Russian dolls and epistemic crypts: A lived experience reflection on epistemic injustice and psychiatric confinement

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Abstract
Seclusion and restraint are the psychiatric practices most often considered in the context of ‘confinement’. This paper argues that confinement goes beyond just locked places, describing experiences of epistemic confinement, where people’s personal truth can be locked up inside the dominance of biogenetic psychiatric narratives which frame contextual distress as ‘mental illness’. The author draws on her lived experience and perspective as a survivor academic, first to reflect on the University of Melbourne workshop ‘Confinement: Spaces and practices of care and control’, and then to consider personal experiences and implications of confinement. Both bodily and epistemic confinement are explored, including how these were experienced in the midst of emotional crises, the ways in which confinement worsened and reinforced distress, and its enduring impacts. It is proposed that bodily and epistemic confinement can cause serious, lasting trauma. The validity of confinement is questioned, in a sector which purportedly seeks therapeutic outcomes. Resistance is briefly examined as a reasonable, predictable and perhaps therapeutically beneficial response to these injustices. It is proposed that tackling epistemic injustice in confinement necessitates academic partnering with survivors, to coproduce new ways of knowing.

Keywords
Mental health, seclusion and restraint, confinement, human rights, service user, trauma

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Introduction

I am a survivor of psychiatric ‘care’. Technically, my confinement ended over a decade ago, but I have never really escaped. I still wake in my bed, shivering and breathless, clutching at a wet pillow. In these nightmares, I am again locked in a small room, alone, terrified and powerless. Sometimes it’s dark and shadowy, sometimes it’s glaring. In one especially vivid dream, I clasp my own dismembered hand, thirstily sucking on it for comfort.

I am astonished – with all I have learned and witnessed – that this traumatic injury was done to me in the name of ‘care’. That this was done to me by health professionals, in the public ‘health’ system, and it was done with the knowledge and support of the State. My astonishment about state-run traumatic ‘care’ turns to outrage when I consider that the root cause of my distress was childhood trauma. My confinement involved ten admissions to psychiatric inpatient units, over nine years. My experience of psychiatric confinement was so profoundly damaging that it inspired me to take up a career as a psychiatric survivor advocate, in which I am still immersed years later. It’s a ‘survivor mission’ (Dillon, 2013; Herman, 1992).

Here, I share some of my personal reflections on a workshop held in mid-2019, hosted by the School of Social and Political Sciences at the University of Melbourne, entitled ‘Confinement: Spaces and practices of care and control: A research and practice workshop’. I bring a lived experience/survivor perspective of confinement in the psychiatric system. Although seclusion and restraint are the psychiatric practices most often considered in the context of ‘confinement’, this paper argues that confinement goes beyond just locked places. It describes experiences of epistemic confinement, where people’s personal truth can be locked up inside the dominance of biogenetic psychiatric narratives which frame distress as ‘mental illness’. Bodily and epistemic confinement can cause serious, lasting trauma: the validity of confinement is questioned in a sector that purportedly seeks therapeutic outcomes. As a secondary form of suppression and epistemic injustice, the failure to hear, and listen to the voices of others amounts to ‘testimonial oppression’ (Fricker, 2007). I propose that tackling epistemic injustice in confinement necessitates academic partnering with survivors, to coproduce new ways of knowing.

A shared community or a place to agitate?

I came along to the University of Melbourne Confinement workshop with my curiosity clutched in my hand. Psychiatric confinement is woven into my own lived experience, and in my work as a peer, advocate and activist in the psychiatric survivor movement, I have heard and read hundreds of other survivor narratives. It’s something I think about every day, though I wish that I didn’t.

The contemporary psychiatric survivor movement (also known as the Consumer/Survivor/eXpatient movement, or C/S/X movement) began as the Mental Patients Liberation Movement in the early 1970s, as a part of the larger disability movement, intersecting with other rights-based activism (Chamberlin, 1990). Although the focus of activist work has shifted and evolved over time, it retains an enduring focus on human rights, by and for people who have been patients of psychiatric services. Early priorities of the movement persist today, including freedom from oppressive psychiatric practices and access to peer support (O’Hagan, nd). In the 1990s, as deinstitutionalisation progressed, the movement focused on a new concept of ‘recovery’, that considered more than just symptoms (Slade et al., 2012) and is described as ‘a life that is chosen, beyond the constraints of illness or illness identity; a life of hope that is unique and deeply meaningful to the individual’ (Byrne et al., 2015). However, consumer/survivor activists internationally have argued that activism
for recovery failed to achieve what many had hoped and that the concept of recovery has been co-opted by the psychiatric system and stripped of its intended purpose (Rose, 2014; Watts, 2016). In Australia, Byrne et al. (2015: 939) describe this co-option of recovery as a ‘re-naming of existing processes’ where the intended meaning of recovery has been so significantly altered by the mental health system that it resembles old concepts of clinical recovery. Similarly, in Canada, Costa (2009) points out a kind of ‘cherry picking’ of the apolitical aspects of recovery, stating that the ‘magnetism of recovery talk, the ‘hope talk’ is picked up while the contentious bits regarding citizenship and advocacy are left behind.’ (Costa, 2009: 35). Meanwhile, in the United Kingdom, Rose (2014) describes the co-option of recovery as a process of ‘instrumentalising and mainstreaming’ what began as a ‘liberatory discourse’ into neoliberal discourses of individualising, economics and normalisation.1

Over decades of advocacy, peer support has grown to become a recognised, albeit underfunded and under-pressure, discipline of its own. Consumers/survivors have developed our own philosophies of practice such as Intentional Peer Support (Mead, 2014), and more recently, an emerging academic discipline in survivor research and Mad Studies has emerged (Faulkner, 2017; Rose et al., 2017). Since the early days of the movement, psychiatric practice has shifted from large, old institutions to discrete units within hospitals. However, human rights violations in contemporary institutions remain common practice (Maylea et al., 2021; Puras and Gooding, 2019; VMIAC, 2019), as do serious adverse effects of treatment, homelessness, unemployment, poverty and social exclusion. Many of us in the psychiatric survivor movement compare hospitals to prisons, detention centres and the like. But are they really? I did not actually know. Was there an opportunity for change that could arise from collective knowledge about confinement? I didn’t know this either, but I was interested to find out.

I also brought some simmering outrage to the workshop. ‘Why isn’t psychiatric confinement on the agenda?’ I thought to myself as I trudged across the university campus that morning. ‘Why are we so invisible?’ Thankfully, and tragically, of course, I did find a new community of allies and intersectional issues. Whether the conversation was about the offshore detention of asylum seekers, youth justice, prisons, aged care or disability services, I heard consistent themes of coercion masquerading as ‘care’, of deep and broad human rights violations, of little accountability, of hidden places, of silenced voices, of trauma. In most of these presentations, it would have been easy to replace the type of system with ‘psychiatry’ and hear a story that I already know. Like many activists, I am immersed in my own specialised area, so it was powerful to realise that these human rights issues and harms are indeed common in many other spaces beyond psychiatry. I left the workshop knowing that there are real opportunities for greater cross-sector and intersectional collaboration in advocating for change.

Roots of confinement

Invariably, one of the justifications for confinement is to contain or control perceived risks of harm or ‘dangerousness’: either that people may be a danger to themselves, which seems grounded in paternalism and ableism; or that people may do harm to others, which is subjective and contestable.2 These common themes in psychiatry are hotly contested by survivors (O’Hagan, 2003; VMIAC, 2019).

Punishment seems a messier motivation for confinement. It is an explicit (although contested) rationale for prisons and immigration detention. There is, however, a tendency in law and research to draw upon a narrow frame for understanding confinement, and especially coercive confinement, through what can be rendered visible, or concrete, with ideas about confinement typically situated
along a carceral continuum. Accordingly, the notion that places of ‘care’ can also be places of punishment, brutality and violence is rarely acknowledged. These ideas have been at the heart of Australian governmental resistance for example, to the inclusion of aged and disability care under the National Preventive Mechanisms of the Optional Protocol to the Convention Against Torture and the Cruel, Inhuman or Degrading Treatment or Punishment (Sadler, 2021). Places and systems of ‘care’ – aged, disability or psychiatric – never overtly express punishment as their aim or intention. As Repo (2019: 237) has shown in her research, and as several Royal Commissions in Australia have recently found (Briggs and Tracey, 2019: 75, 105; State of Victoria., 2021: ix) it does not take much for places of care to transform into ‘quasi-carceral experiences’, especially when there is a culture of control that underpins practices there. Punishment – whether it hides behind behaviour management or modification or is straight-up cruelty and abuse – is a common experience for the people these systems are supposed to serve. As voluminous testimonies from repeated Royal Commissions and inquiries into these systems attest, these are places where individual workers can and do practice coercion, violence and abuse. This should be no surprise. When we lock the doors, pull the blinds, and give one group of people enormous power over another group of people, it rarely ends well. For example, compulsory treatment orders, and poor monitoring and regulation of the effects of control over those subjected to them, leads to abuse. The problem lies not with the individual but with the ‘broken and traumatic system’ (Royal Commission into Victoria’s Mental Health System, 2021*: ix) that enables such abuse. In their final report, Commissioners from the Royal Commission into Victoria’s Mental Health System wrote: ‘We have heard confronting stories of how some people’s experiences of the current mental health system have exacerbated their pain and distress. This is unacceptable. Establishing a royal commission can shine a light on what has remained hidden for too long’ (State of Victoria, 2021: vol. 1, 5). The report describes the long history of these traumatic practices and identifies complex barriers to reducing or eliminating them, including the lack of transparency and accountability in what happens behind these locked doors (vol. 4: 344–345).

**Russian dolls: External, bodily places of confinement**

Although more commonly applied to places of detention for asylum seekers (Hodge, 2014; Holt, 2003; Jenkins, 2004: Perera, 2002), Weller (2017) and others (Adams and Everelles 2017; Spivakovsky, 2018) have shown how the application of Agamben’s theorisation of exceptional spaces – marking a division between bare life and political life – also applies to institutions ‘caring’ for those seen as ‘lacking’ mental capacity. The suspension of ordinary rights and legal protections disappear for anyone categorised in this way, reflecting the biopolitical division between bodies that matter, and bodies that don’t. At the same time, the very notion that legal rights can be suspended in these sites is ‘normalised’ and accepted (Weller, 2017: 403). Any failure to register as a breach in a person’s rights is, argues Weller, ‘because [the breach itself] is taken for granted. It is … always justified by a strong narrative of benevolence’ and accompanied by ‘historical patterns of exclusion, paternalism and institutionalisation’ (Weller, 2017: 403). These are bodies that are relegated to exceptional spaces where ‘lawful violence’ is permitted (Minkowitz, 2007; Steele, 2015)³, either because their suffering does not register as suffering at all, or is just not seen as important (Weller, 2017: 406).

The most noticeable forms of confinement and breaches of rights occur in psychiatry in the form of locked units, solitary confinement (or seclusion), and restraint, commonly understood to include mechanical restraint (straps), physical restraint (being held down), chemical restraint (drugs) and
psychological restraints (threats). In Australia, only the first two of these forms of restraint are defined, acknowledged, regulated and monitored across psychiatric services in all states. My personal experience includes being in locked units and solitary confinement, commonly known in this context as ‘seclusion’. Psychological restraint in the form of threats was both a big thing and a small thing for me. And chemical restraint was ubiquitous. At the very least, I was spared mechanical restraint, but I hardly feel grateful for that.

Psychiatric units are designed like a scary version of Russian Matryoshka nesting dolls, with increasingly smaller but more secure spaces within them. So, the overall unit, housing about 20 patients, is locked. Within that, a high dependency area, for perhaps six patients, is locked. And inside that space will be the seclusion (solitary confinement) rooms, locked again. In each area of increasing security, there is more isolation and progressively less sensory experience. The spaces are often separated by thick, heavy fire doors that used to make me wonder if I was more like a dangerous or repulsive animal than a scared, hurt human. Like the dolls, within each level of psychiatric enclosure, our humanity is made smaller.

In the context of decades of apparent mental health system ‘reform’, I find it disheartening that in my early years of psychiatric admissions the overall unit that houses low dependency, high dependency and seclusion rooms was rarely locked, but in my later years, it was never open. It may be no surprise, given my lived experience of childhood abduction and abuse, that a locked unit was something I found neither helpful nor safe. I made many attempts at escape, occasionally succeeding. Sometimes, I would spend hours focused on how to get out. As patients, we’d share stories in the courtyard about the best escape strategy. I always thought it made sense to head further into the main hospital rather than make a break for the street. But escape from the high dependency area or a seclusion room wasn’t possible.

I hold one pungent memory of admission into the psychiatric unit where I was brought directly into the high dependency area, strip-searched, and medicated against my will. It was like a facsimile of my childhood abuse. They couldn’t have planned a more frightening or disempowering response to my distress, and I ended up heavily sedated, and more despairing.

I recall a time when I attempted suicide while on the unit. When the staff found me, I was forcibly walked directly to a seclusion room, with no conversation. Those hours of being locked up all alone, with nothing for distraction, had felt like torture. I could only conclude that I was, indeed, as evil as my voice had told me, or they wouldn’t have punished me this way. I punched myself in the head, over and over. With all that I now know about trauma, recovery and healing, this treatment is even more shocking. The alternative, of course, would have been to simply sit with me, to ask what had happened, to listen with empathy, to support me to explore ways to decrease my emotional pain and to find connection and hope.

**Epistemic crypts: The confinement of personal truth**

Not all confinement occurs in physical space and time. Confinement can sometimes entail locking up emotions and truth (Bueter, 2019). In sharing my experiences of psychiatric confinement, I am compelled to begin by stressing the way that my own knowledge about my own experience was systematically ignored over many years. This silencing of personal truth, for me, was the most insidious and damaging kind of confinement, but it was the one that was hardest to see. As Weller (2017: 404) has argued, mental capacity laws are a form of exclusion, which shut down recognition of speech and voice, through laws about decision-making, and the denial of credibility as a ‘rational’ subject and as a person who holds knowledge. When I was a patient, the psychiatric
interpretation of my experience was delivered through different diagnoses; and the diagnosis with
the most harmful and ‘sticky’ consequences for me was schizophrenia. My diagnostic labels were to
become a kind of epistemic crypt, locking out my personal truth of what was actually happening,
while trapping me – quite literally – into situations of serious harm and hermeneutical injustice.

Hermeneutical injustice is defined by Fricker (2007:1) as ‘...a gap in collective interpretive
resources [which] puts someone at an unfair disadvantage when it comes to making sense of
their social experiences.’ I am not the first to argue that, in seeking to make sense of diverse experi-
ences of human distress, psychiatry draws on a narrow, biogenetic source of knowledge, sometimes
very out of step with contemporary thinking, and frequently out of context of social determinants.
Indeed, it was only in the 1970s that psychiatry removed homosexuality from the Diagnostic and
Statistical Manual as a defined ‘mental illness’ (Drescher, 2015). In my case, the gap in collective
interpretive resources was the exclusion of my own ideas about the meaning of this experience,
along with the absence of any kind of psychological or social interpretation, of which there could
have been many. This is made possible in psychiatry, I think, because of unequalled and extensive
legislated powers granted to this profession in the name of protection, often resulting in violent prac-
tices used against people like myself who express our distress in ways that fall outside of accepted
norms, and which attract ableist assumptions about our capacity as knowers or testi-

Epistemic injustice is a form of confinement and control that can be experienced either as ‘tes-

timonial quieting’ or ‘testimonial smothering’ (Dotson, 2011). In the former, silencing occurs when
‘an audience fails to identify a speaker as a knower’, when the speaker’s voice is undervalued, and
not regarded as plausible (Dotson 2011: 242). Testimonial smothering operates at a deeper level and
is more complex, in which the speaker smothers their own testimony, in an act of ‘self-silencing’. In
this latter instance, a person limits their own speech so that it conforms to expectations of what is
regarded by others as credible speech. Both are a form of ‘epistemic oppression’ (Dotson, 2014) and
‘epistemic injustice’ (Fricker, 2007). Paradoxically, as I have already described, this is experienced
as another form of confinement, exceeding the confinement experienced within institutions them-
selves while being connected to it (Fricker, 2007: 4). Epistemic injustice also exists within a
‘broader pattern of social injustice’ (Fricker, 2007). In other words, my words are not believed
or understood because of my situatedness which is presumed to generate partial or unreliable
‘knowledge’ (Haraway, 1988).

Crichton et al. (2017: 65) have argued that people with ‘mental disorders’ are even more vulner-
able to epistemic injustice than those with somatic illnesses. They describe ‘epistemic injustice as

a harm done to a person in her capacity as an epistemic subject (a knower, a reasoner, a questioner) by
undermining her capacity to engage in epistemic practices such as giving knowledge to others (testify-
ing) or making sense of one’s experiences (interpreting). It typically arises when a hearer does not take
the statements of a speaker as seriously as they deserve to be taken. The prime case of epistemic injustice
is testimonial: the hearer deflates the level of credibility she gives the speaker because she is (often
unconsciously) prejudiced against the social group to which the speaker belongs.

As the authors go on to observe, this leads to assumptions that those with ‘mental disorders’ lack
credibility, delivering a ‘distinctive’ experience of injustice in which a person’s testimony and
knowledge is disregarded (Crichton et al., 2017: 65). For me, it was slightly different. I never
even got the chance to ‘testify’ about trauma, it was denied to me. Yet the volume of research
into trauma⁵ indicates that I should have been asked.
When I first appeared at a psychiatric service, dishevelled, distressed, and escorted by police, I have no doubt that I was a walking stereotype of madness. I had been injuring my body for months and had attempted to kill myself. I heard a voice in my head that told me I was evil, a threat to society, and that I needed to be destroyed. I was drowning in floods of emotional pain. But being a relatively sensible person most of the time, I knew quite well that admitting I heard voices would not end well. I was frightened and said very little. A small part of me wanted to tell them about a thing in my past that I thought might be relevant, but I didn’t have the words. I thought, if it mattered, surely, they would ask.

In a typical treatment course, I was detained and given lots of drugs, so-called ‘antidepressants’, ‘mood stabilisers’, ‘antipsychotics’ and lots and lots of benzos. The adverse effects of these drugs are massive. Within months, I had gained over 50 kg. I was so sedated I could hardly think clearly, I lost my intellectual ability, and I slept for 12–16 h every day. I was, as so many of us survivors say, like a walking zombie. I view these impacts as chemical restraint – but that’s only part of it.

In the early days, I took my pills and did what I was told. I remember the time a psychiatrist sat with me, kindly, or so it seemed, and told me I had a serious disease in my brain, a kind of chemical imbalance, and that I had to be realistic about my future. He indicated I would need medication for the rest of my life and may never work again. (How I long for a Tardis, to travel back in time and give that psychiatrist a new version of realism. To tell him that one day I would be delivering university lectures to psychiatry registrars, be employed by government as a senior advisor to the Chief Psychiatrist, that I would lead campaigns and publish papers, and do all of it without a single psychiatric pill. If only.)

That conversation was another kind of confinement, I guess. It locked me into hopelessness. Until that moment, I could still get occasional comfort from my history. I had a degree, I’d had a successful career in business. I might be mad, I’d thought, but at least I had a good education and life skills. But at that moment, hearing that my brain was diseased, it felt like the door to any kind of future slammed shut on me. I wish I had known that the idea of disease, of chemical imbalances as a cause of mental illness, was just an unproven, heavily critiqued theory, not fact. I wish I had known that thousands of people with this diagnosis recover and heal without any medication at all and even lead extraordinary lives. But I didn’t know these things. I just believed the psychiatrist and sank deeper into despair.

Most of all, I wish they had known enough, and cared enough, to ask if I had any thoughts on why this might be happening, before deciding that I had a ‘disease’. To ask about what had happened in my life to lead me to this point. I wish they had valued my knowledge. But this is the epistemic trap of psychiatry. Madness means you get confined, but it also means you can’t know anything of value. And that means you can’t get yourself out. Still, in those early days, there was a fleeting kind of hope. I remember thinking that maybe, now I had a diagnosis, they would give me treatment that helped. Maybe all this painful weirdness would go away if I just took my pills. If I just agreed to those shock treatments. But over time, the reality was unavoidable: everything was getting worse, not better.

It took me many years to free myself from psychiatry, and none of the things that helped me to recover and heal came from psychiatry. In fact, many were completely contrary to their advice. Eight years after I was first diagnosed, I went to a public talk by Ron Coleman, a man who had been on a similar journey to myself. He’d been diagnosed with schizophrenia, had spent years in and out of hospital, and was told he would never recover. And yet here he was, travelling the world as a public speaker and educator, talking about recovery (Coleman and Taylor, 2012). I
was enthralled. And what moved me the most was hearing him describe the real issue behind his voices and distress: his experience of child abuse in the Catholic church. This struck deep. That thing, that thing that had happened when I was 13. That thing I had never told anyone about but wondered if I should. That thing that frightened me and made my voice become enraged. That thing was child sexual abuse.

I then invested a lot of time learning about the hearing voices movement that Ron described (Corstens et al., 2014; Longden et al., 2012). I met other voice hearers, allies, even psychiatrists, who worked with this approach. The idea was simple: voices are a meaningful experience, rather than a symptom of disease, often linked to painful experiences in our lives like trauma and adversity. By listening to them, making sense of them, we can find a way to healing. The Hearing Voices Movement emerged in the 1980s, as grassroots, international movement (Higgs, 2020) dedicated to peer support and an affirmation of those who experience ‘auditory verbal hallucinations’ as the experts on this phenomenon. So rather than dismissing these as pathological experiences, the movement asserts that they are ‘meaningful’ (Corstens et al., 2014: 285–286), forming ‘part of the diversity of the human condition’ (Corstens et al., 2014: 286, 289). As Corstens et al. (2014: 291) note, the Hearing Voices Movement asserts that those

Individuals who are distressed by their voices may potentially benefit most from approaches that incorporate acceptances and normalization…

Put simply, the movement challenges the assumption that hearing voices is a mark of mental illness, and places those who hear voices at the centre, as the experts (Higgs, 2020: 134).

And so, after 27 years of keeping this thing secret inside me, I began to speak about my experience of child abuse, about how, aged 13, I had run away from home, only to be abducted on the first day. About how I was kept for two weeks in a dilapidated old farmhouse on the outskirts of a regional town, with little food, but lots of alcohol. How I was raped. And how, after the police found us, they locked us together in the paddy wagon, and my abuser begged me not to tell. How, after I was reunited with my Mum, before I could tell her anything, she told me never to speak about what happened, ever. And so, I kept this dreadful, painful secret. And over the years, it grew into a great and terrible shame that was too big for me to hold. It got so big that it became an externalised voice, that screamed at me to die.

Through all those years, what the staff seemed to notice about my distress were things such as hallucinations, delusions and self-injurious behaviour. Yet for me, the voices and cutting were just superficial manifestations of an emotional tsunami. There was terror and desperation, and underneath that was a shame that had engulfed me.

I had to lie to my psychiatrists to get free of medication. I started pretending that it was finally helpful, I told them everything they wanted to hear. Then I got away and worked with peer support workers and a sexual assault counsellor. In less than a year, I was well on my way, and I have never been an inpatient again. It turned out that this brain disease I was supposed to have could be transformed by thinking, feeling and talking. That actually this was not a physical phenomenon with causation in a diseased brain, or faulty genetics. It was an emotional and social phenomenon, rooted in secret experiences of childhood sexual abuse, about which I was taught to feel shame.

I should note that healing is not cure, at least, not for me. Arguably, cure is not even a relevant concept in the space of trauma and madness. What was done to me cannot be undone or forgotten.
I have found ways to mostly live with what has happened to me, but sometimes the trauma, pain and madness return with new lessons for me to learn. In recent times, the Power Threat Meaning Framework (Johnstone et al., 2018), which was developed as an alternative to psychiatric diagnoses, has been a refreshingly helpful and non-medicalised framework for understanding my distress in ways that account for epistemic injustice. By outlining many ways that misuse of power, including social discourses, can create threats, meaning and understandable threat responses in our lives, the framework has given me a sense of hermeneutical justice in making sense of trauma. Whereas psychiatric diagnoses reinforced the messages of past abusers and common patriarchal discourses, that is, that I was broken, unreliable and ‘mad’, the Power Threat Meaning Framework (Johnstone et al., 2018: 203–204) critiques the pathologisation of human distress in relation to epistemic injustice:

…the great majority of the experiences that are described as ‘symptoms’ of ‘functional psychiatric disorders’… can be understood… with no assumption of ‘mental disorder’, once the meaning-based threats have been identified and their links with the protective threat responses restored…. a number of factors combine to ensure that these links are obscured in most of what is called ‘mental illness’…. The influences above combine to deprive people of a socially shared framework of thought within they can make sense of their own experiences in their own terms…. The impact on the person who is diagnosed can be seen as a form of ‘epistemic injustice’…

Despite the heavy weight of trauma and the tight grip of psychiatric confinement, there are moments of light in my story, and in the stories of many others. I believe that in those moments when we resist, when we fight back against the control, we move towards a kind of liberatory healing. There were times when I escaped the unit, literally seeking freedom, and these were acts of survival. The recently launched Absconding Archives (nd) are an online place for survivors to share and celebrate similar stories. In those times, I had not yet articulated my trauma history, and while parts of me wanted to die, there was another part that knew this place was not safe and struck out for freedom. There was a survivor in there, all along.

There were other times, in the early years, when I embarked on a campaign of ‘appropriating’ objects that belonged to the hospital. I didn’t view it as theft, per se, because I only did it when they took something from me without consent, such as privacy, autonomy or dignity. Over time, I built up a collection of stolen towels, sheets, biros, disposable gloves and even a blanket. I would record the date, time and location of each appropriation. I still have these appropriated artefacts, tucked away at the top of my wardrobe, carefully labelled and boxed. They were attempts to take back my power and remind me that even in the worst of times, a part of me was fighting to live, and I got there, eventually. This was no thanks to psychiatry or confinement, but through finding and honouring my own hard-won truth, and putting the shame where it belonged, at least, most of the time.

**Working in the system: Resisting the system**

As I began to work in the mental health system, first as a peer, then as an advocate, I was shocked to find that my trauma history was not unique or even rare. Repeated studies have found that around 80% of people diagnosed with schizophrenia have a history of trauma, frequently child abuse and neglect (Goodman et al., 1997; Read et al., 2008; Varese et al., 2012). I could not understand why they never asked me about this. I could not understand why they told me I had a disease and offered nothing but drugs and shock treatments. I could not understand why a medical way of knowing was privileged over my own story, and
over the obvious social and psychological lens of trauma. I cannot imagine how many other people have been told, and believed, that their distress is a result of illness, rather than a meaningful consequence of trauma.

The implications of epistemic confinement were unnecessary and devastating. Most of my 30s had gone by the time I was well on the way to healing, along with all the important life moments that might have been: relationships, becoming a parent, further study, career and travel. My physical health was in tatters after years of psychiatric treatments. And in those years of emotional torment, psychiatry had unwittingly helped to feed my shame. The message from my mother that I should never tell. The message from my abuser was that no-one will believe me. The social message I’d internalised that it was all somehow my fault, that I was broken and wrong. That I had frozen and never said no. In telling me that my broken brain was the source of my distress, rather than the broken world that had hurt me, these words built up my shame, rather than my truth. Roper (2019:10) describes this kind of hermeneutic injustice as a form of ethical peril and violence:

the medical response means our bodies are violated and we cannot effect our own power to say no and have it respected. Under this process, other ways of being and knowing are disqualified. This is likely to leave us feeling ‘dehumanized by human beings’, alienated, set apart from humanity.

The final insult came for me when a sexual assault counsellor said it was not too late to file a report about the abuse, even after all those years. After 27 years of silence, I had finally been able to testify my experiences to another and be heard and believed. I had experienced a measure of epistemic justice. However, I knew what happens to witnesses in child abuse and sexual violence cases, and then I realised the additional, suffocating layer of testimonial injustice (Fricker, 2007) that psychiatry had imposed on me. As someone with a diagnosis of schizophrenia, it was unlikely I’d ever be considered a credible witness (Cadwallader, cited in Law Council of Australia, 2018: 155). Psychiatry denied me the chance to be seen as a credible knower about my life, and by blaming my biology for the impacts of child abuse, they took away any possibility of seeking justice. This was a misuse of psychiatric power with profound implications in my life. And as Beaupert (2018) has also commented:

The symbolic power of psychiatry and the mental health paradigm operates to constrain and silence ways of knowing, expressing, opining, and being that may be vital to a person’s sense of self, a process of symbolic violence that cultivates the ontological nullification of users and survivor.

Shared imperatives

During the workshop organised in Melbourne, in August 2019, on ‘Sites of Control and Confinement’, I heard much that resonated with my own experience and understanding, as well as with literature from the broader psychiatric survivor movement. The great gulf between expressed intentions for a sector, and the too-often dreadful reality of practice on the ground was clear. Calls were made for abolition, for genuine human rights. For rebalancing of power. Calls to tackle woeful oversight mechanisms and rights protections. Calls for an end to violence and abuse.

The magnitude of trauma across so many of these spaces and places is what stood out most for me. Trauma as causation, and then trauma as consequence. Trauma ignored and hidden. Exponential trauma. Perhaps this sets up a new level of significant epistemic injustice caused by
places of confinement. In locking us away, it is so much easier for society to pretend that the original harms never happened at all. Society can hold on to false but comfortable beliefs that institutional harms live only in history books, that inequality is a battle largely won, that the world is a safe place. If we lock away the people who wear the scars of child abuse, family violence, the devastations of war, the personal costs of racial, gendered and homophobic harassment and abuse, then we make it easier for violence, hate and inequity to continue.

I close with a cautionary note, which brings with it, I hope, rich opportunity. Although much of the content at the Confinement workshop was necessary and welcomed, I invite critical reflection on the processes and voices that primarily delivered it. This was a space largely dominated by academic and practice allies, rather than people with lived experience of confinement. Survivor researchers, Russo and Beresford (2015: 156) have argued that ‘academic activity must look more carefully and inclusively at what role those experiencing epistemic injustice can and should play… How can academia be opened up to the contribution of ‘outsider’ perspectives and ensure that the work towards epistemic justice is undertaken in equal partnership?’ Certainly, in the ‘mental health’ domain, lived experience ways of knowing are flourishing in research (Faulkner, 2017), peer-delivered practice (Byrne et al., 2018) and conceptual understandings (Beresford, 2020).

In understanding, addressing, and perhaps someday abolishing, places of confinement, genuine allies are welcomed and much needed. However, the risks of epistemic injustice will remain if we do not shift from the position that traditional academia is best placed to interpret lived experience. As former prisoner and prison abolitionist, Tabitha Lean (Lean and Kilroy, 2020) has remarked, we must be recognised as ‘experts in our own oppression … [who] can bring unique and valuable insights to the table. We don’t need a piece of paper to allow us to speak because the scars of imprisonment are carved into us’. Instead, there is a need to move towards partnering in the coproduction of new ways of knowing that authentically privilege lived experience/survivor knowledge and elevate the credibility and power of lived experience/survivor voices.

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Notes

1. The critical theorist and activist group ‘Recovery in the Bin’ emerged in response to the failings of the ‘Recovery model’, describing itself as ‘a User Led group for MH Survivors and Supporters who are fed up with the way co-opted ‘recovery’ is being used to discipline and control those who are trying to find a place in the world, to live as they wish, trying to deal with the very real mental distress they encounter on a daily basis.’ https://recoveryinthebin.org/

2. Bonnie Burstow (2015: 33–40), for example, has highlighted historical patterns of classifying and ‘understanding’ distress that often leads to confinement and control. See Burstow, B. (2015). Psychiatry and the business of madness: An ethical and epistemological accounting. Springer.

3. See also in Penny Weller (2017: 404–405), for example, lawful violence is described as ‘unwanted violence that is authorized by law within an established legal framework’. See Weller, P (2017) Mental capacity and states of exception: revisiting disability law with Giorgio Agamben. Journal of Media & Cultural Studies 31(3): 400–410.

4. The work of Miranda Fricker on epistemic injustice has also been applied to those in the prison system: see also Hanan, E (2020) ‘Invisible Prisons’ University of California Law Review, U.C. Davis L. Rev. 1185, 54). Similar accounts have been made regarding the health system, see Kidd, I J and Carel, H (2017) ‘Epistemic Injustice and Illness’ Journal of Applied Philosophy, 34 (2): 172–190. And in his book written while detained as a refugee, in an Australian immigration detention centre, Kurdish writer and scholar Behrouz Boochani reflected on the collapsing of identity of refugees as a form of epistemological violence (Boochani, B 2018, No Friend but the Mountains, Pan McMillan: 98–99). In many respects, this book dedicates itself to the refusal of epistemic injustice towards refugees.

5. There is voluminous research into the prevalence of trauma and its association with mental health diagnoses. See for example: Johnstone et al. (2018: 98–113); Varese et al. (2012); Read et al. (2008); Read et al. (2006); Felitti et al. (1998); and Goodman et al. (1997).

6. Benzodiazepine, a psycho-active drug with tranquilising effects.

7. For a discussion of the vulnerability of individuals with ‘mental health disorders’ to epistemic injustice, see Kurs, R., & Grinshpoon, A. (2018). Vulnerability of individuals with mental disorders to epistemic injustice in both clinical and social domains. Ethics & Behavior, 28(4): 336–346.

8. Similar observations have been raised by Newbigging, K and Ridley, J. (2018) ‘Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health’, Social Science & Medicine, 219, 36–44, and by O’Donovan, O. and Madden, D (2018) ‘Why do medical professional regulators dismiss most complaints from members of the public? Regulatory illiteracy, epistemic injustice, and symbolic power’, Journal of bioethical inquiry, 15(3), 469–478.

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