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Digital Self-Monitoring, Bodied Realities: Recasting App-based Technologies in First Episode Psychosis

Suze G. Berkhout
University Health Network, The University of Toronto
suze.berkhout@uhn.ca

Juveria Zaheer
Centre for Addiction and Mental Health, The University of Toronto
juveria.zaheer@camh.ca

Abstract

Smartphone technology has seen expanding interest across nearly all areas of medicine, including psychiatry. This paper discusses the burgeoning use of digital technologies for symptom monitoring in the field of first episode psychosis. Drawing on Foucauldian theory as well as intersectional feminist materialist and critical disabilities scholarship in science and technology studies (STS), we trace a novel landscape of technologies of the self. We explore the discursive strategies that position first episode psychosis and digital technology as progressive, curative paradigms and utilize our own ethnographic work within the field of first episode psychosis to consider how lived experience is transformed within and through digital technologies. We trouble the unfettered enthusiasm for digital technologies in first episode psychosis in light of how these transformations can be understood within a larger neoliberal political rationality and demarcate the importance of having intersectional feminist STS scholarship attend to this burgeoning field.

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> It was so devastating. Um, it was shocking because it's like I spent three years in psychosis, like three years. Yeah, like, with wasting my life. And I mean it wasn't my fault in many ways, but it's like, you know? I…like…it just, it was, there are no words to describe how I felt.
> —Sam

Introduction

The incredible breadth of app-based and smartphone technologies relating to mental health is continuously growing: from mindfulness meditation, to interpersonal and social rhythms, to mood and medication tracking, to distress tolerance and coping skills—digital self-monitoring applications exist for nearly all diagnostic categories and across therapeutic modalities. At the individual level, the aim of such technologies is often a "more active and empowered" patient (van Os et al. 2017, 481–482), which is frequently seen as being achieved through "giving voice" to their experiences (Allen 2016, 42). Digital technologies are also lauded for the wealth of biometric data they can track with relative ease (Allen 2016; Hollis et al. 2015, 263; D'Arcy et al. 2020). Mobile digital technologies are employed *both* as interventions for ill health and as a means of generating novel information for psychiatrists about patients and pathologies (Pickersgill 2019, 16). Proponents of digital technologies in mental health have suggested that digital care tools provide a way to capture clinical presentations more robustly, which could translate into more accurate diagnostic practices and more meaningful interventions (Torous et al. 2019, 269–71). Such perspectives frame digital technologies as offering opportunities for collaborative practices in relation to diagnosis, promising innovative engagement strategies, increased efficiency, and greater control by patients over the medical knowledge and practices that impact them (Banner 2017, 1–2).

These latter objectives—surrounding diagnosis and intervention—are prominent within the field of first episode psychosis. First episode psychosis (FEP) refers to an early point in time in the diagnosis and management of psychotic illnesses stemming from a range of potential causes (Breitborde, Srihari, and Woods 2009). As a result of illness demographics, FEP program are geared toward late adolescents and young adults and integrate symptom monitoring, medication management, and a host of psychosocial interventions such as educational and vocational supports. Here, we see a rising interest in the use of digital platforms not only for patient self-management, but for assessment of symptom domains as well (Ben-Zeev et al. 2014; Bell et al. 2018). Self-monitoring technologies in FEP increasingly serve as proxies for digitized behavioral "phenotypes" (Firth and Torous 2015). And it is this tracking of phenomenological data that the digital psychiatry literature references as capturing lived experience (Torous et al. 2019, 269).[1]

In what follows, we explore the growth of digital care tools based on ecological momentary analysis (EMA) and its related technology, experience sampling method (ESM). These are used in both clinical and research settings within the FEP context to collect indices of behavior, cognition, and/or emotion in near real time through electronic devices (Trull and Ebner-Priemer 2009, 457). We focus specifically on claims that digital care technologies offer a means of giving voice to the heterogeneity of lived experience. Examining the rhetoric and discursive strategies within this literature, we draw on Foucauldian technologies of the self and insights from feminist materialist thought within science and technology studies (STS), bringing these in conversation with crip technoscience scholarship and mad studies. We suggest that understanding digital technologies in FEP within these theoretical frameworks makes evident two concerns. First, a deep resonance exists between rhetorics surrounding digital technologies and first episode psychosis: those of futurity and progress, which extoll what has been termed "biomedical virtue" (Pickersgill 2019, 17). Both fields also espouse what Meryl Alper has identified as a technophilic rhetoric of revolution that embraces paternalistic discourses of technology as an "equalizer" (2017, 2). Despite claims of giving voice to those struggling with mental distress, we argue that these overlapping discourses are part of what is called the curative imaginary (Kafer 2013), which renders certain aspects of lived experience illegible, and disability inevitably in need of intervention.

Second, we consider claims that self-management through digital technologies is a mobilization of a neoliberal political rationality, particularly through the responsibilizing of citizens. This claim, offered from a range of scholars within STS, bioethics, medical anthropology, and sociology of medicine, takes on different meaning in the context of the early intervention (EI) paradigm within which FEP operates. Within the EI framing of FEP, responsibilization and healthism are *also* seen as normative developmental tasks for young adults experiencing psychosis. Such tasks are facilitated by the digital platforms in question, naturalizing neoliberal assumptions concerning "health" behaviors and undercutting critical or dissenting views of such technologies. This naturalization of neoliberal presuppositions likewise contributes to the curative imaginary that structures FEP services.

We develop these arguments through a granular view—interrogating digital care tools in FEP through what Rose Galvin has called the "micro-political technologies of health" (2002, 127). In the context of a three-year ethnographic study within a FEP program in Toronto, Canada, we explore how the curative imaginary has both material effects upon individuals who utilize early intervention services *and* materializes its own forms of distress, particularly through the narrowing of experience into symptom domain and psychiatric nosology. We argue that a parallel issue of epistemological narrowing may likewise be generated by the digital platforms themselves, giving pause to some of the unfettered enthusiasm for self-monitoring technologies in FEP. We also take seriously crip technoscience insights that explore how, in certain instantiations, technologies can also facilitate the imagining of alternate visions of care (Banner 2019) as well as new and different temporalities and socialities for disabled people (Hartblay 2015).

Specifically, our ethnographic encounters in the FEP clinic suggest that endorsements of monitoring technologies as giving "voice" to lived experience miss a larger issue of health politics. When biodata is seen as somehow speaking for itself while serving as a proxy for the complexity of experiential knowledge, challenges of epistemic injustice arise. Lived experience, in this context, serves as knowledge *only* when translated through expert-designed tools (Swartz 2018, 66). We then discuss the challenge of epistemic injustice within digital technologies, understanding these challenges in relation to intersectional axes of social power while also recognizing how these might offer potentially novel, meaningful forms of healthcare engagement. Grappling with this tension is of critical importance in light of the expansion of such platforms in clinical and research environments.

Study Setting, Historical Context

Our analysis of the emerging trend toward employing digital technologies in FEP is part of a larger study that has examined socio-historical, experiential, and biological narratives of FEP, along with the early intervention (EI) paradigm that structures this field. Although it is now widely recognized as a gold standard clinical organizing concept, FEP has not always been part of the psychiatric lexicon. As Berkhout (2018) describes, the concept of FEP emerged in the late 1980s and early 1990s, arising as a foil to chronic, multi-episode schizophrenia. FEP has become a clinical organizing concept through interrelated networks of researchers and psychiatric professionals based primarily within North America, Western Europe, and Australia.[2] Valued for the opportunities it offered researchers into the natural history, prognostication, and disease mechanisms of schizophrenia-spectrum illnesses, FEP is embedded within the EI paradigm, a concept that extends through learning and other disabilities (Berkhout 2018). EI holds that the earlier the intervention, the better the prognosis for recovery or reduced morbidity through the provision of treatment early in an illness course (Csillag et al. 2016, 540). A fairly large body of data in FEP suggests that the longer the duration of untreated illness, the worse the clinical outcome (Perkins et al. 2005; Loebel et al. 1992). FEP clinical programs are organized, then, to provide the earliest possible interventions for psychotic-spectrum illnesses (antipsychotic medications, psychoeducation, family support, vocational training), limiting the duration of untreated illness (McGorry et al. 2008). Most FEP clinical programs provide approximately two to three years of multidisciplinary and coordinated specialist services, before individuals "age out" of the programs and return to care-as-usual (NAMI 2016).

It is in the setting of a large FEP clinic in Toronto, Canada, that we have carried out a three-year study (the Psychosis Narratives Project). Our critical qualitative approach is based in ethnographic and narrative inquiry, informed by theoretical frameworks of feminist materialism, postcolonial theory, and disability studies (Willey 2016; TallBear 2017; Pitts-Taylor 2016; Lupton 2019; Schalk 2017). As we describe elsewhere, this study entailed a number of onto-ethico-epistemological commitments: that "fundamental" human processes (such as self or emotion) are invariably mediated by culture and context (Jenkins 2004); the importance of "experience-near" categories, understanding these can only be known incompletely (Kleinman 1995); attention to social meanings, practices, discourses, and interpretations as meaningful data; a commitment to account for the social and symbolic processes and meanings in *all* domains of knowledge generation; and that the social, political, and cultural narratives that shape subjective experience are structured by legacies of colonialism and imperialism, intersecting with other aspects of identity, including gender and (dis)ability (Berkhout, Zaheer, and Remington 2019, 447). Our larger project was guided by the importance of attending to these intersectional aspects of identity and of questioning the contexts and histories that shape the intelligibility and conditions of possibility for understanding so-called objects of science.

In total, thirteen FEP service users, seven family members, and five staff members took part in a series of longitudinal open-ended narrative interviews. We engaged in numerous informal interviews during periods of participant observation and at events such as FEP conferences and workshops. Observational fieldwork was carried out within the FEP clinic setting, including clinic appointments, follow-up visits, family psychoeducation groups, research meetings, conferences, and staff meetings. It was from our observational fieldwork that the claims surrounding digital care apps became of interest to us, both in relation to claims made about these (e.g., as important tools in research settings) and what we saw to be the increasing presence of such apps in the larger field of FEP as our study went on. A final component has been a series of visual arts-based workshops with service user participants. Here, we explored the limits of narrative-based methods for understanding psychosis through the creation and witnessing of art/mark-making that expressed what was "unspeakable" about psychosis (see Berkhout and Stern 2019). Data presented in this paper were analyzed collaboratively between Berkhout and Zaheer, within a reflexive, interpretivist-constructivist frame;[3] findings were discussed within the larger research team and member-checked through informal interviews within the clinic. The project was approved by the research ethics board at the Centre for Addiction and Mental Health (CAMH) where the work was carried out (CAMH REB 098-2014).

Digital Psychiatry: From "Phenotype" to Lived Experience

The first published trial describing the feasibility and validity of using smartphone technology for the assessment of psychotic symptoms was reported in 2012 (Palmier-Claus et al. 2012). Since that time, numerous applications and mobile health technologies have been developed and tested. Most of these have had the explicit goals of improving diagnosis, symptom monitoring, and treatment uptake and adherence (Firth and Torous 2015, 2). In this paper, we focus specifically on the phenomenological research tool termed "ecological momentary analysis" (EMA). EMA is often used synonymously with a related tool, the "experience sampling method" (ESM).[4] EMA/ESM are defined by their use of digital platforms (typically via smartphone applications) to track behavior and phenomenological experiences as people move through the world in near real time. EMA/ESM typically entail structured data collection techniques where individuals respond to randomly timed repeat assessments while carrying out their day-to-day lives (Trull and Ebner-Priemer 2009, 457). Data is generated by inquiries into emotions, contexts (where are they, with whom, events happening), activities, food/alcohol or other substances/medications, aspects of psychopathology, somatic symptoms, and stress (van Os et al. 2017, 482). This can take the form of responding to particular questions with different emoticons to represent emotional states or replying to prompts using a Likert-type scale (e.g., "this activity is difficult for me"). Sampling is designed to be completed within one to two minutes, to minimally disrupt a service user's daily routine. Items sampled are meant to be those that vary momentarily (i.e., states), rather than items that reflect a more stable or enduring "trait" (van Os et al. 2017, 482).

EMA/ESM technologies have exploded within the area of early intervention—notably in relation to "activating" service users with respect to their own treatment and assessment, while providing "in-the-moment reports not subject to memory biases and 'global evaluation' distortions" (van Os et al. 2017, 482–483). The framing of technologies in early intervention is similar to literature surrounding self-monitoring technologies in youth across a range of other psychiatric diagnoses (e.g., depression), which postulate that such tools assist young people in understanding their mental health symptoms through emotional self-awareness (Kauer et al. 2012) as well as increasing their insight into the need to seek professional supports (Rickard et al. 2016).[5] EMA/ESM technologies are simultaneously lauded for their ability to collect biodata through methods that require *minimal* insight or subjective report from users, for instance, through global positioning systems or accelerometers that correspond to social and physical activity (Kauer et al. 2012; Torous et al. 2018). To understand this apparent incongruency, it is worth citing at length from one such paper:

> Reports, often in diary format, are completed several times per day usually at random intervals with the goal of capturing a patient's state in "their natural setting." ESM offers several advantages over

> retrospective recollections of patient symptoms. First, it reduces the need to rely on episodic memory, which can be unreliable. Second, it creates the potential to capture transient, randomly occurring symptomatic experiences. Third, it allows a better understanding of daily fluctuations and patterns of change anchored in time to activities, social contexts, and time. (Torous, Friedman, and Keshavan 2014)

Likewise, from a different research group, we hear in one breath that momentary assessments can substantially contribute to the mutual dialectical process by which a clinician and service user come to agree on the nature and causes of a patient's problems. But only a few short lines of text later, ESM is lauded for its ability to stand in for what is seen as unreliable personal experience.

> ESM can contribute to better understanding of day patterns of social interactions or activities that someone is involved in. People are often poor judges of these patterns and this may be particularly true for patients with unstructured day patterns who often experience cognitive problems. (Oorschot et al. 2012, 406)

This justification is seen across the literature, even while the same papers postulate that engaging EMA/ESM technologies is meaningful to users. This conflicting view of "lived experience" and its reliability also finds expression in the excitement around using biodata from mobile technologies that rely on *no input at all* from service users:

> An innovative way to meet this challenge is to monitor indices of emotional health using methods that require minimal insight or subjective report from the user. Mobile phones contain a range of embedded sensors and features, including accelerometers and global positioning systems and apps, which can automatically record information about a user's behavior. (Rickard et al. 2016)

These viewpoints seem to suggest that EMA/ESM methods, especially when used in young adult populations, may help sensitize young people to their emotional and cognitive states and the need for support, while generating information that is useful to clinicians without solely relying on a person's own understanding of their present state. We will return to a more critical analysis of this stance later.

For now, to appreciate the intersecting nature of the challenges we are raising, it is worth taking some time to attend to the language and metaphors that depict digital care tools in FEP such as EMA/ESM. There is a striking overlap between how these tools are conceptualized and the imagery that shapes FEP and the EI paradigm itself. Within early intervention in psychosis, hope is indexed through the temporality of interventions. The framing of biological treatments in FEP, for instance, is one of a medical "cure" (or near-cure)—intervention in FEP is frequently referred to in editorials, scientific articles, and infographics as a "new era," and a "bridge to the future" (McGorry 2015; Saraceno 2007). The temporality of hope, here, speaks to "a futurity that casts mental disability as an obstacle to the arc of progress" (Berkhout 2018, 179). A recent discourse analysis of an information campaign targeting help-seeking in FEP similarly describes these patterns: temporality is central, framed as an urgency that begs a larger responsibility to be vigilant for possible symptoms (in oneself and others) and act quickly to prevent disability. Within information campaigns, early intervention is framed as a gift and a public service, improving prognosis through knowledge as well as hope (Hansen et al. 2019, 6–7). The EI paradigm in this field additionally links hope to novelty, knowledge, and innovation.

Similarly, digital care tools are a "new hope" (Torous et al. 2019, 269); innovation, novelty, and even "elegance" in design are predominant themes, as is the notion that EMA/ESM fundamentally increase important, fine-grained, and *personalized* knowledge about individual lived experience in psychosis, "tailored" to a given person's characteristics and mental states (Oorschot et al. 2012). The temporality of both the EI paradigm and digital care tools attaches hope and optimism to the rational deployment of scientific facts. Martyn Pickersgill (2019) has described this discourse as reflecting "biomedical virtue"—a praxis of goodness, as understood by practitioners. Biomedical virtue can be deployed both strategically as well as spontaneously, and operates in support of various professional goals. The canonical biomedical virtue is the prevention of death (Pickersgill 2019, 17), which relates closely to the virtue of preventing disability. Turning back to the overlapping discourses of digital technologies and FEP, we can see how the biomedical virtue these extoll serves the purposes of galvanizing hope (and resources) toward these fields. The prevention of death/disability is framed within an enlightenment-laden progress narrative, which is itself steeped in virtues of harnessing reliable evidence to carry out disability-prevention aims. There are echoes here of what has been termed a "white savior narrative" within technoscience—a narrative that imagines structural inequality to be erased through the rational benevolence of the entrepreneurial technophilothropist (Banner 2019, 12).

As a whole, these are also part of what Alison Kafer (2013) calls the curative imaginary: an understanding of disability that sees medical intervention as benevolent and unquestionable. Within medicine's curative imaginary, treatment is expected and assumed whatever the personal cost, and any other way of living is unimaginable (Kafer 2013, 27–28). Eli Clare (2017) explains how cure, as an ideology, offers an inflexible set of virtues that multiply into numerous technologies and processes within biomedicine. These virtues are in the service of one goal: to ensure that bodymind trouble no longer exists—as if it had never existed to begin with. And when cure (or its approximation) fails, the blame is held by the patient/service user themselves leaving the notion of cure undisputed (Clare 2017, 76).

Biomedical virtues embedded within a broader curative imaginary suffuse both digital technologies and FEP. Much of the attention of digital psychiatry is focused on prediction as well as prevention. We need to grapple, therefore, with the ways in which prognostication is likewise part of the curative imaginary. Recall that one of the stated aims of digital care tools—like that of FEP clinical programs—is to better identify, understand, and control heterogeneous and changeable presentations of psychosis. Digital technologies in FEP facilitate an explicit goal of the EI paradigm—to predict and control uncertainty so as to return individuals to (or closely approximate) a pre-morbid state, presumably with the help of antipsychotic medications that are also more easily managed through digital care tools. The emphasis on prognostic and diagnostic practices speaks to a futurity that demarcates disabled bodyminds as unquestionably in need of biomedical intervention (Clare 2017).

Moreover, the EI paradigm structuring FEP is also embedded in, and reflective of, neoliberal biopolitics: here we see a naturalizing, individualizing, and depoliticizing of disability along with an emphasis on futurity (Berkhout 2018). Individual responsibility, optimization, and market fundamentalism, neoliberalism has replaced an ethic of state care, making health maintenance a responsibility (rather than a right) and encouraging a view of oneself as a biomedical subject (Ericson, Barry, and Doyle 2000; Pitts-Taylor 2010). Contemporary neoliberal biopolitics is *infused* with futurity (Rose and Abi-Rached 2013, 13). And because of *who* is most often impacted by having a new onset of psychotic experiences, this neoliberal political rationality finds new meaning (and less resistance) in FEP.

It was common to hear within the FEP clinic where we carried out our study that this was a “special” population developmentally. That is to say, clinicians, clinic managers, and even family members would flag that FEP was unique because it often occurred in late adolescence and early young adulthood—times when young people were individuating from their families, asserting independence, and shaping a deeper sense of self. Medicolegally, confidentiality was a concern for clinicians and family members alike. One parent, frustrated by a lack of information about their adult child struggling with psychosis who was living at home, loudly exclaimed, “I call in the prescription, I pick up the meds, I pay for them, I give them out, but I can’t have any information about my kid?!” Clinicians would indicate that a developmental “lens” was needed in order to understand actions, such as non-adherence to medications or difficulties attending appointments (e.g., sleeping through these). It is not surprising that the digital technologies designed for FEP likewise discuss their ability to facilitate a normative developmental task for young adults with mental health needs: the task of self-management and responsibilization. Digital care tools for youth especially are described as being beneficial with respect to the challenge of "empowering" young people "take control of their health" (Reid et al. 2013, 2) and for building "insight" and positively reinforcing help-seeking behaviors (Oorschot et al. 2012, 406). Patient involvement, lived experience, empowerment, participation, and ownership are the buzzwords of EMA/ESP apps; Monica Greco similarly describes these as the keywords at the forefront of the politics of contemporary healthcare and its neoliberal context (Greco 2019, 6).

The uses and roles of smartphone technologies in FEP can be read, in this light, as a practices or techniques by which an individual is integrated into the social entity—a technology of the self, whereby the subject actively constitutes or transforms itself to attain a certain state of wellbeing (Foucault 1988). Practices of the self, as Foucault explains, are not invented by the individual themselves; they are models within a given culture and time that are proposed, suggested, or imposed on someone within their social group. An individual constitutes themselves through these as a moral subject of their own actions (Foucault 1997). When we understand the responsibilizing function of digital technologies within the developmental narrative, along with how these technologies index the imperative of a particular kind of futurity, EMA/ESM in FEP are not merely a matter of getting young people to their appointments on time. Holding crip- and disability-informed insights regarding futurities alongside the notion of *co-production*, the Foucauldian reading of digital technologies becomes that much more compelling. Evolving scientific concepts, technological artifacts, and associated beliefs may emerge hand in hand with representations, discourses, and identities (Jongsma, Bredenoord, and Lucivero 2018). As such, EMA/ESM apps built into smartphones and tablets can be said to be coeval with beliefs about what constitutes psychotic phenomena and beliefs about psychiatric service users themselves. Such tools do not simply carve up the world at its joints but materialize particular kinds of subjects. For EMA/ESM in FEP, the developmental framework naturalizes the constitution of neoliberal subjectivity as the performance of normative tasks of emerging adulthood. With this in mind, we turn now to our ethnographic work in particular to further problematize the claims that such technologies open a door to lived experience so as to reveal the truth of psychosis and of the subject.

Self-Technologies in FEP: From a Discursive to Granular View

> Where I was in my worst time, I was so anxious I couldn't, like, even, you know, I couldn't function and I, and I was so—yeah, I had all this, like—yeah, I mean I wasn't able to, like—I was so sensitive to people giving me bad energy and this kind of stuff that I couldn't really be in society. I couldn't travel around. I was always looking at the power

> lines and feeling their, like, electric stimuli, and couldn't be in front of TVs or computers. Like, it was pretty horrible in terms of what I was limited to…I'm just grateful that I'm not—[I] don't have to go back there or don't have to, like, live my life always, you know, always looking out for the next stimuli, what might hurt, what might damage me, what might hurt me.
>
> And you know, other people might have different opinions of what it was, but for me it was real and what happened was real and I just needed some way to get out of that, to get out of that state. And I was provided that by the medication they gave me. (Dan)

Dan's words were part of the first interview that he and Suze Berkhout did together, shortly after the Psychosis Narratives project began. Meeting in a fairly impersonal office within the clinic where he received care, Suze asked, "How did you come to be connected with the folks here?" Dan entered into a story that began many years earlier with depression, a search for a mind/body practice that would help him manage his mood, and ended with a very physical kind of grappling—the loss of his ability to determine the meaning of the flurry of tactile and somatic sensations faced by his bodymind on a daily basis.

We turn to Dan's text at this point in our discussion to explore how experiences of psychosis are overdetermined by personal biography, cultural context, and historical contingency. His words highlight central issues that index the challenges we are raising toward digital technologies in FEP. First, how should we approach the distress, the struggle, and the pain of psychosis that Dan describes? One might call this an aberrance of salience as he processes thoughts and perceptions (Kapur 2003; Pankow et al. 2016), or a dysregulation of dopamine in the mesolimbic and mesocortical area of the brain. Could this be a spiritual crisis? The explanations are multiple and simultaneous. But beyond his particular descriptors, a second question arises: How might we read the filled pauses and discourse markers—the "like's," "yeah's," and "so's" that break up the flow of his narrative? On one level, we hear of a struggle with symptoms that are so real to him—symptoms that others have read as being "in" his head and a reflection of un-reality. On another level, the filled pauses are a reflection of a struggle to even *articulate* the very reality that he had been inhabiting—the reality that others opined on, disagreed about, and provided a medication to eradicate.

Other participants identified this difficulty articulating what psychosis was like, and what it meant to them:

> So, like, I understand that there's no fix to schizophrenia. So, I'm not necessarily looking for a fix. Schizophrenia has helped me to grow in

> ways that I can’t even explain. I don’t even know how to verbalize it, you know? But I can identify it. (Nico)
>
> I’m not sure if it’s something that can be described. I don’t know—I don’t want to sound kind of like pessimistic here, but I just don’t know if it possible to explain it in any other way than to experience it. That what I struggle with all the time, just like trying to get people, even people in my family, new people in my life, partners, like no matter what it’s like, this is what I go through. (V)

Just as with the paper’s epigraph, Nico, Dan, and V all offer a view of how challenging it is to express the lived experience of psychosis. These limits of expression were shared across nearly all participants and were often noted by family members.

FEP clinic service users and their families also endorsed many different (and at times internally competing) models of psychosis. There was a relationship between a participants’ explanatory model of psychosis and their sense of self. These explanatory models ran across a wide spectrum, from brain chemistry to voodoo practices, to simply inexplicable. The models were shifting and had various dissonances, even within a single narrative. Experiences that were categorized as psychosis were often distressing, but they were also held by participants to be important and complete aspects of one’s social world and inner life. The tensions within a given narrative or particular experience were part of what was so challenging to communicate about psychosis itself. These tensions were often higher for service users whose social identities were racialized or “othered” along lines of religion, geography (migration), and sexuality.

What was also striking was how the experience of psychosis was so fundamentally *real* for participants, something that Dan’s quote illustrates. It was challenging to reconcile the veracity and immanence of the lived experience of psychosis with the common explanation that this was “all in your head.”

> While I was going through that episode I went to a place where I wasn’t in control. I did not know the difference between what was going on in my head and what was happening right in front of me…I couldn’t decipher what the problem was. But I knew there was a problem. (Nico)

Attending to this real vs. unreal dichotomy exposed familiar dualisms within medicine—mind vs. body, subjective vs. objective—which functioned in ways that structured bodied experience once someone was embedded in the clinical enterprise.

Not surprisingly, medications and medication-taking were a site where frictions would play out, particularly when the clinical worldview narrowed, constrained, and conflicted with service users' own lived experience. The experience of psychosis and entry into the mental health system frequently served as a fulcrum in a before/after narrative of selfhood and identity. As we have discussed elsewhere, to whatever degree the experiences of psychosis constituted a disruption in self-identity, at least *some* aspects of such disruptions stemmed at times from clinical situations themselves—in particular, from the ways in which asymmetries of power were enacted within the mental health system. These enactments were often stratified along axes of oppression and social identity and looped back to be re-inscribed as symptom (Berkhout, Zaheer, and Remington 2019). Similarly, anthropologists Neely Myers and Tali Ziv (2016) have discussed how such asymmetries of power relate not only to one's status as a psychiatry service user, but also to dimensions of self that are sources of disadvantage and oppression, such as racialized identity.

And yet, pills and injections did index a hoped-for "cure" and were seen by many service users as a part (but not necessarily the foundational part) of their recovery. Family members and clinicians tended to have a more myopic view toward the place of antipsychotics, holding these as the linchpin to mental wellbeing. The relationship that service users and family members had to the curative imaginary that structures FEP was complex—hope for the future and the possibility of stopping distressing and painful psychotic symptoms were important aspects of recovery. At the same time, it was not so simple as to take a medication and act as though nothing had changed.

> I think sometimes people that I have been around—friends and family and acquaintances—it's, they almost don't want to hear me express how dark my mind can get. They don't want me to talk about it. They would rather me speak like everything is unicorns and butterflies because then "I'm just being negative." And I think all of us just want to be understood by someone. I think that is one of the biggest goals is just to be understood by someone in this world. I think mental illness or not, I think that is just a human kind of need. (V)

In medicine, a curative imaginary is one that sees disability as universally negative—a problem always to be solved and intervention obligatory (Kafer 2013; Clare 2017). As discussed, the entire EI paradigm that structures FEP is suffused with the rhetoric of cure—steeped in a language indebted to a futurity whereby mental disability is eradicated, enacting a metaphysics of purity within this particular futurity. Scholars from across disability studies have argued that curative imaginary forsakes a disabled person's present bodymind, instead offering nostalgia and longing for the past or clutching at hope for a future that may never be (Clare 2017). As V's excerpt suggests, the cost of the curative imaginary and its hoped-for futurity is failing to be seen and understood by those in the present moment.

Thinking about what Dan, Nico, and V were struggling to articulate, considering the frictions generated within the clinic power struggles, and holding in mind what was both appealing (perhaps necessary) as well as invalidating with respect to the curative imaginary, we ask, what does it mean to then translate overdetermined explanations, the multiple layers of meaning, the filled pauses, and the tensions through digital technologies? Do emoticons or Likert scales prompted by questions about stress, or even the acceleration of a mobile phone in space, capture the incongruencies, the internal struggles, the unspeakability of psychosis?

We turn to these questions in the section that follows. Before that, we want to pause for a moment to reflect on how challenges of translation might *also* prompt us to ask, does it matter whether one uses an emoticon or a Likert scale or a narrative interview, if *any* attempt to "voice" psychosis will only ever offer a half-hearted approximation? Digital technologies are often used in creative, open-ended ways by disabled people—harnessed for political action while resistant to curative demands (Hamraie and Fritsch 2019). Digital sociality, for instance, has been described as a way to hack normative communication practices, embracing of "crip time," that is, temporalities of non-normative embodiments. This can embed individuals in meaningful and lively networks they might not otherwise have access to (Hartblay 2015). These insights should lead us to ask whether digital health technologies can be *other* than what Olivia Banner (2019) terms "extractive racial capitalism," with fantasies of digital futures that reify tropes of white savior technophiles while governing mental disability. The struggles expressed by our participants, particularly in relation to what was unspeakable in the clinic environment was, for many, a major aspect of lived experience that service users found so meaningful to have witnessed. They did not necessarily experience this kind of witnessing within the structure of the clinical environment:

> I felt like my history with psychiatry or just meeting with my psychiatrist and doctors in general was just so cold and so—"what are your symptoms," and "let's jot them down"—that's as far as it goes, it never kind of expanded beyond that when it's…it was almost like it was—to me, I see it as just like point-form notes of symptoms and everything that is so, almost, in a box. Mental health to me is not in a box. It's like, the conversation was never welcomed to expand anything, it was just like, "okay let's get to the point." (V)

Similarly, we find seeds of possibility in relation to technologies and witnessing in other qualitative research we have carried out within the same clinic setting: both service users and family members have discussed how standardized metrics and scales were not only acceptable at times, but were actually welcome—*only* when it was the case that these were used as a starting point to open a larger discussion that enabled a witnessing of complex experiences. Such scales and metrics could not be an end in themselves or attempt to offer a totalizing narrative of experience (Cuperfain et al. 2021, under review).

Our concerns regarding digital care tools and the transmutation of "lived experience" are directed, then, at the extent to which such tools are used to *avoid* the messiness of lived experience, the extent to which they are un-hackable, the extent to which their design is not relational or collaborative. Some of these concerns are reflected within our earlier descriptions of the benefits of EMA/ESM in terms of reliability over self-report from the digital mental health literature. The potential for novel engagements is undercut by the view of such technologies as a proxy or simplified stand-in, rather than their being an opening for further witnessing. Additionally, Banner's work suggests that digital health apps that collect and utilize biometric data have a very different valence and connotation when these are stand-alone, member-participatory technologies rather than third-party-hosted systems that function in aid of a broader biopolitical project (2019, 10–13). In what follows, we develop further Banner's insight, that context is crucial to determining the potential consequences of the transmutation of lived experience through such technologies.

Novel Engagement or Epistemic Narrowing?

Our argument thus far has seen a number of different threads develop—we want now to braid these together. First, we have considered the increasing interest in, and use of, self-technologies in FEP. We have looked at the discourses of both FEP as these operate within the early intervention paradigm and digital technologies themselves. There is considerable overlap and alignment with respect to metaphors of hope, progress, and temporality. Digital technologies, like other areas of FEP, are designed to predict and control uncertainty and heterogeneity in psychosis. All of this points to a shared investment in a curative imaginary.

Moreover, we have examined the way in which the neoliberal political rationality indexed by self-technologies is naturalized within the developmental frame of FEP. Both the curative imaginary *and* the naturalization of neoliberal ideologies limit the force of potential criticisms and dissenting views relating to digital technologies in FEP. This enables the enthusiastic uptake of views such as the one we take aim at in particular—namely, that EMA/ESM technologies offer a way of collaborating with service users around their psychiatric symptoms and offering a view to lived experience while at the same time rationalizing the use of biodata in light of the "unreliability" of subjective experience and recall. Then, in contrast to the claims that EMA/ESM technologies providing a window to lived experience, we turned to a granular view of the experiences and meanings of psychosis from

FEP service users themselves. *This* view of lived experience (though certainly not unmediated—no qualitative data is) offered themes relation to tensions, incongruencies, and unspeakability within FEP.[6] We have linked these themes with frictions generated by the curative imaginary in this clinical setting.

We turn now to deepen our critique of the enthusiastic claims from proponents of EMA/ESM technologies, particularly that these tools relay lived experience for clinicians to draw on to better understand psychopathology. We want to raise a worry surrounding unintended impacts from having one's experience structured by a biomedical narrative of what psychosis *is* and what is entailed by its treatment. Such biomedical narratives are operationalized through self-monitoring vis-à-vis smartphone technologies and EMA/ESM.

As Greco details, the notion that clinical shortcomings of a reductive biomedical model could be addressed by incorporating the "patient's point of view" can be problematized on a number of fronts (2019, 6). First, there is a baseline assumption that participants in digital technologies ought to be able to consciously articulate the totality of their values and experiences, and furthermore that the technologies themselves accurately capture this. Such assumptions are of course complicated by the fact that, *qua* psychiatric service users, deep skepticism also simultaneously surrounds the reliability of those experiences, even when an individual is not experiencing a psychotic episode. Studies of EMA/ESM certainly attempt to address these issues in various ways—they are *very* interested in whether or not the emoticon or Likert scale has fidelity with a user's experience, and as we've discussed, the interest and enthusiasm for metadata (i.e., biometric data captured by the technologies) belies the claims to capture and engage "subjective" experience. And yet through our ethnographic investigation, we have seen how inaccurate this assumption was for many of the individuals. It was not simply a matter of their being "too unwell" to meet standards of reasoned judgments or communication. When this difficulty of expression is combined with social and cultural norms surrounding oral speech communication—standards of narrative coherence, linearity, clarity of articulation—we see the potential for counterproductive amplification of certain views and voices (Alper 2017, 2). Normative performances of communication universalize expectations of rational human subjectivity, including through demarcations of communicative purity, autonomy, and self-mastery (St. Pierre 2015). Tools that "give voice" do not necessarily dismantle structural inequalities and can, in fact, concretize these.

Second, within EMA/ESM, experience only comes to be valued through the abstractions that translate these into "evidence"—that is, through the digital technologies themselves. As Anna Swartz has posited with respect to digital technologies within psychiatry, the idea that biodata speaks for itself glides over the reality that claims to accuracy resist generalizability beyond their immediate context (2018, 65). The entire *point* of EMA/ESM technologies is to understand the context or "ecology" of the service user. Yet the experiences of services are only valuable when they are transmutated through the expertise and authority of biomedicine, as indexed by the technological applications. Digital health technologies such as EMA/ESM configure bodies to revision fleshy matter as a system of data codes, and illness as a kind of information malfunction (Lupton 2015, 574). As Deborah Lupton (2015) explains, the ability to overcome current or potential ill health is through the self-knowledge gained by the data produced. Biodata is viewed as objective—pure sources of bodily knowledge—and the orderliness of digital data contains and controls the entropy and mystery of disease. This standpoint fails on many accounts, but it especially fails to acknowledge how disabled people are already experts and designers of everyday life (Hamraie and Fritsch 2019), while obscuring the arbitrariness of the line between normal/abnormal (or defective) (Banner 2019).

The larger sociohistorical context—that the technologies are themselves performative of the norms of a neoliberal political rationality—is likewise ignored, through the naturalization of self-management and personal responsibility for health as developmental tasks. Moreover, as Swartz further argues, insofar as psychiatric service users are "simultaneously locked into and out of the practices that involve them most directly, based on a prevailing clinical stereotype that undermines their capacity to provide truthful and reliable accounts of their own lives" (2018, 65), they experience testimonial forms of injustice through these practices. Broadly speaking, testimonial forms of injustice within psychiatry are ever more prominent for racialized individuals, and prominent along axes of gender, migration, economic status, and sexuality, where intersecting social identities have been deemed indicative of a lack of credibility (Dotson 2011). As we identified earlier, experiences structured by social power along intersectional lines of identity were more likely to be read through unexamined assumptions within psychiatric medicine concerning normal vs. abnormal (Berkhout, Zaheer, and Remington 2019).

In psychosis, digital technologies risk sidelining certain ways of knowing and being, flattening and erasing certain experiences that are not easily incorporated into the structure provided by the technologies themselves. The view of mental illness that venerates professional expertise and is predicated on an individualist understanding of mental illness obscures how someone's social-material world is central to understanding their distress and marginalizes the knowledge of those deemed mad (Coles, Keenan, and Diamond 2013; Faulkner 2017). Even if EMA/ESM were to robustly capture someone's phenomenological experiences (a claim we have cast doubt on), that these experiences are only legible through digital expertise reifies this problematic dynamic. Feasibility studies of EMA/ESM do note that initial compliance providing responses drops off considerably with ongoing use, and that users have complained about intrusiveness, repetitiveness, and lack of representativeness or personalization of their particular challenges (Rickard et al. 2016). Such criticisms from users themselves have been framed as a problem of application design rather than a concern about the kind of epistemological and ontological narrowing that the applications produce. Our own study did not explicitly ask participants about their experiences with digital health technologies—apps such as those employing EMA/ESM technologies were only in early discussion within the clinic's research groups when we carried out our work. Toward the end of the study period, however, tablets arrived in the clinic waiting areas, where service users could complete a medication side effect survey that would be automatically sent to their clinician's email address just prior to their appointment time. The questions did, at times, prompt what might have been otherwise difficult topics to broach (e.g., sexual side effects of antipsychotic medications). But the emails were also sometimes fake/joke survey responses from anonymous service users within the clinic—perhaps a creative resistance to the digitization of suffering. Complexities that exist within the use of digital mental health technologies require greater care and attention than simply building a more user-friendly app.

Conclusion

We have traced a novel landscape for technologies of the self within psychiatry, exploring the competing views espoused within this landscape—EMA/EMS claim to collaboratively bring in lived experience to assessments of psychosis while simultaneously positing service users' recall and subjective experience as unreliable. We have critiqued this tension first, in relation to the capacity for digital technologies to epistemically narrow lived experience, and second, in light of the reliance on professional or expert tools to render that narrowed experience legible. We have highlighted how the curative imaginary that is mobilized within digital care tools has material implications for those who experience psychosis in relation to this epistemic narrowing. Such narrowings are reinforced by other sources of subordination and disadvantage. Mental (dis)ability intersects with gender, race, and geography or migration status within the FEP setting, erasing and flattening particular lived experience especially. By bringing our ethnographic work into conversation with feminist STS, crip technoscience, and mad studies, we have provided an analysis of the micro-political technologies of digital care tools in mental health, while demonstrating the significance of methodologies such as our own for further insights in these same fields.

What *would* a more meaningful engagement look like? For all of the critique we offer, we are not advocating to banish technologies from FEP services. We identified, at the outset, that there are many important and meaningful uses in peoples' lives, including for those in more precarious situations—having a mobile phone from a clinic might mean the difference between having or losing case management support, let alone being able to use that same technology for peer support and social connection. But meaningful engagement cannot simply be a matter of asking participants to improve the emoticon design or give feedback on the beeps or pings that ask them to respond to survey questions. As the authors of the CAMH report "More Than Paint Colours: Dialogue about Power and Process in Patient Engagement" argue, meaningful engagement is about a much deeper process, a more sustained dialogue, and fundamentally about addressing power differentials (Devaney, Costa, and Raju 2017). Those power differentials are linked to the politics of whose knowledge is valued *as* knowledge. Meaningful engagement has to mean that experiential knowledge is not merely distorted, erased, or co-opted by the discourses and practices of conventional biomedicine. Ultimately, meaningful engagement is about opening different and more diverse forms of futurity for psychiatric service users.

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Notes

[1] *Lived experience* is a term that stems from the consumer/survivor/ex-patient movement in psychiatry, referencing the importance of first-person understandings of the socio-material worlds of psychiatry services users, mad-identified people, and individuals with mental disabilities. As it is used in this context, the term has ties with the critical social epistemology of mad studies and disability studies; it is deeply linked to notions of experiential knowledge and is often used in contrast with conventional professional knowledge in psychiatry, which is embedded in a positivist biomedical paradigm. It is notable that the notion of digital "phenotype" is deployed alongside claims to lived experience, given that the term *phenotype* is deeply embedded in scientistic language, reflective of normative models and curative practices implicated in ableism and sanism. See Banner 2019 and Faulkner 2017.

[2] These networks of psychiatric medicine are reflective of an Anglo-colonized world. As Berkhout (2018) describes, the concept of FEP arose in relation to the expressed desire for a more pure research population from which to study schizophrenia. The research strategy was launched in 1988 through a National Institutes of Mental Health (NIMH) National Plan for Schizophrenia Research and then later concretized in the form of an NIMH workshop on first episode psychosis in 1991, driven largely by clinician-researchers in the US, UK, and Australia (Berkhout 2018, 174). This has subsequently expanded to include New Zealand, Western Europe, and Canada especially, as personnel, trainees, research

methods, and clinical protocols and training are shared across key sites in each country. Such networks are significant, as Subramaniam and Willey explain, because it is within the expansion of Western colonial powers that scientific knowledge as "superior" knowledge materializes (Subramaniam and Willey 2017). It is this same legitimation of particular forms of knowledge that generate the dynamics of epistemic injustice we discuss in the paper.

[3] Suze Berkhout was the study's lead researcher and was a psychiatry resident who had previously completed a PhD in philosophy, with experience with ethnographic and narrative methods at the time the project was carried out. Juveria Zaheer is an emergency psychiatrist with expertise in intersectional feminist theory and qualitative methods and provided methodological support as well as contributing to data analysis and theory development. Additional research team members included a psychiatry resident with a background in medical anthropology as well as a psychiatrist/senior scientist with extensive expertise in schizophrenia research. We offer these descriptions of the research team and the process of data analysis in the spirit of transparency regarding our ethnographic methods and to enable a sense of the ways in which our own positionalities as researchers within the study might contribute to our interpretation of the interviews, field notes, conversations, and practices within the clinical setting.

[4] As Trull and Ebner-Priemer describe in their introduction to the 2009 special section on ESM/EMA in the journal *Psychological Assessment*, ESM and EMA have arisen from different research traditions. Because they hold in common the practice of collecting self-reports or indices of behavior, cognition, and emotion in near real time in participants' day-to-day lives, the terms are often grouped together (Trull and Ebner-Priemer 2009, 457). Other forms that digital technologies take within FEP include the use of text messages as reminders for appointments, check-ins after discharge from hospitalization, or welcoming messages when an individual service user enters into a new FEP clinical program. We do not want to detract from the positive impact that some programs can have, for instance, when FEP clinics are able to provide mobile phones to service users who face economic precarity and unstable housing, allowing them to remain connected with case managers and clinic supports.

[5] *Insight* is a term of art in psychiatry that makes references to a particular kind of neurocognitive skill whereby an individual is able to make accurate assessments about their mental state and apply these to themselves. Deficits in insight are frequently discussed in psychiatric settings, and often with FEP there is a presumption that a lack of insight is reflective of the underlying pathophysiology of psychosis itself (Quee et al. 2011). As a heuristic, "insight" is often granted when a service user's understanding of their experiences aligns with that of their care-giving professionals. See Gong 2017.

[6] Berkhout and Stern explore the issue of unspeakability in lived experience, within psychosis and across other medical and psychiatric diagnoses in their editorial to the Fall 2019 issue of *Ars Medica*. Within the issue's special feature on psychosis, three pieces from participants of the Psychosis Narratives ethnographic study described in this paper were published. A small group of the larger project's participants took part in a series of arts-based knowledge translation workshops, where we explored personal as well as group themes from the ethnographic study through art-making, poetry, and pose. See Berkhout and Stern 2019.

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Author Bios

Suze G. Berkhout is a clinician-investigator and acute care psychiatrist. Her program of research in feminist philosophy of science/STS utilizes ethnographic and narrative qualitative methods to explore social and cultural issues impacting access and navigation through health care systems. She focuses on the epistemic and ontological importance of lived experience in relation to knowledge in/of medicine and mental health and carries out this work in a range of areas, including in treatment resistance in mental health, early psychosis, transplant medicine, and Placebo/Nocebo Studies.

Juveria Zaheer is a psychiatrist and researcher at the Centre for Addiction and Mental Health and assistant professor within the University of Toronto Department of Psychiatry. Clinically, she works in the Gerald Sheff and Shanitha Kachan Emergency Department at CAMH, where she also oversees resident education. Her program of research focuses on suicide and suicide prevention. She serves on the Board of Directors of the Canadian Association of Suicide Prevention.