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Quantifying the Changeable Self: The Role of Self-Tracking in Coming to Terms With and Managing Bipolar Disorder

Mark Matthews,[1] **Elizabeth Murnane,**[2] **and Jaime Snyder**[2]

[1] *Cornell University*
[2] *University of Washington*

There has been a recent increase in the development of digital self-tracking tools for managing mental illness. Most of these tools originate from clinical practice and are, as a result, largely clinician oriented. As a consequence, little is known about the self-tracking practices and needs of individuals living with mental illness. This understanding is important to guide the design of future tools to enable people to play a greater role in managing their health. In this article, we present a qualitative study focusing on the self-tracking practices of 10 people with bipolar disorder. We seek to understand the role self-tracking has played as they have come to grips with their diagnosis and attempted to self-manage their health. A central motivation for these participants is to identify risky patterns that may be harbingers of mood episodes, as well as positive trends that support recovery. What emerges is a fragmented picture of self-tracking, with no clear delineation between clinician-initiated and self-initiated practices, as well as considerable challenges participants face in making observations of themselves when their sense of self and emotional state is in flux, uncertain, and unreliable. Informed by these observations, we discuss the merits of a new form of self-tracking that combines manual and automated methods, addresses both clinician and individual needs, helps engage people with bipolar disorder in treatment, and seeks to overcome the significant challenges they face in self-monitoring.

Mark Matthews (mark.matthews@cornell.edu, www.aplayspace.com) is a computer scientist researcher with an interest in the interplay between technology and mental health; he is jointly a Research Associate in the Department of Information Science and cofounder of HealthRhythms. **Elizabeth Murnane** (elm236@cornell.edu, http://www.cs.cornell.edu/~elm236/) is a computer scientist with an interest in developing interactive technologies that support self-management of wellness; she is a Postdoctoral Associate, having recently received her PhD from the department of Information Science at Cornell University. **Jaime Snyder** (jas1208@uw.edu) is an information scientist with an interest in visualization practices; she is an Assistant Professor in the Information School at the University of Washington.

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1. INTRODUCTION

The notion of self-tracking is not novel. Explicit self-monitoring in the form of mood charting can be traced back to the 18th century (Martin, 2007). At a fundamental level, systematic recording of behaviors, activities, and attitudes aligns with human tendencies to be self-curious, analytical, and habitual (Swan, 2013). Much of the contemporary rise in self-tracking seen in recent years is due to a swell in the production of digital personal informatics tools such as smartphone applications, wearable activity trackers, and other specialized devices for self-monitoring. This current technological landscape is enabling significant changes to self-tracking practices by increasing the accessibility and availability of sophisticated tools that generate uninterrupted records of human activities in more detail and more continuously than previously possible.

Self-tracking is often motivated by a desire to manage a wide range of health conditions. For example, people will often record daily food intake when trying to control weight or will take regular glucose readings when managing diabetes. When recording personal behaviors and activities, individuals can use a range of tools, from conventional pen-and-paper instruments to interactive software applications and, more recently, specialized biometric devices. These tracking practices enable people to provide detailed health information to a clinician or doctor when professional services are required, monitor their conditions in between clinic visits, and potentially self-manage their own health in ways independent from clinical treatment.

In this article, we focus on self-tracking as a means of managing bipolar disorder. Due to the lack of objective instruments for measuring states of mental illness—no objective test currently exists to diagnose or even assess most mental illnesses—patient-reported experiences, predominantly recorded via paper-based charts, have played a central role in diagnosis and treatment of psychiatric conditions for more than a century. Bipolar disorder, in particular, is a mental illness for which tracking is used very commonly as part of clinical management to identify early warning signs, titrate medication, and adjust behavioral interventions (Goodwin & Jamison, 2007). Self-tracking is also used, at least by some, as part of a self-initiated practice for maintaining emotional stability (Murnane et al., 2016; Murray et al., 2011).

We argue that in the domain of mental health, the act of observing, recording, and analyzing one's daily activities takes on a distinctly different role than when these same activities are performed in other quantified-self (QS) contexts. People living with bipolar disorder often experience a high degree of emotional instability and chaos that can make it difficult to know what to expect from one day to the next (Goodwin & Jamison, 2007). Patients and clinicians often describe the experience of managing bipolar disorder as a "roller coaster." Unlike, for example, the course of clinical depression, which typically follows a predictable trajectory from relapse to recovery, bipolar disorder has no unidirectional pathway (Frank, Swartz, & Kupfer, 2000). It is characterized by an unpredictable cycle between clinical states. A person can move rapidly from a healthy state to a manic one, where they might experience high self-esteem, irritability, and sleeplessness and then transition to a deep depression. This trajectory is multidirectional: A person can fluctuate unpredictably between the clinical phases of relapse, recovery, remission, and recurrence. Treatment can also have a negative impact, triggering a surge of mood into a manic phase and then back down to a depression. Finally, people with bipolar disorder are almost never dealing with just their bipolar disorder; approximately 70% of people with the condition will also experience three or more other disorders over the course of their lifetime (Merikangas et al., 2007).

Within the context of long-term management of serious lifelong conditions like bipolar disorder, self-tracking can provide both therapeutic benefit and psychological risk. However, despite indications that the self-tracking practices of individuals with bipolar disorder are more extensive than what is currently supported through existing clinical instruments (Murnane et al., 2016), most research on self-tracking has focused on a narrow, clinician-centered conception of self-tracking (i.e., tracking factors that clinicians consider important) and has centered on the clinical management of this

illness. As a consequence, the broader psychosocial self-management needs of individuals with bipolar disorder, from a self-tracking perspective, have not been investigated.

Through a series of interviews, surveys, and participatory design activities, we interacted with 10 people living with bipolar disorder in order to identify (a) tracking practices used by people with bipolar disorder, including both digital and analogue methods, the range of factors recorded over time, and the intended purpose of these tracking activities; (b) the aspects of bipolar disorder that impact self-tracking practices and motivations, such as extreme fluctuations in mood and impaired memory; and (c) the ways in which current self-tracking technologies meet or fall short of the needs experienced by those suffering from serious mental illness along with design considerations to address those current limitations. We then use these findings to contribute insights and recommendations regarding the future design of self-tracking technologies targeted to both people self-managing serious mental illnesses, such as bipolar disorder, and more general populations of users who might be susceptible to some of the same vulnerabilities as the individuals in our study.

2. BIPOLAR DISORDER

2.1. Prevalence and Characteristics of Bipolar Disorder

Recognized as one of the 10 most debilitating illnesses worldwide (Murray & Lopez, 1996), bipolar disorder is a lifelong condition that is associated with poor functional and clinical outcomes (Judd et al., 2003), high suicide rates (Baldessarini & Tondo, 2003), and huge societal costs (Woods, 2000). The illness is characterized by drastic fluctuations in mood along with other disruptions to biological and behavioral rhythms, most notably sleep and physical activity (Goodwin & Jamison, 2007). Individuals living with bipolar disorder typically experience transitions between manic and depressive states, often referred to as "cycling," reflecting a rhythmicity that has some regular characteristics but that can still be difficult to predict (Soreca, Frank, & Kupfer, 2009). These fluctuations can be quite rapid (e.g., within a matter of days) or extend over weeks, months, or years.

The fundamental poles of this disease are mania and depression. Mania is typically a state with heightened mood, more rapid speech, increased rapidity of physical and mental activity levels, impulsivity, decreased need for sleep, and perceptual acuity (Goodwin & Jamison, 2007). Depression, on the opposite end, can be characterized by decreased activity, speech, and energy; inability to experience pleasure; and low mood.

Differences in rhythms and symptoms are reflected in the categorization of different forms of bipolar disorder, with Type I characterized by recurring episodes of depression and mania and Type II characterized by depression and hypomania (a less severe form of mania). When an individual's symptoms do not clearly fall into

either subtype, a diagnosis of bipolar disorder not otherwise specified (BD-NOS) might be given.

2.2. Phases of Illness

One of the greatest challenges for those experiencing bipolar disorder is that receiving a clear diagnosis takes 10 years on average (Suppes et al., 2001). That means that the initiation of therapeutic and/or psychopharmaceutical intervention can be delayed for years after the onset of symptoms.

The course of bipolar disorder can vary. Berk, Hallam, and McGorry (2007) proposed a staging model that is helpful in identifying four progressive phases of the condition. A period of *latency*, when mild or nonspecific symptoms of a mood disorder may appear, is typically followed by the *first significant episode* of distinctive bipolar symptoms. This in turn is followed by a period of fluctuation between *remission* and *relapses*, ranging from mild to more severe depression or mania. Ultimately, a state of persistent, unambiguous cognitive and emotional *impairment* is experienced.

There is currently no cure for bipolar disorder. People who are living under the diagnosis of bipolar expect to manage their condition for the rest of their lives. Although effective therapeutic techniques and medications can help to reduce symptoms, there is still an alarmingly high suicide rate associated with the condition, estimated at 20 times higher than in the general population (Tondo, Isacsson, & Baldessarini, 2003). Preventing relapse is challenging, and as a result, quality of life for those living with bipolar disorder can be extremely poor due to relationship problems, loss of productivity impacting career advancement, and physical and emotional stress of managing the disorder over a lifetime (Goodwin & Jamison, 2007). These negative effects are not limited just to the individual. The illness also has significant impacts on the family, friends, and caregivers of individuals with the disorder.

2.3. Identity Development

Although there is limited research on identity and bipolar disorder, there are indications that several aspects of the disease can negatively impact identity formation and interfere with developing a clear sense of self. A majority of individuals with bipolar disorder experience onset of the condition during their teenage years (Perlis et al., 2004), a period of development characterized by significant cognitive, biological, social, and emotional change. Inder et al. (2008) suggested that, as a result, bipolar disorder may have a considerable impact on individual psychosocial development, and in particular on the development of a sense of identity and self.

In one of the few studies on this topic, Michalak et al. (2011) conducted a qualitative study with 32 high-functioning individuals with bipolar Type I or II, reporting that many of the participants acknowledged that their sense of self/identity had been affected by their bipolar diagnosis, although not all negatively. Inder et al.

(2008) performed a qualitative analysis of transcripts from 49 hr of therapy sessions with 15 individuals to assess the impact of the disease on participants' sense of self. Confusion over the "true" self, contradictions in experiences of the self across different mood states, and difficulties with self-acceptance due to an inability to integrate these different experiences and develop a stable sense of identity were all identified as common struggles related to self-construction. Mood state was a central defining factor that led to the development of different, and at times contradictory, selves depending on the mood or illness state.

Patients can also experience a schism between a sense of self before diagnosis and afterward (Frank, 2007, p. 105). People who had previously experienced the soaring emotions of manic highs often go through a period of grieving when that part of themselves is brought under control through behavioral treatment and medication. Indeed, part of the work of some psychotherapy involves helping patients gain acceptance of and grieve for a previously healthy or manic self that has been lost to their bipolar disorder or as a result of stabilizing treatment.

In summary, although more empirical data are needed, the developmental timing of bipolar disorder onset, along with ever-fluctuating moods and the vicissitudes of the illness itself, may have an impact on the development of a sense of identity and self. This may be one area where self-tracking can help both to target the specific factors associated with an underdeveloped sense of identity and to facilitate the processes of self-construction and acceptance.

3. SELF-TRACKING

Self-tracking plays a central role in the treatment of bipolar disorder: Clinical guidelines suggest that daily mood monitoring be incorporated into routine clinical management of the disorder (Kahn et al., 2000). Patients are often asked by their psychiatrists or therapists to self-track factors considered clinically relevant such as their mood and adherence to medication. In her book exploring what it is like to live under a diagnosis of bipolar disorder in the United States, Emily Martin (2007) described some of the other underlying mechanisms of self-tracking practices:

> Americans living under the description of manic depression today are often encouraged to keep a "mood chart" in order to manage their manias and depressions. Filling out a mood chart—a small act of individual discipline—can have dramatic effects. When many people fill out the same charts or register their moods on a numerical scale, they make their distinct experiences comparable. When people assign a number to a mood, they are paving the way for statistics that describe the moods of a population and their changes over time. (p. 178)

Paper-based patient diaries are by far the most common method for self-tracking in clinical settings. Several paper-based self-tracking charts have been validated for use in the treatment of bipolar disorder. For example, the National Institute

of Mental Health's Life Chart Method is a validated self-report instrument that tracks mood (on a + 3 to −3 scale; Denicoff et al., 2000), medication, sleep, weight and alcohol/drugs.

Although paper-based diaries are the dominant method for symptom tracking for bipolar patients in both general psychiatric care and nonpharmacological interventions, evidence suggests that individuals with bipolar are generally receptive to using technology-based methods. Bopp et al. (2010) found that SMS messaging was well accepted as a method for individuals with bipolar disorder to chart their symptoms in lieu of clinician reports. Schärer et al. (2002) adapted the National Institute of Mental Health Life Chart for use on a handheld PDA; they found that participants preferred this medium to paper, reporting that they felt less social stigma and enjoyed the perception that they had a more involved role in their treatment.

Despite the ready availability of self-tracking tools, the unpredictable mood swings that characterize bipolar disorder can be difficult to recognize and self-assess by the person experiencing them, resulting in personal records being incomplete or inaccurate and warning signs going unnoted. Both retrospective tracking, which carries biases, generally speaking, but can be particularly problematic in this context, and self-assessment during manic phases of the illness, when mood is considerably elevated, can be unreliable (Kupfer et al., 2002; Lish, Dime-Meenan, Whybrow, Price, & Hirschfeld, 1994). Further, periods of relative emotional stability have been associated with lapsed adherence to medication due to individuals feeling that they no longer need their drugs. It is reasonable to expect similar lapses or inconsistencies in self-tracking activities. Although such lack of adherence is a well-recognized hurdle when it comes to self-tracking (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003), it is particularly challenging in this context and can negatively affect the power of this personal record to serve as a tool for symptom self-awareness and relapse prevention.

Recent research has provided promising evidence that sensors can detect aspects of behavior related to bipolar disorder. In the MONARCA project, Frost, Doryab, Faurholt-Jepsen, Kessing, and Bardram (2013) developed a smartphone app to provide insights regarding disease progression by collecting data relevant to the behavioral trends of bipolar disorder. Based on data collected over 6 months, they found that patient self-reported mood correlated with physical activity, levels of stress, sleep, and phone use. Another study used phone call duration, speech analysis, and movement data from smartphones to identify manic and depressive states (Grunerbl et al., 2014). From 12 weeks of data with 10 patients, their system recognized bipolar states and the transitions between those states (assessed using the Hamilton Rating Scale for Depression and Young Mania Rating Scale) with 76% accuracy.

However, approaches like those just noted are still in their infancy and not commonly available to people with bipolar disorder. Perhaps as a result, technology-enabled biometric sensors and other semiautomated techniques developed for a more general set of users have become therapeutic resources for individuals with bipolar disorder (Murnane et al., 2016). These technology-mediated self-tracking practices produce large personal data sets, comprising time-stamped and often-overlapping

streams of behavioral, personal, and contextual information such as physical activities, mood, and biometrics. To make sense of this data in the context of their lived experience of bipolar disorder, individuals must have not only a familiarity with tracking technologies but also deep knowledge of the ways in which their condition manifests in their daily lives. As just noted, this is likely to change over time depending on which phase of the illness people find themselves. Although such tracking technologies may support healthy self-awareness, there is also a general risk that they might foster hyper self-scrutiny and unrealistic normative expectations of health (Lupton, 2013; Snyder et al., 2015).

Yet despite some evidence that a broader conception of self-tracking is helpful in self-managing bipolar disorder (Murnane et al., 2016; Murray et al., 2011), little is known about the self-tracking practices of people with this disease. Therefore, this study focuses on a broader conception of self-tracking that encompasses more than the standard narrow clinical band of factors (e.g., mood, medication etc.). We set out to understand self-tracking from the experience of people with lived experience of bipolar disorder. We sought to understand how and why participants engaged in tracking, the impact their illness has on self-tracking practices, and their attitudes and thoughts on the potential of technology to support these activities over time.

4. METHOD

Data were collected during a 4-week study investigating the potential of smart-phone sensors to predict clinical factors related to bipolar disorder (Abdullah et al., 2016). Potential participants were identified through the Depression and Manic Depression Prevention Program at University of Pittsburgh. The Institutional Review Board at the University of Pittsburgh approved this research. Inclusion criteria required participants to be already participating in a treatment program at the clinic, to be able to provide informed consent, and to have a confirmed diagnosis of bipolar disorder. Participants were stable at the time of recruitment and in contact with the clinic during the study. All participants were engaged at the clinic in Interpersonal and Social Rhythm Therapy (IPSRT), a clinically validated psychosocial treatment for bipolar disorder that focuses on establishing interpersonal supports and stabilizing social rhythms (Frank, Swartz, & Boland, 2007). Studies of IPSRT indicate that when patients achieve greater regularity in their daily schedule as measured by the Social Rhythm Metric (SRM; T. K. Monk, Flaherty, Frank, Hoskinson, & Kupfer, 1990), a paper-based self-report instrument, they remain well longer and function better (Frank et al., 2005).

Participants were excluded if they were unwilling or unable to comply with study procedures or had active suicidal ideation requiring inpatient or intensive outpatient management. Our sample consists of 10 individuals (5 females, 5 males) between 25 and 64 years of age who had a confirmed diagnosis of bipolar disorder and consented to participate in the study (see Figure 1). Six participants had the milder form of bipolar disorder, Type 2; two participants had Type 1, and two had BD-NOS. No record was taken of participants' medication schedule.

FIGURE 1 Demographics of participants including the type of bipolar diagnosed and the number of mood episodes (i.e. periods of depression, hypomania, mania or mixed moods) experienced over a lifetime.

Participant	Age Range	Gender	Diagnosis	# of Mood Episodes
P1	45-54	Female	BD-I	6
P2	25-34	Female	BD-I	10+
P3	35-44	Male	BD-NOS	10+
P4	55-64	Female	BD-II	10+
P5	45-54	Male	BD-II	10+
P6	25-34	Female	BD-II	10+
P7	35-44	Male	BD-NOS	2
P8	55-64	Male	BD-II	10+
P9	25-34	Male	BD-II	5
P10	25-34	Female	BD-II	6

Data were drawn primarily from a semistructured interview and two questionnaires (see Appendix A1 and A2 in Supplemental Material online)—one focusing on self-tracking practices and another on attitudes toward sensor-based self-tracking tools. Individual interviews were conducted by one of the research team. Each participant was compensated $50 for the interview and $25 for each completed questionnaire. Additional data related to self-tracking practices were incorporated from e-mail correspondence with participants along with custom tracking artifacts they shared with us. Interviews were recorded and transcribed, and e-mail correspondence was collated into one file per participant for analysis.

A thematic analysis was used as a qualitative method to analyze the data, as we were interested in identifying patterned meaning and sought a flexible, inductive approach. Thematic analysis entails first analyzing the data set to identify patterns and then organizing these patterns into individual themes (Boyatzis, 1998). Three researchers each reviewed the data set independently to identify initial themes, which were then shared, discussed, and iteratively refined. This resultant set of themes was then used to reanalyze the data set, resulting in the findings described next.

5. RESULTS

5.1. Vignettes

We begin by presenting a series of vignettes in order to situate participants' self-tracking in their daily lives. These vignettes also foreshadow the thematic analysis to come while providing a holistic experiential context. We selected these individuals because they illustrate a set of scenarios that are diverse within the sample yet are representative of experiences reported by other participants. Pseudonyms are used to protect participants' anonymity.

Rachel

Rachel (P1) has been diagnosed with Type I bipolar disorder. She experienced her first bipolar episode in her early twenties, about 25 years ago, and has had a handful of subsequent episodes since then. Rachel recently earned a master's degree in social work and started working in that field. She currently considers herself to be very stable, crediting her highly structured schedule for keeping her bipolar under control. She started tracking her moods around the time that she had her first episode, creating line graphs on paper that she shared with her mental health care providers. She has continued tracking over time, explaining that the act of recording helps her to recognize patterns sooner than she would otherwise, which enables her to make adjustments to restabilize her mood.

Rachel's tracking practices currently focus on things like feelings (e.g., hopelessness), symptoms (e.g., irritability, rumination, anxiety, pressured speech), triggers (e.g., stressful events, lack of sleep, skipped medication), and mood boosters, (e.g., positive events or rhythms that improve her overall mood or stability such as healthy eating, exercise, sunshine, a supportive person, or a leisure activity). She also keeps track of her medications. For Rachel, things like sleep and exercise are easiest to track and can be recorded when she has a chance. On the other hand, she has found that tracking moods or other feelings works best and is more accurate when she can record them in the moment, as she experiences them, rather than waiting until the end of the day. Currently she

shares her tracking data only with her clinician when she is having trouble with things like socializing, sleeping, or her diet.

Rachel is enthusiastic about technology and uses a computer on a daily basis. Her preferred device is an iPod Touch, which she periodically connects to the Internet via Wi-Fi. She is not on social media. Although in periods like her current state of relative stability she tends to track more in her head, she does set about nine daily alarms using her iPod Touch for things like waking, eating, and exercising. She also creates weekly reminders using Google Calendar to prompt herself to check in on various aspects of her day-to-day experiences. Rachel has used a variety of bipolar apps downloaded to her iPod Touch, such as Optimism, in order to track her mood, identify changes over time, and record her daily rhythms. She has found these apps only moderately helpful because the list of things she likes to track is long and, to a degree, idiosyncratic. She finds that most apps do not have adequate customizability. Rachel would consider using automated or semiautomated sensor technology to improve some of her tracking practices, but she has concerns about privacy, confidentiality, and intrusiveness, which she thinks "has to do with the stigma of my mental illness. … I'm sort of hypersensitive to anything that connects me to bipolar in a public way."

As a result, she created her own self-tracking tool: a spreadsheet in Microsoft Excel, as seen in Figure 2. In addition to providing a record of a fuller range of her day-to-day experience, Rachel's spreadsheet includes a simple macro that

FIGURE 2 Example of one participant's custom tracking setup to capture personally meaningful variables, assess daily status, and deliver messages of encouragement. Diary entries have been blurred to protect the participant's privacy.
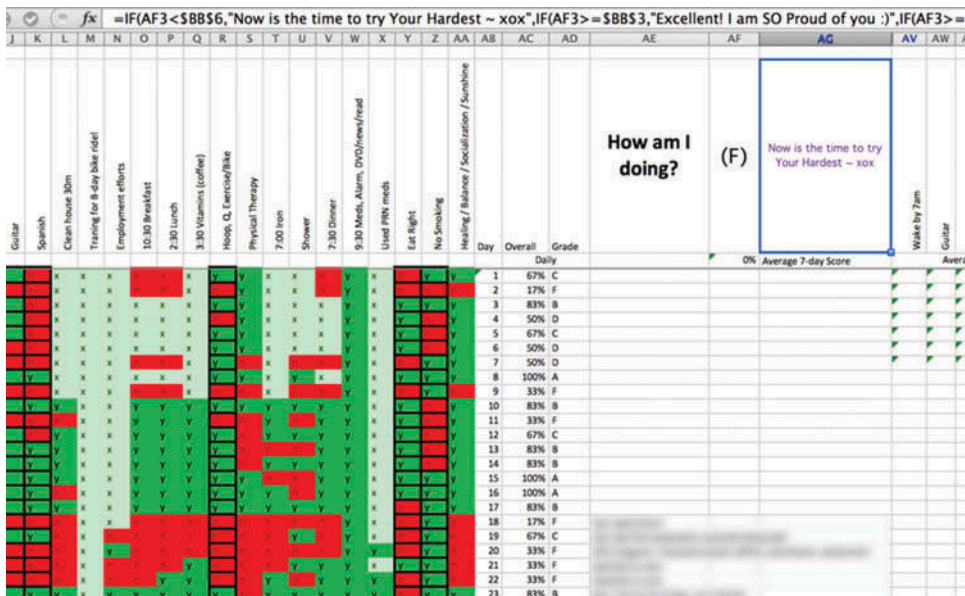
displays personalized messages of encouragement based on patterns in her data. This custom tool gives her a way to record the things that are most important to her, providing the motivation that she believes is the ultimate benefit of her tracking practices.

David

David (P3) was originally diagnosed with bipolar disorder when he was on federal probation, about two years ago. In reviewing his records, his probation officer noted that he had never held a job for longer than 1 year. Combined with other observations about David's personal history and current challenges at the time, the officer ordered a psychiatric evaluation that resulted in diagnoses of both bipolar disorder (BD-NOS) and anxiety. David explains, "I knew something was there, I just didn't know what it was. I just thought it was just me being moody." For David, the bipolar disorder and anxiety diagnoses enabled him to begin making sense of his past behaviors and better understand why various things were happening in his life. He was able to trace his first bipolar episode back to when he was 6 or 7 years old—a very young age for bipolar disorder to manifest—and has had more than 10 additional episodes since then.

When his diagnosis was confirmed, David was given medication and made efforts to establish new habits for himself. In doing so, he was able to gain enough control that he could begin the process of identifying triggers and learning behavioral techniques for keeping his moods somewhat regulated through meditation and martial arts. One of the biggest challenges David faced in coming to terms with his condition was understanding what it means to live with a diagnosis of bipolar disorder. Therapists and doctors answered a lot of his questions, and he sought out others with similar experiences. However, he came to realize that "no two people may necessarily go through the same things, the same ways. Everybody's life is different." Now that he has a greater understanding of his moods and behaviors in the context of bipolar disorder, one of his main concerns is reaching and maintaining stability.

David's diagnosis about two years ago is relatively recent in the context of a lifetime of symptomatic behaviors and emotions. Soon after his condition was recognized, he entered a clinical study for people with bipolar during which he was introduced to the SRM, a paper form that assists people in tracking their mood, social rhythms, and other factors (Monk et al., 1990). David found that weekly tracking using the SRM helped him to recognize when his daily routine was normal and to maintain that consistency over time. However, the SRM's paper format meant that he did not always have it with him. David tends to forget things easily, which is not unusual for individuals living with bipolar disorder and can make remembering to track more challenging, especially when tools for entering data are not constantly available.

David currently focuses on tracking mood and sleep in order to maintain a stable routine, saying that he is most interested in knowing "how I'm doing, how I've

been doing, am I doing the same things the same ways, and do I feel the same way when I'm doing them." He is very open to using technology to support his daily self-tracking, explaining that he believes technologies allow a person to "notice things you probably wouldn't have noticed as easily if you didn't have that type of device." He uses the alarm and calendar on his phone to remind himself of things he should record or tasks he needs to perform, especially activities he considers very important and is afraid of forgetting. David recently purchased a watch that allows him to monitor his heart rate, steps taken, and calories burned. As part of another study, he also tried out a smartphone app to support his self-tracking activities and noted a particular desire for that system to "learn" his routines and automatically remind him about items to record or tasks to perform. David expressed similar interest in highly automated and predictive technology, where "all those factors can be used to figure out what can trigger a negative mood"—a vital part of his therapeutic objectives.

Robert

Robert (P5) is approaching middle age and lives in the country with his son. Robert is on disability and consequently spends most of his time at home, frequently texting and sending e-mails and instant messages to friends, some of whom are also home all day on disability. Robert has been diagnosed with Type II bipolar disorder. He has had more than 10 bipolar episodes over the course of his life, with the first occurring about 25 years ago. He describes his experience of bipolar disorder as "a roller coaster, lots of ups and downs. … You do things you normally do not do, and when you come out of that manic moment, you rush and panic on how to fix all that you did."

Although Robert is very enthusiastic about technology, when his laptop recently died he decided to not replace it with another full-size computer but instead got a Samsung Note 4 smartphone. One of his motivations for this change was the amount of time that both he and his son had been spending online with the laptop. Since replacing his laptop with a smartphone, Robert and his son spend the evenings after dinner going for walks rather than staring at the screen; however, he still spends more time online than he would like, explaining that because of his disability he could be online 24 hr a day, 7 days a week, if he did not limit himself.

Robert has worked with a number of therapists over the years, but only recently has a mental health care provider talked to him about the benefits of self-tracking. He uses the paper-based SRM to record things like his mood, physical activity, sleep, first contact of the day with another person, mealtimes, and use of money. He also tracks the weather. Robert is a little surprised that no one mentioned this technique to him previously and that he had never come to consider stabilizing his routine in this way himself:

> If I go to bed at a certain time and I wake up in the morning, I feel better than if
> I would go to bed later than that. But I never just put it together as, "Hey that's a

routine." But once it's brought to your attention—"Hey, get a steady routine, you're gonna feel better"—it seems like common sense.

Tracking is now an important tool for managing his stability and bipolar disorder: "It's almost like second nature to watch for things that, you know, mess up my routine. And then I try my best to avoid it."

In addition to using the paper SRM to record his routines, Robert uses software on his phone to keep track of his use and time spent online. He has also tried Lark, a self-tracking app that presents behavioral feedback through conversational prompts rather than abstracted charts. He highlights the positive aspects of this type of interaction, saying, "It's such a nice way of learning about yourself. Rather than just looking at the graphs, it kind of talks you through your patterns." Robert also appreciates the encouraging tone of the messages: "It's nice to hear the pat on the back. Because that's a great motivational thing, and especially if it's talking to you like it's a buddy." In addition to these more popularized means of observing his behaviors and moods, Robert uses a sleep apnea machine and studies the data it collects not only to discover and "fix" sleep disruptions but to better understand positive experiences as well: "Even though I might have a great night's sleep ... I'll still go back and look at it, because I want to know *why* that was the best night's sleep compared to the night before." Further, Robert uses feedback from family and friends, who act as a sort of "social sensor" to help monitor his status, especially to notify him when behaviors begin to portend the onset of symptoms.

5.2. Patterns of Tracking Practices

To complement these vignettes, we also report on patterns of tracking practices we identified across participants. These are presented in the context of the three questions that motivated this study:

1. How and why do participants engage in self-tracking?
2. How does the experience of bipolar disorder influence self-tracking practices?
3. What role does, or could, technology play in supporting the self-tracking practices of individuals with bipolar disorder?

We have summarized key findings related to these questions in Figure 3 and discuss each group of results in more depth next. These findings support our argument that for the individuals in our study, the acts of observing, recording and analyzing daily activities are inextricably entwined with the experience of bipolar disorder.

How and Why Do Participants Engage in Self-Tracking?

All the participants in our study engaged in some form of self-tracking. As part of their introduction to IPSRT treatment, each had been asked to complete the SRM

FIGURE 3 Summary of results of thematic analysis.

1. How and why do participants engage in self-tracking?

- Participants use a combination of methods to self-track, with the central goal of *maintaining normalcy and self-stabilization* (as opposed to optimizing performance or achieving an aspirational goal).
- Individuals seek to *identify negative patterns early on in order to anticipate mood episodes*, performing *personal analytics* by "sifting" through their data to make connections between behaviors, symptoms, and warning signs.
- Tracking practices are often most *explicit, elaborate and intense just after diagnosis*, embodying a form of *vigilance* against negative emergent patterns.
- Self-tracking can become *a means to exert control* over the bipolar condition.
- Because the nature of feedback is seen as not only representative of a current state but also as a possible trigger clinical intervention, the *accuracy* of self-tracking techniques and tools is a primary concern.

2. How does the experience of bipolar disorder influence self-tracking practices?

- *Adherence* to self-tracking protocols is often deeply entangled with the *syncopated rhythms* of the experience of bipolar disorder. A mood transition away from a stable state can undermine the desire to track. Poor adherence can be a precursor of a mood episode.
- *Excessive self-tracking* can have negative effects, such as hyper self-scrutiny.
- *Momentary mood fluctuations (an hour or a day) or extended mood episodes (weeks or months)* can affect the *reliability* of the data.
- *Appropriate clinical guidance and grounding* can help scaffold self-tracking.

3. What role does, or could, technology play in supporting the self-tracking practices of individuals with bipolar disorder?

paper-based instrument (Monk, Frank, Potts, & Kupfer, 2002), a clinically validated measure of social routine that is central to IPSRT therapy. For many, the practice of formally recording things like mood, sleep, and social contact was introduced by a clinician at the onset of a treatment plan. Many participants also independently started using software such as spreadsheets, calendars, or mobile phone apps to manage their condition. Tracking practices were often the most elaborate and intense just after diagnosis, as individuals attempted to both establish new tracking habits and establish a baseline of "normal."

Once a tracking routine had been established and an individual became more familiar with their particular bipolar experience, some participants transitioned from more active self-observations to daily or weekly reminders to reflect on specific types of behaviors or emotions they deemed effective indicators of their mental health. P3 had established an internal rhythm of checking in and used this in conjunction with other tracking methods to gauge how he is doing: "Every now and then, I just gauge how I'm doing, how I've been doing it, am I doing the same things the same ways, and do I feel the same way when I'm doing it." Several people mentioned sometimes setting an alarm to prompt such self-evaluation of their recent behaviors. Some reported that tracking in this way also improved an overall sense of well-being, as it helped relieve excessive self-awareness and scrutiny, as articulated by P1.

Several participants, such as P10, also described reaching a point when they started keeping track of behaviors and moods in their head rather than on paper: "It wasn't so much just the recording that helped me but just being intentional about the times that I did things, trying to make it the same every day. I didn't always record things." Such mental tracking often followed periods of more explicit and structured recording practices, reflecting what we came to understand as "phases" of tracking behaviors that participants would transition through as they tried to manage their symptoms and experiences.

The extremes of bipolar disorder are severe and the after-effects of episodes are potentially devastating, with each relapse causing permanent neurological damage (Deicken, Pegues, Anzalone, Feiwell, & Soher, 2003). Further, it is a chronic condition that progressively worsens over a lifetime. Accordingly, self-monitoring practices tended to become more frequent and structured around periods of crisis or perceived heightened risk for relapse. Minimizing future mood episodes was therefore a central motivation for many participants who saw tracking as a way to protect against these disruptions as much as possible:

> It [the tracking] is important to me, I'm afraid that any deviation will take me back to a place I don't want to be. Even though it might be annoying at times, its purpose is to keep me on track, and I could see the improvement with mood and energy although it's not constant, sometimes a little more energy than normal, and how do I deal with the extra energy. (P8)

Self-tracking was used by P1 and P2 to provide increased vigilance during or in anticipation of stressful periods:

> I just started [working] at the hospital 2 months ago—so all this change and instability is not in the best interest of my wellbeing. I anticipate it will take a lot of personal monitoring to keep myself in balance over the next few weeks. (P1)

But too much tracking led to a negative feedback loop for P1:

> When I was tracking all that time on the excel sheet, I felt my moods constantly. When I stopped using excel & just started "checking in with myself each night"—I felt more normal. My rhythms were well established & the overall mood, I'm sure, improved because I wasn't looking at myself under a microscope anymore.

Although the issue of adherence in the management of bipolar disorder is typically associated with taking medication (Martin, 2007), establishing strong habits related to self-tracking was also an issue for the participants in our study. Prior work, with a nonclinical sample, has shown that lapses in tracking personal information such as physical activity, location, and finances are often associated with forgetfulness and with the challenges of maintaining tracking devices (Epstein, Ping, Fogarty, & Munson, 2015). Similarly, many of our participants talked about barriers to recording behaviors and feelings "in the moment," such as getting sidetracked, not carrying a paper chart around, or not having access to a home computer throughout the day. For example, one participant shared, "After a certain time you give up keeping record of these activities when you use pen and pencil." (P7)

All participants viewed feedback as central to engagement and adherence to this tracking: "For me, the feedback is actually one of the most important things because, like you said, it's a motivator. So the more feedback I get the more useful it is, the more likely I continue with it." (P1) "When people are struggling every little bit of feedback makes a difference in how you feel about yourself." (P4)

Overwhelmingly, participants reported finding positive feedback highly motivating, which matches with prior work on the persuasiveness of positively framed feedback (Choe, 2014). Some participants noted that smartphone apps they had used outside the context of bipolar disorder offered forms of positive feedback they thought could also be helpful for managing their illness. Given the perceived benefits of encouragement, P1 integrated brief positive comments for her routine checklist into her custom Microsoft Excel setup (see Figure 2), with messages ranging from "Excellent! I am SO Proud of you:)" for a perfect score (based on completion of a set of self-defined activities) to "Now is the time to try your hardest ~ xox" during periods of low adherence.

At the same time, participants cautioned that feedback framed in a negative or judgmental way could be demotivating and potentially exacerbate symptoms, which in turn did cause some participants to disengage with those tools:

> I always think positive reinforcement is better … but a lot of apps don't go that way, a lot of them are more negative, and maybe they don't even know they're

doing it that way. Like the S-Health [app]—they're mean! That's the only way to put it. Because it's like, "You haven't moved in an hour!!" And I'm thinking, "Umm I've been vacuuming the floor, I did the dishes, and I went upstairs and cleaned the bathroom. I just didn't have my phone on me. Stop yelling at me like I didn't do anything. (P5)

You track caffeine. I gave up on it. … It's a little too judge-y about you. Telling you that "Youuuu are going to be jittery …" But I couldn't tell it, "No, I'm going to be fine." (P9)

Similarly, prompts to track were perceived as more motivational when conversational rather than interrogating, as articulated by P5:

The app can get all that stuff out of you just by a little wee conversation, which is a lot better than being, like, the spotlight in your face, "Answer my question! If you don't answer, I'm gonna smack you with a ruler!" (P5)

Participants particularly valued feedback that enabled them to anchor positive activities helpful for recovery from an episode or to identify patterns in order to avoid a mood swing in the first place. Indeed, finding personal patterns is a central motivation for self-tracking and quantified-self practices in general (Li, Dey, & Forlizzi, 2010), but what exactly constitutes a pattern and the value of its discovery can be quite different in the context of bipolar disorder. Although individuals in a normal population can experience periods of low mood or "bad days" in terms of meeting goals, these changes can be a harbinger of an oncoming relapse for people with bipolar disorder:

I think I look at it everyday because for me to watch my bipolar disorder I'm constantly looking at patterns. … I like to see trends, because if I have a depressive day that might be just be a bad day, but if I notice 3 depressive days in a row then that's a sign to me that I need to do something. (P1)

This process of discovery can also help participants develop better strategies for managing their condition going forward, including making lifestyle changes that can preempt future disruptions. A picture emerges, for most participants, of the self acting as the principal "investigator" of itself. Several participants described a process of "sifting" through their data looking for patterns and actively making and readjusting hypotheses in order to make connections between behaviors, symptoms, and warning signs, for instance, when it comes to relations between sleep and subsequent mood:

When you wake up in the morning and you're like, "Ahh, I feel kinda crappy" or my mood is an "Arg, don't mess with me today" kind of attitude, then you look back and you go, "Oh, well maybe because I went to bed at 1:30[am] instead of 11:30[pm], like I was supposed to. (P5)

Aside from identifying patterns and warning signs, several participants felt that the act of self-tracking is of value in and of itself. For P10, it supported an increased mindfulness and facilitated a commitment to behavioral intentions: "Wasn't so much the recording that helped me, but being intentional about times I did things, trying to make it the same every day, [even if I] didn't always record" (P10).

For others, self-tracking helped counter the loss of autonomy and sense of being out of control brought on by bipolar disorder. "The more I know, the more I have control of my life" (P5). "Is the act of self-tracking of benefit in and of itself? Absolutely. It keeps me grounded in reality" (P6). "[Tracking] helps me feel more in control." (P10)

In the following two sections, we explore the ways in which these positive associations with self-tracking are complicated by (a) the symptoms of bipolar disorder, such as extreme mood fluctuations, which can make it difficult to establish and recognize a stable behavioral baseline, and (b) the nature of automated sensing technologies that both provide opportunities for more accurate self-tracking data but also remove agency from the individual user.

How Does the Experience of Bipolar Disorder Influence Self-Tracking Practices?

Although the experience of bipolar disorder colors many aspects of life, mood instability is perhaps the most notable characteristic. People with bipolar fluctuate from manic highs to deep depressions, and a primary goal of treatment is to maintain the individual in a balanced state that is not too high or too low. However, this precariousness can be another factor that can compromise adherence to self-tracking routines and can impact the reliability of any collected data. Fluctuating mood states, which for some individuals vary considerably over the course of even a single day, are associated with experiences of "confusion, contraction, and self-doubt" (Inder et al., 2010). Participants in our study conveyed a similar distrust of their self-assessments: "Sometimes due to the nature of bipolar I feel like I can't trust the emotions I have at any given moment (or their possible triggers) and it's a relief to know that these are patterns" (P6).

In addition, prior research indicates that for people with bipolar disorder, personal insight is dependent on emotional state and most affected during mania, when self-assessment is often erroneous (Goodwin & Jamison, 2007). Several of our participants similarly identified their current mood state along with levels of social interaction as factors that significantly impact self-tracking adherence and reliability, including when it comes to the difficulty of appraising past moods:

> The problem with tracking things at night, even mood, is that it is somewhat relative. … I could be horribly crabby in the morning and if I feel fine at night, I will say that I feel fine. … The sleep and the exercise are a little more accurate, in that I can't really lie about that. It's just a fact. (P1)

> I dissociate badly when I'm in deep, either direction, I lose more and more time.
> The Big Bad episode, the one where my psychiatrist found me, was depressive. I
> was nearly catatonic. I don't remember it. My memory is shot and nonlinear. (P6)

A mood transition away from a stable state can also undermine the desire to track: "Another person in the group was dedicated and logged frequently in the beginning until he started to go into a hypomanic episode and couldn't be bothered" (P2). "We [people with bipolar] are least likely to track when our symptoms become more acute—which is just the time we need it the most & our doctors need to be aware" (P1).

Given the possible impact of bipolar disorder on the development of a sense of self, along with the fact that it is necessary to manage radically fluctuating mood, it is perhaps unsurprising that participants feel a desire to gain a greater sense of control over their lives via rigorous self-tracking. Indeed, unlike many health conditions where self-tracking is limited to a few variables, tracking among the participants in our study spread across a wide range of factors to encompass anything that they perceived could affect their condition, including menstrual cycle, diet, sleep, physical activity, and various daily routines. Although therapeutics treatments such as IPSRT advocate recording data about certain key behaviors, many participants also recorded a host of other variables.

However, independent data sleuthing to uncover connections among these variables can be risky without the proper skillset or support. To understand and act upon information collected through self-tracking, our own research experiences have led us to suppose that a person requires several proficiencies: (a) high degree of comfort with technology, (b) an awareness of the limitations of the collection method, and (c) an understanding of how to interpret the data, particularly in a mental health context. Further, this interpretive process takes time and effort, which can be especially challenging to harness amidst the distraction and instability common in bipolar disorder. P6 spoke of this difficulty in managing even mundane tasks, much less delicate personal sense making, when in the midst of an episode.

> At times I will refer to "the gypsy," an external character who places obstacles in
> my path (and this increases when I am depressed—the obstacles feel like
> concrete walls around my ability to do things). Sometimes I am so unable to
> do a normal task that I call it an "unwinnable scenario." (P6)

For several of the participants in our study, this process of becoming familiar, comfortable, and proficient with self-monitoring was facilitated by therapists—who also introduced most participants to self-tracking in the first place, though others like P1 and P6 had been tracking even before diagnosis. As part of this process, some participants needed to experience evidence before "buying into" the therapeutic value of self-tracking. For instance, P8 negatively perceived clinical treatment at first (e.g., "I just thought those clinicians live in their own little world, I'll humor them") but later developed a positive relationship with his current therapist when she helped him

use self-tracking as a way to notice patterns and mark distinct changes in his functioning. He was then introduced to a smartphone-based version of the SRM, which became an extension of his work with his therapist; though initially not at all confident self-tracking using a mobile device, he eventually came to find the experience empowering, especially compared to the paper-based form:

> Now I have a constant companion, I felt alone a lot of times, now it feels like I have a companion … and I don't want to let my companion down. It gives me some reasons for doing this or that, and then you realize that if you do this you feel better, and who doesn't want to feel better? Before, I almost resisted everything. I went from resisting to accepting to embracing. (P8)

Other participants expressed a similarly favorable outlook regarding the potential for technology to support the therapeutic work of self-tracking and help to mitigate some of the challenges faced in adhering to these practices. However, the introduction of technology into these practices is not without challenges, as we summarize in the next section.

What Role Can Technology Play in Supporting Self-Tracking Practices of Individuals With Bipolar Disorder?

Participants in our study reported using mainstream technology in their lives. All used a desktop or laptop computer on a regular basis. Many had a smartphone and regularly texted or sent instant messages, and all but three participants reported using social media. However, many talked about limiting or regulating their technology use in association with managing their condition over time. As mentioned in the preceding vignette, Robert (P5) sought to control his use of technology after recognizing that it may have been negatively impacting his quality of life, including jeopardizing his relationship with his son, contributing to wasted time, and encouraging poor sleep behaviors. P7 identified similar potentially problematic aspects of overuse while also articulating the potential benefits—and altogether, technology's two-edged nature:

> [With] technology it is easy and time saving to keep record of these activities. Many times the technology is motivating too. [And] if someone is in depression, these electronic gadgets are very helpful, to keep your mood up. It helps to maintain your wellbeing during depression. … But when someone with bipolar disorder is in "manic phase" it is very dangerous, … there is no self-control. So my thoughts on new technology is, it depends on how you use it. (P7)

In addition, participants described ways in which symptoms of bipolar episodes can manifest through technology use. P6 expressed this observation, seeing her technology use as a reflection of her mental state:

Searching for web information about jobs, school, anything to improve my situation seems related to (hypo)manic episodes. During depressive times, if I am spending a lot of time soaking in personal blogs like someone might watch a soap opera, that can be an indicator that I am avoiding other responsibilities and using the Internet as escapism. (P6)

Given that bipolar disorder is a lifelong condition the inherent characteristics of which limit adherence to self-tracking, there seems a natural fit with sensing techniques that can relieve the burden of manual tracking. Such automated approaches might be capable of passively monitoring behaviors, detecting changes in mood, and reporting feedback about the potential onset of symptoms. Participants described their attraction to current consumer-grade tracking technologies that automatically collect data in the background. Although manual tracking was highlighted as an important practice by some individuals, in particular due to the aforementioned agency and intentionality it can provide, not all participants agreed that consciously recording behaviors and moods was a key factor in managing their illness. These individuals expressed concerns about the potential fallibility of tracking "by hand" while expressing beliefs that the primary value of self-tracking practices came from the data—not necessarily the act of recording it. One participant explained how they would willingly cease manual tracking if possible:

If I could automatically track all the factors, I would in a heartbeat. That would take out the human factor of forgetting to enter the time for the event and having to go back and enter it and having to guess when the time actually was. … I think that the data is the benefit in and of itself not the act of self-tracking." (P4)

In the light of the confounds associated with manual tracking, perhaps it is unsurprising that several participants were already using sensor-based devices and open to their use to help manage their condition. Participants reported using wearable devices like the Fitbit to measure indicators like sleep, activity, and heart rate in order to become aware of how related behaviors can impact moods and other bipolar symptoms:

I use [my smartwatch] every now and then. I'll check my heart rate just to see where it's at. And it allows me to realize, "Okay, I'm a little more excited than I should be, I need to calm down sometimes." And it allows me to see how active I've been, like the calories burned, steps taken, stuff like that. So it has helped me in realizing some different things that can affect my energy level, my mood, things of that nature. (P3)

Participants also explained that they see such passively sensed data as more "honest" and less susceptible to personal biases:

I have the Fitbit, and I really love that, and I really like the sleep-tracking component of it, because not only does it help me keep track, but when I'm

going through a tough time I can be lying to myself about how much sleep I've got—so it keeps me accountable, or like if I think if I'm having a lot of insomnia but I look at my data and I'm not, that's really helpful. (P2)

These comments introduce a possible role that sensor technologies could play in acting as a more objective witness that tracks and provides feedback about factors that individuals with bipolar disorder find challenging to reliably self-assess, for instance, fluctuating levels of social interaction:

It would be so cool if you could have a social monitor that you could track because I've been noticing at a conference, that I'm getting way more people interaction than usual. Particularly when I go from no people—low social stimulation—to loads of people—high stimulation. That can be very destabilizing to me, and I don't always catch on, so it would be great if you could have something like a Fitbit device that you could have that warns me, that says, "[P2], maybe you should go and have some quiet time." (P2)

To provide those extrinsic perspectives, some participants currently rely on friends and family, who help with self-management both by watching for warning signs of episodes and by supplying reminders to adhere to behavioral routines. Referring to social nudging, P9 explains, "It's very, very easy without some external force to, yeah, kind of let everything slide." These participants identified that they would find it helpful for technology to take on these support roles:

"I'd tell my friends: if you happen to notice certain behaviors, let me know. It was almost like having an alarm system. … My friends will go, "You might be heading for trouble—you might want to be careful." An app … could similarly let me know if I need to start being on the lookout." (P5)

Several participants believed that sensor-based devices might provide insights that humans would find difficult to discover on their own:

Because the phones do have so much technology in them, they are able to do things or tell us things that we're not necessarily thinking about or whatever. So that in a way would be really helpful for a lot of people. (P3)

However, not all participants were so eager to hand everything over to technology, revealing a tension between agency and automaticity. Individuals like P8 identified a trade-off between sensing systems improving tracking accuracy yet diminishing independence:

If it automatically tracked you, the accuracy would be better. But you almost have no input, no control—it's more the machine is dictating to you and you are

following the commands. I suppose I would do it for the accuracy. The tradeoff is dependent on the machine, you almost have no role in your own life. (P8)

Further, participants acknowledge that although today's devices may be able to enhance human capabilities when it comes to noticing patterns and making predictions, there is still a limit to the precision they can achieve:

> The positives, the good things about it, are it allows you to notice things you probably wouldn't have noticed as easily if you didn't have that type of device. The drawbacks would only be that it's limited to the software and the hardware of the system it's part of. (P3)

Several participants expressed this awareness of the limitations of sensing technologies and considered it crucial information to convey to new users for the sake of transparency:

> I think if there is a disclaimer that says it is 80% accurate, I would use it. I mean 80% is still pretty good to me. If there's an app, and there are so many apps on the web, that will monitor your sleep and things like that, and you try them and they just seem totally inaccurate, I would actually stop using the app within 2-3 days. (P1)

P1 additionally felt that her clinician should be similarly informed of these limits, as it would be essential for them to be conscious of potentially erroneous aspects of data if they were to effectively incorporate that information into treatment:

> And for my clinician, I think if there was a note, that said, "The app is 80% accurate, your clinician is aware of this," that would help. The downside would be the clinicians who look at it and don't stay conscious of that 80% and do start taking action or something like that. If a clinician phoned me and told me I wasn't getting enough sleep and I knew that I was, I would also probably stop using the app. (P1)

The perspectives on technology reflected in these statements show that, for individuals managing bipolar disorder, technology holds promise but is not a panacea. As with mainstream user groups, the sheer volume and nature of sensor data can be both a useful tool and self-imposed constraint. A primary concern related to this connection is the way in which mobile devices and ubiquitous access to the Internet can exacerbate or even trigger bipolar episodes, incite addictive tendencies, or feed into avoidance behaviors—those activities that distract us from the things that are difficult and/or truly important to us. Our research contributes to emerging scholarship systematically examining the relationship between technology use and mental health (Rosen, Whaling, Rab, Carrier, & Cheever, 2013) by highlighting some of the mechanisms by which one impacts the other and raising important questions of automaticity and agency.

6. DISCUSSION

6.1. The Nature of Self-Tracking for Bipolar Disorder

"Zero" Days

Technology-mediated self-tracking, often associated with the QS movement, is typically aimed at increasing self-knowledge through systematic collection, quantification, and interpretation of personal data, with the ultimate goal of improving some aspect of daily functioning. Individuals with bipolar disorder can be particularly hands-on in learning about their condition, especially just after receiving a diagnosis (Inder et al., 2010). This has traditionally included researching the condition by reading popular and academic writing and watching videos but has recently grown to include using QS tools to monitor personal patterns of behavior (Murnane et al., 2016).

Although the individuals diagnosed with bipolar who took part in our study reported some of the same activities commonly associated with QS practices, self-tracking in this context is seen not as much as a means for obtaining information in order to optimize performance or lifestyle but rather is undertaken in an effort to find balance within an experience of self that is in flux and volatile. Our participants were primarily concerned with finding, accepting, and stabilizing themselves and guarding against future relapse. In her discussion of the tracking practices of individuals with bipolar disorder, Emily Martin (2007) highlighted the tension between optimizing and balancing in terms of the "zero of normality" (p. 187). For typically functioning individuals, a "zero" day is usually far from desirable. In contrast, for people with bipolar disorder, no change can actually be an improvement. For these individuals, having an unremarkable day—annotated as a "zero" on a scale of –5 to +5, for example—often requires an enormous amount of time, energy, and discipline. This distinction has implications for the ways in which personal data are represented, presented, and made available to users through self-tracking systems.

Clinical & DIY ("Do It Yourself") Self-Tracking

The goal of most self-tracking for bipolar disorder is to provide clinicians with timely information on mood and medication adherence in order to enable earlier interventions to prevent relapse, evaluate the impact of current medication, and characterize mood instability. Currently, therapeutic self-tracking tools are predominantly clinician oriented: They are designed to provide mental health professionals with the information they need in order to assess and treat their patient. As such, these tools are mostly clinician generated and have been designed predominantly from a clinician's perspective. Although most participants in this study were introduced to self-tracking through clinical engagement, many individuals expanded their self-tracking activities to monitor a wider range of behaviors than traditional clinical instruments support. This encompassed creating entirely personalized spreadsheets,

seeking out bipolar and non-bipolar-oriented tracking apps, and incorporating data from consumer wearables like Fitbit. Prior research into quantified-selfers' tracking practices has similarly found that some individuals create custom tracking tools when no existing tools meet their needs, often motivated by a desire to perform self-experimentation in order to determine correlational and causal connections between behaviors and outcomes of personal interest (Choe, Lee, Lee, Pratt, & Kientz, 2014).

We saw a distinction between self-tracking tools that focus primarily on collecting data about daily activities that will subsequently be incorporated into clinical diagnosis, decision making, or treatment (i.e., *clinician-oriented tracking*) and those designed or assembled by participants to help themselves monitor, regulate emotion, and make sense of their own patterns of behavior (i.e., *person-centered tracking*). Although there is an obvious benefit to the former for providing clinicians with timely and relevant information on their patients, there are challenges associated with this approach. If self-tracking is only considered in the context of standardized rubrics, there is risk of both normative expectations and pressures related to adherence. On the other hand, the latter person-centered approach may be more difficult to use in a clinical setting but may provide a more robust and idiosyncratic view of an individual's progress and experiences.

Further, person-centered self-tracking has the potential to contribute to evolving approaches to the diagnosis of bipolar disorder. Prior work has called for a move away from traditional methods of diagnosis like the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.)—criteria used by mental health professionals to assign a diagnosis to patient—toward treatments that "convey the reality of the patient's experience" (Licinio, 2005). Where current clinical criteria for mental illness make it easier for clinicians to identify and treat clusters of common symptoms, in reality each mental illness category—be it bipolar disorder or major depression—are umbrella terms for heterogeneous diseases. Self-tracking, particularly objective behavioral sensing, offers the potential to refine these categories into more atomic groupings and work toward more personalized treatments.

Participants in our study employed a broad range of self-initiated tracking activities to help them gain control and insight into their condition. Many of these tools included elements notably absent from most clinical tools such as positive motivating feedback and the identification of positive anchoring patterns of behavior. They also facilitated a collection of data across a broader expanse of real-world behavior that may account for the fact that bipolar disorder affects almost every aspect of life.

Self-tracking tools that are oriented to variables of individual concern, that integrate psychosocial factors into the capture of data, and that feed this information back to users in a manner appropriate to individual needs may help improve acceptance and engagement in treatment. However, the degree of self-tracking that current QS tools enable introduces questions of granularity and both data and mental health literacy that have implications for both clinicians and individuals with bipolar disorder. Sajatovic et al. (2005) suggested that clinicians must take an active role in attempting to understand a person's stance towards illness and adherence. This might be extended toward self-tracking to the extent that clinicians might try to better support individuals with bipolar

disorder as they try, through the use of QS-type technologies, to understand their patterns and find a sense of self.

Although the self-tracking practices of the individuals in our study, particularly those that were self-fashioned or self-initiated, indicate a need not being met by existing clinical tools (e.g., lack of personalization and motivating feedback), these instruments also possess their own limitations. For starters they are not necessarily clinically sound.

It is perhaps this lack of patient-centered clinically grounded solutions that led to the piecemeal approach to self-tracking, reported by most participants that required collecting personal information across different devices and software.

Custom approaches, such as P1's spreadsheet, are tailored entirely to the needs of one person and as a consequence can not harness data aggregated from other people with bipolar disorder, also making it challenging to use efficiently in clinical settings. Although many participants reported trusting the data from off-the-shelf sensor devices in lieu of manually collected data, most of these technologies have a lack of transparency about the accuracy of their measurements, which could lead to misinterpretations and inaccurate data.

In summary, more work is clearly needed in this area, but future studies should investigate the specific affordances and characteristics of person-centered self-tracking in contrast to clinician-oriented approaches. Based on findings from our study, we would anticipate that this type of investigation would identify a host of requirements for personal informatics systems that are adaptive, responsive, and more conducive to the sharing of personal information in ways that respect privacy while keeping health professionals apprised of a patient's current status.

6.2. Self-Tracking as a Process

Researchers studying the growth of personal informatics tools and self-tracking practices have conceptualized tracking as a five-stage iterative process (preparation, collection, integration, reflection, and action) through which individuals capture and act upon information (Li et al., 2010). Subsequent work has expanded this model in a number of ways including identifying additional styles of tracking such as goal-driven or documentation-based activities (Rooksby, Rost, Morrison, & Chalmers, 2014), supplemental stages of tracking such as a maintenance phase (Li et al., 2010) or lapsed tracking (Epstein et al., 2015), and ways to accommodate clinician–patient collaborations when self-tracked data from commercial tools is used as part of clinical treatment (Chung et al., 2016).

Synthesizing this work with the staging model of bipolar disorder identified by Berk et al. (2007), described in Section 2.2, and the phases of self-tracking identified by participants in this study, we propose the following progression for self-tracking in the context of bipolar disorder:

Prediagnosis: Nontracking or self-initiated tracking.

Postdiagnosis: Beginning shortly after diagnosis, preparing and initiating formal tracking (at a clinician's behest) for discovery, to gain control, and to maintain stability.

Maintenance: Self-motivated tracking of therapeutic and personally relevant variables with a priority on adherence.

Lapsed: Unreliable, sporadic, diminished, or abandoned tracking often as a result of fluctuating moods that cause distorted perceptions of self and interfere with an individual's ability to self-track.

Internalization: Deliberately decreased or discontinued instrument-based tracking (potentially replaced with mental checks) once awareness of patterns is established or symptoms reduced due to medication or nonpharmacological treatment.

Targeted: Resumed or increased tracking during stressful periods or to recover from a mood episode.

Although this cycle implies a linear chronology, we know from prior work that the course of bipolar disorder is rarely predictable and is often multidirectional (Frank et al., 2000). We have seen in the narratives of our participants that stages can be skipped (e.g., going from maintenance to internalization) or can loop (going from maintenance to lapsed back to maintenance to internalization). However, this framework captures an initial understanding of the evolving goals, intentions, and value of self-tracking at different points in the life cycle of a bipolar diagnosis. Our study is just one step toward validating such a schema. Refining it will require a better integrative understanding of how bipolar disorder develops over a life span (Miklowitz & Cicchetti, 2006) and more extensive work examining generalized self-tracking practices as technologies evolve.

Such a validated schema would enable us to (a) look at the self-tracking practices of individuals with bipolar disorder as part of a broader set of behaviors related to technology-mediated representations of self and (b) make more exhaustive use of data being collected by patients for diagnostic, treatment, and assessment purposes. Better understanding of the phases just outlined could enable researchers to examine whether self-tracking at different points in the bipolar cycle has different effects on mood state. This information could be used develop technologies that adapt to a user's current state to support appropriate types of tracking practices.

6.3. Design Considerations

Participants' practices of self-tracking change over time according to their understanding of their condition and life factors. Instead of static self-tracking tools, there is a need for agile instruments that address participant needs as they learn about their condition postdiagnosis and move into a maintenance phase. The assemblages of tools and DIY practices described by our participants tools appear to be filling a gap left by current clinical

tools. The individualized practices described by our participants offer hope that personal informatics technologies can be developed that address some of the significant challenge of bipolar disorder such as coming to terms with diagnosis, learning about personal patterns and risk factors, stabilizing a sense of self and accepting that self, and accounting for some of the biases and blindsides associated with bipolar disorder. Successful design and deployment of this type of self-tracking technology is not just an issue of the ways in which personal information is sensed and recorded but also related to issues about the ways in which these data are represented and presented to users. Currently, as designers we tend to focus on the quantitative, but as our participants have shown, these numbers have deeply personal and qualitative associations.

To account for the phases just identified and the unpredictability with which one transitions between them, we suggest that a self-tracking system should have the ability to move back and forth between fully manual and wholly automated tracking. The threshold for automatic versus manual should respond to the phases of a person's illness, as they transition in and out of different states. For instance, tools for self-tracking during discovery or diagnosis might be designed for temporary and targeted use, whereas those geared toward treatment or maintenance might be designed in ways that better align with longer term and even indefinite use. As another example, systems might promote manual tracking during early stages postdiagnosis to build self-awareness and agency, provide automated though highly visible tracking during mood episodes when adherence and reliability of data is particularly critical, and transition over time to more passive sensing as an individual becomes more familiar and adept at managing their condition without technology-mediated assistance.

Our findings also indicate there are important bipolar-specific and idiosyncratic factors that designers should take into consideration when developing technologies to support the management of bipolar disorder or other chronic health conditions. These include (a) accounting for mood state and inherent biases in self-tracking at different phases of the illness and (b) recognizing that this population is especially vulnerable to avoidance behaviors that can make it difficult to moderate technology use.

Connecting tracking technologies to online networks can provide access to a world of temptations including overuse/misuse of social media, online shopping, gambling, and other obsessive behaviors that can potentially fuel or even trigger symptoms. Many conventional self-tracking applications incorporate social media features for sharing successes and tapping into a supportive community when faced with challenges. However, the nature of bipolar disorder can result in these conventional social features being implicated in avoidance behaviors, violations of privacy, and feelings of shame or demoralization, if not implemented in ways that are sensitive the vulnerabilities of this population.

Further, more objective methods of self-tracking may increase the reliability of self-reported data, but the limits of these technologies should be clearly communicated to improve acceptance and reduce the possibility of clinical misunderstandings. There is also a potential tension point wherein automated tracking approaches (which passively monitor behavior and provide intervention, potentially preemptively, when symptoms or their onset is detected) can relieve some of the difficulties associated with adherence

and reliability—but they can also interfere with some of the agency building and identity-development afforded by manual tracking.

7. LIMITATIONS

The data presented here are necessarily limited and subjective. The sample, recruited via a clinic where each participant had been treated, is unlikely to be representative of the larger population, and hence descriptions of self-tracking practices may be limited in terms of generalizability. It is also important to mention that characteristics of the disease may have introduced bias: Cognitive deficits and mood states associated with the condition may impact on the accuracy recollection. Nevertheless there is significant value to examine the self-tracking experiences of people with lived experience of this disease, which at the least contribute a personal dimension that is often lacking in clinical accounts and approaches to the management of the condition (Goodwin & Jamison, 2007).

In future work, we would like to explore the self-initiated use of self-tracking tools on a broader scale via a survey-based instrument in order to identify the prevalence of the themes identified in this article. It would also be interesting to understand how common it is for people with this disease to create self-fashioned tools to gain personal insights and whether additional design insights may be gained through their examination. Several participants in this study indicated an interest in automated monitoring sometimes with concomitant concerns about personal privacy. Last, we are interested in further exploring the nature and affects of self-representation via these tools and practices by better understanding the ways in which standard data visualizations techniques influence ideas of normative baselines in self-tracking data.

8. CONCLUSION

Because it is a complex disease, effective treatment of bipolar disorder can involve many elements including identifying personal risk factors, accounting for individual mood patterns and triggers, regularizing daily routine, and managing medication. Our study indicates that people with bipolar disorder can be very engaged in the self-management of their illness and that self-tracking tools can serve a vital role in this process. Digital self-tracking technologies are well placed to provide self-tracking that includes psychosocial aspects of the illness that current clinical tools leave out. Technology-mediated tracking of bipolar could also enable broader collection of data from distributed, diverse populations over long periods, which could in turn contribute to a more comprehensive foundational understanding of bipolar disorder, including its impact on developmental processes like identity construction. However, these tracking techniques also raise issues of the effects of normative scales, the ultimate benefits or dangers of self-inspection, and the ethics of comparing across individuals and populations as if they are all sharing the same

experience. Unlike typical QS self-tracking, self-tracking in bipolar disorder is less about self-improvement and more about maintaining normalcy and self-stabilization. Designing for a particularly vulnerable population like individuals with bipolar disorder can throw these issues into relief, making aspects of the human experience more visible.

NOTES

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