Harmony: Close Knitted mHealth Assistance for Patients, Caregivers and Doctors for Managing SMIs

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Ubicomp/ISWC'16 Adjunct, September 12-16, 2016, Heidelberg, Germany
ACM 978-1-4503-4462-3/16/09.
http://dx.doi.org/10.1145/2968219.2968301

Abstract
Serious mental illnesses (SMIs) like depression, bipolar disorder, etc. are one of the dire health concerns throughout the world. According to WHO, depression is one of the prime causes of disability with 350 million people suffering from it globally. Patients with SMIs require prolonged care and management which in long term adversely affects the caregiver's health. Existing studies leverage the potential of mobile technology to build healthcare systems for mental illnesses. Most of these studies are patient centric with an aim to assist patients in self-management of their illness. The studies focused only on patients have neither exploited the potential of caregiver's role, nor have explored the solutions for managing their burden. We aim to provide a solution that leverage the role of caregivers in providing healthy cooperation between the patients and the doctors in managing SMIs. In this paper we present our work in progress –*Harmony* - a system designed to encourage the patients in adopting an efficient morning routine. Aim of the current prototype is to reduce the morning efforts of the caregiver by assisting the patient in becoming independent.

Author Keywords
Harmony; mental health; mobile health; mHealth; SMI

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; J.3. [Computer Applications]: Life and Medical Sciences – Health;

Introduction

Mental illness is one of the rising cause of global health concerns. It is a form of an invisible disability which not only affects the patients but also impacts the lives of their family members, friends and caregivers. A study conducted in America shows that the person suffering from serious mental illness (SMI) including but not limited to depression, schizophrenia and bipolar disorder tend to have a shorter lifespan [1]. The study states that on an average these patients die 25 years early as compared to rest of the unaffected population.

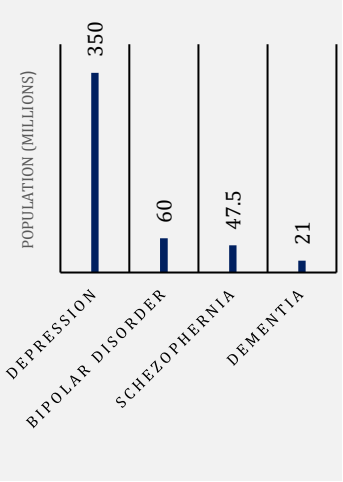

Figure 1. Population affected by various serious mental illnesses (SMIs) across the globe.

According to the World Health Organization's (WHO) factsheet on mental disorders, the efforts made by health systems across the world to cope up with the increasing casualty due to SMIs are still in their nascent stages [2]. Figure 1 shows the disease burden imposed by various SMIs across the globe. The WHO highlights an existing gap between the requirements for treatment and treatment provisions. In high income (HI) countries 35% to 50% and, in low and middle income (LAMI) countries 76% to 85% of the people suffering from SMIs do not receive the treatment.

Existing work has demonstrated the feasibility, acceptability and utility of mobile based technologies for implementing psychosocial interventions in various mental illnesses [3, 4, 5, 6]. The studies collected data using mobile applications designed to perform both active (participatory) and passive (unobtrusive) data sensing. The collected data is then analyzed and visualized to provide the users with the provision of health information, prompts, feedbacks, reminders and self-monitoring. Thus, the mobile based interventions in conjunction with clinic based services is a promising approach for bridging the gap between mental healthcare services and users.

Most of the related studies come from the HI countries with a well-developed community care service in the form of social security benefits, support for vocation, housing and education, social workers and case managers, all geared towards making the patient stay independently. In contrast, in the low resource settings as in LAMI countries, due to lack of community care services, the families play a significant role in the treatment, as most of the patients stay with families which is within the cultural expectations [9]. Families are responsible for initiating the treatment, procuring and supervising medicines to providing psychosocial support including opportunities for education, vocation and recreation. Therefore, it is essential that the mHealth intervention in such low resource settings should be tailored to accommodate cooperative approach between the patient and her caregivers for managing SMI.

According to a study, the potential a patient's family holds in facilitating her recovery has generally been unrecognized [11]. A family caregiver has to play multiple roles in life long management of SMIs while dealing with patient's maniac episodes. Thus, experiencing stress and needs help in coping with it [9]. The stress with which caregiver undergoes throughout the period of providing care management to the patient is known as caregiver burden. Prolonged caregiver burden may adversely affect the caregiver's

health both mentally and physically. Sometimes, the burden may lead to emotional breakdown, frustration, anger and burnouts, adding them with a feeling of remorse. A study states caregiver burden to be a universal phenomenon with almost 80% of the caregivers suffering from it [12].

In the existing literature, most of the undertaken studies including MoodRhythm [5] and BeWell [6] have focused on providing a self-management mobile healthcare systems for the patients with SMIs. In MONARCA system, the patient's relatives require her authorization to view the treatment related data [3, 4]. Involvement of relatives is dependent on patient's choice and limited to viewing her progress. But so far none of these have addressed the consequences of caregiver burden, nor have explored the potential of family caregiver in managing SMIs.

In this paper we present our work in progress – *Harmony* - a system composed of (a) an Android application for patient; (b) an Android application for caregiver; and (c) a web dashboard for clinical usage by doctors. The system follows cooperative approach by close knitting the patients, caregivers and doctors, working together towards common goal of managing SMIs. As of now, the patient module assists the patients in establishing an effective morning routine, the caregiver module helps in validation of data sensed by patient's module and web dashboard enables doctors to configure the parameters (e.g. set alarm time) for individual patient's module as per the requirement. The system provides easy sharing of data between patients and doctors, and caregiver and doctors. The long term goal of the project is to develop an efficient system for SMI patients, caregivers and doctors, to assist them in management of the illness in low resource settings.

System Design

The patients with SMIs suffer from persistent psychopathology and dysfunction. Designing of mobile based assistance for such patients requires addressing of various psychosocial factors. *Harmony* was conceptualized and formulated during various meetings involving a team of computer science researchers from IIITD and a team of psychiatrists from AIIMS. The interactions with the medical professionals helped us in narrowing following three factors as pivotal for SMI patients, in achieving a stable mental state:

- Abide to daily routine (physical activities & social interactions)
- Adherence to medication
- Psychosocial-education

The challenge here is to design a system to persuade and assist patients in achieving these goals, while dealing with the constraints of leveraging mobile intervention in LAMI countries. The design phase of our study includes frequent meetings with medical professionals, a focus group discussion with caregivers, prototype development and a pilot study to evaluate the developed system prototype.

Interaction with Caregivers

To understand the role and burden of caregivers, a three hour interactive session of focus group discussion (FGD) was conducted at the Psychiatric department of AIIMS. The participants included four caregivers, an interdisciplinary team composing of three psychiatrists and two members of clinical staff from AIIMS, and two

computer science researchers from IIITD. The caregivers who volunteered to participate in the discussion included two fathers [C1, C2], a son [C3] and a brother [C4]. Prior to the discussion, all the caregivers were introduced and explained about the agenda of FGD, to which they verbally consented to participate.

The discussion was approached as an open session, with caregivers participating as co-designers on our project. The idea of using a smartphone application to provide assistance in managing SMIs appealed to all four caregivers. All of them were enthusiastic while contributing their suggestions. The following subsections present the conspicuous themes outlined during the FGD.

Feature to promote medication adherence
Most of the suggestion were associated with promotion of medication adherence. Caregiver C1 felt the requirement of an alarm system to remind the patient about her medication schedule, followed by an acknowledgement that she has taken her dose. C4 indicated a possibility of patients cheating the system: *"Patients could provide the doctors with false feedback using the acknowledge button to get rid of medication adherence."* In response to the above statement, C3 proposed a new dimension to be explored: *"But doctor we should not only go by the messages given by the patient as feedback, we should also confirm from the caregiver."*

Sharing his experience, C2 highlighted the non-cooperation from the patients in taking medication. He told that his son would search the prescribed medicines on internet and would refuse to adhere them on the basis of their mentioned side effects:

"For instance once he was prescribed certain medicine, my son had already told me that it would affect his liver [...] by chance he had this problem before, and now he tells me that look, I already told you. When he got his liver tested, the reports showed that he really has a problem. According to his view, the long adherence to the medicine has caused side effect on his liver." [C2]

Feature to track self-improvement
A study in the literature has proposed a model for designing better solutions for treatment adherence [7]. It emphasizes on the importance of patient's beliefs and awareness about their illness in therapy adherence. According the study, a patient would adhere to the treatment if she believes in the diagnosis and therapy, while being aware about her situation. In consensus, C1 suggested that the system should be able to assist in convincing the patient about her illness and the improvement that can be achieved through continuous treatment. Assenting to C1, C3 suggested:

"*If a patient can upload a self-video about how he is feeling, this is more than enough, if not once in 5 days then once in a week he could upload a video of 5 to 10 minutes and then the patient can be shown look, this is what happened."* [C3]

The above quote saliently proposes a novel approach for patients to track their improvement by recording short duration self -videos. In addition, C3 also suggested that improvement of other patients adhering the same treatment can be used to motivate the patients and develop their faith in medication.

Connectivity with the doctors
Apart from medication adherence, another suggestion which kept reoccurring was availability of a ubiquitous communication link between the patient and the doctor. Caregivers felt that certain situations where patients doubt the treatment or not adhere to the medication, require intervention from the doctor itself. One of the caregivers [C1] suggested a system where patients could drop their recorded queries and later listen to the recorded response from the doctor: *"Now days call center facility of the Division of Family and Children Services is available, where one can record the question and later the expert will tell by calling him on his mobile, if this is the problem then what can be done to tackle it because… mental illness is an illness which can't be treated like other common diseases."* [C1]

C2 suggested that a session of live counselling with the doctor, in situations of non-cooperation, may prove to be nourishing. C4 accorded with C2, suggesting that a message from the doctor assuring the quality of treatment would ease the patient. One of them [C3] felt that a discussion forum connecting all three- doctors, patients and caregivers- will encourage patient's social interactions with other patients, provide a platform for caregivers to connect and will help in reaching out to the doctors easily.

Application for Caregivers
The feedback from FGD highlighted the importance of cooperation among caregivers and patients in carrying out their daily routines respectively. There were cases where caregivers would encounter the feeling of being challenged, frustrated or helpless in providing the needed structure to assist patients in following their routines. Caregiver C4 mentioned how he sometime feels helpless and frustrated in convincing his brother for taking medication. C3 shared his remorse on locking up his father inside the lobby due to his maniac behavior: *"[…] I feel sad thinking about what kind of son I am?! I am getting aggressive on my father who was never aggressive with me."* [C3]

One of the suggestions which surfaced was to design a mechanism to appreciate the caregiver and his efforts. C4 suggested that an appreciation message would keep him motivated to continue with the work. Meanwhile, emphasizing the need of caregiver's module, C3 shared his experience:

"Patient related information is available on the internet but I have spent nights after nights in search of information on how a caregiver can handle patient in certain situation, there is no data available for caregivers…information about patients is available, doctors are taught but caregivers need the maximum support from application." [C3]

All the caregivers concurred that the system should provide a prediction mechanism which could notify them just before when patient is about to enter a maniac episode. In light of our FGD, rather designing a solo Android application, we chose to design two Android applications -one for the patient and one for her caregiver.

Miscellaneous ideas & requirements
The participants shared various ideas on the basis of the prior knowledge about similar technological solutions and their daily experience in managing the patients. One of them [C3] suggested the use of game application similar to Age of Empires or SIMS to

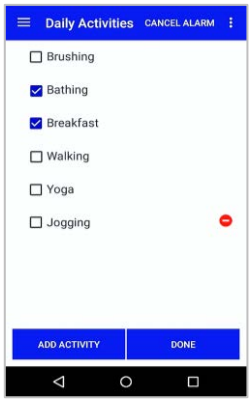

Figure 3 The Patient module's daily activity screen

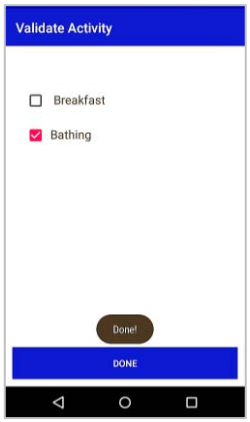

Figure 4 The Caregiver module's activity validation screen. Once the patient updates her activity log, a notification including patient's response is sent to the caregiver for validation.

increase social bonding and attention span of the patient. Caregiver C2 thought that a game about the daily routine would help and motivate the patient in abiding to a routine.

Outlining the user expectations in case of remote access, C4 suggested the mobile application should be light and work even in offline mode. Also, all the caregivers concurred on the requirement of a brief training session about the applications.

Use of mobile application for scheduling an appointment with the doctor and fetching real time information about availability of doctors or beds in the clinical ward was also put up by the participants. The suggestions, being very specific to AIIMS administration, do not fall in the scope of our study. Hence, we won't be incorporating these in our applications.

Harmony

Based on the salient themes highlighted during the FGD session, we have built an initial prototype of a mHealth system – *Harmony*. The current prototype is designed to be used by the patients, caregivers and clinicians to achieve a common goal of helping the patient in abiding an effective morning routine. The system is composed of three components: an Android application for patients, an Android application for caregivers and a web dashboard for clinicians. Figure 2 shows the system architecture of *Harmony*.

Android Application for Patient

The medical professionals weighed on the importance of proper morning routine for patients with SMIs. An Android application was designed for such patients to pursue and assist them in establishing a basic and efficient morning routine set by the doctors. The long term goal of this module is to assist the patient in becoming independent and, decreasing the caregiver's feeling of helplessness and frustration.

In cooperation with the medical professionals, a morning routine was designed to motivate the patients to wake up at scheduled time and engage in minor physical activity like taking hundred steps. To meet the system requirement, a personalized alarm system was developed incorporating certain aspects of the themes outlined during the FGD session.

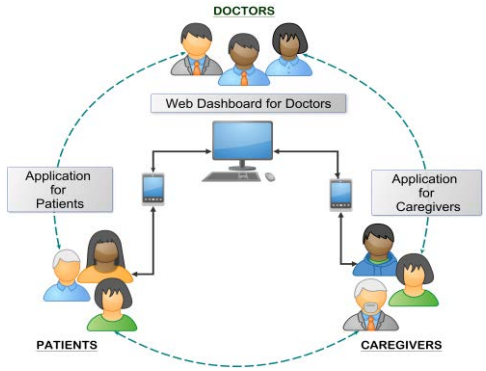

Figure 2. The *Harmony* system architecture. The dashed lines represents the social interaction between the patient, her caregiver and her doctor. The bold lines represent the two way system communication links between these entities.

Personalized Alarm System

A basic alarm system would not fit to our requirement of pursuing a patient with SMI to wake up and engage in minor physical activity of taking hundred steps. We require an alarm system which would motivate the patient to start her day as per the schedule without

triggering any adverse behavioral reaction. Thus, we have tailored the basic alarm system to serve our requirement by including an alarm song and C3's suggestion of patient's prerecorded pledge, in addition to default alarm tune. The pledge assists dual purpose, one motivating the patient and second helps in tracking self- improvement. The patient can revisit the self-recorded pledge to realize her deviation from the promised course of action.

The patient is provided with a flexibility to choose and set the alarm song, but is not allowed to set the alarm time. It's the clinician who pushes the alarm time for the patient module using the web dashboard, depending upon patient's medical condition and prescribed medications. Figure 5 depicts the iterative algorithm used for implementing the alarm system (for patient module). The current functionality of the patient's module includes daily activity logging, pledge recording and, passive recording of call logs and application usage. All of the sensed data is periodically pushed to the server, where it is made available to the doctors for further analysis. Prior to the deployment, the patients will be informed about sensitive data logging of their call logs and application usage and a consent for the same will be taken.

Android Application for Caregiver

The caregiver module was conceived and conceptualized to serve three main objectives. First, to help caregivers in providing assistance to the patients. Second, to help in the verification of data entry by the patients. Third, to assist in management of caregiver's burden. The current prototype of the caregiver module is designed to serve (1) and (2) using cooperative approach in coordination with patient's module. The caregiver module forms one of the connecting ends of cooperative approach implemented by *Harmony*, where the system not only assists the patients with their illness but also helps the caregivers in providing assistance to the patients and managing caregiver's burden.

VALIDATING PATIENT'S DAILY ACTIVITY LOG

A healthcare system's performance, patient's early symptom detection and course of the treatment are dependent on the quality of the sensed data. False data entry is one of the issues that has plagued the design and implementation of personal health management systems. A study on an IVR system- TAMA- for supporting patients suffering from HIV/AIDS showed that out of 50 participants, 6 accepted to have cheated the system by faking dosage intake while 2 participants faked their symptoms [10]. Later, both the participants were surprised when the course of their treatment was altered as per the reported symptoms. The study shows that despite being familiar with severe consequences of missing out on a single medication dosage, still the patients risk their lives by providing fake data.

The data from caregiver application is being used to assist in validation of sensed data from patient module. On receiving daily activity log from patient module, the server pushes a notification to the caregiver module prompting for validation of patient's filed data. The sensed data from both the modules can further be analyzed to find out data discrepancies.

Web Dashboard

The web dashboard is designed and developed for clinical use by the doctors. It supports two types of views- one for the system administrator and other for

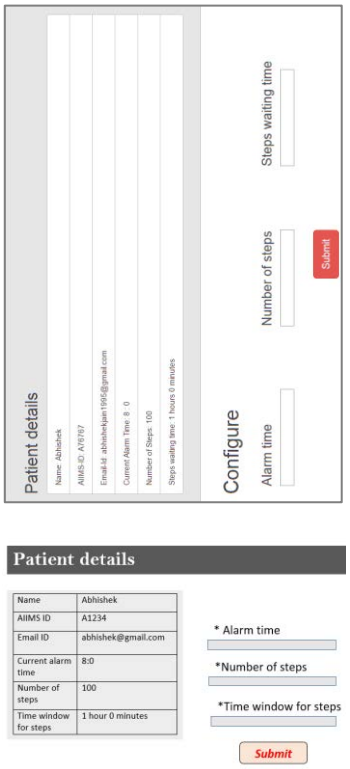

Figure 6 Representative visual snapshot of *Harmony*'s web dashboard for a particular patient record. The dashboard allows configuration of various parameters of patient's application like alarm time, number of steps and time window for taking steps as per the requirement of an individual patient.

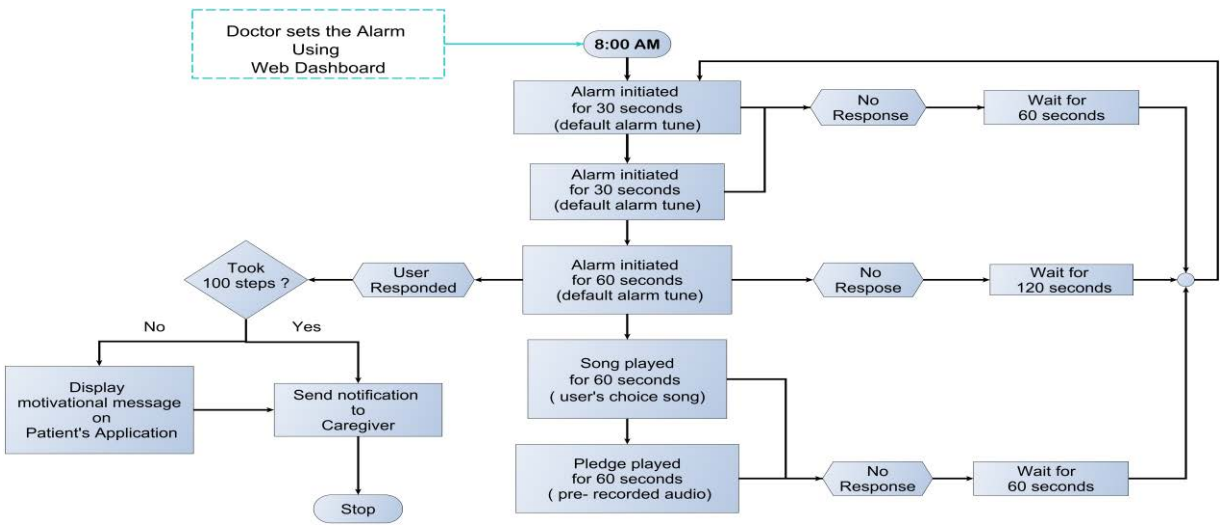

Figure 5. Algorithm used in implementation of alarm system for patient's Android module. Based on the years of experience in dealing with the mental illness patients, the psychiatrists from AIIMS have designed the time intervals for the algorithm.

the doctors. It provides the doctors with a list of their patients and patient profiles, including the application sensed data for both the patient and her caregiver. The doctors can further decide on the course of the patient's treatment by analyzing this data. Along with sensed data for each patient, it allows customization of various parameter of the patient module like alarm time and set of daily activities as per individual patient's needs.

Future Work

In this paper we present our work *Harmony,* an ongoing multidisciplinary project currently in its preliminary stages. The long term goal is to explore and provide mHealth solutions for management of SMIs in low resource settings. We are preparing to deploy the first prototype of our system to conduct a pilot study in the Psychiatric ward of AIIMS, Delhi. To the best of our knowledge, ours is the first system to include a dedicated application for the caregivers. As of now, the caregiver's application supports the patient's treatment only. We aim to extend its functionality in future to support the caregivers in managing their burden. Using the feedbacks and observations from the pilot study, we will modify and update our prototype to make it suitable for undertaking the system feasibility study. While working towards the long term goal of our study, we anticipate *Harmony* will: (1) facilitate in understanding how mobile intervention can support families in dealing and managing patients with SMIs;

(2) how well mobile interventions can assist in managing caregiver's burden; (3) identifying a self-sufficient suit of technologies to support the management of SMIs in low resource settings.

Acknowledgement

Authors would like to acknowledge the support provided by ITRA project, funded by DEITy, Government of India, under grant with Ref. No. ITRA/15(57)/Mobile/HumanSense/01 and Visvesvaraya PhD Scheme for Electronics and IT grant with Ref. No. PhD-MLA/4(31)/2015-16/01. We would also like to acknowledge the help received from Deepika Yadav throughout the course of this work.

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