
Paradox of Safety: Remote Monitoring of ICD Patients

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Abstract

A growing number of implantable cardioverter defibrillator (ICD) patients are being remotely monitored while at home enabling hospital staff to access clinical information, e.g. heart rate, rhythm electrograms. Previous research has shown that such monitoring leads to increased patient safety, e.g. on mortality.

We illustrate a paradox of safety of remote monitoring from a qualitative study of nineteen ICD patients and their spouses, as they feel less safe while connected to a remote monitoring service. Based on this, we describe three challenges for health technologies in the home namely device feedback to patients, physical appearance of devices, and lack of in-clinic visits.

Author Keywords

Remote monitoring, implantable cardioverter defibrillator, ICD, safety, anxiety

ACM Classification Keywords

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

Introduction

We are currently witnessing a growing number of technologies that are being used for health-related

purposes in the home. In particular, telecare or home-monitoring technologies are widely being adapted as they hold enormous potentials in societies where people are currently ageing at an unprecedented rate [6] and where hospital costs are constantly growing. Remote monitoring of ICD (implantable cardioverter-defibrillator) patients is one of the areas where the potential benefits are significant. Previous research has found that ICD patients often suffer from anxiety or depression [4] and while remote monitoring is found to be intrusive in the private sphere [2], very little is known on how people live and interact with ICD remote monitoring technology.

In this paper, we report from a study on remote monitoring of ICD patients and their spouses. Based on our study, we illustrate that health technology for remote monitoring in the home can create a paradox of safety where patients feel less safe while they are actually safer. Based on this observation, we outline three challenges for designing health related technologies for the home.

Study

Nineteen people (M=59.5 years old) participated in our study including eleven ICD patients (three women) and eight spouses (six women) having in total eight couples, two singles, and one male patient where the spouse did not participate. On average, they have had their ICD for six months to 14 years (M=5.4) and their remote monitor for a little more than a year (M=1.3). Our participants used one of two remote monitors either the CardioMessenger™ by Biotronik or the Merlin.net™ by St Jude Medical. These monitors retrieve clinical data (heart rate, rhythm electrograms

etc.) and technical data (battery status etc.) from the ICDs.

We did a qualitative study where we conducted semi-structured interviews with the nineteen participants and all participants were interviewed at home. Prior to this, participants were invited to keep a diary for two to three weeks. In the following, we focus on one particular aspect identified in our study namely a paradox of safety when connected to a remote monitoring service. The entire study and findings are described in our CHI 2015 paper [5].

Paradox of Safety

We found that monitoring technology for ICD patients and spouses can lead to self-reflection of the persons being monitored as they are constantly reminded of their situation (illness). In particular, we discovered in our study that ICD remote monitoring created a *safety paradox* of patients feeling less safe while actually being safer because some of them became more anxious while living with their monitor. This is interesting and surprising, as previous research has shown increased patient safety when connected to an ICD monitoring service. As an example, Hindricks et al. [12] found in a recent study with 664 ICD patients that after one year of study, the remote monitoring participants suffering from heart failure had significantly better composite scores (i.e. all-cause deaths, overnight hospital for heart failure, etc.) than participants without monitoring.

Several of our participants expressed that the monitor made them aware of their illnesses, and therefore they were constantly reminded that they were ill. And at the same time, many of them argued that that they wanted

to live a normal life after they had the ICD implantation and received the monitor. This further led some of them to decline other hospital offers, e.g. ICD café. We found that many of our participants in general had limited knowledge on when the monitor was operating, what it retrieved from the ICD, what it transmitted to the clinic, and who is looking at the data and when they are looking at the data. This lack of knowledge led to that some of them formed incorrect perceptions on how the remote monitor actually worked, e.g. that it provided live monitoring of their ICD, and it made them more anxious. Also, several participants tried to cover or hide the monitor (usually placed next to their bed).

For hospitalized patients, Leith [3] saw a similar paradox, where intensive care unit patients sometimes experience increased anxiety when moved from ICU to a general ward, despite the fact that these patients were actually recovering. But the loss of close observation in the ICU made them anxious. Perhaps our safety paradox is best exemplified from the following episode involving a couple from our study. The ICD clinic called them one day as the clinic had received an alarm from patient's monitor, and the nurse called him in for a follow-up. The safety paradox is that for the couple to in fact witness the safety provided by the monitoring system, the patient had to have a heart incident so the ICD could report an alarm.

Challenges for Home-Health Technologies

While previous HCI studies have demonstrated how living with monitoring technology is challenging and complex, i.e. [2,6], our study illustrates three challenges for designing and introducing health monitoring technology in the home:

1. Technology feedback
2. Physical appearance of the technology
3. Fewer in-clinic visits

Firstly, while remote monitoring offers a powerful tool for health professionals at the hospital, i.e. cardiac staff [1], the included monitors in our study provided little support for ICD patients or spouses while at home. The lack of feedback induced anxiety, and made participants insecure on data retrieval or transmission, e.g. whether the monitor worked correctly. A key challenge for home-health technology is how can we design feedback to the person being monitored, e.g. what kind of information is feasible and useful?

Secondly, the physical appearance of the monitor made some participants annoyed or made others reflect upon their situation. For example, the green LED light (indicating that power is on) was found to be highly annoying where some participants tried to cover the monitor, and several of them found it difficult to sleep as the monitor would illuminate their bedroom. A key challenge for home-health technology is how can we design these technologies so they become better embedded in a private context (which is clearly different than a hospital setting)?

Thirdly, fewer scheduled in-clinic visits concerned several of our participants. ICD remote monitoring naturally leads to fewer scheduled follow-ups at hospital, e.g. most of our participants went from having a follow-up every 3-6 months before receiving their monitor to having a follow-up every 12-24 months after receiving the monitor. This was a clear problem for some participants as the follow-ups served different

purposes for the patient than just checking and adjusting the ICD, e.g. reassurance chats with cardiac nurses. This is in line with findings in previous studies [2], and a key challenge for home-health technology is how can we replace the continuous in-person contact through technology?

References

- [1] Hindricks, G. et al. Implant-Based Multiparameter Telemonitoring of Patients with Heart Failure (IN-TIME): A Randomised Controlled Trial. *The Lancet*, Vol. 384, No. 9943 (2014), 583-590
- [2] Huber, L., Shankar, K., Caine, K., Connelly, K., Camp, L. J., Walker, B. A. and Borrero, L. How In-Home Technologies Mediate Caregiving Relationships in Later Life. *International Journal of Human-Computer Interaction*. Vol. 29, No. 7 (2013), 441-455
- [3] Leith, B. A. Patient and Family Members' Perceptions of Transfer from Intensive Care. *Heart and Lung*, Vol. 28, No. 3 (1999), 210-218
- [4] Magyar-Russell, G., Thombs, B. D. et al. The Prevalence of Anxiety and Depression in Adults with Implantable Cardioverter Defibrillators: A Systematic Review. *Journal of Psychosomatic Research*. Elsevier, Vol. 71 (2011), pp. 223-231
- [5] Skov, M. B., Johansen, P., Skov, C. S., and Lauberg, A. (2015) No News is Good News: Remote Monitoring of Implantable Cardioverter-Defibrillator Patients. In *Proceedings of the International Conference on Human Factors in Computing Systems (CHI'15)*, Seoul, Korea, ACM Press
- [6] Vines, J., Lindsay, S., Pritchard, G. W., Lie, M., Greathead, D., Olivier, P., and Brittain, K. Making Family Care Work: Dependence, Privacy and Remote Home Monitoring Telecare Systems. *Proc UbiComp '13*, Zurich, Switzerland, ACM Press (2013), 607-616