

‘Maybe I Shouldn’t Talk’: The Role of Power in the Telling of Mental Health Recovery Stories

Qualitative Health Research
2022, Vol. 32(12) 1828–1842
© The Author(s) 2022



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/10497323221118239
journals.sagepub.com/home/qhr



Joy Llewellyn-Beardsley¹ , Stefan Rennick-Egglestone¹, Kristian Pollock² ,
Yasmin Ali¹, Emma Watson³, Donna Franklin⁴, Caroline Yeo¹, Fiona Ng¹,
Rose McGranahan⁵, Mike Slade¹, and Alison Edgley²

Abstract

Mental health ‘recovery narratives’ are increasingly used within teaching, learning and practice environments. The mainstreaming of their use has been critiqued by scholars and activists as a co-option of lived experience for organisational purposes. But how people report their experiences of telling their stories has not been investigated at scale. We present accounts from 71 people with lived experience of multiple inequalities of telling their stories in formal and informal settings. A reflexive thematic analysis was conducted within a critical constructivist approach. Our overarching finding was that questions of power were central to all accounts. Four themes were identified: (1) Challenging the status quo; (2) Risky consequences; (3) Producing ‘acceptable’ stories; (4) Untellable stories. We discuss how the concept of narrative power foregrounds inequalities in settings within which recovery stories are invited and co-constructed, and conclude that power imbalances complicate the seemingly benign act of telling stories of lived experience.

Keywords

mental health and illness, recovery, marginalised or vulnerable populations, stigma

Introduction

Stories of mental distress which foreground aspects of survival and flourishing have been of interest within mental health activism, research and services for at least 20 years (Spector-Mersel & Knaifel, 2018). Such stories are often referred to in research and practice as ‘recovery narratives’ (Kerr et al., 2020; Llewellyn-Beardsley et al., 2019; Mancini, 2019; Piat et al., 2019), and interest in them has increased within services in tandem with the global adoption of a recovery paradigm by healthcare policy and practice (Nettleton, 2020). Their use has become widespread in services for diverse purposes, including within staff training to improve service delivery and increase empathy (Salter & Newkirk, 2019); public health campaigns and living libraries to challenge stigma (González-Sanguino et al., 2019; Kwan, 2020); online interventions to increase access to self-care resources (Slade et al., 2021; Williams et al., 2018); and as a distinctive feature of peer support (Moran et al., 2012; Truong et al., 2019).

As it has been a core challenge for people with lived experience to establish our/their¹ perspectives as legitimate within services (Slade & Sweeney, 2020), the use of recovery narratives by services could be seen as empowering; providing opportunities to (re)claim often-denied epistemic authority (Fricker, 2007) over individual biographies, and to effect change in healthcare systems (Fisher & Lees, 2016; Fricker, 2007). However, such use

¹School of Health Sciences, Institute of Mental Health, University of Nottingham, Nottingham, UK

²School of Health Sciences, University of Nottingham, Nottingham, UK

³Nottinghamshire Healthcare NHS Foundation Trust, Nottingham, UK

⁴NEON Lived Experience Advisory Panel, University of Nottingham, Nottingham, UK

⁵Independent researcher, London, UK

Corresponding Author:

Joy Llewellyn-Beardsley, School of Health Sciences, University of Nottingham Triumph Road, Nottingham NG7 2RD, UK.

Email: joy.llewellyn-beardsley@nottingham.ac.uk

is complicated by contested understandings of ‘recovery’ as a concept (McCabe et al., 2018).

Core principles of recovery were first established in a number of papers which shared the view that recovery is primarily a social rather than an individual or clinical concept (Fisher & Lees, 2016). Within social justice movements, the practice of sharing stories of lived experience has a history of emancipatory use (Davis, 2012; Ganz, 2001; Riessman, 2008; Voronka & Grant, 2021). For activists and survivor-researchers, key motivations for foregrounding recovery or rehabilitation aspects of their stories included offering hope to others facing difficulties, critiquing narrow understandings of rehabilitation and myths of ‘incurability’, creating counter-narratives of resistance to dominant biomedical narratives, and organising for systemic change (Beresford, 2019; Costa et al., 2012; Deegan, 1996; Fisher & Lees, 2016; Jacobson, 2001; Ridgway, 2001; Sapouna, 2021).

However, survivor-researchers, critical and community psychologists, medical sociologists and others suggest that the concept of recovery has since been co-opted by mental health policy and practice to serve more neoliberal purposes, with an over-emphasis on individualism, a paradoxical focus on deficit/illness, and a de-emphasis of the social and structural causes of mental distress (Beresford, 2019; Harper & Speed, 2012; McCabe et al., 2018; Pilgrim & McCranie, 2013). With this shift, activists and researchers have raised concerns that stories of lived experience are being similarly co-opted to fit normative organisational agendas at the expense of offering more diverse understandings and templates of recovery (Kaiser et al., 2020; Topor et al., 2021; Woods et al., 2019; Yeo et al., 2022). In these contexts, the risk is that telling ‘recovery’ stories can become more about conformity than about emancipation.

For example, a multiple-case study investigated elicitation of recovery narratives in global mental health contexts, and raised ethical questions about some institutional practices (Kaiser et al., 2020). One case described an inpatient clinical service in Kashmir as requiring service users to recount an ‘acceptable’ recovery narrative, demonstrating improvement as a result of their inpatient treatment, as a prerequisite to discharge. Another described an Australian non-profit which trained people with lived experience to share their stories with the public. Narrators were instructed to avoid ‘risky’ subjects like self-harm and suicide, follow a structure of beginning, middle and positive ending, and speak positively about mental health services to encourage others to seek help. After the training, some participants were invited to become speakers but many were not. The selection process was not explained, leaving the experience unresolved for participants whose stories were not deemed appropriate to share. The resulting stories that were shared fitted a

narrow template of being ‘risk-free’ and reflecting well on mental health services, arguably reinstating professional power and a central role for services at the expense of validating other experiences of recovery (Fisher & Lees, 2016).

This co-option may or may not occur as a result of deliberate or conscious strategy. Services may actively select particular narratives which fit organisational agendas, as studies of curatorial influence on recovery narrative collections show (McGranahan et al., 2019; Yeo et al., 2020). Or services may invite stories which reproduce social structures and dominant cultures through more inadvertent actions (Fisher & Lees, 2016). Either way, the effect may be that the resulting recovery stories suit the purposes of an institution, which may differ from those of the narrator in significant ways (Yeo et al., 2022).

Implications of co-option have been described for services and service users (Costa et al., 2012; Fisher & Lees, 2016), narrative research (Russo, 2016) and social work education (Sapouna, 2021; Voronka & Grant, 2021). Yet despite these rigorous critiques, the perspectives of people with lived experience of mental distress on what it is like to tell our/their stories have not to our knowledge been explored at scale. Understanding more about the process of telling lived experience stories in healthcare and other settings, from the perspectives of a wide range of tellers, may offer further insight into the possibilities and problems associated with such storytelling. Our study aims to contribute to the field by addressing this gap.

Theoretical Framework

Our study was underpinned by a critical constructivist approach to narrative-based research. Constructivist approaches treat stories not as “objective, spontaneous outpourings” (Kaiser et al., 2020, p. 8), but as situated within and contingent upon their contexts (Given, 2008). Following Riessman (2008), we adopted a multi-level definition of context, viewing stories as being constructed in relation to factors at three intersecting levels – local/personal (micro), interpersonal/group (meso) and societal/structural (macro).

Critical constructivist approaches note further that stories are constructed within a “hierarchy of credibility” (Plummer, 2019, p. 66), wherein some ways of understanding are more available and socially sanctioned than others (Johnstone et al., 2018). These more socially acceptable narratives can be referred to as the dominant narratives of a particular society, or those which a critical mass of people accept as ‘common sense’ (Hagström & Gustafsson, 2019). Such dominant narratives provide an overall context within which personal narratives function; for example, the dominant biomedical narrative within the Global North, which defines distress in terms of mental

dysfunction and disease, and both describes and dictates how people conceptualise their own narratives (Adame & Hornstein, 2006). Dominant narratives privilege some people's accounts and marginalise others (Coghlan & Brydon-Miller, 2014). Therefore it matters whose stories are legitimised and whose are not.

The experiences of mental distress and stigmatisation can be co-occurring (Azhar & Gunn, 2021; Colizzi et al., 2020; Devendorf et al., 2020; Gronholm et al., 2017; Robinson et al., 2019). Having a stigmatised identity is associated with being discredited and discounted (Goffman, 2009). Stigmatisation may also interact with other forms of stigma related to marginalised social identities based, for example, on race, ethnicity or sexuality (Jackson-Best & Edwards, 2018). It seems likely then that the lived experience narratives of people with marginalised social identities in particular might be "carefully constructed and contextually situated", rather than "unconscious productions" (Jacobson, 2001, p. 250). Thus, these accounts are even more vital to pay attention to, in terms of exploring how we/they might be better served by healthcare organisations and institutions.

Our aim was therefore to explore how stories of lived experience are told in various settings, from the perspectives of people from specific marginalised groups. Increased understanding of what it is like to tell such stories may sensitise mental health practitioners, policy-makers and researchers to some of the "complications, considerations and consequences" (Voronka & Grant, 2021, p.977) that may exist for those undertaking the storytelling.

Method

Research Context

Research was undertaken as part of the Narrative Experiences Online (NEON) study (researchintorecovery.com/neon), a six-year programme funded through the Programme Grants for Applied Research scheme of the National Institute of Health Research in England from 2017 to 2023. Ethical Committee approval was obtained in advance (Nottingham 2 REC 17/EM/0401) and all participants provided written informed consent. Interviews were conducted primarily to inform the development of conceptual frameworks describing recovery narratives and their impact, with the objectives of (1) accessing the recovery stories of a diverse population, and (2) exploring positive and negative impacts of accessing other people's stories. Findings on this data have been published elsewhere (Hui et al., 2021; Llewellyn-Beardsley et al., 2020; Rennick-Egglestone, Ramsay et al., 2019; Slade et al., 2019). A secondary aim was to explore people's experiences of *how* they told their stories

in various settings, and these experiences are reported here.

Recruitment and Sampling

We used purposeful sampling in order to access information-rich cases likely to yield in-depth understanding (Patton, 2002). We recruited 84 people with lived experience of mental distress (hereafter 'lived experience') from specific marginalised groups.

Inclusion criteria common to all groups were: aged over 18; willing to discuss experiences; able to give informed consent; fluent in English. Additional inclusion criteria were as follows: Group A, people with self-identified experiences of psychosis, who are more likely to experience stigma and discrimination than those experiencing other forms of mental distress (Colizzi et al., 2020; Gronholm et al., 2017); Group B, people from Black, Asian and minority ethnic communities, who experience persistent inequalities in accessing mental healthcare (Lawrence et al., 2021); Group C, people from groups not well-engaged with by mental health services, including lesbian, gay, bisexual, trans and queer (LGBTQ+) communities (Rees et al., 2021) and people with multiple complex needs (experiences of homelessness, substance misuse issues and/or offending) (Kuluski et al., 2017); and Group D, peer support workers, trainers or researchers in statutory or voluntary roles, who report marginalisation and discrimination around their role and use of their lived experience (Firmin et al., 2019; Voronka, 2016).

Setting

Participants were recruited across England; Groups A and B primarily from London, and Groups C and D primarily from the Midlands. Group A were recruited through primary care services, online support groups, Hearing Voices networks and online advertising; Group B through community groups, a Recovery College and secondary mental health services; Group C through university networks, voluntary and community sector organisations (LGBTQ+ participants) and secondary care mental health services (participants with multiple, complex needs); Group D through community groups and secondary care mental health services. Snowball sampling was also used with all groups.

Data Collection

Interviews were conducted by five researchers² from sociology, psychology, advocacy and public health backgrounds, of whom three also brought lived experience mirroring the population sample (including mental

distress and being from Black, Asian and minority ethnic or LGBTQ+ communities). Participants took part in a 40–120 minute interview conducted either in health services or community organisations, according to their preference. The interview comprised two parts: (A) an open-ended question designed to elicit a narrative (Riessman, 2008); and (B) a semi-structured topic guide which invited participants to reflect on how other people's recovery stories had impacted them, and how their own storytelling might vary in different settings (topic guide shown as [Supplementary Material 1](#)). Interviews were recorded, transcribed and pseudonymised. Field notes were written post-interview by researchers. The current article reports only on findings from data responding to the question about how stories might vary in different settings.

Protocols were created to mitigate participant and researcher distress, in recognition of the risks of retelling potentially traumatic experiences (Jaffe et al., 2015) and researching sensitive subjects (Nguyen et al., 2021). These included assurance that participants could stop at any time; provision of signposting to support organisations; professional support available pre- and post-interview for participants with multiple, complex needs; and access to line-management and research team support for researchers. Some participants reported instances of abuse by others in the course of their stories. In these instances, researchers worked with participants to verify that appropriate support was in place. The topic guide was flexible, with team agreement to minimise questions if the participant was experiencing distress at any point.

Data Analysis

Within a critical constructivist methodology, we used a reflexive, inductive approach to thematic analysis (Braun et al., 2019). Semantic-level (descriptive) and latent (interpretive) approaches to coding and theme development were used; at first a largely semantic approach, to capture and stay close to participants' verbatim statements, with latent coding in later stages (Terry et al., 2017).

Transcripts were professionally produced and uploaded to QSR NVivo version 12. The first author familiarised herself with the data and checked transcriptions for accuracy. A preliminary list of initial codes was drawn up ([Supplementary Material 2](#)). On subsequent readings, initial themes were generated through exploring possible relationships within and between codes. This led to identification of factors which influenced stories at five levels ([Supplementary Material 3](#)). These were discussed and reviewed with co-analysts³ to enrich understanding, followed by an iterative process of re-reading transcripts and development of final themes based on a central organising concept which provided an overarching finding. We asked several questions of our data: how do

participants report varying their stories according to the setting? What reasons are people giving for varying their storytelling? What is at stake in each setting? What do participants report not speaking about?

Using a non-exhaustive checklist of quality indicators for narrative research as a guide (Andrews, 2021), we provide information about the study context, interview settings and settings described by participants to *contextualise the research*; provide extensive quotations and our findings at key stages of analysis to enhance *trustworthiness*; and describe opportunities for *critical reflexivity* throughout the study. Sensitivity to *multi-layered stories* or the interconnection of the micro and macro, *co-construction of meaning* and *attention to the untold* are central to our findings.

Reflexivity

Since “scholars are not just detached observers, but also narrators” (Hagström & Gustafsson, 2019, p. 398), and “data doesn't just happen” (Olson, 2021, p. 1569), we reflected throughout the study on our own positionality as co-constructors of participants' narratives. This included a reflexive section within field notes, which informed the ongoing interviews and analysis; discussion within analyst meetings of our professional and personal approaches, including lived and professional experience of mental health services; and discussion of how the research context shaped interviews (for example, asking specifically for ‘recovery’ stories). In addition, we present further reflections here from the lead author, as primary analyst.

I bring to the analysis an academic background in literature and sociology, and a professional background in community and youth work, including mental health service provision. Youth work is underpinned by a ‘pedagogy of the oppressed’ (Freire, 2013), an educational approach based on the lived experience of people from marginalised communities, from which critical constructivism arose. I also bring lived experience of intersecting marginalised identities, as a queer woman who has experienced and survived recurring mental and emotional distress, who is nonetheless relatively privileged educationally and as a white cis-gender woman. I have known the power of stories to exclude or shame (for example, being on the receiving end of cultural stereotypes of lesbians), to liberate (for example, encountering LGBTQ+ ‘coming out stories’ as a teenager), and to exclude others in their turn, in what Plummer (2020, p. 64) refers to as a “continuing paradox of othering” (for example, witnessing the exclusion of trans people in some women's and queer spaces). These understandings shaped my relationship

with the accounts, for example, heightening my awareness of issues of epistemic injustice (Fricker, 2007).

Findings

Participants. We recruited 84 participants, of whom 71 were asked the supplementary question about how stories might vary in different settings. Thirteen were not asked due to time constraints or because of participant distress (either the participant indicated they wanted to finish, or the interviewer made a judgement to minimise supplementary questions). Of the 71 participants, 39 were women, 29 were men and 3 chose ‘prefer not to say’. All self-identified as experiencing mental distress, with some using services and others not, either by choice or due to lack of access. Four were aged under 25; 13 were 25–34; 13 were 35–44, 26 were 45–54, five were 55–64 and two were over 65 (eight preferred not to say). 25 participants identified as being from Black, Asian or other minority ethnic communities. 15 identified as being LGBTQ+. 39 had self-identified experiences of psychosis, and 28 had paid or voluntary peer trainer or support roles.

Four participants resisted the suggestion that they might vary their stories. One said “I just get far too effusive having the opportunity to speak”. Others linked the concept of varying stories with hiding parts of themselves due to stigma or shame, which they were committed to challenging. As one said:

Otherwise it’s like there’s something wrong, and there isn’t anything wrong. It’s just that stuff has happened in my life. That is unfortunate but it’s not going to define everything about me, so I wouldn’t change [my story] for anybody now.

Settings Reported by Participants

Participants with paid or voluntary peer roles (hereafter ‘peer participants’) almost exclusively reported on how they told their stories in work settings, including giving talks at conferences and to services, training practitioners and delivering peer support. Participants who did not have such roles (hereafter ‘non-peer participants’) reported on how they told their stories within everyday interactions, including formal settings (health, housing and employment services, support groups, on application forms for jobs, benefits and funding, and when completing questionnaires), and informal conversations (with family, friends, work colleagues, church members, others with similar lived experience and online). All participants were simultaneously producing *stories about their stories* in the research interview, and some offered thoughts about how the research setting was shaping their telling.

Overarching Finding: Power Dynamics Affect How Lived Experience Stories are Told

Questions of power were central to all participants’ accounts of telling their stories. This first came to our attention when we noted that peer participants were reporting fundamentally different experiences than other participants. Peers, whether paid or unpaid, mainly described how their roles afforded them some authority to use their stories positively, to support or educate others. In contrast, non-peer participants mainly described their own relative lack of agency whilst telling their stories. They rarely reported using their stories to positive effect. This alerted us to ways that varying power dynamics in different settings were affecting participants’ storytelling. Within this overarching finding, four themes were identified which further describe how questions of power affected the way participants’ lived experience stories could be told.

Challenging the Status Quo

Peer participants reported opportunities for using their stories to challenge conventional assumptions and change attitudes. For example, this participant describes sharing her own adverse childhood experiences with work colleagues, to challenge stigma and potentially judgemental attitudes:

[The reason] I like to share is that I’ve somehow come to a point where people always think I’m posh, and there’s so much power to sharing the parts of you that people don’t expect. Because actually when I share my story, it changes the way that people perceive people that have those experiences [...]. It’s easy for people to think [of those who] have grown up around heroin addiction and squats as lesser [...] But when you’re making those judgements, you’re making those judgements about me. When you are judging someone that’s begging, I’ve been a child doing that. That’s circumstance. And I think I have so much opportunity, in sharing my story, to make people really aware of circumstance, privilege, the fragility of the social status.

Delivering talks and training to the general public and other professionals offered opportunities to undermine/resist the dominance of biomedical narratives through presenting different accounts:

In sharing [my story] with a more broad audience, I have this conscious urge to still try and dispel any notions of disease or illness, because as a society I think we are becoming increasingly inculturated to all this stuff, so I will try and focus on experiences. In environments where I am teaching health and social care professionals, the purpose is slightly different.

I am trying to help them be better practitioners. Part of that is about pointing out the vagaries of diagnostic terminology. So I will talk about the ontology, the epistemology, the history of the science. I will refer to philosophical underpinnings. And it might just go over the heads of some of them, but I know that sometimes I'm hitting home.

In supporting others with lived experience, peers described using their stories in ways that might inspire hope, normalise potentially shameful experiences and offer learning. They reported having opportunities to disrupt traditional power relationships within health services, through reciprocal exchange of personal experience. This could have powerful effects, as can be seen in this account from a recovery college trainer:

It's really lovely sometimes when people come to recovery college, and it feels like they have been through so many different parts of the service and they just don't know where they are and – 'ok then, teach me something', arms folded, sitting back, here we go again. And oftentimes, even though we tell people that we're peers, the penny doesn't start dropping until they've been there a while and it comes out that we've got these stories. And it's almost like sometimes you can see people, their arms drop from in front of them and they start leaning forward, and they start looking at you differently and a barrier's gone. Not always but it's happened enough for me to realise how powerful it can be, to have somebody in front of you who knows the territory, still lingers in the territory, but works on it.

Here, the fact that people in positions of authority also have 'these stories' is reported as a welcome surprise for course attenders ('they start leaning forward'), who may have been in the system for a long time, and become disillusioned about what was on offer ('arms folded, sitting back, here we go again').

Risky Consequences

Peer and non-peer participants alike overwhelmingly reported or alluded to a strong sense of risk when telling their stories. Getting their story 'right' really mattered, because the consequences of getting it wrong were perceived to be, or had been, potentially serious for themselves or others.

Non-peer participants described how telling their stories in certain ways could exacerbate their own shame or distress, cause others distress, lead to being stigmatised by others or result in unwanted clinical treatment or the potential loss of assets such as benefits, jobs or funding. Thus, fine judgements were made about what to share, when and with whom:

I suppose, when I'm talking to a clinician I would be very wary, I think, because if I say half the stuff that has happened in my head, they might go, 'right, lock you up'!

There was a reported sense of watchfulness and need for protection – sometimes protection of others, but mainly of themselves – due to the perceived damage that sharing some aspects of their stories might inflict. This sense of caution was echoed in the use of phrases such as 'sussing out' recipients prior to telling parts of their stories. Others described an in-the-moment process of gauging how to proceed, depending on cues perceived in their recipients:

I do vary about it because you know, with communicating, with watching people's expressions and things like that [...] if I felt like somebody was going to be overly judgemental there might be things that I choose not to share. Or equally if I saw somebody was understanding and receptive and interested in what I was saying I might choose to share a little bit more.

Additional intersecting experiences of stigma and discrimination such as racism or homophobia could compound a sense of stories being risky to share. Participants from LGBTQ+ and Black, Asian and minority ethnic communities reported missing out elements of their experience entirely or not accessing services, to avoid having one more stigmatising label, as exemplified by this participant:

I haven't talked about [mental health] in job applications, I have definitely not accessed NHS [National Health] services because I felt – I guess when you have so many things stacked against you, so my life experiences, being a Black woman, do I want to stack against me the potential that I might reveal myself to a service that I then later want to work for or have colleagues from? [...] Maybe if I was a white middle class woman that didn't have any of those experiences, I might feel – or a white middle class man, if you really get down to it – I might feel like, oh you know what, I believe in non-discriminative legislation so I can do that. But I think that when you have got other things stacked against you, you don't want to then add another thing to the mix. So I haven't been to NHS services, at least in part for that reason.

Some participants expressed a desire to talk more freely, often described as being more open – 'you do feel like you want to tell, because this is a big part of me' – but felt this was better avoided: 'you want to say but you, you hold back'. This participant had a stark example of the potential risks of talking openly:

I didn't know who I could talk to, and who I was safe talking to [...] because, with my therapist, she was lovely and I trusted her, but then suddenly she bought on the psycho-blah person, and I just seized up and I was like, why are you here? And that's when they led to trying to lock me up, and I was just scared [...] I was being really open with my therapist because we'd got to a really nice, kind of trusting place [...] Also, because I wasn't saying a word, for ages, I felt like it really would help me to talk, so when I finally got comfortable enough to talk, then all *that* happening [being sectioned], it was like, oh shit, maybe I shouldn't talk.

A strong sense of betrayal was present in this account. The participant was aware of the risks ('I didn't know ... who I was safe talking to') and had shared her story only after building up trust over time with a specific professional. Yet choosing to tell her story in a particular way led to a direct loss of freedom and the onset of unwanted treatment. Perhaps unsurprisingly, she concludes that her previous strategy of *not* telling her story might have been less harmful to her.

One participant reported feeling naïve about her previous openness:

I am always encouraged by not-so naive people that I should not say anything [...] My partner is a very strong believer that if they don't need to know, don't tell them, and my mum would probably say the same [...] A colleague once said to me, never give away too much [...] I think she's got a point. You know, it is very personal, and yeah, it's sort of the weaker part of you as well isn't it?

Here, she is both judging herself for her previous approach and inviting the interviewer's endorsement of a view that her experiences of distress are a weaker part of herself ('isn't it?').

As well as risk of judgement for describing distress, participants also described fear of judgement for describing their recovery:

It's weird [...] you can't be too brazen about your [recovery], you can get unfortunately probably perceived as being a bit boastful; you know, 'I have had a psychosis but I have recovered'.

Peer participants also described a careful, considered process of 'tailoring' their stories; of gauging what might be relevant or useful to share whilst not being overwhelming. The risk in these cases was to those they were supporting:

You've got to tell them in a way that it doesn't paint a dark picture, that they [think] 'Oh my God, is this what happened

to him, I'll never...', you know. You've got to make sure that you tell a story as it is, to a degree, but also give them hope.

The fear expressed here is that telling their story 'as it is', presumably including difficult times as experienced by the peer, risks producing 'a dark picture'; the opposite of the desired effect incumbent on a peer worker, of embodying hope. A related, recurring concern was the potential to trigger traumatic memories for recipients – for example, where stories contained similar details. One peer reported the careful balancing this could sometimes require:

It's a real juggling act as a peer to judge when the moment is right. And you can get it wrong. And when I get it wrong, I just go now, 'I've got it wrong. I'm so sorry. I've really messed that up'.

This peer had previously described herself 'shaking' as she began to tell the person she was supporting about an attempt to end her own life, in response to a direct question about whether she had ever been suicidal. She foregrounds twin yet potentially conflicting values of honesty with people she is supporting, and avoiding risk of harm, which she returns to repeatedly in the interview. This account, with its repeated stress on her awareness of risk, can be seen as addressing a fear based on the current unequal status of peer work within mental health practice; that peers may be perceived as somehow less professional than others through their disclosure, or even simply possession, of their own stories of distress. A peer who delivered training of other peers perhaps also speaks to this fear when she reports advising them to avoid sharing any potentially traumatic content:

Generally speaking in my job I would keep away from 'hot button' issues, no matter what. We tell our students if you think about the emotional response to something you're talking about on a scale of 1 to 10, then we like to keep things in a 1 to 4 if we are sharing relevant experience, and keep away from big topics that we know are general triggers for lots of people. So, without saying it, we are talking about abuse stories, those sorts of things.

This account describes a paradoxical situation of being expected to provide support on the basis of shared experience, whilst being instructed not to include subjects which may have played a key role in experiences of mental distress.

Producing 'Acceptable' Stories

Participants also reported a perceived or actual pressure to reproduce normative and acceptable stories in some

settings, rather than authentic and possibly dissonant ones. This was experienced by some during the data collection process. One peer participant, for example, expressed a struggle between what he perceived was being asked of him in the interview and other ways he could tell his story:

I could be ranting and raving...I could have a diatribe against psychiatry or mental health services, from my own experiences or generalising about things more broadly. I'm trying to focus on my own story for these purposes [the interview] but it's very hard for me to detach that from my political affiliations, from my beliefs, from what I think are my understandings of the world and the way things work.

He perceived a need to 'detach' his own story for the purposes of this research interview from his 'understandings of the world' as a whole. The impact was perhaps to give a less emotional, more individualist account than he would have liked, whereas a more holistic account of his recovery might involve anger ('I could be ranting'), involvement in politics and resisting dominant biomedical narratives ('I could have a diatribe against psychiatry').

Participants in settings which encouraged alternatives to dominant narratives could also experience subtle pressure to conform to acceptable narratives. For example, in a support group emphasising spiritual over biomedical interpretations of psychosis, one participant felt reluctant to share how difficult things were for her, because of others' focus on good news stories:

I go to a peer support group now, a spiritual mental health thing. I really struggle [to share difficult experiences] because I feel like I'm bringing the group down.

Psychosis experiences were frequently reported as being less acceptable than other forms of mental distress and were often minimised. For example, this participant described feeling that a certain amount of 'losing it' was acceptable in her field (the creative industries) but only within certain limits:

You're allowed to say, 'I've been having a difficult time'. But, telling somebody that you've been sectioned? It does not go down well. It really doesn't. It's really hard, people just think, 'who are you?' And I've been in that situation where [I mentioned something about my story] and there's just this ... instant judgement. And I don't mean it in a terrible way. It's just that you can see people go, 'Ooh. God. You've lost control of *life*'. You know, 'you couldn't keep it together'. It's almost like, you're allowed to have difficulties but you're supposed to do it in a really, I don't know, glamorous, interesting way. But to actually fall to pieces in a huge heap?

No. That's ugly. So no [...] it's not something I advertise ... at all.

Not 'advertising' her experience of being sectioned was perhaps exacerbated for this participant by being a freelance worker whose employment depended on her reputation. She expresses fear of the consequences of straying away from a permissible narrative in her professional world, where 'difficult times' can retain a sheen of glamour, towards an unacceptable narrative in which her life is viewed as out of control ('you couldn't keep it together'), and 'ugly'.

Intersecting experiences of stigmatisation and inequality again compounded the pressure for some participants. For example, a Black peer participant reflected to his white interviewer on how he had told his story thus far in the interview, comparing this to other occasions where his telling might vary:

Interviewer: Have you ever felt that are parts of your story that you're not allowed, unable or unwilling to tell in a certain context?

Participant: Yeah. So [...] if I was really going to be brutally, what I call, where I am right now, authentic, I'd mention more about global genocide on Black people. Yeah? All over Africa, the effect it has here, and the effect that still has ongoing as a society, has an impact – impoverishment, marginalisation, I'd expand on that more. And [...] there'd be more emotion loaded with that. So I'd have to watch my own level of resentment, while I'm doing that, do you see what I mean?

Interviewer: So that would depend on the audience, who you're talking to?

Participant: Exactly, so when I do a BME [Black and Minority Ethnic] group – I don't even like that term but that's what we are at the moment – I do talk about the global genocide on Black people, you know. And it's my belief, which might change going forward, but currently it seems to be that we're, we're being killed all over the world in one way, shape or form. And how that will affect your mental health. I mean, what? Really? [Laughs]. Do you know what I mean, it's a no-brainer.

His emotion at the often-unacknowledged links between living within racist structures and mental distress would not be acceptable to some audiences. Furthermore, it must be self-managed ('I'd have to watch my own level of resentment'). He raises the subject in the interview in response to a direct question, but still suggests he hasn't said as much as he would/could elsewhere, perhaps because the interviewer was white ('If I was going to be brutally... authentic, I'd mention more...'). And in another, structurally (even) more unequal position than that

of research participant, he reports that telling his story from this perspective could result in serious loss of resources:

Participant: For instance when I was going for some funding from [accounting company], that [the effects of racism on mental health] didn't get mentioned [laughs].

Interviewer: So there's something about structures here, that perhaps you'd avoid talking about?

Participant: Yeah [...] it wouldn't be worth me ... to be honest, it would be wasted energy, there'd be nothing positive that comes out of it.

The risk of losing funding, the emotional labour of having to explain links between racism and mental distress, and the risk of his experience being denied led to this participant being highly selective about when he would tell a more authentic version of his story. The interviewer asks how he decides in which contexts it is worth expending that energy. He responds:

I'm getting better at it, I'm not brilliant at it. Sometimes [...] when someone gets killed on a ward or something, then it's hard to contain the kind of, argh, you know. I'm getting better at just ... you know.

He reports his anger and grief as responses that must be 'contained'. Perhaps for his own mental wellbeing, or as a strategic decision to avoid damaging his own interests, he perceives that he must 'get better' at how he manages this. Thus, people from marginalised communities can be in the dual role of absorbing the ongoing trauma of (in this case) racism, while also ensuring that their storied responses to this experience do not unduly trouble those around them.

Untellable Stories

Finally, some participants reported being unable to speak about certain traumatic parts of their stories, either at all, or at different points in their lives. Stories were described as containing 'things that really scar us deeply and are really painful', which were subsequently not mentioned or brushed over. These included accounts of psychosis-like experiences, sexual abuse, suicide and rape:

Certainly being raped, I would [omit this]. That was one thing that, until recently I hadn't tackled that[...]. I'm going to a men's group. And it allows me to talk about it fairly openly now, whereas I definitely wouldn't have done in the past [I: Because you felt that you just wouldn't have been listened to or ...?]. I think I just felt deep shame about it really. Yeah.

This participant's experience demonstrates how narratives can be a double-edged sword; either oppressive or liberating, depending on the balance of power in a given setting. Dominant social narratives about rape being a shameful experience, possibly exacerbated by being seen as something that happens to a woman, contributed to the silencing of this aspect of his story for many years. Conversely, it is hearing counter-narratives of similar experiences in the safe context of a group for male survivors which eventually 'allows' him to resist this internalised stigma and share his own story.

Sometimes, untellable aspects of stories were demonstrated in the interview by participants, rather than being directly reported. It was striking how often sentences faded away when participants were broaching traumatic subjects such as childhood experiences of abuse:

I've left some bits out, and I would never talk in real detail about ... stuff that's been [indicates speech marks] 'done to me' by men, cos I just ... you know, nobody needs ... you just need to say, or something ...

One participant's speech appeared to dissolve almost entirely when returning to his experience of multiple incidences of organised sexual abuse as a child:

Interviewer: Have you ever felt like there are parts of your story that you are not allowed, or unwilling, or unable to tell in a certain context?

Participant: Yeah. Those are deep dark, dark, dark, dark, don't, don't ... that you don't do. Some things like pornography, okay, what happened with the pornography.

Another interpretation could be that the participant's speech, rather than dissolving, very precisely captures the splintering effects that such prolonged exposure to trauma can have. His account may also reflect that not all experiences can be sufficiently represented or reproduced in verbal form, perhaps traumatic experiences in particular.

This theme highlights an important form of risk inherent in telling lived experience stories, exacerbated by power differences in particular settings; that they can be re-traumatising for the narrator. They raise serious issues of whether, in what circumstances and for whose benefit people with lived experience should be asked to recount their stories.

Discussion

Our aim was to explore how stories of lived experience are told in various settings, from the perspectives of people from marginalised groups who experience multiple,

intersecting inequalities. Our overarching finding was that differences in power dynamics affected how participants told their stories. Four themes describe this finding in more depth: personal stories could be told by peer participants in ways which might challenge and empower; while for peers and non-peers alike, their stories must be told carefully to avoid risk and remain acceptable within the constraints of particular settings, or not be told at all.

The concept of narrative power (Plummer, 2019) usefully summarises this complex interaction of the micro-level, individual stories of people with marginalised identities with the macro-level cultural narratives which exist about them, and ‘people like them’. As our first theme *Challenging the status quo* demonstrates, narrators have some power or agency to challenge dominant narratives, producing beneficial effects for themselves and others through their stories. These findings support previous studies on ways in which peers can disrupt traditional clinician/patient power structures within health, where clinicians were always the experts and patients’ opinions were less valid. Mancini (2019) describes how the ‘strategic storytelling’ of peers can help others create meaning, develop empowered and healthy identities, and learn what a ‘recovery-oriented lifestyle’ might look like. Sapouna (2021) explores the uses of lived experience narratives in social work education, finding that the inclusion of user narratives can sometimes provide transformative opportunities to model collaborative and dialogue-based learning with students. Plummer describes this perspective as engaging in “a language of liberation, and the capacity [of stories] to do things” (2019, p. 31).

However, these studies also draw attention to the structural inequalities which limit peers’ capacity. Mancini (2019) notes that peer contributions continue to be minimised and misunderstood in mental health settings dominated by non-peer professionals. Sapouna (2021) highlights the continued power of recovery-oriented mental health and education systems to implicitly discourage expressions of distress that do not suit their aims. Plummer (2019) describes how dominant narratives can be a productive resource, but tend to favour the status quo, and are asymmetrical, favouring some forms of narrative and content more than others. They make some lives “abundant in capacity”, whereas others are “diminished, inferiorised, marginalised” (Plummer, 2019, p. 31).

Furthermore, as critics of anti-stigma campaigns have pointed out, those who do choose to disclose lived experience stories differ greatly in their individual capacities to withstand, resist or avoid the potential consequences of dominant narratives, depending on their social status: “there are substantive differences between a Prince or a pop star disclosing their struggles with mental health to the public, a precarious worker disclosing to an employer,

or a mother disclosing to a social worker” (Tyler & Slater, 2018, p.723). Our subsequent three themes reflect these limitations on the power of storytelling, and problematize the use of lived experience narratives within services for three reasons.

First, the theme *Risky consequences* draw attention to the fact that people with lived experience are still largely telling their stories in contexts where narratives of stigma, deficit and inferiority prevail. The biomedical model of mental health – the dominant narrative within policy and practice in the global North – defines mental distress in terms of individual dysfunction, deficit and/or disease – a ‘what’s wrong with you?’, diagnostic approach. This creates and reinforces narratives of inferiority. For example, a recent study on the recovery and identity narratives of people experiencing psychosis across ethnic groups highlights how diagnostic classifications may enhance the perceived ‘differentness’ of people with lived experience from the rest of the population, leading both to public and internalised stigma, particularly for those from already-marginalised populations (Lawrence et al., 2021). Plummer describes this process as “narrative othering”, a process which creates ‘out groups’ and ‘outsiders’ who can become ‘the other’ and even ‘the enemy’ (2019, p. 72). These macro-level cultural narratives wield more power than the individual stories of people with marginalised identities may be able to counter. Moreover, valorising the use of individual stories constructed for specific pedagogical or therapeutic purposes within services can mask or divert attention and resources from the realities of telling lived experience stories and their consequences in everyday life which, as our findings show, continue to be fraught.

Second, the theme *Producing acceptable stories* gives examples of both peer and non-peer participants feeling pressure to suppress or minimise aspects of their stories. These aspects included their anger, experiences of abuse, political involvement, ongoing distress, less palatable types of distress and their perspectives on the contribution of systemic oppression such as racism to mental distress. These findings support concerns raised by existing studies that being asked for or required to produce narratives in mainstream contexts may constrain and restrict which experiences can be shared (Costa et al., 2012; Fisher & Lees, 2016; Heinemeyer, 2019; Russo, 2016; Sapouna, 2021; Voronka & Grant, 2021; Woods et al., 2019; Yeo et al., 2022).

By contrast, a recent study outlined processes by which experiencing stigma can lead to the formation of collective identities within ‘health social movements’ (Smith, 2020). It describes how social support networks outside of mainstream services facilitate interactions with others who share a stigmatised status. These interactions “transform personal problems into problems of the collective. In developing a positive collective identity,

stigmatised individuals reject oppressive cultural and structural systems, and mobilise and engage in collective action to disrupt these systems” (2020, p. 8). Thus, collective narratives resist ‘narrative othering’ through normalising stigmatised experiences and, if the historical moment allows them to reach critical mass, ultimately functioning as tools for political change (Plummer, 2020). This process describes how recovery stories were originally used within activist and survivor-researcher contexts (Rose, 2014). But, as Voronka and Grant suggest, the “meaning and value of such knowledge is inevitably recalibrated once reworked and incorporated within dominant mental health paradigms” (2021, p. 2).

A fundamental critique of the recovery paradigm is that, as it has been formulated within mental health service policy (Harper & Speed, 2012), it returns the responsibility for becoming well to the individual, while denying, or taking as unalterable, the contextual root causes of mental distress (Heinemeyer, 2019). Thus, the emancipatory origins of recovery, and its narratives, are at risk of being neutralised when transposed into the context of services operating from a paradigm which continues to be more likely to focus on, and encourage stories of, individual-level solutions to mental distress. To use Riessman’s (2008) model of narrative analysis, the recovery paradigm, and its accompanying narratives, return the focus to micro causes of mental distress, at the expense of understanding and addressing the macro causes.

Finally, the theme *Untellable stories* supports the findings of other studies on the links between experiences of trauma and mental distress (see Sweeney et al., 2016 for a summary). It highlights the potential costs to the teller of relating their experiences, and raises ethical questions about the circumstances in which people with lived experience should be invited to tell their stories. A move towards more trauma-informed approaches to mental distress may mitigate these concerns and provide a more inclusive context for all aspects of lived experience storytelling. Trauma-informed approaches are primarily focused on contextual understandings of human distress rather than individual pathology (Johnstone et al., 2018). Social factors such as poverty and racism can be considered forms of trauma; and traumatic experiences are more common for people from minority ethnicities and other marginalised groups (Sweeney & Taggart, 2018). Topor and colleagues (2021) argue that emphasising themes of recovery within narratives risks forming a blind spot in terms of the social and structural causes of mental distress. They state the necessity of paying attention to people’s experience-based knowledge not only about recovery processes but also about the relationship between the structural and social (as well as individual) explanations for mental distress. Yet social and structural contributors to mental distress, such as abuse, violence,

poverty and experiences of institutionalised racism, sexism and homophobia, are often infused with stigma, shame and unacceptability, or met by the recipient with denial. As our findings show, they are currently likely to be de-emphasised, minimised or silenced within people’s stories. This is likely to continue in settings which treat mental distress as illness or dysfunction, instead of an embodied response to trauma and social injustice.

In this light, we might paraphrase Harper and Speed (2012) and ask, is the use of recovery stories recoverable within services? Our findings do not deny the many positive as well as negative impacts that lived experience stories can have on individual recipients (Nurser et al., 2018; Rennick-Egglestone et al., 2019; Rennick-Egglestone, Morgan et al., 2019), or the undoubted benefits of peer support (Gillard, 2019). However, they do support ongoing work which calls for practitioners and researchers to be alert to the ways in which lived experience narratives may be misused by services (Yeo et al., 2022), and to be highly reflexive about how and why we are using them. Sapouna (2021) frames this in terms of a dual process of honouring what had been achieved by personal narratives, whilst problematizing what may be lost. We echo the call of Voronka and Grant (2021) for frank conversations and environments that acknowledge the power dynamics associated with storytelling, particularly for those experiencing additional intersecting forms of stigma and marginalisation. Being asked to tell one’s recovery story, in particular by those in positions of greater power or aligned with a dominant narrative perspective, is never a neutral act.

Distinctive Features of the Study and Future Research

Distinctive features of the study include being led by researchers with lived experience of mental distress and other marginalised identities; a large dataset; and a diverse cross-section of people from marginalised communities, whose perspectives are still under-represented within research. Our data collection may have been constrained by occurring in the context of a health sciences study which was actively asking participants to recount their recovery stories. Although interviewers were at pains to present recovery as self-defined, this will inevitably have shaped participants’ responses and prevented more inclusive framings of lived experience. Another constraint was analysing only the data collected in response to one question. Although practically helpful in a dataset of 71 participants, the irony was not lost on us that, in being selective, we were taking responses to questions about contextual storytelling *out* of their contexts. Future research is planned to apply performative analysis (Frank, 2012; Riessman, 2008) to some of these narratives as case studies, to further enrich our understanding of the

performative aspects of lived experience narratives, and continue to take a critical approach to their use within services. Such ‘small story’ approaches to analysis (Bamberg & Georgakopoulou, 2008) may allow further insight into the troubled subject positions that speakers negotiate as they tell their stories. This may be a particularly relevant approach when considering the narratives of people from marginalised communities (Russo, 2016). Finally, our findings draw attention to power differentials within the mental health recovery paradigm. They may provide a platform for further, in-depth research on this issue of pressing importance, at a time of heightened worldwide attention to the links between mental distress and social justice.

Conclusion

In this article, we have made a contribution to a growing body of work on the ‘politics and possibilities’ (Woods et al., 2019) of recovery narratives, by taking a critical constructivist approach, which allows for attention to be paid to issues of asymmetrical narrative power. It draws attention to the macro as well as micro contexts within which mental health recovery narratives are co-constructed, and the ways in which stories are shaped and constrained by dominant cultural narratives, making any stories which deviate from these norms difficult or impossible to tell. It highlights the variable, evolving, selective and partial nature of the stories told in different contexts and circumstances, and a high level of vigilance from narrators around sharing their lived experiences. This may lead to a more sensitised approach to the complexities of eliciting and using lived experience stories within services, and a greater acknowledgement of the power imbalances which continue to problematize their use.

Acknowledgements

We would like to thank study participants and the individuals and organisations who contributed to this article by assisting with recruitment. We also thank the other interviewers, Kate Morgan, Amy Ramsay and Zivile Jakaite.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This article contains independent research funded by the NIHR under its Programme Grants for Applied Research Programme (Programme Grants for Applied Research, Personal experience

as a recovery resource in psychosis: Narrative Experiences Online (NEON) Programme, RP-PG-0615-20016). Mike Slade acknowledges the support of the Center for Mental Health and Substance Abuse, University of South-Eastern Norway and the NIHR Nottingham Biomedical Research Centre. The work of the research group is supported by the Economic and Social Research Council (grant numbers ES/J500100/1 and ES/P000711/1). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

ORCID iDs

Joy Llewellyn-Beardsley  <https://orcid.org/0000-0003-0525-6358>

Kristian Pollock  <https://orcid.org/0000-0002-6836-8595>

Supplemental Material

Supplemental material for this article is available online.

Notes

1. We use ‘our/their’ in this article as some of the authorship team are researchers with lived experience of mental distress. It is a strategy to ‘dismantle the binary between service users and practitioners’ (Fisher & Lees, 2016), and counter the practice of ‘narrative othering’ (Plummer, 2019) whereby people with lived experience are often rendered within academic and clinical texts as ‘other’ than researchers or practitioners.
2. Including co-authors JLB and RM
3. AE, SRE, EW, YA, DF and KP

References

- Adame, A. L., & Hornstein, G. A. (2006). Representing madness: How are subjective experiences of emotional distress presented in first-person accounts? *The Humanistic Psychologist, 34*(2), 135–158. https://doi.org/10.1207/s15473333thp3402_3
- Andrews, M. (2021). Quality indicators in narrative research. *Qualitative Research in Psychology, 18*(3), 353–368. <https://doi.org/10.1080/14780887.2020.1769241>
- Azhar, S., & Gunn, A. J. (2021). Navigating intersectional stigma: Strategies for coping among cisgender women of color. *Qualitative Health Research, 31*(12), 2194–2210. <https://doi.org/10.1177/10497323211025249>
- Bamberg, M., & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk, 28*(3), 377–396. <https://doi.org/10.1515/text.2008.018>
- Beresford, P. (2019). Including our self in struggle. *Canadian Journal of Disability Studies, 8*(4), 31–59. <https://doi.org/10.15353/cjds.v8i4.523>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. In P. Liamputtong (Ed.), *Handbook of research*

- methods in health and social sciences* (pp. 843–860). Springer.
- Coghlan, D., & Brydon-Miller, M. (2014). *The SAGE encyclopedia of action research*. Sage Publications.
- Colizzi, M., Ruggeri, M., & Lasalvia, A. (2020). Should we be concerned about stigma and discrimination in people at risk for psychosis? A systematic review. *Psychological Medicine*, 50(5), 705–726. <https://doi.org/10.1017/S0033291720000148>
- Costa, L., Voronka, J., Landry, D., Reid, J., Mcfarlane, B., Reville, D., & Church, K. (2012). “Recovering our stories”: A small act of resistance. *Studies in Social Justice*, 6(1), 85–101. <https://doi.org/10.26522/ssj.v6i1.1070>
- Davis, J. E. (2012). *Stories of change: Narrative and social movements*. SUNY Press.
- Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19(3), 91–97. <https://doi.org/10.1037/h0101301>
- Devendorf, A., Bender, A., & Rottenberg, J. (2020). Depression presentations, stigma, and mental health literacy: A critical review and YouTube content analysis. *Clinical Psychology Review*, 78, 101843. <https://doi.org/10.1016/j.cpr.2020.101843>
- Firmin, R. L., Mao, S., Bellamy, C. D., & Davidson, L. (2019). Peer support specialists’ experiences of microaggressions. *Psychological Services*, 16(3), 456–462. <https://doi.org/10.1037/ser0000297>
- Fisher, P., & Lees, J. (2016). Narrative approaches in mental health: Preserving the emancipatory tradition. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 20(6), 599–615. <https://doi.org/10.1177/1363459315600774>
- Frank, A. W. (2012). Practicing dialogical narrative analysis. In J. Holstein, & J. Guber (Eds.), *Varieties of narrative analysis* (pp. 33–52). Sage Publications.
- Freire, P. (2013). *Pedagogy of the oppressed*. Routledge.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- Ganz, M. L. (2001, August 18–21). *The power of story in social movements*. [Conference presentation]. American sociological association 2001 annual meeting, Anaheim, California, United States.
- Gillard, S. (2019). Peer support in mental health services: Where is the research taking us, and do we want to go there? *Journal of Mental Health*, 28(4), 341–344. <https://doi.org/10.1080/09638237.2019.1608935>
- Given, L. M. (2008). *The SAGE encyclopedia of qualitative research methods*. Sage Publications.
- Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- González-Sanguino, C., Potts, L. C., Milenova, M., & Henderson, C. (2019). Time to Change’s social marketing campaign for a new target population: Results from 2017 to 2019. *BMC Psychiatry*, 19(1), 417. <https://doi.org/10.1186/s12888-019-2415-x>
- Gronholm, P. C., Thornicroft, G., Laurens, K. R., & Evans-Lacko, S. (2017). Mental health-related stigma and pathways to care for people at risk of psychotic disorders or experiencing first-episode psychosis: A systematic review. *Psychological Medicine*, 47(11), 1867–1879. <https://doi.org/10.1017/S0033291717000344>
- Hagström, L., & Gustafsson, K. (2019). Narrative power: How storytelling shapes East Asian international politics. *Cambridge Review of International Affairs*, 32(4), 387–406. <https://doi.org/10.1080/09557571.2019.1623498>
- Harper, D., & Speed, E. (2012). Uncovering recovery: The resistible rise of recovery and resilience. *Studies in Social Justice*, 6(1), 9–25. <https://doi.org/10.26522/ssj.v6i1.1066>
- Heinemeyer, C. (2019). “Roving” and recovery in storytelling for mental health: Reclaiming the city, resingularizing ourselves. *Storytelling, Self, Society*, 15(1), 13–30. <https://doi.org/10.13110/storselfsoci.15.1.0013>
- Hui, A., Rennick-Egglestone, S., Franklin, D., Walcott, R., Llewellyn-Beardsley, J., Roe, J., Yeo, C., Deakin, E., Brydges, S., Penas Moran, P., McGranahan, R., Pollock, K., Thornicroft, G., & Slade, M. (2021). Institutional injustice: Implications for system transformation emerging from the mental health recovery narratives of people experiencing marginalisation. *PLoS One*, 16(4), Article e0250367. <https://doi.org/10.1371/journal.pone.0250367>
- Jackson-Best, F., & Edwards, N. (2018). Stigma and intersectionality: A systematic review of systematic reviews across HIV/AIDS, mental illness, and physical disability. *BMC Public Health*, 18(1), 1–19. <https://doi.org/10.1186/s12889-018-5861-3>
- Jacobson, N. (2001). Experiencing recovery: A dimensional analysis of recovery narratives. *Psychiatric Rehabilitation Journal*, 24(3), 248–256. <https://doi.org/10.1037/h0095087>
- Jaffe, A. E., DiLillo, D., Hoffman, L., Haikalis, M., & Dykstra, R. E. (2015). Does it hurt to ask? A meta-analysis of participant reactions to trauma research. *Clinical Psychology Review*, 40, 40–56. <https://doi.org/10.1016/j.cpr.2015.05.004>
- Johnstone, L., Boyle, M., with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E., Pilgrim, D., & Read, J. (2018). The power threat meaning framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behavior, as an alternative to functional psychiatric diagnosis. *British Psychological Society*. www.bps.org.uk/PTM-Main
- Kaiser, B., Varma, S., Carpenter-Song, E., Sareff, R., Rai, S., & Kohrt, B. A. (2020). Eliciting recovery narratives in global mental health: Benefits and potential harms in service user participation. *Psychiatric Rehabilitation Journal*, 43(2), 111–120. <https://doi.org/10.1037/prj000038>
- Kerr, D., Deane, F., & Crowe, T. (2020). A complexity perspective on narrative identity reconstruction in mental health recovery. *Qualitative Health Research*, 30(4), 634–649. <https://doi.org/10.1177/1049732319886285>

- Kuluski, K., Ho, J. W., Hans, P. K., & Nelson, M. L. (2017). Community care for people with complex care needs: Bridging the gap between health and social care. *International Journal of Integrated Care*, 17(4), 2. <https://doi.org/10.5334/ijic.2944>
- Kwan, C. K. (2020). A qualitative inquiry into the human library approach: Facilitating social inclusion and promoting recovery. *International Journal of Environmental Research and Public Health*, 17(9), 3029. <https://doi.org/10.3390/ijerph17093029>
- Lawrence, V., McCombie, C., Nikolakopoulos, G., & Morgan, C. (2021). Navigating the mental health system: Narratives of identity and recovery among people with psychosis across ethnic groups. *Social Science & Medicine*, 279, 113981. <https://doi.org/10.1016/j.socscimed.2021.113981>
- Llewellyn-Beardsley, J., Rennick-Egglestone, S., Bradstreet, S., Davidson, L., Franklin, D., Hui, A., McGranahan, R., Morgan, K., Pollock, K., Ramsay, A., Smith, R., Thornicroft, G., & Slade, M. (2020). Not the story you want? Assessing the fit of a conceptual framework characterising mental health recovery narratives. *Social Psychiatry and Psychiatric Epidemiology*, 55(3), 295–308. <https://doi.org/10.1007/s00127-019-01791-x>
- Llewellyn-Beardsley, J., Rennick-Egglestone, S., Callard, F., Crawford, P., Farkas, M., Hui, A., Manley, D., McGranahan, R., Pollock, K., Ramsay, A., Sælør, K. T., Wright, N., & Slade, M. (2019). Characteristics of mental health recovery narratives: Systematic review and narrative synthesis. *PLoS One*, 14(3), Article e0214678. <https://doi.org/10.1371/journal.pone.0214678>
- Mancini, M. A. (2019). Strategic storytelling: An exploration of the professional practices of mental health peer providers. *Qualitative Health Research*, 29(9), 1266–1276. <https://doi.org/10.1177/1049732318821689>
- McCabe, R., Whittington, R., Cramond, L., & Perkins, E. (2018). Contested understandings of recovery in mental health. *Journal of Mental Health*, 27(5), 475–481. <https://doi.org/10.1080/09638237.2018.1466037>
- McGranahan, R., Rennick-Egglestone, S., Ramsay, A., Llewellyn-Beardsley, J., Bradstreet, S., Callard, F., Priebe, S., & Slade, M. (2019). Curation of mental health recovery narrative collections: Systematic review and qualitative synthesis. *JMIR Mental Health*, 6(10), Article e14233. <https://doi.org/10.2196/14233>
- Moran, G. S., Russinova, Z., Gidugu, V., Yim, J. Y., & Sprague, C. (2012). Benefits and mechanisms of recovery among peer providers with psychiatric illnesses. *Qualitative Health Research*, 22(3), 304–319. <https://doi.org/10.1177/1049732311420578>
- Nettleton, S. (2020). *The sociology of health and illness*. John Wiley & Sons.
- Nguyen, M., Goldsamt, L., Mazibuko, N., Zondo, S., & Fielding-Miller, R. (2021). Emotional distress among frontline research staff. *Social Science & Medicine*, 281, 114101. <https://doi.org/10.1016/j.socscimed.2021.114101>
- Nurser, K. P., Rushworth, I., Shakespeare, T., & Williams, D. (2018). Personal storytelling in mental health recovery. *Mental Health Review Journal*, 23(1), 25–36. <https://doi.org/10.1108/mhrj-08-2017-0034>
- Olson, K. (2021). What are data? *Qualitative Health Research*, 31(9), 1567–1569. <https://doi.org/10.1177/10497323211015960>
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1(3), 261–283. <https://doi.org/10.1177/1473325002001003636>
- Piat, M., Spagnolo, J., Thibodeau-Gervais, S., Deschamps, C., & Gosselin, Y. (2019). Mental health recovery narratives: Their impact on service users and other stakeholder groups. *Mental Health and Social Inclusion*, 23(4), 173–184. <https://doi.org/10.1108/MHSI-08-2019-0021>
- Pilgrim, D., & McCranie, A. (2013). *Recovery and mental health: A critical sociological account*. Macmillan International Higher Education.
- Plummer, K. (2019). *Narrative power: The struggle for human value*. John Wiley & Sons.
- Plummer, K. (2020). “Whose side are we on?” revisited: Narrative power, narrative inequality, and a politics of narrative humanity. *Symbolic Interaction*, 43(1), 46–71. <https://doi.org/10.1002/symb.449>
- Rees, S. N., Crowe, M., & Harris, S. (2021). The lesbian, gay, bisexual and transgender communities’ mental health care needs and experiences of mental health services: An integrative review of qualitative studies. *Journal of Psychiatric and Mental Health Nursing*, 28(4), 578–589. <https://doi.org/10.1111/jpm.12720>
- Rennick-Egglestone, S., Morgan, K., Llewellyn-Beardsley, J., Ramsay, A., McGranahan, R., Gillard, S., Hui, A., Ng, F., Schneider, J., Booth, S., Pinfold, V., Davidson, L., Franklin, D., Bradstreet, S., Arbour, S., & Slade, M. (2019a). Mental health recovery narratives and their impact on recipients: Systematic review and narrative synthesis. *The Canadian Journal of Psychiatry*, 64(10), 669–679. <https://doi.org/10.1177/0706743719846108>
- Rennick-Egglestone, S., Ramsay, A., McGranahan, R., Llewellyn-Beardsley, J., Hui, A., Pollock, K., Repper, J., Yeo, C., Ng, F., Roe, J., Gillard, S., Thornicroft, G., Booth, S., & Slade, M. (2019b). The impact of mental health recovery narratives on recipients experiencing mental health problems: Qualitative analysis and change model. *PLoS One*, 14(12), Article e0226201. <https://doi.org/10.1371/journal.pone.0226201>
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24(4), 335–343. <https://doi.org/10.1037/h0095071>
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage Publications.

- Robinson, P., Turk, D., Jilka, S., & Cella, M. (2019). Measuring attitudes towards mental health using social media: Investigating stigma and trivialisation. *Social Psychiatry and Psychiatric Epidemiology*, 54(1), 51–58. <https://doi.org/10.1007/s00127-018-1571-5>
- Rose, D. (2014). The mainstreaming of recovery. *Journal of Mental Health*, 23(5), 217–218. <https://doi.org/10.3109/09638237.2014.928406>
- Russo, J. (2016). In dialogue with conventional narrative research in psychiatry and mental health. *Philosophy, Psychiatry, & Psychology*, 23(3), 215–228. <https://doi.org/10.1353/ppp.2016.0021>
- Salter, L., & Newkirk, J. (2019). Collective storytelling for health: A three-part story. *Storytelling, Self, Society*, 15(1), 108–129. <https://doi.org/10.13110/storselfsoci.15.1.0108>
- Sapouna, L. (2021). Service-user narratives in social work education: Co-production or co-option? *Social Work Education*, 40(4), 505–521. <https://doi.org/10.1080/02615479.2020.1730316>
- Slade, M., Rennick-Egglestone, S., Blackie, L., Llewellyn-Beardsley, J., Franklin, D., Hui, A., Thornicroft, G., McGranahan, R., Pollock, K., Priebe, S., Ramsay, A., Roe, D., & Deakin, E. (2019). Post-traumatic growth in mental health recovery: Qualitative study of narratives. *BMJ Open*, 9(6), Article e029342. <https://doi.org/10.1136/bmjopen-2019-029342>
- Slade, M., Rennick-Egglestone, S., Llewellyn-Beardsley, J., Yeo, C., Roe, J., Bailey, S., Smith, R. A., Booth, S., Harrison, J., Bhogal, A., Morán, P. P., Hui, A., Quadri, D., Robinson, C., Smuk, M., Farkas, M., Davidson, L., van der Krieke, L., Slade, E., & Ng, F. (2021). Recorded mental health recovery narratives as a resource for people affected by mental health problems: Development of the Narrative Experiences Online (NEON) intervention. *JMIR Formative Research*, 5(5), Article e24417. <https://doi.org/10.2196/24417>
- Slade, M., & Sweeney, A. (2020). Rethinking the concept of insight. *World Psychiatry*, 19(3), 389–390. <https://doi.org/10.1002/wps.20783>
- Smith, N. C. (2020). How can stigma contribute to our understanding of the formation and mobilization of collective identities in health social movements? *Sociology Compass*, 14(6), Article e12796. <https://doi.org/10.1111/soc4.12796>
- Spector-Mersel, G., & Knaifel, E. (2018). Narrative research on mental health recovery: Two sister paradigms. *Journal of Mental Health*, 27(4), 298–306. <https://doi.org/10.1080/09638237.2017.1340607>
- Sweeney, A., Clement, S., Filson, B., & Kennedy, A. (2016). Trauma-informed mental healthcare in the UK: What is it and how can we further its development? *Mental Health Review Journal*, 21(3), 174–192. <https://doi.org/10.1108/mhrj-01-2015-0006>
- Sweeney, A., & Taggart, D. (2018). (Mis)understanding trauma-informed approaches in mental health. *Journal of Mental Health*, 27(5), 383–387. <https://doi.org/10.1080/09638237.2018.1520973>
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig, & W. Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 17–37). Sage Publications.
- Topor, A., Fredwall, T. E., & Larsen, I. B. (2021). Before recovery—a blind spot in recovery research? Users' narratives about the origins and development of their mental health and/or addiction problems. *Journal of Recovery in Mental Health*, 4(2), 29–47. <https://jps.library.utoronto.ca/index.php/rmh/article/view/36989>
- Truong, C., Gallo, J., Roter, D., & Joo, J. (2019). The role of self-disclosure by peer mentors: Using personal narratives in depression care. *Patient Education and Counseling*, 102(7), 1273–1279. <https://doi.org/10.1016/j.pec.2019.02.006>
- Tyler, I., & Slater, T. (2018). Rethinking the sociology of stigma. *The Sociological Review*, 66(4), 721–743. <https://doi.org/10.1177/0038026118777425>
- Voronka, J. (2016). Researching the politics of inclusion. <https://radssite.wordpress.com/2016/03/14/researching-the-politics-of-inclusion>
- Voronka, J., & Grant, J. (2021). Service user storytelling in social work education: Goals, constraints, strategies, and risks. *Social Work Education*, 41(5), 1–16. <https://doi.org/10.1080/02615479.2021.1908251>
- Williams, A., Fossey, E., Farhall, J., Foley, F., & Thomas, N. (2018). Recovery after psychosis: Qualitative study of service user experiences of lived experience videos on a recovery-oriented website. *JMIR Mental Health*, 5(2), Article e37. <https://doi.org/10.2196/mental.9934>
- Woods, A., Hart, A., & Spandler, H. (2019). The recovery narrative: Politics and possibilities of a genre. *Culture, Medicine, and Psychiatry*, 46(2), 1–27. <https://doi.org/10.1007/s11013-019-09623-y>
- Yeo, C., Hare-Duke, L., Rennick-Egglestone, S., Bradstreet, S., Callard, F., Hui, A., Llewellyn-Beardsley, J., Longden, E., McDonough, T., McGranahan, R., Ng, F., Pollock, K., Roe, J., & Slade, M. (2020). The VOICES typology of curatorial decisions in narrative collections of the lived experiences of mental health service use, recovery, or madness: Qualitative study. *JMIR Mental Health*, 7(9), Article e16290. <https://doi.org/10.2196/16290>
- Yeo, C., Rennick-Egglestone, S., Armstrong, V., Borg, M., Franklin, D., Klevan, T., Llewellyn-Beardsley, J., Newby, C., Ng, F., Thorpe, N., Voronka, J., & Slade, M. (2022). Uses and misuses of recorded mental health lived experience narratives in healthcare and community settings: Systematic review. *Schizophrenia Bulletin*, 48(1), 134–144. <https://doi.org/10.1093/schbul/sbab097>