Collaborative Symptoms Interpretation for Cardiac Patients as Diagnostic Agents

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ABSTRACT

Home monitoring of cardiac patients with an implantable cardioverter-defibrillator (ICD) holds promising benefits such as improved mortality rates, but HCI research shows that patients dislike the passive role imposed by current home monitoring technology. In this paper, we report from a study on how cardiac patients reacted to taking on a more active role of being a diagnostic agent. We developed and implemented a technology probe for reporting symptoms and other health metrics to health providers daily and studied ten ICD patients interacting with the probe for eight weeks. Our analysis resulted in three themes; patient reflection and obsession, patient roles and responsibility towards healthcare staff, and opportunities for nurses to use reports at the hospital. We contribute to HCI research on home monitoring by discussing the role of the diagnostic agent and the potential for implanted chronic patients to engage in collaborative interpretation with health providers.

Author Keywords

Home monitoring; diagnostic agent; collaborative interpretation; technology probe.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

INTRODUCTION

Technology plays an increasingly important role in people's homes as we integrate and embed more and more devices in our everyday lives. One of these technologies in our homes are systems that enable people or patients being monitored remotely while at home by caregivers, e.g. hospital staff or family. This is often referred to as home monitoring.

Figure 1 A patient reporting through CardioTalk probe

This paper deals with cardiac patient home monitoring and in particular patients with an implantable cardioverter-defibrillator (ICD) device connected to a home monitoring service. Such patients are at risk of sudden death, e.g. due to uncoordinated contraction of the heart muscle [10]. Thus, home monitoring of ICD patients provides extra safety as it gives access to clinical patient information, and studies have shown that such home monitoring is very successful in terms of e.g. mortality rates, reduced costs, and reduced number of in-clinic visits [8].

Despite significant advantages, a number of challenges characterizes such home monitoring. First, existing home monitoring places the ICD patient in a passive role where data is automatically collected and transmitted and where no patient input is directly required. While research has shown that patients usually would like to play a more active role or be more involved when being monitored [3,9] and Skov et al. found that the passive role sometimes lead to increased anxiety [25]. Secondly, ICD clinic health caregivers often have to request and collect additional information from the patient when they receive an alarm from the home monitoring system in order to properly evaluate the alarm. This is often quite resource demanding as patients have to be contacted over phone, and recall past events.

The concept of a diagnostic agent for cardiac patients was introduced by Oudshoorn, and recently applied to ICD patients by Andersen et al. [3,20] who studied how patients could provide information about their situation while at home and just before going to a scheduled control at the hospital. In this manner acting as a diagnostic agent in collaborative interpretation with health providers. However, we still lack empirical studies on how patients can contribute with information about their own lives, symptoms, and general health condition, and how technology can play or should play a role in this contextualization. This paper presents a study where we designed a technology probe for

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ICD patients called CardioTalk, parallel to existing home monitoring, with the purpose of exploring how ICD patients react to taking on a more active role in monitoring and how patients engage in interpretation of own condition, in a collaborative effort with health providers. As well as, how health providers interpret ICD data in collaboration with patient generated data. This study contributes with insights from daily long-term reporting to explore the potential for use in between and in consultations, both unscheduled and scheduled, when information is available to review for both patients and health providers.

RELATED WORK

Interacting with monitoring technologies in the home and patient generated health data is not a new area for HCI research. Recently home monitoring for ICD patients has focused on the patients' perception of monitoring [9,25] or possibilities for collaboration in monitoring illness from home [3,16].

Patient generated health data as collaboration

Recent research has suggested that patients can and should contribute with valuable knowledge about how their illness is experienced in their everyday life and collaborate on diagnosis and treatment [2–4,24]. In home monitoring, it is worth understanding how treatment prescribed by health providers in hospital, can meet the routines of patients' everyday lives at home [4]. Traditionally the patient has been viewed as a receiver of information, with the health professional as a provider of information, diagnosis and treatment [2]. However, patients want to understand how their actions impact certain clinical parameters and there is a need for supportive tools for this [4,21].

Patient-generated health data is a concept that actively include the patient in collaboration, to contextualize single measurements and provide own interpretations and sense-making of their illness [1,3,4,7,12,17,24]. Visualizations are often used to provide overview of collected health data, in asynchronous collaborative systems [24]. As well as encourage to engage in experimentation with own health and wellbeing, while at home, by introducing a measure of patient control [12]. Ballegaard et al. emphasize it is important that patients can initiate measurements themselves and preferably integrate it into other digital tools they are already using [4]. A broad range of technologies exist for collecting information about activity and context, often mobile devices. In an effort to, among other things, control their health and manage healthy behavior (e.g. [7,14]). However, few of these are accepted for use in clinical practice, as they are not understood or accepted by health providers. Studies have found that doctors doubt the data quality and credibility of the measurement equipment, as well as argue there are insufficient resources to make out what is of clinical value [1,26]. Additionally, health providers trust in patient interpretation of own wellbeing can be an issue [1,24].

Collaboration in ICD Home Monitoring

Home monitoring devices is an often seen solution to moving healthcare services out of the hospital, into everyday life and into the homes of citizens. In this paper we focus on home monitoring for a heart patient group with implanted devices; Implantable Cardioverter-Defibrillator (ICD). An ICD is a battery-powered device that combines a cardioverter and a defibrillator into one implantable unit. ICD patients are typically at high risk of sudden death. Thus, ICD devices have been introduced in order to restore the normal cardiac activation sequence by means of electrical therapy, to treat a malignant arrhythmia (irregular, slower or faster heartbeat than usual) [8,25]. The implanted unit collects information automatically, and when coupled with a stationary monitor, transfer this information to the hospital [6]. The implanted device can easily function without the monitor, but coupled with the home monitoring it shortens the time from the onset of relevant medical and technical events to evaluation by health provider.

As the device is implantable, it differentiates itself from other medical technologies for chronic illness (e.g. glucometers for diabetes care). The implantable device is always physically present, vital for the patient's well-being and most often even life critical, consequently the patient can't walk away from it. This interaction mode leaves patients passive. Within HCI research, studies have emphasized issues of privacy and safety for ICD patients. In a study by Denning et al. ICD patients rejected proposed safety interventions that left them passive and not informed about decisions involving their device [9]. Despite this, recently Skov et al. found that ICD patients were often unaware of what information is shared, with whom and for what purpose [25].

Studies argue that with the right tools, patients are able to co-interpret their symptoms into actionable treatment plans, together with health providers. A practice that Andersen et. al. concludes is not present in current ICD home monitoring set-up, where the distributed consultation represent the patient primarily in form of numbers and graphs, compared to the former collocated consultation. They argue that this seriously 'disables' data interpretation in cases of uncertainty [3]. In a study by Pollack et. al. authors suggest that using HCI methods to (re-)design health technologies for use outside of hospital has potential to bridge resource and knowledge gaps faced by patient and health provider [21]. Andersen et. al. concluded that using their myRecord application for collaborative interpretation proved successful at re-introducing patient interpretation for ICD data and wellbeing just before going to a yearly to biyearly scheduled consultation [2,3]. However, as these long intervals between consultation has been made possible, we see the potential value of including patient-generated health data and interpretation on a more frequent basis.

THE STUDY

To explore how ICD patients respond to taking on the role of a diagnostic agent in their home monitoring, we involved

ICD patients from the Aalborg University Hospital (AUH). Involving patients in studies requires certain methodological and ethical considerations, of which some are particular to the severity of chronic illness and living with an ICD. The focus of our study was on how these patients responded to regular reporting of their current health status. We also wanted to understand the value of this reporting to health providers.

Methodological and Ethical Considerations

We needed to make both methodological and ethical considerations for this study, as ICD patients have severe chronic illnesses. Studies have shown that ICD patients often suffer from psychological stress, such as fear of death, anxiety or depression [15]. As well as these issues to be considered, Oudshoorn and Nielsen argue that patient involvement in (digital) reporting often introduces unnecessary work and demands on the patient [18,20]. Since we wanted to know about things that happen in their home, we needed a data collection method that was not perceived as overly intrusive on their daily habits and personal space and suitable for ‘in the wild’ deployment [22]. Intervention methods such as diary writing, (technology) probes or prototypes have been successfully used in HCI research, for health awareness (e.g.[4,5,12,17]) and cardiac patients (e.g.[2,16,25]). Technology probes work by installing a technology into a real use context, remotely logging how it is used over a period of time and reflecting on that use. It is not a prototype, but a tool that can inspire design of future technologies [11]. We chose to use a technology probe for our study, because it is a real-time data collection method sensitive to people’s privacy and autonomy.

For the study we were granted ethics approval for non-invasive studies by AUH, as well as complying with the principles described in the Helsinki Declaration on ethics for medical research involving human subjects [27]. A study nurse trained in cardiac research studies and an ICD-clinic registered nurse participated in the study both as collaborators and informants. Their role was to assist us with all patient contact. Additionally, they ensured that participants felt safe and had confidence in the credibility of the study. All participants signed a consent form, after receiving information about the study. Our consent form stated that all participation was voluntary, and that at any point participants could withdraw or refuse to participate in activities without consequences. Furthermore, we ensured that all information collected was anonymized.

Home Monitoring at Aalborg University Hospital

The way that home monitoring typically works is that a monitoring device is installed in the patient’s bedroom, which wirelessly connects to the ICD implant. Once every night the monitor pulls data from the ICD, if the device is in range, and transfer that data to AUH. Nurses will be notified if anything have occurred that would trigger an alarm e.g. heart rhythms are out of individually set bounds. The particular monitor used by participants in this study relays information daily regardless of whether alarms are triggered. When a nurse receives an alarm or an irregularity in the readings, they review it and if additional clarification is necessary they contact the patient by phone and/or talk to a specialist. If defibrillation has been delivered, the nurse will ask the patient to attend a follow-up consultation at the hospital. Regular follow-ups also happen at scheduled intervals, for elaboration see [25].

CardioTalk

We created a web-based application, CardioTalk, to act as our technology probe and to facilitate users submitting daily reports about their health. The probe information can then be used in combination with the ICD home monitor readings to give nursing staff a better understanding of the participant’s health status. The probe was designed through interviews and a design workshop, which took place few months prior to deployment.

Design Workshop

The design workshop included health providers from AUH specialized in heart disease, as well as a product specialist from Biotronik, the company who manufactures the home monitoring equipment used by our participants.

Design

The design of CardioTalk was informed by the design workshop. It comprises two design components, namely the patient and health provider interfaces. The patient interface is concerned with how they can submit reports or browse their history, while the health provider interface is used to review patient reports.

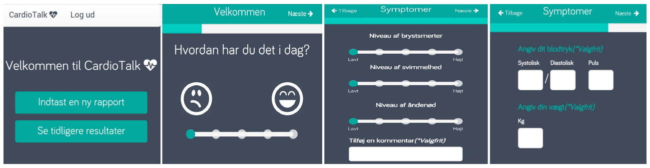

Figure 2 Screenshots from CardioTalk probe

Patient Interface

The patient component of the system is accessed via a personal mobile device (i.e. smartphone or tablet) and enables patients to make reports regarding their health status by answering a set of questions. Patients can quickly answer these questions using sliders (e.g. on a scale from low to high), but there is also the possibility to make additional comments, if they want to elaborate on their symptoms. CardioTalk also has a feature that lets participants view their previous reports. We added visualization of the reports in grouped plots, for the purpose of increased awareness of their own health and progress.

The questions posed are grouped into three categories, which are: *physical symptoms*, *health metrics*, and *psychological symptoms*. Questions on *physical symptoms* were limited to three commonly occurring symptoms for this patient group: chest pain, shortness of breath and dizziness as reflected in questionnaires used for this patient group for research (e.g. OASIS, SF-12 and MLHQ). Questions on *health metrics*, such as, blood pressure and weight were optional as not all participants had equipment for measuring them at home. Nurses said that these measurements could be beneficial when compared with the ICD readings, although, they are not normally captured during regular consultations. Questions on *psychological symptoms* enquired about general mood and levels of stress and anxiety, as these are often seen in ICD patients [15].

Health Provider Interface

In the health provider component of the system, they can select which patient's results to review. For each patient, data displayed are grouped according to patient report structure and arranged in tables with report submission dates and times. Date and time are essential for comparison with monitored readings in a parallel system. Additionally, diagrams are plotted for each table, as requested by nurses, to provide an overview of the patient's results.

Participants

Ten ICD patients (3 female) agreed to participate in our study. The average age of participants was 62.4 years (min-max; 45-74 years). They had lived with implanted devices from 7 months to 15 years, on average almost 6 years (M=5,8). Seven out of ten received the ICD after experiencing a near-fatal episode (blood clot or cardiac arrest), the remaining had the ICD as an elective procedure. All participants had an implant and monitor from the manufacturer Biotronik.

Regarding occupation, three of ten was full-time employed. The remaining seven were retired, whereof three held part-time jobs or freelancing. Together, they represented diverse socio-economic backgrounds, as they were or was currently occupied as teachers (kindergarten and public school), university professor, blacksmith or project manager. One participant had worked in healthcare, as a carer for elderly, while additionally two had spouses who was currently working as healthcare professionals. All participants in the study told us that they used mobile technology every day and self-assessed that they were relatively competent or even expert users. Except for one participant, who happens to be the oldest participant in the study, who only recently acquired a tablet. Only one participant was familiar with using health applications on the smartphone regularly. All participants, except for one, was living together with someone whom they were in a relationship with.

Participants were recruited using specific inclusion criteria, that is, they had an ICD implant and owned a smartphone or tablet with internet access. Each participant was given a personal account in the system. As we did not have access to personal patient information, collaborating nurses advantageously chose and established contact with candidates for the study. Three out of 13 possible candidates, did not end up participating. One did not feel like participating, while the two others did not have access to a mobile device or internet connection.

Three participants had a cardiac resynchronization therapy defibrillator (CRT-D), which compared to the ICD has three leads instead of only two. CRT-D is the device primarily used for heart failure, the patients are often more fragile and are at greater risk of frequent events and symptoms. With regards to home monitoring, the procedure is the same, consequently we will continue to refer to both as an ICD.

Procedure

The study lasted eight weeks, during which time we conducted three separate interviews with each participant. Additionally, we held an interview with the collaborating nurses. Participants were not compensated for their participation, except for covering travel expenses.

First interview - Deployment and reminder

The purpose of the first interview was to obtain formal consent from participants and explain the study protocol. We set up the technology probe, CardioTalk, on their personal devices. We demonstrated and guided participants on how to use the system until they felt comfortable using it at home without our assistance. One week into the study we contacted all participants by phone, to remind participants of the study protocol and to inquire of any potential problems.

Second interview - Follow up and Understanding

The purpose of the second interview was to offer participants a consultation with a nurse based on their reports, and to talk with them about their experiences with CardioTalk. This interview took place between three to four weeks after the first interview, at the hospital but outside the usual consultation environment. The collaborating nurse was instructed to view reports from participants once a week, and in the case alarms were detected. The following interview, carried out by the authors, was semi-structured.

Third Interview – Reflection and Debriefing

The purpose of the third interview was to follow-up with participants, and ask them to reflect on their extended use of CardioTalk. This was done over the phone focusing on any observations we made on their patterns of use and to elaborate on particularly interesting findings. This was also a debriefing for participants.

Nurse Interview – Perspective and Reflection

The interview with the two collaborating nurses aimed to get feedback on their experiences with CardioTalk. We wanted to know how they perceived the corroboration between the reports submitted by participants and the ICD monitor readings. The semi-structured interview took place at the hospital and was conducted two weeks after the third interview. At this time, we made a presentation to the nurses of our initial findings, to inspire discussion and reflection.

Data Collection and Analysis

We employed hybrid data collection [13], using two different sources of data, which supplemented each other. Firstly, we used digital logs of participant reports from CardioTalk, and secondly we used interview data. The participant logs gave us empirical data about how participants interacted with the system in their homes. This data was then used to inform the design of questions for our interview guide. Interviews were organized using the guide to provide contextual high-order details, based on pre-prepared research themes, as these details could not be learned from the automated logs alone. Data from patient report logs were also used in interviews, to improve recalling. Through participant consent, we audio-recorded all interviews.

For analysis, inspired by the study by Kendall et al. [12], we made use of the affinity diagram technique to find natural relations between data, as a joint undertaking by two researchers. We iterated on themes, until relatively atomic connections presented, the output of which is highlighted in the findings section.

FINDINGS

In our analysis of interviews and probe logs, we have identified three themes that characterize cardiac patients when acting as diagnostic agents. These themes concern patient reflection or obsession, patient roles and responsibility towards healthcare staff, and opportunities for nurses to use reports at the hospital. All participants are anonymized. We refer to cardiac patients as P1-10 and nurses as N1-2.

Patient Reflection and Obsession

Our first theme focuses on the cardiac patients' transition to diagnostic agents. Andersen et al. argue that this is a big shift from being a passive source of device data to being engaged and active [3]. We found that some participants started to *reflect* upon their situation and condition (usually positive) whereas other participants were afraid to become *obsessed* with their illness (usually negative).

Reflection can be seen in the ways that reports inspired thoughts about current situation and health condition and was usually considered something positive. As an example, P5 stated that "*You think about; how has your day been? Instead of just carrying on.*" CardioTalk also made visualizations of report history available to each participant. Although most participants had relatively stable, and in their own words "*predictable*" report history, they expressed a potential value of these representations: *"Now, let's say that suddenly the numbers start to change, you might have some benefit from going back and seeing; how was it really"* (P6).

One participant experienced an incident, where a non-health related event influenced their report; *"When I wrote about my friend's death, then I thought they* [reports] *were good. But when everything is normal, you have no use of it. However, nobody can promise you that it's going to be normal tomorrow."* (P3).

Several participants appreciated having a temporal record of their symptoms, as it helped them to detect variation in symptoms. Three participants felt that reporting daily was ideal to establish a baseline and to make reporting a normal part of their everyday routine. Whereas the remaining seven argued that frequent reporting on own initiative was preferred. All agreed that reviewing the reports was mainly useful episodically, at times when a lot of variation in symptoms occurred. Two of the participants (P4, P8) already had experience with (analog) symptom logging. P4 started this because of fluctuations in symptoms and was able to recognize, from experience, that headaches was most often due to high blood pressure and did not require immediate medical attention. P8 additionally suffered from diabetes and kept records of blood pressure measurements.

Obsession was articulated as an experience of emotional loss of control and thus, perceived as something negative. Participants expressed strongly that technology can't be allowed to "control you" - "*All the pulse-watches and what not people are carrying around... you have to be careful, when it suddenly shows you something, that you don't panic.*" (P5). Seven participants feared that with the introduction of daily reporting, thoughts on illness would take up too much space and become an obsession. P9 shared the view that measuring health metrics can have negative health consequences, e.g. blood pressure measurements would cause higher blood pressure; "*What is happening in here is so delicate, that you can feel when something is not right, you can feel it right away. I don't need a machine to tell me that. I can feel when my* [heart] *rhythms are not right.*" (P9)

While they wanted to be in control of their health, focusing daily on how they felt and whether their symptoms had changed could sometimes have the opposite effect. We saw a tendency in participants to want to ignore or suppress some symptoms, particularly stress and anxiety, as five of the participant claimed that they had a negative impact on their sense of wellbeing. P4 reported, "*I try not to be the heart patient I am ...I do not want to be ill, I do not want those labels on me, I just want to be here.*" P2 simply disregarded symptoms when asked if s/he felt generally healthy, "*I can't very well convince myself of that, but I will try to live like that anyways*".

That being said, participants also expressed more healthy habits to deal with anxiety and stress; "*Sometimes I just take my pulse and I assure myself that it can't be all bad...If your body is doing something, your brain can start to imagine all sorts of things.*" (P5). Participants would carry certain items such as a mobile phone, always in close range for emergency situations. Even if they never had a need for these items in relation to their illness, just knowing they had them gave a sense of security.

Patient Roles and Responsibilities

The second theme concerns the roles and responsibilities of a diagnostic agent. Compared to current ICD home monitoring, our participants were placed in more active roles in providing symptoms to the healthcare staff, and this raised issues.

The new role for the participants afforded answers to questions that they both wanted and needed to know more about, to properly act in this role of diagnostic agent. Participants valued the positive benefits of the home monitoring. Despite this, they expressed doubts about how to interact with the physical monitor. We observed that half of participants asked us and nurses questions about home monitoring during interviews. Issues that were not clear to them included understanding about appropriate proximity to the monitor, how to know whether transmissions of data from the ICD were successful or not, and insight into what information was available to nurses, e.g. *"...maybe we go around thinking something at home, while something entirely different is going on out here* [hospital]*, then maybe there is a need for a different type of information*" (P5).

The responsibility of taking initiative to act on a symptom presenting itself, was not clear for all. As an example, P2 argued that the healthcare staff at the hospital would have all the information they needed: "*When I come for a scheduled consultation, it will show everything from that half a year where I haven't been.*" However, we found that all participants expressed doubt or directly asked questions about how home monitoring worked. N2 explained that, sometimes, patients come into the emergency room, and they are confused about why nurses have not contacted them. Tragically, N2 pointed out that this confusion could be potentially dangerous for the patient: "*If the box (ICD data) says 'everything is fine', but the patient is very ill, then you have a problem.*" P2 was hospitalized during the study. To our surprise s/he kept reporting which clearly affected the reports, allowing details about experienced changes in symptoms.

With CardioTalk, participants were aware of and informed on what information the probe was sharing with the health providers and they felt in control of when and how often they shared this information. They assumed it would be helpful in a scheduled follow-up consultation with the nurse, as the information from CardioTalk was visible to both of them. This detailed information would otherwise not be easily accessible to health providers prior to consultations.

For the collaboration to be successful, it requires trust and openness to both the interpretation of the diagnostic agent and the health provider according to Andersen et. al [3]. Participants point to a personal connection with nurses. P3 jokingly said "*it is almost like she is my girlfriend, that's how much I appreciate her.*" For all that, P6 feared that nurses would see patients' own interpretations as irrelevant since they did not have the appropriate medical insight. This was quickly dismissed by both participating nurses. Participants saw the potential for regular reports to aid recalling past events regarding illness as this is not easy to retain in memory and, as a responsibility of the diagnostic agent, to provide this insight to nurses.

Collaborative Interpretation at the Hospital

The third theme focuses on opportunities (and limitations) for nurses to experience the value that the participants, as diagnostic agents, brought to the collaborative interpretation. Our participating nurses were asked to look at patient reports via CardioTalk throughout the study.

Collaborative interpretation demands sharing symptoms information, in order to reach an informed actionable plan. All but one participant used the comments feature to varying degrees. In the interview set up as a consultation, we experienced how nurses used this information. For the consultation, the nurse brought up a particular report of P3 as a point of interest, as this could not be explained solely from the ICD data and this might not normally have been picked up on. In connection with that, nurses explained that ICD therapy might not be recognized by the patient but instead present itself as a symptom, e.g. dizziness. This symptom information could cause nurses to review the individual settings for a patient and, therefore, patient inputs can be very valuable. However, in most of our cases, the reported information was either too sparse or too fragmented to make a difference for the duration of the study.

Participants expressed that the motivation for participating in this study was, on one hand, a need for giving something back and, on the other hand, the comfort of the "*extra attention on me*" (P2). They regarded their contributions as beneficial to themselves, other patients and in particular health providers. P1 shared a noticeably larger amount of details about past, present, and future health, notions and feelings in general compared to the others. "*With all the things I've written, maybe that can help patients sometime in the future. The more insight you get into how patients are feeling, or what they can feel, that can be helpful*" (p1).

Nurses expressed that for the information delivered by the diagnostic agent to have value, it had to be the right information at the right time. Despite of the perceived importance, nurses barely had the time to consequently read the daily reports of all participants and certainly not the thousands of patients they monitor every day. One of the nurses saw a correlation between the reports on CardioTalk and the readings of the ICD monitor when P2 was hospitalized. Although, admitted that s/he did not look at the CardioTalk reports, before after the condition of P2 was more stable. This indicates that the report information might not be as relevant to consult during an emergency event, as other clinical metrics are needed.

The nurses' view on reports through CardioTalk was generally positive, as a supplement to current practice, but they felt that it couldn't replace the immediate feedback of a phone call. N2 was particularly afraid that patients might experience a false sense of security, leading them to believe that nurses were watching their reports immediately after they were submitted. Conversely, N1 said that it did not seem to vary much from current practice and therefore didn't think it would cause additional problems. In light of that, nurses would like to also be able to request information from patients or deliver information directly through the home monitor.

DISCUSSION

Our study employed a technology probe to explore an alternative scenario for nurse and ICD patient, wherein the patient approached a more active role of a diagnostic agent. Our findings showed that collecting and monitoring symptoms supported participants in being able to explore underlying causes to presently experienced symptoms. Our patients articulated that they would like to participate in their illness management, but only to a degree that it didn't negatively impact their wellbeing, the negativity was attributed to the symptom metrics reported on as well as frequency of reporting. Our findings indicated potential to facilitate sharing symptom information, as well as recalling symptom information in a consultation setting, based on reports through the CardioTalk probe. That being said, it revealed conflicts in how patients relate to home monitoring, in particular the physical monitor as well as their role and responsibilities as a diagnostic agent. Additionally, we argue for the suitability of the mobile platform. Finally, we found that our participating nurses would like to accommodate patient uncertainty with informing feedback, to facilitate patients managing their illness at home. In the following we identify and discuss contributions in this paper that advances HCI research on home monitoring.

The role of a diagnostic agent

Our findings indicate that current practice leaves a large portion of accountability for filling in the gaps between consultations to patients, although patients seem to some degree unaware of what is required of them. Our findings also revealed that patients were not sure how to relate to the physical home monitor. This is in line with Skov et al. [25] who found that ICD patients are often unaware of what information cardiac clinic staff receives from their home monitors and how they handle this information.

Our participants express potential for digital tools, like CardioTalk, to support reflection and recognizing patterns. However, some rejected that health reporting would be allowed to have a big impact on them. They would not put too much focus on their illness in fear of becoming obsessed with management routines and controlled by increasing anxiety. Our findings emphasized that our participants did not always identify as a patient, and many would not like to be reminded of this too often and be considered or referred to as one. Similar argumentation can be found in a number of studies focusing on chronic patients [1,4,16,23]. Recent HCI research by O'Kane et al. on chronic patients (diabetes) shows a tendency to want to hide or conceal medical devices in some situations in fear of judgements or to keep some privacy [19]. Similar to this, our participants showed positivity towards the mobile platform, as it appeared non-medical, as well as it was always kept in close range.

We argue that it has relevance for ICD patients to collaborate on symptoms interpretation with health providers. Still, it is not trivial and requires collaboration and inclusion of the expertise and knowledge that the patients possess. This inclusion brings along benefits for the patient who wishes to be involved, but might also bring challenges for the patients who are not equipped for this level of involvement [18]. Maitland et al. [16] found that very few of the cardiac patients in their study owned or used mobile technology every day. For our selected participants, owning mobile technology was a prerequisite and as such we can't conclude on the patient group as a whole in regard to preference for using technology. Ancker et al. [1] points to issues of age and technology use, in this regard we found no issues for our group of participants. With an age span of 45-74 years and a mean age of 62,4 years, all had experience with and were using mobile technology daily in their work and/or private life. As well, Ancker et al. [1] point to other demographic traits, that we can't conclude on for our participants.

Ancker et al. argue that their findings strongly support the perception of patient generated health data, that it is considered as work. They found that this perception in some cases discouraged patients. Authors therefore argue for a preference for automated uploadable device data. This is central for the outset of our research focus on the ICD patients, as the automation as a result leaves the patient passive in monitoring own illness. Despite this, our findings suggest that the task is manageable. One issue raised was the perceived emotional burden of the frequency and symptom metrics reported on. Daily reporting on psychological symptoms e.g. stress and anxiety, was perceived as contributing negatively. As such the balance between reflection and obsession, particularly in terms of reporting frequency and metrics, is a topic for further study.

Purposes and uses for patient generated data

Collecting and viewing data on health metrics and symptoms seemed to benefit the diagnostic agent to predict the need for clinical intervention. As also emphasized by Kendall et al. [12], our findings show that reporting regularly (for a few, daily) was seen as necessary to establish a baseline of health for comparison, but also to establish routines of reporting.

Kendall et al. [12] use the term a 'snapshot' of health, which is how measurements are often taken in a clinical environment, however as patients are not limited to the duration of a consultation, they can reflect on how they have been feeling over the span of a day. This also means that they can take into account activities that stretches in time and what feelings, thoughts and perhaps symptoms they experience in relation to this. This information is valuable to health providers, but not easily captured. It has to be the right information at the right time and requires further study to conclude on the exact information needs.

Patients in the study by Ancker et al. described multiple purposes of personal data; real-time decision making to determine action here and now, tracking over time to self-assess how 'well' they were doing e.g. progressing towards a goal, tracking for sense-making overall and finally, tracking because a health provider told them to do so [1]. We found examples of all these purposes for our participants, but primarily our findings suggest that the real-time decision making was carried out relying on experience. The sense-making from reported data was carried out in collaboration with health providers when a lot of symptom variation was detected.

Collaborative interpretation and design opportunities

Scheduled consultations can happen as far apart as every two years, when patients are asked how they have been since the last consultation, it seems natural to recount the big picture and forget the details. Relying on memory is something that is emphasized in our findings as problematic. Patients are already encouraged to write down if symptoms occur and when, however it is not always practical in any situation to carry pen and paper. As well, we found that in some situations it was not convenient to report on the mobile device, for example in a meeting, carrying out physical tasks at work or when exercising. Some participants requested an unobtrusive way to mark an event for later reporting.

Chung et al. also found for chronic patients in their study, the need for information on what to do in between consultations. As well as, how to help focus the collaborative review of generated data [7]. Authors point to this as a design opportunity to explore tailor made visualizations and collaborative interfaces, in order to capture manifold patient aims of collaboration; self-reflective, action-oriented and affective. Our findings suggest that a reporting tool like CardioTalk could be imagined as a memory trigger for consultations, as the information is stored and has the possibility to be shared with health providers. There is a need for a common ground to get an overview in order to collaborate. As well as Chung et al., our findings suggest that a more precise agreement about the expectation of both parties is essential to the collaboration, if the effort should not be in vain.

Although design and symptom metrics have been informed by health providers working closely with the patients, the lessons we learned by deploying our probe has value for future work on home monitoring. Our findings clearly showed that some metrics did not have much value in themselves. However, a symptom contextualized in form of event or action when experienced, or in comparison with other specific health metrics, could mean a big difference in value for health providers. These relationships between metrics should be informed by patients and health providers prior to design of reporting tools, in order to avoid too fragmented information.

CONCLUSION

HCI research on home monitoring of cardiac patients has shown that patients usually would like to play a more active role when being monitored as passiveness sometimes lead to increased anxiety. We conducted a study with ten ICD patients where they interacted with a technology probe called CardioTalk. This probe supported collection and sharing of symptoms and health metrics, and we studied the use of the probe over eight weeks. Our study showed that collecting symptoms encouraged reflection for participants, as well as this information was incorporated into a consultation with the health provider. Our participating patients articulated that they would like to actively participate in their illness management, however some were concerned with the balance or tradeoff between reflecting on symptoms and being obsessive towards symptoms management.

Our study has explored patients taking on the role as a diagnostic agent as well as possibilities and challenges for collaborative interpretation with health providers. Our findings highlight that the relationship between the participants and nurses benefitted from a great trust and openness. Although, some barriers present when it comes to responsibilities as participants demonstrated uncertainty about their role in home monitoring. The exact information provided in reports need further study to be of real value. In spite of this, both participating ICD patients and nurses argued that collaborative interpretation will benefit both parties if organized appropriately.

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