

Opportunities for Collaborative Clinical Work: Predicting Relapse Onset in Bipolar Disorder from Online Behavior

Johnna Blair
jlb883@psu.edu
Penn State University

Erika F.H. Saunders
esaunders@pennstatehealth.psu.edu
Penn State College of Medicine

Dahlia Mukherjee
dmukherjee@pennstatehealth.psu.edu
Penn State College of Medicine

Saeed Abdullah
saeed@psu.edu
Penn State University

ABSTRACT

Bipolar disorder (BD) can negatively impact the lives of individuals. Symptoms of BD can manifest not only in their offline behaviors, but online as well. Being able to identify manic and depressive mood episodes early on can lead to more effective interventions. In this work, we focus on understanding the feasibility and acceptance of an early warning system for patients with BD that leverages online behavioral data to infer mood episode onset. For this, we interview three participants with BD to probe how they envision this type of intervention system and might use it to manage BD. Our goal is to uncover the opportunities and constraints of the future of work in BD healthcare that connects intelligent tools and objective data to provide an effective partnership between patients, caregivers, and clinicians. Toward this goal, in this paper, we focused on understanding concerns and gathering design ideas from patients with BD. We present this study as a case for a new type of work, incorporating clinical perspectives from start to finish—both as collaborators and active participants—to enhance clinical work experiences and provide better care.

KEYWORDS

Intervention design, Health informatics, Collaborative work in healthcare, Mental health, Bipolar disorder

ACM Reference Format:

Johnna Blair, Dahlia Mukherjee, Erika F.H. Saunders, and Saeed Abdullah. 2020. Opportunities for Collaborative Clinical Work: Predicting Relapse Onset in Bipolar Disorder from Online Behavior. In *14th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '20)*, May 18–20, 2020, Atlanta, GA, USA. ACM, New York, NY, USA, 5 pages. <https://doi.org/10.1145/3421937.3421947>

1 INTRODUCTION

Bipolar disorder (BD) is one of the leading causes of years lived with disability and has a substantial economic burden at a societal level[6, 8]. 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[2]. Shifts from a stable mood state into depressive or manic mood episodes can be often be unpredictable and require long-term treatment, involving both medication and psychological counseling. BD can be very difficult to manage, especially without adequate support from both clinicians and social support networks[5].

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[6]. The outcomes of these symptoms, such as stressed relationships and increased spending, can be socially and financially detrimental to individuals with BD[2]. BD symptoms are no longer limited to offline life, but can also reflect in online behaviors of individuals and the way they use technology[1, 7]. 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. Past work has investigated this connection and the different ways in which each mood episode may present itself through online behaviors[1, 7].

Leveraging this objective online behavioral data could help individuals learn about and manage their BD, as well as enhance the work lives of clinicians. Our body of work aims to test the concept of using online data of individuals to infer the onset of BD mood episodes—both from the standpoint of data feasibility, but also the acceptability from those who would use the resulting intervention system. In this paper, we will focus primarily on the acceptability of this hypothetical intervention system from the perspectives of patients and clinicians. More specifically, we wanted to understand patients' concerns for using their online data as an early warning system, such as privacy and accuracy of information, as well as how they foresee implementing such a system to manage BD and share information with their clinicians.

Additionally, it is imperative to understand how these clinician insights align with those shared by BD patients. In future work, we intend to gather the perspectives of clinicians who treat those with BD using a participatory design approach[10]. What are their concerns with using patient online data for this purpose? How could this system change their work experiences? What are the possible challenges involved in this intervention approach? We consider both perspectives crucial to build an intervention system

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

PervasiveHealth '20, May 18–20, 2020, Atlanta, GA, USA

© 2020 Copyright held by the owner/author(s). Publication rights licensed to ACM.

ACM ISBN 978-1-4503-7532-0/20/05...\$15.00

<https://doi.org/10.1145/3421937.3421947>

that supports the treatment needs of patients, but also leads to more effective and rewarding work experiences for clinicians.

We present the initial findings and future directions of this larger study as a case for a new type of clinical work. We describe the ways in which we have incorporated clinical perspectives throughout the research process—as research collaborators and participants. We highlight the ways in which behavioral interventions could improve the work experience for BD clinicians and provide suggestions to get clinicians involved with future mental health intervention systems. We also suggest a possible need for a new type of work—one that acts as an intermediary between technologists, clinicians, and patients—to help users smoothly transition to new interventions. If data-driven interventions can effectively take on some of the burdens of BD treatment, clinicians can more easily focus their efforts on the professional strengths that these data systems cannot replicate, such as building supportive relationships and fostering positive growth in their patients.

2 METHODS

Understanding and empathizing with the lived experiences of those with bipolar disorder is key to developing a supportive and effective intervention system. We also wanted to acknowledge the value of their unique insights and provide a sense of user agency in the design of a system for such an often stigmatized condition. For these reasons, we took on a participatory design approach to this work to give our participants a more active voice in the design process. Our first step with this work was to interview patients with BD. We recruited participants who had experienced at least one manic, hypomanic, and/or depressive episode within the past year. For this paper, we have interviewed three participants, between the ages of 46 and 73—one who experiences primarily manic mood episodes, one who experiences primarily depressive episodes, and one who has experienced significant manic and depressive episodes within the last few years. The first patient was interviewed in-person at a medical research center. Due to constraints imposed by the Covid-19 pandemic, we interviewed the later two using Zoom.

The methods and research protocols for this overall study were developed in collaboration with a clinical professional, who regularly works with BD patients, both in research and clinical practice. This clinician was involved in developing our inclusion criteria, accessing a pool of BD participants, and helping us craft an interview script to adequately investigate both clinical and design-based goals. These interviews were also conducted with a clinician present. This was done as an additional measure to judge participants' capacity to consent to research activities, insure patient comfort and safety should any psychologically triggering topics arise in discussion, and provide an additional point of view on patient responses.

In these interview sessions, we aimed to understand participants' thoughts about their own online behavioral data to signal changes in mood episodes and help them manage BD. To do so, we first walked participants through downloading their own data from Google—data that we will later analyze against their medical records to test the technological feasibility of inferring mood episode from online data. Then, we asked a set of questions about how they use technology during manic and depressive mood episodes. This included their most common activities during each type of mood

episode, like online shopping, gambling, email, and web browsing, and their periods of high and low activity, such as high night activity during manic episodes and a drop in all use during depressive episodes. We then presented them with the concept of using their online data, from Google or social media sites like Facebook and Twitter, to help infer future mood episodes. We left this concept open-ended to allow users to describe the intervention system as they pictured and how they envisioned using this type of system to meet their unique needs for BD management. We discussed potential concerns, such as data privacy and how accurately they believed this information could infer their mood episodes. We also probed different design ideas. These ranged from how much data they wanted to be shown and how often, to more complex functions, such as the ability to have the system to act on their behalf in key situations. Specifically, we wanted to gauge the level of agency they expected to have in this type of system, through features like automated alerts for "red flag" behaviors and the idea of disabling specific online activities (e.g. online shopping) when in a mood episode. We wanted to understand how they would incorporate such a system within their daily life, as well as how they might wish to share information with clinicians using this proposed system.

3 INITIAL FINDINGS

3.1 System Expectations

Because one of our research goals was to gather design ideas and key features, we did not present a concrete picture of what this resulting system might look like. Despite this, P1 and P2 leveraged familiar behavioral tracking technologies, such as FitBit, in how they envisioned the system. Instead of physical activity, P1 pictured the system automatically tracking his online activities carried out on both his computer and smartphone. To P1, this system would include a dashboard feature to show high-level usage information and options to isolate different online behaviors or key time frames for more granular information. All three participants liked the idea of having both day to day activity logs and longitudinal trends presented in an easily digestible and familiar form. They saw this as a way to learn about and compare behaviors over the span of time. P3 suggested this could be useful across multiple years, as she can go several years between manic mood episodes, but only a few months between depressive mood episodes.

3.2 Disabling Problematic Activities

When discussing the idea of user agency and how comfortable they would feel letting a system perform actions on their behalf, those who experienced manic mood episodes (P1 and P3) had mixed opinions. We discussed example scenarios, such as limiting purchases or late-night emails, and the ways the system could intervene. For instance, with online shopping, the system could restrict purchasing actions on different websites, ultimately disabling the problematic behavior. Conversely, the system could instead provide a message such as *"Are you sure you want to purchase this item for \$199?"*, prompting them to take a moment to think about the action before making the decision, but still ultimately allowing them the choice and maintaining their sense of agency.

P1 discussed that in his current mindset (e.g. not in a manic or depressive mood episode) he could see benefits to both. He would

feel more in control if he was provided the ability to make his own decisions. However, he knew that if was faced with a prompt to think through decisions while in a manic episode, he wouldn't follow it. *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.* He then felt that it would be more effective to have a system step in for certain high risk behaviors, such as spending money and browsing the web on his phone while driving. *I know that me, in a manic state, would hate being told by a computer that I'm not allowed to do something. But me, in a sound mindset, knows that it would be for the greater good.* P3 held similar views for activities such as online shopping. She noted that, when in a manic mood episode, the system would likely make her angry for restricting activities, but would ultimately be useful, rather than giving her the option to continue—something P3 would *likely choose on impulse every time it was offered.*

3.3 Patient-Clinician Relationships

3.3.1 Clinician Burden. In terms of sharing information with their clinician, P1 believed this system could potentially be an effective management tool, but also had many concerns. When talking about the types of behavioral data used, he was less concerned about the level of sensitive information his clinician might see, but was more concerned about over burdening them. He did not want the system to push too much information to his clinician, not because of that would be in his data, but because of the perceived amount of information his clinician would have to go through, the amount of extra time it could involve, and any after-hours interruptions that might occur if the system was to automatically notify his clinician of red-flag activities or a mood episodes sensed. He wanted to minimize notifications to only those most important to their clinician, as to not add to their workload. P2 and P3 held similar worries about burdening their clinicians, but showed more concern that their clinicians could receive sensitive data out of context.

3.3.2 Facilitating Communication in Clinical Settings. It became apparent, especially for P1, that there were concerns about how this type of system would impact their therapists' work life. Rather than the system giving their data to the clinician all at once, participants thought that their behavioral data could also be used to prompt discussion in therapy sessions. They saw this as a helpful, more effective way for them to update their therapists during limited therapy sessions. In addition to behavioral data visualizations, they wanted the option to leave contextual notes within the system. As P1 illustrated, if his data showed a sudden spike in late-night YouTube viewing for a particular week, he could leave notes about how he was feeling and what was going on in his offline life at that time. P2 and P3 currently logged their behavioral triggers in paper diaries—something they wished to integrate into the system. In doing so, they could learn new associations between offline and online behaviors, as well as common coping behaviors.

P1 talked in great depth about his struggles to stay focused, remember information, and effectively communicate his thoughts in therapy session. He believed this often made his therapist's job more difficult. Therefore, he hoped to use this proposed system as a communication tool and saw it as an opportunity to improve his relationship with his therapist. By using his data as a reference point, he could more easily stay on task, remember specific events that

had occurred between sessions and important issues he wished to discuss, as well as take a more active role in his treatment. Similarly, P3 believed this could help her stay on task in sessions, as she also experiences ADHD. P2 also thought it could benefit her relationship with her therapist if she could include personalized voice messages along with system notifications as to *"not overly worry [her therapist] over something minor."*

4 FUTURE WORK

The next stage of our work is to address the clinician's point of view on this online data-based intervention system by engaging in participatory design methods [10] with therapists who regularly treat patients with BD, but also other BD care providers, such as social workers. First, we want to investigate their own needs for this type of system, as well as address their patients' needs and any concerns they may have with our initial insights gathered from patients. We also want to probe existing design concepts that have provided benefits to users in other health contexts, such as gamification [9], and discuss their suitability for those experiencing different mood episodes, how they align with BD treatment goals, and any challenges they could cause for the user. Using other co-design activities, including paper prototyping and concept ranking, we want to better understand how clinicians envision this type of intervention and prioritize its potential features. Lastly, we want to contextualize this type of intervention within clinicians' own work. This can help us understand what the other side of the intervention system needs to look like, how it should integrate within their work rhythms, and the ways its use could lead to a more rewarding workplace experience. Considering the proposed features of early mood episode detection and automated warning notifications, we need to understand how the implementation of this system would impact their lives, on and off the clock, and how that may alter their role and responsibilities as a clinician.

5 DISCUSSION

Our key goal is to leverage granular and objective data that can be used for effective monitoring of BD patients over a longitudinal period of time. However, the success of such a system requires a symbiotic relationship across stakeholders. For example, are patients comfortable with collecting and sharing potentially privacy sensitive data? How should the system intervene when it detects anomalous interactions? Additionally, how can we identify what will work best for different patients? This paper is a step toward answering these questions and specifically aims to rethink the clinical work space by creating a symbiotic relationship among clinicians, caregivers, and patients.

5.1 Leveraging Clinical Experience

5.1.1 Minimizing Risk. Because mental health treatment is highly unique, dependant on individual needs, and varies over time, developing one intervention to address all potential users is a difficult task. There are many existing choices for online and mobile health monitoring systems—for general users or specific conditions, some of which are not evidence-based. Given this, there is an inherent risk to users if interventions do not properly align with individual patient needs and backed by clinical evidence. As technologists,

we can attempt to minimize these risks, but without the help of clinicians, others can go unnoticed. Although unintentional, common design features can produce adverse effects to patients. A good example of this is the use of food tracking apps for patients recovering from eating disorders, critiqued in the works of Eikey et al. [3, 4]. While these systems can help users maintain healthy calorie consumption, the core of the design was geared towards weight loss. Because of this, information useful for tracking weight gain can be presented in triggering and counterproductive ways.

In the case of our work with BD interventions, future users could face similar adverse outcomes if the clinician perspective was not baked into the research process as a whole. In a future stage of our work we want to discuss our initial concerns with BD clinicians and uncover any additional issues to help mitigate these potential risks. For instance, could too much information about their BD behaviors be overwhelming to some patients? Does this have the potential to exacerbate specific BD symptoms? Are there some situations in which these risks outweigh the potential benefits? By talking to clinicians, we can better understand the patients for which this type of intervention is best suited and how to design a system in direct alignment with their needs. By minimizing the potential high risk situations faced by clinicians, their work can take on a more proactive, rather than reactive approach.

5.1.2 Adapting Existing Clinical Procedures. By collaborating with clinicians and establishing a better understanding of clinical treatment, we can build these existing procedures into the design and system architecture of future interventions. For instance, clinicians regularly deploy behavioral contracts with their patients, depending on the nature and severity of their conditions [11]. These traditional, paper-based legal contracts can provide patients and clinicians with clear directions and expectations for what will occur when a patient is not in a state to make their own decisions or dictate who can act on their behalf in different situations.

This concept and its core functions closely align with the idea of automated restriction of high-risk online behaviors and clinician notifications when a mood episode has been sensed. In this case, the system settings, decided on by the clinician and their patient, could be incorporated into this traditional behavioral contract. Likewise, this existing protocol could be used to structure the range of activity-limitation options provided and how the system could act on behalf of patients when put in place. It would be beneficial to better understand the clinician's point of view on patient agency regarding online behaviors. This perspective could help clarify what degree of agency is most beneficial to individual patients of varied severity, as well as how flexible this type of design should be to meet a range of needs. If designed effectively, this could be an additional tool used to help streamline clinical work.

5.2 Communicating Clinical Value

5.2.1 Benefits to Patients. By including clinician insight throughout the research and development of BD intervention systems, we can help ease the adoption process for all users. Concerns over therapeutic validity and effectiveness can be addressed by the checks and balances managed between technical and clinical researchers. This can help assure that the patient's best interest is embedded in design and the activities supported by the system are in alignment

with their treatment needs, as well as the clinicians' own needs for supporting multiple patients without feeling overburdened. This can help minimize potential risk to patients early on and avoid potential negative outcomes. Simply put, intervention systems are more likely to be accepted and actively implemented if they have been built in line with clinical perspectives, which lends credibility.

5.2.2 Benefits to Clinicians. Despite the possible burdens faced in the early stages of implementation, this type of mental health intervention still stands to benefit both the clinician and their patients. For instance, the behavioral tracking features of this type of system could be leveraged as a tool for better self-reflection and communication. This could help streamline therapy sessions, allow patients and clinicians to prioritize key issues and be able to cover more content in an efficient, but still effective way. Given the cost and availability of mental health resources in the US, this is especially important for patients who may have financial limitations dictating how often they can meet with their clinician. At the same time, it could allow over-extended mental health professionals better manage rising case loads, while still providing critical care and meeting a wide range of patient needs.

5.3 A New Type of Work

By modeling new data-based interventions after familiar consumer tracking systems, we can make systems more intuitive to non-technical users, attempt to make adoption less of a burden, and reduce implementation challenges. However, as we extend these types of intervention to more complex conditions and treatments, this becomes more challenging. It is important for future research to consider the need for new type of work within intervention design. This new role could act as intermediary support between those with a formal data science background, clinicians, and their patients. By introducing this alternative type of "technical support", intervention systems could be more easily deployed by those who stand to benefit from them most—such as social workers, who may face a high demand from a large pool of patients, but less time and fewer resources available. This role could divert some of technical workload and help reduce the burden put on clinical professionals and patients. This could be especially beneficial in the early stages of implementation, allowing clinicians to focus on providing the best care, without compromising the benefits that technology-based interventions can provide their patients.

6 CONCLUSION

As clinicians make up one side of the patient-clinician relationship, intervention systems must to also be built in alignment with their goals, consider their existing work routines, and leverage their existing clinical procedures. Incorporating clinical perspectives as research collaborators and participants can insure that resulting interventions sufficiently support patient needs and mitigate high-risk situations, as well as strengthen supportive patient-clinician relationships. Not only could this improve care for patients, but lead to more fulfilling work experiences for clinicians. This increased use of objective data and behavioral tracking to facilitate clinical care, rather than using subjective self-reporting alone, may suggest a new form of work to ease the transition to technology-based interventions and improve access to mental health treatment.

REFERENCES

- [1] Saeed Abdullah, Mark Matthews, Ellen Frank, Gavin Doherty, Geri Gay, and Tanzeem Choudhury. 2016. Automatic detection of social rhythms in bipolar disorder. *Journal of the American Medical Informatics Association* 23, 3 (2016), 538–543.
- [2] Joseph R Calabrese, RM Hirschfeld, Mark A Frye, and Michael L Reed. 2004. Impact of depressive symptoms compared with manic symptoms in bipolar disorder: results of a US community-based sample. *The Journal of clinical psychiatry* 65, 11 (2004), 1499–1504.
- [3] Elizabeth V Eikey. 2018. Unintended users, uses, and consequences of mobile weight loss apps: using eating disorders as a case study. In *Current and Emerging mHealth Technologies*. Springer, 119–133.
- [4] Elizabeth V Eikey and Madhu C Reddy. 2017. "It's Definitely Been a Journey" A Qualitative Study on How Women with Eating Disorders Use Weight Loss Apps. In *Proceedings of the 2017 CHI conference on human factors in computing systems*. 642–654.
- [5] National Collaborating Centre for Mental Health (UK et al. 2006. Bipolar disorder: The management of bipolar disorder in adults, children and adolescents, in primary and secondary care. British Psychological Society.
- [6] Terrence A Ketter et al. 2010. Diagnostic features, prevalence, and impact of bipolar disorder. *J Clin Psychiatry* 71, 6 (2010), e14.
- [7] Mark Matthews, Elizabeth Murnane, Jaime Snyder, Shion Guha, Pamara Chang, Gavin Doherty, and Geri Gay. 2017. The double-edged sword: A mixed methods study of the interplay between bipolar disorder and technology use. *Computers in Human Behavior* 75 (2017), 288–300.
- [8] Kathleen R Merikangas, Robert Jin, Jian-Ping He, Ronald C Kessler, Sing Lee, Nancy A Sampson, Maria Carmen Viana, Laura Helena Andrade, Chiyi Hu, Elie G Karam, et al. 2011. Prevalence and correlates of bipolar spectrum disorder in the world mental health survey initiative. *Archives of general psychiatry* 68, 3 (2011), 241–251.
- [9] Aaron S Miller, Joseph A Cafazzo, and Emily Seto. 2016. A game plan: Gamification design principles in mHealth applications for chronic disease management. *Health informatics journal* 22, 2 (2016), 184–193.
- [10] Michael J Muller and Sarah Kuhn. 1993. Participatory design. *Commun. ACM* 36, 6 (1993), 24–28.
- [11] Michael L Volk, Sarah R Lieber, Scott Y Kim, Peter A Ubel, and Carl E Schneider. 2012. Contracts with patients in clinical practice. *The Lancet* 379, 9810 (2012), 7–9.

ACKNOWLEDGMENTS

We would like to thank the Tronzo Medical Informatics Endowment and Penn State Institute for Computational and Data Sciences (ICDS) for partially funding this research.