Ubiquitous Context Aware Monitoring Systems in Psychiatric and Mental Care: Challenges and Issues of Real Life Deployments

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ABSTRACT
In this paper we introduce two real-world examples of successful deployments of ubiquitous monitoring technology in mental care: one related to monitoring elderly dementia patients at a nursing home and one to the diagnosis of manic and depressive episodes in bipolar disorder patients. We will elaborate the most relevant challenges that had to be dealt with and introduce the solutions that helped us to overcome them.

Categories and Subject Descriptors
I.m [**Computing Methodologies**]: Miscellaneous

Keywords
real-life deployment, mental care, challenges and issues, solutions

1. INTRODUCTION
During the past decade pervasive computing and context aware systems have conquered the world. Numerous groups work on integrating technical systems into every day life. However, most groups like [8] prefer to work in laboratory-like settings where different parameters can be influenced. This has a reason. Deploying technology in real-life is difficult, as in the real world various issues can complicate the work. Nevertheless, by careful preparation and consideration of possible challenges, real-life deployments indeed can be successful.

In the this paper, two different real-life deployments of context aware systems in health care are analyzed. We will mainly focus on the issues and challenges that had to be dealt with. Yet, we furthermore will shown how it was possible for us to overcome these issues. Even though some of them might seem to be obvious from an outside perspective, in the planning phase of a study, the most obvious aspects are easily forgotten.

2. LITERATURE REVIEW
In terms of literature about challenges and lessons-learned during real-world deployments the amount of available publications is fairly small. One of these publications is from Hansen et al. [5] who describe work in creating systems for hospitals and highlight the value of real-world deployments by observing that issues seeming trivial in the laboratory can become major obstacles in the field. In [6] Hightower et al. present a retrospective on the Place Lab project, mainly focusing on practical lessons from deploying Place Lab.

Ko et all. [7] reviews a number of studies that work towards wireless sensor networks for healthcare. Besides introducing different fields of application of wireless sensor networks in healthcare, the authors analyze some challenges. These challenges, however, only focus on technical issues and comprise trustworthiness, privacy/security and resource scarcity.

In [9] Mayora et al. introduce the lessons learned from the Monarca project and [11] Pool et al. provide guidance for introducing ubiquitous computing technologies in institutions with established norms and rules. They base their theories on a study of a school-based health intervention study.

3. EXAMPLE I - MONITORING OF DEMENTIA PATIENTS
Dementia is a summary term for a set of mostly neuro-degenerative diseases that, broadly speaking, lead to a progressive loss of cognitive abilities and with it to the loss of ability to deal with basic every day situations. An obvious way to asses the progress of dementia is to monitor the way a person deals with common activities of daily living (ADLs). Constant monitoring on a long term basis is difficult to handle and expensive. This almost calls for the use of pervasive technology.

A participation in a project (www.k-licht.at), deployed in 2008, which aimed at enhancing the condition of dementia residents in a home for the elderly by appropriate lighting, enabled us to install a UWB (ultra wide band) real-time location system in one of the

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wards and keep it running for over a year. The aim of this system was to evaluate the possibility to determine the residents' mental state by location monitoring.

3.1 The Study

The UWB location system was deployed between November 2007 and September 2008 in one home-like ward at a home for the elderly [2, 1]. The ward was comprised of 13 residents, all suffering from dementia. 3-4 nurses were present at the ward throughout the day, to help the residents in dealing with daily living. During the study-period, the residents were asked to wear a small sensor tag (of the size of a credit card and placed as a necklace underneath the residents clothing), which was necessary for the location system to detect the residents position in real time. During the morning routines the nurses were asked to make sure that the patients were putting on the tag and if necessary search for tags (usually unintentionally) discarded by residents. The location system itself was running completely automatically.

3.2 Challenges to Overcome

3.2.1 Appropriate Technology and Dealing with Technical Issues:

Choosing a location system fitting the requirements was constrained not only by the availability of technology but also by a number of restrictions imposed by the nursing home authorities. These constraints included: no structural changes to the building, removability of all deployed components after the end of the study, no additional burden to the nurses and sufficient certifications of the system. Necessary devices placed at the residents' bodies had to be small and light-weight and could not disturb the residents. Furthermore, the system had to be able to run autonomously on a long-term basis and/or remote maintenance needed to be possible.

Numerous systems were evaluated, yet almost all of them did not fit the requirements. Fortunately, the UWB Ubisense Location (www.ubisense.com) system, by then just recently certified, satisfied all of them. The necessity of remote maintenance when there was no internet-connection available on site, was solved by installing a UMTS-router running a dyndns service. Regular system crashes due to instabilities in the power-network (caused by high ampere devices in the neighboring hospital) could be solved by installing a UPS (uninterruptible power supply) system.

3.2.2 When Sensors do not work as expected:

Initially, the study included the measurement of sleeping quality. Following the idea that restless sleep would be expressed by a lot of movement during sleep, it was planned to use inertial sensors (accelerometers and gyroscopes) and attach them to the slatted frame of the residents' beds. These sensors were meant to detect any movement in bed and the tests at the researchers' homes worked well.

However, in the home for the elderly, some of the residents' beds were of a special orthopaedic design, partially with stable metal panels instead of a slatted frame, which suppressed the forwarding of any in-bed movement to the sensors. Other patients received a high dosage of sleeping medication and were therefore hardly moving at all. For these reasons the sleep monitoring with simple inertial sensors failed.

3.2.3 Dealing with Mentally Ill People:

Technical issues have a large influence on the success of a study. Yet besides, dealing with humans is a much more uncontrollable factor with very high influence on the success. This is amplified even more when it comes to dealing with mentally ill patients. The success of our study was depending on residents, suffering from dementia, who had to wear a sensor tag every day. Convincing them to do this took some effort by the nurses. Nevertheless, it was clear at all times that it was not allowed forcing residents to participate. Therefore, in total, out of 13 residents, data of only six was usable for us.

An idea to alleviate this problem would have been to include the nursing stuff in the study (possibly with some kind of beneficiary system). The nurses might have been able to encourage the residents to wear the tags more often. Unfortunately, during the planing phase the importance of the nursing staff was underestimated. Moreover, the study was arranged with the nursing home authorities only, and the nursing staff was not included until the beginning of the data recording. Therefore, the nurses did not see the benefit of this study and hence, the motivation of the nurses to deal with extra issues (searching for layed-aside tags) was limited.

3.2.4 Gathering Sufficient Ground-Truth on a long-term basis

In any kind of pattern recognition study, one of the essential aspects is to get sufficient ground-truth. While collecting data in a real-life set up, this can prove difficult. Especially for long-term 24 7 studies ground-truth recording is almost impossible. Therefore, it is essential to exploit mechanisms to get all the ground-truth potentially available.

Depending on the study setting, many restrictions may apply. E.g. in this case, deploying technology in a home for the elderly, any kind of constant labelling (e.g. by using video cameras) was not possible due to privacy reasons (privacy not only of the residents, but also of the nurses and visitors). Furthermore, even though an MMS score (standard score for determining the grade of dementia) had been assigned to all residents when moving in at the ward, throughout the entire study this evaluation could not be repeated. Hence, the only source of ground-truth available for us were the residents' care records.

At the time the study was conducted the state of the residents was not documented in the form of systematic quantitative analysis but through observations and events noted on a regular (but not always daily) basis. Besides of visible appearance of a patient, these entries were the main source for indication of state and state changes (e.g. to determine a patient's medication needs or necessary examinations by a physician).

In order to get the largest amount of usable information out of the care records we decided to extract all positive and negative entries about physical well-being, mental state and sociability. Approximately 80% of the record's entries could be categorized in this way. Even though a simple collection of record entries does not allow one to come up with a subtly differentiated state assessment (which, anyway was not the intention as a simple location system is beyond providing such detailed information) the extraction of broad classes (positive state, normal state, negative state) is feasible. Unfortunately, as described earlier, the health records did not provide entries for every day, and a closer look into the records revealed that, additionally, not all entries could be assigned to a specific day. Furthermore, all entries were rather patient-specific, which means that the extraction of each resident's state parameters had to be done individually. After consulting nursing professionals, we decided to calculate state parameters by comparing (and normalizing) positive and negative entries over a time period of two weeks (shorter time periods were not possible due to lack of record information), which resulted in state values between 0 and 1 for each time period, ranging between the residents' worst and best state respectively. These resulting state values could then be used to actually extract different rates of well being (e.g. positive state (0.5-1) and negative state (0-0.49)).

3.3 Wrap-up

Despite all the challenges that we had to overcome this study was successful. After analyzing the location data we were able to correctly classify the states of the residents with an accuracy of 80-90%.

4. EXAMPLE II - COLLECTING BEHAVIORAL DATA FROM BIPOLAR PATIENTS

4.1 The Study

Cognitive, mental and emotional disorders are an obvious application field for activity recognition. In order to evaluate the possibilities of assisting monitoring and treatment of bipolar disorder patients we conducted a real-world study described in [3, 4]. During ten months, data was collected from 10 bipolar patients in a rural area psychiatric hospital in Austria (12 weeks of data recording per patient). Each patient was given an Android smart-phone running a logging application developed by our group [3], which was designed to record all sensor data automatically in the phone's background.

4.2 Challenges and Issues

4.2.1 Ethics Board Approval:

Specifically in deploying technology in health care, the ethics board (in terms of including patients) or the worker's council (in terms of including clinic personnel) plays an often underestimated but crucial role. Normally, the ethics board is comprised of professionals from healthcare and natural science and furthermore includes a few members of other scientific areas. Therefore, when it comes to deploying a technology-based study in healthcare it is essential to prepare all information in a way that professionals from other disciplines have a chance to understand. Otherwise, if the proposal is rejected or even if there is the request to re-apply in a modified form, it can postpone the deployment for several month.

A possible way to limit the risk of being rejected is to include people from other professions, specifically from the healthcare sector, in the process of creating the ethics board proposal, and to take all concerns, as unimportant as they might seem to an engineer, very seriously.

In our study, in order to get approval from the ethics board, some restrictions were imposed: The most important of them was the need to anonymize all sensor readings before analyzing them to guarantee the privacy of the participants. In particular, GPS coordinates were transferred into a neutral coordinate system. This still allowed features like number of different locations or amount of time spent outdoors, while at the same detaching the data from real world locations. Furthermore, in order to be able to use frequency-analysis of voice during phone calls, algorithms had to be developed which scrambled the sound in a way that it was not be restorable yet would still keep the characteristics of the voice. Phone conversations were anonymized before stored on the smart phone [10] and the audio signal was sliced into small chunks and these slices were randomly permuted within each second, resulting in a very low speech intelligibility. This insured privacy of conversations but at the same time did not hinder the acoustic analysis of the speech.

4.2.2 Technical Issues:

Next to the constraints imposed by the ethics board a number of further technical aspects had to be dealt with.

Data Transmission:. So the original set-up of data transmission was designed to automatically transmit the data. All data would have been transmitted to a secure server belonging to the psychiatric hospital facilities via a secure connection. However, even though the infrastructure was already set up, this plans had to be changed before the study started as it turned out that most of the possible participants neither owned an appropriate wireless Internet connection at home, nor could full 3G Network and DSL coverage be guaranteed. Hence, the set-up was changed to internal storage of all sensor readings, which were transmitted every 2-3 weeks during the appointment of the patients at the psychiatric hospital facilities.

Performance and Battery Life:. First deployments of the running smart-phone application revealed that the smart-phone tended to get rather hot. First the reason for this was not clear, as this never happend during test in the laboratory. Nevertheless, some of the participants were living in rural areas (where most of the time no WiFi was available), which by default of the OS triggered the WiFi port to increase the scan-frequency. Moreover, next to increasing the smart-phone's temperature it decreased the battery-life tremendously.

As in numerous other technical applications, the main critical part in using a smart phone for data recording is the phone's battery life. Constant operating of all sensors in a high resolution reduces the battery life to a couple of hours and therefore, make this application unusable in real-life.

To overcome these issues of perfomance and battery life, the design of the system was optimized. The acceleration sensor was used to trigger most other sensors. This is feasible as for example an unmoved cell-phone will not change its position. Thus, GPS/WiFi sensing can be reduced to a minimum while the cell-phone is not moved. Further more, as long as a person stays inside a building, GPS is only of little use, while WiFi, if available, will provide the needed position information. So in our system, the usage of GPS, which itself is highly power consuming, was turned off while WiFi is available (and vice versa)!

4.2.3 Limited Available Data due to Real-World Smartphone Usage:

In theory, with 10 patients and 12 (or even more) weeks of trial duration more than enough data (> 800 days) should be available for our purpose. However, in reality, as we were dealing with a real-life setting, factors like patient's complience influenced the amount of data that actually was suitable for training and testing of a recognition system. Since the trial had been conducted under uncontrolled conditions, during normal live, there was no way to make sure that the patients always carried their devices with them. In addition, some patients would even switch off some sensors at certain occasions. Therefore, for some sensors and some patients the available amount of data was only half or a third of the expected amount [4].

4.2.4 Gathering Sufficient Ground-Truth in Open World Settings:

As already mentioned above, specifically for experimental data-recording deployments, it is important to obtain sufficient ground-truth. In terms of data-recording in an open world real-life study (participants are not restricted to specific buildings or locations) with strict privacy constraints (imposed by the ethics board), gathering sufficient ground-truth is a notable challenge.

Further complicating this, in the particular case of this study, the required ground-truth was twofold: first of all, it was important to know what the psychological state of the participant was (depressive, manic, improving, worsening, ...). On the other hand it was necessary to get at least a course picture of the participants' daily activities in order to be able to analyze what kind of activity/data would express the current state best.

Our solution to this issue was to use questionnaires the participants had to fill-in. Note, that it is also essential not to overexert the participants. For example, study subjects who need to document their actions every hour of every day for several weeks/month are likely to fatigue soon (resulting in deteriorating compliance with study requirements). On the other hand, asking subjects to report on their activities and state once a week will very likely mix up days in their memory, lowering quality of the ground truth. It is therefore necessary to find a balance between the required granularity and the willingness of subjects. In our study it was decided to ask the participants to fill-in a short questionnaire (app. 10 questions about daily activities, places visited and self-rating of the current mood) on a daily basis. This questionnaire was implemented to pop up automatically on the study-smart-phone in the evening, alleviating the need to actively remember to complete it.

4.3 Wrap-up

Again, this study was successful. Despite the challenges, we were able to perform state recognition with an accuracy of 70-80% and moreover a state change detection with precision and recall of 97%.

5. LESSONS LEARNED

After each real-life deployment, it is wise to sit down and think about what lessons could be learned. Most problems that we encountered during the first study can be attributed to *underestimating the complexity of the social environment and individual attitudes.* Even if it they are not directly concerned by a study or their concern is not clearly related in the first place, while a study is ongoing it is very difficult to react to negative attitudes of concerned parties. It is therefore important to try to involve as many of them as possible from the beginning. During the course of this study, some of the limitations we had to accept, specifically with the reduced amount of available data, could have been eliminated if the nursing staff had been involved.

The second study provided us a number of new insights. First of all: *the novelty of ubiquitous technology means that even well exercised procedures for dealing with legal and ethics issues are no guarantee for smooth execution.* Even though we were very well prepared for the ethics board hearing and therefore got its support for the study quite quickly, getting the final official approval actually delayed the study for almost a year. The only reason for this delay was a not clearly regulated definition in the medical device act, which left the question open whether a smart-phone used in the way intended in this study was to be defined as a medical device or not. If so, a certification process would have had to be started and would have caused even longer delays. During the application for the ethics board approval no one thought about such an issue, which could have been clarified before hand.

Another lesson we learned in both studies was the *importance of repeated on site testing*. Besides the issues already described, we learned that cross-country, even within Europe, systems can behave differently. Parts of the application had been developed and tested in Switzerland, yet during the first weeks of deployment in Austria, these parts of the App would not work due to differences in the operation of the telecom networks.

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