A Framework for Overcoming Challenges in Designing Persuasive Monitoring and Feedback Systems for Mental Illness

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***Abstract*—Persuasive personal monitoring and feedback systems could help patients and clinicians manage mental illness. Mental illness is complex, difficult to treat, and carries social stigma. From a review of literature on bipolar disorder and interviews with bipolar disorder experts, we developed a framework for designing a persuasive monitoring system to support management of the illness. The framework applies a user-centered design process that is especially sensitive to the complexity of the illness, the difficulty of treatment, its stigma, and the goals of patients and clinicians. We describe our application of this framework to designing a persuasive mobile phone monitoring system. We discuss how our use of the framework can help overcome the special challenges posed by designing systems for mental illness: (1) accommodating a complex array of symptoms, (2) supporting an uncertain treatment process, and (3) maintaining a high level of sensitivity to the seriousness and darkness of the illness, as well as the social stigma associated with it.**

Keywords-bipolar disorder; mental illness management; user-centered design; personal monitoring systems

I. INTRODUCTION

Persuasive personal monitoring systems have been suggested for the management of a wide range of health-related issues. These types of systems help users by enabling them to monitor and visualize their behaviors, keeping them informed of their physical states, reminding them to perform tasks, providing feedback on the effectiveness of their behaviors, and recommending healthier behaviors or actions. In addition to numerous studies on general behavior change [15], research has targeted health-related behavior change [7] such as physical activity [10, 3], healthy eating habits [17], cardiac rehabilitation [11], and the management of chronic illnesses like diabetes [12, 21], chronic kidney disease [20], and asthma [8].

Persuasive monitoring systems also have the potential to help with the management of mental illnesses such as depression, bipolar disorder, and schizophrenia. These systems can monitor data on mood, behaviors, and activities, providing timely feedback to patients in order to help them adjust their behaviors. Review of data by patients and clinicians can support illness management in many ways. For example, patients and their clinicians can use the data to determine the effectiveness of medications, find illness patterns and identify warning signs, or test potentially beneficial behavior changes. Data collected could be used to predict and prevent the relapse of critical episodes. Through monitoring and persuasive feedback, systems can help patients implement preventative long-term habits and effective short-term responses to warning signs.

However, designing for mental illness poses several challenges. Due to the complexity of mental illness, it is unclear what data should be monitored. Symptoms vary from patient to patient, and may be difficult to recognize. It is difficult for patients to reflect on their own mood and behavior, and their families and others around them may only recognize symptoms if they understand the illness and know what to look for. Therefore, one key role of the system may be to help patients find out what their symptoms are through monitoring and exploration of their data, rather than prescribing what signs to monitor.

In addition to the complexity of an illness and its symptoms, the treatment process is also complicated. There is no singular treatment regimen or set of medications that will work for all patients. Treatment of mental illness therefore 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.). The level of uncertainty involved in the treatment and management of mental illness makes the design of persuasive technology difficult [6]. It is challenging to try to persuade users when it is not entirely clear what will help them.

Finally, mental illness is highly stigmatized in many cultures, due to a lack of common knowledge about its causes and implications. Stereotypes portray individuals with a mental illness as unstable, unpredictable, and even dangerous. The symptoms of mental illness are often attributed to an individual's personality, resulting in judging one's character rather than understanding one's struggle with the illness. As a result, many individuals to reveal their illness only to a few trusted family members or close friends. Personal monitoring systems must therefore be discrete and protect the patient's privacy.

In addition to these particular obstacles, persuasive monitoring systems for mental illness must meet the requirements

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found in literature on the application of these systems in a variety of healthcare domains. For example, typical requirements of healthcare systems include: meet the sometimes conflicting goals of patients and clinicians [9], empower the patient, strengthen the patient-clinician relationship, support the clinical assessment of treatment protocols, and be evaluable as a clinical tool [1].

In this paper, we describe how we approached the challenge of designing persuasive systems for mental illness using a framework that we developed for this purpose – the Patient-Clinician-Designer (PCD) Framework. This framework provides guidelines for overcoming the challenges of designing for mental illness through sensitivity to the needs of these patients, and the equal involvement of both patients and clinicians in the design process. We demonstrate the use of this framework through the design of the MONARCA system, which, through pervasive data collection and persuasive feedback to the patient, supports the treatment of bipolar disorder. Using the PCD Framework helped us overcome several challenges to develop a system design with solutions appropriate for all user groups.

II. Treating Bipolar Disorder

Bipolar disorder is characterized by recurring episodes of both depression and mania, with treatment aiming to reduce symptoms and prevent recurrence throughout a patient's lifetime. One approach to the treatment goal of predicting and preventing episodes is to train patients to recognize their own Early Warning Signs (EWS) – indicators that they are headed toward an episode [19]. This training requires extensive psychoeducation (teaching patients how the illness works to equip them for managing it) and psychotherapy (one-on-one therapy to determine personalized management strategies). Training is resource-intensive and its success varies highly from patient to patient. Some patients are never able to identify patterns in their episodes that reveal EWS.

The only tools currently available to patients to help them with EWS are mood charts [2, 13, 14, 18]. Mood charts allow patients to track their mood, symptoms, medication, and other indicators or strategies on a daily basis. This monitoring can help patients get a better understanding of their illness by reflecting on detailed quantitative data. Mood charts are available in several formats: paper forms, websites, and mobile phone applications. Each of these has significant limitations. In our investigation of paper forms, which can be provided by a patient's own clinician or distributed by medical organizations on the Internet, we found that these mood charts are inconvenient to fill out and subjective. Patients are inconsistent with filling them out due to forgetfulness or symptoms, and data from different patients may differ because fields can be interpreted differently or completed using different scales or criteria. Existing websites and mobile phone applications solve the problem of inconsistency, but none are developed nor endorsed by clinicians [13, 16]. In fact, many of these applications are developed by patients [16], who may have valuable insights, but as we will discuss in this paper, their perspective alone is not enough to design a successful personal monitoring system. As a result, we found that these systems tend to suffer from a lack of usability and generalizability.

We aim to design a personal monitoring system utilizing the perspectives of both patients and clinicians. This system, developed as a mobile phone application to benefit from the already central role of smart phones in daily life, is a component of the European MONARCA project. The MONARCA project is a cross-institution effort to develop and validate solutions for multi-parametric, long-term monitoring of behavioral and physiological information relevant to bipolar disorder. The focus of this paper is the user-centered design process, with the application of a new framework, for the development of the project's mobile phone application.

III. Patient-Clinician-Designer Framework

A review of literature on bipolar disorder and interviews with bipolar disorder experts revealed the challenges of living with and treating bipolar disorder. To overcome these challenges during the design process, we developed the Patient-Clinician-Designer (PCD) Framework. This framework outlines how the key principles of user-centered design [5] – including user focus, active user involvement, evolutionary systems development, prototyping, and usability champions – can be applied in the context of designing for mental illness. Applying these key principles defined in the literature, the framework focuses on the needs and perspectives of the three players of a user-centered design process for a persuasive healthcare system: patients, clinicians, and designers. The framework consists of four design phases: (1) understand the illness and its challenges, (2) sensitively involve patients in design, (3) mediate co-design with patients and clinicians, and (4) accommodate different evaluation goals. For each phase of the user-centered design process, the PCD Framework provides questions to be addressed and considered.

A. Understand the illness and its challenges

First, it is important to understand the illness, its causes, symptoms, treatment, and challenges. This knowledge not only helps with determining system requirements, it also helps to ensure that the design process protects patients. Symptoms, stigma, and other serious topics related to living with the illness must be handled respectfully and cautiously. The following questions should therefore be explored before design begins:

- What are the symptoms? How does the illness limit patients in their capabilities, activities, and lives?
- What is the treatment? What are the obstacles to adherence?
- How is the illness stigmatized? How does stigma affect patients?

B. Sensitively involve patients in design

Having addressed relevant aspects of a patient's experience with the illness, the second phase of the design process involves patients in the design process in a sensitive manner, by considering what methods are most appropriate, and how illness-related topics should be approached. For example, the following issues should be considered:

- What methods can help patients feel as comfortable as possible sharing personal information that may be sensitive, private, or difficult to talk about?

- Can familiar settings and people be utilized to make patients more comfortable?
- How do patients' symptoms affect their involvement, and how can these effects be handled to help both the patient and the design process?

C. *Mediate co-design with patients and clinicians*

The third phase is mediation of co-design activities to reach appropriate solutions and compromises. With their protection ensured, patients can be highly involved in the design process and provide valuable input. When patients co-design with clinicians, the perspectives of these two groups can conflict. To address the challenge of mediating conflicting perspectives, we apply established design practices of persuasive healthcare systems in identifying concerns to be addressed during design. Table 1 outlines these concerns from three perspectives. The Patient and Clinician perspectives represent the two broad groups of users of persuasive systems; the Designer perspective represents the developers and/or the suppliers of these systems.

The Patients perspective captures the perspective and motivations of the patients' realm, including the patients themselves, relatives, friends, community of other patients, and other stakeholders that are present in this part of the system. From the patients' perspective, important questions to address in the design of persuasive technology are related to adoption, acceptance, and sustained use. For example, in order to foster patients' and relatives' adoption of the technology, it is important to consider questions like: What do patients and others gain from using the system? What will motivate them to use the system? What can patients learn about themselves, and what can they and others do with this knowledge? Similarly, for patients and others to accept the technology as a part of their lives and routines, the following issues should be addressed: Will the system fit into the daily lives of patients, including both aspects that are and aren't related to their illness? How will the system handle fluctuations in the health and stability of patients? Are sufficient levels of privacy and confidentiality established? Finally, for use of the technology to be sustained over time, we should consider the following issues: Do the type of data collected and the method of collection make the patient feel comfortable enough to divulge frequent and honest personal information? Is data collection nonintrusive and convenient enough to sustain regular use of the system?

The Clinicians perspective represents the perspective and motivations in the clinical realm, including nurses, doctors, residents, interns, nursing home staff, therapists, and other stakeholders in the more institutionalized part of a healthcare organization. Similar to the patients' perspective, important questions to address from the clinicians' perspective in the design of persuasive technologies are also related to the issues of adoption, acceptance, and sustained use. For example, in order for clinicians to adopt a persuasive healthcare system, it is crucial that it can provide evidence for improved patient treatment and care. Further, it must adhere to established clinical practices to be incorporated into the daily clinical practice in the clinic that is going to host the system. Similarly, concerns about acceptance by clinicians are related to whether they are able to document their care and treatment when using the system, and whether the system would bypass normal patient-clinician communication channels and potentially impose additional work on the clinicians' part. Finally, in order to ensure sustained use by clinicians, evidence must be provided for long-term improvements in care and treatment, and long-term usability issues must be solved, such as the scalability required to handle many patients over long time periods. The latter often implies support for access to concise patient overviews and notification mechanisms.

In addition to the concerns about adoption, acceptance, and sustained use, concerns for embedding the system into the technical and organizational infrastructure of the clinic are crucial to the success of a persuasive healthcare system. It is important to consider how the system integrates and works with the existing clinical systems infrastructure. For example, how will the data from the persuasive system be moved to the electronic medical record (EMR) and vice-versa, how will relevant data like medicine prescriptions be synchronized from the EMR to the persuasive healthcare system? Moreover, the overall organizational socio-economic context of the clinical system setup needs to be scrutinized. For instance, will the clinic be reimbursed for their service to patients using the system? In Denmark, for example, clinics are only reimbursed when a physical consultation between the patient and a doctor takes place.

The Designers perspective is partially reflective in capturing the perspective and motivations of those designing the system. We, as designers, assess our role in co-designing with patients and clinicians. In addition, this perspective captures the motivations of other figures such as implementers, commercial partners, research institutions, and related stakeholders who are responsible for designing, building, running and potentially selling a persuasive system to the patient and/or clinician stakeholders. From this perspective, important questions to address in the design of persuasive technologies are more traditional, such as: What is the motivation of building the system? What is its cost-benefit tradeoff? The motivation for the designers of the system is related to the existence of a clear and evidence-based "business case" for the system; *i.e.*, is there clear evidence that a solution potentially will help patients in their treatment, and what other related and competing solutions already exist? Moreover, the designers' motivation is tightly connected to system acceptance by patients and clinicians – there has to be a clear indication that the system can be designed in a way that will be accepted by both user groups. Therefore, working with the questions associated with users' acceptance of the system is fundamental to the designers' motivation of engaging in the design in the first place. Other important questions to consider relate to what happens to the data, who owns it, what it can be used for, and in what format it is in. It is also necessary to consider the costs needed to implement and run the system, paying particular attention to the continuous maintenance and hosting of the system, and how these costs are distributed. For example, it may be assumed that hidden costs in data transmission from a mobile phone will be absorbed by patients, but this may prevent adoption – especially if the system is being used as part of a clinical trial. On the other hand, if the patient is given a phone with free telephony and data transfer, these services may be misused.

Patients, relatives, communities of patients	Adoption	What do patients gain from using the system? What will motivate them to use the system? What can patients learn about themselves, and what can they and others do with this knowledge? Does the perceived value of using the system outweigh the burden and sacrifices?
	Acceptance	Will the system fit into the daily lives of patients, including aspects that are, and aren't, related to their illness? How will the system handle fluctuations in the health and stability of patients? Is the system perceived as trustworthy by the patient and others? Who gets access to the data?
	Sustained use	Do the type of data collected and the method of collection make the patient feel comfortable enough to divulge frequent and honest personal information? Is data collection nonintrusive and convenient enough that regular use of the system can be sustained?
Clinicians, doctors, nurses, GPs, therapists, nursing home staff	Adoption	Does the system use evidence-based treatment strategies? Does the system adhere to clinical practices? Can it be incorporated into typical interventions and treatment? Do the clinicians and their organization have the resources to run the system? Do they have the skills?
	Acceptance	Does the system present a liability for clinicians? Is the system going to impose an additional workload on the clinicians? Does the system encourage patients to make decisions without consulting a clinician – whether explicitly or implicitly? Or does the system assume increased communication between the patient and clinician? Will the system bypass normal patient-clinician communication channels?
	Sustained use	Are the data collected relevant, applicable, and customizable for a variety of cases? Is the data presented to clinicians in a useful and convenient way for analysis to support decision-making? Does the solution scale over many patients over long time? How can the system provide evidence for continuous improvement in clinical care and treatment?
	Infrastructure	Is the system integrated with existing systems in the clinic, like electronic medical records? Will data flow into the back-end biomedical infrastructure of the clinic? Will data from the clinical systems flow into the system, like medicine prescriptions? Are sufficient resources and technical infrastructures in place for hosting, running, and maintaining the system? What are the consequences for the incentive and reimbursement infrastructure in the healthcare organization?
Designers, researchers, software architects, commercial stakeholders	Motivation	Is there a clear, evidence-based business case for the suggested treatment? What is the competitive edge in relation to competitors or related research? What is the main contribution of this system? How will the system be evaluated, and perform, in usability evaluations and pilot deployments? Will this be accepted in large scale by patients? And clinicians?
	Benefit	What are the revenue patterns for the system? Is data collection as convenient and user-friendly as possible? Who owns the data? Can data be used for other purposes? What are the requirements for data anonymization and protection? Are appropriate and adequate data protection methods being used? Is data quality high enough for clinical evaluation, statistical analysis, and/or machine learning?
	Cost	What is the cost to produce the solution? What is the minimum required functionality? What is the cost of running the system? Maintenance? Support? Subscriptions to e.g. telecommunication? How much of this can be offloaded to the patients and/or the clinicians?

Table 1. The second phase of the Patient-Clinician-Designer (PCD) Framework involves consideration of different, sometimes conflicting, concerns from the perspective of each group, and mediating co-design activities to find appropriate solutions.

D. Accommodate different evaluation goals

Evaluation goals are an additional area of compromise due to the need to accommodate differing, and sometimes conflicting, goals of technical evaluation versus clinical evaluation. The following issues should be considered throughout the design process:

- How can the system be evaluated as both a piece of technology and a clinical tool?
- How can designers work with clinicians to determine an adequate plan for evaluation?
- How do design decisions accommodate the goals of both types of evaluation?

E. Using the PCD Framework

The PCD Framework can be used both in the design of a new persuasive technology – which was the case in the MONARCA project – as well as in the organization and clinical implementation and use of an existing system. Therefore, when we use the term "design", we mean both technical systems design as well as organizational design of usage and work practices involving the system.

The PCD Framework is to be inserted and used within a user-centered, participatory design process. Hence, the three groups of stakeholders (patients, clinicians, and designers) should work together in workshop sessions. In this user-centered design process, the questions in the PCD Framework are continually addressed and gradually answered. The aim is not to ensure that the system has a positive answer to all of the many questions addressed; the aim is merely that the different

questions are addressed and a conscious and shared consensus on the items are reached. For example, there might be an inherent conflict between the patients' need to constantly contact the clinic, and the clinicians' need for shielding themselves from a massive telephone storm from anxious patients – a tradeoff existing between the patients' concerns in achieving sustained use versus the clinicians' concerns of acceptance (see Table 1). This conflict may not be solvable, or a decision may be taken to allow for patients to call their doctor directly – as we did in the design of the MONARCA system. As such, the system will shortcut normal patient-clinician relationships, but in this case this decision has be deliberately taken. And we know that this decision and system feature will introduce problems if the system is going to be deployed in a large-scale setup.

In using the PCD framework, we argue that it is important to always consider all three stakeholder dimensions. Even though some persuasive healthcare technologies are entirely targeted towards the patient's perspective, and leave out the clinical perspective, we argue that it is still important to consider the clinical perspective for several reasons. First, if the system cannot provide clinical evidence, then the success of the system may be hard to obtain, at least in the long run. Moreover, any personal healthcare system seldom exists in a vacuum; often these systems and the data they provide are brought to the clinic. Hence, even though the clinical use of a system may seem limited, it still needs to be designed with its role in a clinical context in mind.

IV. METHOD

We applied the PCD Framework to the design of the MONARCA system. First, a literature review on bipolar disorder and interviews with bipolar disorder experts provided the domain knowledge required to embark on the design of a system for bipolar disorder. These investigations informed the development of a user-centered design methodology that could be sensitive to the symptoms and limitations involved with bipolar disorder. We collaborated with a bipolar disorder treatment program at a local psychiatric clinic in order to piggyback on their personal and trusted services. Patients and clinicians were recruited through the clinic, and design activities were held at the clinic. This approach allowed us to quickly gain the trust of our participants and easily build rapport.

Through their participation, patients and clinicians were instrumental in making decisions about system features through collaborative design workshops and iterative prototyping. Workshops were held every other week for six months. At every workshop, 1-3 individuals attended from each of the three groups: patients, clinicians, and designers. The designers led each three-hour workshop by facilitating discussion about particular design goals and issues; system features and functionality; and feedback on mockups and prototypes of the system. During initial workshops, key members of the project introduced the general goals of the system from both clinical and technical perspectives. Sharing these perspectives of the project involved drawing from their respective best practices: both medically and practically, clinicians know what works with patients; and designers are aware of related systems and technologies. Design activities then began with hands-on brainstorming and lo-fi prototyping (see Figure 1). We provided materials such as documents summarizing the goals of the system, images of existing tools and methods, large poster paper, writing materials, scissors, tape, *etc*. The sketches that came out of this initial brainstorming formed the basis for the first mockups. For the rest of the process, at each workshop we 1) discussed a few design goals and system features in depth, and 2) received feedback on the next iteration of the mockups. Mockups presented during workshops progressed from sketches to wireframes to interactive prototypes.

During workshops, we were sensitive to the varying symptoms of the patients participating. Some displayed manic symptoms, participating heavily and vocalizing all of their ideas and concerns. Others displayed depressive symptoms, participating very little in discussions or missing workshops several weeks in a row. Still others displayed no symptoms at all. We handled these differences by moderating discussions to attempt to equalize the amount of input from all patients, and sometimes dividing workshop participants into groups. We also supplemented workshop activities by engaging patients in informal one-on-one conversations to ask for their input and opinions. Often these conversations would take place before or after workshops, giving more quiet patients a chance to express their thoughts in a more private offline setting.

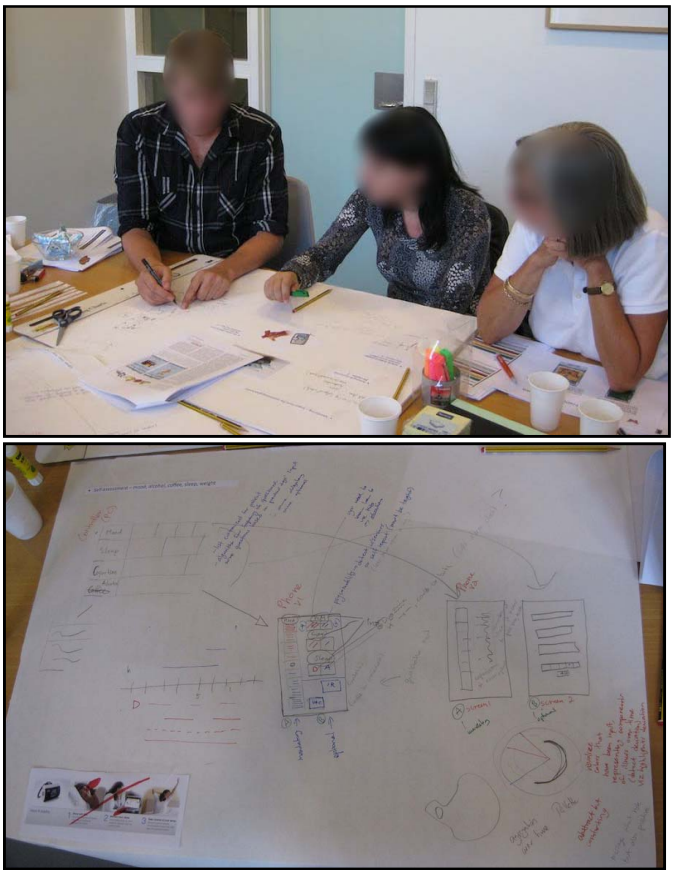

Figure 1. (top) A patient, designer, and clinician working together on a design activity using prototyping materials. (bottom) A sample result of a design activity, including sketches of interfaces and notes on functionality.

Seven patients also participated in semi-structured interviews lasting 1-2 hours. These interviews took place either at the clinic, or at the patient's home or university. All interviews were one-on-one, and conducted in a private space. The focus of the interviews was on the management of their own illness, thus complementing workshops by giving patients a chance to speak more openly about their personal experiences.

V. RESULTS

Using our PCD Framework, we were able to overcome several major challenges of designing persuasive personal monitoring systems for mental illness: (1) accommodating a complex array of symptoms, (2) supporting an uncertain treatment process, and (3) maintaining a high level of sensitivity to the seriousness and darkness of the illness, as well as the social stigma associated with it. We demonstrate how facets of our framework helped us with these challenges by discussing the ways that applying this framework impacted design activities and decisions.

A. Accomodating a complex array of symptoms

Management of bipolar disorder is based on identifying symptoms, called early warning signs, that are indicators of oncoming episodes, and learning how to respond to these symptoms to prevent and reduce episodes. The success of this process varies from patient to patient. Some patients have a hard time identifying warning signs, with some of our participants stating that after years of being ill, they still have no idea what their warning signs are or how to even try to identify them. Other patients have reliable and easy to identify warning signs. Examples from our participants include changes in sleeping habits, mood changes such as irritability, or impulsive behavior such as dying one's hair or purchasing square shaped furniture and décor. As these examples demonstrate, while some warning signs are easy to identify by humans, they may not be easily detectable by technology. To overcome these challenges with the monitoring of symptoms, we considered the needs and perspectives of both patients and clinicians. We found that the interests these stakeholders have in the data collected can differ or even conflict, echoing similar findings by others [9]. We applied the PCD framework in the mediation of their conflicting perspectives to develop appropriate solutions.

Using the PCD framework, we developed a straightforward but flexible solution for the monitoring of symptoms. The clinicians advised on what the most common and reliable warning signs are, which they expect to be relevant and useful for most patients. We incorporated the monitoring of these universal warning signs into the core design of the system. However, to accommodate the variety of symptoms that patients experience, we also discussed the inclusion of personal warning signs that patients could customize. Patients and clinicians disagreed on this feature. Clinicians argued that there should be as few warning signs to monitor as possible, even stating that one personal warning sign was difficult enough for some patients to attempt to track and understand. On the other hand, patients argued that having more flexibility would allow them to explore multiple warning signs simultaneously in order to determine which ones applied to them. Through the moderating phase of our framework, we found a solution that everyone could agree upon by suggesting that the feature be limited but flexible. The solution would allow patients the option to include up to three personal warning signs. Those patients who could only handle tracking one item at a time could customize the system to show only one at a time. Other patients, meanwhile, would have the freedom to include more based on their needs.

B. Supporting an uncertain treatment process

Our design process allowed us to navigate the uncertain treatment process to find simple but effective solutions for a persuasive system. One of the main goals of the user-centered design process was to design a system to help patients manage their own illness through monitoring and persuasive feedback. In particular, we found that the following three parameters are crucial in keeping a bipolar patient stable:

1) *Adherence to prescribed medication:* Taking all medication on a daily basis.
2) *Stable sleep patterns:* Sleeping 8 hours every night and going to bed at the same time.
3) *Staying active both physically and socially:* Getting out of the home every day, going to work, engaging in social interaction.

At first glance, this list may seem simple, but numerous studies have shown that each of these items are very difficult to achieve for many patients, and achieving all three at the same time every day is inherently challenging in combination with a mental illness. Hence, the core challenge is to create technology that would help – or "persuade" – the patient to do these three things daily. Narrowing the target of our system to these three primary parameters helped focus our design decisions.

Still, some design decisions required considerable mediation of the conflicting perspectives of patients and clinicians. A self-reported stress level scale was strongly rejected by a clinician who argued that stress is not a clinically useful measure, nor is there any clinical definition of stress that would support accurate data collection. Interestingly, a second clinician suggested the stress level scale, and argued for it from a very patient-centered perspective based in psychotherapy. Drawing from her experiences with psychotherapy, this clinician stated that external stressors play a significant part in the mood of her patients, and it is useful for her to consider a patient's reported stress level when assessing how that patient was doing. She believed that patients would find it useful to assess their own level of stress, regardless of the fact that they would be interpreting its meaning for themselves in the absence of a clinical definition. The patients tended to agree with her, so although this feature was under debate for several weeks, we opted to keep it in the design because enough participants saw potential benefits in patients assessing their own stress level. The decision to include this feature was therefore based on consideration of the questions that comprise the framework, and mediation of stakeholder concerns.

The concerns outlined in our framework from the perspective of clinicians, in particular those relating to infrastructure, also helped us eliminate a feature that could have caused problems for users. In order to strengthen patient-clinician communication, a feature was suggested to allow patients to call the clinic based on early warning signs. One design suggestion coming from a patient was to show a big easy-to-hit button

labeled "Call the Clinic" when an early warning sign was detected. The motivation behind this feature was to encourage the patient to reach out for help when needed. But the clinicians ultimately rejected the idea because we could not find a reasonable protocol to make the benefits to the patient outweigh the burden on the clinic's resources. In order to avoid features that might present a liability, clinicians were more likely to reject ideas and limit the role of the system to be on the safe side. Any kind of text messages or notes written by the patient and made available to the clinic were kept out of our design, because we could not ensure that the clinicians would always read these messages, and we could not make the clinicians liable for their content. Clinicians' limited resources became a recurring theme throughout the design process – if the organizational implementation of a feature would imply too much time or attention on the clinician's part, the clinicians would reject it.

C. *Maintaining sensitivity*

Through the first two phases of the PCD Framework, we were able to maintain a high level of sensitivity to the seriousness and darkness of bipolar disorder. Patients were so comfortable in workshop sessions that they expressed their enjoyment in participating and showed genuine interest and effort in their participation. Additionally, they were open to talking about difficult and emotional topics. While they shared some experiences and anecdotes at workshops, they were much more open within one-on-one interviews. During interviews, patients shared experiences and opened up about topics that were difficult to talk about because they were dark (deep depression, suicide attempts), stigmatized (psychosis, hospitalization, medication), or emotional (the effects of their illness on loved ones, their shortcomings as parents and spouses due to their illness). Interviews therefore informed the design process by revealing the most challenging aspects of living with mental illness, which would need to be accommodated by any system to be used in their daily lives. With an understanding of the patients' backgrounds and experiences from interviews, it also became easier to interpret their input during workshops.

Most persuasive health-related Ubicomp systems have adopted metaphors to motivate the patient to perform healthy behavior. Examples of such metaphors include a garden that blooms when the user is physically active [3]; a fish that grows when the user is physically active [10]; and pets that are happy and cared for when the user adheres to healthy behaviors such as eating a nutritious meal [17] or self-managing their asthma [8]. Common to all of these metaphors is a simple-to-understand relationship between behavior (*e.g.* exercise) and visualizations in the metaphor (*e.g.* more flowers in the garden). In the design of the MONARCA project, we tried to adopt the same strategy of creating a metaphor. Five different metaphors were prototyped and evaluated in a series of design workshops: a river landscape with water, a dartboard, a music equalizer, a scale, and dynamic abstract art. The patients rejected all of these metaphors, despite our numerous attempts to appeal to their needs and interests. This persistent problem during our design process led us to believe that something fundamental was at stake. One of the patients made the comment,

"*I do not want my illness to be reduced to a game.*"

We think that this is an important insight into the design of persuasive technologies for mental illness and self-management. Many of the technologies and metaphors reported so far deal with personal life-style related health management, which is fundamentally different from patients with a mental illness. Thus, we used a variant of the metaphor strategy to provide feedback to the patient that would be more sensitive to their illness – a trigger and coaching system, which is described in the next section as one of the goals of our system design.

Figure 2. The MONARCA application on an Android phone. Left: The self-assessment form. Right: A graph showing data collected over two weeks on mood, sleep, activity, and medication.

VI. THE MONARCA SYSTEM

Overcoming several challenges of designing a persuasive system for mental illness through the application of the PCD Framework, our design efforts resulted in a system supporting 5 main features: self-assessment, activity monitoring, historical overview of data, coaching & self-treatment, and data sharing. The system is made up of 2 main components: an Android app and a web portal, each supporting all 5 features. Figure 2 shows two screen shoots from the Android app used by the patients.

A. *Self-assessment*

Subjective data collection is done on the mobile phone through a simple one-page self-assessment form (Figure 2, left). Less than 10 items are entered by the patient on a daily basis, including mood, sleep, level of activity, and medication. Some items are customizable to accommodate patient differences, while others are consistent to provide aggregate data for statistical analysis. An alarm reminds the patient to fill out the form.

B. *Activity monitoring*

Using sensors in the phone, objective data is collected to monitor level of engagement in daily activities (based on GPS and accelerometer), and amount of social activity (based on phone calls and text messages). This data is abstracted for

analysis, to protect the patient's privacy while still supporting self-assessment using objective data.

C. Historical overview of data

When the patient has filled in the self-assessment form, a simple historical overview of the data is shown on the phone (Figure 2, right). On the web portal, both the patient and the clinicians have access to a much more detailed historical overview of the data. This will give them the means to explore the data in depth by going back and forth in time, and focusing on specific sets of variables at a time.

D. Coaching & self-treatment

Psychotherapy will be supported through everyday reinforcement in two ways. Customizable triggers can be set to have the system notify both patient and clinician when the data potentially indicates a warning sign or critical state. Second, after patients are advised by their clinicians about which actions to take in response to warning signs, they can keep track of and review them through the system.

E. Data sharing

In order to strengthen the psychotherapy relationship data and treatment decisions are shared between the patient and his/her clinician. Similarly, sharing data with family members or other caregivers empowers them to support the treatment process. Finally, sharing data among patients helps with personal coping and management efforts by re-assuring patients that they are not alone, and helping them see how others manage their illness.

I. Conclusions

We have introduced the PCD Framework, a framework based on key principles of user-centered design developed to help with overcoming challenges in designing persuasive monitoring systems for mental illness. Illustrating the use of this framework for the design of the MONARCA system, we demonstrated how it helped us overcome challenges related to the complexity of bipolar disorder, the uncertainty of treatment, and the need for sensitivity to the seriousness of the illness and social stigma associated with it. Moving through the phases of the framework and addressing the questions outlined changed our design process, increasing sensitivity to patient needs and giving us tools to mediate conflicting stakeholder needs – an issue often encountered in persuasive monitoring systems for healthcare domains. This mediation process resulted in compromises that gave us workable solutions for the challenge of treating bipolar disorder. Many of the challenges we encountered are similar to those involved in the design of many healthcare systems. Some of the specific challenges may apply to certain domains, such as chronic illnesses that are difficult to treat and manage, or other illnesses that carry social stigma. Therefore, the PCD Framework can also be applied to these related problems.

References

[1] Bardram, J. E. Pervasive Healthcare as a Scientific Dicipline. *Methods of Information in Medicine*, 3(47):129-142, 2008.

[2] Bipolar Mood Chart, HealthyPlace. http://www.healthyplace.com/bipolar-disorder/diagnosis/bipolar-mood-chart/menu-id-67/.

[3] Consolvo, S., McDonald, D. W., Toscos, T., Chen, M. Y., Froehlich, J., Harrison, B., Klasnja, P., LaMarca, A., LeGrand, L., Libby, R., Smith, I., Landay, J. A. Activity Sensing in the Wild: A Field Trial of UbiFit Garden. Proc. CHI 2008, ACM Press, pp. 1797-1806.

[4] Fogg, B.J. *Persuasive technology: using computers to change what we think and do*. 2003, Morgan Kaufmann.

[5] Gulliksen, J., Go□ransson, B., Boivie, I., Blomkvist, S., Persson, J., Cajander, A□. Key principles for user-centred systems design. Behaviour & Information Technology, 2010, 22(6), pp. 397-409.

[6] Judd, L. L., Akiskal, H. S., Schettler, P. J., Endicott, J., Maser, J., Solomon, D. A. et al. (2002). The long-term natural history of the weekly symptomatic status of bipolar I disorder. *Arch. Gen. Psychiatry*, 59, 530-537.

[7] Korotitsch, W. J., and Nelson-Gray, R. O. An Overview of Self-Monitoring Research in Assessment and Treatment. Psychological Assessment, 1999. 11(4), pp. 415-425.

[8] Lee, H. R., Panont, W. R., Plattenburg, B., de la Croix, J., Patharachalam, D., Abowd, G. Asthmon: Empowering Asthmatic Children's Self-Management with a Virtual Pet. Proc CHI 2010, ACM Press, 2010, pp. 3583-3588.

[9] Lee, M., Dey, A. K. Reflecting on Pills and Phone Use: Supporting Awareness of Functional Abilities for Older Adults. To appear in Proc CHI 2011, ACM Press, 2010.

[10] Lin, J. J., Mamykina, L., Lindtner, S., Delajoux, G., Strub, H. B. Fish'n'Steps: Encouraging Physical Activity with an Interactive Computer Game. Proc. Ubicomp 2006, LNCS, pp. 261-278.

[11] Maitland, J., Chalmers, M. Self-monitoring, self-awareness, and self-determination in cardiac rehabilitation. Proc. CHI 2010, ACM Press, pp. 1213-1222.

[12] Mamykina, L., Mynatt, E., D., and Kaufman, D., R. Investigating Health Management Practices of Individuals with Diabetes. Proc. CHI 2006, ACM Press, pp. 927-936.

[13] Mood Chart. www.mood-chart.com.

[14] Mood Chart, Massachusetts General Hospital Bipolar Clinic & Research Program. http://www.manicdepressive.org/moodchart.html.

[15] Oinas-Kukkonen, H. Behavior Change Support Systems: The Next Frontier for Web Science. Web Science Conf. 2010.

[16] Optimism. www.optimismonline.com.

[17] Pollak, J. P., Gay, G., Byrne, S., Wagner, E., Retelny, D., Humphreys, L. It's Time to Eat! Using Mobile Games to Promote Healthy Eating. Pervasive Computing, IEEE CS, 2010, pp. 21-27.

[18] Sachs, G. S. Bipolar Mood Disorder: Practical Strategies for Acute and Maintenance Phase Treatment. J. Clin. Psychopharm. 1996,16(2), suppl, 1, pp. 32S-47S.

[19] Scott J., Colom F., Popova E., Benabarre A., Cruz N., Valenti M., Goikolea J. M., Sánchez-Moreno J., Asenjo M. A., Vieta E. Long-term mental health resource utilization and cost of care following group psychoeducation or unstructured group support for bipolar disorders: a cost-benefit analysis. J. Clin. Psychiatry. 2009, Mar 10.

[20] Siek, K. A., Connelly, K. H., Rogers, Y., Rohwer, P., Lambert, D., and Welch, J., L. When do We Eat? An Evaluation of Food Items Input into an Electronic Food Monitoring Application. Proc. Pervasive Health 2006, IEEE.

[21] Smith, B. K., Frost, J., Albayrak, M., and Sudhakar, R. Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes selfmanagement practices. PUC, 2007, 11(4), pp. 273-286.