


LIVED EXPERIENCE NARRATIVE **OPEN ACCESS**

Reflections From the Wrong Side of the Glass: Lived Experience of Conducting Research in a Mental Health Ward

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1 | Introduction

There has been growing interest in bringing lived experience experts—former patients, psychiatric survivors and mental health services users—into psychiatric facilities as professional staff and researchers over the last 30 years (Castles et al. 2023). Increasing lived experience involvement has also become a research priority. Despite some evidence that lived experience researchers have been excluded from authorship of academic outputs (Banfield et al. 2018), this group are generally interested in research (Wyder et al. 2021). They add profound value to the studies they are included in by enabling ‘two-way growth’ of lived experience experts and traditional researchers (Banfield et al. 2018, 1227), ‘disrupt[ing] the dynamics and established hierarchies of privileging certain forms of knowledge and expertise’ (Dembele et al. 2024, 4), and offering ‘unique insight’ into the experiences of communities often targeted for research (Honeywell 2023, 130).

As a result of the growing interest in lived experience research and the strong values of my senior colleagues, I was named on a grant investigating the low use of seclusion and restraint in the mental health wards of a semi-regional hospital in Victoria, Australia. I was to bring my experiences as a patient to the research team, informing decisions like who we spoke to, what questions were asked and how the interviews were to be analysed. I would also be responsible for conducting all interviews—almost all of which happened on the ward.

In this article, I use my experiences in one study to reflect on the challenges for lived experience researchers working on mental health wards. Reflexivity is an established research method that can be used to explore experiences and perspectives in depth (Mortari 2015). This paper is a response to contemporary research challenges for people with lived experience and addresses a dearth in research ‘exploring how people who have experienced madness produce knowledge and overcome their personal challenges when they do qualitative mental health research’ (Johnston 2019).

Even though I was engaged in decision-making and supported at every stage of the project, it wasn't until we had HREC approval to enter the ward and speak to clinicians, patients and carers that the real work of lived experience research began.

2 | From Patient to Observer

The hardest part of the study had nothing to do with the technical aspects of the work—it was being in the hospital. When I was a patient, I relied on the nursing staff for almost everything. They decided when and what I ate, who I could see, when I could take and make phone calls and what belongings I was allowed to have. My belongings (including clean underwear) were taken from me as punishment for challenging behaviour, and calls from my friends and family were withheld from me at the nurse's discretion—something I only learned when I asked my

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Summary

What Is Known on the Subject

- It is becoming more common for people with lived experience of mental distress and/or mental health ‘treatment’ to be engaged as ‘lived experience researchers’.
- Lived experience researchers have experiences that enhance research conduct—for example, through their familiarity with mental health system and their capacity to understand what research participants may have experienced.

What the Paper Adds to Existing Knowledge

- Lived experience researchers face challenges directly related to negative experiences of psychiatric treatment.
- Being listened to and having their experience and feedback taken into account can support lived experience researchers to be comfortable engaging in personally challenging research.

What Are the Implications for Mental Health Nursing

- Lived experience researchers bring specific expertise to research projects, and should be valued for these contributions and the personal cost of sharing their lived expertise.
- Support for engaging lived experience researchers is essential to maintaining this workforce.

loved ones why they didn’t call while I was in hospital. I experienced this control as hurtful.

While the staff in this study responded to me differently to those who I met as a patient, I expected to see power differentials between staff and patients as a primary characteristic of the environment. I felt that I had more than enough experience as a patient or visitor on the restrictive side of the glass to understand what I could expect to see during the fieldwork. Yet, I didn’t think through that my engagement in this would mean I would spend time inside the nurse’s station. Further, I did not expect to feel unsettled by my first experiences of being on the other side of the glass.

Scepticism towards the psychiatric system is common in the lived experience movement. Chamberlin (1978) is often credited with the inception of this movement through her writings on how power was exercised over her when she was a patient in the 1960s and 1970s. Since then, the system has changed significantly. In Victoria, Australia, where I lived and work, patients now spend an average of 14 days per admission (Australian Institute of Health and Welfare 2022)—a far cry from the months of incarceration that Judi Chamberlin endured. Nonetheless, patients continue to have diverse experiences of treatment—some of which, like use of seclusion rooms, forced medication and physical restraint lead people to feel that psychiatry is something to be survived and not a viable ‘treatment’ (Daya, Hamilton, and Roper 2020). These lived experience perspectives challenge the dominant cultural assumption that psychiatric treatment

is benevolent. Experiences of being harmed under the guise of ‘treatment’ is common in the contemporary lived experience movement (Daya, Hamilton, and Roper 2020). Daya, Hamilton, and Roper (2020) argue that in the mental health system, people have experiences of ‘treatment’ and ‘care’, which are distinct. Treatment refers to recovery and alleviation of symptoms, and care refers to how people are treated by staff. My experiences as an inpatient did not feature treatment or care, and it was against this backdrop that I found myself on what felt like the wrong side of the glass.

3 | Bearing Witness

Coming to a hospital as a researcher positioned me differently to how I was responded to as a patient. Patients viewed me as a professional. They would approach me and ask me for help; things like access to their phones that were kept in the nurse’s station, for craft supplies, to be let out on leave, for information on when treatment decisions would be made. Some asked me to relay messages to staff on their behalf. A patient who hadn’t had access to music for 3 weeks asked to listen to their favourite songs on my laptop.

There was little I could do to address the concerns and requests patients directed to me. I was a visitor to the institution, and my access could be revoked if my actions caused harm or interfered with the care staff were trying to provide. I couldn’t make decisions except as related to the conduct of the research. Yet, I knew what it was like to have every part of my life restricted. Without the context of why patients had concerns and why these were being directed to me, I could only reflect on how it felt when I was in their position.

Despite my discomfort, I saw examples of staff working to meet the individual needs of patients. I saw a patient yelling at a member of the nursing staff with reasonable concern. They were frustrated that they didn’t know when they would be discharged, and that they hadn’t seen their beloved cat for 3 weeks. In many hospitals, this kind of confrontation would lead nursing staff to detain the person in a seclusion room or administer drugs to manage their behaviour. But what I saw was a member of the nursing staff listening to this person’s concerns and expressing empathy about their wish to be discharged. I know this wasn’t enough—I found out later that this patient had their status changed from ‘voluntary’ to ‘involuntary’. I can only assume this was because they insisted they be discharged against the advice of clinicians. Regardless, it comforted me to know that at least in this hospital, participants could express their wishes without being incarcerated in the seclusion room.

Some of my discomfort was managed in regular supervision with an external lived experience supervisor who I had been working with prior to working on this study. They suggested that I handle the discomfort of knowing what it is like to be a patient but not being able to do anything about it by thinking of myself as bearing witness to how patients were treated. Then, I could use what I had seen to inform research findings that might make psychiatric systems more reflexive to the needs of those caught in it. This idea of watching and then sharing what I saw was consistent with how my research colleagues understood my role as

a lived experience researcher, but to them, this role was related to my employment. For me and my supervisor, it was a way to come to terms with my incapacity to address requests patients addressed at me.

4 | Going Home

Every day I visited the ward had its own challenges, but I did not expect that one that would consistently arise for me would be going home. Every day I got to pack up my stuff and walk out, but the patients who I spoke to—people who generously shared their time and observations with me—were bound by the authority of the institution. To me, it didn't feel like I was going home from work; it felt like I was abandoning an earlier version of myself.

I managed by scheduling my daily debrief with my senior colleagues during the time it took to walk from the ward to my car. I could start with the technical stuff—the number of people interviewed that day, whether they were staff, patients or carers, and how many more I planned to do at my next site visit. Then, when I got to my car, I could share more detailed observations—challenges from the day, questions I had about consent processes following individual queries from potential participants. The purpose of this was to distract me from the fact that I got to leave, while the participants I had spoken to that day, who had told me about their wishes to go home, were made to stay.

During the fieldwork and immediately following it, I experienced competing pressures of wanting to tell my colleagues and our research partners—who allowed me to work in their hospital—that everything is fine. And to be fair, everything was going well. No participants showed signs of experiencing distress because of their participation. I was well supported by staff members at the hospital, and I saw my position there as validating me as a lived experience researcher, and not a liability to the project because of my mental health diagnosis (Honeywell 2023).

However, I was dealing with my own internal challenges related to the base functions of psychiatric hospitals and my previous experiences in them. But I think the discomfort was worth it. I was an active decision maker in the research and its conduct. My colleagues often asked for my opinion and took my feedback seriously. I wasn't asked to simply provide feedback that senior members of the research team would decide to use or discard as they saw fit. This was a risk—as the most junior member of the research team, I had little formal power to determine the conduct of the research. In other words, my team members could veto my ideas. However, this never happened. I was treated as a collaborator with influence on key decisions about how participants were treated and how the key findings were determined—something that Michelle Banfield and her team hoped for the future of consumer research in their 2018 paper. That my research team valued my opinion—rather than simply asking for it and moving on—made me feel at peace with the discomfort I experienced. I was on the wrong side of the glass, but what I learned there mattered to the study I was a part of.

Still, every day I left feeling guilt that patients who had generously spoken to me that day, who had asked me for help, were still

there. Lived experience engagement in mental health research is essential to understanding how patients experience psychiatric treatment, but this fledgling workforce needs ongoing support and meaningful investment (Honeywell 2023) from traditional researchers, or the challenges lived experience researchers face through their work will be for nothing.

5 | Relevance to Mental Health Nursing

Collaboration with lived experience researchers is increasingly required within the dynamic field of mental health nursing. However, as this narrative illustrates, the journey of lived experience researchers in mental health wards unveils a distinct set of challenges, particularly in navigating evolving dynamics with nursing staff. This personal narrative not only sheds light on the hurdles encountered but also underscores the vital need for tailored support mechanisms. By heeding these insights, future research endeavours within mental health nursing can be fortified, fostering an environment where lived experience researchers can have their reflections taken seriously, enabling continued work to improve mental health nursing practice.

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Ethics Statement

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Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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