight and activity. In addition, the program allowed providers to monitor the patient remotely via a secure server.

Methods

Project goals and research design process

The project was developed by an interdisciplinary team comprised of three cardiologists, two HF nurse practitioners, three HF clinical specialist nurses, a social worker, the chaplain for our Heart and Vascular Institute, an epidemiologist, a health economist, a psychologist, a public health sciences data manager, and a web developer/programmer. Social cognitive theory (SCT)[27] provided the broad theoretical framework for the intervention. Self-efficacy, an important component of SCT, has been found to moderate the effect of determinants of self-care on self-care in previous studies conducted by members of our group.[28–30] Our intervention thus was designed to include opportunities for observational learning for the patients, development of mastery in carrying out self-care tasks, and feedback in the form of personal data graphs. Each of these features have been linked to improved self-efficacy.[31]

The team identified patient inclusion and exclusion criteria and a tablet computer assisted-intervention which included (1) daily recording of medication use, weight, and time using an exercise program and (2) an educational video of one of the cardiologists teaching about HF causes and symptoms. We used a prospective, nonrandomized, proof of concept study for 30 days with 12 HF patients recently discharged from the hospital. Patients would be asked to enter into the tablet computer what medications were taken that day, their daily weight measured on a home scale, and how many minutes they spent that day in a simple step exercise using an aerobic stepper. The information would then be transmitted via home wireless router to a secure server. A professional programmer with experience in developing health technology applications took the design plan and developed the software program. After alpha prototypes were developed, two research assistants (RAs) tested two tablet computers over a 3-day period, discovering minor technical issues which were corrected by modest software adjustments.

Special considerations of the study population

As HF occurs primarily in older adults who are less likely to be familiar with navigation on mobile devices, we used the following five concepts to make the overall program as user-friendly as possible. First, we created a series of simple screen prompts to lead the patient through their daily program using large font/icon size and colors easily seen by older adults. Second, we used these screen prompts to create a hard copy step-by-step instruction manual, with instructions in large font size. (Readers may contact the corresponding author directly for access to this instruction manual.) Third, we created a 5-min introductory video which featured an older adult, acting the part of a HF patient, using the tablet computer at home and going through each of the daily tablet computer-directed activities. The video was used during recruitment activities when the potential participants were still in-patients in acute care in our hospital. Fourth, an RA visited the home of each consented patient, brought the tablet computer to be loaned to that patient and went over it and the instruction manual, and left the tablet computer and the manual with the patient. The RA also left a dedicated phone number that the patient could call if she/he needed help with any part of the program.

Security of personal health information

To achieve the desired level of security of personal health information (PHI), required by federal regulations, the team selected Research Electronic Data Capture (REDCap), a secure, web-based application designed to support data capture for research studies. REDCap is maintained by the REDCap Consortium (http://project-redcap.org/) which includes over 600 institutional partners including Penn State University. REDCap is Health Insurance Portability and Accountability Act (HIPAA) compliant; all data are encrypted and stored on a secure server; access to databases requires user authentication with password and data access is based on the individual's role on project. Logging and audit trails are kept on all data interactions. REDCap can remove identifiers from a data set prior to exporting for analysis to create either a limited data set or a safe harbor data set.

Participants

Inclusion criteria are as follows: adults, alert and oriented, documented NYHA class II-III HF in the electronic health record, currently hospitalized with a HF-related admission, reliable home wireless Internet access, English speaking and willing and able to participate. Exclusion criteria are as follows: chronic cognitive impairment documented in the electronic health record, dialysis patients, discharge disposition to a skilled facility, refusal to participate, and NYHA class I or IV or weight greater than 300 lbs (due to the exercise component).

After obtaining Institutional Board Approval, potential study patients were approached in the critical care unit by one of the team physicians or an HF nurse practitioner. Potential participants were shown in the 5-min introductory video. Patients who agreed to take part in the study and provided informed consent before leaving the hospital were contacted by the RA who arranged to meet them at their home between 24 and 48 h after their hospital discharge.

Procedures

The RA hand-delivered the tablet computer and an aerobic stepper to the patient's home and at that time the RA created the patient's specific medication table in REDCap in consultation with the patient and with the patient's current cardiovascular-related medications in front of them (prescriptions and/or pill bottles). In this pilot study of 12 patients, medications prescribed for HF remained constant over 30 days and it was not necessary to adjust any of the individualized patient medication table in REDCap. Each patient supplied demographic data that the RA then entered into REDCap. The demographic data consisted of age, gender, marital status, living arrangement, education, employment status, smoking history, and body mass index (BMI); left ventricle ejection fraction (a measure of heart health) was also collected. The RA then went over the use of the tablet computer, demonstrated the use of the aerobic stepper, instructed the subject to use the stepper daily, left the subject with the illustrated instruction manual, the aerobic stepper, and a telephone number which the patient was to use to contact the RA directly if they had questions. For each of the next 30 days, the patient was to enter their daily medication use, daily weight, and time spent using the aerobic stepper into REDCap. Patients were enrolled between 26 June and 3 August 2015 and all completed their 30-day use of the Penn State Heart Assistant by 4 September 2015.

Quantitative analysis

Proof of concept was assessed by analyzing group compliance in completing three daily tasks: (1) recording medication intake, (2) recording daily weight, and (3) exercise. Compliance with reported medication intake was measured as the patient selecting the "yes" radio button each day on the tablet computer for a particular medication entered by the RA into REDCap. Compliance with daily weight monitoring was measured as the patient entering a weight each day from their home scale. Compliance with reported exercise was measured as the patient entering their time using the aerobic stepper each day. With respect to medication adherence, for each patient we calculated the number of medications taken per day according to the REDCap medication table and then summed over all days for a total number of doses taken during the study period. Overall, medication compliance per patient was calculated as the total number of doses taken divided by the total number of doses the patient should have taken based on his/her list of prescribed medications. The overall medication compliance was calculated as the sum of the total doses taken over all patients divided by the sum of total doses prescribed over all patients. Linear random coefficients models were fit to assess the relationship between weight and time, as well as exercise and time over the 30-day period.[32] The magnitude of the relationship was quantified using the slope (i.e. rate of change) of the regression line. The linear random coefficients model accounts for the repeated measurements per patient due to daily acquisition of data. Residual diagnostics were assessed to determine the appropriateness of the model fit.

Results

Proof of concept was supported as follows. We enrolled 12 qualified patients prior to hospital discharge who had a primary diagnosis of HF after approaching 56 patients. In all, 44 of the 56 patient approached were excluded for one of the following reasons: no Internet access,[17] educational barrier,[7] language barrier,[4] NYHA Stage 4,[7] or refused.[9] Demographic characteristics for the study patients are presented in Table 1.

Table 1. Participant descriptive statistics.

	Median (25th, 75th percentile) [n]
Age (years)	66.5 (52.0, 74.5) [12]
BMI (kg/m^2)	33.0 (25.9, 36.4) [12]
LVEF (%)	40.0 (30.0, 60.0) [8]
	N (%)
Sex	
Male	7 (58.3%)
Female	5 (41.7%)
Marital status	
Married	8 (66.7%)
Widowed	3 (25.0%)
Single	1 (8.3%)
Living alone?	
Yes	3 (25.0%)
No	9 (75.0%)
Home caregiver	
Spouse	6 (50.0%)
Relative	1 (8.3%)
Friend	4 (33.3%)
Other	1 (8.3%)
Highest level of education	
High school	5 (41.7%)
Some college	3 (25.0%)
Associate degree	2 (16.7%)
Graduate degree	2 (16.7%)
Employment status	
Employed	3 (25.0%)
Retired	7 (58.3%)
Sick leave	2 (16.7%)
Smoking history	
Former	6 (54.5)
Never	5 (45.5)

BMI: body mass index; LVEF: left ventricular ejection fraction.

Detailed results are presented in a three graphics (Figures 1 to 3) with each patient identified by a separate shading code. Overall, the group compliance in completing each day's individualized tasks was 84 percent. Linear random coefficients models were fit to assess the relationship between weight and time as well as exercise and time. Figure 1 shows the individuals' daily recorded weights, and it is notable that none of the patients showed a persistent weight gain (often a harbinger of re-hospitalization). In fact, overall, patients reduced their weight at a rate (i.e. the slope) of 0.17 lbs per day (95% confidence interval, CI: (−0.26, −0.08); $p = 0.002$; Figure 1). This translates to a mean weight loss of about 5.1 pounds over the 30 days of the intervention (although this appears to be driven primarily by larger weight loss among a subset of users). Figure 2 shows the

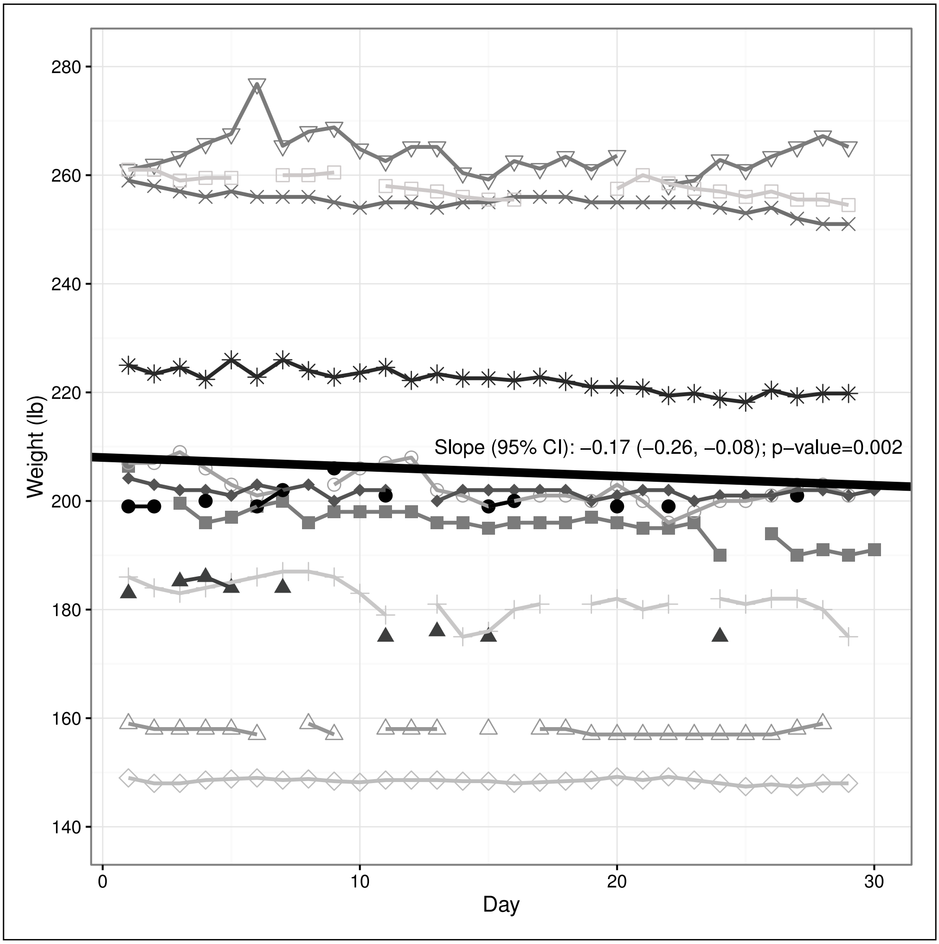

Figure 1. Participant daily weights over the 30 day study period.

number of minutes that patients completed stepper exercise each day. Overall, patients slightly increased their activity time at a rate of 0.08 min per day (95% CI: (0.004, 0.15); p=0.04; Figure 2). This mean change in use of the aerobic stepper translates to a mean increase in 2.4 min over the 30 days. Figure 3 shows that two-thirds of the group reported taking 75 percent or more of their medications as prescribed.

Discussion

The purpose of this study was to conduct a proof of concept test of a custom, web-based, secure application delivered via tablet computer to improve HF patient self-care. The software program consists of user-friendly icons to step the patient through the daily tasks of recording his/her weight, medication use, and daily activity. Several of the entry screens are electronic surveys designed to transmit patient data to a centralized REDCap database.

In this article, we have shown that our intervention and study procedures are feasible and appropriate for future testing in a fully powered, larger study. Although we were not powered to assess significance, and our sample size was modest, we were still able to provide preliminary evidence

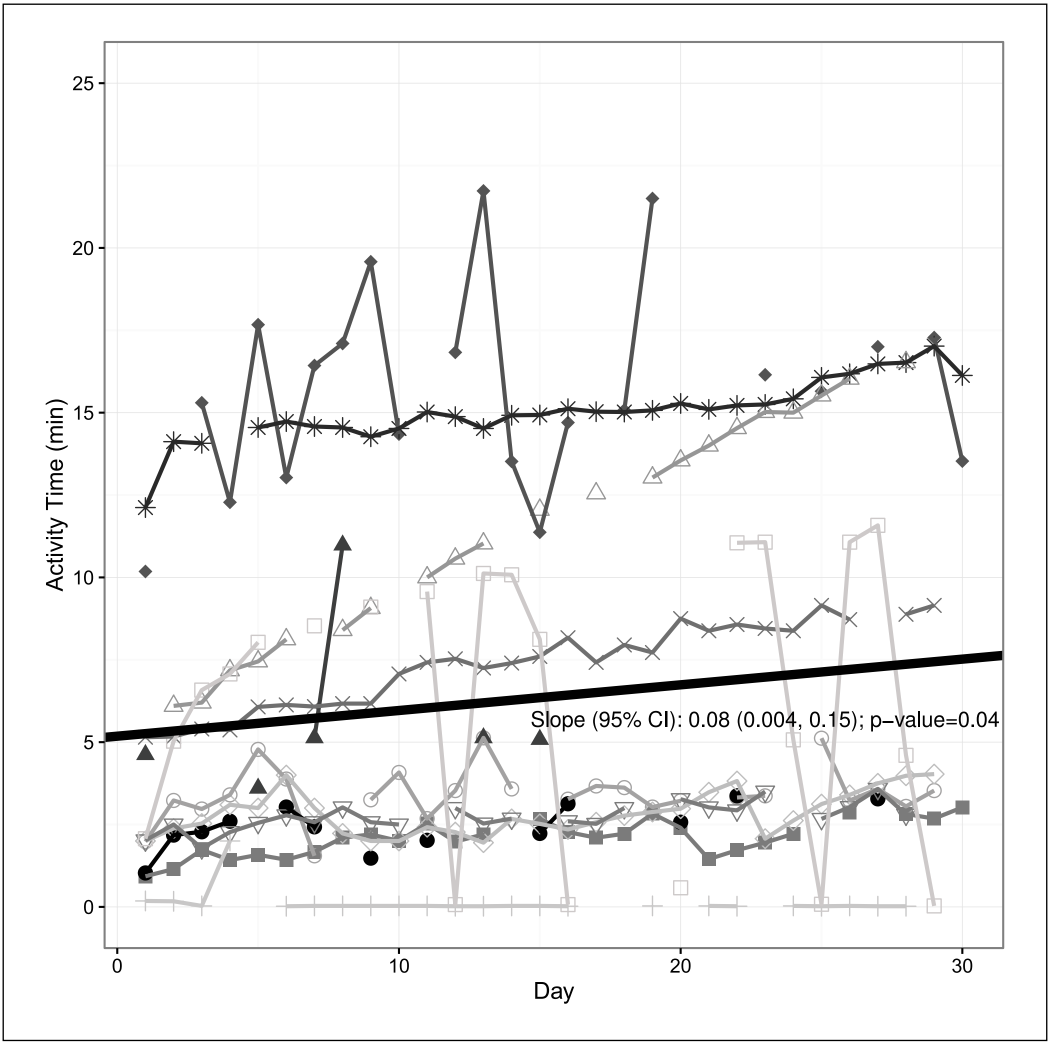

Figure 2. Participant aerobic stepper use in minutes over 30-day study.

that our tablet-delivered intervention may have enhanced patients' motivation and capacity to improve their adherence to self-care practices (although noting considerable variability both between patients and within patients over time). Several things bear further discussion in light of the existing literature.

First, two-thirds of our patients reported taking 75 percent or more of their medications as prescribed using our technology. This is comparable with the findings of a recent meta-analysis of technology-based medication adherence studies (n = 16 randomized clinical trials) which found that medication adherence rates improved from 50 percent to almost 68 percent with use of technology.[33] Even when taking into account social desirability in reporting medication adherence, this suggests that our technology perhaps helped patients to remember to take their medication, and motivated them to act upon the information. Equally interesting was that almost one-third of our sample felt comfortable reporting non-adherence; although speculative, this suggests

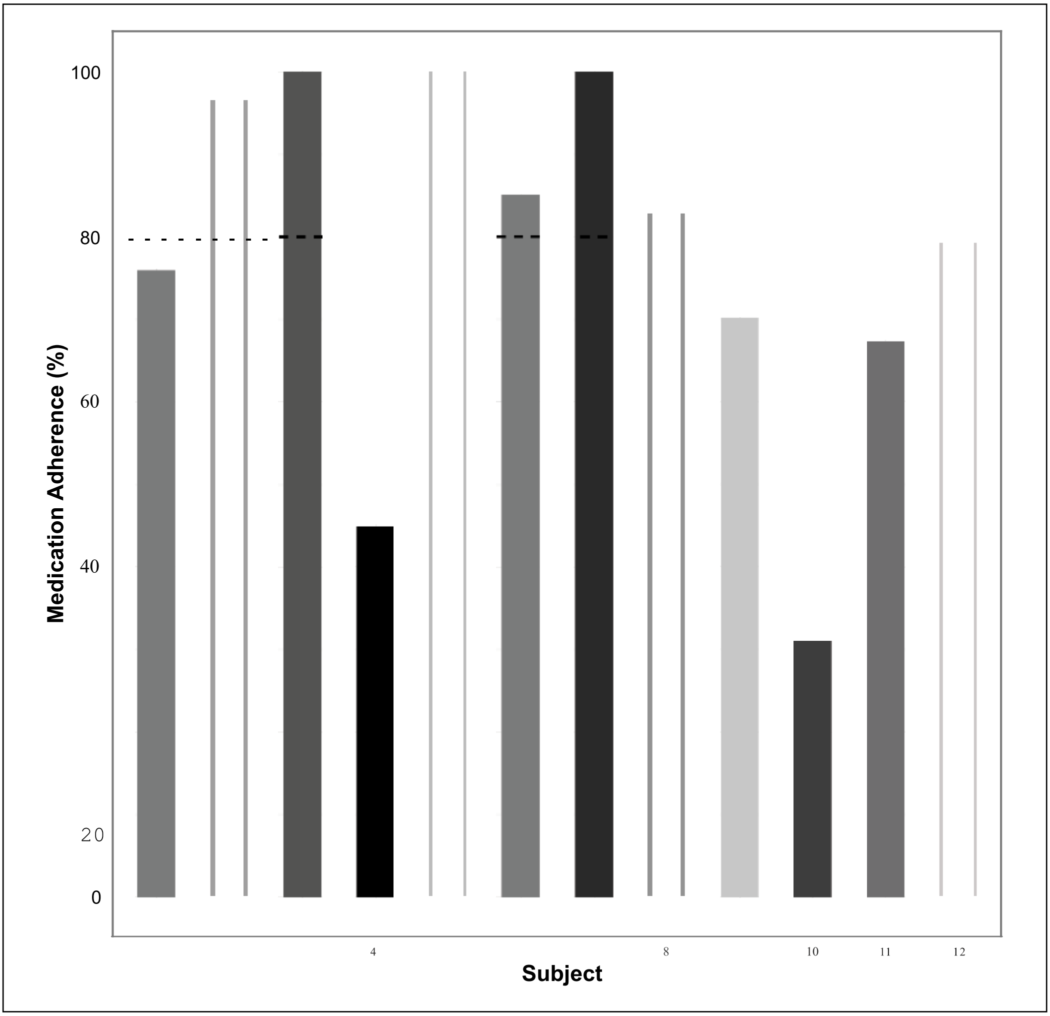

Figure 3. Participant medication adherence, as percentage of prescribed.

that technology-based adherence assessment may actually improve the accuracy of self-report assessment in medication adherence as has been found in other populations.[34] It could be that patients feel more comfortable reporting their actual practice online rather than to a human who they fear would judge or reprimand them. We suggest that this be examined further in future studies, as this has clear implications for the design of self-reported adherence in clinical trials.

Second, the patients were generally very consistent in use of the aerobic stepper and, overall, slightly increased the number of minutes they performed over time. This is a very interesting finding. First, it is known that functional impairment and hospital readmission rates are highly correlated.[35] Therefore, anything that improves functional status is projected to decrease readmission rates. Exercise was added to the American Heart Association Class I recommendations[36] because it has been shown that exercise does improve functional status and as importantly, patient quality of life in HF.[37,38] So although we set out to determine whether a simple exercise intervention was feasible in recently discharged hospital patients, we also were able to show patient improvement over time suggesting that our patients did not find this simple exercise onerous. Moreover, it is possible that they may have experienced improved functional status and quality of life as a result of this intervention although we did not measure these outcomes in this pilot study.

A final issue bears further reflection. The results of the BEAT-HF[18] trial were published during the conduct of our study. BEAT-HF was designed as a 2-arm randomized trial using both telephone health coaching and technology transmission of patient information (weight, blood pressure, heart rate, and responses to three symptom questions) with threshold triggers versus usual care. However, no significant differences between the two arms were found on the primary or secondary outcomes (readmission and mortality). Particularly concerning is the finding that a little over half of the participants were only 50 percent adherent to the protocol. This supports a similar finding from an earlier large trial where 14 percent of the intervention patients never used their equipment and only 55 percent were still using the system at the end of the study (180 days out from baseline).[19] These results add to the body of literature that suggests that technology solutions to HF management can be ineffective, yet the reasons may have little to do with technology or intervention *per se* but rather with the delivery, engagement, and utilization of the intervention elements. Yet, more and more chronic illness management is delivered using some form of telehealth. We suggest that it is important and informative to engage patient stakeholders early in design phases of technology programs, keep them engaged as co-researchers in clinical trials, and listen to the technology end-user voice when evaluating technology programs in order to better understand how to create engaging and effective mHealth interventions and programs. We hope that our study, with its assessment of the end-user experience, is a small first step in this direction.

Limitations and future directions

A number of limitations to this preliminary work should be kept in mind when reviewing our findings. First, this was primarily a feasibility study; as we did not have a comparison group, we can only speculate that the positive findings we observed were due to the intervention. Given the uncontrolled nature of this trial, an essential next step is testing of this very promising technology in an appropriately powered RCT of HF patients, and extending the study to 3 or 6 months in length, and ideally collecting objective indicators of health and healthcare utilization (including costs, readmissions, and mortality). We also believe that it will be important to evaluate the intervention for use with patients and caregivers in a more diverse sample at a different site. As noted above, stronger causal inferencing will be possible following such an RCT. Second, our sample size was very small and homogenous, raising concerns about selection bias (e.g. due to its convenience sampling frame and to the possibility that patients motivated to improve their health may have been more likely to volunteer) and generalizability. We also recruited only about one in four of the HF patients approached in the hospital. The largest reason for exclusion, however, was lack of Internet access. Were this not a barrier, and assuming most of those lacking access would have otherwise been interested, it is plausible that our enrollment would have been close to 50 percent of those approached. We hope to address this barrier in the next phase of the project by providing portable WiFi Hotspot devices (along with the intervention tablets) to patients without home Internet access. Third, our only measure of exercise was by the aerobic stepper; future studies should use additional measures, such as by wearable actigraphy.

Conclusion

In summary, we suggest that mobile technology offers cost-effective opportunities to manage HF patients safely at home. In our study, we showed that the Penn State Heart Assistant tablet computer, a custom, web-based, secure application, is a feasible and acceptable way to educate HF patients and motivate them to become engaged in their own self-care while monitoring them on a regular basis. Moreover, the use of the program provided exciting preliminary evidence of benefit, resulting in improved medication adherence, weight monitoring, and daily aerobic activity.

Declaration of Conflicting Interests

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Data quality shortcomings with the US HIV/AIDS surveillance system

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Abstract

This study investigates some of the data quality challenges facing the HIV surveillance system in the United States. Using the content analysis method, Center for Disease Control annual HIV surveillance reports (1982–2014) are systematically reviewed and evaluated against relevant data quality metrics from previous literature. Center for Disease Control HIV surveillance system has made several key achievements in the last decade. However, there are several outstanding challenges that need to be addressed. The data are unrepresentative, incomplete, inaccurate, and lacks the required granularity limiting its usage. These shortcomings weaken the country's ability to track, report, and respond to the new HIV epidemiological trends. Furthermore, the problems deter the country from properly identifying and targeting the key subpopulations that need the highest resources by virtue of being at the highest risk of HIV infection. Several recommendations are suggested to address these issues.

Keywords

accuracy, completeness, content analysis, data quality, granularity, HIV surveillance systems, representativeness, systematic review

Introduction

The purpose of evaluating public heath surveillance systems is to ensure that problems of health importance are being monitored efficiently, effectively, and regularly.[1–4] Public health surveillance systems provide data that can be used for several purposes. In particular, the analysis and interpretation of data from HIV/AIDS surveillance systems plays a critical role in observing emerging trends and making intervention decisions.[5–8] HIV Surveillance data in the United States are used

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"to monitor the spread of HIV infection, to target HIV prevention programs and health-care services, and to allocate funding for HIV prevention and care."[7]

HIV/AIDS continues being a key challenge in the public health arena in the United States. At the end of 2012, 1.2 million people were living with HIV/AIDS in the United States[9] with 70.2 percent receiving antiretrovirals (ARVs) in 2015.[10] About 658,507 people in the United States with an AIDS diagnosis have died by 2012.[9] Furthermore, HIV/AIDS interventions continue to consume a considerable portion of the nation's budget. For example, President Obama's fiscal year 2014 federal budget request included a US$29.7 billion for HIV/AIDS funding.[11]

Even more worrying is the direction that the prevalence rates are taking. While new infection rates are declining globally by 19 percent, and in 22 sub-Saharan Africa countries by 25 percent during 1990–2009,[12] the US diagnosis of new infections has increased by 8 percent during 2005–2008.[13] In the District of Columbia at the end of 2006, at least 3 percent of residents had HIV or AIDS with the rate reaching almost 6.5 percent among African American men.[14] This represents a 22 percent increase in HIV and AIDS cases over the previous data period.[14] These rates are higher than those of some countries in West Africa and at par with the rates in some parts of Eastern Africa.[12] These facts suggest a critical need for increased surveillance of HIV/AIDS epidemiological trends to identify the key subpopulations that need resources most.

This study contributes to research by evaluating the "quality of data" from the CDC HIV Surveillance Systems in the United States. We start by describing how the CDC system work followed by the methodological approach and evaluation criteria for HIV surveillance systems from previous literature. After that, we comment on current HIV surveillance system's data in light of the emerging epidemiological trends at the national levels and the shortcomings identified. Finally, we conclude with a few recommendations. In order to do so, it is necessary to understand the current US Center for Disease Control and Prevention (CDC) HIV/AIDs surveillance system (Figure 1).

As shown, CDC employs both passive and active strategies in collecting national HIV/AIDS surveillance data. In the passive strategy, physicians and related laboratory sends a positive test result to the state's department of health as per national guidelines (Center for Disease Control and Prevention, 2006). In active surveillance, the local health department personnel actively solicit for information by contacting healthcare practitioners and reviewing medical records in hospitals and clinics to ensure data accuracy and completeness. The local health department then reports this information to the state health department who in turn transmit the information to the national center for disease control after removing the duplicates.

However, little is known about the quality of data from the current HIV surveillance systems, hence the importance of this study. We evaluate the data quality using relevant frameworks from the fields of information quality[16–19] and healthcare data quality.[1,20–22] Previous work in the information quality field[16] has suggested a standard framework for evaluating the quality of data from any system which includes 12 data metrics namely: Accuracy, Objectivity, Believability, Reputation, Value-added, Relevancy, Timeliness, Completeness, Appropriateness, Interpretability, Ease of understanding, and Representativeness. The healthcare field has suggested an additional metric of granularity.[20]

This study will demonstrate that the current US HIV surveillance data has shortcomings with representativeness, completeness, accuracy, and granularity.

Representativeness measures the extent to which the surveillance systems data is a true reflection of the general population distribution.[2] For example, representativeness can measure how well the different demographics are represented by the HIV surveillance system. Completeness refers to the "extent to which data is of sufficient breadth, depth and scope for the task" at hand.[17] This is applicable in this study because the stakeholders will need a complete picture of the HIV menace to structure effective counterprograms among others. Accuracy refers to "the extent to which data

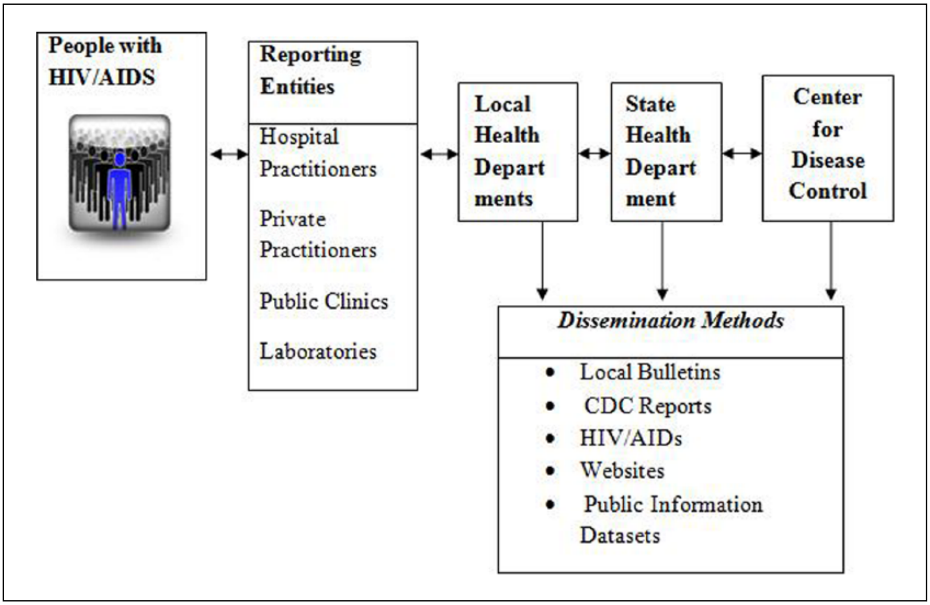

Figure 1. How the CDC HIV/AIDS surveillance system works.[15]

is correct, reliable, and certified free of error."[17] Data accuracy is the foundation dimension of data quality because all the other dimensions matters little if the data are not accurate.[23] Data Granularity refers to the "level of detail at which the attributes and values of healthcare data are defined."[20] Different data usage may require different levels of granularity. Most important, Data must be "fit to use" to be of high quality.[19] In line with this paradigm, the HIV surveillance data must be granular enough to fit the various usage identified in the beginning of this section.

Method

We used the content analysis method to systematically evaluate the data quality of HIV surveillance annual statistics reports (1982–2014) published on CDC website. These reports are published by the CDC every year usually with a 2-year lag in the data report year publication to allow the data to stabilize. Content analysis is a "technique for making inferences by objectively and systematically identifying specified characteristics of messages."[24] We have extracted data from each of the 30 reports on the following parameters: age, gender, race/ethnicity, HIV or AIDS, residency by state and District of Columbia, number of states reporting HIV, number of states reporting AIDS, modes of transmission, incidence HIV, prevalence HIV, incidence AIDS, prevalence AIDS, and number of deaths as shown in Online Appendix 1. We summarize the milestones, strengths, and shortcomings of the national HIV surveillance data from the above evaluation and then make recommendations on how the shortcomings can be mitigated.

Results and discussion

Notable HIV surveillance data quality achievements

The analysis of the HIV reports demonstrate the CDC HIV surveillance system's data has played a crucial role in helping the government monitor, control, and publicize the HIV pandemic. CDC has taken several bold measures, which have resulted in key improvements in the quality of the data. The first measure concerns integrating different data sources. CDC, working with state and other government agencies, planned for a National Electronic Disease Surveillance System (NEDSS). The primary goal of the system was to connect different states surveillance systems, expand, and allow the government to respond more quickly to public health threats.[25] The base module is already working allowing states to manage more than 140 diseases and conditions.[25] This has significantly improved the timeliness of the data at the national level. For example, a specific input at one corner of the country is quickly reflected at the national level. This has helped address the previous lack of integration among the different systems.

The second measure involves creation of HIV/AIDS definition guideline. Different physicians/hospitals were using different criteria to determine who has HIV-AIDs; hence, there was a need for the US government to give a common criterion to be used to determine who was eligible for US government assistance benefits. CDC came up with a definition criterion that stated that a person has AIDs if they are diagnosed with one or more of the “AIDS indicators” diseases or be HIV-positive with a CD4 T-lymphocyte count of less than 200 cells/mL as defined by the CDC guidelines.[26] This has created a uniform baseline for determining the qualifying cases for all the physicians.

Third, CDC has moved to HIV-based reporting[26] rather than reporting based on previous AIDS infections guidelines.[27] The use of ARV medicines has slowed down the progression of HIV to AIDS meaning AIDS-based reporting can no longer be relied upon to give updated disease trends which is required for timely response.[7] Thus, HIV-based reporting gives a more complete picture of the HIV/AIDS pandemic and can help predict the expected level of AIDS in the future based on the average progression rates.

Fourth, as of April 2008, CDC requires that all the 50 states and the 5 dependent areas report the HIV/AIDS cases by individual names which are kept confidential by CDC.[28] This gives higher accuracy and is easy to compare with other related name-based infections.

Fifth, since January 2008, CDC is encouraging and funding states to use the latest technology to estimate the infection time for all the HIV cases being detected.[25] This is because a new HIV diagnosis incident does not necessarily mean that the infection is recent. The person could have been with HIV for several years undetected. A significant number of people with HIV in the United States have never been tested. A previous study noted that there are 25 percent of people with undiagnosed HIV who are responsible for 54–70 percent of new infections.[29] More recent data show that about 14 percent of those living with HIV nationally are undiagnosed and varies from a low of 77 percent in Louisiana to over 90 percent in New York.[30]

The recommended testing method developed by CDC is called Serologic Testing Algorithm for recent HIV Seroconversion.[31] This method uses two enzyme immunoassays (EIAs) with different sensitivities to the levels of HIV antibodies. A specimen reaction to the standard EIA, but not to the less sensitive EIA, suggests a new infection.[32] This measure will give more accurate infection data and hence lead to better evaluation of the HIV incidence. In summary, data from the HIV/AIDS surveillance systems have helped achieve several notable successes that should be recognized.

HIV surveillance system data quality outstanding shortcomings

The analysis of the CDC reports reveals four major shortcomings with the quality of data from the HIV reporting and surveillance systems in the United States. The data are unrepresentative, incomplete, inaccurate, and lacks the required granularity, thus limiting its usage.

The first shortcoming is that the data are not representative of the general population. Current US HIV/AIDS surveillance data are based on estimates.[33] The data only include the cases of those individuals who have been tested.[15] There are various reasons why an individual may not have been tested for HIV: it could simply be that the individual is healthy and has not had a reason for being tested. Other reasons include structural barriers to healthcare access such as lack of health insurance, lack of information about availability of testing, cost of testing, and confidentiality of results, stigma, and misconceptions.[34–37] The health provider may also not have recommended a test. For example, in Washington DC while in a 2006–2007 survey 79.7 percent said they had seen a healthcare provider, only 49.4 percent were offered a test.[38] More recently, of 3,343,633 CDC-funded HIV tests completed in 2013 in over 23 testing site types by 61 health departments and 151 CDC-funded community-based organizations, none of the sites met the primary goal of the National HIV/AIDS Strategy to link 85 percent of all new HIV positives to medical care within 90 days of diagnosis.[39]

Despite the fact that CDC now recommend routine testing for all patients aged 13–64 years,[40] nationally only about 53 percent of the population above 18 years report having been tested in 2009.[37] Public awareness of HIV is also going down. For example, the share of those reporting seeing advertisement and hearing about the domestic HIV epidemic today has declined to about half that of 5 years ago.[37] This would suggest that there is need for more awareness campaigns to increase the number of people being tested which studies show can result in reduced new infections[41] and is cost-effective.[42,43]

The second shortcoming is that the data are incomplete. CDC advised states to move from code-based to name-based HIV case reporting in 1999 which was later strengthened to a recommendation in 2005 and into a requirement in 2008[26] following stoppage in October 2006 of Ryan White Care Act funding to states not reporting by name.[44] One unintended consequence is that the CDC directive resulted at least in the short term in incomplete data. We will use the state of California to demonstrate this point. California was using a code-based reporting method from 1983 but changed to the name-based system in 2006. However, as of April 2009, only about 36,000 cases of HIV had been reported by local health departments to the state by name despite the fact it was estimated in 2008 that California had between 68,000 and 106,000 HIV cases.[45] This suggests that more than half of the HIV cases were yet to be captured by the name-based reporting system making the current figures incomplete. This may result in California getting less state funding which is based on the number of reported name-based HIV cases.[46] Thus, the incompleteness of the system may skew the allocation of resources and may weaken the nation's capability of predicting new disease trends.

Furthermore, starting to report the data using confidential name reporting does not guarantee inclusion of all the data either. Rather, there is a delay period because CDC requires that states must have been in the confidential name-based reporting for 2–3 years before the data are considered stable enough to be included in the national data reports.[13] As of the 2010 report, only 37 states and 5 dependent areas had been doing confidential name-based reporting long enough to be considered stable as per this requirement.[13] This means that the data from the remaining 13 states are missing which adds to the incompleteness of the current national data. This represents approximately 32 percent of the data[13] which is substantial by any count. Additionally, CDC expects that the name-based reporting system matures in 4 years when trends could be regarded as reliable.[47]

The third shortcoming is that the data are inaccurate. While the CDC reports 1.2 million people are living with HIV/AIDS,[9] two recent studies show these figures to be overestimated. The landmark Global Burden of Disease (GBD)[10] Study puts the figure at 833,000 in 2014 based on mixed methods data collection, whereas another study finds the figure to be 819,200 in 2011 based on laboratory reporting.[48] CDC[49] estimates of newly diagnosed (44,073) in 2014 were twice as high compared to those (23,040) of the GBD.[10] Further inaccuracy may result from adjustments in data reported to the CDC and to the Health Resources Services Administration (HRSA) based on gaps in code-based and name-based reporting. HRSA continually monitors the care and treatment of groups and areas funded under the Ryan White. As the main instrument of federal funding for HIV countrywide, under the 1987 Ryan White Act, living non-AIDS cases reported directly to the HRSA from the eligible code-based reporting areas are adjusted by 5 percent to cater for duplicative reporting.[46] The rule is applied unevenly—it is not applied to areas with name-based reporting which affect the tallying of cases and resulting accuracy. This can affect funding levels which are based on these numbers; all other factors like politics being held constant.

The fourth and most critical shortcoming is that the data are not granular enough to help focus resources on the subpopulations at the highest risk of infection.[50,51] First, in terms of mode of transmission, the reports do not distinguish between homosexual and bisexual contact, despite the fact that these represent different transmission patterns within a population as shown in Online Appendix 1. The percentage of the people diagnosed with HIV infection attributed to male-to-male sexual contact increased from 60 percent in 2010 to 67 percent in 2014.[49] These are key subpopulations that need to be targeted with resources.

Second, in terms of racial categorization, the reports only consider six different racial categories (Asian and Pacific Islander were only separated in 2007) which is not granular enough to reveal the racial subpopulations needing the most resources. Over the years, the percentage of AIDS diagnosis in adults and adolescent whites has decreased while the percentage of same in Blacks/African Americans and Hispanics/Latinos has increased.[52] In 2008, 52 percent of the Americans diagnosed with HIV were Blacks/African American despite the fact that they only consist of 12 percent of the US population.[13] In 2010, the percentage of Blacks/African American came down slightly to 48 percent but this is still about half of the whole HIV/AIDs diagnosed population.[52] The same report shows that the estimated rate of new "HIV among black/African American males (116.0) was more than 7.5 times as high as the rate for whites (15.3) and more than 2.5 times as high as the rate (44.7) for Hispanics/Latinos."[52]

The latest statistics shows that from 2010 through 2014, Blacks/African Americans had a HIV diagnosis of 44 percent.[49] Thus, the percentage of Blacks/African American came down slightly, but this is still about half of the whole HIV/AIDS diagnosed population. Even worse, approximately two-thirds (63%) of diagnosed HIV infections attributed to heterosexual contact were among Blacks/African Americans.[49]

To be fair, CDC has been working with various groups on several initiatives to combat HIV especially among African Americans.[53] The doubling by CDC of its investment in 2008 to US$70 million to increase HIV testing among African Americans and the launching of a US$10 million "Act against AIDS campaign" with 14 of the nation's leading African American organizations are two examples of such initiatives.[54] However, these pale especially when calculated as a fraction of the whole CDC budget of US$515 Billion allocated for HIV prevention to the 50 states and dependent areas for the 2008 fiscal year.[55] While we acknowledge the political nature of resource allocation, this suggests that the HIV data have not helped as much as it should in focusing resources on the community at the highest risk of infection, a matter that is the focus of a recent modeling exercise for more efficient resource allocation.[56]

Furthermore, CDC uses "Black/African American" to include all people Black, as does the recently released National HIV Strategy.[57] This classification fails to recognize the diversity of the Blacks/African American label and may be missing some important pockets of these subpopulations. This fact was recently demonstrated by studies done by analyzing HIV data in states with high African-born communities.[58,59] One of these focusing on California, Georgia, Massachusetts, Minnesota, and New Jersey and in King County, Washington, New York City and the portion of Virginia included in the Washington, DC, metropolitan area found that African-born individuals accounted for only 0.6 percent of the population yet had 3.8 percent of the HIV cases diagnosed in the participating areas.[59] Even more alarming, they consisted up to 50 percent of the HIV cases diagnosed in Blacks in some areas like Minnesota, where cases for 2009–2011 in females born in Africa remained the majority.[60]

In another example, immigrants and refugees born outside the US compromise 20 percent of the total population of Massachusetts residents living with HIV/AIDS yet they only consist of 12 percent of Massachusetts general population.[61] The report further indicates that the infection rate of the non-US-born population rose from 19 percent in 1999 to 34 percent in 2007 showing that the infection rate in this section of the population is rising rapidly. The largest proportion (34%) of the non-US-born population diagnosed with HIV/AIDS within the 3-year period 2005–2007 was from sub-Saharan Africa. It is highly likely that HIV prevalence for the immigrants from these countries follow them as they come in and settle in their specific preferred neighborhoods.[62]

Immigration will likely play a factor in future new HIV patterns especially following the removal of the ban in 2009 in which an estimated 1073–6409 HIV-infected immigrants will be granted legal permanent residency resulting in 170–1014 new infections in the host population.[63] Hence, studying immigration patterns and behavior of immigrants from high-risk countries would be a key step in understanding and overcoming the spread of infection among these groups[64] and lead to a more effective and responsive surveillance system. These cases also suggest that classifying HIV cases occurring in African-born population as “African American” or “black” can be misleading and could lead to neglecting critical subpopulations in the allocation of resources. Thus, the HIV surveillance data are not “fit-for use” when evaluated against this expected usage.

Conclusion and recommendations

This study assessed the data from current HIV surveillance system in the United States on the basis of prior established criteria for evaluating public heath surveillance systems.[2,17] Data and sources of data are of critical importance in measuring the HIV/AIDS epidemic.[5] We assessed the quality of the current US HIV/AIDS data and its fitness for use. The results suggest that the system has achieved certain worthy goals. For example, the system has integrated different data sources at the national and state levels. Furthermore, a standardized HIV case definition, testing, and reporting guideline has been established, thus improving surveillance.[13,31,33]

However, there are several shortcomings with the current surveillance system primarily due to the type of methods used to collect the data and the sources of that data. First, the data are not representative of the general population but rather only reflect the population that has undergone testing. We recommend increasing HIV/AIDS awareness that encourage early testing through campaigns and strengthening of the HIV/AIDS services systems to link testing to care which is vital.

Second, the data are incomplete due to exclusion of states that do not meet certain stability requirement and use of name-based reporting.[48] This can lead to unfair resource distribution based on the incomplete numbers. We recommend the continued use of existing resource allocation percentages until the data stabilize on a state-by-state level.

Third, data are inaccurate with CDC data being highly overestimated in some cases, which can also lead to inaccurate resource allocation. We join other scholars in recommending that comprehensive HIV laboratory reporting be used to estimate national and local data.[48] Without reliable and timely estimates of incident HIV achieving the national and global goals of ending the epidemic will not be possible and makes for an urgent call.[65]

Fourth, the systems lack the required granularity especially because of the usage of “catchall labels” like “Blacks” without inclusion of country of origin or other unique identifiers leading to overgeneralization. We recommend that certain changes be made to bolster the usefulness of the data. As HIV transitions into a more heterosexual transmission,[13] with the lifetime risk of infection[66,67] reaching 1 in

64 Americans (1 in 20 among Black men and 1 in 48 among Black women compared to 1 in 132 and 1 in 880 white men and women, respectively); more specification in population-based capture and reporting, not less, will be needed. Reporting by the current racial groups does not adequately capture the increasingly complex transmission risks due to the cultural and ethnic diversity.[58,59] We recommend that future strategies should not just be race-based but also include country-of-birth-based reporting to account for the role of migration in transmission.[58,59] In addition, research methods like targeted surveys that aim at hard-to-reach[68] subpopulations can be used to supplement the CDC reports in getting more data on the subpopulations at risk. We admit that including all these additional details may make the database complex. However, CDC can use emerging ways of organizing and reporting data to automate some of this work. For example, a new semantic framework for global disease surveillance[69] has been suggested that will make automation of surveillance report easier and make it easy for machine-to-machine communication of disease surveillance entry attributes. These recommendations will help to boost the successful implementation of the National HIV/AIDS Strategy[57] now updated to 2020, whose focus is reducing new infections, improving access to care, reducing disparities, and achieving a more coordinated national response to the HIV epidemic.[70,71]

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Cybersecurity and privacy issues for socially integrated mobile healthcare applications operating in a multi-cloud environment

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Abstract

Social media has enabled information-sharing across massively large networks of people without spending much financial resources and time that are otherwise required in the print and electronic media. Mobile-based social media applications have overwhelmingly changed the information-sharing perspective. However, with the advent of such applications at an unprecedented scale, the privacy of the information is compromised to a larger extent if breach mitigation is not adequate. Since healthcare applications are also being developed for mobile devices so that they also benefit from the power of social media, cybersecurity privacy concerns for such sensitive applications have become critical. This article discusses the architecture of a typical mobile healthcare application, in which customized privacy levels are defined for the individuals participating in the system. It then elaborates on how the communication across a social network in a multi-cloud environment can be made more secure and private, especially for healthcare applications.

Keywords

cybersecurity, healthcare, multi-cloud environment, privacy, social networks

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Introduction

Social network analysis (SNA) aims at understanding the underlying social structure in a social network by description, visualization, and statistical modeling. Social network data consist of various elements which can help to explore and visualize patterns found within collections of linked entities that also include people. SNA is now becoming a very active area of research, and many individuals and organizations are putting their efforts in this area. Many researchers[1–4] have defined SNA as the methodology for examining the structure among actors, groups, and organizations in order to explain the variations in beliefs, behaviors, and outcomes. Hatala[1] also highlighted that the process to conduct a SNA mainly involves eight steps which include the following: determining the type of analysis, defining the relationships in the network using a theoretically relevant measure, collecting the network data, measuring the relations, determining whether to include actor attribute information, analyzing the network data, creating descriptive indices, and presenting the network data. Kietzmann et al.[5] describe the essential components of social media structuring, namely, presence, sharing, relationship, identity, conversation, group, and reputation. It has been observed that the description of the user identity can often be investigated by the thoughts, feelings, likes, and other subjective information if they are not disclosed directly. Tong et al.[6] have identified that a friend's profile on *facebook.com* is a major source of personality evaluation for any given individual. An effective semantic analysis can provide an exploratory analysis about an individual by examining the profiles of his or her friends, his or her likes and posts, and so on.[7,8]

The use of social media is naturally diverse.[9–13] For instance, many people use social networks to exchange information on healthcare issues. This is a significant use of social media platforms, which in turn asserts their growing presence in the healthcare domain. The utility of the use of social media is outstanding and so is the outcome when the procedures to use the social media for healthcare are in place. Griffiths et al.[14] have elaborated that in such systems, individuals take the responsibility to provide up-to-date information about their health either by the use of some system or by interventions such as cognitive therapy, and some other researchers have also argued the same.[15–18] Self-reporting systems can be applied where it is observed that the patient is not in a stable state, for example, those patients observing the bipolar disorder or the like. Healthcare data are kept confidential and people are informed as to where and how to upload data. Over the years, many large data sets have been collected which can be used for experimental purposes in subsequent research.

Healthcare is a two-sided process between patients and medical professionals. As far as the platform used is concerned, it supports the interaction among the patient, doctors, or community health services. In the two-sided healthcare system, a network of components is associated with a number of platforms. Roughan et al.[19] and Papadimitriou et al.[20] have addressed those significant issues such as inter-clinic communication, data privacy, and information synchronization. In the current trends, many public and private organizations deal with cloud-based healthcare systems and social networking is changing people's perspective toward health-related issues. Social networks have emerged over time as a great platform for sharing medical opinions, and it has been noted that online communities can develop quasi-professional knowledge about the health status of the communities in general and about the individuals in particular. The topic of preparing effective communication guidelines for online communities and distance learning education have been addressed in several studies,[21–23] where a number of improvization methods are identified to make the communication more effective in an environment where the meaningful information can be extracted from the communication.

The orientation and application of a broad range of new e-Health applications help improve the exchange of health information between consumers and providers for the purpose of promoting healthy behaviors. Kreps and Neuhauser[24] have argued that the new and exciting health information technology (HIT) gave responsibility to the designers of e-Health systems to design such tools that are capable of providing the right information irrespective of the time and location. The role of communication is vital in the improvization of public health, and it is important to appreciate that understanding human communication requires the strategic design, monitoring, and responsiveness of an e-healthcare application. Higgins et al.[25] have specified certain behavioral factors that contribute in problematic lifestyles including alcohol. Ylimäki et al.[26] have identified that the adaptation of e-healthcare systems to improve the lifestyle in order to decrease health-related problems has been very slow. e-Health communication has made it attractive by providing databases to compare data by other providers, and it was identified that the number of individuals using healthcare systems is increasing but the increase is not very robust. According to a recent study,[24] it has been observed that Americans go to the Internet first, rather than to a provider, for health information. The authors have further claimed that HITs should have an interactive feedback system and must be designed to work effectively and efficiently.

The advent of wearable devices has enabled a wireless access to the healthcare data to help the medical professionals to save time and overcome data latency issues, but there is a tendency to wait for these technologies to become mature before they are used. Sensor networks are being used to monitor human activities, which can be broadly divided into the areas that relate to medical and non-medical applications. Wearable devices have been used to check a patient's temperature, blood pressure, and so on, and implanted devices are used to check cardiac arrhythmia, brain liquid pressure, and so on. Applications of wireless sensor networks in the medical domain primarily address the monitoring of a patient's health condition. Wireless sensor networks are becoming popular, and they are being adapted rapidly. For example, they are being used to capture the data of elder patients for long-term treatments. Such devices and wireless sensor networks have certain cybersecurity vulnerabilities which can be categorized as follows: privacy, security, buffer overflow, exposure of sensitive data, broken session management and authentication, injection vulnerabilities, security misconfiguration, and legal issues.[27,28] Research in the healthcare application of wireless technologies has been performed worldwide in many domains and also in many dimensions.

To that effect, Sezgin et al.[29] have studied the possibility of using mobile healthcare applications and the user perception about these applications. Li et al.[30] have studied the adaptation patterns of wearable devices for the healthcare. It has been observed that the risk to adopt a new wearable device is higher in the beginning but with the passage of time, the trust on the device improves and further grows when the associated risks are deemed to be less than the associated advantages. Guo et al.[31] have reported that the privacy deficit is a major factor in determining the goodness of a healthcare system and recommend that healthcare devices should be secure enough to provide only a restricted access to the defined individuals. The authors also hail the concept of considering the geographical diversities of human behavior before recommending suitable devices. Nurses can use radio frequency identification (RFID) to identify patients in intensive care units (ICUs). Wireless devices are being used for real-time monitoring of patients' electrocardiography (ECG) signals, and the doctors have access to the latest and always up-to-date records of patients using multimedia messages. Furthermore, the adoption of mobile healthcare is attractive considering such factors as patient behavior, subjective norm, personal innovativeness, perceived behavioral control, and behavioral intention.[23,32]

As is the case for wireless sensor networks, healthcare applications are also vulnerable to active and passive attacks. The attackers can cause much harm to the process by malicious attempts such as data modification, impersonation, eavesdropping, and replaying. The primary purpose of these attacks is to steal the patient's data, which are not only valuable but also private and sensitive. In some cases, implanted medical devices are used to administer drugs (such as insulin), and attacks could lead to serious outcomes for the patient if the administration of drugs is compromised. If the security issues with the healthcare applications are not resolved in a timely fashion, the impact may be catastrophic and may also cause the rise of socio-technical problems. So, while designing socio-technical integration of mobile and other electronic devices with healthcare applications for the purposes of sharing patients' data, information, and messaging, it is vital to incorporate system security, administrative- and physical-level security, and information security into such applications.

In this section, an introduction of the healthcare systems and its integration with social media platforms is presented. Possible challenges in such integration have also been elaborated on. Section "Related work" discusses some related works which have taken place in this domain. Section "Architecture of a healthcare model based on social networks" discusses the privacy concerns of healthcare models based on social networks, while section "Privacy concerns" elaborates on social media models. Section "Privacy and security" discusses the security issues while highlighting the mitigation-related work. Section "Conclusion" concludes the article with a summary of our findings.

Related work

In healthcare applications, SNA has been used to understand communication patterns between and collaboration of healthcare providers. Bae et al.[33] have identified that healthcare providers' interactions contribute to the culture and knowledge of healthcare organizations. Without any interaction between professionals and patients, it is obviously not possible to share information between them. SNA can be used to study the interactions, as well as the performance of teams and organizations. Many researchers have used SNA in healthcare, especially in the context of hospitals, nursing homes, and clinics.[34,35] To improve communication among healthcare providers, it is critical to find the optimal structure of communication under a certain healthcare setting. It has been observed that the operating rooms, the type of surgical specialty team, and facility layouts were critical factors contributing to the characteristics of inter-professional social networks.

In a study conducted in the United States, Hendryx et al.[36] studied the variability of access to healthcare across 22 major cities in the United States and observed that the access pattern to healthcare instruments and institutions is not similar in all the states. It was hypothesized that reported access to care is positively associated with the community social capital. Four different informatory resources were used for this purpose which include the following: Counseling and Testing System (CTS), National Institute for Health Care Management (NIHCM), National Profile of Local Health Departments (NPLHD), and a multicity media marketing database. The results can be seen to put forward the hypothesis that the social capital has a relation to the improvement in access to healthcare. The result of this study also supports the work done by other researchers. The study, however, could not identify how and why the social capital may help in improving access. The study argues that the social capital has a vital role to play if compared with the structural healthcare variables. Berkman[37] has elaborated that in the social network model, we have a personal cell which then extends step by step to different zones. Social networks may impact health by cultural differences, economic factors, and social changes. For example, it has been observed that people with no social support have the highest blood pressure.[38]

Boukerche and Yen[39] and Hwang et al.[40] have argued that mobile healthcare is becoming popular and security and privacy are the critical issues. Security is one of the most important issues in mobile healthcare, and devices like bi-directional telephones are tested to overcome the issue of health parameters. Mobile healthcare has such features as the use of wearable devices (such as sensors and implantable devices), the mobility of users, data transmission, and remote medical control. There are many types of devices being developed to secure the data and maintain the privacy of patients. In a mobile healthcare system, a trust relationship can be defined between two nodes, that is, the sender and the receiver. In a simple trust model, if one node routes a packet of data over another node by choosing it among many others, then we can say that it has the highest level of trust placed on it by the sender. By routing data again and again over the same chosen node, the value of trust placed on that node is increased. It can then be argued with confidence that a trust-based multicast strategy can be a means of ensuring reliable communication and pervasive healthcare networks.

Developers in medical and computer networks have been working to develop some innovative ideas like the adoption of wireless sensor networks, which generally consist of body area networks (BAN) and personal data networks (PAN). Alemdar and Ersoy[41] have identified that the gateway subsystem has the responsibility of establishing a connection among the BAN and PAN subsystems and connecting them to a wide area network (WAN). As the magnitude of communication grows with the healthcare data, satellite communication may further help ease the communication load. By the virtue of cognitive disabilities that emerge fast in the elderly and chronically ill people, medical noncompliance has also been observed. The need to give high-quality medical care to new-born babies is also a matter of utmost importance. In order to address such issues, medical monitoring systems are needed, and more sensitive sensors can report in such cases more effectively. It is essential that the communication is noise free, which can be ensured by low transmission power and small-size antennas of wireless sensor devices; furthermore, the interoperability problem is observed when multiple sensing devices operate at different frequencies.

There are a number of security requirements to which a healthcare system must adhere. These requirements include privacy, data integrity, accountability, readiness, and access control, all of which have been advocated by several researchers.[42–44] The security and privacy requirements of healthcare applications based on the social media are discussed in the following sections. In a recent work, Li et al.[45] have found that the leakage of information from the social network can still happen even when the user has adequate knowledge of the privacy controls with which he or she can effectively configure the privacy settings. Külcü and Henkoğlu[46] have argued that there should be more social awareness in ensuring privacy and that the non-existence of strict cybercrime laws is also a factor in reducing the resistance against the privacy concerns. It can be observed that mobile-based healthcare solutions are needed by the society, especially for the elderly patients who strive for movement in case of emergency. There is a significant improvement in this area, and the application of mobile devices, sensors, wearables, and cloud computing is being witnessed which has really assisted with patients' healthcare needs. Along with the improvements in the clinical part of healthcare, the security and privacy issues of the data have increased and are of intense interest in recent research. Since privacy factors are of significance for the healthcare data, access control is required to be prominent and effective as well. The architecture and privacy controls are discussed next to overcome the research gap in this area.

Architecture of a healthcare model based on social networks

A healthcare model based on social networks includes the actors of the system, the system itself, the environment, and the communication between the actors and the system using the environment to perform a meaningful communication. The system is designed for the patient who is in continuous need of monitoring, where the off-hospital view and review of the patient are deemed necessary for the safety, and the recovery of the health, of the patient. The proposed model relies on the basic assumption that all the components are well integrated to react on a call and that the connections for communication are available. The physical infrastructure is readily available to respond when there is an emergency call. This article does not discuss the physical infrastructure of the

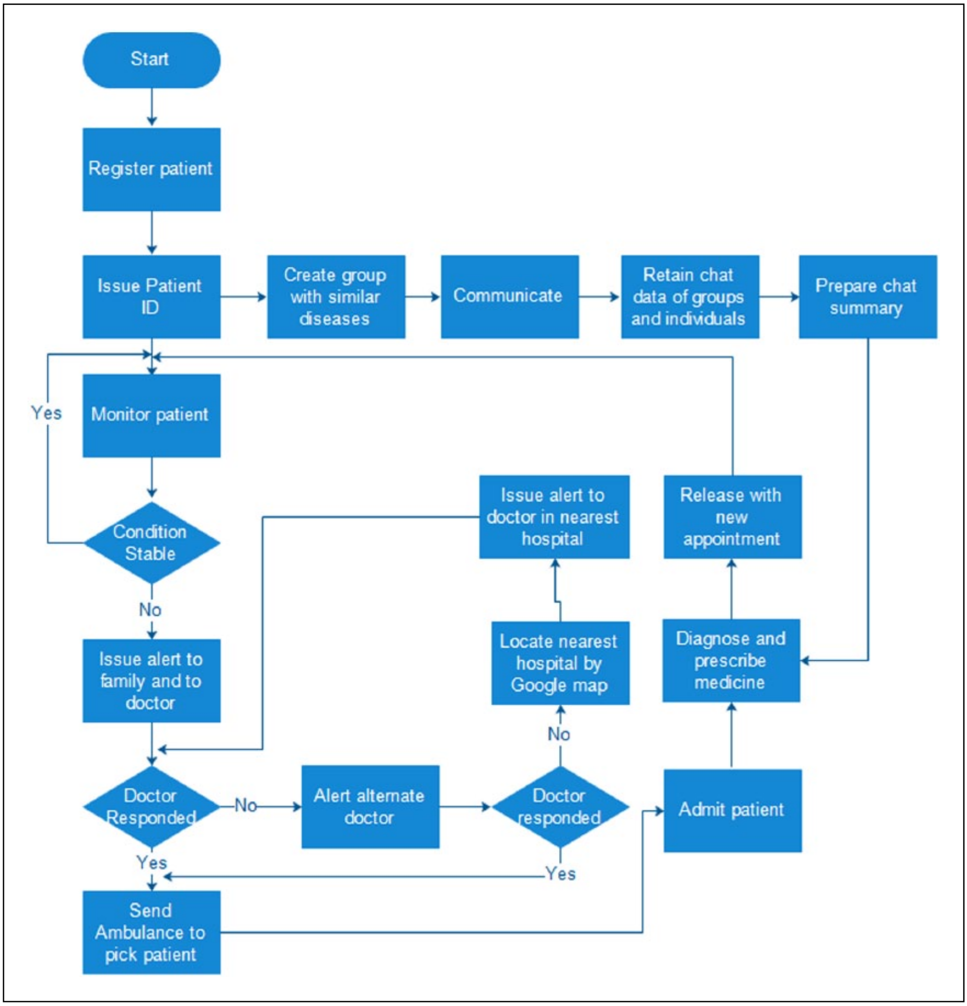

Figure 1. Flow of events for monitoring, registration, and medication of a patient.

system, and the communication aspects of the system are also beyond the scope of this research. In this article, we present a scenario where we identify how a patient will be treated in case of an emergency. The primary focus of this article is to discuss the privacy and security challenges and their possible mitigation framework in the healthcare system. There are several roles involved in such systems including the patient, the patient's family, the system administrator, doctors, ambulance drivers, and paramedical staff. The communication among different actors is essential while the system is in execution. A flow graph of the activities and communication among the actors is presented in Figure 1. An overview of the system is presented in Figure 2 which illustrates the overall composition of the system by describing the possible ways of interaction among the entities of the system.

In a normal scenario, a patient is registered with the system through the social network application when brought to the hospital. The registration takes place in a specific group where the patient can communicate with other patients of the same illness and symptoms. The communication is

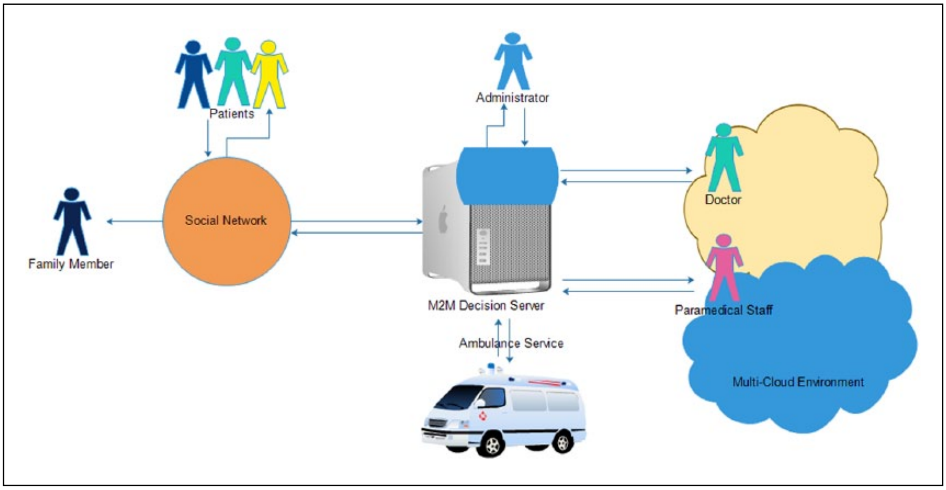

Figure 2. Overview of a healthcare system.

logged for providing an input in the reports of the patient. Summaries of such communications are prepared by applying data mining techniques to extract meaningful facts from the communication. The patients are kept in a stage of continuous monitoring by applying bio-medical sensors and any irregularity in the healthcare data readings is immediately forwarded to the family and to the system. While the family member prepares the patient for transportation to the hospital, the system generates an emergency alarm to the designated doctor. As an immediate response is needed, the system generates an alarm to an alternate doctor in case the primary doctor does not respond within designated time. Even if the alternate doctor does not respond, the system is capable of locating other nearby hospitals using the Google Maps application. Once the doctor is located, the ambulance picks up the patient and transports him or her to the hospital where he or she is admitted and diagnosed in light of his or her medical history, test reports, and the summarized chats. The multi-cloud setup integrates/communicates within itself for data transmission from one cloud segment to another. The doctor may decide to keep the patient admitted or may decide to release him or her if the patient's situation is found stable. However, regardless of whether the patient resides in or outside of the hospital, his or her continuous monitoring is done by the system. Several studies reported in the literature[47–49] have implemented such an idea without the utilization of a multi-cloud environment by overcoming the risks in such a system.[50–52]

While it is well understood that the security concerns in a mobile-based solution is a major concern, the privacy issues are also vital to be addressed especially when it comes to healthcare applications. This paper focuses on the description of the privacy and security of the data when the healthcare applications are integrated with social networks in a multi-cloud environment to communicate and disseminate the information among specific groups on the networks. The information access control and privacy schemes for the social-media-based healthcare applications are discussed in the next section.

Privacy concerns

The utility of data is increased when the relevant persons in the domain use it. Some data or data sets are publicly available, while many other types of data have different levels of privacy. Medical

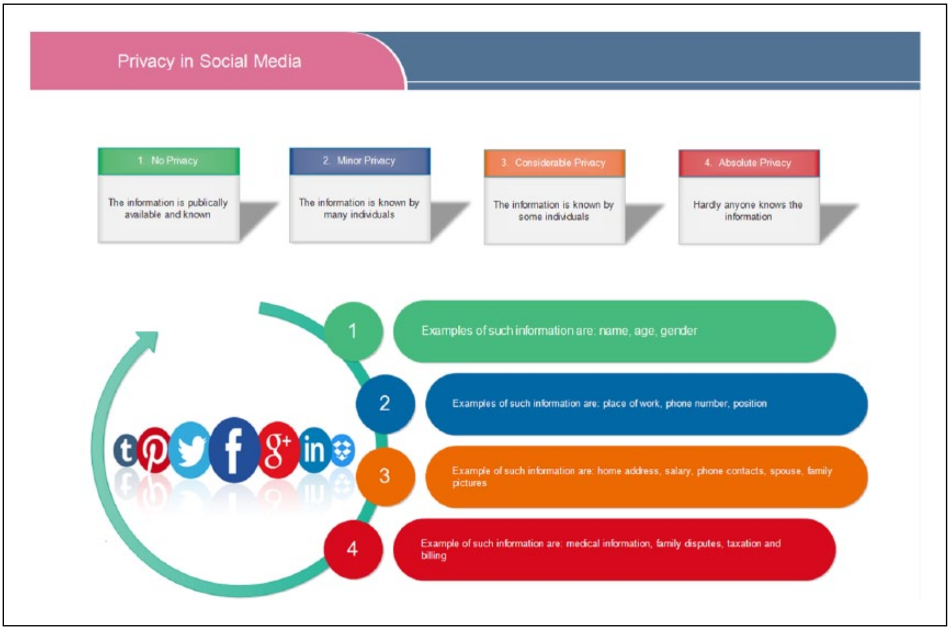

Figure 3. Privacy with respect to types of data.

data are considered among the most private types of data and access to this data is highly sensitive and can only be authorized to be accessed by designated professionals. Since, in this article, we address the healthcare data, we identify the possible security and privacy breaches and propose ways in which they can be mitigated against. In the context of social-media-based application data, the data can be classified into different categories, as shown in Figure 3.

Zhang et al.[53] have identified that the structure of online social networks (OSN) is such that it allows a user to flexibly share the information and in that effort to succeed, sometimes the privacy and security of the profiles and OSN are compromised. The threats to an OSN are diverse and can cause the security and privacy breaches if not addressed with high confidence. The potential challenges to security and privacy are discussed below.

User identification

The user identification syndrome is common in OSNs and is defined as a feature that helps the individuals recognize each other. For example, some social networks only allow viewing the first name of a user, while some others, such as *match.com*, assign an anonymous identification number to the user. However, the purpose of an OSN is compromised if the identification is not the real name but some arbitrary name or a number. Hiding the real identity of a user can be a solution in the friendship-seeking websites where the picture and other characteristics apart from the name also have a significant value, but in an OSN, like *facebook.com*, this anonymity is not really a good solution. We also recognize that the healthcare data are the most valuable data and as such it requires adequate access control. A social network that deals with the alike patients to form groups and communicate without privacy/communication protocols in place may be an open target of compromising sensitive data. In such a case, anonymity may be the solution that keeps the patient un-identified, even if the communication among the patient's group is compromised.

Privacy of user's personal space

The visibility of a social profile has a different type of presence on different social networks. Popular OSNs like *facebook.com* allow the user profiles to be seen and browsed unless the user has declared them to be private. However, once a user can have access to a private profile, the friends list of that private profile also becomes public, which in turn enables massive information-sharing. In healthcare-oriented social networks, the user's profile will need to be kept private by default and the profiles of their friends and family will be kept private to secure the system from outside attempts of recognition.

Users' communication

Along with the information that a user shares with the other OSN users, there is some default information-sharing that is done with the OSN provider. This default information includes the IP address, the time of connection, visited profiles, and the messages sent. It is also important to note that the digital footprints of any activity may also provide a ground for breaking into the personal profile of some individual, possibly making them a victim of cyberbullying, sexting, harassment, and/or Facebook depression.[54]

Considering these aspects of security and privacy, the OSN and the user data are vulnerable to the attacks/information-seeking requests of unauthorized persons. Since the healthcare data are critical and required to be kept private, additional security and privacy filters are to be applied to ensure that the security and privacy of the system are not breached at any time and the data are consistently available with the prime focus of communication. For a healthcare system, we propose to have role-based security and privacy that is implemented with the concept of access control. As shown in Table 1, role-based access control provides an informatory look that describes the legitimate and illegitimate access controls based on the role of the user.

Table 1 shows what can be done ("can") and what cannot be done ("can't") to elaborate the privacy policy. The "privacy requirements" column demonstrates the minimum privacy level that is required to make the system work effectively without breaching the privacy. In Table 1, it has been elaborated that the privacy requirements of each role are different based on the sensitivity of the information being handled by that specific role, for example, the system administrator's role requires high privacy in conducting his affairs in accordance with the patient's information, medication, stay, treatment, and communication. Consequently, the doctors and the pharmacists also need to observe a higher level of confidentiality in protecting the patient's medical data. The moderate privacy requirement allows a patient and his or her family to share the information with the general public. If this minimum privacy level is observed within the system, it is expected that the system will no more be a subject of internal privacy breaches and more concentration can be given to handling the external attacks (if any).

Privacy and security

The concept of a privacy breach is associated with the intentional and un-intentional or conscious and un-conscious activities that may compromise the privacy of a patient. Although some measures can be taken to protect the privacy of data, the most significant part of privacy is yet to be implemented and ensured by the user. A significant privacy level can be achieved by communicating less and hiding the personal details and plans. For example, sharing too much information about our travel, visits, and personal likes and dislikes in public exposes us to the world where certain patterns about our lifestyle can be deduced with a significant level of accuracy.[55] In contrast

Table 1. Role-based access control to implement extended privacy and security in healthcare-oriented social networks.

Role	Can	Can't	Privacy requirements
System administrator	• Register patients • Delete patients • Assign doctor/student • Collaborate among healthcare units	• Diagnose and prescribe medicine • Make medical decisions	• A high level of privacy is required to deal with data and medical records of the patients
Doctor	• Diagnose • Prescribe • Give a new appointment • Make critical decisions based on reports and other data sources	• Change the schedule without a justified reason	• A high level of privacy is required to deal with medical records, diagnosis, and medical history of the patients
Pharmacist	• Provide medicine based on the prescription	• Diagnose and prescribe medicine • Make medical decisions	• A high level of privacy is required to issue the medicine without sharing this information with others
Patient	• Talk to fellow patients in his or her group • Can broadcast a message • Describe his or her situation • Send an emergency signal to the system	• Prescribe medicine to each other • Take medicine on his or her own	• Moderate
Patient's family	• Be alerted by the system to respond in facilitation	• Diagnose and prescribe medicine • Make medical decisions • Change the schedule without a justified reason	• Moderate
Paramedical staff	• Provide assistance • Conduct tests	• Diagnose and prescribe medicine • Make medical decisions • Change the schedule without justified reason	• A high level of privacy is required to deal with medical records, diagnosis, and medical history of the patients
Medical students	• Read reports anonymously • Read chat logs anonymously • Prepare summary history based on chats and treatments	• Diagnose and prescribe medicine • Make medical decisions	• A high level of privacy is required to deal with medical records, diagnosis, and medical history of the patients
Ambulance driver	• Drive the patient from the current location to the hospital • Provide assistance regarding transportation	• Diagnose and prescribe medicine • Make medical decisions	• Moderate

to this concept, however, the attacks and exploitation of breaches in security of data are deliberate in nature and may come from outside. Security issues of the data are a superset of the privacy issues faced by the users on social networks. Some privacy concerns have been discussed in this

Table 2. Security and privacy concerns for the data on social media.

Major security threats to data on social networks	Major privacy concerns to data on social networks
1. Corporate impersonation 2. Traffic hijacking 3. Account takeover 4. Click bait attacks 5. Information leakage 6. Watering hole phishing and malware 7. Customer scams	1. User identification 2. User communication 3. Privacy of user personal space

article, and the mitigation strategies have been proposed while highlighting a number of security concerns. The privacy threats, however, can be considerably reduced if the communication of the user is not redundant and specific in nature. The specific communication provides the benefits such as follows: less data to be managed, no-unnecessary disclosure of data, and identity preservation (Table 2).

Nerney[56] has identified that there are some significant security concerns to the data on social media. Among the concerns, he has identified the "mobile apps" from unrecognized companies as a major security threat. One major reason for using third-party apps is that the user needs are extending and trusted apps are not always available. The user, while downloading an app, may regard the number of downloads as a feature of trusting the credibility of some application. Although this may be a feature in this regard, yet it is likely that the number of downloads does not truly reflect the credibility of the downloaded app. The user reviews about the app, however, can give some explanatory feedback about the quality and trust level on the application. Since a rating is a quantitative measure and users have to choose from, for example, a scale of 1–5, the application score is less illustrative in defining the problems faced by the application. The comments of the user or those of a trusted party about the quality of an application can however be a more important, realistic, and direct way of establishing the trust and quality for an application. Other major security threats are social engineering and malicious code on the social network sites.[57,58] Nerney[56] further identified that the "employee trust" is also vital in training them in such a way that any internal communication, resentment, and policies of the firms are not shared in public. The ZeroFOX[59] has identified that many other security threats to data on social networks exist which include the following: executive impersonation, account takeover, watering hole phishing and malware, customer scams, corporate impersonation, information leakage, click bait attacks, and traffic hijacking. The "executive impersonation" can be overcome by introducing two-way authentication, education and by choosing the right financial partner. The mitigation of each of these can be made by following the respective strategies discussed in the literature.[60–63] Since the healthcare data are very sensitive in nature and are not an exception from security breaches, mobile healthcare applications are more vulnerable to such attacks posing a threat to mobile devices or the information security otherwise. The healthcare data and applications, in association with the social networks, need to be doubly secured as a person's social network's security is more trivial to reach. In a multi-cloud environment, a small access point (security breach) can eventually compromise the significant part of the healthcare data on the cloud. By adopting the measures, suggested by Delerue and He,[60] the healthcare system can gain significant confidence, as far as the security is concerned. These measures include the following: developing a social media acceptable use and security policy, routine social media sites monitoring, monitoring employee's Internet activity, user education and training program, archiving social media content, and developing a social media incident and response planning.

Conclusion

There are many threats/concerns to the data on social networks that may compromise the privacy and security of mobile applications and data. Since the healthcare data are of utmost interest to the phishers and intruders, making it available on social media for the purposes of discussion may actually invite the invasion. In order to address the visible threats of a diverse nature, a healthcare model has been presented in this article, which, in integration with the social media and physical infrastructure, presents a viable solution for ensuring the privacy and security of data. The architecture is based on a multi-cloud environment that ensures the availability of data and resources at all the times to deal with the catastrophic nature of the pressing healthcare requirements of a patient in need. The privacy concerns, such as user identification, user space, and user communication, have been discussed and the strategies to mitigate these risks have been elaborated. Along with this, the security concerns have also been identified and are important to be addressed to ensure the privacy and security of the data. Furthermore, the role-based privacy customization has been introduced that leads to the system security and privacy by defining the profile definition of the concerned individuals.

There are several promising research directions that deserve to be investigated in the near future. A detailed study can be conducted on the architectural composition of the multi-cloud environment for healthcare applications to investigate the possible computational gains that can be derived from such advancements. Another direction of work is to investigate the reliability of social media applications while working with the healthcare data in a multi-cloud environment, where the level of reliability, the threats, challenges, and opportunities of such a system can be identified.

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The agency of patients and carers in medical care and self-care technologies for interacting with doctors

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Abstract

People living with Parkinson's disease engage in self-care for most of the time but, two or three times a year, they meet with doctors to re-evaluate the condition and adjust treatment. Patients and (informal) carers participate actively in these encounters, but their engagement might change as new patient-centred technologies are integrated into healthcare infrastructures. Drawing on a qualitative study that used observations and interviews to investigate consultations, and digital ethnography to understand interactions in an online community, we describe how patients and carers living with Parkinson's participate in the diagnosis and treatment decisions, engage in discussions to learn about certain topics, and address inappropriate medication. We contrast their engagement with a review of self-care technologies that support interactions with doctors, to investigate how these artefacts may influence the agency of patients and carers. Finally, we discuss design ideas for improving the participation of patients and carers in technology-mediated scenarios.

Keywords

collaborations, patient–doctor interaction, self-care, self-care technologies

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Introduction

People living with chronic conditions, such as Parkinson's disease (PD), spend most of their days in self-care but, two or three times a year, they visit their doctors to discuss old issues, new challenges, and treatment adjustments. While consultations in chronic care are seen as collaborative,[1] there are different ways of participating in these encounters.[2] Some studies show that patients and doctors sit as equal partners in decision-making, in recognition of their specific expertise and commitment to an appropriate treatment,[3–5] while other studies suggest that patients only provide input to the decisions of doctors.[6–8] Either way, when given a chance to participate, patients and carers bring useful insights to the table and actively contribute to building a better quality of life for themselves.[9]

The agency of patients and carers in care, or in other words, the ability to contribute, influence, and decide on treatment, is not dependent solely on their willingness to participate in interactions. As Suchman[10] explains, agency is inherently situated and tied to specific socio-material arrangements, which offer different capacities for actions. People living with Parkinson's, for example, are usually motivated to participate in their care because of the ability to shape treatment according to their issues and aspirations.[11] Yet, their agency in care is often constrained by doctors who proceed under a paternalistic model[12] of care where patients are considered as mere informants incapable of participating in decision-making.[2,13] Besides such prejudices of doctors, the agency of patients and carers is influenced by a multitude of human and non-human entities, which include the following: self-care technologies, information systems, standards, as well as everyday activities, clinical processes, and procedures. Together these entities form what we refer to as the healthcare infrastructure.[14]

One factor that increasingly influences agency in care is new technologies. Since self-care technologies for interacting with doctors often introduce new care activities and redistribute existing ones,[15] they are likely to change the ways patients and carers interact with doctors.[16] Self-care technologies for interacting with doctors are defined here as tools that support data exchange or collaborative interactions between patients, carers, and doctors. There are self-care technologies that do not offer interactions with doctors,[17] but these are not considered in this article. Self-care technologies for interacting with doctors appear in the literature under different names, including Telehealth,[18] Telehealthcare,[19] or Telecare.[20] The term Telemedicine is also used,[21,22] but the overlap is restricted as Telemedicine also includes tools for supporting collaborations between healthcare practitioners. By using the expression self-care technologies, we emphasise the role of patients and carers in medical care, in opposition to terms such as Telehealth or Telecare that suggest care is remotely provided to patients, driven from a clinical perspective.

Previous research in human–computer interaction (HCI) and computer-supported cooperative work (CSCW) has explored numerous self-care technologies to support interactions with doctors, from videoconferencing systems for interacting with doctors remotely,[21,22,23] technologies for collecting symptoms at home,[24] and apps for learning about one's body in everyday life.[25] Nevertheless, due to the complexity of this topic, HCI and CSCW researchers are still discussing how best to enable patients and carers to participate in their own care and what sorts of healthcare infrastructures could support more participatory interactions.[26]

This article contributes to the discussion on the agency of patients and carers in technology-mediated care scenarios. In particular, we contrast the agency of people living with Parkinson's within current healthcare infrastructures, with the participation that is promoted in self-care technologies for interacting with doctors. For understanding existing healthcare infrastructures, we draw on interviews, observation, and online ethnography, and for investigating the agency promoted by self-care technologies, we review technologies published in scientific venues and the iTunes App Store. Our findings show that patients and carers living with Parkinson's are very proactive, and that they play an important role in defining diagnosis, medical decision-making, learning, and addressing inappropriate medication. The review of self-care technologies shows they have potential to improve the agency of patients and carers, but in some cases, also present obstacles to their participation. We use our findings to discuss the agency of patients and carers in healthcare infrastructures and present implications for design to promote an active participation in technology-mediated care scenarios.

Methods

This article draws on two complementary studies. First, we examined how patients and carers interact with their doctors in consultations and in an online community. Second, we reviewed descriptions of self-care technologies for interacting with doctors, in search for understanding the role patients and carers can play in their care using them. The goal was to contrast the agency patients and carers had in their care in different scenarios.

Ethnographic fieldwork

To better understand the encounters between patients, carers, and their doctors, we analysed two different settings in two distinct care contexts. The first one consisted of face-to-face consultations of people living with Parkinson's with their specialist in a European city. The second consisted of online conversations between patients or carers with doctors in a US-based online community or forum. The choice of using different contexts and settings was motivated by the possibility to compare field data and thus improve the depth of analysis. As Glaser and Strauss[27] explain, maximising the differences between groups in the data collection can help uncover meanings or assumptions that might otherwise be taken for granted.

To understand the existing healthcare infrastructures and gain broader insight into living with Parkinson's, we used observations and interviews.

Observations. To understand consultations of people living with Parkinson's, we observed 14 sessions at a neurology outpatient clinic in a major hospital in Portugal (the observed participants are named using a code. For example, OP5 refers to the patient on the fifth observation). The observation spanned several days and was always held in sessions with the same neurologist. The 14 sessions were with participants we recruited from the waiting room while they were waiting to see this doctor, and who agreed to let us sit in on their consultation. As such, the observation was divided between two rooms of the clinic. In the waiting room, the participation level of the researcher was moderate,[28] balancing between being an insider waiting in the room, and being an outsider who asks questions to patients and carers who are about to see their doctor. At this point, discussions with the participants were captured in hand-written field notes. In the consultation room, the observation was passive, with the researcher behaving as a spectator and not interacting. The consultations were audio-recorded (5 h), and later transcribed verbatim for analysis. Moreover, we obtained informed consent from participants and ethical clearance from the hospital ethics commission.

Interviews. To complement the understanding of consultations, we interviewed another 10 patients and 10 carers living with Parkinson's (the interviewed participants are named using a code. For example, IP1 refers to the first interviewed patient, and IP10_C1 to the first carer of the interviewed patient 10). The interviews were intense,[29] qualitative, and loosely structured. The interview guide covered issues such as diagnosis, treatment, consultations, and overall everyday life.

The interviews were audio-recorded (20 h) and transcribed for analysis. Participants were recruited through a local chapter of the Portuguese association of patients with Parkinson's in an urban town. We obtained informed consent from all interviewed participants.

To understand the interactions between patients, carers, and doctors in a different context, we used online ethnography[30] in an online community.

Online ethnography. The community chosen was the National Parkinson's Foundation (USA) online forum that offers a range of different sections including the following: 'Newly Diagnosed', 'Caregivers Forum', 'DBS Forum', or 'Ask the Pharmacist' (available at: http://forum.parkinson.org/). For this study, we focused on the 'Ask The Doctor' section where patients and carers could ask questions about their particular case to a handful of specialised volunteering neurologists from the association. A total of 800 posts from the online community were read using a standard web browser, and when relating with data that appeared relevant, copied and coded in Scrivener™ (n = 332). We chose to analyse older threads of the forum, with closed conversations, and thus screened posts from 2007 to 2012. The posts in the online forum were publicly available and the names of patients anonymised (appearing as Guest__*), so we present them as they were online.

The analysis of the fieldwork followed a constructivist grounded theory approach.[31] In particular, we coded iteratively, constantly compared different excerpts, and regularly wrote memos about the emerging themes. We used the Scrivener writing software for collating relevant excerpts and writing memos. The data from the different methods was initially analysed separately and resulted in larger categories such as becoming a patient, self-managing Parkinson's, collaborating in self-care, learning to live with the condition, and interacting with doctors. However, as the theme around interacting with doctors grew overall, we decided to approach it more systematically and merge the codes from the different methods together. The codes emerging from the more selective coding coincide with the headings in the findings discussed below.

Review of self-care technologies

We contrasted the fieldwork with an analysis of self-care technologies for people living with Parkinson's to interact with doctors. Our focus was on how these technologies promoted participation of patients and carers in these care scenarios. The idea was not to be comprehensive and include the whole spectrum of self-care technologies, but rather to acquire an overview of the potential offered by these technologies.

To locate relevant technologies, we used different search strategies:

- We searched for 'Parkinson' in *HCI Bibliography* – the main index aggregating HCI/CSCW research – and also in relevant journals in (bio)medical informatics, including *Health Informatics Journal, International Journal of Medical Informatics, Journal of American Medical Informatics Association, Journal of Biomedical Informatics, Journal of Biomedical and Health Informatics, Journal of Medical Internet Research*, and *Journal of Telemedicine and Telecare*;
- We searched for 'telecare', 'telehealth', 'eHealth', and 'self-care technology' in the archives of the *Movement Disorders* journal, the key venue for research on Parkinson's. We also followed the citations of the studies that we selected;
- We searched for 'Parkinson' on the iTunes App Store for capturing technologies, that while not published in academic studies, patients and carers could access on their smartphones.

The criteria for inclusion in the review were technologies for patients or carers living with Parkinson's that supported face-to-face or remote interactions with their neurologists. Our analysis was based on the descriptions that the research articles or web pages made about the technologies. This included features, ways of operating, and the expected interactions between patients, carers, and their doctors; this all helped in getting an understanding of the potential agency that patients and carers would be able to exercise when using them. Moreover, in the case of self-care technologies described in research papers, we also analysed the findings related with their use, mostly in feasibility studies, as another source of input to understand agency in care. Analysing technologies by their description does not reveal the same results as observing their use in practice because users might appropriate the technologies in unexpected ways, consequently promoting or hindering the agency of patients and carers in care. However, in the absence of detailed pilot studies of these technologies, there is still much to learn from their descriptions, because technologies influence greatly how people can interact, and their potential to exercise agency in care.

Interactions between people living with Parkinson's and their doctors

Parkinson's disease is a progressive chronic condition that impacts the neurological system.[32] It is characterised by four main symptoms: rigidity in the muscles, slowness of movement, impairments in the gait, and the most well known, tremor. Non-motor symptoms are also common and include depression, pain, and sleep disturbances. PD does not have a cure yet, but there are some medications that can attenuate the symptoms of the condition. Living with Parkinson's is complex and requires significant work. The self-care of Parkinson's includes[33] taking a cocktail of medication at specific times, exercising to keep muscles fit and stimulate areas of the brain, adapting lifestyle to increasing disability, and accepting the current and future state of the condition.

Two or three times a year, patients and carers have a chance to discuss their issues with the neurologist and collaboratively adjust treatment. These occasions are critical for people living with Parkinson's (we use the expression 'people living with Parkinson's' in this article to refer to the collective formed by patients and carers. All of them live effectively with the condition, even if the carers do not experience it directly in their body[33]) because changes in medication can promote or hinder patients from performing specific activities. As the medication for Parkinson's is solely concerned with addressing the symptoms of the condition, being able to articulate well one's issues and discuss possible solutions is thus key to achieve a life with the quality that one aspires to. The medical care of PD can involve doctors, nurses, therapists, and other healthcare personnel. However, in this article, we discuss solely the interactions with doctors as they are the ones involved in neurological consultations and, consequently, the potential users of technologies for that context.

In this section, we explore the interactions patients and carers living with Parkinson's have with their neurologists. In particular, we refer to five different interactions: (1) making explicit issues of concern, (2) evaluating movement, (3) discussing treatment adjustments, (4) getting an understanding of what to expect, and (5) getting inappropriate medication revised. These categories will now be described in detail.

Making explicit issues of concern

Many symptoms of Parkinson's can be softened or removed using the right medication cocktail, so patients and carers carefully monitor the issues that appear and, during in-clinic consultations, report them to doctors. Neurologists support patients and carers in this task by asking questions such as 'How are you doing?', 'Can you do everything you need in your day-to-day life?', and 'Do you need help from others for performing specific activities?'. In online exchanges, patients and carers usually express their concerns in the posts they publish, but doctors also prompt for additional information about the everyday experience. In both cases though, patients and carers are the ones defining the focus for the discussion and diagnosis, or in other words, what is important to address (or not) by what they mention to doctors. The word diagnosis is used here to name the identification and investigation of the causes of patient's issues. As Arriscado Nunes et al.[34] explain, diagnosis is not only about getting a name for the condition but also addressing the agenda that the patients (and carers) bring to the consultation. In the case of Parkinson's medical care, finding out the condition name is usually an activity that is held in the first encounters, but after that is settled, diagnosis becomes about understanding which of the identified symptoms and signs is indeed an issue for everyday life, and what are the causes of such problems.

Knowing what is an issue for Parkinson's is not straightforward. As Parkinson's affects the brain, its symptoms and signs appear in multiple areas and influence different functions. Furthermore, people have to investigate the issues caused by the condition, as well as the side effects of the medication. Issues related with Parkinson's include not only movement problems such as tremor, or gait impairment, but also depression, delusions, and impulsive behaviours that one would not normally associate with a 'movement disorder'. Thus, patients and carers adopt an attitude of actively investigating the issues they are faced with to understand whether and how they can address them:

> When I have a slow movement problem I cannot walk slowly in a crowd in front of me, but I can walk very fast around them and continue to walk at a rapid pace, if I slow down to try to walk normally I can only maintain a turtle pace. Is this a common experience in movement disorders in beginning Parkinson disease? (Guest__*)

This patient asked whether the gait issues they experienced when walking around others were caused by Parkinson's. In the reply, the doctor confirmed that this was an issue of the condition and that it could be fixed with medication adjustments. Interactions like these were frequent in the forum. Posting questions in the online platform enabled the patient to get some sense of direction on how to act regarding this issue. However, it is important to note that writing a post was often the last of a long line of actions by the patient (or carer). Before that, we can assume that the person was carefully observing the issue, comparing different situations, and reflecting on whether it always happened at the same time. This investigative attitude was essential if patients were to have their treatment optimised to their needs.

Having identified an issue, patients and carers make their own judgment about whether it should be addressed with treatment changes:

> OP5: I always wake up at 4 in the morning to go to the toilet. I have nights in which I have … My legs get very heavy, they hurt, and I have to get off the bed to cool them down. Then, I return to bed.
>
> Dr: And then you can sleep, right?
>
> OP5: I can sleep then.
>
> Dr: You can sleep then.
>
> OP5: These are little details. I don't think it is worth changing the medication [because of them].

This patient has issues in the legs at night but does not think they are worth addressing with medication adjustments. At first sight, refraining from treating a disturbing symptom could sound masochistic, but on a closer look, the excerpt reveals great reflection about the leg issue. The patient knows that there is no ‘silver bullet’ in the treatment of Parkinson’s; adding more medication might improve the leg issues, but bring other problems as well. In the whole picture, the leg issues are minor problems, ‘little details’ as the patient calls them. She can still perform most daily activities satisfactorily, so trying out a new medication scheme does not seem like a requirement for her at the moment, especially when it might entail other consequences.

Evaluating movement: refraining from hiding symptoms and documenting unobservable issues

In complement to the issues reported by patients and carers, doctors also observe the body of the patient during consultations. Part of the observation is unstructured and happens throughout the appointment. However, at some point during the consultation, the doctor performs the neurological examination, a more structured movement assessment. The examination is not the same for every patient but usually includes walking along the corridor, being pulled backwards while standing (‘pull test’), moving the elbow back and forth, opening and closing the hands fast, touching the finger alternately to the doctor’s and one’s nose, and following the finger of the doctor with the eyes. While observing the patient move, the doctor evaluates the rigidity of the muscles, symmetries in the body, difficulties in coordination, presence of tremor, gait impairments, and other characteristics of the condition. The doctor guides the neurological examination, but patients play an active role by letting their symptoms be visible (symptoms they might hide in everyday life), and by complementing the assessment with verbal details that cannot be observed.

Some symptoms of Parkinson’s bring unwanted attention to the patient, so people learn to mask and hide their issues from others. Tremor is a common example of a symptom that people usually try to hide. However, during the movement assessment, people need to refrain from hiding their symptoms for the doctor to be able to observe them at their full potential:

> Dr: Now let’s walk, with a fast pace, until the end of the corridor, ok?
>
> (OP8 walks)
>
> Dr: You can come back, now.
>
> OP8: This hand is misbehaving [trembling]. […] If I press my hand it stops.
>
> Dr: No, let yourself relax.

While walking, the hand started to tremble, and the patient began hiding it by pressing the hand. The doctor quickly asked the patient to relax and let his hand shake as she needed to observe the symptoms in all their strength. Here again, the contribution of the patient is essential to ensure that the doctor can gain useful information and that care is appropriate. Unless the person refrains from hiding the symptoms, the result of the movement assessment will be misleading. However, if the actions of both patients and doctors are aligned, the assessment can inform medication adjustments.

Signs and symptoms are not always easy to observe. Sometimes, they only happen in specific circumstances that are not available in the doctors’ office (e.g. walking around a crowd, as shown in the previous section). Other observation difficulties occur in the initial phases of the condition if Parkinson’s signs and symptoms are subtle:

> Dr: There is something I would like you to tell me. Before taking Madopar or Sinemet, because they are equivalent, were you better or worse?
>
> OP2: You know … I was never very [better]. At least, it did not seem to me.
>
> Dr: So we are going to do it like this. I am going to remove the medication. You're going to get off the medication around one week before the next consultation. I will make a plan to show you how to do it, ok?

The patient in the excerpt has some symptoms that could be caused by Parkinson's, but they could as well be due to the medication she has taken for years for another mental illness. When faced with Parkinsonian symptoms, neurologists usually prescribe Levodopa to patients. If they get better, people probably have Parkinson's. If they don't, the condition might be a different one. In this specific case, improvements were not clearly visible to the doctor via the neurological examination. So, the neurologist asked the patient whether she had noticed overall improvements since starting the medication. This feedback was essential, as the doctor could not observe the subtle changes felt in the activities of daily life. The observations of patients and carers provided the information to make a decision, which in this case is to stop taking the medication and re-evaluate the symptoms in some weeks.

Discussing treatment adjustments

One of the most significant moments of consultations is the discussion of treatment adjustments. During this exchange, patients, carers, and doctors agree on the medication to take during the next months and, as a consequence, define the activities patients will be able to perform. Doctors propose treatment options considering the needs of the patient, existing medications, and their previous experience with other patients. However, these suggestions are carefully scrutinised as only people living with the condition can assess whether they make sense:

> If I increase the dosage of Stalevo my movement problems improve, but I get dyskinesias. […] Because the 150 mg [pill] improves my gait significantly, but the problem is the dyskinesias. And so she [the doctor] reduced from 150 mg to 100 mg but shortened the intake period. I feel better with that [regimen]. (IP2)

In this excerpt, the patient reflects about two recent medication plans and concludes that he 'feels better' with the latest one. With that regimen, the dyskinesias disappear, and the walking is almost at its best. There are no straightforward treatment options for Parkinson's. Choosing the right medication, as Solimeo[35] explains, is an exercise of finding balance in abilities and side effect that is different for everyone. In any case, people living with the condition will be the ones weighing the various options provided by the doctor and choosing which direction to follow. Sometimes, they will even choose paths that are against the doctor's recommendation:

> Dr: You have a big gap between 8:00 and 15:00. This is even shameful [for me], but that is how Sir […] likes to do it, right?
>
> OP3: I have been doing it as the doctor instructed me.
>
> Dr: No, I did not instruct you to do it like this. We ended up adjusting it in this way. This is a difference of 7 hours, right?

This patient has a large interval between two medication intakes. Instead of the typical 3–4 h interval to keep the effect lasting the day, this patient has 7 h between two of his intakes. For the doctor, this interval is too long and inappropriate. For the patient, however, the medication regimen works just fine. He can do the activities he wants, and the regimen fits well with his routines, so from his perspective, there is no reason for changing it. The doctor tried to give arguments for making an adjustment, but as the patient finds it appropriate, 'and he is the one living with it', the doctor refrained from further persuading the patient to change.

Getting an understanding of what to expect

In consultations or online exchanges, patients and carers try to understand and prepare for their future situation. This includes understanding how the condition will evolve, the potential a treatment has, and whether they will be able to pursue their activities in the future. Doctors provide information, but it is the people living with the condition who seek to inform and prepare themselves. The insights patients and carers acquire are valuable to them as they enable them to prepare their self-management for when these future situations arrive:

> Guest__*: It seems to me that a lot of the PD meds cause drowsiness. Do most PWP [people with Parkinson's] continue to work full time jobs while being on the meds or do you find that most PWP usually cut back on work dramatically or quit altogether? thank you, MJ
>
> Dr Okun: This is a mixed bag. Many PD patients continue to try to work but must reduce hours, stress and anxiety which can all make symptoms worse. Many PD patients also find it hard to work after the 5th year of the disease, but this is highly variable as I have patients still working at year 20!

This patient (or carer) went online to ask whether patients with Parkinson's continue to work after starting medication. They know medication can cause drowsiness, and people might be too sleepy to concentrate or keep their eyes open. In reply, the doctor explained that some people quit their jobs while others continue with reductions in their schedule. Knowing this information helps this person prepare for the future. In case she is a patient, these insights help her in preparing to cut hours on her current job, or even finding a new one, should cutting hours be impossible. In case this person is a carer, knowing about these possibilities can encourage her to help the patient manage this loss and prepare for her own work re-arrangements. The question posed might be read as a general interest question, but the consequences of having it answered have a significant impact on daily life.

Besides the progression of the condition, people also try to understand what to expect from their treatments:

> Guest__*: I'm currently taking .5 mg Selegi[li]ne 2×/day and 2 mg Requip 3×/day. I am not experiencing any noticeable side effects on this dosage. My Neurologist says we can increase the dosage substantially slowly over time. Is it likely that on increased dosages of Requip that I will experience side effects of the drug?
>
> Dr Fernandez: It is possible that you will experience side effects, but it is possible also that you will not. The only way to find out is to try it, right? I personally do not go lower than 3 mg three times per day with my patients. […]

The patient asked in the forum whether they would experience side effects with a larger dosage of the medication. In reply, the doctor put things into perspective and even mentioned that the patient was on a very low dosage, smaller than the one he would initially suggest to his patients.

Side effects might never materialise, but reading medication leaflets packed with potential side effects might be daunting, and so referring to the forum was a way to get some answers quickly. In asking the question, this person received information that might help planning the future. Common to both excerpts is the agency of patients and carers in understanding and preparing their self-management for the future.

Getting inappropriate medication revised

The medication for Parkinson's is very sensitive. Too little of it and the symptoms will not be softened, and if medication is too much, it can lead to side effects. For this reason, medication should be carefully adjusted. However, sometimes, the medication regimen will bring more unwanted than beneficial effects and need to be adjusted before the next consultation – up to 6 months away:

> Guest__*: […] I use lately 2 mg Mirapex, 3× a day at each meal, breakfast, lunch, and dinner, for a total of 6 mg per day. I have lately developed strong swelling of the ankles. My question is: Can this swelling be due to the Mirapex? I have no heart problems and I am sure it is not due to the heart.
>
> Dr Rodriguez: Very likely is a result of the Mirapex and if bothers[o]me you will need to stop the medication or at least reduce the dosage (try 1.5 mg tid).

This patient recently increased the medication dosage and around the same time experienced swelling in the ankles. These events seemed connected, so the patient went to the forum looking for confirmation. The doctor explained that the swollen ankles could be due to the medication and suggested adjustments to ease the swelling until the patient could reach the doctor.

The Portuguese patients we interviewed and observed did not use online forums but had other ways of getting their medication adjusted:

> We call the doctor and she … It is not easy getting her on the phone. But she [says:] take this or take that. She changes medication, over the phone, she does. (IP10_C1)

Also, in this case, people were able to get their medication adjusted before the next consultation. As the medication plan brought unwanted side effects, they phoned the doctor, discussed the adjustment, and implemented changes. The participants we interviewed also mentioned that sometimes they went directly to the hospital to address the problems in the medication. What is common between these examples is that patients and carers proactively created a way to access the doctor's advice between consultations. By using the forum, the doctor's mobile phone, or by visiting the clinic earlier, patients and carers created an alternative channel to access care and to ensure necessary adjustments would be timely.

Playing an active role within the healthcare infrastructures

The fieldwork showed that patients and carers exercised a very active agency in their interactions with doctors. They helped define diagnosis, engaged in discussions about treatment adjustments, directed learning to certain topics, and acted when medication adjustments were inappropriate. Their active agency was not a coincidence of circumstances, but rather a consequence of the socio-material arrangements where they acted.

While at home, patients and carers carefully investigated issues that appeared. They compared between different situations, reflected on their differences, and considered whether they were worth addressing with medication adjustments. Patients and carers also reflected on which activities and routines were important to keep, and which ones could be stopped or adapted. These engagements helped people enlist issues, priorities, doubts, or other topics to potentially bring up in consultations.

But to actually bring up these issues while interacting with the doctor required that the doctors provided an interactional dynamic that invited and enabled people to be able to raise issues, discuss solutions, and steer discussions to certain topics. Had doctors aligned with a more paternalistic model of care, these engagements would have been much briefer and disconnected from the agenda of patients and carers. It was also important that patients had access to the mobile phone number of the doctor or the online community to be able to adjust inappropriate medication.

Self-care technologies for interacting with doctors

Having analysed how patients and carers currently interact with their doctors, our analysis now shifts to self-care technologies for interacting with them. These technologies influence the role people can play in care, by the features, interactions, or roles they offer; thus, investigating them can help understanding the sort of agency patients and carers will potentially exercise if these technologies are integrated into healthcare infrastructures.

Overview

The review resulted in a total of 15 self-care technologies for interacting with doctors. From this set, eight were published in scientific journals and conferences from the years 2006 to 2014 and the remaining seven found through the iTunes App Store.

The self-care technologies in the review can broadly be categorised as either tools that enable remote consultations through videoconference or technologies that enable some sort of tracking practices and, for that reason, contribute to interactions with the doctor. Table 1 analyses the features of the technologies in terms of how they capture and present data, and how they facilitate sharing of data and interaction with the doctor. We go on to discuss how these technologies support some of the key aspects we found in the fieldwork for exercising agency: investigating issues, participating in discussions, and adjusting medications.

Investigating issues

The self-care technologies for tracking, such as *Parkinson's Diary*[40] and *Montfort iTug*,[37] were mostly targeted at helping people to learn about their body and condition. Since these technologies usually provide visualisations, they can potentially help patients quantify the severity of symptoms, identify trends, and overall collect issues that they can bring to discussion with their doctors.

Despite the potential of these technologies though, there are several characteristics that might hinder the patient from investigating certain issues. The most common issue is the lack of variety in tracking or logging features. While Parkinson's affects numerous activities, logging is fixed on certain characteristics, such as medication or (motor) symptoms, and sensing is restricted to movement issues. The problem with the lack of variety is that it restricts the investigation of issues to a subset of Parkinson's problems.

Another issue preventing technologies from enabling patients to investigate issues is the inability to visualise the collected data. While *REMPARK*,[43] *Kinesia*,[36] and *SPARK*[44] all enable patients to capture or report data about specific symptoms and signs of the condition, only doctors can

Table 1. Characteristics of the self-care technologies for interacting with doctors.

Name	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
Kinesia[36]	iPad, sensors	Patients perform activities while wearing sensors, and log medication and symptoms. Doctors analyse their data in the clinic and adjust treatment.	–	Movement	Medication, symptoms	No	Auto	In clinic
Montfort iTug[37]	iPhone	Patients perform activities holding the iPhone, and log symptoms. They can analyse data by themselves or with doctors.	–	Movement	Symptoms	Yes	Option	In clinic
myHealthPal[38]	iPhone	Patients perform activities on the iPhone, and log medication. They can analyse data by themselves or with doctors.	–	Movement	Medication	Yes	Option	In clinic
OneRing[39]	iPhone, sensors	Patients wear ring (or hold iPhone) for some seconds to track movement. They can analyse data by themselves or with doctors.	Movement	Movement	–	Yes	Option	In clinic
Parkinson's Diary[40]	iPhone	Patients log exercise, mood, meals, medication, and sleep. They can analyse data by themselves or with doctors.	–	–	Exercise, mood, meals, medication, sleep	Yes	No	In clinic
PDApp[41]	Android, sensors, PC	Patients wear sensors that track symptoms passively and actively. They can analyse and annotate data, with mood or activities, to discuss with the doctor.	Movement	Movement	Mood, activity	Yes	Auto	In clinic
PDmove[42]	iPhone	Patients play game that tracks their movement. They can analyse data by themselves or with doctors.	Movement	–	–	Yes	No	In clinic
REMPARK[43]	Android, sensors	Patients wear sensors that track symptoms. Doctors review the data in the clinic and adjust treatment.	Movement	–	–	No	Auto	In clinic

(Continued)

Table 1. (Continued)

Name	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
REMPARK[43]	Android, sensors	Patients wear sensors that track symptoms. Doctors review the data remotely and adjust treatment.	Movement	–	–	No	Auto	No
SPARK[44]	Android, sensors	Patients wear sensors that track symptoms passively and actively, and answer prompts. Doctors review the data and adjust treatment.	Movement	Movement	-	No	Auto	In clinic
StudyMyTremor[45]	iPhone	Patients perform activities while holding iPhone. They can analyse data by themselves or with doctors.	–	Movement	–	Yes	No	In clinic
Video Consultations[*][19]	Camera, screen, PC	Patients use videoconference to attend consultations.	–	–	–	–	–	Remotely
Video Recordings[*][46]	Camera, screen, mic, printer, PC	Patients record activities and note complaints. Doctors review the data and adjust treatment.	–	Movement	Complaints, symptoms	No	Auto	No
Virtual Consultations[*][20]	Camera, screen, PC	Patients use videoconference to attend consultations.	–	–	–	–	–	Remotely
Virtual Housecalls[*][23]	Camera, screen, PC	Patients use videoconference to attend consultations.	–	–	–	–	–	Remotely
@Point of Care[47]	iPhone	Patients answer prompts. They can analyse data by themselves or with doctors.	–	–	Activity, medication, mood, symptoms	Yes	No	In clinic

[*] Technologies authors did not name.

visualise or analyse the data produced. Patients cannot access their own data, which defeats the purpose of investigating issues. Patients may still reflect about their condition each time they track a symptom or log an issue, but the opportunity for technology-mediated analysis is missed by not giving them the tools for reflecting more thoroughly on their data.

Participating in discussions

Most self-care technologies in the review potentially supported the discussions with doctors. In some cases, technologies enabled discussions to take place through videoconference, such as with *Virtual Housecalls**[23] and *Virtual Consultations**.[20] In other cases, self-care technologies could be used to feed discussions with issues identified while tracking or analysing data, such as with *PDApp*[41] and *OneRing*.[39] Participating in discussions about one's health is essential to playing an active role in care, so it is positive that many of these technologies support and, in some cases, even potentially enrich the discussions with issues from everyday experience.

However, there were some cases in which the technologies eliminated discussions with doctors altogether. For example, *Video Recordings*[46] is a technology where patients answer questionnaires about symptoms and perform specific movements in front of a video camera. Once tracking and logging are complete, the data are transferred to the doctor who updates the medication plan without holding any discussion. Even though patients play a role in collecting the data, they are rendered as passive actors, who instead of contributing with their lived experiences only produce the data stream that informs the decisions of doctors.

Fixing inappropriate medication

The reviewed self-care technologies did not account for the possibility of getting inappropriate medication, since patients could not signal their need for treatment adjustments through the technologies. For example, the technologies for enabling remote consultations did not enable patients to initiate videoconference sessions. And while numerous self-care technologies enabled logging, it was not possible to report that medication needed revision. The inability to trigger medication adjustments through these technologies does not imply that corrections were impossible. One can extrapolate that patients would still be able to phone doctors or go to the clinic sooner as the fieldwork participants. However, by not providing direct paths within the technology, people might have missed a more straightforward process for adjusting medication.

Discussion

Our fieldwork showed that patients and carers were very proactive when interacting with doctors. Existing healthcare infrastructures enabled them to participate in diagnosis and decision-making, direct learning activities to certain topics, and adjust medication when it was inappropriate. Nevertheless, their agency might change if certain technologies that promote a more limited participation, as evidenced in the review, are integrated into healthcare infrastructures.

This article adds to the growing body of literature that describes the crucial role of patients and carers in making healthcare infrastructures work. Previous research had called attention to how they were essential in sending measurements remotely,[21] bringing medical exams,[48] and exchanging information between doctors.[49] With this article, we show the role patients and carers play in participating in the discussions that lead to appropriate treatment.

While this study is about people living with Parkinson's, related studies of other chronic conditions argued that patients and carers similarly demonstrated active agency. For example, Cicutto et al.[50] described how people living with Chronic Obstructive Pulmonary Disease contributed to their diagnosis and argued for adjustments in medication timing to better fit their activities. Similarly, Funnell and Anderson[51] argued that doctors needed to work together with people with diabetes towards the goals they want to achieve, because that is the only way to reach appropriate treatment.

Acknowledging the active agency of patients and carers in medical care

Recognising the active agency of patients and carers has consequences for how we understand their role within healthcare infrastructures. For this reason, this section will now describe some properties that characterise the engagement of patients and carers when interacting with their doctors. Practical implications for the design and planning of self-care technologies and infrastructures will also be discussed.

Active role in diagnosis definition. Patients and carers played a critical role in the diagnosis definition. The neurological examination could easily become misleading if patients hid their symptoms, or if patients and carers did not describe the differences between the observation at the clinic and the everyday experience. Moreover, many symptoms, signs, and issues were brought up by patients and carers to the discussions; they were also the ones deciding how problematic each issue was.

This active participation contrasts with some perspectives on patient–doctor interaction (the expression 'patient–doctor interaction' undermines the key role that carers play in interactions with doctors. Still, as this is an expression commonly used in the literature, it is employed here) that expect diagnosis to be performed only by doctors after collecting issues and complaints.[6] Even the patient-centred care model, that advocates for shared decision-making, commonly understands the diagnosis and treatment definition as activities performed solely by doctors.[7,8] Our fieldwork favours a more collaborative conception. Similar to Epstein et al.,[52] our work shows that diagnosing is about understanding issues from the standpoint of the lived experience, together with other complex needs, fears, or expectations. The doctor's role is thus not to decide but to help people reflect on their situation and priorities, so they can articulate what is most important to address.[3]

In general, the reviewed self-care technologies promoted an active participation in diagnosis. By enabling people to track and visualise their data, the technologies potentially enabled patients to learn about their body and condition and thus elicit issues to discuss with doctors. However, there was an important obstacle preventing people from collecting issues to discuss, the inability to visualise the data collected. While most technologies enabled people to visualise their data, some did not and thus greatly reduced the reflection people could make of their data.

Recognising the active participation of patients and carers in the diagnosis motivates developing tools that enable people not only to track issues but also to visualise and analyse their own data. Without these, it will be hard for the tools to support people in investigating issues, and consequently bringing them to discussion.

Active role in decision-making. The fieldwork has shown that patients and carers participated actively in medical decisions concerning their health. While doctors suggested treatment adjustments, patients and carers scrutinised the potential of these to reach their needs and aspirations, and it was the collaborative engagements between all participants that resulted in appropriate treatment decisions. These collaborations were made clear with the excerpt of the patient with a 7-h interval between intakes, who kept to his own medication plan despite the doctor's advice to change it, because it served him well and there was little to gain from changing.

Collaborative decisions were common in the fieldwork, however, as mentioned before, the literature on patient–doctor interaction often portraits these encounters under a paternalistic model, where doctors solely make decisions. The regular use of the terms non-compliance or non-adherence also indicates that medical decisions are not shared, because problems in implementing treatment or practical decisions are attributed to a willingness to go against the doctors' 'instructions'. As Funnell and Anderson[51] elegantly put it, non-compliance only exists when there are '2 people working toward different goals' (p. 1709). Our fieldwork offers an alternative conceptualisation to patient–doctor interactions where medical decisions are collaborative. All participants sit as equal partners at the table, in recognition of their specific expertise and the mutual commitment to reach appropriate treatment.[3,4] Making decisions collaboratively recognises that a treatment embodies both a clinical and a value judgment, and that the value judgement that matters is that of the patients and carers.[5]

Most self-care technologies in the review supported discussions with doctors; however, there were some technologies that eliminated medical discussions. In fact, some technologies were designed for doctors to decide based only on the health data, which can be quite problematic. Based on symptoms alone, the patient with a 7-h interval would probably have had his medication changed, because that was the sensible decision to make with the available information. Yet, in changing his medication, the doctor would have forced unnecessary changes to the routine of a patient who does not feel like he needs them. Previous research also showed negative consequences of excluding patients and carers from the decision-making. For example, when patients with diabetes were removed from the interpretation of glucose values in a patient record, they felt frustrated because numbers did not explain their decisions or the context in which they acted.[53] In *myRecord*,[54] a technology where doctors could remotely diagnose and adjust an implantable pacemaker, the decisions became much harder after excluding patients to the point that they had to be later re-introduced. However, when patients and carers were indeed included, there were benefits to the care received. The doctors addressed issues after analysing measurements they did not consider before,[54–56] and interpreted values differently after understanding the context in which they occurred.[54,57]

Recognising the active role patients and carers play in medical decisions involves developing tools that enable them to be 'present' when decisions are taken about their health. Even if the symptom data are sent remotely, collaborative discussions are the only way to ensure the treatment addresses the relevant concerns and fits with everyday life. Being face-to-face helps achieve this objective, but there might be alternatives, such as using videoconferencing[19,20,23] or phone calls.[54]

Active role in learning. The fieldwork has shown that patients and carers actively sought to learn about their condition, treatment, and prospects during interactions with doctors. They often raised questions and directed discussions to certain topics to get information from their doctor.

While patients and carers engaged actively in learning, literature usually refers to this activity as a passive one. The word used to name the learning that happens in interactions with doctors is usually patient-education, a concept that suggests that doctors educate the *naïve* patients who visit them. According to that perspective, patients do not understand the consequences of their choices, and so doctors need to educate and persuade them in specific ways.[58] However, this perspective does not adequately describe the interactions in our fieldwork. In fact, patients and carers were well informed about their condition, and that is why they raised issues in the first place. People sought advice on what to expect, what to look for, and what to consider, so that they could make informed decisions and prepare for the future.

As mentioned before, the reviewed self-care technologies could enable people to investigate their issues by supporting logging and tracking. These investigations would potentially raise doubts, problems, or other topics that people might want to discuss with their doctors. Nevertheless, there is an important obstacle that can hinder people from learning more: the lack of diversity of features that can be tracked or logged. Swelling ankles, pain in the legs, or problems walking around a crowd – all of which were mentioned in this article – could not be straightforwardly tracked or logged with the reviewed technologies. As the technologies focused mostly on motor symptoms, they fail to support the everyday experience and could restrict learning to certain aspects.

Recognising the agency of patients and carers entails offering them tools that support a rich investigation of issues. Making available self-care technologies that are open to capture different signs and symptoms without restriction to certain aspects or symptoms, as Storni[25] suggests, may be useful in enabling people to get in contact with more issues and thus better learn when interacting with their doctors.

Active role in adjusting inappropriate medication. The activities of patients and carers did not end when consultations finished. While at home, people carefully observed the effects of the updated medication plan in the patient's body and activities. If symptoms became worse or unexpected issues appeared, patients and carers quickly went to the doctor, phoned their specialist, or went to the online forum, in search of a solution to their problem. These actions created ways to access medical care and ensured the disruptions were kept as short as possible.

However, the literature on Parkinson's did not seem to discuss the experience of finding oneself with inappropriate medication. It was as if the treatment was always adequate or at least good enough to wait some months, because there were no mentions to having consultations or phone calls before the next appointment (in a focus group organised by Van der Eijk et al.,[11] patients requested telephone consultations to follow up on treatment changes and asked for the email and phone contacts of their doctors. These requests suggest that those patients might have experienced the need to adjust medication before the next consultation, yet these practices were not documented in the article). In our fieldwork, however, it was clear that sometimes medication was not well received by the body and that medical care was essential before the next encounter. These urgent adjustments may also explain why patients and carers so often had the mobile phone number of their doctors.

Self-care technologies for Parkinson's did not enable people to trigger the need for treatment adjustments. For example, in videoconference technologies, patients could not ask for having an earlier appointment, and in technologies that collected symptom data, it was not possible to signal inappropriate medication.

Recognising the role patients and carers have in addressing inappropriate medication changes requires technology or supporting infrastructures to enable people to signal their need for medication adjustments or advice on how to proceed.

Involvement of both patients and carers. Patients were rarely alone in their interactions with doctors. Most of the carers in our fieldwork accompanied the patients and engaged actively in discussions. Similarly, in the online community, both patients and carers asked questions to the doctors which give evidence of their collaborations.

The literature on Parkinson's showed a similarly active engagement of carers. Both Pinder[2] and Martin[59] documented that carers accompanied the patients to the clinic and also that they participated actively in these encounters.

It is thus surprising to observe how often carers lacked a role in self-care technologies. Apart from one technology, carers were not even mentioned in the descriptions of the technologies, which lead us to assume they did not have a role to play.

Recognising the active agency of carers motivates the development of self-care technologies and infrastructures that enable carers to participate together with patients in their interactions with doctors. Otherwise, an important part of self-care may be disregarded.

Conclusion

This article has investigated the interactions of patients and carers with their doctors in different care scenarios. In particular, we have contrasted how patients and carers living with Parkinson's act within the current healthcare infrastructures, with the participation that is promoted by self-care technologies for interacting with doctors. Our findings show that patients and carers play a very active role when interacting with doctors, and that technology has the potential to support or even enrich these engagements, provided some obstacles are eliminated. We discussed the implications of recognising an active engagement of patients and carers to the understanding of healthcare infrastructures, and propose practical implications for design. Our findings should contribute to the design of technologies that promote an active participation of patients and carers.

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Impact assessment on patients' satisfaction and healthcare professionals' commitment of software supporting Directly Observed Treatment, Short-course: A protocol proposal

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Abstract

Doctors, nurses, and other healthcare professionals use software that affects the patients. Directly Observed Treatment, Short-course is the name given to the tuberculosis control strategy recommended by the World Health Organization. The main goal of this work is to propose a protocol for evaluating the impact of healthcare software supporting Directly Observed Treatment, Short-course on patients, healthcare professionals, and services. The proposed protocol consists of a set of instruments and steps. The instruments are reliable and validated existing questionnaires to be applied before and after using the software tool. The literature points out the need for standards on the software assessment. This is particularly critical when software affects patients directly. The present protocol is a universal tool to assess the impact of software used to support the fight against the tragedy of tuberculosis where a rigorous evaluation of IT in healthcare is highly recommended and of great importance.

Keywords

e-health, healthcare policy, healthcare professional training, IT healthcare evaluation, quality control

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Introduction

There is evidence for the positive impact on the patients and healthcare professionals of the investment in healthcare information systems (HIS).[1] When the software is considered a medical device[2–4] and the expenditure in healthcare has a tendency to grow,[5] a rigorous evaluation of software in healthcare is needed. Studies on the evaluation of the health systems[6–8,13] have identified that there still are key challenges to overcome and have concluded that a broadly accepted framework for software evaluation in healthcare is necessary. This evaluation must focus, not only, but essentially on users.[9,10] Accordingly, we justify the need of instruments, a model and a methodological approach to assess the impact of the use of software on the patients, healthcare professionals and services.[6]

About one-third of the world's population has latent tuberculosis (TB) infection. Over 95 percent of TB deaths occur in low- and middle-income countries.[11] TB causes one-fifth of all deaths of people with HIV infection.[11] DOTS or Directly Observed Treatment, Short-course is the internationally recommended strategy for TB control that has been recognized as a highly efficient and cost-effective strategy.[11] Our main goal is to study the relationship between the adoption of software and the impact on the patient, on the professional, and on the services that deliver the DOTS. In this way, we propose a protocol for DOTS software evaluation.

The article, in the next section, introduces the concepts related with the approach, namely, the perspectives of assessment of satisfaction of software. The following sections detail the research question and objectives of the study, as well as the methods applied. The proposed protocol presents a set of instruments and a set of steps. The article follows with a discussion of the proposal and ends with summarizing the conclusions and future research work.

Background

It is possible to identify innumerous studies for evaluating healthcare information technology.[7,8,12] Ammenwerth et al.[6] sum up the evaluation questions as follows: (1) Which information technology should be selected and installed? (2) What is the usability of the information technology? (3) What are the technical and system features, for example, performance or software quality, of the information technology that affects its use? (4) Do users accept the information technology and use it as intended? If not, why not? (5) How does the information technology affect structural or process quality (time saving, data quality, clinical workflow, and patient administration) with regard to different users (physicians, nurses and administrative staff)? Does it work effectively? If not, why not? (6) What are the effects of an information technology on the quality of care? (7) Are the patients satisfied with the information technology? and (8) What are the investment and operational costs of information technology? Is it cost-effective?

We will use Ammenwerth et al.'s[14] definition of HIS evaluation: "the act of measuring or exploring attributes of a HIS (in planning, development, implementation, or operation), the result of which informs a decision to be made concerning that system in a specific context." All along the years, it is possible to register the shift from pure technical evaluations to more complex models, including the importance of the human factor,[15] and the social and organizational issues.[10,16] Payton et al.[10] and Paul et al.[9] emphasize the key importance of including the patient–user perspective in the evaluation of the systems. Regarding the questions of "What are effects of an information technology on the quality of care?" and "Are the patients satisfied with the information technology?" we can identify several key works, summed up in Table 1. It is possible to conclude the absence of a consistent instrument, model and methodological approach to evaluate the users'—patients and healthcare staff—perspective of HIS. If the use of software in healthcare has the purpose to improve

Table 1. Key works for evaluation of health information systems' satisfaction.

Author(s) (year)	Title	Goals	Methods	Findings/conclusions
Rojas-Mendizabal et al. (2013)[17]	Toward a model for *Quality of Experience* (QoE) and *Quality of Service* (QoS) in e-health ecosystems	Proposal of a health ecosystem involving the quality of experience and quality of service in e-health systems	Literature revision	Their view is that the deployment of e-health projects centered only on technical requirements tends to provide marginal results. They pose that the starting stage must be the understanding of the patient and medical specialist needs, the understanding of the context and its social reality
Lazakidou et al. (2012)[18]	Patient satisfaction as part of quality assurance in e-health	Justifying the need of including patients' satisfaction as part of quality assurance in e-health	Literature revision	Assessment of patient satisfaction with the process of care is important as a measure of quality care. The study of the effect of different providers' characteristics in patients' satisfaction would also be useful in improving the process of healthcare
Currell and Urquhart (2003)[19]	Nursing record systems: effects on nursing practice and healthcare outcomes (Review)	To assess the effects of nursing record systems on nursing practice and patient outcomes	Eight trials involving 1497 people included randomized controlled trials, questionnaires, interviews, patient satisfaction surveys and data quality comparison	No evidence was found of effects on practice attributable to changes in record systems. The research undertaken so far may have suffered both from methodological problems and faulty hypotheses. Qualitative nursing research to explore the relationship between practice and information use could be used as a precursor to the design and testing of nursing information systems

the quality of healthcare services and the level of effectiveness, then it must be evaluated from these two perspectives and therefore we need a consistent protocol for that assessment.

Research question

The research question is as follows: How can the impact of healthcare software supporting DOTS on patients, healthcare professionals, and services be assessed?

The goal of this research is to propose a protocol for DOTS software evaluation from the perspective of its impact on patients, healthcare professionals and services.

Methods

The first step was to perform a literature revision to identify the existing key works to evaluate the impact of healthcare software either on patients or on software professionals. This literature revision allowed us to identify the need of approaches to use similar instruments and methods to evaluate and compare different software tools. The second step was to perform a second literature review on instruments to measure: patient satisfaction, healthcare professional's satisfaction, and TB service evaluation. The third step was the definition of criteria to select instruments for the protocol. The fourth step was the definition of criteria for the selection of the steps to include in the proposed protocol. The fifth and final step was the development of the protocol.

The protocol

The proposed protocol is composed of a set of instruments and a set of steps. The adoption of the instruments follows the following criteria: (1) instruments must be based on studies demonstrating their fundamentals of validity, namely, the number of the sample, internal consistency reliability, convergent validity, discriminant validity and predictive validity; (2) instruments used in several other studies published in renown publications; and (3) the instruments must assess patient satisfaction, and the impact on healthcare professionals and on the TB services.

The adoption of the steps for the present protocol follows the following criteria: (1) the steps should allow the use of the protocol in different geographies; (2) the protocol should include all procedures of the selected instruments; and (3) the protocol should indicate how to use the results of the application of each instrument.

Only few instruments meet these demanding requirements. Despite the large number of existing instruments and studies, only few met these criteria. Based on a thorough literature review, the selected instruments are the key renowned instruments that met the criteria and indicated in the literature.

The instruments

To evaluate the patients' satisfaction, we propose the use of the following questionnaires: Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)[20] and the Patient Satisfaction Questionnaire Short-Form (PSQ-18).[21] The intent of the CAHPS Hospital Survey, also known as Hospital CAHPS or HCAHPS, is to provide a standardized survey instrument and data collection methodology for measuring patients' perspectives of hospital care. The HCAHPS survey contains 21 patient perspectives on care and patient rating items that encompass nine key topics: (1) communication with doctors, (2) communication with nurses, (3) responsiveness of hospital staff, (4) pain management, (5) communication about medicines, (6) discharge information, (7) cleanliness of the hospital environment, (8) quietness of the hospital environment, and (9) transition of care. The survey also includes four screener questions and seven demographic items, which are used for adjusting the mix of patients across hospitals and for analytical purposes. The survey is 32-question long. The PSQ-18 has been validated for use in different settings. It was developed through rigorous research and abbreviated from much larger questionnaires,[22,23] maintaining internal consistency and reliability.[21] PSQ-18, Likert scale questionnaire, proposes seven dimensions of patient satisfaction directed toward their healthcare professionals: (1) general satisfaction, (2) technical quality, (3) interpersonal manner, (4) communication, (5) financial aspects, (6) time spent with doctor, and (7) accessibility and convenience. Each domain is tested through different related questions, which is of substantial benefit when one aims to identify a particular area to improve on. The general satisfaction has strong correlation with the other domains, and thus, it is important to improve all.

Morisky Medication Adherence Scale, version with 8 questions (MMAS-8) evaluates the adherence to the medication.[24] Different tools have been used to evaluate and assess patients' adherence to medication, and there is no "*gold standard*" measure of medication adherence.[25] MMAS-8 is proposed to evaluate the impact of the software on medication adherence.

To assess the impact of a software on the healthcare professionals and services, we propose the use of the Organizational Commitment Questionnaire (OCQ), the Computer System Usability Questionnaire (CSUQ), and the organizational dimensions and the performance of the services of the basic attention centers in the management of TB, Tuberculosis Primary Care Assessment Tool (TPCAT). Human resources in healthcare are defined as "*the heart of the health systems of the countries*," "*the most effective part of the health care services*," and "*a critical component of the health policies*."[26] According to the World Health Organization (WHO), healthcare professionals are the people who protect and improve the health level of the society.[27] To assess whether a software affects the work of the healthcare professionals, we propose the OCQ.[28–32] Organizational commitment can be defined as the strong feeling of an individual as a part of the organization and defining himself or herself in that way.[33] Affective commitment expresses the emotional attachment of the employees. Numerous studies have examined the correlates of commitment. Positive associations were found between affective commitment and motivation, organizational citizenship behavior, job satisfaction, performance, and productivity.[34–36] The OCQ[32] relates to the measurement of affective commitment and counts among the most frequently used measurement instruments.[37,38] The OCQ consists of 15 items, of which 6 are negatively poled. Positive associations were found with job satisfaction[39] and with the readiness to remain in the organization,[40] and negative correlations were found with the intention to leave the organization.[41,42] Maier and Woschée[43] prove the construct validity of the OCQ with the help of a confirmatory factor analysis by showing that the OCQ represents a construct that can be empirically distinguished from other work attitudes (job satisfaction and job involvement).

To assess the satisfaction with the usability of software in health, we propose the use of the CSUQ.[44] CSUQ was validated with 825 employees who worked at nine IBM development sites: Atlanta, Austin, Bethesda, Boca Raton, Dallas, Raleigh, Rochester, San Jose, and Tucson. The questionnaire works well in non-laboratory settings.[44]

Concerning the healthcare professionals, we did not identify any reference tool to evaluate healthcare professionals' satisfaction. However, there are several works to evaluate nurses and doctors.[45] Two works must be referred—Beaglehole and Dal Poz,[46] with the Public Health Workforce: Challenges and Policy Issues, and Mollahaliloğlu et al.,[47] with the Healthcare Employee Satisfaction Survey.

Finally, to evaluate the impact of software in the services, we will evaluate the organizational dimensions and the performance of the services of the basic attention centers in the management of TB by using the questionnaire developed by Tereza Villa and Ruffino-Netto (48,49) (TPCAT) Villa and Ruffino-Netto used an instrument of the Primary Care Assessment Tool (PCAT). This tool was formulated and validated to evaluate the critical issues of the primary care in industrialized countries, developed by the John Hopkins University (50–55). This instrument was adapted and validated for Brazil by Macinko, Almeida, and Oliveira (55,56). The same was adapted to evaluate the TB attention by Villa and Ruffino-Netto (49).

The steps

The protocol consists of five steps. It starts with the definition of the sample (Step 1) and the adjustment of the instruments (Step 2), followed by their validity (Step 3). The next step is the application of the instruments (Step 4). The analysis of the results and expected outcomes is the fifth step (Step 5). Figure 1 presents the steps of the protocol.

The first step concerns the definition of the sample and where to apply the instruments. Statistical approaches are used to determine samples and the definition of the inclusion and exclusion criteria in the study. Having a control group is mandatory in order to guarantee that the

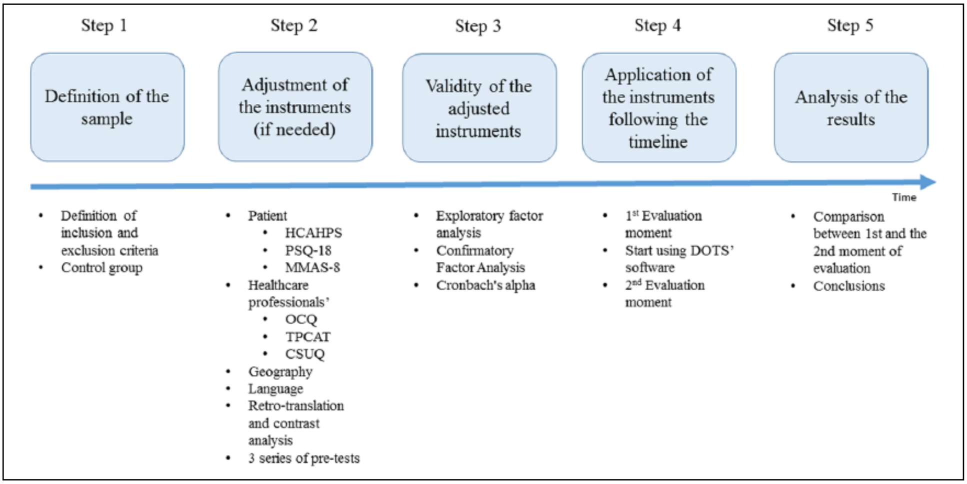

Figure 1. Five steps of the protocol.

software is the only factor that affects the final results. Steps 2 and 3 apply when the instruments need to be adapted to a particular geography and language. The instruments first need to be translated to the mother-tongue and tested before being used in the field. A "forward–backward" procedure should be used to translate the instruments. Retro-translation and contrast analysis to reduce the bias involved in the translation must also be applied. HCAHPS has several domains (constructs) regarding hospital internment and hospital discharge. As the majority of the TB patients do not need internment, and consequently have no discharge, these constructs are not used. We suggest three series of pre-test of the instruments with a sample of patients and professionals based on the similarity of the demographic characteristics of the sample that will be used. The pre-tests will allow (1) the replacement of several expressions by others more comprehensible for the patients, (2) the improvement of the procedures of application of the instruments leading to a normalization of the application of the questionnaires, (3) the developing of a checklist and procedures' manual for the team that will apply the instruments, and (4) the training of the team. The application of the pre-tests should be recorded (video) and carefully post-analyzed by the research team. Patients participating in these pre-tests must sign a consent term. The next step, Step 3, consists of making the internal consistency analysis of the adapted instruments. Construct validity estimates the ability of an instrument to measure the underlying construct of interest.[57] Exploratory factor analysis (EFA) has traditionally been employed by researchers as a tool to determine the number of underlying dimensions in a data set by grouping variables that are correlated.[58] The technique of Confirmatory Factor Analysis analyzes a priori measurement models in which both the number of factors and their correspondence with the indicators are explicitly specified.[59] Reliability can be assessed by Cronbach's alpha internal consistency reliability coefficients. Values greater than 0.6 are considered generally satisfactory, and those greater than 0.8 indicate high internal consistency. Step 4 consists of the application of the instruments. This step must follow a specific timeline. Using the (adjusted) instruments either in patients or in healthcare professionals, before and after the introduction of a software, and by comparing the results, it is possible to verify whether the use of the software has any impact, and whether it is positive or negative. The ideal scenario should be using the instruments for each patient and health professional before and after the use of the software. However, when applying the instruments, different patients will be in different moments of the treatment. Some will be at the beginning and some

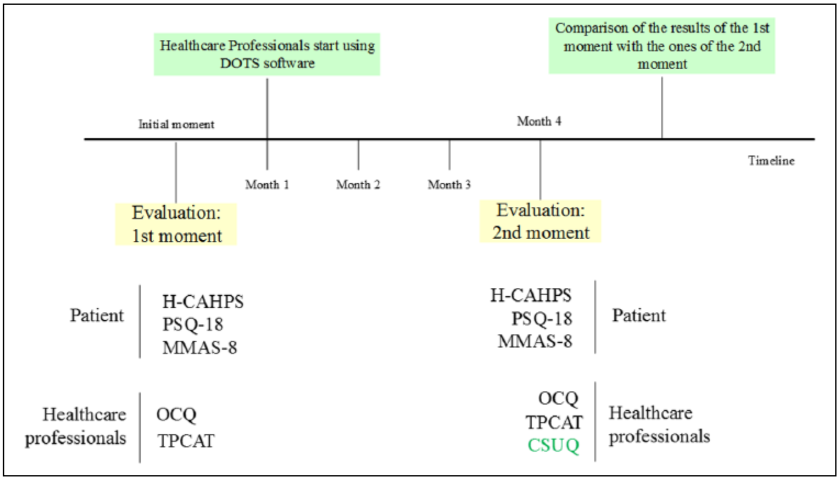

Figure 2. Feasible timeline application of the protocol.

will be at the end, which makes it difficult to apply the instruments, exactly to the same patients, both before and after the use of the software. Therefore, the only possible solution is to apply to existent patients in the beginning and to existent patients in the end even if they are not the same. Thus, we propose that the first evaluation moment for all the patients, regardless of their status of treatment, should be in the first month. Then, we will introduce the software, training the professionals by teaching them how to use the system. After 3 months of consistent use of the system, we can consider that the professional is totally adapted to the tool, having overtaken the learning curve and adaptation. Figure 2 presents the timeline to adopt.

After the 3-month use of the software, a new application of the instruments, added with the CSUQ[44] to verify whether the usability has some correlation with the other results, should occur. Comparing the first measures with the second, we would find out whether the software had some impact on the patients, healthcare professionals, and the services. All the procedures of each instrument must be followed. Results come from the comparison between the first and the second moments of evaluation (Step 5). PSQ-18 and HCAHPS allow the patients' satisfaction to be measured. A similar development is expected between the results of these two instruments, either positive or negative. MMAS-8 will offer the impact on the medication adherence. A progression in line with PSQ-18 and HCAHPS is also expected. The evolution in the professionals' attitude is measured using the OCQ. CSUQ will help in understanding whether the evolution is related to the software. If OCQ demonstrates a positive evolution, it is expected that CSUQ shows a good level of satisfaction with DOTS software. The contrary may also be a possible outcome, that is, a negative evolution in OCQ with a correspondent negative evolution in the CSUQ. However, if these two curves are not aligned, we can still conclude that software has no impact on the professionals' commitment. Finally, using (TPCAT), we expect a result in line with OCQ.

Discussion

The number of different instruments identified in the literature was significant. When several instruments met the criteria, the number of publications, degree, and generality of use were the final factors for the decision. This applies to the HCAHPS, CSUQ, and OCQ. The number of instruments may be an adverse factor in the application of the protocol. Each instrument has its own procedures and some are extensive. The number of steps is also considerable, but using validated instruments, most of them, already adapted and used in several geographies, allow us to minor the impact of Steps 2 and 3. The validity of the protocol relies on the validity of the instruments and on the standard procedures selected. It is a protocol that allows the practitioners in the field to use the protocol to measure the impact of the software on the patients, professionals, and services. It is a complete 360° tool, but grounded in reliable and solid sources. Creating one single validated instrument and reducing the number of steps are the goals of future work.

Conclusion

The patients' and healthcare professionals' perspective is a key factor in the evaluation of the healthcare software. The protocol proposal represents a new approach to the problem of the evaluation of the software by patients and health professionals. Several existing studies use different instruments and different methodological approaches to evaluate patients' and professionals' satisfaction. Therefore, we can conclude the relevance of the development of an instrument, a model, and a methodological approach that could be used in the evaluation of the impact of the healthcare software either on the patients' satisfaction or on the professionals' commitment. With a set of instruments and a set of steps and procedures organized in a protocol, it will be possible to define a way of standardizing the assessment of software for supporting DOTS. The steps allow the use of the protocol in different geographies, and the validated instruments reduce bias. Future studies should be designed to (1) identify the key determinant factors in the evaluation of the impact of a DOTS software for patients, healthcare professionals, and services; (2) develop and test a new instrument based on those factors and demonstrate its validity; and (3) propose a scale to determine the "good," "bad," and "fair" impact of a DOTS supporting software on the patients and professionals, allowing the comparison of different software applications.

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Friction forces and patient-centredness: Understanding how established logics endure during infrastructure transformation

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Abstract

In this article, we examine three cases of e-health solutions for patients in Norway. For the analysis of the three cases, we focused on friction forces that come into play when different established arrangements need to change to accommodate novelty. We argue that the design of new technologies was shaped by friction related to institutionalised practices, regulatory regimes and entrenched patient roles. These friction forces connect the past with the present, come into action when aiming for novelty and result to the perpetuation of constituents of the past during change processes. Specifically, the e-health solutions under study were strongly influenced by established healthcare provision logics. All three initiatives expanded the healthcare information infrastructure towards the patients with as little disruption to established arrangements as possible.

Keywords

e-health, friction, information infrastructure, patient-centredness, transformation

Introduction

In current e-health research, there is considerable discussion on leveraging information systems to shift healthcare towards patient-centredness. In the medical domain, patient-centredness is a model of care that entails keeping patients informed, involving them in decisions and self-care management activities, and acknowledging their experience of illness and psychosocial context.[1–4] Accordingly, patient-centred care indicates a shift towards seeing the patient as an integral part of

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the care team, giving responsibilities of self-care and monitoring to patients and ensuring personalisation of care treatment and care paths.

However, when it comes to putting in place e-health solutions for patient-centredness, there is no clear model for the functionality to offer. As a principle, designing e-health solutions for patient-centredness entails providing information and communication tools for both patients (that need to be enabled to contribute meaningfully in decision-taking) and providers (that need to get better insight on patient circumstances). Hence, solutions related to communications, information sharing and distributed data management are needed in order to facilitate a redistribution of tasks and new types of collaboration and coordination between actors.[5] These novel solutions are transforming the current healthcare information infrastructure that was historically shaped by established logics based on the communication and information needs of health providers.

In this perspective, the introduction of patient-centred e-health solutions can be seen as an attempt to shift current healthcare information infrastructures, from being provider-oriented and institution-centric, towards a balance between the information and communication needs of patients and those of healthcare professionals, supporting care provision that is respectful of patient preferences, needs and values.[6] This shift entails questioning and changing the ways in which patients, healthcare providers and health technologies co-constitute each other.[7] In addition, it entails intervening into how health information infrastructures support the practices of diverse communities that accrete around them.[8] Such interventions are complex, challenging and can lead to unexpected outcomes. Specifically, in this article, we examine how the relational nature of infrastructures shapes the process of putting in place e-health solutions for patient-centredness.

In the following sections, we analyse three different cases with the aim to advance our understanding of infrastructure interventions for patient-centredness. For our examination, we build upon prior research on change as a continuous process that addresses the relation between past and present in innovation.[9,10] To understand change processes, this prior research proposed the concept of friction as an alternative to the concept of inertia. While inertia is linked to inaction and connotes an indisposition to motion or change, friction shifts attention to forces created through the interaction of different established arrangements that need to change in relation to each other. This relational focus is in line with the information infrastructure perspective. Accordingly, our aim is to understand how infrastructure interventions for patient-centredness take place and what is the role of friction forces. Therefore, we formulate the following research question ‘how are e-health initiatives that aim for patient-centredness being shaped by friction forces?’.

Based on the analysis of three case studies, our findings show that designing e-health around patient needs is shaped by friction forces leading to processes of negotiations and trade-offs between past arrangements and novelty. Furthermore, our findings also show that friction forces lead to the perpetuation of constituents of the past during change processes. In the cases considered in this study, the resulting solutions bring as little disruption to established arrangements as possible as established logics endure during infrastructure transformation. Overall, by bringing friction forces in focus, our study contributes to insights into how e-health solutions for patient-centredness find a fine balance between (a) introducing new orientations in care and (b) reproducing established healthcare arrangements.

The remainder of the article is structured as follows: first, we describe the theoretical background and the concept of friction. We then present the background of the cases studied and the method used to collect empirical data, subsequently, we present our findings, and finally, we conclude by discussing insights from our findings and relations to prior research.

Theoretical background

In general, the term infrastructure implies a focus on underlying structural supports which enable action, create connections and have durability.[11] Infrastructures are *relational* because they 'work in between' meaning different things to different groups that share infrastructures in their everyday practices. Infrastructures are also *ecological* because they are part of, made of and inseparable from actions, tools and their environment.[12] Accordingly, infrastructures are always a social and political matter as much as a technical one. However, the everyday experience of infrastructures is not about ongoing deliberations, but rather about boring background arrangements operating smoothly unless breakdowns happen. Studying the work of infrastructuring means attending to issues of maintenance and repair, and approaching infrastructures not as stabilised interlinked structures, but rather as continuous processes. Such a process view exposes how an information infrastructure comes into existence in relation to organised 'technical, material and knowledge interventions' and through 'infrastructural work'.[8] This view implies shifting the emphasis from changes in infrastructural components to changes in infrastructural relations by unfolding the political, ethical and social choices made throughout infrastructure development.[13]

In their inquiry into why and how technological systems are so often difficult to change, Håkansson and Waluszewski observed how different established arrangements often seem to be 'cemented' upon each other impeding alterations and novelty, and yet, these cemented arrangements do transform through interaction.[9] They conceptualise friction as an 'active force' of interaction, causing changes in existing arrangements, with a strong tendency to favour existing (i.e. historical) values due to their accumulated weight – or 'economic heaviness'.[9,10] Hence, friction is a peculiar relational force that can appear both as a stabiliser and a de-stabiliser during change processes.[9] We investigated the shaping of e-health initiatives for patient-centredness by viewing them as infrastructuring processes shaped by friction.

Cases background and method

We conducted three qualitative case studies (Table 1) of design and implementation activities for three separate e-health initiatives in Norway throughout the 2012–2015 period. The case studies are part of a large research project on the interplay between new information technologies and existing systems and modes of organising. For all three cases, data collection was confined to the design activities. We did not have access to use data after solutions' launch.

The first case concerns the design of novel services upon the national e-health platform, which citizens can access over the Internet (HealthNorway). A key aim for this initiative was to facilitate patients to assume a more active role in their own healthcare by providing more expedient means for interacting with healthcare providers. The platform was launched in June 2011 by offering quality assured information on medical conditions, treatments and healthy living. Then, in August 2013, a service for accessing personalised information (such as vaccination and e-prescription information) was launched. Since 2013, four key patient-oriented interactive electronic services are being designed and developed (in early 2017 about to transition from pilot to roll-out status). These four services support information sharing between patients and general practitioners' (GPs) offices and are the focus of this article. The four services are booking of appointments, renewal of prescriptions, electronic contact for administrative purposes and e-consultation. While collecting data on the case, we attended project weekly meetings, workshops and other thematic meetings where we took detailed notes. We also conducted interviews (28 in total) with members of the project team. Additionally, we analysed the replies collected through a national survey of GP

Table 1. Overview of the three case studies.

Case	Description	Data sources
HealthNorway	National initiative, focus on four e-health services for information exchange between patients and GP offices	Notes from project weekly meetings, workshops, and other thematic meetings. 28 interviews. Responses collected through a national survey of GP offices. Project documents
MyRec	Hospital initiative, e-health services for information exchange between patients and hospital clinics	Notes from design workshops. 15 interviews. Internal reports, presentation material for various audiences articles from specialised Norwegian journals
MyBook	Joint project between a doctor/entrepreneur and a University, e-health services for information exchange between patients and healthcare providers chosen by the patients	Notes from 18 design meetings. Working drafts and specifications

GP: general practitioner.

offices. Finally, we reviewed meeting documents, presentation slides and project reports as we have been granted access to project documents.

The second case concerns a hospital-based, patient-oriented web portal named MyRec. The first functionality within MyRec was launched in 2006 and the portal has since been under continuous development and expansion. It offers general functionalities such as secure email with clinical personnel, access to selected Electronic Patient Record (EPR) documents (e.g. discharge letters) and tailored functionalities for specific departments and patient groups including a functionality for notifying hospital clinics for the need to change an appointment and functionalities for data exchange between chronic patients and clinics. Hence, the users of MyRec are both patients and healthcare practitioners. Data collection for this case entailed interviews with hospital personnel (15 interviews in total), observation sessions during design workshops and document analysis (internal reports, presentation material for various audiences, policy documents, laws and articles from specialised press).

The third case concerns a small local project named MyBook. This was initiated by a doctor who identified the opportunity to create a solution for information sharing between patients and healthcare providers. MyBook allows patients to assume a central role in information management for their own health and provides a solution to a practical problem. The practical problem relates to the slowness of existing mechanisms for communication among healthcare providers in Norway. If a patient is discharged from a hospital on one day and has to consult a GP the next day, the discharge report will not have reached the GP. Furthermore, the mechanism is too restrictive: reports are sent only to the doctor who referred the patient; other relevant care providers do not receive them. The solution conceptualised was named MyBook. MyBook is an e-health application that supports patients to create digital copies of documents received after a care event and upload them in a central database from where healthcare professionals could access them. The information-handling approach proposed by MyBook brings the patients in the process and relies on their work to collect and share information. A joint project (between the University and the doctor/entrepreneur) was defined with the aim to deliver a prototype. We followed this project collecting data from 18 design meetings and reviewing documents including working drafts and specifications.

Our research is within the interpretive tradition in information systems research[14,15] and we have taken a process approach to examine how 'things change over time'.[16] In particular, our analysis was focused on taking stock of how functionality was influenced by friction forces between different established arrangements. The three cases allowed us to follow design processes of patient-centred solutions and to investigate the sequence of events that led to the specific functionalities offered. Our interest was focused on the friction forces that came into play when the features of the solutions were being decided. The cases studied relate to initiatives that stem from different levels within the same healthcare system (a national initiative, a hospital initiative, an initiative that was started by a practitioner) and illuminate different types of frictions. Hence, the cross-analysis of the three cases can provide insights on how e-health initiatives that aim for patient-centredness are being shaped by friction forces at different levels.

Findings

Frictions related to GP office established arrangements

The HealthNorway team in charge of the design of the four national electronic services distributed a questionnaire to all GP offices in Norway at the end of 2013 (completed questionnaires received by February 2014). Among other questions, doctors and secretaries working in the GP offices were asked to articulate (in free text format) perceived benefits and disadvantages/issues of web-enabled interaction with patients. There were 369 relevant answers (on benefits and disadvantages/issues) received from 230 distinct GP offices (approximately 15% of the total GP offices in Norway). Out of the 369 completed answers, 219 were submitted by doctors while the remaining were submitted by secretarial staff.

More than 80 per cent of both doctors and secretaries noted potential benefits. These benefits are linked mostly to the effects of introducing asynchronous modes of communication with patients.[17] Specifically, the expected benefits relate to both improvements for work organisation within GP offices (freeing time from answering/returning phone calls, less stressed secretarial personnel, less traffic due to less patients coming to the office to book appointments, improved documentation of patients' contacts) and improvements of service quality (doctors being more accessible, service not linked to opening hours, less frustrated patients).

Although there were no significant differences between doctors and secretaries on the expected benefits, their perceptions differed on potential disadvantages/issues (Table 2). Secretaries were less inclined towards writing about issues than doctors (51% of Secretarial Personnel noted issues vs 71% of GPs). Secretarial personnel mostly worry about the need for lots of 'back and forth' due to insufficient information. Doctors mostly worry about the increase of demand.

GPs and secretarial personnel seem to worry about specific types of potential patient behaviour. In the free text replies, we found references to specific types that we classified under three

Table 2. Perceived issues in electronic information exchange between patients and healthcare providers.

	Workload increase due to many channels	Lots of back and forth due to insufficient info	Inflow of complex requests	Inflow of requests for trivial issues	Data security concerns	Impersonal relationship with patients	Technical issues
Secretaries	7%	15%	5%	3%	3%	3%	2%
Doctors	11%	5%	7%	8%	5%	3%	3%

categories. The ‘demanding patient’ may expect immediate replies or ask trivial questions on things that can be found out without healthcare providers’ involvement. The ‘difficult patient’ may write very long and very frequent messages or may ask ‘too often’ for an appointment. The ‘non-competent patient’ may not be able to formulate requests in a concrete way or may not be able to provide information about current health status and medications used.

The responses to the survey illustrate how the introduction of e-health services seems unchartered territory for professionals. They are overall positively disposed but they also have concerns related to the impact of the new services to the existing work practices. Their concerns created friction with the overall intentions of the design team to offer patients more ‘control’ similarly to other domains (e.g. booking hotels and flights). The four e-health services designed and developed aim to be widely adopted by GP offices around the country so there was a clear need to configure them in a way that would not alienate professionals while pursuing enough novelty to set the ground for future advancements. In other words, the novel functionalities were shaped by the aim to minimise disruptions while maximising the perceived benefits of institutional actors.

For instance, the technological solution developed made it possible to offer a view into the GP’s calendar so that the patients could see the availability of slots and directly select and book one of the empty slots. However, this was not offered as standard functionality. It was up to the individual GP office to decide whether they wished to offer their patients this kind of access. The implemented solution can support both an interaction model close to the current one (with GP offices having full control over the calendar) and a model which is closer to the self-service paradigm (from banking and the travel industry) and requires significant changes in GP office practices.

Frictions related to regulatory arrangements

The design and development for the e-health initiative examined as a second case (MyRec) started within the IT department of a major Norwegian hospital.[18] As the initiative started from within the hospital, the MyRec team members had good access to clinicians and patient representatives and started working closely with them both to elicit requirements and to stimulate their interest. Starting from general ideas, the design team sketched out and experimented with multiple possibilities. In the initial version of the solution, on the main screen a right and a left set of icons used to appear. The icons on the left side were related to a set of services for which the hospital would be responsible (as for example access to information from clinical systems). The icons on the right were related to another set of services for which patients would be responsible (as for example a personally maintained medication list and a personal diary).

Some services proved to be very successful. A service that quickly took off offered functionality for online appointments change. This service solved the problem of lengthy waiting times for patients calling the hospital during peak hours. Also, services aiming to support patient groups living with chronic conditions were well received. In such cases, patients need to report information on a regular basis over long periods, monitoring their own health status and informing clinicians. Nevertheless, eventually some of the initially conceptualised services had to be abandoned. For instance, a functionality that allowed patients to keep a personal diary online had to be removed. This was because the envisioned patient ownership of the information collided with the regulations that stipulate that all personal health data treatment in hospital systems has to be closely monitored by the hospital’s privacy ombudsman.

Overall, e-health services that could enable patients to register their own private information without necessarily sharing it with healthcare professionals collided with regulations about hospital systems. As MyRec kept evolving, the categorisation of services in two distinct groups (left and right sides of the screen indicating hospital vs patient responsibility) was eventually abandoned.

Since MyRec is a hospital-based system, the responsibility for the whole of it lies with the hospital so the two sides could be confusing. Although the health strategy documents instruct hospitals to include patients more actively, this created frictions with the existing regulations related to health-related data repositories that are not always congruent with such a vision. Hence, it was tricky to accommodate in a hospital-based system novel e-health services inspired by Web 2.0 such as keeping personal health diaries and engaging with patient groups without the intermediation of healthcare personnel.

Frictions related to reconciling patient needs to medical practices

In the early stages of the MyBook joint project (between the University and the doctor/entrepreneur), a design and development team worked closely with the doctor who initiated it to further elaborate the idea and develop concrete functionalities. The functionalities developed support patients to (a) digitise and tag paper copies from their records received after a care event (by scanning or photographing), (b) upload in a central database and (c) manage access rights to a personal data ‘folder’ in the central database. According to the doctor’s idea the documents uploaded would be categorised in five fixed document categories: record extracts, blood tests, medical images, medication and ‘other’.

After the functionality was defined, a demo was presented in a workshop with patients where the desirability for such a solution was discussed together with functionality options and opinions regarding security and privacy. The patients expressed wishes for specific additional functionalities such for note keeping (on health events or questions for the next appointment with a doctor). Also, they wanted to be able to register data and display them in a graph. Additionally, they expressed the wish to selectively share single documents rather than opening up access to the whole folder which includes everything uploaded.

The doctor/entrepreneur, for whom simplicity was an overall design goal, maintained that a minimal functionality should be pursued. A persona often mobilised by the doctor in the discussions was ‘Aunt Olga’. She was 80 years old and had several conditions that made her need health services from different providers frequently. She was not very into technology, she was expected to have a mobile phone with which she could call, take pictures and access the Internet. The doctor used this persona and made clear that this was the type of patient to be supported by the new solution. A functional prototype for iOS (iPhone) and a web interface to a secure database were developed. The prototype included only the functionality initially specified with the fixed five document categories (that could not be altered by patients) and no additional support for personal notes or graphics. Thus, the potential for the solution to deliver support both for doctors (that needed access to documentation produced after care events) and for patients (that needed a way to complement the information generated from within the healthcare system with their own notes and other data) was downplayed. The role of MyBook was confined to being a remedial addition to the existing healthcare information infrastructure: new means to carry information between health providers but without enriching this information. The patient, however, could decide for how long the ‘book’ was to be shared and with which healthcare provider and was in control of generating and distributing the access code required. In addition, the patient could see whether the provider actually had used the access right granted or not and could revoke or renew (extend) the access.

Following this case, we find that the new solution rendered patients as mere ‘carriers’ of information rather than full ‘owners’ with discretion over content and structure. Nevertheless, it should be noted that even the carrier role is novel, since patients in Norway are not responsible to carry their health data between providers. The concept of the new e-health solution circumnavigated the legal and interoperability issues that health records applications commonly face. However, it revealed numerous aspects around which there are different views between patients and healthcare personnel. This included which information types should be stored, how this information should be organised, what one should be able to do with the information (e.g. analysis functionality) and the granularity of access control. In this case, we witnessed how the e-health solution has been shaped by frictions between patient needs and established healthcare practices.

In practice, the technical realisation of the prototype left open possibilities for unintended usage and exertion of patient autonomy. For instance, initially, only image file types (jpg) are supported and no editing or annotation functionality is provided. Still, this data format is so generic that it is possible for patients to write notes or draw graphs on a paper sheet, photograph or scan this sheet and upload it. Actually, it would also be possible to photograph anything – for example, a patient could upload a photo of medication boxes rather than a textual medication list. The decision to rely on patients to upload information and the decision to use generic image files led to the development of an application that allows patients to deviate from the intended use although what is actually inscribed in functionality follows a specific healthcare provider's view.

Discussion

Our cases show attempts to shift healthcare towards patient-centredness by designing and developing e-health solutions. Our aim is to understand how infrastructuring for patient-centredness takes place and what the role of friction forces is. Towards this aim we examined three cases at different levels within the Norwegian healthcare system (a national initiative, a hospital initiative and an initiative that was started by a GP practitioner). The concept of friction from innovation studies[9,10] was used as an analytical lens orienting our attention to the confrontations between different established arrangements that need to change in relation to each other. Friction is a relational force with both stabilising and de-stabilising impact on change processes, with a strong tendency to favour existing (i.e. historical) values.

We applied the concept of friction and answered our research question by exposing how established logics endure and have a strong influence on the design of the new e-health solutions for patient-centredness. In the case of the national solution, GP office arrangements were in friction with the overall intentions of the design team to offer patients more 'control' (e.g. similarly to booking hotels and flights). The national solution aspires to be widely adopted by GP offices around the country so there was a clear need to configure it in a way that would not alienate practitioners while pursuing enough novelty to set the ground for future advancements. In the case of MyRec, friction emerged from the existing regulations that are aligned with a provider-centric care model. Although the national health strategy documents instruct hospitals to include patients, the regulations related to health-related data repositories are not always congruent with such a vision. Finally, in the case of MyBook, the medical logic associated with the doctor's initial idea shaped the design process and rendered patients as mere 'carriers' of information rather than full 'owners'. The healthcare providers' views were privileged when deciding which information types should be stored, how this information should be organised and what kind of analytical functionality should be included.

Although in all three cases we observed the strong influence of established provider-centric arrangements on the new e-health solutions, we also found that the resulting functionality was indeed a step towards a more active patient role. The national solution for patient–GP office communications gives patients and citizens more control over their interaction with healthcare providers (e.g. they can use the new electronic channels at times that are convenient for them without fitting their agendas to GP office contact hours). Similarly, the hospital solution is a new entryway to the hospital and also a common space between patients and healthcare providers that supports information exchange. In the case of MyBook, patients were not only provided with new means for sharing information with health providers but also with decision rights on how long information will be shared and with which health provider.

The idea of shifting healthcare towards patient-centredness is present in policy documents but it is not detailed or specific. The shift is linked to multiple rationales (e.g. to improve the efficiency, or the quality, or the inclusiveness of health services). Furthermore, there are multiple possible modes of orienting services to the patients (viewing them as recipients/customers, co-creators or full owners of service).[19] Patient-oriented e-health initiatives are seen as opportunities to pursue innovation in healthcare services by strengthening the patients' role. An underlying assumption in the arguments about the pivotal role of e-health initiatives for patient-centred care is that technology can be used to induce change and to disrupt the existing configuration of healthcare. Essentially, an agenda for 'IT-led transformation' is interweaved in the discourse about patient-centredness[20] feeding expectations for the accomplishment of swift and momentous changes. The assumption of technology accelerated change needs to be viewed in the light of our case findings: technology is not an independent factor that comes in to catalyse change processes, but rather, as technological artefacts are outcomes of design processes influenced by established logics, technology has to be studied as an interdependent part of these processes. In a sense, even when aiming to shift towards new visions and care models, we are always 'amending' in some way. There are always underlying arrangements that enable care work that need to be incorporated, adapted or migrated into a different way of doing things. As Huy and Mintzberg[21] point out, 'change has to be managed with a profound appreciation of stability'.

Our findings make two contributions: first we show that infrastructuring for patient-centredness is an ongoing process of negotiations and trade-offs and that novelty in infrastructures is always a social and political matter as much as a technical one. These findings raise issues on how patients should relate to technology and health expertise.[22] Designing e-health around patient needs as proposed by advocates of patient-centred health technology[23] is not straightforward because friction forces emerge when attempting to change different established arrangements in relation to each other.

Second, our findings show that friction forces connect the past with the present, and result in the perpetuation of constituents of the past during change processes. Specifically, the e-health solutions under study were strongly influenced by established healthcare provision logics. All three initiatives resulted in expanding the healthcare information infrastructure towards the patients with as little disruption to established arrangements as possible. Hence, the e-health solutions are coming out of 'mindful deviations',[24] cautious steps that break away from established healthcare arrangements in a limited way. Such initiatives may not radically depart from existing healthcare models but can still be viewed as seeds for change.[25]

In the cases we studied, we find actors that balance between persistence (keeping the electronic service initiatives going) and desistance and this reflects the exploratory and learning character of designing for patient-oriented services with the strategic aim of reshaping established relationships. Our three cases align with prior research on the need to reconcile the needs of clinicians with those of patients for patient-oriented e-health[26] but also, bring to surface the role of time as a resource and the need for stepwise strategies as the transformation of a complex and diverse sector such as healthcare, takes time.[20]

Our article has a specific focus on infrastructures for patient-centredness facilitating patient–provider interactions. This is a relatively new domain for health informatics. Prior research on healthcare information infrastructures has mostly focused on infrastructures oriented solely to health practitioners. For instance, past research investigated hospital infrastructuring and pointed to unexpected side effects due to reflexive processes generated by complexity and to inertia caused by existing practices and technologies.[27,28] Expanding research to infrastructures that need to work ‘in between’ patients and providers is critical for addressing the ongoing transformations of patient-healthcare provider relations in healthcare.[29] Our article contributes to building a body of knowledge specifically for these new types of infrastructural expansion and complements earlier research on new care models that does not cover technology aspects (e.g. research on patient-professional partnerships for chronic conditions,[30] research on patients’ information seeking behaviour[31]).

Future research may proceed in two directions. The first direction is towards the analysis of other e-health initiatives for patient–provider communications to explore whether similar friction forces apply. This direction can lead to analytical generalisation by the comparative examination of multiple cases. A second future research direction is related to extending our research by following the three specific e-health cases in the future aiming to collect data on actual use. Our study has a focus on the design activities and we have not been able to cover use. By collecting and analysing data on use patterns and actual users’ perspectives (both patients’ and healthcare providers’), it will be possible to follow emergent and unanticipated change through actual use[32,33] and examine how friction forces play out in the long run. Future transformations could be an effect of the potentialities that are opened up and that can be (but do not have to be) realised.

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Grappling with the future: The messiness of pilot implementation in information systems design

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Abstract

Pilot implementation is a method for avoiding unintended consequences of healthcare information systems. This study investigates how learning from pilot implementations is situated, messy, and therefore difficult. We analyze two pilot implementations by means of observation and interviews. In the first pilot implementation, the involved porters saw their improved overview of pending patient transports as an opportunity for more self-organization, but this opportunity hinged on the unclear prospects of extending the system with functionality for the porters to reply to transport requests. In the second pilot implementation, the involved paramedics had to print the data they had entered into the system because it had not yet been integrated with the electronic patient record. This extra work prolonged every dispatch and influenced the paramedics' experience of the entire system. We discuss how pilot implementations, in spite of their realism, leave room for uncertainty about the implications of the new system.

Keywords

emergency medical services, patient transports, pilot implementation, sociotechnical systems

Introduction

Healthcare information systems are inherently sociotechnical and their success is determined by the mutual adaptation of technology and organization.[1–3] Many unintended consequences of healthcare information systems, including under-use and workarounds, flow from discrepancies between the technology and the organizational setting.[4,5] To avoid such discrepancies, a rich variety of design methods exists for assessing, ensuring, and otherwise working with the fit between new healthcare technologies and the needs of healthcare organizations and users. Table 1 gives

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Table 1. Examples of methods for working with the fit between technologies and their use context at different stages of the design process.

Method	Description	Reference
Visioning study	A method for better understanding the potential of new technologies through discussions stimulated by, for example, concept-level videos and for identifying social and technical challenges even before prototypes are available	Söderholm and Sonnenwald[6]
Scenarios	A method for creating technologies by first making descriptions of people using the technology, thereby emphasizing use and inquiries into the use context and postponing commitment to specific technological designs	Rosson and Carroll[7]
Prototyping	A method for making design ideas manifest and for simulating use in the laboratory (i.e. away from real work) in order to traverse a design space and test the fit between a proposed design and the user	Lim et al.[8]
Pilot implementation	A method for learning about the fit between a system and its context by employing a properly engineered, yet unfinished, version of the system for real use in its intended environment for a limited period of time	Hertzum et al.[9]
Continuing design	An approach for gradually evolving a system after it has entered full-scale use by providing on-site technical support to assist users in tailoring the system to their evolving needs and in maintaining a working configuration of systems	Karasti et al.[10]
Versioning	An approach for evolving a system after it has entered full-scale use by periodically releasing new versions developed to exploit new technological possibilities and incorporate feedback on the use of previous versions	Cusumano and Selby[11]

examples of these methods, which span from the first to the last stages of the design process. We focus on one method, pilot implementations, and show that in spite of their realism it is difficult to learn from them because they are situated and "messy."

Hertzum et al.[9] define pilot implementation as "a field test of a properly engineered, yet unfinished system, in its intended environment, using real data, and aiming—through real-use experience—to explore the value of the system, improve or assess its design, and reduce implementation risk" (p. 314). This definition makes pilot implementation a meeting ground between the system and its environment and, thereby, an opportunity for learning about the mutual adaptations needed to make the system a success. A subset of these adaptations can be anticipated through analysis ahead of use or discovered through in-the-lab use of nonfunctional prototypes. The rest must be learned through practical experience with the system in real use.[12–14] Pilot implementations supply such practical experience, but their limited scope and the unfinishedness of the pilot system necessitate preparations to enable real use and safeguard against errors.[9]

We will analyze pilot implementations from the point of view that they are situated and messy activities. They are situated because the particulars of the pilot site influence the pilot implementation, irrespective of whether these particulars are representative of the conditions under which the finished system will subsequently be used. As a result, it may be difficult to distinguish the aspects of a pilot implementation that reflect what it will be like to use the system once it is fully implemented from the aspects that are specific to the pilot implementation and, thus, do not reflect what it will be like to use the system once fully implemented. This difficulty makes pilot implementations messy in the sense that they may yield ambiguous or misleading messages about the value of the system and about how to improve its design or reduce implementation risk.

To illustrate the difficulties in learning from pilot implementations, we analyze two pilot implementations in healthcare. The first is a pilot implementation of a system for coordinating patient transports internal to hospitals, the other of an electronic ambulance record. Both pilot implementations were conducted in Region Zealand, one of the five healthcare regions in Denmark. The starting point for our analysis is that pilot implementations are themselves sociotechnical processes.[2] That is, just as pilot implementations contribute to design, they also need designing. It is through the designing of the pilot implementation that the particulars of the pilot site are taken into account and the learning becomes messy.

Background

As a preamble to the analysis of the two pilot implementations, we elaborate the notions of pilot implementation and messiness.

Pilot implementation

Pilot implementation belongs in the later stages of the design process (see Table 1): after prototypes have been tested in the laboratory but before the system is ready for full-scale implementation in the field. The defining characteristic of pilot implementation is that the system is sufficiently functional and robust to enable testing in its intended environment but is not yet finalized.[9,15] That is, the results of a pilot implementation can affect the finalization of the technology as well as feed into its organizational implementation. A pilot implementation consists of five activities:[9]

- *Planning and design*, that is defining the pilot implementation. This activity involves determining where and when the pilot implementation will take place, what facilities the pilot system will include, and how lessons learned during the pilot implementation will be collected.
- *Technical configuration*, which consists of configuring the pilot system for the pilot site. This activity involves migrating data to the pilot system and developing interfaces, or setting up simulations of interfaces, to other systems at the pilot site.
- *Organizational adaptation*, which means that the pilot site revises its work procedures to benefit from the pilot system. This activity also involves providing users with training in the system and the revised procedures and devising safeguards against user errors and system breakdowns.
- *Use*, during which real work is performed with the pilot system. This activity involves striking a balance between incorporating the system in the normal procedures at the pilot site and maintaining a focus on the system as an object under evaluation.
- *Learning*, which involves collecting information about the introduction and use of the pilot system. Learning about the fit between the system and the pilot site may be derived from all four of the other pilot-implementation activities, not just from the period of use.

It has been argued that failures are more valuable opportunities for learning than successes.[16] Seen in this light, pilot implementations provide opportunities for learning in settings that have been devised to constrain the consequences of failure. It is, however, not apparent how a sustained focus on learning is ensured. Hertzum et al.[9] point out that because the pilot system is used for real work, the learning objective may become secondary to concerns about getting the daily work done. In addition, Winthereik[17] shows that the view of pilot implementations as learning processes may not be shared across the groups of actors involved in pilot implementations. Another challenge in conducting pilot implementations relates to defining their scope. A narrow scope saves resources and constrains the consequences of failure. A broader scope means more use experiences to learn from, in terms of quantity as well as diversity. Finally, it is also challenging to decide on the duration of a pilot implementation. A short pilot implementation consumes fewer resources and proceeds quickly to the full-scale implementation that awaits the completion of the pilot implementation.[18] Conversely, a long pilot implementation is more likely to be unaffected by the start-up problems that are common with new systems. These challenges are nontrivial and inherently sociotechnical.

Messiness

The introduction of information systems in healthcare organizations involves both organizational and technological change.[1,19,20] However, only some of the imaginable changes can be realized with any one information system, and these changes affect only part of the clinicians' work. In spite of the changes, a lot remains the same. It is the system in combination with the local contingencies surrounding its use that determine what changes and what remains the same. Orlikowski[12,21] describes the process as improvisational to emphasize that change is not always planned, inevitable, and discontinuous. Rather, it is often realized through the ongoing variations that emerge in everyday activity and are opportunistically incorporated in work practices, or left unexploited. The improvisational, emergent, and opportunistic character of the process makes change situated and messy as opposed to context-independent and orderly.

There are two main drivers of messiness. First, the introduction of a healthcare information system is a sudden and often substantial change whereas the work that is performed with the system may not evolve as quickly.[22] For a period of time, the system will present possibilities that have yet to be incorporated in work practices and the work practices will include activities that have yet to be aligned with the system. The misalignments may gradually disappear or they may persist as unused system facilities, workarounds, and the like. At any one time, it is uncertain whether a misalignment will persist or subsequently disappear. Second, the meaning of a system is determined by the meanings attributed to it by relevant actors; it does not reside in the system itself. This interpretive flexibility[23] means that different meanings may simultaneously be attributed to the same system by different actors. A system may, for example, be perceived as overly bureaucratic by some actors, while others embrace it because they see it as enforcing best practice. The result of such differences may be different use practices, and this may in turn lead to confusion, uncertainty, and misunderstandings—a messy situation.

Pilot implementations embrace the situated view of change by assigning key importance to subjecting the system to the real conditions of the pilot site. At the same time, the premise of pilot implementations is that agreement can be reached about what is learned and that the resulting learning is valid beyond the pilot site. This premise tends toward a view of change as more orderly and context-independent. As an example, Winthereik[17] analyzed the pilot implementation of an electronic maternity care record. The organization that steered the project approached the pilot implementation as a controlled experiment "where the setup could and should not be adjusted, but kept stable" (p. 56).[17] That is, the organization believed the maternity care record had an essence independent of local circumstances and considered it important to keep the pilot implementation stable in order not to distort the clinicians' experience of the maternity care record. The nurses who used the maternity care record experienced the pilot implementation as an externally imposed, inevitable change in their work: "there is not much one can (or should) do about this" (p. 54).[17] While the nurses had to adjust their work practices to take part in the pilot implementation, they felt peripheral to its learning objective. To them the pilot implementation was largely a ritual. In contrast, the clinicians who had been involved in designing the maternity care record saw the pilot implementation as an opportunity "to learn from clinical practice, and to let what they learned inform the development process" (p. 58).[17] From their point of view, the maternity care record was a malleable object that could and should be changed if it did not fit the clinicians' ways of working.

The example of the maternity care record begins to illustrate how different actors in pilot implementations may perceive the system as well as the situation differently. This messiness evolves over time because the system evolves in use and because the situation is affected by the uncertainty, confusion, and disparity that arise from the messiness. In the following, we will analyze how such messiness makes it difficult to learn from pilot implementations.

Method

We report from two pilot implementations in Region Zealand, Denmark. Our involvement in the pilot implementations was approved by the healthcare region. We obtained informed consent from the involved nurses, porters, paramedics, and other clinicians prior to our observations and interviews.

The first pilot implementation (see Torkilsheyggi and Hertzum[24] for further information) concerned a system for patient transport coordination (PTC) internal to a medium-sized hospital. Our role in this pilot implementation was twofold. First, we facilitated the activities through which the porters and nurses participated in the technical configuration and organizational adaptation. Second, we were responsible for eliciting, collecting, and documenting the learning that resulted from the pilot implementation. The means for fulfilling the first role was three workshops for specifying the PTC system and the associated work practices. For practical reasons, the two first workshops were attended by porters only and the third workshop by nurses only. Thus, the porters and nurses developed their pre-use perceptions of the PTC system in isolation from each other. On the basis of input from the workshops, the pilot system was configured by the vendor and a local configurator. The second role was our main involvement in the pilot implementation. To fulfill this role, we conducted 23 h of observation during the start-up of the pilot implementation to become acquainted with the work of the porters and nurses and 40 h of observation during the 3-week period of use to learn about their use of the PTC system. During the observations we had informal conversations with porters and nurses about their experiences with the system. In addition, we had more in-depth discussions with porters and nurses in five interviews at the end of the 3-week period and in a group interview after the pilot implementation. The interviews were informed by the interviewees' experiences with the system and by our observations of their use of it.

The second pilot implementation (see Hansen and Pedersen[25] for further information) concerned an electronic ambulance record (EAR) for use throughout the healthcare region. Our study of this pilot implementation also consisted of observation and interviews. We observed the paramedics at work for 173 h, which included 67 dispatches where we drove with the ambulance to the scene of the emergency and from there to the hospital. The observations also included observation of the paramedics' work in-between dispatches and of two workshops. The first workshop gathered paramedics, emergency-department physicians, and pre-hospital managers to discuss the effects pursued in the pilot implementation. Through the discussions, the participants were subjected to each other's expectations and requirements to the EAR system. The second workshop aimed at proposing improvements to the design of the EAR interface. This workshop was convened and driven by the paramedics in response to their frustrations with using the EAR system. During the observations, we talked informally with the participants, mainly paramedics, about their work, their expectations toward the EAR system (during technical configuration and organizational adaptation), and their experiences with it (during the period of use). In addition to the informal conversations, we conducted 41 interviews with paramedics, ambulance dispatch managers, prehospital top management, and others. The interviews focused on the interviewees' experience of the EAR system and of the activities of the pilot implementation.

For both pilot implementations, the observations were documented in real time in field notes. The interviews were audio-recorded and subsequently transcribed, except three interviews in the first pilot implementation, which were documented in detailed notes. The workshops and group interview in the first pilot implementation were audio-recorded, and detailed minutes were written on the basis of the recordings. We analyzed the empirical data by reading them multiple times while making annotations of incidents and themes. In this open coding, the annotations initially consisted of snippets taken directly from the data.[26] Through our discussions, the annotations were grouped and we then reread the data about each group. In this process, some groups were combined or split up, others dropped, and still others written into memos. The memos served to elaborate the annotations and, especially, to link annotations together in themes. While the themes evolved gradually—as we learned about our data—the writing of the memos was throughout directed by our research focus on the situatedness and messiness of pilot implementation. We inferred situated and messy characteristics from observation notes about what participants did during the pilot implementations and from interview statements about their thoughts on the pilot implementations.

We studied the pilot implementations from planning and design to use and learning. While this gave us indispensable insights into the pilot implementations, we cannot rule out that our interactions with the participants affected their thoughts about the pilot implementations. However, the participants interacted much more with each other—during the workshops and their everyday work. Our analysis of the pilot implementations was based on groups of annotations and, thereby, internally validated by data from multiple observations and participants.

Two pilot implementations

The following analysis of the two pilot implementations proceeds from their planning and design, through their technical configuration and organizational adaptation, to the period of use. The learning derived from the pilot implementations is emphasized during the descriptions and summarized at the end.

Coordinating patient transports

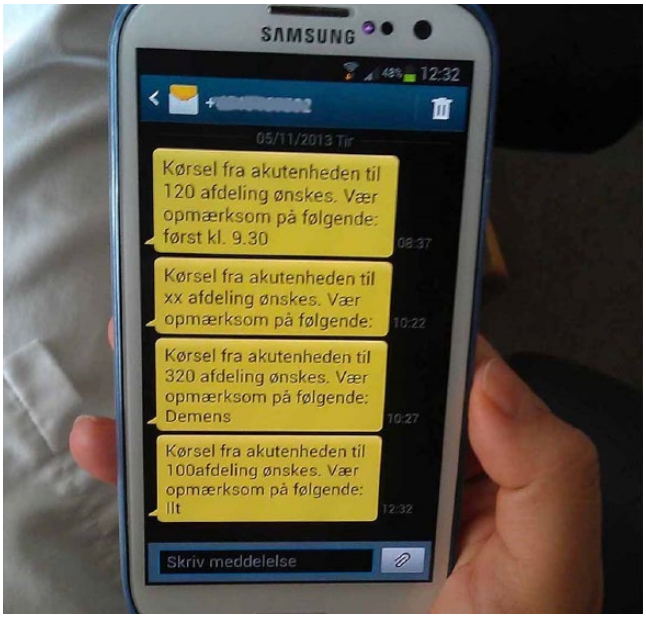
Patient transports are an inevitable part of hospital procedures. Most of these transports are internal to the hospital and involve bringing patients to diagnostic tests, scheduled operations, other medical procedures, and then back to their in-patient department. Timely patient transports presuppose efficient coordination between the nurses who order the transports and the porters who perform them. To support this coordination, the studied hospital decided to extend its electronic whiteboards. The whiteboards had recently been mounted on central locations in all wards of the hospital to provide at-a-glance access to an infrastructure for interdepartmental communication and coordination. The extension of the whiteboard to support patient transports involved a pilot implementation because the porters needed to be able to access the information while they were on the move and, thus, benefitted little from the stationary, wall-mounted whiteboards. The aim of the pilot implementation of the PTC system was twofold: (a) to evaluate a system with which nurses ordered patient transports on the whiteboard and porters received notification of these transports via text messages on their phone and (b) to get initial experiences with mobile extensions of the whiteboard. In total, the pilot implementation lasted from March to November, 2013.

In March 2013, the planning and design of the pilot implementation started with considerations about its scope. During dayshifts the porters worked in teams responsible for a specific department, and they proposed the emergency department (ED) as the site for the pilot implementation. An important reason for this choice was the constant flow of patients from the ED to other departments. To limit the number of nurses who had to be trained in ordering patient transports via the whiteboard, the scope was further limited to one of the three wards in the ED, although this meant that the porter team had to respond to two workflows because the nurses in the two other wards of the ED would still be phoning the porters to order a transport. The technical configurations and organizational adaptations necessary for the pilot implementation were made during September and October. To make the ordering of transports easy for the nurses, they were provided with a template that had predefined dropdown menus for the type of transport ordered and for any equipment, such as oxygen, required to perform the transport. A key characteristic of the PTC system was that the porters could not reply to the notifications they received from the nurses. The porters emphasized the importance of being able to reply, for example, to inform about delays and to request additional information. It was, however, decided—and the porters accepted—that reply functionality would not be part of the pilot implementation. The reasons for this decision were mainly technical difficulties in finding a way to present the replies so that they would be noticed and reacted upon but also some skepticism from management about whether reply functionality was truly needed or would merely be nice to have.

All ED nurses working dayshifts during the 3 weeks of pilot use, November 2013, were included in the pilot implementation. These nurses had received a user manual explaining the new way of ordering patient transports, but it immediately became apparent that most of the nurses had not read the manual and therefore did not feel prepared to use the PTC system. As a consequence, demonstrations of how to order patient transports via the whiteboard were improvised at the nurses' morning meeting for a couple of days. The porters valued receiving information about the required equipment before showing up to collect patients. Previously, they often had to leave the ED again to fetch necessary equipment. With the template for ordering patient transports, the equipment was specified more persistently.

While the PTC system enabled the porters to prepare for the individual transports, it reduced their opportunities to communicate with the nurses about scheduling issues because the porters could not reply to the notifications and because the system was presented as a replacement of coordinating patient transports over the phone. Phone calls were considered a major source of interruptions in the clinical work and avoiding phone calls to the nurses was, therefore, integral to the rationale for coordinating the patient transports via the PTC system. The porters stated that whereas it previously could be a challenge for them to keep track of the incoming phone calls for several transports at a time, they could now receive several text messages in a row without worrying about the information getting lost (Figure 1). The nurses started utilizing the porters' improved overview of pending transports by increasingly ordering transports in advance, rather than waiting until the patient was ready for the transport. The porters saw the advance orders as an opportunity for increased self-organization of their work. At the same time, they experienced that the absence of reply functionality prevented them from exploiting this opportunity.

At the end of the pilot implementation, the porters stated that they wanted functionality for responding to orders before they were prepared to go forward with the PTC system. This requirement was supported by the nurses, who found that they did not receive sufficient feedback from the



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Kørsel fra akutenheden til 120 afdeling ønskes. Vær opmærksom på følgende: først kl. 9.30 08:37

Kørsel fra akutenheden til xx afdeling ønskes. Vær opmærksom på følgende: 10:22

Kørsel fra akutenheden til 320 afdeling ønskes. Vær opmærksom på følgende: Demens 10:27

Kørsel fra akutenheden til 100afdeling ønskes. Vær opmærksom på følgende: Ilt 12:32

Figure 1. Porter phone with four messages about transports.

system and, on multiple occasions, phoned the porters to make sure that they were aware of a pending transport. Independent of the pilot implementation the hospital considered reorganizing the porter service. The current dayshift organization of the porters into separate teams serving different departments would be replaced by a central dispatcher coordinating all patient transports at the hospital, an organization already in use during evening and night shifts. If this reorganization was carried through, the nurses would coordinate transports with the dispatcher rather than directly with the porters. The porters maintained that they would also need reply functionality in communicating with a dispatcher, though the pilot implementation provided no data about this issue because it was restricted to dayshifts. While the considerations about introducing a dispatcher during dayshifts were not part of the pilot implementation, they were part of the context in which the pilot implementation was conducted, the system experienced, and the results interpreted. For example, the porters' wish for more self-organization was interpreted in the light of the possibility of a reduction in their self-organization if a central dispatcher was introduced.

Electronic ambulance record

Paramedics' observations at the scene of an emergency are pertinent to their work and to the work of the ED clinicians who assume responsibility for the patient upon arrival to the hospital. In addition, information about the paramedics' treatment of the patient en route to the hospital is important documentation of their work. To support paramedics in documenting their observations and treatment, the studied healthcare region pilot implemented an electronic ambulance record. The aim of the pilot implementation was threefold: (a) to evaluate the match between the regional pre-hospital services, especially the paramedics' work, and the EAR system; (b) to enable the extraction of data about the paramedics' work in order to show that a regional decision to remove physicians from the ambulances did not have adverse consequences for patients; and (c) to provide input to a nationwide tender for an EAR system to be used in all five Danish healthcare regions. In total, the pilot implementation lasted from January 2011 to August 2012.

The first phase of the pilot implementation, January to September 2011, was spent planning and designing the pilot implementation, technically configuring the EAR system, and organizationally adapting the pre-hospital service to the use of the EAR system. During this phase it was, for example, decided to pilot implement the EAR system in ambulances across the region and from both of the ambulance operators contracted by the healthcare region. It was also decided to exclude integration with the electronic patient record in the hospitals from the scope of the pilot implementation. The EAR system was configured so that it contained a superset of the information in the paper-based ambulance record it replaced. The technical configuration also involved some mundane but time-consuming hardware issues, such as replacing the brackets for mounting the EAR computer in the ambulances because the brackets initially delivered were recalled by the manufacturer. In terms of organizational adaptations, a workshop was held to involve representatives of paramedics and ED clinicians in a discussion of the effects pursued with the EAR system. Also, the paramedics received basic training in the use of the system. The paramedics, nevertheless, remained uncertain about the capabilities of the EAR system as well as of the progress of the activities preceding the period of use.

The period of use started in September 2011 and involved 17 ambulances, distributed across 13 ambulance stations and both ambulance operators. It was mandatory for the paramedics to use the EAR system for documenting all acute dispatches with these ambulances. To emphasize the primacy of the patients, the paramedics were instructed that should situations arise in which the use of the EAR system conflicted with concerns for patient health, the paramedics could revert to the paper-based record. Right from the start of the pilot use of the EAR system, the paramedics experienced multiple technical and procedural issues. For example, data entry was divided onto more than 20 screens, thereby degrading the paramedics' overview of what information they had already entered and what information they still needed to enter. In addition, the absence of integration with the electronic patient record in the hospitals meant that the EAR records had to be printed upon arrival to the EDs (Figure 2). The printing turned out to be exceedingly time consuming and the resulting printouts to be several times longer than the old paper-based records, thereby delaying and degrading the handover of the patients from the paramedics to the ED clinicians. Although the paramedics immediately flagged these issues as detrimental to their work, many of the issues were not resolved until months later or not at all. It was not fully transparent why the issues were not resolved, but the reasons included that the supplier of the EAR system lacked resources, that the supplier was not immediately informed about all the problems flagged by the paramedics, and that though the problems were obvious the solutions were often not. Consequently, the paramedics gradually lost faith in the EAR system, and their use of it declined. In an effort to improve the user interface of the EAR system and reduce the number of screens, five paramedics and a health personnel manager met for a workshop during which they reorganized the interface and proposed a version that was simpler and better aligned with the paramedics' work. After a month, the period of use was officially put on hold, pending a resolution of the critical issues. Two ambulances started using the pilot system again in March 2012 to assess whether to resume the pilot implementation. While the pilot implementation was not resumed, the system remained in use for a subset of the dispatches with these two ambulances until the pilot implementation was officially discontinued in August 2012.

The motivation for the pilot implementation of the EAR system made it a politically textured process. While the consequences of removing physicians from the ambulances may be an unusually sensitive element in a pilot implementation, it was not unusual that multiple interests influenced

Figure 2. Paramedic printing EAR record at the ED.

the pilot implementation because it was set in the field and concerned people's real work. The process became further politically textured because the pilot implementation included two ambulance operators that were competing for contracts with the healthcare region and because the employees of the ambulance operators (i.e. the paramedics) were increasingly not using the EAR system although its use was mandated by the healthcare region. Such circumstances more likely foster caution and concealment than open dialog. In addition, the substantial impact of the printing problems on the pilot implementation exemplifies the difficulties involved in defining its scope. Another issue that hampered the pilot implementation was the tension between the paramedics' daily frustrations with the EAR system and the month-long periods required to make revisions of the system. This difference in timeframes meant that the paramedics faced the same problems again and again, also after they had reported them.

Discussion

It was difficult to learn from the pilot implementations of the PTC and EAR systems. In the following, we discuss this difficulty, the complexity it adds to methods for grappling with the future, and the limitations of this study.

Table 2. Key instances of confusion and uncertainty arising from the messiness of the pilot implementation of the PTC system.

Issue	Description
Absence of reply functionality	The absence of reply functionality was decisive to the porters but it remained unclear throughout the pilot implementation whether reply functionality would, or just possibly could, be added later
A replacement of phone calls	The system was presented as a replacement of phone calls and this rationale remained uncontested to the extent that occasional supplementary phone calls were seen as indicating that the system was inadequate
Effect on phone calls hard to assess	The effect of the system on the number of phone calls was, probably, diluted by the continued practice of phone-ordered transports in the two ED wards not included in the pilot implementation and, therefore, hard to assess
Considerations about reorganizing	The porters' wish for more self-organization was amplified by the independent considerations about extending the central dispatcher to all shifts, and it was partly seen by others as a response to this possible reorganization of the porter service
Not prepared to use system	Improvised system demonstrations at the morning meetings countered that an accidental aspect of the pilot implementation (i.e. that many nurses had not read the user manual) had knock-on effects on the perception and use of the system

PTC: patient transport coordination; ED: emergency department.

Messy learning

The main finding of this study is that in spite of their realism, the two pilot implementations left room for confusion and uncertainty about the implications of the new systems. Tables 2 and 3 give key instances of such confusion and uncertainty. For example, it remained an uncontested assumption in the pilot implementation of the PTC system that the system should replace, not supplement, phone calls. Consequently, occasional supplementary phone calls were seen as indicating that the system was inadequate. If the focus on replacing phone calls had been contested, then the nurses and porters could, possibly, have arrived at a practice in which the system and phone calls supplemented each other in achieving the best coordination of patient transports. As another example, the paramedics approached the user interface of the EAR system as changeable and took initiative to a workshop proposing a simpler interface. While the interface was configurable, it turned out that the process of reconfiguring it took months and only solved part of the problems. That is, the initial version of the interface was, in practice, fixed to a much larger extent than the paramedics had assumed. We want to raise three issues in relation to the messy character of the learning in pilot implementations:

First, the learning that can be derived from a pilot implementation is not a final or static statement about the fit between the system and the organization. By testing in the field, pilot implementations gain a realism that sets them apart from testing prototypes in the laboratory,[9] but the realism does not end discussions of what using the system will be like. Rather, the realism entails that the system becomes salient to the users because it starts to affect their work and require them to change their practices. Wagner and Piccoli[27] argue that it is at this point most users start reacting to a system and become motivated to influence its design. For example, the porters learned that with the new system they more consistently received information about the equipment necessary for the transports, but they also worked around the system by, occasionally, phoning the nurses and they strove to have reply functionality added to the system though it remained unclear whether it would be added. The learning derived from the pilot implementations was the current state of an evolving

Table 3. Key instances of confusion and uncertainty arising from the messiness of the pilot implementation of the EAR system.

Issue	Description
Printing of EAR record at the ED	It was exceedingly time consuming to print the EAR record upon arrival in the ED, thereby delaying the handover, but it remained unclear whether/when an integration with the electronic patient record in the hospitals would replace printing
Data entry on 20+ screens	Data entry was divided onto more than 20 screens, thereby degrading the paramedics' overview, but they approached this as a changeable aspect of the pilot implementation and initiated a workshop to propose a reconfiguration of the EAR interface
Same problems again and again	The paramedics experienced the same problems over and over again, even months after they had reported them, thereby exacerbating their frustrations and making issues that were in the process of being changed appear unchangeable
Uncertainty about system capabilities	The paramedics attended workshops about the effects pursued with the EAR system and received basic training in using the system but they remained uncertain about its capabilities and about the impact of the pilot implementation on these capabilities
Not using a mandatory system	It was a sensitive issue that the paramedics were increasingly not using a mandatory system and, therefore, difficult to maintain an open dialog about their experience of the EAR system, especially in a context with two ambulance operators competing for contracts

EAR: electronic ambulance record; ED: emergency department.

process, which contained planned change, workarounds, uncertainty, emerging opportunities, unsuccessful efforts, and other reactions by the involved actors to the technology and the modified contextual conditions. Such reactions, shaped by the particulars of the local context, are not likely to provide unequivocal insights about the wider implementation of a system.

Second, different stakeholder groups experience pilot implementations differently because each group has its own set of tasks and responsibilities in relation to the system. For example, nurses order patient transports and remain largely unaware of other departments' competing needs for transports, while porters perform transports and are continuously organizing their work so as to meet the needs of multiple departments.[28] As a consequence, different groups experience different uncertainties, possibilities, and frustrations in relation to the possibilities provided, and not provided, by a system. The nurses in the pilot implementation of the PTC system realized that the system enabled them to order transports in advance. This new work practice emerged during use as a welcome but unplanned effect of the PTC system and showed that the nurses' old practice of not ordering transports until the patients were ready had been an unrecognized bottleneck in the coordination of patient transports. In contrast, the porters' experience of the PTC system was dominated by the absence of reply functionality and the lack of clarity about whether this lack was temporary or permanent. The study by Winthereik[17] gives further examples of how the stakeholders in a pilot implementation may get quite different learning experiences from it.

Third, the messy learning from pilot implementations may in part resemble uncertainty about their essence and accidental aspects. According to Aristotle, the essence of an object is the part that is retained during any change through which the object remains identifiably the same object; in contrast, the accidental aspects of an object are not bound to its essence but can change independently of it.[29] To the extent that this distinction can be applied to pilot implementations, the essence

Table 4. Key difficulties in learning from pilot implementations.

Pilot-implementation activity	Difficulty related to learning
Planning and design	Confusion about what the pilot implementation seeks to explore if it has multiple aims and they point toward different priorities or stakeholders
Technical configuration	Uncertainty about whether the components of the system have been finalized or are the temporary state of yet unfinished design work, system integration, and data migration
Organizational adaptation	Uncertainty and misunderstandings arising from recent training, revised procedures, temporary precautions, and the absence of knowledge about how long work will be in flux before it has re-stabilized
Use	Uncertainty about whether the current way of using the system reflects what it will be like to use the system once it is fully implemented
Learning	Difficult to maintain a focus on learning in the midst of day-to-day operations with their focus on getting the daily work done

would be the aspects that are inherent in the system and its use. These aspects accurately reflect the system and what it will be like to use it once it is fully implemented. In contrast, the accidental aspects of a pilot implementation are brought about by the pilot-implementation activities, such as the safeguards necessary to subject an unfinished system to real use. These aspects are not inherent in the system and its use, and they may or may not reflect what it will be like to use the system once it is fully implemented. Several of the difficulties experienced in learning from the two studied pilot implementations appear to involve expectations about a clear division between essence and accidental aspects but difficulties in telling them apart in practice. If essence is mistaken for accidental aspects, or vice versa, confusion and faulty conclusions will ensue.

Grappling with the future

Table 4 summarizes how learning from pilot implementations becomes a situated, messy, and therefore complex process. The complexity is not attributable to a single pilot-implementation activity but rather involves all five of them. For example, the threefold aim of the pilot implementation of the EAR system was a planning and design issue that created uncertainty about what the pilot implementation sought to explore because the different aims pointed at different stakeholders in a politically textured process. And the possible reorganization of the porter service independent of the pilot implementation of the PTC system influenced the organizational adaptations in the pilot implementation as well as the way in which these adaptations were interpreted. To reduce the messiness of pilot implementations, practitioners should first acknowledge it. Second, they should carefully plan and communicate the temporary measures necessary to bridge between the activities supported by the pilot system and those external to it. It may be tempting to assign secondary importance to these measures during planning because they are merely temporary; the printing of the EAR records upon arrival to the EDs exemplifies the consequences of an inadequate temporary measure. Third, communication to counter emergent confusion and uncertainty should continue throughout the pilot implementation. Refraining from such communication—to let the pilot implementation run its course—will most likely make it increasingly messy and thereby reduce the learning that can be derived from it.

While we have investigated the messy character of learning in pilot implementations, it is worth noting that the use of other design methods is also a situated sociotechnical activity.[2,30] Thus, visioning studies, scenarios, and other alternatives to pilot implementation also add complexity, just as they contribute to the mutual adaptation of system and organization.

Given the complications involved in learning from pilot implementations, one may ask: What is the use of pilot implementations? We want to point at three uses of pilot implementations: clarifying, kick-starting, and aborting. First, a pilot implementation can be used to clarify what using the forthcoming system will be like and to align expectations with possibilities. Using a pilot implementation for clarification does not mean that the implications of the system will be left uncontested; the meeting between expectations and possibilities may gradually transform the work practice. However, a focus on clarification aims at easing and smoothing the transition to the new system by avoiding uncertainty and confusion and, thereby, making it more readily appreciable what working with the new system will be like.

Second, a pilot implementation can be used to kick-start a process of transforming the system and organization. The transformations accompanying new systems are often slow or they congeal before the full potential of the system has been realized.[31] A pilot implementation may provide inspiration for the kinds of transformation that can be pursued, constitute a forum for negotiating what transformations to pursue, exemplify how they can be pursued, and identify changes in the system necessary to make attractive transformations possible.

Third, a pilot implementation may lead to the abortion, or postponement, of full-scale implementation if there is a severe mismatch between system and organization. The pilot implementations of the PTC and EAR systems are examples. Assessing whether to proceed with full-scale implementation is an important use of pilot implementations because a decision to abort is easier to make after pilot than full-scale implementation and because a pilot implementation shields the organization at large from a system not (yet) fit for use.

In principle, the primary aim of a pilot implementation is to learn about the fit between the system and its use context, while the primary aim of full-scale implementation is efficient quality treatment of the patients. In practice, the learning objective of a pilot implementation may be contested or simply difficult to maintain in the midst of real ambulance dispatches that affect the health of real patients. Clarity about the distinction between pilot implementation and full-scale implementation is however important because it sets expectations and success criteria. For example, Bossen[32] hesitates to call the pilot he studied successful because it did not run smoothly but, at the same time, he lists several important learnings about the system functionality, technical challenges, and organizational issues. Increased clarity about the objective of pilot implementations might have made it easier to assess the pilot implementation. Aarts et al.[14] studied a full-scale implementation and discuss how emergent change and the mutual shaping of technology and organization blurred whether it was a success or a failure. It appears that part of the blur could be explained as uncertainty about the extent to which a successful full-scale implementation may, inadvertently, contain elements of pilot implementation. The study also shows that uncertainty and discussion about the consequences of a system continue into full-scale implementation.

Limitations

Three limitations should be remembered in interpreting the results of this study. First, the data are from pilot implementations in one healthcare region of one country. While the two pilot implementations differ in many respects and show that the results of the study are not peculiar to a single pilot implementation, we acknowledge that both pilot implementations are about transporting patients and, at least partially, about resource optimization. The results may also be influenced by local circumstances, such as the particulars of the Danish healthcare sector. Second, both pilot implementations revealed severe problems in the tested systems. We acknowledge that pilot implementations of more finalized systems will likely be less messy, but they will likely also yield less learning about problems that can still be addressed. This dissonance appears a reminder of Buxton's[33] law that it is always too early to evaluate until suddenly it is too late. Third, in a healthcare context, porters and paramedics are more peripheral and less powerful user groups than, for example, physicians. The presence of additional aims, beyond that of supporting the porters and paramedics, is more likely for peripheral user groups and it probably increased the messiness of the pilot implementations. More work is needed to examine the transferability of our findings to other circumstances and user groups.

Conclusion

Learning from pilot implementations is messy because they are situated and, thereby, influenced by local contingencies that may or may not reflect what the fully implemented system will be like. In spite of their realism, the two studied pilot implementations left room for confusion and uncertainty about the implications of the new systems. For example, the month-long process for making revisions of the EAR system meant that the paramedics experienced the same issues repeatedly and became increasingly uncertain whether the system could and would be changed to fit their expressed needs. Such confusion and uncertainty temper the contribution of pilot implementations to the mutual adaptation of system and organization because the peculiarities of a pilot implementation may overshadow the aspects that proceed into ordinary use, because the resulting learning may not be valid beyond the pilot implementation, and because the messiness of the learning may preclude directed action. A corollary of this conclusion is that the messy learning in a pilot implementation derives as much from the pilot-implementation activities that lead up to the period of pilot use as from the period of pilot use itself.

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‘Two clicks and I’m in!’ Patients as co-actors in managing health data through a personal health record infrastructure

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Abstract

One of the most significant changes in the healthcare field in the past 10 years has been the large-scale digitalization of patients’ healthcare data, and an increasing emphasis on the importance of patients’ roles in cooperating with healthcare professionals through digital infrastructures. A project carried out in the North of Italy with the aim of creating a personal health record has been evaluated over the course of 5 years by means of mixed method fieldwork. Two years after the infrastructure was put into regular service, the way in which patients are represented in the system and patient practices have been studied using surveys and qualitative interviews. The data show that, first, patients have become co-actors in describing their clinical histories; second, that they have become co-actors in the diagnosis process; and finally, they have become co-actors in the management of time and space as regards their specific state of health.

Keywords
ehealth, electronic health records, health data, health infrastructures, health practices, personal health record

Introduction

In recent years, due to the economic crisis and cutbacks in resources following decades of continuing expansion, it has become increasingly urgent to take action to ensure the sustainability of public health systems, without, however, reducing the expected quality of service.[1] However, the first consequence of these changes is a growing demand for co-responsibility on the part of patients, who must take increasing responsibility for a capacity to pre-empt healthcare issues and manage their treatments independently. The healthcare system has also traditionally responded to these challenges by investing in healthcare infrastructures aimed at improving professional coordination and streamlining workflow. For these reasons, the infrastructures in healthcare have attracted increasing interest from scholars regarding their relevance in ‘connecting practices, change existing practices and create new practices’.[2–6] More recent developments, however, have focused on infrastructures

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for patients, such as patient portals and personal health records (PHRs). These infrastructures should be able to support the relationship between patients and healthcare systems without losing the quality of service that people expect, while maintaining trust in their contact with healthcare professionals. This requires a special investment in infrastructures that are especially sensitive to the needs of patients, that are designed according to their needs, while at the same time increasingly able to support the relationship between patients and healthcare professionals.[3] Recently, infrastructures have moved from a general interest in the health system as a whole, to specific patient needs and pathologies such as diabetes, heart disease and many others. Individuals are quickly becoming the new focus of interest.

The PHR infrastructures are specifically created to furnish patients with access to the documents produced by various health information systems. The intention of national and European governments is that all citizens should soon be able to acquire their data from the network and make it accessible to the doctors treating them in whatever country they may be (Italian Law 17 December 2012, no. 221).[1]

As we shall see, research on these infrastructures is particularly suited to understanding how patients deal with such situations. PHR systems enter people's lives, and it is important to determine how patients alter their health practices because of PHRs. The article reconstructs the development of a PHR by an Italian regional health authority and closely observes how the role assigned to citizens/users has changed over time. In the space of a few years, in fact, the rhetoric and practices related to PHR have exhibited varying degrees of the 'shift' and 'drift' as recently observed by Davidson et al.[4] in the United States. Through analysis of this case study and an extensive monitoring programme conducted with both quantitative and qualitative empirical observation, we show how patients derive notable benefit from innovation, despite the fact that it is not specifically designed for them.

Related work

This work concerns a computerized patient records system centred on patients themselves. A common name for this kind of system is PHR. The PHR was originally defined within the American context and more as a policy project than as a concrete operational one. The basic design was developed with reference to the American healthcare system in the early 2000s. In particular, the Markle Foundation was among the first to define the nature of the instrument. In a report devoted to the American healthcare system of the future, published in 2003, the PHR was defined as 'an internet-based set of tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it'.[3–5] This type of system differs from the better known EHR (electronic health record) because it is constructed with direct consideration of citizens and their needs to access health data. In EHR systems, in fact, it is the medical staff who administer the data on behalf of the patients.

The possibility of extending these experimental projects to the entire population of a larger administrative territory – such as a number of metropolitan cities (e.g. Copenhagen), certain large private players (Google Health, MicrosoftVault or myRecord by Epic) and the English National Health Service (with its HealthSpace project) have done – is more complex and uncertain.[4,6] Studies that have analysed the UK experience, which is possibly the most ambitious in a Western country (12 billion pounds was the cost after 6 years despite an initial provision of 4 billion), have underlined the superficiality with which the interests of actual groups of patients were treated.[7] In the English system today, only the repository of the clinical data of English patients known as the summary care record (SCR), which is only available to the health service and which stores over 20 million medical records, is available. The HealthSpace system, which was a PHR conceived to give access to data available from the SCR, to which personal data could also be added, was finally closed down at the beginning of 2013, and the data were securely deleted (National Archives 2013). In a private context, Google Health, which was also finally shut down in 2013, suffered a similar fate.) These experiences have directed attention to the issue of organizational practices in healthcare. In particular, scholars have highlighted the fact that the design of the infrastructures does not take sufficient account of the user's knowledge and generally undervalues the role of knowledge in organizational practices in innovation processes.[8–10]

Reflection on organizational practices in sociology rests on a long tradition. Authors such as Goffman,[11] Garfinkel,[12] and Bourdieu[13] propounded the first theoretical frameworks within which to analyse social practices. More recently, the field of organization studies has developed various approaches and given rise to diverse research programmes.[14–16]

These works have evidenced that materiality and social relations cannot be easily separated; hence, the social practices of the actors become the prime object of study.[16,17] For this reason, practices may be the most appropriate way to study implementation processes in such complex domains. When developing healthcare systems, established institutional knowledge, the expertise of healthcare staff and patients, and the role played by technology and policy decisions require paradigms which are able to take this complexity into account. As Suchman et al.[16] suggest concerning the study of technological prototypes, constructing new technologies is a 'practice of configuring new alignments between the social and the material that are both localized and able to travel, stable and reconfigurable, intelligibly familiar, and recognizably new' (p. 164). In particular, the authors highlight the presence of two 'shifts' in the realization of prototypes that characterize the practices which surround them. The first 'shift' is from the representation of the artefact by its designers to the design embedded in the artefact itself. The second 'shift' concerns the nature of the users' needs, which must be encoded and included in the artefact. This second 'shift' is particularly evident among early users and helps bring out what may be 'somehow latent, unarticulated or even unrecognized by practitioner themselves'[16] (p. 166).

The case study presented here is additionally interesting since the PHR infrastructure to which this study refers seems to have been a success, even if the initial expectations were disappointing. Approximately 4 years after it was implemented, and with the functionalities for patients reduced to the minimum, it continues to attract end-users, is used by over 10 per cent of the reference population and is showing signs of continuing growth.

Thus, from this point, the article endeavours to set out the following question – if projects centred around patients shift from the original aims, why does it appear that this PHR project is working? More specifically, what are the patient practices that have stimulated the adoption of this system and have resulted in its being so widespread in its reference context?

The setting: a story of a public regional PHR

The PHR infrastructure that we have studied was promoted by the central government in an area of Northern Italy that is not only mostly mountainous but is also characterized by the fact that approximately half the population is urbanized. The infrastructure was developed by a research centre, with the initial enrolment of about 500 experimental patients recruited by word of mouth in 2010. It finally became operational in 2012. Today, the service is part of the information system of the regional health authority and has around 60,000 registered users.

The project, funded by the regional administration, began as early as 2005. From the outset, the research centre commissioned to develop the prototype drew inspiration from existing experiences and pursued a vision of the PHR as entirely open and user-centred. The methodology used to identify requirements and to design the graphic user interface (GUI) was participatory, and for this purpose, it involved various stakeholders in defining the requirements: users, hospital medical staff and general practitioners, together with patients' associations with the support of an academic team.[18] A project coordination board comprised representatives of the regional administrative authorities, the health authority and the research centre. Although the regional healthcare service offered the opportunity to access data centres, this choice was taken up without any enthusiasm, considering that this project, just as many others, would be closed down sooner or later.

The first mock-ups produced by the research centre had as their 'killer application' online access to laboratory reports and medical examinations produced by any of the regional public health centres, and as a consequence, by hospitals. This option was subsequently extended to cross-viewing between adults and family members. Hence, those authorized can view the data of their partners, people for whom they are caregivers, family members and so on. Furthermore, the initial design also included advanced widgets regarding drug usage, a diary to record health problems, graphical tools and some others.

For political reasons, and to justify the large economic investment, at the end of 2010 the regional authorities instructed the regional health authority to bring the system into service. Thereafter, development of the software was no longer under the direct control of the research centre. It was the health authority which decided how to structure the new system, although it did so on the basis of the research centre's work. As a result, no further investment was made in configurable widgets designed for users. Furthermore, security-related issues meant that the methods for recruiting citizens became more rigid. The system's users would be authenticated by means of a smartcard and reader, which were issued by the regional administration to all users requesting them. Of course, this solution made access more difficult because it involved the installation of the reader by users on their personal computers. A help desk was set up to respond to calls for help and to answer emails regarding technical problems, which were then analysed.

Since that time, other services, such as online payments, virtual prescriptions and other minor services, have been made available. Since the official service opened, people have continued to take up the offer to register with the system, and they have consented to what is a quite demanding level of formalization in order to complete the registration process. The service for access to healthcare data alone now has over 60,000 registrants out of a population of over 500,000.

Methods

Since it began, the project has been monitored by means of quantitative and qualitative studies planned and developed by the author with other colleagues for the entire duration of the trial phase, as well as the first 2 years of operation (2008–2013). This article presents data related to four of these activities in particular: the assessment and monitoring actions carried out between December 2013 and February 2014.

Data was provided by means of:

1. A survey conducted with the CAWI (computer-assisted web interview) method to explore user satisfaction. Respondents are given a questionnaire to compile online which automatically produces the data matrix. The technical support was provided by the Department of Sociology and Social Research of Trento. The web interview addressed 6836 users registered with the system at the end of the first year of operation and who had accessed the system at least three times by 2013. Following the invitation by email, 4743 users (69%) viewed the web questionnaire. Among these, 4269 users (62%) completed the questionnaire (90% of those who clicked on the view link). Most of the questionnaires were completed in the first week after the email (59%, the first 2 days 44%). The subsequent reminders

sent at the beginning of the third and fourth weeks were able to collect an additional 39 per cent of online questionnaires (after the first reminder 1160 questionnaires, about 27%, were returned).

2. An analysis of approximately 500 email messages sent to the system's help desk by patients between January and December 2013 as a sample of the period as a whole. The emails were post-coded according to content and evaluated both quantitatively and qualitatively.
3. Ten semi-structured interviews with institutional and technical actors who were responsible for designing the system and putting it into operation. The interviews with institutional stakeholders and designers of the project explored the artefact's trajectory from the initial conception to entry into service. The goal was to acquire from various viewpoints a clear evolution of the vision and design of the system. The interviews, which lasted almost 1 h, were conducted in the actors' workplaces. They were all recorded and transcribed for analysis.
4. Ten detailed interviews carried out by selecting the 10 most frequent patients/users of the system. The interviews with the users explored the changes brought about by this new way to archive and use data after the system's introduction. The interviews concentrated especially on initial expectations with respect to the system, the degree of satisfaction at the time of the interview and interest in future developments. The interviews had an average duration of about 1 h and were all recorded and transcribed for analysis. The interviews took place in the homes of the interviewees.

The overall approach and the analyses that we carried out followed an open-type constructivist logic, as suggested by Holstein and Gubrium,[19] as well as a 'grounded' logic, since there are not many materials for the evaluation of institutional PHR systems in the literature.[4] Initially, the research data were analysed following typical procedures for each activity (quantitative or qualitative). They were then presented and discussed in a cross-wise and multi-method manner with the stakeholders responsible for the project. Moreover, the qualitative materials were analysed following approaches with special regard to the study of organizational practices. In particular, following the recommendations of Nicolini,[20] we tried to get closer to certain practices enacted by patients in relation to changes in the system. Our analysis also includes grounded theory labelling while reflecting on the part played by the researchers who contributed at each stage of the research. When a consistent pattern was recursively found in the texts transcribed, a label was established. Then going through all the transcribed material we merged coherent labels in knots and then subsequently tried to compare the analysis with further readings of the materials collected.

Findings

Thanks to the composite evaluation plan, it was possible to gain a variegated picture of how the system was regarded by its users. In what follows, we discuss some accounts concerning the four actions considered here: the CAWI survey, the emails sent to the system, the interviews with the institutional respondents and the interviews with the most frequent end-users.

A web survey to determine the users of the system

The survey allows us to compare the system population with the demographic and structural population. The data show a clear division of registrants by gender, and the fact that the white-collar middle class was over-represented, especially at the cost of the working class. This confirms that literacy and access to the system presuppose that the user has specific skills.[21–23] Finally, to explore different kinds of users, we used simple variables to divide the registrants on the basis of their access to healthcare facilities (28% for chronic problems, 30% for short-term problems and 40% for general check-ups). With regard to patient expectations associated with the infrastructure, it emerged that at the time of registration, approximately 8 out of 10 individuals registering with the system expected to receive precisely those functionalities that were actually available: that is, the direct visibility of the medical reports recorded in the healthcare service's computer system (79%). A further 18 per cent of registrants expected to have a historical record of their data available, while only 2.5 per cent expected to be able to communicate with medical personnel. Just 0.5 per cent of registrants believed at the time of registration that they would be able to send or enter self-measurements. These two latter expectations are the only ones, among those evaluated, which were not actually made available by the system.

Some key questions in the questionnaire may aid understanding as to the reason for the positive assessments of the system obtained by the survey. To the question 'Do you think that the system has been designed and constructed to fit the user', 87 per cent of respondents replied 'very or quite'. To the question 'Do the services provided meet your needs', 92 per cent of respondents replied 'very or quite'.

With regard to the overall evaluations offered by registrants on the system, there was confirmation that the infrastructure simplified their actions (94% very or quite in agreement) and was more advantageous than traditional channels such as telephone, fax and information counters (96% very or somewhat agree).

Help desk emails

A second evaluation action involved analysis of the content consisting around 500 emails sent by users to the help desk, which were sent to report difficulties regarding access to, and use of the system. The questions mainly fell into categories such as 'access problems' (20%), 'problems with viewing reports' (38%) and 'incorrect data problems' (14%), plus other minor categories. As often happens in these cases, the semantic coverage indicated by users did not always correspond to the category of problems treated in the text message. Around 10 per cent of the messages also expressed explicit appreciation of the system. Besides these communications, the emails comprised various dialogues that also included feedback as well as requests. There were emails harshly critical of the difficult access to the infrastructure, but there were also emails which created further opportunities to develop the relationship between citizens and the health system. The two excerpts that follow, despite reporting some difficulties in access, express a highly active, precise and interlocutory attitude by users:

> Unbelievable … One of the worst systems I've ever seen … 20 attempts to enter … every time the same story … For me, 'username' and 'password' would be enough … to hell with privacy … in my opinion you should give a choice … If someone wants to do a login like on all the websites in the world, more than smart!! And then the possibility of having the mobile service … on your mobile phone (smartphone) … Not to mention that before viewing a report you have to open 10 pages to be redirected … I do not see the point of all this complication … (E121)

> The urine tests performed at the private laboratory Alfa, completed on 1st February, are still not available online, even though the laboratory has confirmed the regular transmission of the report. This delay undermines the efficiency of the information procedure and creates considerable distress, considering the user's need for timely information. I await your reply. (E151)

Users also sent emails to the help desk to suggest various ways to change the system. For example, in the following excerpt, the user urges elimination of paper-based transmission because it is no longer useful, which actually occurred about a year later:

> Good morning, because I access the system online, I would ask you not to send the reports of my analyses by ordinary post. Best regards. (E250)

Moreover, some emails stated that the design, as conceived for patients, was incomplete and required further functionalities, as evidenced by the following extract:

> It would be appreciated if Print included the Labels and Notes entered by users. Thank you. (E471)

Governance witnesses

The 10 interviews with institutional respondents involved the project stakeholders who sat on the governance board. Among them, interviews were conducted with the director general of the health authority, the head of the regional administration, the head of the research centre, the managers of the information system of the health authority, some chief doctors at major hospitals and so on. The interview materials showed that the system was regarded principally as an experimental opportunity to develop a vision on the implications of a PHR model – which had not yet been integrated into the system of health services provided to citizens, and whose use by the entire population was not considered imminent. Even today, in 2016, in fact, healthcare practitioners are not significantly encouraging people to register on the system, and promotional campaigns have not been particularly incisive in regard to enrolments. However, institutional managers, who were aware of the innovations that the infrastructure entailed, also spoke of the system as one that needed to be developed precisely in order to simplify the lives of citizens/patients:

> The first time we considered this infrastructure project was in 2010, and my first impression was that it was a system for involving citizens, for handing them management of certain personal information that has always been very distant from them. Initially, the project was conceived for certain specific categories of individuals: educated and chronic patients, and those with particular needs. It is an extremely useful tool for empowering patients. At that time, most people were not aware of its potential. […] It was only later that we gradually understood its potential as a platform for gathering together many of the digital services offered by the healthcare system. It was the local government that imposed it on us. (Manager 1, Regional Health Service)

> What was my initial feeling when they presented the project to me? My wife comes [from a foreign country], and my first thought was that if something were to happen to me during one of my many trips to that country, with a system like this one, a hospital in this foreign country would be able to have access to my information … This is one of the reasons why I'm in favour of this infrastructure. (Manager 2, Regional Health Service)

These excerpts confirm the distance between the perception of citizens and that of the stakeholders within the regional health authority. The citizens made specific use of the service, and they understand its value in terms of simplification. In contrast, the managers did not seem greatly committed to supporting the process. This attitude had shifted the system's focus from the citizens' needs to those of the health authority, also in response to national directives on the subject of access to health data.

User interviews

The interviews with patients were conducted in order to determine their reasons for accessing the system and to understand the processes by which they adopted it. Of course, these patients were self-selected in view of their frequent use of the system, which often depended on continuous access to facilities – especially for cardiac problems or cancer. The interviews showed that the PHR service was not considered an ordinary health service, but a privileged channel of access to health services. It was a completely new service, which allowed a 'direct' encounter with the healthcare system and created new ways to relate with the organization. The rules of access and the services available regarding personal health data were compared unfavourably to the expectations people usually have when utilizing other common Internet services. The benchmark for its functionality was everyday experience with other online services. The citizens interviewed insisted on the novelty of this data reception channel, which had made their lives easier. Immediacy, browser-based access and the ease of immediately printing reports were the aspects most frequently cited by the patients interviewed. These interviews evidenced a new attitude from patients. Over time, the system had moved closer to patients' needs, and those in an intense relationship with the health services drew great benefit from it. This generated new practices of data access and use, freeing patients from the materiality of traditional documents and the need to constantly consult healthcare information desks.

For this reason, it is important to move closer to the citizens' practices of system use. It is difficult to identify those practices that have actually been strengthened by the system and foreseen in the design. However, it is appropriate to explore certain new practices generated by patients, as well as those issues discussed with the interviewer. We limit the zoom-in so as to identify the three most interesting practices.[20] These should aid understanding of why the system is gaining a growing amount of appreciation from the population, notwithstanding its limited potential.

Practices of representation of healthcare histories. With the infrastructure in place, the practice of representation of personal healthcare history also belongs to patients. For instance, during an interview at the home of a patient with heart disease, who lived in a remote valley in the region subject to this study, we discovered that a computer had become an official part of the environment, in the centre of the room, and in the middle of the table. The patient can easily show the interviewer his new analyses, which he can finally consult freely as soon as they are ready as if he were in a doctor's surgery, or even better, as if he 'were a doctor':

> I have never experienced any problems. My son installed everything and now I check my exams for my heart treatment. I print everything so I can keep them separately and for my check-ups with my cardiologist. In this way, I can do my tests here in town and receive reports from the hospital without having to go there any more to pick them up. At the hospital I go to for my consultations (which is outside the Region), I don't think they even know I do everything by myself. They don't have this service! I'm proud of it. Once, I was on holiday and I got all the information with me and the doctors were greatly surprised by it!! They said: 'At least one of the patients has all the exact information about his pathology!!' Look how good I am at using the system: two clicks and I'm in, and I keep everything under control! (Flavio)

Diagnosis becomes a patients' practice as well. After receiving some unusual results from a test, patients can immediately google the Internet, send their test results to their friends and colleagues for advice or directly to the specialist working with the patient on the various aspects of his or her illness:

> I'm one of the oldest users of the system. I've also given advice on how it could be improved and they listen to me. As a blood donor, I consult the system very frequently after each donation. The thing that really amazed me is the speed: having your exams immediately. For us donors, exams used to arrive in 4 to 5 days, but occasionally even after 10 to 12 days. Sometimes I go and see how my blood parameters are developing … but now I look at the system and my labels. It's really convenient! Even if the line isn't working I've saved all my tests! On one occasion, I had a problem with my prostate and I did the PSA exam, the 'total' one, and I saw it had gone up, so I got a prescription for more tests to see the 'free' PSA, and the day after I had the results and everything was OK! I look at my wife's tests in the same way! (Giovanni)

Although communication with doctors is not yet supported by the infrastructure, patients can autonomously communicate their health data to various interested parties in order to verify the data and possible effects. Patients become active, and because information is available to them at an earlier stage, they ask the health service to deal with it or seek further consultations.

Management practices of time and space. Our work on the interviews with those individuals who used the system more frequently illustrated a series of changes in practice, which chronic patients had put to use in order to comply with articulation work. In one particular case, for example, a cancer patient had his partner help him manage the infrastructure. This permitted a new method of interfacing with the cancer unit: for example, his partner was able to manage the tests freely without ethical issues arising, because under Italian law, she could not access the test herself because she was not a relative. The couple, who were in constant contact with a variety of specialists in other areas, forwarded the tests as soon as they received them so that the treatment to be followed could be verified. In addition, because chemotherapy can only be performed where a certain balance of blood components is present, the couple were able to manage every movement of the patient remotely and avoid having to travel to the hospital if the proper treatment conditions were not present. They could check them on their own without going to the hospital, and without consulting a doctor:

> It coincided with my husband being diagnosed with a tumour. I wanted to have his exams looked at by whom I wanted and how I wanted without always having to ask … partly because we weren't married at the time, which meant that as far as the hospital was concerned I couldn't access his medical records. They always gave me the laboratory analysis, but not CAT scans, MRIs and PETs. This system has simplified everything for me: I don't ask anyone for anything and I can see everything immediately, so I have more control over the situation. Previously, you needed a few days and we often went for chemo but had come back home because they discovered while we were there that his transaminase was high. When I'm waiting for exam results, I'll go into the system as much as 20 times a day! This is exactly what I expected when I heard about the system. It's also happened that at first, when I travelled outside the Region, I thought I would find the same technology, but it's not like that. On one occasion, we made a pointless trip because there was no wi-fi at the hospital and I wasn't able to show them the tests in our system! One time, we were going on holiday in the Marche and we stopped at a motorway restaurant so I could go onto internet and see the results of the tests without waiting for them and then leave again. (Maddalena)

Conversely, for the same reasons, the husband of a cancer patient asked for his wife's access to the infrastructure to be blocked because she was checking it so often in order to learn new 'signals' from tests, and she would often try to obtain new consultations and treatments with other specialists. This could destabilize the treatment already under way that in cancer therapies must be completed cycle by cycle to measure the results.

Discussion and conclusion: PHR to enact a co-actor

The infrastructure presented in this article enables us to see closely how patients, during the course of the project 'entering' the infrastructure, changed their role and practices in relation to the health data and health professionals. We saw how many changes were made by the system itself over the years, overall reducing the centrality of user needs. Despite this, the patients continued to use the infrastructure, by changing their practices, thanks to the new data provided by the system. We underlined the fact that the changes had developed in terms of three different directions: (1) new possibilities in looking at personal, clinical history; (2) new opportunities in dealing with the diagnostic phase; and (3) new relationships between time and space constraints.

As provided by many other researchers, we have observed severe limitations regarding technological design which involve patients.[4,7,24] And besides substantial problems of interoperability between databases, we confirm that a lack of interest persists on the part of patients in entering their personal data and doing so continuously.[21,22,24] Thanks to this system, patients enact what Gherardi[25] has called 'formativeness'. This means looking at 'how the object of practice is formed and how in its forming the necessary knowledgeability is invented and deployed' (p. 114). The system, in fact, allows a narrative driven by the patients' clinical history, which is usually extremely fragmented and dispersed. The infrastructure makes it visible on the basis of computerized design criteria. When a new clinical examination is carried out, patients no longer focus on only one examination, but have the immediate possibility to assemble this new set of clinical knowledge in a sequence that is assured by the filing methods used by the system. This represents an opportunity that was once only available to healthcare personnel.[26] Although the infrastructure is anchored to a design guided by the healthcare system, with its existence it 'liberates' patients, who invent new practices for managing a new state of independence, thereby becoming co-actors in the management of their diagnosis and treatment.[27,28] These practices confirm the need to safeguard the autonomy of patients, especially when the care activity is particularly intense. Patients with their local practices question the centre of gravity of treatment from hospital care[29] and thus free up new relationships and socio-material arenas.[30] This is possible through access to a greater amount of information, but also through the capacity to articulate it in time and space.[27,28,31] Every infrastructure, including the one examined in this case study, must support the situated knowledge of the subjects, and as suggested by Gherardi[10] and Orlikowski[17] it should permit dialogue with the everyday experience of the subjects.

This study confirms that patients, despite infrastructure design quality, when included in a health infrastructure, become proactive subjects and look at the way in which they face personal needs as both consumers and producers. Their personal clinical challenges are the main impetus to make PHR systems a success story.

We can say that good acceptance of the PHR infrastructure does not depend on the design in itself, but rather on the subjects' ability to identify new care practices through the functionalities made available to them through the system. When patients have access to their personal data, they can reconfigure their relationship with the healthcare system. This seems to be the main reason for the success of the system observed.

Declaration of Conflicting Interests

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Disparities in patient record completeness with respect to the health care utilization project

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Abstract
Patient data completeness is an important characteristic in maintaining accurate health records and providing the highest standard of care. Furthermore, finding discrepancies in care based on different subpopulation parameters is important to identify areas of underlying systemic issues in order to address concerns and alleviate those discrepancies. In this project, the investigators use the Data Completeness Analysis Package to find trends in patient record completeness using Healthcare Cost and Utilization Project's State Inpatient Database for the state of Florida, specifically focusing on finding discrepancies among subpopulations along the variables of age, race, and gender. The results from testing Data Completeness Analysis Package with State Inpatient Database show a variety of patterns that provides insights to the health care delivery in Florida.

Keywords
data completeness, Data Completeness Analysis Package, subpopulation

Introduction

An important area of focus in current health care research involves understanding disparities in care and figuring out how to solve them. These disparities manifest themselves in various forms ranging from provider bias to the actual care or treatment provided.[1] Disparities occur across various subpopulation axes such as race, ethnicity, socioeconomic status,[2] and primary language,[3] insurance status,[4] age,[5] and gender.[6] Furthermore, while the issue of health care disparity is extensively documented, there are still limitations in disparity identification and actually addressing the underlying issues.[7]

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While the problem of health care disparity has been analyzed from a perspective of treatment provided and qualitative analysis of care, this article seeks to integrate the issue of disparity with a quantitative analysis of electronic health care records. As electronic health care records grow in usage and importance,[8] it is important to ensure the completeness and validity of patient data. Contextualizing this issue within health care disparity, the following question is raised: "*Are certain patient subpopulation's health care records more vulnerable to incompleteness or inaccuracy?*"

Based on this overarching question, this article investigates subpopulation record keeping vulnerability based on age, gender, and race. First, a null hypothesis that all subpopulations are equal in their vulnerability in record completeness is established to base analysis from. The Data Completeness Analysis Package (DCAP) is used on patient data from the Healthcare Cost and Utilization Project (HCUP).[9]

Disparities in health care have been well documented. For example, the Department of Health and Human Services (DHHS) has found overwhelming evidence of health care disparity in minority groups, including disparities in care for cancer, cardiac disease, AIDS, asthma, and other illnesses.[10] Research further shows that "racial and ethnic disparities in health care exist even when insurance status, income, age, and severity of conditions are comparable."[1] There is also evidence in health care decision-making at multiple levels of bias against individuals based on age,[5] creating health care disparity for the elderly. From a gender perspective, differences in health care expenditures and resource utilization lead to better quality of care among females.[11]

While the identification of health care disparities can often be objectively displayed, the underlying sources for these disparities are harder to identify.[7] For example, a physician's assumption of literacy among patients disproportionately impacts minority patients, becoming a factor leading to disparity in care.[12] Research also points to social sources outside of interactions within the health care provider environment (such as neighborhood pressures, socioeconomic circumstances, education, segregation, impact on income, violence, and impact of segregation) contributing to real disparities in health care provided to minorities.[13] These factors, often embedded and persistent historically, complicate the ability to determine tangible sources of disparities, ability to measure these sources' effects, and ability to create effective solutions to these sources of disparities.[13] Within the provider context, "barriers in the patient–physician relationship contribute to racial disparities in the experience of health care."[14] Furthermore, prejudice, clinical uncertainty (e.g. different interpretations of symptoms from minority patients), and stereotyping contribute as sources of health care disparity within the medical environment.[15]

After identifying health care disparities and the underlying sources, efforts must be undertaken to solve them but may however come with limitations. Fiscella et al.[7] argue that

> … disparities represent a significant quality problem; current data collection efforts are inadequate to identify and address disparities; clinical performance measures should be stratified by race/ethnicity and socioeconomic position for public reporting; population-wide monitoring should incorporate adjustment for race/ethnicity and socioeconomic position; and strategies to adjust payment for race/ethnicity and socioeconomic position should be considered to reflect the known effects of both on morbidity.

From a racial/ethnic health care disparity perspective, the framework of cultural competence has been described and expanded upon as a solution to address disparities that are anticipated to increase with changes in demographics.[16] Research has also found that access to insurance and its corresponding coverage can explain a sizable proportion of health care disparities.[17]

In terms of research on electronic health records, there does exist work and literature on the topics of data completeness and accuracy. Majeed et al.[18] investigate this issue and note sources of

Table 1. Summary of various scores produced By DCAP used for subpopulation analysis.

Metric	Description	Example
Record Strength Score (RSS)	Evaluates the completeness of an individual patient's record as a weighted average using Importance Weights	Mrs Jane Goodman's record has a 80% RSS score
Patient Database Score (PDS)	Evaluates the strength of the entire patient record database at a health care center by averaging RSS scores	AAA Medical Center's PDS Score is 50%
Patient Subgroup Score (PSS)	Evaluates the strength of the patient records of a specific population of the patients seen by the health care center by averaging RSS scores for patients that meet the subpopulation criteria	The PSS Score of female patients over the age of 70 is 92%

errors in completeness and accuracy in patient records, as well as problems in obtaining patient data quality. Some of these issues are addressed in subsequent research which undertakes additional literature review and focuses on providing a generic framework of procedures to improve data quality, including "(a) the prevention of insufficient data quality, (b) the detection of imperfect data and their causes, and (c) actions to be taken/corrections."[19] Prior research in finding disparities in health care record keeping is sparser. One study has found that certain races are at disparity in care based on patient self-usage of Personal Health Records (PHR).[20]

The research discussed previously (especially projects concerning patient data analysis) contributed in developing the DCAP research project.[9] That research developed both the software needed to analyze the data and a framework through which to understand results. DCAP examines native patient data with a master map indicating Importance Weights (IWs—indicates the relative importance of a specific data field's completeness versus other data fields on a scale from 0 to 100). DCAP bases program files in comma-separated values (CSV) and based on the master map, IWs, and patient data outputs the results. The Record Strength Score (RSS) measures the completeness of an individual patient's record as a weighted average using the IWs provided. The Patient Database Score (PDS) measures the strength of the entire patient record database at a health care center by averaging RSS scores. The Patient Subgroup Score (PSS) measures the strength of the patient records of a specific population of the patients seen by the health care center by averaging RSS scores for patients that meet the subpopulation criteria. Table 1 provides a brief summary of the metrics used within the DCAP framework of understanding and comparing record completeness.

The research paper was developed with the following objectives:

1. Use an existing tool, the DCAP, to find trends in patient record completeness using HCUP's State Inpatient Database (SID) for the state of Florida from 2004 to 2012.
2. Analyze the patient data completeness from a subpopulation perspective, aiming to find statistically significant and practically meaningful differences in data completeness along the axes of age, race, and gender.
3. Further the development of DCAP by creating a subpopulation network that can handle completeness data analysis for complex, layered subpopulations.

Methods

This article focuses on analyzing HCUP[21] data, specifically the SID[22] with data from Florida from 2004 to 2012. Since the database contains millions of patient records within any given year, the data were sampled for 100,000 records per year to run into DCAP. In setting the IWs, it should be noted that many fields were used to handle excess information (e.g. there are 31 fields for up to 31 diagnoses, but having a blank in those fields was not actually resultant of missing information and thus IWs were adjusted to 0). Otherwise, IWs were set first to Importance Weight Balanced (leading to IWB results) and then based on general view of importance (Importance Weight Unbalanced (IWUB)). These "unbalanced" weights are discussed further in the "Discussion" section. Due to the large number of data variables contained in the HCUP data, the IWs for both balanced and unbalanced results are included in the online Appendix. Furthermore, the results from the IWUB analysis are also included in the online Appendix, with the main results focusing on IWB analysis. Deviations in results between IWB and IWUB analyses, however, are highlighted.

In order to analyze meaningful information within the data, some baseline statistical assumptions had to be made. The analysis assumes the normality of RSS within the database population in each year. Based on this assumption and the 100,000 patient record sample size, it is further assumed that the samples tested in DCAP should produce a normal distribution of RSS with both balanced and unbalanced IWs (an assumption which is tested in the results section). Furthermore, the subsequent subpopulation analysis should also follow a normal distribution given the relatively large sample sizes. The sample data were also obtained randomly from within the larger HCUP SID for each year.

This combination of normality, sample size (in both the sample database and within subpopulations), and variables allows us to determine[23] the use of both one-sided analysis of variance (ANOVA) testing[24] using F statistics[24] and then further t-test-based statistical analysis to determine discrepancies in patient data completeness among subpopulations and among different years.[25,26] The ANOVA testing is covered in the online Appendix and provides the foundation for conducting two sample t-tests (results are provided in the online Appendix) that are discussed in further sections. The ANOVA tests are used to determine whether a statistically significant deviation exists within subgroup data, and then t-test-based analysis is used to delve into determining trends.

In terms of subpopulations, this article focuses on age, race, and gender. For age, five different age "baskets" are used. Gender is divided between male and female (as reported within the HCUP SID data). Race is divided based on the defined groups in the HCUP SID database. Given these subpopulations and having datasets for different years, the following null and alternative hypotheses were constructed:

H_{01}: PDS and PSS overall and by subgroup stay consistent over time

$$\mathrm{PDS}_{\mathrm{YEARX}} - \mathrm{PDS}_{\mathrm{YEARY}} = 0 \tag{1}$$

$$\mathrm{PSS}_{\mathrm{GROUPAYEARX}} - \mathrm{PSS}_{\mathrm{GROUPAYEARY}} = 0 \tag{2}$$

H_{A1}: PDS and PSS scores do not stay consistent over time

$$\mathrm{PDS}_{\mathrm{YEARX}} - \mathrm{PDS}_{\mathrm{YEARY}} \neq 0 \tag{3}$$

$$\mathrm{PSS}_{\mathrm{GROUPAYEARX}} - \mathrm{PSS}_{\mathrm{GROUPAYEARY}} \neq 0 \tag{4}$$

H_{02}: PDS and PSS scores stay consistent between different subgroups/between subgroups and the sample database average

$$\mathrm{PDS}_{\mathrm{YEARX}} - \mathrm{PSS}_{\mathrm{GROUPAYEARX}} = 0 \tag{5}$$

$$\mathrm{PDS}_{\mathrm{YEARX}} - \mathrm{PSS}_{\mathrm{GROUPAYEARX}} = 0 \tag{6}$$

H_{A2}: PDS and PSS scores do not stay consistent between different subgroups/between subgroups and the sample database

$$\mathrm{PDS}_{\mathrm{YEARX}} - \mathrm{PSS}_{\mathrm{GROUPAYEARX}} \neq 0 \tag{7}$$

$$\mathrm{PSS}_{\mathrm{GROUPAYEARX}} - \mathrm{PSS}_{\mathrm{GROUPBYEARX}} \neq 0 \tag{8}$$

Alongside this analysis of sample HCUP SID data, this article also seeks to improve DCAP by creating a function through which the user can examine more complex, layered subpopulations, such as Race Black Males Ages 20–40.

Results

Study sample

To ensure the data were being properly analyzed through t-tests, normality of RSS scores needed to be confirmed. Figure 1 shows the distribution of RSS scores in each sample database for each year for IWB RSS. While there is movement in the probability mass function between years, each year confirms normally distributed sample data. This distribution along with random selection allowed for statistical hypothesis testing through the two-sample t-test.

Noticing the movement of the mean between different years within IWB RSS data, the next step involved analysis of the database mean and standard deviation.

For IWB and IWUB data, Figure 2 shows the PDS for each year with standard deviation error bars for context. From a simple visual analysis, one can note significant movement in PDS in each year with a general decline from 2004 to 2012. The standard deviation error bars show that a roughly 4-point movement in RSS is within one standard deviation of the sample population in any given year. The IWUB dataset highlights a similar pattern, albeit at a lower PDS score (with the average fluctuation in PDS at around 2 points). This difference between IWB PDS and IWUB PDS is discussed further in the "Discussion" section. Also of relative interest was the spike in standard deviation that coincided with the drop in PDS, specifically in 2007, for both IWB and IWUB. Upon further correlation analysis, however, this relationship proved tenuous at best (at the database level, the correlation between PDS and PDS standard deviation was 0.47 for both IWB 0.42 for IWUB).

In order to determine the statistical significance of the difference between two data years, two sample t-tests needed to be analyzed in reference to the first null hypothesis and its corresponding alternative hypothesis. Based on these hypotheses, the two-sided t-test was conducted (the results for all t-tests are included in the online Appendix). For both IWB PDS and IWUB PDS, it is immediately clear that virtually all movements in PDS are statistically significant. For example, for a 1 year lag from each year, every year from IWB and almost every year from IWUB (except 2011–2012) show significance at the alpha = 0.01 level. Furthermore, both IWB and IWUB show statistical significance over the course of the samples from 2004 to 2012 (2004 with 8 year lagged comparative sample). These two sample t-tests provide ample evidence in favor for the alternative hypothesis in that there is statistically significant difference in PDS between different years of the database sample. However, this statistically significant difference may not be practically significant, a matter further discussed in the "Discussion" section.

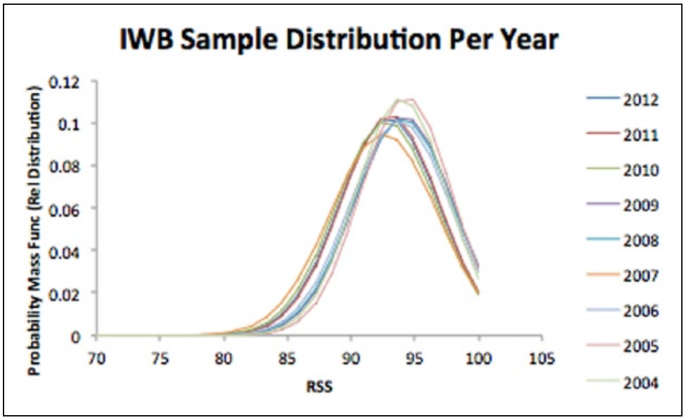

Figure 1. IWB RSS score distribution for each year.

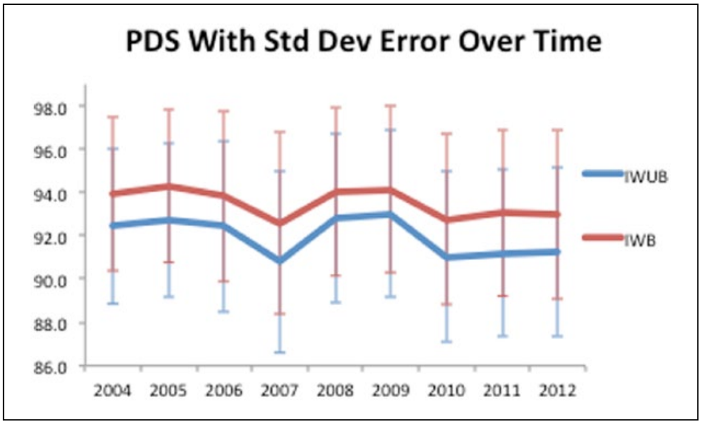

Figure 2. PDS with one standard deviation error over time for IWB and IWUB.

Sample subpopulation analysis—foundation

In terms of confirmation of normality within subpopulations, since the sample size of each subpopulation was sufficiently large and the database from which the subpopulations were drawn from were shown to be normally distributed, it could be reasonably assumed that the subpopulation data were also normally distributed. This distribution along with random selection allowed for statistical hypothesis testing through the two-sample t-test. It is also important to note that the relative sizes of the subpopulation studies (along the axes of age, race, and gender) remained stable and showed little to no shift between different years.

Sample subpopulation analysis—age

Having established the conditions for normality, randomness, and consistency in subpopulation sample size, the analysis continued onto comparing different subpopulations with the database and their direct comparatives. Figure 3 shows PSS for different age subpopulations based on the IWB

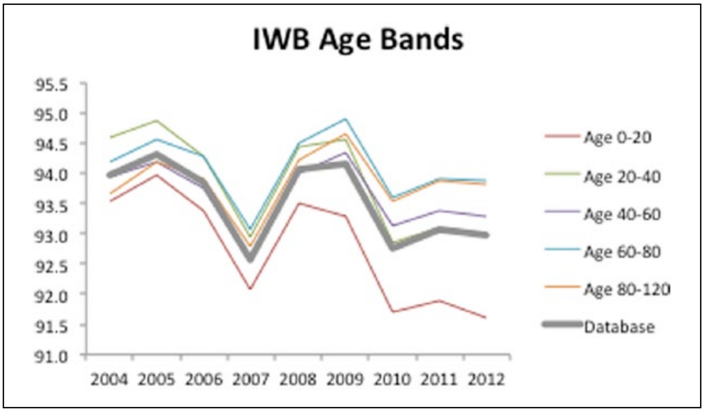

Figure 3. IWB PSS per year based on age subgroups.

dataset. Upon visual inspection, it is clear that the age 0–20 subgroup tails significantly lower from the database and other age subgroups, consistently at the bottom of PSS scores. At the top, the age 20–40 subgroup starts with the highest PSS score but exchanges position with age 60–80 after 2008. From a standard deviation perspective, ages 40–60 have a much larger PSS standard deviation than the database and other subgroups. All other age subgroup standard deviations fall below the database standard deviation. This analysis was repeated for the IWUB dataset, showing a similar trend as pointed out in the IWB analysis. One important distinction to note, however, is that in comparing standard deviations, IWUB shows the age 0–20 subgroup having the largest standard deviation among subgroups.

Upon analyzing two sample t-test results, it is clear that the same pattern of statistical significance exists year to year as it did for the sample database (namely, that virtually every year PSS movement is statistically significant). In terms of significance in difference between the sample database, the only group to not show it in every year was the age 40–60 basket. Analyzing the magnitude of t-scores, however, it becomes clear that the age 0–20 subgroup has a significant difference in PSS in a negative way and the age 60–80 subgroup has a positive significant difference in PSS. The two sampled t-tests support the alternate hypothesis in both comparisons over time for the different age categories and between the different age categories, most notably in terms of a lower PSS for age 0–20 and a higher PSS for age 60–80.

Sample subpopulation analysis—gender

Figure 4 shows the gender data for IWB for PSS. In both cases (IWB and IWUB), there is minimal difference in RSS between genders, with the female subgroup having the slight edge. The two sample t-tests confirm the same result over time as shown in the sample database test, but show little to no significance in comparison between the two genders. This allows us to accept the first alternate hypothesis and the second null hypothesis with regard to gender.

Sample subpopulation analysis—race

Figure 5 shows the race PSS data from the IWB dataset. In terms of major trends, the White subpopulation is consistently above the sample database and all other race subgroups. Conversely, all

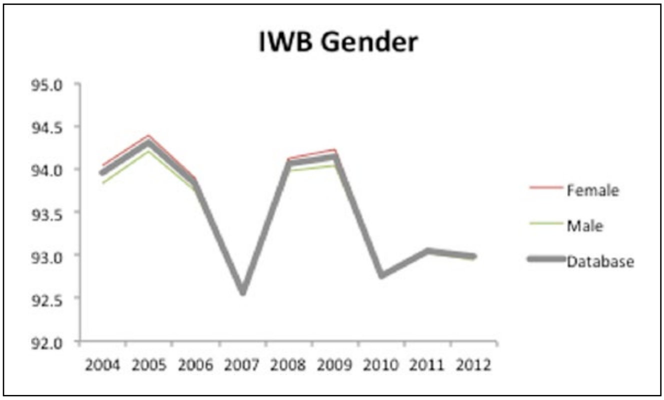

Figure 4. IWB PSS per year based on gender subgroups.

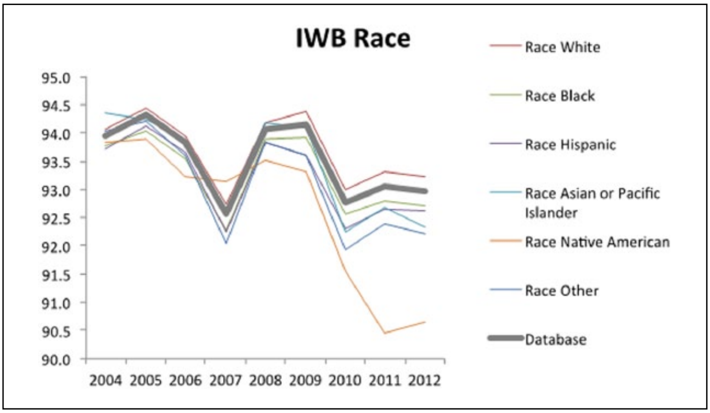

Figure 5. IWB PSS per year based on race subgroups.

other race subpopulations fall below the sample database trend, with the Native American subgroup falling significantly below the other subpopulations. In terms of standard deviation, Native Americans and the Other subgroup have higher standard deviations, while the White subgroup and the Asian/Pacific Islander subgroup have lower standard deviations. These trends are mirrored in the IWUB dataset. From the two sample t-tests, the same trend over time is noted as is seen in the other subgroup and sample database analysis. Comparing different subpopulations, however, the t-tests show statistically significant difference between the White subgroup and other subgroups/the sample database, indicating sustained positive PSS within that group. The two-sided t-test also shows negative significant difference among the Black and Hispanic subgroups, and in recent years (2010–2012) negative difference in Asian/Pacific Islander, Native American, and Other. These results are also supported in the IWUB two-sided t-test.

Sample subpopulation analysis—correlation analysis

Along with the descriptive analysis and t-test analysis, correlation analysis was used to see the strength of relationship among different elements. Table 2 shows these correlation analyses for

Table 2. IWB correlation analysis.

IWB PSS values		IWB PSS SD		IWB RSS vs SD	
Series	R^2 w/PDS	Series	R^2 w/PDS SD	Series	R^2 w/in each
Age 0–20	0.89	Age 0–20	0.88	Age 0–20	0.18
Age 20–40	0.97	Age 20–40	0.24	Age 20–40	0.02
Age 40–60	0.92	Age 40–60	0.49	Age 40–60	0.14
Age 60–80	0.86	Age 60–80	0.68	Age 60–80	0.33
Age 80–120	0.61	Age 80–120	0.82	Age 80–120	0.47
Female	1.00	Female	0.98	Female	0.56
Male	1.00	Male	0.98	Male	0.37
Race White	0.99	Race White	0.99	Race White	0.51
Race Black	1.00	Race Black	0.90	Race Black	0.28
Race Hispanic	0.98	Race Hispanic	0.94	Race Hispanic	0.27
Race Asian or Pacific Islander	0.90	Race Asian or Pacific Islander	0.48	Race Asian or Pacific Islander	0.56
Race Native American	0.47	Race Native American	0.19	Race Native American	0.34
Race Other	0.95	Race Other	0.67	Race Other	0.51
				Database	0.47

IWB. The first column, tracking the movement of subpopulation PSS trend with the sample database PDS, shows significant strength in correlation, indicating a relationship with the trend of the database to the trend of various subpopulations (with notable exceptions being the Native American subgroup and the ages 80–120 subgroup). The second column shows correlation in standard deviation between the subgroups and the sample database. While about half of subgroups have a strong correlation in this category, the other half shows moderate to weak correlation. The third column shows the correlation within each subgroup/sample database between the score trend and the standard deviation trend, showing little to no correlation.

DCAP complex subpopulation function and decision tree analysis

Alongside analyzing the sample database and subpopulation data, this article aimed to enhance DCAP by adding a facility to analyze more complex, tiered subpopulations. Previously, one could find completeness data for a certain age group or a certain race independently, but could not combine the groups into a smaller subset. Figure 6 shows a sample complex subpopulation tree created from the results of this new DCAP facility. Note that due to the number of total possible complex subpopulations in this three-tiered dataset (age, gender, and race totaling 72 different complex subpopulations), the figure shown is abridged and traced to a sample complex subpopulation of interest (specifically analyzing Hispanic females ages 40–60 from 2008 IWB data). The different branches of this subpopulation tree, however, show the statistics that can be used to compare different complex subpopulations or complex subpopulations to larger, less complex populations.

Having this facility allows for the use of decision trees in conducting complex subpopulation analysis. This can help determine important trends of interest that occur in subpopulations bound by multiple constraints but may not be obvious when comparing between subpopulations bound by one variable. Note that the facility can handle complex requests in any order, and of any subpopulation parameter (both text bound and numerically bound). This facility also allows for organization

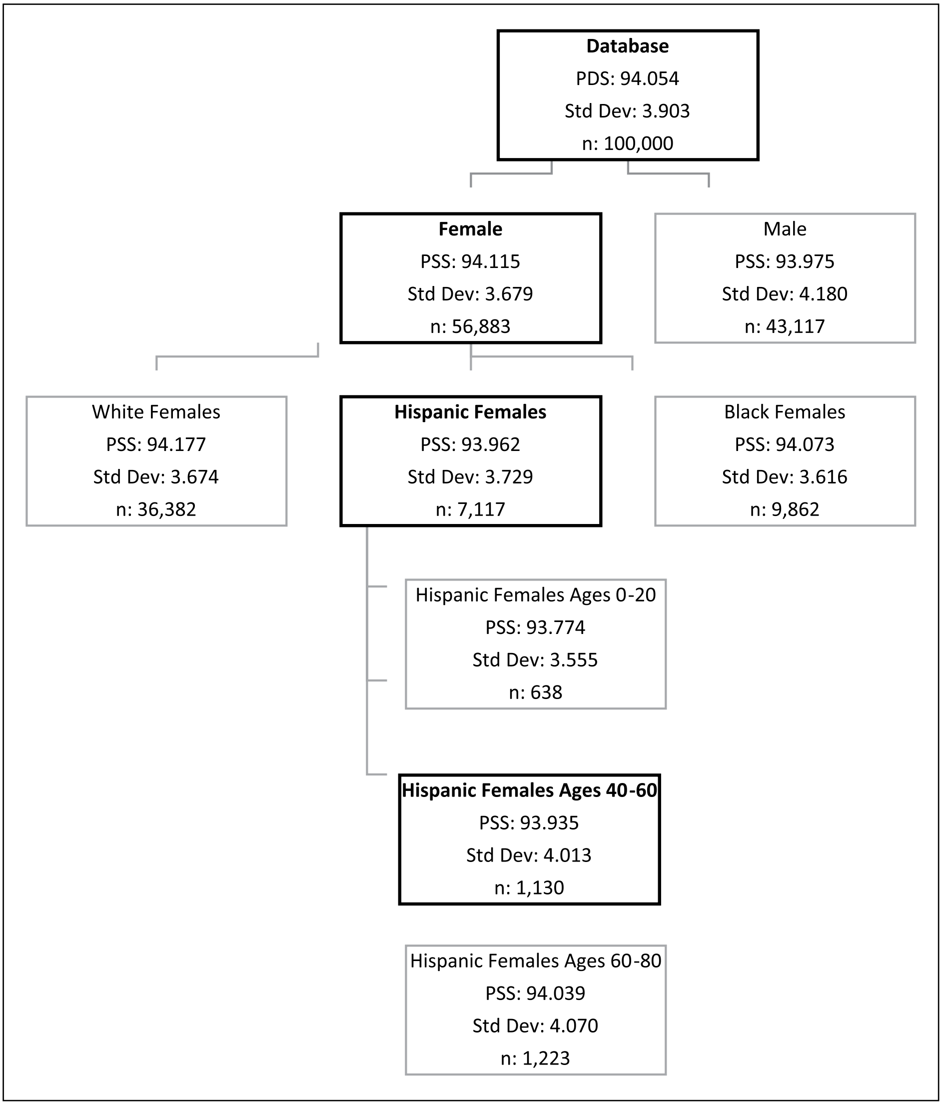

Figure 6. Example of complex subpopulation facility analyzing Hispanic females ages 40–60 from HCUP SID Florida 2008, IWB data.

and integration of data to be used by more complex analytical tools, such as DTREG,[27] that can use this data to build accurate predictive models that can help better uncover important underlying issues in data completeness.

To develop a basic framework for this complex subpopulation analysis, Figure 7 shows PSS over time for the database (highlighted in black) and all complex subgroups over time for the IWB dataset (with IWUB data covered in the online Appendix). As seen in the graph, most complex subgroups cluster around the database, both in absolute PSS score per year and the trend over time. However, there are some complex subgroups that deviate significantly. In preliminary analysis, it appears that Native American Males and Females Ages 40–60, Asian/Pacific Islander Males and

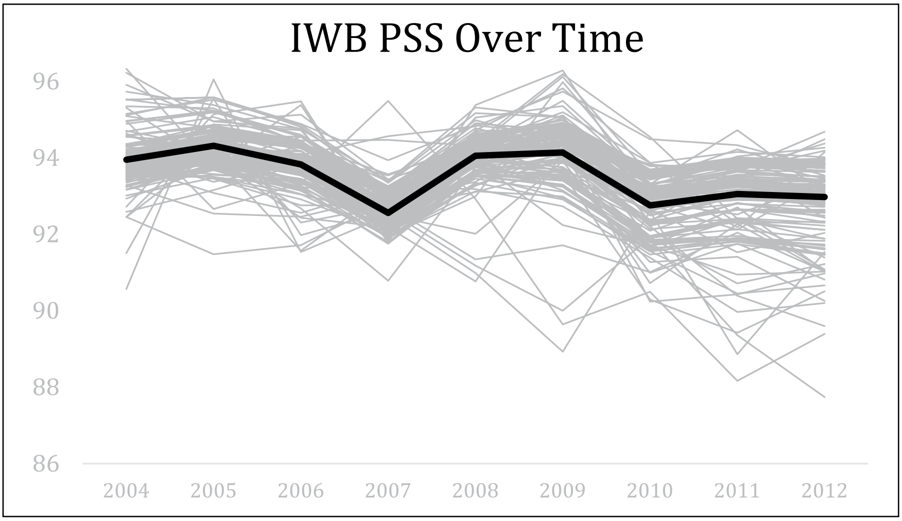

Figure 7. IWB PSS per year based on all complex subgroups (database highlighted in black).

Females Ages 0–20, and Black Males Ages 0–20 deviate most significantly below database average in their PSS values (calculated as average difference between the complex subgroup PSS and the database over time), indicating that these complex subpopulations are at high risk for having incomplete data. Asian/Pacific Islander Males Ages 60–80 and White Males and Females Ages 0–20 are among the groups that deviate most significantly above the database values, indicating more completeness among those complex subgroups.

However, one important facet of using complex subpopulation analysis is to see what happens when the different subgroup categories interact. For example, if one subgroup category trends above the database over time and another category trends below, where does the complex subgroup that belongs to both of these subgroups have RSS values relative to the database? To illustrate this analysis, we use Figure 8 to examine Black Males Ages 20–40, comparing them over time to the database, Black patients, patients ages 20–40, and Black patients ages 20–40 of both genders. This graph shows that over time, patients ages 20–40 tend to be above the database value for completeness. However, Black patients tend to be below the database, as well as Black Males Ages 20–40 who trend even further below. To confirm this analysis, Table 3 shows a comparison of correlation values between the complex subgroup (Black Males Ages 20–40) and the respective subgroups it belongs to. Based on the graph and correlations, it appears that this complex subgroup aligns more with its Race subgroup and less with its Age subgroup. It also shows strong correlation between genders within the subgroup of Black Males and Females Ages 20–40, indicating gender has a relatively negligible impact in this complex subgroup analysis as well. This analysis is important since examining age in this case alone may have ignored the systemic underlying issue within this subgroup that trends consistently below other members of its age subgroup, as well as the database as a whole.

This complex subgroup analysis is vital to better understanding trends and underlying issues regarding health care data management for different patient populations. Further rigorous analysis and testing (such as inferential statistical testing, regression analysis, and other modes of analysis) is also required to better understand the role of subgroup interactions as it relates to data completeness in complex subgroups. Given the depth of this complex research and the

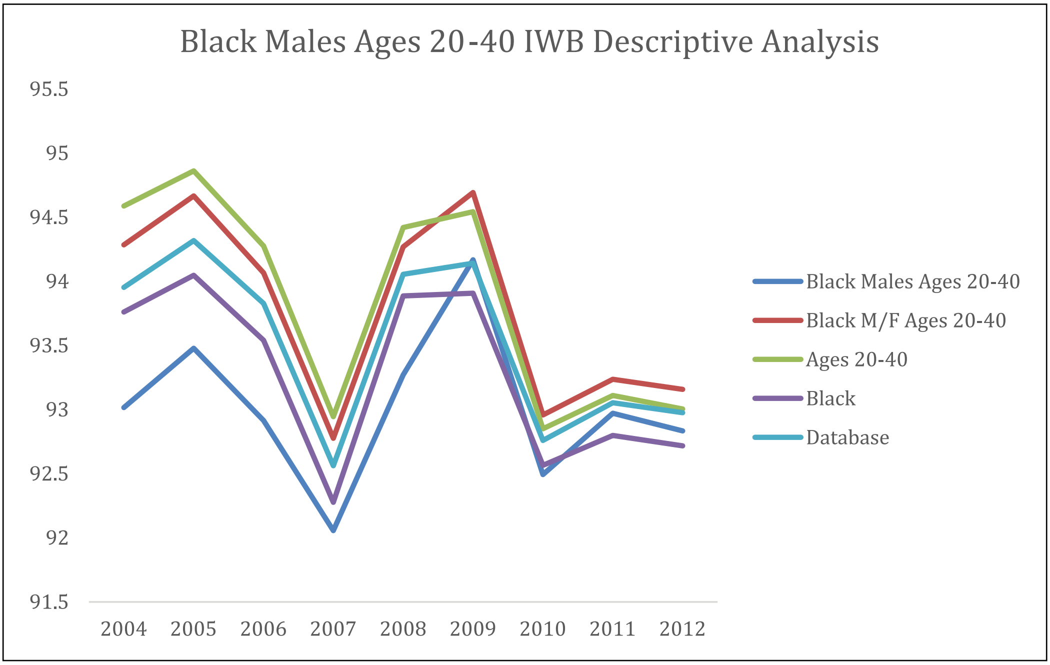

Figure 8. Black Males Ages 20–40 IWB descriptive analysis showing PSS scores over time for related subgroups.

Table 3. Black Males Ages 20–40 correlation analysis correlating the complex subgroup to its related groups.

Subgroup	Correlation with Black Males Ages 20–40
Race: Black, Ages 20–40	0.86
Ages 20–40	0.73
Race: Black	0.82
Database	0.82

analysis required, this analysis is left as an area for further research and discussed in the corresponding section.

Results summary

Based on the analysis detailed in the previous section, the following results can be summarized:

- The sample database has statistically significant movement in PDS between years, causing the rejection of the first null hypothesis.
- There is a statistically significant gap between IWB (higher) and IWUB (lower) completeness scores (among the sample database and different subpopulations)
- The age 0–20 subgroup is statistically significantly below the rest of the sample database and other age-based subpopulations while the age 60–80 subgroup is higher. Each of these specific subgroups rejects the second null hypothesis.

- There is negligible difference between the gender-based subgroups, allowing for the acceptance of the second null hypothesis for gender.
- The White race subgroup is statistically significantly above the rest of the sample database and other race-based subpopulations, while the Black, Hispanic, and Native American race-based subgroups are significantly below. Each of these specific subgroups rejects the second null hypothesis.
- There is a strong correlation between subpopulation PSS over time and sample database PDS over time with the exception of the Native American race-based subgroup and the age 80–120 subgroup.
- There is moderate correlation between different subgroup scores' standard deviations with the standard deviation of the sample database score each year, and little to no correlation between a subgroup/sample database score and standard deviation.

Discussion

Limitations

During the course of this article, various important limitations were encountered that we hope can be addressed in subsequent work on the topic of health care record strength and subpopulation analysis.

One important limitation of DCAP is its ability to only monitor patient record completeness and not veracity. While determining completeness within patient data is important, being able to verify that the data are accurate is an important step forward in building stronger patient data systems. Having the capacity to find erroneous data can help correct possible errors in data collection and can improve the health care provided to patients.

Another important limitation is the difficulty in ascertaining "live" data in practicing health care settings. Obtaining data from health care service centers and putting it into a uniform file across various database software packages is a difficult task with various obstacles. The willingness of health care service centers is vital, with patient–doctor confidentiality and Health Insurance Portability and Accountability Act (HIPAA) regulations limiting access to data. Limitations of staff at health centers also create difficulty in excising data (since very few private practices have on-site data technicians able to export fully de-identified and HIPAA compliant data). It should also be noted that even when data are obtained, such as the HCUP data, there are still some degree of manual data handling to make it compatible for use with DCAP (ex. correct file format, understanding what an incomplete variable means per data element, etc.).

The use of statistical methods also implies limitations in the analysis of results. For example, the use of the two-paired t-tests, even under the proper conditions as specified in the assumptions needed for the analysis, carries inherent error. There is also an important distinction between statistically significant results and practically significant results that can only be analyzed through further work.

Areas of further exploration

These limitations discussed above lead in to areas of further exploration that subsequent research might delve to learn more about. For example,

- Further work should focus on clarifying differences between statistically significant differences in RSS scores and practically significant differences. One way this can be accomplished is through analysis of linking RSS scores to discrete health care outcomes, such as length of care and diagnoses codes.

- While this research paper focused on HCUP SID data for Florida from 2004 to 2012, the data can be widened to other states and can also benefit greatly from other data sources, especially from practicing health centers.
- The IWUB analysis provided in this research was cursory in order to show how imbalance in data fields can affect results. For more meaningful information, however, further work should consider developing a framework from the proper authorities that can determine numerical weights to common medical database data fields.
- While this article added a complex subpopulation facility to DCAP and discusses preliminary work briefly, future work can focus on analyzing complex subpopulations to uncover trends in completeness. There are important trends to be uncovered among comparisons between complex subpopulations that belong to multiple subgroups in terms of age, gender, race, and other variables. Finding these trends and analyzing specific discrepancies can be useful for a variety of research inquiries and can use techniques such as predictor tree analysis (such as DTREG[27]), inferential statistics, and regression analysis to account for the complex nature of the subpopulations.
- Currently, DCAP uses CSV files and has limited parameters for input data. Future work can focus on expanding the capabilities of DCAP to handle a variety of data formats. Furthermore, DCAP can also be restructured to handle larger datasets and eliminate the need for sampling.
- Future work should also focus on integrating veracity capabilities to DCAP. For example, the issue of automated veracity could be investigated through common data heuristics, through communication with a central database as a cross reference, or by tracking data in records to specific sources that can be checked against. Special attention needs to be paid to free-text data variables and the statistical measurement of veracity as opposed to completeness.
- Focusing on solutions involving using new software packages and database standards that integrate lessons learned in maintaining complete and accurate data.[28] This includes topics such as data entry control, use of contextual information, incentive alignment, user requirement analysis, measurement of improvement, data entry checks, enhanced data analysis, and creating strong networks among disparate databases to cross-check information.

Conclusion

The core contributions of this article are as follows:

- Uncovering of trends in data completeness within HCUP SID data for the state of Florida from 2004 to 2012, with special focus with regard to subpopulations based on age, gender, and race.
- The development of a complex subpopulation facility within DCAP to analyze layered subgroups and provide a platform for future analysis.
- The foundation for future work that can focus on a variety of areas within patient data integrity and determination of subpopulation vulnerabilities through suggestions such as automated veracity, linking RSS scores to discrete health outcomes, and expansion of DCAP (in both its data handling and data analysis).

In terms of hypothesis testing, the following conclusions were reached:

- The first null hypothesis (H_{01}: PDS and PSS overall and by subgroup stay consistent over time) was rejected since there was statistically significant difference in completeness over time.

- The second null hypothesis (H_{02}: PDS and PSS scores stay consistent between different subgroups/between subgroups and the sample database average) was rejected in certain instances and accepted in others based on the subgroups compared.
- More details regarding the testing of these hypotheses can be found in the "Results" section.

Based on the original objectives mentioned in the "Introduction" section, this research paper has proved successful in analyzing the HCUP SID data to uncover trends at both the database and subpopulation level, as well as added to DCAP through creation of the complex subpopulation facility. While limitations such as determining data veracity and analysis of results within a practical framework exist, the foundation for future work has been built. Overall, this article provides a step forward in uncovering patient data vulnerabilities, especially along subpopulation lines, and provides promising areas for future research.[29–32]

Clinical relevance statement

The use of DCAP to evaluate the HCUP SID data in terms of variance between subgroups is important clinically in order to determine areas of incomplete information and finding asymmetries that can be attributed due to disparities in delivery of care. Current systems in place do not address the collection and maintenance of health care data with regard to identifying underlying disparities among various subpopulations, such as those based on age, gender, and race. The use of DCAP with an objective of highlighting disparities in care helps provide a useful foundation of evidence upon which further exploration could be done to identify and correct the underlying systemic issues that can alleviate these disparities.

Involvement of human subjects

The investigators have conducted the experiment after getting appropriate approval from the Institutional Review Board (IRB) of the institution (IRB Exempt). Therefore, all the required ethics and standards have been followed.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Effects of context-aware patient guidance on blood pressure self-measurement adherence levels

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Abstract

Hypertensive disease and preeclampsia are serious medical disorders affecting pregnancy. Screening in early pregnancy may identify women at risk of developing hypertensive disease and enable prophylactic treatment. Accurate blood pressure measurement is an important part of this screening. The aim of this study was to investigate whether patients, with the aid of a context-aware sensor-based blood pressure self-measurement system, were able to correctly self-measure their blood pressure adhering to internationally established recommendations. Furthermore, to evaluate patient acceptance levels of performing self-measurements using context-aware adherence aids for guidance. A total of 100 pregnant women attending a routine ultrasound, at gestational week 12, at the outpatient clinic of the Department of Obstetrics and Gynecology, Aarhus University Hospital, were recruited in the waiting room before the scheduled scan. Blood pressure self-measurement was performed using a blood pressure self-measurement system called ValidAid consisting of a clinically approved blood pressure device, a sensor chair registering rest-time, back-supported, legs-crossed, and ambient noise levels respectively recording participant compliance, as well as a touch screen–based computer application with an interactive user

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interface for patient guidance and feedback, as well as a built-in decision support system. Acceptance of the automated self-measurement was evaluated by a questionnaire. In all, 99 percent followed the instructions with regard to both rest time and not talking. For both of these, ValidAid offered interactive and context-aware guidance. The recommendation of keeping legs uncrossed was only adhered to in 69 percent of measurements and back supported in 35 percent of measurements. For both of these, no interactive guidance was provided. The majority of the participants, 93 percent, felt comfortable using self-measurement equipment, while a minority of 8 percent would have preferred personnel-assisted measurements. The majority of participants were able to take reliable blood pressure self-measurements. Results indicate that recommendations that were not actively enforced were not followed to the same extent as those that were enforced. Thus, providing interactive context-aware guidance for all recommendations should be considered in the future. Furthermore, we found patient acceptance levels of performing self-measurements to be overall positive.

Keywords
clinical decision-making, context-aware sensors, decision-support systems, ehealth, hypertension, IT healthcare evaluation, pervasive technologies, preeclampsia

Introduction

Sensor-based systems could be useful for supporting more reliable and efficient self-measurement of health parameters in the outpatient clinical setting in the future. However, this area has not yet been studied for clinical effect, including feasibility and acceptability of the patients for being part of such a system. This article investigates the feasibility and acceptability of an intelligent self-measurement station based on a combination of context-aware and medical sensors providing interactive patient guidance and registering additional context information that is important for pregnant women that needs to self-measure their blood pressure (BP) as part of a screening process for preeclampsia (PE).

Hypertensive disease and PE are some of the most common medical disorders affecting pregnancy today.[1,2] Approximately 2–8 percent of all pregnancies are complicated by PE,[3] a condition which is associated with an increased risk of fetal growth restriction, fetal death, and maternal morbidity including generalized seizures, intracerebral hemorrhage, and severe/lethal effects of multiple organ systems.[1]

PE is defined as elevated BP levels of over 140/90 mm Hg after gestational week 20, accompanied by proteinuria (an excess of serum proteins in urine).[4] Early diagnosis is essential to reduce the risk of complications.[5]

Recent studies indicate that screening of asymptomatic pregnant women in their first trimester of pregnancy, and prophylactic medical treatment, can reduce the risk of developing severe PE.[5–11]

Accurate BP measurement is an important part of this screening and in order to be valid for diagnostic use, a range of recommendations must be followed.[12,13] Recommendations include: a quiet setting before and during measurements, being rested for 5 min before first measurement, not moving or talking, being correctly seated, legs not crossed, back supported, feet flat on the floor, arm supported at heart level, and finally correct cuff size and mounting. Screening of pregnant women in their first trimester will generally require increased resources of trained personnel to perform BP measurements.

Existing BP devices do not track behavioral data in order to measure adherence/compliance to recommendations. It is necessary for direct observation and intervention by staff in order to manage the quality of measurements, as there are no other means to validate measurements. Blood pressure self-measurement (BPSM) could save on staff resources and may perhaps also help reduce the risk of white coat hypertension, which is a well-known source of bias in 20 percent of patients visiting a clinic.[13,14]

White coat hypertension is a psychological anxiety–induced phenomena, which generally results in artificially high BP, compared with the actual BP measurements of the patients.[13] There have, in recent years, been studies evaluating the ability of patients to self-measure BP and this has proved to be challenging.[15]

The aim of this study was to investigate whether patients, with the aid of a context-aware BPSM system, are able to correctly self-measure BP adhering to internationally established BP measurement recommendations and to evaluate patient acceptance levels of performing self-measurements using context-aware adherence aids for guidance.

Materials and methods

Study design

We included 100 pregnant women attending routine ultrasound, at gestational week 12, at the Department of Obstetrics and Gynecology, Aarhus University Hospital. Participants were approached in the waiting room, before the scheduled scan. Verbal and written information regarding the study purpose and structure was given to all participants. Women who had a normal first trimester scan, and who accepted to participate, were included in the study. Twin pregnancies were excluded. BP measurements were performed using a BP station, ValidAid. The ValidAid system was also used to gather information on BP measurements and relevant context parameters.

Patient age and actual gestational week were also recorded. Upon completion of the three measurements, each patient received a questionnaire to evaluate the acceptance of self-measurement. The questionnaire included seven questions, where participants were asked to score the experience of using the ValidAid system. Scores were divided into six categories; strongly agree, partly agree, neither-or, partly disagree, strongly disagree, and do not know.

ValidAid system

The ValidAid system (Figure 1) was developed by The Department of Engineering, at Aarhus University, as a research system for exploring patient adherence during self-measurement of BP. The ValidAid platform is an automatic context-aware system for capturing self-measured BP data, combined with data regarding the patient's adherence to the instructions according to the international recommendations regarding BP measurement.[16] Two of the recommendations were actively enforced, rest time and not talking, while keeping legs uncrossed and back supported were not actively enforced.

The ValidAid system runs on a tablet computer (ASUS Eee EP121, Asus Inc., Taiwan) that integrates the BP device and sensor chair components, provides a user interface for the users, as well as performs audio classification of the data obtained. The ValidAid system uses a clinically approved BP device (A&D Digital BP Monitor UA-767PBT, A&D Company Limited, Japan), a sensor chair with built-in piezo-resistive sensors (FlexiForce A201 piezo-resistive sensor, TekScan Inc., USA) for registering leg placement and correct seating, including whether the back is supported.

The user interface consists of a screen guiding the patient through a series of three measurements (Figure 2). This is done through a countdown timer providing an indication of whether

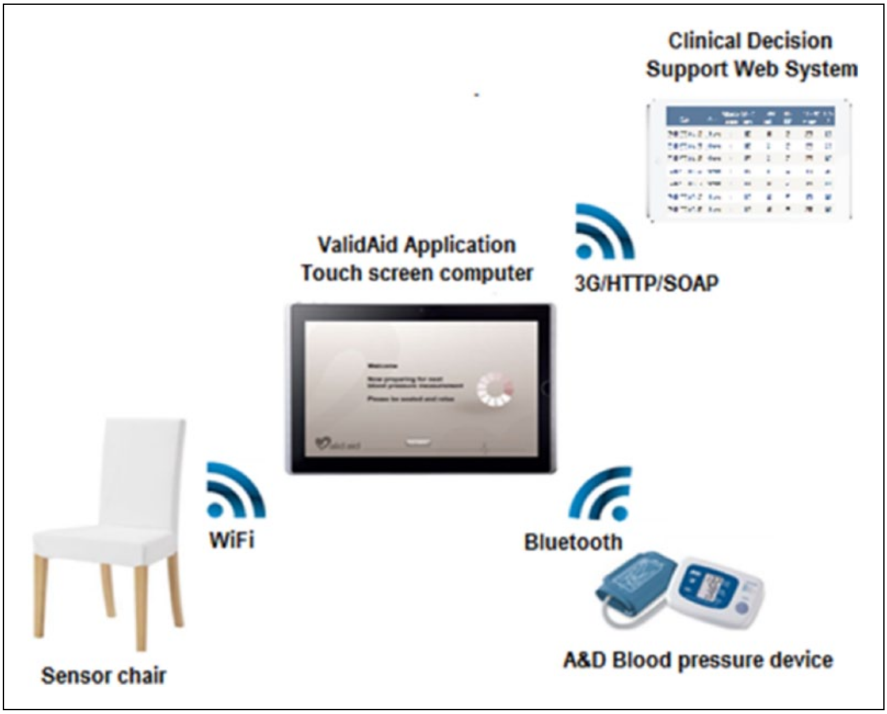

Figure 1. Overview of the ValidAid platform, consisting of a context-aware sensor chair based on piezo-resistive sensors, a touch screen computer running the ValidAid application. Finally, the A&D blood pressure device is connected using Bluetooth. The chair shown is the actual chair used for this study.

sufficient rest time has been achieved. Also, warnings are provided during measurements, for example, if the user speaks during measurements, or if the user moves during the measurement process.

The sensor chair has previously been validated in a laboratory study[17] and has also been used in a clinical study for measuring patient adherence to BP recommendations without interactive guidance provided, with the participation of 113 kidney disease patients.[18]

The ValidAid audio classification algorithm, which was used to detect talking and ambient noise levels during measurements, is based on machine learning techniques including feature extraction and classification using an artificial neural network classifier to detect patients talking during measurements.

The algorithm has previously been validated and described in a laboratory study[15,16,19,20] where 80 unique test subjects participated for training purposes and another 20 test subjects were used to validate the performance of the algorithm.

The ValidAid sensor chair has also been validated with regard to its ability to assess whether the patient is correctly seated during measurements, and if they have adhered to the recommended rest time.[19]

The ValidAid system used in the study features both adherence verifiers, as defined in the Adherence Strategy Engineering Framework (ASEF) framework,[21] for assessing the ability of the patient to follow the required procedure and report non-adherent behavior to the healthcare professional, as well adherence aids[21] for active and context-aware guidance of the patient which aims to improve adherence levels.

Hviletid: 00:01:28 - Vent yderligere 211 sekunder før første måling!

Velkommen

Du starter blodtryksmålingen ved at trykke på
"Start" knappen på blodtryksapparatet

Følg nedenstående retningslinjer:

- Vent 5 minutter før første måling
- Tag 3 målinger i alt
- Vent 1 minut mellem hver måling
- Sid tilbagelænet med ryg støttet
- Dine ben må ikke være over kors
- Hold begge fødder fladt på gulvet
- Brug korrekt størrelse manchet
- Manchetten skal være korrekt påsat
- Arm med manchet skal hvile på bordet
- Undlad at tale under målingen
- Undgå høj baggrundsstøj
- Sid roligt under målingen

Figure 2. Screenshot from the patient user interface. In the top left corner, we find an active adherence aid that provides a countdown timer indicating when the next measurement should be taken. If a patient performs a measurement prematurely, she is instructed to redo the measurement using on-screen messages. In the center of the screen, the passive adherence aid is located consisting of the list of recommendations that the patient needs to follow in a text-based list format. All screen text is provided in Danish only.

BPSM

Participants received an anonymous id number and, after careful verbal instruction on how to take reliable BPSM, they were left to autonomously perform three self-measurements in the ValidAid test setup with the aid of a BP device.

They were instructed to be seated comfortably in a quiet area; their arm was supported at heart level, back rested, and legs not crossed. A small (<22 cm), normal (22–32 cm), or large (33–42 cm) adult cuff was used, depending on mid-arm circumference.[22] Participants were required to rest 5 min before the first measurement and at least 1 min between the three measurements.

All participants were actively guided with the aid of a countdown on the tablet computer; they were able to follow how long they had been seated and when to take the three measurements. There were no active context-aware adherence aids used for the remaining context parameters: ambient noise-level, legs-crossed, and talking. These parameters were, however, recorded and stored for future analysis. All measurements were automatically stored and data were made available to staff via a web-based system.

Data analysis

The primary outcome was the assessment of whether patients would be able to self-measure their BP adhering to internationally established recommendations and to evaluate patient acceptance

Table 1. Background and blood pressure measurement data obtained.

Variable	Value, mean (95% confidence interval), p-value
Age (years)	29.9 (95% CI: 28.9–30.8)
Gestational age (weeks)	12+4 (95% CI: 12.3–12.5)
Systolic BP, mm Hg	109.2 mm Hg (95% CI: 107.5–110.9)
Diastolic BP, mm Hg	72.3 mm Hg (95% CI: 70.6–73.9)
Pulse, beats per minute (BMP)	79.1 bpm (95% CI: 77.0–81.3)
Mean arterial pressure (MAP)	84.6 mm Hg (95% CI: 83.0–86.1)
Difference between first and second measurements (MAP1 vs MAP2)	0.0 mm Hg (95% CI: 0.5; 1.8), $p < 0.05$
Difference between second and third measurements (MAP2 vs MAP3)	1.1 mm Hg (95% CI: −0.4; 0.5), $p > 0.05$
Difference between third and first measurements (MAP3 vs MAP1)	1.2 mm Hg (95% CI: 0.6; 1.8), $p < 0.05$

levels of performing self-measurements using context-aware adherence aids for guidance. In addition to this, intrapatient differences between the three performed measurements were investigated. For this, we calculated the resulting three mean arterial pressure (MAP) value series based on the recorded BP measurements, performed normality testing using qq-plots and histograms, and then applied three paired t-tests to investigate for differences in means between the three MAP value series. All data analysis was done with MiniTab and verified with Excel. Patients having performed fewer than three measurements were excluded, as well as all measurements recorded after the third measurement of a patient, which were considered as operator errors.

Results

Participant background and BP measurement data

We recorded a total of 308 individual measurements from 100 unique patients. Detailed results of patient data, including age, gestational age, systolic and diastolic BP, heart rate, and MAP values can be seen in Table 1. Of these, 300 measurements from 100 patients were used to investigate for intrapatient differences between first, second, and third MAP value series. The mean and confidence interval and corresponding p-value are likewise presented in Table 1.

Measured adherence levels

In all, 93 percent of participants took the required three measurements. The remaining 7 percent of participants performed either four (6%) or five (1%) measurements. In six out of the seven cases, each participant took a “premature measurement” prior to the required 5-min rest limit. These measurements were taken within 0–198 s after the patient was first seated. The six participants did, however, eventually manage to take their first measurement after the correct 5-min rest time, achieving three valid BP measurements.

One participant took extra measurements during the rest time between measurements two and three. Participant adherence to the recommendations rest time and not talking was 99 percent. Keeping legs uncrossed was adhered to in 69 percent, while back supported was adhered to by 35 percent of the participants. One percent of participants failed to self-report correct measurements. Table 2 presents the percentage of patients adhering to the individually measured recommendations.

Table 2. The number of patients adhering to the recommendations during self-measurements while using the ValidAid system to self-measure blood pressure.

Recommendation adhered to	Patients adhering
Performed at least three measurements	93%
Rest time (5 min)	99%
Not talking	99%
Legs not crossed	69%
Back supported	35%
Correct self-reporting of BP	99%

Patient acceptability questionnaire results

The questionnaire results (shown in Figures 3 and 4) show that 95 percent felt "very comfortable" with self-measurement, 81 percent strongly agreed to this, while 14 percent partly agreed. In all, 17 percent felt "uncomfortable" having to self-measure, while 7 percent expressed strongly agreeing to this. In all, 93 percent disagreed that they felt unnecessarily monitored by the BP equipment, 87 percent strongly disagreeing to this. Eight percent would have preferred that BP measurements were performed by healthcare personnel.

Discussion

We found that the majority of participants (93%) took exactly the required three BP measurements. Adherence to the actively enforced recommendations, rest time and not talking, was 99 percent. Adherence to keeping legs uncrossed was 69 percent, while back supported was only adhered to by 35 percent of the participants, which was likely due to these recommendations not being actively enforced by the ValidAid system.

The questionnaire also showed that 95 percent felt comfortable with self-measurement after having used ValidAid, of which 81 percent strongly agreed. This indicates that performing self-measurements is perceived as acceptable to the vast majority. In all, 93 percent disagreed that they felt unnecessarily monitored by the BP equipment. Eight percent would have preferred that BP measurements were performed by healthcare personnel. However, this does not imply that they did not feel comfortable with performing self-measurements.

Participants were actively guided, with the aid of a countdown on the monitor. They were able to follow how long they had been seated and know when to take the three measurements. The six participants who performed premature measurements, eventually managed to take their first approved measurement after the correct 5-min rest time, therefore achieving three valid BP measurements. Such extra measurements are of no clinical importance and thus acceptable.

The participants' ability to correct their measurement process after having taken invalid measurements is likely due to the context-aware adherence aid which, upon premature measurement, would inform the participants of the insufficient rest time and instruct them to redo the measurement after the 5-min rest time, but the underlying mechanisms should be studied further.

Participant adherence to recommendations that were enforced with a combination of verbal staff explanations and active interactive guidance aids, rest time and not talking, was observed as being satisfactory achieving 99 percent adherence. However, verbally explained recommendations that were only passively enforced as on-screen guidance showed much lower adherence levels.

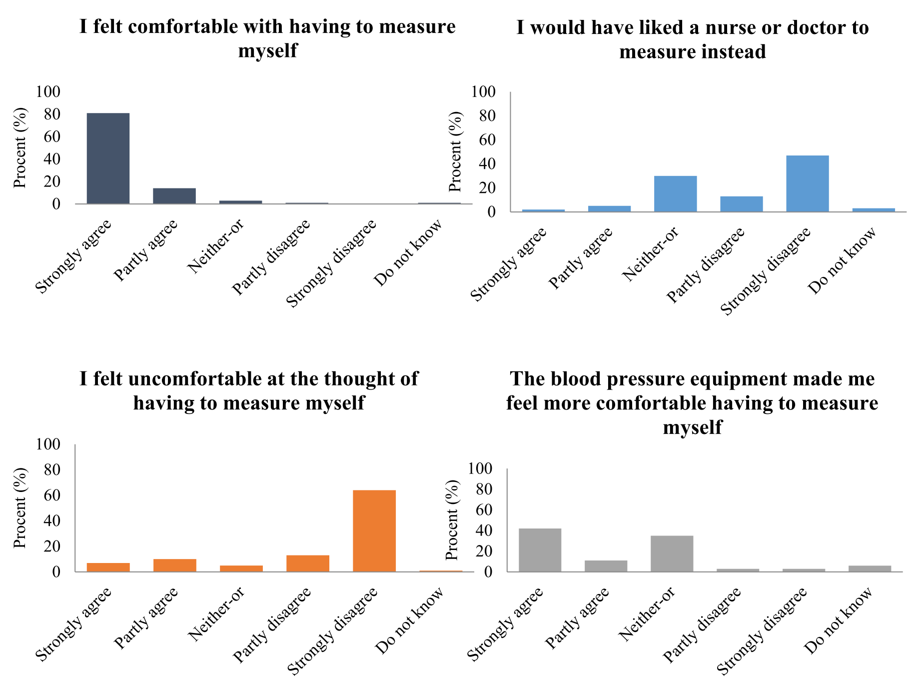

Figure 3. Questionnaire results detailing the participants' experiences with the self-measurement process. The first four questions focused on the patient's initial attitude toward self-measurement, and whether they would have preferred a nurse or doctor instead of a sensor-based self-measurement station, and finally whether they felt comfortable having to measure themselves using the ValidAid context-aware self-measurement station.

This indicates that active guidance aids are more effective in achieving adherence than passive aids. The participant's inadequacy to adhere to the recommendations may cause critical bias.[13] Further studies are needed to detail the underlying mechanisms.

Three paired t-tests were performed on the recorded MAP values, in order to investigate any differences in means between the first, second, and third measurement sets. Although the t-tests did indicate a difference in means between the first and the second MAP series and the first and the third MAP series ($p < 0.05$ for both), the actual differences were well below the typical variability of BP measurements that is commonly accepted (up to 5 mm Hg is not considered a difference due to BP variability and device precision). For both the relevant MAP comparisons, the differences in mean were below 1.3 mm Hg and with a 95 percent confidence interval between 0.5 and 1.8 mm Hg (see Table 1). Thus, no practical difference could be found between the three paired MAP values, and all three measurements series are thus assumed to be equal in means.

The ValidAid system was designed to provide active guidance in the shape of a context-aware adherence aid[21] with regard to rest time only; all other parameters were not provided for. Whether context-aware adherence aids could be beneficial, if introduced to all of the recommendations, would need to be verified further, but appears likely. Specifically, we passively collected data on the participants ability to keep legs uncrossed and back supported, but we did provide an interactive context aid, reminding the participants to "sit back" and "uncross legs" once such erroneous

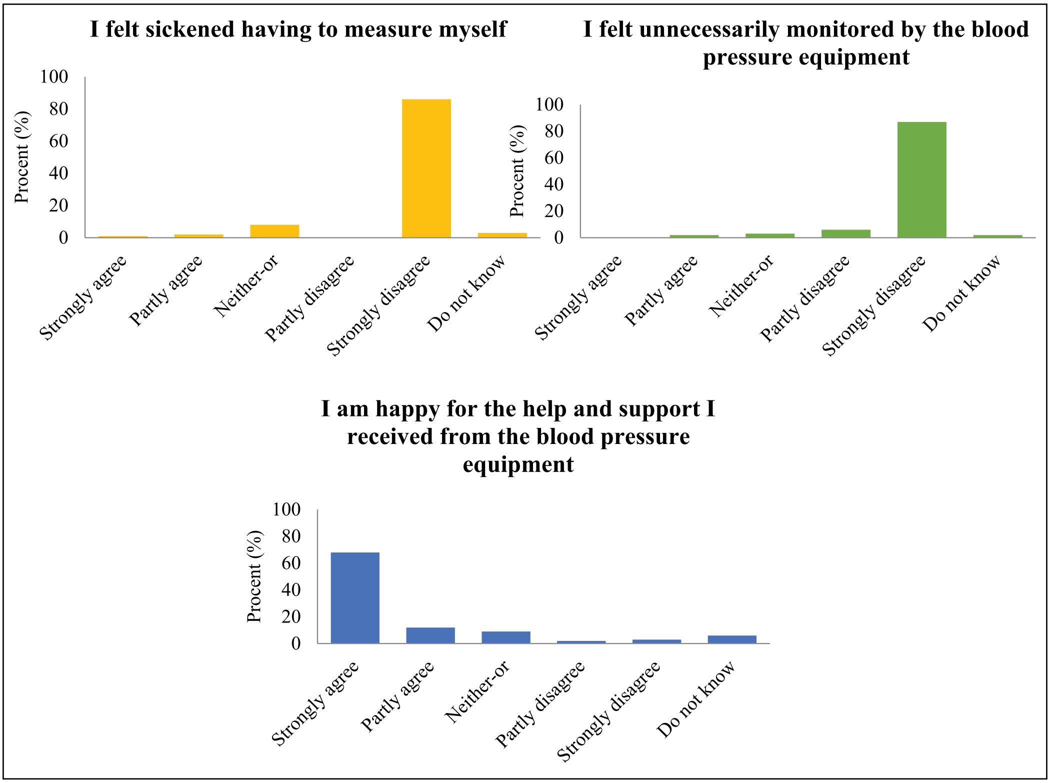

Figure 4. Questionnaire results detailing the participants' experiences with the self-measurement process. The last three questions focused on the patient's experience after having completed the self-measurement process. This includes whether the self-measurement process made them feel needlessly sickened (stigmatized) as patients, and whether they felt overly monitored by the extra sensors. The final question focused on whether the participants felt they had received sufficient support from the system.

behavior was detected. This was, in part, due to not wanting to overwhelm the participants with interactive advice during this initial study. However, these two interactive aids should be implemented in future self-measurement systems, if possible.

It could be argued, that a basic countdown timer could be sufficient for achieving relevant rest time of the participants. However, in a previous study, where only a simple clock was provided for countdown and no active adherence aid was used, we found that only 8 percent of the patients adhered to the required rest time of 5 min before taking the first measurement; less than half of all measurements, including the second and third measurement, were performed after the required 5-min rest time.[18] Existing BP devices and tele-monitoring systems are not equipped to detect non-adherent behavior. Thus, in order to validate measurements taken with state-of-the-art equipment, it is necessary for manual staff observation in order to guarantee the quality of the measurements. Relying on manual observation would require increased staff resources and would therefore not be cost-effective.

Patients could, alternatively, be equipped with telemedicine devices, featuring relevant context-aware aids to self-measure in the comfort of their homes. This approach would, however, incur increased costs in regard to both equipment and maintenance.

Our results showed that only one percent failed to self-report correct measurements, which is very low compared to related studies. Previous studies have found that up to 50 percent of all the self-reported BP data did not match the data stored in device memory.[18,23–25] This difference could be explained by the study setup, where measurements were indicated both on the touch screen and on the BP device itself. In the related studies, the participants were not aware that the measurement was being automatically recorded.

Furthermore, it could be speculated that an active guidance system, such as ValidAid, could have a negative effect on some participants in terms of building up anxiety levels. Being continuously corrected by the ValidAid system (or similar active guidance systems) might result in increased anxiety, which is well known to be associated with artificially increased BP values.[19] In other words, it could be speculated whether the increased use of technology could result in anxiety effects similar to the "white coat effect."[19]

These results, combined with the findings on participant adherence levels to the recommendations, indicate the relevance of introducing a self-measurement tool with active adherence guidance aids to support the participants.

Our results are in line with previous work,[18,23–26] which likewise found that adherence improves when using active and context-aware adherence aids.[21] However, the work presented in this article is the first to study the effects of patient adherence to recommendations when using active adherence aids in a large cohort of patients, thus demonstrating a novel application of context-aware sensors in a smart environment clinical healthcare scenario. Specifically, clinical procedures with regard to the screening of PE currently relies on manual BP measurements which is resource consuming and impractical for large-scale screening efforts.[6,11] With self-measurement stations, such as ValidAid, our results indicate that automated self-measurement is feasible and safe, although more work is needed in order to refine this procedure. As a further novelty, we have investigated the user experience of patients being exposed to a self-measurement system, which has not been reported elsewhere in the literature to our knowledge. The user experience is of pivotal importance, as a negative user experience could cause bias to readings and hamper proliferation efforts further. Thus, more work is needed in order to determine the optimal level of active adherence aids and verifiers used to achieve accurate measurements and self-measurement user experience. This work should be undertaken in the shape of randomized controlled experiments in one or more clinical settings with a sufficient patient population in order to provide sufficient statistical power.

Finally, the use of self-measurement stations relying on a combination of context and medical sensors could be extended to other areas, including in the telemedicine and ambient-assisted living settings.[27,28]

Conclusion

It was found that the majority of the participating healthy pregnant women were able to take reliable BPSMs using the BP self-measurement station ValidAid, adhering to internationally established BP measurement recommendations. Thus, we found it feasible to use the context-aware system ValidAid, to improve self-measurement adherence.

There was an interesting difference in the degree of compliance between the recommendations that were actively enforced (93%–99%) contra those that were not enforced (35%–65%). Participants generally complied when being actively guided by adherence aids (including time seated at 99%), while compliance to those not enforced was low (back supported at 35% and legs not crossed at 69%).

The majority of the participants felt comfortable having to self-measure, while only a small percentage would have preferred the measurements to be taken by healthcare staff. Further development of the interactive features of the platform may potentially facilitate increased adherence to the recommendations and reduce insecurity related to self-measurement.

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Declaration of conflicting interests

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Context-aware grading of quality evidences for evidence-based decision-making

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Abstract

Processing huge repository of medical literature for extracting relevant and high-quality evidences demands efficient evidence support methods. We aim at developing methods to automate the process of finding quality evidences from a plethora of literature documents and grade them according to the context (local condition). We propose a two-level methodology for quality recognition and grading of evidences. First, quality is recognized using quality recognition model; second, context-aware grading of evidences is accomplished. Using 10-fold cross-validation, the proposed quality recognition model achieved an accuracy of 92.14 percent and improved the baseline system accuracy by about 24 percent. The proposed context-aware grading method graded 808 out of 1354 test evidences as highly beneficial for treatment purpose. This infers that around 60 percent evidences shall be given more importance as compared to the other 40 percent evidences. The inclusion of context in recommendation of evidence makes the process of evidence-based decision-making "situation-aware."

Keywords

context-aware evidence grading, evidence-based medicine, evidence-based practice, evidence informed decision, quality recognition

Introduction

There is an exponential growth in the medical literature, and medical practitioners are finding it difficult to obtain the most relevant information in their limited time span. Young physicians,

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particularly, are open to innovation, but they seek to minimize the costs either to themselves or to their patients.[1] Without automation, processing of huge amount of literature is a costly and a challenging task for even the existing systems, leave aside manual efforts of the medical practitioners. Practicing evidence-based medicine[2–4] requires the medical practitioners to extract high-quality evidence from published research in addition to their own knowledge and experience.[2] Finding high-quality evidence is essential for successful practice,[3] but medical practitioners face many barriers in using evidence-based answers at point-of-care.[4] If done at all, most of the time, seeking best evidence is done manually.[5] It requires a lot of manual computation time in order to reach to the desired quality appraised evidences. The importance of recognizing and appraising the evidences can be realized from the fact that more than 100 grading scales are in use today as reported in Agency of Healthcare Research and Quality research report.[6] Regardless of a grading scale, the strength of computing evidences should consider three key elements: quality, quantity, and consistency. A few of them such as Grading of Recommendations Assessment, Development, and Evaluation (GRADE)[7,8] and Strength Of Recommendation Taxonomy (SORT)[9] focus on developing guidelines for quality of evidences and strength of recommendations. GRADE provides the definitions for grading the quality of the evidence on four levels: high, moderate, low, and very low. SORT, on the other hand, provides a taxonomy to determine the strength of the recommendation of a body of evidence based on three ratings: A (strong), B (moderate), and C (weak).

Currently, some approaches[10–12] focus on query building to find information resources but lack automatic appraisal of evidence quality. Using Boolean approaches with search filters, "hedges" can improve the retrieval of clinically relevant and scientifically sound studies from MEDLINE and similar databases,[13,14] but the statistical approaches[3,5] presented a proof of better accuracy in recognizing quality articles as compared to Boolean approaches. Very recently, Sarker et al.[15] presented an approach of evidence quality prediction through supervised classification model. The approach uses the SORT[9] to grade the evidences. A number of other approaches[16–18] are proposed in the area of text classification. Ruiz-Rico et al.[16] combine the existing techniques innovatively for the classification of MEDLINE abstracts based on a noun phrase extraction. Kim and Choi[18] provide automatic classification of key sentences to support evidence-based medicine. A support vector machine (SVM)-based approach is presented for systematic review of related high-quality article classification.[18] Domain-specific post-retrieval re-ranking approach[19] is proposed in the domain of depression that attempts to re-rank the articles returned by the search engine.

The investigation leads us to the conclusion of utilizing quality-based context-aware graded evidences in the evidence-based decision-making process. The strengths of the existing work motivated us to explore improvements in the area of automatic quality processing and grade computation. Based on this motivation, we formulated a consistent two-level methodology: quality evidence recognition (level 1) and context-aware grading (level 2). The methodology is capable of identifying high-quality evidence for recommendation to the medical practitioners or caregivers, or even patients according to their contexts.

We differentiate our proposed approach with the existing ones in the following areas: (a) automatic extraction of metadata features and standardization for improved quality prediction through a supervised classification model called quality recognition model (QRM) and (b) context elements identification, mappings, and aggregation to grade evidences through our proposed method called context-aware grading (CAG). In our approach, we exploited the strengths of existing approaches[3] using the data features (title, abstract) and metadata features (MeSH terms and publication type) for developing the QRM model. We adhere to the suggestions of GRADE[8] and SORT[9] grading scales in CAG-based grading with the exception of involving decision-making context influenced from the conceptual framework for context-based evidence-based decision-making.[20,21]

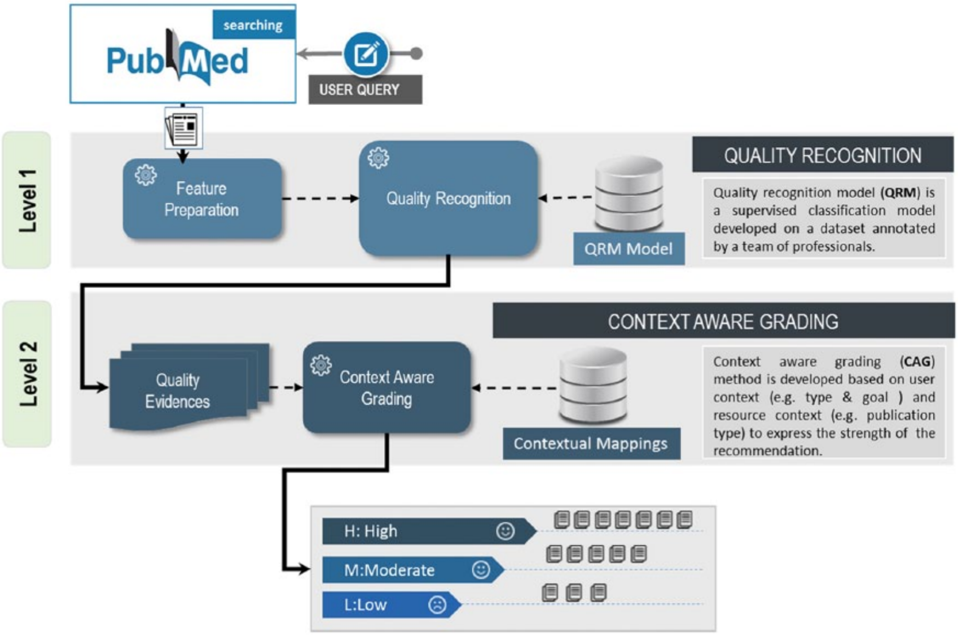

Figure 1. Two-level evidence evaluation: quality recognition and context-aware grading.

Objective

Physicians, whether serving individual patients or populations, always have sought to base their decisions and actions on the best possible evidence.[22] Based on evidence-adaptive clinical decision support systems,[23] the researchers and developers need to customize the literature-based evidence for local conditions. Adhering to these needs and recommendations, the task of finding best possible evidence from the literature, customized to the local conditions, becomes a priority. We aim at developing methods to automate the process of finding quality (best possible) evidences from a plethora of literature documents and grade them according the context (local condition). Previously, we developed automated methods for knowledge-based query construction, assisting the medical practitioners in query preparation.[24,25] This work is a step forward to focus on evidence quality evaluation and CAG.

Materials and methods

We propose a hierarchical strategy for the evaluation of quality evidence at two different levels as depicted in Figure 1. At first level, the quality of evidences is recognized on the basis of methodological rigorousness through the QRM classification model. If an article passes the criteria of being methodological rigorous, the article is recognized as a quality evidence. At second level, the recognized quality evidences are graded on the basis of user and resource contextual information using CAG method.

Level 1: quality recognition

Prior describing the method of quality evidence recognition, it is necessary to agree upon quality parameters. Quality of an evidence and what makes an evidence a quality evidence for a user are two different considerations. The definitions of a quality evidence are available in the literature for clinical care. SORT[9] includes ratings of A, B, or C for the strength of recommendation for a body of evidence. The analogy of a best evidence aligned with category "A" of SORT grading which is defined as "Recommendation based on consistent and good quality patient oriented evidence."[9] Good-quality patient-oriented evidence has different meanings with respect to different purposes such as diagnosis, treatment, and prognosis. For treatment purposes, the meaning of good quality evidence is provided in Definition 1.

Definition 1. "Systematic Review or meta-analysis of randomized controlled trials (RCTs) with consistent findings or high-quality individual RCT.[9]"

In a study protocol,[14] an article is considered as high quality if it passes the "methodological rigorous" criteria. Methodological rigorous article for different purposes has different meanings. For treatment purpose, a methodological rigor article is defined as in Definition 2.

Definition 2. "Random allocation of participants to comparison groups, outcome assessment of at least 80% of those entering the investigation accounted for in 1 major analysis at any given follow up assessment, and analysis consistent with study design."[14]

For this study, Definition 2 is considered for quality evaluation of the evidences. For quality evaluations, we develop a supervised classification model called QRM. We follow the steps of data collection, feature selection, corpus preparation, algorithm selection, and parameter tuning for QRM development.

Data collection. We use the data that were manually created by a team of specialized experts for the purpose of clinical query filters in PubMed.[14] The data collection consists of 50,594 MEDLINE documents, of which 49,028 documents are unique. The collection is classified across four dimensions: format (O = original study, R = review, GM = general and miscellaneous articles, and CR = case report), human healthcare interest (yes/no), scientific rigor (yes/no), and purpose (diagnosis, etiology, prognosis, treatment, economic studies, reviews, and clinical predication guides). Among 50,594 documents, 3363 are labeled as being scientifically rigorous.

Feature selection. Feature selection plays an important role in predicting performance. From the existing studies, we come across features including data features (title, abstract) and metadata features (MeSH terms, publication type, publication year, publication venue, and publication authors). In some studies, concepts used are semantic prediction, UMLS concepts, and UMLS relation in predictions.[3] The data features that are used in earlier studies[3,15] have proved their importance. Publication type (one of the metadata features) is the most important feature reported from the same studies. MeSH terms is also reported in Kilicoglu et al.[3] as one of the important contributors. Other metadata features including publication year and publication venue are reported as less significant features to affect the classification accuracy. In our experiments, we also found that publication year, venue, and author are the least significant in metadata feature list as compared to other metadata. Finally, we select four features; title, abstract, MeSH, and publication type.

Corpus preparation. Getting the data for the selected features, we implemented eUtils service API[26] to retrieve the documents from the PubMed database. The documents are processed to get individual features and store to MS SQL Server database for experimentation.

Word vector preparation. The selected features are composed of "bag-of-words" which need to be cleaned prior to use for learning methods. We apply the text processing method "process

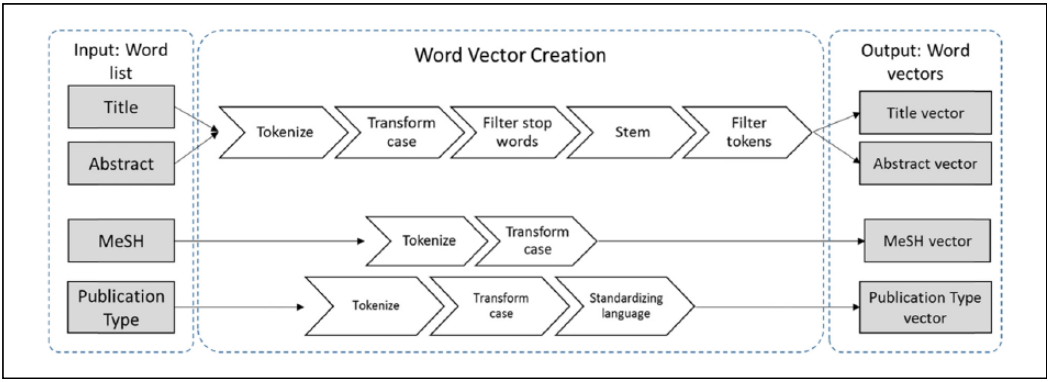

Figure 2. Process of word vectors (title, abstract, MeSH, Publication type) creation.

documents from data" using TD-IDF[27] in RapidMiner tool.[28] To remove the least and too frequent words from the list, the prune method is set to absolute with below absolute = 2 and above absolute = 100. The preprocessing steps are described in Figure 2 to get the final word vector. Title and abstract are first tokenized, transform the case, remove English stop words, stemming the words using the Porter[29] stemmer, and filtering the tokens by length having minimum characters of 2 and maximum of 999 characters. Unlike data features (title, abstract), vectors of the metadata features (MeSH, publication type) are created through tokenization and case transformation as there was no need to remove stop words and stemming. The complete workflow designed in RapidMinor tool is made available on a public domain (https://www.myexperiment.org/workflows/4958.html?version=1) for the general public to reuse for their own experimentation.

Standardizing language of publication type. The publication types text retrieved through eUtils API[26] are not consistent with the vocabulary of publication types provided by PubMed. Publication types found in PubMed are reported in count as 73,[30] which is quite less than the count 248 returned for the documents in our selected data set. Algorithm 1 mapped the inconsistent publication types to standard publication types taking the list of articles as input. The publication type of each article is a string which may contain one or more than one publication types. Using getPType() function, the string is parsed into a list of atomic publication type. For each atomic publication type, rank is determined with getRank() function. The getRank() function finds the rank of each publication type in R mapping table. Ranks of each publication type are dependent on the goal of the study such as diagnosis, treatment, and others. The ranks for publication types based on their importance and effectiveness are derived from the literature evidences[8,9,14,31,32] as shown in Table 1. The rank value 1 shows the highest rank of publication types of the treatment goal with respect to their importance. For instance, meta-analysis of RCTs is considered the most important publication type for treatment, so it is ranked on top by assigning value 1. Table 1 is not an exhaustive representation to have a rank entry for each possible publication type rather it holds the most prominent and influential publication types for the treatment goal.

Parameter setting. Rigorous recognition on the articles is a binary classification problem. We surveyed multiple methods from different sources and selected some that work well with text categorization tasks.[33,34] For the chosen methods, Naïve Bayes (NB) kernel,[35] k-nearest neighbor (kNN),[36] SVM linear,[37] and decision tree (DT),[38] we tested the performance at different parameter settings. NB is experimented with kernel values 5, 10, and 15 with a minimum

Algorithm 1. Standardizing language of publication types.

```
Begin
    inputs: $A - \{a_1, a_2, \ldots, a_n\}$ ;//the list of articles
    output: $A' - \{a_1, a_2, \ldots, a_n\}$ ;//the list of articles with standardized publication type
    Let;
        pt represents publication type;
        rank represents the rank of pt;
        tempRank = 0; //holds the previous rank temporarily for comparison
        spt represents the standardized publication type;
    for each a in A
        do
            pt ← a.getPublicationType();
            rank ← getRank(pt, R); //where R is the rank table for publication types.
            if (rank > tempRank)
                tempRank ← rank;
                spt ← pt;
            endif
        while (a.getPublicationType exists)
        a.PublicationType ← spt;
        A'.add(a);
    endfor
    return A';
End
```

Table 1. Rank values of publication types (1 shows the highest and 4 is the lowest).

Publication type	Rank
Meta-analysis of RCTs	1
Systematic Review of RCTs	2
RCT	3
Meta-analysis of CTs	4
Systematic review of CTs	5
CT	6
Cohort study	7
Case-control study/report	7
Guidelines	8
Opinion	9
Observational study	10
Any other publication type	11

RCT: randomized controlled trial; CT: control trial.

Table 2. SVM complexity cost (*C*) parameter setting and the corresponding results.

Method	Parameter	Value	Result (accuracy)
SVM	Complex cost parameter *C*	−0.2	80.15
		−0.1	80.15
		0.0	80.15
		0.1	75.38
		0.2	75.38

SVM: support vector machine.

Table 3. Performance of machine learning algorithms in terms of accumulative sum score of F-measure, accuracy, and AUC using data and metadata features with standard publication type on training and development test data.

Algorithm/criteria	Training			Testing			Sum score
	F-measure	Accuracy	AUC	F-measure	Accuracy	AUC	
SVM	0.849	0.771	0.807	0.870	0.785	0.735	**4.818**
DT	0.914	0.883	0.969	0.289	0.316	0.762	4.134
NB	0.835	0.764	0.752	0.721	0.602	0.548	4.223
kNN	0.812	0.707	0.782	0.847	0.752	0.777	4.678

The bold value shows that SVM secured the highest accumulative sum score thus selected for the experiment;
AUC: area under curve; SVM: support vector machine; kNN: k-nearest neighbor; DT: decision tree; NB: Naïve Bayes.

bandwidth of 0.1, and it was found that kernel value = 10 showed slightly better performance. Finding the best value of k for kNN, we experimented k values in the range of 1–20 for odd values and found $k=5$ with measure type = NumericalMeasure and numerical measure = CosineSimilarity as better setting. DT performed better on RapidMiner default settings with confidence value of 0.25 for the pessimistic error calculation of pruning. SVM with different parameter settings is tested to find the best value of complex cost parameter C. Values less than 0.0 showed similar results to $C=0.0$. Similarly, values greater than 0.1 produces similar results to $C=0.1$. The kernel cache value is set to 200 and maximum iterations are set to 100,000. Finally, we were left with $C=0.0$ and $C=0.1$ to choose from; however, $C=0.0$ for our experiment produced better results as compared to $C=0.1$. The performance for different parameter settings of SVM is shown in Table 2.

Method selection. We choose a subset that is treatment-related documents of our selected data set for the experiment to find quality evidence. The subset includes 6882 documents out of which 4999 are labeled as "non-rigor" and 1883 are labeled as "rigor." We determine the performance of chosen methods on F-measure, accuracy, and area under curve (AUC) criteria (Table 3). F-measure and accuracy are included to judge how accurately the rigorousness of an article is predicted and AUC criterion is included to judge how consistently they are predicted. In the literature, it is reported that AUC is statistically consistent and more discriminant than accuracy.[39,40] SVM classifier performs the best in accuracy than DT and kNN; however, it is lower than NB. AUC of SVM was lower than DT; however, it was higher than NB and kNN. Overall, SVM showed better overall ranking score than all other competing algorithms and kNN showed poor performance as compared to others. Because of the higher performance, SVM is chosen for the development of QRM.

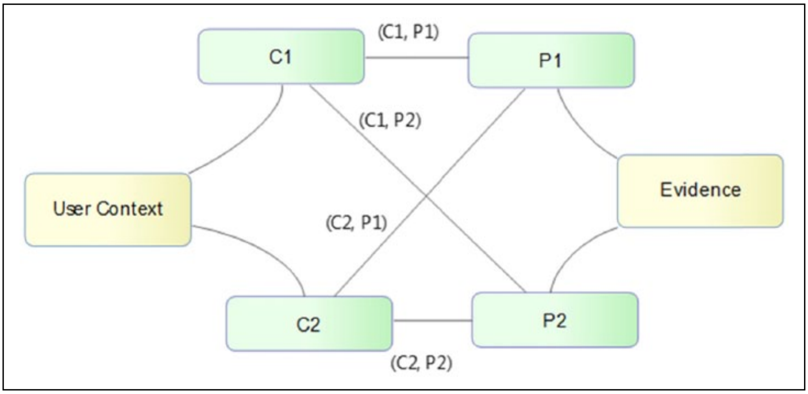

Figure 3. User context mapping with evidence properties.

Level 2: context-aware evidence grading

Evidence recognition on the basis of user query and statistical methods may not fully determine the user preferred evidences. The statistical approach described in Level 1: quality recognition recognizes the evidence quality on the basis of methodological rigorousness, which is a necessary step; however, it is not sufficient to reflect the user perspective. In order to reflect the user perspective, we conceive the user context in relation to a resource (evidence) context. Context has a vast meaning, it exhibits its characteristics according to the goal and application domain. Vebert et al.[41] present a context framework that identities relevant context dimensions for technology enhanced learning applications. We derive the classification of context information that is relevant to evidence-based clinical applications. In evidence-based clinical applications, user's main objective is to interact with online resources for finding support in evidence-based decision-making. We derive the contextual elements from the context framework in Dobrow et al.,[20] Verbert et al.,[41] and Rycroft-Malone[42] that is relevant to the objective of evidence-based clinical applications. User context has multiple elements such as basic information which shows user educational level, background is the experience of the user, goal shows short-term learning or long-term learning, interest represents the preferences, and learning style is the pattern of user learning such as textual and visual. An evidence possess multiple properties such as the publication type, publication avenue (journal, book, etc.), and year of publication. For grading an evidence, we design a method as shown in Figure 3 and describe in Algorithm 2, which evaluates an evidence on the basis of different user context elements.

First, the properties associated with the evidences are extracted and each property is evaluated with each of the elements of different contexts. For instance, an evidence E has properties P_1 and P_2 and user U who is interested in E possesses the contexts C_1 and C_2. The algorithm first evaluates the property P_1 of E according to C_1 and C_2 by putting the grading value from expert-based contextual mappings. The process is repeated for property P_2 in the similar way as that of P_1. If there are more contexts or properties, this process will occur for all of them. In Figure 3, user contexts C_1 and C_2 are mapped to the two properties P_1 and P_2 of an evidence. The mappings of context to evidence are made based on two type of analysis: literature-based and expert-based. We investigate the well-known study protocols and grading systems[8,9,14] and two senior physicians to grade evidence with different contexts. The grade values are chosen as L=low, M=Medium, H=High, and U=Unknown, for each user context against a property of an evidence. The grade values for evidences are stored in the form of matrix where rows represent the user context elements and columns represent the properties of evidence as shown in Table 4.

Algorithm 2. Grading evidences based on user context.

```
Begin
    input: $E - \{e_1, e_2, \ldots, e_n\}$ ;//the list of rigor evidences
    output: $GE - \{\{e_1, g_1\}, \{e_2, g_2\}, \ldots, \{e_n, g_n\}\}$; //where g represents the grades h, m, l, u.
    Let;
        $C - \{c_1, c_2, \supset, c_n\}$; //current context
        $P - \{p_1, p_2, \ldots, p_n\}$; //properties of E
        $G - \{g_1, g_2, \supset, g_n\}$; //properties of E
    for each e in E
        for each p in P
            for each c in C
                grade ← computeGrade(p, c);
                G.add(grade);
            endfor
        endfor
        finalGrade ← getHighestGrade(G);
        GE.add (e, finalGrade);
    endfor
    return GE;
End
```

Table 4. Grade value population for an evidence with respect to contexts.

Context\evidence	P_1	P_2	…	P_n
C_1	(*H* or *M* or *L* or *U*)	(*H* or *M* or *L* or *U*)	…	(*H* or *M* or *L* or *U*)
C_2	(*H* or *M* or *L* or *U*)	(*H* or *M* or *L* or *U*)	…	(*H* or *M* or *L* or *U*)
…	…	…	…	…
C_n	(*H* or *M* or *L* or *U*)	(*H* or *M* or *L* or *U*)	…	(*H* or *M* or *L* or *U*)

Context aggregation. Based on the grade values, the aggregate contextual grade values are inferred from each column of Table 5. The aggregate contextual grade values accumulatively make the aggregate contextual vector. Table 5 shows the aggregate contextual grade vector (ACGV) consisting of aggregate contextual grade values. The aggregate contextual grade values are inferred using a simple rule of picking the highest rank value among *H, M, L*, and *U* in the respective column. Highest to lowest definition is provided in equation (1). For instance, *L* is selected as the aggregate value because $L > U$.

$$H > M > L > U \tag{1}$$

Final grade value (FGV) is inferred from the values of ACGV on the same rule as in equation (1). For the user explanation, the FGV value is interpreted according to equation (2)

Table 5. Aggregate contextual grade values and vector.

Context\evidence	P_1	P_2	…	P_n
C_1	(H or M or L or U)	(H or M or L or U)	…	(H or M or L or U)
C_2	(H or M or L or U)	(H or M or L or U)	…	(H or M or L or U)
…	…	…	…	…
C_n	(H or M or L or U)	(H or M or L or U)	…	(H or M or L or U)
Aggregate contextual grade values	(H or M or L or U)	(H or M or L or U)	…	(H or M or L or U) (H or M or L or U)

Aggregate Contextual Grade Vector

Final Grade Value

$$F(\text{FGV}) = \begin{cases} \text{if } H \rightarrow \text{highly beneficial} \\ \text{if } M \rightarrow \text{moderate beneficial} \\ \text{if } L \rightarrow \text{less beneficial} \\ \text{if } U \rightarrow \text{unknown} \end{cases} \tag{2}$$

Experimental results

As mentioned, the proposed methodology is implemented in hierarchical fashion. The implementation framework for conducting different experiments is described in Figure 4. Using this implementation framework, three types of experiments are conducted where two of the experiments are pertinent to QRM and one of them is related to CAG:

Experiment 1. Demonstration of QRM performance on development test data set for four different features and their combinations.

Experiment 2. Comparison of QRM performance on publication type feature in default (non-standardized) and in a standardized form.

Experiment 3. Contextual grading results CAG method on the basis of "physician interested in treatment" case study.

Experiment 1: QRM performance on development test data set

We here present the classification results obtained in the 10-fold cross-validation performed on the training set of 5682 documents and development test set of 1300 documents. In Table 6, accuracies on different features are presented. Using publication type feature, QRM produced second better results (79%) for testing documents. At training stage, the combination of three features (title, abstract, and standard publication type) stand second with 89.7 percent accuracy. Title feature remains the lowest in both training and testing cases and abstract feature remains second lowest. At training stage, MeSH feature performed better than standardized publication type (SPT), while at testing stage, it is reversed. Overall, in both training and testing, QRM performed exceptionally well on the combination of all features (title, abstract, MeSH, and standard publication type).

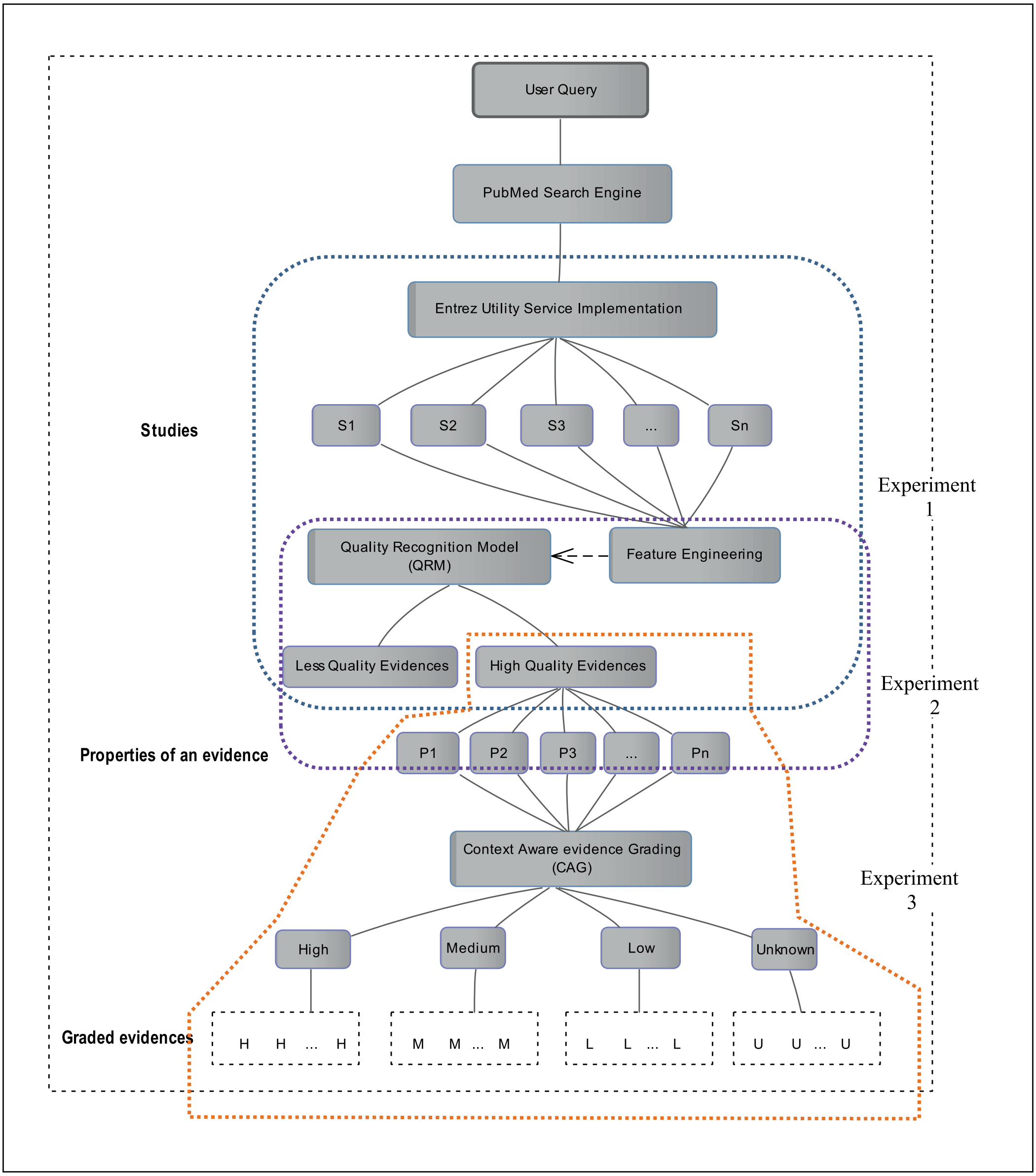

Figure 4. Proposed methodology implementation framework for conducting experiments.

Table 6. QRM accuracy on features separately and their overall combination.

Features	Title (%)	Abstract (%)	MeSH (%)	SPT (%)	Title, abstract, SPT (%)	All (%)
Training	76.28	82.81	86.4	85.71	89.7	92.14
Testing	73.31	75.46	76.9	79	78.15	80.15

QRM: quality recognition model.

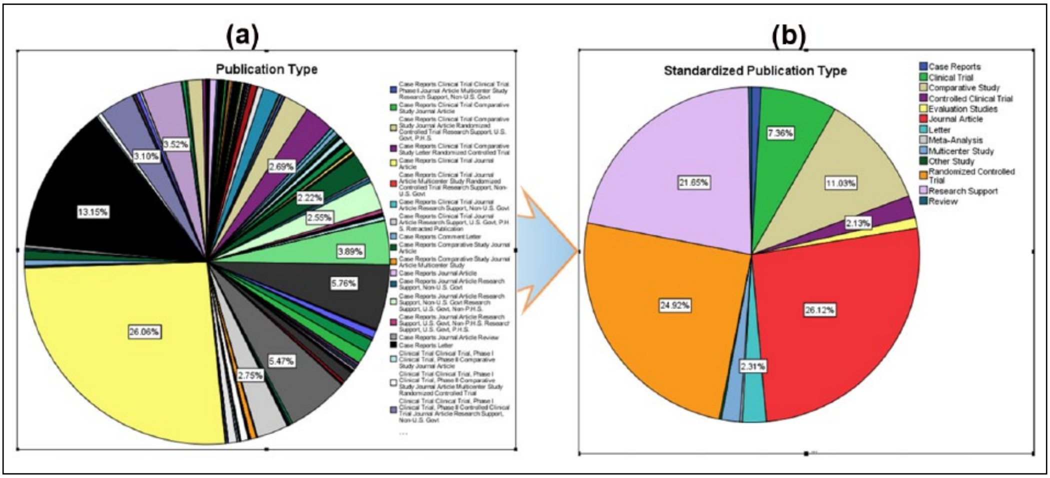

Figure 5. (a) Publication types and (b) standardized publication types.

Table 7. QRM performance on standard and non-standard publication types.

Recall (%)		Precision (%)		Accuracy (%)	
Non-standard	Standard	Non-standard	Standard	Non-standard	Standard
66.07	68.27	40.81	80.52	61.56	85.71

QRM: quality recognition model.

Experiment 2: QRM performance on standardized and non-standardized publication types

With Entrez eUtils service, we get the publication types for the 5682 articles in our training data set. Overall, 249 different variations are found in publication types as shown in Figure 5(a). Using algorithm 1, we normalized the 249 variations into 13 standard publication types having different frequencies as shown in Figure 5(b). We experimented the performance of QRM on 5682 documents on publication type both in default and standard form. Journal article, RCTs, and research reports are in the higher distributions of 1484, 1416, and 1230, respectively, depicted in Figure 5(b). The standard form publication type produced better results as described in Table 7. QRM performed exceptionally on standard publication type. The recall value showed about 2 percent, precision about 40 percent, and accuracy about 24 percent increase in the standardized form.

Experiment 3: CAG results for "physician interested in treatment" case study

The QRM model predicted 1355 out of 5682 documents as Rigor. Using equations (1) and (2), all 1355 documents are assigned aggregate value for the contexts as; user type = physician and user goal = treatment. As shown in Table 8, Out of 1355 documents, about 60 percent documents are graded as *H* which means highly beneficial for the physician to benefit in treatment-related clinical decisions. Other approximately 20 percent are graded as *M* (moderate beneficial), 8 percent as *L* (low beneficial), and 13 percent as *U* (unknown).

Table 8. Evidence grading distribution among high, moderate, low, and unknown.

Grade	*H*	*M*	*L*	*U*
No. of evidences	808 (59.63%)	266 (19.63%)	110 (8.12%)	170 (12.55%)

Table 9. Queries designed for retrieving evidentiary documents from PubMed database.

Query no.	Query terms
Q1	(Oral Cavity) AND (cancer AND head neck) AND (Therapy/Broad [filter])
Q2	(Oral Cavity) AND (T1 OR Clinical Stage 1) AND (cancer AND head neck) AND (Therapy/Broad[filter])
Q3	(Oral Cavity) AND (T3 OR Clinical Stage 3) AND (Squamous cell carcinoma) AND (cancer AND head neck) AND (Therapy/Broad[filter])

Table 10. eUtils web service URLs for retrieving evidentiary documents from PubMed database.

Query No	PubMed service URLs
Q1	http://eutils.ncbi.nlm.nih.gov/entrez/eutils/eSearch.fcgi?/db=pubmed term = Q1
Q2	http://eutils.ncbi.nlm.nih.gov/entrez/eutils/eSearch.fcgi?/db=pubmed term = Q2
Q3	http://eutils.ncbi.nlm.nih.gov/entrez/eutils/eSearch.fcgi?/db=pubmed term = Q3

URLs: universal resource locators.

The higher number of *H* graded evidence complements the QRM performance and also it confers the definitions of quality (Definition 2). Moreover, these evidences need to be evaluated from the experts in particular domains. In this study, since the documents are not related to any specific domain so human evaluation is not feasible to conduct.

Case study: results evaluation

To assess the performance of the models on a field test data, we perform experimentation on a real-world case study. The study is related to the retrieval of evidentiary documents pertinent to head neck cancer treatment decision-making. We utilize eUtils functions of PubMed and run the three types of queries described in Table 9. The reason of having three different queries is to test queries of various scales, small, medium, and large.

In the next step, universal resource locators (URLs) are generated as described in Table 10 for execution of these queries on the PubMed search service.

All the queries are executed on PubMed database and retrieve the evidentiary documents. The retrieved documents are processed and the processed documents are passed through the trained QRM. On the average, 17.53 documents are filtered out from the final set of evidentiary document list as shown in Table 11.

Discussion

QRM model

Considering appraisal using the SORT scale as performed in a very recent article,[15] we compared the results on the basis of same feature set. Unlike,[15] our appraisal model evaluates articles on two

Table 11. Performance results of QRM in terms of filter rate.

Query	No. of documents retrieved	Pred. rigor	Pred. non-rigor	Filter rate (%)
Q1	2218	1771	447	20.15
Q2	228	192	36	15.79
Q3	168	140	28	16.66

QRM: quality recognition model.

classes "rigor" and "non-rigor." The gold standard data set is not the same; however, we here present the comparison on the basis of feature set and machine learning algorithm equivalency. MeSH terms feature set is not included in their experiment, which produced better results for most of the feature sets in our experiment. Repeating the same method with SVM classifier proposed in Sarker et al.[15] on our data set and comparing the results, we obtained approximately 3 percent better results (89.7% increases to 92.14%) for the feature set that includes MeSH terms at the training stage as described in Table 6. At the testing stage, QRM showed 2 percent improved results (78.15% increases to 80.15%) as shown in Table 6.

CAG model

The proposed approach is different from existing approaches in terms of user context consideration for evidence grading. The existing approach[15] uses SORT[9] taxonomy to grade the evidences. SORT taxonomy is a strong system to determine a grade for an evidence; however, it may not decide whether the evidence fits in user context or not. Our approach introduced CAG; a scalable and robust method to include contexts applicable in a particular domain. The only requirement for the extension is the identification of values for the contextual mapping tables. The aggregation contextual vector (section "Context aggregation") parsing method is independent of contextual mappings' identification and population in the tables.

Feature significance

During evaluations, we noticed that publication type is the most influential feature to contribute in determining the quality of an article. This publication type feature has the highest accuracy level among the pool of evaluated features especially when it is transformed into a standard form as shown in experiment 2. In addition to publication type, the metadata feature "MeSH terms" has also produced good results. By combining both publication type and MeSH term features with data features; title and abstract produced the best and stable results across majority of the machine learning algorithms.

Limitations

The proposed CAG method requires prior contextual mappings for the aggregate vector generation. The proposed method will not be able to grade evidences where mappings of user context against the properties of evidences are not available. This limitation can be overcome by conducting a survey on a larger scale to cover multiple user contexts with maximum evidence properties and store the contextual mappings in a global repository or provide access for local utilization.

Conclusion

Getting high-quality evidence from a large volume of diverse literature is an important task in clinical care. Automation to improve the evidence appraisal process is still required for clinical efficiency. We demonstrate the automation at the evidence appraisal stage by developing a supervised classification model called QRM and CAG mechanism. This approach assists medical practitioners and other stakeholders making evidence informed clinical decisions in clinical setups.

We plan to extend context-aware evidence grading task creating domain-specific data set in order to make the evaluation more consistent and precise to a particular domain. The approval of evidence by domain experts will be a step toward generating domain-specific training data having characteristics of relevance and high-quality acquired by the methods presented in this study.

Declaration of conflicting interests

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A "matter of communication": A new classification to compare and evaluate telehealth and telemedicine interventions and understand their effectiveness as a communication process

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Abstract

This article attempts to define functions and applications of telemedicine and telehealth in order to achieve a simplified and comprehensive taxonomy. This may be used as a tool to evaluate their efficacy and to address health policies from the perspective of the centrality of information in the healthcare. Starting from a lexical frame, telemedicine or telehealth is conceived as a communication means and their action as a communication process. As a performance, the communication is related to the health outcome. Three functions (*telemetry, telephasis*, and *telepraxis*) and nine applications are identified. Understanding the mechanisms of telemedicine and telehealth effectiveness is crucial for a value-driven healthcare system. This new classification—focusing on the end effect of telemedicine and telehealth and on the type of interactions between involved actors—moves toward a new and simplified methodology to compare different studies and practices, design future researches, classify new technologies and guide their development, and finally address health policies and the healthcare provision.

Keywords

communication, decision-making, efficacy, eHealth, evaluation, taxonomy, telecare, telehealth, telemedicine

Introduction

Dramatic changes in the economic, regulatory, political, technical, cultural, and social environments in which healthcare organizations operate suggest that healthcare providers may need to re-examine their healthcare-delivery approaches for future success and survival.[1]

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The promise of improved quality, greater and fairer access to care, timeliness of service, shortage of medical personnel, and costs savings in healthcare provision has led to swift development of telemedicine and home-telecare services worldwide.[2–7] Today, it is difficult to find a country without an established telemedicine program or plans for developing a telemedicine capability.[8] A commitment to increased utilization of technology in healthcare was announced in the United States[9] and in European Union.[10] Moreover, "technology has become a basic factor determining the quality of the health services."[11] (p. 79)

Given this, and related significant financial investments, it is surprising that new applications are not rigorously evaluated.[12] Several challenges should be carefully considered before adopting technology: for example, strategic alignment, process management, patient satisfaction, performance measurement, and project management.[1]

In the last two decades, several authors[13–17] suggested the need of researchers to further explore issues concerning the effectiveness of information and communication technologies (ICTs), especially as a process enabler in healthcare organizations.[1]

This demands "innovative and interdisciplinary approaches to address efficiency, productivity, and quality of the health delivery."[5] (p. 591) However, it is difficult to address the complexity of ICTs systems[18] and make "valid generalizations about the effectiveness […] across disparate health services, technological configurations, and settings,"[19] (p. 317) without a unified classification as the basis for an evaluation framework. Indeed, the lack of a taxonomy limits the full understanding of the scientific and sociological issues impacting ICTs' use in the healthcare.[20]

Previously, ICTs were classified by user, purpose, operating method, type of technology, and field of application.[8,21–23] Two of the oldest and most famous criteria relate with the transmission of data:[2,4,5,8,24,25] timing (synchronous or asynchronous) and channel (e.g. wireless or wired). Another taxonomy for telehealth[26] considered four categories determining a telehealth encounter: type of interaction, location of controlling medical authority, emergency of care, and timing. More complex and structured classifications[8,25] labeled ICTs by clinical and non-clinical practices, diagnostic and monitoring uses, medical specializations, and organizational dimensions.

Nevertheless, a lexical confusion[8,27] still spreads in this field, even because of the continuous introduction of new terms (like mHealth or uHealth), often interchangeable and incorrectly used as synonymous.[8,27,28] The major reason of such a continuous evolution is probably the technology itself,[6] which has developed rapidly during the last decades in the healthcare sector, as in other fields of modern society.[3] Therefore, while any attempted taxonomy should not be based on a descriptive approach[29]—a technology-based lexicon, simply describing ICTs from a technological point of view, or considering the technological forms of their use (e.g. timing or type of interaction)—it must remain flexible and dynamic[20] at the same time.

The standpoint is that

> when we don't know which name we should give to things, and how they are ordered in their relationships, our problem is theoretical. But it has at least two practical consequences: it prevents us from drawing comparisons and adopting repeatable methods in […] research; and it hinders the identification of the most appropriate […] application in healthcare."[29] (pp. 601–602)

Without a unified, shared classification, we cannot frame the true mechanisms underlying the effectiveness and efficiency of interventions.[29,30] We also cannot understand whether the real scope of ICTs is to measure biological parameters, to enhance communication and relationship, or to trigger and to support behaviors. Actual taxonomies do not give us an answer.[29]

A basic conceptual framework for a new classification was provided by a previous study.[29] It starts from the core meanings of ICTs lexicon, acquired through an etymological analysis. Before all, it considers a domain (*telehealth*) and a subdomain (*telemedicine*), denoting the semantic background that justifies the use of ICTs. Even if there is not a uniform telemedicine application, telemedicine can be conceived as a subset of telehealth.[6,31] The prefix *tele-* implies above all a spatial distance between two actors (doers). (The two actors are not necessarily two individuals. As in the Shannon–Weaver model of communication, in order to perform a communication, we need at least a sender and a receiver. However, each of these two doers can be intended as collective entities. For example, the receiver may be a group of people or a population, as it occurs in media campaigns.) However, a "socioeconomic distance," for example, a "divide" caused by personal demographics, should be included as well: in this case, ICTs contribute to face disparities and inequalities in accessing healthcare services.[5,11,29,31] The point is "a separation of patient and doctor"[6] (p. 575) that is bridged through technology.[6] Because of such a distance, the healthcare action cannot be afforded without the help of ICTs.

An action qualifies both domain and subdomain, characterizing the relation between actors, "two different entities [who] are bearers of consumer and provider roles."[23] (p. 1108) When performed, the end user (the recipient, for example, a patient or a person without a disease but requiring some kind of assistance) must always be involved directly in the action; in other words, he is necessarily one of the two actors.[29] Even if a patient is lying inside a computerized tomography (CAT) scan, waiting for the execution of a tele-diagnosis, he is a doer: he is contributing to the action because the action cannot be accomplished (the content of the communication, the "image," cannot be taken nor exists) without him. Moreover, the other actor is always appointed by the health system to attend the action.[29] Therefore, contrary to other taxonomies or perspectives,[5,26] medical education, which occurs without a patient as a doer, is not considered here as a form of telemedicine, but rather as a form of tele-education about medicine, for example, the so-called telementoring;[2] it could be said the same of a consultation among physicians or specialists[31] (it does not necessarily involve the patient as a doer) or of an automated in-home monitoring system (it does not necessarily involve a health professional).

Actions[29] are as follows (Figure 1): (1) *Telecare*—it occurs when someone advances a generic (health-related) request for assistance. A disease is not necessary to evoke such a request, and the other actor is not necessarily a health professional. (2) *Telecure*—it characterizes the action of taking charge of a specific problem (a disease). Since it implies a specific expertise (curing, treating, or managing a disease), the other actor must be a healthcare professional. This perspective fits with the idea of "telemedicine as practice of medicine"[6] (p. 575) and is the most common among the definitions of telemedicine in the literature.[6]

Having established a semantic hierarchy in the lexicon of ICTs, the next step is to define functions and applications for the two actions or, in other words, their operative rules and purposes. In particular, the proposal of this study is the theoretical attempt to pursue a comprehensive classification which may be used to compare ICTs-based programs, achieving an improved evaluation of their efficacy, in order to address new health policies. This perspective is crucial for a value-driven healthcare system:

> The centrality of information in health systems … means that information and communication technologies (ICTs) that ensure the timely and accurate collection and exchange of health data are likely to foster better care, and the more efficient use of resources.[32] (p. 12)

Methods

Other taxonomies in the medical literature

Before all, classifications or taxonomies for ICTs' use in the healthcare were searched in PubMed and Google Scholar, using the following keywords in titles: *taxonom** (Boolean operator

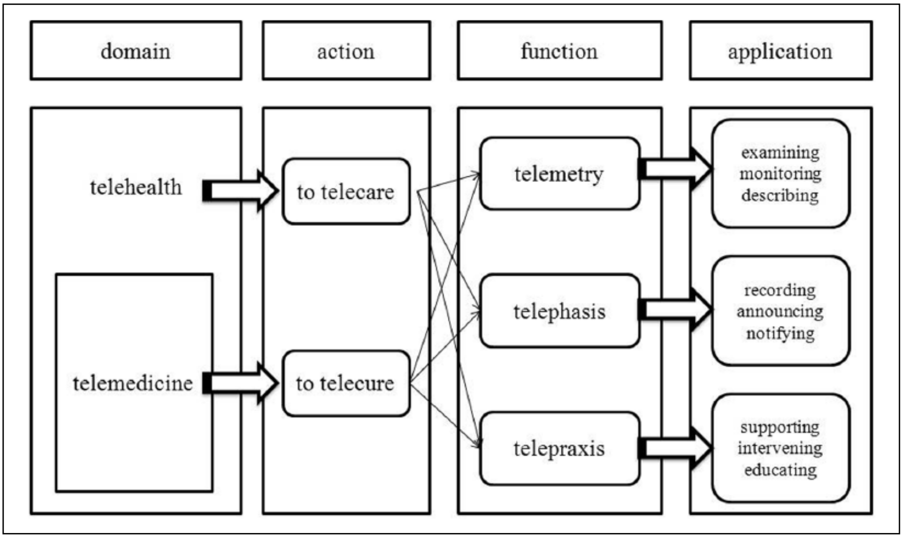

Figure 1. The classification: domains, actions, functions and applications.

OR) *classif*, catalog*, categor** matched with (AND) *information technolog** (OR) *telemed**, *telecar**, *telemonit*, telehealth, ehealth, mhealth, telesurg**, *teleconsult**, *teleadv**, and *remote*. Also, in PubMed, two Mesh keys were used: “Telemedicine/classification” or “Medical Informatics/classification.” Eight papers[4,8,20,21,23,25,26,33] focusing on ICTs classification, or addressing it, were considered.

An etymological starting point

Since words are the structural elements of every taxonomy, the conceptual framework of this classification will start again from the etymologies of ICTs lexicon, as previously attempted in another study:[29] this allow us to find out those intrinsic, non-contingent characteristics categorizing the essentials of ICTs phenomenon.

As mentioned above, the classification will be based on four categories:

1. Domains;
2. Actions;
3. Functions;
4. Applications.

This scheme finds analogies in the method for building systems already used for ICTs.[34] Since domains have been described elsewhere,[29] here we start from the second category.

The term “action” relates to the idea of motion: it comes from the Latin verb *agere*, “to do,” literally “to lead, to drive, to carry forward.”[35,36] Therefore, we may consider an action as a communication between two actors: it is a communication because it is a shared function, something that is put in common (*communis*, coming from Latin preposition *cum-*, “with, together,” and the noun *munus*, “function, task”).[35,36] Indeed, its effect goes from an actor to another.

Instead, a function—from the Latin verb *fungor*, “carry through, to an end”[36] or “to make a boundary”[35]—may be seen as a relation of any type, that occurs according to an intrinsic property. In mathematics, for example, it is a link between two variables determining the properties of a geometric entity (e.g. the equation of a parabola). Therefore, a function is a rule inherently capable of describing the non-contingent elements that an action owns. In particular, functions are relations developing in a communication process;[37] in the ICTs use, they occurs as the "exchange/sharing of information."

In this classification, while the operating mode of these exchanges is called "function," the concrete fulfillment of a function, according to its purpose, is called "application." In fact, "to apply" indicates precisely to juxtapose two things (from the Latin verb *applicare*, to "bring into contact";[36,38,39] by extension, "to assign, to attribute"). In the mathematical language, the application would be the co-domain, that is, an element associated with a domain (*health* or *medicine*) through a function.

Summarizing, in a given domain, an action is a motion from an actor to another: this creates a relation characterized by a property (function) and a purpose (application).

A matter of communication

Such a conceptual framework, however, relates to the following perspective: what mainly characterizes ICTs is a transmission (the "motion' we spoke about). Indeed, they remotely deliver a message or an "information by electromagnetic means."[40] However, ICTs are more than mere means: at a second sight, behind them we can see a real action, a performance; or, better, a process, that is a sequence of aimed actions.

Here, we consider ICTs as activities that integrate, store, analyze, retrieve, or transfer information.[41,42] The information processing and the resulting communication are aimed, as we said, they are used for problem-solving and decision-making in the healthcare sector,[5,43] for example, in order to generate knowledge, manage healthcare, or to make an event possible (an intervention, a medication, etc.). That is to say that the communication, in this situation, is strongly related to an outcome. Therefore, understanding the communicative aspects of ICTs in the healthcare sector is probably the key in determining their success[5] or, in other words, their effectiveness. As previously noticed, ICTs are used to support

> the provision of health care services—that is, to support communication … [In order] to reach that goal one must first understand what the communications are, and which related clinical tasks are actually involved in health care delivery process.[44] (p. 30)

Given such premises, and moving beyond the etymological analysis, ICTs can be conceived essentially as a communication strategy for sending messages remotely: because they perform an information exchange between a sender and a receiver, and in order to analyze them, we need to focus on the underlying communication process. Consequently, functions will be conceived as the communication rules of the actions, and applications as the concrete finalization of a single communicative act through ICTs.

For communicative functions, three levels[45] are identified, depending on the degree of complexity of related transmission:

1. *Integrated data*. Raw data have "no intrinsic meaning when standing alone."[43] (p. 361) However, they can be composed according to rules that specifying relations between signs (syntax) make them intelligible. A typical "data only modality"[5] (p. 593) of communication is telemonitoring.
2. *Meaning*. A meaning is attributed to the integrated data, according to the relation between signs and their designated objects (semantics). This happens when "data are endowed with relevance and purpose."[46] (p. 129)

3. *Behavior*. It occurs when the meaning of the data comes into a relation with a human interpreter (pragmatics), eliciting a performance.

The usefulness of this frame relates with the idea that the assessment of the efficacy of ICTs in the healthcare should discern between the mere information level and the level where we may find a modification of a condition—a health result or a health behavior.[33]

Results

In this proposal, a specific function encompassing all possible remote applications for the communicative act is defined for each level of a communication process (Table 1). The three functions are given as follows (Table 1):

1. *Telemetry (from Greek, tele- + metron, "measurement at a distance")*.[47,48] This function integrates simple data according to pre-established rules, so a first-level information is collected and transmitted. It encompasses activities such as monitoring, collecting a medical history, completing a questionnaire, and performing a CAT scan. The first step of a medical (or a healthcare) practice is collecting data, in order to address the cure/care action. Data are provided to generate knowledge. Also, we may consider a single or a continuous collection of data and their whole framing and organizing in a complex net of relationships. Related applications are therefore as follows:

- *Examining*. In Latin, an examen is the "tongue of a balance,"[35,49,50] so this term expresses the attempt to test and quantify data.
- *Monitoring*. This term is chosen because of its common sense in the healthcare field: "to check for, to control, to oversee." In Latin, a monitor is properly "one who reminds"[49] (p. 996) an adviser.[36]
- *Describing*. In the sense of "to draw, to mark, to describe,"[36,50] to portray entirely an environment, an individual, a population.

2. *Telephasis* (from Greek, tele- + phasis, "to declare, to make known, to show at a distance").[47,48] From previously gathered data (first-level information), this function generates a more complex and meaningful second-level information. Information is generated in order to be recorded, indifferently spread to some recipients, or transmitted to the recipients who have intentionally asked for it. Related applications are as follows:

- *Recording*: through this action something can be remembered, recalled to mind.[36,49,50] This includes several administrative applications.[2] This application is mostly focused on registering, storing, and retrieving information.
- *Announcing*: literally, "deliver a message to."[36,50] Here, for example, information is used to raise awareness in the population, through a media campaign. This application is mostly focused on spreading information.
- *Notifying*: literally, "to make known."[49,50] For example, in this case, information is used to express a clinical evaluation or a diagnosis. This application is mostly focused on the comprehension of information that is relevant to the end user, because it is the outcome of the healthcare assistance he requested.

3. *Telepraxis* (from Greek, *tele-* + *praxis*, "accomplishment, activity, practice from a distance").[47,48] This function uses the first- and/or second-level information to trigger and

Table 1. Functions and applications.

Function	Communication level	Action type	Content	Application	Example
Telemetry	Syntax	Integrating data	First-level information	*Examining*	A laboratory test, a medical imaging exam, and a clinical examination
				Monitoring	Monitoring vital signs and receiving emergency calls or requests for help
				Describing	Using environmental, demographic, and personal data
Telephasis	Semantic	Attributing meaning	Second-level information	*Recording*	Accessing a health registry, preparing a medical certificate, and downloading a medical report
				Announcing	Awareness campaigns, risk management, and advertising
				Notifying	A diagnosis, a prognosis, the outcome of intervention, and the results of a survey
Telepraxis	Pragmatic	Activating behavior	Behavior	*Supporting*	Sustaining adherence to medication or lifestyle changes and bioethical consultations
				Intervening	Prescribing a treatment, psychological therapy, and treatment at a distance
				Educating	Training at a distance on how to promote health or manage a disease

develop behaviors, to maintain them, or the transmitted information is the behavior itself (as discussed above, there is a correspondence between communication and performance;[37] in the healthcare system, this clearly occurs when the communication performs an intervention, for example, in telesurgery). Related applications are as follows:

1. *Supporting*: from the Latin *supportare*, "to carry near,"[49,50] to convey tailored information in order to sustain and give positive reinforcement to behaviors,[51] for example, periodic messages about a healthy lifestyle.
2. *Intervening*: literally, "to come between, interrupt."[49,50] It denotes an act or an event that change the natural course, and thus the outcome, of a condition or a disease (e.g. prescribing a treatment during a videocall, or remotely schedule a medication and release it through a delivery unit).
3. *Educating*: literally, "to bring out,"[36,49,50] "nurture."[35] It is the act to train and empower individual or communities—developing knowledge, skills and capability to use healthcare services—in order to improve health.[52]

Since *telemedicine* is a subset of *telehealth*, some functions relate to both, while others are specific: for example, *telemetry* can be used to monitor the progresses of a health promotion program (*telehealth*) or the progression of a disease (*telemedicine*); healthy people as well as patients may require a health/medical certificate (*recording, telephasis*), but prescribing a medication at a

Table 2. How to use the classification.

Example	Domain	Action type	Function	Application
A diabetic patient monitors his blood sugar levels at home. Data are sent to the physician via a telephone line	- The subject engaging in the action is ill (patient); - There is a distance (prerequisite); - The other actor is necessarily a health professional. →*Telemedicine*	The object of the action is an organic alteration →*Telecure*	The action generates data →*Telemetry*	The purpose of the data is to control the disease →*Monitoring*
A health promotion service has created a smartphone app that, during office hours, sends messages such as: "Don't use the lift, take the stairs!" to motivate people to get more exercise	- Subjects involved in the action are not ill; - There is a distance (prerequisite); - The other actor may not be a health professional →*Telehealth*	The object of the action is not an organic alteration. →*Telecare*	The action triggers a behavior →*Telepraxis*	The purpose is to maintain a healthy lifestyle →*Supporting*
A person at home download some blood test results from a laboratory website	- If the subject is ill (patient), the object of the action is an organic alteration →*Telemedicine* - If the subject only had a routine check-up, but is not ill →*Telehealth*	→*Telecure* →*Telecare*	In both cases, data gathered with the laboratory tests are second-level information →*Telephasis*	A document is created to store the information →*Reporting*

distance (*telepraxis*) is specific to *telemedicine*. Obviously, in all these functions, one of the actors must always be the end user.

Summarizing, the last structural elements of this new classification are (Figure 1) as follows:

1. Three functions: telemetry, telephasis, and telepraxis.
2. Nine applications.

Table 2 shows some examples about how to use the classification.

Discussion

Framing eHealth

The term *eHealth* was deliberately not included, because it is the paradigm of a lexicon describing a phenomenon from a merely technological perspective.[29] This term comes from merging "health" and "electronic." An electric circuit only carries electricity to power or actuate an activity. An electronic circuit (a type of electrical circuit), because it processes electromagnetic informative signals, performs a communication activity.[53–55] Thus, a washing machine is electric and a smartphone is both electric and electronic. The term *eHealth* denotes everything capable of generating health-related information by electromagnetic means.

In the scientific literature, *eHealth* characterizes virtually everything computer related.[56] It is like the other "e-words" (*e-commerce, e-mail*) used to describe Internet application,[56] as Internet expanded in the late 1990s—the term *eHealth* came into use in the year 2000,[57] and the World Health Organization (WHO) approved its eHealth resolution in 2005.[58] Even one of the best-known definitions of *eHealth*—"intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies"[56]—implies the ICTs use in the broadest sense.[57,59]

According to another definition, telemedicine is one *eHealth*-specific application.[11] (p. 80) Probably, *eHealth* is a hyperonym encompassing both *telemedicine* and *telecare*.[57] But, if eHealth "refers to all forms of electronic health care delivered over the internet,"[2] (p. 31) and telemedicine is something related to a professional,[29] eHealth could be driven by non-professionals,[2] including patients themselves[58,59] and also businesses and consumers.[2]

A systematic review[60] identified 51 different definitions of eHealth and no clear consensus on its meaning. However, two common themes emerged: health and technology. The former was mainly used to discuss the health service delivery, or the care process (it is related more to services and systems than to individual's health). Wellness was seldom evoked, and only one in four definitions focused on outcomes such as cost-effectiveness and efficiency. So, eHealth refers to "health care as a process rather than to health as an outcome."[60]

If eHealth is seen as a way to use Internet in the health sector, the word is merely a descriptive term identifying a communication channel or a technological means. In this case, it stands out of this new classification.[29] But if it identifies the use of "electronic technologies" in a broader sense and if (1) it is linked to health as the whole health sector, "health as a world" (systems, processes, organizations, as well as specific caring and curing activities) and (2) it does not necessarily depends on the concept of "distance" (*tele-*), then *eHealth* should actually be understood as the greater hyperonym to which *telehealth* and *telemedicine* belong, and with which they share a communication activity.[57] In this sense, this word describes all the actions that *telecare* and *telecure* encompass and some actions that they do not encompass, when

1. There is only one actor, the end user, for example, an individual seeking health information through Internet.
2. No end user is involved in the action, for example, a consultation between two health professionals or a surgical intervention in which one surgeon gives another surgeon instructions (tele-/e-consultation) and academic lessons (tele-/e-training, tele-/e-learning, tele-/e-conference).
3. The two actors are both end users, for example, exchanges of information within a social support groups or a virtual community.
4. The two actors are a patient and a physician, but there is no distance, for example, during a face-to-face anamnesis, the physician records the clinical history on a tablet (this may be defined an "e-medicine" application).
5. Information comes from impersonal actors, for example, monitoring air pollutants, an engineer collects data remotely by means of sensors.

For all these reasons, the term *eHealth* was not included: it is only indirectly linked to the concept of health, as previously discussed,[29] and it does not necessarily implies a distance, nor an end user.

Why do we need a new taxonomy?

The first argument is simplification. Although this classification introduces new terms (Figure 1), it is based on 16 "words" (17 if we include the prerequisite "*tele-*"), encompassing both telehealth and telemedicine. The most developed taxonomies we considered uses 15[8] or 14[25] elements to classify only telemedicine (the former provides three additional domains—telehealth, eHealth, and mHealth—each owning four elements). So, we found a more comprehensive simplified structure that works following a linear, hierarchical, one-directional flow, while other taxonomies are three-dimensional.

Second, this classification will ease comparison between different studies and various ICTs practices. It is an urgent need to compare trials with a rational, orderly, and reproducible method. Published studies present interventions with a high variability of components. Reviews usually group and compare them using a common contingent element (e.g. a disease, a technology, and a content); however, this is an empirical strategy, applied without considering critical components as actors' involvement, type of performed action, and underlying mechanism. As long as we compare studies relying on descriptive elements, it is hard to understand why an intervention is effective. For example, trials are often described focusing on technology, as it was effective by itself; instead, we should analyze them examining what technology makes happen[61,62], the communication process (i.e. the interaction between actors) that ICTs allows and strengthens (Table 1). This classification goes beyond the communication channel or type of technology involved: if we consider a behavior supported by a text message, an app, a telephone call, or an e-mail, these different means all imply the same communication process, the *telepraxis* function. If a medical report is sent by e-mail, but is received and read on a smartphone, it is not a matter of eHealth or mHealth: despite the combined technologies, a common purpose classifies the intervention as a *recording* application (see Tables 2 and 3 for further examples). We can also compare ICTs regardless of setting. For example, it is useless to distinguish between home-provided or workplace-provided *telecare*, as some papers claimed:[63] the setting, like the demographics of the actors involved, is a contingent element. It may influence the efficacy of the action, but it does not qualify the action itself.

The third argument is the chance of a new methodology, a framework that may "be used as a reference for evaluation studies."[33] (p. 191) Because the need to understand the true mechanisms of effectiveness should be the main aim of research on ICTs, this classification may guide in designing trials and reviews, focusing on the end effects (application) and on the type of interactions between actors (functions). Indeed, other methods (Table 3) compare interventions with different components, each of them potentially affecting outcomes, with a loss of information and the risk of confounding. Such a new proposal provides a more detailed analysis degree, because it examines an intervention discriminating its underlying process separately and progressively, limiting or avoiding overlapping, but allowing different combination of categories (components) to form "complex networks"[33] of ICTs-based interventions (see Table 3):

- In domain-based analysis, grouped interventions have comparable actors.
- In function-based analysis, grouped interventions have also comparable activities (here, the focus is on the type of action performed, that is, the dynamics of interaction between actors).
- In application-based analysis, grouped interventions have comparable mechanisms of action (the focus is on the purpose of intervention, the pursued effect).

Finally, assessing ICTs under an "actions and functions" perspective may allow to identify more accurate indicators for measuring outcomes, leading to an improved decision-making process when planning an intervention is crucial.

Once clarified the role of functions and applications in affecting effectiveness, further research may address the role of other components as setting, target, organizational model, and patients' and providers' perspectives. This study does not intend to address this topic: if anything, such an objective

Table 3. New methods to compare ICTs-based interventions.

Examples of ICTs-based intervention in chronic disease management (end user is a patient)	Possible evaluation according to actual classifications	Possible evaluation according to the new classification
Trial 1: peer-support through social networking. *Trial 2*: online portal with educational contents and a tailored program (physical activity and nutrition) written by health professionals. *Trial 3*: individualized education (through videophone sessions) by a trained nurse. *Trial 4*: self-management based on self-monitoring and an Internet-based computer program (tailored goal settings and educational contents). *Trial 5*: monitoring of vital parameters and feedback by physician (a biweekly e-mail report with trends, advices, and encouragements). *Trial 6*: a program to self-manage the medication delivered through a mobile application. *Trial 7*: monitoring and telephone follow-up (twice a month) by a trained nurse, with advices and educational contents. *Trial 8*: monitoring intervention data are gathered and elaborated through a mobile application. Data are accessible to the patient only. *Trial 9*: monitoring intervention data are gathered and elaborated through a mobile application. Data are sent to the physician (SMS) *Trial 10*: the Health Department sends periodic SMS, with practical tips to prevent the disease, to local population (affected and not affected people)	*Telemonitoring interventions* (trials 4, 5, and 7–9). Common element: a monitoring device (technology). *Disease management interventions* (trials 1–10). Common element: the disease. *Internet-based interventions* (trials 1, 2, 4, and 5). Common element: Internet use (technology or communication means). *Phone-based interventions* (trials 3 and 7): Common element: telephone (technology or communication means). *Nurse-based interventions* (trials 3 and 7). Common element: the health professional (actor). *Mobile-based intervention* (trials 6 and 8–10). Common element: functions of a mobile phone, for example, apps or SMS (technology). *Educational intervention* (explicitly trials 2, 3, 4, 7, and 10; may be 1 and 5). Common element: education (content). *All trials are grouped despite of actors' involvement, type of performed action, and underlying mechanism of interventions.*	*Domain-based analysis*: *Telemedicine/telecure interventions* (trials 2, 3, 5, 7, and 9): end user is a patient and other actor is a health professional. *Telehealth/telecare interventions* (trials 10): end user is not necessarily a patient, other actor is a health professional. *eHealth interventions* (trials 1, 4, 6, and 8): there is only one user (the patient), or all the actors are patients. *All grouped trials have comparable actors.* *Function-based analysis*: *Telemetry-based interventions*: - As a component (trials 5, 7, 9) - Telemetry alone (trials 9) *Telepraxis-based interventions*: - As a component (trials 2, 3, 5, and 7) - Telemetry alone (trials 2 and 3) *Telephasis interventions* (trials 10). *All grouped trials have comparable activities.* *Application-based analysis*: *Education-based interventions*: - As a component (trials 2 and 7) - Educating alone (trial 3) *Supporting-based intervention*: - as a component (trials 2, 5, 7) *All grouped trials have comparable mechanisms of action.*

will be the next step of our research; moreover, in another study, our aim is to show the effectiveness of this new taxonomy in reviewing telemedicine and telehealth applications.

At present, therefore, we hope that this new approach will help researchers in developing more studies and evaluations on this topic and clinicians and health providers in making decisions about which telemedicine or telehealth intervention is the most suited to implement, according to the action and the purpose they pursue.

Some other theoretical issues

As previously discussed,[29] the opposition between health and medicine[8] is solved, and the latter is integrated in the general dimension of the former.

The lexical reduction was achieved at the expense of some words often used in the medical literature. It seemed inappropriate to include contingent terms such as "mHealth." Technologies change faster than concepts like health and medicine, so merely descriptive terms should not be considered as structural elements in a taxonomy. If new ICTs (or new medical specialties) will be invented and introduced in the future, this classification may be flexible enough to accommodate them, without adding new categories. Historical terms, such as telemonitoring, may be included in the classification according to their function and purpose (for telemonitoring, these are *telemetry* and *monitoring*, respectively), but only as descriptive terms, not as categories.

The greatest limit of any classification based on words lies in the words themselves. This classification is grounded in a Greek-Roman or English lexicon, and it may not be adaptable to other cultures or languages.[29] This can pose a challenge, as already identified for the general use of ICTs.[64]

Conclusion

In this new classification, *telehealth* and *telemedicine* are qualified as a communication strategy involving an action (*to care* or *to cure*) taken remotely. This action has three main functions, corresponding to the level of complexity of the communication process.

The terms *telemetry, telephasis*, and *telepraxis* are introduced to describe such functions, each further defined by applications and their specific purposes. The stability of the new classification depends on the stability of the meanings of its words. The structure is built on a logic pathway, proceeding from core meanings to purposes: thus, the ICTs phenomenon is theoretically justified and not only described from a technological perspective. It analyzes the underlying communication process, that is, the action itself, and therefore is related to the health outcome: this allow to better evaluate the ICTs' effectiveness. Finally, the simplified comparison of different ICTs-based practices will be useful for further research in order to address health policies and the healthcare provision, classify future ICTs, and guide their development for a better response to the health need.

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