

When Madness Meets Madness: Insider Reflections on Doing Mental Health Research

International Journal of Qualitative Methods
Volume 18: 1–13
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DOI: 10.1177/1609406919835356
journals.sagepub.com/home/ijq



Matthew S. Johnston¹ 

Abstract

Insider–outsider relations in qualitative research have been heavily studied. Yet there is a dearth in the literature exploring how people who have experienced madness produce knowledge and overcome trying circumstances when they do qualitative mental health research with other survivors. This article fills this gap through a critical reflection on my experiences with psychosis and involuntary hospitalization and how they shaped dialogue with my participants. Situated within a narrative framework of inquiry, I reveal how self-disclosure and critical forms of relationality during interviews with 10 psychiatric survivors produced a survivor-centered knowledge that nuances biomedical understandings of mental illness and the mental health system. Practices of self-disclosure revealed how survivors and I had to navigate familial expectations as we recovered and tried to regain a sense of identity. Doing insider research also helped me overcome the periods of embarrassment and stigma in my psychosis, as I learned through critical dialogue how traumatic events can provide unique avenues for intense self-reflection and the development of greater empathy for mental health survivors. I also discuss some of the ethical concerns and limitations of having an insider status in qualitative mental health research, and how self-disclosure may present certain epistemological challenges in the research process.

Keywords

narrative inquiry, emancipatory research, social justice, narrative research, ethical inquiry

Introduction

Doing research of any kind, especially if we are doctoral students, makes us vulnerable to encountering serious mental health challenges during all the intensive, creative, and cerebral phases of the research process (Clark & Sousa, 2018; Evans, Bira, Gastelum, Weiss, & Vanderford, 2018; Guthrie et al., 2017). Research is difficult: It tests our knowledge, pushes our boundaries, and challenges us to grow as people while we deal with the pressure of being there for our participants in ways that we never predicted or believed were within our capacity to do. Being an empathetic qualitative researcher means that we sympathize with our participants, we try to understand them, we are kind, we avoid judgment, we share our emotions, and we build compassionate relationships, however long or brief, so that they can learn to trust us (Howe, 2008; Gair, 2012).

There are, of course, many other professions in the world that carry grand responsibilities. But qualitative researchers working within any emancipatory paradigm are special because they are tasked with sharing another person's story or collaborating with them for the purposes of enacting social

change, accurately representing their (often marginalized) lives, and opening our own hearts to learn (Clark & Scharf, 2007; Schneider, 2012). Doing so does not mean we are invincible, for we can easily burn out, experience our own triggers and psychological discomforts, or just fail to live up to the grandiose expectations placed on us in an intensifying neoliberal academy (Alma & Smaling, 2006; Chavez, 2008; Figley, 2002; Fox et al., 2009; Haggerty & Doyle, 2015; Ross, 2017).

While it is well-documented how researchers experience the research process in the various projects they undertake (see, e.g., Court & Abbas, 2013; Johnston, 2018, 2016; Johnston & Johnston, 2018; Suwankhong & Liamputtong, 2015; Taylor,

¹ Department of Sociology and Anthropology, Carleton University, Ottawa, Ontario, Canada

Corresponding Author:

Matthew S. Johnston, Department of Sociology and Anthropology, Carleton University, 1125 Colonel By Drive, Ottawa, Ontario, Canada K1S 5B6.
Email: matthew.johnston3@carleton.ca



2011), there is a dearth in the literature exploring how people who have experienced madness produce knowledge and overcome their personal challenges when they do qualitative mental health research. Most of the extant reflections in this field come from professionals who have worked in the mental health system or those who have done intensive archival research (Brunero & Jeon, 2015; Davies, 2005; James, Andershed, Gustavsson, & Ternestedt, 2010; Links, Bender, Eynan, O'Grady, & Shah, 2016; Prestwich, 2012). In this article, I examine how my own experience and recovery from psychosis shaped my interactions in my doctoral research with 10 survivors who identified as having experienced a serious mental condition or illness.¹ I discuss how self-disclosure and critical forms of relationality produced a survivor-centered knowledge that nuances current and dominant biomedical understandings of mental illness and the mental health system and resists the everyday stigmas that entangle survivors' lives.

The goal of this article is to practice reflexivity in relation to my doctoral thesis, which explores how mental health survivors navigated, resisted, disengaged, and conformed to the mental health system. This article does not report the findings of my doctoral study so much as it assesses the impact my insider knowledge and use of self-disclosure had on my findings. I also discuss the many ethical and epistemological concerns and tensions that arose when I shared my mental health challenges with my participants.

This article is organized into four parts. First, I review the relevant literature on insider–outsider relations in qualitative research. Second, I describe the narrative framework of inquiry and research design that shaped the project's preconceptions and political drives. Before concluding this research, I then move to the analytical sections of this paper where I unravel the interview moments of self-disclosure, criticism, appraisal, stigma resistance, and empowerment that led to the mutual creation of user-based knowledge.

Insider and Outsider Relations in Mental Health Research

Researchers who are “outsiders” do not closely identify with the population they wish to study nor have they shared many of the experiences the community has dealt with and managed (Armitage, 2008). The benefit of this status, especially for those working under a postpositivist paradigm, is that it can afford researchers with some level of objectivity if they do not wish to distort their study with politics, emotions, and personal partialities derived from their own experience (Teusner, 2015). The drawback is that participants can be suspicious of researchers if they believe the lack of inclusion in their community will make them less empathetic and caring (Watts, 2006). Trust, for outsider researchers, is not impossible to gain if you have some form of “insider knowledge” (Bucierius, 2013), but it can be difficult. An “insider,” on the other hand, knows and has personal experience with their targeted group of study, to varying but significant degrees, before the research formally commences. Holding the “insider” status carries its own distinct

set of advantages including easier access, higher levels of trust between participants and researchers, and a “head start in knowing about the topic and understanding nuanced reactions of participants” (Berger, 2015, p. 223).

Of course, there are limitations to any degree of reflexivity, as the relationship between knower and known is never uncomplicated and trouble free (Adkins, 2002). Insider relations can create role confusion in the field, present ethical quandaries when the researcher–researched relationship shifts (Johnston, 2016), distort the production of knowledge, and force us to grapple with the assumption that insider knowledge is authoritative and “offers an absolute or correct way of seeing and/or reading the culture under investigation” (Taylor, 2011, p. 6). Being an insider in a community where gossip networks are strong can also jeopardize the confidentiality of participants (Heslop, Burns, & Lobo, 2018).

Reflexivity refers to the constant critical self-reflection of the researcher throughout all phases of the research process. Hence, there is a responsibility on the insider researcher to critically understand the role of the self in the production of knowledge and “carefully self monitor the impact of their biases, beliefs, and personal experiences on their research” (Berger, 2015, p. 220). Doing so ensures that the tensions between the involvement and detachment of the researcher and participant will be taken up epistemologically and enrich the rigor of the study.

There are a number of important works on insider and outsider relations in mental health research. For example, over the course of many years of archival research, Prestwich (2012) learned about the problem of silence in mental illnesses, that is to say, how difficult it is for survivors to communicate inefable experiences that, in words alone, become nearly impossible to describe. If one accepts that survivors' knowledge about their own suffering is equal or greater than the knowledge of psychiatric experts and caregivers (Cohen, 2015; Joseph, 2014; Kirmayer, 2000; LeFrançois, Menzies, & Reaume, 2013; Pattadath, 2016; Rose, 2009), then drawing conclusions about patient treatment and care without insider knowledge or consultation presents challenges (Faulkner, 2017; O'Reilly & Parker, 2014). Gaining the trust of respondents in mental health research can require years of membership in the community, not to mention a great deal of skill in navigating Research Ethics Board processes and requirements (Links et al., 2016). Even amid collaborative efforts (Brunero & Jeon, 2015; Rose, 2003), some people in the user movement argue that since health professionals are socially dominant in relation to survivors, their professional assumptions tend to override the voices of the suppressed (Davies, 2005).

Despite these obstacles, Schneider (2012) found that the research participation of survivors of schizophrenia promoted health equity and inclusion to the extent that they could claim full and equal citizenship in Canadian society. Their involvement and the presence of their voices actively produced a counterpsychiatric knowledge that debunked dominant and paternalistic ideas, categories, and perceptions of people with mental health labels and empowered service users to take their

due “place in society as people with the right and ability to speak about issues that concern them” (Schneider, 2012, p. 153). Secker’s (2004) experience of being “all shook up” doing mental health research in psychiatric wards demonstrates that the goal of research is not just about trying to change policies and legislation, or even understanding how to see people differently, but also trying to work through our lack of knowledge, so that we can work with survivors in new ways. It was eye-opening for Secker (2004), a psychiatric nurse, to learn that people who fit the diagnostic criteria of mental illness can live fulfilling and normal lives without becoming distressed or requiring treatment. Recovery, in this work and other research (Bentall, 2003; Kruger, 2000), moved beyond the clinical sense of word as the freedom from symptoms but was now measured according to the fulfillment survivors experienced in their lives.

Different forms of expertise can certainly compete in mental health systems when there are strict hierarchies constituting what counts as epistemologically sound research (Faulkner, 2017; Smith et al., 2008). Even though imbalances of power between caregivers and service users remain complex and difficult to measure (Beresford, 2005; Lofgren, Hewitt, & das Nair, 2015), Faulkner and Thomas (2002) see the possibility for there to be a marriage of evidence based on experience and professional expertise. Gillard, Simons, Turner, Lucock, and Edwards (2012) put this claim into practice by designing their research in a reflexive way that involved a range of scientific and nonscientific expertise, was less hierarchal, and moved “away from academically led research institutionalized within the university” (p. 1132). Participants in the study helped with the coding of data, which helped the researchers strengthen the validity and complexity of their analysis.

Drawing on Russo (2016), Kelly (2016) sees the lines of insider/outsider and survivor/expert as more blurred (see also Blix, 2015). They emphasize the importance of developing critical reflexivity measures and ethics of engagement in the research process as a way of developing dialogic relationships that diminish the potential for symbolic violence. Something as simple as fostering good communication practices between health-care professionals and survivors can preserve the kind of dignity, respect, and transparency needed to build an intimate and trusting research relationship (Schneider et al., 2004). This is not to say that negotiating the politics and tensions of identity in mad studies and disability research is an easy task. Fawcett and Hearn (2004) stress that the measures of deciding what counts as legitimate, truthful, and authoritative research is a messy process, and one that must be evaluated on a case-by-case basis.

Particular political and policy agendas, whether more or less anti-oppressive and anti-exploitative will undoubtedly have a bearing on how the research is viewed. There are clearly no simple solutions to the dilemmas posed. Research carried out into disability by a disabled researcher cannot on the basis of experience alone be seen to be more legitimate than research carried out into disability by a non-disabled researcher. It is how the research project is

conducted, how the participants are involved, how attention is paid to ethical issues and the extent of critical reflexivity, that have to be regarded as key factors. These aspects in turn need to be subject to ongoing critical appraisal at each stage of the research. (p. 216)

Taking these considerations seriously, this article will critically reflect on the ways in which being mad shaped the phases of the research process and built relations with service users during interview encounters. I use reflexivity as a means of turning

the researcher lens back onto oneself to recognize and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation. (Berger, 2015, p. 220)

I fill a gap in the emerging mad studies literature by exploring my own self-disclosure, that is to say, how I put my own mental health struggles and trauma on the table with my participants. I demonstrate how those experiences helped me to recover, and with the help of fellow survivors, cocreate an appraisal and critique of the Canadian mental health system and its actors.

Methodology: Narrative Inquiry

This research was grounded in a narrative framework of inquiry,² which is a fusion of interdisciplinary and disciplinary approaches to research, methods, and analytic lenses that gravitate around an interest in “biographical particulars as narrated by the ones who live them” (Chase, 2005, p. 651). The narrative turn in social sciences is broadly characterized as a movement from the locus of objectivity and postpositivist realism to that of subjectivity and interpretative constructions and analyses of meaning (Clandinin, 2007). Some mental health narratives can wield enough power to change culture and institutional practices, whether they circulate in policy documents, everyday talk, or various forms of media (McKenzie-Mohr & Lafrance, 2017). Both the sociological and psychological narrative traditions idealize storytelling “because narratives help people to organize their experiences into meaningful episodes that call upon cultural modes of reasoning and representation” (Fraser, 2004, p. 180). The ableist assumption that storytelling is the purest form of meaning-making has not been resolved since Bruner (1986) articulated the position; however, researchers in critical disability studies have recently turned to the idea that narratives (not limited to storytelling but also encompassing performative, artistic, and autoethnographic designs) can assist us in understanding the complexities of the social world of people who are not identified as able-bodied and able-minded (Smith & Sparkes, 2008). I adopted a post-structural narrative positioning, which means that I believe people narrate stories to others in order to convey their emotions, beliefs about the world, and the blurred ways of knowing that bring about messy accounts of lived experience and to “make sense of the

epiphanies or existential turning points in their lives” (Denzin, 1997, p. xvii).

Following this framework, I conducted 10 unstructured, narrative interviews with 10 people who experienced a serious mental affliction in their lifetime and whom also identified as having recovered (or partially recovered) from their suffering. I also wrote an autoethnographic chapter in my dissertation drawing on songs, poems, diary entries, and visual art I created during and after my mental health struggles. Narrative interviewing helps the researcher respond to different communication styles, avoids turning the interview into an extracting exercise, builds trust, provides participants with freedom in how they respond to and ask questions, and lastly, helps researchers account for and make sense of the politics involved in making knowledge (Fraser, 2004). Like many other types of qualitative research, the penultimate goal of narrative interviewing is not to be generalizable but reveal deeper meanings, biographies, and small and big stories that provide context to identities, all of which can stem from a small number of encounters (Anderson & Kirkpatrick, 2016; Bernhard, 2015). I do not see the small sample size of this research as a weakness but rather a shift in thinking more about how the micropolitical realms of experience and storying speak to some of the macro issues and structures shaping mental health experience (Johnston & Steckle, 2018; Newman, 2016).

Reflexivity and critical self-evaluation change researchers’ mind-sets and worldviews (Mauthner & Doucet, 2003) and help us strike a balance between personal and universal experiences (Berger, 2015). Especially for insider researchers who may have trouble articulating balanced, neutral points of view, practicing reflexivity allows researchers to take responsibility for their own situatedness and influences on the research process (Finefer-Rosenbluh, 2017). Practices of reflexivity encourage researchers to be thoughtful and considerate of the ethical implications of their positionality, as their subjectivities may come across as biased, egocentric, judgmental, or lack transparency (Hastings, 2010). Reflexivity also helps us see the world from alternative viewpoints, challenging us to make room for, and reflect on competing perspectives that our participants might share. This article traces how my own perspectives were (re)shaped or strengthened by the knowledge shared by fellow survivors.

The interviews lasted between 50 min and 2.25 hr, exclusive of taking short breaks. Seven of them were held in a private study room on campus that could not be overheard by other people, while the remaining three, at the request of the participants, were held at a public coffee shop and fast-food location. Before commencing the interviews, all of the participants signed an informed consent form outlining the project details, risks, and sensitive nature of the study. Participants were compensated with a \$20 (CAD) Tim Horton’s (coffee shop) gift card for their time, and this was advertised on the recruitment materials. Seven of the participants were recruited from posters I placed in various locations on two university campuses in Ottawa, Canada. The other three participants were recruited purposively, two being good friends of mine and the other

being somewhat of a public figure in my local community who does community-based mental health advocacy work. The interviews were confidential, and the participants’ names have been replaced with a pseudonym of my choosing.

The participants’ ages ranged from 20 to 35 years old. Four participants identified as women and six as men. Six of the participants were born in parts of Canada, one was born in Northern China, one in South Vietnam, one in Pakistan, and another was born in Nigeria. Nine of the 10 participants had come into contact with the mental health system, with three experiencing hospitalization (one for bipolar disorder [involuntary], one for suicidal ideation and attempts [voluntary], and one for eating disorder [voluntary]), and one recovered without any assistance from the formal mental health system. One person, however, only accessed counseling services for a couple of sessions before making the decision to discontinue because of financial worries. Another participant who was experiencing psychotic symptoms did reach out to psychiatric emergency services and requested hospitalization but was turned down because his issues were “determined” to be the result of his poor socioeconomic status. Seven of the participants accessed counseling services with a certified counselor or psychologist over the course of their mental health journey, and six engaged in psychiatric outpatient care and took medications (including the three who were hospitalized). Services were primarily accessed across Canada in four cities: Ottawa, Toronto, Montreal, and Sudbury.

I am a survivor of psychosis, which involves (among other things) auditory hallucinations, visual disturbances, and outbreaks of paranoid thinking and suspicion. I suffered from a psychotic break in 2013–2014 during my first attempt at doctoral studies that lasted about 5 months in varying intensities, and I was hospitalized for approximately 3 weeks during the acute phase of recovery. I was treated with medication for a year, and after experiencing a remission period of about 4 years (3 years without medication), I experienced another (milder) psychotic break in the winter of 2018. I currently take an anti-psychotic drug to deal with the symptoms, and I find that I manage quite well on it. In spite of this condition, I am a highly productive academic when at the top of my game and have published extensively on the topics of gender, mental health, and security. Like some of my participants, I delicately accept my label, reject the stigma attached to it, and do not allow it to deter me from being open and honest about my condition. I will now describe in this article how this experience shaped my relations with participants, the research process, and findings of the study.

Knowledge Production Through Self-Disclosure

Talking about mental illness and mental health is a cumbersome exercise. Overt and secreted stigmas mark survivors in ways that produce silence and fear. One primary worry is that our relationships will crumble or people will not fully appreciate or be able to understand what we went through if we make ourselves too vulnerable with self-disclosure. I grappled with a

lot of insecurity during my recovery from psychosis. I moved to Halifax, Canada, in 2014, and with all the new friends I made, I was hesitant to talk about what I was going through. What would they think of me? Would I be seen as a lesser human in their eyes? Would they still want to be my friend? Within my own family, I was also dealing with their newfound perceptions. I was no longer the person who was an all-star, funded academic on his way to bigger and brighter things. I was damaged, traumatized, and unstable, and many of them wondered if I would ever be the same again after a psychotic attack that caused a great deal of terror and grief to my wife and parents. While I was struggling to regain my identity and relationships with them, I could hardly feel animosity toward my family since they were also instrumental in seeing me through my treatment and recovery.

By the time I was doing my fieldwork, some of this stigma had lifted. At the comprehensive exam stage, I disclosed to my committee that I was doing mental health research because I wanted to put to rest some of my own traumatic experiences and try to make sense of it all in as deep a way as possible. I also wanted to meet people who had experienced similar events, so that I would feel less alone. And that is just what happened. During my interview encounters, especially with participants who I was meeting for the first time, I disclosed personal details about my mental health struggle to help make them feel at ease and build the rapport needed for them to open up to me about their experience. I shared with Doug, my first participant who is a friend of mine and identifies as bipolar, how my family made me feel during my recovery.

Interviewer: So how did your family take it when you had your break? Like you said what they wanted you to conform to was a little different than what you were willing to give up, right? I mean I went through that too, my parents were like “no get a job, you’re better now after a month” and I wasn’t. Um, you know for me it was like, I actually did want to do less, because I was just exhausted right. Were they supportive though, would you say, overall?

Doug: I, I think that . . . they humored me. Because I didn’t want to stop, but, so they would let me register and take classes. But, I think that they were hopeful it would work, but I don’t think any of them thought that it would have worked. Fun fact is that after I got my bachelor’s at [university]. My father told me like after I got my diploma basically that he didn’t think I’d ever be able to do it . . . so . . . although I didn’t feel like they showed it, I don’t think they really held up much hope that I would be able to do all that much . . . their expectations were pretty much non-existent.

Some members of my own family expected me to turn around quickly from what was a very disturbing psychological experience full of dark visions, hallucinations, paranoid thinking, and many on-going voices taunting and tormenting me. Encounters with the surreal changed my brain and grip on

reality, and even with psychiatric treatment, it took nearly a year for me to put into perspective the ideas I thought and believed were real. I was hardly ready to live in the “real world” again, let alone hold down a low-paying job that was quite different (and more degrading) than being a PhD student. Doug, on the other hand, had parents who did not think he would ever amount to anything because of his illness. His father was not secretive about his feelings, either, as he went so far as to tell Doug that he never thought it was in his capacity to become a university graduate.

I felt camaraderie between us as we worked out our feelings about our families’ demands, pressures, and viewpoints that did not align with what we thought of ourselves. Sometimes these damaging experiences resulted in laughter, and at other times anger, yet by opening up to one another in an interview setting, I could feel a deeper bond and friendship growing between us—one that produced revealing knowledge about family mental health narratives. After about 2 weeks of doing call center work, a job I had taken under pressure from my parents who I was living with at the time, I resigned. With my wife’s emotional and financial support, and eventually my parents’ acceptance, I took more time to recover. Doug likewise persevered and went on to graduate, despite his family’s infantilization and low expectations of him. Our shared stories demonstrate the capacity of mental health survivors to take control of their own recovery.

Yet it must be said that there is a lot of risk one can encounter when they go public as a mad person. Although they have been supportive, I risked my committee questioning my capacity and vulnerability to do mental health research. I risk being seen on the academic job market as a crazy person who should be feared and avoided. And my participants could have viewed me less as a researcher and more as an unstable character. They may have wanted more of a professional boundary between us, where my role should have been more of an active listener than co-participant. Even the mad have the capacity to stigmatize one another, so by going out on a limb and becoming that interpersonal with my participants, I could have lost the requisite trust needed to make my participants comfortable enough talking about serious mental illness.

Apart from that, I knew in advance that Doug had delved into the arts to help express his experiences with psychosis and recovery, so I asked him whether he thought that art could be construed as a “gift”—one that many who suffer mental health issues seem to access in their journey (Solli & Rolvsjord, 2015).

Interviewer: Did you feel it shaped your artistic endeavors, like—was there a gift from this too?

Doug: I used to write a lot of poetry and all kinds of stuff. I used to play like guitar and all that. But I dropped all of that. I think it still exists . . . so I don’t want to say it’s dead . . . I wrote one poem last year and I was really drunk and angry, and I just came out like that. It seems to me the only time I can kind of elicit that creative impulse or draw it out is with the help

of alcohol and suffering. But I've, I feel that I've like come at peace or I'm ok with the suffering so I don't have that urge anymore to like outwardly create something from that . . . I feel that you really have to . . . to suffer, I feel that there has to be some sort of torment. I just don't feel it anymore.

Interviewer: I hear you though. I think of my art and my music at least, it's pain. If it goes away I don't need to express it. I think you're on to something with that. You know, maybe that art was part of the journey to deal with it but yeah.

Doug: Yeah, it, it was instrumental I guess . . . when I first went through my first [psychotic] break and when things were . . . when I was in the trenches of it . . . there was so much going on and it's like I was . . . I needed to get it out like I, but . . . I've done the legwork, I don't do that anymore.

Prior to our interview, Doug had shown me several poems he had written about madness, which he later destroyed to put his past behind him. After going through years of getting a grip on his affliction, and managing the identity of being bipolar, Doug eventually found a way to live his life without experiencing the need to flush himself out through art. The acoustic rock album I pieced together in November, 2017 (Johnston, 2017), albeit difficult to record, allowed me to get out the emotions I had been bottling up and also served as a medium to express ineffable memories and feelings that words alone cannot adequately describe. I learned that art and suffering are not mutually exclusive. Even after a 4-year period of being (generally) psychosis free, my suffering was not yet over in November, 2017. I have found that toward the end of my doctoral research process, I too have become less musical, and this finding makes me believe that my recovery has progressed into a realm where I am not perpetually haunted and stirred by past events and emotional triggers. Having had psychotic breaks long before I experienced the phenomenon, Doug appeared to me as something of a mentor figure who could impact my own well-being, increase my psychological awareness, and put my experiences with mental illness into a broader, relational perspective.

Childhood abuse, stresses, and struggles can greatly impact mental health later in one's life (Choi, Reddy, & Spaulding, 2012). Most of my participants documented in grave detail their struggles growing up, which ranged from physical abuse on the part of parents, abnormal parental pressure to do well in school, domestic violence in the household, to intensive school bullying. I experienced bullying as a child and was assaulted on a number of occasions, both at school and in the household. I have often wondered whether these experiences changed my brain chemistry and made me more vulnerable to mental illness in my adult life. I disclosed some of these details to a participant whose mental health problems were closely related to her less-than-ideal social life at school.

Interviewer: So like I know for boys kind of getting bullied, you know, it can be physical violence, at least at my

age, like you said, there wasn't Internet bullying the same way but you get called gay all the time, or, if you're not popular, you have to kind of perform having friends, just to get through the day. You can make friends with kind of, an unpopular crowd, but then there's bullying within that We were called "the dirties," I recall.

Clara: Oh yeah, I remember hearing those terms . . . I'm like wow, it's unbelievable, it's like you can't feel secure in any friendship because you know the second you walk away, it's like what are you saying about me. And there was a lot of that. It's like the *Mean Girls* . . . take that movie and put it into high school, and yeah you see that.

Interviewer: When did you feel like this suffering was developing like into like a mental health problem?

Clara: Grade 9 and 10 is when it was full blown, I'd say half way through grade 9 is when it all kind of caught up with me. Um . . . that's when I started breaking down, and, grade 10, I would say is probably the worst year for depression. I never saw a psychologist, I never saw anyone for it, but yeah I started speaking to my mom I was basically asking like, I'd love to go see someone, I was like it's getting really bad, and we live in the country, so resources are next to none . . . there was nothing in regards to counselling, um . . . anything in the hospital, nothing mental health related whatsoever You have to go into the city. I grew up 45 minutes out of the city, and my parents were farmers so like again their hours, nothing was convenient for help.

There is a lot to reflect on in terms of how women and men experience mental health similarly and differently. I was concerned from the outset of the research that my presence as a larger, straight-White-cisgender male might have an intimidating presence on the women who participated in my study. Being vulnerable in that kind of space is daunting, especially among people who are meeting for the first time. In this case, disclosing to Clara that I had been bullied as a child made her more comfortable teaching me about some of the gender differences of bullying, and how this affected her mental health. Up to that point in the interview, we had not spoken directly about mental health or her depression, and my narrative provided a segue for talking about experiences more related to my research question. Some might question the risks of having an unstructured interview, but by allowing the questions and probes to come naturally, and allowing the participant to take their time before disclosing details about their personal lives, the interviews became a safer and more fruitful space.

Although this was the result, coming forward with my past traumas risked triggering both myself and my participants. It is never easy reliving past pain, and there was a chance that sharing these details may have caused my participants to experience discomfort rather than solidarity. I also gambled making the interviews more of a space to go off on tangents rather than extract precious stories and knowledge from the survivors. I did

not intend to make these encounters all about me, but I found myself, out of empathy and interest, unable to restrain myself at times from sharing my accounts of personhood that related to my participants. This certainly has epistemological implications, as Berger (2015) and Taylor (2011) warn that personal biases may trouble and nuance the knowledge shared. Ethically, I owed my participants the space to ensure that their full story could be heard rather than have them to listen to mine. The unstructured nature of the interviews really facilitated the shared dialogue routine that materialized between us, and I would recommend researchers drawing on this technique to be mindful of their positionality during the interviews, constantly reflecting on how much they are speaking and listening. There is a balance to be struck, but one that can only be mediated through complex systems of relationality and intuition.

Yet by not having a “list” in front of me that I worked through, it also gave me the flexibility to know when not to ask a question. In one instance, I could tell when my participant who identified as female did not want to elaborate on the uncomfortable questions her psychologist and psychiatrist would ask her.

Heather: Most of the time, like I would just be honest but there were some things I was just no, I’m not answering that question.

Interviewer: So you’d just say something and then that moved the conversation on. Yeah . . . were you worried that would impact the drug you’d got, or you’d just think it’s a bullshit question? Irrelevant.

Heather: uh . . . I mean I’m sure some of the questions affected what medicine I got but uh . . . I’d rather just . . . not answer it and get slightly different medication than answer the question.

Interviewer: . . . Well it’s hard right, a stranger . . . so you don’t necessarily know and then you . . . all of a sudden you have to reveal aspects of your life . . . like people with mental health suffering, should be entitled to that kind of secretness. Like, should be able to keep some things to themselves and go through that then have to be this open book.

This was a moment in the interview encounter where the gendered differences between the participant and I created a need for question avoidance to keep the space safe. Having been asked questions by mental health professionals about my sex life and traumatic details about my symptoms—details I did not always admit to due to concerns with embarrassment or fear they might assess me as dangerous—I had a deep respect for the personal boundaries of my participants. I was not going to probe what exactly the professional asked her, as it was just something I did not feel I needed to know.

In contrast, there were times when I took a risk with questioning. All of the interviews were sensitive in nature, and sometimes there was little point in beating around the bush. To demonstrate, I asked one participant, who suffered from an

eating disorder during her adolescence and had many bouts with depression, what hospitalization was like for her.

Interviewer: So what was that like for you, you have to go to the hospital?

Hannah: It was pretty impactful, on my life in general probably because it’s something that I am still like, like it’s something that I wouldn’t necessarily tell most people I guess.

Interviewer: No I’ve been in there too and it’s uh . . . a lot of people I talk to sometimes, they think it’s something to be ashamed of or maybe the experience wasn’t so good and it’s bad memory . . . you know there’s this division between this mental health patient and this person, did you feel that at the time or just kind of now?

Hannah: So, I was a little different cuz I was still technically a kid at the time. And because I was so like, physically ill too. I wasn’t actually in like a mental health unit, I was in a physical, like a general hospital until they could get me like, stabilized I guess. And then I was in mental health addiction center in [city] and um . . . I actually found it amazing. They were so good, they had a whole like unit for eating disorder specifically. Um . . . but then, they didn’t just deal with like the food cuz it’s not really about the food anyways it’s about like you know, you’re trying to control your life or like deal with things you can’t control.

This was another opportunity where admitting that I too had been hospitalized (mostly against my will) made me a person worthy to be told her story about hospitalization. While I believed participants were going to be at least upfront about some aspects of their story, since they knew beforehand the study was about their experiences with mental illness, it is sometimes what we do not tell that hurts us the most. I felt a great deal of relief getting my story out and building trust between other survivors and using my own experiences to give them the necessary security to discuss their personal afflictions. In this case, Hannah’s experience of hospitalization was successful and really provided her with a turning point in her life. Both her family and professionals were there for her and saw her through her recovery.

I would have preferred to live out my recovery in the comfort of my parent’s home, but my psychiatrist felt I was too lost and sick for that to be a safe option in the beginning stage of recovery. Up to this point, I had viewed involuntary hospitalization as generally a bad thing (or lesser evil) since I believed that patients’ freedom and autonomy is a necessary dignity that should be valued and respected at all costs. Hannah’s story, however, gave me hope that the mental hospital can reshape lives and heal people, despite its many drawbacks and intensive security protocols that can hinder dignity and human rights (Johnston & Kilty, 2014, 2016).

That being said, I have not always agreed with my participants in the past about mental health issues and practices nor

chose to learn from them (Johnston, 2016). Having worked in a psychiatric ward setting as a security guard, I openly disagreed with my former colleagues who I interviewed for my master's-level research about their views pertaining to how psychiatric inpatients should be managed in hospitals. Engaging in critical dialogue with our participants carries a great deal of ethical risks, since after all, they are the ones giving you the time of day to share their stories. Coming from this background, I went into this research with the idea that I would not do that again, even if I found tensions in what my participants were saying. The epistemic benefits of critical dialogue did not overshadow the fact that I was now working with a vulnerable population who I had to be sensitive to. By sharing my personal testimony, I risked them disagreeing with me, and thus, I was aware of the need to redirect any potential conflict back to the point of the interviews, which was to listen and cocreate mental health knowledge safely. The loss in situating myself this way was that I could not ask certain questions I wanted answers to. For instance, many of my participants who described tension with how their psychiatrist treated and framed their mental health problem complied nonetheless with their directions because they felt it was important to follow their doctor's orders and authority. I could have said, "why did you not resist this more overtly?" but by avoiding this impulsion, I respected my participants' autonomy to make decisions about their own care and live with them.

Developing a Survivor-Centered Mental Health Critique

Many of the antipsychiatric pioneers wrote from a (sometimes polemical) first-person perspective (Guattari, 1996; Szasz, 1972, 2004). The limits of this kind of individualist thinking about a system that is responsible for the safety and treatment of many different lives certainly hold its drawbacks and concerns (Schaler, 2004). As I just mentioned, I went into this research with many preconceptions, some of which were strengthened, while others were washed away as I learned about experiences that contradicted my own. Still, I did feel during the interviews that I could reveal my opinions when necessary, which facilitated the cocreation of survivor-centered mental health knowledge. Through gentle story sharing and light rebuttals that did not breach any ethical responsibilities, we built a critique of the mental health system that was nuanced and measured.

One of the reasons I did not enjoy hospitalization was because I found it difficult to cope with all of the people around me who were also suffering and, given their distress, environment, and circumstances, were not, for the most part, polite or accommodating. I found it easy to get along with my participants, but it was challenging to engage with survivors in a psychiatric ward when trying to recover was at the forefront of my mind. Remembering this experience, I asked Doug what he thought about hospitalization, and rather than condemn it totally, he showed me how the experience can also be an important opportunity for self-reflection.

Interviewer: What you do think about that idea of taking people who are mentally ill and putting them all in a room together? What do you think about that having gone through it?

Doug: I think it's pretty crazy. But . . . I'm sorry (laughs).

Interviewer: No it's ok. We're survivors. We can call it inside humor. It's all good.

Doug: I think it's good . . . I'm not saying it's the best one, but I can say that being forced to look at it . . . it's kind of like holding the mirror to your own behavior. Because, if someone is doing something that's like really awful, off the wall, like it's upsetting you, like this person is so stupid. Like hopefully at one point we're gonna stop and think well . . . I'm also bipolar like that's . . . that's me, like, I do that shit. It forces you to confront who you are and the effects of the illness . . . if you don't hate that person for acting that way because you understand what's going on . . . you learn not to hate yourself as much.

Doug's words reminded me of an incident when a psychiatric patient who was labeled as bipolar kept walking into my room without my permission. I asked her a few times to stop, and when she didn't, I told her off quite sternly. I am sure that I hurt her feelings, but in reflecting on Doug's commentary, it reminds me of the people I upset and annoyed while psychotic. There is much debate over the level of autonomy that patients should be circumscribed during episodes of madness. Perhaps some things are just not a person's fault, and when we accept this, it becomes easier to forgive ourselves. Doug's point is that rounding up several mental health sufferers into a room may at first glance appear to be an unhealthy and even wild scenario, but it also provides the survivors with an opportunity to learn from and even support one another when possible. This narrative made me look back on my low point of enduring psychiatric incarceration with more ease and sound judgment, and I am liberated from previous thinking that tended to always/already label hospitalization as a curse.

I was astounded by how profound some of the survivors' insights were into their varying conditions, some of which nuanced or challenged dominant biomedical understandings. Heather, an undergraduate neuroscience major, discussed some of the problematic ways that labels become rendered on people who may not neatly fit the categories.

Interviewer: There are challenges, there's people, myself included . . . sometimes those labels can do more harm than good, right, especially if the person doesn't identify with that. Do you think your label matches what you have, like if someone was to have say depression and anxiety, how would you feel about that?

Heather: Well . . . I don't agree that it should be two separate labels. Because there's a lot of times when the depression and anxiety do go together. And a lot of people have both. And I feel like people who have

both is, it's different than having, this is depression, this is anxiety . . . like . . . the depression affects the anxiety, and the anxiety affects the depression. So I feel like it's its own category. Like it's different than having two separate things because they interact with each other.

Interviewer: That's pretty profound . . . Would you feel comfortable telling your psychiatrist that?

Heather: I just don't see what the point would be . . . that's . . . "your opinion" I don't see what you want me to do with it.

Interviewer: "I'm the expert." Ok, yeah . . . So . . . have you always had that kind of understanding of this . . . or for a while were you just buying into what you were being told by the professionals?

Heather: I always knew I always had depression, and then I didn't realize it was anxiety until they told me it was anxiety. And then . . . like as I was educated in university . . . I was like well . . . knowing what depression, knowing what anxiety is, considered in medical terms, I don't feel like that's the right definition.

Heather, who is not a doctor but has scientific knowledge, does not align with some critical psychiatric thinkers who at times address labels as being, more or less, always/already stigmatizing or unneeded (Burstow, 2016). She instead shares some profound insights into how the diagnostic categories could be improved based on her experiences with depression and anxiety. When I threw the idea out there that mental health labels may do more harm than good, it catapulted into a reformist discussion about how to properly hand them down, rather than abolish them, from social and medical conventions and sociality. The knowledge she shared here, with a fellow survivor, is not something she felt she could tell her psychiatrist or health professional because of the power dynamics involved in her treatment. She never felt comfortable telling her psychiatrist to switch her medication to something that would treat her anxiety primarily and deferred to her professional caregiver's concern that treating depression was more important because of the risk of suicidal ideation.

In addition to concerns raised about hospitalization and medical labeling, most participants lamented at some point in our conversation about the stigma they feel or fear. No matter the number of community initiatives or social media awareness campaigns, people who have experienced a serious mental disorder are always going to have to live with the fear that others will think that they are crazy and therefore a less valuable human being. Toward the end of the interview, Aisha, who suffered from self-injurious practices, depression, and suicidal ideation, spoke against this stigma.

Interviewer: You felt stigma?

Aisha: A lot. So much.

Interviewer: Yeah, we all do. That's not right though.

Aisha: It's really not right. It's just not fair, you know? Um, especially because, I've lost friends because

of this . . . people who were like you know, you're just too depressing so even if I don't talk to them about it, they're just like "no your body language is just too depressing," or you know we don't want to deal with this. I'm dealing with it, you don't have to, you can just walk out the room.

Interviewer: So they stopped the friendship?

Aisha: Yeah . . . So I've always been kind of . . . I'm very careful now.

Interviewer: It probably made it harder to open up about it because you're wondering—

Aisha: Oh yeah. But um, now it's a lot easier for me to talk about it, I've gotten through this without crying once, that's a big difference.

I felt both discomfort and solidarity as we shared our anger and frustration over the injustice of losing friendships and the positive perceptions people once held of us when they thought we were "normal." The two types of stigma resistance Thoits (2011) researched consisted of challenging and deflecting. Challenging involves opposing other people's negative attitudes toward their character, illness, or way of being, while deflecting consists of rebuking others' stereotypes as inapplicable to themselves. In both our cases, we never really directly confronted the way we felt toward those stigmatizing us but instead shared our concerns survivor-to-survivor. This "survivor support" reminded both of us that while the hardships of encountering mental health suffering will always feel very real and can lower our self-esteem, that does not make them right or valid. People should not have to lose relationships because they are sick or present differently, and the focus on the illness or character takes away from how hard survivors work to get a grip on their lives. By calling out these issues, we overcame, even if only for a moment, the everyday stigma that continues to have a grip on our lives.

Still, Aisha describing how she was holding back tears suggests that these epiphanies do not come without pain. Her interview was especially challenging for me to listen to, as she described in detail her practices of self-injury and abandonment from friends. She was the ninth person I interviewed of the 10, and I recall in the moments of our conversation wishing for the research to be over, and seriously questioning how much more agony I could listen to and relive. Researchers often abandon their participants following the completion of the study, and her words made me seriously interrogate my responsibility to stay in touch with my participants and show them the results of the study. When we do research with vulnerable populations, we can forget that our vulnerability does not go away through catharsis. We still have to live on in a stigmatizing world and continue to confront our mental health challenges. And we have to admit our own limitations as researchers to provide all the comforts and social support for fellow survivors, and work through these difficulties as best as we can. Thus, I made a decision after this interview that I would complete the study after securing a 10th participant, and this prevented me from

experiencing serious burnout, which could have impacted other participants.

Departing on Empowerment

One of the drawbacks to carrying out unstructured interviews is that we cannot predict or plan, with much detail, how they will end. Mental health narratives are rhizomatic; no matter how they spin, flip, yo-yo, or digress, they are going to be sensitive and difficult to share and listen to. At the end of some of our discussions, I told my participants how much their stories meant to me. This research was not just about changing other's lives; it was definitely something I had to do for myself. I did not plan to engage in as much self-disclosure as I did, but the participants drew it out of me. In that sense, I was as much a participant of this study as they were.

Perhaps it was because I wanted to be, or perhaps my participants were curious after I told them I was a fellow survivor what exactly my story was. Nonetheless, the relational dynamics we engaged together made me feel that there was a higher purpose in this research beyond completing a dissertation. We were meant to help each other, to learn from one another, and gain the hope that our suffering could be used to help others conquer their challenges in the here and now. However brief they were, our encounters were much more than research interviews. They were the beginnings of friendships and the creation of memories I can look back on and realize have a greater sense of purpose and meaning.

I told Edgar these very things after hearing his story that involved a great deal of child abuse, domestic violence, bullying, and what I felt were psychotic experiences with alternative realities and artistic endeavors of escape such as film making and story writing.

Interviewer: One of the things that is, I was gonna ask you is... what would you say to somebody kind of going through something similar... they've got some of the same problems and they're trying to find some way to cope, what kind of advice of would you give them?

Edgar: Well... I'll tell anyone that's going through that... they don't have to go through that alone. And I'd even offer to support the person, if they need a friend I'll be there... To be honest... if I had a time machine and I travelled back in time I probably go and tell my younger self that... at a time when I had fake friends that it was, there's no point clinging to people that don't care about you. That life goes on. And that... my present would be, my future would be influenced by... decisions I make.

Interviewer: Yeah. That's amazing. I mean a bit of my story... I didn't have like a ton of friends either in school- it was kind of hard, but in 2013 I had psychosis, I just like slipped from reality and it was a really intense period. But unlike yourself I just didn't have sort of any control... but I've found I've been

trying to make sense of that event for quite a few years now and sort of like yourself... I think like the art accesses something that helps makes sense of that. And just you know, hearing your story, um... kind of gives me the same kind of hope because I think it's amazing how people get through life. Considering all these circumstances like yourself you just didn't have a lot of help and uh, the fact that you can say I'm gonna be a support for somebody or... you don't have to go through it alone, that's pretty empowering right, because I don't think you can say that if you hadn't gone through something like that... I just think that's really powerful, and you know, like it will help people, and I appreciate that.

Giving thanks to Edgar allowed me to see just how much this research and mental health experience impacted my life. It also revealed to me the greater purpose of the study, which was to help people such as myself realize they are not alone in their struggle, and that they can use traumatic experiences to help others recover and become empowered. Leaving this discussion on that note made the interview encounter not just about research but also about friendship and love.

Conclusion

Doing mental health research as an insider means that you may have to confront your personal tragedies, help others navigate theirs, and be willing to create a mutual kind of data that do not invalidate contradictory experiences but rather marries them to the wide spectrum of user knowledge. This study fills a gap in the extant literature on insider-outsider relations in mental health research (Berger, 2015; Gillard, Simons, Turner, Lucock, & Edwards, 2012; Kelly, 2016; Prestwich, 2012; Schneider, 2012; Secker, 2004; Taylor, 2011) by showcasing how periods of self-disclosure, critique, and empowerment shaped knowledge production, improved my own recovery, and led to intense periods of reflection. I have demonstrated that mental health research and writing can be as therapeutic and liberating as it is traumatic and cumbersome.

More specifically, practices of self-disclosure allowed me to explore and vent about family relations, and how survivors navigate their expectations as they recover and regain a sense of identity through self-reflection or art. The unstructured nature of the interviews allowed the mental health narratives to evolve at an organic pace, which made the interview setting more comfortable for participants and helped me build trust with them, especially if I was meeting them for the first time. Doing insider research also helped me overcome the periods of embarrassment in my psychosis, such as involuntary hospitalization. I learned through critical dialogue how traumatic events can provide avenues for intense self-reflection and the development of greater empathy for mental health survivors who become confined because of their suffering or presentation of self.

While there are several positive implications for doing insider research in the field of mental health, researchers must be weary of the ethical risks they pose. Particularly, self-disclosing traumatic events or ideas about the mental health systems can be triggering for both participants and the researcher. Researchers have to be comfortable enough in their own skin to engage in reflexive dialogue, so as not to jeopardize the trust that is needed from participants to be able to disclose very personal narratives. They must also interrogate their responsibilities to follow-up with participants in meaningful ways and ensure that the interview setting facilitates listening to participants rather than a venting session for the researcher.

Overall, this research shows how insider relations provide an important opportunity for the creation of a survivor-based mental health knowledge that is empowering and resists the stigmas of everyday life—stigmas that, while very powerful, can be overcome. On a more general level, the insider perspective is useful to researchers across all disciplines, as it invites them to get to know their researcher identities in greater depth. These realizations may help them overcome aspects of their life that they carry into the research—problems, situations, and traumas that cannot be ignored but must be taken up critically so as to produce a more situated knowledge. We should not be afraid to research what we know and have lived. In fact, our ingrained capacities to be reflexive demand it. It is not narcissistic to do so either, but rather demonstrates the researcher's ability to take what they have learned and experienced in life, and locate it in the universal plains of truth. We can take our suffering, make meaning of it, and transform it into knowledge. It is with these new understandings that we become more learned beings and greater than we ever imagined.


Declaration of Conflicting Interests

The author(s) declare no potential conflicts of interests with respect to the 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: The author wishes to thank the Ontario Graduate Scholarship Program for the funding provided during the second and third year of his doctoral program.

ORCID iD

Matthew S. Johnston  <https://orcid.org/0000-0003-0622-2838>

Notes

1. I have not totally avoided using the terms “mentally ill” or “patient” in this article, although like Boschma (2007) and Landry (2017), I am aware of the socially and culturally constructed use of the term. Using these terms implies knowledge that there is always cooperation between a person and their caregiver, when in reality, we cannot assume that each person who experiences mental pain, anguish, and suffering accepts that they are ill or wishes to be treated in accordance with the established psychiatric diagnoses, treatments, and discourses available. With tension remaining, I

tend to refer to these people as “people,” “mental health sufferers,” “service users,” and “psychiatric survivors” who suffer mental “afflictions” or “mind problems.”

2. This study was approved by Carleton University's Research Ethics Board-A (CUREB-A, Project, #108479).

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