

Fragile minds, porous selves: Shining a light on autoethnography of mental illness

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journals.sagepub.com/home/qsww**Alison Fixsen** 

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Abstract

This article sheds light on autoethnographic accounts of mental illness, to address author and reader concerns and questions and to consider what practitioners can learn from these narrative accounts. Drawing from my own and others' trajectories, I discuss the drawbacks and dangers of exposing a 'flawed' identity, the stigma of serious mental illness, intertextuality issues, the tangled nature of revelation and redemption, framing the 'Other' in mental illness autoethnography and depictions of 'life in the asylum.' I explain how in telling my own 'psychiatric' tale, I looked to the symbolic concept of 'communitas' as a means of examining inter-relational processes and collective experience in a psychiatric facility. I argue that, while the act of writing about one's illness experience can be rightly perceived as a way of reclaiming personal 'power' and facilitating healing, attempts to 'evidence' recovery can run counter to the writer's reality of life with or beyond mental illness as personally and socially messy. In answer to the question, 'at what point does a 'life in the asylum' narrative become autoethnographic?' I argue for the potential of autoethnography to contribute to broader sociological, ethnographic and medical debates and thus impact on policy. Speaking up about mental health through autoethnography can help to promote awareness of the unpredictability and socially constructed nature of mental illness and can inform strategies toward reducing public stigma, tackle the cyclical impact of labels, highlight the need to change social and medical attitudes, and revisualize treatment and support.

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Introduction

Despite their growing popularity, no studies to date have specifically focused on mental illness autoethnographies to consider the tensions within these accounts and what practitioners can learn from them. This article seeks to shine a light on this genre of narratives and to address questions such as: what are the drawbacks and dangers to exposing a flawed identity to the view of strangers? How does the writer balance and interpret subjective feelings—anger, guilt, shame, sadness—alongside the social and political aspects of mental illness experience? In any autoethnography choices have to be made about the literature one chooses to review, the theoretical and socio-political slant one takes, and the degree of self-exposure one can tolerate. How does the writer approach the issue of intertextuality? And from a dissemination perspective, how might mental illness autoethnography be used to better inform researchers and practitioners of health and social work?

My article is organized in the following way. First, I explain the dilemmas I faced in the telling and retelling of my mental illness narrative. I address general arguments against autoethnography and those directed at more emotive forms of illness autoethnography. I go on to consider mental health stigma, revelation and redemption, and how the ‘Other’ is variously positioned in illness autoethnography. Finally, I consider the significant potential of mental illness autoethnography to promote awareness and tackle issues of misunderstanding and stigma and other insights it can offer to the health and social work professions.

With regard to the term ‘mental illness’, I use this concept in the sense that it is part of the recognized vocabulary around the assessment, diagnosis and treatment of certain types of mental distress in contemporary society. In no sense do I ascribe mental illness and other terms associated with it, such as ‘psychosis’ and ‘depression,’ to reduce individual experiences of suffering to some common label or to imply any personal ‘defect.’

A fragile identity

In October 2013 I was recovering from a serious psychiatric episode, precipitated by prescribed medication and its withdrawal. After a year off work, I was back again, but part of me was still mulling over and processing the events that had befallen me. A work colleague at this time suggested that, as a clinician and academic who studied stories of illness and recovery, I might write my own. During my illness I had kept detailed diaries, but much of what was written I now thought of as self-indulgent or angry rambles. Yet, within and beyond the personal story

lay wider concerns such as the use of psychiatric labelling, shifting and misdiagnoses, misinformation about prescribed medication (in this case benzodiazepines) and the multifactorial nature of recovery. Also, although my journey into and out of illness was deeply isolating, I was never totally alone in this endeavor. An assortment of professionals had various degrees of involvement in my diagnosis and treatment over time. The constants in my life, close family and friends were also there, although the latter tend to drift away during serious illness. There were also my new ‘buddies’ in similar predicaments with whom I communicated on an Internet support forum. As I began to formulate my first paper, my sense of obligation to this latter group and others who might find themselves in a similar predicament became more pressing, resulting in two ethnographies featuring benzodiazepine withdrawal. There are few safe platforms for those going through serious mental health difficulties to use their voice; once recovered I appreciated the opportunity of using my position as a ‘patient-expert’ to draw attention to what for many had been a catastrophic, iatrogenically induced experience.

In the summer of 2020, I again fell ill. This episode resulted in hospitalization for a brief but intense period. In my deeply shamed state, I pledged not to share this story in any shape or form. This vow did not last; once discharged from hospital I felt impelled to write another autoethnography around my illness. Initially the process was easy, the experience of hospitalization had been sufficiently vivid and my fellow patients so fascinating that I wanted others to appreciate our common experiences. Yet, its writing and publication threw up new concerns about the wisdom of exposing a ‘flawed’ identity in full view and the resultant responsibility that writing others into the illness narrative placed on myself as author.

Autoethnography follows a long tradition of qualitative sociology and hermeneutics and their searches for a method that illuminates how subjects give subjective meaning to their life experiences, and then connect to the groups and social relationships that surround and shape them (Denzin, 2014). There are multiple approaches to autoethnography: this article includes examples from collaborative autoethnography (Liggins et al., 2013), interpretive autoethnography (Fixsen, 2016–2021), performance autoethnography (Brooks, 2011), poetic narrative autoethnography (Gallardo et al., 2009); feminist autoethnography (Frankhouser and Defenbaugh, 2017) and post-colonial autoethnography (Fabris, 2012; McMahan, 2020). Whatever their chosen approach, each author must seek their own balance between focusing on the world of the personal and the collective (Karki, 2016). Yet, even highly personalized illness autoethnographies are more than self-narratives. Unlike other forms of illness trajectory, the autoethnographic account deals with broader social issues and injustices, as affecting the marginalized (Ettorre, 2005; Karki, 2016) and the ‘muted’ (Fixsen & Ridge, 2017, Orbe, 1998). As I already hinted, assuming responsibility for fair representation of vulnerable participants and subjects (as the ‘Other’) can be a particular source of anxiety for the writer. After publishing my first illness autoethnography, it was to my great relief that I received messages and emails voicing approbation and even gratitude from ‘fellow sufferers.’ It seems I am not alone in this; prior to her subsequent successes, Ettorre

(2006) experienced anxiety and concern about the reception of her first illness autoethnography. I suspect we share these worries with others who are bold enough to believe their personal accounts of illness to have messages and meanings beyond that which concerns their own minds and bodies.

Autoethnography under fire

In addition to personal doubts, writers of illness autoethnographies face external critique on several fronts. Western medical practitioners still represent the final, authoritative voice of medicine (Defenbaugh, 2008), and while with the advent of patient-centered medicine patients are increasingly invited to 'tell' their stories, this is predominantly within clinical contexts and as a means of confirming diagnoses and formulating treatment plans (Robertson et al., 2017). It is highly unusual for patients to be encouraged to frame their mental health experiences within a socio-political context as this could undermine medical authority and upset the status quo. Even today 'observational studies' (in which autoethnography can be included) remain possibly the most controversial element of qualitative research in health studies (Ettorre, 2006). The 'emotional narrative mode of autoethnographic writing' appears to go against established canons of medicinal research (Ellis and Bochner, 2006), and mental illness and recovery autoethnographies are almost always published by social science rather than medical, or high-impact, health research journals.

Within sociology and qualitative health studies, personal narratives are awarded more regard, and autoethnography as methodology and practice has assumed a niche in these worlds. But there are still instances in which autoethnography has been subject to strong criticism from within these disciplines. In a paper first delivered at a European Sociological Association conference plenary, Sara Delamont (2007) raised some controversial arguments against autoethnography: it is lazy, lacks analytical outcome and empiricism, it focuses on the powerful (social scientists) and not the powerless, and it is almost impossible to publish ethically. It is true that ethical issues around autoethnography are convoluted; situated in some or other social world, the autoethnographic account includes human subjects who may or may not be fully consulted in this process. As Tolich (2010) suggests, the 'auto' in autoethnography is a misnomer because 'the self is porous'; it leaks out to the other 'without due ethical consideration' (p.1608). Edwards (2021) points out that it is virtually impossible to know how one's autoethnographic work will be received, whether or not people will recognize themselves in the narratives and how they will feel and respond. She writes of her discomfort at finding herself the subject of an institutional autoethnography without her foreknowledge; 'I felt silenced and judged' she says (p.2). This right to speak about or even for others via autoethnography requires self-interrogation, deep reflection and integrity, she concludes (Edwards, 2021). It remains imperative that the writer of autoethnography follow common ethical guidelines, including ensuring that anonymity is observed and that identities are protected (Fixsen, 2021). On the other hand, in its telling and witnessing of real life stories leading

to actions that critique dominant norms and practices and support ethical social change, autoethnographic inquiry can be regarded as one of the most ethically motivated and grounded of methods (Lapadat, 2017).

Concerning Delmont's criticism of autoethnography's focus on the powerful rather than the powerless, I would argue that, although the mental illness autoethnographer may be highly literate and inquisitive, they are never in an unequivocal position of privilege. As those of us who have written about difficult life trajectories well know, in times of personal distress other forms of social, political and medical power completely overshadow academic advantage. Those diagnosed with mental illness are inevitably caught up in the 'net' of biopower¹, whose norms include the conflicting expectations that the 'sick patient' submits to the authority of medical institutions and that individuals employ 'technologies of the self' in order to put their own minds and bodies in order (Foucault, 1980).

Another question concerns the hidden and often silenced knowledge of similar others, to which the autoethnographic recorder of illness narratives may have unique access. Ellis, Adams and Bochner (2011) explain how the writer of autoethnography employs personal experience, insider knowledge and existing research to understand and critique cultural experience, break silence, and navigate through confusion, pain, uncertainty and anger. In my autobiography of biographical disruption and reconstruction during recovery from prescribed benzodiazepine use, I adopted the concept of the 'muted group'(Orbe, 1998) to examine the co-cultural language and symbols employed by benzodiazepine users and ex-users, to provide a 'shared voice' and make sense of user realities (Fixsen, 2015). Had I not spent many months in this inconspicuous social world it is unlikely I would have felt able or inclined to speak out for those less privileged than myself.

Delmont's forceful critique of autoethnography appears to pale in comparison to the 'vile, misogynist and cruel trolling of autoethnographers and their work' on the social media platform Twitter. 'Apparently being a self-obsessed C**T is now academically lauded' was one of multiple insulting comments written by academics and quoted by Campbell in her article on autoethnography trolling (Campbell, 2017). These emotive forms of criticism can be viewed as a form of microaggression and can hit the vulnerable writer hard.

Even researchers who are sympathetic to autoethnography can take issue with its lack of empiricism and the emotional slant and language of many autoethnographic accounts.

In the late 1990's, Atkinson initiated a hot debate over claims made by authors of illness autobiographies based on highly subjective narrative data and limited narrative analysis, citing Frank's popular book *The Wounded Storyteller* (Frank, 2013) as one example (Atkinson, 1997). One of these criticisms concerned the way in which authors of illness narratives frequently privilege narrative data – typically interview data – by granting them properties of transparency and validity that other forms of data (such as those associated with conventional diagnosis) do not possess: 'In this way self-knowledge is celebrated in comparison with the *impersonal* knowledge of the medical practitioner', Atkinson (2009) concludes.

The contemporary fashion for ‘evocative autoethnography’ too often leads to unreflective uses of personal accounts which undermine qualitative research (Atkinson and Delamont, 2006). There is, Atkinson later insisted, a need for further analytic strategies that treat illness narratives as speech acts, based on socially shared resources (Atkinson, 2009).

Chang, while supportive of some forms of health-related autoethnography, berates those illness self-narratives which ‘evoke emotionally compelling responses from readers but offer insufficient sociocultural insights about the illness phenomenon’ (Chang, 2016: 443). She goes on to contrast the approach relying on ‘thick description of personal experience’ (Chang, 2016) (sometimes designated as ‘evocative ethnography’) (Liggins et al., 2013) with analytic autoethnography (Anderson, 2006), judging the latter to be more rigorous, inclusive and more grounded in the realist tradition of ethnography (Chang, 2016; Anderson, 2006; Liggins, 2013).

Interpreting emotion

In answer to critics of interpretive autoethnography, Denzin (2014) argues that autoethnography cannot be judged by positivist criteria because autoethnography locates itself within the ‘broader enterprise’ of qualitative inquiry, which ‘seeks to disrupt the binary of science and art’, as well as boundaries such as objective/subjective, insider/outsider, theoretical/empirical and so on. Ellis and Broacher (Ellis et al., 2011) describe how, in autoethnography, the researcher uses a back and forth gaze, focusing outwardly on social and cultural aspects of personal experience, then inwardly to expose a vulnerable self. This inner life of the person, the ‘performative-I’ revealed through their stories, is de facto empirically unstable (Denzin, 2014). So, how does one assess the authenticity and validity of illness autoethnography? The simple answer is that one cannot. Since memory is fallible, and autoethnography is usually written after the event, authenticity and validity are determined by how a reader responds to a representation; thus an autoethnography should be judged less in terms of accuracy than whether it moves others to ethical action (Denzin, 2014;).

Far from rejecting the introspective and emotive aspect of autoethnography, there is a strong case for making it central to one’s methodology (Ellis, 1991). Resurrecting introspection (or self-examination) as a systematic sociological technique would, Ellis (1991) argued, allows social constructionists to examine emotion as a product of the individual processing of meaning as well as socially shared cognition. In narratives of mental illness, expressions of vulnerability, sadness, anger, fear and shame may be fundamental to the truthful telling of the story. In those moments of crisis that provide ‘dramatic tension’ and ‘around which ‘the emplotted events’ revolve (Denzin, 2014: 4), the recording of such events may be particularly difficult or impossible. In my own case, I was literally paralyzed with depression and despair at some points. In such cases, emotional recall – a technique achieved ‘in dialogue with the self and represented in narratives’

(Ettorre, 2006)- may be an important and useful device for the illness autoethnographer. Defenbaugh (2008) used this method to explore her own experiences of naming and renaming illness in the medical community and how it felt to be voicelessly shunted along a system in which medical practitioners remain ‘the voice of medicine’ (p.1403). I employed emotional recall to access my experiences and observations of life in an acute psychiatric unit. Since the circumstances leading me to that study were unanticipated, my recollections concerning being back in the scene emotionally and physically assumed particular significance.

Stigma and shame

At the heart of the mental illness autoethnography lies a tension between speaking out and protecting the author’s reputation and inherently fragile self. Some might consider the idea of a ‘flawed identity’ misleading; the writer of autoethnography has several identities, including that of literate scholar and, in some instances, teacher and/or clinician. However, I would argue that a person who is giving an account of their *mental illness* is revealing an aspect of themselves that can be described as flawed and deviant in the sense that mental illness is identified with such things as social incompetence, unpredictability and violence. Serious mental illness is still one of the most feared and discriminated against of all types of illness, with self-stigma occurring when these public attitudes are internalized (Goffman, 1963; Corrigan & Rao, 2012)). Empirical studies indicate that people with mental health conditions feeling invalidated and marginalized even in health settings (Liggins and Hatcher, 2005). Being ascribed a label or ‘psychiatric diagnosis’ such as schizophrenia places people at particular risk of public stigma and to the internalizing of the social stereotype (Corrigan and Rao, 2012). Johnston (2020), whose autoethnography draws from the tradition of Mad Studies to trace his struggles with psychosis, arrest, psychiatric institutionalization and recovery, makes it clear that the stigma of mental illness does not necessarily diminish over time, indeed the shocking realization that such a thing could have happened to one leaves a lasting and possibly indelible psychological and social mark:

About a year into my recovery from a battle with psychosis, I was still very much at war with the stigma, trauma, regret, and utter loss of self-confidence felt as a result of being mentally unwell. My ontology had been struck; my entire sense of self and being was hidden in a place I could not find. I endlessly questioned how I should proceed with a life I thought was irreversibly ruined. (Johnston, 2020: 137)

At the very beginning of her thesis on living with schizoaffective disorder, McMahon (2020) gives a taste of what is to come: ‘As I have mentioned many, many times in the writing forthwith, I fundamentally believe that I am lacking, that I am a sub-citizen, a sub-human and a social misfit.’ Biomedicine, she says, holds the capacity to stigmatize and dehumanize people with mental health conditions,

and it is extremely difficult to resist the definitions and psychiatric labels that its people and institutions impose on the sufferer (McMahon, 2020).

Studies suggest that a 'hierarchy of stigma' exists for psychiatric conditions (Huggett et al., 2018), with certain 'labels,' such as schizophrenia, generally more feared and stigmatized than others such as depression (Mann et al., 2004). This should not deflect from the weighty feelings of guilt and stigma affecting individuals in their own bleak moments. Writing of her experiences of postpartum depression, Frankhouser says:

I was a mother in those moments, buried under feelings of failure and guilt, unable to see a way out. I was lost within the same cultural system patients with postpartum depression navigate daily, internalizing social stigma and holding myself to an idealized good mother standard. (Frankhouser and Defenbaugh, 2017)

Shame and stigma are strongly interlinked. As an academic I reassure myself that the reviewers and readership of peer review journals are sufficiently broad minded, objective and informed to prevent any gross indignities resulting from self-exposure. Additionally, reviewers are generally not personal acquaintances of the author; however those who subsequently read one's work may be work colleagues and managers, which can trigger concerns about flawed identity, sense of shame and loss of face (Goffman, 1963). After writing a poem about his depression, Furman shares his anxieties about what people will think if it were published; 'What will my colleagues say if they read this? Will they worry about me, we will they think I am strange?'(Gallardo et al., 2009: 272).

Revelation and redemption

A rationale for the illness narrative already suggested is that the act of telling is in itself a form of personal catharsis and a means of escaping or abandoning a passive sick role. The act of writing about one's illness experience can be rightly perceived as a way of reclaiming personal 'power' and facilitating healing (Ettorre, 2005, 2006; Frank, 2013), and even as a rebellion against medical hegemony (Ettorre, 2005) or colonialism (McMahon, 2020). In an autoethnographical account of thyrotoxicosis, argues that the study of autoethnography as a 'technology of the self' (Foucault, 1980) with liberating possibilities requires deep consideration. 'The way of out of the narrative wreck is telling stories' says Frank (Frank, 2013: 55). In writing about my own and others' mental illness I have sometimes bantered with words such as 'mad' and 'crazy', both as kind of dark humor and to challenge the stigma attached to such terms. 'Madness need not be all breakdown. It may also be breakthrough' (R.D Laing) is a sentiment that in my better moments I hold to be true. Yet it takes courage to write an honest account of your weakest and darkest moments, and to cast it to one's potential critics (Smith, 1999). Parts of the narrative may be too painful or humiliating to relate. Johnston (2020) admits; 'My story is incomplete: there are darkneses and shames I am simply too fragile to

share with others.’ (p.140). He goes on to say that some of what is omitted from his narrative is in order to protect others close enough to be affected by such revelations:

Most of us know that the repercussions of many forms of mental illness can be permanently damaging, life altering, and greatly traumatic to family members, communities, and those afflicted. Therefore deciding what to share and not to share was intrinsic to the ethics process. (Johnston, 2020: 140)

Rather than finding redemption, there is the possibility of getting even more stuck in one’s illness narrative through its telling. Atkinson warned of the ‘blind alley’ in which writers of personal narratives can find themselves (Atkinson, 1997). Here, Atkinson is largely objecting to a lack of methodological rigor, yet his insinuations of a sticky web in which the over-revelatory author can trap her/himself hold some truth. It may be simpler to compose an autoethnography of mental illness than to subsequently dispose of it.

That the writer considers their illness narrative worthy of sharing implies that, through this episode they have experienced some kind of existential crisis, turning point or epiphany (Denzin, 2014; Ellis, 2016). As Denzin (2014) points out, the idea that lives revolve around a significant event resulting in personal transformation has been a central part of the autobiographical form for millennia. Thus, on planning my first illness autoethnography it seemed obvious that my findings should conclude with a section on self-reconstruction:

I discovered that, for me, the key to self-reconstruction was to capitalize on any signs of improvement or happiness when I saw or felt them, and to ignore the nagging pains and voices telling me to doubt that I could change. I gained a sense of empowerment from willing myself to keep going forward. ...I wrote in a personal email that I was “clawing my way back. Reducing these drugs is the hardest but most empowering thing I have ever done. Miles to go yet, but I am optimistic (most of the time)”. (Fixsen, 2015)

In an autoethnography of her journey to mental health recovery, Robertson explained how she, as ‘wounded researcher’, used the processing of reframing her lived experience within the personal narrative to support the development of a more positive identity:

Developing my autoethnography has been like walking a tightrope over a precipice. It was scary and perhaps in many ways easier to stay where I was. Growth, development, insight, agency and a more positive sense of self lay over the other side. (Robertson et al., 2017: 24)

Writing about personal epiphanies in autoethnography may be commonplace, but it puts onus on the writer to demonstrate both inner knowledge and an

appreciation of more far-reaching effects of transformation. 'I (JL) know I have a story to tell but can that story be transformative, can I move it beyond the simply therapeutic?', Liggins asks in her autoethnography of mental health care. 'Can I use my story to consider wider issues in mental health . . . to be political, to provoke change?' (Liggins et al., 2013). Concepts such as recovery and transformation suggest a linear path in life, whereas the course of mental illness is more akin to a roller coaster and far messier and less satisfying than most narrators would care to reveal. Attempts to evidence positive personal transformation, or transformation at all, may run counter to the writer's reality. Racheal McMahon's (2017) powerful account of living with schizoaffective disorder illustrates the flaws in this thinking. She writes of her story as that of transformation but 'in a profoundly negative sense of the word; how my life has been stripped bare by my illness and the institutions which now control it.' Johnston (2020) is less unequivocal about the delusiveness of recovery but acknowledges that his autoethnographic storytelling has left him 'bewildered, grateful, and with many questions' including, 'what place do the mad have in society to resist those who conceive of madness as an ontology or space that must always be fixed and exited?' (p.3). We, as readers, may be seeking both narrative closure and redemption where neither may exist for the author.

Speaking out for the others

Illness autoethnographies are peopled by various actors and voices; cultural context, and the players within it, represent the 'ethno' in autoethnography. However intense or personal the experiences and feelings revealed in the narrative, the reader should be left with an abiding impression of the 'Other' or 'Others' in the narrative and have a clear grasp of the collective messages within the text. Within these parameters, the way in which the 'Other' is framed in the illness autoethnography will vary widely; some may be framed as fellow sufferers, others as oppressors and yet others as advocates. At one end of the spectrum are those illness autoethnographies in which the main author has direct experience of the phenomenon under investigation but remains in close collaboration with a research team who are also studying this phenomenon. Potential advantages of this method is that it counters objections concerning the purely subjective nature of autoethnography. Arguably it also allows for greater analytical distance between research and narrative, and is therefore favored by those who demand a return to more traditional ethnographic roots and the inclusion of multiple participants (Anderson, 2006).

Liggins et al. (2013) used multiple researcher autoethnography to critically reflect on a project which, two decades on closure of the last large mental health institution in New Zealand, sought to investigate the acute care environment and its capacity for healing. The first author, a previous patient in such a psychiatric unit, expressed confidence about their own position in the project, but questioned how the other researchers without her experiences might place themselves within

the autoethnographic narrative. It was agreed that the ‘we’ within the account was authenticated by the fact that all around the table were confronting ‘geographies of power within the acute care experience’:

I know that this project begins with my story and autoethnography invites me to embrace the personal, to use the subjective ‘I’, to challenge that more objective, impersonal style of academic writing. But here it is not just ‘I’ it is ‘we’. We are all part of this research journey. (Liggins et al., 2013: 108)

Given the potentially catastrophic nature of serious mental illness, it is unsurprising that autoethnographies are frequently written from a point of resistance. The writer seeks not just non-collusion with conventional paternalistic models of illness and diagnosis but to speak as the voice of challenge and defiance. Such authors hold a stance that opposes traditions in which psychiatric patients are excluded from interpretation and theory around mental illness and disability and against the stigmatizing or categorizing of mental illness and inhumane treatment of those in asylums. ‘I am part of the Silenced Manifesto’, McMahan states; ‘defined by and hidden behind a dominant discourse.’ (2020: 18). Here she writes as a spokesperson for all those colonized, marginalized and silenced by dominant elites:

Within a space for commensurability comes a message from the marginalized, those living with mental illness; where there is a site of creativity and power; where the mentally ill recover; where we meet in solidarity to erase the categories of colonized/colonizer. (McMahan, 2020: 19)

Erick Fabris (2012) assumes an anticolonial antiracist framework to recount his story both as a ‘privileged white male’ and as a ‘survivor’ of enforced psychiatric drug treatment. One of the ‘others’ about whom he writes is his mother who was sent away to a psychiatric institution when Erick was a child and the ill-effects of the treatment she received:

As we waited for my mother to “get better” after her institutionalization, I imagined what it would be like to run in the fields and see the snow. The institutional logic of brain disease required toxic treatments that only made my mother worse. It took several years for my father to convince her family to try sending her back to Canada with us. Upon my return I saw the snow piled high for the first time in years, and I was ecstatic. But my mother still didn’t “get better”. (Fabris, 2012: xvii)

Underlying the resistance story is an ‘Us’ and ‘Them’ social world, in which the ‘Us’ are largely silenced by ‘Them’ as the medical elite. Depersonalization of the mentally ill patient may, for example, be evidenced through patient notes, where the patient is typically written about in the third person. Matthew S. Johnston’s

(2020) autoethnography contains extracts from his psychiatric notes which include the following extract:

On mental status exam, Matthew appeared his stated age, somewhat disheveled and gaunt and wearing a knit toque through the interview. He was initially guarded and reluctant to speak, particularly about his wife. There were some electricians doing some work in the building, and we heard the sound of wires running through the walls. He suddenly became very paranoid and refused to talk to me anymore and rapidly left the room and the building. . . Matthew's affect was restricted and anxious. His cognition was not formally tested, and his insight and judgment were poor. . . (Johnston, 2020: 145)

So, what of mental illness autoethnographers (such as myself) with a foot in both worlds; who have been both patient and medical practitioner? It is not uncommon for health professionals to recount their own illness narratives; how do these writers reconcile the 'Us' and 'Them' elements of their accounts? Burnard grapples with this insider/outsider issue in his description of a visit to his psychiatrist. Both practitioner and long-term user of mental health services, Burnard (2007) is largely complementary about the way in which this interview is conducted; 'Overall I had a sense of being listened to.' While conscious of some distancing on the part of psychiatrist, Burnard expresses his personal view that professional and physical boundaries are in such situations 'probably necessary.' At the close of the interview he also noted a 'pulling out of the patient role and back into a more equal role', although whether this was his perception or by tacit agreement is left to the reader to decide. Subsequent medical notes, based on this interview and written in the third person, describe him as 'well turned out, pleasant and cooperative', which felt to Burnard like a moral judgment that reinforced his sense of being an outsider.

Yet, postmodernism emphasizes that, as part of narrative interpretation, the context of the researcher be considered from all angles - class, gender, ethnicity and institutional affiliation (Angrosino, 2005). Burnard is referring to the emotional difficulties of holding a dual role in clinical practice (one chosen and one of necessity), which should be distinguished from the role of autoethnographer as author (which may come later). Instead of adopting the insider-outsider dichotomy, the autoethnographer's position can be conceptualised as a 'space in between' (Dwyer and Buckle, 2009), allowing for multiple angles from which they can study themselves and others. Another way is to consider the author (and other players in the narrative) as a 'body multiple' (Mol, 2003), with each enactment representing a different version and interpretation of a phenomenon such as 'clinical diagnosis' or 'treatment'.

A further way of surmounting any dichotomous assumptions is to present the patient and medical professional as fellow players within an oppressive socio-cultural order, using an overarching theoretical framework such as anticolonialism (Fabris, 2012; McMahon, 2020). Theoretically framing one's research in such a

way is in keeping with the social constructionist position and can bypass concerns about personal blame and victimization. Nevertheless, the conflation of personally shocking medical experiences such as enforced medication with global socio-political ills such as stigmatization of the mentally ill may flounder through over-identification. Even more in keeping with the ethnographic tradition of full cultural immersion is for the autoethnography to be framed as a joint production between researcher and participants. Essentially, Berger (2001) explains, this creates a collective understanding in which the 'Other' is recognized as a human being with thoughts and feelings, such that the reader themselves is able to interact with the characters in the text, 'becoming ethnographers themselves and coming to their own conclusions about what it all means' (p. 508). The extent to which other participants are involved in the data collection will vary, however usually participant observation or, at the very least, the eliciting of other participants' stories on the part of the researcher, is required. This may be easier to achieve in a communal setting such as a hospital or care home, where the experience can more clearly be viewed as that of a 'shared subjectivity' (Angrosino, 1998: 265). It also throws up questions about who is, or should be, involved in the actual business of writing autoethnographies and how these partnerships can be subsequently acknowledged by the auto ethnographer, as 'project lead'.

Life in the asylum

Those who do not want to have their space infiltrated by anti-social behavior do not want to see the mentally ill (and frequently homeless person) in their public space. They label such people as social misfits, and commonly the social misfits are admitted to psychiatric wards. (McMahon, 2020: 21)

There is growing recognition of the benefits of involving those with mental illness in the reframing of their own recovery narratives (Petros and Solomon, 2021; Fixsen, 2021). Yet, those removed from 'normal' society are generally deemed less capable of independent, coherent thinking. That the mentally ill are increasingly treated in the community has only enhanced the catastrophic image and stigmatization of being detained in a psychiatric institution. Lelliott and Quirk (2004) wrote as practitioners that the most pessimistic view of acute psychiatric ward hospitals is that they were no more than nontherapeutic 'dumping grounds' for service users who cannot be managed through community services (p. 297).

There are a good number of first-person accounts of life in a psychiatric institution, but most do not purport to be autoethnographic. Some, such as Taylor's (2014) autobiographical account of her years spent in the asylum system and Kaysen's (1995) brilliant account of minor bullying, patient squabbles and acts of rebellion in a 1970's psychiatric unit ('Girl Interrupted'), contain strong messages concerning these psychiatric units and the treatments they and others

received in them, as deeply flawed. Yet neither author makes theoretical claims about the ethnographic significance of the documented relationships in institutional settings. So, at what point does a 'life in the asylum' narrative become autoethnographic? One means of checking is to consider the extent to which the narrative presents particular embodied events with people in time. Another concerns the narrative's intention to test out established ideas (based on theories and data) in fresh contexts and/or to create new theory, in order to contribute to broader sociological, ethnographic and medical debates and to fill gaps in the literature. For example, noting a lack of literature on the psychiatric hospital as a therapeutic landscape and site of healing, Liggins et al (2013) considered users' experiences of psychiatric hospital spaces as 'critical sites and spaces of transition on the illness journey'. In the passage below the writer is distinctly effusive about the external physical environment in which she finds herself:

The Hall is a privately run psychiatric hospital. . . situated 10 miles from the center of town. . . The grounds are wonderful (even in winter), they are part of the specialness of the place. . . Quite magical and for me a haven, then a place of healing. (Liggins, 2013: 107)

The above quote illustrates the author's experience of a psychiatric hospital. This is one perspective, for others psychiatric hospitalization has very different connotations or associations. McMahon described her psychiatric unit as 'not a place of nurturing or love. It was a place that worshipped the science of medicine, of sterility and hygiene, of dead germs' (p.133). My own experience of the psychiatric unit as a physical and emotional space was distinctly varied, a 'mixture of hospital, boarding school and prison.' Most alarming for me were the acoustics of the place:

A week or so in and I'm getting accustomed to most things except the noise level. Whoever designed this place in the 1970's was either a sadist or had delusions of grandeur, as the ridiculously high ceilings create an echo, such that every conversation becomes a chorus of undecipherable words. In my original paranoid state I was sure that I was not only imagining this whole scenario but going deaf to boot. (Fixsen, 2021: 1)

Physical and social environs, though they impact on one another, are still distinct. Victor Turner (1969) constructed the term 'communitas' to refer to a temporary sense of shared pleasure or companionship which accompanies the 'liminal' (middle) phase of an interaction ritual and which is significant for being both temporary and relatively status-less. I borrowed this concept of communitas to analyze the largely informal interactions between myself and fellow inhabitants in an acute psychiatric unit during the Covid-19 pandemic. Although medical staff were part of the narrative, my principal interest lay in informal peer to peer

relationships on psychiatric wards, a topic I found to be largely absent from the medical and sociological literature on patient in-care:

The acute psychiatric ward represented for me a ‘communitas in crisis’, a transitory place in which I, and my fellow inmates, found themselves stripped of their customary freedoms, relatively status-less and cohabitants in a social world in which others (the nurses, support workers, psychologists etc) attempted to ‘re-aggregate’ their inner and outer worlds. (Fixsen, 2021: 4)

Conclusions

This article is best read as a re-imagining, rather than as an authentic re-enactment, of the mental illness autoethnographies summarised within it. All texts, but particularly compilations such as this, which openly borrow and quote from other authors, represent a ‘tissue of citations resulting from the thousand sources of culture’ (Barthes, 1967). Intertextuality issues, such as how to present different data, which elements of my own and others’ stories to include or exclude, avenue/s of dissemination, and the ontological and axiological position of readers and other audiences (Norris, 2020), all required consideration.

In autoethnography, the empirical data is human experience, in all its richness and raggedness. I am inclined to dismiss any advocacy of a ‘scientific’ set of rules for writing mental illness autoethnography, over and above that it is true to the ethnographic tradition in the sense of being culturally embedded and ‘connecting the autobiographical and personal to the cultural, social, and political’ (Ellis, 2004, p. xix). I am also inclined to agree with Richard’s (2008) assertion that autoethnographic accounts of illness have the advantage over professional accounts of patients’ experiences of illness in that the latter inevitably ‘represent these experiences through their own professional lenses, however much they might try to do otherwise’ (Richards, 2008). I propose instead emphasis on the interpretative ethnographic nature of the narrative by looking to traditions such as symbolic interaction for novel ways of examining inter-relational processes and cultural events to create a more ‘collective’ story.

There is still a way to go before mental illness autoethnography finds its way into the mainstream medical literature, yet this seems an unfortunate omission. There are messages that practitioners and social workers in particular, can take from this work to inform their practices, theories and reflections in the direction of social justice. Examples of this genre, such as discussed in this article, eloquently and poignantly present the real-life experience of mental illness, and as such can be used to deepen understanding, concern and empathy for a vulnerable and marginalized group in society. Speaking out about mental health can also help to promote awareness of the unpredictability of mental illness. Literatures cited in this paper can be used to: inform strategies toward reducing public stigma, tackle the cyclical impact of labels, highlight the necessity to change social and medical attitudes, and

re-visualize short and long-term treatment and support from the user perspective. In conclusion, I hope that this article will entice those from different health and social disciplines to award mental illness autoethnography more credence and, even better, to include examples of this work on student reading lists.

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Note

1. Mechanisms and tactics of power which are focused on control of individual bodies and populations.

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