Experiences from the trenches in Danish hospitals

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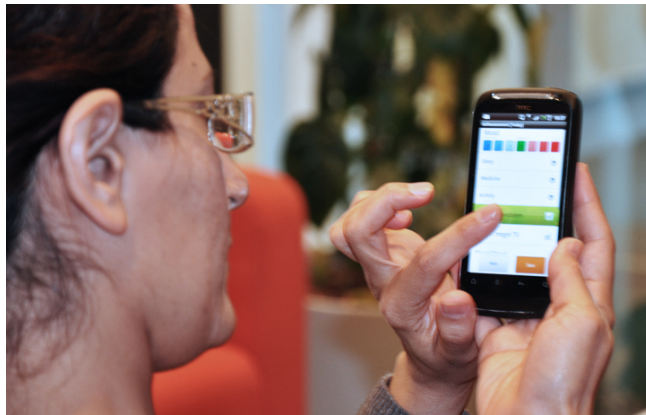[madsf, shou]@itu.dk

Figure 1: The MONARCA Self-Assessment System

Abstract

This paper brings forth experiences, situations and lessons learned from the perspective of two HCI researchers working on research projects in Danish hospitals. The work areas include both physical and mental illnesses.

Author Keywords

Experiences, Hospitals, Patients, Clinicians, Bipolar Disorder, Mental Illness Management, Personal Monitoring Systems

ACM Classification Keywords

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

General Terms

Design, Human Factor, Experimentation

Research focus

There are a lot of things to be aware of in hospitals when *'being there'*. This paper describes some of the experiences and lessons learned during our work *in the trenches* of two of the biggest hospitals in Copenhagen, Denmark. This work was done in two different projects; iCareNet and MONARCA.

The overall approach in the MONARCA project is to make the treatment of patients suffering from bipolar

disorder more efficient. Bipolar disorder is a mental illness characterized by recurring episodes of both depression and mania. The work is done in collaboration with patients and clinicians at the Affective Disorder Clinic at the University Hospital of Copenhagen. By using a personal Smartphone-based pervasive healthcare application, the patient is provided with a greater awareness of the disease and can exercise a much greater degree of self-care and self-treatment. The system lets the patient self-assess and review of various health parameters and supports illness management. For example, patients can use the data to determine adherence to medications, investigate illness patterns and identify early warning signs for upcoming affective episodes, or test potentially beneficial behavior changes. Data collected can be used to predict and prevent the relapse of critical episodes. Through monitoring and persuasive feedback, system helps patients implement effective short-term responses to warning signs and preventative long-term habits. This reduces the need for clinical supervision, treatment, and care, while at the same time empowers the patient in dealing with the disease.

iCareNet is European project that focuses on context-awareness on the areas of healthcare, wellness, and assisted living (HWA). As part of this project, we are studying information management, collaboration and multi-device configuration problems in patient wards. The project is done in collaboration with Bispebjerg hospital in Copenhagen. The workflow of clinicians in a patient ward can be described as nomadic. In addition to sitting in an office or fixed location (knowledge work), clinicians also roam through the hospital while doing their work (mobile work). This work typically includes collaborations with a large number of people and usage of physical tools and computing devices that are spread over multiple locations.

Clinicians thus roam from one location to another while interacting with both mobile and stationary tools and devices. The study includes field observations, interviews, contextual inquiries and user-centric design methodology focused towards co-designing a novel pervasive information infrastructure in close collaboration with clinicians and the intention to validate the system in the wild.

Study Design

To get an understanding of the experiences we have had, a more detailed introduction to the projects are required. These descriptions are trying to capture the setting of the work to enlighten what the conditions were.

The MONACA system [1] consists of two main parts; an Android mobile phone application used by the patients (see Fig. 1), and a website used by patients, clinicians, and relatives to the patient. The design of the MONARCA system was done in a user-centered design process involving both patients and clinicians [2]. Patients and clinicians participated in collaborative design workshops, as seen in figure 2. Three-hour sessions were held every other week for twelve months. These workshops were focusing on two main issues: First on understanding how patient were affected by their illness and how they coped with it in daily life. Second on the design of the overall goals for the new system, its more detailed system features, and its user interface and graphical design. This were gradually evolving and refined using hands-on evaluation of paper-based mockups and early prototypes of the system. The system first went through a field trial with 12 patients using the system for 12 weeks, to ensure it's stability, feasibility and usability. After this, a randomized clinical trial with 60 patients were started, running for two years, to be able to assess

the clinical effect of the system. The lessons learned from the first field trial were furthermore included into a new line of design workshops with patients and clinicians, to make a version 2.0 of the system, which again was tested in a field trial with 20 patients for 12 weeks.

Figure 2: A patient, designer, and clinician working together on a design activity using prototyping materials.

For the iCareNet project, we performed observational studies in 5 different hospital patient wards of Bispebjerg Hospital in Copenhagen over a period of two months. The visited patient wards included those of the surgery department, emergency room department and endoscopy department. During this field study, we performed observations, contextual inquiries and interviews. Observations included first of all task-centric observations

of nursing work in patient wards to get a better understanding of the different types of work that is typically performed in these types of wards. Secondly, we performed artefact-centric observations of the use of computing devices (such as digital whiteboards, mobile PDA devices, traditional desktop computers and specialized medical equipment such as monitors or blood sugar meters), traditional paper-based records, whiteboards, carts and other medical equipment. Finally, place-centric observations of work in the ward, meeting rooms and patient rooms were conducted to better understand the nomadic nature of work in a patient ward. In additional to these three types of observations, we followed one nurse on each department through contextual inquiries and post-hoc interviews to get a more detailed understanding of work on each department.

Study Experience
Through our work in these research projects, many interesting questions arose, many thoughtful moments occurred, many considerations were done, and many lessons were learned – way to many for this paper. Thus, we have tries to summarize some of the key issues we have encountered:

Exposure to Patients   During several instances of the iCareNet field studies, the conducting researcher was exposed to patients that were seriously sick or even in life-threatening situation. In one case, during observations at the emergency room, an elderly woman with a serious cardiac arrest was admitted to the emergency room. The woman was moved into an examination room while screaming and crying as the doctor and nurses where removing her clothes to clear her chest. Because of the stress, the woman defiled herself as the nurses and doctor were working on helping her. During this process, the

researcher was present in the room to observe collaboration between the nurses and doctor as well as the interaction with tools and computing devices in the room.

During this experience, the researcher refrained from using his camera and positioned himself to a corner of the room so the woman could not see him. Because of the extreme situation, the duality between respecting the integrity of the patient and the unique possibility to see a doctor and team of nurses work in a real life-threatening situation, was challenging and distracting. The experience of being exposed to this types of situation for an HCI researcher is not straightforward but a good way of dealing with this is (i) making sure the researcher understands the types of patients that are admitted but more importantly (ii) a good relation with a nurse or doctor present that can help you orientate during these situations.

In the MONARCA project, working with mentally ill patients also provided several challenges. Not only the fact of experiencing people who are so deeply depressed that they don't want to live anymore, or people who are so manic that they are restrained and fixed to a bed, but also getting to know the patients, especially when they are participating in design workshops, to be able to avoid the bias the illness is causing. The patients can be so ill that they don't show up, so high on medication that they are not mentally present or fall asleep, so depressed that they don't have the energy to participate, or so manic that they have a trillion wild fetched ideas which you need to filter out. Especially one middle aged lady springs to mind. She was what is know to be a 'rapid cycler', which meant she experienced severe mood swings every 2-3 days, going from deeply manic to deeply depressed, and vice versa. The researcher got to know her and her illness so well, that when she walked through the door, he could

immediately tell what state she was in, just from her appearance. She had an extremely difficult life trying to cope with the disease, but was determined to participate in the design process, as she wanted to contribute so that hopefully others could be cured from the *living hell* she was going through.

Data collection in the wild   Although official approval may be granted to collect data in a particular way (e.g. photo material), there are situations where e.g. a doctor does not allow taking pictures on a specific department or patient room. During the iCareNet field studies, the basic data collection methods where note and picture taking. Although the hospital approved the use of a camera, there were numerous cases where the researcher was explicitly requested not to take any pictures but also many cases where the researcher refrained himself of taking pictures because of the sensitive nature of the situation or event. Specifically, in situations with arguments between nurses or involvement of patients, the researcher switched to a secondary way of data collection.

Functional vs. non-functional challenges   Often we as HCI researchers are very focussed on the technology aspect of the work we are doing in collaboration with patients and hospitals. However, there is a big difference from building something that works, getting the functionality in place, to actually having it implemented and working. There are a lot of non-functional aspects that have to be in place for the technology to work. From the MONARCA project, there are examples of ensuring patients have a data plan for their 3G connection, enabling them to transmit their data from the phone to the hospitals server. Teaching the clinicians how to operate the system, to be able to access the data, and prepare user guides as well as a hotline for technical

assistance for when they encounter issues they cannot solve. Many small things might seem trivial and not part of the technical solutions, but are extremely important for the success of the project.

Trust and Transparency   When it comes to the relationship between patients / clinicians and technology, the attribution of trust indicates a positive belief about the perceived reliability of, dependability of, and confidence in a person, object, or process. Trust is especially important in health care, as we are dealing with highly personal and potentially life critical information.

In MONARCA we had implemented a voice analysis feature, where the application would record the first two minutes of a patient's phone call, encrypt it, analyze it in terms of e.g. loudness of speech, frequencies, length of talk, and a range of other features. Thus, analyzing not what was said but how it was said. When the analysis was done, it would delete the recording and save the results in the database. The hypothesis is, that it is possible to assess the patient's mood from these voice features.

However, one day one of the patients called the hotline, stating that he had uninstalled the application. He explained that he was using the phone and was about to listen to music. He plugged in the earphones and suddenly heard his farther talking. He got confused and started answering "hello, hello?!?" but his farther just kept on talking. Then he heard his own voice replying his farther, and he realized it was a recording of a previous phone call conversation. He examined the SD-card on the phone, and found two unencrypted phone call recordings, even tho the app had gone through extensive testing before release. When it was discovered, the feature was immediately removed, and a update was released on the

Android *'Google Play'* market, and all patients' phones was checked – fortunately no one else experienced the same issue. But it led to an interesting conversation with the patient on how he was glad that he was neutral when this happened, as he at times suffered from paranoia, and this could really have freaked him out. After this event he had checked the *'Google Play'* market, and was curious to what we actually had access to on his phone. He knew which informations we were monitoring from all the information he had reviewed from us, but when going through the market, it said the application had access to a lot more than what we expressed we gathered. For instance, it took some time trying to explain that even tho it said the application had access to his text messages, it only counted the number sent and received, and did not access the content of the messages. As he explained, it was not that he didn't trust the us and the application, but it was just not transparent enough what was going on under the hood. He reinstalled the app after the update was issued, and finished the trial without any hesitation. This depicts a clear need for transparency in the technology issued, which can be a complicated matter when we are dealing with platforms and infrastructures we do not fully control. Furthermore, building a trustworthy relationship with the participants help ensure the commitment and willingness to provide intimate personal data.

Conclusions

There are a lot of things to be aware of in hospitals when *'being there'*. This paper describes some of the personal accounts we had in our work at hospitals in Denmark. There is nowhere near room enough for all of them, but below is an exclusive summary of some of our key exploits:

Exposure to Patients and treatment   Effects of exposure to sick patients – both physically and mentally. Patients crying, throwing up, defiling themselves, wanting to die, etc., can create shocking experiences for non-clinical researchers. It is hard to prepare for this, but at least you should be aware of it.

Data collection in the wild   Although official approval may be granted to collect data in a particular way (e.g. photo material), there are situations where e.g. a doctor does not allow taking pictures on a specific department or patient room. Therefore, multiple capturing techniques should be prepared and ready to be used in case of these *special cases*

Functional vs. non-functional challenges   For a project to be successful, it is important to pay attention to non-functional aspects, as they can become show-stoppers if not taken into consideration. This is a highly difficult and exhausting task, especially with elaborate and multi-user systems, but it must not be neglected.

Safety and Transparency   Trust and transparency is important in health care, as we are dealing with highly personal and potentially life critical information. Building a trustworthy relationship with the participants help ensure the commitment and willingness to provide intimate health care data, and is maintained by a transparency in both systems and actions.

About the Authors

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Acknowledgements

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