Empowerment through Transparency and Feedback for Home Monitoring of Implantable Cardioverter-Defibrillator Patients

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"I repeat, Feedback is a method of controlling a system by reinserting into it the results of its past performance. If these results are merely used as numerical data for the criticism of the system and its regulation, we have the simple feedback of the control engineers. If however, the information which proceeds backward from the performance is able to change the general method and pattern of performance, we have a process which may be called learning" (Wiener, 1954)

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1 PREFACE

This report presents our Master Thesis, within the specialization of Human-Computer Interaction (HCI) for Software Development 4th semester. ¨

This report contains an introduction to the project focus, summary for our research contribution, as well as an overall conclusion. In appendix two scientific papers are considered as our research contribution. The two scientific papers can be read individually.

2 INTRODUCTION

Due to the growing ageing population and other socio-economic and cultural factors, public health expenditures is increasing and may continue to increase to approximately 8.5% of GDP in 2060, according to projections from the European Commission. The aging population is expected to result in a higher incidence of chronic diseases and in this respect, long term care expenditure is on average projected to almost double from 2012-2020. This will create additional burden, on already pressured public budgets. As demands and expectations from citizens for higher quality services and social care is growing, in contrast there is a steady decline in the number of health personnel. They propose that digital solutions can empower patients with modern and effective services like telemedicine [1].

When using telemedicine for managing chronic conditions, mental health and health promotion it meets demands of more personalized healthcare, which is more targeted, effective and efficient. It facilitates benefits such as socio-economic inclusion and equality, quality of life and patient empowerment through greater transparency [1].

Telemedicine allows home monitoring (HM), which means that patients are monitored remotely by health providers when they are at home. This study focuses on HM for a heart patient group with implanted devices; Implantable Cardioverter-Defibrillator (ICD). Various studies have shown that HM leads to lower rates of hospitalization and mortality, compared to chronic patients without HM [2] [3] [4]. Additionally HM allows for shorter intervals between follow-up in the clinic, without compromising patient safety, as well as offer early detection of arrhythmias due to continuous monitoring [5].

3 RESEARCH CONTRIBUTION SUMMARY

Our contribution is divided into two papers, which serve different purposes, here summarized below. The one compliments the other well, although they can be read separately.

3.1 CARDIOTALK: COLLECTING AND SHARING SYMPTOMS AND HEALTH METRICS FOR HOME MONITORING OF ICD PATIENTS

The existing architecture of ICD HM provides the ICD recipient with hardly any information about the health-related data that are transmitted to the hospital. Thus, feedback is mainly intended for health care providers; a fact that is also confirmed by Skov et al. showing that albeit ICD recipients are generally content with HM, they lack knowledge on the information that is shared with the hospital, when this sharing takes place and by whom data are reviewed [6]. The low level of information transparency might make ICD recipients feel less assured while it forces them to take a passive role in the illness management. Apparently, this goes against the modern digitalization practices that attempt to assign patients with more responsibilities. In line with this trend, ongoing research projects such as SCAUT put patients in the frontline of symptoms detection and illness progression, either on their own or with help of health providers [7]. Having patients utilize various digital (mobile) application for reporting and reviewing symptoms over time can be seen as an invitation to them to be actively involved with their illness management.

This study aims at exploring how ICD recipients would use a digital application for symptoms reporting as well as how it will help reflection and recognition of patterns in their illness progression via history diagrams that visualize their overall health condition over time. For that purpose, we designed and implemented CardioTalk, a web-based application that enables patient-initiated health reports and overview of history reports that can reviewed by both the ICD recipient and health providers. CardioTalk works independently of the existing ICD HM system and therefore we are further interested in investigating if such an application can help health providers to better evaluate the condition of the ICD recipient when CardioTalk logs are used together with the ICD monitor readings.

Based on participants CardioTalk use and conducted interviews with them, we grouped our finding into three themes; 1) Collecting and Sharing Symptoms and Health Metrics, 2) Reflection and Obsession on Symptoms, 3) Transparency and Feedback in HM. All in all, we found that ICD recipients were comfortable with sharing information via CardioTalk while appreciated its use when experiencing symptoms fluctuations. They agreed that CardioTalk increased the transparency of ICD HM, however even more transparency (feedback) is required as they seem to show blind trust on health providers. Finally, they expressed concerns that overuse of such application may make them obsessed with their illness.

3.2 PATIENT EMPOWERMENT OR DISEMPOWERMENT IN ICD HOME MONITORING: AWARENESS, ASSURANCE, AND ACCESSIBILITY

This paper focuses on patient empowerment. The interest for this impeded from above mentioned contribution. The focus on empowering, has put the patient at the center of Telemedicine strategies [2] [1]. This brings along transparent 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 active involvement [3].

Health IT strategies point to a need for develop more supportive tools to manage self-care, as well as adding transparency to measurements from home monitoring. The patient's role is highlighted as an active one, where they should provide information to health providers in an effort to help them deliver relevant and updated information and better, more personalized care. Patient generated data has been highlighted as a decision support tool for health providers to systematically evaluate if there is a need for more follow-up. In this way health providers and patients will use their resources where they are most needed [2]. However, it is not mentioned how or if this information is disclosed to the patient and in what way they are being equipped to collaborate on the decision support.

For this contribution we highlight empowerment potentials as well as challenges that we found. Through iterative analysis and refinement we landed on three key themes: Awareness, assurance and accessibility. We suggest how these can be reflected in the work of designers as well as health providers, when their goal is to empower home monitored ICD patients.

4 CONCLUSION

Long term care expenditures for chronic patients are expected to almost double, within a foreseeable future, due to a growing ageing population resulting in higher incidence of chronic diseases. To mitigate this, research focus turns to digital solutions to empower patients with modern and effective services like telemedicine. Our focus have followed this trend, to focus on a specific rapidly increasing patient group, namely chronic heart patients with implantable cardioverter defibrillator (ICD) referred to in our report as ICD recipients.

We suggest that digital efforts to increase transparency, have potential to inform ICD recipients and to reduce misconceptions of data inferred from ICD monitoring and thus inspire to active participation in management of illness and wellbeing. Our work shows that transparency, in the form of feedback on monitor operations and invitations to participation as exemplified by digital health reporting, afforded an increased feeling of control and that this is worth keeping in mind for both designers of health IT and health providers in their efforts to increase patient empowerment.

5 APPENDIX

Attached contributions are as follows; Paper 1 and Paper 2. Appendix C illustrates the consent form sent to participants prior to study (Danish).

A. Paper 1: “CARDIOTALK: COLLECTING AND SHARING SYMPTOMS AND HEALTH METRICS FOR HOME MONITORING OF ICD PATIENTS”
B. Paper 2: “PATIENT EMPOWERMENT OR DISEMPOWERMENT IN ICD HOME MONITORING: AWARENESS, ASSURANCE, AND ACCESSIBILITY”
C. Consent Form: “HVILKET POTENTIALE HAR DIGITAL INFORMATIONSDELING FOR ICD PATIENTER?”

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Appendix A

CardioTalk: Collecting and Sharing Symptoms and Health Metrics for Home Monitoring of ICD Patients

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ABSTRACT

The purpose of this study is to explore how ICD recipients use digital applications, to collect and share information on symptoms and health metrics. We explored how patient's shared information in correlation with ICD measurements support nurses evaluation. Thus, we designed and developed CardioTalk; a technology probe, deployed on mobile devices of home monitored ICD recipients. We also conducted interviews with participants and nurses. Our findings show that participants were anxious that too much structure of management would cause obsession with their illness. We found that participants expect to be contacted by health providers when experiencing symptoms, although health providers claim that patients are responsible in initiating contact. This study conclude that there is a need for feedback on monitor operations for ICD recipients for assurance, and suggest that there is a connection between the transparency of shared information and ICD recipients wish for being in control. This transparency lacks in home monitoring and should be considered in future design and research.

Author Keywords

Home monitoring, ICD, feedback, technology probe

ACM Classification Keywords

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

INTRODUCTION

Innovative health care using electronic and mobile devices (i.e. smartphone, tablets) is promoted in both national and international digitalization strategies [11, 30]. Exploiting digital services, along with incentivizing patients to be actively involved in their health management, are means to reach the goal. The goal is to relieve the burden on the pressured health care system that is the result of a growing aging population's need for medical attention. It is hypothesized that digital solutions can empower patients with modern and effective services [11].

HM has been concluded through various studies and recognized by medical companies to lower rates of hospitalization and mortality, compared to chronic patients without HM [7, 10, 13]. Additionally it allows shorter intervals between follow-up in the clinic, without compromising patient safety, as well as offer early detection of arrhythmias due to continuous monitoring [24].

One of the most promising applications in telemedicine is home monitoring which enables patients to be monitored over a distance by health providers. We focus on home monitoring (HM) for a heart patient group with implanted devices; Implantable Cardioverter-Defibrillator (ICD). We focus on this high-risk patient group, as this shows steady increase of new patients [14, 26]. HM has shown potential for reducing hospitalization, in-clinic visits and even mortality rates [11].

Patients have become the center of digitalization strategies, as they are assigned more responsibility. Previously, we conducted a literature study where we concluded that the main architecture of HM is designed to propagate information about patient health towards health providers, but very rarely inviting the patient to view this information [18]. Our study focus is additionally inspired by e.g. Skov et al. found that although patients are highly satisfied with HM, they were often unaware of what information is shared, with whom and for what purpose and lack feedback on monitor operations [29]. This shows a low level of transparency, which we found interesting to investigate. An ongoing research project SCAUT focus on supporting patients to detect signs and symptoms of deterioration, for themselves or in collaboration with health providers. Efforts for inviting the patient to be involved in managing illness and evaluating their own health, has been presented as patients reporting through various digital (mobile) applications [3, 17, 34 etc]. Current feedback is either not adequate or designed solely for health providers, as information is not presented on the patient side [24].

This study investigates how ICD recipients would like to use reports of symptoms and health metrics, together with how it might help reflection and recognition of patterns in illness progression through visualizations of history diagrams. Meanwhile, to understand what information could help nurses in correlation with ICD measurements to provide patient evaluations. For that purpose, we designed and implemented a web-based application named CardioTalk for sharing health related information between ICD recipients and health providers. CardioTalk is a technology probe that elicits information and inspires reflection on use. CardioTalk operates independently of the existing ICD home monitoring system of the hospital.

RELATED WORK

Home monitoring is the name we use to describe a broader collection of concepts hierarchically arranged under umbrella-terms like Telemedicine and eHealth. Home monitoring expresses a system where health providers continuously monitor patients remotely. This is made possible by a combination of IT and other technologies. Firstly, we give an overview of research limitations and challenges, as well as benefits for home monitoring of chronic (primarily, heart) patients. Secondly, we will focus on ICD patients and the benefits that motivate us for doing research for this patient group. This group is a steadily growing patient group, both because of the older population's medical needs, but also due to the development in technology.

Home Monitoring in HCI Research

Home monitoring in HCI research rarely focuses on patient feedback. Up until fairly recently, limited research focused on providing feedback to patients and thereby genuinely, actively including them in home monitoring (HM) [26, 28, 29].

Patient-centered communication behaviors are suggested to be important factors in the active involvement of patients in managing chronic illness [23]. Compliance, also mentioned as adherence, is a key concept. Patients might be aware of how to manage their illness, but often ill-informed about the importance of complying with care regimens like medicine, diet, exercise etc. (mainly activities going on outside of clinical environments). Studies such as Burry & Senouf and Barlow et al., have shown that good compliance might have the possibility to decrease frequent hospital readmissions and follow-up consultations and generally positively influence patient health [4, 8]. Non-compliance oppositely, might lead to weakness, injury or even death [32].

HM research with respect to feasibility studies often focus on the clinical feasibility, often quantitatively measured in medical effect on symptoms and wellbeing. Feasibility is additionally centered on the technology used for HM, early technologies were not as accurate as they are today and not as accessible, as noted in a meta review by Mair et al. [22]. On the other hand, Costa et al. highlight that the complexity of the information shared today makes high demands on the technology [9]. A challenge also highlighted by Skov et al. and Kendall et al. regarding the technology today, is how to design modern medical technologies that accommodate understandable and actionable patient feedback [17, 29].

Additionally, other studies focus on the relationship between elderly and technology use, stating both willingness to participate, but anxiousness that they might make mistakes or break technological devices [6, 16]. Generally there is a focus on novice technology users, old or young, or disabled in terms of motor skills in HM studies, especially for utilizing mobile devices [2].

ICD and Home Monitoring

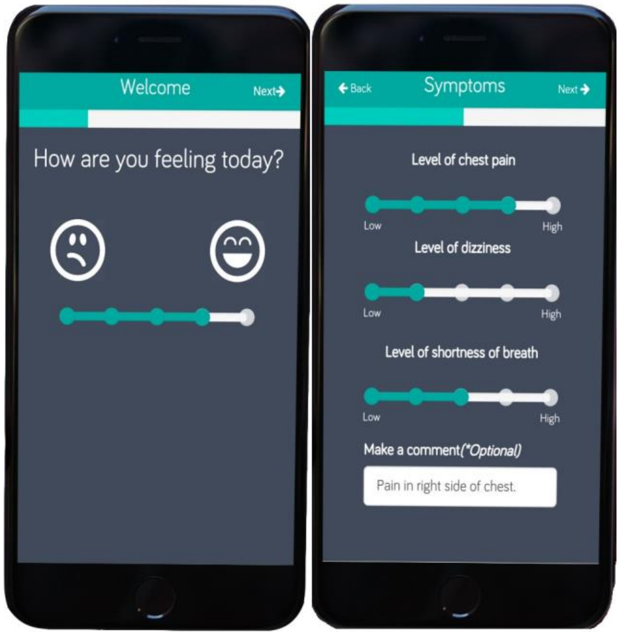
An ICD (Implantable Cardioverter-Defibrillator) is a battery-powered device that combines a cardioverter and a defibrillator into one implantable unit. ICD patients are typically at high risk of sudden death. Thus, ICD devices have been introduced in order to restore the normal cardiac activation sequence by means of electrical therapy, to treat a malignant arrhythmia (irregular, slower or faster heartbeat than usual) [9, 29].

The implanted unit is coupled with a stationary monitor, often conveniently placed at the patient’s bedside or in the bedroom, as it automatically transfers data at night to the hospital [29]. The transferred information is collected throughout the day automatically by the implanted device. The implanted device can easily function without the monitor, but coupled with the HM it shortens the time from the onset of relevant medical and technical events to evaluation by health providers [24]. ICD patients with HM typically have scheduled in-clinic consultations every two years, as opposed to ICD patients without HM, for whom the interval is typically 3-6 months [29].

Nowadays, certain limitations necessitate physical consultations at the clinic, so called follow-ups (FU). Since the device is battery driven, the battery at length needs to be changed. However, unscheduled FU can occur if the health provider receives alarms due to irregularities in the transmissions that cause them to worry for the patient’s wellbeing. The patient is then called in for a consultation. If the device has given a false alarm, the physician has the option of reprogramming the device to ignore this state in the future or toggle the sensitivity barriers of the alarm [24]. Reprogramming can only be done in the clinic. This is ultimately to prevent hostile attacks or unauthorized reprogramming due to the wireless nature of the signal [12]. It is suggested that the privacy concerns inherent in sharing this personal and sensitive information, might be traded off in favor of the feeling of safety from monitoring, for vulnerable patients [29].

Patient Generated Reports: A Supplement for HM

Continuous monitoring of context depending factors along with blood pressure (BP) measurements, was the case in the research of Kendall et al. [17]. Continuous monitoring of BP variations, can reliably predict risks of cardiovascular diseases. Participants had to self-report BP in an application, along with checking off some factors known to influence BP, additionally they could write comments related to the BP measurements. The reports were illustrated to the participant, in an effort to promote reflection. The findings showed that participants started to recognize patterns in their measurements and the illustrations would in some cases help to clear up misconceptions of the way certain things influenced BP [17]. As the contextual information puts into perspective vital sign readings, which is most often quantitative in nature. Context dependent information in this perspective adds a dimension of personal and mainly qualitative information for comparison and more precise interpretation.



How are you feeling today?

Pain in right side of chest.

Figure 1 Illustrates separate screenshots of CardioTalk, showing elements of the application as they appear on an actual mobile screen.

CARDIOTALK

CardioTalk is a web-based application enabling users to submit reports about their health status. Each user has a personal account. Health providers can use CardioTalk information in combination with the ICD home monitor readings for making patient evaluation and give appropriate feedback to patients. Our design is based on interviews and a design workshop. In this section we describe the design of CardioTalk including the design activities and the technical implementation.

Design Workshop

We held a design workshop with health professionals from Aalborg University Hospital (AUH). All workshop participants were nurses working with heart diseases while one of them was a product specialist from Biotronik. During the workshop we focused on what kind of information they would like to exchange with patients and how often and thus we identified three main themes: 1) Contextual Feedback 2) Assurance 3) Awareness.

1) Workshop participants stated that they lack patient information that might be vital in making a holistic evaluation of their health status. Thus, they wanted to receive additional patient data for comparing them with the ICD monitor readings and eventually make a more precise interpretation of the severity of episodic alarms and symptom irregularities. 2) Participants stated that they wanted to give assurance to patients through feedback. 3) Participants imagined having more resources, if mechanisms are designed to make patients more aware of their own health, while simultaneously enabled patients to manage their illness. Our goal was to reflect these needs in the CardioTalk design. To validate the relevance and usefulness of CardioTalk design, we presented our initial mock-ups to a nurse participating both in the workshop and in this study.

Design

CardioTalk comprises two design components, namely the patient and health provider interaction. The former refers to how patients submit reports or browse their history of reports, while the latter refers to the interface used by health providers to review patient reports.

Patient Interaction

CardioTalk is accessed via a mobile device (i.e. smartphone or tablet) and enables patients to make reports regarding their health status using their personal device. The questions posed are grouped in three categories, which are: a) physical symptoms, b) health metrics, and c) psychological symptoms.

CardioTalk takes the form of questions in which sliders have been used for quick fill-in of the symptoms scale (e.g. from low to high). Participants can navigate easily through the system with the top bar buttons (next/back). We added possibilities for more open-ended answers in comment fields. A progress bar will show how patients are progressing through the record. Figure 1 illustrates some CardioTalk elements.

For physical symptoms, we learned in previous work that some symptoms are specific or frequent for this patient group. We chose three to include: chest pain, shortness of breath and dizziness [31]. These are also reflected in various other structured questionnaires used for this patient group (examples: OASIS, SF-12 and MLHQ [31]).

Blood pressure and weight were optional health metrics, if equipment for measuring them wasn't available. One nurse stated that these measurements could potentially be beneficial for her judgment, compared with the ICD readings. We were informed that these are not measurements that are normally captured for regular follow up visits.

For psychological symptoms we inquired about level of stress and anxiety. We view the stress level to be influenced by activities and events outside of the illness and home monitoring, e.g. rough schedule. Whereas we see anxiety level as a measure connected to illness, device and home monitoring, e.g. Anxious about not receiving feedback, experiencing symptoms or changes in illness.

Additionally CardioTalk implements a feature that enables participants to view their own previous reports. We added visualization of the reports in grouped plots, for the purpose of increasing awareness of own health and how it progresses (see Figure 2). Except for the blood pressure, pulse and weight, which were reported in a table, arranged by type. Comments made in the comment fields were not available to view in this feature.

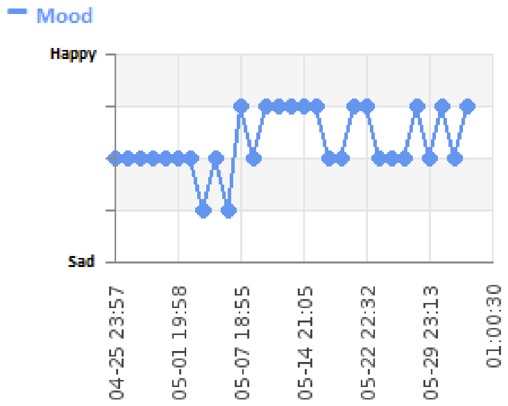


Figure 2. Example of a mood history plot of an actual participant in the study

Health Provider Interaction

Health providers can access CardioTalk via desktop computers. They can log in to the system from multiple computers, to check the patient health progress while being outside of the hospital. When logged in, health providers could choose from a selection menu which patient to review and were redirected to the respective patient results page. All displayed data were grouped in different sections (physical symptoms, psychological symptoms, and health metrics) and were structured in tables with descending report submission date/time order. Additionally, diagrams were plotted for each table to provide nurses a better and clearer overview of the patient results.

Technical Implementation

We built CardioTalk using Bootstrap, which integrates HTML, CSS and JavaScript into a web development framework. CardioTalk runs both on iOS and Android mobile devices (i.e. smart-phones/tablets) but also on desktop computers. The software is further connected with a SQL database server where user account information and patient reports are stored. This connection is managed by the PHP programming language, which we used for storing and retrieving information from the database. Finally, graphical output of the database content (e.g. patient report charts) is implemented with an object-oriented PHP-written library named JpGraph.

STUDY

Involving patients in studies requires certain ethical considerations, of which some were particular to the severity of chronic illness and living with an ICD. This study took outset in the home monitoring of ICD patients at AUH. In this section we describe how they organize home monitoring and patient evaluations for their out-clinic patients. For our study, we will refer to the patients as ICD recipients as they are not currently hospitalized. We outline the frame of the study; the participants, the procedure along with data collection and analysis.

Methodological and Ethical Considerations

We needed to take ethical considerations for this study, as ICD recipients have severe chronic illnesses. Studies have shown that ICD recipients often suffer from psychological stress, such as fear of death, anxiety or depression [21]. Additionally the method applied was considered obtrusive to their habits as this was reaching into their domestic space. Nielsen argues that electronic records in patient involvement in (digital) reporting often introduces unnecessary work and demands on the patient [25]. However intervention methods such as diary writing, (technology) probes or prototypes are commonly used in HCI research, both for this patient group and for our purpose [1, 3, 29]. CardioTalk is designed as a technology probe. According to Hutchinson et al. technology probes work by installing a technology into a real use context, watching how it is used over a period of time and then reflecting on the use to gather information. It is not a prototype, but a tool helping to determine which types of technologies would be interesting to design in the future. The technology probe is particularly flexible compared to observation, which is very resource demanding both for participant and researcher [15].

For the study we were granted ethics approval for non-invasive studies at AUH, as well as complying with the principles described in the Helsinki Declaration on ethics for medical research involving human subjects [33]. A study nurse with GCP diploma trained in cardiac research studies and an ICD-clinic nurse, who is trained and experienced in reviewing data transmission for ICD, participated in the study partly as collaborators and as informants. Their role was to assist us with all patient contact; recruitment and supervision for study activities. Additionally, they were ensuring that patients felt safe and had confidence in the credibility of the study. They also made sure that we were in compliance with the conditions of our approval.

All participants signed a consent form, after receiving information about the study. Our consent form stated that all participation was voluntary, and at any point participants could withdraw or refuse to participate in one or more activities without consequences. Furthermore, we ensured that all information collected was anonymized and not retraceable to their person.

Home Monitoring at AUH

Aalborg University Hospital offers home monitoring for their associated ICD recipients. The remote monitoring service at the AUH ICD Clinic routinely monitors approximately 1000 ICD patients. Over the last decade (2004-2013), AUH has performed a little more than 700 ICD implantations [29]. The year 2015 the numbers of new implants for AUH was 89 for ICD and 15 for CRT-D.

The description of home monitoring at AUH has been formed through formal and informal interviews with nurses and backed up by data from www.icddata.dk (an online repository of ICD information closed for public view).

Once every night, the ICD transfers data to the monitor (only successful if device is in range) which transfers data to AUH. A nurse specially trained to evaluate the ICD readings, will review them the next morning. Many home monitor technologies exist and they have different functionality [24]. Some will only send data in the form of an alarm if certain conditions are met, but the particular monitor used by patients in this study will relay information every day regardless if alarms are triggered.

When a nurse receives an alarm or an irregularity in the readings, they will review it and if additional clarification is necessary they will contact the patient by phone and/or talk to a specialist. They will initiate the conversation by asking how the patient is feeling, in general. They then proceed to inform the patient about why they are calling, ask questions about whether the patient experienced any symptoms. Note here, that many asymptomatic events can present. The therapy administered up to a certain point might not even clearly present or be noticeable to the patient, it might present as symptoms such as dizziness or chest pains etc. Sometimes the patient might not even have experienced shocks, due to being unconscious prior to. The nurse will often call in the patient for a follow-up (FU) consultation following an irregular activity in cardio function or when therapy has been delivered. Regular FUs also happen at scheduled intervals.

Implantable devices

We will use ICD as a common term for implanted devices, which have the defibrillator function (electrical therapy). In our study, three participants had a CRT-D, which is slightly different than the ICD in terms of design, but the same with regards to home monitoring. CRT-D is the device primarily used for heart failure patients, these are often more fragile and are in high risk of frequent events and symptoms. This happens due to the fact that leads, which measure the heart rhythms, are not secured with surgical screws like the ICD and therefore become unstable.

Participants

Participants were recruited using specific inclusion criteria, i.e. had an ICD or CRT-D, owned a smartphone or tablet and had Internet access. Collaborating nurses acted as link between us and possible participants, by choosing and contacting appropriate candidates. To have nurses initiate contact lent us a great deal of credibility for the study.

Ten ICD recipients participated in our study (three female). Average age was 62, 4 years (min-max; 45-74 years). They have lived with implanted devices ranging from only a few months to 11 years. All participants had an ICD and monitor from the manufacturer Biotronik. Almost all participants received home monitoring immediately following their implant or within a relative span of months after (up to eight months).

A total of 13 possible candidates were contacted, where three did not end up participating. One participant said no to participation, as it did not interest him. The remaining two would have liked to participate, but didn’t own a smartphone or a tablet and had no internet access at home. The criteria for appropriate candidates, besides the aforementioned inclusion criteria, were set by the nurse recruiting. They made an effort to find people, who lived within a maximum approximately 100km from the hospital. Transport might have been an issue since some ICD patients are not allowed to drive a car because of their condition. The participation rate was relatively high.

Procedure

The study lasted for seven weeks, during which we conducted four separate interviews with the participants. Additionally we had an interview with the participating nurses. The study was initially presented to participants to last for three to four weeks, but all agreed to extend the study.

First interview - Deployment and Consent

The purpose of the first interview was to obtain consent from participants and explain the study protocol. We conducted a structured interview with each participant for collecting their demographic information. We installed CardioTalk on their personal devices together with providing them with username and pin code for login. Finally, we demonstrated how to use the system and thereafter each participant made three consecutive reports. Two of them were made with our help, whereas the participants made the third alone. Our primary intention was to make sure that all participants would feel comfortable using CardioTalk at home without our assistance.

Second interview – Steering and Catch up

The purpose of this activity was to steer participants’ behavior to comply with study protocols, additionally to catch up on if any technical or other issues had occurred. Approximately one week after the initial interview we contacted all participants by phone. During the phone call, we reminded them for how long they were expected to participate in the study, as well as schedule the date of the third interview.

Third interview - Follow up and Understanding

The purpose of this activity was to offer participants an extra consultation with a nurse, supported by their reports, while we further conducted an interview with them to understand their experiences with CardioTalk. This interview took place approximately three to four weeks since the first interview. The participating nurse had been instructed to view the reports of the participants once a week and if alarms were detected. The interview was semi-structured and held at the hospital, with a study nurse observing. We scheduled seven interviews in Danish and three in English. As one of the participants was admitted to hospital the night before the scheduled interview, we rescheduled the interview for a week later.

Fourth Interview – Reflection and Debriefing

The purpose of this activity was to make a follow-up of the participants following the extension of the study period, to reflect on their continued use and to debrief the participants. We called them on the phone to follow up on any observations we made for their patterns of use since last time and for elaboration of particularly interesting findings.

Nurse Interview – Perspective and Reflection

The purpose of this activity was to interview the two participating nurses on their experience on using the CardioTalk. We wanted to know how they perceived the correlation between the reports and the ICD monitor readings. The interview took place at the hospital and was conducted two weeks after the primary interview. It was formed like a semi-structured interview. Additionally, we had prepared a presentation and a following discussion to inspire reflection based on initial findings.

Data Collection and Analysis

We applied a hybrid data collection, in the sense that we had two channels of data, from different data collection methods, which supplemented each other; CardioTalk automatic logs and interview [19 p.330]. The CardioTalk logs gave us insight into measurable interactions in a natural environment, creating raw data, which was used to elicit questions for the interview guide. Interviews structured via a guide provided contextual high-order details, which is a natural shortcoming of the automated logs. We structured an interview template to guide the interview questions to cover pre-prepared research themes and questions. Visualizations of logs were also intended to potentially improve recalling-bias.

We recorded third and nurse interviews for recall purposes, consent was given by all participants. Most interviews were partially translated from Danish to English, prior to joint discussions of results. Comments from logs were grouped by each participant and categorized for comparison.

For analysis, we were inspired by the study of Kendall et al. [17] and made use of affinity diagram technique to find natural relations between data, in a joint effort by both authors. We iterated on themes, until relatively atomic connections presented, the output of which is highlighted in the findings section.

FINDINGS

We initially describe some average trends observed from the CardioTalk logs over the whole study period and thereafter we analyze our main findings which are categorized into three themes, 1) Collecting and Sharing Symptoms and Health Metrics, 2) Reflection and Obsession on Symptoms, 3) Transparency and Feedback in HM.

We anonymized our participants and refer to them as (p1-p10) for the ICD recipients and (n1-n2) for participating nurses. When we state a number of participants e.g. (7/10) it should be read; this is observed for 7 out of 10 participants.

Generally, we found that all participants were systematically using CardioTalk during the study period submitting a health report almost every day. Nevertheless, there was only one participant (p1) that only missed a single day of reporting. The majority of participants indicated throughout the study a very good mood while the remaining reported a medium level of mood (8/10). Regarding the physical symptoms, none of the participants reported chest pain, only one (p9) reported regularly low-to-medium levels of dizziness and some indicated low-to-medium shortness of breath, most often followed up by comments indicating physical exercise (3/10). Additionally, few were observed with low-to-medium stress (2/10) and one participant (p2) showed low-to medium anxiety levels. One participant in particular commented on their anxiety, in relation to activities where they have previously experienced shocks (p9).

Concerning the health metrics, we observed that the majority of the participants were at least reporting their weight most days (8/10). Only three participants were consistently measuring their blood pressure (BP), pulse and weight on a daily basis while one participant (p5) never reported any health metrics. Differences between participants are explained by the fact that they either didn’t possess the required equipment to perform the measurements or didn’t care for taking these measurements. Surprisingly, one participant (p10) suddenly started reporting his/her pulse after the third interview.

Lastly, it is worth mentioning that almost all participants used at least once the CardioTalk comment fields (9/10). This was for describing daily physical activities (biking, golf, etc.), factors that in their perception induced symptoms (busy day, exercise, emotional state etc.), thoughts about their health status or narrating stories from their daily life and even commenting on the weather. Comments were used independent of reporting one or more symptoms.

Collecting and Sharing Symptoms and Health Metrics

We identified three main findings about participants’ attitudes towards collection and sharing of symptoms and health metrics. We also provide insight to a nurse perspective on receiving additional health information. Firstly, we found that history of reports can serve as a digital diary for being aware of symptoms variations over time, despite seeing benefit of reporting every day, participants only found it useful to follow up on episodically when experiencing irregularities in symptoms. Secondly, we found that participants had no problems with sharing symptoms and health metrics with health providers via CardioTalk as ICD home monitoring already has familiarized them with sharing. Thirdly, we identified participants' desire to understand how daily activities and habits affect their general health, as they requested extra features that would give access to such information. Finally, in spite of seeing benefits for ICD recipients, nurses assess that the shared information through CardioTalk needs to be better sorted if it should have any practical use in the clinic. We will unfold these findings below. All participants saw potential for collecting data on symptoms variation, to try to detect the underlying cause of the variation. They saw usefulness for collecting symptoms data over time to detect patterns and act on them. However, they argued that was mainly useful episodically, when you feel a lot of symptom variations. Some participants felt that reporting every day was necessary, both for establishing a baseline of good health and for routine to make reporting a habit (3/10).

"If you see there are more fluctuations and more frequently, then maybe there is something you need to have looked at, because 'why is it doing that?' you can use it like that, too see if there is something you need to deal with in advance. If you are getting stressed, are you too busy, shortness of breath is it increasing, are you running too fast, the anxiety is it coming back?"(p5)

"*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? Because you are not that good at remembering a long time ago, we have to admit that. Then maybe it will be a benefit to have the numbers in writing, if you can use it for anything."(p6).*

Few of the participants already used paper-based diaries for collecting their own measurements manually, to control their health progress and for recalling personal information during consultations (2/10). One of the two showed little trust in mobile technology and preferred to keep notes on paper instead "*I think it is good if you can avoid technology [...], a book is fairly reliable*" (p8). The other of the two participants used a diary before being implanted, by self-motivation he/she started collecting data (p4).

"*I have a book I note into. That's something new in my life. I started in the fall, when I got the fluctuations. I started because, when I go to the doctor, I am not good at remembering what happened to me [...] maybe it was because I sensed that something was really wrong with me, so I had to explain what it was*." (p4).

We found that all participants felt comfortable with sharing information on CardioTalk, especially since they were already doing so via the ICD monitor. E.g. "*I'm so used to that, because I have the device. They make a backup of me every night. It was a strange feeling to begin with, but that's how it is"* (p9). As an example, one participant directly highlights the benefit of using technology for digital information sharing. "*It is easier for everyone, instead of all the time meeting up physically*" (p4). All participants experienced feeling secure knowing that nurses are looking at their reports, the importance of this was fairly high but varied e.g. on one end of the scale *"That means a lot to me!"* (p10). The same participant argued that after ICD implantation people are confused and worried about their health status thus such a reporting system could properly address these factors by making them feel more relaxed, "*I wished it was there 3 years ago. I think it is a good idea to have things like that out there.*" (p10)

Concerning information sharing via the comment fields, some participants mentioned that comments were reasonable whenever there was a need for elaborating something (4/10). We emphasize a specific example, where both the participant and nurse found comments useful, as expressed by both for independent interviews. It was informative as the nurse took initiative to address this in interview and talk about how it affected the participant.

"*When I wrote about my friend's death, then I thought they 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, so I think it's okay they are there (p3)."*

From the health provider perspective, comments could be useful in certain situations by giving an explanation of the reported symptoms; however, in great volume they are impractical *"I have a thousand people on home monitoring [...] For patients, it will be a benefit to have the possibility to report. But I am not sure how, practically, you would sort it*" (n2). In addition, not all reports were related to her/his field of expertise. Thus, they wished for receiving only the most relevant comments *"We need the information that are useful for us, and the information that is not useful we need to sort out or else we will drown in information"* (n2)

All participants found technology potentially useful for e.g. symptoms control, medication management and monitoring irregularities of their health condition. E.g. p7 mentioned, "*Most people are keen on monitoring their lives*".

We found that the majority of the participants used technology for measuring their health status while being at home (e.g. blood pressure device, weight scale, blood sugar monitor) (8/10). Only one participant was familiar with using health applications on the smartphone "*I always carry my phone on me [...] It's probably the security, if something is going to happen*" (p4). Surprisingly, the use of technology is praised by one participant in particular; the oldest participant and most novel technology user (p1) "*I think it is the future. [...] you get the knowledge you seek fast, and that would be an advantage.*" Similar statement about technology playing a big role in the future was also expressed by (p2, p3).

Concerning collecting information on symptoms, most of the participants wished for extra features such as reporting sleeping patterns, location and various other symptoms or even making CardioTalk able to retrieve information from other devices (e.g. step counter, ICD unit) (7/10). One participant (p8) desired detailed reporting of daily activities (i.e. exercise, traveling/flying etc.) and diet so as to better understand how these factor correlate with his/her health condition. "*I want to know what makes the difference*" (p8). Additionally, there was also a wish to collect information and compare across multiple diagnoses "*I have diabetes and I wanted to see if something is relevant with my heart"* (p8).

Despite a wish to collect information on an abundance of symptoms and other factors, not every circumstance allows for this immediately after experiencing the symptoms. One participant (p7) stated that it is impractical to manually report a symptom right after experiencing it, when e.g. sitting in a meeting.

Reflection and Obsession on Symptoms

Reflection is a vital element in understanding collected health information, which is mirrored in studies that focus on gathering health metrics for tracking progress [5, 20]. We found that participants were anxious that too much structure would cause them to be obsessed with their illness. As self-reporting had the possibility of triggering reflection, which in order to achieve awareness of own health was encouraged by participants. Oppositely, all participants were afraid that if the focus on symptoms was too structured it would lead to obsessive behavior, that would take away the focus on every other aspect of their lives. Many participants reflected on their own health in non-structured ways, without the aid of technologies. As they would not like to identify as patient, many of them would deliberately ignore or moderate certain symptoms, in favor of feeling a sense of wellbeing. These findings will be unfolded below.

We found that self-reporting could potentially lead to increased reflection on own health. As two participants explicitly expressed (p5, p2), while other participants acknowledged the possibility for reflection, but did not experience the need for this during the study duration. "*In the evening, where you sit down and it's quit, you think about; how has your day been? Has it been a good day? Then you think about it, instead of just carrying on.*" (p5)

One participant was hospitalized during the study, where he/she, to our surprise kept up the reporting and presented a variation in symptoms unlike earlier reports (p2). For the interview, he/she explained feeling motivated to fill out reports because he/she was in the study. Briefly after being released from hospital, the participant followed the same pattern of use as before the hospitalization.

We found that in order to avoid being obsessed with illness management, all of the participants emphasized the importance of actively managing their use of technologies and rely on them to manage their illness. As use of technology might oppositely lead to obsessive behavior that would negatively impact living with their illness. Almost all participants cautioned against technology taking control of your illness (7/10). "*Measuring blood pressure and that sort of thing, I am of the type who thinks that it creates a high blood pressure*" (p9). Two participants (p5, p6) both imagined that technology could directly support bad habits, when used carelessly.

"*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. […] It's a good thing it is there and we have use for it, but it shouldn't control you.*" (p5),

"*It can get a little too structured, because if I have a pain somewhere, I can go and look at my phone like; this and this symptom […] you might just get sicker sitting there, looking at it all.*" (p6)

None of the participants felt that the use of CardioTalk for this study made a big difference for how they reflected on their overall health and wellbeing, as they already have a positive view on this.
"*It's not something I think about every day, that I have the pacemaker. Sometimes I think to myself; you are almost like you were before.*" (p1).

"*I try not make me sicker than I am, by saying 'this is the life I should have and the pills I take is my vitamins' that is how I manage.*" (p9)

We even saw a tendency to want to ignore or even denying certain symptoms, particularly stress and anxiety, expressed by half of participants (5/10). They argued that these feelings had a negative impact on their sense of wellbeing. One participant (p2) simply disregarded the variation in symptoms when asked if he/she felt generally healthy looking at her reports in CardioTalk by saying, "*I can't very well convince myself of that, but I will try to live like that anyways*" (p2).

"*I try not to be the heart patient I am. So I won't use it (CardioTalk), […] I do not want to be ill, I do not want those labels on me, I just want to be here*." (p4)

"*[…] Maybe I'm a special kind of person – but I believe that illness should not be cultivated, but something you live with*" (p3).

Some participants argued that they had developed mechanisms to cope with the anxiety that can present when experiencing symptoms (real or imagined).

"*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, and if you can dispel that like 'now you're making assumptions' then you have come far in curing yourself*" (p5).

The attitude towards technology's ability to support awareness of own health, was even sometimes marked with distrust, particularly for (p9, p4, p3). "*You know what, 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).

The history feature was mainly used to double check the reports, or because they were curious to see the plots. The majority of them didn't use it because they felt healthy and they knew how the plots would look like. This might on one hand be contributed to the short duration between the deployment and the interview, on the other hand, participants demonstrated awareness of their general health. As an example, one participant (p4) argued she was aware of how different scenarios affected her BP, that when she had a headache, often it was a symptom for high BP. A participating nurse (n2) corroborated this: "*The patients are very knowledgeable about their own illness and they master it, most of them.*" Only the oldest participant of the study didn't use it even once, because he/she was afraid of navigating deeper into the system (p1).

"*I can go back myself and look at and observe; okay, maybe something is on its way again, you know. You can use it for that, it is measurable, when you arrange it like that with the diagrams. I could use it for that."* (p4).

At the last interview over half of participants expressed that they would like to use health reporting if it was provided by the hospital (6/10). Despite some negative attitude towards the use expressed in interviews, all participants complied well with the study protocol, with few exceptions. One of the reasons might be found in their willingness to participate in studies, as all participants expressed a strong wish to give something back to the hospital because they had received good and life-saving treatment.

Transparency and Feedback in Home Monitoring

Transparency in HM refers to the degree of information from ICD operations (e.g. transferred ICD measurements) that is visible to ICD recipients. Transparency has been highlighted as a barrier to deployment and adoption of especially mobile applications for health and wellbeing. The lack of transparency regards the utilization of data collected by such applications [11]. Additionally this is expressed in the study of Skov et al. concerning data for HM [29]. Actionable and timely feedback have possibilities to increase transparency. We found one particular contradiction concerning transparency that we unfold for this theme; participants showed great trust in the HM system, mainly as an extension of their trust in health providers. However, a lot of them expressed doubts and asked questions about HM in interviews. Nurses even saw the amount of trust displayed towards HM as an issue in some situations. We found through comparison of transparency with HM and CardioTalk, some initial ideas for how to structure feedback.

We observed that the level of transparency and feedback today, was not always sufficient to keep participants fully informed about their ICD, illness or HM. We noted that half of participants directly asked questions about HM or expressed doubts about how it was working (5/10). In our case the questions were mainly focused on when data was sent to the hospital, what proximity was needed to the monitor to transfer information from the ICD, what happened if they experienced a shock when they are not in proximity of the monitor etc. and finally, how nurses actually handled information from the monitoring.

The lack of transparency was made clear in the following case. Some doubts were indirectly expressed by (p2) who during the study, besides being admitted to hospital, had an incident of the ICD making a buzzing sound, which he/she dismissed. This happened, because the participant was not aware that the sound was coming from inside him/her or knew how to react to it, which resulted in taking no action. Some confusion of what nurses can actually see from ICD monitor readings presented, when argued why he/she did not contact anyone or subsequently reported this on the CardioTalk (p2). One of the nurses explained that sometimes patients come into emergency and they are confused why nurses have not contacted them, because they have the monitor at home (n2). When in fact all patients are informed to initiate contact whenever an event occurs that they usually do not understand. They rely on the fact that nurses can see everything from the ICD readings.

"*They can see it in there (the hospital). When I come for a consultation, it will show everything from that half a year where I haven't been. So if there has been something it will show.*" (p2)

"*If the box says 'everything is fine', but the patient is very ill, then you have a problem.*" (n2)

The transparent nature of CardioTalk was reflected in the design of showing the same information both to patients and health providers, but it was not embraced in the way we predicted. Despite informing all participants that we and two nurses would review their reports, there was still a lack of transparency of who received the reports. One participant expressed that he/she didn't know who they were writing the reports for (p8). Similarly (p2) stated that he/she might have used the reports differently, if he/she was actively made aware whom they were directed to. One participant thought that the interaction through CardioTalk was lacking transparency, by saying "*Something like this is like magic to me*" (p3).

"I don't know who I am writing for, the purpose for this program, is for me to communicate with someone else or for me to communicate with myself or for me to communicate with something out there? Ideally I would like all 3 things," (p8)

One participant (p10) saw potentials in introducing feedback to improve transparency "*If I was aware when nurses viewed my reports that could make me more secure."* (p10) One participant expressed that it would be good feedback to receive guidance notifications from health providers, to structure management of illness in a certain way, to reduce the possibility of a potential incident (p7). One participant pointed out that a study like this involving both ICD recipients and nurses, could point to some issues with transparency in HM and try to bridge these gaps with the right kind of information (p5). As another perceived benefit of the study protocol (p7) claimed he/she felt a sort of connection between the ICD readings and his reports. He/she would like to see this implemented more directly, as opposed to the parallel way that we have designed CardioTalk in relation to web-based ICD monitoring information systems.

"[...] maybe we go around thinking something at home, while something entirely different is going on out here (at the hospital), then maybe there is a need for a different type of information and what kind is needed?" (p5).

Nurses' view on CardioTalk was positive, but they judged that the immediate feedback of a phone call can't be replaced by reporting. One of the nurses (n1) saw a possibility of incorporating some history besides the measurements in the already existing web based system, but (n2) although mentioning that patients might benefit from this, dismissed it saying the resources were simply not there.

"*I would really like to spend all the time that is necessary on my patients, but that is not how my daily routine works [...] then we would have to take it (resources) from other patients, and where would you take that from?*" (n2)

DISCUSSION

Our findings show that feedback on health status was only necessary when experiencing symptoms fluctuations that made participants feel unable to control their illness on their own. We found that maintaining control of how they were feeling was important for participants, who did not wish to be characterize themselves as patients and be treated as such on a daily basis. Our findings suggest that technology can be used to support being in control through awareness of illness progression, by reporting and sharing information on symptoms and health metrics. To add with the use of technology, put them in control of what and when information is shared. Despite that, our findings show that participants feared the possibility for technology to take over this control, as obsessing over illness progress might cause them to be too dependent instead of listening to their own bodies. The perceived feeling of being in control has been emphasized as a big issue in our findings, but we discovered a great contradiction that the technology of HM received almost blind faith, as an extension of their trust in health providers. Almost to the point of renouncing responsibility.

Based on our findings, we highlight a contradiction that we recommend should be emphasized in further work with ICD recipients and HM, as it is potentially critical. It concerns how our findings suggests that there is an expectation for both health providers and participants that the other part should initiate contact when symptoms are experienced. Our findings propose a connection between increasing transparency and making ICD recipients more aware of when and how to act on symptoms.

Feedback – What, When and How Often?

Feedback is highlighted as important factors for ICD recipients, as studies have shown that more and better feedback should be provided for assurance that HM is working efficiently. However, it is not clearly stated what, when and how often they would like feedback. A study by Petersen et al. found that for a sample of 385 ICD recipients, 84% wished for more detailed feedback. Authors found that patients wished for thorough feedback after their transmissions both scheduled and unscheduled transmissions by means of letters, phone calls and e-mails. Moreover, immediate confirmation of successful transmissions A few wanted all data collected by the ICD to be available, but the majority preferred to have the same feedback as for follow-up; medicine, overall health, ICD programming and battery status [26]. Even more recently Skov et al. has suggested feedback as an apparent avenue for research.

Meanwhile, our findings suggest that although participants enjoyed talking to nurses for the interview, they wouldn't have missed their feedback for this study. In connection with all participants being relatively stable and feeling healthy throughout the duration of the study, it makes good sense, as there was not much to give feedback on. While one participant was hospitalized and even underwent surgery, all information needed was provided at the hospital during his/her stay. Our findings point to that feedback was more likely to be missing, in cases of experiencing frequent symptom variations. No feedback on health status was needed, unless there was something to talk about.

Our findings show that the visualization of history was not used as intended for the short duration of the study. However, one participant suggested that in order to better understand this feature, trend lines for the plots could help to have a clearer focus in reflection. Guiding trend lines would shift the focus mainly to deviations. As our findings state that variations was something to look out for, illustration of deviations might be beneficial. Kendall et al. implemented this feature, showing trends of blood pressure (BP) measurements; average, highest and lowest measurements [17].

From our findings we see that feedback from nurses, might guide reflection, as it is not always easy to know what to look for, but if one or more factors were pointed out by nurses, it might provide focus e.g. they might tell the patient that their weight was becoming unstable and suggest ways to manage weight. For Bentley et al. their application 'Health Mashup' generated a sort of automated feedback, as statistical methods automatically compared data from a multitude of data streams to highlight significant trends for users. It presents the statistical data in an easily relatable form e.g. "*On Wednesdays you X more than usual*" [5]. It is then up to the user if he/she feels a need to act on this information.

The automated feedback might inspire the ICD recipient to make better health decisions. However, using automated fragmented data to say something general, will sometimes show a picture that doesn't mirror the perceived reality of the user [19 p.332]. We tried to put in an element of context with open-ended comments; in this case it will be too complex for simple automation. Additionally, our findings highlight that ICD recipients enjoy the personal relationship and contact with the nurses and would rather not be without it. Participants argue as well, that not all of them place great trust in technology. Our findings for this corroborate previous studies on the importance on these factors; relationships with health provider and attitude towards technology [27].

Participants and nurses expressed a wish for more feedback on monitor operations, as we observed in interviews this was cause for doubts and questions for HM. We see a connection between providing the history of reports and a decreased need for feedback, as we introduced more transparency. It gave participants an experience of control over what data was sent and when. Although, it still caused doubts about who was viewing the data and when. Nielsen refer to this as filtration work; the dilemma that patients can't see who they are directing their reports to. They therefore experience it as challenging to address the right health provider, as inherently health providers have a broad range of specialties and professions [25]. A nurse confirmed that some information received from CardioTalk was out her field of expertise.

Expected Increase in Symptoms Self-Management

Treatments outside of clinical environments like HM are expected to increase in order to save resources for the increasing amount of chronic patients. Therefore ICD recipients need to be more independent in monitoring their own health and self-managing symptoms. The trust that participants expressed in the HM system is mainly an extension of their trust in health providers. This serves as a means of security for the patient but at the same time it works as a barrier to independence that we see could cause potential problems if not properly addressed.

Some participants expressed a "wait and see" attitude that nurses viewed as a problem. Participants seemed to expect nurses to take initiative for contact, but as the monitoring is not inspected by nurses in real time, this could cause misunderstandings and potentially dangerous situations for patients. Nurses stated that this had a connection to the overload of information that ICD recipients get when they are newly implanted. In an attempt to address the problem of information overload, in the study by Aarhus et al. patients would film their conversation with health providers to review again in their personal digital profile. Through their profile they also had access to a digital platform with links and information managed by health providers [1].

We observed that participants didn't express that a shared digital platform existed for finding knowledge and information about their illness, ICD and HM. For all that, they highlight the ICD café a service provided by AUH or follow-up consultations to meet most of their needs for information. However, ICD recipients who wish to go for ICD-café have to invest personal resources e.g. transport and scheduling with other activities, such as work, hobbies, appointments with friends and family or even other of the multiple services from the hospital. They might belong to more than one patient group, according to their illness, treatment and personal needs. A normal day for an ICD recipient doesn't necessarily revolve around constantly managing illness, and therefore it doesn't always take top priority. Our findings show potential for digital tools to support reflection and recognizing patterns. However, some purely rejected it would have an 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 participants did not always identify as a patient, and many would not like to be considered or referred to as one. Similar argumentation can be found in the study by Sanders et al., as this study focused on exploring heart failure patient's barriers to adoption of home monitoring [27]. Our findings show clear positivity towards the mobile platform, despite some usability concerns of screen size, etc.

Reporting alongside HM for ICD recipients has also been in focus for Nielsen, referring to this as homework and concluding that there is a limit to how much complexity patients are willing to go through for their illness management [25]. Our findings as well advice keeping in mind the importance of designing for simple and quick reporting, for future initiatives. Especially if the task is as frequent every day. Our findings additionally point out to also consider relatedness, as participants mentioned things they would personally like to monitor, and expressed a need for applications to be more individualized and even more context aware (including diet, places, daily activities, physical activity etc.)

Future Works

Participants demonstrated awareness of own health and how to manage symptoms. Nurse corroborated this, however he/she also notes that not all patients are good at this and we should use the resources on them.

Our participants mentioned specific target groups which would benefit from using an application such as CardioTalk. Particularly, they mentioned newly implanted patients, anxious patients, or patients with frequent symptoms and people living alone. Future studies might focus on (symptom) self-management for these niche groups within the population of ICD recipients.

One participant in particular framed the ICD-café as a way of getting feedback. This might be an overlooked opportunity, as nurses here have more time for the individual patient and patient education than for follow-up. Perhaps taking the CardioTalk into the ICD-cafe instead of follow-up, could be an alternative solution. However, nurse mentions that structured efforts (different ICD themes) before have failed to impress patients. Future studies might look into this.

LIMITATIONS

Due to the qualitative nature of our study, we believe that eight weeks might constitute a short time period for collecting information about the experience of ICD recipients. Thus, more time might be required for identifying behavioral patterns during symptoms fluctuations over time.

CONCLUSION

Focus on transparency for home monitoring, has shown that transparency is relatively low, as patients are often not able to view what data they are sharing or how their data are being utilized and by whom. In line with this, our findings illustrate that misconceptions happen among ICD recipients, due to the lack of transparency. Particularly, we observed that since ICD recipients have misconceptions towards ICD home monitoring readings and what can be inferred, their trust in HM becomes instead an extension of their trust in the nurses. As their trust in nurses was very strong, we saw a tendency to hand over responsibility for own health to nurses. We conclude that this is critical, as the consequences of being passive can have a negative impact on the health of ICD recipients. Additionally, this results in a passive patient role, in a health care system that is now demanding an active patient role.

In collaboration with AUH, we conducted a study where we deployed CardioTalk (a technology probe) on personal mobile devices of ten ICD recipients. The aim was to explore their use of this tool for digital collection and sharing of symptoms and health metrics. Our findings highlight three main themes on home monitoring of ICD recipients for collection and sharing on symptoms, reflection and obsession on symptoms, transparency and feedback for home monitoring. To be more precise, we found that participants found it useful to collect and share health information digitally, in order to recognize patterns on their symptoms. These patterns could be used to find underlying causes for symptom variation. To do this, reflection was needed and health reporting have the potential to inspire reflection. However, participants feared that they might become anxious and create obsession with their illness, if too much structure for health management is implemented. Finally, our work shows that transparency, in the form of feedback on monitor operations and invitations to participation as exemplified by digital health reporting, gave a perceived feeling of control, which was appreciated for participants. We suggest that efforts to increase transparency, have potential to inform ICD recipients and to reduce misconceptions of data inferred from ICD monitoring and thus inspire to active participation in management of illness and wellbeing.

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Appendix B

Patient Empowerment or Disempowerment in ICD Home Monitoring: Awareness, Assurance, and Accessibility

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ABSTRACT

As current ICD home monitoring practices affords a passive patient role, while at the same time demands are being made for patients to be more actively involved, patient empowerment is of paramount importance to investigate. By means of a technology probe and interviews, we identified awareness, assurance and accessibility as three key components for increasing the empowerment of ICD recipients. Thereby, based on our findings we propose design guidelines for IT health services for home monitoring of ICD recipients, as well as we provide general guidelines to health care providers for increasing empowerment of ICD recipients.

Author Keywords

Home monitoring, ICD, patient empowerment, patient involvement

ACM Classification Keywords

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

INTRODUCTION

The focus on empowering the patient, has put the patient at the center of telemedicine strategies [4, 11]. This brings along transparent 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 active involvement [7].

Strategies in health care state that patients should have more supportive electronic tools to manage self-care, and they specifically mention better overview of measurements from home monitoring. Efforts should be taken to make better use of data collected for patients, to deliver relevant and updated information for learning and providing better care. Patient reported outcomes could be used systematically to evaluate if there is a need for more follow-up. Unnecessary follow-up visits can be replaced by clarifying phone interviews. In this way health providers and patients will use their resources where they are most needed [11].

Broad agreement exists that telemedicine initiatives results in cost-effectiveness and improvement for patients' quality of life in terms of health benefits; lower hospitalization and mortality rates and fewer in-clinic visits [4]. One of the most promising applications in telemedicine is home monitoring which enables patients to be monitored over a distance by health providers. We focus on home monitoring for a heart patient group with implanted devices; Implantable Cardioverter-Defibrillator (ICD). Contrary to the notion of involvement, Skov et al. found that patients are mainly unaware of who views their personal health data, how often and when [10].

This study focuses on patient empowerment, through involvement. The interest for this impeded from a parallel study, where we deployed a technology probe; CardioTalk, to elicit information on patients' use of and attitude towards digitally sharing symptom and health metrics with health providers. For this study we highlight some empowerment potentials as well as challenges and suggest keeping in mind, awareness, assurance and accessibility, for empowerment of home monitored ICD patients.

PATIENT EMPOWERMENT IN HEALTH RESEARCH

Aujoulat et al. conducted a literature study consisting of 27 papers. The study focuses on how the term empowerment has been used in relation to care and education of patients with chronic conditions over the past decade, in theory and in practice [3]. The multitude of outcomes point more towards ambiguity than clarification in finding a shared definition of empowerment. Despite this, the underlying philosophy is clear: Human beings have the right to choose for and by themselves. Authors conclude that as a result of the process of empowerment patients are expected to better self-manage not only their illness, but their lives as well.

Main stated outcomes of empowerment were related to illness and treatment, along with clinical outcomes e.g. better pain management. In addition empowerment is strongly coupled with psychosocial outcomes e.g. enhanced quality of life, enhanced capacity to cope with negative feelings, and capacities to resume life activities sooner. Through development of psychosocial skills patient self-efficacy, assertiveness, self-awareness and sense of autonomy are expected to maximize. Oppositely, disempowerment they found is most often the result of not recognizing the potential in patients experiential knowledge, build up around their own experiences and ontology. Disempowerment can also be a result of providing inadequate resources in terms of time and continuity, as it is important to keep in mind that patients learn at different rates and most express a need for stability while learning and forming own judgments about proposed interventions. Half of the 27 papers examined during this study concerns evaluations of empowerment interventions, however it is not emphasized whether or not these are digital or analogous.

Misconceptions of Empowerment

Anderson et al. have studied patient empowerment and has developed empowerment programs for clinical practice since around 1991 [2]. They view empowerment as a paradigm; the antithesis to what they call the compliance-paradigm. Empowerment requires that health providers should go into a collaborative relationship with the patient, where they acquire awareness of patients' lives and act as a facilitator, rather than a hierarchical role. They point out, that the reality is that health provider's perceived responsibility for patients is wrong, as they lack control to ensure their recommendations are carried out. As a result they often label patients as non-compliant and patients become frustrated and feel blamed for not carrying out health providers recommendations. What is clinically best for the patient, might not be the best for the patient's life. HPs who implementing empowerment must ask themselves: *Do I respect patients' right to make decisions with which I disagree?*

In their study authors point to several misconceptions about empowerment, experienced in working with HP or patients. An example of this is a misconception that patients carry full responsibility for health outcomes, they argue that it is an existential fact that "*patients are responsible for the consequences of their self-management, regardless of whether or not they are aware of, accept or act in accord with their responsibility*" [2]. They stress that empowerment is not about giving or taking power, for HP it is to facilitate and help patients to use their innate ability to master their illness. Empowered patients can freely choose to turn their self-management tasks over to the HP, but they can at any time change their mind about the decision. No matter how much patients wish to surrender control, they can't, they remain in control at all times. Finally, authors view empowerment not as a dichotomous outcome; empowered or not empowered as the process and outcome is different for each patient [2].

STUDY

The themes awareness, assurance and accessibility impeded from the study conducted with a technological probe; CardioTalk. This study was conducted simultaneously. Empowerment emerged as an interest topic, that we wanted to further unfold. CardioTalk was designed as a web based application for sharing health information directly from home monitored ICD recipients to health providers. For the study, participants would report daily and nurses would correlate reports with ICD monitor data. Submitted reports were accessible to view and review through a feature visualizing their health progress during the study period, for both nurses and ICD recipients.

The primary data consisted of logs from the CardioTalk, along with a total of five interviews with ten participating ICD recipients, as well as two participating nurses from Aalborg University Hospital (AUH). Both authors worked together on gathering empirical data, which was iteratively analyzed and refined to become the analytical themes.

PATIENT EMPOWERMENT IN ICD HOME MONITORING

Patient empowerment is a process through which people gain control over decisions and actions affecting their health [12]. In this study, we have identified three components affecting positively patient empowerment in ICD home monitoring. Specifically, these components are awareness, assurance and accessibility.

Facilitation of awareness and understanding of consequences of self-management decisions lays a foundation for empowering and collaborate relations between patient and health providers. Additionally, information sharing supports health provider's awareness of patients' lives and needs, thereby enabling them to give relatable advice in shared decision making [2]. As ICD recipients are remotely monitored, they are most of the time away from the hospital and therefore must be supported enough to self-manage their disease. In this respect, it is important to be aware of factors impacting their empowerment, feel the necessary assurance that everything is fine while being in home and ideally be able to access relevant information and communication technologies (ICT) applications for controlling their illness. Lack of any of these components may lead to disempowerment, as we will argue here.

We anonymized our participants and refer to them as (p1-p10) for the ICD recipients and (n1-n2) for participating nurses.

Awareness

Awareness in patient empowerment for ICD recipients refers to the situation where patients are aware of their overall health condition, as well as being in control of the involved information sharing. As awareness, according to our participants, is the main instrument to know how to act and re-act to maximize positive health outcomes. Health providers should facilitate awareness as well as ICD recipient actively practicing awareness [5]. We found that increasing awareness by viewing history diagrams and managing the information sharing process can empower ICD recipients, in meeting with the health provider, as they are more informed to make decisions. On the contrary, three challenges that contribute to disempowerment are patient's inability to retain large quantities of information, not being in control of sharing data and attitude towards dependence on technology.

Surprisingly, we found that our participants already expressed great awareness of their own health status and at the time of the study, all felt generally healthy. This was also confirmed by the nurses who stated that the majority of ICD recipients were generally good at self-managing their illness. Nevertheless, our participants were positive about health reporting mentioning that it can be useful for detecting underlying causes of symptoms, either on their own or with the guidance of health providers. Furthermore, participants saw potential in using the history plots when their condition is unstable and when they experience symptom variations. In this way, the history feature could help them recall details in consultations with health providers and enable them to steer the conversation according to their agenda. Awareness of own health progression could therefore empower patients to actively contribute to decision making, together with health providers.

We found that participants appreciated the fact that they could submit their own reports. As it meant that they were in control of the information sharing process and thus had no doubts about what information was shared and when. In fact, the reporting feature and the visualization added a new dimension of transparency that usually does not exist in existing ICD home monitoring systems where the ICD recipient only passively shares information. As stated by one participant, it is empowering to be trusted with some responsibility "*It is important the feeling that I am part of it and it is not just electronics, not much information*." (p7).

Despite seeing potential in health reporting through applications, our participants strongly underlined not to be fully controlled by technology. They emphasized that it is important to learn how to feel on their own body when something is not right. High dependency on technology for managing illness was viewed as disempowering, as own awareness should always be the main instrument.

Assurance

We define assurance in patient empowerment as the condition of being certain whether a health service meets particular patient expectations. We found that assurance can impact patient empowerment positively if ICD recipients are receiving feedback from home monitor operations, if digitalized applications are used for specific target ICD groups. This is because such services promote self-involvement. Oppositely, two factors contribute to patient disempowerment; the lack of human contact and the inadequate feedback from existing home monitoring processes.

We found that our participants and participating nurses emphasized the need for assurance in home monitoring. Specifically, participants expressed a wish for assurance through feedback on monitor operations, mainly the first time setting up the monitor so as to be sure that technology works properly. Lack of feedback from monitor operations has also been emphasized as a problem for Petersen et al. who found existing feedback insufficient [8]. Moreover, they also favored the human contact as they put much value in their close relationship with nurses and almost all would like to regularly come into the clinic to receive personal assurance that everything looks fine. Very few expressed that they could see it replaced by technology. Our findings reflect the findings by Sanders et al. when they studied barriers to adoption of telemedicine services, they found a fear among patients that the service would in all aspects replace human contact with technology [9]. While on the other hand, we found that nurses preferred viewed the immediate feedback that a phone call provides as sufficient to give assurance to patients.

The personal contact is resource demanding, we found that participants acknowledged that assurance mechanisms could potentially be mediated through technology for specific target groups: Newly implanted patients and ICD recipients living alone. Considering the newly implanted, one participant mentioned that such a system would benefit this target group, with the result of making people feel more relaxed and calm. The ICD implant forces them to make a lot of life changes and thus they have an abundance of worries and questions for their health and new habits. *"I wished it was there three years ago. It is nice to have things like that out there*" (p10).

Sharing health information digitally, will give a sense of security knowing that nurses will follow their progress to intervene with assurance when deemed necessary. Anderson et al. point out that it is an often seen misconception for health providers to assume that new patients are not ready to take the responsibility that comes with entering into a collaboration as an empowered patient. They argue that it must be even more confusing to just be told what to do, without knowing why, which is active disempowerment [2]. Other participants support the overall benefit for healthcare for ICD recipients, by stating that receiving unfiltered reports from newly implanted ICD recipients could give insight into what kind of information they need to settle into their new life, to make the information better for future ICD recipients in the same situation. Confirming a vital point made by Maliski et al. who found it easier for patients, through empowerment efforts, to resume life activities sooner [6]. Regarding ICD recipients living alone, participants mentioned that such a system would be beneficial for ICD recipients living alone as these people are more likely to have increased anxiety due to the fear of an incident without having no one to help them. In equal measures as feelings of anxiety and depression is often seen for this patient group, the ability to confide in someone and seek assurance was regarded as important by most participants. The participant in our study who was living alone, shared by comparison a significant amount of information covering a range of topics primarily illness, everyday events and life stories. This participant in particular expressed their relief in just sharing all of this information, which in itself had a kind of therapeutic effect.

Accessibility

We define accessibility in patient empowerment as the ability of patients to fully exploit the capabilities of a digital service for controlling their own illness. We found that the convenience of using a digital service for self-management purposes depends on the IT skills and age of the ICD recipients. In this respect, we found one main challenge that contributes to patient disempowerment; namely, the inequality. We define inequality as how ICD recipients with different age and IT skills can equally handle interactive technologies.

Inclusive design is very important when designing health-related digital systems. Based on the conducted interviews with the participants, we found that IT skills in general can be a barrier in equally benefitting from a digital health service. As an example, one participant (p1), who was also the oldest participant, was reluctant on using the visualization of history feature. "*I couldn't remember it, really and I was afraid to get way too far outside of what I have and if I can't go back*" (p1).

Nevertheless, despite the navigation problems, he/she was the participant with the highest interest and willingness to contribute by consistently making reports every day acknowledging the importance of technology by stating "*it's the future* "(p1). Another participant (p3) when asked to explain why mobile technology is not good for managing symptoms, he/she referred to age and emphasized, "*Something like this is like magic to me" (p3).* An explanation on why elderly cannot use health applications arrived from the youngest participant who showed doubts whether elderly people can cope with IT services stating that their age combined with the inexperience of technology aim for that behavior. "*It is not easy for them to learn*" (p10).

AWARENESS, ASSURANCE, ACCESSIBILITY

Our work shows that awareness, assurance and accessibility are key design guidelines to consider when developing health applications for patient empowerment in ICD home monitoring.

Our findings show that applications providing patients (i) digital diary features for recalling history measurements, (ii) control of the information sharing with the hospital, (iii) while not making them feel fully dependent on technology would be appreciated by ICD recipients for illness self-management. Patient-initiated digital information sharing (e.g. daily health reports) seem to have positive effect on the assurance feeling of the ICD recipient as it clarifies concerns about what data are sent to the hospital and when. Nevertheless, there are yet accessibility challenges to be addressed by IT designers specifically for novice technology users.

From the healthcare perspective, we propose that health providers should adopt a more patient-centric attitude focusing on increasing the awareness and assurance of ICD recipients. Awareness involves making ICD recipients more educated of how the ICD monitor operates while assurance refers to feedback that should be delivered to ICD recipients so as relief them from concerns related to their health and ICD home monitoring device In any case, newly implanted ICD recipients, people living alone and ICD recipients suffering from depression or anxiety should be primary groups of interest. For these special cases, we believe that additional support by means of personal digital applications might be beneficial for the empowerment. We propose more research to look into this.

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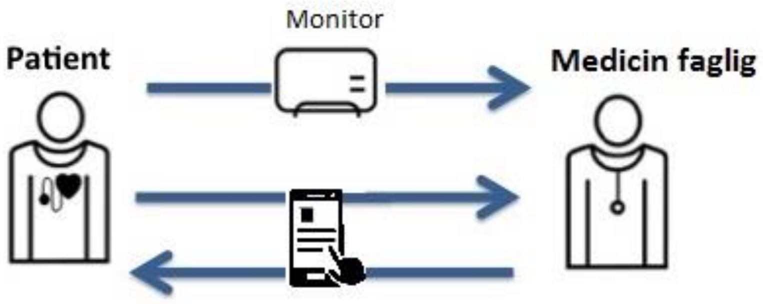
Appendix C

Hvilket potentiale har digital informationsdeling for ICD patienter?

Læs denne deltagerinformation grundigt og spørg, hvis der er noget du er i tvivl om. Du vil også blive informeret mundtligt, inden du tager stilling til, om du vil deltage.

Baggrunden for projektet:
Hjemmemonitorering af patienter med ICD har den fordel at sundhedspersonale kan følge med i patientens helbred på afstand, samt har den store fordel at kunne opdage eventuelle forværringer i patienters helbredstilstand i opløbet. Dette resulterer dog i at patienter og sundhedspersonale ikke har den samme regelmæssige kontakt, som før hjemmemonitoreringen blev introduceret, hvilket har både positive og negative konsekvenser.

Formålet med studiet:
Det er studiets formål at undersøge, hvordan digital informationsdeling og feedback spiller en rolle for patienter og sundhedspersonales vurdering af helbred og velbefindende, samt organisationen af hjemmemonitorering.



Figur: 1 viser informationsdeling mellem patient og medicin faglig via mobil teknologi

Selve studiet indebærer følgende:
Når du siger ja til at deltage i studiet, siger du ja til regelmæssigt (foretrukket dagligt) at angive oplysninger via et fast skema på en hjemmeside via mobiltelefonen omkring dit helbred og velbefindende, i overensstemmelse med de på forhånd angivne instruktioner. Du siger dermed også initierende ja til yderligere aktiviteter; et møde ved studieopstart, en kort samtale undervejs for eventuelle spørgsmål og vejledning, og interview som afslutning på studiet, som vil hjælpe os med at identificere eventuelt potentiale i den digitale informationsdeling. Disse interviews vil blive foretaget af specialestuderende fra Aalborg Universitet. Hele processen bliver nøje fulgt af sundhedspersonale som til daglig arbejder med teknologi og hjertesygdomme, og en repræsentant vil ligeledes være tilstede under interviews.

Hvem kan deltage:
Det er helt frivilligt, om du vil deltage. Selvom du har sagt ja til at deltage, kan du på hvilket som helst tidspunkt og uden begrundelse trække dig ud af studiet igen. Hvis du vælger at deltage, skal du underskrive den vedlagte samtykkeerklæring.

Du kan deltage hvis du opfylder følgende krav:

- Du har en ICD eller CRT-D enhed
- Du er over 18 år
- Du ejer en smartphone/tablet med internetforbindelse

Databehandling:
Behandling af data som indsamles som led i studiet vil i alle tilfælde blive anonymiserede før videre bearbejdning. Dette indebærer at personfølsomme oplysninger ikke vil kunne relatere til dit CPR nummer eller din person. Disse informationer vil udelukkende blive håndteret af sundhedspersonale.

Ved yderligere spørgsmål:
Hvis du har spørgsmål vedrørende deltagelse i studiet, er du velkommen til at kontakte:
Sygeplejerske Charlotte Skov. Kardiologisk Afdeling: www.css@rn.dk tel: 9932 3729

Vi ser frem til at arbejde sammen med dig.
Maria Kjærup og Stefania Kouzeli
(10.semester) Specialestuderende i Software Udvikling, Aalborg Universitet

Samtykke og Fuldmagtserklæring

Titel:

Hvilket potentiale har digital informationsdeling for ICD patienter?

Jeg bekræfter hermed, at jeg, efter at have modtaget ovenstående information såvel mundtligt som skriftligt, indvilliger i at deltage i det beskrevne studie.

Jeg er informeret om, at det er frivilligt at deltage og at tilsagnet om, at deltage når som helst og uden begrundelse kan trækkes tilbage, uden at dette vil påvirke min nuværende og kommende behandling.

Hvis jeg stopper min deltagelse i studiet før planlagt tid, accepterer jeg at den information, der allerede er indsamlet må bruges.

Denne fuldmagt kan til enhver tid tilbagekaldes.

Patient underskrift: ____ Dato: ____________

Sygeplejerske underskrift: ____________________________________ Dato ____________