

Understanding Patient Experience: A Deployment Study in Cardiac Remote Monitoring

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ABSTRACT

The term ‘patient experience’ is currently part of a global discourse on ways to improve healthcare. This study empirically explores what patient experience is in cardiac remote monitoring and considers the implications for user experience (UX). Through interviews around the deployment of a mobile app that enables patients to collaborate with clinicians, we unpack experiences in six themes and present narratives of patients’ lifeworlds. We find that patients’ emotions are grounded in negative feelings (uncertainty, anxiety, loss of hope) and that positive experiences (relief, reassurance, safety) arise from getting feedback on symptoms and from continuous and comforting interaction with clinicians. With this paper, we aim to sensitise UX researchers and designers of patient-centred e-health by proposing three UX dimensions: *connectedness*, *comprehension*, and *compassion*.

Author Keywords

Patient experience; user experience; patient-clinician interaction; phenomenology; participatory design.

ACM Classification Keywords

H.5.3 Group and Organization Interfaces: Computer-supported cooperative work; J.3 Life and medical sciences: Health.

INTRODUCTION

The experience of patients is increasingly being considered clinically important and the concept of ‘patient experience’ has become front and centre of a growing global discourse on how to improve healthcare [1,24,31,34]. The fast spread of the term is supported by research showing that good health outcomes are not driven by safety and clinical effectiveness alone, but moreover by the engagement of patients [34].

Similarly, the turn towards the experience of users has been established as important when designing technology interfaces of high quality. User experience (UX) design takes the ‘human’ perspective by focusing on the user’s context and on positive emotional outcomes from using technology as opposed to task-accomplishment and usability [18]. Early on, beauty and aesthetics have been proposed as important non-instrumental qualities of technology. This was followed by designing for the good life and attention to hedonic UX dimensions such as joy, fun, and pleasure [11,18,25]. Others have argued for the importance of addressing needs, such as surprise or mystery [16]. Lately, eudaimonic user experiences have been found to be about meaning such as pursuing long term personal goals and helping friends and family [25].

However, these emotional responses appear less applicable in the context of healthcare and the lived experience of patients. While UX research have much to offer the design of healthcare IT, few have explored healthcare as a particular domain for UX and considered the implications this might have. With this paper, we show how patients are particular users with particular experiences, situated in contexts that are different than those typically subject to UX design. In our study, we focus on understanding the experiences of patients with an Insertable Cardiac Monitor (ICM) who undergo long term diagnostic monitoring of their heart due to preventive reasons or due to unexplained symptoms such as rapid heartbeat and pauses. For this study, fourteen patients and their relatives have been invited to try out a prototype of a mobile app we have developed to support interaction with clinicians. What we find is that emotions of uncertainty and anxiety and feelings of e.g. being uninformed pervade the everyday lives of these patients. We also find that patient experience is bound to the social, long-term interaction that patients have with clinicians through the remote monitoring system or through the telephone.

BACKGROUND

This section reviews relevant literature, primarily from health-related research fields, that conceptualises patient experience and considers the links to UX and related work in human-computer interaction (HCI), computer-supported cooperative work (CSCW) and participatory design (PD).

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Patient experience

The term ‘patient experience’ has recently attracted much attention amongst researchers and policy makers within healthcare. Some healthcare leaders consider patient experience top priority and it is increasingly acknowledged as being a valuable vehicle for improving healthcare [1,24,31,34].

In some recent studies, positive links are found between patient experience, clinical effectiveness and patient safety [10,24]. In a systematic review, Doyle et al. [10] found that the positive associations do not entail causality but indications, suggesting that patient experience is clinically important and that “the three dimensions of quality should be looked at as a group and not in isolation”. Other studies conclude that the associations between patient experience, clinical effectiveness and patient safety are weak but acknowledge that patient experience is a valuable outcome in its own right [22]. Nonetheless, the term itself – patient experience – is used with varied meanings, and often with little or no explanation. Only a few publications systematically define the concept [34]. When it comes to defining patient experience within this body of work, there are two general findings, which warrant attention.

More than patient satisfaction

The first general finding is that there is consensus that one should be cautious when trying to measure patient experience. Often referred to as ‘patient satisfaction’, authors warn about using the terms interchangeably, since patient satisfaction essentially is measuring a “service experience” whereas patient experience is a clinical quality indicator [1,24,31,34]. Other concerns about measuring patient experience include the feedback biases patients introduce by responding strategically to the surveys to achieve certain goals (e.g. a request for a certain drug) and factors, unrelated to care, such as general happiness. Some patients also mistake the assessment to be about their experience of their health status [24].

Interpersonal aspects

The second general finding is that definitions of patient experience tend to emphasise the interpersonal aspects of care over subjective experiences of illness. The concept of experience may direct attention towards the psychological aspects of being a patient, i.e. human perception and the mind, but in studies reviewing definitions of the term tend to foreground the sociological dimensions of care experiences. From, for example, Jason et al.’s [34] literature review, it is clear that patient experience is understood as a relational and interpersonal concept. They found that “patient experience is not just one encounter, but spans over time and includes many touch points”. Patient-centred care and individualised care is essential and includes aspects such as compassion, empathy and responsiveness in staff-patient interactions, involvement in decisions, and support for self-care. Similarly, Ahmed et al. [1] draw attention to how effective doctor-patient communication can have an impact on emotional health and physiological measures.

Doyle and others [10] define patient experience as, on an overall, being about relational and functional aspects where the former involves “participation of patients in decisions”, and treating patients with respect, dignity, compassion, thorough clear and comprehensible communication tailored to patient needs.

User experience

In HCI, the orientation towards the experiential qualities of technology use is not new. User experience research began in the 1990’s as a countermovement to the almost exclusive focus on usability evaluation and analysis of task accomplishment in work settings. This meant that designing for non-instrumental qualities of technology became more accepted and *experience* is, today, more often a pivotal point for HCI analysis, design and evaluation [4,18]. Similar to the term patient experience, many still find ‘user experience’ to be used with a wide variety of meanings [4,14,18]. Hassenzahl and Tractinsky [18] describes UX as being about “technology that fulfils more than just instrumental needs in a way that acknowledges its use as a subjective, situated, complex and dynamic encounter”. UX is a *consequence of* a user’s internal state, the characteristics of the designed system and the context within which the interaction occurs. This understanding is in line with definitions of patient experience where experience is understood as the unique and subjective emotions and affects (e.g. compassion, trust, understanding, and relieving fear and anxiety). As presented in the introduction, the many suggestions for dimensions in UX research (beauty, joy, fun, pride, surprise etc.) are, nonetheless, rarely derived from studies in health-related settings. Bargas-Avila and Hornbæk [4] have reviewed empirical UX publications in HCI from 2005-2009 and found that leisure usage clearly dominates UX research (64%) followed by work or mixed work and leisure (each with 18%).

HCI & CSCW user studies in healthcare

When turning to related research in HCI, CSCW, participatory design and health informatics it becomes clear that although few have dealt explicitly with patient experience as a UX problem, there is a very long tradition of user and workplace studies as well as design of IT for healthcare [13,20,27]. This research tends to focus on behaviour, social collaborative practices and the agency of patients and clinicians as opposed to an explicit focus on experience. For example, Grönvall and Verdezoto [17] explored the non-functional aspects in everyday self-monitoring activities such as motivation and routines, Nunes and Fitzpatrick [26] show how self-care is a collaborative process involving family and relatives and Chung et al. [9] study expectations in collaboration practices around patient-generated data. Some user studies do consider the emotional side of healthcare technologies. Chen et al. [8] found that the flexibility of online messaging made patients feel empowered and having a closer relationship with their primary care physician. Others found

that patient and physicians can have different health information sharing preferences around emotional issues such as loneliness [19], and that emotions and mixed feelings such as anxiety, stress, empathy, and freedom are tightly bound to self-tracking in chronic care [21]. Mamykina et al. [23] experimented with letting patients create free-form accounts of their diabetes experiences (voice, image, text) and argue that monitoring technologies should be designed to support identity construction. The research approach presented in this paper is in line with these studies and some of our findings support or extend earlier results. In the following we present the method used to unpack the mental states, feelings and emotions related to remote monitoring in cardiac care.

SCAUT: PARTICIPATORY DESIGN PROJECT

This study was organised as part of a long term participatory design project in Copenhagen, Denmark (2014-2017) where we have collaborated with chronic heart patients with an Implantable Cardioverter Defibrillator (ICD), their relatives, cardiologists, nurses and lab technicians at the Heart Centre at Copenhagen University Hospital. The problems we address include the invisible extra clinical burden of communicating remotely with patients [3] and patients' anxiety and concerns from the lack of feedback in remote monitoring [32]. In the main part of the project, we created a living lab to iteratively co-design, develop and test a prototype of an mHealth platform that extends remote monitoring of cardiac device patients [2]. The SCAUT platform enables patients and clinicians to communicate and coordinate remotely and asynchronously around transmissions of ICD data using patient-generated input.



Figure 1. A patient at home (Kathrine) showing the home monitoring box and the symptom activator (in her hand).

Intervention study in cardiac remote monitoring

The study reported on in this paper is a sub-project where the aims was to explore and appropriate the SCAUT platform to patients with another type of cardiac implant and, ultimately, what kind of experiences they have from remote monitoring. We have enrolled fourteen patients with an Insertable Cardiac Monitor (ICM). An ICM is used for diagnosis in patients with recurrent, but unexplained episodes of palpitations (rapid and irregular heartbeat),

unexplained fainting, or for patients at risk of atrial fibrillation to avoid stroke. The success of engineering has made ICMs the size of a little finger. Implantation is now a brief procedure, often conducted by a nurse who makes a small incision and inserts the device in the chest under the skin. This enables long term (up to three years) monitoring of the heart through remote transmissions of recorded data. In the future, ICM monitoring may become standard of preventive care for millions of people. Our study includes both types of patients, i.e. patients with and without a diagnosis. This means that for patients who have already been diagnosed, monitoring is a means for determining the severity of their disease, e.g. for determining whether the patient should have an ICD, pacemaker or an operation such as an ablation. For patients without a diagnosis, the monitoring process helps clarify whether the symptoms they experience are caused by a heart rhythm disorder. The age of the patients range from 9 to 62 years and for some of them, their spouse or parent acts as informal carer.

Patient/Relative	Age	Diagnosis/Surgeries	Monitoring Reason
August Isabella (mother)	9	None/None	Tachycardia
Johannes Anne-Mette (spouse)	62	None/Ablation	Tachycardia
Mathilde	22	None/Ablation	Tachycardia
Jeanette Mogens (boyfriend)	59	Brugada syndrome, Anxiety/None	Palpitations
Therese	47	None/None	Dizziness & fainting
Kathrine	29	Long QT syndrome/None	Palpitations & fainting
Malene	22	AVNRT/None	Fainting
Preben	53	Cardioversion/None	Bradycardia
Freddy	49	Fabry disease	Pause

Table 1. The nine patients quoted in the paper (anonymized).

Data Collection

The data collection is based on an early deployment of the SCAUT mobile app, slightly appropriated for ICM patients, and took place from Feb-Aug 2016. All patients in the study had an ICM for a longer or shorter period before being invited to try out the mobile app. We introduced them to the app, helped them install it, and instructed them to answer questions in the app when automatic or patient-initiated ICM data was transmitted through the home monitoring box (see figure 1). We collected three types of data: twelve semi-structured interviews with nine patients (before and during the use of the platform), data from use of the mobile app from all fourteen patients (patient-generated data such as symptom experiences, personal information, medication lists, etc.), and ad hoc telephone conversations and SMS messages and emails to enrol patients or to solve technical issues. Informed consent is obtained from all patients and the SCAUT project is approved by the Danish National Committee on Health Research Ethics and the Danish Data Protection Agency.

Data analysis: Phenomenology and patient narratives

Our analytic approach is empirical and inductive. For the analysis, we use a phenomenological approach, which is concerned with understanding emergent qualities of individuals' lifeworld. In phenomenology, this refers to the world people experience and in which they live [7]. We use the combination of developing patient narratives and themes to grasp the multiplicity of patient experience and to enable the reader to get a feel of the lived experience of patients going through a diagnostic process of their heart. Narratives, composed by the researcher, are in phenomenology recognised as products of ethnographic research [28], particularly because 'experience' is narratively constructed. Narratives allow researchers to compose and represent the events, characters and subjects that have been studied [6] in subtle, yet phenomenological ways – so to speak. In the qualitative work of collecting descriptions of concrete experiences, these often take the form of stories. The French philosopher Paul Ricoeur suggests narratives, as stories, that make it possible to recall the past in a contemporary perspective by generalising to a certain extent [12]. Within UX, narratives are recognised as a useful method for understanding and designing user experiences [15].

In conducting the analysis, we proceeded through meaning condensation: First, all interviews were transcribed; then long interview texts were condensed into short, meaningful sentences iteratively discussed by the authors to identify themes characterising patient experiences. At the same time, we wrote and discussed patient narratives; Finally, we reviewed the themes and narratives together to arrive at six overall themes and narratives. We should make clear that the findings presented in this study is specific to cardiac patients in remote monitoring and that patient experience should be regarded as one example of representing a phenomenon that is inherently unique, situated and multiple.

SIX THEMES DESCRIBING PATIENT EXPERIENCE

To unpack patient experience in cardiac remote monitoring, we present six key themes and patient narratives: Coping with unexplained symptoms, being uninformed, feeling uncertain and anxious, dealing with identity change, concerns about new responsibilities, and having expectations. The themes describe some of the key dimensions of ICM patients' lifeworlds. The findings are organised in themes with analyses that cut across the empirical data and each with a patient narrative that expands the patients' experiences while grounding them.

Coping with unexplained symptoms

An essential part of the diagnostic process in the remote monitoring setup is that patients experience, record and transmit ICM data to the clinic. The clinicians analyse the incoming data to assess and compare experienced symptoms with device detected signs. The balance between symptoms and the ICM's detected signs has great influence on the patients' experiences of the diagnostic process. Consistency

between symptoms and signs often helps the patients cope with their condition, whereas inconsistency between symptoms and detected signs can create frustration and discouragement. This balance between what is felt and what is measured, influences the way the patients react emotionally, and influences how they cope with their situation. Three situations can occur in the balance of symptoms and signs: 1) The patient experiences symptoms, which are also detected by the device; 2) the patient experiences symptoms that are not detected by the device; 3) the patient does not experience any symptoms, but the device detects signs.

Confirmation on symptoms creates relief

Malene describes feeling relieved about the coexistence of her symptoms and device detected signs. It confirms that her symptoms are not caused by something different: *"I like the fact that I now get a short feedback [in the app]. For example, they write: 'It's clear to us [the clinicians] that what you felt can be seen in the data as well...' So, you get confirmation on what you felt is there. It's always hard for me to know whether I actually felt something. Like knowing when I get dizzy is related to the heart"* (Malene).

Missing detection of signs creates frustration and despair

When symptoms are not detected by the device, it can be extremely difficult for patients to cope with their situation: *"It's there [fast, strong and irregular heartbeats], and at the same time it is not there – if only I could go to the doctor and take a test to show what I sensed at 8.30 am this morning"* (Therese). Some patients experience an increased feeling of despair and frustration, because their symptoms were not detected by the ICM.

Therese is a 48-year-old woman, who lives with her husband and children in a smaller town outside Copenhagen. For several years, she has experienced symptoms of a heart condition, but the clinicians have not been able to diagnose it – even after she got the ICM. Some years ago, Therese was ill with the flu, and it may have caused scar tissue around her heart, and later she began experiencing elevated heart rate and fainting.

Therese is very frustrated because of her symptoms and the fact that the clinicians have not been able to clarify her condition. She is not used to discussing her symptoms or portraying herself as a sick person, and therefore she is a little resigned when it comes to communicating with the clinic about her symptoms. After many transmissions with no events detected, the clinicians told Therese not to make manual ICM transmissions unless she sensed her condition to be serious. She has had some difficulty following these instructions, and she has developed very low expectations that further monitoring will lead to any conclusions about her condition. To some extent, she has given up on the diagnostic process, because she does not feel that it is moving forward towards a diagnosis or treatment plan.

Narrative 1: Therese finds it difficult and frustrating to cope with her unexplained symptoms of fast heartbeats.

Patients like Therese experience loss of hope and despair, because their symptoms cannot be measured in ways that are significant for diagnosing the patient. Another patient,

Preben expresses frustration over the inconsistency between symptoms and the signs that the ICM records. He does, on the contrary, not experience symptoms and does not feel sick: “...but so far I’m having trouble grasping the need for a pacemaker, now that I don’t feel any symptoms or being affected by the episodes [recorded by the ICM]” (Preben).

Being uninformed

A characteristic part of the diagnostic process in ICM remote monitoring is that patients experience the feeling of ‘not knowing’ or being uninformed. This is grounded in the overall situation that patients find themselves in – that of waiting for a potential diagnosis. But it is also a consequence of the “no news is good news” script built into the process of home monitoring [32]. The standard design of all device manufactures’ monitoring procedures is that clinicians only needs to engage with patients if necessary. However, we find that this collides with the needs of patients. Continuous contact with the clinic is key in obtaining knowledge and information. For patients who are asymptomatic, the relation to the clinic is particularly important. Information from the clinic is their only chance to learn about and relate to their condition.

Preben is 53 years old and he lives on a Danish island (Bornholm) with his wife. He discovered his heart condition about two years ago by coincidence at a visit to his primary care physician. The physician discovered a fast and abnormal heart rhythm and sent him to the emergency room where he was diagnosed with atrial fibrillation and treated with beta blockers. Subsequently, he received a cardioversion (corrective procedure using electrical shock). Unfortunately, this resulted in a very low heart rate, and caused his heart to sometimes skip a beat. However, the clinicians he was in contact with at the time, did not assess that his condition was severe enough to give him a pacemaker. To keep an eye on Preben’s condition and clarify whether he should have a pacemaker, he got an ICM and was monitored at the Heart Centre in Copenhagen.

For several months, the ICM transmitted many weekly reports of Bradycardia (slow heart rate). But Preben never felt anything and therefore didn’t understand why clinicians suggested a pacemaker. Quite the contrary – after getting the ICM he was back to work, played football and didn’t feel any of the signs that the clinicians found in the ICM data.

Then he was invited to participate in the SCAUT project and installed the mobile app. Immediately after, he started to receive almost daily notifications and feedback from the clinicians about the detected Brady episodes. More than 40 times ‘Brady’ was detected and shown in the app. This made it clearer and convinced Preben that the clinicians were right. Soon after, he decided to accept a pacemaker.

Narrative 2: Preben finds it hard to relate to his condition when not being informed immediately about detected episodes.

Preben describes it as reassuring when the clinic contacts him to tell him about his episodes, and the timely feedback in the app supports his reflection and understanding of his condition: “I wish I had the app from the beginning. It’s very nice to get notifications when something is detected”.

Information and feedback on ICM transmissions help patients understand and relate to their condition

Preben would like to have greater contact with the clinic and to be more informed about the episodes detected by his device: “Before I got the app, there could very well go between 2-3 months without any contact with the clinic. I did not hear from them. It makes you wonder if the device is working or if the episodes have stopped or what is happening” (Preben). Another patient, Freddy, expressed a similar need for more information. Freddy does not know how to relate to his condition, because he feels that the clinic has not fully informed him about the episodes, which the ICM has detected: “I need to get some feedback. A realistic plan for further treatment” (Freddy). As the experience of being uninformed creates an unpleasant feeling of doubt and uncertainty, the patients seek information to remedy these unsettling circumstances: “I am curious to know it all, I must know everything, and if I have doubts or uncertainties I ask about them” (Isabella).

Feeling uncertain and anxious

Besides having to mentally cope with the existence or non-existence of symptoms, some patients develop feelings of uncertainty and anxiety. This is inherently related to not knowing what the monitoring will reveal and the related consequences it may have.

Waiting produces uncertainty

Patients with an ICM must wait for what often feels as a very long time. The ICM device has a battery life of three years, and typically patients undergoing the diagnostic monitoring process find themselves waiting for an episode to be detected by the device. It typically takes months or years before the clinic have the data necessary to assess the severity of the potential heart disorder. This waiting time has consequences for patients’ experience of the process: “...the uncertainty is the worst part. It can eat you up from the inside, because you are in a position where all you can do is wait for an attack or episode to happen before you can get any diagnose or indication of what is wrong with you” (Isabella). This means, that some patients find it hard to navigate between being a patient and being healthy. This also means that every aspect of life can be filled with a feeling of uncertainty and, worse, anxiety. The following narrative shows how patients can experience uncertainty over an extended period and how this feeling can pervade all areas of life and at times produce anxiety.

Jeanette is 59 years old and diagnosed with Brugada syndrome - a hereditary disease, which causes fast and irregular heartbeats (known as palpitations or Tachycardia) and at worst it can cause cardiac arrest. Because of the severity, patients with Brugada are commonly offered a pacemaker. For this reason, Jeanette has an ICM implanted. This will allow the clinic to monitor her heart and assess if her disease is severe enough to give her a pacemaker. Jeanette also suffers from severe anxiety and related anxiety attacks. She is very affected by her anxiety as her everyday life is filled with uncertain factors and physical symptoms.

Her worrying is an ever-present part of her life and it surfaces,

for example, when a friend asks her to join her for a classical concert. Although she is a huge fan of the performer, the combination of loud music, a big crowd and the excitement of going to a concert, fills her with uncertainty and anxiety directed towards how her heart and body will react to the surroundings. She is afraid that she might panic, because she gets very hysterical when she feels anxious or scared.

Jeanette is, therefore, not able to look forward to the concert. The uncertainty sets in long before and she is worried whether something as joyful as a music performance will cause her to have heart problems. This fills her with opposing feelings of wanting to live and enjoy life while being afraid to do so.

The uncertainty about the severity of her heart disease means that Jeanette's experience of her illness is neither defined by place nor time. It cannot be turned off when going out to social activities. The severity of the disease makes her very observant of little things and she often shies away from situations that potentially could affect her heart and her mental health in a negative way.

Narrative 3: Uncertainty and anxiety pervade all parts of Jeanette's life.

Information reduces uncertainty

Several patients explain that despite what clinicians find relevant to tell, a little more information could help reduce their feeling of uncertainty. Sometimes little cues, comments and general information, given at the right time, can help: "...for them [clinicians], it's just normal work with us patients. But we think a lot more about it than they do. They just see it as a job. It affects us in a different way. So, somehow it would be nice to have some place to see answers to common questions – so that you know that you're not 'kicking the bucket'" (Therese).



Figure 2. Jeanette in her home using the SCAUT mobile app to communicate with the clinic about ICM transmissions.

One patient explains that this does not have to be someone calling or as face-to-face conversation in a consultation. It could just as easily be shown on the mobile app: "I mean... they can just make some sort of standard message, where it says everything looks fine, or we have some questions, could you please call us" (Anne-Mette). Feedback and proper communication can help to reduce the uncertainty that pervades many of the patients' lives (see figure 2).

Dealing with identity change

Another important part of patients' experiences of undergoing a long-term diagnostic process, is their identity and self-image. Some patients accept their disease or deal with unexplained symptoms by sharing it with others while other patients have a hard time convincing people that they have or may have a heart disease. In the following narrative, we show how being undiagnosed challenges identity and how it relates to behaviour change.

Mathilde is 24 years old and studying at the Technical University of Denmark (DTU). Throughout her youth, she has been experiencing abnormal elevation of her heart rate. The rapid heartbeats happen randomly and clinicians cannot detect what triggers them. Mathilde is very frustrated and wishes to be free from her worries. Now, she has an ICM and takes part in remote monitoring to rule out potential heart diseases.

Mathilde enjoys social life. She likes spending time with fellow students at the university and going out with her friends. Parties is a big part of her life, and it's something she enjoys. Like many others in her age, Mathilde is quite observant of how she is viewed by her friends and by others whom she meets.

She keeps her illness a secret and only a few of her best friends know about it because they happened to be in the same room as her, when she experienced the unpleasant and worrying palpitations. She is afraid to tell people about her symptoms. She thinks that sharing it with others will label her 'the sick' or 'weak' person in the group. The long-term diagnostic process has made her nervous, sad and anxious and to take care of her self-image she prepares and acts carefully around social situations, for example when going out drinking with friends: "I don't drink Jägerbombs or shots or what it's called. And I don't drink energy drinks. It's a bad idea, I think, and it's not good for my heart."

Narrative 4: Mathilde's experience of being ill challenges her identity and how she acts around social situations.

Patient identity influences behaviour and social interaction

Like Mathilde, other patients note that challenges of identity carry into their social life. Johannes has gotten used to his disease and have learned to cope with his symptoms but his relatives have changed how they view him: "Many people take my situation all wrong. Like at my sisters. She no longer allows me to do anything. Back then I helped her to move and carry around heavy things. Now I try to explain, that it's not like I'm dead or anything. It's just when I get an attack I'm not 'there' but apart from that I'm just normal... like I used to be" (Johannes). Anne-Mette, who is Johannes' spouse, cares for Johannes to an extent where she almost takes the role of being him. One time the ICM detected Tachycardia (rapid heartbeat) and using the SCAUT app, Anne-Mette made an audio recording explaining about her husband's symptoms as if it was herself: "I didn't do anything when my heart began to beat faster..." (Anne-Mette).

Concerns about new responsibilities

Having an ICM implanted and being monitored makes patients more or less aware that they, themselves, are responsible for making sure that the clinicians have a basis

for diagnosing them. This means that ICM patients are exposed to a range of new responsibilities. For example, they need to make ICM data transmissions when they experience symptoms, bring along the home monitoring box, and keep track of and share their medication list. The patients and their relatives cope with the responsibilities in different ways. Some find it easy and unproblematic to handle while others get emotionally affected and find the new responsibilities stressful. In the following we present a narrative that shows how a patient and his relatives cope with their responsibilities in their own way.

August is 9 years old and has an ICM implanted because he experiences unexplained fainting and palpitations. August's mother, Isabella, is diagnosed with three different heart diseases and has a pacemaker. As August's mother, she is naturally worried about August's health, especially because she has heart problems herself and knows what it means.

August's diagnostic process is associated with a lot of technical equipment, such as the implanted ICM device, the home monitoring box and the little handheld symptom activator. This influences August everyday life substantially, because he alternates between his father's and his mother's house. This means that the home monitoring box must travel with him from one location to another.

Handling the monitoring equipment also influences August when he sleeps over at a friend's house. Unlike normal children, it is not enough for August to ask his parents for permission. They also have to make sure that all his equipment is moved to the friend's house. The symptom activator is, for the most part, in his school bag, but the box that sends data to the clinic at night must be brought from August's room to his friend's house. Additionally, the box needs power so it needs to be located near a power outlet and near the bed where he sleeps.

Although the clinic does not require patients to sleep beside the box every night, Isabella, as a concerned parent, is comforted by making sure that the information from the ICM reaches the clinic as soon as possible.

Narrative 5: August's parents take extra precautions when August wants to sleep at a friend's house.

The responsibilities in remote monitoring often becomes a collective matter. The obligation of recording symptoms or making sure that the ICM can connect to the home monitoring box and transmit data, is typically made a shared project. August and his parents adhere to their responsibilities by taking extra precautions, which makes them feel safer.

The difficulties of living up to new responsibilities

When patients use the symptom activator to record data and initiate transmissions manually, they are obliged to call the clinic and describe what they feel. However, it is only possible to call between 9-11am and there are often long waiting times. One patient expresses that she feels guilty when she does not do it: "... There was a short period, where I sent a lot of transmissions, and I just never took the time to call them. So I felt bad about it. It's a bit stupid that

I keep from doing it, right..." (Kathrine). Another patient, Mathilde is a bit more worried about not living up to her responsibilities. She is very concerned about forgetting to give the clinicians all the right information: "...I have been very worried about whether I forgot to tell the clinicians about the symptoms I experience (...) but they will ask me about the things that are relevant, I know that. But I'm still a bit scared that there would be something, somewhere that I had forgot to tell them. Something that would change the game completely" (Mathilde). The patients are aware that remote monitoring comes with some responsibilities. Sometimes the responsibilities are embraced, since it creates a sense of security to collaborate. Other times – especially if the symptoms continue to be unexplainable – the responsibilities create confusion and concerns from failing to integrate the new tasks into their lives.

Having expectations

So far, we have found that being uninformed and 'not knowing' challenges identity and creates uncertainty. Furthermore, we have found that the ICM comes with a range of new responsibilities, which affects some patients with negative feelings such as guilt and concerns. Some patients feel helpful to clinicians when dealing with their responsibilities. As the remote monitoring setup introduces new responsibilities, it also brings out new expectations from both clinicians and patients. We have found that some patients expect clinicians to show sympathy and take the time to give feedback. As the following narrative shows, we have also found that assumed expectations from clinicians can make patients feel guilty.

Kathrine is 29 years old and soon graduating university. During a very stressful exam period she started experiencing dizziness and nausea, which caused her to go to the doctor. She also felt palpitations and tightness in her chest. Because of these alarming symptoms and no signs showing up in normal examinations, Kathrine got an ICM implanted to monitor her heart. Two months later, she was diagnosed with long QT syndrome, yet the clinicians decided to keep monitoring her heart.

Once, she tried to contact the clinic by telephone to tell them about the symptoms she experienced. She couldn't find the direct telephone number, so she called the hospital's main number. This turned out to be a very dissatisfying experience. Her call was transferred several times and she had to explain everything again and again and when she reached the nurse who could help, the nurse was confused about the type of device Kathrine had implanted. This experience combined with Kathrine's discomfort with speaking on the telephone has resulted in low expectations of what she can expect from calling in. She now hesitates to contact the clinic and mostly blames herself for 'giving up'.

Narrative 6: Kathrine's impression of what is expected of her makes her feel guilty.

Katherine feels like she cannot live up to the clinicians' expectations, which makes her feel guilty if she does not comply. However, since she finds the clinic to be difficult to reach, she rarely contacts the clinic to describe her symptoms.

Expectations of being understood

Patients would like the clinicians to care for their situation but the clinicians' limited resources leave only little time for it. Some patients, mostly patients experiencing long-term monitoring, no longer expects to be comforted: "*So I think it has become more like an assembly line, right? Before they thought about how I was doing... They don't do that anymore. Now it's more like I'm a number in the line... But that's just the way it is. It's just a job for them. They cannot sit there and comfort you*" (Therese). Therese refers to resource cuts in the public health care system, which she feels has led to a change in clinicians' practice; a change that leaves no time for considering the patient's situation. Jeanette has also experienced a lack of empathy and explains how much clinicians' feedback on transmissions means to her: "*I've been very scared, but since I spoke with the last nurse, who was very caring, I've been more relaxed. It's important to get a hold of the right people. You should feel comfortable with the people you speak with*". Communication without comfort, care, or compassion can leave patients feeling uncomfortable even though they are aware of the resource limits.

CONCLUDING DISCUSSION

Next, we summarise our findings and discuss the implications the six themes have for UX.

General findings: Negative feelings and relatedness

When looking across the six themes there are some general findings that cut across patient experiences in cardiac remote monitoring. This has implications for UX. First, patients' emotions are, to a large degree, grounded in negative feelings. Experiences of unexplainable symptoms, 'not knowing' and being uninformed creates worrying, frustration, despair and anxiety. The experiences related to changes in identity, new responsibilities and expectations creates doubt, guilt, and concerns. Second, positive experiences such as the feeling of relief and being able to take decisions, emerge from receiving feedback on symptoms and from continuous comforting communication with clinicians. Third, the patients' experiences are often relational and interpersonal. When patients give accounts, and tell about their illness and the remote monitoring process, their experiences often involves informal caregivers, friends and family, and clinicians. Fourth, such experiential 'stories' are individual, unique, and situated, which means that patients develop their own personal narratives based on selected memorable events.

Implications for UX in health

To relate our findings to UX in healthcare, we propose three dimensions for patient-centred e-health: *Connectedness*, *comprehension* and *compassion*. The dimensions are selected as a response to patients' experiential problems and needs that we found in our study. They embody the intention of empowering patients and supporting clinicians in dealing with the negative experiences. In the following we connect our findings with related literature as recommendations for UX.

Connectedness

Negative feelings and emotions in remote monitoring are a consequence of, for example, not getting feedback from the clinic and not 'hearing anything'. Preben begins to doubt that he has a heart condition when not hearing about what the ICM detects, Kathrine gives up on calling the clinic, and Isabella (August's mother) describes how uncertainty can "eat you up from the inside". This is also found by Skov et al [32] who studied how people live and interact with ICD monitoring technologies: "[L]ack of feedback through the remote monitor caused participants to be more anxious" and "patients experience less safety". Pols and Moser [29] found that seemingly "cold" monitoring technologies become "warm" when patients learned how they could use them to get in contact with nurses: "The Health Buddy is a success because it can connect patients and nurses, even though the device was not intended to do so by its designers."

Affective connections are enacted when patients experience that a "nurse is sitting on the other end". This suggests that e-health technologies should be designed for 'co-experience' rather than experience. Co-experience [5,14] emphasise that meaning and emotion is created together through technology use. It suggests being attuned to the interpersonal aspects of UX in settings such as healthcare.

We propose *connectedness* as a dimension that orients UX designers towards the sensibility of how patient-centred e-health needs to support co-experience and the feeling of relatedness. From our studies, we learned that written feedback on ICM transmissions from clinicians in the SCAUT app generates positive feelings among patients. Even small automated informational ques showing attachment can reduce negative emotions.

Comprehension

From our interviews, we also learned that Jeanette is worried about going to a concert because she is unsure if it will affect her heart, Freddy does not know how to relate to his condition, and Preben does not understand the clinicians' decision for suggesting a pacemaker. These negative feelings can come from 'not knowing' and not having developed ways of how to cope with, for example, unexplained symptoms.

A large part of the patients' negative experiences can be related to how well they have developed competences and their own ways of how to go about living their life with a (potential) heart condition. As Storni [33] argues, "[t]he patient's knowledge and expertise is critical to grounding, integrating and complementing technical-medical/clinical knowledge in everyday chronic self-care." Pols [30] calls this 'know-now' to accentuate that patients develop their own situated activity of knowing. Patients use different sources for reflection and development of ways to recognise one's limits, prepare for, or knowing what to do in situations. Just think of how Mathilde worked out her own way of dealing with her heartbeats when partying or how

Isabella used the home monitoring box to create a sense of safety when her son spends the night at a friend's house.

We suggest *comprehension* as a second dimension for UX in patient-centred e-health to orient designers towards making it easy for patients to develop self-care expertise and 'know-now'. In ICM monitoring this could be supported by enabling clinicians and patients to collaboratively reflect on the relation between symptoms and ICM data. Visualising health data is suggested to be beneficial for patients, as it can enable reflection on multiple dimensions [27].

In remote monitoring, improved patient comprehension could be achieved by presenting historic ICM data along with symptoms (patient-generated data) in the app. This could, over time, enable patients to reflect on and develop a better understanding of their condition. It should be combined with easy ways for clinicians to give feedback on the data and easy ways to attach guidelines on how to interpret ICM data as well as instructions about how to cope with unexplained symptoms. This would entail development of continuity of care [34]. Clinicians' collaborative engagement would be needed to shape an effective patient learning effort.

Compassion

The final point we want to bring attention to, is that negative emotions are unique and situated. Patients have individual needs. Johannes feels that his sister overprotects him by not allowing him to carry heavy things, Therese is restless and misses someone to take care of her when she feels alone, and Jeanette expects clinicians to show sympathy when she calls about her symptoms. Some patients lose hope in the diagnostic process and feel guilty from not living up to their responsibilities. Either way, improving patient experience is about attending to *individualized care*. Jason et al.'s [34] describe it as: "knowing the patient as an individual" and "tailoring healthcare services for each patient" and suggest to integrate dimensions of care such as "compassion, empathy and responsiveness, [...] emotional support, relieving fear and anxiety, and the involvement of family and friends".

We suggest *compassion* as a third dimension for UX in patient-centred e-health. It should sensitise designers to the importance of patients' needs for sympathy and empathy in e-health solutions. In ICM remote monitoring, an extension in the app could include a feature making it easy for patients to raise concerns about anxiety and uncertainty and easy ways for clinicians to select comforting feedback. Such asynchronous communication needs to be personalised through designing support for clinicians to e.g. collectively remember patients' individual preferences and expectations of compassionate feedback.

Limitations and future work

The aim of this paper has been to understand what 'patient experience' is in cardiac remote monitoring and to consider

the implications for UX in patient centred e-health. Although we have pointed to some references that relates to findings in the paper, there are bodies of literature that would be beneficial to consider in future work on patient experience. This includes nursing literature on illness experience, phenomenological studies of the meaning of illness, sociology of emotions in health, feminist STS scholars' studies of telecare and the work on self-determination theory in psychology. Furthermore, future work should empirically explore patient experience among other chronic conditions and with other technologies and consider how UX research can connect with healthcare user studies in HCI, CSCW, PD, and health informatics.

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