

DWELLING WITH MULTIPLICITY:  
NEGOTIATING BORDERS IN THE LIFEWORLD OF FIRST EPISODE PSYCHOSIS

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ABSTRACT

*This paper explores intersections of cure, harm, diagnostic practices, and lifeworlds of people with mental disability within the field of first episode psychosis. Drawing on findings from a collaborative art workshop developed within an ethnographic study of first episode psychosis, we contrast the experience and phenomenology of psychosis within the art workshops with the construction of psychosis in traditional clinical spaces. Engaging concepts of dwelling, borderlands, and lifeworld within this context, we detail how the workshops countered the ways in which institutional structuring of narratives of psychosis reinforce diagnostic boundaries. In contrast to the clinical setting, a fuller lifeworld was made available through the creation of artwork and witnessing of its aesthetics and form within the project.*

*Keywords:* Multimodal ethnography, first episode psychosis, lifeworld, dwelling, multiplicity, borderlands

INTRODUCTION

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... 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. (Dan)

Dan<sup>2</sup> a 32 year-old white man, born and raised in central Canada, shared his description of psychosis within the confines of a clinical consulting room as we began our first interview together. We had met early in the course of a three-year-long ethnographic study called the Psychosis Narratives Project which was taking place in the first episode psychosis (FEP) clinic Dan attended. FEP is a term used to describe an early point in time in the trajectory of a psychotic illness – a form of mental distress whereby one experiences a ‘break’ from reality that is demarcated by hallucinations, delusions, and disorganised thinking and behaviour (Breitborde *et al.* 2009). FEP is now a dominant clinical organising concept in the field of mental health. Within the last thirty years, the FEP clinical framework has emerged as a gold standard of care. This framework is constructed such that people experiencing early psychosis utilize multidisciplinary clinics that offer two-to-three years of coordinated specialist services including medication management, vocational and educational supports, psychological and addictions support services, and (often) family navigation (NAMI 2016). It was in one such FEP clinic we undertook the ethnographic work this paper draws on.

The first episode setting is particularly interesting from an ethnographic standpoint for a number of reasons: at the level of the individual psychiatric service user,<sup>3</sup> it is often the first time that individuals have navigated the mental health system and experiences of psychosis in this setting can be a fulcrum in a before/after illness narrative, linked closely to identity (Berkhout *et al.* 2019; Conneely *et al.* 2021, 309–311; Myers 2019). At a systemic level, FEP is linked to a unique set of cultural metaphors as compared to other psychotic-spectrum illnesses such as schizophrenia (*e.g.* hope, futurity, and novelty as compared to a much more nihilistic view of schizophrenia), and has emerged relatively recently as a clinical organizing concept, enabling a fairly direct grasp of the conditions of possibility that have led to it becoming so central to contemporary psychiatry (Berkhout 2018).

We have centred Dan’s words at the outset because these highlight the issues and challenges we aim to discuss in this paper: how to understand the layers that exist within the descriptions and meanings of psychosis, layers that Dan attempted to articulate with some difficulty. On one level, we can look to understand the phenomena he experiences – the energy and the stimuli. But we can also ask how to read the filled pauses and discourse markers – the ‘likes,’ ‘yeah’s,’ and ‘so’s’ that mark the narrative flow. On this level, we hear of a struggle to convey his experiences: what others read as symptoms that are ‘in his head’ and a reflection of un-reality. On another level though, the filled pauses also tell a story. These are a reflection of his struggle to simply name his reality.

Our paper takes its impetus from this meaningful struggle, to name and frame a new reality, something that is shared by many participants in the Psychosis Narratives Project.

Dan ultimately sought relief from Olanzapine, a second generation (or ‘atypical’) antipsychotic medication. And as he would describe in our interviews, it helped him get out of the state he was in. But it also indexed his experience within a biomedical worldview. This worldview is one that many in the humanities and social sciences argue is marked by a profound ‘epistemological narrowing’ (Squier 2007, p. 334; Clarke and Shim 2011; Conrad 2007); adopting the centrality of a biomedical frame transforms life itself (Rose, 2001). In what follows, we consider the notion of epistemological narrowing as a problem with special relevance to the FEP context. In doing so, we are prompted to ask, what gets left behind, when life itself is transformed by a biomedical worldview (Foucault 1989)? What aspects of experience hang in the spaces between the lab tests, imaging studies, and biologic therapies (Burri and Dumit 2007; Delvecchio Good and Good, 2000)? What meanings are not conveyed, *what is not spoken*, in the language of biomedicine?

Engaging decolonial philosophies (see Smith 2012) to think through our arts-based ethnographic method, we explore that which remains interstitial in the FEP clinical setting. We examine the in-between – what is left outside diagnostic boundaries – offering a different lens through which to understand experiences of psychosis.<sup>4</sup> Psychosis (schizophrenia specifically) has been described to be constituted as liminal and anomalous through the psychiatric practices that shape how it is experienced (Barrett 1998). With this in mind, we suggest that our attention to the particularly difficult to grasp aspects of psychosis is also an invitation to shift into thinking through mental (dis)ability in terms of border dwelling. Predominantly stemming from the fields of cultural and literary studies, gender studies and feminist philosophy, geography, and anthropology, the concept of the border has been used to express and trouble the ways in which intersections of race, class, sexuality, gender, and geography (amongst other axes of identity) shape subjectivity and consciousness, and how an in-between space is created and enables contradictions within competing group memberships to co-exist (Anzaldúa 1999; Almarza 2013; Saldívar-Hull 1991; Yarbrow-Bejarano 1994). Here, our analysis draws on the notion of border dwelling to extend discussions of multisensory and imaginative ethnographic methodologies and practices. We suggest that multisensory modes of study were able to speak to partial truths, truths in the telling, and multiplicity in realities within the FEP context – lived experiences of psychosis that could be encountered within a borderland and that are often ‘uncontainable by words’

(Hodgman 2001) within the more epistemologically and ontologically narrow confines of the clinical setting.

#### THE ETHNOGRAPHIC STUDY

As we describe elsewhere, the Psychosis Narratives Project<sup>5</sup> explored meanings of psychosis from the perspectives of psychiatry service users, their physicians, case managers, other health professionals, and family members, within a FEP clinic in Toronto, Canada between 2015 and 2019 (Berkhout *et al.* 2019). In total, thirteen service users, five staff, and seven family members took part in formal longitudinal interviews (47 interviews total). Participant observation took place over a series of time periods during the three-year study, and included outpatient clinic assessments, research, clinical, and administrative meetings, family psychoeducation and support groups (approximately 50 hours) as well as public spaces within the clinic and larger hospital setting (more than 100 hours). One-on-one time with young people experiencing psychosis predominantly took place during interviews as well as some of the more general observation periods (approximately 50 hours). During observational periods, numerous informal interviews also took place. In addition to more structured periods of observation, the author leading the project (Berkhout) was a psychiatry resident during the course of the study and was doubly positioned in their experience of the FEP setting. Berkhout attempted to have some distinction between their positions: she did not engage in research with service users with whom they had a clinical relationship and attempted to make temporally distinct the periods of clinical work and periods of research (to ensure that participants understood that their clinical care was distinct from taking part in research). That said, it was the case that Berkhout's experiences providing clinical care in the field site inevitably informed how she understood the space, particularly which issues facing staff, service users, and family members, should be further investigated during the periods they were undertaking research. Over the three-year time span, Berkhout moved between research and clinical positions numerous times. Her experience was akin to what has been termed 'observant participation' (Moeran 2009; Seims 2021), whereby the researcher occupies and enacts a pre-existing role in the field to capture insights in an active, embodied, and proximal way (Holmes 2013; Wacquant 2015). And since a clean separation between the role of researcher and care provider was not entirely possible, even for as much as she was careful to ensure that participants understood that participation in research had no bearing on what clinical care was provided, Berkhout tracked this dual positionality through their reflexive fieldnotes. This meant paying attention, for instance, to when they found themselves engaging with participants' experiences and wondering about clinical implications or the reliability of a

diagnosis that was being discussed or wondering about how issues within the inpatient first episode setting where they were carrying out clinical training might have been experienced by the study participants. This aspect of immersion in the field consisted of 3 months of full-time clinical work on an early psychosis inpatient unit while also following a small number of first episode service users as outpatients and in a subsequent year, 30 weeks of outpatient clinical care that took place two days per week.

Across the various parts of the project we were interested in listening to stories in a way that questioned what is frequently taken for granted in first episode settings, exploring practices of diagnosis, the impact of illness, and the role of medications in recovery. The reflexive tracking of issues that were experienced by Berkhout was framed through a 'clinical hat' versus 'research hat' lens, which aided in her attempts to question the familiar. The larger study also tracked a socio-historical narrative of the early intervention paradigm within psychotic illnesses, asking how FEP and the early intervention paradigm came to be the predominant clinical organising concept in this domain of contemporary psychiatry (Berkhout 2018). As a final component of the project, a small group of participants embarked on a series of art workshops facilitated by the authors. Eva-Marie Stern joined with the project toward the end of the interviews and fieldwork for these workshops specifically, bringing her past clinical and artistic experience leading trauma therapy art psychotherapy groups. The workshops were conceived of as a way to express, witness, and understand experiences of psychosis from outside the confines of qualitative interviews, which rely more heavily on conventional narrative structures and interpretive practices even when they are built upon a reflexive, dialogical model. This paper is our attempt to describe and theorize the workshop process, linking our approach to wider literatures in multimodal and imaginative ethnography, border thinking within decolonial theory, and notions of ontological multiplicity.

The art workshops had two main intentions: to provide the time, space and materials for participants to work as freely as possible; and to provide a framework that was conducive to exploring and witnessing personal experiences of psychosis. We wanted to create a forum that was simultaneously as open and as safe as possible. For these purposes, we provided the art materials and the locale, and engaged in art-making facilitation that had previously been developed for art therapy groups with survivors of complex trauma (Macaulay 2020). The workshops were audio-recorded and transcribed, and themes within the discussions brought forward for further discussion at subsequent workshops enabling participants to provide feedback and clarification; these were also triangulated through additional informal interviews and checked against pre-

vicious longitudinal interview transcripts. The descriptions we offer below, and the way in which we link the descriptive aspects of the piece to larger meanings and experiences of psychosis have come from these iterative discussions within the workshops.

The workshops were divided into two main parts: mark-making (the creative visual expressions of the workshop participants), followed by sharing/witnessing. In the mark-making part, time was devoted to scribbling (any freestyle mark-making) as a means to help participants move into a non-verbal expressive mode. Then we (facilitators) offered a two-sided prompt in words that the group could respond to or improvise on with art materials. Examples of prompts include, 'this is what I show/this is what I hide,' 'this is my light/this is my dark,' 'this is what I can say/cannot say.' We referred to the practice as mark-making rather than art-making in order to decrease pressures surrounding what kinds of expressions could be created and any expectations related to producing representational images. The second part of the workshop was reserved for participants to share their work with the group if they chose to. Participants showed their pieces and spoke about them any way they wished, or simply showed them to the group without words. We invited others around the table to respond to a piece by first saying what they noticed about its formal aspects or aesthetics: what shapes, colours, lines, composition, light or dark stood out to them, and what movement, textures, and relationships between the elements most caught their attention. We then asked the witnesses to voice whatever feelings the aesthetics evoked in them. This way of responding to artwork ensured that there were no value judgments or interpretations about the images, but rather a deliberately slow and careful observation of each piece's visual and formal elements, and an offering of the observer's emotional response to these elements and to the piece as a whole.

The mark-maker showed their creations, and the group actively witnessed them. The facilitation was participatory, in the sense that we as facilitators likewise engaged in mark-making while also responding to others' pieces during the sharing component of the workshop. The workshops' facilitation promoted spontaneous, un-tutored mark-making – art that didn't need to heed representation. The witnessing practice did not ask the images to have any kind of linear narrative or accountability to naming things, people, or concepts, a divergence from standard qualitative interviews or focus groups that inevitably rely on narrative coherence in the generation of themes and meanings.

We could not, of course, entirely operate outside of narrative convention. The prompts for each workshop were spoken; participants often did choose to use

words to describe what they had tried to bring forward with their piece, and our witnessing practice used verbal communication to communicate what elements we observed and to relay our own affective responses; and of course, we are relying on narrative coherence to explore and theorize the workshops in this paper. As one reviewer rightly noted, through our academic writing we are containing by words a borderland that we have framed as *uncontainable* by words. When we reflect on this, we can say that we were certainly not operating outside the confines of narrative altogether. This is perhaps a larger difficulty faced by multimodal and sensory ethnography: how to undertake the translation of material, social, affective resources, events, and practices into semiotic modes. That said, the discussion that we give below of the pieces themselves and the way in which they reveal difficult-to-articulate aspects of psychosis, emerged within the dialogue between ourselves and the workshop participants that began from a sensory starting point focused on form, shape, texture, and affect. Attentive to issues of representation and speaking-for, we have included participants' own spontaneous reflections on the process of taking part in the workshops. Further, we also note that the intention of the workshops was also to enable participants to create works that were meaningful to them and have those pieces mobilized as sources of knowledge, credited and published under their chosen names/identifiers. In addition to being the subject of our reflection in this paper, the larger body of workshop pieces were featured in a special issue of the health, arts, and humanities journal, *Ars Medica*, which the authors co-edited (see Berkhout and Stern 2019).

Considering again the process itself – of slow and deliberate observation paired with emotional engagement – we posit that this brought forward aspects of participants' experiences that *had* been challenging to articulate in other settings, whether that was the clinical consulting room or even the narrative interviews that had been part of the earlier stages of the project. The making/doing within the workshop was an embodied immersion, and the describing and responding to a piece was a stepping back that could be fraught with ambiguities and difficulties in expression. When this happened, we made space for challenges of articulation, while also returning to what was immediate and observable as a way to anchor our group's discussion if the mark-maker wanted to explore their piece further. The emphasis on the uptake of the pieces through sensory, affective, and embodied engagement enabled us to encounter novel expressions of the participants' lifeworlds<sup>6</sup> through the forms, shapes, textures, and colours of the pieces created within the workshops. Through this process our group of researchers, artists, and participants came to witness the experience of psychosis as an ontological multiplicity rather than a unitary entity encapsulated by a homogenous narrative.

MARK-MAKING AND LIFEWORLDS OF PSYCHOSIS

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's 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. But is there any point? because you won't understand. I'm trying to get you to understand, I'm trying to help you, but you won't really get it. (V)

As we engaged with each others' artwork within the workshops, we were able to bear witness to the complexities that exist within the lifeworlds of psychosis. Just as V describes above, many of the participants expressed a kind of pessimism that they could even put the experiences of psychosis to words at all. And yet, by encouraging affective responses to the qualities of images that



Figure 1. On a black background, we see a series of repeated gestures of many colours. There appears to be an outer ring and an inner series of scribbles. The outer ring is made of concentric, organised marks; the inner, more tangled lines take most of the page's space and feature unpredictable gestures in white, red, and black.

were created through the workshops, we could share, take in, and resonate with these difficult-to-articulate experiences. We have drawn here on the concept of lifeworlds so that we can emphasize what Biehl and Locke have identified as the moral and analytic value of experience – the micro, the singular and the partial that make up the self-world entanglements. And as they explain, art, along with ethnographic theorizing and writing, can push the limits of language and imagination to bear witness to people, worlds and thought that is not reductive or a caricature (Biehl and Locke 2017, 8–32). Lifeworld, in this project, prioritizes the phenomenological experience of service users, and in doing so can try to embrace the ‘messy realities and subjective experiences of psychosis’ that makes space for the meaning and complexity of psychotic experiences without the structure imposed by clinically organized categories and symptom lists (Jones and Shattell 2016, 3–4).

The image presents immediately notable contrasts between light and dark, and between inner and outer. K described this piece as a reflection of what she experienced in psychosis.

K: Sure. This is what I did – this unorganized blob in the middle represents the dark and then around, I guess the order is the light and I feel like this is me – like inside I’m so unorganized and like chaotic and there is so much going on but on the outside I seem like things are okay and like in order I guess – yeah.

*Facilitator 1:* Can you hold it up and we can take a look?

K: And these colours on the outside because they are more like friendly and inviting.

*Facilitator 1:* How did you find using your non-dominant hand?

K: It was kind of hard but since I did this [pointing to the image] it was easy – I tried to figure out what to do so that it wouldn’t look so chaotic with my left hand.

*Facilitator 2:* Did you feel it was hard to do?

K: It was still a little bit difficult because I still want the chaos to be in order I guess, but I didn’t really have control over that so...

*Facilitator 1:* Hard to let go of that kind of control?

K: Yeah.

*Facilitator 2:* What's it like to look at it now?

K: It came out a lot better than I thought it would, so, yeah.

As she articulated during the witnessing of this piece, K felt this reflected the way in which confusion and a sense of chaos permeated her mental experiences during an episode. Later in the workshop she also identified that just making the marks in this case was challenging: the prompt brought forward painful memories of being in the midst of psychosis. The notion of service users' lived experiences as 'chaotic' was one that resonated across the whole of the project. Service users frequently linked psychosis to a sense of losing control, and engaging with that was, as K said, 'hard'.

K's description also harkens back to Dan's articulation above: his sense of the stimuli that attacked him was often marked by challenges differentiating inner and outer, self and world. Reflecting on the separations between the forms in her image, K identified that in managing psychosis, she was constantly trying to maintain some kind of boundedness over the chaos – an organised outer surface that belied swirling inner tensions. That organised outer presentation of self was discussed by service users across the larger project – often a veneer of control was seen as necessary in order to avoid involuntary hospitalisation or medication adjustments. This same veneer of control and put-togetherness was articulated by participants as what enabled them to be taken by others (clinicians, case managers, family members) as credible knowers, even with respect to knowledge of their own experiences. Having had the lived experience of psychosis frequently led to service users being seen as unreliable narrators, unjustly excluded as epistemic agents through the diagnostic practices of the clinic setting.

Beyond issues of epistemic injustice in psychiatry (Crichton *et al.* 2017), the dark, difficult affective experiences connected to psychosis were not easily witnessed by family, friends, or clinical staff in service users' lives. V said, in one workshop, '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...'. In addition to the challenge of articulating what it is like to live with multiple states – order/chaos, inner/outer, light/dark – we hear of the isolation that comes when one's lifeworld is difficult to express or untenable to others.

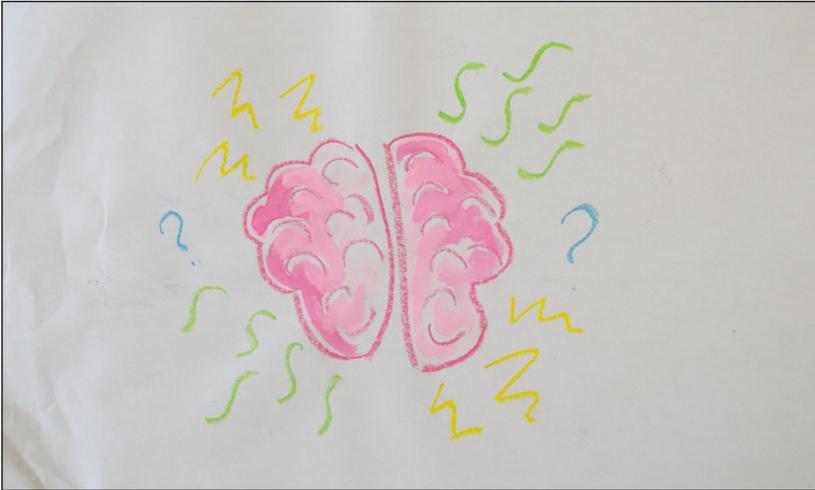


Figure 2. On a white background, we see a centred composition of confidently drawn, simple shapes. Overall the image displays symmetry; negative space emphasises groupings of separate elements; the colours feature a bright pastel range, with some careful pink shading added with watercolour. The artist deploys figurative alongside non-figurative elements in comic-book style, bookended with question marks.

There is a great effort here to simplify the representation of a brain in the context of psychosis and yet a tremendous uncertainty of what to say; we see clarity and ambiguity as well as separation.

*Facilitator 2:* I guess what you ended up using to depict – what are the things that stand out?

S: So mine is my brain and I find that still with my mental health issues it's hard to discern what is me, my intuition – what is true from what is illness, so like I am always still – I have a very strong and powerful intuition but it's easy for me to be very delusional, like totally off, and so I am always checking in with – I'm lucky I have friends and my siblings and I just always have to check in because a lot of the times I'm very wrong – I'm either right or very, very wrong and so I find – so this depicts my brain, what's true, what's not true, not knowing and always trying to figure it out just so that I don't fall back into any old issue that I had when I was sick. You know I think a lot of my illness was falling prey to delusions and hallucinations

and now, although I'm better, it's very easy to fall prey to those so I'm always having to – it's a very fine line is what I think and that's kind of – this is the line and my brain – I'm always just trying to find that middle ground where I'm not you know falling prey to delusions or being delusional, so being in truth – I know that's where my health is – it's when I was in truth, yeah, so it's still a constant battle...

The pink contained shapes and texture reflected, per the artist, a brain – an interesting choice of subject matter. Amongst clinicians, the notion of episodes of psychosis as 'toxic' to the brain was common and added urgency and a weightiness to the importance of adhering to pharmacotherapy regimens. As an explanatory model, the concept of aberrant brain chemistry (primarily involving dopamine) was commonly heard amongst service users, family members, and clinic staff, though service users often simultaneously endorsed additional explanations of their experiences. As Chris Salter, Regula Valérie Burri, and Joseph Dumit (2017) explain, art and design work inject ambiguity, speculation, and complexity into standard ways of understanding science, medicine, and the body, generating forms of knowledge that may destabilize scientific facts. Figure 2 can be read as simultaneously reinforcing *and* making more speculative and uncertain dominant biological models of psychosis.

The vibrancy of the colour choices we see in figure 2 stands in sharp contrast to the loss and grief that many service users spoke of *after* they emerged from psychotic episodes or began to engage in pharmacotherapy and had to reconfigure and sometimes forsake their previous narratives of their experiences to be able to function within biomedical terms. They often didn't have the words to describe this loss. As Joshua St. Pierre (2015) writes, normative performances of oral speech communication are the *sine qua non* of rational human subjectivity, universalizing communicative purity, autonomy, and self-mastery. Insofar as speech communication is seen to be an initiation and marker of what it means to be human, non-normative and disabled voices are frequently excluded from communicative connection and the privileges of full social participation (St. Pierre, 2015).

The marks of figure 3 speak to the way in which participants experienced psychosis within non-linear temporalities. As we discuss below, there is a struggle to dwell with simultaneity in the clinical setting, but here we encounter it clearly through this visual expression. The piece stands in contrast to a dominant medical view of psychosis that presumes a singular, accessible, externally valid truth. The challenge of explicating the multiple, simultaneous states was voiced by V during one of the workshops, as she reflected on psychosis as suffocating and

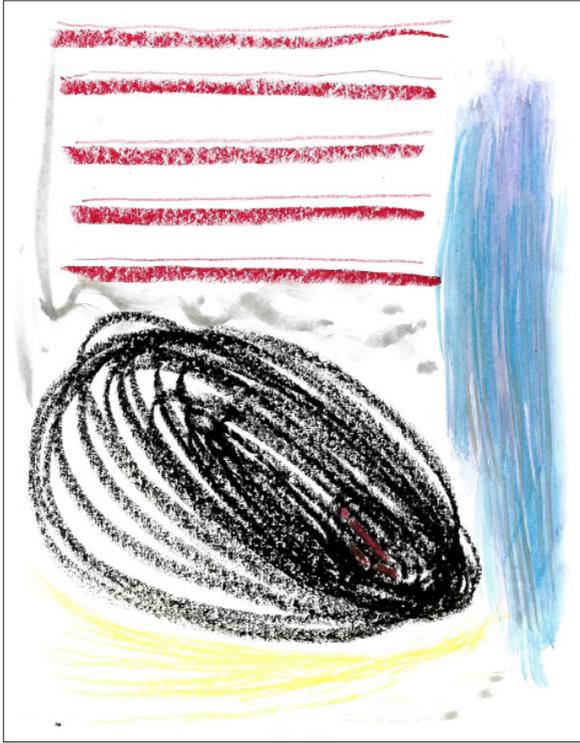


Figure 3. This untitled anonymous piece offers multiple gestures or states on the same page, created to be distinct and simultaneous. Red striped lines, both thick and thin on one side of the page, a bright yellow curved line on the other, a central black concentric gesture enclosing a speck of red, grey smudges, all hover above a more subtly mixed patch of blue, grey, green, and lilac scribbles.

overwhelming as well as inexplicable to others. These qualities made psychosis deeply isolating, as V found it disheartening to try to introduce people to her lifeworld. Through the larger project we also heard that when service users try to express a concurrence of states and clinicians don't pay attention to this, there can result a misunderstanding of service users as confused or perplexed. This confusion and perplexity can be subsequently coded as symptom (*e.g.* of a cognitive symptom domain in schizophrenia), and as a result epistemic injustice can take place – reinforcing dominant views of individuals with mental distress as lacking credibility or being unreliable about their experiences (Berkhout and Zaheer 2021; Kurs and Grinshpoon 2018).

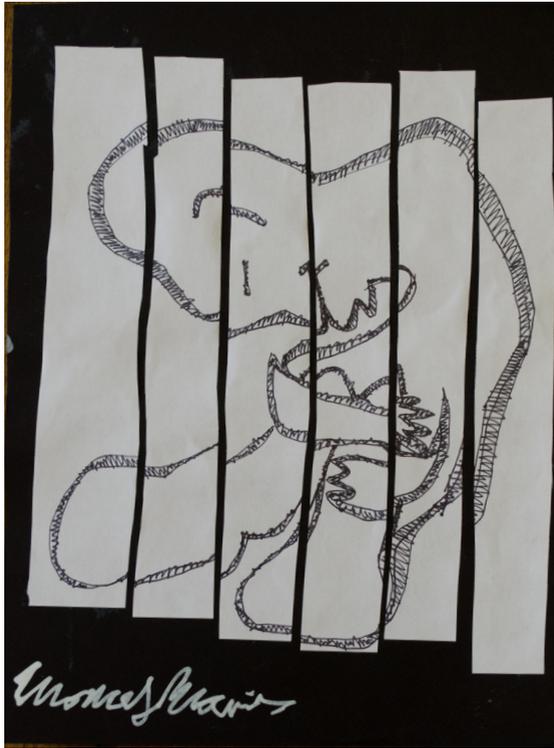


Figure 4. In this piece the mark-maker has drawn an ambiguous figure with a hatched-in double contour line. The artist has chosen stark contrasts: black lines on white paper arranged on a black background; and the play of a unitary figure evenly segmented into strips of drawing that disrupt the figure's integrity. A seamless white signature at the bottom left of the page also contrasts the graphic drama.

The self-containedness of the figure speaks to themes of isolation and to loss and grief. These were significant issues that service users in the FEP clinic struggled with, particularly at two points in their journeys – early on, as they grappled with the larger impacts of what it might mean for them to have had a psychotic episode, and also as their time within the clinic started to wrap up, and they transitioned away from the care that had been offered.

The themes of loss and grief are not without friction in the field of FEP. As a clinical organizing concept, FEP is something of an anomaly in relation to other forms that severe, persistent mental disorders take. As part of the early interven-

tion paradigm, hope, novelty, and futurity are prominent themes within FEP (see McGorry *et al.* 2005). And though the therapeutic nihilism traditionally attached to diagnoses such as schizophrenia is both a source and reification of stigma, the way that futurity in FEP operates in clinical settings is not without difficulty (Berkhout and Zaheer 2021). Within the FEP context, approximations of cure and anticipation of a return to pre-illness life leave little space for grief, loss, and trauma in psychosis, and render unspeakable the more troubling and challenging aspects of lived experience in the first episode.

The clinical emphasis on symptomatology and diagnosis likewise structures experience in challenging and sometimes troubling ways. As one workshop participant, V, explained:

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)

These clinical conversations construct reality within the narrowed epistemic frame of medicine (Delvecchio Good and Good 2000; Kleinman 1980).

Although we communicated our experiences verbally (while trying to shift away from an exclusive reliance on verbal modes of expression) the process as a whole was quite different from either clinical encounters or the narratives interviews that had taken place earlier in the project. We attribute this to the way in which the verbal communication we engaged in during the workshops was focused on aesthetic and emotional experiences that were constructed and shared in our workshop space. Our experience of the workshops is that this primary focus was what enabled the expressions of understanding we’ve presented in this paper to develop. MM contrasted art/mark-making with narrating his experience in the clinical context, describing how the spontaneity and immediacy of the visual marks and gestures communicated a more raw, unfiltered expression that better captured his experiences compared to his attempts to verbalize them:

I think that’s the thing about art versus words – to me, one of the differences is we are so used to kind of hiding ourselves with words

or having the words pre-packaged – we kind of know what to say generally to keep ourselves hidden but when it comes to making things we don't have usually often the ability to censor properly or to hide exactly how we want to hide – it kind of all comes out very immediately. (MM)

The art workshops offered an opportunity to dwell-with participants' experiences outside of the psychiatric systems of nosology and symptom domain. As we use the term, we take *dwell-with* to reference both spatiality and temporality, as well as a larger existential sense of engagement. And though the notion of *dwelling* has been argued to reference a sedimented or static quality, to dwell-with implies a more relational and dynamic process.<sup>7</sup> The witnessing practice enabled us, as a group, to inhabit each others' lifeworlds, at least in some partial way.

Importantly, the spatiotemporal quality of dwelling-with also emerged within the images themselves as a form of multiple, simultaneous states that could be held together and engaged with through both sensory and affective means, expressed in the relational witnessing context. One participant expressed how this was possible through artistic (rather than narrative) modes, saying:

I feel like the abstract nature of art itself helped encapsulate in this end – encapsulates something that is difficult to home in on in therapy and with a psychologist. But it's like art can just be a collection of states of mind that it's, like, otherwise don't get expressed. (Sam)

Gabrielle Bendiner-Viani (2013; 2005) has described how imagistic entities can reveal the everyday, small pieces that make up one's lifeworld in new and vivid ways, particularly when those everyday experiences are multiple, layered, and contradictory. These same qualities are what limit a straightforward narration through oral speech communication. For as much as the workshop participants could state that their pieces expressed what was hard to voice, it was through the process of attending to (visually, emotionally) the formal qualities of the pieces themselves that words could be found for *why* it was hard to express these experiences and *what* those experiences were. It's significant, then, that we witnessed through visual and affect cues within many of the workshop images a kind of simultaneity: in figure 1, we have both order and chaos; figure 2, simplicity and mystery held in the same space; in figure 3, varieties of concurrent colour and form; and in figure 4, a simultaneous holding together and cutting apart. The workshop created a holding space for experiences that were unspeakable due to their simultaneity and plurality. Convergences, juxtaposi-

tions, contradictions, as well as repetitions and similarities could be experienced concurrently, without needing to endorse any sort of linearity or order; the emphasis on affective responses to these states generated understanding of the layered dynamics of psychosis that are otherwise challenging to communicate. We turn now to reflect on this plurality: how the art workshops offered a sense of the ontologies of psychosis – psychosis as a multiplicity.

#### BORDERS, DWELLING, AND MULTIPLICITY IN FEP

As Annemarie Mol and John Law have described in relation to biomedicine (and science more broadly), multiple realities are produced, held together, and enacted as a plurality of ontologies or *multiplicities* (Mol 2002; Law 2004). Rather than carving the world at its joints, the concept of multiplicity understands reality to be a coexistence of multiple, overlapping ontologies constructed through our methods and approaches. Whether with atherosclerosis (Mol 2002), anaemia (Mol and Law 1994), asthma (Willems 1998) or in this instance, FEP, a range of practices and methods are coordinated to create an overarching or dominant narrative that stands in for a singular ontology. But this singular story is belied by the ways in which the threads of the thing must be woven together – this weaving reveals it as a multiplicity. In FEP, a dominant biological narrative is held together by the coordination of neuroimaging studies, tagged dopamine receptor ligands, antipsychotic medications, narratives of ‘brain chemistry’ in psychoeducation materials, clinical scales such as the Brief Psychiatric Rating Scale (BPRS) or Clinical Global Improvement scale (CGI), emergency room discharge templates, addictions consultations, psychoeducation groups, and outpatient referral letters, amongst other technologies, events, and practices. These technologies and practices perform boundary work (Gieryn 1983; Addison 2017), discursively marking out the territory and authority of science to author the story of psychosis. The story that is provided by biomedicine and contemporary psychiatry has certain advantages and benefits – it mobilizes resources in prominent and often helpful ways. And yet, we found from our participants’ narratives that their experiences of psychosis are overdetermined. Aberrations in brain chemistry is one story that has to coordinate with spiritual crises, bad psychedelic trips, voodoo spells, and the simply inexplicable. Similarly, Luke Kernan has discussed in relation to his own autoethnographic work on psychosis and bipolarity, there is a struggle for identity within the sensory diversity of psychosis, and that these lived sensoriums offer multivariant engagements with one’s ontology. Kernan draws on poetry to explore the way in which trance, alternative states of consciousness, religious experiences, mysticism, and the poetics of spiritual breakthroughs are all also descriptive of engrossing mental states where one loses contact with reality, and the dif-

fering valences of these ways of understanding one's experience translate into different ontologies of the self (Kernan 2020). The service users we met with throughout the Psychosis Narratives Project had to negotiate a range of stories and practices – some could be easily reconciled with one another, while others not so much (Berkhout 2017). The difficulty was when the dominant biomedical narrative excluded or minimized important aspects of the lifeworlds of service users, through that fraught process of coordination.

While the dominant narrative leaves little room for the breadth and simultaneity of lived experience, understanding the implications of multiplicity is of crucial importance for those whose lives are structured by FEP as a clinical organizing concept. As we saw from the art workshops, there is a deep need for service users to have their experiences understood. Neely Myers has likewise discussed how central mutual understanding and the ability to act in intimate connections with others is to recovery in the aftermath of psychosis (Myers 2019; Myers 2015). This need stands in contrast to the epistemological narrowing that takes place within the biomedical frame and makes these experiences even more challenging to express and explore (Berkhout and Zaheer 2021). After explaining how family and friends often don't want to (or can't) hear how 'dark' her mind can become, V went on to say:

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)

To that end, we shift now to consider how multiplicity and the ontologies of FEP speak to the notion of a border dwelling self, and how border thinking can help develop a deeper appreciation of FEP's multiple ontologies.

As outlined above, the framing of border dwelling is meant to draw attention to what it means to live in-between worlds demarcated by boundaries that are ideological, social, geographical, and spiritual, and the links between boundaries and identities. While it is arguably much more than a metaphor, the concept of a border is helpful in this instance, for thinking about how the art workshops opened the space for multiplicity: a borderland was created. Borderlands, writes Cheryl Mattingly, help us to recognize the porous, fluid, and contested aspects of social worlds, binding people together – often through geographical space, but also through practices. And as Mattingly articulates, the term borderland can designate a flexible space shaped by acts and practices, where healing is carried out (Mattingly *et al.* 2011 15–16). In comparison to a

clinical context, there was a relative ease with which the art workshops were able to provide a space for practices that allowed plurality and simultaneity to be expressed, reflecting the fluidity of experiences surrounding psychosis. The workshop practices were also particularly powerful ways of bringing forward what would otherwise often be contested knowledges and viewpoints, prone to being subsumed within the larger needs and objectives of a clinical encounter.

Moreover, to dwell in the border, articulates Walter Mignolo (2017), is to express the experience of double consciousness – in-between the Western modernity indexed by a biomedical frame of reference and the languages, memories, and experiences that are constructed to oppose and exceed this frame. Similarly, Maria Lugonés explains border dwelling consciousness:

The mestiza consciousness is characterized by the development of a tolerance for contradiction and ambiguity, by the transgression of rigid conceptual boundaries, and by the creative breaking of the new unitary aspect of new and old paradigms. The mestiza consciousness participates in the creation of a new value system through an ‘uprooting of dualistic thinking.’ (Lugonés 1992, 34)

A borderland is an in-between space that can be inhabited within and through competing and fluid, yet coexisting ways of being. This allows for a kind of consciousness that can hold simultaneity and multiplicity without needing these experiences to be coordinated into a singular narrative. In fact, the concept of border dwelling exposes the singular narrative as an impossibility. Lugonés (1992), citing Anzaldúa, further explains that the state of border dwelling expresses the self *as* multiple – the plural personality operating within a pluralistic mode (32). And just as our participants articulated, in relation to the challenge of articulation within the clinical space and the vulnerability that the workshops generated through their communicative potential, there is risk to dwelling within a borderland insofar as it is a state of making new sense – there is a familiarity to self and others that is risked, and the terrifying possibility that the new sense might not be made (33). Exploring and exposing oneself through the witnessing practice of the workshop was risky, even though it was in aim of being understood in a more complete (and often, *less* familiar) way.

The notion of a borderland stands in contrast (ontologically, epistemologically) to a frontier. Frontiers ‘mark the limits of civilization,’ (Mignolo 2017) – we see such a frontier in the diagnostic and classificatory practices within psychiatry, which delineate normal from abnormal form and police a particular kind of boundary through its exclusions (Foucault 2006). As Rosalba Icaza explains,

the self-ascribed privileges of the knowing subject of the West are organized around interpretation and representation (Icaza 2017, 30). Biomedical knowing subjects and biomedical knowledges are, unlike our workshop's affective witnessing practice, disembodied and masculinist – knowledge practices that reify dualistic or bifurcated colonial logic. Diagnostic practices in clinical settings often function as b(ordering) strategies, crafting the category of disabled in relation to able-bodied and able-minded (Kafer 2013). Crucially, the work of demarcating boundaries (policing the frontier, as it were) sits in service of biomedicine's curative imaginary: a disciplinary matrix within biomedicine that sees disability as inevitably in need of intervention and cure as always desirable (Kafer 2013; Clare 2017). Such an imaginary is prominent within the first episode field (see Berkhout 2018; Berkhout *et al.* 2019). A curative imaginary is lockstep with the colonial, 'frontier' epistemology, reinforcing dualistic notions of cure vs. harm and normal vs. abnormal, and locating the 'problem' of disability within the excluded Other. Within the biomedical context we can think of bodied experience itself as a 'border territory' in relation to the classificatory practices that surround illness experiences (see Hahn 1985, cited in Mattingly *et al.* 2011, 352).

By being able to explore and witness *together* the diversity and simultaneity of experiences of FEP through an embodied, affective, sensory practice of observation and noticing rather than interpretation, the boundaries and binaries that are typically upheld (policed) in clinical settings were shifting and ephemeral. As Donna Haraway explains, 'bodies as objects of knowledge are material-semiotic generative nodes. Their *boundaries* materialize in social interaction' (Haraway 1988, 595). The social interaction of the clinic materializes one set of boundaries, and a particular *kind* of body. Moreover, as Homi Bhabha has argued, shifting boundaries hint at the existence of 'third spaces,' emergent and liminal spaces resulting from negotiations of cultural difference (Bhabha 1994). Reflective of a borderland, the art workshops allowed us to dwell-with the simultaneity of psychotic experiences without having to embrace an epistemological or ontological framework that delineate who or what constitutes an Other. We can look again to Lugonés to think through the importance of the group setting: for new meaning to be made, the context must be social otherwise it is doomed to fail (Lugonés 1992, 36).

The experiences and lifeworlds of FEP clinic service users were akin to border dwelling – complete and important on their own terms, full of tensions, ambiguities, pushes, and pulls. These same experiences were transmuted through a singular biomedical narrative when service users were connected to the clinical FEP space. In contrast, we (briefly) created a space for hybridity,

multiplicity, and simultaneity. This FEP borderland accessed through the art workshops – a space-in-between – allowed for dwelling-with the multiplicity of psychosis by virtue of stepping away from the demands of representation and interpretation. The reliance on witnessing vis a vis affective response is connected to a different way of thinking than the conventional dualistic epistemological frame of biomedicine.

## CONCLUSION

Even with the self-portraits that I was doing...I kept going back and saying 'I need to redo it – I need to redo this.' It wasn't doing it justice. It wasn't doing my vision or my experience justice in a still photograph. I needed to make it a multimedia piece where there is the sound, there is the action, the movement. There are all these aspects to it because psychosis is so multi-faceted almost. There is so much to it that a still wasn't cutting it for me. (V)

As medical anthropology, science and technology (STS), and other scholars across the humanities have argued, contemporary Western medicine is embedded within a modern epistemology – one that makes sense of, justifies, and legitimizes coloniality (Mignolo 2017; Bhattacharya 2014; Wynter 2003). As we've discussed, in FEP there is also an epistemology that engages frontier logic. Insofar as the conventions, practices, and technologies that demarcate contemporary biomedicine reflect ontological and epistemological commitments of colonial structures, a singular universal 'truth' is offered. Lugonés explains the profound isolation that society places border dwellers in (Lugonés 1994). As we explored within our project, exclusions, isolation, and epistemic injustices were experienced by those classified within, and Othered through, universalist logics that operated in the FEP setting.

In contrast, multisensory, multimodal arts-based approaches in our study generated *openings* that exposed and named the limits and boundaries of conventional diagnostic practices and clinical care. Ethnography that engages with multimodal approaches offers a novel way to complicate narratives, whether these are biological or experiential. Sensory ethnography continues to be a growing field, focusing both on the conveyance of emotional states through aesthetic-sensual immersion and on multisensory-experiential qualities that emerge through embodied practices (Nakamura 2013, 132). Importantly, sensory ethnographic approaches can offer forms of inquiry that layer meaning and provide information while also leaving uncertainties and ambiguities intact. As our reflections in this paper suggest, there are still challenges for the field,

for example in relation to the ways in which findings from multimodal and sensory ethnographic work might be communicated and expressed, without relying on the same conventions or approaches that are argued to be overly narrow and motivate a shift in methodology in the first place. We might ask how it is that we can best mobilize understandings developed from practices that provocatively generate affective responses, in a way that does not undermine what is generative and novel about those approaches. These issues are significant and in need of further consideration: embracing the multiplicity of experience through its affective, emotional, and sensory qualities is a crucial step to counterbalancing the epistemic narrowing that so readily takes place in clinical medicine.

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#### NOTES

- 1 Suze G. Berkhout is an Assistant Professor in the Department of Psychiatry and an affiliate of the Institute for the History and Philosophy of Science and Technology at the University of Toronto. She is an early career clinician-investigator and practicing psychiatrist. Her program of research in feminist philosophy of science/Science and Technology Studies utilizes ethnographic and narrative qualitative methods to explore social and cultural issues impacting access and navigation through health care systems. Within this work she focuses on the importance of lived experience in relation to knowledge in/of medicine and related to mental health especially. Eva-Marie Stern is a registered art psychotherapist and Assistant Professor in the Department of Psychiatry at the University of Toronto. She is an artist and medical educator. She led the art therapy program at the Trauma Therapy Program at Women's College Hospital for over 20 years and has consulted to the cardiac rehabilitation team at UHN and the nephrology team at Sunnybrook HSC on the use of arts-based methods to explore issues in post-surgery patient care. Please address correspondence to Suze Berkhout, 200 Elizabeth St. 8th Floor Eaton North. Toronto, Ontario, Canada. M5G 2C4; suze.berkhout@uhn.ca

- 2 Participants varied in how they wanted to be identified within the Psychosis Narratives Project. Some had chosen pseudonyms, some preferred to use their own first initial, some asked for the study team to create a pseudonym to attribute their ideas and thoughts to. The variety within this paper reflects participants' choices on that matter, which we supported.
- 3 We use the term 'service user' to reference individuals who are engaging with the mental health system in order to acquire medical care. We have chosen this over the terms 'patient' or 'client,' as service user has connections with the psychiatry consumer/survivor/ex-patient movement which originated in the 1960s and 1970s, and to our minds better avoids both the late capitalist and neoliberal connotations of 'client' as well as the passivity and medicalisation of mental distress inherent in the notion of a psychiatric 'patient.' This choice of language is not without controversy, however. For a thorough overview and debate regarding terminologies relating to collective nouns in psychiatry, see Christmas and Sweeney 2016.
- 4 As we discuss further on, we do not claim that our engagement through the arts represents psychosis as it 'truly' is. Following STS scholars such as Annemarie Mol (2002), John Law (2004, 2015), Isabelle Stengers (2005), and Bruno Latour (2014) amongst others, we understand psychosis in terms of an ontological multiplicity – different things that exist as entities through the relationships, enactments, technologies, and so on, that exist within different practices.
- 5 The study received approval from the Centre for Addiction and Mental Health research ethics board (CAMH REB 098–2014).
- 6 The concept of lifeworld, which we rely on here, stems from phenomenology, and refers to the world as it is experienced through the subjectivity of everyday life. This includes the contexts and dimensions of social action that shape the shared meanings and mutual understandings of agents/actors (Ryan 2005).
- 7 Within the literature that discusses the notion of 'dwelling,' there is frequently made a distinction between space and place that is used to expose the limits of dwelling (in relation to border-dwelling) as too sedentary a concept (see Radu 2010). One might question then whether the term 'dwelling' adequately captures simultaneity. In contrast to the sedentarist critique of the concept of 'dwelling,' our use of 'dwell-with' to make reference to a more dynamic and emergent existential state, in keeping with the way in which Lugonés follows Anzaldúa in discussing a Mestiza consciousness. Similarly, the notion of 'dwelling' has received attention in relation to fluidity and movement in the works of Trnka (2020) and Ingold

(2016). Even to 'dwell in habit,' as Ingold describes, is an active, dynamic process of *undergoing*, an unfolding animated by the enactment of experience from the inside (Ingold 2016, 16).

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