MONARCA: A Personal Monitoring System for Bipolar Patients

Mads Frost
Jakob E. Bardram
Pervasive Interaction
Technology (PIT) Lab,
IT University of Copenhagen,
Rued Langgaards Vej 7, 2300
Copenhagen S, Denmark.
madsf, bardram @itu.dk

Abstract
This position paper presents the development of a solution for monitoring and treatment of bipolar disorder – the MONARCA Self-Assessment System. It touches upon the design, the technical solution, and the deployments of the system, as well as how users found the system.

Author Keywords
MONARCA, Bipolar Disorder, Mental Illness Management, Personal Monitoring, Behavior Change, Android, Self-Assessment

ACM Classification Keywords
H.5.2 [User-centered design]; H.5.m [Miscellaneous].

General Terms
Design, Human Factor, Experimentation

Introduction
Personal monitoring systems have been suggested for the management of a wide range of health-related conditions. These types of systems help users by enabling them to monitor and visualize their behaviors, keeping them informed about their physical state, providing feedback on the effectiveness of their behavior, reminding them to perform specific tasks, and recommending healthier actions or alternatives. Comprehensive electronic
monitoring systems have been presented for patients with bipolar disorder [6, 5]. Also limitations and use of paper-based mood charts are considered along with paper versus mobile-based mood monitoring [4], as well as initial design and evaluation guidelines for mental technologies have been provided [2].

However, designing for mental illness poses several challenges. In addition to complexity of an illness and its symptoms, the treatment process is equally complicated. There is no singular treatment regimen that will work for all patients and thus requires an ongoing process of experimenting with different combinations of medications and learning how to cope with and reduce symptoms through healthy behaviors (e.g., good sleeping habits, daily routines, avoidance of alcohol, etc.).

Thus, one of the core research questions are to what degree systems for mentally ill patients can be designed and to what degree such technologies will be used and adopted, and lead to new ways for the patients and clinicians to treat this group of patients as compared to the existing approaches.

**Development Process**

The design of the MONARCA system was done in a user-centered design process involving both patients and clinicians [3]. 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 18 patients for 12 weeks.
The MONARCA Self-Assessment System
The MONARCA Self-Assessment System consists of two main parts; an Android mobile phone application used by the patients (see Fig. 1), and a website used by patients and clinicians. The technical implementation has been presented in [1], where much more technical details can be found. The system contains 5 core features supporting patient self-management: (i) self-assessment of self-reported data like mood, sleep, and alcohol; (ii) activity monitoring in terms of sampling sensor data from the phone; (iii) historical overview of self-assessment and sensed data; (iv) coaching and self-treatment based on customizable triggers and detection of early warning signs; and (v) data sharing between the patient and clinicians.

Android Phone Application
The main goals of the MONARCA phone application are to; (i) provide an input mechanisms for patients to fill in their self-assessment data; (ii) collect objective sensor data from the phone; (iii) provide a simple historic visualization of the data entered; (iv) provide feedback and suggest actions to take in situations that presents risks; and (v) help patients to keep track of their prescribed medication.

The main reason for using a mobile phone application is that the phone is always with the patient. This is useful not only for the objective activity sensing, but also for collecting the self-assessment data, since the phone is much easier available than a web browser.

The MONARCA application consists of a main screen, linking to 5 different subscreens; (i) Self-assessment, (ii) Visualizations, (ii) Actions to take, (iv) Medicine and (v) Settings. These can be seen in figure 3. On a daily basis, an alarm on the phone reminds the patient to report self-assessment data. In addition to these self-assessment data, the phone is constantly sampling more objectively sensed data. This includes physical activity data as measured by the accelerometer in the phone and social activity as measured by the number of in- and outgoing phone calls and text messages.

Website
The website is designed to be used by patients and clinicians. Patients can see and update their personal data, manage personal triggers and early warning signs, and configure the system. When a clinician logs in, a dashboard provides an overview of his or her patients, and shows how they are doing on the core parameters of mood, activity, sleep, and medicine adherence for the last 4 days. This dashboard is shown in Figure 4. They have access to their patients detailed data, and are able to configure the system for the individual patient.

Field Trial
In order to evaluate the usability and usefulness of the MONARCA Self-Assessment System, it was deployed in a field trial at the Copenhagen Affective Disorder Clinic, from May to August 2011 – a total of 14 weeks. The study included a total of 12 bipolar patients and a psychiatrist. The main objective of this study was to establish the feasibility of the systems and answer the following questions: Is the system sufficiently stable for general use? What is the usefulness of the system in term of helping bipolar disorder patients in coping with their disease? Will this system – if used on a daily basis by bipolar patients – be useful to them in the future?

The aim of the study was, however, not to study the medical effect of the system, but to establish the feasibility of the system, investigating the usefulness and the perceived usefulness for the future. The study aimed at establishing the benefit for bipolar patient in managing their disease - and if positive, to move into a clinical trial.
The field trial results will be published at CHI’13, but the outcome is captured very well in the following quote from P12, who says that:

"What I have gotten out of it is to try and keep me on track – try and keep track of the triggers [early warning signs], and my history [data] – and in that way it has helped me enormously. Previously, I went into periods where I encountered random mood swings, up and down, and I didn’t have any history [data] to relate to, so it kind of surprised me. But now I can actually follow how I’m doing – also back in time – and what caused it. It has really been great, and I think I have been able to keep track of myself."

About the Authors
Mads Frost is a PhD student at the IT University of Copenhagen. His research interests lie on the intersection of human-computer interaction, motivation, persuasion, pervasive and ubiquitous computing, and is focused towards healthcare systems perused on motivating patients through technology.
http://itu.dk/~madsf

Jakob E. Bardram is a professor in computer science at the IT University of Copenhagen. His main research interests are software architectures and middleware for pervasive computing, with special focus on the challenges pertaining to healthcare, both in hospitals and in the home of the patients.
http://itu.dk/~bardram

Acknowledgements
This work has been done in collaboration with a group of psychiatrists and patients from the Copenhagen Affective Disorder Clinic at the University Hospital of Copenhagen. MONARCA is funded as a EU FP7 STREP project – see http://monarca-project.eu/.

References