

In Situ Design for Mental Illness: Considering the Pathology of Bipolar Disorder in mHealth Design

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ABSTRACT

In this paper, we argue that atypical cognitive, perceptual and behavioral characteristics associated with serious mental illnesses should be taken into consideration when designing health technologies. While applications have been developed to assist in the treatment of these illnesses, the specific psychological characteristics of these disorders have rarely been considered extensively in the design process. Here, we explore how an understanding of the low-level characteristics of bipolar disorder, combined with a clinically-validated treatment and patients' lived experience, can inform mHealth design. We present a novel method – in situ design – to support ecologically valid design, and demonstrate its use through the co-development with 9 individuals with bipolar disorder of MoodRhythm, a mobile application designed to track and stabilize daily routines. We provide evidence that mHealth design elements tailored to the characteristics and needs of individuals with bipolar disorder can result in engaging interactions.

Author Keywords

Mental health technology; mobile health; mHealth; bipolar disorder; participatory design.

ACM Classification Keywords

H5.m. Information interfaces and presentation: Miscellaneous; J.3. [Computer Applications]: Life and

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INTRODUCTION

Serious mental illnesses, including schizophrenia and major mood disorders such as bipolar disorder (BD), account for three of the six leading causes of long-term disability worldwide [18]. These are some of the most challenging illnesses to treat, and they are associated with considerable personal and societal costs (e.g., higher rates of death, chronic disease complications, increased health care costs, and burdens to families and communities).

Although there has been a recent increase in the use of mobile technologies to detect changes in mental health, there is also an acknowledgement that merely deploying these technologies may not be enough, and that the design of the patient-facing element is crucial to patient engagement [24]. Previous work in mental healthcare technologies have mostly looked at deploying “off the shelf” technologies like SMS, psycho-educational websites and online forums in mental health care settings, providing evidence that these approaches can be effective (e.g. [6]).

Obtaining ecologically valid data at the early stages of application development is challenging [7]. The stigma associated with mental illness and the difficulties that designers face in understanding the lived experience of mental illness are considerable. Role-play has been used to gain an understanding of context and clinical settings [21], but it is also necessary to involve individuals with direct experience of a mental illness when developing patient-facing systems. Researchers traditionally rely upon focus groups with patients which center on identifying needs and eliciting feedback on early designs. More recent approaches in the HCI community have included patients and therapists in the design process through participatory workshops [1, 10, 20]. These efforts, while valuable, tend to focus on high-level user needs and do not get at the lived experience and context of people living with mental illness.

Characteristics associated with serious mental illness like bipolar disorder have an impact on the daily experience and the interactions of those people struggling with the illness. Because much of what we know about mental illness and its lived experience comes from patient internal experience, we argue that it is important and potentially very helpful to mHealth design to center the process around this contextualized real world experience. Studies which integrally involve individuals with serious mental illness throughout the design process—and, particularly, those that incorporate *in situ* design and evaluation of evolving tools—are rare. While field studies can provide helpful feedback, this data tends to be summative in nature, focusing on metrics like adherence or usability and provides fewer opportunities for understanding the impact of individual design elements on use and engagement.

Our contributions in this paper are twofold: First, we provide evidence of the value of *in situ design*: incorporating ongoing real-world use of a system into existing participatory design practice. This approach yielded important insights about the practical use of everyday technologies in ways that we would not have uncovered by asking clinicians and patients to engage with the design process using abstract scenarios and hypothetical thinking; we believe this is an important methodological advance that can be applied to other mHealth contexts. Second, we present the design of *MoodRhythm*, a support system for patients with BD that reflects intentional design choices informed by low-level cognitive and physiological understandings of the disease and grounded in a clinically validated, evidence-based social therapy treatment from the field of clinical psychology. In addition, while many approaches have focused predominantly on how patient-collected data could be used in clinical settings, we explore how to provide valuable, meaningful and privacy-sensitive feedback back to the patient, thereby closing the loop and potentially increasing the incentive for recording data.

BACKGROUND

Bipolar disorder

BD is a common illness which affects between 3–6 % of the world's population [30]. The World Health Organization ranks bipolar disorder as the 6th leading cause of loss of disability-adjusted life in the world for people between 15-44 years of age [18]. The illness affects both developing and industrialized countries and both men and women equally, regardless of socio-economic status. The illness is associated with extremely poor functional and clinical outcomes, high suicide rates, and huge societal costs [37].

The Diagnostic and Statistical Manual of Mental Disorders categorizes bipolar disorder as a mood disorder defined by a cycle of manias, where the individual experiences high self-esteem, irritability and sleeplessness, and devastating

depressions. It affects a person's cognition, mood and energy levels.

Social Zeitgeber & Rhythmicity

While there is no cure for bipolar disorder, effective management can reduce the symptoms and the amount of medication required, but it remains a very challenging illness to treat. One of the most prominent features of BD is its rhythmicity, with manic and depressive episodes that cycle on a more or less regular basis. A growing number of studies link social rhythms, such as changes in sleep timing and other routines to mood changes, with episodes for individuals with BD. The *Social Zeitgeber* hypothesis [11] suggests that certain life events may lead to episode onset due to their effect on individuals' social routines. This effect may lead to mood symptoms and, in vulnerable individuals, to relapses.

Interpersonal Social Rhythm Therapy (IPSRT)

Substantial evidence indicates that interventions targeting social rhythms, sleep-wake rhythms, and light-dark exposure may markedly improve outcomes [22]. Interpersonal Social Rhythm Therapy (IPSRT) is a psychosocial therapy specifically devised to help patients maintain a stable daily and social rhythm in order to prevent relapse. Increased regularity of social routines is associated with symptomatic improvement and significantly longer intervals between episodes [8, 22].

The work of therapy includes improving interpersonal relations but focuses on the timing of social events in order to establish regular social rhythms that help to keep the patient well. To establish and keep track of daily routines, mood and energy, patients use the Social Rhythm Metric (SRM; Fig. 1), a 5-item self-report scale that has been clinically validated [25].

IPSRT targets activity patterns as well as sleep timing and sleep duration, factors that are assumed to mediate treatment outcomes [13]. This treatment has been validated in a series of single- and multi-site studies [36] and is associated with remission of bipolar depression[23], longer symptom-free periods [12], and improved occupational functioning [14].

The SRM is used in evidence-based psychosocial interventions for affective illness, and has become a central tool in IPSRT. It helps patients track their social routines, and is used as both a research and a therapeutic self-monitoring tool. During therapeutic sessions, the therapist and patient review the previous week's data, exploring patterns of daily activities, relationships between mood and routine regularity, and sources of routine disruption. Increased regularity of routines, as reflected in SRM scores, has been shown to protect against new episodes of bipolar illness.

SRM II-5

Directions:

- Write the ideal target time you would like to do these daily activities.
- Record the time you actually did the activity each day.
- Record the people involved in the activity: 0 = Alone; 1 = Others present; 2 = Others actively involved; 3 = Others very stimulating

Date (week of): Feb. 18 - 24 2013

Activity	Target Time	Sunday Time People	Monday Time People	Tuesday Time People	Wednesday Time People	Thursday Time People	Friday Time People	Saturday Time People
Out of bed	6:30am	8:30am 0	6:15am 0	8:30am 0	6:45am 0	7:00am 0	8:00am 0	7:00am 0
First contact with other person	8:40am	9:00am 2	8:00am 1	11:00am 2	8:30am 2	11:00am 2	1:00pm 1	2:30pm 3
Start work/school/volunteer/family care	8:40am	10:00am 2	8:10am 2	11:40am 1	8:30am 2	11:40am 1	9:00am 0	7:00pm 0
Dinner	5:00pm	6:00pm 0	7:00pm 0	5:40pm 0	5:30pm 0	5:30pm 0	5:30pm 0	6:00pm 0
To bed	12:00am	2:10am 0	3:00am 0	12:30am 0	2:00am 0	1:00am 0	1:45am 0	12:00pm 0
Rate MOOD each day from -5 to +5 -5 = very depressed +5 = very elated		+1	0	-1	+1	-1	-1	-2

Figure 1. Pen-and-paper Social Rhythm Metric

However, maintaining a stable daily routine is a significant challenge for patients. Although the SRM has been proven effective for tracking social routines, its paper-and-pencil format has multiple disadvantages, both as a clinical tool and a research instrument. These shortcomings echo previously identified limitations of paper diaries [35].

RELATED WORK

Within the HCI community, there has been a significant increase in the study of mobile health (“mHealth”) applications. Most of this work has centred on physical health such as diabetes. A more modest amount of work has taken place in the mental health space, which might reflect some of the challenges inherent in working in this area, which are outlined previously [10, 20].

Prior work has focused mostly on identifying new mediums that result in more reliable self-report data. While paper-based diaries are still the dominant method for symptom tracking for bipolar patients in both general psychiatric care and psychotherapies like IPSRT, evidence suggests that bipolar individuals are receptive to using technology. Bopp et al. found that SMS messaging was well accepted as a method for bipolar individuals to chart their symptoms in lieu of clinician reports [6]. Sharer et al. adapted the NIMH Life Chart for use on a handheld PDA; they found that participants preferred this medium to paper, reported feeling less social stigma and enjoyed having a more involved role in their treatment [34]. More recently, Blum et al. have developed a prototype system which combines worn sensors and self-monitoring [5].

The prior work most relevant to our research is Monarca, a system designed to serve as a “personal monitoring system for bipolar patients” [1, 2]. Monarca, unlike many previous support technologies, uses both self-assessment reports and sensor data to provide insights about individual patterns indicative of mental state for bipolar patients. It is not based on a specific treatment model, but is informed by multiple clinical and patient perspectives. This system was co-designed with various medical practitioners including psychiatrists, nurses and psychologists and is intended for non-specific psychiatric treatment. The system was developed with 1-3 users representing designers, patients

and clinicians in fortnightly workshops over 6 months [19]. These sessions focused on higher level issues of adoption, acceptance and sustained use including protocols of use for the technology (e.g., should patients be able to phone the clinic if a warning sign is identified, or which symptoms should be tracked) and decisions about system features. Most of the sensitivity to bipolar disorder was achieved through 1-on-1 interviews which “were much more open” – sharing expressions of depression and suicide, stigma and emotional issues all of which informed the design.

The work presented in this paper differs from Monarca and previous work in two primary ways: (1) the basis of our approach, IPSRT instrument and therapy, provides a specific clinical and interventional basis for the structure and content of the data collected; and (2) we focus on identifying motivational and self-reflective facets of the patient-facing interface, informed by iterative ecological feedback from individuals with bipolar disorder.

DESIGN CONSIDERATIONS

Mental illness uniquely involves distinct trait and state characteristics that affect the way individuals perceive and interact with their surroundings; here, we discuss the cognitive, emotional, and behavioral aspects of bipolar disorder that might have particular relevance for therapeutic system design.

Effects of Medication

Medication is generally a central part of treatment for bipolar disorder. Drugs like lithium reduce mood elevation and help patients maintain balance. However, they have attendant and significant side effects that could feasibly have an impact on a patient’s interactions with therapeutic tools. For example, relatively common and design-relevant side effects of lithium include: (1) hand tremor, (2) blurred vision, (3) mental slowness, (4) poor concentration, and (5) impaired memory. According to one therapist that we interviewed, medication can directly impact self-reporting:

“Especially for patients on lithium and other drugs that lead to tremor, those little spaces [on paper diaries] can be so frustrating they don’t even try to respond.”

While these side effects could affect a person’s interactions with technology or their ability to read onscreen text, design strategies might reduce their impact by making interactions more straightforward (for example, by increasing navigational button size) and by using larger, clearer fonts.

Patient Adherence & Engagement

Given the considerable cost and side-effects of medication, it is not surprising that adherence to treatment can be low [32]. Non-adherence is a significant issue across medicine, but is likely more significant for mental illnesses:

“The intrinsic nature of psychiatric disorders that very often compromises decision-taking procedures – may cause even greater impact of non-adherence to prescribed medications” [8].

Non-adherence to medication is a very common in bipolar disorder (as low as 20%), with serious consequences and substantial societal costs [8]. A recent survey asked individuals with bipolar disorder to rate treatments according to effectiveness and popularity¹. The results showed that medications, when compared to other forms of treatment, were rated as least effective and least popular by respondents. The treatments that people rated as most effective and most popular (regimented sleep schedule, exercise, mindfulness, etc.) all require the person to maintain sustained action (e.g., journaling) or inaction (e.g., abstaining from alcohol).

Sensitivity to Reward-Based Stimuli

Dopamine is a neurotransmitter that has been associated with the brain's reward centers. Recent research has indicated that dopamine plays a role in reward incentive—not that it is associated with liking rewards or knowing which rewards a person will like, but rather with an individual's *desire to pursue* these rewards [4].

Bipolar disorder is associated with a dysregulation of dopamine. Dopamine's role in BD is linked to an increased pursuit of rewards and can be characterized “by a hypersensitivity to reward-relevant stimuli” [29]. Indeed, bipolar disorder is often associated with a high drive and ambitious goal setting [28]. In a recent study—the first to compare reward processing in stable bipolar and control individuals—participants played a simple ‘higher or lower’ card-guessing game and received a monetary reward if they correctly guessed whether the next card drawn from a deck would be a higher or lower value than the current card. BD patients showed a statistically significant elevation in the reward centers of the brain when they were anticipating rewards [29]. The authors conclude that these distinct differences in neural activity may be useful for “*novel interventions to help individuals with Bipolar disorder develop strategies for effectively regulating their behavior in response to reward-relevant environment events*” [29]. For a review of the role of Dopamine in BD see [9]

Bipolar Disorder and Creativity

Bipolar Disorder has been correlated with higher than normal levels of creativity [16]. A significant body work suggests that bipolar participants might be more open to creative collaboration in this regard; studies indicate that there are “*underlying neurobiological commonalities between people with mood disorders and individuals involved in creative disciplines, consistent with the notion of a temperamental contribution to enhanced creativity in individuals with bipolar disorders.*” [27]. Enhanced creativity is not just present during manic episodes but also when a patient is stable (euthymic) [33]. According to therapists engaged in this study, bipolar individuals tend to

be particularly independently-minded and engaged in the management of their illness. This independent drive and above average creative abilities suggest people with bipolar disorder could contribute more extensively than other users in participatory design.

DESIGN OF MOODRHYTHM

In this section, we describe the *in situ* participatory design work that we undertook over the course of a year to develop *MoodRhythm*, a cross-platform mobile app built using the Open mHealth Architecture². For a more detailed description of the MoodRhythm system please see Vaida et al. [38]. This is the first app in HCI that is based on a psychotherapeutic and clinically-validated therapy for bipolar disorder (IPSRT).

The goal of our approach is, consistent with IPSRT, to help patients maintain consistent circadian and activity rhythms in their day-to-day lives. Our system, *MoodRhythm*, aims to enable users to *reflect* on their *momentary* experiences throughout the day. Like Monarca, we aim to take advantage of a *combination* of sensing and self-report interactions on a smartphone. In this paper, we focus on the long-term co-development of MoodRhythm. The primary contribution of this research is our use of an *in situ* participatory design process that foregrounds consideration of not only the lived experiences of BD people and the therapeutic requirements of their clinicians, but also the specific cognitive, perceptual and behavioral characteristics of bipolar disorder.

Method

Over the course of one year, we drew on the expertise of members of an academic research team (primarily information and computer scientists at a research university in the northeastern United States), a team of professional psychological researchers and clinicians with expertise in conducting (and training others in the use of) IPSRT therapy, and a group of 9 individuals with bipolar disorder.

This latter group of participants were asked to use various prototype versions of our app on either an Android smartphone or iPhone for 7–10 weeks, to report on their experiences each week, and to suggest novel ideas that might better support their self-management in context. When possible, participants used their own devices. All face-to-face experimental procedures took place at a mental health clinic in northeastern United States. The majority of the participatory design process was conducted remotely, including design communications with participants. These discussions were conducted one-on-one over email and/or telephone between participants and one member of the research team

¹ <http://curetogether.com/blog/2012/02/15/bipolar-managed-best-without-drugs-227-patients-report/>

² <http://www.openmhealth.org/>

Id	Type	Duration	Age	Gender	Prior Relapses	SRM Entries
P1	I	418 days	45-54	Female	6	1237
P2	I	212 days	25-34	Female	10+	216
P3	NOS	184 days	35-44	Male	10+	21
P4	II	188 days	55-64	Female	10+	N/A
P5	II	52 days	45-54	Male	10+	363
P6	II	54 days	25-34	Female	10+	N/A
P7	NOS	70 days	35-44	Male	2	141
P8	II	70 days	55-64	Male	10+	102
P9	II	99 days	25-34	Female	5	609

Table 1. Study Participants.

Over the course of the research, iterations of the prototype app were wirelessly sent to participants' smartphones via TestFlight to minimize the overhead of managing app distribution. Participants shared their feedback, design insights, and suggestions for enhancements to the app at least once a week with the University members of the research team. At the conclusion of the study, participants completed a formal interview with one University member of the research team, which was recorded and transcribed. Participants received \$40 for each week they used the app, up to a maximum of \$400 and \$25 for the final interview. This level of compensation is in line with the amounts typically offered at the research clinic. Furthermore, patient participation was not contingent on adherence to a daily protocol of use.

Participants

Nine participants with bipolar disorder participated as co-designers on our research team (see Table 1). Inclusion criteria included having a diagnosis of bipolar disorder, prior experience with IPSRT and a willingness to use the app and engage in discussions for between 7–10 weeks. Five users voluntarily prolonged their involvement considerably beyond this minimum participation commitment. Participants had a range of types of bipolar disorder and were located mostly in and around a single city in the northeastern United States. While we focus on patient feedback in this paper, 6 IPSRT-practicing therapists and the creator of IPSRT, Dr. Ellen Frank, also participated, providing design input on patient- and clinician-facing aspects of the system. Where their feedback is relevant to the patient-facing components of the app, it has been included.

Scope of Participant Involvement

The feedback provided over the course of this study by our cohort of patient co-designers included a total of 363 emails and 21 interviews. We audio recorded and transcribed each

interview, and we used open coding to analyze the transcripts and email exchanges to identify common themes and to extract illustrative vignettes. As a participatory design study, the app was both deployed as a shared co-design artifact among members of the University research team and the co-designer cohort and as a design probe to help us document how mHealth system design might interact with and respond to specific characteristics associated with an illness. As such, adherence is not a valid metric, although app use does provide a measure of user participation. Seven of the 9 participants made a total of 2689 entries (mean = 384, SD = 423). Due to technical errors, the entry data for 2 participants was not considered reliable.

RESULTS

In presenting the outcome of our participatory design process, we focus on the central design elements of the patient-facing app, how they emerged from the initial design considerations, and how they were refined through iterative *in situ* participatory design. Broad classes of participant feedback included: debugging, reporting their app use in context, suggesting both major and minor design changes, prototyping novel elements of the app, and providing broader considerations of how technology supports might vary across stages of the illness.

Self-Tracking

MoodRhythm allows patients to track the 5 basic activities used in the paper version of the SRM—waking time, first contact, starting the day, dinner, and bedtime—but also to add custom activities tailored to a patient's routine or preferences (Figure 2). Patients, often in consultation with their therapists, can set daily routine targets and track how closely they meet these target times.

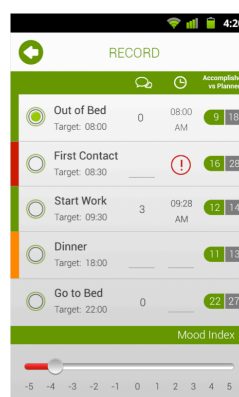


Figure 2. MoodRhythm Record Screen

customizable time window (the default is 45 minutes), then the bar to the left turns green. When the time window is about to expire and an event is not yet recorded, the bar appears amber (a “warning” that a potential rhythm disruption is occurring). If a patient misses the target, then the bar turns red. This momentary feedback was considered very helpful by participants:

Notes can be used to record additional information, such as the amount of medication taken or other factors that may have affected a patient's routine or mood.

The diary is designed to provide an at-a-glance summary of the patient's successes in meeting their rhythm goals for both the current and preceding days. If the patient completes an activity within a

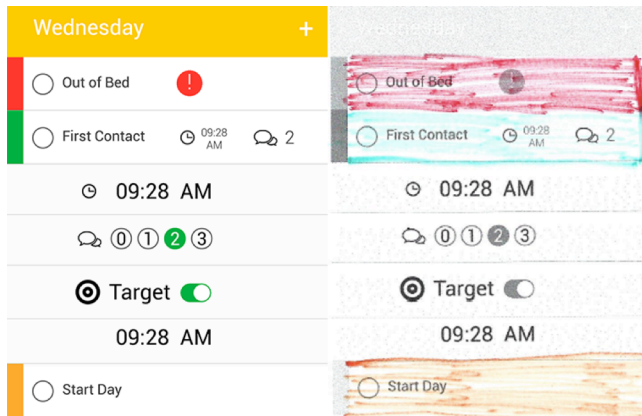


Figure 3. Evolutionary co-design artifacts demonstrating interface proposals and counter-proposals created as part of a conversation with participant P5.

"I like the Green->Orange->Red (initially I wasn't so sure about having red, but have since changed my mind)." [P4]

"On an ongoing day just the difference between red and green can make a difference. It's good to see green." [P1]

"I have the paper and the device, and much more likely to do it on the device. Find myself looking forward to entering it, is it the novelty. For some reason I'm much more likely to enter on the device than on the paper." [P8]

While the idea of the green/amber/red labeling appealed to most participants, P5 thought the design could be improved and proactively created designs that he felt would improve the app (Figure 3): *"make the whole event box turn green, orange or red for more of a dramatic effect."* P4 felt that a screen full of red bars could be very discouraging for some users, particularly if they were in a depressive phase or if they were struggling to maintain a stable routine, and suggested instead: *"How about a full green circle, a 1/2 green circle, and empty?"*

Maintaining adherence to self-tracking over a long period of time can be extremely challenging. A further complication stems from the fact that memory can be unreliable for patients with BD. One therapist commented:

"We rely almost entirely on patient memory to make treatment decisions, and when a person experiences depression, hypomania and/or anxiety, the memory is often blurry at best."

P2 suggested that it would be very helpful (to the individual and their clinician) to make it easy for people to log *why* they didn't log:

"If you miss a day, you can't really go back and input accurate info. But from a simplistic bipolar standpoint there are probably three reasons you might not log. You're down, just forgot, or manic-y and can't be bothered. It would be cool if on days you missed you could have a drop box where you chose why you didn't enter anything. It would be useful data." [P2]

Setting Targets

Maintaining a stable daily routine is a significant challenge for people with bipolar disorder. In the clinic, therapists typically use the patient's SRM in two stages. Initially, it is used to *map* the patient's daily routine, without setting targets. Stage two requires using this collected data to *set targets* that the therapist and patient both agree are realistic. To mirror this clinical use of the paper diary, *MoodRhythm* supports both open-ended and target-based tracking.

A point of tension emerged in our efforts to support personalization of the time windows for assessing whether individuals met their event targets. In IPSRT, 'hitting' a target means completing an event within 45 minutes of (either before or after) the target time. People with BD struggle to maintain consistent routines. Two participants suggested that the timeframe for assessing whether a target is hit be customizable: *"say missing by 1–2 hours earns you a yellow check box, and anything over that earns you a red check box?" [P2].*

We received a similar request from a therapist: *"It would be nice if we could adjust the window depending on where the patient is at – sometimes they struggle to hit sleep targets within 2 hours."* However, the creator of IPSRT disagreed, commenting that *"even though patients (and clinicians) may see these changes as a good thing, they could actually undermine the efficacy of the intervention."* As a result, we elected not to implement these proposed design alternatives.

Mood Tracking

The concept of *balance* is central to IPSRT. Part of treatment involves helping the BD patient grieve for his or her "lost manic self" and understand the value of stability.

According to one therapist, BD can feel like being *"addicted to your own brain—you can spend a long time trying to recapture previous highs you've experienced."* To emphasize the importance of stability, mood and energy scales for bipolar disorder are usually mapped along a -5 to +5 scale, with the ideal rating being 0. This is contrary to most other mood scales, which tend to be tracked on a 1–10 scale, with 10 being the ideal. In one design session, a therapist commented that it would be great if *"we could make 0 sparkle"* in order to emphasize the goal of equilibrium. We carried this idea into the design of the Mood and Energy scales (Figure 4), which visualize the -5 to +5 scale in an arc with '0' at the top and center.

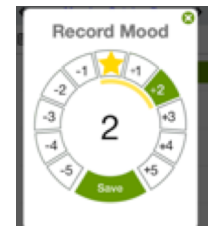


Figure 4. Mood entry interface mockup

Engaging Interactions

Because individuals with bipolar disorder are *"excessively sensitive to events in the achievement domain"* [28], the design team thought that the use of similar feedback elements in our system might be a promising avenue for exploration. Our hypothesis was that a range of rewarding

interactions, from showing green checkmarks to indicate task completion to awarding a badge for hitting therapeutic targets, might provide an external cue and consistent motivational thread that could lead to increased adherence to goals and greater engagement in the app. To explore if these rewarding elements were appealing to patients, we added several related features.

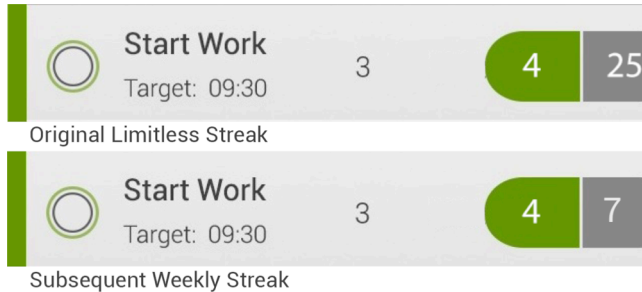


Figure 5. Evolution of the Streak feature.

Encouraging Adherence with Streaks

To further encourage adherence to daily targets, we added a “Streak” UI element that displays the current run of days in a row that the user has achieved each target (e.g., got out of bed on time) and the longest-ever recorded run (Figure 5). Participants were generally positive about this element. However, P1 thought that the streak feature could be demotivating in certain contexts:

“Sometimes, when you’re eking out of a depression, a prior streak like 22 can be overwhelming & unachievable... I’d like the option to ‘reset’ all my streaks, so I’m not a big zero looking at a 22 (makes me depressed just to think of it).” [P1]

Thus, the streak feature risked de-motivating participants in a depression and incentivizing overachievement during manias—a common risk for individuals with bipolar disorder. In collaboration with P1, we adjusted the streak to emphasize stability and balance by resetting automatically every week. This placed the emphasis on a maintaining a weekly rhythm:

“I ABSOLUTELY LOVE the idea of the weekly streak. It would help to stay in tune with my progress/regression as I eke in/out of a depression/manic phase. It’s relative to where I am at that point in my life. I also think it’s more motivating, if in a depression, to try to do better than the week before as opposed to a number that may not be achievable again for quite some time.” [P1]

Other participants who used this new version of the streak also responded favorably:

“I like the streaks... I like that it lets you see at a quick glance that you are on track with your routine or need to work harder to back on track.” [P5]

“I think it is useful because you give you an idea of how many times you have filled the survey so it is kinda motivating.” [P7]

Badges

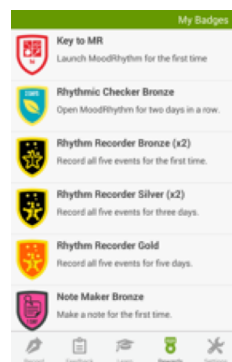


Figure 6. Badges

The goal of IPSRT is to help patients establish and maintain a stable social rhythm. Therapists rely on patient self-tracking to gain insights into their lives outside the clinic and to assess their emotional state. *MoodRhythm*’s Badge system (Figure 6) provides users with frequent positive feedback both for using the app to self-track and for adhering to therapeutic goals. For example, the user receives the ‘Early Bird’ badge if he or she gets up on time for 5 out of 7 days in a single week. Within the app a screen pops up with an image of the badge and some brief text explaining why it is awarded. Animated confetti is also displayed and, for the original version, a default audio file of children cheering was played.

All participants were enthusiastic about the badges: *“I like the rewards” [P5]; “I think the badges are kind of cool” [P3]; “Yes, I LOVE badges” [P1]; “I got the badges. It is really good. It gives me personal satisfaction that I have completed something. And, that’s good. It keeps motivating.” [P7].*

Although Participant 6 was less keen on badges in and of themselves, she was interested in the specific badges that provided encouraging feedback on adhering to therapeutic elements:

“As far as badges, I don’t really find that especially compelling in so much as “unlocked achievement reward”, but that’s just me. It is a nice marker to have one show up that says “you’ve completed this task for X days”, and I find that a good informative measure for sure.” [P6]

P3 thought the badges could be used to provide a boost to people who were down:

“if a person going through low spot, positive badge would possibly help – give them a little push – a little encouragement, can completely change their day.” [P3]

P7 thought that the badge system could be used to encourage participants to meet specific therapeutic goals: *“It gives you lots of possibilities to motivate for a particular event or for overall stability across many days.”* In practice, this could involve users setting custom badges with their therapists based on specific therapeutic goals, or it could be automated by the app, based on a variety of data-collection and goal-achievement metrics. However, this same participant warned that a more nuanced approach to design was needed for bipolar disorder to account for changes in mood:

“For example, if I am in mania phase, all these badges would enhance my mood further, which I don’t want. But ... if somebody is in depression [and] sees the badges coming up [it] may be positive for him.” [P7]

Feedback

The initial prototype of the mobile app did not provide a summary feedback screens. This functionality was considered important by most participants, so it became a subsequent focus of the participatory design. Participants many of whom had prior experience with various self-tracking apps, were keen to identify patterns broader than

diurnal variations, which serve as a warning sign warranting attention and response:

"I am looking for confirmation that I had similar symptoms in the past, because sometimes due to the nature of bipolar I feel like I can't trust the emotions I have at any given moment (or their possible triggers) and it is a relief to know that these are patterns." [P6]

The research team worked closely with P2 to develop an initial version of the feedback screen, trying to incorporate the needs of both experienced and novice users. P2 began by suggesting that we use a layout and interaction metaphor similar to that used on the Record screen:

"Let's say, within the app you can switch between two different tabs/windows. Entering data like you currently have, and a quick sensing summary. it could be a bit of fun high-level feedback. Maybe the red, yellow and green coloring could be used to emphasize the point." [P2]



Figure 7. Participatory co-design evolution of the app's weekly feedback interface.

She created a very rough mockup of this idea (see Figure 7, left). Responding to this conceptual design, we created a higher-fidelity wireframe and sent it back to P2 over email. In this version, each metric had a text label indicating whether a person was "in rhythm" or not. P2 iterated on this with an idea for providing additional detail to users:

"Instead of just talking about whether logging has been occurring/its frequency, what about something like: 'Your average wake time is 7:32 AM based on five loggings this week.' You're rewarding the user with a bit of information that will likely motivate them to click and see more of their data." [P2]

After iterating through several more interface mock-ups with P2 and other participants, we implemented the final design (Figure 7, right) and distributed it to participants to seek feedback. All participants responded positively:

"I like how it gives you a up-to-the-minute look at the week to see how you are doing on your routine, which helps maintain the routine. Also, looking at the feedback you can figure out what might of happened to throw you off your routine" [P5]

"I was AMAZED when I scrolled back through the Android weeks to see how much my mood has stabilized since I started [medication]. The weeks themselves weren't as meaningful as the pattern over time." [P1]

Based on this design, P2 and P3 both suggested that feedback might be altered according to mood:

"If the app can sense when a person is in or going into a mood episode (especially depression), would there be a way for the app to respond to the user accordingly in terms of feedback? [...] What about encouragement of some kind—the user is probably logging less, but somehow be more rewarding of even scant logging during episodes of 'sensed' depression." [P3]

Many additional suggestions related to stage of illness or mood emerged from our participants in the study. For example, P7 suggested that deeply integrating an awareness of a person's current state into the app would be valuable:

"The moment I start the app in the morning, it would ask me what phase are you in? For example, I can enter depression and then all the features would be customized for depressed people."

Medication & Self-Tracking

All of the BD participants reported experiencing noticeable side effects from their medication. While many reported momentary (and sometimes longer-term) effects, such as reduced fine-finger dexterity and blurred vision (e.g., *"I do have some minor challenges with this but find it to not be difficult on the app"* [P6]), only one participant (P8) reported that these side effects impacted his use of the app:

"I do get the tremors in my left arm....when I have the device in my hand I have to put it down. I have a fear of dropping it....I get blurred vision which generally lasts for minutes, have to look away from the device let my eyes readjust" [P8]

It should be noted that P8's fear of damaging the device may be due to a lack of familiarity or comfort with the hardware; his participation in the project marked his first use of a smartphone.

Drowsiness was the most common side effect reported by participants. For example, Seroquel, an anti-psychotic drug used by many patients in the study, exerted a significant impact on nighttime routines, sometimes effecting self-tracking:

"It doesn't knock you out but makes it really easy to fall asleep. By the time I got drowsy, I couldn't record time to bed.... But now I have it down it pat. I record bedtime as soon as I take the pill, and go to sleep without trouble within 30 minutes." [P8]

Stigma & Anxiety

The initial versions of the app did not have alerts to remind participants to record social rhythm data, but all participants requested that this be added to subsequent versions. However, when implemented and deployed in context, one participant—perhaps crucially, a first-time smartphone user—expressed concern about receiving audio notifications in public settings:

"I have 2 alerts, going to do the rest some time. I wanted to make sure it wasn't going to go off a lot throughout the day and maybe disturb me when I'm interacting with someone - if it sounds in public it can be embarrassing. I

wouldn't mind being alerted, (with a) low-volume beep or silent pulse." [P8]

This example draws attention to issues of stigma surrounding mental illness, in general. According to one clinician on our design team, individuals with bipolar disorder are particularly sensitive to issues of stigma and often refuse to use any device that might identify them as being 'different.' Anxiety, a very common comorbid condition [17], in bipolar disorder may also play a role in these responses:

"This may sound silly, but as a person who has social anxiety along with bipolar disorder, I feel like the "congratulations" banner with a sound bite of a cheering group of fans is startling. I noticed that I can turn off the sounds so it is not so startling, but perhaps an alternative could be a choice of settings with options like a single-creature avatar giving a thumbs up." [P6]

We subsequently added a range of alerts, including a vibration-based alarm to the app. P8 reported that with this modification, the app was *"way more interactive. Part of my schedule. Basically, it's helping me on stay on schedule"* [P8].

DISCUSSION

HCI and Mental Illness

Novel medications and psychotherapies to treat serious mental illnesses are often grounded in the pathology of the illness in question and its manifestations. In parallel, many clinical studies have demonstrated the positive impact of commonly available and well-accepted technologies to improve mental health outcomes. While the "one size fits all" approach typified by many of current mHealth apps has demonstrated value, we believe that there is an opportunity for a tailored approach which is particularly suited to mental healthcare because individuals with mental illness possess distinct characteristics associated with their illness. Incorporating the same notions of using pathology as a grounding for patient-centered mHealth solutions seems to be a fruitful direction for research and development in this domain.

The mental health domain features a number of unique requirements not often present in other mHealth domains. In bipolar disorder, patients' failure to accept a treatment, manifested, for example, in poor- or non-adherence of supporting technologies over the long term, can severely limit the effectiveness of current approaches [12]. Systems to support BD need to support varied use over long periods of time, particularly when the patient may be at certain times insufficiently stable or motivated to actively participate in using the technology. Furthermore, these systems should be adjustable to meet the varying needs and moods of patients during different phases of illness and stages of treatment.

While there is an acknowledged lack of health applications for individuals with serious mental illnesses [31], there has

been an increasing amount of work seeking to develop usability guidelines that account for concomitant cognitive impairments. For example, Rotondi et al.'s Flat Explicit Design Model takes into consideration cognitive impairments as well as less experience with technology in the design of E-health applications. Ben-Zeev et al. presented similar usability guidelines for mobile e-health applications for schizophrenia [3].

This study presents the first work that we are aware of that focuses on design elements relevant to characteristics of BD which could impact individual use of mHealth apps. Our qualitative study provides initial evidence that patient-centred and -involved design grounded in the specific characteristics and context of bipolar disorder and deployed in naturalistic settings can lead to positive outcomes and outright enthusiasm for the adoption of a novel mHealth technology. Throughout our study, each respondent suggested ways that design elements might adjust according to mood and phase of illness. This study helped identify important considerations specific to bipolar disorder that might otherwise not have been encountered. Examples include: (1) the impact prevalent comorbid social anxiety can have on aspects of design, (2) the benefits of recording the reasons why some individuals might have neglected to log, (3) the need to support a hierarchy and range of feedback based on individual needs and preference, and (4) an awareness of the possible value in adjusting app design and interactions with sensitivity to the considerable variance in bipolar mood.

One important caveat to our work is that the co-designers of our system with BD were all individuals who were (1) already receiving treatment and (2) euthymic at the time of the study. As such, these individuals were less likely to be representative of more unstable and cognitively impaired individuals suffering from bipolar disorder.

Ecologically valid in situ design

Participatory *in situ* design through long-term, hands-on involvement served to ground and contextualize *a priori* design ideas that were based on the research literature and IPSRT clinical intervention. This novel method supports a highly iterative design cycle; participants can try instants of design ideas in real world settings which can then be discussed, adjusted or entirely changed. As a result, the entire design team is better positioned to rapidly respond to participant feedback with updated versions of the technology.

Most of our participants were highly motivated to participate in the study ("to help others with BD") and opted to continue design involvement after completion of the formal study. While this will obviously not always be the case for individuals suffering the effects of illnesses as serious as bipolar disorder, it demonstrates the feasibility of *in situ* participatory design in this population. Participants suggested novel ideas and, in many cases, created mock-ups that directly contributed to the design. The *in situ* design

process facilitated more extensive co-design with participants, allowing them to use robust system prototypes on their own devices and provide ecologically valid feedback on an ongoing basis in the context of their daily lives.

Participatory design studies can be defined by directness of user interaction, length of their involvement and their control over design decisions [26]. In terms of participation, this study involved 9 individuals with bipolar disorder for on average 118 days (SD = 149); this degree of patient involvement is comparable to that reported in the Monarca work, which featured 1–3 users in fortnightly workshops over a year [19].

While design workshops have been used to identify user needs, provide feedback and contribute to designs, as in Monarca, *in situ* design goes a step further and grounds design in patients' daily experience. This thereby enables more ecologically valid contextualized experience with the app. The end goal is similar to *Situated Experience Prototypes* (or Paratypes)[15], a technique developed to reproduce user interactions in real world situations. It involves surveying people's thoughts on technologies as they go about their day. Paratypes could also be used in conjunction with *in situ* design to provide even more momentary reactions to design elements. Indeed, in our study one participant in a manner similar to paratypes spontaneously used the Notes feature of the app to record their experiences with the app.

In situ design supported extended real world use of designs. Prolonged access to design prototypes altered individual responses to certain design elements. Some participants for example did not like the *idea* of badges initially but did appreciate some aspects of them after using them over time. Prolonged deployment not only helped identify potentially de-motivating, or at worst risky design elements such as the unlimited streak element, but also supported iterative development of a non-traditional streak element that emphasized balance and thus was in harmony with individual needs and IPSRT principles.

This contrasts with the design process of Monarca, which focused on broader issues related to adoption, acceptance and sustained use and discussion of system features. It is difficult to know exactly which app features will work in abstract. Our method support a more narrow focus on individual elements of mHealth design while providing ecologically valid feedback to support design decisions and hence increase confidence prior to clinical deployment. An approach which combines both participatory design workshops early on to identify needs and early design directions followed by *in situ* design later might be ideal. The resulting system could then be evaluated in a clinical pilot. Beyond mental health, this method which maximizes the ecological validity of feedback, provides an opportunity to innovate and empowers participants to suggest design elements should be applicable to other health domains

Rewarding Interaction & Therapeutic Activity

Increasing patient engagement in managing their illness is likely to have a positive impact on adherence and overall outcomes. The degree to which a patient is engaged in their treatment and the extent to which they have the required skills to make a change are significant in leading to positive outcomes. Design strategies that seek to increase engagement in treatment and develop a sense of empowerment by drawing on characteristics of the target users are more likely to be successful.

We have described how design elements ranging from basic UI feedback for completing a self-tracking task to badges can emerge from a combination of the characteristics of the illness and patient and therapist input. Our findings suggest that mobile health interactions for this population, who are dealing with an illness that can be severely debilitating and stigmatic, can be rewarding, informative, encouraging, reinforcing—and even fun.

Gamification approaches like leaderboards and badges involve using game-like feedback elements, often to make challenging or unappealing tasks more engaging. Our findings suggest that participants valued a broader range of rewarding interactions. For example, no one collected the badges in and of themselves, but reported richer experiences because of the availability and persistence of these elements. We also discovered positive effects of badges: participants found them encouraging (“you can do this”), informative (“you’ve done this X times before”), and empowering (“you’ve managed this before”).

While our study does not show that positive acceptance of elements like badges and streaks are a result of the underlying tendency of individuals with bipolar disorder to respond positively to reward-based stimuli, all participants suggested that careful deployment of a wide range of rewarding elements had appeal for them. The reward-sensitivity hypothesis suggests potential for these elements with this population and should be explored more systematically.

Our findings stand in contrast to those of Bardram et al., who resisted including novel visualizations in the design of the Monarca mobile app because one patient in their focus group session dismissed them as trivializing of their illness – “*turning their illness into a game*”[2]. There may be several reasons for this difference. In the Monarca study, the participant responded to the *idea* of using visual metaphors to provide feedback on wellbeing. Isolated discussion of specific app elements *ex situ* might be difficult for participants to envision. Furthermore, the imagined extremes of such a design might enhance a perception that an implementation would serve to trivialize one's illness. In our study, where participants used an app with badges (and other rewarding elements) over a long period of time as part of their daily lives, they gained direct hands-on experience of these elements and could respond based on first-hand experience of these features. Another

factor might have been cultural differences; the Monarca study was conducted in Denmark; our study, in the United States.

Best practice and pragmatism

While it is vital to allow patients to shape the tools they will use to manage their illness, incorporating the perspectives of multiple stakeholders (i.e., developers, researchers, clinicians, and other family members), while sometimes challenging, as evidenced by the back and forth debate over the Target feature, can further help to identify and accommodate needs that may initially seem to be at odds.

On one hand, changing aspects of a therapeutic intervention could undermine a therapeutically sound intervention grounded solely on clinical research. However, it was apparent in our Target example that most people struggled to live up to best clinical practice and that the role of the therapist was to work with patients on this basis and set practical therapeutic goals that would move them towards greater stability.

Bipolar individuals can be skeptical about the effectiveness of treatment and are often independent-minded about identifying and applying treatment. As a result, the work of therapy is to tailor the instantiation of IPSRT to each patient. It would be a missed opportunity if a technology instantiating this treatment did not do the same.

In an ideal case, we may think of therapeutic systems as flexible tools that will need to serve different purposes for different patients at different times. One way of approaching this conflict between best practice and pragmatism is to follow a therapist-like approach, starting with what the patient feels they are capable of, and leading them towards the ideal through various strategies (advice, empathy, motivational strategies and rewards), appropriate to their illness and mood. In future work, it would be valuable to explore the value of machine learning techniques to create adaptive interfaces and interactions that are sensitive to mood changes, illness characteristics, individual factors.

CONCLUSION

Serious mental illnesses, including bipolar disorder and other major mood disorders, account for a considerable share of the overall healthcare burden. In this paper, we have argued that design for people with serious mental illnesses should take into consideration the distinctive characteristics of these illnesses in order to identify more innovative and effective designs. To achieve this we present *in situ* design an iterative method to elicit ecologically valid feedback by supporting hands-on experience of design prototypes by patients in their everyday lives. Our central contribution is an illustration of how, when working with people with bipolar disorder, and in mental health care generally, technology design can fruitfully integrate input from basic research about the characteristics of an illness, a validated therapy, and the lived experience of people who

have and are working to manage their particular illness. Additionally, we have shown that mobile health interactions tailored for this population, who are dealing with an illness which can be severely debilitating and stigmatic, can be rewarding, informative, encouraging, reinforcing and even fun. With an increasing understanding of the distinct cognitive, behavioral and emotional dimensions specific to other mental illnesses, there is now an opportunity for mHealth design to better support people trying to manage these conditions.

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