Digital Phenotyping and the Cumulative Burden of Self-Management of Bipolar Disorder

Karin Bogdanova
Human-Centered Design
Delft University of Technology
Delft, Netherlands
e.bogdanova@tudelft.nl

Nazli Cila
Human-Centered Design
Delft University of Technology
Delft, Netherlands
n.cila@tudelft.nl

Olya Kudina
Values, Technology & Innovation
Delft University of Technology
Delft, Netherlands
o.kudina@tudelft.nl

Alessandro Bozzon
Knowledge and Intelligence Design
Delft University of Technology
Delft, Netherlands
a.bozzon@tudelft.nl

Abstract

Living with a chronic condition involves ongoing work: tracking symptoms, managing medication, coordinating care, and maintaining routines to prevent recurrence of acute episodes. In psychiatric care, this workload is equally complex yet rarely examined in HCI and design research. Digital phenotyping, a nascent AI/ML-based approach to monitoring behaviour, passively collects sensor and device data and is promoted as an unobtrusive and scalable tool. Yet, this promise of passivity obscures the skilled labour that takes place–from data sense-making to fitting new tools into existing care practices. In this position paper, situated in the context of outpatient bipolar disorder treatment in the Netherlands, we seek to problematise the current approach and apply Burden of Treatment Theory to unpack this hidden workload. We argue that digital phenotyping design lacks sensitivity to the care ecologies of self-management it intervenes into and call for HCI researchers to further engage with this problem space.

CCS Concepts

• **Human-centered computing → HCI theory, concepts and models**.

Keywords

AI in psychiatry, self-tracking, self-management of chronic condition, treatment burden, bipolar disorder

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1 Introduction

The growing role of AI in mental health has sparked considerable enthusiasm and deep concern among the general public, design practitioners, and researchers [19, 33]. Yet, the clinical psychiatry side has received comparatively little attention in HCI research. Among the most widely endorsed technologies is digital phenotyping (DP), a nascent AI/ML-based approach to diagnostics and behavioural monitoring [59, 70]. DP passively collects sensor data, device usage patterns, online activity, and other digital traces from a service user's everyday life, from which algorithmic models derive so-called digital biomarkers: proxy indicators of health states such as mobility patterns, sociability metrics, and circadian rhythms. This data is later accessed through an app or other dashboard system by the service user, the clinician, or both. While several commercial and research instances of DP already exist, the technology is still in the early stages of development, with no established conventions for how these systems should be designed and how the data should be interpreted and further applied in practice. That said, considering far-reaching care transformation and ethical regulation that DP presupposes, we believe that the HCI community needs to move conversations around it beyond narrow concerns of clinical accuracy and business viability.

The two main promises of DP have been its unobtrusiveness and the ensuing bias reduction, as well as a shift towards quantifiable metrics of behaviours and mental states. Furthermore, there is an inherent assumption among the proponents of DP that those systems are universally scalable, as they are structured around existing diagnostic manuals and do not require human intervention [43, 46]. Some recognition of cultural variety is present in critical papers, yet culture is understood in the sense of varieties of group expressions and articulations of mental health, rather than a structural culture of mental healthcare systems in question [24].

In this position paper, we would like to complicate those statements by putting forward an instance of outpatient bipolar disorder management in the Netherlands. Although this case might appear narrow, such an approach is not exclusive to this diagnosis nor to a specific country. Yet, providing a grounded illustration in a situated context allows to highlight gaps in the design of AI-based DP systems, which are projected to become a part of the mental healthcare practice [11]. Importantly, while we inevitably engage

with a system level of Dutch infrastructures of care, in this paper we focus specifically on how they are reflected in the individual practices of service users.

Bipolar disorder is a chronic condition characterised by alternating episodes of mania (or its milder form, hypomania) and depression, with periods of stability (euthymia) in between. The episodes are usually separated by months or years and can be particularly distressing and disruptive. In terms of treatment, the first-line intervention is psychopharmacology, followed by therapy and self-management tactics, with the salience of the latter two depending on individual situation, clinician's previous experience, and regional practice norms.

Clinical researchers and developers of DP have focused extensively on its technical elements, presenting passive data collection and pattern analysis as its core capabilities. However, we argue that the most important production of health knowledge occurs after all those phases–that is, when it is already in the hands of a person with a given diagnosis, who now has to embed new practices of sense-making, negotiation, contestation, and mobilisation of data into their everyday regimen. In this position paper, we seek to contribute to health HCI scholarship by (1) extending Burden of Treatment Theory (BoTT) [37] to chronic *psychiatric* conditions; and (2) bringing to the attention of designers the relevance of treatment burden in the development of DP and, potentially, other AI-based mental health technologies.

While we will elaborate further on why bipolar disorder is particularly illustrative, we first draw attention to several key aspects that distinguish DP from other non-AI ambulatory assessment tools, such as mood trackers or ecological momentary assessment:

(1) The "unobtrusiveness" of DP is presented as a delegation of active tracking from the service user to the tool, relieving those producing the data from any interpretive work related to it–they simply receive a completed assessment.
(2) Consequently, this delegation applies not just to collection, but also to the interpretation of personal data, leaving the person with already processed data visualisations, while the underlying algorithms remain opaque.
(3) DP's analysis carries greater epistemic weight in shaping the experience and articulation of mood states: not simply because the passivity becomes commensurate with impartiality, but also due to DP's aim to operate within clinical categorical systems, such as DSM or RDoC, thus interpreting deviations in data as a *health* concern.

As a result, the design of DP obscures invisible work that people with bipolar disorder have to perform in order to adopt and adapt to the new tracking practices situated, in turn, within a broader practice ecology.

Importantly, we do not make any clinical arguments. Our goal here is to draw the attention of designers and HCI researchers to understand the needs, preferences and capacities of a sensitive group of people, which have now been positioned as a potential user group for an incipient disruptive technology. By doing so, we hope to engage designers and HCI researchers in the discourse and practice of upholding the values of privacy and patient autonomy in pursuit of *technology-enabled person-centred care* [30, 39].

This topic emerged as a reflection following the authors' design research conducted with three people diagnosed with bipolar disorder in the Netherlands and Belgium[1], comprising two participatory sessions and a booklet probe study. The study was approved by the main institution's ethical board. While the full empirical findings are reported elsewhere, a key insight of these engagements was the self-management work that those people relied on to keep themselves stable. The present paper thus develops this observation analytically, with anecdotal empirical evidence, principally drawing on treatment burden [37] and cumulative complexity [13, 58] literature and the publicly available documentation on mental healthcare standards and practice recommendations in the Netherlands [1, 17, 29, 67] to articulate what "passive" sensing obscures. Before moving to a discussion on DP specifically, we first map existing circumstances that people with bipolar disorder could be dealing with day-to-day.

2 Existing Labour of Self-Management in Bipolar Disorder Treatment

In chronic conditions, including bipolar disorder, the burden of treatment often refers not so much to the goal of necessarily curing them, but to proactively preventing the recurrence of acute episodes, their progression and relapse [37], as well as maintaining quality of life [42]. Shared decision-making is part of standard clinical recommendations for bipolar disorder treatment in the Netherlands, with the service users seen as experts of their experience (except for cases requiring a coercive approach) [1]. Self-management is a crucial element of Dutch clinical care, focusing on structured (self-)evidence production through coordinated plans, protocols, and tracking systems that develop a sense of control and self-efficacy [56]. As van den Heuvel notes, "At the core of self-managing bipolar disorder lies 'having a plan' to stay well" [64, p.12]. Notably, mental healthcare standards suggest using old diaries or schedules at early stages to retrospectively determine the presence of (hypo)manic episodes [1]. These record-keeping practices are cultivated under clinical guidance, while active involvement of family members or other informal caretakers is seen as particularly beneficial in creating and sustaining these systems [49].

In Table 1, we outline common tools that people with bipolar disorder employ as part of their self-management routine in–though not exclusively–the Netherlands. This list is produced based on the guidelines and recommendations provided by Dutch psychiatric care institutions and research organisations, which consistently prescribe the use of the following tools [1, 17, 29, 67], as well as the anecdotal empirical evidence from a separate authors' study.

Both the reviewed guidelines and our empirical study consistently foreground the Life Chart, Early Warning Plan, and Emergency Plan as key self-management tools, alongside medication tracking and counter-behaviour strategies. They are intended to be used in a sequence: a person might record a state in the Life Chart, consult the Early Warning Plan to identify emerging signs or triggers, and then turn to counter-behaviour or crisis protocols to offset them.

[1]While psychiatric systems are organised differently in those countries, the Belgian participant's experience matched that of Dutch peers, therefore, the focus here remains on the Dutch context.

Table 1: Common Tools for Self-Management of Bipolar Disorder in the Netherlands

Tool	Purpose	Frequency	Note
Life Chart	To track mood score, sleep, life events, weight or other relevant metrics and daily activities, thus recognising patterns	Daily	No single template, formats vary: -5 to +5, -4 to +4, 1-10, 0-100
Medication tracking	To track type and quantity of medication, its effect on the state	Daily	Often part of Life Chart tracking
Early Warning Plan	To be consulted when mood changes are sensed	Updated periodically, as the need arises	Can be developed together with the Crisis Plan
Counter-Behaviour Plan	To be consulted to support a mood change is noted (according to the Early Warning Plan)	Created once, updated if needed (i.e. if there were changes to the Early Warning Plan)	Can be developed together with the Crisis Plan or Early Warning Plan
Emergency Plan	To provide instruction of agreed-upon actions to be taken when the psychiatric crisis arises, facilitates shared decision-making (even if coercive methods are involved)	Created once, can be reviewed	Mostly used for service users with an unstable condition
Social Rhythm Metric	To log daily activities and time, thus stabilising routine and disrupted circadian rhythms	Daily	Optional; can be used as an alternative to or together with Life Chart
Triade Map	To distribute care responsibilities between the service user, informal carer(s) and the clinician	Created once, can be reviewed	Optional
Diary	To record personal reflections on the day and one's state	Daily, weekly or when the need arises	Optional
Physical activity tracking	To maintain the level of activity within therapeutic limits	Episodically	Optional
Menstruation tracking	To understand the effect of the menstrual cycle on the mood	Episodically	Optional

The practices of using these tools depend on the service user, the severity of symptoms, and clinical judgement. The selection and number of tools employed in self-management are contingent on what is sufficient to efficiently manage one's condition, the availability of informal care, and personal preferences and capacities (e.g. if physical activity–lack or surplus of it–or menstrual cycles are the triggers).

Dutch philosophers of psychiatry Dings and Glas [16] view self-management as enabling the resolution of "self-illness ambiguity," whereby the diagnosed person learns to differentiate whether the particular mood and behaviour is a manifestation of an individual trait or of a condition. Yet, the benefit of these practices is not universal. For some, they could bring anxiety, pressure, and frustration, particularly when the capacity to sustain the discipline is insufficient, and expected results do not materialise, resulting in "a hypervigilance that often [feels] exhausting and joy-dampening" [51, p.7]. As people become reliant on these tools to keep themselves stable, the work also carries emotional and moral burden and can exacerbate self-stigma [31, 63]. Evidence-based benefits notwithstanding, structured self-management requires advanced observational capacity, phenomenological expertise, and organisational consistency. Self-management becomes a skilled and largely invisible labour.

Below, we elaborate further on how the practice of self-management is positioned within the treatment burden ecology and explain how digital interventions–however passive–could compound an already significant complexity.

3 Cumulative Complexity

May, Montori and Mair [36, 37] draw attention to the concept of treatment burden among people with chronic conditions. Initially focusing primarily on diagnoses such as diabetes, cancer, asthma, and dementia, they argued that treatment work constitutes a burden distinct from, yet compounding, the illness burden of living with a chronic condition. As they state, "patients experience new and growing demands to organise and coordinate their own care, to comply with complex treatment and self-monitoring regimens, and to meet a whole range of expectations of personal motivation, expertise and self-care" [37, p.2]. The demands of this treatment work encompass mobilisation of physiological, cognitive, affective, sensory, relational, material and infrastructural resources [37].

Building on their earlier work, May and colleagues [58] determined that treatment burden encapsulates the balancing act of two components: patient workload and capacity. The workload here indicates the responsibilities and demands that the person has to maintain daily, while capacity refers to abilities, resources, and readiness to grapple with that workload. The accumulation of these demands is described by Shippee et al. [58] as *the cumulative complexity*. As the workload begins to outweigh the capacity, adherence to treatment regimens, quality of life, health outcomes, and consumption of health services begin to be affected. Meanwhile, although the burden of family and informal carers is widely researched and should certainly be acknowledged [7, 15, 20], the illness and treatment workload of people with mental health conditions themselves remains comparatively underexplored.

3.1 Conventional Patient Work in Bipolar Disorder Management

3.1.1 Comorbidity and Associated Risks. Research on physical chronic conditions renders the presence of multiple interconnected conditions and increased risks for certain illnesses as an increased burden [36]. The same remains relevant for psychiatric diagnoses. Research suggests that people with bipolar disorder face a higher risk of gastrointestinal issues (especially women; [8, 26, 53]) cardiovascular events [18], and even potentially cancer [5], as well as other psychiatric and neurodevelopmental comorbidities, including ADHD and anxiety disorders [28]. The management of those comorbidities and risks is further complicated by polypharmacy in the treatment of bipolar disorder (as it could involve taking 3+ medications simultaneously), creating potential for drug interactions, especially if lithium is involved [10]. Since co-occurring physical and psychiatric conditions can trigger mood episodes, it can be argued that successful self-management of bipolar disorder equally includes vigilant monitoring of all of these conditions simultaneously.

3.1.2 Medication and Side-Effects Monitoring. Lithium, the most commonly used medication for bipolar disorder, carries significant side effects. In the Netherlands, the rate of prescription of lithium remains high, as Renes et al. [54] reported a remarkably significant number (70%) of lithium prescriptions for people with bipolar and schizoaffective disorders receiving pharmacotherapy. In some cases, the "therapeutic level of lithium [...] is perilously close to the toxic level" [25, p.93], resulting in people experiencing side effects from mild tremor to loss of coordination. Other side effects vary by drug type and can include weight gain, cognitive changes, hair loss, metabolic problems, and other physical symptoms requiring additional monitoring and medication correction.

Changing mood symptoms might similarly require pharmaceutical adjustment, meaning people must repeatedly adapt to new dosage levels and their associated consequences. As such, some people experience difficulties staying on prescribed treatment, as they come off and on medication. That said, some people with milder forms of bipolar disorder manage to limit or cease medication completely, which, in turn, might require additional (attention to) self-management strategies.

3.1.3 Coordination of Care. People with bipolar disorder in the Netherlands navigate a fragmented care landscape. Outpatient treatment typically involves psychiatrists managing medication, psychologists providing therapy, and sometimes community psychiatric nurses monitoring symptoms and providing psychoeducation [21]. General practitioners serve as gatekeepers for specialised mental healthcare and continue to provide physical health monitoring, creating an additional coordination point between mental and somatic care systems. Regular blood work is required for users of some medications like lithium, while somatic check-ups are recommended for people with a bipolar disorder diagnosis [1]. In severe cases, FACT-teams may be assigned, adding home visits to the coordination load. Our small empirical study further suggests that service users engage in complementary and alternative practices such as yoga, meditation, herbal and vitamin supplementation, acupuncture and somatic therapies, adding another layer to the coordination work (also [68]).

3.1.4 Fluctuating Capacity. Bipolar disorder presents a notable example of potentially extreme dynamics of changing capacity. Depression–both uni- and bipolar–can lead to physical and mental exhaustion and impede future-directedness [32], incapacitating the person and making dealing with the treatment burden extremely difficult. Meanwhile, Shipee et al. [58] warn that increased capacity can also lead to ineffective care. To some people, manic episodes grant (an illusion of) extended capacity. In line with that, Radden reports that both mania and depression upset expectations of "functionality, affective appropriateness and cognitive bias" [52, p.82], thus disrupting the capacity for prioritisation, synchronisation of demands, and coordination [58]. While those disruptions could be overcome, they "may require more persistence, effort, and ingenuity" (p.99). Taking that into consideration, treatment work in bipolar disorder might shift the demands from manageable to overwhelming and from valuable to dismissible (and vice versa), without any significant changes to the workload itself.

3.1.5 Gendered Burden. The cumulative complexity model recognises everyday labour as treatment burden but ignores its gendered dimension. Women typically maintain domestic duties, childcare, and employment while managing their condition, while failure to do so can trigger isolation and self-stigmatisation [62, 68].

Furthermore, some research links hormonal fluctuations to mood stability. Menstrual cycles may cause significant mood shifts, though findings remain inconsistent with unclear patterns [4, 61]. Menopause, in turn, can necessitate medication changes, trigger rapid cycling, and induce mood variations [23, 48].

Pregnancy and childbirth heighten relapse risk and psychosis sensitivity, creating additional stress and demanding extra relational work with partners and clinicians [3]. Parents with bipolar disorder often vigilantly monitor their children for early warning signs, given the genetic risk.

Meanwhile, traditional gender expectations demand stability of men—i.e., emotional, relational, and financial. Employment difficulties may therefore carry greater emotional weight for men [40]. Additionally, Martin [34] observes that contemporary culture might have romanticised mania as a masculine trait, almost requiring men to "perform" it in professional, high-stress contexts.

3.2 Digital Layer of Patient Work in Bipolar Disorder

Back in 2014, Rooksby et al. [55] argued that it is misleading to treat people engaging in personal informatics practices as rational users collecting objective evidence. Whereas health technologies have advanced in the broader embedding of AI, we believe this claim remains true. In conceiving technologies that can support not just physical but mental health conditions, this new category of users gets entangled in "the site[s] of radical dependencies, collaborative care arrangements, and wider sociopolitical concerns tied to new forms of technical labour and shifts in medical expertise" [27, p.49]. Recognising the fast expansion of digital health tools for self-management, Cross & Alvarez-Jimenez [13] have extended the cumulative complexity framework to the integration of digital mental health interventions into care. The goal of their proposition was to improve adherence to these tools, which was affected, as they argue, by a "one-size-fits-all" approach and the lack of contextual considerations and individual workload-capacity balance.

The reliance on paper-based methods and subjective insights is seen as a significant drawback of the current self-management system, soliciting a technological intervention [2]. Increasingly, the consideration of passive, background collection of disorder-related data has been discussed in the literature [41, 47, 57, 69]. Matthews et al. [35] have reported the interest of self-trackers with bipolar disorder in autonomous background tracking.

That said, it has to be further investigated whether passive sensing really relieves these tracking burdens rather than duplicating or exacerbating the practices of self-monitoring. Below, we further unpack how DP-based tracking might counterintuitively increase treatment workload.

3.2.1 Intensifying Epistemic Work. DP systems rest on an implicit assumption of a concordant "data-reflection-action" sequence [12] that supposedly functions identically whether data collection is paper-based or digital. However, the expanded capacity of continuous sensing to capture data that would otherwise be impossible or unreasonable to collect also intensifies the process of sense-making [9]. Data is presented in raw or quantitative form and still requires integration into one's experience, as the diagnosis and episodes could precipitate biographical disruption, i.e., of one's self/disorder narrative [14]. Yet, people with bipolar disorder are unlikely to abandon their existing structures of "record-keeping", as easing up on established self-monitoring practices risks missing the onset of a severe episode. As the bipolar disorder treatment approach continues to emphasise self-efficacy and self-mastery, service users accustomed to working with interconnected protocols and embodied observational skills must now also integrate discrete data points and automated proxy measures, engaging in multimodal health knowledge practices, while deciphering and deliberating on the conclusions AI made.

3.2.2 Responsibility of Acting On The Data. Early Warning Plan and Life Chart structure a practice of self-observation and an appropriate response. Crucially, in the paper-based tools, those processes are carried out by the same agent (if no external observers are involved). The person who notices a warning sign is the same person who engages in determining what that sign means and what should follow. DP disrupts this order: by delegating observation to the passive sensing of behavioural signals, it divorces the process of sensing (and thus, sense-making [9]) from the process of acting.

In that case, multiple questions arise. Detached from a broader system of "record-keeping", does the user continue to be responsible for acting on the passively sensed early warnings? Who needs to be implicated in this process and how, if at all? Is it sustainable to expect continuous monitoring—with its perpetual stream of actionable alerts demanding ongoing attention and decision-making—from people already navigating the compounded burdens of the disorder, work, family, and other responsibilities? Potentially, this would require an extension of the already existing Triad Map and Crisis Plan, where the person with bipolar disorder would also need to decide on the contingency protocol for the digitally sensed triggers. For people whose capacity to attend to, evaluate, and act fluctuates with their mood shifts, the assumption that DP aids their responsive vigilance without negative effects seems too optimistic.

3.2.3 Evidencing Work. While the assumption of objectivity and impartiality of DP is showcased as a long-awaited innovation in psychiatric tools, it comes with its unexpected consequences. People with bipolar disorder already have to manage not just their condition, but also the evidence of a condition: decisions and interactions have to be protocolised and every day should leave a paper trail. One study participant kept their paper-based Life Charts from multiple years in the past and was using them to justify to the psychiatrist a change in medication. A data-driven tool might change this dynamic. DP data may be perceived by both service users and clinicians as more authoritative than subjective self-reports, precisely because it appears to bypass the biases and limitations of self-monitoring and possesses additional intelligence. Service users could use data from passive sensing to substantiate their experience and advocate for treatment adjustments in contested situations where their self-report has historically been doubted or attributed to impaired insight. At the same time, the data could be used against the service user, where it might carry a more epistemic weight. As such, people with bipolar disorder would now have to learn to mobilise collected data and AI diagnostic conclusions for decision-making and deliberation in clinical encounters.

3.2.4 Relational Work. The practices of collaborative sensing and sense-making through both digital and non-digital means have long been a part of chronic condition management [44, 50, 65]. Both in our design research and in the wider literature (e.g. [60]), informing family and friends about one's mental state was identified as a desired function of self-management apps. Some of these options include automated notifications to a select few individuals about significant changes in mood or daily overviews. Passive sensing data can thus implicate people present in the person's care networks into participatory data work, making them a part of the sensing and response processes.

On the other hand, a person with bipolar disorder might become responsible for managing the anxiety and hypervigilance of others, further engaging in negotiation and providing (counter-)evidence to captured data. If the person decides to cut off access to avoid these conflicts, they need to perform relational repair, caused by erosion of trust or strain in the relationship.

Therefore, introduction of DP into the existing ecology of practices necessarily carries an additional layer of burden, building up on already existing treatment work, "record-keeping", and other life demands. Not only does it seem to be uncoupled from the support systems and protocols that people have taken time to master and have come to rely on, but it demands of them a cultivation of completely new practices in order to integrate those tools into their regimen.

4 Design Implications

While the attention of researchers and developers of DP methods and systems in the current moment is directed towards the validation of digital biomarkers, there are crucial design requirements and considerations to be examined and addressed, even as these technologies are nascent. It is crucial to recognise that DP practices are supposed to intervene within already established ecologies of relations, interactions, and enactments, which change from culture to culture. In a country like the Netherlands that emphasises watchful self-monitoring and evidence-making through structured, guided protocols, DP can present a new kind of sensibilities and responsibilities. Whereas its ambient operations might resolve the imminent issues of adherence to data generation, the system must enable coherent integration as a part of the ecosystem, considering all the trade-offs that it might need to adopt. Otherwise, it risks becoming a medical surveillance accessory, without any particular practical objective.

Drawing on the outlined burden and demands that the people with diagnosed bipolar disorder face on a daily and episodic basis, we suggest to future designers and HCI researchers of DP the following:

(1) *Design of DP systems (or any digital psychiatric intervention for that matter) as personal informatics tools should start from evaluating the existing service user workload.* Both quantitative (borrowing it from the treatment load in physical conditions) and qualitative methods could be developed. While current and expected developments in ML and AI promise radical innovation, DP designers must adopt a curatorial approach, deliberately evaluating what DP contributes to and alleviates from existing demands to achieve a balanced approach. Murray and colleagues [45] suggest employing Normalisation Process Theory (NPT) as a methodology for unpacking the burden in particular contexts and making existing gaps or overlaps visible. While NPT is more actively used as part of implementation science, it can be equally used in the design-informing foresight and assessment of technological interventions [45]. In addition, the DP field lacks knowledge of how those tools would be "domesticated": qualitative and ethnographic approaches examining self-management practices and the significance people attach to them are indispensable.
(2) *Designers of DP need to consider which levels of the care infrastructure would tackling complexity implicate (technology, service or otherwise).* After completing a burden analysis, the question becomes whether DP should integrate existing labour and practices into the digital system itself (for example, combining existing tools like Life Chart, Emergency Plan, and Triade Map into DP) or whether it should be accompanied by guidance disseminated through mental healthcare professionals and other support channels, incorporating DP into everyday regimen. The first option has a significant concern: data loss through a technical issue or the system becoming "abandonware" due to any mismanagement of the provider can be devastating, as people with bipolar disorder rely on consistent "record-keeping" and "evidence-making" about their condition–whether for themselves, their caregivers or for clinical purposes [6, 38]. Meanwhile, the second option pushes the responsibility onto a human factor, thus requiring additional resources to be properly acted out. Moreover, it might introduce a form of paternalism, where the integration of DP into everyday life could become too prescriptive [66]. Neither option is likely to be sufficient on its own, as it remains an open design question how to ensure sustainable, safe, and meaningful integration of DP, without completely dismantling and devaluing critical "legacy tools".

(3) *DP systems need to be developed with an embedded person-centred approach.* As BoTT demonstrates, the "patient role" is not performed uniformly but enacted differently across various dimensions of everyday life. AI-based systems like DP have the potential for flexibility and adaptability to the changing states and needs of the user. In some cases, that role requires a stronger grip on the condition (e.g. in child-care and work), while elsewhere a degree of vulnerability is called for (e.g. in clinical encounters, when recording the "evidence"). A system that focuses on its user uniquely as a patient misses the multiplicity and complexity of mental health. Existing research already indicates that some users with bipolar disorder are drawn to widening the scope of monitoring beyond direct clinical signs or immediately relevant disorder indicators to encompass multiple spheres of life [22, 41].

5 Conclusion

In this position paper, we drew attention to the overlooked treatment burden in chronic psychiatric conditions by outlining the various forms of workload that people with bipolar disorder actively manage. We have highlighted that besides "conventional" patient work, such as managing medication, side-effects, comorbidities, and coordination of care, those diagnosed with bipolar disorder must keep a vigilant paper trail of their condition–be it protocols, tracking, or decision-making instructions for themselves and their care networks. If advanced digital tools are introduced atop these existing demands, they risk overwhelming users or imposing a parallel self-management system without integrating into their existing practices. That said, people with severe mental conditions may willingly accept this additional burden if it affords them greater control over their state and earlier detection of warning signs. It opens, therefore, a variety of questions that are yet to be tackled in DP design: Should DP consolidate all "paperwork" into a single system in contexts where structured self-management already exists? Or would it be primarily addressed to those lacking such a structure? If additional burden is inevitable, how must DP design support service users in navigating it? And whether it should at all, as we are yet to see what the outstanding benefits of DP are clinically and individually. This field requires sustained attention to empirical research in HCI and design that unpacks lived experience and lived (ill) health in relation to AI-based diagnostic and management tools, enabling sharper recognition of user needs and preferences.

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