Designing for Serious Mental Illnesses: Enabling Early Detection and Supporting Financial Wellbeing in Bipolar Disorder

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ABSTRACT

Serious mental illnesses (SMIs), like bipolar disorder (BD) can have a significant negative impact on individuals' lives, but ability to anticipate manic and depressive mood episodes before they occur can lead better treatment outcomes. BD and its symptoms can also show through online behaviors, suggesting an opportunity to use an online data-driven approach to managing BD. However, designing technologies to support individuals with SMIs have unique concerns, such as privacy and agency. In this proposed work, I mean to understand the feasibility and acceptance of a BD intervention system that uses online behavioral data to infer mood episode onset. Throughout this I mean to explore patient and clinician needs for managing BD through a data-driven intervention, as well as attitudes toward sharing personal data within social support networks to help support treatment, to develop a prototype for future evaluation. In conclusion, I present preliminary findings on patient acceptance, common problematic behaviors, and the role of patient-clinician relationships.

CCS CONCEPTS

• **Human-centered computing** → **Ubiquitous and mobile computing systems and tools**; *Ubiquitous and mobile computing*.

KEYWORDS

mental health, behavioral interventions, intervention design, mhealth, bipolar disorder, health informatics

1 INTRODUCTION

Serious mental illness is a critical global public health issue [17]. For example, Bipolar disorder (BD) is a mood disorder that affects

approximately 5.7 million US adults. About 83% of which are considered of "serious impairment", meaning that their BD symptoms have a significant impact on all aspects of their daily lives, including employment and interpersonal relationships [15]. This impairment rate is the highest among all mood disorders [15]. Bipolar disorder is also one of the leading causes of disability on a global scale and leads to an average 9.2 year lifespan reduction [16]. Ideally, the keys to successful BD treatment include: an early diagnosis, anticipating mood episode onsets, the right balance of medications, and social support systems [14]. However, this can be highly complex and individualized, as well as come with significant challenges. The onset of mood episodes can be difficult to predict and symptoms associated with BD can strain social support relationships.

BD is characterized by cycling between different mood states, from depressive episodes to manic mood episodes [15]. When in a depressive mood episode individuals will experience feelings of extreme sadness, low-energy, lack of interest in activities, changes in sleep behaviors, indecisiveness, poor concentration, and social withdrawal—much like depression. Whereas in a manic mood episode, individuals may experience euphoria or irritable moods, increased energy and goal-directed activity, high risk-taking behaviors and impulsivity, be easily distracted, or have a decreased need for sleep [12]. The duration of these mood episodes and how often one cycles between them can be highly variable from one person to another, but the more one can learn about their BD episodes and symptoms, the easier it can be to manage, treat, and lessen the impacts to daily life. [14]

Previous work has developed technology-based interventions for serious mental illnesses. These approaches attempt to accommodate complex, individualized treatment needs by providing a range of different options, from remote clinician access and social support to teaching new coping skills and suggesting activities to improve overall mood state [10, 11, 18]. However, these types of interventions often see high-drop off rates which are a challenge for treating long-term conditions [18]. Mood tracking and other mHealth apps have provided options for behavior and symptom tracking. While these systems can help promote self-reflection, many are not evidence-based [11]. Additionally, those that are clinically-supported are still largely reliant of self-report measures, which pose challenges for accuracy and user-burden for those with BD [4].

Because technology is so embedded in daily life, the use of smartphones and social media can be telling of behaviors and overall mental wellbeing. This provides an opportunity to move beyond self-report measures. While smartphones can be used as a delivery mechanism for remote mental health assessments and monitoring behaviors [5, 9], they can also be used to infer behavioral patterns,

by way of location, sleep patterns, and social interactions—all which correlate with common mental health indicators [2]. Similarly, studies have shown how social media content can be used to infer mood state and depression on a broad scale by using timestamps and activity periods, post frequency and engagement, along with the content, sentiment, language use of what people choose to share online [6, 7].

Initial work has shed light on how mood episodes of bipolar disorder may manifest in online behaviors [13]. For instance, manic mood episodes may show a sudden increase in social interactions, such as emails and social media posts. Individuals may also show an increase in online shopping and gambling or a high volume of Google queries. Conversely, a depressive mood episode may show an overall drop in technology use, especially in the case of social media interactions or email responses. This suggests that there are key patterns in online behavioral data that could be used to infer these different mood states [8]. Despite this, the full picture of how BD episodes present in online data remains unclear, including the baseline behaviors of BD patients when not in a mood episode and key indicators for mood episode onset that may be missed by online behaviors alone.

Leveraging objective online behavioral data could potentially help individuals learn about and manage their BD, as well as enhance the work lives of clinicians. However, before taking on the computational task of building a system to infer mood states from online behavioral data, it is necessary to determine the range and nuance of behaviors on which to base this type of system, and more importantly, thoroughly understand the first-hand needs, expectations, and potential concerns of users. More specifically, I want to understand patients' concerns for using their online data as an early warning system, such as privacy and accuracy of information, as well as how they foresee implementing such a system to manage BD and share information with their clinicians and other members of their social support networks to facilitate help-seeking behaviors. Additionally, it is imperative to understand how these clinician insights align with those shared by BD patients.

My body of work aims to build a full list of BD-related online behaviors, address user acceptability of using online data for this purpose, and understand the role of this system in the daily lives of patients and clinicians to promote better BD care. I will use the following research questions to guide this work and further address existing research gaps:

- What are the key online behaviors BD patients exhibit in a) manic and b) depressive mood episodes?
- How comfortable are patients and clinicians with the concept of using online behavioral data to help manage symptoms and help infer mood episode onset?
- How could this type of system be used within social support networks to a) support BD patient care and b) prompt help-seeking behaviors?

My work will provide contributions to research within both the domains of HCI and psychology and result in actionable recommendations for design and clinical application. This work will help fill existing gaps in HCI research on the relationship between technology use and bipolar disorder and provide an in-depth understanding of how people with BD use technology, perform different tasks, and

engage with others online during different mood episodes. This can help answer why these behaviors are common and the purpose they play for individuals when experiencing different mood episodes. Through this, I will uncover online activities that are especially challenging for BD patients and highlight key opportunities where technology can intervene to help patients better manage these behaviors—such as financial decisions and social interactions. The resulting design recommendations could be used to build out a full functioning BD intervention system, as well as provide new features to implement into existing systems to better support users with BD.

From the clinical perspective, I mean to contribute a framework for developing new collaborative technology-based interventions that are clinician-supported and in alignment with recommended BD treatment efforts. By taking this multi-stage approach—gathering patient perspectives and experiences, grounding with clinician insight, and developing design features to suit the needs of both patients and clinicians—I hope to promote greater acceptance of technology and personal data-driven interventions within clinicians. By not only involving clinicians as participants, but throughout the development of research protocols, I mean to communicate the validity of this approach so it can be applied toward other treatment needs within the psychology domain. In doing so, it could help lower barriers to mental healthcare access for patients and streamline the workload of clinicians, leading to overall higher quality care.

2 METHODS

This body of work will be conducted in three phases, involving patient interviews, clinician interviews, and a prototype evaluation—each part building on insights from the phases prior. In phase 1 and 2, patients and clinicians will be presented with a hypothetical intervention system that would use online behavioral data from patients with bipolar disorder to help provide early warnings for mood episode onset and help manage symptoms. This concept was left open-ended to allow patients and clinicians to describe the system as they imagined it and talk through features and functions that would be useful, from their own perspectives. To give an idea of what types of online data could be used for this future intervention, patient participants downloaded their activity data from Google Takeout (including usage data from Gmail, Chrome, and other Google applications) [1]. This data, in its "non-content" form (e.g., using elements like time stamps and sentiment of emails, rather than the full email message) would then be compared with their medical records to test the computational feasibility of predicting mood episodes from online behaviors in a related study outside the scope of this body of work. While no online data will be collected from clinicians, the data types included in Google Takeout will be presented to clinicians as part of the proposed system for their feedback. Phase 3 will involve the resulting prototype, including an early warning system for mood episodes and a tool to help patients manage online spending.

2.1 Phase 1: Patients

I conducted open-ended, semi-structured interviews with BD patients to better understand the acceptability and feasibility of our

proposed system. I recruited 10 patients with a BD diagnosis who had at least one manic, hypomanic, and/or depressive episode within the last year. During the first part of the interview, I focused on understanding the patients' self-perception about their online behavior changes across different BD phases. I specifically asked about their communication (e.g., Gmail), searching, shopping, and overall technology use trends across manic and depressive mood episodes. Understanding how a patient's self-perceived use of technology changes across illness phases were helpful in identifying potentially useful data features in our later analysis. I then focused on understanding the acceptability issues and potential privacy concerns of the patients. Toward this goal, I explored 1.) general attitudes of participants towards using online data for relapse prediction; 2.) how they envisioned using the proposed system presented to them within their daily lives, including their example use cases; 3.) design recommendations for feedback and useful features from the perspective of the user; and 4.) data sharing attitudes from the patients' perspective. This phase of data collection has recently been completed and its preliminary findings will be discussed in a later section.

2.2 Phase 2: Clinicians

The next stage of my work is to address the clinician's point of view on this online data-based intervention approach through individual interviews and co-design activities with clinicians who regularly treat patients with BD, but also other BD care providers, such as social workers. These sessions will involve an overview of the proposed system concept—a BD symptom management mood episode early warning system based on online activity data, help determine whether the findings and initial features derived from patient insights would be clinically suitable, and explore the ways clinicians envision using this type of system and features that would help improve their own work flow.

In this phase, I want to understand, from a clinician's perspective, what different types of online behaviors may look like in depressive and manic mood episodes and further ground my overall understanding of how BD symptoms manifest in online behavior. I also mean to address perceived accuracy, privacy, and other concerns they may have with this system concept. For instance, in what ways could this type of behavioral feedback be detrimental to patients in a certain contexts or mood episodes? I want to gather insight on how this type of behavioral feedback information should be provided to patients to best align with clinical treatment goals. I will discuss the different design ideas generated from the patient interview sessions and whether they would be suitable for BD patients and in what specific contexts. I also want to investigate their own needs and expectations for this type of system and to contextualize this intervention within clinicians' own work flows. This can help me understand what the other side of the intervention system needs to look like, how it should integrate within their work rhythms, and the ways its use could lead to a more rewarding workplace experience.

2.3 Phase 3: Prototype Evaluation

Following phases 1 and 2 of this work, I will develop a prototype for potential users—both patients and clinicians—to interact with and provide feedback. This prototype will show mock-up data visualizations of different online behaviors across time, such as the frequency of different activities (e.g., number of emails sent, Amazon orders purchased, posts made on Twitter, etc.) and example "early warning" notification procedures that could be sent by the system if the onset of a mood episode was detected, as well as other key features that will be identified through the patient and clinician interviews. Based on preliminary study data and past BD research, this prototype will include feedback mechanisms for financial and social interaction behaviors, as these are some of the most common decision-making challenges faced by individuals with bipolar disorder. This could be in the form of in-situ feedback— such as a push notification prompting a user to think twice about purchasing an item or making a post online.

This prototype will then be evaluated by both patients and clinicians in one-on-one sessions. Participants will then be presented with a clickable prototype. First, they will be asked to interact with the prototype freely, as they see fit. I will prompt the participant to engage in a think-aloud exercise as they explore the prototype—in particular, they will talk through their rationale for their actions with the prototype. This will provide insight as to their expectations of the system, anticipated use cases, and highlight potential challenges or roadblocks in the prototype design. Following this exercise, participants will fill out a questionnaire to provide ratings across different categories such as, perceived usefulness, relevance, and ease of use, as well as how likely they would be to use the different features highlighted in the prototype. I will then ask more targeted open-ended questions about the different features, how useful they would find them, how they imagine using them in a full-functional application, and other related features or additions that could benefit the system, as well as any criticism or suggestions related to the features provided. Participants will have access to the prototype device throughout the whole session and will be encouraged to demonstrate or reference different features while responding to these evaluation questions.

3 PRELIMINARY FINDINGS

At this point in time, all phase 1 patient interview data has been collected and analyzed regarding patients' acceptance of the overall concept of using online data sources to manage BD, common problematic behaviors, opportunities to leverage existing clinical practices, and initial insight on the role of patient-clinician relationships within future interventions. These ten patients ranged from 22-73 years of age with a variety of BD types and backgrounds. For instance, some experienced primarily depressive episodes or primarily manic mood episodes, as well as some experiencing a mix of both types.

3.1 Patient Acceptance

Overall, patient participants were generally positive and accepting of the overall concept of using their online data for the purposes of learning more about their BD symptoms and receiving feedback about future mood episode onsets. While there were concerns about personal privacy, the leading consensus was "if it helps me, it's worth it". Thinking through their common online behaviors while in manic or depressive mood episodes, they believed that this type

of information would accurately highlight clear patterns leading up to the onset of a mood episode, as well as allow them to discover new online behaviors associated with BD.

When asked about the idea of sharing their behavioral data or feedback from this intervention systems with other people, it largely depended on what type of information and with whom. Participants showed a preference for tiered data access, where some individuals would have access to more granular information than others. In most cases, a clinician was granted the widest access to this information, including all longitudinal behavioral data and notifications for mood episode onset warnings or other red-flagged behaviors. This was then followed by a key trusted member of their social support network, like a parent or a spouse, who might receive high-level updates or warning notifications. However, when this information was to be shared with non-clinical members of their support networks, patients wanted it to include additional context, as to not worry them or provide concrete examples of what they should do in response (e.g., check-in with the patient, give them some personal space, etc.).

3.2 Problematic Behaviors

Patients discussed two leading problematic behaviors that they believed this proposed system could help them address: online shopping and social interactions. All patients described having compulsive or over-spending habits at times, especially online. When asked which online behaviors had the greatest effect on their offline lives, all patient participants referenced the amount of money they had spent online. They believed this could be an opportunity for the system to intervene by either prompting them to think through their actions or disabling shopping actions entirely while in an active mood episode to help control overspending.

Patients also mentioned that online social interactions were often a point of concern. They were sometimes unable to infer the tone of their social media posts. This led them to share polarizing, negative, or aggressive posts while in mood episodes without realizing, which would then cause conflicts with friends and family. Because of this, patients thought it would be helpful to receive in-situ feedback about the tone of their messages before they were allowed to post them online—such as "This message may be seen as overly aggressive. Are you sure you want to share?" Patients believed this type of feature could help them avoid future interpersonal conflicts and better maintain their existing support systems.

3.3 Digitizing Existing Practices

Talks with patient participants highlighted opportunities to digitize existing clinical practices within an online intervention system. Many patients were used to keeping a paper-based journal as part of their current therapy and treatment plans and wished to incorporate this type of function within the proposed system. They wanted to provide additional context to their online data logs to help explain environmental factors that might be related to their behaviors and make note of new triggers they had discovered, as well as keep track of medication changes in conjunction with their online behaviors.

Related to the problematic behavior of online spending, patients described actions similar to advanced directives—or a legal tool that allows a person with a mental illness to state their preferences in advance of a crisis [3]. In the case of online behaviors, the patient, while not in an active mood episode, could decide with their clinician what actions the intervention system should take to limit specific online behaviors and carry them out on the patient's behalf. Should the patient want to target overspending, the system could be set to automatically disable all spending, add an additional "are you sure you want to spend $150 on this item?" question prior to purchase, delay the purchase by 24 or 48 hours, or prompt a trusted individual to approve the purchase—depending on what they decide with their clinician. This continued focus on spending as a behavior patients wanted to manage more effectively further justifies the need for incorporating additional financial support tools in future interventions.

3.4 Patient-Clinician Relationships

When discussing the hypothetical use of this system, patients were concerned about how this may affect their clinicians and could see it having both negative and positive impacts on their patient-clinician relationships. First, they perceived additional burdens to their clinician, such as an increase in workload due to patients sharing large amounts of data and the time needed to review that extra data before therapy sessions. They were also concerned that system notifications may bother clinicians off-the-clock. While this may be needed in emergency situations, patients thought this could be problematic if these red-flag notifications were sent in error outside of work hours.

At the same time, patients believed this could help improve their relationships and interactions with clinicians by acting a communication tool. They thought using their personal data as a reference could help facilitate and streamline therapy sessions, as it could give them tangible behaviors to prioritize and remind them of key discussion points. This idea was seen as especially important for BD patients who recalled an inability to concentrate and stay on task, or had additional conditions (such as attention-deficit hyperactivity disorder) that presented challenges for remembering information between therapy sessions.

These initial patient insights about their own behaviors and the role of clinicians in data-driven intervention systems are currently being used to refine interview protocols and will be explored further with BD clinicians in phase 2 of this work.

4 CONCLUSION

Using the perspectives of patients and clinicians, this work means to contribute the following outcomes: computational criteria for online behaviors that signal mood episode onset, design recommendations (including ideal feedback types and opportunities to target problematic spending behaviors), and a system prototype. Additionally, this work can serve as a clinician framework for involvement in intervention development—both as participants and active members of a research team. Additionally, this work can have broader implications, such as improving the adoption of data-driven interventions, providing more widely accessible mental healthcare, increasing help-seeking behaviors leading to better treatment outcomes overall.

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