

Traversing Epistemic Injustice within a PhD Program

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Abstract

Within Australia, as with many countries, mental health service users are increasingly included within research. Whether or not these inclusionary measures achieve epistemic justice for individuals with lived experience is debatable. Writing as postgraduate researchers, one of us as a ‘survivor researcher’ and one not, we reflect on the emotional dissonance and ethical distress we have experienced trying to adopt anti-oppressive and user led research approaches within academia. We consider the productive value of these affects in highlighting both ongoing epistemic injustice, and the limitations of current inclusionary practices. Reflecting on our experiences together, we contribute to a growing body of literature calling for collective alliances in re-imagining research spaces and practices that might truly value lived experience within academia.

Key Words: lived experience, research

Introduction

Within Australia, as with many countries, mental health service users are increasingly included within research spaces. Whether such inclusionary measures achieve epistemic justice for individuals with lived experience is debatable (Beresford, 2002; Daya, 2022; Jones et al., 2021; Kalathil & Rose, 2019; Russo & Beresford, 2015). Jones and colleagues (2021, p. 591) have recently called attention to the need for lived experience research leadership, calling for “serious investment by the mental health services research community in developing and sustaining a pipeline of mental health services

researchers with experience of significant disabilities”. We aim to contribute to these discussions by reflecting on our experiences as PhD students attempting to actualize meaningful involvement of individuals with lived experience, and the resulting emotional dissonance and ethical distress we have experienced. We suggest such affects are a result of witnessing, navigating, and attempting to resist, epistemic injustice within academia, and are productive in helping us collectively think through some of the barriers that must be overcome to achieve lived experience leadership in academia.

Positionality

Writing this paper, we grappled with how to articulate our positionality, despite recognizing our ethical duty to reflect on this positionality. Such struggles are representative of our broader feelings of discomfort regarding where we ‘fit’ in, and outside of, academia, and the way in which the psy-complex creates a rigid and hierarchal separation between individuals with psychiatric diagnoses and those without (Tseris et al., 2022). We do not recognize ourselves as essentially different to each other; however, we acknowledge the material-discursive flows that sit around and between us, differentially impacting our citizenship and the research we do. We both conduct our research on Indigenous land, as white colonial settlers, and are privileged as white students enrolled within the university setting.

I, Aimee, identify as ‘Mad’, using it as a reclaimed term, as someone who has been labelled and treated as mentally ill, but resists biomedical hegemony. Whilst my experiences and subjectivity has negatively impacted my PhD journey, it is important to recognize I also hold privilege in this regard, having no history of severely stigmatized diagnosis or intersecting experiences as described in Jones et al (2021). I, Sophie, have multiple and intersecting privileges in research spaces which in this context includes as a person who has not been labelled with a psychiatric diagnosis. Due to our differing positionality, we tend to use language differently. We thus use the language of madness and lived experience interchangeably in our discussion, whilst recognizing the contested nature and limitations of language within mental health (Byrne et al., 2021).

Resisting and replicating epistemic injustice

Working to overcome epistemic injustice is central to our values and research. As such, we strive to adopt anti-oppressive, and survivor led research methodologies. Yet despite our striving, we have been constrained by entanglements of academic policies, ethics committees, PhD structures, time and discourses around what it means to be a ‘good academic’, all of which uphold and (re)produce

epistemic injustice. Trying to navigate such entanglements, we fear we have often become instruments of reproduction rather than agents of change. In this first section, we share some of our struggles attempting to navigate and resist such practices, forming the background to our emotional dissonance and ethical distress. We use Miranda Fricker's theory of epistemic injustice to frame our experiences.

Epistemic injustice, defined as injustice related to one's ability to convey knowledge and make sense of one's experiences due to prejudice (Fricker, 2007), is a common experience for individuals with lived experience of distress (Daya, 2022; LeBlanc & Kinsella, 2016). Epistemic injustice can be understood as both testimonial and hermeneutic (Fricker, 2007).

Testimonial injustice occurs when one is undermined as a giver of knowledge because of prejudice held by the hearer, who then discredits the person's testimony and interpretations. Whilst there is a long history of lived experience being excluded from academia, over the last twenty years a push for 'service user participation' has seen such testimonies increasingly included (Beresford, 2002; Jones et al., 2021). However these continue to be subject to judgements around being irrelevant or insufficiently articulate, with only certain testimonies deemed worthy of inclusion (Brosnan, 2019; Jones et al., 2021; Kalathil & Rose, 2019; LeBlanc & Kinsella, 2016; Poole et al., 2012). Sophie, for example, was asked by an ethics committee member how a "mental health patient" was expected to understand and give perspectives on mental health service cultures, which is the focus of her PhD research. Similarly, in order to gain ethics approval, Aimee had to problematically emphasize how her research involved talking with fellow peer workers as 'different' to others with 'mental illness', given the conflation of mental illness with reduced decision-making capacity in Australia's ethical standards (The National Health and Medical Research Council et al., 2007).

Within our positions as PhD students, we have both struggled to resist such injustices and enact epistemic responsibility (Medina, 2013). For example, Sophie felt confused and disorientated during the aforementioned response from an ethics committee: *I remember thinking that I had not been clear in my response, or perhaps I did not understand their questions. Upon reflection, it seemed that the committee were questioning how "mental health patients" had knowledge or capacity to comprehend and contribute to knowledge generation on a complex subject like mental health service cultures.*

Testimonial injustice can also manifest as objectification where individuals with lived experience are

'included' as participants but relegated to the role of passive object or as a source of information rather than informant. When individuals are relegated to the traditional role of 'participant', it is the 'expert' researcher who maintains control of the research objective, agenda, and process - the limitations of which have been thoroughly documented (Brown & Jones, 2021; Russo, 2012; Russo & Beresford, 2015; Voronka & Costa, 2019).

One of the ways testimonial injustices may be unsettled by a non-lived experience researcher is by collectively designing the research and objectives with Lived Experience expertise. However, within a PhD structure, engagement with lived experience is often restricted until after ethics approval. This means that the research design must be established prior to engaging with people with lived experience in any formal capacity. Sophie utilized Lived Experience Consultants (LECs) in paid roles to oversee her research, however this was only possible after ethics approval was granted as LECs were considered research 'participants' and thus, vulnerable. This demonstrates both a lack of value placed on the need for research to be informed by lived experience and sanist constructions of lived experience as highly 'vulnerable': *As a result, my project potentially becomes an example of 'allies' inviting lived experience into spaces constrained by broader structural inequalities, rather than co-creating new ways to do research.*

Hermeneutical injustice refers to one's social experience being obscured from collective understanding due to a lack of shared resources for interpreting or making sense of experiences (Fricker, 2007). In other words, this form of injustice occurs when individuals or groups do not have the language to articulate their experiences, or shared theoretical frameworks to make sense of them, due to exclusion from knowledge generating practices.

Hermeneutical injustice may be overcome through research contributors engaging in critical analysis so that alternative epistemological perspectives may be developed. We have both attempted to create this space through dialogic interviews and collective analysis. Yet again, we encountered constraints. For example, there is a level of emotional vulnerability and relational care involved to do this work (Brosnan, 2019), which has been unsustainable within the demands of a PhD. Further, ethical review processes biased towards quantitative research and notions of 'professionalism' produce the subject position of researcher as separate to, and emotionally distanced from 'the researched' and research, impeding collective meaning making (Carroll, 2013; Dickson-Swift et al., 2009).

Affective potentials

These experiences, of trying to resist, yet often replicating epistemic injustices, have impacted us in unexpected ways. Below we share our journal entries to illustrate these impacts: Sophie's at the point of data collection, and Aimee's at pre-data collection. Our entries speak to the hopelessness, guilt, sorrow, frustration, shame, and feelings of being overwhelmed that we have experienced. We share them tentatively, recognising our privilege and not wanting to distract from the epistemic injustices experienced by individuals who are positioned as research participants (or denied the opportunity to even participate). Yet we also believe the affects we describe are productive: they have potential for highlighting changes required to enable lived experience leadership in academia (Jones et al., 2021).

Sophie:

"The security guard opened the heavy locked door, and I hand back my visitor card. I had just completed an interview with a mental health practitioner working in what is often considered the 'pointy end' of the system characterized by mental distress, homelessness, substance use and contact with the criminal 'justice' system. I drive away with a sick, knotted feeling in my stomach and heavy weight on my chest. I try to write a 'reflective journal'. I think all night about some of the people that were referred to in the interview, and their families, and what they would have endured. I feel sadness and grief, and a futility – these feelings aren't helping anyone. The words of the workers play in my head; "it's [service sector] getting worse" and "we have nothing to offer people". I think about other interviews, one with a service user who spoke about her time held in an involuntary psychiatric ward for three months where she was ignored and never asked what she needed or about her experiences; and a family member who said: "We just don't have an option that actually works ... and when hope runs out, where do you go..."

The next morning, I try again to record my reflections but struggle to string together coherent sentences. Then I do the dishes and leave the house for another interview."

Aimee:

"I sift through my journal entries and am taken aback by the struggle that seeps through each piece. I feel my body getting heavy, and tears rising to the surface. I let out a large sigh, the type I associate with grief and overwhelm. I reflect on Sophie's experiences of the 'in-between spaces'; trying to move between distressing interviews to the everyday, mundane acts. Whilst I can

rationally comprehend this dis-embodiment, I can't quite grasp it myself. I think about what it means to perform as an academic; reflecting on the expectation that, as PhD students, we should be able to 'collect' these stories in interviews, and then simply shake it off, do the dishes, and get on with the next interview. Physically and emotionally, I will not be able to do this when it comes to my own data collection. Perhaps I don't recognize my in-between spaces because they don't exist for me. Madness seeps through it all.

I'm reminded of feedback on my candidature application that I need to be more specific about the exact 'mechanics' of my analysis. I'm thrown because I want my analysis to be collective, something that I figure out with fellow peer workers. I'm thrown by concerns about whether there will be discussion around findings with other 'expert' researchers, but not with peer workers. By questions that ask about power imbalances within interviews but seem unconcerned with how power imbalances extend so much further within research practices. It brings up feelings that I cannot quite articulate- of being misunderstood and unheard as a Mad person within the mental health system, and society at large. It's all the little things built up. Its having spent months reviewing academic literature written about me. It's about wanting the research I do to not make others feel the way I do, but not knowing how to do so.

I try to explain it within a supervisory meeting, but words fail me. It's like I don't have a common language to articulate myself. I leave the meeting hastily because I don't want to be the student that cries in the first few months of her PhD. Particularly one who openly identifies as Mad. I am all too conscious of the easiest interpretation of my distress. I partly believe it myself - I bawl my eyes out to my partner on the phone, saying how I don't belong here, that I am both too much and not enough."

For Sophie, data collection was unsettling and isolating: *I questioned what else I could do to ensure my research practice was ethical and reflected my commitment of 'doing' research that did not replicate harmful institutional dynamics. I frequently felt as if I was not doing enough. This reflected tensions between what I considered important in participant relationships, and my enculturation into 'good' procedural ethical practice; what it meant to be a 'professional' researcher. I often felt physically overwhelmed by the futility of the research to 'do' anything for the person I was interviewing. Conversely, Aimee found her data collection, which involved discussions with fellow peer workers, enriching: I would come away from these meetings feeling*

lighter, hopeful. Yet the neoliberal emphasis on academic productivity in compressed time frames meant I quickly felt disconnected from these feelings.

For both of us, there was no time for thinking, sharing, building collective knowledge in a way that allowed for epistemic justice. Instead, we felt we should ‘just get on with collecting the data’ and meeting student progress requirements, putting us at odds with our values. Both emotional dissonance and ethical distress have been common throughout our PhD journeys, from project conceptualisation through to analysis.

Professional marginalisation has also impacted us. We already feel like outsiders within both mental health systems and the academic community and doing critical research risks pushing us further to the outskirts. Sophie was reminded of this with workers wanting to speak ‘off the record’ because they were acutely aware of the consequences for whistleblowers within healthcare settings. As someone who identifies as a Mad researcher, Aimee exposes herself even further to this bias against her work: *I have experienced what Grey (2016) refers to as ‘benevolent othering’ from both academics and mental health professionals.*

Sweeney (2016), a survivor researcher, talks about how the approaches we draw upon can affect our access to fair peer review, research funding, positions and opportunities. At the same time, being part of academia, opens us up to critique from the consumer/survivor movement. For individuals who have been labelled as ‘mad’, there is often a valid distrust of academia for the reasons we have explored here (see also Sharma, 2019). Thus, we navigate feelings of being exposed to critique from multiple angles, feeling torn, isolated and precarious in our belonging and identities.

These affects are unwelcome within a neoliberal academic environment that values outputs and centres valid research as objective and emotion free. They are also risky in a mental health space that pathologizes emotions. Thus, to perform as ‘good’ PhD students we must disconnect ourselves from these emotions. Shame or inadequacy was often experienced when we could not, or marginalisation when we refused to.

And yet, within Mad studies, survivor and feminist research, these affects are valued as embodied ways of knowing. As Roper (2016, p. 204) articulates: “my body is like a barometer, constantly on the alert for unsafety, my body tells me, for example, when something is ethically wrong”. Thus, we

suggest our affects - the sick, knotted feelings in our stomach, the heavy weights on our chest, the paralysis and never-ending exhaustion, the clenched jaw - tell us something valuable about ethical wrong doings and risks within the research space. They tell us that epistemic injustice continues to exist within academia despite commitments to 'inclusion'.

Surviving

How then, might we survive as PhD students and support our Mad peers and allies to enter and navigate such oppressive systems? We are wary of suggestions of debriefing, supervision, and access to university counselling services for PhD students. Whilst we have found these useful, such solutions absolve the university of their responsibilities to move past assimilationist notions of inclusion. There is also an assumption that these spaces do not replicate sanism, which is not always the case. For example, whilst we have both been lucky to have a lived experience academic as part of our supervisory team, which we would argue is vital to ensuring hermeneutical justice, this is far from the norm. Accessing university support services often requires a medical certificate declaring one's 'mental illness', a diagnosis that some find harmful, and reinforces notions of individual flaws. Aimee has experienced sitting through PHD/ECR 'development' sessions, where the affects described here were relegated to symptoms of 'imposter syndrome'.

We do know that sharing and collectively reflecting on our experiences has helped us to turn our focus outward, onto the research assemblage. It has helped us see how the assemblage produces both epistemic injustice and emotional dissonance and ethical distress for early career researchers trying to navigate and resist such practices. Whilst these affects land differently based on our positionalities, as a 'survivor' researcher and 'non-survivor' researcher, reflecting together has helped us think through the complexities involved with these positions (Russo et al., 2018; Tseris et al., 2022), and consider together what might need to change to achieve epistemic justice. As such, we argue that both concrete investment in workforce development is needed for 'building a pipeline of mental health service researchers' (Jones et al., 2021, p. 591), as well as changes to ways in which research is undertaken, and lived experience knowledges are valued (Brown & Jones, 2021; Kalathil & Rose, 2019).

Conclusion

In this paper we have aimed to contribute, as early career researchers, to a growing body of work that

considers how academic assemblages continue to (re)produce epistemic injustice in relation to lived experience, despite claims of 'inclusion' (Beresford, 2002; Brosnan, 2019; Daya, 2022; Faulkner, 2017; Kalathil & Rose, 2019; Russo & Beresford, 2015; Warren & Boxall, 2009). In reflecting on our experiences together, we work towards collectively imagining a future of research spaces and practices that truly value a diversity of lived experiences and what they bring to academia.

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