

Personal Informatics in Interpersonal Contexts: Towards the Design of Technology that Supports the Social Ecologies of Long-Term Mental Health Management

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Personal informatics systems for supporting health largely grew out of a “self”-centric orientation: self-tracking, self-reflection, self-knowledge, self-experimentation, self-improvement. Health management, however, even when self-driven, is inherently social and depends on a person’s direct relationships and broader sociocultural contexts, as an emerging line of research is coming to recognize, study, and support. This is particularly true in the case of mental health. In this paper, we engage with individuals managing the serious mental illness bipolar disorder and members of their support circles to (a) identify key social relations and the roles they play in condition management, (b) characterize patients’ complex interactions with these relations (e.g., positive or negative, direct or peripheral, steady or unstable), and (c) understand how personal informatics mediates these recovery relations. Based on these insights, we offer a model of this social ecology, along with design implications for personal informatics systems that are sensitive to these interpersonal contexts.

CCS Concepts: • **Human-centered computing** → **Human computer interaction (HCI)**; **Collaborative and social computing**;

Keywords: Personal Informatics; Quantified Self; Collective Intelligence; Collaborative Sensemaking; Self-Management; Mental Health; Serious Mental Illness; Bipolar Disorder

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1 INTRODUCTION

Recent years have seen a significant increase in the availability of technologies for tracking various details of one’s life. The term Personal Informatics (PI) was coined to refer to such tools aimed at helping users collect and reflect on personal information [57]. While people use PI for a number of reasons (e.g., to track finances, document visited locations, out of curiosity, or to receive rewards

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on social networking sites) [29], most users are interested in capturing and accessing data relevant to health, specifically in an effort to change behavior (e.g., to lose weight, quit smoking, or improve sleep) or as part of self-managing a chronic condition [77, 92]. Quantified Self (QS) practices, which refer to individuals examining various facets of their lives and bodies through self-tracked data, often similarly have the goal of optimizing health and wellness [62, 79].

Initially, the design of PI systems for health typically emphasized an “ego-centric” perspective focused on a single person [53], reflecting a tendency to self-orient engagement with personal data by placing individuals at the center of tracking practices. The term itself, *personal informatics*, stresses this model of tracking as an *individual* activity.

Our research extends a growing body of literature that reflects an increasing interest in studying and designing for more *collective* PI practices, such as socially sharing personal data, tracking on someone’s behalf, and pooling communal data [10, 53, 61, 66, 92, 93]. Further, even when PI activities do not explicitly involve multiple parties, independent collection and interpretation of data is still shaped by social institutions [63]. These evolving use cases throw a number of sociotechnical issues into sharp relief, such as representation, privacy, provenance, brokerage, sensemaking, knowledge production, and decision making. In this paper, we offer an operationalization of these issues based on Bronfenbrenner’s ecological model of social relations [14, 15] in order to strengthen and expand the theoretical tools available to PI researchers seeking to move beyond ego-centric applications. We use our work with individuals who self-track as a form of mental health therapy in order to demonstrate how our model can be applied even when social relations are especially complex.

Indeed, the deep embedding of health management practices in social contexts is particularly salient in the case of serious mental illness (SMI), which affects 1 in 25 adults in the United States in a given year [80]. Prior work has established that many individuals facing SMI adapt off-the-shelf PI tools (e.g., self-tracking apps, wearables, spreadsheets, calendars, etc.) for the long-term management of their condition [51, 69, 76]. However, this comes with challenges such as a lack of support for tracking SMI-specific indicators, usability issues that impede logging during unwell periods, and the fact that technology use in general can disrupt emotional balance by interfering with sleep or fueling a sense of social inadequacy [70].

While these types of personal data do not necessarily make it into standardized healthcare records [104], they are often informally shared with clinicians and care managers in the course of establishing lifelong self-care practices. Further, when individuals with SMI share their self-tracking information with members of their support networks, a diverse and potentially revolving set of interpersonal connections (referred to in this paper as “social relations” or “stakeholders”) are activated around personal data practices, influencing and contributing to the use of these traces in ways that extend beyond single-user requirements.

In working in this space, we have been particularly inspired by the notion of “relational recovery” [86] from the mental health domain that overtly acknowledges the role that family, friends, antagonists, peers, organizations, cultures, and numerous other potential relations play in the process of coping with SMI. However, even this term — referring to “recovery” — can be problematic because there is no cure for many SMIs, and managing chronic mental illness often spans a lifetime. Because of tensions like this, the social implications of siloed tracking and personal data practices become highly acute in the long term management of SMI. However, as shown by recent work highlighting the beneficial impacts of social support and advocating for more socially-embedded approaches to interaction design [2, 39, 91], these issues apply to broader populations as well.

To better understand how PI systems can leverage a model of social and technological relations, we explore the connections and bonds — both positive and negative, weak and strong, current and past — between individuals with SMI and the social relations that surround them. Through a series

of one-on-one interviews with individuals with SMI ($N=14$) as well as focus groups involving both individuals and stakeholders ($N=8$), this paper undertakes that conversation.

Our specific contributions are as follows:

- A characterization of the social relations and roles in dynamic support systems surrounding the self-management of SMI.
- The operationalization of a model grounded in ecological systems theory and our empirical data that formalizes these social relations and roles.
- A series of implications of this work for PI system designers who want to leverage the structure of a social relations model to address collective and dynamic contexts of use.

As such, our work contributes to recent PI research in several ways. First, while a number of studies have focused on patient-provider relationships, including with regard to electronic health records (EHR) and the sharing of patient-generated data in clinical settings [17, 20, 58, 74] (or the reluctance to share given issues of perceived relevance, time constraints, or provider rapport [58]), we focus on the “long tail” of self-management characterized by individuals’ ad-hoc, SMI-specific, and “vernacular”, or everyday, PI practices [8, 16, 100] that are often performed outside of a healthcare provider’s oversight. In particular, the longitudinal nature of these experiences means that social relations will come and go, evolve and disappear, providing a rich set of complications when applying a social ecology model. Second, while prior work has begun to focus on understanding social PI practices (e.g., sharing, comparing, and pooling data), we are also interested in the ways that the introduction of tracking artifacts (e.g., tools, data, visualizations, etc.) influence social practice in emergent and at times unpredictable ways [91]. Finally, prior conceptualizations of the social ecosystem that surrounds personal health management portray a relatively static constellation of stakeholders; in contrast, we highlight the ecological dynamism of lived social experiences for individuals coping with SMI.

2 RELATED WORK

2.1 Serious Mental Illness — The Case of Bipolar Disorder

In this paper, we focus on individuals with bipolar disorder (BD), an SMI that affects approximately 60 million people globally [78]. BD is characterized by fluctuations in mood as well as disruptions to biological and behavioral rhythms (particularly physical activity and sleep). BD is chronic and has no cure; those with the condition must manage it for a lifetime. Recognized as one of the ten most debilitating illnesses worldwide, 1 in 5 cases results in suicide [3]. Quality of life for those with BD can be quite poor due to relationship problems, interrupted education or undermined career advancement, and the physical and emotional stress of indefinitely managing the disorder [36]. These negative impacts are not limited to the individual — they can have destructive and costly effects on family, friends, and society, with the frequency of episodes having an additive association with social morbidity, including divorce, injury to oneself or others, and minor crime [60].

Encouragingly, recent research on behavior-based interventions has shown that tracking and stabilizing everyday activities such as light exposure, sleep-wake routines, and social rhythms can result in pronounced functional improvements and minimized symptom severity for people with BD [32, 72]. Clinical guidelines therefore encourage incorporating daily self-monitoring into condition management [48]. Furthermore, self-tracking can provide a sense of agency for people whose disorder makes them feel out of control [76] and can help individuals establish and maintain a sense of identity as their condition evolves [45]. However, the unpredictable mood swings that characterize BD can be difficult to recognize and self-assess by the person experiencing them, resulting in warning signs going un-noted and unrecorded [55, 60]. At the same time, appropriate disclosure and communication about BD experiences can help build stronger and more empathetic

social support networks [38]. These are all areas in which improved tools for more collective capture, verification, and interpretation of personal data can positively impact the long-term management of BD.

Coming to grips with both public and private impacts of periodic, unpredictable fluctuations in mood and behavior is central to the experience of living with this SMI. Individuals with BD must navigate complex social contexts where the benefits of support and the risks of stigma regularly collide. Altogether, BD therefore makes for a particularly compelling case study in considering collective social engagement in PI – not only due to the opportunities for PI advancements to improve quality of life for this population, but also because the ways this SMI unfolds over time brings issues of personal information, complex social contexts, and dynamic user requirements into specific relief.

2.2 Personal Informatics for Mental Health

PI tools, biometric sensors, and semi-automated techniques originally developed for a more general set of users (e.g., to track movement, communication, and context [33]) have become therapeutic resources for individuals managing SMI [76]. As early as 2006, the U.S. Institute of Medicine recognized the potential of innovations in mobile technology to transform mental health services by providing more continuous and precise information on patient-specific behavior, symptoms, and medication effects [81].

However, it can be quite challenging to develop PI technologies that are sensitive to the unique needs of individuals with mental health conditions like BD (e.g., due to degraded functional abilities [71], inaccurate reporting [55], or lapsed adherence [44]). Systems like MoodRhythm [68, 99] and MONARCA [5, 34] are therefore exploring passive data collection and symptom detection that relieve some of the burdens and limitations of purely manual tracking.

In addition, off-the-shelf tracking technologies can support healthy self-awareness, but there is a general risk that the ways data is presented back to users can foster hyper self-scrutiny and unrealistic normative expectations of health or identity for vulnerable individuals like those with BD [62]. These standardized data representations do not always align with the lived experiences of individuals, potentially complicating the process of using these personal records to build understanding and empathy among family and friends [52]. Further, streaming or “always on” data collection can make it challenging for individuals to practice intentional self-disclosure [69], raising important issues of privacy and data curation [75]. Finally, efforts to integrate self-tracking data into EHR systems and broader clinical practices are still in the early stages, which can lead to individuals with BD experiencing feelings of resentment and a sense of self-tracking futility when PI data goes unaccepted or unvalued by doctors with whom it is shared [76].

2.3 (Inter)-Personal Health Informatics

In examining the social context for tracking tools used in the long-term management of SMI like BD, the most visible and studied relationship is that between patient and provider (e.g., therapists, psychiatrists, general practitioners, neurologists, and so on). In fact, healthcare has long been a topic of interest to the CSCW community, often focusing on the collaborative nature of healthcare practices as well as the implications for designing technology that supports such work [31].

In formal care settings such as clinics and hospitals, patient health information (PHI) is documented and coordinated through medical records [9]. A significant body of literature exists around the role of PHI as not only information artifacts but as mediators of collaborative healthcare work. Relatively new innovations, like the EHR and a host of online portals for managing personal health information, promise to improve efficiency and overall care quality, in part by improving providers’ ability to communicate and share data, even when remotely located [42]. While such medical

records are provider-facing, personal health record (PHR) systems are patient-facing tools for collecting, managing, and sharing information (e.g., about medical history and medications) [98]. In the SMI context, a common use case for such a system has been to enable patients to fill in self-assessment data as part of their daily routine, with a psychiatrist using the system's clinical portal to monitor all of his or her patients as well as review historical data together with patients during therapy sessions [37].

Recently, work has begun to examine how patients and providers can also coordinate over more vernacular or individualized forms of patient-generated data, captured using commercial PI applications and other non-clinical logging instruments [20, 46, 74, 104]. However, researchers have observed barriers to such data being effectively used as part of formalized healthcare practices. For instance, the volume of information collected can be overwhelming and hard to interpret [94]. The introduction of digital systems can also degrade face-to-face interactions by drawing attention away from patient-clinician communication [58]. As self-tracked information becomes an increasingly significant part of the health data equation, researchers have therefore been making efforts to develop "shared care" systems that specifically support the integration of meaningful PI data streams as well as active engagement of both the professional care team and the patient in monitoring and treatment [6].

Researchers have also investigated how informatics technology can support collaboration around health management *outside* of the clinical setting, particularly in the context of family-centered practices – for instance to track on behalf of other family members including children [50], deliver digestible representations of detailed family-level data streams, and manage privacy concerns especially in complex arrangements such as families with divorce [85]. Work looking at coordination among patients and close caregivers, including spouses, has further identified the importance of determining and balancing values (e.g., with respect to shifting responsibilities, mutual support, and patient autonomy) when designing systems for collaborative self-care [10, 82].

The personal informatics literature has also identified a number of other considerations around if, how, with whom, and why people share health-related PI data. Much of this work has been done in the context of contemporary sociotechnical systems like social media. These platforms have been taken up by individuals as a way to record, broadcast, and reflect on their personal health – for instance, by using Instagram to track and share food data [19], Twitter to seek quick health advice [64], or Facebook and condition-specific sites to connect with a wide support network of peers and caregivers [75]. Recent work on mental health specifically has explored the potential for remote peer support to be delivered through online chat interfaces [83].

Willingness to share personal health data in such venues is by no means the default stance, however, often due to perceived threats to reputation or privacy [13]. For example, research has observed that while sharing heart rate data might enhance a sense of connection for couples, such disclosure is seen as less desirable when the recipient could be a boss or other relation who may misinterpret the data or pass negative judgment [95]. Other studies suggest that people are more likely to share summaries, which are more easily digested and privacy-preserving than raw data, which might be overwhelming or too revealing [26, 27].

Altogether, prior work offers pointers to the presence of socially-driven attitudes, assumptions, and values influencing personal data practices. While a variety of motives can influence how and why people share their PI data, such as to receive feedback or emotional support, produce a sense of accountability, provide information, or manage impression [28], little is known about the ways that these perceptions and values change over time as a result of social factors [91]. Further, sensitive conditions like SMI carry a host of vulnerabilities that heighten concerns regarding what data is visible to whom.

In order to support evolving personal data practices in health and wellness contexts, the PI research and design community critically needs ways to consider social relations and roles, especially in terms of how they might change over time. Our work draws on and extends prior efforts by adapting and applying a model of social and technological relations to the use case of self-tracking to support SMI. In the process, we identify design implications for supporting collective engagement in personal health *across* clinical and non-clinical settings and *over time* as social support systems ebb, flow, and evolve.

3 CONCEPTUAL MODELS OF HEALTHCARE STAKEHOLDERS AND ECOLOGIES

In contrast to a “single-loop” approach to personal health informatics that focuses on self-tracking, self-reflection, and self-improvement chiefly from the perspective of the individual [53], recent work has advocated for a “double-loop” model involving both the patient and the clinician in tandem [6]. Still necessary, however, is accommodating the broader network of relations, beyond professionals, potentially involved in an individual’s health management in various implicit and explicit capacities. Devices used for self-monitoring often lack “situated support” across the full range of care networks, which need to at a minimum acknowledge not just the needs of the individual but also the needs of these wider stakeholder connections in the use of self-monitoring health technologies [2, 39].

Partners, relatives, and professional caregivers are commonly identified as stakeholders [25] who could benefit from shared information spaces. However, research specifically focusing on the context of SMI care has identified at least eight such stakeholder groups (e.g., patient associations, financiers, researchers, and other organizational entities that support institutionalized care such as clinics and facilities, police departments, social work, and home care services) [11]. Still, recent research advocates for the deeper study of additional physical, organizational, social, and cultural contexts of care to inform the development of collaborative informatics technologies that capture and support health-related activities in both clinical and daily-living environments [84]. Through interviews and focus groups with individuals managing SMI and the people who provide them direct support, we seek to better understand not just the roles of direct and professional stakeholders involved in mental health care, but any type of social relation implicated in an individual’s bipolar experience, from close friends and co-workers to peers in community support groups.

Salient to this investigation is Bronfenbrenner’s Ecological Systems Theory (EST) [14, 15], which describes a spectrum of macro-level influencers through micro-level relational support units. The EST model (see Figure 1) captures the breadth of influences on an individual’s life, which can operate at various degrees of proximity, from biological attributes all the way to the broad sociocultural contexts that structure human interactions [21]. Research connecting EST to SMI has recognized that mental health issues must be viewed together with cultural factors, which influence the acceptance, stigmatization, and even definition of mental illness [7, 21, 89, 97]. Our work expands the EST model by also investigating the influence of technological factors to account for the ways in which modern PI systems’ data and usage can mediate layers of the social ecology. Additionally, while prior EST research has typically focused on the negative impacts

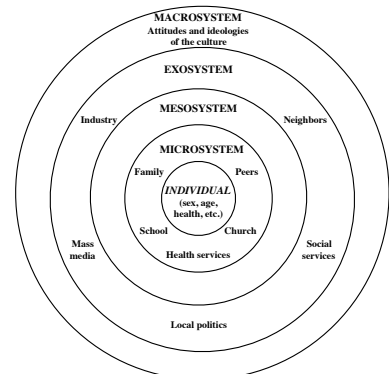


Fig. 1. The systems of Bronfenbrenner’s original Ecological Systems Theory (EST) model [14], which we expand and operationalize to the context of serious mental illness.

of technology on individual development (e.g., violent media content, sensory overload, and attentional problems), we examine potential benefits that personal data can have as well.

Overall, our research is focused on understanding how this model plays out in the context of PI-supported treatment and management of bipolar disorder, with the goal of better representing and supporting the diversity of relations and roles in the social ecology surrounding the self-management of SMI. This empirical work will help us to expand and operationalize EST theory in ways specifically tailored to the development of future PI systems — collaborative computing architectures, data representations, and interface designs to better enable self-knowledge, self-awareness, and collective support in this complicated and important health context. We expand on the details of our application of EST in the discussion.

4 METHOD

In order to identify and better understand the personal data practices of individuals with bipolar disorder, their inner circle of care providers, and the wider social ecologies that influence their self-management experiences, we employed a combination of surveys, interviews, focus groups, and a visual elicitation activity to engage with participants and members of their social support networks. Due to the potentially sensitive nature of these practices, we worked closely with our Institutional Review Boards (IRBs) to ensure that our data collection fell within an ethical and acceptable scope for all concerned. This included minimizing paperwork through verbal consent and careful screening of participants to exclude those in mental health crisis or suffering from comorbid conditions like post-traumatic stress disorder (PTSD) that could be triggered by interview questions. We also relied solely on self-reported details about health conditions and history.

4.1 Study Procedures and Participants

Our research spanned the summer and fall of 2017 at two different sites, using complementary protocols: in Study 1, run at the University of Washington, we conducted one-on-one interviews with individuals diagnosed with BD; in Study 2, run at the University of Colorado Boulder, we conducted a mix of interviews and focus groups with people with BD and other stakeholders. Participant demographics from both studies are reported in Table 1 in the paper's Appendix. Focus groups offer an opportunity to study individuals in social contexts and in conversation with people who might have the same or similar experiences, countering assumptions that the individual is the best or "purest" unit of analysis [102]. Combining one-on-one interviews with focus groups thus provided a way to contextualize data within a social setting, which supported our goal of learning more about social dynamics, how individuals with bipolar disorder and their families and friends cope with the illness, and how data practices might be influenced by social experiences.

4.1.1 Study 1 — Interviews. Participants ($P, N=14$) were individuals diagnosed with BD, in a stable state of their illness, and willing to share their personal data practices with us. We recruited through a solicitation on a website run by a regional health organization, through posts to listservs for the local chapter of the National Alliance for Mental Illness (NAMI), and using flyers posted in neighborhood mental health clinics. Psychiatric clinical partners also assisted, including with question vetting. Screening interviews were conducted over the phone and were used to verify that participants were over the age of 18, had received a BD diagnosis, had not been hospitalized for mental health reasons in the last 6 months, and did not have other mental or physical health issues that would prevent them from sharing their experiences with us (trauma, cognitive impairments, etc.) Participants' ages ranged from 20–64 (mean of 46 years old); 9 were female, 5 male. A pre-interview survey asked about general mental health history and technology attitudes and use.

Face-to-face semi-structured interviews allowed us to establish a rapport with participants, determine the scope of condition-relevant social circles, and ask deeper questions about attitudes towards technology and self-tracking, personal experiences living with BD, and concerns about privacy or other issues related to sharing personal data. We also requested that participants bring examples of any self-tracking documents (including digital and non-digital formats) used to help manage their illness that they felt comfortable sharing. Finally, we worked through an exercise in which we asked participants to use a digital tablet to draw a series of timelines representing their experiences with BD, on both individual and interpersonal levels. This visual elicitation was used to clarify, probe, and augment the personal narratives described in the first half of the interview. Each interview lasted approximately 60 minutes.

4.1.2 Study 2 – Interviews and Focus Groups. Participants included both individuals diagnosed with BD (Primary Participants – *PP*, $N=5$) and people they identified as being close to them and who provided assistance or support in some way around the management of their mental illness (Secondary Participants – *SP*, $N=3$). Not all recruited PP identified or were accompanied by SP. All participants were over the age of 18, with an average of 37 years old; 6 were female, 2 male. To recruit, we distributed flyers and postcards both around campus and in local coffee shops, restaurants, and other social settings. We further disseminated recruitment materials by asking participants to share information about the study with their friends and family members (e.g., a PP asking one or more SP to join them in the study or vice versa) and other social networks (e.g., one interested participant took a stack of flyers to her support group of families of BD patients). We also advertised in digital settings by sharing flyers to our Instagram, Facebook, and Twitter networks. In addition, we recruited through a local BD evaluation and treatment center and coordinated with DBSA (Depression and Bipolar Support Alliance), local NAMI chapters, and local therapists. Elicitations took place as face-to-face focus groups and individual interviews, depending on the configuration and scheduling availability of recruited individuals.

The semi-structured prompts for Study 2 were based closely on those used in Study 1, adapting phrasing and flow to be more suitable for group sessions and adding a handful of questions to probe issues related to the stigma surrounding BD in more depth. Interview sessions lasted an average of 48 minutes, and focus group sessions lasted an average of 100 minutes.

4.2 Analysis

For analysis, interview and focus group data were transcribed and de-identified. The set of questions that were asked of participants in both studies were analyzed together and will therefore be reported together. We performed an inductive thematic analysis using open coding techniques, where at least two researchers viewed each transcript and agreed on emergent themes. As we will describe, Bronfenbrenner’s social ecological model reflected many of the past and present social relationships our participants identified, leading us to perform a round of focused coding of our data through an ecological systems theory lens to better understand interrelations among social networks, PI practices, and technology.

5 FINDINGS

Returning to the idea of relational recovery [86] overviewed earlier, we first describe how our participants talked about social relations, the roles that other stakeholders play in their experience of BD, and the ways PI technologies mediate the connections between these relations and the individual with BD at the center of care. This organization of our findings foreshadows and parallels the elements of our descriptive model of this sociotechnical ecology that we later formalize in the Discussion section.

5.1 Social Relations and Roles

To begin, we characterize social relations relevant to long term self-management of BD – that is, the individual people, groups, institutions, and more broadly encompassing sociocultural ether with whom individuals with SMI have direct relationships or operate within, for better or worse.

5.1.1 Healthcare Professionals. All participants described their intimate connections with health professionals, including general practitioners, nurses, psychiatrists, therapists, and counselors. Forming these relations could be distressing, particularly right after initial diagnosis (e.g., *“The first doctor I talked to was worthless. Never connected with me, never helped me. And I worked with him for about six months trying to make it happen.”* – P1). Participants noted that when these relationships were frustrating or uncomfortable, it was often because the care professional was too busy, did not “click” in terms of personality or working style, or that they were dismissive or minimized the individual’s BD condition (e.g., *“I had one nurse in particular the first time I was in there. We didn’t get along. She actually said to me it would take a miracle for ‘somebody like me’ to get better.”* – P4).

Overall, however, participants described a number of positive attributes and experiences from their professional care experiences, once they found the right “match”. Making this initial connection was often viewed as a stroke of luck (e.g., *“I took a referral from a friend to see [my therapist]. I stayed with her for 35 years until she retired a couple years ago. So she was a huge– another lucky break for me to have someone like that in my life.”* – P1). To describe positive relations, participants used words like “amazing”, “enlightening”, and “supportive” or explained that being connected to a professional caregiver was “one of the best things that happened to me” (P9). In describing the key ingredients that made such relations successful, participants called out the importance of access, trust, and stability (e.g., *“I trust him more than I’ll probably trust any provider. He was able to be in close contact. I have the ability to text him... I have that access. It’s a very comforting fact.”* – P2). While prior work has similarly identified that patient–provider trust is key in the successful treatment of any number of health conditions [58], it can be particularly crucial for those individuals whose BD is linked with paranoia, a common symptom.

Similarly, given the dynamic nature of BD, having stability in clinical relationships and the ability to work with the same person for many years was highly valued by many participants. Unfortunately, maintaining this stability was often not possible, leading to many participants working with multiple doctors over the years with very different care styles (e.g., *“I’ve had legions of therapists... I’ve been in therapy for roughly 40 years.”* – P8). Changing doctors was understandably upsetting to participants, who explained that it was often due to changes in their health insurance coverage, status, or network.

Additional coordination was necessary among care providers when such patient “handoffs” occurred. It was also common for participants to work with teams of care specialists who worked in concerted management of additional health conditions (e.g., ADHD, pain) that are often comorbid with BD [54] or lifestyle problems (e.g., nutrition, fitness) that arose as a result of their BD. For example, P6’s care team included a psychiatric practitioner, nutritionist, acupuncturist, and a massage therapist in an effort to cope with his additional psychological issues, poor eating choices, pain, and tension, respectively, that he attributed to his BD. Clear communication was also mentioned as crucial, especially considering that BD can be associated with disorganized thinking or other cognitive issues, especially when experiencing symptoms. Several participants discussed how they developed a “common language” with their doctor over time. Participants also appreciated the ability to be honest and open with these professional care relations, especially for those who normally did not disclose their BD to the outside world or who did not have strong support networks (e.g., *“I just needed somebody to talk to. It was like a paid friend because I didn’t have any of those sisters or friends. She was getting paid just to listen to me.”* – P9).

5.1.2 Inner Social Circles. Beyond health professionals, family and friends also often played a central role in the management of participants' BD, although participants tended to be split in whether they were closer to their families or their friends.

On average, participants strongly valued and relied on their family members for emotional, monetary, and other forms of instrumental support (e.g., cooking meals, driving to appointments, and obtaining medication). For these participants, they identified various members of their families as a "life raft" essential in helping to navigate the initial BD diagnosis or make it through subsequent episodes. On the other hand, the remaining participants described a much stronger affinity for their friend networks (e.g., college roommates, childhood friends, and more recent but strongly bonded friendships). One participant succinctly articulated this choice:

"I rely on nothing from my family with regard to any kind of illness. If I didn't have the same DNA as my parents I would not ever have contact with them again. You don't get to pick your family is what I'm getting at. But you get to pick your friends. So I think a lot of people wind up getting much more support because they can choose their friends. They can choose people that are going to help them." (PP1)

Participants explained that having known their families from birth meant that a literal lifetime of negative memories could build up and never be escaped. In contrast, participants pointed out that while someone could not go find a new family, it was possible to "start fresh" with friends once their BD had stabilized (e.g., "I had a bad falling out with my old friends... I just f'ed up too much and they weren't understanding and they were also— it was kind of a toxic friend group... So then I actually started making really good friends once I was stable, and those are still my friends." – P13).

These negative memories often stemmed from the sense of shame participants perceived they brought to their family, both due to the consequences of erratic symptomatic behavior and simply from having the label of mental illness attached to their identity. In several cases, participants noted that their family members "won't accept", "won't acknowledge", or are "in denial" regarding their BD, and in turn, provide no support. Dynamics became particularly complex for participants in families with a history of mental illness, with support, co-dependence, blame, and dysfunction becoming entangled and multi-directional.

Participants noted that a family member's prior awareness and attitude towards mental health would often determine whether they would react to the individual's diagnosis and need for help with compassion and support or with embarrassment and rebuff. Participants also explained that even if they did not have outright poor relationships with their families that it was often simply difficult to maintain these bonds over time, for instance when moving away for school or work imposed a geographical distance and physical separation, and in particular due to the nature of their condition itself (e.g., "It's very exhausting to be super engaged with somebody and super close to them... It's really hard for people with bipolar to maintain just your average basic relationship. It's like you really need somebody and then you really don't care." – P10). Similarly, most participants would also get worn down from a sense of guilt associated with overly worrying their families due to having a mental illness, which could further drive them to disengage. In some cases, when family situations became too antagonistic or even abusive, participants severed ties altogether.

The sorts of needs that participants sometimes felt were unmet by their families are precisely the same qualities they sought in close friends: "acceptance", "compassion", "forgiveness", "tolerance", and "understanding". As one focus group participant put it, "I have someone I can talk to about it that's not going to judge me. Because [SP1] has never judged me. Ever." (PP1). Even though not related by blood, participants recounted stories of close friends that indicated deep nurturing and protection (e.g., "I had a couple very close friends that were trying to keep an eye on me and were

literally chasing me around and making sure I was taking my medication, taking alcohol and drugs out of my hand... trying to get me to go to sleep and sitting there until I did.” – P10).

Beyond individual friends, participants also explained the importance of group-based support in managing their BD, whether they be BD-specific support or therapy groups; casual groups of friends with BD who occasionally met to share mutual support; or online groups connected through blogs, fora, or general-purpose social media platforms. It was interesting to note that some participants expressed having a sense of connection with the abstract community of all people with their same condition, “*my people*”, even though they had never met nor could articulate specific details about whom those individuals were. This perceived in-group gave participants an encouraging feeling of not being alone and in some cases even helped them cope with their initial diagnosis, as it was a relief to know that what they had been experiencing had a name and that there were other people in the world to whom they could relate (e.g., “*I finally felt like, oh my God, there’s a whole community of people that experienced the same thing that I do.*” – P13).

Overall, similar to professional caregivers, stability was seen as a key ingredient in supportive family and friends. One participant shared that she intentionally sought a husband who was extremely predictable and staid – her “*human metronome*” – explaining that she appreciated the fact that “*he’s boring*” because “*It’s very reassuring. I don’t need surprises and I don’t like surprise parties. It’s consistently like knowing night follows day.*” (P9). Some participants acknowledged that change was an inevitable part of long-term SMI management (e.g., “*You have friends and relatives that come in and out of your life that are going to be able to handle it or not, and it takes a while to get a caregiver support group that meets your needs.*” – P6). In some cases, change could be in a positive direction (e.g., “*I actually am okay with the level of support I’m getting from my family now. They’ve grown an understanding of the disorder.*” – P2). However, most sorts of instability were perceived as quite distressing, for instance due to the death of a family member, a divorce, or a break up. Also similar was the sense of feeling “*fortunate*”, “*lucky*”, and “*blessed*” to have long-term, stable relations. For two participants, animals and pets were called out as additional examples of comforting consistent relationships in their lives that helped keep self-management on track.

5.1.3 Outer Circles and Sociocultural Backdrops. We identified a number of more peripheral social units that also impacted participants’ BD management, including places of employment (bosses, coworkers) or education (teachers, classmates, school administration), local community or religious organizations, and medical insurance groups.

While employment benefitted participants’ self-management in terms of income, access to healthcare, and overall empowerment, it was also noted as a source of distress due to the difficulty associated with finding work and the fear of losing existing or prospective employment if their SMI condition was discovered (e.g., “*In my world, you don’t talk about it for purposes of wanting to be in the working world.*” – PP2). Participants also had mixed experiences with local community and religious organizations, which for some provided a sense of structure and safety; however, becoming disconnected (e.g., due to a move) from such “*sheltering and nurturing communities*” (P9) could be destabilizing and trigger symptoms. Further, the conservative perspectives of military or religious communities in which a few participants grew up were noted to have approached their early signs of mental illness with denial, which left participants with a sense of rejection and uncertainty, rather than a sense of how to constructively move forward with proper treatment. Identified as another undermining influence, a number of our participants discussed health insurance with us (namely, losing it or the inability to afford it), indicating how insurers could indirectly enable or disable condition management. It seems this lack of access to medical care was in many cases the reason behind why participants reached for technology as part of self-managing their SMI.

Finally, it was clear throughout our conversations that societal attitudes surrounding mental health had left deep impressions on all of our participants. SMI, and the well-recognized stigma associated with the condition [22], had largely been absorbed into participants' identities, who pointed out that this could make self-compassion and self-care a challenge when they viewed the self from this demeaning external perspective. One participant, who was of African descent, specifically pointed out racial differences she had experienced in terms of not only the aversion but even the acknowledgement of SMI as a legitimate condition (e.g., *"My boyfriend just says [about my aunt's depression and BD], 'That sounds like white people problems.'" – SP3*). Such biases also motivated a general tendency for participants to conceal their SMI. Encouragingly, however, a number of participants had come to shed these societal attitudes, for instance to embrace a healthy identity distinct from their illness (e.g., *"I'm managing an illness, instead of being bipolar" – PP5*) or to be open and vocal about BD in an effort to increase awareness, humanize the condition, and ultimately lift stigma and support others in the broader SMI community.

5.2 Personal Data as a Relation and a Relational Mediator

As participants navigated these spheres of social relationships, we identified that the entity constituted by personal data itself could also resemble a kind of social relation for them, in that they regularly interact with and are influenced by these reflections of themselves, as part of managing SMI. In addition, this personal data entity could play a mediating role among an individual's other social relations identified above.

5.2.1 Personal Informatics Practices and Perspectives. Here we describe how our participants engage with personal informatics (PI) as part of supporting informal and long-term condition management. Our findings align with those from prior work [51, 76], which indicates the representativeness of our study samples, though we add new insights regarding the ways that many of these PI practices and attitudes are socially constructed.

Participants made use of a number of different PI methods and mediums, both analog and digital, including post-it notes, lists, journals, hand-drawn charts and graphs, calendars, spreadsheets, paper-based or online BD forms (e.g., from the DBSA), smartphone apps, and activity trackers (e.g., pedometers, Fitbit). Tracking could also happen invisibly by taking mental notes or by entrusting tracking to close social connections who had the ability to keep an eye on an individual's behavior to watch for changes, notice warning signs, or help fill in memory gaps.

Participants used these methods to track a variety of items — foremost mood — along with medication adherence and dosing, sleep, exercise, weight, spending, and alcohol/drug/tobacco use, which were all identified as behavioral proxies of symptom severity or an oncoming episode. Participants also self-tracked time, noting the value in sticking to routines as a way to minimize symptoms but also because this made it easier for others to help monitor for erratic behavior (e.g., *"It's very much planned. 'This is where I'm going... if you don't hear from me by four o'clock, you gotta call me.'" – P12*). Similarly, social events were often tracked, not only as a way to monitor healthy social rhythms and avoid social isolation as part of BD management, but also as an opportunity to notice and celebrate adhering to social commitments, which can be challenging to maintain during those phases of BD marked by depression or paranoia.

Participants had been engaged in PI for various spans of time, ranging from months through to fifteen years (P1). In addition, PI records were kept at various levels of tracking granularity. For participants that tended towards keeping highly detailed data, they noted that while this was valuable as a concrete representation of their experiences, the associated burdens could be *"overwhelming and confusing"* (P2) or *"tedious and difficult to manage"* (PP4). For some, this eventually led to abandonment of their PI regimen. Participants also described tradeoffs between digital tools

being easier to manage but also harder to customize (e.g., by using colored pens or stickers to annotate paper-based tracking materials with personally meaningful schemas).

Just as participants had varied experiences with particular types of social relations (e.g., positive vs. negative family relations, etc.) participants were mixed in their overall receptivity toward PI as well. For instance, some considered themselves natural self-trackers, self-identifying as the tracking “type” or inherently “inclined” to engage with PI; accordingly, these participants typically found PI beneficial and often self-initiated tracking outside of clinical care. In contrast, other participants were strongly turned off by the premise of PI (e.g., “I have never done [self-tracking] because I find it repugnant... I’m already objectified enough – why would I want to do it to myself?” – P3). Similarly, some participants valued PI tracking artifacts as an archive and a means to support future self-reflection about their BD management, whereas others felt such traces solidified evidence of their BD hardships and failures or led to increased rumination. Another parallel between PI engagement and social relations is again the importance of stability in the interaction, with participants explaining how technological problems (e.g., software crashes, lost data, an update removing relied upon functionality, etc.) could be destabilizing, particularly when it disrupted self-tracking routines that they had come to strongly depend on for BD management.

5.2.2 Interpersonal Engagement through Personal Informatics. Beyond identifying these ways that individuals with BD engaged with PI, we also saw how PI could mediate participants’ engagement with their social relations and those relations’ roles in long-term BD management. In particular, our findings speak to choices and behaviors around collaboratively collecting, sharing, and interpreting personal data.

Participants described a few different co-tracking scenarios and motives. Sometimes, a social relation would take over the capture of personal data (e.g., about medication use or observable symptoms) when the individual was unwell and therefore unable to self-track, yet the information still needed to be captured to maintain the continuity and usefulness of the record. In other cases, collaborative tracking activities (e.g., maintaining a shared notebook or digital calendar) were used to aid co-reflection and build mutual awareness about how the person was experiencing BD and to help the social relation “see in” to what the participant might be going through. Despite the potential benefits of such collaborative tracking activities, the deliberate choice was sometimes made to avoid co-tracking, in the interest of enhancing the participant’s agency (e.g., “I think [PP4]’s been great at tracking information. I think it was important that she was the one tracking it and keeping control of her own ship rather than me or somebody else stepping in. I mean, it just doesn’t seem right for her.” – SP2).

Further, an interaction among participants with BD in one of our focus group sessions highlighted how tracking, even if performed on one’s own, can still impact interpersonal awareness – although in this case, in a problematic way, as the conversation identified how current self-tracking interfaces can reinforce a sense of normative social comparison:

PP1: *Pushing it into categories is so difficult to know: are you high, medium, or low/high? What does that mean?!*

PP2: *Is that normal? Is that how other people feel?*

PP1: *It also makes me feel like everyone else has such a different perception of how the world works. That can be further alienating in some ways.*

While assessing oneself in terms of coarse grained buckets can be difficult for people self-tracking any variety of personal data, prior research has identified that individuals managing SMI are particularly vulnerable to feeling judged, flawed, and isolated when confronted with normative PI measurement scales and visual representations that do not align with their own mental models that they use to gauge and make sense of their condition [69].

When it came to sharing personal data, participants varied in their behaviors and preferences. Sharing with health professionals was typically seen as standard and acceptable, largely in order to support better patient–doctor communication. Particularly notable is how participants felt PI sharing could put them on a more equal footing with their clinician, including to push back during disagreements (e.g., about whether a medication should be adjusted or avoided), because the data served as a resource that could be called on to support their point of view. For some participants, simply knowing that an experienced person would be looking at and making sense of the data could lift a sense of PI burden, given that it could otherwise become overwhelming to feel they were solely responsible for managing, interpreting, and deciding how to act upon collected information. One participant mentioned using a self-tracking app that, with permission, would automatically email data to a clinician. However, when participants experienced uncertainty about whether doctors actually reflected on shared data, it left a reduced sense of confidence, both about the value of self-tracking and about the quality of their care relationship.

With family, tracking data was sometimes shared to improve loved ones' ability to notice if the participant had forgotten to take medication or overlooked some other aspect of condition management, in which case they could provide prompts or reminders — or if deemed necessary, more extreme protective measures could be taken. One participant described an explicit, detailed “*emergency plan*” that he had constructed together with his therapist and sisters: “*If I start pacing a lot, if I want some money, if I start drinking again. That’s stage one. Stage two - I’m just not paying attention to you, still pacing, and I’m giddy - that’s when you need to take me to the hospital.*” (P12). Another participant explained how she had similarly “*taught*” a new but trusted friend how to monitor and interpret her online social networking in order to notice behavioral patterns that forebode an episode. In other cases, data was shared as a way to foster empathy and understanding from a family member or friend or in an attempt to explain erratic behavior. A similar desire to build compassion could motivate participants' decisions to share data with wider social layers to whom they would not normally have contact in everyday life. For instance, some participants reported using online social networking platforms as a means of sharing PI outputs and establishing or strengthening social connections.

Sometimes, however, sharing was avoided precisely to limit the chances of making such connections — for instance, one participant thought that sharing data could make it easier for her abusive ex-husband to find her. Relatedly, concerns around privacy and data security (and the consequences of leaking sensitive health data) were the most common reasons noted by participants for disliking or altogether avoiding tracking in general (e.g., “*I think I ended up being too paranoid to continue in tracking. Because somebody is going to find my log and it’s going to be really dangerous for me.*” – PP2). In some cases, these concerns were not only self-centric but aimed to protect relations as well (e.g., “*I threw [my tracking journals] away because I was afraid that someday I would die and people would find them and see things about themselves.*” – P10). Destroying data and other tracking artifacts was a common solution for mitigating perceived risks for oneself and others that might arise if the data were exposed. For others, such danger seemed low, as they felt it would be difficult for relations to decipher their personal data without their involvement.

Another observation to note is the way that personal data can be intended only for personal use but serve socially-facing goals such as impression management. For instance, one participant described how he would use his tracked information to gain enough self-awareness to identify his “*bounds*” (of noticeable versus undetectable symptomatic behavior) in order to then conceal the presence of his BD and maintain an outward appearance of “*normalcy*” (e.g., “*But I decided pretty early on if I could maintain in this range right here, I’d have a life, no one would ever know. And that’s pretty much what I did.*” – P1).

Overall, we saw that participants have diverse perspectives regarding disclosure and complex criteria when determining which data will be shared, with whom, and how [35, 59]. These orientations – which fall on a spectrum of openness – can influence a person’s PI attitudes, practices, goals, and, in turn, the ways that PI can mediate social relations. Where a person falls on that spectrum can be informed by baseline PI literacies as well as positive or negative life experiences, including with PI, their BD condition, and their social relations.

6 DISCUSSION

6.1 Personal Informatics, Collective Engagement

At the core of this paper is the idea that tracking activities and data practices previously considered “personal” are evolving to include – or perhaps more accurately, are revealing themselves to be – collective phenomena, embedded in multidimensional social structures. The socially embedded practices we highlight here are related to sensemaking in organizations [101], collective intelligence [67], distributed cognition [43], and collaborative knowledge production [103]. From this body of literature came the original notion of “collective sensemaking” as a way to describe the activities and interactions that comprise these collaborative practices. In this context, personal data can be seen as a form of boundary object [96], marking the intersections of different social relations in a PI ecosystem.

Seminal PI literature argues that system design should be approached holistically – taking into account the various facets of individual lives and supporting iteration between stages of PI use [57]. Other healthcare technology researchers have advocated for a similarly inclusive approach that considers the overlapping sociotechnical dimensions of personal health management, stresses the importance of lived experiences and situated practices, and incorporates a variety of stakeholders [2, 4, 25, 30, 39, 40, 49, 84].

In this vein, our work has identified some of the primary mechanisms by which social relations in our use case influence decision making, empathy, communication, and mental health self-management. Our findings indicate that improving the ways that PI systems support collective engagement can reduce the huge societal costs of long-term treatment of chronic conditions by (a) **providing a range of different types of stakeholders with appropriate access** to personal data records that might facilitate more effective long-term management of chronic conditions, (b) **scaffolding existing social relations at multiple levels** within support networks that have been shown to play important roles in the management of chronic conditions, (c) **creating sociotechnical platforms for collective and collaborative practices of gathering, validating, and interpreting behavioral trace data** (including contextually sensitive data models, automated and semi-automated tracking tools, and visualizations that more closely align with the lived experiences of users), and (d) **responding to dynamic changes in social relations and contexts over time** in recognition that longitudinal use is inevitably accompanied by reconfigurations of trust and agency.

6.2 A Model of the Sociotechnical Ecology Surrounding SMI Management

Our findings inform the creation of an ecological model for personal data practices that encompasses the range of people, organizational units, and broader sociocultural norms and values that influence and are influenced by the condition and care of a central individual. Our model is illustrated in Figure 2 and described in the following subsections. We leverage Ecological Systems Theory (EST) [14, 15] in creating this model of the social contexts described by participants as playing an important role in the long term management of their mental health. In doing so, we highlight key sociotechnical implications and requirements of conceptualizing personal health informatics

through a collective lens. Our model is descriptive, explanatory, and prescriptive in that it offers conceptualizations and invites further inquiry, proposes explanations of observed relationships and processes, and helps inform the design of novel user experiences [90].

6.2.1 System Layers. In the center of our model is the individual managing SMI, along with the person’s identifying attributes (e.g., age, gender, other demographics, etc.) and condition characteristics (e.g., type of bipolar disorder, symptom severity, time since diagnosis/undiagnosed, etc). Surrounding the individual, we define nested “layers” of relations, which reflect their level of interaction with the person’s condition management.

The **microlayer** consists of the closest relations that are most directly involved in SMI care. Based on our dataset, this typically involves the individual’s professional caregivers (clinicians, nurses, etc.) as well as inner social circles of family, friends, and peer support groups, who together share the bulk of responsibility in monitoring and facilitating the health of their patient/loved one. Other work has similarly identified immediate family and very close friends as constituents of “intimate” care networks that patients involve in health monitoring [39]. For our participants, the care practices of microlayer relations often involved keeping track of symptoms and medications, providing emotional support, maintaining a general awareness of an individual’s current stability, and potentially intervening to adjust behavior or to get help in a crisis. However, we found that participants’ relations in this layer could also be responsible for exacerbating symptoms or generally worsening one’s state of health and well-being — for instance, due to dissatisfactory clinical care, family disharmony (e.g., denial, shame, rejection), or toxic friends who goad triggering behaviors or are otherwise bad influences.

Next, we define the **exolayer** as the wider institutional entities that impact how an individual manages his or her condition. For our participants, these relations included workplaces, schools, community organizations, and health insurers, which engaged less immediately with them but could still exert a potent influence by aiding or obstructing instrumental (e.g., financial, medical) and expressive (e.g., emotional support) needs — for instance, when office politics or admissions criteria made participants feel pressure to conceal their SMI or when changes to a spouse’s health insurance affected their own coverage. As with the microlayer, we observed that interactions with exolayer relations can be beneficial or problematic and that dynamics can and do vary over time.

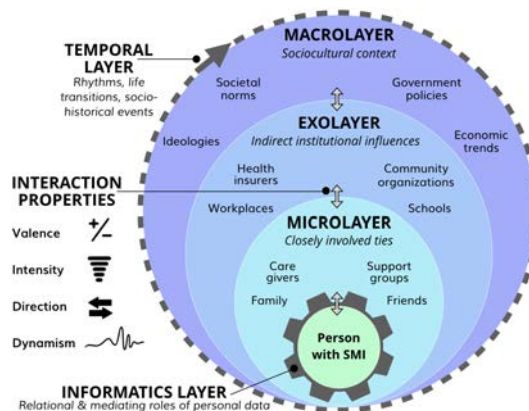


Fig. 2. The layers and interactions of our ecological model for conceptualizing the social and personal informatics entities that influence and are influenced by serious mental illness (SMI).

The *macrolayer* in our model reflects the individual's larger sociocultural context — ideologies, cultures, and societal attitudes — around mental illness. In our case of SMI, this layer also captures how an individual is impacted by current economic trends as well as government policies regarding healthcare. While this layer is the broadest and most in-the-background compilation of relations to the individual, our data illustrated how it can still have a tremendous impact on condition management as well as identity orientation, typically by minimizing participants' capacity for self-compassion and acceptance due to stigmatic societal tropes — although, we did observe that over time and with age and SMI experience, participants could come to cast off this cultural baggage, often in large part due to more self-affirming, positive interactions with supportive relations in their microlayer.

Beyond these nested social layers, our model also contains a cross-cutting *temporal layer* that represents patterns and transitions throughout the course of the individual's life, along with socio-historical events. Prior theoretical research on collaborative work in healthcare has similarly identified temporal rhythms and trajectories in medical work (e.g., in shift changes, morning rounds, medication administration, employee turnover, etc.), although the focus has been on the professional caregiver perspective and clinical workplaces [23, 88]. These dynamics are particularly salient in a mental health context, considering the inherently periodic and repeating biological, psychological, and social fluctuations that underpin an SMI like bipolar disorder [36, 69]. Indeed, in our dataset we observed a number of common transitional experiences (e.g., changing doctors, switching medications, death or other traumatic loss, divorce, losing friends, making amends, discovering support groups, moving house, shifting jobs, and so on) that impacted or were impacted by participants' BD. And while many people encounter such flux throughout life, our participants generally noted that they believed the transitions they experienced were more frequent, extreme, and/or irrevocable as a result of their condition.

Finally, we include an *informatics layer* in our model to capture the relational and mediating roles personal data play in socially-embedded SMI management, as described in Section 5.2. In our study, we observed that PI artifacts and the representation of self embodied by captured data can themselves resemble a relational entity, which exists together with the individual at the center of the ecology. We also saw that analog instruments (notebooks, stickers, paper forms, etc.) were geared more toward use at the personal or microlayer level, with practices either entirely private or shared only with close ties that participants lived with or regularly depended on for care. On the other hand, digital technologies (self-tracking software, online platforms, etc.) enabled interactions with more indirect layers; however, more risk was associated with data captured this way, especially if participants had antagonistic relations at the exolayer (discriminatory workplaces, hostile ex-partners, etc). Further, considering personal data from a macrolayer perspective demonstrates how PI can act in service of both positive and negative cultural values (e.g., mobile self-tracking apps affording broader access to care for a vulnerable population or normative measurement scales reinforcing users' perceptions of societal stigma).

In addition, the informatics and temporal layers of the model can interact as well, given that PI attitudes and practices can evolve over time. For our participants, common changes included tracking more or less based on their level of understanding or progression of their illness, on shifting perceptions surrounding perceived threats to privacy, or in response to discovering new peer support communities where sharing PI could aid individual and collective needs, be they informational or emotional. Overall, including a PI layer in our model promotes the holistic examination of how not only current PI instantiations but also future advances in PI (e.g., to support novel formats of information and in more collective, dynamic circumstances) can impact care practices and social structures.

6.2.2 Dimensions of Relational Interactions. Our model also characterizes the interactions among these various social ecological layers of an individual’s life. While EST uses the notion of a “mesosystem” [14] to represent interactions between social entities, our data indicates a richer conceptualization is necessary in order to reflect the following aspects of relational interplay that our participants commonly experienced. Specifically, we define the following four dimensions of relational interactions that occur among entities in the ecology and the individual at the center: *valence*, *intensity*, *directionality*, and *dynamism*.

We define *valence* as a reflection of where on the support spectrum a relationship falls, in terms of the interaction’s positivity/negativity. We believe these five levels — from deeply supportive, to moderately supportive, to neutral or absent, to irritating, to physically or psychologically abusive — characterize well the range of valence experienced by our participants, based on our conversations and the language they used.

A notion of *intensity* conveys how weakly or strongly influential a relationship is. On one end of the intensity spectrum, participants reported potent, direct influence (e.g., a doctor visiting a patient regularly during hospitalization or a friend arranging an “intervention” to address erratic behavior), spanning to more passive influence perceived in the periphery (e.g., a spouse refilling the patient’s medication once a month without much notice or an individual’s implicit perceptions of their church group’s SMI attitudes). As with other aspects of interaction, we saw that the intensity of influence could oscillate over time — for example, social support would typically intensify in moments of crisis yet relax when a person was experiencing minimal symptoms.

Directionality indicates who is influencing whom, among an individual and the relations in his or her social ecology. For example, EST mostly focuses on the relation-to-individual influence (e.g., a caregiver influencing care). In our study, we frequently observed influence in the opposite direction as well, with an individual’s condition and self-management routines considerably impacting others, particularly close relations in the microsystem. Further, while this influence is often uni- or bi-directional (e.g., between a patient-caregiver dyad), we saw a number of instances of multi-directional influence as well (e.g., among collaborative care teams, when a child’s diagnosis impacts the family’s priorities, and when a peer support group comes together).

Finally, the *dynamism* of engaging with a relation represents whether this relationship or its influence tends to be highly stable (e.g., a lifelong friend or an entrenched cultural norm) or highly unstable (e.g., frequent employment turnover for someone whose condition imposes significant functional challenges). We also saw that participants could experience a “dynamic stability” closer to the middle of this spectrum; for example, one person stayed for years with the same, specific clinician — but that clinician regularly fiddled with her medication or treatment plan, which sometimes led to uncertain outcomes.

Throughout our discussions with participants, we observed that participants encountered diverse combinations of these dimensions when interacting with relations in their social ecologies, although some co-occurrences were more common than others. For instance, participants frequently discussed receiving (*directionality*) deeply positive support (*intensity*, *valence*) from long-term, stable (*dynamism*) friends and family relations from their *microlevel*. An interesting future extension of this work would be to more thoroughly investigate which layers of the relational ecology tend to correspond more or less to which dimensions of interactions among those layers. We return to this point in our discussion.

6.3 Design Implications

The lens of EST provides a means for operationalizing the complex and dynamic social relations that exist in and around the long-term management of SMI. This is essential when designing a collective PI system not just within this space, but in many other situations where longitudinal use

of personal data is entangled in social practices. Here we offer design implications that surfaced as a result of viewing our use case through EST. Some are specific to SMI contexts, while others are more general.

Design implication 1: Systems need to accommodate the emergent and dynamic practices of accruing, breaking, and changing social ties. Changes to social structures — even those that seem “permanent” like family relations — are inevitable, and the impacts of these changes can be unpredictable. For example, switching to new clinical caregivers carries the heavy burden of having to repeatedly recount personal history and assess trust and privacy issues. Access to both personal health information and insights into how a person is really feeling on a day-to-day basis are continually re-negotiated by the individuals at the center of these networks of care. This dynamic management of disclosure [56] needs to be supported as a first-class organizing principle of these systems. Role-based permissions and user scenarios are not adequate because issues of trust and authority are socially constructed and context-specific, which means they are also dynamic. For example, in prior work, researchers developed an interactive visual tool for sharing and jointly making sense of personal tracker data [87]. In this tool, privacy settings were implemented that allowed per-recipient access rights to be set so that users would be comfortable with how different types of PI data would be shared to different members of their social circles. We see this as a baseline requirement for these kinds of systems — a much different approach than is typically taken in commercial, “social-sharing” focused PI systems. However, as seen in similar privacy management contexts like social media, interfaces to facilitate access can quickly become unwieldy [24, 41, 65]. Further, even similar kinds of relations (e.g., patient–provider relationships) can exhibit a significant amount of variation and dynamism: one user’s relationship with a clinician might bear little resemblance to another user’s relationship with a similar type of professional; PI systems must therefore be cautious in implementing disclosure capabilities using stereotypical role labels and disclosure or sharing permissions.

Design implication 2: People find value in comparing their data to others’, in many cases due to the desire to determine baselines and make normative comparisons with others with whom they feel an affinity. While other apps have been designed to support social comparison (e.g., of fitness data [93]), such comparisons can be highly problematic in an SMI context, given the aforementioned risks related to self-scrutiny and unrealistic expectations to which people with BD are vulnerable. Regardless of the specific representations or visualizations employed in health-centric PI tools like these, the *impact of social, cultural, and normative framing* is particularly important to consider in the context of supporting vulnerable populations, given the normative expectations inherent in and underlying most existing personal informatics systems [62]. Prior work on social PI systems has found that leaderboards or other interfaces that allow for the direct comparison of multiple individuals’ data can be motivating due to the sense of competition induced [47, 51, 73, 92]. However, managing chronic conditions like SMI is not a race to a goal post with clear-cut measures of success (e.g., more steps are better). Rather, it is a long-term, day-by-day balancing act of “staying in bounds.”

Careful consideration needs to be given to the social consequences and contracts around sharing. A failure to design without social interaction in mind brings consequences including limiting the types of information that can be shared (e.g., less support for exchanging rich experiential knowledge rather than just statistics), the level of control a user has over that sharing, and the ability to retroactively review and revise disclosed content [53].

Design implication 3: For people managing SMI, self-tracking is about crisis mitigation and crisis management. While some individuals talked about the ways in which they enjoyed or were drawn to personal record-keeping, many also described the vulnerability associated with recognizing potentially troubling patterns in those traces. Participants described a process of

spotting a problematic change in a routine or daily behavior and going directly to a healthcare provider to adjust medication or seek alternative therapies. Others talked about relying on trusted friends or family members to provide perspective during those times when they could not trust their own observations or interpretations of personal data. An impending crisis was not typically signalled by just one event, but by a series of cues. Some participants talked about ways that they masked or hid potentially dangerous shifts in mood by only exposing friends and loved ones to certain behaviors. Others talked about the ways that they compared sets of tracked “variables” (our word, not theirs) in order to make sure that they were getting an accurate picture of how they were doing (e.g., an unusually large pile of boxes from Amazon on the doorstep *plus* a series of sleepless nights indicates that a change for the worse might be imminent). PI tools have the potential to support triangulation of this nature, both across behavioral and mood markers and among trusted stakeholders.

Further, participants described their tracking behaviors as being dependent on a number of factors including their phase of illness, comorbid conditions such as OCD or PTSD, strength and nature of social support networks, access to formal healthcare in the form of regular therapy and medications, and ready access to urgent care for mental health. In these cases, adherence to a tracking regime is not just about the interactivity a tool provides; it can also be a signal to be tracked in its own right and a significant measure of well-being (e.g., less tracking may correspond to decreased urgency). This recognition corresponds with a need for situated methods to articulate, measure, and evaluate use in ways that better reflect holistic PI practices, such as cases where non-tracking (or syncopated tracking) could be seen as a desirable outcome in conjunction with other factors.

Design implication 4: PI systems for collective engagement carry the potential of unintended consequences, related to both *introducing* and *limiting* access to personal data and particularly within the challenging and dynamic social context of managing SMI. In our model, some of the mechanisms or trajectories of these consequences can be traced back to the interactions among levels (e.g., valence, intensity, direction, dynamism). Research and development in this space will need to involve careful application of participatory design techniques that enable the user-centered identification of how to best support dynamic information sharing and data-access needs required in this context. Our participants shared stories of episodes in which tracking practices that seemed to offer social benefits in one context corresponded to risks or harms in another (e.g., being willing to share financial and spending data with a trusted clinician but guarding that same information from loved ones who might become alarmed, judgmental, or reactionary).

Just as EST enabled us to operationalize social relations, approaches like Grounded Design [91] and other participatory methods can help to position PI systems as elements within a dynamic social context rather than as solutions to a single, static, “solvable” problem. According to Rohde et al. [91], empirical design research is inherently entangled with social practice. Research activities exist in an environment that is dynamic, contingent, unpredictable, and organic; this means that the problem that we set out to solve has often transformed by the time we implement a system. Techniques like Grounded Design focus on cultivating a shared language for communicating with community members and a functional understanding of the social practices and contexts to be improved [91]. This requires close collaboration between researchers and community members, which is especially important when working with vulnerable populations and in light of the complex social dynamics underlying the management of SMI, as reflected in our model.

After incorporating participants’ visions and values into exemplars of this new class of collective informatics systems, appropriation studies [91] can be undertaken to examine how they fare when deployed into the “wild” and incorporated into existing and new social practices by groups of

real-world stakeholders. This will enable designers to empirically assess the impacts of various interaction and visualization techniques. Conducting appropriation studies over extended periods of time will also be necessary in order to capture changes in the course of one's illness or social circumstances — and the particular constellation of social relations in which that individual's condition is being managed.

Additionally, if researchers and practitioners are going to take on the challenge of delineating PI ecosystems in terms of multi-tiered social relations — one of the primary outcomes that we make in this work — then we also have to acknowledge that these tools and practices are unfolding in a sociotechnical context where concerns about privacy, identity theft, surveillance, and manipulation are rampant. Many who work in the area of PI are well aware of the sensitivity of personal data; however, significant work in data science is being done to draw ever more refined representations of people and their behaviors from larger and more complex data sets [1]. This work creates a moving target for ethical standards, raising issues of algorithmic inclusivity and normative data models, as well as questions about what consent looks like in our current data landscape. Building on the work of Bietz and others [12, 18], our findings reinforce the need for PI systems designers to be reflective about how tools like automated sensors can catapult a self-tracking app into a data security design space and require more sophisticated models and awareness of the data literacies of end users.

6.4 Limitations and Future Work

In this study, we focused primarily on the patient perspective and the rich attitudes and experiences these individuals hold surrounding their social recovery relations, their use of PI, and their challenges and needs when it comes to engaging others with and through their personal data. While we were able to include a few family and friends in our focus group study, it will be important going forward to interact with additional relations, including members of the exolayer. Such future steps will not only help validate our claims and refine our proposed model, but they will also ensure that additional relations' perspectives are surfaced and considered during the PI design process. Further, there is value in engaging with relations whose interactions exhibit additional dimensions that we identified in our model; for instance, while we worked with secondary participants who were relatively stable relations of positive valence and mostly unidirectional influence, it is also necessary to have discussions with relations of more negative valence or that have a more codependent relationship with the primary participant in order to better understand their point of view and how novel PI systems might work to repair or support those interactions. Further, identifying potential points of tension between the preferences of patients and those relations who have the ability to strongly and positively influence the patient's SMI management will also be important to balance the needs of these diverse user groups.

7 CONCLUSION

Focusing on the case of serious mental illness and bipolar disorder specifically, this paper explored the multidimensional sociotechnical landscape that individuals navigate as part of the long-term management of their condition. In doing so, we provided empirical and theoretical support for how personal informatics systems can better align with the interpersonal needs and values of users, their lived social experiences, and their contexts of relational recovery. In particular, these insights allowed us to formulate an ecological model that conceptualizes the social relations that play a role in self-management, along with the valence, directionality, and other dynamics of those interactions. Finally, we contributed broadly applicable design guidelines that help define an emerging class of collective informatics infrastructures and interfaces aimed at supporting the social ecologies of personal data practices.

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A APPENDIX

	Study 1 (P)	Study 2 (PP)	Study 2 (SP)
N	14	5	3
Average age	46 (ranging 20–64)	38	30
Sex	Female = 9 Male = 5	Female = 5	Female = 1 Male = 2
Marital status	Married w/o kids = 1 Single never married = 4 Divorced = 3 Unreported = 1 Separated = 1 Married with kids = 1 Living w/ partner = 1 In relationship, not living together = 2	Single never married = 3 Separated = 1 Married with kids = 1	Single never married = 1 Married with kids = 1 In relationship, not living together = 1
Education	High school or equiv = 2 Some college = 4 4-year degree = 6 Graduate degree = 1 Unreported = 1	Some college = 1 4-year degree = 1 Graduate degree = 2 Advanced degree = 1	Some college = 2 4-year degree = 1
Employment	Disability = 4 Disabled, works PT = 1 Student = 1 Unemployed = 1 Employed student = 2 Retired = 2 Employed part time = 1 Employed FT = 1 Unreported = 1	Student = 1 Unemployed = 1 Employed student = 2 Employed, FT = 1	Student = 1 Employed, FT = 2
Type of bipolar	Type 2 = 9 Type 1 = 3 NOS = 1 Unknown = 1	Type 2 = 4 Type 1 = 1 NOS = 1	N/A
Age of first episode	Average = 18 Range = 12–27	Average = 9 Range = 11–17	N/A
How long since diagnosis	Average = 10.9 years Range = 1–40 years	Average = 9.4 years Range = 3–14 years	N/A
How long under clinical care	Average = 15.3 Range = 0–40 years	Average = 8.6 Range = 3–20 years	N/A

Table 1. Summary of participants' self-reported characteristics.

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