

Knowing How Long a Storm Might Last Makes it Easier to Weather: Exploring Needs and Attitudes Toward a Data-driven and Preemptive Intervention System for Bipolar Disorder

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ABSTRACT

Bipolar disorder (BD) is a serious mental illness that requires life-long management. Manic and depressive mood episodes in BD are characterized by idiosyncratic behavioral changes. Identifying these early-warning signs is critical for effective illness management. However, there are unique design constraints for technologies focusing on preemptive assessment and intervention in BD given the need for data-intensive monitoring and balancing user agency. In this paper, we aim to establish acceptance, needs, and concerns regarding a preemptive assessment and intervention system to support longitudinal BD management. We interviewed 10 individuals living with BD. To ground the findings in lived experiences, we used a hypothetical assessment and intervention system focusing on online behaviors. Based on the data, we have identified requirements for effective behavioral monitoring across illness episodes. We have also established design recommendations to support dynamic, longitudinal interventions that can address the evolving user needs for life-long BD management.

CCS CONCEPTS

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

KEYWORDS

bipolar disorder, intervention design, privacy concern

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1 INTRODUCTION

Bipolar disorder (BD) is a mood disorder that affects nearly 5.7 million adults in the United States [37]. BD is defined by the occurrence of at least one manic episode (BD I) or hypomanic and depressive mood episodes (BD II) [17, 24]. The length and frequency of these mood episode cycles can be highly variable. Approximately 83% of those with BD experience "serious impairment" resulting from symptoms that significantly impact all aspects of their lives [37].

While BD is a lifelong relapsing, remitting illness, there is no known cure for BD. The ideal BD management plan includes an early diagnosis, the ability to anticipate the onset of future mood episodes, the right balance of medications and psychotherapy, and supportive social relationships [34]. However, BD symptoms can be dynamic and idiosyncratic, which leads to complex and highly individualized needs. This makes lifelong management of BD very challenging. Specifically, early detection of a mood episode is critical for effective BD management [39]. Current clinical workflow involves infrequent visits timed around interval established for monitoring treatment efficacy for an established episode. Once remission is achieved, visit frequent is reduced. Early detection and timely intervention for a subsequent episode remains a serious challenge for most individuals living with BD [34]. Additionally, there is a lack of trained mental health professionals that can provide effective support for individuals living with BD. For example, there is one active psychiatrist for every 8,476 people in the United States [38]. This results in a serious treatment gap.

As a result, there has been a recent focus on developing data-driven, personalized, and objective assessment methods for identifying early-warning signs in BD [1, 15, 16]. However, more work needs to include the voice of those with lived experiences of BD into the design with the goal of integrating these methods to support lifelong management of BD. There are unique design challenges and constraints for technologies aiming to support preemptive assessment and intervention in BD given the varying and dynamic needs across different stages of illness [28]. Specifically, preemptive assessment methods are inherently data-intensive, which might have different privacy implications across stages. Furthermore, effective

illness management might require sharing data and early-warning signs across support groups with different levels of trust and capabilities (e.g., friends vs clinicians). Similarly, balancing user agency and efficacy is a critical design challenge for preemptive assessment and intervention technologies.

This study aims to identify and address these unique design challenges to support longitudinal BD management. Specifically, we aim to establish acceptance, needs, and concerns regarding a preemptive assessment and intervention system by collecting interview data from individuals (N=10) with BD. To ground these findings in lived experiences, we used a hypothetical system focusing on online behaviors. Prior work has established the relationship between BD mood episodes and online behaviors [28]. As such, preemptive assessment and intervention scenarios focusing on online behaviors are particularly relevant for individuals living with BD. Furthermore, prior work has used such scenario-based approaches to assess acceptability [45] and privacy attitudes [25] in other contexts.

Using the scenarios as interview probes, we have identified how a preemptive assessment and intervention system could address BD specific needs across different mood episodes and support lifelong BD management. We have also established nuances of participants' expectations and concerns regarding such data-driven technologies. We found that financial activity was the leading online behavior that affected individual's offline lives, regardless of mood episode type. Overall, participants were open to this online data-driven approach to managing BD and inferring mood episode onset if it was effective and reduced potential harms. In particular, participants shared different use cases for incorporating a data-driven, preemptive assessment system in their current BD management plans. Participants were also open to collaborating and sharing their information with their social support networks, but had specific constraints in mind regarding how much information was shared, with whom, and for what purpose. Based on these findings, we provide design recommendations for technologies aiming to support lifelong management of individuals living with BD.

2 RELATED WORK

With the advancement of mHealth applications and research on ubiquitous use of technology, prior work has demonstrated how we can attempt to infer mental health and mood states with minimal effort from end users. Past work has provided a base understanding of how BD symptoms may manifest through online activities and how this data-driven approach shows promise from the standpoint of clinicians. However, less is known about individual users' perspectives on data-driven approaches to assess and treat BD, as well as the acceptability and privacy trade-offs they may hold.

2.1 Bipolar Disorder in Online Contexts

As the use of the internet and social media has become an integral part of daily life, behaviors and events occurring in our offline lives can reflect in our online lives. In particular, the way people use social media platforms, how frequently they post, what time of day they post, and the types of content they share can give us a snapshot of their life during the specific frame of time [14]. Therefore, online behaviors have been shown to reliably reflect mental health markers and mood disorders [12–14]. Temporal social media data, such as

tweet timestamps or post engagements can be used to map out activity and sleep patterns [13]. It has been shown that one of the most common first and last activities of the day is viewing social media feeds, this can act as a relatively reliable proxy for wake and sleep times. These sleep times can then be used to distinguish users with irregular sleep patterns common of depression [12, 14].

Recent work has established methods for analyzing online content for depression indicators [4]. Sentiment analysis, keyword use, and linguistic patterns have uncovered trends in social media posts associated with depression [12, 14]. This readily available data has been used to measure depression rates at a population-level [13] or predict national suicide rates [51]. This automatic detection shows promise to take the place of more traditional approaches of population-level and individual-level analysis of mood states.

However, this previous work on online behaviors and mood episodes largely focuses on depression, often because it is one of the most commonly diagnosed conditions in US populations [36]. While this may provide insight on the depressive mood episodes, BD has a different illness pattern than depression with mania or hypomania. Additional work is needed to understand BD in online spaces to accurately detect different mood episodes. Much of the literature specifically regarding BD focuses on internet addiction [49, 50]. These works suggest that increased online activity or longer durations of activity is often associated with BD [23, 49] or that internet addiction maybe a common comorbid diagnosis with BD [50]. However, they do not specifically focus on the specific activities that individuals engage with while online across different mood episodes.

Recent work has also explored user needs and concerns across manic and depressive mood states in the context of digital tracking and assessment. For example, Snyder et al. [47] investigated visualization concepts to communicate trends in personal data collected from individuals with BD. Their work also identifies sense-making challenges and the need for tracking idiosyncratic behaviors. Our study extends their findings by specifically focusing on user needs, expectations, and concerns for preemptive assessment and intervention systems aiming to support individuals with BD.

Survey work has provided initial insights about how both manic and depressive mood episodes may manifest, in online activities specifically. Increases in technology use were reported during manic mood episodes. This often took the form of emails, social media posts, search queries, and excessive gambling, gaming, or online shopping [28]. Depressive mood episodes often involve a drop in technology use overall or actively avoiding technology. If technology was used during depressive mood episodes, it was considered more passive, less purposeful, or used as a distraction [28]. The common symptom of risk-taking behaviors during manic mood episodes was central to another study on BD in relation to social media and online dating [43]. This further suggests that online social behaviors are significantly different for individuals with BD and may often lead to self-reported regret and negative social interactions [43]. Given the suggested behavioral differences across mood episodes, other work has acknowledged the feasibility of using online behavior to provide warning signs for BD [15]. However, they suggest carefully considering how and when we provide this information to users. Providing negative feedback when individuals are unprepared to receive it, in a way that is overwhelming

or difficult to understand, or without clear actionable suggestions may be more harmful than good [15].

Several recent studies have established the feasibility of automated assessment of behavioral trends relevant to BD. For example, Abdullah et al. [1] used passive sensor data from smartphones to assess stability in BD. Similarly, Maxhuni et al. [29] used voice and motor activities to identify BD episodes. These methods can be combined with distinct online behaviors to support continuous assessment of early-warning signs in BD and subsequently, designing effective preemptive interventions. Toward this goal, this paper identifies idiosyncratic trends and patterns of online behaviors across episodes by exploring in-depth lived experiences of individuals with BD. For instance, behaviors that significantly change during both mood episodes, such as making social media posts, may take on different characteristics or intentions that could help distinguish between different mood episodes. Additionally, to accurately detect mood episodes in an individual, it is critical to establish a baseline of online behaviors during periods of remission. While online activity for people with BD in remission could be compared to the online activity of general users, other work has suggested that internet use could be characteristically different for users with BD [23, 49, 50]. With a deeper first-hand understanding of online BD activity, we can develop a more robust list of indicators of mood episode onset. Along with determining what type of activity data is informative, it is equally as important to determine the best way to communicate this feedback to people with BD to ensure that it is effective and keeps their well-being in mind.

2.2 Acceptance of Data-driven Systems for Mental Health

Much of the prior work focusing on the acceptance of using data-driven systems to support mental health and specific conditions such as BD have been conducted from the perspective of clinicians. These works have typically sought to gauge acceptance regarding patient suitability and clinical efficacy [11]. Studies regarding the potential for digital phenotyping for BD have shown clinical support [11, 27]. While these studies provide valuable insights into clinicians' perspectives regarding data-driven approaches, it is also critical to assess acceptance and identify potential concerns of individuals living with BD.

Recent research has explored end user acceptance of mental health applications publicly available in the app store [3]. Given these applications are not always clinically validated or tested for clinical efficacy, user acceptance of these types of data-driven approaches can be low, impacting their usage and long-term engagement [3]. A review of mental health apps suggests that the low engagement typically seen with these systems stems from a lack of trust and significant security and privacy concerns [3].

Prior work suggests that even in clinical environments patients have highly nuanced perspectives on data privacy in mental health contexts [46]. Attitudes toward health data privacy can be largely dependent on previous experiences, in that past mistreatment with their healthcare data can have a significant impact on their trust of future data systems, regardless of privacy and security measures taken [46]. At the same time, patients still understand that the

quality of care provided to them is contingent on these data systems, creating a difficult situation for them to navigate [46]. When mental health data is placed in an online setting, such as a virtual mental health clinic, patients preferred to share the minimum information needed to meet their needs and to have an option to omit any mental health data [21]. The leading concerns driving these preferences were the potential for external access to their sensitive data (e.g., records accessible to their university) and the perceived social stigma they could experience if their involvement with the clinic was made known to others [21].

Additional work is needed to expand our understanding of user acceptance of data-driven preemptive assessment systems and the nuanced privacy concerns they may create for individuals with BD. Recent studies have explored ethical challenges of using automated assessment of mental health states using social media data. For example, there are potential concerns and risks to privacy and user agency [10, 44] in using social media data for mental health assessment given stigma and lack of users' consent in using their data for this purpose. False positives regarding mental health assessments can also have negative consequences for social media users [10]. There are also risks of harmful appropriation [44]. This work aims to extend prior work on these ethical challenges. Specifically, we focus on opt-in data collection from users for automated assessment in this work. We then identify how the participants view potential ethical and privacy issues as well as exploring their recommendations to address these issues.

This work aims to fill in these gaps in our understanding 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 individuals with BD to promote better care. Through this work we used qualitative methods to analyze information gathered during interview with individual with lived experience of BD to answer the following research questions:

- (1) What are key online behaviors to computationally assess a) manic and b) depressive mood episodes?
- (2) How do individuals with BD envision using a data-driven, preemptive assessment and intervention system to manage BD symptoms or episodes?
- (3) What are their needs and concerns in using a data-driven, preemptive system for longitudinal management of BD?

3 METHODS

For the study, we recruited 10 participants with a BD diagnosis from an affiliated mood disorders clinic. These participants had at least one manic, hypomanic, and/or depressive episode within the last year and used the internet daily in some capacity. Participants ranged in age from 19 to 73. The sample size is consistent with previous research studies focusing on bipolar disorder [1, 20, 26, 29, 40]. More importantly, the sample size was adequate to reach Glaser and Strauss' data saturation standards for qualitative studies using Grounded Theory [19]. Following data saturation standard and relevant prior work, we argue that the sample size is justified, specifically given the exploratory nature of the study.

We conducted open-ended, semi-structured interviews with them to better understand the acceptability and feasibility of a hypothetical assessment and intervention system, based on online

activity data. To give them an idea of what types and amount of on-line data that could be used in this future intervention, participants were walked through the process of downloading their activity data from Google Takeout (including usage data from Gmail, Chrome, and other Google applications). One interview was conducted in-person in a clinic setting and the other nine were conducted remotely via Zoom following the COVID-19 guidelines. The relevant Institutional Review Board (IRB) approved the study procedure.

3.1 Scenario-based Interviews

In these interviews, individuals with BD were presented with a hypothetical assessment system and data-driven intervention scenarios. Similar hypothetical scenario-based methods have been used to gauge acceptability [45] and understand privacy attitudes [25] in past work. We followed the methodology established in previous studies to design the interview sessions. Specifically, the interview sessions progressed from general to more specific scenarios to avoid user priming and bias. The interview session started with general questions to explore participants' perceived needs and concerns. We then followed up with questions about potential system features and scenarios specific to a participant's needs, as well as exploring related concerns. We asked about scenarios involving preemptive system interventions at the end of the interview.

During the first part of the interview, we focused on understanding participants' self-perception about online behavior changes across different BD mood states. We asked about their communication (e.g., Gmail), searching, shopping, and overall technology use trends across manic and depressive mood episodes. Understanding how self-perceived use of technology changes across illness states was helpful in identifying potentially useful data features in our later analysis. We note such self-recall methods have been validated as an effective data collection tool for BD [8, 28, 47].

We then focused on understanding the acceptability issues and potential privacy concerns of participants. Toward this goal, we explored the general attitudes of participants towards using online data for relapse prediction; how they envisioned using the proposed system presented to them within their daily lives, including their example use cases; design recommendations and data sharing attitudes from the perspective of the user.

3.2 Data Analysis

To analyze the interview data, we used a bottom-up qualitative approach and thematic analysis [9] to identify key themes. The resultant themes reached Glaser and Strauss' data saturation standards for qualitative studies using Grounded Theory [19]. In other words, these themes remained persistent with no new findings or additional variation throughout the full data set.

4 FINDINGS

The section describes the key findings from the interview data including the common online behaviors indicative of different mood episodes and participants' design ideals for a preemptive system to manage their symptoms. We also describe participants' attitudes towards data privacy, data sharing needs and concerns, and balancing user agency to support longitudinal management of BD.

4.1 What Do Online Behaviors Look Like Across Different Mood Episodes of BD?

At a high level, participants reported more online activity during manic mood episodes and less during depressive episodes, versus their perceived non-symptomatic baselines. However, many of their specific activities and the motivations driving them differed between individuals for different mood episodes.

4.1.1 Key Behaviors During Manic Mood Episodes. Overall, seven participants recalled having a more active relationship with technology during manic mood episodes. While behavioral patterns can vary across mood episodes, participants were more likely to engage with the online searcher, email and social media use, entertainment and streaming content, and online shopping during manic episodes as compared to depressive episodes or non-symptomatic periods.

Participants commonly referred to "falling down an internet rabbit hole" during manic episodes. For example, if someone had a new hobby or idea on their mind, they would spend a significant amount of time trying to learn more about it online. This would result in extensive Google and social media searches, watching videos about it, and buying supplies online to support this new hobby or interest. Oftentimes, this increased level of online activity could get in the way of other daily tasks, such as sleep, work, or driving, which could have a significant impact on all aspects of their lives.

Participants also mentioned how online social engagement can change during manic mood episodes. Participants were more likely to seek out social interactions, from known friends and family or other individuals. While many reported engaging with email during manic mood episodes, this was largely dependent on the motive behind those emails. If these emails were more casual and social in nature, participants were more apt to send or respond to emails. However, participants described being reluctant to engage with formal, serious, or work-related emails. Participants mentioned "not having the patience" or not being "able to slow down to think of a response" to those emails during the manic mood episodes. As a result, they would avoid responding to those emails. *"If I had another task on my mind, I couldn't be bothered with email."* (P6)

During manic episodes, online interactions can often be a source of conflict and negativity that could heavily impact their offline lives, as well as their online presence. P4 commented *"I have less of a filter when I'm manic [...] I will not hesitate to call someone out if I feel they deserve it."* As a result, some of their posts would use provocative and inflammatory language, which can result in unintended conflicts. To avoid these issues, participants came up with different strategies. For example, P4 avoided using social media until the afternoon, after they had time to wake up, process their day and put themselves in a less antagonistic frame of mind. Social media conflicts were common across all participants who used social media. Sometimes it would be in the way they responded to others. For others, it stemmed from posting topics or sharing thoughts that concerned their friends or family. Additionally, P7 and P8 worried about their jobs in relation to social media, making statements such as *"at this point, I'm trying to start a more professional online appearance, so if I was to keep posting stuff like that, I would worry about the damage."* (P8)

4.1.2 Key Behaviors During Depressive Mood Episodes. In general, participants believed they experienced significant drops in technology use when in a depressive mood episode. They noted the perceived amount of effort it took to engage in online activities as reason for low usage during depressive episodes. They specifically reported significant decreases in online social interactions. Some preferred to avoid all social situations during depressive episodes. Participants also mentioned decreased online activities for work, such as replying to emails, during depressive episodes.

However, participants also mentioned an increase in passive engagement with online technologies and behaviors during depressive episodes. Specifically, participants noted high media consumption including watching YouTube or video streaming services during depressive episodes. For some participants, this was a case of *comfort consumption*. P6 commented that *“I love binge watching old episodes of shows when I’m depressed or anxious [...] I’m familiar with it and it’s comforting to me.”* Similarly, participants also used streaming services and other sources of online entertainment as background noise that wouldn’t require their full attention or active engagement. P2 noted *“I watch the same familiar tv shows over and over, but I’m not actually ‘watching’ them.”* Participants noted a similar trend for social media as well. Several participants mentioned how they would *“mindlessly scroll through Facebook or Instagram with no real purpose other than to feel like I’m doing something”* (P4). These online activities can often be motivated by a need for distraction or an attempt to change one’s mood.

Participants sometimes also took an active approach in media consumption to improve their moods. As P2 mentioned *“When I realize I’m not doing well, I search for cute animal videos on YouTube to distract me for a little bit.”* Others had incorporated specific types of media consumption into their daily routines or their approaches to managing mood episodes as well. This included using videos featuring sounds that initiate an autonomous sensory meridian response (“ASMR videos”) to help them fall asleep at night, as it gave them something more specific to focus their thoughts on, rather than their current mood. Similarly, some used meditation videos either at the start or the end of their days to help improve their mind set.

4.1.3 Online Shopping as a Universal Behavior. All participants mentioned online shopping as a potential concern regardless of manic or depressive mood episode. During the interview, we asked participants what online behaviors had the largest impact on their lives. All participants mentioned online shopping in response. While this was a common activity for both mood episodes, the types of spending and the motivations behind those financial decisions greatly differed between their manic and depressive episodes.

Similar to “comfort consumption”, participants engaged in *comfort spending* during their depressive episodes. The goal of clicking the buy button was to have something to look forward to receiving in the future. In other cases, participants purchased items to improve their mood or their quality of life—such as an eye mask and a new pillow to hopefully improve their poor quality of sleep. On the other hand, purchasing behaviors during manic mood episodes were more diverse and often reflected their current interests in the moment. For example, if they had recently gotten interested in a new hobby, their online purchases would be related to that hobby.

Impulsive spending is also a common theme during manic episodes [18] as P6 mentioned *“sometimes I’ll just see something in an ad online and suddenly decide ‘I need that’”*

4.2 How Do Users Envision a Data-Driven, Preemptive Intervention System Based on Online Behavior?

Overall, participants believed that a data-driven, preemptive intervention system could be personally useful in their day-to-day lives. In particular, all individuals noted the benefits of accurate early warning of upcoming mood episodes. Participants believed it would be feasible to identify idiosyncratic early-warning signs based on their online behaviors. That is, participants thought that there would be enough variation in their online behaviors to identify and distinguish between different mood episodes. Some participants also noted that a lack of online data—or a sudden drop in technology use—could also be indicative of their mood episodes. For instance, P10 noted that a full abandonment of technology would be highly indicative of their manic mood episodes, as they primarily engage in offline activities, such as artwork or home improvement projects, during those time periods.

4.2.1 Feature Suggestions. For the preemptive intervention system, participants suggested features similar to other behavioral tracking apps that they might currently use (e.g., FitBit). Participants suggested to have a dashboard that would provide an overview of all online behaviors. They also wanted to be able to identify patterns and trends for different behaviors in detail. Beyond a dashboard with detailed visualization, participants also mentioned summary notification as an important feature. These notifications should be system generated and summarize useful trends in an easy to digest format. More specifically, having their online data presented in an easy to understand and meaningful way was especially important to support decision-making during mood episodes. Prior work has similarly noted the importance of easy interpretability while communicating mental health assessments [10].

Most participants wanted to have a weekly summary. They noted that too frequent summary notifications (i.e., daily) would feel overwhelming and not particularly useful. Some participants mentioned that they would likely ignore the summary notifications if sent too frequently. Other participants thought that having information pushed to them daily could be useful when first starting to use the platform and help them get better acquainted with what it could do and establish behavioral baselines. On the other hand, participants believed having a monthly snapshot would not be frequent enough to be useful. That is, they thought a month was too wide of a window and as a result, it would be much too late for any problematic trends in their behavior. Instead, following up week to week would give them adequate time to recognize and take preemptive action on those behaviors before they became a major issue that would be much harder to fix later.

Participants also noted the need to collect contextual and environmental information along with online behaviors for a successful preemptive intervention system. Specifically, they wanted the ability to leave notes in their data to help them reflect and learn from it. Such annotations might include identifying emotional triggers

they had experienced, medication changes, hormone cycles, important life events, and changes or stressors at work or school. Prior work has also noted the importance of logging additional contextual items, such as emotional triggers and life changes, to assess overall BD illness trajectory [47]. These events were known to have an effect on their mood, as well as the onset of episodic periods. Collecting and analyzing such contextual information could lead to a more personalized and accurate assessment and intervention system.

Participants were particularly interested in using data-driven approaches to figure out an optimal medication strategy. P4 discussed the length of time it can take to figure out a medication plan — “one that can soften or prevent episodic periods without leaving you feeling flat and numb”. Having access to granular, objective behavioral data could provide a more accurate picture of medication effects. This can lead to a more efficient strategy for selecting medication plans “rather than feeling like trial and error” (P4).

Overall, participants wanted the system to be able to automatically detect important trends in their behaviors as well as support exploring their data to learn about different behavioral associations including outcomes following medication changes. In other words, the proposed system must be flexible enough to provide data-driven insights and allow self-exploration for individuals living with BD.

4.2.2 Duration of Data Collection and Storage. We also asked participants how long they would want such a system to record and store their data. Their overwhelming response was “the longer, the better” (P4). Participants noted that having longitudinal data from the very start would make it most useful to them, as P10 commented: “give me all of it, everything you have on me, as far back as you can go.” Participants mentioned that the behavioral patterns and trends could span a long amount of time. Furthermore, individuals could go several years without experiencing a manic mood episode, but having data to show what their last manic mood episode looked like and the early indicators of its onset would be useful for longitudinal management. In other words, regardless of what their typical episodic cycle looked like, being able to look back and reflect on as much of their personal history as possible would better prepare them for what could come in their future.

4.2.3 Potential Use Cases. During the interviews, participants also came up with use cases for a preemptive system that would be personally relevant to their daily lives. Participants specifically focused on how they would incorporate the data and outcomes into their BD management plans and how they wanted the system to intervene on their behalf.

Preemptive Measures for Upcoming Episodes. Some participants wanted to use this information for to plan ahead should they move into an episodic period. Being able to look ahead would allow them to plan for extra help, such as increasing the number of therapy appointments in the upcoming weeks or make plans with friends to check in more frequently to see how they were doing or what they might need. Some thought having a wealth of longitudinal data would help them and their clinicians make more informed decisions including medication changes, introducing new medications, or upping their dosage leading into a mood episode. Others talked about how looking back on their past episodes and their duration

could help them enter future episodes with a more prepared and positive mindset. By having a better sense of what those episodes may look like in terms of severity or length, they could more confidently manage it. P4 commented “if I know how long the storm might last, I can ration the energy it takes to weather it.”

Managing Financial Decisions. All participants in our study noted challenges with financial behaviors during episodic periods. P3 talked about impulsive purchases during their last manic episode and how they were still trying to financially recover from it several years later: “I’m retired and live on a fixed income. I can’t physically or financially afford to go through another manic mood episode anymore.” Participants believed that an intervention to prevent financially harmful decisions would be beneficial to them and others. In other words, there is a need for a preemptive intervention system that can support financial management and decision-making for individuals with BD. For instance, the system could add frictions to online purchasing by prompting them and adding extra steps for completing the purchase. It can also restrict online shopping during problematic periods (e.g., late night hours). Participants also suggested to include personalized and spending-focused interventions to help address their financial behavior challenges. Such interventions could include training to recognize and prevent impulsive purchasing behaviors as well as reminders to return items in time to recoup costs.

Avoiding Interpersonal Conflicts. Participants expressed concerns about conflicts resulting from online social interactions. They often found themselves unable to infer the tone of their social media posts during mood episodes, especially mania. P9 noted that “At the time, I’ll think what I have to say is completely reasonable, only to realize how divisive it is once it upsets people”. During mood episodes, participants unintentionally shared polarizing, negative, or aggressive posts. This would then cause conflicts with friends and family. During depressive mood episodes, some participants recalled oversharing very personal, difficult feelings and experiences. While their intended motivation was to vent and relate to others, they often made their friends uncomfortable. This would result in worsening their feeling of loneliness and isolation. Given their prior experiences, participants thought it would be particularly helpful to receive in-situ feedback on the tone of their messages before they were allowed to post them online. For example, the system can notify users with a message similar to: “This post may be seen as overly aggressive to others. Are you sure you want to share?” Participants believed such prompts and in-situ interventions could be very useful for them to avoid future conflicts and improve their existing support systems.

4.3 What Concerns Do Users Have with Data-Driven, Preemptive Systems?

Overall, participants were open and receptive to the idea of using a preemptive assessment and intervention system, especially if it would provide accurate insights about their mood episodes. However, there were nuanced differences in participant acceptance when it comes to data access and sharing. All participants were willing to use a preemptive system when the data and outcomes will be shared with themselves only. However, participants differed

in their opinions when it comes to data sharing with other people. For example, two participants (P8 and P10) had some concerns with data privacy from a technical standpoint— whether their personal data was stored on a remote server or would be subject to third-party access. As long as a future system stored sensitive data on their personal device only, they would be comfortable using it. P8, a cybersecurity student, stated *“the user agreement and privacy policy would need to be clear and transparent, like with whom you’re giving access to this data, whether that be big companies.”* Additionally, P10 suggested that any resulting application be presented to future users within a clinical setting and at the request of a trusted clinician to further lessen potential data concerns: *“Whenever someone hears ‘tracking app’ alarm bells can go off. I want it to be initiated by a clinician as a treatment tool. I know there are a lot of mood trackers out there that are vague about data, but if my clinician told me to use it because the data could help inform our sessions, that would be more important.”*

The overarching privacy concerns of participants were balanced with their perceived benefits from the preemptive system. As P1 noted *“if it is used for a good purpose and ends up being beneficial to me [...]”,* they will be highly willing to use the preemptive system. Similarly, P2 was open to continuous monitoring and data collection if it'd lead to effective illness management: *“if it can help me catch my next manic episode before it happens, it would be worth it to me.”* Such privacy trade-off responses from our participants are consistent with prior work [35, 46].

4.3.1 Data Sharing. Given the nature of BD, effective illness management requires cooperative support and interaction across different stakeholders. As such, it might be necessary for a preemptive system to share data and outcome beyond just individuals with BD. Our participants discussed different data sharing options and requirements including who would have access, how much data they could access, and for what reasons they were involved. All participants had at least one key trusted individual with whom they felt comfortable sharing some level of information. No participants stated that they would only use the system privately, meaning sharing no information at all. Two participants (P7 and P9) expressed discomfort with sharing this type of information with their friends or family, but they were still very open to sharing their data with clinicians.

Sharing with Clinicians. Participants wanted to be able to share data and outcomes with their therapist or psychiatrist. They believed that the more information clinicians had about them, the more equipped the clinicians would be to help them out and understand their experiences outside of clinical settings. Furthermore, there was also less perceived risk and stigma from sharing data with mental health experts. Participants noted that it was the clinicians' job to be understanding and reserve judgment for the types of behaviors they may see in their data logs.

However, participants were also mindful about potential burden on clinicians regarding this data. They did not want to overwhelm the clinicians with their data, which will lead to extra work for the clinicians. Participants also worried about disrupting work-life balance of their clinicians that the system could send red flag notifications late at night or when their clinicians were off duty.

They were particularly concerned about sharing inaccurate early-warning signs with their clinicians. In other words, participants noted the necessity of accurate assessments from the preemptive system when it comes to engaging their clinicians. Prior work has also noted the need to manage clinician burden while developing data-driven assessment methods for monitoring mental health [10].

Participants also noted how data sharing can lead to effective accountability. While participants believed their clinicians would not judge their online activities, they also did not want to let their therapists down if their online data showed that they were failing to make progress or falling into old habits.

Sharing with Care Partners. Beyond clinicians, most participants also wanted to share data and outcomes with key family member or friend. This could include a parent or spouse. Individuals without strong familial ties often had a close friend for support. These were the people who already knew a lot about their day-to-day experience with BD—*“the good, bad, and the ugly”* as P4 stated of their main confidant. Participants wanted to share data and outcomes with these key individuals. However, they wanted the data sharing with these individuals to be privacy sensitive. For instance, they were largely okay with showing patterns and frequencies of Google searches, but they were less comfortable with them knowing the specific search queries or websites they had visited. In other words, participants did not want to share raw data with their care partners in most cases.

Sharing Beyond Care Partners. Participants also wanted to share information with people beyond their immediate care partners, but at a very high level. Some envisioned this as a weekly check-in to give those individuals the reassurance that the participant was doing okay. In the case that they may be entering a mood episode, participants wanted them to be aware of the situation in the simplest terms and provide them with some guidance for how they could help. They did not want to give them too much information and risk alarming them more than their situation warranted.

Overall, participants described a tiered approach to trust, privacy, and data disclosure that is highly dependent on the specific nature and dynamics of their social relationships — clinicians were at the highest level followed by one key ally that was either family or a friend. Prior work has noted similar tiered approach in information sharing and help seeking behaviors [22] including individuals living with serious mental illness [33]. A successful assessment and intervention system should aim support such tiered approaches in managing trust, privacy, and data disclosure.

4.3.2 Balancing Agency with Utility. Informed decision-making can be a serious challenge during mood episodes. We were interested in exploring practical strategies to balance user agency and their long-term wellbeing. During the interviews, we asked participants about different intervention scenarios, how comfortable they would feel if the system was to make on a more active role in these scenarios, why it may (or may not) be useful to them, and their rationale behind those feelings. We also explored participants' opinions on how such a system can support collaborative decision-making by integrating care partners. We also probed how participants would feel about a prompt to reconsider their decision before allowing them to authorize it. For example, with online shopping, they could

be presented with a message asking “*are you sure you want to make this purchase?*”. The same approach could be applied to social media, where, similar to above, they were given a second authorization prompt before letting their potentially controversial post go live.

While these actions would force them to pause and think through the decision, it ultimately would not bar them from making those decisions altogether. Some participants felt this would be enough of a speed bump to slow them down. Especially if it was during a depressive mood episode, any extra steps included in the decision would feel like more effort, which could dissuade them from continuing. Many believed they would feel more in control if they were able to make their own decisions, but that this would not be enough, especially during more severe manic mood episodes. For instance, as P1 stated, they knew that if they were prompted to think through their decisions while in a manic episode, they simply wouldn't: “*when I'm manic, I can't think about my decisions [...] I'd just click through to get what I want. It wouldn't stop me.*”

To explore the other end of user agency, we also presented scenarios where the system would prohibit behaviors outright if it sensed participants were experiencing a mood episode. Many participants believed this would be more helpful, specifically during the manic episodes. P1 thought it would be useful for the system to disable their more high-risk behaviors, such as spending money and browsing the web on their phone, particularly while driving: “*I know that I, in a manic state, would hate being told by a computer that I'm not allowed to do something. But I, in a sound mindset, know that it would be for the greater good.*” P3 thought similarly about online shopping. They noted that the system would likely make them angry for restricting activities when in a manic mood, but would ultimately be beneficial to them, rather than allowing them to continue. These views were mirrored in other participants' responses as well, depending on the type or severity of specific episode they could experience in the future.

Others wanted an option between those two extremes. P6 specifically noted how they would scroll through Amazon, fill up their shopping cart, and at times leave the website without purchasing anything. For them, the act of choosing the products and placing them in the cart was sufficient to keep them entertained. P7 and P10 referenced similar approaches to window shopping. Participants were largely receptive of options to place a hold on their actions, figuring that in 24 to 48 hours the want to make that original purchase or send their original message would have worn off. Additionally, the extra time would force them to think through the implications of those decisions while waiting to complete them.

Lastly, we asked participants how they felt about involving trusted others to help make those decisions. This could either involve making those decisions together or by asking others to authorize their decisions, in place of the system directly monitoring their high-concern activities. Some participants discussed how they currently involved others to help make important decisions or had handed off specific types of decisions to a care partner completely. This was especially the case regarding financial decisions.

Overall, participants were receptive to offloading some agency to others in the cases where they knew they would need extra help, specifically during severe mood episodes or for high-risk decisions. At the same time, they also voiced a need for clear rules regarding how they would hand off control to others. They wanted to dictate

when and how their care partners could act on their behalf, but also ensure that they would not be able to undo those safeguards when in a mood episode and therefore undermine their long-term wellbeing. As P4 noted: “*I know myself well. I could set what I need, right now, and hand it to someone else to change the password, so that way I couldn't go back and switch everything off once I am manic.*” P6 had a similar idea, stating “*I wish someone else could set up a password, someone I couldn't contact to beg to change it for me. That would be a game changer for me at least.*”

4.4 Viewing BD as a Life-Long Journey

Given their lived experiences, participants in our study viewed BD as a life-long journey that requires constant vigilance and longitudinal management. Participants also noted the necessity of identifying warning signs to effectively manage their illness. P2 commented “*the earlier you figure BD out, the better you can take care of it.*” They noted how a data-driven, preemptive system can help them identify idiosyncratic patterns early as well as figure out the ever shifting, dynamic trends and warning signs throughout their lives.

Five participants, with well-established BD treatment plans, expressed a desire to help younger people — those who were newly diagnosed or in the early stages of treatment. They stated that they participated in this study and openly shared their experiences as a way to give back to the BD community. They wanted to help other people learn from their own struggles. They recalled that figuring out their ideal treatment plan involved a lot of trial and error. P10 mentioned taking a decade to work out an illness management plan. Participants were hopeful that, if a preemptive assessment system was available, it would streamline that process for others in the future. As P10 commented: “*Something like this could have helped me get diagnosed sooner and been really beneficial at that time.*”

Furthermore, while some participants had treatment plans in place and had developed significant BD management skills, they still believed that a data-driven system could still help them at their current stage of the BD journey. For example, P4, who had recently enrolled in law school, noted the resultant significant life changes as a risk for future mood episodes. They noted how a data-driven system would make it easier to identify early warning signs in their new environment and that could lead to better support and in-time coping skills.

5 DISCUSSION

By thinking about BD as an evolving, life-long journey, we can better ensure that the systems we design to support their needs are built in a way that can adapt and change with them over time. To make data-driven systems effective and supportive of these diverse and changing needs, we suggest creating opportunities for flexibility and customization, nuanced privacy settings, social support tools, and leverage existing clinical practices. More importantly, we should prioritize involving the triad of stakeholders involved with BD care: individuals with BD, formal clinician support, and informal care partners, such as their family and friends in future intervention design.

5.1 Flexibility and Customization

To effectively support users throughout this life-long journey, future design should empower users to tailor the system to their own unique needs. Any preemptive intervention system focusing on BD must be flexible and adaptable to reflect their shifting needs over time. That is, such a system should accommodate needs over their lifetime. Long-term management of BD also needs to support different types of mood episodes, changing levels of severity, and future life changes. Prior work has identified similar needs for flexibility and customization to support long-term goals [32]. Specifically, given how needs and behaviors might change across different mood states, it is critical to allow flexibility and customization to avoid longitudinal goal misalignment. For example, individuals with BD might need to track different behaviors to support new goals or update privacy settings to meet different needs across illness phases. This flexibility can allow users to better match the level of behavioral surveillance to what is necessary to best support their current needs and reduce the potential mental health harms of over-surveillance raised by previous work [41].

Future design should allow users to choose what behaviors they want to explore within the system, set goals to change or eliminate those behaviors, and develop new criteria for warning signs. As users work toward and meet those goals, they should have the ability to change these settings based on progress and new needs prompted by future mood episodes. At the same time, these features should not be too flexible as to undermine the users' goals to manage their symptoms or make the restrictions on their chosen activities ineffective. Therefore, designers should develop measures to ensure that these restrictions are upheld when the user needs them most and are able to be removed or altered when the user is at lower risk. For instance, some functionality could be disabled automatically if a system detects a mood episode. Additionally, these systems could leverage care partners to assist in this process, such as providing admin access to care partners and view only access to BD users. Supporting a collaborative approach can lead to more effective intervention and data-sharing decisions over time.

5.2 Nuanced Privacy and Agency Considerations

Our findings show that our participants have nuanced privacy requirements and expectations regarding a preemptive, data-driven intervention systems. This further supports the notion that privacy attitudes are highly context-dependent [48]. Our data specifically suggests that longitudinal management of chronic conditions might require a practical and balanced consideration of privacy — trade-offs are often required between potential concerns and effectively supporting user needs. Participants noted how privacy settings, such as how much longitudinal data the system saves and what level of data can be shared with others, should be malleable to evolving needs as well. For instance, users may initially want to share minimal information with others, but over time, they may choose to share more information with care partners as they become more comfortable or see an increased need for disclosure. Conversely, users should have the ability to revoke those permissions, should their situations change. We think systems aiming to support individuals with BD can potentially leverage prior work focusing

on privacy and agency of vulnerable communities. For example, individuals managing memory loss and their care partners often need to adapt privacy and agency boundaries given unpredictable changes and evolving needs over time [30]. Similar flexible strategies and approaches can be integrated into a system designed to provide longitudinal support for individuals with BD while being respectful of users' needs and agency[6].

Longitudinal management of BD might also require strike a balance between user agency and wellbeing. That is, users and their care partners should have options for temporal restriction of agency reflecting dynamic needs and symptom severity. For instance, during mild episodes, users could choose to maintain their agency and receive a prompt to reflection on their activities. However, during a severe episode the system could prohibit those activities altogether or authorize a care partner to step in on their behalf.

Regardless of their preferred privacy settings, participants communicated a need for clear guidelines as to what type of data was used and for what purposes, as well as who had access to that data, both within their immediate social networks and within the system infrastructure itself. These expectations and requirements of data transparency and explainability are consistent with prior work [41]. This also creates new avenues for research to understand the nuanced balance between privacy and agency needs and longitudinal management of a chronic condition. The same can be said for BD care partner relationships and their complex needs for collaborative decision-making. While previous research has shed light on how privacy needs may be negotiated with care partners [22, 30], the complex and often strained social relationships described by many participants indicate that some individuals with BD may face additional challenges. More work is needed to understand how individuals with BD and care partners currently co-manage BD and collaboratively make decisions, as well as their current privacy and agency trade-offs. Through this expanded knowledge, we can develop systems to better support these efforts and help address existing challenges.

5.3 Designing to Support Social Relationships

Social relationships of individuals with BD can suffer following mood episodes. This was often the result of things they had said or done during past mood episodes. This same trend has been shown in other work on the familial and social structures around BD [31] and their experiences online [28, 43]. Future work should focus on identifying problematic behaviors and trends that might impact the social relationships of individuals with BD.

Furthermore, it is an increasingly common practice to involve family members and friends in therapy activities. Recent work has also explored providing therapy sessions to the whole family to support the individual with BD and help facilitate interactions and improve communication within family units [31]. A robust social support network can be crucial for long term mental wellbeing. Therefore, it would also be beneficial to provide options to leverage their existing social networks in a preemptive intervention system, not only to help manage their symptoms and assist with decisions, but also to sustain and mend existing relationships.

5.3.1 Providing Feedback for More Positive Online Communication. Maintaining positive online conversations about mental health, in general, comes with its own unique challenges [5], but BD often increased these obstacles. Participants talked about the challenges they faced trying to communicate with others in online spaces when experiencing different mood episodes. Unlike face to face conversations, they found it more difficult to judge what topics, tone of voice, or sentiments were appropriate in their online communications, such as social media posts or email. If they misjudged the situation, they faced consequences in their friend groups, their family, and even workplace environments. Future design could help mitigate these difficult situations by providing additional feedback on how someone else might interpret their messages or how to more accurately communicate their thoughts and feelings to other people in the moment. We envision features similar to writing assistant tools (e.g., Grammarly) that can provide dynamic communication support based on the severity of episodes. In doing so, this could help avoid tense social situations and help sustain social as well as workplace relations.

5.3.2 Notifying Care Partners of Mood Episodes. Participants described the important role preemptive systems can play in notifying their care partners regarding mood episodes. Such notifications can not only allow effective support from care partners but also provide useful contexts regarding behaviors of individuals with BD during mood episodes. As P4 noted, this feature could help communicate their current status and provide “a disclaimer that I’m having a hard time right now, so please take anything I say with a grain of salt.” By being able to easily share these status updates and better prepare their social support networks of upcoming high and low points, it can be easier to maintain supportive relationships and seek help. This also provides opportunities for care partners to learn about and better understand the experiences and struggles of BD and build up additional coping skills to help their friend or family member in times of high need.

5.3.3 Bridging the Gap in Asking for Help. It can be challenging for individuals with BD to ask for help and communicating their needs, specifically during mood episodes. A social notification function could help users communicate their in-situ needs to care partners when they do not have the energy to do so, or are embarrassed to ask for help. Individuals with BD might also find it difficult to articulate what they need leading to further barriers to help-seeking. An intervention system built to facilitate these social needs could provide actionable directions to care partners when the user is experiencing a mood episode. For example, it can recommend periodical check-ins or even provide actionable suggestions to help individuals with BD in their daily tasks. Given the importance of collaborative support mentioned by participants, we think it will be highly beneficial to explore how patient support networks can be integrated into data-driven systems aiming to support longitudinal BD management. For example, it might be feasible to curate better support groups based on user similarity and perceived needs. Furthermore, privacy-preserving data sharing might help to develop stronger social networks, which can facilitate peer support and help-seeking. We believe support networks will be particularly useful for individuals newly diagnosed with BD and their care partners [42].

5.4 Support Data Integration with Existing Clinical Workflows

Similarly, a data-driven intervention system also have a unique opportunity to complement current clinical workflow to manage BD. For example, it can support existing clinical practices including journaling for self-reflection, improving communication in therapy sessions, and incorporating advanced directives for longitudinal management of BD.

5.4.1 Journaling for Self-Reflection. Talks with participants highlighted opportunities to digitize existing practices within a data-driven intervention system. Many participants kept paper-based journals as part of their current therapy and treatment plans and wished to incorporate similar features in the proposed preemptive intervention system. They specifically wanted to provide additional context to their online data logs to help explain environmental factors related to their behaviors and make note of new triggers. This is consistent with findings from prior work [47]. They also wanted to keep track of medication changes in conjunction with their online behaviors. They believed that integrating contextual journaling with objective data would help improve their ability to learn more about their current behaviors and symptoms.

5.4.2 Data to Help Inform Therapy Sessions and Improve Communication with Clinicians. Some participants discussed how those journaling exercises along with their online data could help prompt discussion in therapy sessions. Using their data as a reference could give them tangible behaviors to prioritize and remind them of key discussion points. This idea was seen as especially important for individuals with BD who found it difficult to concentrate or remember information between therapy sessions. P1 and P3 talked in great depth about their struggles to stay focused, remember information, and effectively communicate their thoughts in therapy sessions and believed this often made their therapist’s job more difficult. Therefore, a data-driven intervention could be used as a communication tool as well and provide an opportunity to improve interactions during therapy sessions. Using data as a reference could help users more easily remember specific events that had occurred between sessions and important topics they plan to discuss, allowing them to take on more active roles in their BD treatment. These scenarios described by our participants closely mirror similar patient-clinician goal-setting scenarios described in prior personal informatics research [32].

5.4.3 Applying Advanced Directives to Online Behaviors. Participants described measures similar to advanced directives—a legal tool that allows a person with a mental illness to state their preferences in advance of highly symptomatic periods [2]. Individuals with BD along with their care partners and clinicians might want to integrate such an advanced directive within the preemptive intervention system. This will include deciding on what actions a system should take to limit certain behaviors and how to balance user agency during mood episodes. This approach could help determine when to limit agency and privacy by allowing users to preemptively make these decisions and maintain their overall sense of autonomy. Past critiques of mental health sensing and notification systems noted potential concerns related to agency, consent, and privacy, as well as risks of harmful appropriation [10, 41, 44].

To address these concerns, we suggest enabling preemptive, collaborative decision-making steps for new users. The system should also periodically confirm user choices to support changing needs over time. This will allow primary users more autonomy in how and when their data is used and shared with others.

Future work should explore how to design and implement clinical advanced directives and provide more opportunities for preemptive decision-making, as well as consider other clinically supported practices and interventions that could be digitally implemented. Moving forward, establishing the clinical value of data-driven systems and their potential benefits to both clinicians and patients will be crucial for the long-term adoption of these systems in clinical settings [7]. Expanding the availability of clinically supported tools could help address additional concerns of inclusivity and broaden accessibility [44].

As many participants suggested, managing BD takes a village, and is not something they can or want to do entirely on their own. Therefore, future design should focus not only on the needs of individuals with BD, but consider the roles of all stakeholders involved in managing BD. Not only should we accommodate the needs of those with BD for interacting with their clinicians and care partners, but we should also explore what unique needs clinicians and care partners have for supporting those with BD and how data-driven systems can help facilitate those interactions.

5.5 Limitations

The study findings are based on a small sample size (N=10). While the sample size is consistent with exploratory prior work with a similar population [1, 20, 26, 29, 40] and the analysis meets qualitative data saturation standards [19], some of these findings might not be applicable to all individuals with BD. Future research should aim to replicate the study findings with a larger sample. Furthermore, the study only collects data from individuals with BD. It will be useful to extend the study findings by collecting data from different stakeholders including care partners and clinicians. Study participants were recruited through a clinical registry and existing trust toward their clinicians may have led to lower privacy concerns. Additionally, part of the study eligibility was having at least one mood episode documented in their records within the past year. Because of this, our sampling consisted of those who had been in treatment for period of time and were less likely to be newly diagnosed. While this may not capture the full range of insights of those with BD, it also meant that those involved with the study had a better understanding of their behaviors and needs across different mood episodes. Though these participants may have been further away from their initial diagnosis, they often drew on their earlier experiences with BD when discussing what features would be helpful to themselves and for those just starting their journey with BD. Data collection relied on participant self-recall, which has been validated in prior studies focusing on BD [8, 28, 47]. Future research should also aim to identify granular behavioral changes and trends across different mood episodes by using different data collection methods (e.g., ecological momentary assessments, journaling, and passive sensing).

6 CONCLUSION

BD is a lifelong journey with dynamic and evolving needs. This work focuses on designing technologies to support lifelong management of bipolar disorder. Specifically, we explored the unique design challenges and constraints for a data-driven, preemptive assessment and intervention system to support individuals across different stages of illness. Overall, participants were willing use technologies to support longitudinal assessment and preemptive interventions. Participants were also open to collaborating and sharing their information with their clinicians and care partners. Our data also indicates important privacy and agency trade-offs for different use cases. Based on these findings, we have also established design recommendations for future technologies aiming to support lifelong management of BD.

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