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# Diagnostic Agents: Collaborative Interpretation for Cardiac Patients at Home

**Maria Kjærup**

Human-Centered Computing  
Dept. of Computer Science  
Aalborg University  
mariak@cs.aau.dk

**Stefania Kouzeli**

Human-Centered Computing  
Dept. of Computer Science  
Aalborg University  
s.kouzeli@gmail.com

**Mikael B. Skov**

Human-Centered Computing  
Dept. of Computer Science  
Aalborg University  
dubois@cs.aau.dk

**Jesper Kjeldskov**

Human-Centered Computing  
Dept. of Computer Science  
Aalborg University  
jesper@cs.aau.dk

**Charlotte Schmidt Skov**

Dept. of Cardiology  
Aalborg University Hospital  
css@rn.dk

**Peter Søgaard**

Dept. of Cardiology  
Aalborg University Hospital  
p.soegaard@rn.dk

**Abstract**

HCI research shows that cardiac patients dislike the passive role imposed by current home monitoring technology. In this paper, we explored how cardiac patients reacted to taking on a more active role of being a diagnostic agent. We developed and implemented a technology probe for these patients to report symptoms and other health metrics to health providers daily and studied their interaction over eight weeks. Our preliminary findings unfold three themes namely; patient reflection or obsession, patient roles and responsibility towards healthcare staff, and opportunities for nurses to use reports at the hospital in the process of collaborative interpretation. We add to earlier studies, by focusing on the daily, patient-initiated reporting and present topics for further studies.

**Author Keywords**

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

**ACM Classification Keywords**

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

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**Cardiac Patients**

Cardiac patients are patients with various heart diseases and usually they are at risk of sudden death. Some cardiac patients have an ICD (implantable cardioverter-defibrillator) implanted to potentially restore the normal cardiac activation sequence by means of electrical therapy. An ICD is battery-powered and automatically and continuously collects data about heart rhythms etc. [3].

**Cardiac Patients at Home**

When at home, a monitor wirelessly connects to the patient ICD, transferring data to the hospital once daily and alarming nurses if measurements are out of individually set bounds. If clarification is necessary, they contact the patient or confer with a specialist. In case of defibrillation, the patient will attend a follow-up consultation at the hospital. Hospital controls happen at scheduled 1-2 year intervals. For more information see [11].

**Introduction**

Technology plays an increasingly important role in peoples' homes as we integrate and embed more and more devices in our everyday lives. One such technology in our homes are systems that enable people being monitored remotely. This is often referred to as home monitoring (HM). Recently home monitoring for ICD patients has focused on the patients' perception of monitoring [4,11] or possibilities for collaboration in monitoring illness from home [1,8]. Beyond significant advantages, existing home monitoring places the ICD patient in a passive role as data is automatically transmitted and no patient input is directly required. However, in a study by Denning et al. ICD patients rejected (safety) interventions that left them passive and not informed about decisions involving their device [4]. Furthermore, Skov et al. found that the passive role sometimes leads to increased anxiety as ICD patients were often unaware of what health-related information is shared with whom and for which purpose [11]. Recent research has also suggested that patients can and should contribute with valuable knowledge about how their symptoms are experienced in their everyday life to contextualize measurements and collaborate on diagnosis and treatment [2,10].

In this paper, we study cardiac patients at home and, more specifically, we investigate how those patients can act as diagnostic agents in collaborative interpretation. The concept of a diagnostic agent for cardiac patients was introduced by Andersen et al. [1] who studied how patients could provide information about their situation while at home and just before going to a scheduled control at the hospital. However, we still lack empirical studies on how patients can contribute with information about their own lives, symptoms, and general health condition, and how

technology can play or should play a role in this contextualization.

**Study**

Our study aimed to investigate how cardiac patients can be engaged as diagnostic agents while at home. Therefore, we designed and deployed a technology probe [5] (CardioTalk) for ICD patients parallel to existing ICD home monitoring. The probe enabled them to share data and information about their health situation.

*Participants*

Ten ICD patients (3 females) participated in our study. The participants were 45 to 74 years old (mean=62.4). They have had an implanted ICD from seven months to 15 years (mean=5.8 years), and seven of the patients received the ICD after an acute cardiac episode (e.g. heart attack) while the remaining received the ICD as an elective procedure. Additionally, a study nurse trained in cardiac research and an ICD-clinic registered nurse participated.

*CardioTalk*

We created an App called CardioTalk to act as our technology probe and to facilitate users submitting daily reports about their health (see figure 1 and 2). CardioTalk was designed in a design workshop involving interaction designers, cardiac specialists including doctors and nurses, and an industry specialist within ICD and home monitoring.

CardioTalk is implemented as an App with a simple interaction flow to provide patients seamless daily use of our system. It can be accessed through personal mobile devices (i.e. smartphone or tablet) and enables

### Ethical Considerations

Some methodological and ethical considerations were implemented, as ICD patients have severe chronic illnesses. Studies have shown that ICD patients often suffer from psychological stress, such as fear of death, anxiety or depression. Hence, we chose a technology probe; a data collection method sensitive to people's privacy and autonomy.

Our study was granted ethics approval from Aalborg University Hospital for non-invasive studies in accordance with the Helsinki Declaration for medical research involving human subjects. All participants signed a consent form, stating that participation was voluntary, and at any point participants could withdraw or refuse to participate without consequences.

the participants to make reports regarding their health status by answering a set of questions. Patients can easily and quickly answer these questions using sliders (e.g. on a scale from low to high) along with the possibility to make additional comments to elaborate on symptoms. For the purpose of visualization, we showed previous reports in grouped plots.

The questions posed in CardioTalk are grouped into three categories: 1) *physical symptoms* were limited to three commonly occurring symptoms for this patient group: chest pain, shortness of breath and dizziness as reflected in questionnaires used for this patient group (e.g. OASIS, SF-12 and MLHQ), 2) *health metrics* such as blood pressure and weight, and 3) *psychological symptoms* enquired about general mood and levels of stress and anxiety as these are often seen in ICD patients [7].

### Procedure

The study lasted eight weeks and involved three interviews with each of the participants. All interviews took place at the hospital.

*The first interview* concerned gathering of demographic data, providing information on the study and instruction for use of the probe.

*The second interview* focused on *collaboration* between patients and the cardiac nurses and also on perception and usage of the CardioTalk App. First, we observed consultations between the participating patients and the cardiac nurses where ICD data and patient's reports generated through CardioTalk were discussed. Secondly, we conducted semi-structured interviews with each of the participating patients to explore perceived benefits and challenges introduced by the reporting and the following consultation. These

interviews took place between three to four weeks after the first interview.

*The third interview* focused on extended use of CardioTalk, and we also debriefed the patients. Along with elaboration on particularly interesting findings, proceeding the researchers' analysis of patient reports and preceding interviews.

*Finally*, we interviewed the two cardiac nurses on their observations of the patient reports for the consultation.

### Findings

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

### Patient Reflection and Obsession

Our first theme focuses on the cardiac patients' transition to diagnostic agents. Andersen et al. argue that this is a big shift from being a passive source of device data to engaged and active [1]. We found that some participants started to *reflect* upon their situation and condition (usually positive) whereas others were afraid to become more *obsessed* with their illness (usually negative).

As diagnostic agents, some of our participants started to reflect upon their situation and health condition. As an example, P5 stated that "*You think about; how has your day been? Instead of just carrying on.*"

In interviews, we discussed participants' opportunities as diagnostic agents to judge what they themselves



Figure 1 Use of CardioTalk at home to report blood pressure measurements



Figure 2 Selection of screenshots from CardioTalk

can do to mitigate symptoms from home. Two of them (P4, P8) already had experience with (analog) symptom logging. P4 started this because of fluctuations in symptoms. All participants agreed that this is when reporting becomes most valuable; to track fluctuations and outcomes for recognizing and determining actions if similar symptoms are present. P4 stated from experience that their headache was most often due to high blood pressure and did not require immediate medical attention. Thus, for some participants the daily reporting of e.g. symptoms was considered as something positive.

On the other hand, though, seven participants found the strict daily reporting less meaningful as they feared that thoughts on illness would take up too much space and become an obsession. For example, P9 dismissed the need for technology, sharing the view that measuring health metrics can have negative health consequences, e.g. blood pressure measurements would cause higher blood pressure. Similarly, P5 cautioned that e.g. constantly wearing pulse watches might prompt panic when alarming of threshold conditions.

After completing the study, six of ten participants expressed that they would participate in health reporting programs using a mobile device, if provided by the hospital. Of these, three participants agreed that daily reporting seemed meaningful. The other three participants stated that frequent and self-initiated reporting made more sense to them.

#### Patient Roles and Responsibilities

The second theme concerns the roles and responsibilities of a diagnostic agent. Compared to current ICD home monitoring, our participants were

placed in more active roles in providing symptoms to the healthcare staff, and this raised issues.

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

For the collaboration to be successful, it requires trust and openness to both the interpretation of the diagnostic agent and the health provider according to Andersen et. al[1]. Participants point to a personal connection with nurses. P3 jokingly said *"it is almost like she is my girlfriend, that's how much I appreciate her."* For all that, P6 feared that nurses would see patients' own interpretations as irrelevant since they did not have the appropriate medical insight. This was quickly dismissed by both participating nurses. Participants saw the potential for regular reports to aid recalling past events regarding illness as this is not easy to retain in memory and, as a diagnostic agent, to provide this insight to nurses.

*"...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*" (P5).

#### *Collaborative Interpretation at the Hospital*

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

All but one participant used the comments feature to varying degrees and, in the consultation, we experienced how nurses used this information. As an example, P3 had a personal, non-health related experience during the study that s/he reported. For the consultation, the nurse brought this up as a point of interest, although this could not be seen in the ICD data. In connection with that, nurses explained that ICD therapy might not be recognized by the patient but instead present itself as a symptom, e.g. dizziness. Sometimes, this symptom information could cause nurses to review the individual settings for a patient and, therefore, patient inputs can be very valuable. However, in most of our cases, the reported information was either too sparse or too fragmented to make a difference.

Participants expressed that motivation for participating in this study was, on one hand, a need for giving something back and, on the other hand, the comfort of the *"extra attention on me"* (P2). They regarded their contributions as beneficial to themselves, other patients, and, in particular, health providers. P1 shared a noticeably larger amount of details about past, present, and future health, notions and feelings in general compared to the others.

*"With all the things I've written, maybe that can help patients sometime in the future. The more insight you get into how patients are feeling, or what they can feel, that can be helpful"* (p1). Despite of the perceived importance, nurses barely had the time to consequently read the daily reports of all participants and certainly not the thousands of patients they monitor every day.

#### **Discussion and Conclusion**

A diagnostic agent is an active participant in the practice of collaborative interpretation between patient and health provider. Recent research emphasizes that patients should initiate measurements, preferably integrated into other digital tools they are already using [2,6,10]. However, few of these are accepted for use in clinical practice as they are not understood or accepted by health providers [12]. Our findings suggest that health reporting via mobile devices have potential to encourage reflection on illness. It was clear that the role of the diagnostic agent required learning how to balance reflection and obsession. Also, Nielsen argues, reporting introduces unnecessary work and demands on the patient [9]. Despite this, our findings suggest that the task is manageable. The balance between reflection and obsession is a topic for further study.

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

collaborative interpretation will benefit both parties if organized appropriately.

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