The Pennsylvania State University The Graduate School

ASSESSING THE DESIGN NEEDS TO SUPPORT LONGITUDINAL STABILITY AND WELLBEING FOR INDIVIDUALS WITH SERIOUS MENTAL ILLNESS

A Dissertation in Information Sciences and Technology by Johnna Blair

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Abstract

Mental health is a growing concern on a global scale. More specifically, bipolar disorder (BD) has been recognized as one of the ten most debilitating mental illnesses worldwide and is associated with poor functional and clinical outcomes, high suicide rates, and large societal costs. Manic and depressive episodes often present decision-making and impulse control challenges that can lead to financial and social consequences. Identifying these early symptoms is crucial to prevent and minimize the impact of relapse, as mood episode onset can be difficult to anticipate.

There has been a recent focus on developing data-driven, personalized, and objective assessment methods for identifying early-warning signs. However, there are unaddressed questions when it comes to supporting lifelong stability. For example, these methods are inherently data-intensive, which might have different privacy implications across illness stages. Furthermore, effective interventions might require sharing data within social support networks, which raises additional concerns for balancing user agency and privacy.

This dissertation aims to address these gaps in designing technologies to support longitudinal stability and wellbeing of individuals with serious mental illnesses. Specifically, I have explored the challenges present for users adopting social media as a source of mental health support, as well as the challenges for using publicly available content to infer wellbeing. Following these insights, I have used BD as a case study to understand users' perceptions of data-driven interventions for longitudinal stability. Through in-depth interviews, I have assessed their needs and concerns for using their behavioral data to inform future assessment and intervention systems. Lastly, given prominent challenges with maintaining supportive social relationships and managing financial decisions, I have developed a large-scale survey to explore the current financial practices of individuals with BD, symptomatic spending, and their existing management strategies.

From this body of work, I highlight the complex needs of individuals with BD over the life course, the ethical considerations crucial in data-driven intervention design, and how this approach may benefit other mental health conditions and the broader population. This dissertation makes three main contributions. This work explores an understudied group of users—individuals with BD—and provides insight into characteristic online behaviors and the unique needs of users for assessing mood and intervening on symptomatic behaviors. Secondly, this work documents the current need for data-driven financial wellbeing resources and how they can be tailored to support individuals with serious mental illnesses (SMIs). Specifically, our findings show that individuals are receptive to data-driven approach for illness management. However, it is crucial that the privacy and agency trade-offs are clearly defined, proportional to symptom severity, and align with

the goals of longitudinal stability. Lastly, this work provides design recommendations for long-term assessment and intervention systems that can better cater to evolving user needs across the life course. Given the global mental health crisis, there is an urgent need for scalable assessment and intervention methods. This dissertation is an important step toward a vision of adaptive technologies that can support longitudinal stability and wellbeing of individuals with SMIs.

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Chapter 1 Introduction

1.1 A Growing Need for Mental Health Support

Mental health is a growing concern on a global scale. Over 970 million individuals were affected by a mental illness as of 2019, and due to the Covid-19 pandemic this rate has been on the rise [1]. In the United States, 1 and 5 adults experience mental illness [2]. More specifically, 1 in 25 adults live with a *serious* mental illness [2], where related symptoms can significantly impact all facets of daily life, from social relationships to financial standing. Managing a serious mental illness (SMI) requires long-term care, often including a unique combination of therapy, medication, and social support [3,4]. However, this can be difficult to achieve. Given the highly stigmatized nature of mental illness and mental health topics more broadly, individuals may find it difficult to seek help or disclose their needs to their social support networks [5]. This is further complicated by accessibility barriers to mental health resources, whether that be physical access or the financial costs of long-term care [6].

These stigma and accessibility barriers often lead individuals to seek out support from online spaces, social media, and mental health support communities [7–9]. Previous work has highlighted the informational and emotional support needs that users seek from these online spaces and the role that disclosing personal experiences with understanding others can have for overall mental wellbeing [10]. While there may be substantial benefits from engaging in these supportive online communities, their public nature and the fact that these online spaces where not originally designed with these specific needs in mind, users may face additional challenges in meeting these support goals.

At the same time, recent work has shown how content produced and shared in these online spaces, like popular social media platforms, can be used to infer mood state and show indicators of mental illnesses, such as depression [11, 12]. When, how often, and



Figure 1.1. The three-part study plan to explore online behaviors related to mental health and how to design systems that leverage this type of data to inform assessments and interventions for longterm care.

what people post can provide insights into individuals social rhythms and sleep and activity patterns, which relate to symptom criteria. This overall concept of inferring mood state from online content and users' tendency to sharing online to receive and provide mental health support provides a unique opportunity to explore how we might leverage this online behavioral data to inform personalized assessment and intervention systems to help support long term care for serious mental illnesses.

Before developing data-driven systems focused on serious mental illnesses, it is important to gather an in-depth understanding of the challenges that exist in using online behavioral data in this context, as well as the key mental health indicators from the perspective and lived experiences of those with SMIs. Moreover, it is crucial to assess their overall acceptance of using their personal data for the purpose of long-term illness management, their overall concerns with using a data-driven approach to care, and the specific needs this type of system should support based on their lived experiences. This body of work aims to fill in these existing gaps across a three part research plan, illustrated in figure 1.1. Part one aims to understand the role of existing social media platforms in the context of mental health to inform the design of systems built on online behavioral data. Part two seeks out the perspectives and lived experiences of those with SMIs in how we might leverage online behavioral data, beyond social media platforms, for assessment and intervention. Part 3 uses a large-scale survey to narrow in on financial behaviors and the involvement of care partners, based on key insights gathered from part two interviews.

1.2 Learning from Online Spaces

First, this work focuses on the use of public online social media platforms for mental health discourse, as they exist "in the wild". More specifically, it aims to understand what we can learn from the current use of existing platforms and its subsequent challenges, to inform the design of future interventions built on online behavioral data.

Through an analysis of Instagram posts with "depression" and "anxiety" tags, I further document what users choose to share about their experiences, the information that is important to them for managing their wellbeing, and the characteristics of this online discourse. More notably, this work uncovers specific challenges that exist within these online spaces that may distract from the positive social support users seek from them. These challenges, such as the promotion of negative behaviors and negative self-thought could be particularly difficult or even dangerous for some individuals, depending on their specific circumstances. The findings of this work communicate a continuing need to provide additional safeguards to protect supportive mental health spaces on public platforms. This further motivates the need for new systems that specifically cater to needs of mental health social support, as well as facilitating support within individuals' offline support networks.

Building on this insight and previous work on inferring wellbeing from online spaces, I explore the use of Twitter and the challenges it presents for using this type of data to assess wellbeing. I specifically choose to investigate how essential workers used Twitter during the pandemic, using this as an opportunity to see how a period of notably increased stress and a shared difficult experience translates to online social media data. While this work shows some negative wellbeing indicators that align with previous work on inference, some findings—specifically those looking at the overall sentiment—showed more positively associated posts, which contradict what one might assume and the findings of previous work. This suggests that the characteristics of some users, such as essential workers whose careers are linked with their online profiles, may affect how they choose to present themselves online, creating a potential disconnect. This highlights some potential challenges for using social media data alone as the basis for mental health assessment and suggests that additional online behaviors, beyond that of social media, should be considered when working towards a data-driven assessment and intervention for SMIs.

1.3 Bipolar Disorder as a Case for Understanding Online Behaviors and Support Needs

Based on this, there is a need for greater understanding of online behaviors more broadly and how they relate to mental health, as well as first-hand insights from those living with SMIs. To better account for a wide range of behaviors and support needs that exist across the live course, I focus on bipolar disorder (BD) as a specific use case. Narrowing in on BD provides a structure to understand the needs and behaviors associated with different mood states, from depressive to manic mood episodes, and how a user cycling between these two episodes may manifest in online data. As the individual symptomatic behaviors associated with either mood episode can be common to other serious mental illnesses, such as impulsivity or depressed mood, the insights gathered based on BD can help shed some insight on how other conditions may present in online data.

More specifically, individuals with BD show a greater need for resources that can support long-term stability. BD is one of the leading causes of years lived with disability and has a substantial economic burden at a societal level [13]. BD is characterized by shifts between depressive and manic mood episodes. Depressive mood episodes can result in persistent feelings of sadness and worthlessness. Alternatively, manic mood episodes feature periods of high energy and low impulse control. Shifts from a stable mood state into depressive or manic mood episodes can often be unpredictable and require long-term treatment, involving both medication and psychological counseling [14]. BD can be very difficult to manage, especially without adequate support from both clinicians and social support [15].

BD symptoms can affect both on and offline behaviors. Depressive episodes can lead to low energy, lack of interest, changes in sleep behaviors, and social withdrawal. Manic episodes can lead to increased energy and activity and impact the ability to think clearly [16]. The outcomes of these symptoms, such as stressed relationships and increased spending, can be socially and financially detrimental to individuals with BD [5]. BD symptoms are no longer limited to offline life, but can also reflect in online behaviors of individuals and the way they use technology [17]. For example, a steep increase in online purchases can often be seen during manic mood episodes for some. A sudden lack of social activity, such as social media use and emails, can be common for some experiencing a depressive mood episode [18]. Past work has investigated this connection and the different ways in which each mood episode may present itself through online behaviors [17]. In this digital age, our social relationships and behavioral routines are often embedded in online activities. This is true for individuals with BD as well, where online activity data can provide unique insights into illness states. Social interactions and behavior differ significantly between different phases in BD — increased social engagement and activity levels are associated with manic episodes while decreased interaction and engagement indicate depressive episodes [17]. Online activities might reflect such drastic changes and thus could be used to identify early warning signs in BD. However, our current understanding about how BD symptoms manifest in online activities is largely nonexistent. That is, we do not know how online behaviors might differ across different phases in BD. There has not been an in-depth study to identify the changes in longitudinal online behaviors across depressive and manic phases. My work is meant to be a step toward addressing this serious gap in knowledge.

To better understand online behaviors and the needs of BD, I conducted in-depth scenario-based interviews with individuals with BD, focusing on a hypothetical assessment and intervention system based on online activity data. This work aimed to better understand the key online behaviors indicative of their mood episodes, the type of assessment and intervention support they ideally want, and their concerns with using an online data-driven approach to long term BD care.

While participants were generally accepting of a system to help them infer and manage their mood episodes, they engaged in some privacy trade-offs, as well as a need to have their own agency and activities limited to varying degrees depending on their illness severity. Based on their own lived experiences, participants identified two key challenges that this type of intervention system could help address—financial decision-making and social relationships, as these had the largest impact on their overall lives.

1.4 Supporting Financial Wellbeing and Care Partner Collaboration for Long-Term Wellbeing

Based on participants' prevailing needs related to finances and social support and the long-standing cyclical relationship between finances and mental health, the next phase of this work focused on understanding financial behaviors and the involvement of care partners more specifically. To address these behaviors and to better understand how the interview findings persist on a wider scale, I conducted a large-scale international survey.

The findings of this survey document the current financial environments and symp-

tomatic challenges individuals with BD face, the role technology plays in complicating these challenges, and the strategies individuals currently use to help manage their impulsive spending. While respondents had a good sense of how their financial behaviors changed during different mood episodes retrospectively, they often lacked this understanding and ability to intervene while making these decisions. However, respondents had a range of strategies they enacted to try to manage their financial decisions and slow down impulsive spending, some involving care partner support. These findings highlight opportunities for future systems to provide in-situ feedback, support existing strategies, and incorporate existing therapy activities into a digital setting.

1.5 Broader Implications

This cumulative body of work helps inform the technical and user-centered needs of future data-driven assessment and intervention systems with a specific focus of supporting the long-term care of individuals with SMI. By taking a specific focus on improving financial wellbeing and sustained social support, future interventions can allow for better long-term management and stability and help individuals achieve a better standard of living. Based on the range of insights gathered through this work, I provide design suggestions to better support users in online spaces, as well as in their offline lives. Additionally, this work details the priorities for future development, such as understanding the nuanced privacy and agency trade-offs taken against potential risk, incorporating the perspectives of care partners and clinicians, and how to protect vulnerable users through design.

This work contributes new interdisciplinary insights to the fields of HCI, mHealth, and psychology and clinical research. First, this work details the common challenges users face when seeking out mental health support in public online spaces that were not specifically designed for this purpose and suggests new design features to help create more supportive spaces. Secondly, this work documents the online behaviors characteristic of mood episodes, the BD management needs, and design features to support them, as well as the privacy and agency trade-offs involved. Lastly, this work establishes a clear need for additional financial management tools catered to the specific needs of SMIs and future interventions to support better financial wellbeing. Overall, the dissertation is an important step toward making personalized tool for long-term management of SMIs more accessible to those who need them most.

Chapter 2 | Literature Review

2.1 Introduction

Here, I will summarize background literature from both the field of psychology and HCI to situate this body work within these two fields. While "serious mental illnesses" can encompass a wide array of experiences, portions of this work focus on bipolar disorder (BD) as a means to understand the unique needs of different mood states and how they are applicable to other serious mental illnesses. Given this focus, I will first provide an overview of bipolar disorder, its subsequent mood episodes, symptomology, and the broad impacts of BD for individuals. From there, I will discuss relevant mental health research within HCI, with a broad scope. Most specifically, I will discuss how mental health behaviors present online, mental health interventions, and social support networks for managing long-term conditions, and complex and cyclical relationship between mental health and finances, as well as what this currently tells about bipolar disorder in relation to online behavioral data. In closing, I highlight the important gaps that remain in this knowledge and how the subsequent research studies aim to provide greater insight in designing and developing data-driven assessment and intervention systems to support long-term care for SMIs.

2.2 What is Bipolar Disorder?

The characteristics of BD provide a unique opportunity to understand different needs across viable mood states. At the same time, the fact that it shares many symptomatic commonalities with other SMIs, a focus on BD allows us to gather insight on the wider range of potential support needs. BD is a DSM-V distinguished psychological disorder, characterized by shifts in mood, or "mood episodes" [19]. More specifically, this prompts one to experience shifts in mood, activity and energy level, and the ability to concentrate and perform daily tasks. Individuals' mood states can range between high manic episodes to very low depressive mood episodes (hence why bipolar disorder was previously referred to as "manic depression" in older versions of the DSM) [19,20]. In a depressive mood episode, individuals find themselves feeling very sad, hopeless, and apathetic, whereas in a manic mood episode they will feel very euphoric, high energy, and sometimes irritable [16]. Manic mood episodes that are less severe are commonly known as "hypomanic" mood episodes, or in other words, do not reach the high highs of a full manic episode, but are still significantly heightened as compared to one's average, stable mood state [18].

There are three different types of Bipolar disorder: Bipolar I, Bipolar II, and cyclothymic disorder, that all experience these key shifts in overall moods [14, 19]. Bipolar I can be viewed as the most drastically felt condition. In this case, individuals experience manic mood episodes that last at least a week in duration and can often come with symptoms severe enough to require inpatient care, such as psychosis, a sudden break from reality [20, 21]. Bipolar I also prompts depressive symptoms that often last at least two weeks. While Bipolar II still shows distinct patterns of prolonged depressive states and some manic episodes, the manic symptoms are classified as "hypomanic" or not reaching the level of a full manic episode as is characteristic of Bipolar I. That is not to say that bipolar II is milder in its impacts to the individual, as mood episodes can last significantly longer that bipolar I and be very distressing [18]. Lastly, there is Cyclothymic disorder, or cyclothymia, which still includes a mix of depressive and manic symptoms. However, in this case, the symptoms do not classify as a depressive or manic "episode" [22]. Often, individuals with cyclothymia will spend a significant amount of time in a depressive mood episode with instances of manic symptoms [22].

In general, bipolar disorder can lead to, not only mood changes, but changes in sleep, activity, socialization, and other aspects of everyday life [14]. During an episode, the moods and behaviors experienced by an individual are very atypical for the person, when compared to their baseline, when not in a mood episode [15,18]. Often, the individual has difficulty noticing that their behaviors have shifted, that they are experiencing a mood episode, or that there are potential consequences to these uncharacteristic changes [23].

In a depressive mood episode, one characteristically feels "down", sad, or hopeless just like the symptoms of depression. Depressive mood episodes can affect daily life in terms of sleep, leading one to either sleep too much or have difficulty going to or staying asleep at night. This can lead people with BD to have very inconsistent sleep schedules and feel exhausted throughout the day, making other typical tasks difficult to complete [21]. Similarly, depressive mood episodes can either increase or decrease one's appetite from their baseline, leading to significant weight changes [18]. Depressive mood episodes also affect cognitive functioning, like difficulty concentrating, remembering information, or making decisions [18]. Social interactions suffer during depressive mood episodes, as individuals usually pull away from their relationships or self-isolate [4,21,24]. Despite often feeling restless, individuals typically lose interest in the activities they usually enjoy, preferring not to engage with anyone or anything during this type of episode. Most troubling of all, just like depression, those going through a depressive mood episode experience characteristic feeling of hopelessness and can even experience suicidal ideation [25].

Conversely, many of these symptoms appear reversed when in a manic mood episode. Instead, one may feel very "up" and euphoric, or a "wired" high-energy type of feeling [14,22]. Feeling constantly on the go, individuals often feel little or no need for sleep and no appetite. Everything feels like it is in high gear—racing thoughts and fast speech, jumping from topic to topic. Unlike depressive mood episodes, where individuals have little interest and low-activity, manic mood episodes lead individuals to attempt multiple tasks at once or be intensely focused on niche tasks. Instead of feeling worthless, manic mood episodes can lead to a boost in confidence and feeling more capable, important, or talented, often prompting them to dive into large or grandiose tasks and projects [16].

While these symptoms of high mood and productivity may sound like a positive experience, manic mood episodes come with a range of consequences. Individuals may experience increased irritability, be more prone to anger, or "lash out" during conflicts, which can negatively impact their relationships with others. Some of this stems from being more impulsive during manic episodes [24]. These quick reactions and impulsive decisions can lead to many negative consequences and risky behaviors. Manic mood episodes can lead individuals to eat or drink excessively or be more sexually active which can all lead to negative health outcomes [18,24]. Most commonly, decisions made during manic mood episodes can have significant financial consequences. Individuals may spend a lot of money, either through constant purchases or big-ticket items or even giving away large sums of money with the best intentions, to help out friends and family or through sudden charity donations [24].

These mood episodes are highly dependent on the individual. Some may have many mood episodes in one year, others may experience them on rare, but still distressing, occasions. Some may cycle more quickly, whereas others experience very slow cycles where their episodes and the periods between them last for an extended period of time [22]. It is also possible for people with bipolar disorder to experience a mix of manic and depressive symptoms in one episode, which adds further complexity to understanding and managing their condition. In these cases, this is considered a mixed episode or an "episode with mixed features" [22]. For example, one may have the down and depressed feelings of a depressive mood episode while also feeling the sped-up thoughts and impulsive behavior of a manic mood episode. Especially true for manic or hypomanic episodes, the individual experiencing them may not even notice that anything is atypical, because they feel good and can be productive, while others close to them can tell that their overall mood has shifted. While this may seem okay, given that the more severe manic symptoms are not present, these lower forms of hypomania can often evolve to a more severe condition over time, if left untreated [5].

While there is not one "cause" of bipolar disorder, research has shown some genetic links for bipolar disorder—particularly an increased chance of bipolar disorder when a parent or sibling has also been diagnosed [26, 27]. Also, periods of high stress or traumatic events can act as a trigger for a first mood episode [28]. The symptoms of bipolar disorder are often recognized and diagnosed in the late teen years or early adulthood—often while "college-aged". Symptoms can present earlier in childhood; however, they can often be overlooked or confused for the normal ups and downs or growing up [29,30]. Depressive mood episodes may be less overt in children and manic mood episode symptoms may first be interpreted as Attention-deficit Hyperactivity Disorder, as childhood is a common onset period for ADHD [29]. Similarly, bipolar disorder may come with other comorbidities, or other present disorders, such as anxiety disorders, ADHD, substance abuse, or eating disorders, which may complicate this important process [20]. Early and accurate diagnoses, and therefore BD treatment, are crucial for positive health outcomes [3, 4]. Regardless of when one is diagnosed with bipolar disorder, their symptoms may evolve or change over time, making the management of Bipolar a lifetime commitment.

The typical route for effective BD treatment involves a mix of therapy and medication, regardless of the specific type of bipolar disorder. Because bipolar disorder is considered a lifelong diagnosis, episodes can continue to relapse over time and some symptoms can linger even into periods of life free of full mood episodes [30]. Because of this, medication is taken to control the neurological determinants of BD and therapy sessions, such as talk-therapy or cognitive behavioral therapy (CBT), are used to retrain thought processes and work on new coping skills, along with many other goals [27, 31]. It is also necessary

to implement new behavioral routines to work on physical and mental health holistically. Sticking to consistent daily routines in regard to eating, sleeping, exercising, and other health behaviors can provide more mood stability. This increased stability can help individuals better understand the patterns in their behaviors and call attention to events that may trigger mood episodes [3, 4, 31].

While persistent treatment is central to managing symptoms long-term, it often takes a lot of time to work out the ideal treatment plan, which can be particularly discouraging. What works for one person and their unique symptoms, experience, and personal background, may not work for the next person, given how variable BD is on an individual level [3,4]. Treatment and daily management can involve multiple people, including therapists for CBT, psychiatrists to assess medication use, and social workers, as well as support networks of family and friends. BD treatment can also involve a wide range of medications, including mood stabilizers, anti-psychotics, and anti-anxiety medications, depending on one's symptoms [32]. The use of multiple medications can involve a complex process of figuring out which medications work for the patient, which symptoms are present, in what dosage, and in what combination with other medications they may be taking [32]. Because of the challenges presented by BD medications, it is very common for patients to stop taking their medications, despite continuing CBT. While trying to find the right combination, patients may experience negative side effects or withdrawal from changing medications [18, 32]. In other cases, patients may not like how they feel while taking medication. In particular, BD patients often like the high energy, high productivity, positive feelings they experience while in manic mood episodes and BD medication can often make them feel flat or listless [21]. A significant period of feeling well or long gaps without a mood episode can often prompt patients to discontinue their medication, which can then prompt very serious withdrawal or episode relapse [5].

It is important to note that while BD is a life-long disorder, individuals with BD can achieve high-quality and fulfilling lives with treatment and social support [31]. However, BD and its symptoms can have significant impacts on one's life, including their finances [24], social relationships, work [6], and overall health [5]. As mentioned earlier, some of this is prompted by the impaired decision-making processes involved with mood episodes, such as lack of motivation and impulsive behaviors. Risky or impulsive behaviors can lead to legal and financial consequences, strain relationships with friends and family, or make steady employment difficult, which also impacts finances [24]. The behaviors caused by BD symptoms can complicate relationships. In other instances, the person

with BD chooses to isolate themselves from others to avoid conflicts or because they perceive themselves as a bother. Despite social support being crucial for BD management, these relationship complications, combined with ever-present effects of social stigma can make it very difficult for BD patients to open up about their experiences with others or to seek out help and support when they need it most [21].

Given the complexity of BD experiences, the following remain key priorities for effective long-term care. First, the first one is accurately diagnosed, the earlier individuals can start the treatment process and intervene before their BD becomes more severe [15]. Second, it is important for individuals with BD to understand their own symptoms, the behaviors associated with them, and the environmental trigger that can bring them about [33, 34]. A thorough understanding of this can allow both patients and their clinicians to monitor symptom changes and work on new skills and coping behaviors to mitigate the effects of these triggers. Third, understanding the complications that can arise from mood episodes, such as excessive spending, can help people with BD develop plans to mediate those behaviors and avoid facing negative outcomes [16, 20]. Lastly, it is highly important to learn how to infer when a mood episode is about to begin. Knowing a depressive or manic mood episode is about to start, patients and clinicians can work together to help lessen its effects through preemptive adjustments in treatment, such as changes in medication dosage [35]. However, due to the nuance involved, accurately inferring mood episode relapse is notably very difficult. These treatment priorities will act as a foundation throughout this work towards developing a data-driven BD intervention system, providing opportunities for BD users to learn more about their BD symptom and behaviors, help inferring mood episode onsets, and exploring new ways to help mitigate negative behaviors associated with BD in online settings.

2.3 Mobile Mental Health Interventions

It has been a standard practice in BD treatment for patients to engage in manual, self-reported mood and symptom logging as a means of monitoring and learning about their symptoms. Self-report measures, such as the PHQ-9 self-report depression [36] and Altman self-rating mania [37] scales are often used in clinical settings to measure progress and symptoms over time. Additionally, patients may be advised to keep handwritten journals to workout associations between mood episodes, symptoms, and life events that may trigger them, as well as providing a record of different medication effects [31]. Given the availability and pervasiveness of technology, mobile smartphones in particular, these standard practices have been translated for technology-based distribution.

Both patients and clinicians have shown increasing interest in using smartphones and mobile applications because of how commonplace and pervasive their use has become, as well as the new opportunities they provide for assessing mood disorders [38]. This includes new methods of delivery, such as prompting self-report data throughout the course of the data outside of clinical settings, and new methods of input, such as digital mood ratings rather than physical logging with paper and pen [39]. Logging mental health data via mobile technology has shown to be less intrusive to daily life, yet allow more realistic, "in the moment" assessments, rather than collecting data only in clinical settings [40,41]. Smartphone delivery also allows for more data to be collected on a more frequent basis, which can account for additional fluctuations in mood and has shown to provide a more accurate assessment of one's mental state [39, 42]. For example, this increased accuracy has been documented in one such study, mobile-captured ratings showed self-report ratings more consistent with clinician ratings of severity as compared to paper-based ratings [43]. Most importantly, largely due to constant availability and limited effort required from the user, other studies have shown users may be more likely to respond and keep up with technology-supported mood tracking than more traditional approaches, when assessment deliveries are conveniently timed and relatively quick to complete [40].

Technology has also been leveraged for mental healthcare, beyond situational mood assessments, in the form of more complex interventions for a range of mental illnesses [40]. While some still incorporate these mood assessments and symptom logging activities, exploratory interventions have incorporated features to provide behavioral and selfmanagement suggestions, engage with users to teach new coping skills, suggest activities to improve overall mood state [44]. Other interventions have incorporated remote access to therapists to promote increased communication between sessions, whereas some have incorporated other forms of information delivery in the absence of a clinician [45].

Evaluation studies of these types of technology-based interventions have shown promise for use even with severe mental illnesses [40, 43, 44]. While some features are more effective or produce better outcomes for different mental illnesses, the interventions as a whole generally show general improvement overall and high levels of patient satisfaction with its use [43]. Because continued use is key for the success of any kind of mental health treatment plan, an important factor for technology-based intervention is patient attrition. This remained minimal across multiple studies for various intervention types and conditions, indicating that this approach to mental health intervention shows promise for long-term use [43].

While many of these interventions rely heavily on self-report data or were developed for the purpose collecting self-report data, other studies have explored the use of smartphone tracking and other more objective mHealth data for use in mental health interventions [46-48]. In particular, it has been shown that smartphone data can be used to monitor some activities of BD patients [38, 41, 46, 49]. The log times in which users physically interact with their smartphones can be used to infer sleep patterns [41, 48]. Sleep data can provide insight about mood, stress levels, and overall wellbeing, as highly interrupted sleep or abnormal sleep patterns are a common result of anxiety and mood disorders, like depression and bipolar disorder [49]. Additionally, smartphone GPS data can be used to infer daily activity (or inactivity, if the device remains home all day) and opportunities for social interactions, pertinent to depression [47,48]. Specific to bipolar disorder, it was found that passive smartphone data such as accelerometer, location data, microphone audio, and communication activity could be used to reliably predict stable versus unstable mood states based on distinct behavioral patterns [47] Additional work has further established how BD could be inferred from geolocation data [50]. When compared to clinically rated symptoms, these objective smartphone measurements of social and physical activity showed a significant correlation, further solidifying this approach as reliable method of inferring mood state [41].

Despite the promising findings of these self-report and passive behavioral monitoring approaches to mental health intervention and evaluation, there are other potential issues for use, such as privacy, data use, patient agency, and scalability, that should be taken into consideration [51,52]. When it comes to the storage of private health data stored electronically, patients typically prefer having an increased sense of agency and greater control over what type of information is stored and shared, who has access to that information, and for what purposes their health information is used [51]. Sharing and use preferences are greatly determined by the level of sensitivity of and detail of that information. The less sensitive the information, the decreased concern patients had over the access to their data [51]. These findings are relevant within the context of mental health tracking and intervention systems, as mental health data is regarded as highly personal and sensitive. This could increase BD patients' concern over how their data, both self-reported and passively collected, is used and shared with clinicians and other actors within collaborative intervention systems. For patients to continually engage with the system overtime, and therefore receive long-term benefits, patient must have a high degree of trust and feel comfortable with the large amount of sensitive data needed to

support a range of intervention and symptom management system [51, 52].

2.4 Online Mental Health

2.4.1 Inferring Mental Health from Online Content

Given the ability to reliably predict mental health markers from mHealth applications and smartphone use, this same general approach has been applied to online behaviors, primarily through the use of social media. As the use of social media and the internet in general becomes a more integral part of daily life, behaviors and events occurring in our offline lives can be reflected 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 [53].

Several studies have used this approach to assess wellbeing factors or infer specific mental health conditions from online behavior data, using social media platforms [11, 12, 53]. Similar to how smartphone data has been used, temporal social media data, such as tweet timestamps or post engagements can be used to map out activity and sleep patterns [12]. 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, which is a common occurrence this depression and anxiety [11, 53].

The content of social media posts can also give us insight about mental wellbeing. Recent work has developed different methods for analyzing online content for mental health indicators [54]. Sentiment analysis-based studies have shown that anxiety, depression, or general stress experienced by the user often reflects in more negative posts shared online [11,53]. Linguistic patterns on social media posts have also been used to help infer mental health status online. For instance, those with depression or anxiety symptoms use more self-focused pronouns, like I, me, and my, as compared to general users [11,53]. Past work gathered keywords commonly used by those with known depression diagnoses. When analyzing the use of these keywords with random Twitter users, it was shown to accurately identify a significant number of users who had disclosed their mental health or depression online [12].

These different methods, when combined with other usage data like temporal patterns, have been shown to reliability predict users' mental health for multiple conditions. This readily available data has been used to measure depression rates at a population-level [12]. In other contexts, it has been used to predict national suicide rates [55]. This automatic detection shows promise to take the place of more traditional approaches of population-level and individual-level analysis. Not only is it more cost effective and less time consuming but is less affected by social stigma than self-report or survey approaches to assess mental health [17, 56].

2.4.2 Bipolar Disorder Online

Much of this previous work on online behaviors and activities associated with mood episodes has primarily focused on depression, often because it is one of the most commonly diagnosed conditions in US populations [18]. While this can provide insight on how the depressive mood episodes of BD are, it does not provide the whole picture of BD. Additional work is needed to understand BD in online spaces to accurately infer different mood episodes.

Previous work has documented how the internet in general is used by patients with bipolar disorder. Most importantly, this has shown that the percentage of BD patients who use the internet is not significantly different from the general public (about 81% of patients) [57]. Just like the general population, those who were older or faced financial or infrastructure barriers were less likely to go online regularly [57]. A common use of the internet for BD patients is for seeking out BD related information, such as symptoms and coping behaviors. Those who felt more confident about their ability to manage BD day to day were less likely to seek out this type of BD information [57].

More broadly, over 71% of BD patients reported being enthusiastic about the use of technology, 85% of which used technology for a range of social functions, such as email, text messages, and social media [17]. However, they noted a preference for more personal forms of social interaction, such as text messages, rather than public forms. Some BD patients (41%) reported being aware of key changes in technology use that often served as warning signs. In some cases, this was an increased sense of anxiety from tech use and overall drops or increases in use, as well as the timing of this use [17].

Survey work has provided initial insights about how manic and depressive mood episodes may manifest in online activities. Increases in technology use were reported during manic mood episodes. This often took the form of emails, social media posts, many search queries, and excessive gambling, gaming, or online shopping [17]. Depressive mood episodes often involved 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 [17]. Other work has acknowledged the feasibility of using online behavior to provide warning signs for BD but suggests carefully considering how and when we provide this information to BD patients. Providing negative behavioral feedback when patients are unprepared to receive it, in a way that is overwhelming or difficult to understand, or without clear actionable suggestions may be more harm than good [56].

While this provides a starting point for understanding BD behaviors online, it does not explore them in-depth or with the nuance that can be provided with an interview approach. For instance, behaviors that present for 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 infer mood episodes, it is also important to better understand the baseline for these online behaviors when in neither type of mood episode for individuals with bipolar disorder. While this could be compared to the online activity of general users, other work has suggested strong associations between bipolar disorder and measures of internet addition and problematic internet use [58]. With a deeper understanding of online BD activity, I can develop a more robust list of potential indicators of mood episode onset. Along with what type of activity data to use, it is equally as important to determine the best way to communicate this feedback data to patients to insure that is effective and keeps the patient's interest and wellbeing in mind.

2.5 Social Support Systems

Following diagnosis and treatment, social support is another key component for long-term mental health care. Given its importance, it is often facilitated through technological means. In some cases, supportive technologies have been adopted in clinical settings or used as a supplement to a more traditional treatment plan. However, much of the support for mental health conditions is sought by the individuals themselves, using online communities and social media to see out others with shared experiences.

2.5.1 The Role of Social Support

Generally speaking, having a social support network comprised of family, friends, and other trusted individuals can have a significant effect on one's mental health and wellbeing [59]. In fact, low levels of perceived social support can increase the risk for depression symptoms [60]. Moreover, having the support of others can buffer the effects of stress, as it provides a network of individuals to turn to in time of need which is especially important for mood disorders and their related symptoms [59]. Social support from others is one of the more influential factors in one's health progress, success-rate with therapy, and ability to maintain wellbeing a higher standard of living for those living with long-term mental illnesses [59]. In addition to this, social support may moderate genetic and environmental vulnerabilities to various conditions, both physical and psychological, and lead to increased resilience to stressful situations [60, 61]. Social support and the increase self-esteem it can produce can have a significant impact on depression and increase psychological functioning [62]. Support and maintaining connections with others have also shown to help protect against developing trauma-related psychopathology, decrease the functional consequences some disorders, such as posttraumatic stress disorder (PTSD) and anxiety, and in more severe cases, reduce morbidity and mortality rates [60].

Social support can take on three different forms: emotional, instrumental, and informational support. Emotional support can help mitigate feelings of loneliness, provide reassurance, or deal with crisis situations [59]. Instrumental support can involve helping with daily tasks or meeting immediate needs. Because of the low physical energy experienced during depressive mood episodes, patients with bipolar disorder often find it difficult to complete daily errands or other activities such cooking or cleaning. In manic mood episodes, patients may be more distracted or forget things, such as taking medication, and can benefit from the involvement of others in completing tasks. Lastly, informational support can involve providing advice, factual information, or acting as a mentor. This type of support can benefit BD patients when they have difficulty making decisions or are undergoing big lifestyle changes [63]. Members of their social support networks can help provide guidance and motivation for important behavioral changes and meeting their BD treatment goals. Overall, social support networks can help take some of the burden of BD off of patients and help improve general mood [61].

Social support functions have also been incorporated within more clinical-based tools. In systems, such as Morris et al's Panoply [64], social support and interaction between users have been leveraged to support and supplement technology-based cognitive behavioral therapy for depression. As a result, these tech-mediated social interactions increased adherence to therapy exercises alleviated some depression symptoms.

2.5.2 Social Stigma and Online Support

As I stated earlier, social stigma is a big challenge, especially for people with BD [65, 66]. This social judgement can even be extended to members of their family and friends or affect their subsequent relationships [67, 68]. It has been found that especially those with more severe BD receive less support and social interaction from caregivers [68]. While some of this is due to social stigma, frustrations with setbacks, symptom relapse, or negative events and interpersonal conflicts during mood episodes can lead caregivers to pull back from those with BD [69]. It is partially for these reasons that some BD treatment approaches directly involve family, friends, and caregivers in therapy sessions to help work through these challenges and provide a better environment for BD support [70]. However, because of these judgmental experiences, people with BD tend to internalize this stigma and characterize themselves as a problem [68]. This can lead them to self-isolate or preemptively cut themselves off from available support networks and the benefits those networks can provide, if adequately encouraged [68].

Because of this, as well as the absence of traditional forms of therapy or close relationships with others, many individuals turn to online sources of support [71]. Additionally, they may have concerns of overburdening their existing support networks [72]. While existing support networks in their offline lives can help with a range of supportive activities, they do not always share the same experiences as those seeking mental health support. While they can listen and sympathize, they may not know the experience of mental health conditions like BD from first-hand experience [71]. Using online sources of social support, such as social media platforms, people can more easily find people who share their same condition and have lived similar experiences than they can in their physical local environments [7, 73–77]. This allows them to seek out advice from others, emotional support, personal motivation, and social accountability for meeting treatment goals [77, 78]. While this closely aligns with the three key types of support, the information sought is more specific, actionable, and heavily rooted in lived-experiences and personal success stories.

Online setting can be highly conducive to mental health support because individuals often communicate anonymously, with the disinhibition effect allowing them to speak more openly [79]. This eases the sensitive disclosure process that is necessary to gather pertinent information and support from others [74, 76, 80]. This type of disclosure-based support system has shown to benefit users by way of community building, providing a sense of shared identity, combatting stigma, and a general sense of not being alone in their troubles [7]. Through analyses of user content, studies have provided a range of

motivations behind this continued activity. A Twitter study by Berry et al. [7] noted these users were drawn to social media for four leading reasons: building a sense of community, raising awareness, and combating stigma, expressing themselves in a safe space, and as means of coping with their condition. This use of Twitter as a coping mechanism has been documented further in other work [81]. Additional research has stressed the importance of providing more time-sensitive support, regardless of physical location [77,78]. Focusing on the collective use of technology, Matthews et al. [17] illustrated the additional benefits of information access, symptom recognition, and receiving encouraging content. In other cases, the activity of providing support to others who need it can improve the wellbeing of the one sharing by giving them a sense of purpose and highlighting their successes or the progress they have made [7].

However, online support comes with challenges otherwise absent in traditional social support relationships. The same disinhibition effect that makes it easier for people to disclose their mental health experiences in public spaces, also makes it easier for others outside of that constructed supportive mental health community to react or respond with negativity and judgment [79]. This can come from others' lack of mental health understanding and social stigma, especially for bipolar disorder, which is largely misrepresented in public knowledge [68]. This can then set off a negative feedback loop-negative interaction leads to more stress, which leads to less sleep and more use of technology, which leads to more negative online interactions [17]. While people sharing their daily experiences and mental health success stories can be really motivating and uplifting, sharing negative experiences or setbacks can act as a negative social contagion [73]. Negativity in one person prompts self-negatively in the next and instead of feeling better and supported by these online interactions, overall mood levels drop and care over into people's offline lives. Lastly, these online interactions can open opportunities for users to be exposed to negative and sometimes triggering content [73, 76, 82]. In the case of eating disorders [76] or self-harm [82], the information and experiences people share may be helpful for those in recovery, but for others who may be struggling, some of this content may push them towards maladaptive goals or trigger problematic behaviors based on this new information [73,82]. The sudden, unanticipated emotional triggers people often encounter online can be detrimental for BD, as they can prompt the start of a mood episode with little forewarning [28].

Engaging in online support is a constant trade-off between the benefits to be found and the negative experiences they may encounter across the way. For some, the perceived positive outcomes of being vocal about their mental health online and building a supportive community with others outweighed the negatives [7]. However, this is not true for all who look for online support. For some specific mental health conditions, it may be especially challenging or, at times, detrimental to their mental health and treatment progress [73,82].

2.5.3 Leveraging Existing Support Networks

It is for these reasons that maintaining open and supportive communication with physical social networks from the beginning is especially important for mental health [18,83]. Previous work has argued that it really is both the medium of communication, as well as with whom the communication happens that makes social support effective, within the specific context of mental health [84]. Studies comparing various types of online and offline sociality found that face-to-face interactions seem more beneficial to mental wellbeing than online social interactions. However, online communication with family and friends can still have positive effects on wellbeing and relieve depressive symptoms [63].

Because of this, technology has often been used to facilitate communication and information sharing in existing physical network of family, friends, and caregivers by breaking down some of the challenges for being open about their condition, disclosing important health information, and asking for help when it is needed, among others [64]. This allows users to take advantage of the physical distance that makes it easier to talk openly about mental health and other stigmatizing topics online to communicate their needs to others in their offline life [79].

Because of the perceived burden of lifetime maintenance and long-term care, this approach has been applied to both chronic physical and mental health conditions. For example, Skeels et al. [85] worked with cancer patients, survivors, and their caregivers to explore ways to make the most of existing support network during treatment and recovery and help facilitate helping behaviors within friend and family groups. Storni [86] focused on diabetes management to understand how they record and share data with their family and physicians, as well as the types of challenges they commonly want to request help from others with the intention of developing a more supportive communication tool. These physical conditions present day to day communication challenges that are very similar to mental health conditions, including managing health information, complicated medication routines, low energy, and inability to complete daily tasks [87,88].

For mental health, technology-mediated social support systems have been used for similar goals, but largely moderated by a clinician [64]. These tools have focused primarily on clinicians communicating with caregivers, to support traditional therapy. These types of communication systems can help facilitate requests for help with daily tasks and mediate health status updates. This is especially important when the information shared may be seen as disappointing, such as setbacks in treatment, or burdensome to others, such as needing significant assistance during bad days [70,87]. While this approach is helpful, it typically targets clinical goals, rather than helping support members understand patients' experience or patients effectively communicate how they are feeling at a given time. By incorporating more opportunities to work on these interpersonal goals, existing offline personal ties can attempt to provide the same understanding and support that people often seek from those more anonymous online sources.

A lot of work in this area has adopted a user-centered participatory design approach to technology-based support systems, especially for those with long-term health conditions [85,86,89]. The first-hand experiences with therapy and the ability to increase participants' sense of agency and trust in an otherwise stigmatizing context, these technological support systems have been shown to be more eagerly accepted by users, more closely align with their needs, and lead to better health outcomes, such as self-esteem, self-efficacy, and therapy adherence [5].

2.6 The Cyclical Relationship Between Mental Health and Money

For decades, we have known that a relationship between socioeconomic status and mental health exists [90]. However, this relationship is highly complex, individualized, and cyclical. Only recently has there been an opportunity to objectively explore this relationship and determine the specific economic variables which are linked to poor mental health.

Previous work has shown that individuals are more than three times as likely to be in debt if they have a mental health problem [90]. This, in turn, can lead to significant poor outcomes, such as an increased risk of suicide and serious mental illness like schizophrenia in areas socioeconomic deprivation [91]. Living with a mental illness can have a significant impact on one's personal income and their purchasing decisions [92]. This can be due to situational factors such as medical costs and employment complications, as well as symptom-related factors like impulsivity or avoidant behaviors. Then, these financial issues can lead to increased money-related stress that further impacts one's mental health, continuing that cycle [93].

Understanding the level of nuance involved in this relationship is key to breaking down this cycle and can help inform new interventions to support individuals with their finances. At an individual level, more knowledge about this relationship can help increase the sense of control for users.

2.6.1 The Impact of Finances on Mental Health

The Easterlin paradox claims that increased real income per head has no impact on individual happiness when looking long term [94]. For instance, there has been no increase in happiness since the 1950s in the US, nor any significant decrease in unhappiness. Similar findings are consistent in Japan, the UK, as well as most European countries.

However, we have seen trends of poor life outcomes and increased risk of suicide and serious mental illnesses, such as schizophrenia, in areas socioeconomic deprivation, suggesting that money still matters in relation to mental health and overall wellbeing [90]. Additionally, systematic reviews of countries facing significant recessions saw a negative impact on health at a population level. Factors like unemployment, decreased income, and high debts were significantly associated with poor mental wellbeing, as well as increased rates of mental disorders, substance-use, and suicidal behaviors [92].

2.6.2 The Impact of Mental Health on Finances

This relationship between money and mental health also goes both ways. Not only can financial hardships impact mental wellbeing, but poor mental health can lead to further financial distress, often making this a cyclical effect. For instance, recent work has shown that an individual is more than three times as likely to be in debt if they have a mental health problem [90]. Other work has highlighted the increased difficulty for paying bills or keeping up with other financial demands when managing mental health conditions [95]. The stress of being in debt or constantly worried about personal finances can bring along additional anxiety to individuals already experiencing other mental health conditions, which amplifies all comorbid conditions [96, 97].

Financial capability has often been the main emphasis when attempting to explain this association. In other words, it asserts that those living with poor mental health lack the capacity to successfully manage their own finances. However, other work suggests this association is not so straightforward. Work focusing on the use of financial technologies has revealed that the shortcomings of existing technologies and the workarounds users sought out did not adequately support their financial and mental health needs.

2.6.3 Symptomatic Financial Behaviors

This poor mental health to poor finances pathway is not a uniform one. These financial struggles can come from different sources, many of which stem from the symptoms of those very mental health conditions, themselves. For instance, many conditions come along with decision-making challenges, impulsivity, and avoidance, as well as memory issues [95]. Some may find it difficult to make a decision, stress about the range of options involved, and may choose to put off making a decision at all [98]. In cases of debt-related stress, individuals may avoid thinking or acting on their finances, leading them to miss deadlines or due dates [99]. Similarly, some conditions involve memory difficulties that make remembering those due dates without significant support or reminder systems [95]. Those with conditions like bipolar disorder often experience periods of high impulsivity that can lead to impulsively made purchases that negatively impact their finances [97].

2.6.3.1 Impulsive and Compulsive Spending

One of the leading issues in the context of mental health and money is compulsive spending [100]. This can be a standalone issue or stem from existing mental health conditions, creating further challenges to mental wellbeing. Compulsive spending, or compulsive buying disorder, is an intense, irresistible need to spend beyond what is necessary, and in many cases beyond one's financial means [100]. This can occur despite the emotional distress it may cause, limited funds, or a lack of actual need for the items purchased. Like other addictive behaviors, the amount of spending or the size of purchases may escalate over time as one needs more to feel the same level of outcome. For many, the desired outcome is the happy feeling or the serotonin boost given that can act as a distraction from depression, anxiety, or other negative feelings [100].

While these purchasing habits may have temporary and fleeting positive outcomes for the individual, they can create increased feelings of stress, guilt, and shame in the long-term [101]. Not only can it affect personal finances, but can also become a stressor in relationships and other parts of their life. This shame and disappointment may then be followed by more spending, as a means of coping with negative feelings, in a cyclical nature. The most common approach to treating compulsive spending is cognitive behavioral therapy (CBT) which can help individuals recognize behavioral triggers, correct problematic responses, and breakdown the underlying issues driving their compulsive spending [102].

Previous work has provided some insight into the varied spending goals and drivers

associated with different mental illnesses, like depression and bipolar disorder, as well as the behavioral patterns people may exhibit. Purchasing behaviors can take on many different patterns. For instance, some may experience highly impulsive "big ticket" purchases—or singular items of a high dollar amount [103]. Others may experience "burst spending" or a large number of lower cost items purchased within a narrow window of time [104].

Individuals may also show differences in the types of things they purchase. Some individuals may purchase items related to "big ideas", such as new business ventures or hobbies that have many upfront costs [105]. In these cases, individuals may also seek out loans to support their new big idea. Additionally, some may spend their money in the form of "excessive charity" or giving to others, often more than their personal finances can support [93]. These different types of purchases all have very different goals associated with them that also differ from one person to the next. Sometimes these purchases are made as an attempt to change one's mood state or to give themselves something to look forward to [106, 107]. For others, especially in the case of excessive charity, this can be seen as improving mood by helping out others. Despite this, our current understanding of the complexities of this relationship still lacks the depth needed to help predict these behaviors and develop personalized interventions to provide preemptive support.

2.7 Conclusion

There has been a recent focus on developing data-driven, personalized, and objective assessment methods for identifying early-warning signs in BD. However, there are unaddressed questions for supporting lifelong management of BD. For example, these methods are inherently data-intensive, which might have different privacy implications across illness stages and may require sharing data within social support networks, raising additional concerns for balancing user agency with efficacy. In other words, there are unique challenges for designing technologies to support lifelong management of BD given the varying needs across different illness stages. This work aims to address this important research gap based on users' lived experiences.

Complex conditions like SMIs require a multi-faceted approach for long-term treatment and day to day symptom management. The incorporation of multiple technology-based and data-driven techniques can help simplify the process. In this work, I mean to explore approaches from previous work— self-report tracking data, auto-inferred data from online sources, and technology-mediated social support platforms—from the perspectives of
patients with bipolar disorder. While this existing body of work suggests the validity and efficacy of these applications within the context of mental health, it cannot speak fully of other user factors that can help determine their success. Patient and clinician acceptance of these personal data-driven methods, level of trust and comfort, and their perception of accuracy and usability within real-life contexts are still largely unknown. I aim to address these concerns, as well as understand the type of role and level of agency patients wish to have in managing BD through the use of this type of integrated system.

The following three chapters detail a set of studies that contribute further insight in this area to help inform future systems to support long term SMI care. First, we will explore the use of social media platforms by users to understand relevant challenges to long term support from online communities, as well as the use of social media data to assess and inform mental healthcare. From there, the later studies will explore online behaviors in relation to SMIs and the support needs for long term stability, from the perspective of individuals with bipolar disorder specifically.

Chapter 3 Online Mental Health Spaces

3.1 Introduction

To understand how we might develop online data-driven mental health interventions, we must first understand how existing online spaces are used within a mental health context. By furthering our knowledge of how people use social media for mental health, their goals and motivations for engaging in public spaces, and the challenges they face along the way, we can, not only improve those existing spaces, but develop new systems in direct alignment with their unique needs.

In this chapter, I will discuss work that explores the use of common social media platforms for supportive mental health and wellbeing discourse. This will include a) community support for clinical mental health conditions such as anxiety and depression as it exists on Instagram and b) the use of Twitter as a coping tool in non-clinical contexts, as illustrated by essential workers during the Covid-19 pandemic. Through this stage of work, we can gain the following from further study of mental health support communities:

- Leverage what already works for user in the design of new mental health specific systems
- Address existing challenges and building in necessary safeguards
- Uncover unsupported needs that have fallen through the cracks on existing social platforms

For using online content to infer status and inform future interventions, this work helps address:

- Methods for sampling and studying niche populations within large public platform data sources
- The challenges of taking public content at face value to infer mental health and mood status and trigger intervention actions

3.2 Supporting Constructive Mental Health Discourse in Social Media

As social media has grown more integrated with our everyday lives, these same mental health discussions have spilled over to other platforms, such as Twitter [7, 108] and Instagram [80, 82, 109]. These new avenues have introduced a wider audience and new obstacles for maintaining a positive environment for discussing stigmatizing topics. For one, the anonymity and distance between users afforded by social media and the internet alike, can lead users to share more and manage how others perceive them [9]. This can have a positive influence on individuals for disclosing their mental health and building a sense of community. At the same time, however, these affordances can help activate the online disinhibition effect [79] and amplify the stigmatizing thoughts and words of others in a mixed audience. Previous work has attempted to understand the trade-offs involved with these sensitive online disclosures and explain the motivations behind sharing, despite the potential negativity, through the public content that users produce. The chance to create a community [75, 82, 109], cope with daily life [7], combat stigma [7–9], and raise awareness in others [7], are among the desired outcomes that drive this activity for many users.

Instagram, in particular, allows users to self-disclose in a way that is less dependent on text, and instead, express their experience through images [110]. The interactions and self-disclosure through images potentially have very different characteristics compared to text-based communication. However, previous studies have mostly focused on platforms that prioritize text-based interactions and cannot fully account for the role that images play in mental health disclosures. Our proposed study on Instagram aims to address this gap. Additionally, I focus on Instagram due to its younger user base. Young Americans, age 18-24 are the leading users of Instagram; 71% of which use Instagram, as compared to 45% that use Twitter [111]. This use has grown over the last few years, despite the use of other platforms remaining constant, with 81% of young users engaging with the platform daily [111]. This same 18-24 age group also coincides with the common onset ages for many mental health conditions [112]. High prevalence disorders, such as anxiety and mood disorders, typically emerge during adolescence and early adulthood, and research has shown that interventions at this critical period may help reduce the severity or persistence of these conditions [112]. Given this convergence, a better understanding of mental health self-disclosure on Instagram could help provide insight for future interventions focused on reaching this critical demographic.

Towards this goal, I attempt to understand the potential issues faced by users while disclosing their mental health experiences on Instagram. Furthermore, I also explore how different functionalities of the Instagram platform might support the disclosure process and maintain a constructive conversation. Specifically, I look into problematic Instagram use, which uncovers the co-opting of hashtags, promotion of negative behaviors, and negative interactions as common issues faced on Instagram.

3.2.1 Instagram Use

To address these potential challenges in mental health discussions, I performed a thematic analysis of Instagram posts. I chose this platform for its unique focus on image content and how the combination of text with images could add to the conversation by allowing users to convey their feelings and experiences beyond textual descriptions.

3.2.1.1 Data Collection and Coding

Given the continuous stream of content uploaded to Instagram every minute, I gathered a sample of posts from the platform, using two keywords as search terms; #depression and #anxiety. I chose these two topics to represent the wider category of mental health, due to their high prevalence within the United States population [21]. Additionally, these two keywords can be used both in the clinical sense to discuss experiences related to a specific diagnosis and in the colloquial sense to share about the feelings they may experience separate from a diagnosis. Choosing these two common keywords will provide insight into the type of content users may encounter when seeking out communities and other users who post about these topics. These more general terms of depression and anxiety may be used by individuals across a range of support needs, from those without a diagnosis using social media as supplemental support. This will allow for a more comprehensive understanding of the discourse that occurs on Instagram and the challenges that different users may encounter when seeking out support. Although these two topics may not

fully represent all conditions, such as bipolar disorder, they relate to a large number of users, generate a significant pool of posts to weigh in on the conversation, and may provide insights that are applicable beyond depression and anxiety, given some symptoms and experiences overlap with other mental illnesses (e.g., depressive episodes of bipolar disorder) [113].

For each search term, I gathered 100 unique posts, 200 posts in total. To reduce the amount of potential bias in the sample, I selected posts from the "most recent" posts, rather than the "most popular" posts. I made this decision because these most popular posts were often part of larger campaigns for mental health awareness or from notable figures, which introduce potential bias. Sample posts for each term were gathered five at a time over three weeks. This was done to reduce the likelihood that the sample was influenced by trending topics or social campaigns active on any particular day. For example, September is suicide prevention awareness month, which affects online discussion and increases the number of posts shared. Because of this, the overall environment could be influenced in a way that does not reflect the norm.

I coded all posts using mixed open and closed coding. All 200 original Instagram posts were evaluated for: context of word use, mental health disclosure, tone, and photo subject. Following this, any comments attached to these posts were also evaluated along these same categories, whenever relevant. Grounded Theory [114] was used to address details that fell outside the scope of the coding scheme. In doing so, additional content was evaluated iteratively for emerging themes. This process was applied to also address the relationship between the post's photo and text caption. The same text-based coding categories were applied to each post's comments, if any were made. Because the posts were selected for the sample as "most recent", many posts initially showed no interaction from other users. To counter this, posts were revisited within the next week to evaluate the comments section. Though this may have excluded any remarks made on later days, previous work has shown the peak for post interaction to be within three hours of the original post [45].

3.2.1.2 The Challenges for Instagram

Out of this inquiry emerged three prominent themes: the idea of "hashtag hijacking", or co-opting #depression and #anxiety for purposes other than talking about either condition, the promotion of negative behaviors, and interaction mirroring that led users to produce more self-deprecating comments in response to other negative or self-deprecating posts.

3.2.1.2.1 Hashtag Hijacking I categorized word choice by three different options: clinical, casual, or unrelated. I determined posts to have a "clinical" use if the specific condition, depression or anxiety, was explicitly mentioned or if a condition could be derived from the context of the post, such as phrases like "mental illness", "depressive mood", or "my therapist". The keyword could also be used in a casual sense, such as in place of general feelings of worry or sadness. This was exemplified by one post stating, "Dad took my phone away yesterday. I was so depressed." Lastly, keywords could be used for unrelated or off-topic posts. Posts were considered off-topic if neither the photo nor the caption included anything overtly about depression or anxiety or provided no related context for such an interpretation.

Though containing the keywords in their hashtags, many sample posts were considered off-topic. The most common form of this was an off-topic photo, including no caption, but a long list of unrelated, high-traffic hashtags. In many of these instances, either #anxiety or #depression was one of over twenty tags, including those like #like4like or #followforfollow. In this case, these hashtags were used to increase the visibility of posts, simply because anxiety and depression are common search words. Also, depression and anxiety tags were often adopted by diet, fitness, and exercise accounts looking to promote blogs or products. These accounts used the same tag listing strategy and made no direct mention of mental health in their post. This same activity carried over to the comment sections, as well. Diet and fitness accounts were also seen commenting on "on-topic" clinical disclosure posts, but to push products such as diet pills or tea, rather than offer support or advice to the author.

Despite their unrelated nature, these off-topic posts provide insight into some of the obstacles to constructive discourse, and guidance for making healthier online spaces. Instances of others trying to push attention to their questionable health products within the comments of anxiety or depression posts could be potentially detrimental for those seeking help, who may be especially vulnerable. However, viewing from the outside only, it is difficult to understand how these interjections affect those who are disclosing.

3.2.1.2.2 Promoting Negative Behaviors Another common occurrence was the adoption of depression or anxiety tags, in place of pro-anorexia and pro-bulimia tags. This is likely due to how often these types of tags are flagged and removed from social media sites. One post in particular called out this fact, "I changed up my tags this time, so maybe Instagram will stop removing all my posts!" Another user included #depression to a post in search of motivation, "For every like this post gets, I'll go four hours without

food." At the time of data collection, the post already had nine likes. At the same time however, it is important to note that eating disorders are often comorbid with depression and anxiety, so users may disclose about both conditions simultaneously [109]. From the user's point of view, the hashtag could be on-topic, but for the sake of this work, these posts were considered unrelated.

Considering the common comorbidity of depression or anxiety with eating disorders, posts and comments promoting negative behaviors could be especially troubling for users who may use Instagram as part of their recovery for either condition. Seeing these types of messages and images while attempting to seek out positive, constructive support from others could be very distressing and potentially lead to a setback in their progress.

3.2.1.2.3 Interaction Mirroring When looking at the posts and their comments combined, this highlighted a theme of self-focused negativity shared between users. Those who posted highly positive or optimistic messages about themselves received not only more comments from other users, but overwhelmingly positive and supportive comments. Those who posted self-deprecating messages received little interaction from other users, many showing no comments or likes. When self-deprecating posts did receive comments, they were often negative. This negativity, instead, mirrored the self-deprecating nature of the original post. The negativity was not directed toward the original author, but at themselves. Instead, this could be interpreted as an act of shared experience or commiseration. While this may be intended as an act of social support, it has the potential to negatively impact some users, leading them to disclose less or seek positive support elsewhere, depending on their own goals of the interaction. Leveraging these behavioral patterns in favor of positive sharing, rather than self-focused negativity, could help establish a more positive and supportive environment for disclosure.

This inquiry provides more insight into the common obstacles for maintaining constructive mental health disclosure and discussion on public internet spaces. This clearly shows that self-disclosure behaviors can be personalized, diverse, and nuanced. However, other modes of communication carried out between individuals on platforms like Instagram are not captured by this public facing approach to content. Users can share content in their public-facing posts, private direct messages, and now a "stories" feature, which allows for temporary content, only viewable to friends or followers. These multiple avenues are not unique to Instagram but exist across many popular social media platforms. Given these temporal options, it is likely that users employ them for different reasons. In the context of the mental health conversation, the differences in who can view posts and for how long, likely introduces more variability in content across these different sharing options.

3.3 Implications for Users and Future Design

Social media platforms can have a positive impact on users regarding their mental health, allowing them to gain social support and build a community of their own, despite physical distances. However, to ensure that these spaces are conducive to productive discourse, their design must closely align with these user's needs and be aware of the challenges that arise in disclosing, often stigmatizing, personal content. This initial inquiry shows that there are a variety of challenges that could potentially impact a user's ability to comfortably disclose their mental health issues, seek social support, or make progress with their own conditions. Given the wide range of features now provided by social media platforms that provide users with more control over how they share information, more involvement from the users is necessary to understand the complex nature of sensitive disclosures. Findings from this study can help existing platforms provide effective support for mental health issues at a large scale, as well as help inform our priorities as we develop new systems specifically aimed to provide long-term support for mental health.

3.4 Inferring Mental Health of Non-Clinical Populations

While this first look at Instagram provides insight on the challenges users may face when turning to social media platforms for support, additional work is needed to understand further challenges to using the content shared on these types of platforms to infer wellbeing, from a design and development perspective. To address this, I turn to Twitter and examine not only content specifically related to mental health, but their full range of Twitter activity during a uniquely challenging period of time, the recent Covid-19 pandemic.

The recent Covid-19 pandemic has had a significant impact on mental health and wellbeing of the population as a whole, leading to large-scale lifestyle changes, social isolation, and increased stress. This has been especially pertinent to essential workers — from those in the medical field treating patients to those in retail supply chains meeting the needs of everyday life. This has introduced new life stressors, such as high workloads, insufficient safety supplies, and risk to their own health and the health of their families when returning home [115,116]. This, combined with reduced in-person support, suggests a highly complex and challenging situation for essential workers.

Approximately 55 million Americans have been deemed "essential workers" since the start of the pandemic [117]. In the United States, the Economic Policy Institute specifies 12 categories of essential employment for providing services critical to the country's infrastructure. The majority of essential workers in the US are employed within the healthcare industry (30%) — including clinicians and any hospital staff, agriculture and food production (20%), and the commercial service industry (12%) — such as retail or grocery store workers [117]. Within these industries, different employee roles can then be determined as essential workers on a state by state level [117]. It is also important to note that the US essential workforce, especially agriculture and service industries, is disproportionately comprised of women, minorities, immigrants, people over 50 years old, and low-income employees [115], which can put these workers at a greater disadvantage and increased stress. For low-income workers or single income families, this can involve making the difficult decision between personal health and safety and earning a paycheck [116].

Essential workers have continued to work outside of their homes, often in highly public-facing roles. This has raised concerns for their health and safety in the workplace and increased the need for safety procedures and protective supplies, especially for those in the healthcare sector facing exposure to individuals with confirmed cases of the Covid-19 virus [116]. Not only are workers' physical health put at risk, but their mental health as well. US healthcare professionals, in particular, are now at higher risk for mental health conditions than the general public, reporting on average enough symptoms to be diagnosed with depression during the pandemic [118]. Essential workers have reported higher levels of stress, anxiety, and tiredness, perceive lower feelings of control over their lives, and are less likely to engage in "proactive coping" — preparing themselves for future stressful events [118]. While this initially only speaks to healthcare essential workers, those in other essential industries face similar stressors that may also put them at risk for depression or other mental health conditions.

Research has highlighted how users leverage platforms like Facebook, Instagram, and Twitter to connect with others about shared experiences, from coping with mental health conditions to voicing workplace concerns. Social media can provide a supportive discussion space for those coping with diagnosed conditions like depression or seeking informational or social support for day to day wellbeing [7, 54, 73, 74, 76], as well as advocate for these concerns [119]. In cases of depression, anxiety, or other sensitive and stigmatizing topics, these platforms can help people connect with similar people outside of their existing social support networks — either because no one in their existing

circle understands their experiences or because they do not feel comfortable sharing [7]. These shared experiences, along with the perceived anonymity available online, can prompt users to disclose their mental health concerns more openly [73,74]. Through the same means, social media platforms like Twitter have also become tools to voice shared societal concerns, allowing individuals to organize online movements for change — such as unionization [120] and Fight for 15, a movement for a higher minimum wage sparked by retail and food service workers across the US [121]. These connections made through social media can help users feel less isolated and allow them to bond with others in similar situations that they lack access to in their offline lives.

Conversely, the way people use social media, how often they post, and the types of content they share can be used to infer wellbeing or specific mental health conditions [11, 53, 74]. For instance, temporal factors, such as tweet timestamps and activity data, can be used to map out irregular sleep patterns, which is a common occurrence with depression and anxiety. The use of sentiment analysis methods on tweet content has shown that the stress, anxiety, or depression experienced by a user often reflects in more negatively associated posts online [11, 53]. This same process applied to large-scale social media posts can be used to assess shared positive and negative experiences on a societal level, over a period of time. This work also highlights keywords most commonly associated with depression. The use of these keywords, along with sentiment and linguistic characteristics have allowed researchers to infer users with depression from non-diagnosed user populations [11, 12]. Given how much we can learn about one's mental health through what they share on social media, I explore how this same process can be applied to essential workers and how their Twitter-use and general wellbeing may differ from average US Twitter users, before and during the pandemic.

The Covid-19 pandemic and its subsequent lifestyle changes has created a unique but important situation to better understand online mental health discourse and the role of social media in times of isolation, economic uncertainty, and additional worklife stressors. Specifically, the experiences of essential workers—who face the stress of working in the public while also physically distanced from many of their offline sources of support—can provide unique insight into preexisting concerns, as well as highlight potential preventative actions for future situations. Our broader body of work aims to understand the ideal role of technology in mediating stress and social isolation, but also helps call attention to larger, societal concerns at play for essential workers.

This study makes the following contributions. Based on multiple US government agencies, I developed a working definition of who is considered an essential worker for the purposes of this research and how these defining characteristics align with information provided on public Twitter accounts. I document our sampling and verification methodology to demonstrate how to infer this niche population from general Twitter users. I provide preliminary findings about the Twitter usage and wellbeing indicators of essential workers across time and in comparison, to the general US Twitter users. Despite assumptions, on average, essential workers' tweets yield a more positive sentiment score, but still show a higher ratio of tweets related to mental health. In closing, I also discuss the potential implications of these findings, the challenges for studying online communities and how this can inform new design features to help support niche populations and remote socialization through online social networks.

Towards the overall goal of developing assessment and intervention systems based on online data, such as Twitter use, this study provides insight on how this type of data can be used to explore users' wellbeing, as well as uncover potential challenges to relying solely on social media data to inform such systems. The specific "Essential workers" studied are not specifically a clinical population and may not have specifically disclosed a mental illness online. However, this provides a timely opportunity to understand how a specific user group who has been notably subject to great amounts of stress during a known period of time chooses to present those experiences in public online space.

3.4.1 Sampling Essential Workers on Twitter

To explore these questions, we first gathered two different samples of Twitter accounts: one consisting of essential workers located in the United States and a random sample of all US geolocated accounts, to represent the average Twitter user. Overall, 4055 accounts were analyzed: 1752 essential workers accounts and 2303 random Twitter accounts. Only publicly visible accounts were included in this sample. Self-authored tweets (not including retweets) were gathered for each account from January 2019 through September 2020.

3.4.2 Method Validation and Primary Analysis

A sub-sample of 50 essential workers' accounts was manually reviewed for accuracy against these criteria. I then reviewed the "I am an essential worker" tweets that qualified each account for sample inclusion to infer from context whether these accounts were from genuine essential workers (*e.g.* about their own experiences, rather than quoting someone else). The co-author also documented if each account disclosed their specific employer, job type, or essential industry. Of this subsample of 50 essential workers accounts, only

one was listed as outside of the US (Canada) at the time of data verification. The other 49 accounts were indeed located within the US. This subsample included users from 20 different states and three who listed their location as the USA, broadly. After manually verifying the essential workers status of each account, 48 of the 50 accounts were confirmed as essential workers based on the context of their self-identifying statement. Two accounts in the sample were not confirmed as essential workers as they had authored tweets quoting the experience of an essential worker in contrast to their own experience working from home. Of these 48 essential workers accounts, many did not specifically disclose their job information or censored the name of their employer (e.q. "St*rbucks" to evade direct search). This is likely because some may be incentivized to keep this information off of public-facing accounts due to social media policies put in place by their employers or to avoid workplace consequences. Conversely, other types of essential workers openly disclosed this information as part of an online presence and media outreach necessary for their careers (e.q. physicians, medical students). Those who disclosed this information spanned multiple essential workers categories, including retail and food service employees, medical students, government employees, public transportation, warehouse workers, etc. Given these characteristics, it was determined that this sample of essential workers on Twitter would sufficiently represent essential workers in the broader US population.

3.5 Twitter Findings

3.5.1 Sentiment Analysis

Based on sentiment analysis, essential workers' sentiment is relatively higher than that of average Twitter users, both before and during the pandemic. Both groups show similar patterns, such as a sentiment peak at the start of each new year consistent with the holidays and a drop off in June 2020, likely due to protests and political unrest that began in the US at that time. However, essential worker tweets remain consistently higher in sentiment, overall. When looking at only Covid-related tweets, tweet sentiment scores drop significantly for both groups, showing a more negative attitude as compared to that of all tweets. However, this does not show a clear distinction between essential worker and average users regarding COVID-related tweets, which is likely due to sample size.

Findings from this study show that the sentiment score of tweets and replies posted for average users and essential workers in each month from January 2019 through September



Figure 3.1. Sentiment Score (compound score) of tweets and replies posted for average users and essential workers in each month from January 2019 through September 2020. The COVID-19 related tweets are extracted starting from January 2020 through September 2020. Overall, EWs show higher tweet sentiment scores than average Twitter users, before and during the pandemic. Tweets related to Covid-19 show a lower sentiment score for both groups.

2020. The COVID-19 related tweets are extracted starting from January 2020 through September 2020. Overall, essential workers show higher tweet sentiment scores than average Twitter users, before and during the pandemic. Tweets related to Covid-19 show a lower sentiment score for both groups, as shown in figure 3.1 [122].

3.5.2 Keyword Use

When looking at the frequency of Covid-19 and mental health related keywords, significant differences were shown between essential worker Twitter users and average Twitter users. In tweets from 2020, average Twitter users showed a higher frequency of the Covid-related keywords, with a usage rate of 0.086 per tweet, as compared to essential worker Twitter users (0.055 per tweet). However, essential worker accounts used mental health related keywords more than average Twitter users. Mental health keywords were used at a frequency of 0.008 per tweet. Average Twitter accounts used these keywords at the frequency of only 0.006 per tweet. This occurrence for average US users is generally higher, due to a higher average number of tweets posted per month, in comparison to essential workers.

3.6 Discussion and Implications of Social Media Analysis

Looking at essential workers across these characteristics, our findings suggest that, although essential workers post a lower volume of tweets, often late at night, they yield a more positive average sentiment score and are more likely to post about mental health related topics. Based on patterns established from general Twitter users [11,53], the temporal use of Twitter and common keywords could indicate potential mental health concerns and help support previous assertions of essential medical professionals [118]. However, there are likely additional factors related to this pattern as well. Other findings are more surprising, such as the higher positive sentiment scores of essential workers tweets, compared to average Twitter users. Despite the stressful lifestyle and workplace changes for essential workers, this positivity remained consistent during the pandemic and sits in contrast to essential workers' higher ratio of mental health related tweets, as compared to average Twitter users. Although we cannot yet confirm why essential workers tweets show these unique characteristics nor speak definitively about their current mental health status, this has prompted new hypotheses to explore in future qualitative work.

For instance, more positive tweets from essential workers, regardless of the pandemic, could suggest that characteristics of essential jobs and the people who hold those jobs could prompt essential workers to have a more positive online presence. For example, some essential jobs—such as healthcare workers—can provide increased job security, higher pay, higher perceived sense of purpose, as compared to those in other job roles, which could affect how they present on Twitter. However, this is not the case for all essential jobs, such as retail and service jobs, which generally provide lower pay and less stability [115]. Those included in the essential workers sample are more likely to be personal individual user accounts, whereas average Twitter accounts can be more variable—such as meme accounts or secondary accounts used more anonymously. Similar to why some users keep employment information private, essential workers may also avoid negative or polarizing topics due to perceived work-related consequences, potentially skewing the average sentiment of their tweets. Conversely, the average Twitter users randomly sampled in this study could possess characteristics that lead them to post more negatively associated content, as compared to essential workers users. Additionally, essential workers may also turn to Twitter for different purposes than the average user. Considering that essential workers use Twitter later in evening, they might be motivated to seek out more positive connections with others following long, stressful workdays. While this initial study helps address how essential workers are using Twitter, additional research is needed to understand what underlying factors drive these characteristics.

I acknowledge that this initial look into the lives and experiences of essential workers based on their use of Twitter does not yet tell the whole story of what has been a very complex and challenging period of time. It does, however, provide us with key insights to guide future work. This could be addressed by taking a more nuanced approach to understand the differences between different essential workers and their unique individual experiences, through both online and offline means. Through the future use of Twitter's full tweet archive, future work could include a larger sample of essential workers and a more accurate sampling of average Twitter users. To examine differences within essential workers Twitter users, future work could refine how to infer not only whether users are essential workers, but the specific type of essential job they hold, from profiles and post content. The use of topic modeling and a more sophisticated sentiment classifier could help increase overall accuracy. Through these steps, future work can explore on the leading issues that drive Twitter discourse for essential workers, help explain the uniquely positive sentiment patterns shown in this work, and better understand how essential workers Twitter use may differ from the platform at-large.

Additionally, qualitative work focusing on individual experiences could help further explain the context of these findings, for this study's use case of essential workers but also that specific to individuals with SMIs. By talking directly to users about the changes and challenges they have faced during the pandemic—like balancing their home and work lives, caring for others, and dealing with the public—we can provide the context behind what they choose to share online. Although this initial work focuses on Twitter use, a discussion on social media and technology use more broadly could help show the impact the pandemic has had on their daily lives, wellbeing, and relationships with others. By better understanding the role that social technologies have had for essential workers in mediating the effects of decreased in-person socialization, stressful workplace environments, and large scale lifestyle change during this critical period can help inform future design. The findings of this work can provide insight to support better mental health online and provide more positive means of online social connections during periods of high stress and crisis situations.

This work provides us with an initial look into how essential workers use Twitter as compared to average users. We see differences in when they tweet, how often they tweet, and the sentiment behind their tweets. While essential workers may author fewer tweets than the average user, their tweets are more likely to include mental health topics and include more positively associated content, both before and during the pandemic. While this sheds light on some unique characteristics of essential workers by way of their Twitter accounts, this cannot yet answer why these differences persist despite the challenges the Covid-19 pandemic has presented for essential workers. Our future research aims to explore the on and offline experiences of different types of essential workers through in-depth interviews and a more nuanced analysis of the topics they share on social media. Through this, we can better understand the role that technology can play in mediating these challenges and help support users in future high-stress, crisis situations.

3.7 Conclusion

These two studies that explore how social media platforms are used in the wild to share experiences and seek support for mental health and overall wellbeing show that there are significant challenges, both to users seeking positive supportive spaces and for researchers who may want to develop mental health assessment and intervention systems informed by this type of data. From the perspective of user challenges, more attention needs to be taken to improve, moderate, and provide additional safeguards within existing social platform to limit the exposure of negative content and help preserve these supportive communities. From the perspective of researchers, it is important moving forward to consider additional online behaviors that may heavily correlate with known mental health indicators, rather than relying on social media content alone. Given it is possible that individual factors may lead some users, such as essential workers, present a more edited or curated version of themselves in online spaces, we should incorporate a more holistic picture of online activity to better understand how we can infer mood state with the amount of accuracy required to develop reliable and useful assessment and intervention systems for serious mental illnesses. The following chapter will explore online activities more broadly in the context on serious mental illness, based on the insights and lived experiences of individuals with bipolar disorder.

Chapter 4 Online Behaviors in the Context of Bipolar Disorder

4.1 Introduction

Bipolar disorder (BD) is a mood disorder that affects nearly 5.7 million adults in the United States [16]. BD is defined by the occurrence of at least one manic episode (BD I) or hypomanic and depressive mood episodes (BD II) [14,123]. 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 [16].

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 [113]. 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 [18]. 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 [113]. Additionally, there is a lack of trained mental health professionals that can provide effective support for individuals living with BD. For instance, there is one active psychiatrist for every 8,476 people in the United States [124], which has lead to a crucial 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 [39, 46, 56]. 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 [17]. 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, I 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, I used a hypothetical system focusing on online behaviors. Prior work has established the relationship between BD mood episodes and online behaviors [17]. 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 [125] and privacy attitudes [126] in other contexts.

Using the scenarios as interview probes, I have identified how a preemptive assessment and intervention system could address BD specific needs across different mood episodes and support lifelong BD management. I have also established nuances of participants' expectations and concerns regarding such data-driven technologies. I 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, I provide design recommendations for technologies aiming to support lifelong management of individuals living with BD.

4.2 Methods

To understand BD behaviors online and receptiveness to data-driven intervention, I 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. This sample size is consistent with previous research studies focusing on bipolar disorder [46, 49, 127–129]. More importantly, the sample size was adequate to reach Glaser and Strauss' data saturation standards for qualitative studies using Grounded Theory [130]. Following data saturation standard and relevant prior work, I argue that the sample size is justified, specifically given the exploratory nature of the study.

I 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 participants an idea of what types and the amount of online 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) [131]. One interview was conducted in-person in at the Hershey Medical Center Mood Clinic and the other nine were conducted remotely via Zoom in accordance with the COVID-19 guidelines. The Penn State Institutional Review Board (IRB) approved the study procedure.

4.2.1 Consideration of Participants

Given the specific sensitive nature of this study and the participants involved, several considerations were made to better support the wellbeing, comfort, and privacy of individuals with BD involved. All research protocols, study activities, and the interview questions used were developed with the guidance of clinicians with specific expertise in bipolar disorder, regarding research and clinical practice. As participants were recruited with the support of the Hershey Medical Center Mood Disorders Clinic, a representative was also present during all interview sessions to observe these procedures.

While no clinician intervention was needed during any of the study sessions, a clinical representative was available if any additional support was to have been needed. Clinicians were available to address any potential concerns had by participants or if any topics discussed throughout were particularly distressing. They were also present to assess whether participants were fit for and able to consent to research activities at the time of the interview, as well as help build and establish rapport. Clinicians were also given the opportunity to ask any follow-up or clarification questions, along with the researcher to gather a greater understanding from both perspectives.

To better support participant privacy and wellbeing, the first interview conducted in-person took place in a familiar setting at the mood disorder clinic. Given the Covid-19 pandemic, study protocols were amended and approved by the internal review board to be conducted remotely using a secure university-affiliated Zoom call. In the case of these nine interviews, special instructions were given to participants suggesting that they join the call from wherever they felt most comfortable and private. Similarly, the researcher and clinicians involved in each session hosted the call from a private location, using headphones, and absent from any bystanders to keep all participant responses private to only critical members of the study. To carry this forward, these interviews were manually transcribed by the researcher and were not shared with any external transcription service, as well as stored without any identifiable participant information.

During informed consent and at the start of each interview, participants were reminded that they should answer questions only to the degree they felt most comfortable with. If any questions made them uncomfortable, they were free to skip individual questions or end the interview at any point in time.

At the start and end of the interviews, the researcher and clinicians reiterated that the main goal of this work and the open-ended, hypothetical approach I took toward technology was to gather a firm, in-depth understanding of their lived experiences and day to day needs. Rather than developing a system and having them evaluate whether it would suit their needs after the fact, it was my goal to use their insights as subject matter experts as the foundation for future design. Given this, I welcomed any and all criticism or concern they may have had of the data-driven approach to BD assessment or any of the intervention scenarios I introduced at the end of the session.

4.2.2 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 [125] and understand privacy attitudes [126] in past work. I 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. I then followed up with questions about potential system features and scenarios specific to a participant's needs, as well as exploring related concerns. I asked about scenarios involving preemptive system interventions at the end of the interview.

During the first part of the interview, I focused on understanding participants' selfperception about online behavior changes across different BD mood states. I 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 my later analysis. Such self-recall methods have been validated as an effective data collection tool for BD [17, 132, 133].

I then focused on understanding the acceptability issues and potential privacy concerns of participants. Toward this goal, I 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. The full interview guide can be found in appendix 1.

4.2.3 Data Analysis

The analysis of the resulting transcripts involves a bottom-up qualitative approach. Given the exploratory nature of this overall inquiry, an open-ended Grounded Theory approach was applied in the creation of these themes and findings. Specifically, a thematic analysis was performed [134] to identify key themes. As part of this process, category labels were applied throughout the data set to individual quotes, as well as those quotes in context to related responses. This same process was carried out through two additional iterations, further consolidating the initial themes resulting from the previous round of evaluation, until these overall themes solidified. These themes were also reviewed by other members of the research team for consistency. These resultant themes reached Glaser and Strauss' data saturation standards for qualitative studies using Grounded Theory [130]. In other words, these themes remained persistent with no new findings or additional variation throughout the full data set.

4.3 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. I also describe participants' attitudes towards data privacy, data sharing needs and concerns, and balancing user agency to support longitudinal management of BD.

4.3.1 Online Behaviors Across Different Mood Episodes

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.

4.3.1.1 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)

4.3.1.2 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.

4.3.1.3 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, I 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 [135] as P6 mentioned "sometimes I'll just see something in an ad online and suddenly decide 'I need that'."

4.3.2 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.

4.3.2.1 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 having 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 [136].

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 [133]. 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.

4.3.2.2 Duration of Data Collection and Storage

I 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.

4.3.2.3 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.

4.3.2.3.1 Preemptive Measures for Upcoming Episodes Some participants wanted to use this information 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 making 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."*

4.3.2.3.2 Managing Financial Decisions All participants in this 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 including 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 4.3.2.3.3conflicts 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.

4.3.3 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 participants are consistent with prior work [137].

4.3.3.1 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. 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.

4.3.3.1.1 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 the potential burden on clinicians

regarding this data. They did not want to overwhelm the clinicians with their data, which would lead to extra work for the clinicians. Participants also worried about disrupting the 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 [136].

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.

4.3.3.1.2 Sharing with Care Partners Beyond clinicians, most participants also wanted to share data and outcomes with a 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.

4.3.3.1.3 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 [138] including individuals living with serious mental illness [139]. A successful assessment and intervention system should aim to support similarly tiered approaches for managing privacy, trust, and data disclosure.

4.3.3.2 Balancing Agency with Utility

Informed decision-making can be a serious challenge during mood episodes. I was interested in exploring practical strategies to balance user agency and their long-term wellbeing. During the interviews, I 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. I also explored participants' opinions on how such a system can support collaborative decision-making by integrating care partners. I 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, I 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 need 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 act on them.

Lastly, I 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 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, I 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.

4.4.1 BD as a Life-Long Journey

Given their lived experiences, participants in this 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.

4.4.1.1 Data-use Across the BD Life-course

Given these insights, future systems could be structured in a way that can provide support specific needs at different points of the BD life-course, from establishing a diagnosis to long-term management, and any key life changes along the way.

4.4.1.1.1 Pre-Diagnosis Some participants made reference to having a family history of bipolar disorder or other psychological conditions, which preempted their eventual evaluation and BD diagnosis. Perceiving themselves as higher risk for BD, they and their families were more attune to the early warning signs of BD. Online data-based assessment system could assist in discovering these early warning signs and help individuals get diagnosed sooner, making way for earlier treatment and management.

4.4.1.1.2 Newly Diagnosed This type of system can also provide users with a head start in understanding their diagnosis. By leveraging online data, users can gain a better sense of their mood episode rhythms and the characteristics unique to different mood episode onsets.

4.4.1.1.3 Finding the Ideal Treatment Plan Once users have a better understanding of their typical rhythms, logging contextual information such as medication changes and perceived mood changes, can help users and their clinicians understand whether a medication is helping stave off mood episodes and improving overall wellbeing. Additionally, clinicians can use behavioral system data and patient notations, to determine whether dosage or medication types should be adjusted.

4.4.1.1.4 Coping with Major Life Events From there, users can better understand what life changes or situational triggers may affect their mood state and make appropriate accommodations. By reflecting of past behavior and its supporting data, users may be better equipped to understand how major life events, such as marriage, parenthood, relocation, or death of family, may affect their mood episodes and overall wellbeing.

4.4.2 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 [140]. 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 [141].

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.

4.4.3 Nuanced Privacy and Agency Considerations

These findings show that participants have nuanced privacy requirements and expectations regarding preemptive, data-driven intervention systems. This further supports the notion that privacy attitudes are highly context-dependent [142]. This 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. 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 [143]. 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 [144].

Longitudinal management of BD might also require striking 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 reflect 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 [141]. 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 [138, 143], 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.

4.4.4 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 [70] and their experiences online [17,145]. 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 [70]. 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.

4.4.4.0.1Providing Feedback for More Positive Online Communication Maintaining positive online conversations about mental health, in general, comes with its own unique challenges [73], 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. This could include 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.

4.4.4.0.2 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.

Bridging the Gap in Asking for Help It can be challenging for indi-4.4.4.0.3viduals with BD to ask for help and communicate 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, 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. I believe support networks will be particularly useful for individuals newly diagnosed with BD and their care partners [146].

4.4.4.1 Support Data Integration with Existing Clinical Workflows

Similarly, a data-driven intervention system also has 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.

4.4.1.1 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 [133]. 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.

4.4.4.1.2Data 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 participants closely mirror similar patient-clinician goal-setting scenarios described in prior personal informatics research [140].

4.4.4.1.3 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 [147]. 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 [136, 141, 148]. To address these concerns, I 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 [106]. Expanding the availability of clinically supported tools could help address additional concerns of inclusivity and broaden accessibility [148].

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.

4.4.5 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 [46, 49, 127-129] and the analysis meets qualitative data saturation standards [130], 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, this 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, my sampling consisted of those who had been in treatment for a 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 [17,132,133]. 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).

4.4.6 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, I 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 to 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. This data also indicates important privacy and agency trade-offs for different use cases. Based on these findings, I have also established design recommendations for future technologies aiming to support lifelong management of BD.

Given the prominent needs of both financial management and the ability to support more positive social interactions uncovered through this work, the next phase will narrow in on the nuances of financial decision making in the context of bipolar disorder and the role of care-partners in co-managing finances. This in-depth analysis will be presented in the following chapter.

Chapter 5 Financial Technologies for Mental Health

5.1 Introduction

Serious mental illness has been considered a public health crisis on a global scale. Affecting over one billion individuals, mental illness accounts for 7% of all global burden of disease and 19% of years lived with disability [1]. This growing issue impacts many facets of daily life—including personal finances. For decades, we have known that a relationship between socioeconomic status and mental health exists. However, this relationship is highly complex, individualized, and cyclical [149].

Only recently have new opportunities presented to objectively explore this relationship and determine the specific financial variables tied to poor mental health. Previous work has shown that individuals are significantly more likely to be in debt if they have a mental health problem [90]. This, in turn, can lead to significant poor outcomes [90]. SMIs can significantly affect one's personal income and financial decisions. Medical costs and employment complications can feed into this situation, as well as common SMI symptoms like impulsivity or avoidant behaviors [92, 93, 135]. These existing financial issues can increase money-related stress, creating a more substantial impact on one's mental health, further reinforcing that cycle [149].

Understanding the level of nuance involved in this relationship is key to breaking down this cycle and can help inform new interventions to support individuals with their finances. At an individual level, more knowledge about this relationship can help increase the sense of control for users. By using newly available objective financial data sources, we can better address these open issues. Understanding the level of nuance involved in this relationship is key to breaking down this cycle and can help inform new interventions to support individuals with their finances. At an individual level, more knowledge about this relationship can help increase the sense of control for users.

5.1.1 What Do We Know About Spending and Mood?

Previous research has shed light on the varied goals and drivers behind financial decisions in associations with different mental illnesses, such as depression and bipolar disorder. These purchasing behaviors can take on many different patterns, including highly impulsive large purchases—or singular items of a high dollar amount [102] or burst spending, consisting of a large number of lower cost items purchased in a short time frame [104].

The types of items purchased under these conditions be highly individualized. In some cases, these purchases could be related to new business ventures or hobbies, which may come with many upfront costs leading individuals to seek out loans to support their new idea [150]. Additionally, may engage in "excessive charity" or giving their money to others, in some instances more than their finances can support [105]. These purchases all come with very different motivations associated with them, varying from one person to the next. These purchases may be seen as an opportunity to change one's mood state or something to look forward to in the future [151]. For others, especially in the case of excessive charity, this can be seen as helping themselves by way of helping out others [101]. Despite this, our understanding of this relationship and its individual-level complexity still lacks the depth needed to predict these behaviors and develop personalized interventions to provide preemptive support.

5.1.2 Emerging Opportunities for Financial Technology

We have more recently seen the increased digitization of finance, moving from tangible cash to digital transitions. Moving these transactions online provides a more complete record of personal financial decisions. This objective data source being more readily available provides a perfect opportunity to further explore the nuance of the relationship between money and mental health, as well as uncover new spending behaviors within this context.

5.1.2.1 Financial Data Access

Until now the lack of objective financial data has impeded progress on understanding the relationship between financial behavior, state and mental health and illness. Although used extensively and resold by banks for marketing and other purposes, only recently has this data become accessible at scale for health researchers, using APIs such as Plaid [152]. Past work has utilized measures of self-reported risk of compulsive spending of individuals rather than actual compulsive spending, which has its limitations [103,107]. This new approach provides an opportunity to complement this work with quantitative methods. Additionally, objective financial data could help uncover important compulsive or impulsive spending patterns, as well as behaviors outside of those recognized by the individuals themselves, which can provide a clearer understanding of mental health status and spending.

These types of objective data sources show promise for providing insight towards early detection of mental health episodes. Spending is among one of the behaviors most referenced by individuals as indicating a potential mood shift in BD [106]. Understanding the nuances of this behavior specifically could help more accurately predict the onset of depressive and manic mood episodes, providing an early warning for mood episodes and an opportunity to quickly intervene. This crucial information can then be used to inform personalized interventions to preemptively target specific financial behaviors and help support users in their decision making. In this paper, we demonstrate how it is possible to access this information, illustrate the potential in a case study and outline key factors to consider when working with this data.

5.1.2.2 Current State of Systems

We also have seen an increase in the amount of digital spending, as much of our spending has shifted to online sources. This makes it easier for individuals to spend money, but also easier for researchers to access a wealth of data on spending behaviors. We now have other spending options, such as contactless pay, and apps to support banking or shopping.

These financial technologies have become very commonplace, but also provide much less friction to spending. Friction, in this context, refers to the amount of time and obstacles involved in the decision-making process [153]. In other words, the features of many financial technologies make it much easier for users to spend their money by removing several steps or other barriers leading to payment. By enabling auto-saved credit card information or one-step payment functions, consumers spend less time on their purchasing decisions. While this lack of friction broadly impacts all users, this poses a big problem, in particular for those prone to impulsive spending.

Rethinking the amount of friction we include in these online spending behaviors can lead to harm reduction—both at an individual level and for banking institutions themselves. This harm reduction could include the potential costs of bankruptcy that are a motivating factor for banks and their users to leverage this type of information.

5.1.3 A Case of Bipolar disorder

In this work, we use Bipolar Disorder (BD) as an example case to investigate the nuance of the relationship between mental health and money. A significant proportion of those with BD are considered to be of "serious impairment" in that their symptoms have a substantial impact on all aspects of their daily lives—including personal finances.

BD is typically characterized by cycling between the highs and lows of manic and depressive mood episodes [154]. A depressive mood episode often features severe feelings of sadness, low-energy, sleep disruptions, a lack of interest in activities, social withdrawal, indecisiveness, and poor concentration, among other potential symptoms. Conversely, manic mood episodes often feature feelings of euphoria or irritability, increased levels of energy, periods of high activity, risk-taking behaviors, impulsivity, a decreased need for sleep, along with other disruptive symptoms.

While this cycle is shared by many, the goals that drive the related behaviors vary from one individual to the next, even within those with the same diagnosis [135]. There are also situational and environmental factors that can impact one's relationship to money and the choices that they make. Mood disorders, like bipolar disorder, pose a big challenge for individual finances, as impulsivity is a common diagnostic criterion, including compulsive spending habits. The debt generated during these spending sprees can follow the individual long after the mood episode has passed [99,105]. This economic weight can have a negative impact on recovery and overall mental health, making financial decision support crucial to long term wellbeing.

The different mood episodes characteristic to BD provides a framework to better understand the relationship between mood and money, the different types of spending patterns that present during different mental health contexts more broadly, as well as help inform the ideal points for intervention to help support healthy financial choices.

5.1.4 Early-Warning Prediction

Considering the complex relationship between mental health and finances, financial technology (FinTech) systems can help users learn about both their financial behaviors and their mental health status throughout time. In particular, using previously established methods like the NIMH Life Chart Manual [155,156] in conjunction with objective financial

records shows initial promise for uncovering important patterns [144]. Over the course of use, such systems could help predict when different mood states are about to happen and serve as an early warning for upcoming spending sprees. Conversely, the financial behaviors detected by a FinTech system could be used to predict the onset of future mood episodes. This would not only help users manage their mental health and financial decisions, but also explain the connections between the two.

Based on prior work, it is reasonable to believe that a system capable of early detection of symptomatic behaviors within financial data could provide actionable feedback at the time of an episode [144]. This could potentially improve self-awareness of risky behaviors and of illness state. Additionally, this use of financial behavioral indicators may be especially useful, considering the length of some episodes and the subtle appearance that some symptoms may have from the individual's perspective.

5.2 A Survey on Bipolar Disorder and Digital Financial Environments

5.2.1 Survey Development and Distribution

To understand the financial landscape within the context of mental health and how to provide support for better financial wellbeing, we developed a survey. This large-scale online survey aims to address the following aspects of financial behaviors: respondents' current financial standing, their perceived change in spending behaviors during episodic periods, the effects of technology on spending behaviors, and their current strategies they have for managing their spending. This survey concludes with a series of vignettes to understand privacy concerns for sharing financial information within a future intervention system. This survey was built and distributed online using Qualtrics.

Building off of our previous work, we chose to specifically recruit individuals with a bipolar diagnosis, as this would allow us to capture the different support needs unique to either mood episode type, manic and depressive episodes. While this information was gathered in the context of bipolar disorder, these insights can be potentially extended to support other conditions with similar characteristics (e.g., ADHD which also commonly features impulsive decision making patterns and major depression) [91, 157, 158]. We leveraged existing connections with BD support organizations, such as Crest BD and Bipolar UK, to share our survey link. To be eligible for our survey study, respondents needed to have a diagnosis of BD (any type) and be 18 years of age or older. Following

informed consent, these inclusion criteria were verified through self-report age and diagnosis questions at the start of the survey. The Qualtrics survey was only programmed to continue if individuals provided responses affirming their consent to the survey and indicated that they were of age and had been diagnosed with bipolar disorder. All other responses triggered an automatic end to the survey before they could begin. This survey protocol was approved by the Penn State Internal Review Board. The list of the survey questions answered by respondents can be found in appendix B.

5.2.2 Participants and Data Analysis

In total, we collected 480 responses from individuals with BD from the US (42%), UK (38%), Ireland (11%), and other countries (8%). We also collected data on whether they were from a rural (19%), urban (47%), or suburban (34%) area, to better account for potential cost of living differences. Overall, this sample was 65% female, 32% male, and 3% otherwise specified. This survey sample included individuals with BD Type 1 (36%), BD type 2 (40%), Cyclothymia (2%), and BD not otherwise specified (14%) — all of which are specific types of diagnoses that may be given by a clinician. We also included an option "I don't know" (7%) to account for those who have a diagnosis of BD, but have not had a sub-type determined.

Survey data and descriptive statistics were analyzed using JMP statistical software. However, given the non-normal distribution within this data set, these responses are not meant to be generalized to all individuals with bipolar disorder, but rather to illustrate initial trends in behaviors and attitudes that exist in this sample. Additionally, while this sample may lean more female and white regarding respondent demographics, there are notable disparities existing in bipolar diagnosis rates. More specifically, Black individuals with bipolar disorder are much more often misdiagnosed with an illness other than bipolar disorder [159]. Diagnostic inaccuracies commonly experienced by minority individuals have led to lower diagnosis and prevalence rates as compared to white individuals [160]. Additionally, regarding gender, women show higher diagnosis rates of some types of bipolar disorder as compared to men [161].

Open-ended responses were analyzed qualitatively using bottom-up thematic analysis and three iterations on overall themes [134], until data saturation was met in alignment with established Grounded Theory standards [114].

5.3 Findings

5.3.1 Financial Environments of Bipolar Disorder

Within our survey sample, 71% of respondents were currently employed—part-time, full-time, or self-employed. Of those who were not employed, 6% described themselves as unemployed, 13% were unable to work, and 10% were either retired, stay-at-home parents, or students.

The vast majority of respondents (96%) currently had at least one back account. When asked how often they checked or reviewed their accounts, the majority respondents did this on a regular basis—either daily or weekly (both groups being 31% of the sample)— showing a relatively active engagement with their finances. Others noted reviewing their finances every few weeks or monthly. Only 8% of respondents noted that they rarely check their bank account and were otherwise "avoidant" of their finances. Despite this, when asked about personal bankruptcy, 22% or respondents had filed for bankruptcy and 37% had at least considered filing for bankruptcy at some point. This is a staggering increase when compared to the general population (i.e., those without bipolar disorder).

We also wanted to understand how individuals were managing and spending their money and how much of that activity took place in digital spaces. When asked about all of the money-related apps that respondents had used, 349 respondents used online banking apps, 325 used online shopping apps, 252 used personal payment apps (e.g., Venmo, Paypal, etc.), 96 used budgeting apps, and 84 respondents used investment apps. Respondents spent more of their money digitally, such as using credit or debit cards or online payment systems. Fifty-two percent reported conducting more than half of all their purchases digitally and 70% reported that "less than 20% of their purchases are made in cash". However, respondents noted that they made cash purchases for specific types of items or in specific scenarios. In some cases, cash payments were used only when digital payments were not available. However, others specifically used cash payments as a strategy to physically limit spending. For some, this was used in scenarios where overspending was likely to happen (e.g., out at bars, on vacation, etc.). Rather than having access to their whole back account with a debit card, limiting themselves to a specific amount of cash meant that "once it was gone, it was gone" and they would not be able to spend more than their original budgeted amount.

5.3.2 Symptomatic Spending with BD

5.3.2.1 Spending During Manic Mood Episodes

When asked specifically about their manic mood episodes, 82% reported that they believed their spending changed. More specifically, respondents overwhelmingly noted that their spending increases during manic mood episodes. When asked to expand on this in open-ended questions, many respondents called out the seemingly random nature of the types of purchases that they made during manic episodes. Other respondents provided more specific categories of purchases or key items that they were more likely to buy during manic episodes. These items fell within the following themes: vices (alcohol, cigarettes, junk food, etc.), luxury or splurge items, hobby-related (music, crafts, plants, etc.), travel or adventure purchases (flights, booking holidays), gifts for others or charity donations, and random incidentals (e.g., low-cost items seen at checkout).

Respondents' purchases made during manic mood episodes had a wide range of motivations driving them. Of our closed-ended list of possible responses, the most common was to "have something to look forward to" (191 respondents) or to "start a new project/hobby (166 respondents). However, respondents made note of other common spending motivators in open-ended responses, such as "to make other people happy. For others, they believed that buying certain items could help them project a new self or status, symbolizing "a new start" or items they would need to get their life organized.

Other notable and highly-specific motivations described did not fit easily with in the broader categories of the overall sample, but help underscore how widespread and individualized spending motivations may be for those with BD. Such instances include following respondent's thought process, "I have no restraint. I buy as an expression of my passion, eg, commonly, a CD I already own, and love—I'll buy six copies, not to give to others, but simply because it's SO GOOD it's the only way I feel to I can express those forceful feelings of excitement and enthusiasm."

When reflecting on their purchasing patterns, respondents noted temporal trends. The largest group of respondents characterized their spending as occurring "all day" (111 respondents). Whereas others noted that their spending tended to occur later in the day, such as late at night (102) or in the evening (96). This overall trend largely aligns with previous work on the temporal activity patterns of those with BD [46].

5.3.2.2 Spending During Depressive Mood Episodes

In contrast to manic mood episodes, only 63% of respondents reported spending changes during their depressive mood episodes versus their baseline. Many characterized this change as a decrease in overall spending, often citing increased anxiety about money, their amount of debt, or their overall financial situation. For some, this money anxiety and increased awareness of their finances forced them to scale back on their spending or motivated them to save more money during depressive mood episodes. "I worry more about spending money and can obsessively track spending and feel guilt over spending." For others, this drop was simply based on a lack of interest in spending, such as one respondent who noted their "spending falls sharply [and I] find personal care items especially don't get bought - clothes, food, etc."

However, this overall decrease in spending was not universal, especially when considering the types of spending respondents engaged in during these episodes and the motivation behind them. Notably, the most common purchase made during depressive mood episodes was food, specifically, followed by other convenience or comfort purchases. These purchases were made as a trade-off of sorts. Many referenced the lack of energy experienced during depressive episodes as the reason why they would purchase more premade takeout food. In this case, cooking food at home would take more energy than they could afford, so they would instead purchase food to ration what energy they did have for other more important tasks. This energy trade-off scenario is exemplified by the following response, "I find cooking for myself really difficult, so I order lots of food and I also start binge-eating to feel better so generally I spend it on money on food, but little on anything else because I don't have the energy to do anything".

For others, key items served as comfort purchases and came with motivations such as: to "improve my mood" (219), to "have something to look forward to" (160) or to "reduce my stress" (131). Some of these motivations were exemplified by specific responses: "I want to purchase items to come in the mail or by Amazon, so I have something to look forward to in my down days to cheer me up." More broadly, "I try to fill the void with items", stated another respondent about their spending motivation.

Overall, spending patterns during depressive episodes were very individualized and could vary by circumstances. This nuance in spending patterns and motivations can be illustrated by one such response, "[I] spend less on activities, travel, or other people — less future spending, as opposed to when hypermanic when I spend lots of future activities/plans/presents...Spend more on takeaway, alcohol. Sometimes more anxious about finances — avoid looking at bank account during depressed periods."

While respondents noted less spending during depressive episodes than manic episodes, the spending that did occur followed a similar temporal pattern of evening (111) and late night (103) purchases. Additionally, this aligns with late night activity patterns common for individuals experiencing depression, often stemming from interrupted sleep schedules [11].

A key takeaway from this is that the majority of those with BD are aware that their spending changes during different mood episodes but are not always cognizant of this in the moment of spending. This provides an avenue for future technological systems to provide in-situ support and prompt in-action reflection [162].

5.3.3 The Role of Technology in Spending

Given the overall rise in digital payments at a societal-level, we wanted to understand the effects of using technology on finances within the specific context of BD. When asked about their first-hand impressions, 82% of respondents believed that technology made it easier for them to overspend. In particular, 76% thought that online shopping was most likely to increase their spending, whereas 18% that believed in-store card purchases were more impactful for them. Only 4% of respondents felt that cash was more likely to increase their spending. Knowing the effect that technology could have on spending, 66% of respondents had taken the step to remove problematic apps from their phones to keep themselves from using them. Of these, only 30% reported keeping those apps off of their phones, whereas 36% percent had since reactivated those apps and continued to use them.

When respondents were asked to explain why they believed technology made it easier for them to overspend, their responses fell into the following categories. 1.) Technology reduces physical barriers to spending. For example, their phone is always present in their pocket. 2.) Technology reduces temporal barriers to spending, allowing users to "shop online 24/7". 3.) Digital payments are very low effort given features like auto-saved credit card details or "one-click pay" features. 4.) Websites feature ever-present advertisements, often targeted at individual user's interests. "I am easily influenced by pop-up ads on Facebook, emails, and texts," noted one respondent. 5.) The internet offers endless options of things to buy. For example, "anything I think of, I can find online" or "There are so many options and sometimes you need to order for a certain amount for free shipping which motivates you to buy more". 6.) Lastly, quick shipping methods provided by many online retailers can provide individuals with instant, or near instant, gratification. "It's very much instant gratification as I get a little buzz when I place an order and it comes the next day".

Across multiple open-ended questions, respondents reflected on how digital payments and technology more broadly led to a reconceptualization of money. As one respondent in particular described, "In my perception, it makes money feel less 'real' than physical cash, therefore giving money less value." Others explained this phenomenon as a result of the lack of physical, tangible money. "There's nothing to directly visualize you spending money." Speaking to technology's role in spending, some responses believed this to be intentional—a feature, rather than a bug of payment systems and online shopping sites. "It's designed to make it easier and addictive. I have an addictive personality so it's hard to stop."

When asked whether they wanted technology to make spending harder, 82% preferred this approach (this includes both responses of "definitely" and "possibly"). Those who responded in favor of technology making it more difficult to spend were asked about a series of proposed system features aimed towards this goal. A high-spending alert feature was most receptive to respondents (245 respondents chose this feature), followed by pausing or freezing their accounts when a spending spree was detected (187 respondents) and simply being shown unique patterns in their spending behavior (185 respondents).

5.3.4 Current Money Strategies

When asked about how they manage their spending, 53% currently had strategies in place. These fell into the categories of avoidance of spending triggers (places, scenarios, apps, or even time of day), constantly monitoring their finances, keeping a budget and actively planning for potential spending sprees, self-imposed friction, and engaging with more mindful behaviors.

Regarding "self-imposed friction", individuals talked about how they would add more steps between them and completing a purchase, essentially adding back in the friction that current technology has removed from many financial transactions. Some referenced restricting the type of money they used, either temporarily or permanently. This included things like not allowing themselves to apply for a credit card and only using money that they already had, as a means of avoiding future debt. Others would limit themselves to only using cash, often for specific occasions, such as going out to bars and restaurants to force themselves to stick to a predetermined budget for the night. Others would restrict access to their own money by way of multiple bank accounts or keeping most of their money in a savings account and only a limited amount available in their checking account. Others referenced adding time friction to their purchases, such as forcing a 24-hour reflection period before completing a transaction or adding an item to a monthly "want list". Others chose to avert common tech features, such as removing easy-pay options or refusing to save their banking information to any website to increase the amount of personal effort in their purchasing.

Some respondents talked about activities to force them to be more mindful of their purchasing decisions. There was a focus on wanting to fully understand their unique triggers and the types of things that could prompt spending sprees so they could help avoid or withstand them in their future. Others made note of specific lists of questions they forced themselves to work through before they could complete a purchase. These questions would help them determine whether there was a real, present "need" for the item or if it was just a momentary "want". Furthermore, they would ask questions such as: "how often will I use this?", "How long will it last?", "how with this improve my life?", and "is there any benefit to me buying right now or waiting?" to further define their needs. Lastly, others discussed how they tried to channel their energy into a different activity to avoid spending more money, such as getting outside, going for a walk, or engaging in a hobby.

5.3.5 Care Partner Collaboration

For 49% of our respondents, some of their financial management strategies involved asking other people for help in some way. These respondents provided specific examples of how they have involved others in their money management attempts, with varying degrees of care partner involvement or, conversely, allowing for different levels of individual agency in their own financial decisions.

5.3.5.1 Collaborative Strategies

Some had given a specific individual, such as a parent or a spouse, full control over their finances permanently or long-term. This included bank access, holding on to their credit cards, and making regular bill payments, especially in the case of shared household finances. This care partner involvement existed on a spectrum of increasing responsibility on the part of care partners and limited agency on the part of individuals with BD. This spectrum of involvement is illustrated in Figure 5.1.

Others discussed handing over financial control temporarily, either when they were experiencing sever episodes or where they were knowingly in a scenario that may trigger spending sprees. For example, an individual would hand over the wallet to a trusted



Figure 5.1. The spectrum of care partner collaboration in regards to financial decision-making, featuring increased involvement and responsibility for care partners and decreased personal agency for individuals with BD.

friend during a holiday or on a night out so that person could help control how much they spend and on what purchases.

Some respondents, while not giving someone else the ability to control their financial decisions, would give full access to view and monitor their banking accounts and financial records. By giving care partners access to this type of information, care partners could potentially intervene on problematic patterns, remind them of their goals, or even confront them about their past decisions.

Rather than providing full access to their personal financial information, others preferred to use their care partners as financial consultants. In this case, they might ask for their advice about individual purchases or prior to making any big decisions, such as taking out a loan. While these partners did not have a legal of technical control, some individuals made it an informal practice to not make certain financial decisions without getting "permission" from a care partner.

For others, their care partners, friends, and family merely served as distractions from spending money. When they felt the urge to spend, they might call up a friend to help keep them occupied with money-free shared activity, such as going for a walk or having a movie night at home.

5.3.5.2 Challenges with Collaboration

However, just because respondents reported involving others in their finances, does not mean these strategies were always successful. Some open-ended responses highlighted how they had struggled with or later abandoned some of their collaborative strategies.

Some discussed being reluctant to share information as they believed it would open themselves up to judgement from others. In other cases, respondents did not know how to ask for help from others or know what type of help they should request. Some respondents mentioned that their care partners are often unsure how to help if asked or how to intervene unless specifically prompted to do so.

5.4 Discussion

5.4.1 Design Recommendations

Based on these insights, future intervention design should help individuals with SMI develop new skills and form good financial habits. This approach should consider levering existing clinical practices, including cognitive behavioral therapy (CBT) [101], cognitive financial behavioral therapy (CFBT) [163], dialectical behavior therapy (DBT) [101,164], and a range of mindfulness activities. The following strategies should be explored further to provide a robust toolbox for a range of user need: 1.) making actionable suggestions to prevent harmful behaviors; 2.) providing alternative activities to replace spending ("urge surfing"); 3.) helping users understand and manage spending triggers; 4.) rewarding users for keeping up with "good spending" (e.g., paying bills on time); 5.) using gamification to develop financial skills and sustain productive habits; and 6.) monitoring user progress toward personal goals.

5.4.2 Supporting Existing Management Strategies

The majority of respondents had established strategies they used to help with their financial decisions. Future systems should leverage these commonly used strategies and provide features to directly support them. This would provide additional data to support respondents assumed personal behavioral patterns, provide structure to these practices, formalize these goals and management activities, and help illustrate progress made toward these goals to reinforce long-term engagement.

5.4.3 Supporting Positive Communication with Care Partners

While involving others in their financial decisions might not be for everyone, as only half of our sample did this, this could be an additional opportunity for future systems. By offering supplementary tools to facilitate more positive communication about otherwise difficult topics can help individuals feel more comfortable incorporating others in their financial intervention activities. Providing options that can support care partner involvement in ways that are more protective of users' privacy and agency can help make this a more viable option for individuals to explore in the future.

5.4.4 Limitations

As this survey study was recruit and distributed online, respondents may be more comfortable with technology in general, which could affect their attitudes towards intervention technologies. While these findings are based on a large sample, the respondents involved were mostly white, educated, and employed. Therefore their insights and experiences may not fully represent individuals from more financially disadvantaged backgrounds which may compound BD-related challenges to financial wellbeing. Other individuals with BD may have unique practices, needs, and concerns not captured by these findings. The majority of these respondents are also privileged in that they have access to a bank account. Future work should explore how to address individuals who are "unbanked", fall through the cracks of the formal economy, and might stand to benefit most from financial wellbeing support resources.

Chapter 6 Discussion and Future Work

6.1 Summary of Key Findings

The findings of this work show that while social media can provide a source of social support for users and a data source for researchers to learn more about the wellbeing of users, more comprehensive sources of behavioral data is necessary to provide an accurate depiction of mental health. This is especially the case when the goal is to use online data to assess mood state and inform interventions for serious mental illnesses. Based on in-depth interviews and the lived experiences of individuals with bipolar disorder, financial behaviors in particular may be the most telling of their mental state. At the same time, financial decision-making support is a key opportunity for future data-driven systems to help improve overall wellbeing and stability—given the significant impact that online spending has had on individuals lives.

The latter two studies focusing on the opinion of potential users show an overall acceptance of using an online data-driven approach to BD management. This is highly motivated by the potential it presents to more easily assess mood and predict the onset of future episodes, as well as intervene on symptomatic behaviors, personalized to their specific needs. However, given their increased need for more information to support their long-term care, individuals engage in varying trade-offs to their privacy and personal agency to achieve that goal.

These findings suggest that while individuals with BD may engage in the same types of online behaviors as those without BD, these activities are often amplified, more severe, and come with more substantial consequences to their overall stability and wellbeing. Because of this, existing support technology, especially regarding finances, may not be sufficient to meet their needs or even exacerbate existing challenges. Given the specific nature of serious mental illness, specific considerations need to be made in future design and addressed through additional research to better ensure that support technologies are sensitive to the high individualized needs of individuals with SMIs and keep their best interests in mind.

6.2 Comparison to General Populations

While some of these findings on privacy concern and online activity support needs may also hold relevance to general populations, this body of work in conjunction with previous research suggest that the needs and concerns of individuals with BD are further amplified due to the specific characteristics of BD itself.

6.2.1 Privacy Concerns

General populations often voice an increased concern about online data privacy, while at the same time exhibiting incongruous behaviors when it comes to actual privacy practices due to various online needs, creating a privacy paradox [165, 166]. In the case of those with BD, these same trade-offs and disconnect in attitudes may still exist, but involve more nuanced factors that they must consider.

Individuals with BD are put in a unique scenario regarding privacy. They have an increased motivation to use these types of assessment and intervention systems that require large amounts of highly personal and sensitive data because they need additional information and insight to improve their long term care (e.g., inferring mood episodes) [106]. However, they are also at greater risk should their data privacy be violated and their information exposed to others, given the stigmatizing nature of BD [9,83,136]. At the same time, disclosing personal information about their mental health to other people can also be beneficial to overall wellbeing, if done on the individual's own terms [74,75]. Choosing to disclose these more private details and experiences can help foster connection and understanding with others [7,12]. This is also why a collaborative family-based approach to treatment is often taken for BD [167]. The important role that personal disclosure plays in social support and the need for greater data to support care makes the privacy trade-off decisions more complex and critical for individuals with BD as compared to the general public, therefore it is important to explore these nuances through further research.

6.2.2 Technology and Behavior More Broadly

Previous research shows that technology can affect impulsivity [168, 169], attention spans [170], distraction rates and other behaviors within the general public [170]. This is also the case when applied specifically to financial behaviors online. Emotional factors and increased access can lead the general population to spend more online [171] and in some cases can lead to increased debt [172]. In fact, some work notes how the Covid-19 pandemic only increased this phenomenon [173].

However, when it comes to individuals with BD, they are at a much greater risk than the general population, given the characteristics of BD symptoms. Impulsivity is highly common of manic mood episodes and serves as part of the diagnostic criteria for a range of BD types, according the the Diagnostic and Statistical Manual of Mental Disorders (DSM) [154]. Additionally, the commonly experienced grandiose state that can present during manic mood episodes can make these behavioral patterns even more difficult for individuals to realize and even more challenging to intervene while they are actively occurring [154]. Therefore, the effects of technology exhibited in general users may be felt to a much higher degree by those who are also experiencing symptoms of BD. Moreover, many individuals in these studies discussed using common financial technologies, such as budgeting software, and regularly engaged in common money management practices, but still face significant challenges with impulsive spending and money management. This suggests that existing solutions, based on the needs of the general public, are not sufficient to support the needs of those with SMIs. This is further supported by previous work that shows the collaborative measures individuals with SMIs take to manage financial wellbeing and decision making [174].

6.3 Priorities When Designing for SMIs

Given this, three main design priorities remain persistent for the goal of providing long-term support for SMIs: flexibility, protecting vulnerabilities, and establishing more active roles for users in their own care plans.

6.3.1 Flexibility and Customization

Living with SMIs is not a one-size-fits all experience. Therefore, specifically designed for long-term management of SMIs should afford a level of customization to accommodate these individual differences. By providing a suite of options, these data-driven systems can help provide adequate support across the life course and illness stages, from pre-diagnosis to achieving relative stability in an established treatment plan.

6.3.2 Protecting Vulnerable Users

Given the vulnerable natural of SMIs, it is crucial to center the users' best interests in future design. As this unique user group is at a higher risk of social stigma, discrimination, and potential exploitation, systems should be mindful of increased privacy and agency concerns. Additional work is needed to explore the nuance of individual trade-offs and the ideal mechanisms for determining what intervention decisions are best for what users and at what time.

6.3.2.1 Privacy-Aware Data Practices

When discussing the trade-offs between the need for extra resources in managing BD and the amount of personal data used, interview participants were overall forgiving of their initial privacy concerns. Often cited was that the potential risk to their privacy was heavily overshadowed by the potential risks related to their BD symptoms (e.g., losing their job because of polarizing social media posts or impulsively spending themselves into debt). Follow up inquiry on these privacy concerns from large-scale survey responses show a little more variation on this, especially when applied specifically to financial contexts, while still wanting technology to help them manage their financial decisions.

Additional work is needed to determine what specific combination of data types, purpose of use, and who that data may be shared with is ideal for users while still allowing systems to provide them with meaningful feedback and intervention actions. However, future design should prioritize minimally-viable, privacy-preserving data collection and analysis and maintain high transparency with users as to what data is used, how it is used and stored, and who may have access to their personal information.

6.3.2.2 Distributed Agency to Prevent Exploitation

Because long-term intervention systems can involve sharing personal data and control with others, this can open up opportunities for misuse, if not adequately considered throughout the design process. This could negatively impact individuals who may already be in a difficult or disadvantaged situation, especially when considering financial interventions [175]. Therefore, it is a priority to proactively prevent misuse, by design. Before developing data-driven systems, we need to carefully consider the range of ways this data could be used to unjustly discriminate against users and how other people or institutions could exploit systems, use this information to further stigmatize users, or take advantage of users who are attempting to better their own situations.

Choosing these third-party allies may be a difficult decision for users to make. Some may feel obligated to choose those who are closest to them, like a parent or a partner, who may expect to be given this role, even if the user does not feel comfortable with it. Others may lack significant relationships or experience strained, unstable, or problematic relationships, leaving them at higher risk for exploitation.

To help protect the interests of individuals with SMIs, when users choose to involve others in their intervention and management plans, additional resources should be provided to help users make these decisions. Additionally, options to incorporate more members of a user's support network, at varying degrees of involvement, can help distribute decision-making power when a user's agency is limited due to symptomatic periods. Furthermore, including clinicians or other professionals within this support panel and leveraging existing validated clinical practices for preemptive decision making, can further ensure that patient users retain an active role in the overall goals of their intervention plan. Additional work is needed on the range of challenges that may present in this context, as well as how to better support users with limited support systems.

6.3.3 Enabling More Active Roles in Care

Because these intervention approaches may temporarily limit the amount of agency and control users have over their own decisions and behaviors, it is important to provide increased opportunities for users to take on more active roles in other areas of their overall care. This can be achieved by providing users the ability to log their own insights and reflections on their personal data and develop personalized short-term and long-term goals. Additionally, the combination of objective data logs and improved information sharing can make it easier for users to communicate their concerns, share their insights within therapy settings, and ask for help from others, among others, to amplify their own voice in long-term treatment plans.

6.4 Assessment and Intervention Strategies

Based on this body of work and a series of iterative design sessions, I have developed possible assessment and intervention strategies and design features to help manage SMIs,

guided by objective behavioral data sources. These components will be developed out into a series of prototypes for testing with individuals with BD and their care partners for further evaluation.

6.4.1 Reflection Opportunities

By collecting mood-related ecological momentary assessments (EMAs) and financial data, such as a purchasing record, a system can show key patterns and relationships between the two data sources, as shown in figure 6.1. This could help users reflect on their past data to understand relevant drivers and triggers of their spending behaviors. At the same time, the system could preemptively alert users at the start of problematic behavior patterns. This is especially important given participants' reported lack of awareness in the act of spending. This could provide greater in-situ awareness and prompt reflection in-action to help prevent specific behaviors, such as overspending [162].

6.4.2 Goal Framing

The way information and behavior are framed and presented to users can have an impact on how users view their behavior, progress, and themselves overall [176]. Because of this, it is important to provide users with ways to also monitor and set goals toward positively associated behaviors that are important to individual users. In a financial context, this could involve goals such as sticking to a self-determined budget, saving a specified amount of money, or consistently remembering to pay bills on time. in the context of social media or internet use, this could involve a reduced amount of screen time or logging off by a certain time at night, especially if users have a goal of going to sleep earlier or engaging in more relaxing behaviors at night to improve their mood and quality of sleep.

By allowing users to center their efforts toward positive progress, rather than solely on setbacks and negatively-framed behaviors, these types of intervention systems can help support long-term, sustained use through more positive feedback. Additionally, gamification strategies could be applied to these types of positive goals to help motivate users to reach them in more entertaining and engaging ways. This could leverage existing mhealth and self-tracking approaches [177, 178]. A high score leader board could allow users to compete, in this case, with themselves to make progress, without sharing personal data with others. Users could also earn badges for key milestones that can serve as visual reminders of the progress they have made. Future design could also explore the



Figure 6.1. An early paper prototype of data-driven interventions to support financial stability for individuals with SMI including identifying the personalized relationship between mood and spending behaviors as well as notifying users about anomalous events detected in their financial data. We will adopt an iterative and human-centered approach for design and implementation by including feedback from multiple stakeholders including individuals with SMI and their care partners.

use of other positive visuals to convey overall progress and wellbeing, using an approach similar to Consolvo's UbiFit garden [179]. This would allow users to still monitor positive progress at a glance, without needing to confront all of their activity data, depending on individual preference.

6.4.3 Alerts and Notifications

It is also important to provide a range of actions that these system alerts can trigger, based on individual user needs and goals for behavior change. This could include prompts to up the level of friction between them and their ability to complete financial transactions as a safeguard. Some users may benefit from a system providing mindfulness activities, allowing them to acknowledge, process, and let go of their impulsive feelings. Users could also preemptively dictate that these alerts should be sent to a trusted care partner, preferably with suggestions of how to help with the situation. These suggestions could include initiating a conversation about their finances, providing another activity to do together that does not involve spending money, or requesting that the care partner take on additional roles in managing or restricting their financial decisions. However, it is important that users are also provided the agency to choose their preferred actions and suggestions to be sent to their support network prior to any symptomatic periods.

6.4.4 System-Generated Suggestions

While providing users with self-guided access to their behavioral data can help them reflect and gather a stronger understanding of the association between mood and behavior, this may not always be sufficient support. This information should also be paired with system generated suggestions based on detected trends and patterns in user data. Future systems could provide users with alternative activities to help improve their current behaviors. For example, if a system detects that a user in engaging in a spending spree, push notifications could be used to suggest an activity that may address the same need or motivation behind their spending, such as elevating their mood, but does not involve spending. These activity reminders could include going for a walk, exercising, calling up a friend, or other "self-care" actions. Systems could have a bank of evidence-based suggestions to share with users, allow users to provide feedback on suggestion suitability, and continue to tailor those suggestions over the course of use. Additionally, options should also be provided to users to add their own activity suggestions for future use, as they become more accustomed to the practice and learn what helps support their unique needs.

6.4.5 Activity Restriction

As previously mentioned, intervention systems should provide users with options to restrict specific online behaviors with varying degrees of control. These restrictions would be predetermined by the users, with or without the involvement or care partners and clinicians, depending on their preferences. Users should be provided with a range of different behaviors, conditions, and the degree of restriction that they can select from. Regarding behaviors, this could include options such as online shopping, social media posts, use of gambling websites, and so forth. The different conditions that could trigger this activity restriction feature could include the system detection of a specific episode type or mood state, the time of day such as late at night or during the work day, or user setting the system to always restrict a specific activity, regardless of state. For example, this sustained restriction could be used in the case of users with known gambling addiction who do not want to access those types of websites under any circumstance. Users should also be able to select the degree of restriction for different behaviors. This could involve full restriction for the specified window of time, a forced cooling off-period of a specified amount of time (e.g., a 24-hour wait), or simply have the system remind them of their current goals to prompt reflection and course-correct their behaviors. However, additional research is needed to understand how users might leverage these options and the ideal means of deploying them based on real-time data.

6.5 Open Challenges for Co-Management

While healthy, active social support systems are key for long-term management of SMIs, there are many significant challenges. This is especially the case when applied to financial contexts, as money troubles, like SMIs themselves, are highly stigmatized and difficult to discuss openly. These feelings of stress, guilt, and shame are further compounded when the financial decisions of individuals with SMIs also affect care partners, as is often the case within families. For these reasons, it is important to consider how these interactive data-based intervention systems can help mediate these tense relationships.

While these types of interventions can provide opportunities to share health or financial information with others to help aid in their overall wellbeing, many survey respondents recalled being reluctant to share information as that opened themselves up to judgement. Others wanted help from their care partners, but either did not know how to ask for help or what help they needed, which was compounded by their care partners feeling unsure how to assist without direction.

For these reasons, it would be beneficial for intervention systems to help provide structure to these co-management activities, whether they are focused on financial behaviors or help managing day-to-day symptoms of SMIs. By providing initial suggestions of the type of help users can request and the ability to add customized notes, needs and expectations can become clearer within the relationship. Additionally, providing resources to help users and their care partners prepare for difficult conversations could improve communication and overall care. Objective data systems paired with clinical therapy activities could help users and care partners maintain a non-judgmental and focus on progress, new goals, and actionable changes, rather than past mistakes.

6.6 Limitations

Despite the valuable insights and lived-experiences gathered throughout the course of this work, they are not without their imitations. While small samples of interview participants have been shown to provide significant findings, it is important to acknowledge that because participants discussed in Chapter 4 were recruited through their clinic, have stronger relationships with their clinicians and thus may be more accepting of data-driven interventions especially if used with the support of their existing clinicians. Additionally, their views of the intervention concept and design needs may differ from those with BD who are not actively seeking treatment or do not have accessible treatment options.

The survey respondents described in chapter 5 were recruited online through the channels of well-established BD support organizations. Due to this involvement, they may be more likely to have existing support networks and established treatment plans and clinical relationships. Additionally, this online recruitment method may have limited the sample to those who are already comfortable and familiar with technology, leading them to be more accepting of technology-based support for financial decision-making and BD management.

While the participant samples described throughout this work maybe at a greater advantage than other individuals with SMIs, both in terms of BD stability and financial wellbeing, they provide important insights for future design. With continued research involving wider representation, we can develop more inclusive tools.

6.7 Future Work

The continuing line of this research will expand its line of inquiry from primary users (e.g., individuals with BD) to other members of their social support networks, evaluate the resulting system for long-term use, and explore how this knowledge can applied to other conditions.

6.7.1 Nuance of Care Partner Relationships

While this body of work focused on the perspective of individuals with SMIs, there are often other stakeholders involved in their long-term care. Considering the roles and responsibilities for clinicians and care partners as described by participants in these studies, it is important to understand what their side of these interventions systems might look like and the needs and concerns they have with engaging with a data-driven assessment and intervention system to assist someone with an SMI. As many participants voiced interest in involving others in their care, it is important to understand the needs, concerns, and expectations unique to care partners and clinicians. For instance, what is their ideal role and level of involvement? What are their current practices, the challenges that they face, and scenarios that could assist their own support roles?

6.7.2 Prototype Evaluation

Future work aims to incorporate this body of findings and design recommendations into a prototype assessment and intervention system. By providing a suite of symptom management tools, powered by active user data, this approach can be further evaluated with a focus on long-term engagement, treatment adherence, and meaningful behavior change and symptom management. These long-term evaluation plans and collaboration with clinical researchers can help bring this hypothetical system concept, originally presented as a discussion probe, to a clinically validated practice.

6.7.3 Support Specific to Other Conditions

Following this, it would be beneficial to explore how this overall concept could be extended to other conditions, including other SMIs or memory-related conditions. Some BD symptomatic behaviors described and documented throughout this work may relate to other conditions, such as impulsivity related to ADHD [97], avoidance behaviors related to anxiety disorders or depression [99], or general cognitive memory-related challenges [95]. This is especially pertinent, as a number of interview participants disclosed having additional diagnoses, such as ADHD, that also played a role in their online activities as well as keeping up with their established treatment plans. This included online behaviors, such as fixating on different search topics, and offline behaviors like difficulty recalling experiences and talking points they wanted to address in later therapy sessions.

However, individuals with different diagnoses may have unique needs and challenges that could be supported by different design features. Additionally, this extended inquiry and subsequent new features could help make systems originally developed in the context of BD more supportive of individuals with comorbid conditions, or the presence of two or more diagnoses, as was the case with some participants from this work.

6.8 Broader Impacts

While this work used bipolar disorder to understand how objective data sources could be used to provide personalized support, the findings of this work can be used as a framework for developing additional resources for mental health support. By further validating this approach and its efficacy for long-term use through future work, this can provide much needed support tools and broaden accessibility of mental health care.

Appendix A Interview Guide

The following includes the interview guide used in the study detailed in Chapter 4. All of the questions listed below was asked of all participants, as well as any follow-up or clarification questions deemed necessary by the researcher or clinical representatives present during these interview sessions.

The section below titled "Covid-19 related questions" were not asked of the first participant, as this session was conducted prior to the start of the pandemic and subsequent procedural changes. This set of questions was added to explore potential behavioral changes related to this period in time (e.g., social isolation, staying at home more often, remote work, etc.).

Following this predetermined set of questions, all participants were given the opportunity to share any additional information, insights, concerns, or questions that they may have developed over the course of the interview.

A.1 Online Behaviors Across Bipolar Disorder

- 1. In what ways do you believe your behavior online changes based on when you are experiencing a depressive episode (where a depressed mood episode is a period of two weeks where you have been experiencing depressed mood, sadness, loss of interest or pleasures in activities you generally enjoy doing)?
- 2. In what ways do you believe your behavior online changes based on when you are experiencing a manic episode (a period of time when you are feeling uncharacteristically happy/euphoric, have excessive energy levels, feel you need less sleep etc)?
- 3. How do you feel either type of mood episode affects your shopping behaviors?

- 4. How do you feel either type of mood episode affects your social media use?
- 5. How do you feel either type of mood episode affects your web browsing (e.g. frequency, or types of information sought)?
- 6. How do you feel either type of mood episode affects your email use?
- 7. How do you feel either type of mood episode affects your use of streaming or other entertainment content (e.g. YouTube, Netflix)?
- 8. How do you feel either type of mood episode affects online gaming?
- 9. How do you feel either type of mood episode affects online gambling?
- 10. In what ways do you feel each type of mood episode affects your general use of technology?
- 11. How do you feel different mood episodes change how often you use different devices?
- 12. How do your more active times online differ during a depressive mood episode, as compared to a manic mood episode?
- 13. How do these changes in online behavior affect daily offline life?
- 14. What negative experiences (such as getting upset by FB communication or interactions with others online) have you encountered online during a depressive mood episode?
- 15. What negative experiences have you encountered online during a manic mood episode?

A.2 Covid-19 Related Questions

- 1. How has your use of technology, the internet, or social media changed since stay at home orders have been issued in response to the Covid-19 pandemic?
- 2. What online activities do you feel have increased for you in the last few months–since stay at home measures have been enacted?
- 3. Have there been new technologies/apps that you have been introduced to in the last few months? If so, which ones and for what purposes?

4. How has your use of social technologies (social media, email, messaging, etc.) or your online engagement with others changed over this time period?

A.3 Acceptability and Usefulness

- 1. If given your own behavioral information, how do you think you would use it?
- 2. How comfortable would you feel with your online non-content data recorded over extended periods of time?
- 3. Do you have any concerns with researchers using non-content data for the purpose of developing a behavioral warning system?
- 4. How accurate you think this information would be?
- 5. How accurately do you feel your online data would reflect your BD status?
- 6. What aspects of your mood episodes would be missed or difficult to capture with your online behaviors alone?
- 7. Would a tool such as this be potentially helpful in your daily life?
- 8. Would it be more useful to you for one type of mood episode over the other (depressive vs. manic)?
- 9. What type of information would be most useful to your personal circumstances?
- 10. Are there other behaviors you would be interested in or think should also be considered in predicting BD status?

A.4 Future Design Aspects and Sharing

- 1. How often would you like to be shown your data? —e.g. regularly (weekly, monthly), or only when a potential issue would be flagged?
- 2. What type of feedback would be most useful? —Accessing data on your own time, Emailed on a weekly/monthly basis, Push notifications to your phone—alert system
- 3. How far back would it be useful to store your data for later comparison? (e.g. across a year or more)

- 4. Would it be useful to incorporate contextual notes or a diary function to supplement your online records?
- 5. Would you be more comfortable accessing this type of feedback on a mobile device or a desktop/laptop web format?
- 6. How comfortable would you be with sharing this info with others?
- 7. What level of specificity of information would you be willing to share with others?
- 8. Would you prefer to share this type of information with other only some of the time?
- 9. Would you feel comfortable is a system was to notify others automatically based on potential severity?
- 10. Would you prefer a system that shares information without your explicit permission?
- 11. How would you feel if a system like this was to limit your online activities automatically (disabling shopping or email actions, limiting the amount of shopping or emails that could be sent)?
- 12. How would you feel if a system like this was to prompt you for additional permissions before completing your online activities; such as, "are you sure you want to purchase this item?" or "are you sure you want to send this email?"
- 13. How would you feel about a system that offered you the ability to customize what online behaviors you wanted to control for future mood episodes?
- 14. What aspects of this information would you be willing to share (e.g. specific behaviors, or general aggregated information)?
- 15. With whom would you be comfortable sharing this type of information? E.g. Spouse, caregivers, parents, other family, friends, clinicians
- 16. How useful do you think this information would be to others, if you were to share?
- 17. If shared, what do you expect others to do with this information?
- 18. What actions do you expect from those given your information? (help, touch base with you, keep to themselves, etc.)
Appendix B Financial Survey Questionnaire

The following details the list of open and close-ended questions as presented to online survey respondents, following their informed consent. As this survey, detailed in Chapter 5, was deployed to respondents in different countries and asks about their financial situations, all questions in reference to money was shown to respondents in their local currency, determined by prior responses about their location. Apart from consent and qualification questions (e.g., age and diagnosis), respondents were permitted to skip any questions they were uncomfortable answering, per IRB requirement.

B.1 Introduction

Respondents started the study by receiving the following message to help prepare them to answer questions as honestly and accurately to their own lived experiences.

"For each question this survey, please select the one response that most accurately describes you, your experience, or your opinion—unless otherwise specified in the question."

B.2 Demographics

- What is your age?
 - 18 to 24 years
 - 25 to 34 years
 - 35 to 44 years
 - 45 to 54 years

- $55\ {\rm to}\ 64\ {\rm years}$
- $65\ {\rm to}\ 74\ {\rm years}$
- 75 to 84 years
- 85 years or over
- Which most accurately describes your gender?

Male

Female

Nonbinary

Prefer not to say

• What is your ethnic background?

Native or Indigenous

Asian

Black/African/Caribbean

Native Hawaiian or Other Pacific Islander

White

More than one race

Other

• Are you of Hispanic/Latino/Spanish origin?

Yes

No

B.3 Location

• Where do you currently live?

Ireland

United Kingdom

United States

Other If US—

- In what state? (drop down list of all states)
- Which of the following best describes the area you live in?

Urban

 $\operatorname{Suburban}$

Rural

• What is your current marital status?

Single, never married

Married without children

Married with children

Divorced

Separated

Widowed

Living with partner

In relationship not living together

• Please indicate the highest level of education completed.

Primary School

Secondary/High School (or equivalent)

Vocational/Technical School (2 year)

Some University

University Graduate (4 year)

Master's Degree (MS)

Professional or Doctoral Degree (MD, JD, PhD, etc.)

Other

B.4 Illness history

• Have you ever been formally diagnosed with bipolar disorder by a medical professional?

Yes No if no — not eligible for survey What type of Bipolar Disorder do you have? Type I Type II Bipolar Disorder Not Otherwise Specified Cyclothymia I do not know Other

B.5 Individual financial environment

What is your current employment status?
Employed full time (40 or more hours per week)
Employed part time (up to 39 hours per week)
Unemployed and currently looking for work
Unemployed and not currently looking for work
Student
Retired
Homemaker
Self-employed
Unable to work

• (if in US\$) What is your current annual individual income, excluding welfare benefits...?

Under \$15,000

15,000 to 29,999

\$30,000 to \$44,999

\$45,000 to \$74,999

\$75,000 to \$124,999

\$125,000 to \$199,999

200,000 or more

• (if in UK) What is your annual income level?

Under £15 000 £15 000 to £29 999 £30 000 to £44 999 £45 000 to £74 999 £75 000 to £124 999 £125 000 to £199 999 £200 000 or more

• (if in Euros) What is your annual income level?

Less than €15,000

€15,000 to €29,999

€30,000 to €44,999

€45,000 to €74,999

€75,000 to €124,999

€125,000 to €199,999

€200,000 and above

• Do you currently have a bank account?

Yes

No

I don't know

• If yes, How often do you review your spending (e.g. check your bank account balance)?

Daily

Weekly

Bi-weekly

Monthly

Every few months

I very rarely check my bank account(s)

• —If yes, How do you currently review your spending?

I check my bank $\operatorname{account}(s)$ on a regular schedule

I check my bank account at random times

I check my bank account only when necessary (paying bills, withdrawing money)

I do not check my bank account

B.6 Digital Environments

• How much of your spending is done online or digitally (e.g., using a credit/debt card)?

Less than $20\,$

20-40

About half

60 - 80

More than $80\,$

• How much of your spending is done in cash-only?

Less than 20

20-40

About half

60-80

More than 80

- What types of purchases do you make primarily in cash? (open-ended)
- What types of money-related digital technologies have you used (check all that apply)?

Online banking apps

Budgeting apps

Online shopping apps (e.g., Amazon)

 $Investment \ apps$

Gambling apps

Gaming apps

Cryptocurrency apps

Personal payment apps (Venmo, Paypal, etc.)

Other

- What type of items do you most commonly purchase online? (open-ended)
- What categories of purchases do you commonly make online? (Check all that apply.)

Food- including takeout/delivery

Clothing

Entertainment/recreation- streaming services, gaming, hobbies, etc.

Transportation

Personal care and beauty

Housing/utilities

Home furnishing and supplies

Travel

Technology

Charity/donations

B.7 BD specific financial trends

When you are feeling high/hypomanic/manic...

• Does your spending change?

Yes

No

- If so—how does it change? (open ended)
- What type/category or items do you often buy when feeling manic/hypomanic? (open ended)
- How often do you make online purchases when feeling manic/hypomanic?
- What time of day do you typically make online purchases when feeling manic/hypomanic?

Early mornings

Midday

Evenings

Late at night

Throughout the whole day

• What are your goals for spending when feeling manic/hypomanic? (Choose any that apply.)

"To improve my mood"

"To have something to look forward to"

"To reduce my stress"

"To start a new project or hobby"

"To keep me busy"

"Because I was bored"

"To make money" (new business idea or investment)

other

When you are feeling depressed...

• Does your spending change?

Yes

No

- If so, how does it change?
- What type/category or items do you often buy when feeling low, stressed, or anxious? (open-ended)
- How often do you make online purchases when feeling low, stressed, or anxious?
- What time of day do you make online purchases when feeling low, stressed, or anxious?
 - Early mornings

Midday

Evenings

Late at night

Throughout the whole day

• What are your goals for spending when feeling low, stressed, or anxious? (Choose any that apply.)

"To improve my mood"

"To have something to look forward to"

"To reduce my stress"

"To start a new project or hobby"

"To keep me busy"

"Because I was bored"

"To make money" (new business idea or investment)

other

• Have you ever had to declare bankruptcy/discharge debts due to large purchases or impulsive spending when you are manic?

Yes

No

• Have you ever considered declaring bankruptcy/discharge debts due to large purchases or impulsive spending when you are manic?

Yes

No

B.8 Strategies for financial wellbeing

Do you currently use any strategies to reduce or prevent impulsive spending?
 Yes

No

- If yes—What strategies have you used?
- Have you ever asked your family/friends to help prevent impulsive spending? Yes

No

- If yes—In what ways have they helped you?
- Which payment method is most likely to increase your spending?

 Cash

Purchases in shops with cards

Purchases online through browser with cards

Purchases via apps

Other

• Does technology (e.g., smartphones, shopping apps, contactless pay, Apple pay) make any difference in how easy or hard it is for you to overspend?

Easier to overspend

Harder to overspend

No difference

Not sure

- If yes —Why do you think this is the case?
- If yes —Would you want to use technology to make it harder for you to overspend (e.g. block certain websites, put limits on daily spending, have a freeze on purchases, etc.)?

Yes, definitely

Possibly

No thanks

Not sure

• If yes —Would you want to work with your creditor to make it harder for you to overspend (e.g. block certain websites, put limits on daily spending, have a freeze on purchases, etc.)?

Yes, definitely

Possibly

No thanks

Not sure

• Have you ever removed an app from your phone to reduce the risk of impulsive spending?

Yes, and I have since kept it off of my phone

Yes, but I later put it back on my phone

No

• Please tick which of the following technology options you would prefer to try and help you manage your finances better and in particular reduce impulsive spending when unwell:

Ability to easily see patterns in what I am buying.

Warnings when I am spending more than usual/about to go into overdraft etc.

The ability for me to pause or freeze large transactions if I am spending more than usual.

My bank/creditor to freeze or pause large transactions if I am spending more than usual.

The bank/creditor to freeze or pause transactions on specific items if I am spending more than usual.

Making it harder to take on new debt (e.g. take out a new loan or credit card).

Not letting apps/websites save my card details.

Having a 'double agreement' or cool off period for large purchases, e.g. have to wait 24 hours and then confirm before going through.

• What other techniques have you used to reduce the risk of impulsive spending?

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PUBLICATIONS

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