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Troubling Service User Involvement in Health Professional Education: Toward Epistemic Justice

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Abstract

It has become increasingly popular in health professional education to solicit the contributions and involvement of people who have firsthand or ‘lived’ experiences of using mental health services – a practice hereafter referred to as *service user involvement* (SUI). SUI is founded on the premise that service users ought to be involved in the development and evaluation of services and systems they experience, which includes the education of future health professionals. Despite the momentum this practice has gained in a range of international contexts, SUI is often conceptualized, organized, and implemented uncritically and with tremendous inconsistency across health professional education contexts. This research adopts a postcritical ethnographic methodology to: (i) deepen understandings of stakeholders’ diverse experiences of SUI, and to (ii) critically examine whether current approaches to SUI support service user educators’ meaningful involvement as *knowers* in health professional education.

The body of this dissertation is comprised of four integrated manuscripts, which aim to deepen and complicate understandings of the ways SUI is approached and experienced. The first manuscript is a theoretical chapter that elucidates the links between epistemic injustice and sanism in considerations of the marginalization of service user (or Mad) knowledge. The second manuscript reports on findings related to the practice of storytelling in SUI, which was identified as a central theme in how service user educators’ knowledge is conceptualized and shared within health professional education. The third manuscript explores one of the most common risks or concerns related to engaging in SUI: tokenism. This chapter draws on the ethnographic data to consider service user- and health professional- educators’ perspectives on tokenism (or lack thereof) in SUI. The fourth manuscript offers a reflexive examination grounded in my firsthand experiences as a service user- and sessional health professional- educator, in conversation with the ethnographic data.

This work contributes to important ongoing conversations around experiential or service user-produced knowledge and its uptake by/within the health professions and stands to inform a range of stakeholders (e.g., service user- and health professional- educators, curriculum committees, administration, policy makers, researchers, etc.) who may be interested in critically engaging in the practice of SUI.

Keywords

Service User Involvement; Health Professional Education; Mental Health; Mad Studies; Mad Pedagogy; Critical Pedagogy; Epistemic Injustice; Sanism; Postcritical Ethnography; Reflexivity

Summary for Lay Audience

It has become increasingly popular in health professional education to solicit the contributions and involvement of people who have firsthand or ‘lived’ experiences of using mental health services – a practice hereafter referred to as *service user involvement* (SUI). SUI recognizes that service users ought to be involved in the development and evaluation of the services and systems they experience, which includes the education of future health professionals. Despite the momentum this practice has gained in a range of international contexts, SUI is often understood and approached uncritically and carried out with tremendous inconsistency across health professional education contexts. Presented in an integrated article format, this research draws from a variety of stakeholder perspectives (collected through in-depth interviews, participant observation, and reflexive writing) to: (i) deepen understandings of the ways SUI is experienced, and to (ii) critically examine current approaches to its practice. This work contributes to important ongoing conversations around experiential or service user-produced knowledge and its uptake by/within the health professions, and stands to inform a range of stakeholders (e.g., service user and health professional educators, curriculum committees, administration, policy makers, researchers, etc.) who may be interested in critically engaging in the practice of SUI.

Co-Authorship Statement

I, Stephanie Maureen LeBlanc-Omstead, acknowledge that this thesis includes three integrated manuscripts that evolved as a result of collaborative endeavors. In these manuscripts, the primary intellectual contributions were made by the first author who: (i) led the design and execution of the research (i.e., researched the methodology; developed the ethics application; conducted the literature reviews; established relationships with gatekeepers; carried out participant recruitment, data collection, transcription and coding), (ii) led the data analysis; and (iii) led the writing of the manuscripts. The contribution of Dr. Elizabeth Anne Kinsella was through supervision of the design and conduct of the research, theoretical and methodological guidance, reflexive dialogue throughout the process, and intellectual and editorial support in crafting the work for publication. As Dr. Kinsella is acknowledged as co-author for the purposes of publication, these three manuscripts (Chapters 2, 5, and 6) are written in a first-person plural voice (i.e. we, our).

Dedication

This work is dedicated to my Maura bird.

Make waves, my love.

Acknowledgments

I owe many thanks, to many people. First, this work would not have been possible without the experiential knowledge so generously shared with me by my participants. To all of you: thank you for trusting me with your knowledge; I have strived to honour it (and you) in my (re)presentation of your stories and experiences. Thank you for your generosity and willingness to engage with this project toward reimagining a more just practice of service user involvement.

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Maura, when I learned that you were on your way I was sure I was nearing the end of this journey. But, your entrance into the world dramatically shifted the course of my life and this work. Being your mother has made me kinder and gentler, and instilled in me an even stronger conviction that this world can be made better. Thank you for bringing joy, newfound curiosity and openness, and much needed balance to my life. Joshua, my love, thank you for your unwavering support and constant encouragement to stay the course. Thank you for keeping me laughing, fed, and cared for; and for minimizing my distractions. Thank you for celebrating my achievements as if they were your own; for wiping my tears; and holding me when there were no words. This journey has been long and winding – at times all-consuming – and I see and appreciate all that you’ve sacrificed in support of my growth. Your involvement in all of this means more to me than you’ll ever know.

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Glossary

Term	**Definition**
Contributory Injustice	A form of epistemic injustice which occurs through the systemic dismissal of the knowledge and language developed within marginalized communities by those situated more dominantly.[1] In the case of contributory injustice, marginally situated knowers are often able to make sense of and articulate aspects of their experience relatively effortlessly among themselves (formulating language, concepts, and insights), yet remain unable to communicate these with the same ease or effectiveness in mainstream discourse.[2]
C/S/X	An acronym for 'consumer,' 'survivor,' 'ex-patient;' all of which signify particular identity politics or relations to the psychiatric system.[3]
Discursive Confinement	Used here to refer to the way service user educators' knowledge and stories – irrespective of their intended meaning – are understood by audiences according to institutional context and available language, limiting what this knowledge can *do* in health professional education.[4] As a result of discursive confinement, "even explicit critique of the mental health system, when expressed within the terms it produces and recognizes, can end up supporting its authority."[4]
Epistemic Communities	A diverse network (formally or informally) of knowers who share common values, beliefs, and/or standpoints related to a particular social issue.

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[1] Miller Tate, A. J. (2019). Contributory injustice in psychiatry. *Journal of medical ethics*, *45*(2), 97-100.

[2] Pohlhaus, G. (2012). Relational knowing and epistemic injustice: Toward a theory of willful hermeneutical ignorance. *Hypatia, 27*(4), 715-735.

[3] LeFrançois, B. A., Menzies, R., & Reaume, G. (Eds.). (2013). *Mad matters: A critical reader in Canadian mad studies*. Canadian Scholars' Press. (pp. 335).

[4] Voronka, J., & Grant, J. (2021). Service user storytelling in social work education: goals, constraints, strategies, and risks. *Social Work Education* (p. 12).

Epistemic Injustice	Epistemic injustice refers to the distinct wrong done to someone in their capacity as a *knower*; restricting their ability to engage in the basic everyday practices of knowing, conveying knowledge to others, and making sense of personal and social experiences.[5] Due to unequal epistemic power relations, certain groups have greater power to determine what constitutes valid knowledge, and whose knowledge should count.[6] Epistemic injustice is taken up in this work as it relates to individuals and communities affected by 'sanism,' or who have received diagnoses or treatment from the mental health system.
Epistemic Objectification	When a person is treated as less than a full epistemic subject; in some cases this involves a denial of someone's epistemic agency.[7]
Hermeneutical Injustice	Occurs when groups of people are wronged in their capacities as subjects of social understanding through structural prejudices which impact the production of (and access to) interpretive resources (language, concepts, theories, etc.) needed to make sense of their social experiences.[5]
Hermeneutic Lacunae	Absences of proper interpretations, language or concepts; blanks where there should be a name for an experience which it is in the interests of the subject to be able to render communicatively intelligible.[5]
Mad	A reclaimed, politicized term to describe broader social, cultural, and liberatory approaches to thinking about and responding to medicalized experiences of mental distress and diversity (widely known as 'mental illness' within psy-systems).[8]

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[5] Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.

[6] Kidd, I. J., Medina, J., & Pohlhaus, G. (2017). *Introduction to the Routledge handbook of epistemic injustice* (pp. 1-9). Routledge.

[7] McGlynn, A. (2019). Epistemic objectification as the primary harm of testimonial injustice. *Episteme, 18*(2), 160-176.

[8] LeFrançois, B. A., Menzies, R., & Reaume, G. (Eds.). (2013). *Mad matters: A critical reader in Canadian mad studies*. Canadian Scholars' Press. (pp. 337).

Mad Studies	A field of scholarship, theory and activism about the lived experiences, history, cultures, and politics of people who may identify as Mad, mentally ill, psychiatric survivors, consumers, service users, patients, neurodivergent, and disabled. Mad studies refers to a body of knowledge that has emerged from psychiatric survivors, Mad-identified people, antipsychiatry academics and activists, critical psy- professionals and radical therapists. This body of knowledge is wide ranging and includes scholarship that is critical of the mental health system and biomedical approaches to the domain widely known as 'mental illness' or 'mental health' and substitutes instead a framework of 'madness.'[8,9]
Testimonial Injustice	Occurs when a speaker is undermined in their capacity as a giver of knowledge, owing to an identity prejudice held by the hearer, impacting the hearer's judgement of the speaker's credibility. The cause of testimonial injustice is a prejudice through which the speaker is misjudged and perceived as epistemically lesser.[5]
Testimonial Smothering	The truncating of one's own testimony in order to ensure that the testimony contains only content for which one's audience demonstrates testimonial competence, or the ability to 'hear.'[10]

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[9] Beresford, P. (2020). 'Mad', Mad studies and advancing inclusive resistance. *Disability & Society*, *35*(8), 1337-1342.

[10] Dotson, K. (2011). Tracking epistemic violence, tracking practices of silencing. *Hypatia*, *26*(2), 236-257.

1 Introduction

In some ways this dissertation began its life as a conversation had with a dear friend and colleague around tensions I felt related to the involvement of *service users educators* in my schooling as an occupational therapy student – a practice hereafter referred to as *service user involvement* (SUI) – which would later resonate with my own experiences in the roles of service user- and health professional educator. I had just begun to make sense of these tensions theoretically; a reflexive endeavour spurred by my introduction to the field of Mad Studies (in my first term as a doctoral student), which led me to the growing body of service user-produced and SUI-focused literature. As I pored over this literature I began to find language and concepts to make meaning of my experiences; concepts like sanism (Poole & Jivraj, 2015), tokenism (McCutcheon & Gormley, 2014; McKeown, Dix, Jones, et al., 2014), representativeness (Beresford & Campbell, 1994) and strategic essentialism (Voronka, 2016), objectification, co-optation, and exploitation (Costa, Voronka, Landry, et al., 2012).

I started to receive invitations to share my experiential knowledge with health and social care professional students (e.g., in social work, psychology, occupational therapy, physiotherapy, speech pathology, and Disability studies) around the time I entered the PhD program. I also began sharing this knowledge on my own accord to help elucidate more abstract concepts in my writing and conference presentations (e.g., on sanism, politics of disclosure, and epistemic injustice). Some educators extended invitations asking that I share my experiences of ‘mental illness’ or madness, and in particular, the ways I was navigating professional practice as an occupational therapist and as a maddened woman. Others asked me to quite literally share my ‘life story’ with their students, including experiences extending back to my childhood, as well as details related to what ‘managing’ my madness has looked like over time. With little to no debriefing following most of these involvement activities – despite my repeated requests for such, and for students’ feedback – I cannot confidently say whether my knowledge contributions aligned with the educators’ hopes or expectations. But if I had to guess, I would suspect they did not (at least not entirely).

For the ‘story’ I wished to tell was not one of adversity and triumph, *overcoming* ‘severe and persistent mental illness,’ or ‘defying the odds;’ but one that might help students, faculty and already practicing health professionals better understand the real life implications of things like sanist oppression and microaggressions, coercion, medical gaslighting, the ethical responsibility professionals have to those they serve, and the powerful influence (positive or negative) of the therapeutic relationship. Each time I prepared to deliver a guest lecture grounded in my lived experience I pried for information about learning objectives, details about the class, and the context of the course more broadly (i.e., where were students *at* in their learning, and where were they going?). On rare occasion the course syllabus or details of the reflective assignment that would accompany my lecture would be shared with me. Some of the tensions I experienced as a service user educator included (but were not limited to):

> a lack of clarity around exactly *what* was being asked of me and *why* my experiential knowledge was being solicited;
>
> a felt sense that my objectives were not in alignment with the course instructor’s, and that the involvement activity lacked adequate *epistemic space* for the things I wanted to discuss;
>
> and, internal conflict related to this felt sense, which often meant grappling with whether I should participate at all or accept engaging in a degree of testimonial smothering; never quite knowing whether exclusion from participation in knowledge sharing or feeling complicit in something bigger than me was worse.

As an occupational therapy student I recalled struggling with the sense that service user educators’ knowledge contributions were somewhat ‘one-note’ in their focus on tragedy and subsequent ‘recovery.’ While these perspectives were certainly valid and important in their own right, they never quite felt representative of the diversity of service user perspectives I knew existed. For instance, I was always waiting to hear from a service user educator whose experience challenged the status quo, countered an inevitably tragic view of ‘mental illness,’ offered a generative critique of occupational therapy practices, or troubled the false service user/provider dichotomy through their embodied occupation of this liminal space.

I have also found SUI to be deeply meaningful and fulfilling – both personally and professionally – even *as* I was simultaneously experiencing the tension and confusion I have just described. My engagement in SUI has inspired an ongoing critical reflexivity related to my experiences within and outside of psy- systems and services, my ever-changing positionality related to these, and my similarly evolving sense of identity from *descriptive* to *political* (Mingus, 2010; See also Chapter 8). The complexity and seeming contradictions inherent in my own experiences of SUI – which also seemed to be reflected in SUI-focused literature – provided the impetus for this project, giving rise to: a slew of burning questions and a desire to pursue answers to these questions through critical examination of SUI; as well as optimism that there was enough epistemic wiggle room within health professional education for a reimagination of the practice of SUI.

1.1 Purpose statement

The purpose of this research was to deepen understandings of stakeholders' complex and varied experiences of SUI, and to critically examine the way SUI is currently conceptualized and implemented within health professional education programs in Ontario. Informed by theories of epistemic injustice (Dotson, 2011; Fricker, 2007; Medina, 2012; Pohlhaus, 2012, 2014) and perspectives drawn from Mad Studies, this research seeks to complicate current understandings and approaches to SUI, shed light on potentially underacknowledged epistemic and ethical dimensions of this practice, and contribute to a reimagining of how we might otherwise approach SUI, but have not yet. This research occurred within the context of four graduate-level preparatory occupational therapy professional education programs in Ontario, Canada, and included examination of the experiences of various stakeholders engaged in SUI within these programs, inquiry into the experiences of service user educators involved in health professions education more broadly, and interrogation of my own experiences using critical reflexivity. Postcritical ethnography was used to address the following research questions: "How is SUI conceptualized, organized and implemented in the context of occupational therapy professional education in Ontario?"; "How do stakeholders (i.e., service user educators and health professional educators) describe their involvement in, and knowledge contributions to, professional education programs?"; and "How do current approaches to SUI support and/or hinder service user educators' knowledge contributions and meaningful involvement in health professional education?" Data were primarily drawn from semi-structured interviews, participant observation, and my own autoethnographic and reflexive writings.

The remainder of this introductory chapter includes an overview of SUI in health professional education, followed by consideration of 'service user knowledge,' epistemic injustice, Mad Studies, and 'involvement' as key concepts and/or theories taken up in this work. The particular language employed throughout this research is also discussed. A summary of issues, and rationale for this research are then presented. The chapter concludes with a 'plan of presentation,' which briefly introduces and outlines the integrated articles which make up the body of this dissertation.

1.2 Service user involvement in health professional education

Mental health SUI as it is taken up in this research refers to the involvement of people who have firsthand or 'lived' experiences of receiving mental health-related services in the education of future health professionals (Tew, Gell & Foster, 2004). SUI as a practice is founded on the premise that, "service users have a right to be involved in the development and control of policies and services they experience," which includes the education of future professionals (Beresford & McLaughlin, 2020, p. 2). SUI is also underpinned by the notion that service users, by virtue of their lived experience, are "experts by experience," with a rich source of experiential knowledge to offer health and social care professionals (Happell & Roper, 2009; Tew et al., 2004).

Although SUI in health professional education has gained momentum in a range of international contexts, as a practice in Canada it generally lacks formal conceptualization or clear objectives. In the absence of formal guidelines, SUI is currently conceptualized, organized, and implemented with tremendous inconsistency across, and even within, health professional programs (Happell et al., 2015; McKeown et al., 2014). The depth and scope of involvement activities, for instance, varies across professional education sites, occurring most often in the form of ad hoc guest lectures, and, in some cases, extended to include activities such as: curriculum co-production or design, content delivery, student selection/admission processes, and program evaluation (Basset, Campbell & Anderson, 2006; de Bie, 2021; Felton & Stickley, 2004; Happell, Pinikahana & Roper, 2002; Tew et al., 2004). Critics remind us how easy it is to turn involvement into tokenism, pointing to a lack of formal conceptualization or clear objectives as reasons why SUI often results in "superficial, tokenistic, or 'tick-box' form[s] of involvement" (McKeown et al., 2014, p. 1175). Many have questioned whether current – often uncritical – approaches to SUI represent pedagogical practices capable of motivating transformative social change (Arblaster, Mackenzie & Willis, 2015; Braye, 2000; Eriksson, 2013; Lathlean et al., 2006; McKeown, Malihi-Shoja, Hogarth et al., 2012). The proliferation of SUI initiatives over the past several decades has given rise to a growing body of literature surrounding SUI in education, research, policy, and practice. This research adds to the existing literature on SUI which aims to center service user educators' knowledge and perspectives, and seeks to address the aforementioned concerns through the adoption of a critical theoretical lens.

With its grounding in a Canadian occupational therapy context, this research also contributes to the still relatively scant body of occupational therapy-specific literature related to SUI. While this research has implications that extend beyond this particular profession, a brief overview of the current state of SUI within occupational therapy education offers important context for this research. Despite growing acknowledgement of the importance of SUI in health professional education, occupational therapy-specific research and writing within the growing body of SUI literature remains limited (Arblaster et al., 2015; Scanlan et al., 2020). Furthermore, as Scanlan et al. (2020) have pointed out, there are only a handful of published studies to guide the practice of SUI in occupational therapy education. It has been suggested that 'professional insecurity' could play a role in the slow development of SUI initiatives in occupational therapy (Wright & Rowe, 2005). While SUI is a mandated requirement for the accreditation of many professional educational programs around the world (e.g., Europe, New Zealand, and Australia), at the time of this research, there are no formal educational requirements or documented accreditation standards requiring occupational therapy educators to engage in SUI. Rather, the practice of SUI depends largely on the individual efforts of those who have chosen to prioritize the involvement of service user educators in their teaching; which may or may not be recognized, supported, or influenced by departmental values or the broader institutional culture.

1.2.1 Service user knowledge

Central to the practice of SUI is, "an essential recognition that this involvement in itself brings with it a particular type of *knowledge"* (Duffy & Beresford, 2020, p. 11). Service user educators' experiential knowledge – that is, knowledge grounded in their 'lived experiences' and encounters with psy- systems – is positioned as an alternative to the largely theoretical, 'expert' knowledge privileged within the health professions. McLaughlin (2009) locates service user educators' experiential knowledge within standpoint theory – building on the work of Harding (1987, 1991), Collins (1986) and Swigonski (1994) – using the term *service user standpoint theory* to describe how service user educators occupy particular standpoints from which unique insights, perspectives and understandings about their experiences of mental health services are developed.

Service user educators' knowledge is commonly understood to be subjective, experiential, embodied, and temporal, derived largely from experiences of mental distress and diversity, and of mental health system encounters at particular times (Beresford & Boxall, 2013; Gillard, Foster & Sweeney, 2020). Gillard, Foster and Sweeney (2020) importantly note that service users' experiential knowledge is, "shaped by the full diversity of our social and political lives, including the inequities that people experience in relation to race and racism, gender inequality and violence and so on" (p. 51). Service user-produced knowledge has the, "potential to critique dominant or taken-for-granted understandings of mental health that are the common currency of psychiatric treatment, mental health research and professional education" (Gillard et al., 2020, p. 42). Service users' experiential knowledge may be viewed as emancipatory discourse in its resistance to psy-produced ways of knowing and responding to 'mental illness' or Madness, and in doing so, represents "a vital force for change" (Gillard et al., 2020, p. 51). This is especially true of the knowledge produced in the context of survivor-controlled research, and that which constitutes the alternative knowledge base proposed by proponents of Mad Studies (e.g. LeFrancois et al., 2013; Russo, 2012; Sweeney, 2016).

While service user educators' experiential knowledge has been increasingly recognised as important discourse in health professional education, this research acknowledges that service user educators' knowledge still represents a form of marginalized, or marginally situated, knowledge (Beresford & Boxall, 2013; LeBlanc & Kinsella, 2016; Russo & Beresford, 2015). That is, service users' experiential knowledge often works in tension with the knowledge of 'mental illness' held by health professionals, where service users' knowledge is generally viewed as overly subjective or illegitimate in contrast to professionals' 'scientific,' 'objective,' and valid knowledge (Beresford & Boxall, 2013; Cameron, Molloy-Graham & Cameron, 2020). The introduction and acceptance of service user educators' knowledge within professional education spaces through SUI has sparked ongoing debate and raised important epistemological questions about what constitutes valid knowledge, and whose knowledge counts (Duffy & Beresford, 2020).

1.2.2 Epistemic injustice

The implications of the described tensions and the imbalance of epistemic power between service user educators and health professional educators (as described above) are of central concern to this research. As such, this research is informed by theories of epistemic injustice (Dotson, 2011; Fricker, 2007; Medina, 2012; Pohlhaus, 2012; 2014) in its examination of service user educators' knowledge contributions to mental health professional education. Epistemic injustice refers to the distinct wrong done to someone in their capacity as a *knower*; restricting their ability to engage in the basic everyday practices of knowing, conveying knowledge to others, and making sense of personal and social experiences (Fricker, 2007). Epistemic injustice has been applied as a theoretical lens to better understand the challenges experienced by service user educators in their efforts to *know* and legitimate this knowledge, as marginally situated knowers in health professional education spaces. Attending to the issue of epistemic injustice in mental health professional education involves troubling existing operations of power and knowledge, and unsettling taken-for-granted ways of knowing and practicing SUI (Brosnan, 2019; Newbigging and Ridley, 2018).

1.2.3 Mad studies and Mad (positive) pedagogy

This research is also theoretically informed by *Mad studies*, a growing interdisciplinary field of social sciences and humanities research, which positions Mad, consumer/survivor/ex-patient (c/s/x), or service user knowledge as central and important for understanding all matters related to ‘mental health’ (Beresford, 2005; Burstow, 2015; Burstow et al., 2014; Castrodale, 2017; LeFrancois, Menzies & Reaume, 2013; Reville, 2013). Mad Studies has been identified as a site with potential to lend support to SUI, as to some it represents a “confederacy of academic and service user activists relating to critical understandings of mental health” (McKeown et al., 2014, p. 1177). This research also embraces the concepts of *Mad (positive)* and *critical pedagogies*, whereby SUI is approached as a strategy which draws on participatory learning practices to maximize inclusion of a plurality of perspectives (Castrodale, 2017; hooks, 2014; Lather, 1995). Furthermore, classrooms are understood as complex discursive environments that shape and reproduce dominant social structures, and service user educators are viewed as “social movement activists” engaging in this work on the politicized and contested territory of health professional education spaces (Brown & Zavestoski, 2005 as cited in McKeown et al., 2014, p. 1176).

1.3 Conceptualizing ‘involvement’

> *“Involvement and action should be seen as inseparable. Involvement is not some kind of academic exercise. It is about real change for the better in real people’s lives, in the real world. And working for such change in professional learning and practice, based on service users’ experiential knowledge and lived experience, is clearly at the heart of this”* (Duffy & Beresford, 2020, p. 15).

It has been suggested that a lack of formal conceptualization or clear definition regarding what ‘service user involvement’ actually entails has hindered its development as a pedagogical approach (Lloyd, 2010; McCutcheon & Gormley, 2014; McKeown et al., 2014; McLaughlin, 2009). Such uncertainty has influenced the development and adoption of evaluative tools and frameworks for taking stock of the depth and range of involvement activities within the practice of SUI (McKeown et al., 2014), including

Arnstein’s (1969) *Ladder of Citizen Participation*; Tew et al.’s (2004) *Ladder of Involvement*; and Tritter and McCallum’s (2006) *Social Citizenship Mosaic*. For the purposes of this research, the concept of ‘involvement’ is not understood as an ‘all-or-nothing’ phenomenon, but rather as taking place to varying degrees along a continuum or spectrum as described by Tew et al. (2004).

Tew et al.’s (2004) *Ladder of Involvement*, provides a useful starting point for thinking about the ‘depth’ or level of involvement of service user educators as reported in this research, as this framework was developed specifically for application in analyses of SUI in mental health professional education settings, and includes occupational therapy educators in its target audience. Health professional educators have identified this framework as particularly useful as it, “illustrates the integration of service-user involvement into curriculum planning and delivery” (McCutcheon & Gormley, 2014, p. 1197). The Ladder of Involvement evaluates the extent to which service user educators are involved in health professional education programs, and which tasks they undertake; mapping the progression in depth of involvement across 5 levels, beginning with ‘no involvement’ to involvement of service user educators as consultative partners and finally to that of equitable partnership (See Table 5 presented in Chapter 6 which details the levels of Tew et al.’s *Ladder of Involvement*).

This framework also takes into consideration, “policies on payment and reward; training and supervision opportunities for involvement experts; and to what extent people with lived experience are involved in decision-making and in shaping and influencing the course, more widely” (Fox, 2020, p. 4). Evidence of “level-5” partnerships in health professional education settings are reported to be rare, with most SUI initiatives aligning with levels 2 (i.e., *limited involvement*) or 3 (i.e., *growing involvement*) on the continuum (McCutcheon & Gormley, 2014). This observation would seem to be supported by the scant body of literature detailing the conceptualization, organization or implementation of SUI initiatives in Canadian occupational therapy educational contexts (Morgan et al., 2009; Williams et al., 2007).

Tew et al. (2004) have argued that if service delivery is to be characterized by an “ethos of partnership,” respect, and a valuing of service user knowledge, then such relationships and values should be established in – and form the foundations of – mental health professional education (p. 10). Unfortunately, McKeown et al. (2011) point out that SUI literature is replete with examples of initiatives that, “whilst attempting full partnership, fall short of reaching this ideal” (p.15). McLaughlin (2006) has suggested that involvement below the level of ‘collaboration’ is more prone to “misuse and abuse” (as cited in Burke & Newman, 2020, p. 55).

1.4 On language

This research adopts the admittedly imperfect language of *service user educator* to describe those who have firsthand experiences as recipients (past or present) of mental health (or psy-) services, and are involved in health professional education to contribute knowledge that is grounded in/informed by these experiences. An array of alternative signifiers are available, including, but not limited to: consumer, patient, client, activist, self-advocate, psychiatric survivor, peer, or expert-by-experience; each reflecting subtly different ideology and social status (McKeown et al., 2011; McLaughlin, 2020; Misra & Cohen, 2001). While use of the term service user has become more prevalent, this language remains controversial, contested and somewhat confusing.

Tenets of poststructuralism suggest that language and discourse are constitutive (rather than merely descriptive), and often associated with dominant discourses and prevailing power relations (McKeown et al., 2011). Indeed, there is power inherent in our labelling and conceptualizations of those who receive (or have received) mental health services, making it important to consider the nuances of language and the messages we are communicating (e.g., about identity or the nature of the professional relationship) in our choice of terminology (McDonald, 2006; McLaughlin, 2020). McKeown et al. (2011) have pointed out that language and terminology applied to this role or identity, “can at various junctures be implicitly or explicitly pejorative, demeaning and stigmatizing” (p. xviii). The term ‘patient,’ for example, has undertones of passivity and certain complaisance with medical authority, while ‘consumer’ and ‘client’ – despite arguably signifying greater personal agency – can be linked to potentially problematic notions of consumerism and a market-driven health care system (McKeown et al., 2011).

My deliberate use of the term service user educator, despite its notable shortcomings, ultimately aligns with arguments presented in favour of the term *service user,* and is in keeping with the language adopted by service user educator communities I have been associated with (Beresford, 2005; McKeown et al., 2011). The term service user, or the more role-specific ‘service user educator,’ represents an active and positive framing, which recognizes that “shared experiences of using services gives members ‘a strong voice to improve services’” and that expertise drawn from personal experience is just as valid as professional expertise (McLaughlin, 2020, p. 36). The term service user has been associated with social justice/change aims, social ideology and collective action (Ferguson, 2008). Cameron, Molloy-Graham & Cameron (2020) importantly stress that, “service users are not just service users” but instead,

> “people with multi-faceted personalities who may have many different roles. They may be professionals, too. They may be activists. They may be seasoned and experienced campaigners. They may be self-advocates or spouses or parents or lovers or students or artists” (p. 70).

McLaughlin (2020) similarly urges us to avoid essentialized conceptions of service users, and troubles the false dichotomy between service user and service provider by suggesting that, “there is a danger that the use of the term ‘service user’ can be a way for professionals to restrict service user identity” implying “a hierarchical relationship between those who commission and deliver services and those who are in receipt of them. (p. 36). McLaughlin’s (2020) acknowledgement that “we can all move in and out at different times or even during the same time in our lives” certainly resonates with my own experiences of moving across and within these unstable identity categories (p. 33). One glaring issue surrounding this term is that its use neglects to include those who are unable to, or decide not to, access mental health and social care services (McLaughlin, 2020). Some members of anti-psychiatry, psychiatric survivor and Mad constituencies may well find this particular language to be ill-fitting and/or exclusionary.

My use of the terms ‘service user’ and ‘service user educator,’ then, is representative of the *strategic essentialism* described by Voronka (2016), whereby we, "unify our divergent ways of making meaning of our [lived] experiences to enact political gain” (p. 190). In other words, for the purposes of this research I have conflated Mad, c/s/x, anti-psychiatry, prosumer, and service user (and presumably endless other) standpoints on the basis that each of these is grounded in experiential knowledge derived from encounters with the powers of psy- systems. Whilst acknowledging the ways that using experience and identity can be used to gain inclusion and access to systems of power, Voronka (2016) warns us that strategic essentialism of this sort is not without risks, including: “undercutting our various differences by effacing interlocking oppressions and the different ways we experience madness, conflating our conceptual and ideological standpoints as universally shared, and reifying mental illness” (p. 190).

1.5 Summary of the issues

The involvement of service user educators in health professional education, “has come about as a result of collective advocacy by service user movements rather than as a result of professional initiatives” (Cameron, Molloy-Graham & Cameron, 2020, p. 68). SUI as a practice is founded on the premise that, “service users have a right to be involved in the development and control of policies and services they experience,” which includes the education of health and social care professionals (Beresford & McLaughlin, 2020, p. 2). SUI is also underpinned by the notion that service users, by virtue of their lived experience, are “experts by experience,” with a rich source of experiential knowledge to offer health and social care practitioners (Happell & Roper, 2009; Tew et al., 2004).

While service user educators’ experiential knowledge has been increasingly recognised as important discourse in professional education, this research acknowledges that service user educators’ knowledge still constitutes a marginalized, or marginally situated, knowledge. That is, service users’ experiential knowledge often works in tension with the knowledge of ‘mental illness’ held by health professionals, where service users’ knowledge is generally viewed as overly subjective or illegitimate in contrast to professionals’ ‘scientific,’ ‘objective,’ and valid knowledge (Cameron, Molloy-Graham & Cameron, 2020; Meehan & Glover, 2007). The introduction and acceptance of service user educators' knowledges within professional education spaces through SUI has sparked debate and raised important epistemological questions about what constitutes valid knowledge, and whose knowledge counts (Beresford, 2003; Duffy & Beresford, 2020).

Despite its growing presence in a range of international contexts, as a practice SUI generally lacks formal conceptualization or clear objectives. As such, there is tremendous inconsistency in the ways SUI is currently conceptualized, organized and implemented across, and even within, health professional education programs (Braye, 2000; Eriksson, 2015; Happell et al., 2015; Lathlean et al., 2006; McKeown, Malihi-Shoja, Hogarth et al., 2012). The absence of formal conceptualization or clear objectives has also been linked to the "superficial, tokenistic, or 'tick-box' form[s] of involvement" (Arblaster, Mackenzie & Willis, 2015).

Without diminishing the hard fought achievements of service users, survivors, Mad activists and other stakeholders who have lobbied for their right to involvement in the production and sharing of knowledge related to mental distress and our responses to it, or the frequently cited positive impacts of SUI, this research draws attention to the (often overlooked) ethical and epistemic dimensions of SUI. Indeed, central to this research is a focus on the epistemic (and by extension, ethical) complexities inherent in SUI as these are represented in the accounts of various stakeholders involved in its practice.

1.6 Rationale

The proliferation of SUI initiatives over the past several decades has given rise to a growing body of literature surrounding SUI in health professional education (Byrne, Happell, Welch & Moxham, 2013; Cleminson & Moesby, 2013; McKeown, Dix, Jones et al., 2014). Much of this literature contributes to a dominant narrative which portrays the practice as unquestioningly positive and uncomplicated (de Bie, 2021; Happell & Bennetts, 2016). This research responds to calls for closer examination of the complexities, risks and challenges inherent in involving service user educators in health professional education. Acknowledging that service user educators' knowledge represents marginally situated knowledge in the context of health professional education

– which privileges expert, professional knowledge – this research attends to the imbalance of epistemic power which disproportionately affects service user educators.

This research is grounded in the experiences of people directly involved in the conceptualization and implementation of SUI, representing various stakeholder perspectives. This dissertation makes an important contribution to the still scant body of occupational therapy-specific literature focused on SUI with its adoption of an openly critical theoretical lens. It is anticipated that the outcomes of this study will have wide-ranging implications for stakeholders interested in critically engaging in SUI, with broad relevance to the health and social care professions (Beresford, 2002, 2003; Beresford & Croft, 1993; Burstow, 2015). This research stands to inform the innovation and development of pedagogical practices that aim to foreground service users' knowledge within health professional education.

1.7 Plan of presentation

This dissertation is presented in an integrated-article format. In this introductory chapter, I have described my firsthand experiences as a student occupational therapist and service user educator as forming the impetus for this work. I have introduced the practice of SUI in health professional education and situated this research project within the growing body of literature which aims to foreground the perspectives of service user educators. I have discussed service user educator knowledge and involvement as it exists along a continuum as two concepts central to this research. I have explained the rationale behind my adoption of the term *service user educator* throughout this work, and I have summarized the issue and provided a rationale for this research.

The second chapter (Manuscript 1) elaborates and conceptualizes the link between the concepts of sanism and epistemic injustice, and makes a case for engaging in critical reflexivity toward greater embrace of a plurality of knowers and knowledge for understanding mental distress or Madness. This chapter was published in a special edition of the Studies in Social Justice journal, which focused on "Mental Health and Distress as a Social Justice Issue."

The third chapter outlines the postcritical ethnographic methodological approach to this research, as well as my guiding theoretical framework, which includes theories of epistemic injustice, Mad Studies, and critical and Mad (positive) pedagogies.

The fourth chapter outlines the study methods (i.e., recruitment, data collection, and data analysis), as well as proposed quality criteria, and ethical considerations.

The fifth chapter (Manuscript 2) examines and complicates the practice of storytelling in the context of SUI. The findings illustrate the importance of a critically reflexive approach to soliciting service user educators' stories in health professional education.

The sixth chapter (Manuscript 3) presents an analysis of participant-reported experiences of SUI, in light of growing critiques of the practice related to tokenism. In this paper, I discuss the importance of fostering more epistemically just conditions for involvement, particularly where greater 'depth' of involvement is not realizable, and service user partnership, or co-production, remain unattainable goals.

The seventh chapter (Manuscript 4) is a reflexive account grounded in my firsthand experiences as a sessional health professional educator, and the lessons I learned in the *doing* of SUI. I present my experiences in conversation with data from the study. In my account I attend to some of the many complexities inherent in facilitating SUI, and in doing so, offer generative insights toward doing this work in a manner that is ethical, and that takes epistemic justice and social justice into account.

A final concluding chapter provides a summary of the contributions to knowledge of the integrated articles. In this chapter I revisit one 'unifying thread' in this work – epistemic injustice. In these final reflections I also engage with the notion of 'slow scholarship,' and how I see my coming to a politicized understanding of my own mental distress – or Madness – as deeply related. This chapter concludes with a discussion around future directions for this research, and plans for dissemination.

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2 Toward epistemic justice: A critically reflexive examination of ‘sanism’ and implications for knowledge generation[11]

Madness as a phenomenon has existed throughout the course of human history, but it was not until the 18th century that the organized field of psychiatry materialized (Foucault, 1988; Hornstein, 2002; Porter, 2002; Scull, 1989). In accordance with the growing dominance of medicalization, the concept of *madness* was eventually replaced by what is presently referred to as mental illness (Foucault, 1988; LeFrancois, Menzies & Reaume, 2013; Rimke, 2003; Rimke & Hunt, 2002; Wolframe, 2013b). Despite its displacement from modern mental health discourse, we use the term *Mad* to describe all persons who self-identify as such, or who have otherwise been deemed mentally ill or in need of psychiatric services (Poole et al., 2012; Wolframe, 2013b). Contemporary uses of this term may be familiar to those acquainted with critical scholarship on madness, however for many readers this may be new territory. For this reason, we preface this work with a brief discussion of the language and terms used throughout our analysis (Wolframe, 2013b).

The term Mad, when used in politicized and empowering discourses, is perhaps most strongly associated with the Mad movement, which materialized in the 1960s and 1970s in protest of the mistreatment and involuntary confinement (or “imprisonment”) of those deemed mentally ill (Burstow, LeFrancois, & Diamond, 2014; Chamberlin, 1990; Poole et al., 2012; Porter, 2002; Price, 2011; Scull, 1989; Wolframe, 2013b). Many of those taking part in the movement embraced the term Mad and chose to reclaim it as a politicized form of self-identification, much like the term *queer* has been reclaimed within the context of the LGBTQ2S movement (Burstow et al., 2014; Poole et al., 2012; Price, 2011; Reid, 2008; Rimke & Brock, 2012).

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Today, an increasing array of signifiers exist for representing the experiences of those living with mental and emotional diversity or distress, including, but certainly not limited to, ex-patient, mentally ill, consumer, psychiatric survivor, crazy, Mad, lunatic, neuro-diverse, disabled or deviant. Of these terms, we have purposely chosen to employ the term Mad, not only in attempt to reflect the multiple social constructions of mental diversity to date, but also to emphasize the politics of resistance to *psy* discourses (Price, 2011; Wolframe, 2013b). Psy discourses are taken as problematic, particularly when alternative perspectives – especially those held by Mad people – are subjugated (Hornstein, 2002; LeFrancois et al., 2013).

Mad people continue to contend with the suppression and dismissal of their knowledge, experiences, and perspectives, as revealed in the frequent absence or discrediting of Mad discourses in academic contexts, media portrayals, healthcare practices, research, policy, and everyday conversation (Fabris, 2011, Reaume, 2006; Russo & Beresford, 2015; Wolframe, 2013a). A broad aim of Mad activists and scholars has been to balance the disproportionate emphasis on “official” knowledge with that of those experiencing madness firsthand (Chamberlin, 1990; Costa et al., 2012; Russo & Beresford, 2015). The subjugation of Mad persons’ experiences raises questions concerning power and knowledge, in particular, what constitutes valid knowledge(s), who are the legitimate knowers, and whose knowledge should count? (Fricker, 2007; Harding, 1991). The under-inclusion (or exclusion) of the perspectives of Mad people from academic, legal, clinical, and everyday discourses demands closer critical analysis. This paper draws on Fricker’s (2007) concept of *epistemic injustice*, as it provides a useful framework for analyzing and challenging the subjugation of Mad knowledge(s), particularly for those who view the political and epistemological struggles championed by the Mad movement as inseparable (Lewis, 2006; Russo & Beresford, 2015). We have chosen to foreground this concept as we agree that the marginalization of Mad persons’ experiences and resultant knowledges constitutes a form of epistemic injustice, and may be seen as an infringement on (Mad) persons’ basic human rights (Fricker, 2007; Medina, 2012; Shotter, 1981). We argue that a failure to recognize the epistemic value of the perspectives of those living with madness is so entrenched in Western social practices and discourses (Rimke & Brock, 2012) that epistemic injustice is often perpetuated without consideration of potential social harm (Fricker, 2007; Perlin, 2003).

This paper provides an overview of *sanism*, a deeply embedded form of discrimination and oppression affecting those who experience madness, and argues it is a system of thought underpinning the practice of epistemic injustice (Fabris, 2011; Fricker, 2007; Perlin, 2000, 2003; Russo & Beresford, 2015; Spandler & Carlton, 2009). This is reflected in what Rimke has termed *psychocentrism*, wherein pathologies are taken to be rooted in the mind and/or body of the individual, rather than the product of social relations, structures and problems (Rimke, 2003, 2010, 2011). In this paper we consider how the material and conceptual outcomes of sanism and psychocentrism marginalize the knowledge(s) of Mad persons. We further show that such marginalization constitutes a form of epistemic injustice, and argue that engagement with Mad epistemological perspectives is a matter of social justice.

2.1 Epistemic injustice and the Mad community

Fricker (2007, p. 1) introduces the concept of epistemic injustice as an injustice concerning "our most basic everyday practices: conveying knowledge to others by telling them, and making sense of our own social experiences," which occurs when a person is insulted or wronged in their capacity as knower. If it is our ability to *know* that makes us distinctively human, as has been suggested, it is no wonder that the "powerful" have historically undermined, insulted, or otherwise wronged the "powerless" in this capacity, as a means for denouncing their humanity (Fabris, 2011; Fricker, 2007; Medina, 2012; Price, 2011). Epistemic injustice is inextricably linked to social injustices, according to Medina (2012, p. 27), who suggests that "inequality is the enemy of knowledge," impairing our ability to *know* and to gain knowledge from others. Social injustice breeds epistemic injustice by weakening epistemic relations between marginalized social groups – unfairly depicted as intellectually inferior and lacking credibility – and their epistemically privileged counterparts (Medina, 2012). Epistemic injustice is comprised of two fundamental discriminatory forms: *testimonial injustice* and *hermeneutical injustice* (Fricker, 2007, 2010). Testimonial injustice occurs when a speaker is undermined in their capacity as a giver of knowledge, owing to an identity prejudice held by the hearer, impacting the hearer's judgement of the speaker's credibility (Fricker, 2007). Alternatively, hermeneutical injustice occurs when groups of people are wronged in their capacities as subjects of social understanding through structural prejudices which impact the production of (and access to) interpretive resources needed to make sense of their social experiences (Fricker, 2007; Medina, 2012). Although Fricker's terminology has seldom been used among Mad scholars and activists, the experience of testimonial injustice is all too familiar, and is an important concept to consider as it describes a serious threat to the citizenship and humanity of Mad persons (Callard, 2014; Carel & Kidd, 2014; Russo & Beresford, 2015; Thachuk, 2011). The Mad community has focused even less attention on the notion of hermeneutical injustice, which perhaps suggests that the detection of hermeneutical injustice is more difficult (Fricker, 2007; Medina, 2012).

2.2 Sanism: The hidden prejudice

We argue that *sanism*, a system of thought deeply embedded in Western culture, contributes to the epistemic injustice experienced by Mad people (Fabris, 2011; Fricker, 2007; Mills, 2014; Spandler & Carlton, 2009). Sanism involves the systematic subjugation and oppression of people who have received "mental health" diagnoses, or who are otherwise perceived to be "mentally ill" (Perlin, 1992, 2003; Poole et al., 2012). The term *sanism* was coined in the 1960s by activist lawyer, Mortin Birnbaum in conversation with prominent feminist lawyer, Florynce Kennedy (Birnbaum, 2010; Fabris, 2011). Michael Perlin, an activist and disability rights lawyer, later popularized the concept (Burstow et al., 2013; Fabris, 2011; Perlin, 2000). The large majority of literature on sanism is comprised of Perlin's writings and his collaborations with others, developed from nearly 30 years of personal observation (Fabris, 2011; Wiliams, 2013). Perlin focused on unfairness and inequalities in the legal system, but his analysis has applicability to many aspects of structural stigma, prejudice and discrimination (Williams, 2014).

Perlin (2003, p. 536) describes sanism as "an irrational prejudice of the same quality and character of other irrational prejudices that cause (and are reflected in) prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry," and every other "ism" society no longer tolerates. Sanism may take the form of blatant discrimination and various forms of stigma, however, it is also commonly expressed in a multitude of *microaggressions*, which consist of "multiple, small, insults and indignities" (Kalinowski & Risser, 2005, as cited in Poole et al., 2012, p. 21; Burstow et al., 2013; Chamberlin, 1990; Goffman, 1963). Sanism is arguably one of the last socially accepted, government-sanctioned forms of systemic discrimination against a large social group (Jones & Brown, 2013). Although sanism is as troubling as other forms of discrimination, it is especially insidious as it remains largely invisible, and is self-perpetuating, socially acceptable, and practiced regularly (Perlin, 1992, 2003; Poole et al., 2012; Wolframe, 2013b).

2.3 Sanism and psychocentrism: The pathologizing of individuals

Sanism is conceptually dependant on, and reinforces the notion that Mad persons are fundamentally different from their "sane" counterparts (Perlin, 2000; 2003; Poole et al., 2012). Such a dichotomy aligns with what Rimke has termed *psychocentrism*: the view of human problems as pathologies rooted in the mind and/or body of the 'pathological individual', rather than the product of social problems (Rimke, 2003, 2010, 2011). Many contend that this "normal" is a mythical standard and that being labelled as mentally ill can occur as a result of performing, or being at risk of performing, socially unacceptable behaviours (Fabris, 2011; Rimke, 2011; Williams, 2014). The establishment of socially accepted and scientifically constructed norms has afforded psychiatry the authority to make inferences about the epistemic trustworthiness, credibility, or intellect of persons, dependant on their positioning in relation to such conceptions of normal (Morrow & Weisser, 2012; Rimke, 2003, 2010).

2.4 Testimonial injustice

Communicating Mad knowledge(s) through stories or *testimonies* has been foundational to the Mad community as a means of resisting psychiatric oppression and dehumanization (Costa et al., 2012). Members of the Mad community have protested that their perspectives are representative of "real" knowledge, only to have the legitimacy of their accounts questioned or dismissed altogether by virtue of their being Mad (Costa et al., 2012; Hornstein, 2002). As psychiatric survivor and activist Erick Fabris (2011, p. 31) writes, “we are not even credited with having experience; we are thought to have lost our minds, to be unreasonably emotional, possibly at the worst of times, a kind of philosophical exemplar of inaccessible life.” The discrediting of Mad persons in their capacity as legitimate knowers represents what Fricker (2007) refers to as *testimonial injustice*. We argue that in this context, testimonial injustice occurs as a result of *negative identity prejudice* stemming from sanist thinking, which tacitly distorts judgments of Mad people’s credibility as speakers (Goffman, 1963; Medina, 2012; Perlin, 2000).

Negative identity prejudice finds its way into discursive settings through a hearer’s use of stereotypes, which he or she engages with as heuristic devices in order to weigh judgments of credibility (Fricker, 2007). Although stereotypes “oil the wheels of testimonial exchange,” when underscored by negative identity prejudice, these can become troublesome for the speaker (Fricker, 2007, p. 32; 2010). This amalgam is referred to as *negative identity- prejudicial stereotype,* which Fricker (2007, p. 35) defines as a “widely held disparaging association between a social group and one or more attributes, where this association embodies a generalization that displays some resistance to counter-evidence.” When prejudicial stereotypes distort the credibility judgments of the hearer, an epistemic harm is inflicted, whereby knowledge that may have otherwise been recognized by the hearer is lost (Fricker, 2007).

In cases of testimonial injustice driven by prejudicial stereotypes that discredit the humanity of a speaker (i.e., the widespread stereotype that Mad people are incapable of rational thought), the harm being done to the speaker should be understood as more than simply symbolic (Fricker, 2007). Denigrating sanist stereotypes are based on, and reinforce, deep-seated social assumptions that mad persons are unable to exercise their full citizenship, and are therefore incapable of fully participating as *knowers* (Fabris, 2011; Fricker, 2007; Perlin, 2003; Williams, 2014). As such, the subjugation of Mad persons’ knowledge, perpetuated each time a speaker is prevented from contributing knowledge to the public domain, becomes both justified and necessary (Williams, 2014). Mad scholarship is replete with examples of testimonial injustice, although they are not often acknowledged or recognized as such (Liegghio, 2013; Fabris, 2011; Saks, 2007; Thachuk, 2011; Williams, 2014; Wolframe, 2013a).

Perlin has written extensively about sanist stereotypes that cultivate irrational fears, ignorance, and so-called "common-sense" beliefs, which tend to inform how many people in society perceive, understand, and treat Mad persons (Fabris, 2011; Perlin 2003, 2006, 2013; Williams, 2014). Indeed, the credibility of Mad persons' knowledge is frequently judged through the hearer's lens of sanist prejudice (Fricker, 2007). Sanist stereotyping fosters a negative perception of Mad persons as delusional, emotionally unstable, unpredictable, untruthful, untrustworthy, lacking all capacity for "rational" thought, and invariably dangerous to oneself or others (Fabris, 2011; Perlin, 2000, 2003, 2006, 2013; Williams, 2014).

Perhaps the most pervasive sanist stereotype is the misconception that violence to oneself or others is a hallmark of madness (Wolframe, 2013a). Cultural assumptions surrounding the *risk* of violence often take precedence over the expressed perspectives of Mad persons, justifying the social control of Mad persons against their will through forced institutionalization or mandated psychiatric treatment (Fabris, 2011; Wolframe, 2013a). Maria Liegghio (2013) shares a moving narrative of her mother's end-of-life care – which was tainted by her mother's psychiatric history and diagnosis of bipolar disorder – and of the consequent injustices to her capacity as a knower. Liegghio (2013) uses the term *epistemic violence* to describe the injustices experienced by her mother, and by herself, as the daughter of a Mad woman. Liegghio (2013) writes:

> I am so angry! Today on this cold, Canadian winter day I am accompanying my mother, dying of cancer, living with physical pain, and struggling with mental confusion to the palliative care unit at the hospital after spending six months caring for her at home. All her in-home nursing and personal care support has been withdrawn and we have no other choice but to consider a hospitalization against my mother's wishes. And why – because someone in their position as helping authority decided she was a risk of harm to the visiting staff because of her history of 'mental illness.' [...] What risk of harm could this woman, too

> physically withered and weak to sit up, possibly pose to herself or others? [...] Is this really just a misunderstanding about a failing liver versus a mental illness? How is it possible that the knowledge of her impending death no longer exists and instead, the knowledge of 'mental illness' and all the prejudices associated with it have taken over and are used to justify such action, as to deny the necessary services and to deny the wishes of a dying woman? (p. 122-123)

Liegghio (2013) explains that in her mother's 20-year history of living with the diagnosis of bipolar disorder she never harmed or threatened to harm herself or others. In accordance with sanist beliefs, however, Liegghio's mother was constructed as dangerous, and as a result, was undermined in her capacity as a legitimate knower.

Testimonial injustices also routinely occur in healthcare contexts when Mad persons' health concerns – even those entirely distinct from their psychiatric histories – are dismissed (Hinshaw, 2007; Rimke, 2003; Thachuk, 2011). Take for example, the report of a 38-year-old Mad woman in her dealings with the healthcare system:

> Speaking to the tainting effects that her psychiatric history has had on her interactions with health-care providers, one woman states, 'I went to my GP with a breast lump . . . [he] sent a referral letter stating 'over-anxious patient, had nervous breakdown at age 17' (20 years ago). Consequently I was greeted by the specialist with 'well, you're a bit of a worrier, aren't you?' Every physical illness I have had for the last 20 years has first been dismissed as anxiety, depression or stress. (Thachuk, 2011, p. 155)

Similarly, legal scholar and mental health-policy advocate, Elyn Saks (2007), who has for decades been diagnosed with chronic schizophrenia, writes of what might be characterized as testimonial injustice. In her memoir, *The Center Cannot Hold,* Saks (2007) writes of seeking medical care for what was eventually determined to be a subarachnoid brain hemorrhage:

> Quickly, they bundled me into the car and took me to the emergency room. Where a completely predictable disaster happened: the ER discovered I had a psychiatric

> history. And that was the end of any further diagnostic work. Stigma against mental illness is a scourge with many faces, and the medical community wears a number of those faces. A psychiatric patient at a program where Steve once worked went for weeks with a broken back; none of the medical people the patient saw took the man's pain seriously – he was a mental patient. So once the ER learned I had a mental illness and was on antipsychotic medication, the diagnosis was written in stone: I was 'just' having an episode. [...] The ER sent me away (p. 232-233).

With respect to navigating this sort of epistemic dilemma, Otto Wahl has suggested that, "the only way to have symptoms accepted as honest and accurate reports is to be dishonest about psychiatric history" (Wahl, 1999, cited in Thachuk, 2011, p. 155). Indeed, in order to be perceived as legitimate knowers, many Mad persons opt to conceal their psychiatric histories when speaking about their physical health concerns. As Thachuk (2011) observes, "Ironically, one had best lie in order to avoid being perceived as a liar!" (p. 155).

2.4.1 Pre-emptive silencing and epistemic objectification

Discrediting expressed knowledge(s) in the midst of conversation is not the only way that testimonial injustices can occur. Fricker (2007) and Medina (2012) discuss two additional forms of testimonial injustice. The first of these is *pre-emptive testimonial injustice* or *silencing*, enacted through exclusion from participation in communicative exchange, where knowledge, judgments and opinions of marginalized groups are simply not solicited. It is important to clarify that this form of epistemic injustice is highly context dependent, and that our argument is largely limited to the constrained participation of Mad persons in the generation of (accepted) knowledge surrounding madness (Fricker, 2007; Medina, 2012). Within this particular context, the pre-emptive silencing of Mad persons can be attributed to the dominance of the 'psy' disciplines' widespread social acceptance of 'psy' knowledges and discourse as the "official" version of the truth.

The second of these forms of testimonial injustice, *epistemic objectification*, "allows" participation in communication for the purpose of knowledge-production and transmission; however, it relegates persons from the role of active epistemic agent (or *subject*) to that of passive *object* to be studied, observed, and in many cases, exploited (Ficker, 2007, p. 132). In other words, it shifts the speaker's epistemic status from informant to source of information. We see evidence of this particular injustice in the production of knowledge surrounding mental health or madness, which consists primarily of work produced *about*, rather than *by*, Mad persons (Jones & Brown, 2013; Russo & Beresford, 2015).

According to Medina (2012), this too is a context-dependent form of injustice, for it is not inherently "wrong" to be regarded as *object* in epistemic interactions, as long as speakers are not solely regarded as such, and are also treated as *subjects* of knowledge within the same context. Moreover, not all objectifying or silencing is avoided when persons are treated as informants (Medina, 2012). Informants may still be undermined in their capacities as *knowers* and constrained or minimized as *givers* of knowledge "at the service of the inquirer's epistemic agency (her questions, her assessments, her interpretations)" (Medina, 2012, p. 92). As such, epistemic objectification may occur even when there is active participation in knowledge production.

Costa et al. (2012) have studied what they refer to as "patient porn" or "disability tourism," involving the personal narratives of Mad persons being co-opted by psy-organizations to further their own interests, rather than to support Mad persons as agents of change. Patient porn is exemplified by mental health organizations' solicitation and subsequent sanitization or distortion of Mad persons' narratives about their "fall into and subsequent recovery from mental illness" owing to their participation within that organization (Costa et al., 2012, p. 86). This form of objectification is particularly insidious as it occurs under the guise of *welcoming* or *embracing* Mad persons' knowledge (as informants), yet the accounts are sanitized in a way that makes Mad knowledge largely invisible. Mad activists' resistance against epistemic objectification was demonstrated at a June 2011 Toronto event titled "Recovering Our Stories," using the slogan "Hands Off Our Stories" (Costa et al., 2012, p. 92). The goal was to "interrupt the proliferation of this popular type of storytelling within the mental health sector –

judging it to be not just problematic but ‘pornographic’,” hoping that this might inspire others to instead, “use [their] stories to change the world” (Costa et al., 2012, p. 86, 92).

2.5 Hermeneutical injustice

Thus far, we have explored the multiple facets of Fricker’s testimonial injustice, as a wrong done to a person as a *giver* of knowledge, whether it be through dismissal and discrediting, pre-emptive silencing, or the objectification of shared Mad knowledge(s). Closely related to testimonial injustice is hermeneutical injustice. Hermeneutical injustice relates to hermeneutics, or the art of interpretation, which affects peoples’ ability to express themselves or to be understood (Kinsella, 2006; Medina, 2012). Through hermeneutical injustice, “some significant area of one’s social experience [is] obscured from collective understanding,” owing to the presence of wrongful interpretive obstacles (Fricker, 2007, p.155). According to Medina (2012) it is through testimonial interaction that hermeneutical injustices occur (and are maintained): “those who are struggling to make sense are persistently not heard and their inchoate attempts at generating new meanings are blocked or unanswered” (Medina, 2012, p. 96). Hermeneutical injustices are revealed in the lack of opportunities for Mad persons to participate in the generation of interpretive resources for making sense of madness. As a distinct social group, Mad persons are often unable to make intelligible the nature of the harms they experience, owing to a lack of available hermeneutical resources for doing so (Fricker, 2007).

Fricker (2007) asserts that collective forms of social understandings are reflective of the perspectives of various social groups, whereby unequal power relations have the potential to skew shared hermeneutical (interpretive) resources. Psychiatrized conceptions of madness – or mental illness – have dominated the West since the 18th century, where the growth of the “psychiatric empire” (Beresford, 2013, p. ix) continues to develop on a global scale (LeFrancois et al., 2013). Oppressed social groups may be *hermeneutically marginalized* to the extent that they must interpret their social experiences, “through a glass, darkly, with at best ill fitting meanings to draw on in the effort to render them intelligible” to others, and in some cases, to themselves (Fricker, 2007, p. 148; Medina, 2012). Members of the Mad community may be particularly vulnerable to this form of epistemic injustice due to the elusive nature of madness (which makes it difficult to understand and communicate), resulting in their marginalization as contributors to the *collective hermeneutical resource* (Carel, 2013; Carel & Kidd, 2014).

The usefulness of the concept of hermeneutical injustice can be seen in Wolframe's (2013a) account of her experience of sanist oppression and sane privilege amid a culture in which the concept of sanism is not yet widely recognized. Upon her discovery of the concept of *sanism*, Wolframe was able to find new interpretive resources to communicate her experiences:

> I did *not* recognize for some time the fact that people who had never been labeled mentally ill – as I had been – and who were thus sane by default, had access to privileges that I did not. I was aware of the discrimination I had faced as a "mentally ill" person, but I accepted that oppression. I believed, at the time, that I was sick, and I believed that this sickness caused me to hurt myself and others. Should I not then, I reasoned, be restrained by the straightjacket of unequal treatment? It was only later when I came to reject the medical model of madness that I questioned my own internalization of an oppression I came to know as saneism [sic]. Though I began to think through the idea of saneism at the same time as I got free of psychiatry, in 2005, I only started to recognize sane privilege recently, as I have increasingly gained that privilege myself... Since people have not always treated me as though I am reasonable, trustworthy, safe to be around, and capable of taking care of and making decisions for myself, because they knew I had been diagnosed as, or they perceived me to be mentally ill, I very much notice it now that they do treat me as though I am all of these things most of the time. Now that I am experiencing it, sane privilege has become obvious to me. It is not necessarily so obvious to those who have never lost that privilege (Wolframe, 2013a, paragraph 6-7).

2.5.1 Hermeneutical injustice through imposed silence

According to Foucault (1980), those in positions of power act in ways that serve to legitimize their own knowledge, while simultaneously undermining other knowledge that may challenge their dominant ways of knowing (Rimke, 2003; Geekie, 2004). Mad persons have been represented as possessing a “lack of insight” should they not interpret their experiences according to dominant psy discourses (Amador & Kronengold, 1998; Geekie, 2004; Kirmayer & Corin, 1998; Rimke & Hunt, 2002). This portrayal serves as a powerful instrument for the hermeneutical marginalization and discrediting of Mad persons (Fricker, 2007; Geekie, 2004). If a *lack* of insight is to understand one’s experiences in ways alternative to the dominant hermeneutical resources put forth by psy disciplines, then all persons deemed to *have* insight must invariably espouse dominant hermeneutical resources. This is supported by a dominant collective belief that if it were not for Mad persons’ insight-impairing “illness” they would embrace these dominant interpretations, and as such, should be “grateful for the imposition of laws and judicial decision-making that ensure they are protected, controlled, and treated” (Williams, 2014, p. 451). Williams points out that despite a growing consciousness around injustices affecting other marginalized populations, sanist belief systems continue to provide justification for the unjust treatment of Mad persons:

> No-one believes that a suffragette would have been grateful for being imprisoned and gastric fed; or an African American would have been grateful for being enslaved; or a cancer patient who is refusing treatment will be grateful for being locked up until they agree, or are compelled, to undergo chemotherapy. (Williams, 2014, p. 451)

Despite the presence of Mad persons’ perceptive, nuanced and well-developed theories surrounding the experience of madness, the collective hermeneutical resource for interpreting the social experience of madness is heavily saturated by psy discourses, such that alternative epistemological perspectives on madness are regularly subjugated and dismissed (Geekie, 2004; LeFrancois et al., 2013; Williams, 2014; Wolframe, 2013b).

2.5.2 Illuminating injustices in the midst of a hermeneutical lacuna

The marginalization of Mad persons’ knowledges may be due to a *hermeneutical lacuna*, resulting in a paucity of language or concepts available to discuss experiences of injustice (Carel & Kidd, 2014; Geekie, 2004; Fricker, 2007). Some persons may find that their experiences of madness, or its related injustices, cannot be communicated in “any direct, propositional manner, and so are only shareable with persons with whom one shares a standpoint or a sense of solidarity” (Carel & Kidd, 2014, p. 530; Geekie, 2004). Fricker (2007) described hermeneutical lacunae as “absences of proper interpretations, blanks where there should be a name for an experience which it is in the interests of the subject to be able to render communicatively intelligible” (p. 160). For Mad persons there may well be an extant hermeneutical lacuna hindering the articulation of the experience of sanist aggressions, both systemic and in the form of microaggressions (Poole et al., 2012; Williams, 2014; Wolframe, 2013b). The danger of hermeneutical lacunae is that even those enacting sanist aggressions are often unaware of the implications of their unjust words or actions (Wiliams, 2014). In this way, both the *harasser* and *harassee* are cognitively handicapped in their ability to make sense of the injustices taking place (Fricker, 2007). However, hermeneutical lacunae do not affect each party equally (Medina, 2012). The harassee is significantly disadvantaged by this gap in hermeneutical resources, which render her less able to make sense of, and to communicate, ill treatment, and thus perhaps less likely to protest the injustice altogether (Fricker, 2007).

Increasing public awareness of racism, sexism, ageism and homophobia as social problems has decreased hermeneutical lacunae in these domains, and contributed to making such systems socially unacceptable (Byrne, 2010; Perlin, 2003). Conversely, many Mad persons still lack adequate hermeneutic resources for describing the prejudice and discrimination against them (Byrne, 2010; Williams, 2014). Medina (2012) cautions, however, against tying too closely hermeneutical capacities and the repertoire of readily available articulations for describing injustices, as Mad persons’ have been expressing their experiences of injustice and oppression since long before coined concepts and terminology emerged. With the proliferation of ex-patient movements in the 1960s and 1970s came a greater realization of the existence of negative prejudices attached to Mad persons (Williams, 2014). This spurred initial attempts to establish definitive language for resisting judgements of Mad persons as invariably incompetent, unpredictable, irrational and violent (Rimke, 2010; Williams, 2014). Judi Chamberlin (1990), one of the early leaders of the ex-patient movement, coined the term *mentalism* (also variously referred to as *sane chauvinism*, *psychophobia* and now, *sanism*), to describe prejudices directed at persons with psychiatric diagnoses or who were otherwise considered Mad (Byrne, 2000; Williams, 2014).

Williams (2014) argues that a crucial first step in propagating the idea of sanism as a social justice issue for Mad persons is universal acceptance of the term. To this end, it is appropriate to briefly discuss the conceptual differences between sanism and mental health stigma as distinct concepts, to deter their interchangeable use in the future. Stigma can be viewed as the outward manifestations of "an overarching oppression constructed on a foundation of sanist beliefs, attitudes and practices" (Williams, 2014, p. 13). According to Poole et al. (2012, p. 21) a focus on *mental health stigma* is too limiting, in that "it minimizes the jagged reality of widespread rights abuse and oppression (or sanism) experienced by individuals with such mental health histories." Sanism, unlike stigma, also has the expressed "aim to unsettle assumptions about rationality, normality, and madness" (Morrow & Weisser, 2012, p. 29). As such, it is an important concept in matters relating to the rights and wellbeing of Mad persons, as it "points to the social, cultural, and material dividing of 'mentally ill' bodies from 'healthy' reasoned ones, while questioning the idea that such categories are easily established and maintained" (Wolframe, 2013b, pp. 9-10).

Following Poole et al. (2012), we argue that the term sanism serves the important cognitive and discursive function of shining light in the hermeneutical darkness that prevents Mad persons' from fully understanding the injustices experienced in the name of healthcare, and public and personal safety (Fricker, 2007). Perlin's adoption of the concept of sanism (drawing on Birnbaum's writings) for making sense of his observations of the legal system's mistreatment of Mad persons, is evidence of a hermeneutical triumph (Williams, 2014). Wolframe too found consolation in discovering the concept:

> At the age of 16, I was assigned to a new psychiatrist and given a new 'adult' diagnosis. I was treated for this supposed disease – on both an inpatient and outpatient basis, using a cocktail of different drugs – for approximately six years. Although I questioned my diagnosis before I got clear of psychiatry in my early

> 20’s, it was not until I became a graduate student that I first read about the Mad movement and finally had words to describe my experiences other than those used by psychiatry. I only wish I had heard about the Mad movement earlier, and that I could have, as an undergraduate student in English and Women's Studies, talked about sanism along-side racism, heterosexism, cissexism, ageism, classism and all those other isms (Wolframe, 2013a, pp. 1-2).

Fricker (2007, p. 148) reminds us that “from a hermeneutical position of relative comfort, one can forget quite how astonishing and life-changing a cognitive achievement of this sort can be.” As a Mad-identified scholar, the first author of this paper can certainly attest to the liberating potential of the concept of sanism from a place of hermeneutical marginalization and social injustice. Exposing the pervasiveness of sanism as a deeply damaging form of systemic oppression should, in theory, render the once invisible, visible, and by extension, the once acceptable, unacceptable (Williams, 2014). However, this exposure does not guarantee that Mad knowledge will not be marginalized by those dominating the collective hermeneutic resource, predominantly the psy disciplines (Fricker, 2007). The possibility for continued hermeneutical marginalization even in light of the exposure of sanism, may be supported by the insights of Fellows and Razack (1998), who suggest that when people cannot relate to a particular “manifestation of oppression,” or are in some way privileged as a result of it, they may be more likely to discredit others’ claims of injustice (as cited in Diamond, 2014, p. 200).

2.6 Critical reflexivity and epistemic justice

Within the past decade interest surrounding human rights and “mental illness” has grown considerably among academics, practitioners, activists, and self-advocates (Perlin, 2000, 2003, 2013; Williams, 2014). As a result, violations of Mad persons’ rights are finally gaining recognition as violations of *human* rights (Perlin, 2013). This being said, many injustices directed at the Mad community have yet to be widely acknowledged (Fricker, 2007; Liegghio, 2013). Epistemic injustice, for example, has not been fully appreciated as a profoundly damaging ethical wrong. According to Fricker (2007, p. 40), with such an appreciation “perhaps we [as a society] would be more ready to voice our resentments and argue them through to some sort of rectification; and perhaps a social shift would occur towards developing a better vocabulary and forum for airing and responding to such complaints.” We have explored the ways in which sanist oppression has contributed to epistemic injustices in the Mad community, and we now wish to open a much needed conversation about possibilities for moving toward epistemic justice.

Williams (2014) suggests that society does not condone prejudice or discrimination being perpetrated against Mad persons; rather, it is simply unable to recognize such transgressions when they occur. They argue, however, that “it is essential that society becomes aware of their own assumptions about human behaviours, values, biases, preconceived notions, personal limitations, and that they try to actively understand the different world view of a person experiencing mental illness, without negative judgment” (Williams, 2014, pp. 451-452). We support Fricker’s (2007) claim that acknowledging the role of negative identity and prejudicial stereotypes in shaping a hearer’s credibility judgment can be a crucial *epistemic resource* for persons who are to become *epistemically just* hearers. We have sought to make Perlin’s concept of sanism more visible, so that its power and pervasiveness might be better understood and appreciated (Williams, 2014). Given that “the social imagination can be a powerful positive force for social change” (Fricker, 2007, p. 40), we argue that reflexive awareness can be a means of moving toward epistemic justice for Mad persons, by altering understandings and beginning to correct identity-prejudiced belief systems. Indeed, we are suggesting that most of the work toward eradicating epistemic injustice needs to be achieved through the reflexive efforts of hearers (Fricker, 2007). Such hearers need not be what Medina (2012) refers to as *hermeneutical heroes*: extremely courageous listeners (and speakers) who disrupt epistemic trends, making room for new meanings and interpretive perspectives. Instead, creating awareness of the conditions that support both testimonial and hermeneutical justice demands reflexive awareness on the part of ordinary, but epistemically sensitive, listeners (Fricker, 2007).

Epistemic sensitivity requires engagement in self-criticism and openness to changing negative patterns of credibility judgment and interpretive habits, so that the unprejudiced perception of another human being might transcend deeply entrenched negative identity prejudices and stereotypes (Fricker, 2007). One must begin to assess not simply the likelihood that the speaker’s utterance is true, but also the truthfulness of the hearer’s interpretation (Fricker, 2007; Medina, 2012). In doing so, a hearer may begin to recognize that perhaps her understandings are embedded within power imbalances related to the production of given knowledges. While hearers cannot be expected to suddenly develop complete openness in this regard, it is important, as Medina (2012) reminds us, to be mindful of the wiggle-room that exists for modifying such problematic habits.

In addition to reflexive *self*-awareness, critical reflexivity in a broader social sense may also be used as an approach to question taken-for-granted knowledge claims related to madness, and for recognizing the ways in which unequal power relations may contribute to the available resources for understanding Mad experiences (Kinsella & Whiteford, 2009). Critical reflexivity, not to be confused with reflection, is defined by Kinsella and Whiteford (2009) in accordance with the work of social philosopher Barry Sandywell (1996), as “the act of interrogating interpretive systems that influence knowledge production,” whereby the “sociality of the process of knowledge production” is acknowledged (Kinsella & Whiteford, 2009, pp. 250-251). Critical reflexivity involves careful interrogation of the grounds upon which taken-for-granted, or normative, claims about knowledge are generated and accepted, along with the situated perspectives from which knowledge claims are produced (Harding, 1991; Kinsella & Whiteford, 2009; Kinsella, 2012; McCorquodale & Kinsella, 2015; Phelan, 2011; Sandywell, 1996).

A critically reflexive hearer attempts to become aware of how the “relation between [her] social identity and that of the speaker is impacting on the intelligibility to her of what [the speaker] is saying and how she is saying it” (Fricker, 2007, p. 169). In this way the hearer is aware that the speaker’s relative unintelligibility to her is perhaps a function of “a collective hermeneutical impoverishment, and [she] can adjust or suspend [her] credibility judgment accordingly” (Ficker, 2007, p. 7). Furthermore, a critically reflexive hearer can acknowledge that while to her a speaker’s testimony is seemingly unintelligible due to the speaker’s hermeneutically disadvantaged position, to another hearer the speaker may be communicating manifestly important knowledge (Carel & Kidd, 2014; Fricker, 2007). Hearers can move toward hermeneutical justice by seeking, including, listening, and being open to speakers' interpretations, and viewing these as important contributors to knowledge generation (Carel & Kidd, 2014; Fricker, 2007).

Using an example provided by Carel and Kidd (2014) to consider what hermeneutical justice might look like, we can suppose that if confronted with a testimonial exchange whereby the speaker's interpretation seemed relatively unintelligible, the critically reflexive hearer might think to herself:

> Although I do not quite understand what you are attempting to communicate, I do not see it as a fault of yours, but mine. Even your best efforts to make yourself understood are failing, not because of their inarticulacy, but because I am unable to appreciate the *sort* of articulacy you are using, and this hermeneutical context does not provide me with those resources (Carel & Kidd, 2014, p. 532).

Badwall (2016) cautions against the use of reflexivity that does not take into account the multiplicity of subject positions that shape identities or the colonial roots of taken-for-granted approaches to knowledge generation, such as the curriculum offered in professional schools or faculties (e.g., Social Work or Medicine). She argues that particular institutional and colonized sites may create conditions in which critical reflexivity does the opposite of its intentions, for example "when the issues that workers can or cannot discuss are determined by their organizations" (Badwall, 2016, p. 16) or are "contingent upon colonial continuities designed to govern the parameters of what can be reflected upon" (p. 17). While deeper engagement with this critique is beyond the scope of the present paper, it is important to acknowledge that sanism is inextricable from other forms of oppression (Poole & Jivrav, 2015). As such, the problem of epistemic injustice should be explored further within the context of intersecting oppressions and prejudices, such as the racialization or gendering of Mad bodies.

2.7 Engagement with alternative epistemological perspectives

Knowledge(s) that differ from dominant discourses and ideologies are too often deemed "alien" and dismissed or ignored. However, epistemic interactions oriented toward *justice* require us to make room for, and embrace, plural and diverse knowledge(s) (Kinsella & Whiteford, 2009; Medina, 2012). In this sense, justice carries with it generative epistemic possibilities, as it is often alien knowledge that forces a radical questioning of taken-for-granted assumptions, and calls for a “rearticulation of epistemic norms” (Medina, 2012, p. 47). It would be limiting to make sense of madness according to psy discourses alone, in light of the multiplicity of meaning(s) to be made of such realities (Fricker, 2007). In order to broaden our epistemic considerations we must first begin to “regard everyone’s self-narrative as central” (Fabris, 2011, p. 31).

Situated stories and firsthand accounts by members of the Mad community offer epistemic resources to which we must attend. According to Foucault (1980), simply giving voice to and hearing subjugated knowledge provides a means for challenging the hegemony of dominant discourses. This perspective is echoed by Fabris (2011, p. 34), who writes that “to contest force in psychiatric arrangements requires more than empathy or technique in the other’s ‘best interest,’ and more than knowledge about us without us.” In order to tap into the subjugated knowledge of Mad persons, Fabris offers an alternative way of *knowing* madness that is filled with epistemic possibility: Madness is sound, but not because we live in a mad world (there is nothing mad about it either). We have identity *in* ‘mad’ experience, in difference, not despite it. I would like to suggest that madness is not only excusable, interesting, or a version of rationality under pressure. Madness is an embodied way to know. It is intelligent, searching, and valuable. It is not regression, but a conscious reaching out, as is technical work, healing love, or creative feeling. Purpose is not impossible in ‘madness,’ but it is also not easily described in a non-normative relation to the world. (Fabris, 2011, pp. 31-32)

2.8 Conclusion

Throughout this paper we have examined Fricker’s (2007) concept of epistemic injustice as it relates to the marginalization of Mad knowledge(s), linking the concept with that of sanism and psychocentrism. We have also engaged with the concept of critical reflexivity as a means to participate in the pursuit of epistemic justice. It is our hope that this work will serve as a foothold for those seeking to further explore epistemic justice(s) for Mad persons, and to engage in critical interrogation of the hegemony of sanism, psychocentrism and psy discourses. Epistemic injustices in the Mad community “call for *epistemic resistance,*” and the fight against epistemic injustices belongs to the entire collective social body (Medina, 2012, p. 3). Each of us has the ability, perhaps even responsibility, to use our epistemic resources toward challenging taken-for-granted ways of knowing madness (Fricker, 2007; Medina, 2012). We argue for a broadening of epistemological horizons, inclusive of Mad knowledges and welcoming of the Mad community’s full epistemic participation.

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3 Methodology

Each of the integrated manuscripts in this dissertation briefly discuss the methodology and guiding theoretical frames used in carrying out this research. This chapter provides a more comprehensive overview of the methodological approach to this research project, including its guiding theoretical framework and the core tenets of postcritical ethnography.

3.1 Theoretical framework

My guiding theoretical frame draws theoretical perspectives and conversations from the field of Mad Studies, critical and Mad (positive) pedagogies (Castrodale, 2017; Lather, 2017), and theories of *epistemic injustice* (Dotson, 2011; Fricker, 2007; Medina, 2012; Pohlhaus, 2012; 2014). Together, these critical theoretical lenses inform an understanding of service user involvement (SUI) as a pedagogical approach with potential to support service user educators' (marginally situated) epistemic contributions to the knowledge base of health and social care professions through involvement in the politicized and contested practice of health professional education.

3.1.1 Mad studies

Mad studies is a growing interdisciplinary field of social sciences and humanities research, which positions Mad, consumer/survivor/ex-patient (c/s/x), or service user-produced knowledge as central and important for understanding all matters related to 'mental health' (Beresford, 2005; Burstow, 2015; Burstow et al., 2014; Castrodale, 2017; Church, 2013; LeFrancois, Menzies & Reaume, 2013; Reville, 2013). Mad studies has been described as a radical, "project of inquiry, knowledge production, and political action" that draws from people "whose lives have collided with the powers of institutional psychiatry" in order to "critique and [transcend] psy-centered ways of thinking, behaving, relating, and being" (Menzies, LeFrancois & Reaume, 2013, p.15-17). It has also been described as an "interdisciplinary and multi-vocal praxis" in the sense of bringing together radical reflective critique with politicized action for social change (Menzies et al., 2013). For some, Mad studies represents a "confederacy of academic and service user activists relating to critical understandings of mental health" (McKeown et al., 2014, p. 1177). In this way, engagement with Mad Studies offers possibilities for deepening understandings of the work of SUI.

In much the same way that Mad studies has emerged as "a counter-narrative and powerful discursive set of beliefs, thoughts, and actions aimed at challenging sanism," the service user educator role has developed as a political strategy to challenge discriminatory attitudes held by health professionals (Castrodale, 2017, p.53; Roper, 2016). In this research Mad studies is used to inform critical conversations about the knowledge contributions of service user educators (many of whom belong to consumer, survivor, ex-patient, Mad, or neurodivergent constituencies under the umbrella of Mad Studies); the systematic marginalization and exclusion of this knowledge from health professional education spaces; the role sanism plays in creating and maintaining such epistemic marginalization (LeBlanc & Kinsella, 2016; Liegghio, 2013); and the centering of service user educators' knowledge in all *mad* matters, and in the practice of SUI in particular (Castrodale, 2017; Roper, 2016).

The term 'Mad', when used in politicized and empowering discourses of Mad studies, is perhaps most strongly associated with the Mad movement, which materialized in the 1960s and 1970s in protest of the mistreatment and involuntary confinement of individuals deemed 'mentally ill' (Burstow, LeFrancois, & Diamond, 2014; Chamberlin, 1990; Poole, Jivrav, Arslanian et al., 2012; Price, 2011; Wolframe, 2013). Many of those taking part in the movement embraced the term Mad and chose to reclaim it as a politicized form of self-identification, much like the term *queer* has been reclaimed within the context of the LGBTQ2SIA+ movement (Burstow et al., 2014; Poole et al., 2012; Price, 2011). It is important to note that not all service user educators participating in this study aligned themselves with, or were necessarily even aware of, Mad studies. Furthermore, not all service user educators and proponents of SUI in professional education necessarily approach the practice as a form of Mad activism. Nonetheless, I see obvious parallels between the centering of experiential knowledge in health professions education through SUI and the broad aims of Mad studies. In the following section I discuss the ways efforts to embrace or centralize the experiential knowledge of service users in professional education potentially constitute important critical and/or Mad pedagogical strategies.

3.1.2 Critical and Mad (positive) pedagogy

Lather positions critical pedagogy as "that which attends to practices of teaching/learning intended to interrupt particular historical, situated systems of oppression" (p.98 in Lather, 2017). According to Lather (2017) such practices should problematize the ‘emancipatory impulse’ often present in discourses of critical pedagogy, moving away from positions of “universalizing spokespeople for the disenfranchised,” and toward greater focus on *who* is speaking, and *what* is being said (p.107). In this focus on *who* is doing the speaking, I turn to Mad studies-informed teaching, such as Castrodale’s (2017) Mad (positive) pedagogy, which demands pedagogical practices that promote the inclusion and valuing of a multiplicity of Mad subjectivities as important sites of learning. As it is taken up in this work, SUI can be viewed as a pedagogical practice with the potential to do just that: promote the valuing of service users’ knowledge as sites for learning within health professional education (Castrodale, 2017).

Mad pedagogy may be a useful theoretical framing to bring to the analysis of current educational programs. Castrodale (2017), offers a useful overview of the qualities of Mad-enabling pedagogies. According to Castrodale (2017, p. 61), critical disability studies (CDS)- and Mad-enabling (or positive) pedagogies:

1. often reclaim disabling and Mad terminology from pejorative roots;
2. seek to represent and appreciate complex disabled/Mad subjectivities and the subjugated voices of disabled and Mad persons, even those voices that are silent or considered to be unintelligible voices;
3. counter, problematize, and nuance dominant psy-narratives on disability and mental health;
4. trouble, resist, and often reject the influence and interests of Big Pharma in education;
5. seek to reveal epistemic, historic, and contemporary violence by psy-sciences in treatment and cure regimes, often by drawing on rich histories and narrative accounts of self-identifying Mad and disabled persons;
6. draw on disabled and Mad experiences and perspectives to inform increasingly compassionate, empathetic, critical professional praxis in biomedical-clinical-rehabilitative fields, including education;

7. recognize and speak against trauma, suffering, violence, discrimination, racism, sexism, classism, heteronormativism, ableism, sanism, abuse, assault, rape, war, precarity, and poverty as impacting individuals' well-being;
8. resist a simple biological pathologizing narrative explanation of mental illness as a chemical imbalance rooted in individuals' minds and discuss recovery in ways that move beyond the individual medicalization of Mad subjects;
9. seek opportunities for disability- and Mad-positive community building and peer support; and
10. de-centre expertise to speak about mental health issues from psy-professionals to value peer support and Mad subjects' (consumers, survivors, ex-patients [c/s/x]) lived experiences (Voronka, 2015).

The transformative potential of SUI in professional education may lie in its capacity to enact the qualities of Mad pedagogical strategies described above.

Informed by these pedagogies, SUI is approached as a strategy which draws on participatory learning practices to maximize inclusion of a plurality of perspectives (Castrodale, 2017; hooks, 2014; Lather, 1995). Furthermore, classrooms are understood as complex discursive environments that shape and reproduce dominant social structures, and service user educators are viewed as "social movement activists" engaging in this work on the politicized and contested territory of health professional education spaces (Brown & Zavestoski, 2005 as cited in McKeown et al., 2014, p. 1176). While not all service user participants in this study self-identified as Mad, complex subjectivities including those that counter dominant discourses of mental health and wellbeing were witnessed. Applying critical and Mad pedagogy as theoretical frames assisted in the elucidation and sharing of such perspectives.

3.1.3 Epistemic injustice

This research is informed by theories of epistemic injustice (Dotson, 2011; Fricker, 2007; Medina, 2012; Pohlhaus, 2012; 2014; 2017) in its examination of service user educators' knowledge contributions to health professional education (Sapouna, 2020). Epistemic injustice refers to the distinct wrong done to someone in their capacity as a *knower*;

restricting their ability to engage in the basic everyday practices of knowing, conveying knowledge to others, and making sense of personal and social experiences (Fricker, 2007). Epistemic injustice has been applied as a theoretical lens to better understand the challenges experienced by marginalized individuals and groups in their efforts to know, and legitimate this knowledge, within contexts of confluent oppression, such as ableism, racism, sexism, and sanism (Carel & Kidd, 2014; Critchon, Carel & Kidd, 2017; Fletcher & Clarke, 2020; LeBlanc & Kinsella, 2016; Liegghio, 2013; Miller Tate, 2019; Molas, 2016; Newbigging & Ridley, 2018; Scully, 2018; Scrutton, 2017). Attending to the issue of epistemic injustice in mental health professional education involves troubling existing operations of power and knowledge, and questioning what constitutes valid knowledge, who the legitimate knowers are, and whose knowledge should count (Newbigging and Ridley, 2018).

At least four varieties of epistemic injustice have been observed and conceptualized. *Testimonial injustice* occurs when a hearer gives an unfairly deflated level of credibility to a speaker's word (testimony) due to nothing more than a prejudice associated with that speaker's social identity (Fricker, 2007). In cases of testimonial injustice, the marginally situated speaker is harmed in their capacity as a giver of knowledge. It is worth stating explicitly, that wherever epistemic injustice is taken up in this research, so too is the concept of sanism. For, as has been elucidated in Chapter 2 sanism is always operating below the surface, contributing to credibility diminishing *negative identity prejudicial stereotypes.*

Hermeneutical injustice occurs when there is a gap in collective interpretative resources (e.g., language, concepts and theories) needed for a group to make sense of, and express, significant aspects of their social experience (Fricker, 2007). In the case of hermeneutical injustice, knowers in both marginalized and dominant social positions are lacking interpretive resources, however, those situated marginally shoulder the disadvantage (Pohlhaus, 2012). Dotson (2011) departs from, Fricker's (2007) hermeneutical injustice, with the concept of *contributory injustice,* which occurs through the systemic dismissal of the knowledge and language developed within marginalized communities (e.g., service user, psychiatric survivor or Mad communities) by those situated more dominantly (e.g., psychiatrists and other mental healthcare professionals) (Miller Tate, 2019, p.97).

Unlike hermeneutical injustice, contributory injustice is not simply a matter of marginalized epistemic communities lacking adequate conceptualizations and language, or “having no contribution to make” (Miller Tate, 2019, p.97). Rather, marginally situated knowers are often able to make sense of and articulate aspects of their experience relatively effortlessly among themselves, formulating “arduously honed concepts” and insights, yet remain unable to communicate these with the same ease or effectiveness in mainstream discourse (Pohlhaus, 2012, p. 722). Contributory injustice is perpetuated by what Pohlhaus (2012) has called *willful hermeneutical ignorance* (Miller Tate, 2019). Willful hermeneutical ignorance is said to occur when dominantly situated knowers refuse, “to acknowledge and acquire the necessary tools for knowing whole parts of the world,” (Pohlhaus, 2012, p. 729) and in particular, those parts which can only be known from situations other than their own.

Epistemic injustices are intertwined with and reinforce relations of dominance and oppression (Pohlhaus, 2017). Psychiatrized persons (i.e., service user educators in the context of this research) are particularly vulnerable to epistemic injustices (e.g., having their knowledge discredited, dismissed or excluded) as a consequence of *psychiatric oppression* (Fletcher & Clarke, 2020; LeBlanc & Kinsella, 2016). Psychiatric oppression reinforces sanist stereotypes about psychiatrized persons’ as invariably dangerous, irrational, and untrustworthy, resulting in unfairly diminished judgments of their credibility, and thereby, the dismissal or discrediting of their knowledge (LeBlanc & Kinsella, 2016; Perlin, 2000; Poole et al., 2012). Psychiatric oppression is also at the core of the exclusion or inadequate uptake of the vast body of epistemic resources (e.g., language, concepts, theories, and research) produced by Mad activist/academic, psychiatric survivor, and peer communities.

At present, dominant epistemic resources for understanding mental distress and diversity consist primarily of ‘objective,’ medicalized knowledge; resources that many deem ill-suited for understanding and communicating their experiences (LeBlanc & Kinsella, 2016; Newbigging & Ridley, 2018). Psychiatric survivors, service users, Mad activists and scholars, along with their allies, are at the forefront of efforts to resist epistemic injustices and validate experiential knowledge; formulating and advancing alternative knowledge and practices, informed by direct experience (Beresford & Russo, 2016; Newbigging & Ridley, 2018). Although mental health professional education has seen considerable growth in co-produced knowledge and peer education, service user-produced literature and research from the base of Mad studies, has yet to gain traction as a valid epistemic resource (Crichton et al., 2017; Groot, Haveman & Abma, 2020; Kidd & Carel, 2017).

Health professional educators and other dominantly situated knowers play an important role in fostering epistemic justice and the 'uptake' of marginalized knowledge (Katzman & LeBlanc-Omstead, 2019; Kurs & Grinshpoon, 2018; LeBlanc & Kinsella, 2016; Scrutton, 2017; Miller Tate, 2019). Marginally situated knowers, for whom mainstream epistemic resources are often ill-fitting, are well positioned to "notice inadequacies in our epistemic resources" and draw attention to "whole parts of the world for which dominantly held resources are not very suitable" (Pohlhaus, 2012, p.719-20). By this logic, Scrutton (2017) suggests re-framing perceptions of psychiatrized individuals as being 'epistemically privileged' (rather than disadvantaged) given their possession of uniquely situated and fruitful insights. Further, calls have been made for an "attitude of listening, rather than 'knowing best'," and a genuine openness from health professionals to take seriously the epistemic resources that service users and survivors have developed, regardless of how "alien" such knowledge may initially seem (Dohmen, 2016; Kurs & Grishpoon, 2018; Scrutton, 2017, p.353, Miller Tate, 2019, p.99). Mitigating epistemic injustice requires familiarity and engagement with knowledges that "diverge enormously from the technical or medical perspective that psychiatrists are under pressure to adopt," as well as an earnest belief that mainstream epistemic resources are insufficient for understanding, communicating, and responding to, important dimensions of people's experiences of mental distress and diversity (Medina, 2012; Miller Tate, 2019, p.99).

Individual efforts on the part of even the most sympathetic health professionals, however, may be inadequate for responding to epistemic injustice, as "the institutions of health and social care hold enormous structural epistemic privilege," necessitating redress at a systemic level (Scully, 2018, p.16). While broader issues of (in)access to knowledge production and meaning-making persist, fostering connections between marginalized knowers and established epistemic communities (e.g., psychiatric survivor, Mad activist and academic, service user educator communities of practice, or peer support groups), stands to allay experiences of epistemic injustice that result from being left to make sense of one's experience in relative isolation (Pohlhaus, 2012).

This work acknowledges that within professional education classrooms, "all voices […] are not and cannot carry equal legitimacy, safety, and power" given present social structures (Lather, 1995, p. 172). For instance, the influence of service users' knowledge is quite often diminished or disregarded in cases when there is a "head on collision between subjective and objective knowledge in a setting where less value is placed on subjective knowledge or if a lay perspective is ostensibly sought but not respected in the hierarchy of professional knowledges" (Roper, 2016, p. 203). Thus, epistemic injustice offers an important conceptual lens for examining SUI in health professional education in light of the imbalance of epistemic power and knowledge hierarchies at play.

3.2 Postcritical ethnographic methodology

Postcritical ethnography is a critical qualitative methodology which combines the critical ethnographic genre with tenets drawn from poststructuralism (Lather, 2007; Noblit, 2004). Postcritical ethnographers are committed to undertaking research as an ethical and political practice. In challenging systemic inequities, they invite their audiences to "consider what could be otherwise in inequitable relations but is not yet" (Anders, 2019, p. 1). Like critical ethnographies, postcritical ethnographies take us "beneath surface appearances, disrupt the status quo, and unsettle both neutrality and taken-for-granted assumptions by bringing to light underlying and obscure operations of power and control" (Madison, 2011, p. 14). Where postcritical ethnographers make their methodological departure is in the "move to contextualize our own positionality, thereby making it accessible, transparent, and vulnerable to judgment and evaluation" (Madison, 2011, p. 19). In other words, postcritical ethnography, "reflects the parallel commitments to study power in social contexts and in the practice of ethnography" (Noblit, Flores, & Murillo, 2004 as cited in Anders, 2019, p. 1).

While postcritical ethnography is not intended to be prescriptive, postcritical ethnographers, "frame research projects in ways that engender the possibility of informing change in practice, policy, and discourse," and in doing so invite their readers to imagine the world differently; to consider what could be otherwise about the experiences they seek to represent (Anders, 2019, p. 2). Postcritical ethnography ultimately aims to produce justice-centered discourses through the amplification of subjugated knowledges and stories (Anders, 2019). While there is no *one* way to define postcritical ethnography, Noblit (2004) contends that it is important that all approaches to postcritical ethnography consider/attend to issues of "positionality, reflexivity, objectivity, and representation" (p. 198). Consideration of these tenets helps to reconfigure notions of the 'critical' to align with post-foundational perspectives and to represent what has been referred to as a 'postcritical' approach to research (Lather, 1995, 2017).

3.2.1 Positionality

In addition to positioning ourselves, "in relation to particular commitments and pursuits of justice" and social change, as postcritical ethnographers we also consider our own positionality as researchers (Anders, 2019, p. 2). Positionality in this sense involves "being explicit about the groups and interests that the postcritical ethnographer wishes to serve, as well as his or her biography" (e.g., ideas, intersecting identities, and commitments) (Noblit, 2004, p. 198). Through the integration of my reflexive writings – a practice I engaged in throughout the whole of this research project – I have endeavored to be as transparent as possible about my various subject positions in this work. In Chapter 2 I first make mention of my self-identified position as a Mad woman and scholar, and the hermeneutical triumph I experienced in coming to understand my encounters with the mental health system as a service user in a politicized (i.e., Maddened) way. My positionality is revisited in greater detail in Chapter 7 as I recount my experience as a sessional health professional educator engaging in the practice of

SUI, and is unpacked further in the concluding chapter of this dissertation as I discuss my becoming ‘politically Mad’.

It is not uncommon for postcritical ethnographers to find themselves positioned “at the hyphens and intersections of identities and multiple ways of knowing” (Anders, 2019, p.6). In the words of Parsons**,** “I live my identity politics on multiple fronts,” and in doing so, I occupy a liminal status, or ‘betwixt-and-between’ positionality (Hart, Poole, Facey & Parsons, 2017, p. 1770). I come to this work as a maddened cis-woman-white-settler-mother-carer; a provider of mental health services; a (former) user and survivor of such services; and an educator drawing from a wide array of personal, professional, and academic knowledge, in different ways and to varying degrees depending upon things like context, audience, and personal safety or comfort. As a postcritical ethnographer concerned with the practice of SUI, I have been able to ‘enjoy,’ “both insider and outsider status”; simultaneously an onlooker, director, and member of the cast (Conquergood, 1992 as cited in Hart et el., 2017, p. 1766).

In many ways, this work represents (to me) a merging of the personal and political (Morris, 1992). The impetus for this project arose out of the confluence of my experiences as a (then) recent graduate of a Master’s in occupational therapy whose formal education included the practice of SUI; a service user educator in various fields of health and social care professional education; and a person and scholar with increasingly politicized understandings of her experiences of Madness. I am inclined to view this liminal status as ‘disruptive’ insofar as it has enabled me to challenge and revisit “taken-for-granted assumptions and everyday experiences” with a “fresh perspective” (Hart et al., 2017, p. 1767). As Hart et al. (2017) caution, however, “being a liminal subject can present existential challenges” (p. 1766). This has indeed been true of my experiences with/in this work. My positionality as a ‘liminal subject’ with membership in both Mad/service user communities (scholarly, activist, or otherwise) and the health professions (through research, education, and clinical practice) has meant an ongoing grappling with my ‘in betweenness’; whereby my critique/critical lens is seldom taken ‘far enough’ for the former, and always ‘too harsh’ for the latter. At times I have experienced this liminal subjectivity as alienating; a felt sense that my experiences do not quite fit neatly into either space.

I have often pondered whether I would have pursued an education or career in occupational therapy had I been introduced to Mad studies sooner. I believe I would have, especially if I had known then about the small (but mighty) networks of disabled and Mad care professionals I have now found myself moving in; small pockets of air that allow me to catch my breath, carrying out their activism on the fringes and embracing their position in the borderlands (Cosenza, 2010). Now that I am here, however, I am determined to lean into the epistemic wiggle room that always surrounds us toward making sure that the health professional spaces I occupy are Mad-informed and Mad-positive.

3.2.2 Reflexivity

Attending to researcher positionality requires a "turning back" on ourselves (Davis, 1999 as cited in Madison, 2011, p. 17), constituting a particularly *reflexive* methodology. For Madison (2011), it is in this turning back that we start to ask ourselves as researchers questions like:

> "What are we going to do with the research and who ultimately will benefit? Who gives us the authority to make claims about where we have been? How will our work make a difference in people's lives? But we might also begin to ask another kind of question: What difference does it make when the ethnographer [their]self" is an 'insider'? (Madison, 2011, p. 17).

Lather (2007) discusses the role of reflexivity in interrogating the emancipatory nature of postcritical research, explaining that, "postcritical methodologies are *hinged* on self-reflexive, double(d) practices of representation that both problematize emancipatory research aims and the production of essentialized and romanticized subjects" (Lather, 2007, p.347). Toward problematizing emancipatory research, Lather (1995) proposes a foregrounding of the reflexive poststructuralist question: "how do our very efforts to liberate, perpetuate the relations of dominance?" (p.169).

My reflexive notes about one particularly confronting interaction during my participation in a *Service User Educator* training course helped me to make sense of the complexity of being both an ‘insider’ and ‘outsider’ in this work. Engaging with Lather’s question and a reflexive turning back helped me to identify an apparent contradiction in my efforts to illuminate instances of epistemic injustice in SUI through this research, whilst simultaneously undervaluing (in a material sense, and by design) the service user educator knowledge I stood to benefit from:

> I was among fellow service user educators enjoying the provided refreshments during our break period when one of the facilitators of this service user educator certificate training mentioned that they had seen my ‘*call for participants*’ in a peer-run newsletter. Following this brief exchange, the woman to my left – I will call her Vera – spoke:
>
> Vera: “Oh! That was *your* call for research participants?!”
>
> Me: “Oh…yeah! – you saw that?”
>
> *(Now, I earnestly – and naively, or perhaps, arrogantly – believed that next she would express her interest in participating, or at the very least, ask me follow-up questions about the study).*
>
> Vera: “I did. No offense, but when I saw that you were offering a $25 honorarium, I just kept scrolling. My knowledge is worth way more than $25 bucks.”

I was taken aback by her comment. I felt sick to my stomach; embarrassed. But, Vera was absolutely right. I had been relying on a faulty, arrogant belief that as someone on the ‘inside’ – one of the ‘good guys’ – prospective participants would be willing to join me in my pursuit of justice no matter the cost (to them). Over the course of my analysis and writing up of my interpretations of the data, this interaction continued to eat away at me. In what I now see as an attempt to soothe my bruised ego, or cling to a vision of myself as *good* or *innocent*, I debriefed with respected colleagues about this interaction. To my relief (in those moments) I was reassured that my offering of a $25 honorarium for a one-hour-long interview was a standardized institutional practice, and one which no one would question. Whilst acknowledging the presence of systemic constraints, I also acknowledge that $25 was inadequate remuneration for participants' knowledge, labour and time.

In Chapter 7 I recount my decision to offer service user educators a $50 honorarium for a one-hour lecture plus travel expenses where appropriate. Although this practice was informed by service user-produced literature and my preliminary research findings, I cannot help but wonder how great a role my unconscious desire to 'right' my earlier wrong played in this decision. As described in Chapter 7, I emailed the health professional education department to request support in providing these funds, firmly stating my position on the matter; a sort of public declaration of my commitment to this ethical practice. As I wrote the letter advocating for fair remuneration, I could not shake overwhelming feelings of hypocrisy.

3.2.3 Objectivity

Stemming from poststructuralist, postmodernist, and feminist critique of conventional ethnography, postcritical (or reflexive) ethnographers "have replaced the grand positivist vision of speaking from a universalistic, objective standpoint with a more modest notion of speaking from a historically and culturally situated standpoint" (Foley & Valenzuala, 2005, p. 218). Postcritical ethnographers reconsider, worry about, and try to work through the dilemma of *objectivity,* through acknowledging that cultures, influenced by social and historical forces, are ephemeral and multiple, and that "our interpretations are always partial and positional" (Noblit, 2004, p. 199). McCadden, Dempsey and Adams (1999) argue that the reconsideration of objectivity should be reflected in the theorizing of postcritical ethnography, "in the same tone as its writing – balancing tentativeness and surety and evoking a sense of temporality" (p. 33 as cited in Noblit, 2004, p. 199). In eschewing claims of objectivity, postcritical ethnographers, "pursue multiple, complex, and performative representations, address the significance of positionality and practice reflexivity" (Anders, 2019, p. 2). Toward this aim, postcritical ethnographies often amplify narratives that counter, resist, deconstruct, and delegitimate unified and final representations or grand narratives (Anders, 2019).

3.2.4 Representation

The issue of *representation* in postcritical ethnography refers primarily to the actual writing or re/presentation of the ethnographic text (Noblit, 2004). Consideration of this issue involves acknowledging and thinking critically about the “uncertainty about adequate means of describing social reality” (Marcus & Fisher, 1986, p. 8 as cited in Noblit, 2004, p. 199). Attending to issues of representation from a postcritical perspective, recognizes that “writing ethnography […] is not about capturing the real already out there,” in a fixed way, but is instead about “constructing particular versions of truth [and] questioning how regimes of truth become neutralized as knowledge” (Britzman, 2000, p. 38). Postcritical ethnographers acknowledge that representations are always limited, “partial, positional, and personal,” that there are gaps in tellings, and that much remains untold (Anders, 2019, p. 18). To this end, the postcritical ethnographer asks: “How might we interpret this experience differently? How might we represent this experience differently?” (Noblit et al., 2004 as cited in Anders, 2019, p. 7). For Mahipaul (2015), approaching representation in light of poststructural critique is the distinction between producing, “texts that envisage a merely passive, receptive reader and those that call upon the reader to be an active creator of meaning” (Mahipaul, 2015, p. 23-24).

It is also important to discuss the notion of ‘voice’ as it is considered within postcritical ethnography. While critical ethnographers may endeavour to, “use the resources, skills, and privileges available to her to make accessible—to penetrate the borders and break through the confines in defense of—the voices and experiences of subjects whose stories are otherwise restrained and out of reach” (Madison, 2011, p. 5), Lather (2017) calls instead for a negotiation of the tensions between the “political imperative to make visible” the experiences of marginally situated groups and “poststructural critiques of representation” (p. 112). Lather (2017) proposes a move to destabilize practices of ‘telling the other’, and rejects the notion of one ‘true,’ privileged or authoritative explanation. In other words, Lather (2017) urges us to move beyond a focus on the limits of our knowing, toward “problematizing the researcher as ‘the one who knows’” (p. 114).

Indeed, my interrogation of power in this research, “does not mean that I do not deploy power myself” (Anders, 2007, p. 46). Following Anders (2007), I have attempted to resist representations that position me as “critical/author [who] poses superior knowledge and insight” by way of keeping my role as critic and my development as a researcher visible (Noblit, 2004, p. 316 as cited in Anders, 2007). I have attempted to “complicate the authoritative critique” by layering complex and often contradictory perspectives shared by service user educators, health professional educators and myself (Anders, 2007, p. 46). An ethics of representation involves researchers making “decisions about how to take the words out of their participants' mouths and reproduce them elsewhere” (Pickering & Kara, 2017, p. 306 as cited in Lester & Anders, 2018). Mahipaul (2015) cautions that, “we must be careful about the stories we tell, about the ways we define ourselves and other people” since “some stories enhance life [and] others degrade it.” (Felske, 1994, p. 190 as cited in Mahipaul, 2015). This layering of accounts has also been used to avoid reducing individuals or groups who may inadvertently contribute to the harm of others to the role of ‘villain’ (Lester & Anders, 2018).

3.3 Summary

In this chapter, I have outlined my guiding theoretical framework which draws from the field of Mad Studies, critical and Mad (positive) pedagogies, and theories of epistemic injustice. I have also discussed the core tenets of postcritical ethnography: positionality, reflexivity, objectivity, and representation, and how I have endeavoured to address these in my design and execution of this research.

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4 Methods

Lather (2017) resituates postcritical method as a “way into the messy doings of science via risky practices that both travel across contexts and are remade in each situated inquiry” (p.115). In this chapter, I describe the methods I used in *doing* postcritical ethnography, and the ways in which postcritical thought informed my approach to methods as, “not simply isolated or immutable activities, but [as] contingent on our purpose, our fundamental questions, the theories that inform our work, and the scene itself.” (Madison, 2011, p. 27). Ethical considerations and proposed quality criteria for evaluating this research are also presented.

4.1 The ethnographic context

This research is concerned broadly with mental health SUI in health professional education, however, the study was grounded in occupational therapy education programs in Ontario, Canada as a means to probe broader questions about the practice. The ethnographic context and data collection was primarily bound to the following four sites: McMaster University, Queen's University, Western University, and the University of Toronto. At each site, data were collected in the form of (a) in-depth, semi-structured interviews with service user educators and health professional educators; (c) participant observation; and (c) textual resources relevant to SUI at these sites (e.g., publicly available curriculum documents, program information, and course syllabi).

In light of the broad aims of the study to deepen understandings of stakeholders’ complex and varied experiences of SUI, and to critically examine the way SUI is currently conceptualized and implemented within health professional education programs in Ontario, ‘key informant’ perspectives of mental health service users involved in professional education beyond the scope of Occupational Therapy were also sought. It was anticipated that these perspectives would offer additional insights into the ‘state’ of mental health SUI as a movement and practice in health and social care education more generally (i.e., notable conversations taking place in the field, experiences of persons with well-established practices of involvement in professional education, different mental health service-user led initiatives that may shed light on or deepen understandings of service user practices).

4.2 Participant sampling and recruitment

4.2.1 Participants

Participants in the study were recruited through purposeful sampling. Participants included stakeholders who have taken part in the practice of mental health SUI in professional education in one of the following capacities: (1) service user educators involved in occupational therapy education programs; (2) service user educators involved in health and social care professional education beyond occupational therapy (e.g., social work, psychiatry, nursing, etc.); (3) educators in occupational therapy education programs in Ontario. In total, fourteen stakeholder participants representing all four of the aforementioned universities (i.e., 7 service user educators in occupational therapy; 2 service user educators from other health and social care education programs; and 5 occupational therapy educators) previously or presently engaged in the practice of mental health SUI participated in this study. Inclusion criteria for participation were as follows:

> *Service Users involved in Occupational Therapy education programs must:* (i) be at least 18 years of age; (ii) be able to comprehend and communicate in English; (iii) use, or have used in the past, some form of mental health and/or social care service; and (iv) have experience in the education of students enrolled in a Master’s level Occupational Therapy program in Ontario.
>
> *Service Users involved in Health and Social care professional education must:* (i) be at least 18 years of age; (ii) be able to comprehend and communicate in English; (iii) use, or have used in the past, some form of mental health and/or social care service; and (iv) have experience in the education of students enrolled in mental health and social care professional education programs.
>
> *Occupational Therapy educational program personnel must:* (i) be at least 18 years of age; (ii) be able to comprehend and communicate in English; (iii) be employed by any one of the Master’s level Occupational Therapy programs in

Ontario; (iv) fulfill a role within said program that is directly (e.g., mental health course coordinator or instructor) or indirectly (e.g., curriculum committee member, administrator) related to mental health education; (v) have experience with the practice of *service user involvement* in professional education.

The following table provides a breakdown of participants' pseudonyms and roles in relation to SUI (Table 1). To protect confidentiality and anonymity, participant demographic data is presented in a separate table (Table 2).

Table 1: *Participant Pseudonyms and Roles in Service User Involvement*

	Pseudonym	**Role**
1	Glen	Service User Educator
2	Kimberly	Service User Educator
3	Heather	Service User Educator
4	Fred	Service User Educator
5	Carmen	Service User Educator
6	Elliot	Service User Educator
7	Joel	Service User Educator
8	Sally	Service User Educator
9	Edward	Service User Educator
10	Nancy	Health Professional Educator
11	Anthony	Health Professional Educator
12	Sara	Health Professional Educator
13	Lindsay	Health Professional Educator
14	Rita	Health Professional Educator

Table 2: *Participant Demographic Data*

Years of SUI Experience	**# of Participants**
1-2	1
3-5	4
6-10	4
11-15	1
16-20	2
>21	2
Gender	**# of Participants**
Non-binary	0
Male	6
Female	8
Prefer Not to Disclose	0
Age	**# of Participants**
18-30	0
31-40	2
41-50	5
51+	7

4.2.2 Recruitment

I contacted occupational therapy educational program personnel at each of the four English-speaking Master's level Occupational Therapy programs in Ontario (Western University, McMaster University, University of Toronto, and Queen's University) via publicly available email addresses and/or telephone numbers to introduce the proposed research project and invite participation. Occupational therapy educators available to support the proposed research project were asked for assistance in the recruitment of further participants, through the circulation of recruitment materials to potential participants (i.e., service user educators, course coordinators, curriculum personnel). Materials included a brief letter of information detailing: the general purpose of the study; expectations of participation in the study; and telephone and email contact information for interested potential participants to obtain more detailed information. Service user educators involved in other health and social care education programs were recruited through the announcement of the study in the Ontario Peer Development Initiative (OPDI) newsletter (considered highly visible to service user educators) and by word of mouth.

Interested individuals made voluntary contact by phone or email as indicated in the recruitment materials. Potential participants were screened via email or phone conversation for eligibility according to inclusion criteria. When it was determined that individuals met the inclusion criteria, they were: (i) sent the *Letter of Information and Consent Form* (See Appendix E) with detailed information about the study objectives and requirements for participation; and (ii) invited to ask any questions relevant to participation in the study. Interviews were then arranged with individuals who then consented to participate in the study.

4.3 Interview

> *"Doing fieldwork is a personal experience. Our intuition, senses, and emotions—or what Wallace Bacon (1979) collectively refers to as "felt-sensing"—are powerfully woven into and inseparable from the process"* (Madison, 2011, p. 19).

Interviewing is perhaps the most widely used method of investigating the social world (Davies, 2012). In keeping with the postcritical ethnographic methodology, I adopted a reflexive approach to interviewing in this study, relying in part on Denzin's (2001) conception of 'reflexive interviewing', and Heyl's (2001) proposed use of reflexive practice as a research strategy in the interview process. In doing so, I approached interviewing as "not merely the neutral exchange of asking questions and getting answers," or as a method of information gathering, but as a "journey from which [I] will return with stories to tell, having engaged in conversations with those encountered along the way" (Denzin, 2001; Fontana & Frey, 2005; Heyl, 2001, p. 371). According to Heyl (2001), reflexivity in the context of ethnographic interviewing has the potential to: (i) bridge differences between researchers and respondents; (ii) aid researchers in the avoidance of unexamined assumptions; and to (iii) create a protected space within which interviewees can "tell their life stories as well as increase the interviewers' understanding of those stories" (Heyl, 2001, p.377).

Semi-structured interview guides (See Appendix B) were developed through an iterative process and ongoing discussion between myself and my doctoral supervisory committee. The initial formulation of questions was informed, in part, by Madison's (2011) presentation of what she refers to as 'tried and true' models for guiding the development of interview questions: the Patton and Spradley Models (See Patton, 1999; Spradley, 1979). Following these models, researchers are encouraged to attend to the various 'types' of interview questions, including: 'behaviour or experience,' 'opinions or values,' 'feelings,' 'knowledge,' 'senses,' 'background/demographic,' 'descriptive,' 'structural or explanation,' 'contrast,' 'advice,' and 'quotation' questions.

Although many of the interview questions naturally evolved out of my personal experiences related to SUI, and a growing familiarity with practices and issues presented in the literatures on SUI, effort was made to ensure that the manner in which questions were written aligned with a diversity of the aforementioned question 'types'. The interview guides were piloted with the first two or three participants and revised or adapted as necessary. Drawing from Heyl's (2001) suggestions for reflexive ethnographic interviewing, with each interview I aimed to: "listen well and respectfully, developing an ethical engagement with the participants at all stages of the project"; "acquire self-awareness of [my] role in the co-construction of meaning during the interview process"; "be cognizant of ways in which both the on-going relationship and the broader social context affect the participants, the interview process, and the project outcomes"; and "recognize that dialogue is discovery and only partial knowledge [would] ever be attained" (p. 370).

All participants in this study were asked to take part in one audio-recorded semi-structured interview. Interviews were conducted with both service user educators and health professional educators. The interviews were conducted at a negotiated location of the participant's choice that is suitable for a recorded interview. 7 interviews were conducted in-person, and the remaining 7 were conducted by telephone. Interviews ranged in length from approximately 40 minutes to 2 hours 10 minutes, with an average time of 76 minutes. In total, 17 hours 38 minutes of audio from these interviews were collected and transcribed verbatim. Basic demographic data, including the length of time involved in activities related to SUI were also collected at the time of the interview.

It has been recommended that during introductions the interview be presented as a joint exploration of the research topic, rather than “a mining of the interviewee for information” (Davies, 2012, p.109). In an effort to privilege participants’ knowledge, and to limit the effects of my preconceived notions about what knowledge is most ‘relevant,’ I invited their introduction of new topics or concerns (beyond the interview guide), expansion on or revisiting of responses, digression, and so on (Davies, 2012). In addition to considerations about the content of the interview, Davies (2012) argues for the importance of a researcher’s awareness of the context in which the interview is set, and a deliberate problematizing of the possible effects of such contexts. The interviews were conducted in a semi-structured format, allowing for a relatively flexible interaction with respect to the knowledge shared, prioritized, and/or deemed relevant by both myself and my participants. Participants were invited to decline to answer any questions at any time and to choose to answer only those questions they feel comfortable with. Despite my efforts to welcome participants’ input regarding important issues or topics, I acknowledge that through my preparation of interview guides, and my role as the asker of questions (Davies, 2012), I possessed significant epistemic control over the focus of the discussion and specific topics raised.

4.4 Participant observation / reflexive insider

Ethnographic participant observation is typically used in attempt to gather, “detailed, authentic information unattainable by any other research method” because its believed to grant research access to ‘real life’ contexts and doing, as opposed to reports from participants about what they did (Li, 2008, p. 101). However, it has been suggested that participant observation is seldom used as a primary method of data collection, and has historically been used by researchers “who [seek] to gain in-depth understandings of cultural contexts in which they had no prior experience” (Katzman, 2018, p. 191). At the outset of this research, I envisioned participant observation taking place in contexts including (but not limited to) guest lectures, curriculum committee meetings, course instruction, or student evaluation. I designed the research study so that participants’ consent to participant observation would be entirely optional, without bearing on their eligibility to participate in the research interview.

I was given consent to attend two service user educator-delivered guest lectures in health professional education courses at two separate universities (amounting to approximately 6 hours of observation). During these sessions my observational notes included (but were not limited to): observations about the layout of the classroom (e.g., was the seating arrangement theatre-style versus roundtable?); my perception of the level of student engagement (i.e., was their focus on their laptops, or were their eyes ‘glued’ to the speaker?); the body language of those in the room; the manner in which the health professional educator introduced the service user educator to the students (e.g., what details – personal, professional or otherwise – did they share with students in this introduction?); the general content of the service user educators’ presentation (e.g., what ideologies, theories, or perspectives featured prominently in their lectures? Did their contribution align with popular psy-informed language and concepts, or more critical/radical theories and perspectives?); students’ reactions or responses, and the follow-up questions they asked; as well as the gesture of ‘thanks’ (e.g., a card signed by the students and a gift card) that ceremoniously ended each involvement activity.

Much of my in-depth understandings of the cultural context in this study, however, comes from my firsthand involvement in the practice of SUI as a service user educator, health professional educator and (former) student occupational therapist. Through my experiences as a ‘reflexive insider’ (some of which is detailed in Chapters 7 and 8) I have gained rich understanding and insight into the culture of SUI (e.g., relations between health professional educators, their department, colleagues and students, and the service user educators involved) and what the practice entails: during, behind-the-scenes, and in the coming after.

Where conventional participant observation limits what can be gleaned from a guest lecture or committee meeting, my role as a reflexive insider gave me ‘access’ to knowing about the *doing* that takes place prior, during, and following a service user educators’ involvement in an education program. For instance, knowledge of: the serendipitous meeting between health professional educator and service user delivering the keynote at a conference, which would be recalled by the health professional educator years later as an old course is being ‘revamped’; or the relationships that develop over the course of a decade and one day give rise to the question, “*would you consider sharing your story with my students?”*; or the tentative email sent to the service user-led community organization that feels as much promising as it does a shot-in-the-dark; or the unsolicited email from a former student to a health professional educator requesting floor time to ‘tell their story’ of using mental health services. In the after, there is knowing about the shift in students’ attitudes and perspectives, and their sharing of this shift with friends and families supported by re-told service user stories; or the slew of student emails to the health professional educator asking, *“what am I supposed to do with this knowledge?”* and/or *“how is this relevant to my future practice?”*; or the end-of-term course evaluations in/directly impacted by the involvement of service user educators in their learning; or the inevitable *stirring* that takes place in the service user educator in the moments after they have left the classroom and in the days, months, years to follow.

As a reflexive insider, I am also aware of the thought and planning behind a health professional educators’ *ask* (i.e., why are they/we soliciting SUI in the first place?); the messiness inherent in the back-and-forth between service user and health professional educators in negotiating the logistics and other fine details of the engagement (i.e., where is the involvement to take place? For how long? Are parking passes required? Have these been arranged? Are there pre-defined learning objectives? And how much leeway does the service user educator have around addressing these?); and the (often frustrating) communication between health professional educator and their department regarding all of the above (e.g., guest lecturers’ names and contact details are often required in advance of the semester, as well as decisions made about remuneration or other form of compensation).

4.5 Reflexive journaling

The insights that I gained as a reflexive insider were realized and unpacked through an ongoing practice of reflexive journaling. Reflexive journaling served numerous purposes in this research; including, but not limited to: interrogation of my ‘insider/outsider’ position (as described in the previous section); navigation of ethical and epistemic (among other) tensions throughout the research process; data analysis, interpretation and representation of my findings, and consideration of my positionality as it related to arriving at particular findings; and re-orienting myself toward justice as a way out of the ‘stuckness’ I often felt in doing this postcritical ethnography.

Evidence of this reflexive practice can be found throughout this dissertation. The introduction to this dissertation itself begins with discussion of the tensions I experienced as a witness, and eventually a participant, in the practice of SUI. It was my reflexive journaling and related conversations around these tensions that would provide the impetus for this project. In the previous chapter (Chapter 3) I share an excerpt from my reflexive journals related to a confronting and formative experience during this research process, and how this experience raised questions for me around my liminal positionality as insider/outsider. Chapter 7 is centered around my reflexive interpretations of my experiences as a sessional health professional educator tasked with facilitating SUI, and the lessons I learned through this doing. In the concluding chapter I share reflexive insights related to my efforts to illuminate and challenge – and in doing so, potentially perpetuated – *epistemic injustice,* and on my becoming ‘politically Mad’ throughout the course of this research.

4.6 Data analysis and interpretation

> *“From our experience, however, patterns, themes, and categories do not emerge on their own. They are driven by what the inquirer wants to know and how the inquirer interprets what the data are telling [them] according to subscribed*

> *theoretical frameworks, subjective perspectives, ontological and epistemological positions, and intuitive field understandings. In short, rather than being an objectivist application of analysis procedures, the process is highly reflexive"* (Srivastava & Hopwood, 2009, p. 77).

With more than 250 pages of interview transcription, a growing collection of reflexive journals, and observational field notes in front of me, I wondered, "what do I do with all this stuff?" (Ellingson, 2013, p. 421). Ellingson (2013) suggests that "no substitute exists for wading through the interpretive process oneself" (p. 421). I approached data analysis as a process of reflexive iteration, which involved visiting and, "revisiting the data as additional questions emerged, new connections [were] unearthed, and more complex formulations developed along with a deepening understanding of the material" (Berkowitz, 1997 as cited in Srivastava & Hopwood, 2009, p. 77). I transcribed the interviews verbatim, making reflexive notes as I went about significant conversations, concepts, and connections that stood out to me within and across participants' interviews. After transcription, I began by re-reading each of the interview transcripts from beginning to end in order to better familiarize myself with the data as a whole (the forest). I then turned to Quirkos, a qualitative data management software, to help me organize the data into visual and thematic representations called 'quirks' (the trees). I used the significant concepts and conversations I noted during transcription and re-readings of the transcripts, as well as my theoretical frames (e.g., epistemic injustice and Mad studies) and research questions to guide my coding of the data.

My primary list of concepts (or quirks) included: conceptualizing SUI; (learning) objectives; getting involved; motivation; organizing SUI; implementing SUI; forms of involvement; depth of involvement; roles; context; service user knowledge; relationships; student engagement; challenges; barriers; professional constraints and considerations; benefits to service user educators; language; ethical tensions; sanism; epistemic injustice; power; and future directions. The vast majority of these concepts contained several sub-concepts not detailed here. To offer one example, the primary concept Service User Knowledge contains the sub-concepts: story; lived experience; critique; message/lesson; 'valuable knowledge'; and content shared. Chapter 5 was largely framed around this primary concept and its related sub-concept *'story'* (See Appendix C for visual representation of the Quirkos canvas, which illustrates connections or relationships between thematic codes).

I used Srivistava and Hopwood's (2009) framework for analytic reflexivity to guide my reflexive analysis of the interview data. The following three questions were used to refine the research focus and integrate data: (1) What are the data telling me? (2) What is it I want to know? And, (3) what is the dialectical relationship between what the data are telling me and what I want to know? (See Table 3). The first of these questions was also used to question my role as interpreter, by way of asking, "what is the data telling me that they might not tell someone else"? According to Srivistava and Hopwood (2009) this reflexive analytic framework "might offer one of the many ways of writing yourself into the narrative without being self-indulgent or distracting from the purpose of research"; an endeavor consistent with a postcritical ethnographic methodology. Table 3 offers a sample of the reflexive analytic process as it related to one subsection of the data (i.e., the primary concept 'Service User Knowledge' and its sub-concept, 'Story,' as described above), which eventually formed the basis of Chapter 5.

Table 3: *Application of a Reflexive Analytic Framework*

First Iteration	
What are the data telling me?	**What is it I want to know?**
What is the interview data from *service user educators* telling me about how service user knowledge is conceptualized in occupational therapy programs? What is the interview data from *health professional educators* telling me about how service user knowledge is conceptualized in occupational therapy programs?	• How has service user educators' knowledge been conceptualized as a unique form of knowledge? • Do service user educators' and health professional educators' conceptualizations of service user knowledge differ or overlap in meaningful ways? • Are there any theoretical issues or dilemmas reflected in said conceptualizations? (e.g., epistemic justice, issues of credibility or legitimacy, emotional labour, issues of representation, etc?).

The data are telling me: that participants most often use the term ‘story’ to refer to, or interchangeably with, service users’ knowledge contributions.

I want to know: why is the use of the term ‘story’ so prevalent in participants’ accounts? And, what does that mean for the uptake of service user educators’ knowledge in health professional education?

Second Iteration

What are the data telling me?	What is it I want to know?
Stories are performed – there is a perceived power in this performance	• Should we expect service user educators to be entertaining? Even engaging? • Do we place these same expectations on non-service user educators? • What are the potential issues in expecting service user educators’ stories to be powerful, moving, engaging, etc.? • Is this the only form in which we will accept service user-produced knowledge?
Storytelling entails emotional labour/work	• In what ways is the work of service user educators’ storytelling distinctly emotional work? • Does storytelling (or SUI more generally) necessarily have to be emotional? Or cathartic? • Is the extent of the emotional work required of service user educators known to those soliciting service user educators’ stories? • What supports do service user educators’ have in engaging in this emotional work?
Service user educators’ knowledge is often conceptualized *as* story	• Are there any theoretical issues/dilemmas reflected in conceptualizations of service user educators’ knowledge as story? • Why is the term ‘story’ used so often? And, what does that mean for the uptake of service user educators’ knowledge in health professional education? • In what way(s) is service user educators’ knowledge conceptualized *beyond* storytelling?

My interpretation of the data involved, “thinking within theoretical frames and holding conversations with theory and with the findings of other research in ‘the literature’” (Bathmaker, 2010, p. 202). As part of this iterative process I reviewed my interpretations of the data in discussion with others. The findings of this research were “subjected to challenge and reinterpretation” through regular dialogue with members of my doctoral supervisory committee, esteemed colleagues in the fields of health professional education and both Disability and Mad studies, activists in my personal and professional networks, and public presentation of my preliminary findings to practitioners/professionals and academics at health professional education seminars and occupational therapy conferences (Colley, 2003, p. 45). Other collected data (participant observation field notes, curriculum documents, course outlines, and reflexive journal records) were referred to regularly to help contextualize and inform interpretations arising throughout the analysis of the interviews.

4.7 Quality criteria

> *“Qualitative research is not a lesser cousin, but a different relative, who does different things, asks different questions, and has different goals. We can remind ourselves that as long as we have done rigorous, reflexive, and theoretically and methodologically grounded work, we need (and in fact should) not question or be defensive about our methodology; indeed, we do not need to doubt the fundamental value of qualitative research in general, or critical qualitative health research more specifically”* (Hart et al., 2017, p. 1767).

4.7.1 Reflexivity and positionality

Evidence of engagement in reflexivity constitutes an important criterion for evaluating postcritical ethnographic research (Guillemin & Gillam, 2004; Noblit, 2004). Reflexivity is used to ensure rigor as it aids in “improving the quality and validity of the research” by way of “recognizing the limitations of the knowledge that is produced” (Guillemin & Gillam, 2004, p. 275). In postcritical ethnographic research it is accepted that the worldview and positionality of the researcher influences the entirety of the research process, including how language is used, questions are posed, and theoretical lenses are selected for “filtering the information gathered from participants and making meaning of it” which may, “shape the findings and conclusions of the study” (Berger, 2015, p. 2).

Madison (2011) argues that, “positionality is vital because it forces us to acknowledge our own power, privilege, and biases just as we are denouncing the power structures that surround our subjects” (p. 17). A reflexive researcher engages in a “continual internal dialogue and critical self-evaluation of [their] positionality” and demonstrates an awareness of how their positionality might influence their interpretation and role(s) in the research process (Berger, 2015, p. 2). As such, postcritical ethnographic researchers’ positionality should be apparent in the research design and presentation of the findings (Guillemin & Gillam, 2004). Foregrounding my positionality and creative presence (e.g., through the use of “I”) in this work has been used to take greater, “ethical responsibility for [my] own subjectivity and political perspective” and resisting the presentation of my findings as if though they have no ‘self’ (Madison, 2011, p. 19). In other words, my interpretations and representation of the data should be read with, “understanding that a different sample, in a different time and place may offer a different set of perspectives, as might a different researcher analyzing the data through a different lens draw different interpretations and conclusions” (Katzman, 2018, p. 94).

4.7.2 Crystallization

Crystallization – a postmodern-influenced approach to triangulation – offers a useful framework for evaluating the quality of postcritical ethnographic research (Ellingson, 2009). Ellingson (2009) describes crystallization as combining,

> “multiple forms of analysis and multiple genres of representation into a coherent text or series of related texts, building a rich and openly partial account of a phenomenon that problematizes its own construction, highlights researchers’ vulnerabilities and positionality, makes claims about socially constructed meanings, and reveals the indeterminacy of knowledge claims even as it makes them. (p. 4).”

Reflexive consideration of the researcher’s self in the design, execution and representation of research constitutes an important tenet of crystallized texts (Ellingson, 2014). Crystallized texts also eschew, “positivist claims to objectivity and a singular, discoverable truth” and embrace, reveal, and celebrate, “knowledge as inevitably situated, partial, constructed, multiple and embodied” (Ellingson, 2014, p. 446). To this end, I took care to present complicated, often contrasting perspectives among research participants, as well as between participants and myself. In Chapter 6 I also attempt to navigate theoretical tensions between my participants’ conceptions of tokenism and those explored within and across service user-produced and health professions education literature.

The integrated article format of this dissertation has lent itself to both *integrated* and *dendritic* crystallization. A ‘woven’ form of integrated crystallization is seen in Chapter 7 through the layering of narrative (autoethnographic) and more conventional (theoretical) writing genres. When considered as a whole, this dissertation reflects the dendritic form of crystallization – or the “ongoing and dispersed process of making meaning through multiple forms of analysis and multiple genres or representation in a series of disparate texts” (Ellingson, 2014, p. 447). For instance, Chapter 2 is deeply theoretical and appears to have had greatest appeal to academic audiences (e.g., Mad Studies, Disability Studies, and health and Social care professional scholars), whereas Chapters 5 through 7 have been written with service user educator and health professional educator audiences in mind. Beyond the confines of this dissertation the use of dendritic crystallization has facilitated effective communication of the findings with multiple (lay) audiences, including practitioners, community members, and other stakeholders (e.g., through conference presentations, practice journals, activist organizing). Future dissemination of this work will also adopt this framework so that findings might be transformed for use in “industry newsletters, website content, blogs, editorials, professional workshops, and community performances, thereby helping to promote social change” (Ellingson, 2014, p. 447).

4.7.3 Commitment to the promotion of justice

Research is always already, “political, potentially revolutionary, and never neutral” and “researchers must choose between research that is ‘engaged’ or ‘complicit’”

(Conquergood, 1995 as cited in Ellingson, 2013, p. 435). Postcritical ethnographers declare commitments to exposing unequal power and redressing injustice explicitly (Anders, 2019; Noblit, 2004). Such commitments to inspiring social change and reimagination acknowledge that refusing to advocate for change is to "reinforce existing power relations, not to remain impartial" (Ellingson, 2009, p. 178). This research is underscored by a commitment to moving *toward epistemic justice* – and social justice more broadly – in the practice of SUI, in its attempts to shed light on underacknowledged or altogether overlooked breeding grounds for injustice of this sort. Transparency about my convictions and commitments has been employed in an effort to build trustworthiness, "even if the audience chooses other political alignments" (Lester & Anders, 2018, paragraph 24).

4.7.4 Community resonance and engagement

As Katzman (2018) explains in the context of their reflexive ethnographic research, "quality may be assessed in terms of the resonance or representativeness of knowledge generated in the research. It may also be measured in terms of its usefulness to the implicated community or communities" (p. 95). Prioritization of community resonance and engagement represents a logical extension of the praxis and justice-oriented undertones of postcritical ethnography, and express, "commitments to the people with whom one worked" (Noblit, 1999, pp. 19-20). This commitment also shares obvious overlaps with the aim of reaching multiple stakeholder audiences through (dendritic) crystallized texts. This work was undertaken with the hope that it would be useful across communities, including but not limited to, service user educators, health professional educators, curriculum committees and evaluators, policy makers, Mad studies and Disability studies scholars and activists, and other stakeholders interested in critical engagement with the practice of SUI.

While postcritical ethnography is not intended to be prescriptive, I have presented my findings so that they might stimulate a reimagining of SUI in those who read this dissertation. For instance, in Chapter 7, I recount some of the lessons I have learned through the *doing* of SUI, layering my firsthand experiences in a sort of conversation with excerpts drawn from participants' interviews, service user-produced literature, and relevant theoretical frames. I have shared these lessons, as well as other preliminary insights and revelations with various communities (scholarly and otherwise) at local and national conferences and educational seminars.

Validation of my use of epistemic injustice (Fricker, 2007) as a guiding theoretical frame for exploring SUI – a practice which centers service user-produced knowledge – can be inferred from the publication of Chapter 2 by the *Studies in Social Justice* journal, and the prevalence of its subsequent citation in a wide range of areas including, but not limited to: Mad studies, Disability studies, service user involvement, peer work, critical public health research, ethics in mental health, philosophy, gerontology, occupational therapy, psychology, psychiatry, and social work. My hope is that the remaining manuscripts forming the body of this dissertation will be found similarly useful to a range of stakeholders across the aforementioned areas, as well as to service user educators (both to individuals and organized communities of practice), and health professional educators actively engaged in the practice of SUI.

4.8 Ethical considerations

This section explores important ethical considerations related to this research, framed using Guillemin and Gillam's (2004) notion of *procedural ethics* and *ethics in practice*, as well as Ellis' (2007) notion of *relational ethics*.

4.8.1 Procedural ethics

Guillemin and Gillam (2004) describe procedural ethics as being mandated by ethics review boards, in order to protect the basic rights, privacy, and safety of research participants. Procedural ethics offer researchers a sort of, "ethics 'checklist' by reminding the researcher to consider such issues as the potential risks to participants, the balancing of the benefits of the research against those risks, the steps needed to ensure confidentiality of data, and the inclusion of consent forms and plain language statements in the material provided to participants" (Guillemin & Gillam, 2004, p. 268). In compliance with standard procedural ethics protocols, approval to conduct the proposed research was obtained from the Western Non-Medical Research Ethics Board (See Appendix D).

Obtaining free and informed consent is central to procedural ethics (Guillemin & Gillam, 2004). Before any data was collected from participants, a detailed letter of information written in plain language explaining the purpose of the study, procedures involved in the study, measures to ensure privacy and confidentiality, and risks and benefits of participation in the study were provided. Participants were invited to ask clarifying questions and written consent to voluntarily participate in the study was obtained. Interviews were digitally recorded and stored in password-encrypted files. Only the study investigator and principal investigator had access to the collected data. The anticipated risk associated with participation in this study was extremely low. While it was possible that talking about personal experiences would bring up thoughts and feelings that study participants found distressing, the content of the interview questions were not expected to evoke particularly distressing thoughts or feelings. The long-term benefits of this study are unknown, however, it is possible that participants found participation meaningful or consciousness raising. It is also possible that participants did not experience any direct benefit from participation in this study.

4.8.2 Ethics in practice

Ethics in practice, “pertain to the day-to-day ethical issues that arise in the doing of research” (Guillemin & Gillam, 2004, p. 264). Unlike procedural ethics, ethics in practice are “ethical concerns that can often not be foreseen nor are they generally addressed by ethics committees and boards” (Lester & Anders, 2018, paragraph 6). Guillemin and Gillam (2004) propose reflexivity as a potential tool for ethical practice as a “process and way of thinking that will actually lead to ethical research practice” (p. 273). According to Guillemin and Gillam (2004), reflexivity offers researchers – as opposed to the research ethics board – a framework for taking responsibility for the ethical conduct of their research. I have used reflexive journaling (described above) throughout the course of this research project to, “constantly take stock of [my] actions and [my] role in the research process” (Guillemin & Gillam, 2004, p. 274).

4.8.3 Relational ethics

Relational ethics constitutes an "ethics of care," foregrounding "human dignity and connectedness between researchers and researched" as well as between "researchers and the communities in which they live and work" (Ellis, 2007 as cited in Lester & Anders, 2018, paragraph 6). Relational ethics call upon researchers "to act from our hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversation" (Ellis, 2007, p. 4). Lester and Anders (2018) remind us that postcritical ethnographers' "primary responsibility in research is [arguably] to the people we study" (paragraph 20). In this way, postcritical ethnography is never innocent or neutral, but a political or moral activity that is enacted or produced by the researcher as they advocate for change (Lester & Anders, 2018; Noblit et al., 2004). Madison (2011) argues that ethics is always already present in postcritical ethnographic research, regardless of our consideration of ethics in the process of (re)imagining change.

In an earlier section on *Reflexivity* (See Chapter 3) I shared an excerpt from one of my reflexive journals, which briefly details an interaction between myself and a member of the community at the heart of this research (i.e., service user educators). The active, ongoing process of reflexivity has deepened my appreciation for the ways in which my social and political locations have influenced this research. In the particular instance described, my uncritical consideration of my own positionality as an 'insider' in this work clouded my sense of responsibility to the participants in this study and the community I have centered in this research. This muddied sense of ethical responsibility to my participants was revealed in my underappreciation of fair remuneration as an ethical practice at the outset of this research. This is just one of the methodological commitments that come to mind in my consideration of Lester and Anders' (2018) question for critical and postcritical ethnographers: "how do we pursue justice and practice ethics through methodological commitments?" (paragraph 23).

4.9 Summary

In this chapter I have described the methods I used in my design and execution of a postcritical ethnography. I have outlined my recruitment of participants and approach to data collection, which included ethnographic interviewing and participant observation as a ‘reflexive insider.’ Next, I presented and discussed my approach to data analysis and interpretation. This chapter concluded with a discussion of various ethical considerations and proposed quality criteria for evaluating this research.

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5 “Come and share your story and make everyone cry”: Complicating service user educator storytelling in health professional education

5.1 Introduction

Health professional education programs have seen a rise in service user involvement (SUI) initiatives over the past several decades (Beresford, 2002; 2003; 2005; Beresford & Croft, 1993; Happell, Pinikahana & Roper, 2002; McKeown & Jones, 2012; McKeown, Malihi-Shoja & Downe, 2011; Repper & Breeze, 2007). It has now become relatively common practice within health professional education to invite people who have been on the receiving end of health and social care services (hereafter, ‘service user educators’) to share their stories with students as part of a neoliberal push toward a broader commitment to SUI (de Bie, 2021). Storytelling – typically in the form of ad hoc guest lectures – remains the most common manner in which service user educators are involved in these programs despite emerging role developments (e.g., curriculum design and delivery, overseeing admissions, or student evaluation) which have been elaborated in efforts to resist tokenistic involvement (de Bie, 2021; Happell & Bennetts, 2016; Sapouna, 2020).

The solicitation of service user educators’ stories seems to represent an important shift – at least nominally – toward greater embrace of plural and diverse knowledge contributions and wider acceptance within the health professions of a diversity of *knowers*. Most literature related to service user educators’ storytelling practices tends toward portrayals of its positive and uncomplicated aspects (de Bie, 2021; Happell & Bennetts, 2016). Findings from a recent critical interpretive review of this literature suggest that service user educators’ stories are most commonly used for the purpose of, “engaging students in active learning; cultivating student empathy; complementing (or resisting, in some cases) academic/professional knowledge; illustrating abstract theory and providing ‘real’-life connections to course content” (de Bie, 2021, p. 3). Indeed, storytelling has been praised for its capacity to bring added value to the educational experience, provide “students with a unique insight into an individual’s emotional distress” (Felton & Stickley, 2004, p. 89), and promote transformative learning (Gidman, 2013; Troop & O’Riordan, 2017). Service user educators, Mad scholars, activists, and critical health professionals have suggested that the use of storytelling in SUI remains insufficiently critiqued; pointing to the comparatively little attention that has been paid to its risks, challenges, and complexities (Brosnan, 2019; de Bie, 2021; Happell & Bennetts, 2016; Sapouna, 2020; Voronka & Grant, 2021).

Storytelling from lived experience has long been central to the activist work and scholarship of Mad-identified people, psychiatric survivors and service users (de Bie, 2021; Church, 1995; Costa et al. 2012; Crossley, 2006; Morrison, 2005; O'Donnell, Sapouna & Brosnan, 2019). In this context, storytelling has been posited as having potential to inspire radical change, identify and disrupt unequal relations of power, and redress injustices (Costa et al., 2012). Storytelling has also been used by service users to assert "lived experience as power, value, and knowledge" within and outside mental health systems (Voronka, 2015, p. 269). Storytelling has also been at the heart of pedagogical approaches to teaching for social change (Razack, 1993). When used as critical pedagogy, storytelling has the potential to invoke "opposition to established knowledge," reveal "suppressed knowledge", and make visible experiences of the world that are "not admitted into dominant knowledge paradigms" (Razack, 1993, p.55). When used critically and intentionally mental health service user educators' stories stand to represent important ways of knowing mental distress beyond those typically represented within medicalized and "norm-enforcing" discourses of "descent into mental illness and heroic recovery" (de Bie, 2021, p. 1).

Although the potential for storytelling to be used as a tool for social change is remarkable, Razack (1993) cautions that storytelling should never be used uncritically as, "there are land mines strewn across the path wherever story-telling is used" (p. 56). Indeed, Sapouna (2020) warns that uncritical storytelling risks reinforcing and reproducing dominant biopsychosocial epistemologies of 'mental illness' – as opposed to Mad epistemologies – and neglects to disrupt the status quo. As such, the extent to which storytelling can be viewed as a productive means for conveying service user knowledges and Mad epistemologies in these spaces remains a contentious issue (Sapouna, 2020). This paper responds to recent calls for a closer examination of the ethical and epistemological tensions in the pedagogical use of storytelling in SUI. Data analysis focused on participants' reports of both the obvious and more subtle tensions and complexities they experienced in relation to storytelling as a predominant approach to SUI. The findings of this study complicate taken for granted assumptions about the benefits of storytelling by service user educators within health professional education spaces.

5.2 Methodology

5.2.1 Theoretical framework

This study is informed by theoretical perspectives from Mad studies. Mad Studies is an emergent and growing interdisciplinary field of social sciences and humanities research, which centres the "ways of knowing, being and doing of Mad-identified people" (de Bie, 2021, p. 2) and related constituencies (e.g., consumer/survivor/ex-patient, service user) in all matters related to understanding and responding to mental health (Burstow, 2015; Burstow et al., 2014; Castrodale, 2015; Church, 2013; LeFrancois, Menzies & Reaume, 2013; Reville, 2013). This research also embraces Mad and critical pedagogical perspectives, whereby health and social care classrooms are understood as complex discursive environments that shape and reproduce dominant social structures (Castrodale, 2017; hooks, 2014; Lather, 1995). SUI is approached as a critical pedagogical strategy that draws on participatory learning practices to maximize inclusion of a plurality of perspectives. The research further draws on theories of epistemic injustice (Fricker, 2007; Medina, 2012; Pohlhaus, 2012; 2014; 2017) to explore issues related to service user-produced knowledge and its uptake in mental health education.

5.2.2 Postcritical ethnography

The findings reported in this paper arose from a postcritical ethnographic study into SUI in mental health professional education (Noblit, 2004; Lather, 2001). Postcritical ethnography combines tenets drawn from poststructuralism with the critical ethnographic genre, constituting a research methodology which aims to produce "justice-centered discourses," inviting audiences to, "consider what could be otherwise (and is not yet) in the everyday lives of people who navigate oppression, inequitable social systems and material conditions, and disenfranchisement" (Anders, 2019, p. 2). Central to postcritical ethnography – in its commitment to approaching research as an ethical and political practice – is the importance of contextualizing our own positionality as researchers so as to avoid presenting our interpretation as though it has no 'self' (Anders, 2019; Olomo, 2006).

In clarifying our positionality within this work, our aim is to make it, "more accessible, transparent and vulnerable to judgement and evaluation" (Olomo, 2006, p.343). The first author is a maddened woman and scholar who has at various times (and simultaneously) occupied the stakeholder positions of service user/ educator and health professional/ educator and her experiences in these roles provided the impetus for this research. The second author is an academic whose scholarship focuses on critical reflexivity, conceptions of knowledge and social justice in health professional education in solidarity with service user educators. In keeping with postcritical ethnographic methodology, we engaged an ongoing practice of critical reflexivity through: dialogue inspired by the first author's reflexive journaling; critical interrogation of emerging insights; and dialogic debriefs with our other team members. Critical reflexivity was also employed as a means to navigate the first author's 'insider/outsider' positionality as researcher with experiences as a service user- and health professional- educator.

The broad aims of the study were to (a) deepen understandings of the complex and varied experiences of SUI from the perspectives of both service user and health professional educators, and to (b) critically examine SUI as a pedagogical strategy for supporting the contribution of service user educators' knowledge in health professional education. The research questions asked: (a) How do various stakeholders describe service user educators' contributions to the education and knowledge base of future health professionals? And (b) To what extent does SUI as a practice support service user educators in contributing knowledge within the context of health professional education? The perspectives of both service user and health professional educators were collected in this study.

5.2.3 Participants

Fourteen stakeholders engaged in the practice of mental health SUI participated in this study. All participants were engaged in the practice of mental health SUI in professional education in one of the following capacities: (a) mental health service user educator involved in occupational therapy (n=7) or other health and social care (n=2) professional education program(s) in Ontario (total n=9); or (b) health professional educator facilitating SUI (n=5). Pseudonyms are used in place of participants' names (see Table 4). Participants were recruited through the distribution of recruitment materials within four occupational therapy programs in Ontario, accompanied by a request for circulation of materials to known service user educators with current and/or prior involvement in these programs. In addition, service user educators involved in other health and social care professional education programs were recruited through the announcement of the study in the Ontario Peer Development Initiative (OPDI) newsletter (considered to be highly visible to service user educators); and by word of mouth. Potential participants contacted the first author to express interest.

Table 4: *Participant Pseudonyms and Roles in Service User Involvement*

	Pseudonym	**Role**
1	Glen	Service User Educator
2	Kimberly	Service User Educator
3	Heather	Service User Educator
4	Fred	Service User Educator
5	Carmen	Service User Educator
6	Elliot	Service User Educator
7	Joel	Service User Educator
8	Sally	Service User Educator
9	Edward	Service User Educator
10	Nancy	Health Professional Educator

11	Anthony	Health Professional Educator
12	Sara	Health Professional Educator
13	Lindsay	Health Professional Educator
14	Rita	Health Professional Educator

5.2.4 Ethics

Approval to conduct this research was obtained from the Western University Non-Medical Research Ethics Board (NMREB).

5.2.5 Data collection

Data sources for the study included in-depth recorded interviews, participant observation, and the first author’s autoethnographic and reflexive writing. Each of the participants completed an in-depth semi-structured interview that inquired into their experiences of SUI (e.g., their experiences as educators; reasons for becoming involved and/or soliciting involvement; perceived benefits and challenges), and other pertinent details related to their role(s) and context of involvement (e.g., recruitment/hiring practices; role title; remuneration; involvement expectations or objectives). Participant observation took place during 2 service user educators’ guest lectures in 2 separate occupational therapy programs.

5.2.6 Data analysis

Interviews with service user and health professional educators were transcribed verbatim. Data analysis of the interviews was carried out using a reflexive approach guided by Srivistava and Hopwood’s (2009) framework for analytic reflexivity. The following three questions were used to refine the research focus and integrate data: (1) What are the data telling us? (2) What is it we want to know? And, (3) what is the dialectical relationship between what the data are telling us and what we want to know? The first of these questions was also used to question the role of the researchers as interpreters, by way of asking, “what [are] the data telling [us] that they might not tell someone else”? According to Srivistava and Hopwood (2009) this reflexive analytic framework “might offer one of the many ways of writing yourself into the narrative without being self-indulgent or distracting from the purpose of research"; an endeavor consistent with a postcritical ethnographic research methodology.

Quirkos, a qualitative data management software, was used to organize the data into visual and thematic representations (See Appendix C for Quirkos 'canvas' illustrating connections or relationships between thematic codes, or 'quirks'). Other collected data (i.e., participant observation field notes and reflexive journal entries) were compiled and referred to regularly to help contextualize and inform interpretations arising throughout the analysis of the interviews. In addition, we used regular dialogue meetings to discuss and explore evolving thematic representations of the data.

5.3 Findings

'Story' was identified as a pronounced overarching construct from our reflexive inquiry into participants' conceptualizations of service user educators' knowledge contributions to health professional education. Informed by the critical theoretical frame described above, we identified three prominent themes centered around participants' accounts of the complexities and tensions they experienced related to SUI through storytelling: (a) performative expectations; (b) the invisible work of storytelling; and (c) broadening conceptualizations of service user educators' stories.

5.3.1 Performative expectations: "Come and share your story and make everyone cry"

Service user educators' stories were frequently described as "powerful" (Sara) in their capacity to enhance learning, deepen student engagement, evoke emotion, or "strike a chord" (Lindsay) in listeners. Most health professional educators discussed the impact that service user educators' stories have on students' learning; many describing them as being 'memorable'. Rita noted how learning from stories "stays with the students" long after they have forgotten the content of conventional lectures. She explained:

> The messages are very powerful… students become very engaged and most have a point of reference, right? They know somebody in their lives that can compare.

> It's touching a chord because of their own position, and relationship to mental health issues. So, it's just one step less removed, and it really infiltrates, not only their thinking, but their being.

Lindsay shared this perspective, stating:

> The students remember [service user educators' stories] for the rest of their career. I can tell you every person with lived experience that came in to present to my program when I was doing my [health professional] Master's. They were very powerful; but I can't remember every lecture.

Several service user educators used metaphors centered around forms of entertainment or performance (e.g., a play, concert, or movie) to describe the knowledge they share through storytelling. For Kimberly, stories help theoretical knowledge, course concepts or "textbook examples" to "come alive." She drew parallels between hearing stories told by service user educators and seeing a play, rather than reading the screenplay:

> I remember in high school when we had to read Shakespeare, and I'm like 'oh, this is so boring'… but I can go to a Shakespearian play and love it. It's easier to hear something and see something, than it is to just pick up the words on a page.

Edward likened hearing a service user educator's story to seeing a live concert: "What can I say? I'd rather see The Rolling Stones than read about them. As good as the writers are, and the interviews are great; when you see them, you get a rush." Sally compared the dialogue between students and service user educators to speaking with an actor about their role in a movie, noting that it gave room for more inquiry and depth of understanding:

> I think [with a] textbook… you hear a story; versus when I'm presenting the story about my life [students] can ask deeper into it. Like, for me, if I'm going to watch [a movie], I'm going to watch it 10 times and I'm not going to get more information. But, if I speak to the woman who played it; played the role, or lived that life, I can understand the depth.

Others spoke about their goals of "modeling wellness" (Elliot) or presenting students with the embodiment of "success stories" (George). Elliot discussed that an important part of his role was presenting students with a picture of:

> How well [service user educators] can be, how much insight we can have, and therefore, break down some of that stigma people have. We're not always unwell…we're not always in crises…we're often just as well as anybody else in the room.

He further explained:

> On an acute ward [health professionals] never see anybody when they're well. They only see them when they're unwell. So, in some ways I'm presenting wellness… They lose a bit of hope when they only see somebody at their worst... So, I always felt like I was modeling wellness. And, therefore, giving them hope. Giving them context that recovery is possible and probable.

Fred stated, "I wanted to share my story to give [health professional students] hope that people can change, and there are success stories out there…" He recalled:

> I was definitely asked to share my personal story of going from homeless and suffering mental health and addiction issues to how I became housed, a business owner, working and traveling… you know, my story of changing my life around.

Other participants spoke about offering firsthand insights into *why* service user educators might engage in certain behaviours (especially those typically deemed 'difficult' by health professionals), in order to instill in students greater feelings of empathy, understanding and patience. Fred offered students "personal knowledge" of, "say, why I used to miss doctor's appointments" explaining that, "if [students] can understand how the client – what their life is like, what they've gone through, or how their day has been – then it would help [students] to better serve the client." Glen described seeing "real value" in being able to "explain *why* [he] was doing things" during periods of significant mental distress and/or addiction, as well as presenting students with a contrasting image of himself "as [he is] now."

Some participants spoke less about ‘success stories’ and more about telling their story for the purpose of ‘humanizing’ mental health experiences, and helping student health professionals to see them as ‘real people.’ For Fred, this meant helping students to, “see a wounded person, not a bad person.” And Sally said:

> We can tell a bit of our story; they can see us as *real* people who are, you know, standing in the room with them… So, yeah, I think just seeing people for being who they are and how they are and not scary monsters.

While many service user educators acknowledged that story can be used as a powerful tool for engaging students, shifting attitudes, elucidating mental health-related concepts, and ‘humanizing’ experiences of mental distress, some problematized the expectation of performative or evocative storytelling; drawing attention to the consequences of placing such high emphasis on these parameters for SUI. Joel suggested that the performative expectations placed upon service user educators can be internalized as a pressure to possess a particularly compelling or unique story, and to perform that story in an engaging or entertaining way:

> We tend to judge ourselves… [For example] ‘Do we have what it takes to do X or Y or Z?’ and in this case, because of what this work requires, what it ends up being is, ‘well, have we been crazy enough? is our story outrageous enough?

Heather rejected the expectation that service user educators should be entertaining, saying, “I'm not there to entertain! …It's serious. It's people's lives!” And Glen underlined the potential for objectification in soliciting deeply personal service user educator stories for the purpose of education, stating: “Right, so what is it you're accessing when you're putting the service user ‘on stage’? I call it emotional pornography.”

Some academics described conflicted feelings about seeking service user educators’ stories for their evocative potential, or for the sake of enhanced student engagement. Sara expressed having “mixed feelings” about soliciting personal stories:

> Sometimes what [service user educators] are sharing is actually quite personal… They're sharing their experience of a loss sometimes... And, we're asking them to stand up in front of 60 strangers and share that. And I think that's really hard. Then we say to them, ‘Thank you very much, here's a gift card.’ And, something about that, at times, can feel quite… I don't know the right word for it, maybe... quite perverse… For lack of a better word, it feels a little perverse, to just say: “come and share your story and make everyone cry.”

5.3.2 The invisible work of storytelling: “Sharing your story can be very draining”

Participants described various facets of work that goes into storytelling, beginning with the labour involved in composing a story to tell. For instance, some described a certain difficulty inherent in attempting to condense years, or decades, of lived experience into a single lecture or self-contained story. In Heather’s words “…you're only given so much time, and how do you put 72 years into a 2-minute talk? Or, you know, 10 to 15-minute talk? It’s hard.” Several participants described feelings of uncertainty about what service user educators ought to be sharing with health professional students, which appeared to stem, at least in part, from a lack of clearly communicated expectations between health professional academics and service user educators. Sara offered this reflection: “Where I think things get awkward; more awkward perhaps, is when… it's just, "come and share your story", and I think nobody's clear on what they're doing, both the students and the person who's speaking.”

Carmen suggested that the “onus” of establishing, or communicating, clear expectations should be placed on health professional educators.

> I think that being transparent about what it is they're expecting from you when you come in to tell the story is really important; and that onus can't necessarily be on the service user… it has to be on the person who's inviting them in, to really think that through, and to have a framework for what they can expect. Who is in the room? And, why are we asking you now? What is the context of why you've been asked?

Several participants described finding it difficult to reach decisions about which experiences should be incorporated into their stories; in part, because stories were described as evolving over time with the accumulation of new experiences, personal growth, and opportunities for self-reflection. In Sally's words:

> I'm not the same person today that I was 15 years ago; and the story that I told 15 years ago would be very different than the story I told today. Partly because of the interaction with the people that I tell that part of my life to.

Glen cautioned that this process of refining one's story at the interface of health professional education (or in tandem with health professional educators) is not without the risk of sanitization, or the loss of a sense of authenticity:

> One of the things that I find is by the time people have a really good grasp on their story, they're academized [sic] and, is that a word? And so far from the street, and so far from the experience, that they've absorbed – they've been absorbed – into the textbook mindset.

Sara acknowledged that she "probably has a responsibility" to assist service user educators in refining their stories; however, she also described feeling somewhat unprepared to take on this role herself, suggesting that perhaps this was a "resource issue."

> Yeah, I would say that, if I'm going to ask people to share their story, I probably have a responsibility to [help them prepare], but, it's not really traditionally part of my role. I don't even know if I have the expertise to do that. I'm an educator, so I have expertise in education theory and pedagogy, and all that stuff, but I don't know that I'm the right person necessarily to help someone hone in *how* to tell their story in a way that's impactful and meaningful to them and to students.

Some participants also described discrepancies between health professional educators' perceptions of – and the actual – work involved in storytelling. In speaking about his role as a service user educator, Fred stated: "I take it very seriously. You have to take it seriously, because as a teacher or educator, it's a serious thing to affect a student's mark, or their profession, or their path in life." However, he also recalled the well-intentioned remarks of a health professional educator in her attempts to reassure him: "[She] tried to make me understand that 'you can't fail at this. You know there's no high expectations of you or anything like that, we just want you to share your story.'" In a similar instance, despite taking her role very seriously, and placing importance on being prepared and organized, Sally was met with a reminder that, "'[Sally], you're telling your story, nobody knows it but you.'"

Both service user and health professional educators spoke about the emotional work of telling stories. In Fred's words: "sharing your story can be very draining." For Sally, arriving at the decision to share her story publicly was a lengthy and emotional process:

> "It took two or three years to be able to share my story… [I did] some sharing with [my peers]. You know, we had each other, kind of. Writing the story, sharing the story, and then supporting each other after we'd done the presentation."

For some, the emotional work of storytelling involved "managing anxiety," while others attributed it to reliving difficult or "triggering" experiences. Fred stated, "sharing your story… it can bring up bad things, and I think one time…it made me a little sad…it makes you look at, you know, 'me'." Elliot suggested that considerable thought be given to this aspect of storytelling: "It's difficult for people. You're asking people to do things that trigger [them]; it could actually be detrimental to their health leading up to and presenting." Anthony made a point of discussing the risk of "re-traumatization" with all of the service user educators he invited to speak to his students. In his words, when service user educators "go back down that path, [they] 'open up that door' because [they] feel like it's part of [their] recovery journey" but there's "the potential for their re-traumatization."

Some participants also spoke about managing the emotions of the student audience and other listeners. Glen described this as a balancing act between inspiring "deep level change" and maintaining "emotional containment." He stated, "we have to deliver enough content in a memorable experience, but not blow their minds. So, [the course coordinator and I are] searching together for that balance."

Several participants identified support or ‘follow-up’ after storytelling as something that was both an important part of this work, and a largely unmet need. Sara shared:

> As an educator I think about what it does to the students, and I'm always thinking that... but I don't typically worry about the mental health of my speakers, and... sometimes people will get emotional… it will bring up feelings from their past… none of that is a bad thing, but we don't really… we don't really do any follow-up. We kind of say, “thank you so much! That was lovely!”

Elliot expressed that the emotional work of storytelling could very well be one of the drawbacks of SUI:

> Re-thinking things that you don't think about every day, because you don't want to... Your past breakdowns or your past psychoses or your past failures or successes, even that is emotionally taxing. And for people with a mental health disability, those strong emotions can actually make them worse. So that also, that's one of the drawbacks.

Sara shared her suspicion that the emotional work of storytelling may actually impact service user educators’ decisions not to return when invited back; or to set boundaries for their involvement when doing so. She recalled the words of one service user educator who said:

> “I want to come back, but I will not talk about my father's suicide the way I did last year. It took me too long to... it brought up too much for me. So, I will come back and speak to your students, but I can't speak about that stuff.”

In a personal effort to reduce the emotional toll of storytelling, Carmen explained that as she has gained experience as a service user educator, she has also made a conscious decision to tell less of her personal story, and rather, focus on concepts, theories, and values that have been identified as important by service user educator communities. She described her approach by saying:

> I go in and talk to the [health professional] students; I tell them a little bit of my story. As time has gone by, I say less and less actually… I really, you know – I give them the broad strokes.

5.3.3 Broadening conceptualizations of service user educators' knowledge: "I have knowledge that can help them in their actual practice"

Both service user and health professional educators spoke of stories as central, and oftentimes as an entry point, to SUI. Stories were described as the "unique knowledge" (Sara) of service user educators, and in particular, as the sort of knowledge that health professional educators are unable to offer. Rita asserted that "[service user educators'] firsthand accounts are really an important part of what the students need to hear." She asserted that, "consumers are really effective in helping [students]… in ways that [she], or other faculty, could not." Lindsay echoed this, saying, "[service user educators] offer something that we can't."

One of the most commonly cited motivations for sharing, or eliciting, service user educators' stories was for their potential to be used as a powerful tool for effecting change and inspiring action toward "improving the system"; something Sara described as an "advocacy objective." She explained: "It becomes a very powerful tool when people, with this capacity to effectively share their story… express their story in a way that effects change," and recalled the involvement of one service user educator whose, "career has become about using his story as a platform to help policy and service providers and frontline workers and decision makers think in different ways about trauma, and understanding trauma."

Other participants spoke about using their stories to challenge a dominant narrative, or contribute to a diversity of stories. Heather explained that she tells her story because,

> I believe in the importance of education, and I think that the only way that the whole story can be – the whole mental health system and the outcomes – can be understood, is when you hear all of [the story]; not just part of it. And the only

> way you're going to hear all of it, is for myself and others to come forward and say, this happened and this is what the outcome was.

Despite many participants' motivations to share their stories to elicit change, it was not uncommon for participants to describe experiences of storytelling that involved, "a whole session" wherein one service user educator, "just tells his whole story. You know, how his mental illness influences his ability to function in daily life, and his work, and all that kind of stuff" (Lindsay). Heather noted that she and fellow service user educators, "just went in and told [their] story…and answered a bunch of questions afterward." Likewise, Kimberly said of her contribution:

> So, it's like a life story, it's not really a lecture. It's more stories… I talk about my childhood, I talk about high school, I talk about university, I talk about meeting my husband, my family's involvement in my care, and then where I am at now with work.

Several participants offered critiques of such practices, calling for a broader conceptualizing of service user educators' knowledge, beyond stories of (overcoming) mental distress, diagnosis or treatment. Joel stated:

> There's this idea that what we're sharing with [students] is our perspective, and giving them a window into our experience; and yes, that's great, that's good… But actually, you know what? I think I have knowledge that can help them in their actual practice… There's really knowledge out there; it's not just about listening to someone tell their story of being admitted [to hospital], or being restrained…"

In response to such criticisms, Carmen, a service user educator with experience in coordinating SUI, described trying to recruit service user educators who were able to offer insights beyond their stories of 'illness.' She recalled:

> We had people who were able to couch their narrative a bit… so, we didn't get the 'play-by-play,' but you were able to get a bit of an understanding of why they said what they said. We were looking for people who had an analysis that was broader than their own situation. So, people who talked about, for example, coercion or

> justice; people who talked about the social determinants of health; people who talked about power and privilege in some way, and either pertaining to their own, or what they saw in people who had helped them or hurt them.

Fred offered one example of sharing his lived experience (outside of the realm of personal storytelling) to educate students, wherein he drew from his firsthand knowledge of the lesser-known community-based mental health resources (e.g., “a local church”), to act as a “facilitator” in systems navigation. Fred explained that his goal was to, “try and get the students to think outside the box a little bit; to utilize more services that are available. Because, often the [government-run] services are limited.”

Some health professional educators also suggested that service user educators’ knowledge contributions should extend beyond telling “life stories,” to include, for example, a more focused discussion of a particular concept or practice approach, or a focus on service user educators’ unique areas of expertise. Rita described this as, “a much more focused approach…than just telling; no, I won't say *just*, but telling a story of one's life. It's really looking at a particular approach in [therapy] and talking about how that facilitated [their] growth.” Sara spoke about treating service user educators’ knowledge as a sort of “lived experience expertise,” versus a life story; asserting:

> We can't just have people come in and share their experiences. I think we need to treat [service user educators] like we treat any other speaker, and you know we're asking people who are experts at whatever we're asking them to speak about, and whether they're clinicians or- whether it's clinical expertise, or lived experience expertise. So, treating them not as just a story, but actually saying- inviting them to be part of the curriculum, in a meaningful way.

5.4 Discussion

While storytelling was described by participants as central to the way service user educators convey their knowledge in the context of health professional education, the findings illuminate some of the complexities in using storytelling as a means for sharing service user knowledge. The discussion is framed around three important tensions made visible through the study: (i) the performance and consumption of stories (Voronka, 2019); (ii) the emotional labour of composing and telling stories (Brosnan, 2019; Hochschild, 1979; Oksala, 2016; Voronka, 2019); (iii) and epistemic injustice (Fricker, 2007; LeBlanc & Kinsella, 2016) as it relates to the *kinds* of stories that seem to be welcomed into health professional education spaces. The discussion of these issues is followed by a set of reflexive prompts for educators and other stakeholders interested in critical engagement with service user educators in health professional education.

5.4.1 Performance and the consumption of service user educators' stories

Both service user and health professional educators described storytelling in the context of SUI as 'powerful'. In particular, participants linked storytelling to popular forms of performance and credited the performative or evocative nature of service user educator storytelling with deepened student engagement and memorable learning experiences. The ways in which this element of storytelling was regarded, however, seemed to differ between and within these stakeholder groups. Some participants problematized the expectation that service user educators should 'perform,' or share particularly moving stories as a means for conveying their experiential knowledge; with one participant describing this work as "emotional pornography," and another describing the practice of soliciting emotional stories to enhance student learning as "perverse." These particular findings resonate with what Costa et al. (2012) describe as 'patient porn,' in their discussion of the interactive nature of service user storytelling, explaining that, "while some people reveal their most intimate personal details, others achieve relief through passive watching" (p.86).

These findings also resonate with discussions of the performance and consumption of service user educators' stories as 'commodities,' and in particular, the "commodification of Otherness" (hooks, 1992 as cited in Voronka, 2015, p. 261). Expecting service user educators' stories to be powerful or moving (read: entertaining), risks shifting the focus to one of student engagement, rather than compelling students and other listeners, to, "explore their own complicity in the oppression of others" (Razack, 1993, p. 66). Voronka (2017) has urged Mad scholars and activists to continue to reassess the ways in which “marginalized identities” are mobilized and enacted, “when commodifying our experiences within the systems that sustain our subjugation” (p. 337). For instance, when service user knowledge is solicited for the purpose of ‘illuminating’ a concept, theory, or practice with roots or origins in professional knowledge (i.e., underpinned by biomedical models for understanding mental distress), storytelling may actually serve to reinforce dominant narratives (Voronka, 2016). Several participants described being invited to speak to students about their experience of a particular psychiatric diagnosis and their subsequent “recovery” (typically facilitated by health professional intervention) for the purpose of enlightening students about the *why* behind service users’ more ‘difficult’ behaviours (e.g., non-compliance or frequent ‘no-shows’). In this way, service user educators’ stories of Otherness are often ‘consumed’ by health professional education students as a “‘teaching tool’ and ‘learning material’, where they become objectified and commodified as ‘a living textbook, a *means* (of learning) *to an end* (of greater competence)’” (de Bie, 2021, p. 9). Rather than spark transformative, systemic change, such stories risk supporting, confirming, or reinforcing dominant discourses, which maintain the status quo. Although these may make for entertaining, or ‘good stories,’ there is risk that their telling may simply inspire more storytelling, rather than actual political or social change (Polletta, 1998).

Within health professional education service user educators have not always been regarded as active epistemic agents (see section on *Epistemic Injustice* below for elaboration), but rather were studied as objects to *know about* (Costa et al., 2012). Without control over the context in which a story is told, or over the gaze of the audience (i.e., a uniquely psychiatric gaze), service user educators may find themselves faced with an audience who is unable to truly comprehend what they are sharing (Voronka, 2019). Despite service user educators’ best efforts to share their knowledge, their stories come to be understood within the discursive confines of dominant ‘mental illness’ discourse, with their intended meanings altered (Voronka, 2019; Voronka & Grant, 2021). Razack (1993) has stressed the importance of troubling the positionality of tellers and listeners, suggesting that despite our calls for respect for different voices, “insufficient attention [is] paid to the contexts of both the teller and the listener” (p. 65).

Health professional education students are unlikely to possess the alternative epistemic resources (i.e., language, concepts, and theories developed by/within service user and Mad communities) required to interpret and understand some critical stories as they are intended. As such, it is vital that careful consideration be given to the conditions for service user educators' epistemic participation when seeking to do the work of including or integrating service user educators' knowledge in health professional education. That is, creating conditions whereby service user educators have power over the knowledge being produced and shared; not simply over the content of their stories, but also the broader contexts in which their stories will come to be understood and interpreted (O'Donnell et al., 2019). As de Bie (2021) has recently suggested, SUI oriented toward social justice requires consideration of, "a more expansive, service user-informed ethics for engaging with first-person accounts" where our focus is less on whether students enjoy, learn, and glean a greater sense of empathy from their engagement with these stories, and more on how we might "engage ethically and well with stories of madness and trauma" and teach in ways that, "facilitate more ethical relations with Mad people and communities" (p. 9).

5.4.2 The emotional labour of storytelling

Participants' accounts of the work required to craft and share stories is consistent with recent literature discussing the emotional or affective labour of SUI (Brosnan, 2019; Voronka, 2017). Brosnan (2019) suggests that acknowledging the emotional labour of service user educators – which they contend, "is often silenced, unacknowledged, and invisible" – is ethically and politically imperative (p. 2). Brosnan argues that despite notable contributions (Church, 1995; Church & Reville, 1988; Voronka, 2017), little attention has been paid to the emotional or affective costs of involving service user educators in health professional spaces (Brosnan, 2019). *Emotional labour* is described as an immaterial form of labour which involves, "...the management of feeling to create a publicly observable facial and bodily display," (Hochschild, 1983, p. 7), and shares similarities with *affective labour,* wherein, "workers are expected to mobilize emotional and social skills for professional goals, resulting in the blending of the private and the public" aimed at producing affects (Oksala, 2016, p.284). Voronka (2017) used the language of affective labour in the context of peer support work to describe how, "experiential knowledge is being mobilized in particular ways: to modify the emotional experiences of clients" (p.335). Several participants in this study described managing emotions and affects in themselves and others as part of the work of storytelling.

Perhaps the clearest example of emotional or affective labour in this study can be found in participants' accounts of a perceived expectation or personal desire to 'perform' or "model wellness" in order to quell fears or instill in their audience a deeper sense of empathy, compassion, or humanity. Several participants specifically linked this performance of wellness to the goal of 'humanizing' themselves and others who have experienced mental distress. These findings are consistent with Voronka's (2019) contention that service user storytelling as a means to address the problems of stigma and discrimination, places responsibility on service users, to diminish the discrimination they experience "by sharing our stories with others who may discriminate against us. In effect, to counter dehumanization, it becomes our job to share our stories in attempt to humanize ourselves" (p. 13). In other words, service user educators perform a sort of emotional or affective labour to produce (or elicit) feelings of sympathy, compassion, and understanding in students and faculty, so that they might view service users as "redeemable subjects worthy of pity and investment" (Voronka, 2015, p. 300).

Brosnan (2019) describes a certain emotional labour required in communicating stories in contested, "sometimes hostile," health professional spaces, where service users are not necessarily regarded as equal knowers, or even as bearers of valid knowledge (p. 1). Church (1995) has asserted that SUI is "never unemotional," and it is possible that the emotionality of this work precludes service users' knowledge being afforded validity (as cited in Brosnan, 2019, p. 3). Furthermore, service user educators may be required to navigate difficult emotions and possible "re-traumatization" for the purpose of upholding appearances of rationality, composure, and 'stability,' in order to convey oneself as a legitimate knower (Brosnan, 2019). Despite the emotional dimensions and products of this work, described by some participants as what makes storytelling particularly "powerful," many also identified the emotional or affective labour of storytelling as one of the "downsides" of this work. Several participants described strategies for managing the emotional "toll" of storytelling, such as establishing supportive networks and opportunities for debriefing, or “telling less” in the way of intimate personal details, and setting firm boundaries related to the content of their stories. For some participants, a shift away from overtly emotional storytelling meant speaking more to societal issues and injustices informed by and/or grounded in experiential knowledge.

There appeared to be some discrepancy between the actual labour undertaken by service user educators in sharing their stories and the perceptions of health professional educators in recognizing the magnitude of this work. The emotional labour, and other work involved in storytelling by service user educators, appeared to be largely *invisible* to, or at least minimized (though perhaps unknowingly, on account of its invisibility) by those soliciting stories (Brosnan, 2019). The invisibility of this labour may offer some insight into why this work is seldom fairly remunerated. The invisibility of this work was also reflected in the way participants spoke so casually about service user educators “having a story” [to tell], as if to suggest that by virtue of having direct/lived experience(s) with the mental health system that one automatically possesses a singular, coherent, or even intelligible story that could be readily shared with health professional students. This contrasted with some participants’ reports of a complex and laborious process involved in both storying and telling their knowledge. Participants described attempts to condense years of lived experience into a coherent and impactful story; making difficult decisions about which anecdotes would have the greatest impact on students (i.e., deciding what is most likely to “inspire deep-level change”); navigating risks of “re-traumatization”; and managing anxieties related to storytelling and the ways their story would impact students’ professional approach.

5.4.3 Epistemic injustice: Which stories are (not) being told?

Some participants described stories grounded in lived experience as the “unique knowledge” of service user educators, and most service user educators described invitations to share personal stories detailing their lived experiences of mental illness and recovery. These were stories that might offer students “a window into their experience,” and insight into *why* service users might engage in particular behaviours within clinical interactions (e.g., non-compliance or missed appointments). Such invitations seemed to contrast with many service user educators’ described motivations to tell their stories as a means to address systemic issues (e.g., justice, coercion, or stigma); impart practical wisdom regarding system navigation; and effect change in the mental healthcare system (e.g., reconceptualizing trauma, or instilling a greater sense of empathy and compassion in future health professionals).

These findings resonate with recent literature highlighting the epistemological implications of soliciting service user educators' stories for use in health professional education; particularly, the (likely unintentional) infliction of epistemic forms of violence or injustice (de Bie, 2021). Some participants called for broader conceptualizations of storied experiential knowledge beyond "life stories" centered around overcoming 'mental illness,' or what de Bie (2021) has referred to as *mental illness narratives*. In this way, the findings also serve to complicate the uncritical inclusion of service user educators' stories, drawing attention to the knowledge that may be overlooked, suppressed or excluded from health professional education spaces in the *kind* of stories being invited and told. These findings align with Costa et al.'s (2012) observation that the use of service users' stories have moved "away from the history of psychiatric survivor storytelling" which was intended "to work towards radical change," and instead are being used to "further solidify hegemonic accounts of mental illness" (p.87). While such stories may informing health care practices in important ways, Costa et al. (2012) contend that:

> "if we listen only for the 'lived experience' of individuals, and only for processes of illness and recovery – we will miss many other vital storylines. We need to complicate what we are listening for: to listen less for stories of healing and recovery and more for stories of resistance and opposition, collective action and social change" (p.96).

Service user educators' knowledge represents a form of marginalized (or marginally situated) knowledge in health professional education contexts given the dominance of 'professional' knowledge. As such, the concept of epistemic injustice provides a generative theoretical perspective for thinking about the ways in which this service user knowledge has come to be – and in some cases, remains – suppressed or marginalized within these spaces (Dotson, 2011; Fricker, 2007; LeBlanc & Kinsella, 2016; Pohlhaus, 2017). Epistemic injustice refers to the distinct wrong done to someone in their capacity as a *knower*; restricting their ability to engage in the basic everyday practices of knowing, conveying knowledge to others, and/or actively participating in the production of a collective knowledge base (Dotson, 2012; Fricker, 2007; Pohlhaus, 2017). Engagement with this concept gives rise to questions such as, what constitutes valid knowledge? Who are deemed 'legitimate knowers'? And whose knowledge should count? When service user educators' stories of overcoming 'mental illness' are uncritically solicited, alternative (and typically more radically marginalized) knowledge (e.g., stories of resistance or survivor activism and collective action) is at risk of being excluded or overlooked, constituting a particular form of epistemic injustice known as *contributory injustice* (Pohlhaus, 2017).

Contributory injustice occurs through the systemic exclusion or dismissal of the knowledge and language developed within marginally situated communities (e.g., service user, psychiatric survivor or Mad communities) by those situated more dominantly (e.g., mental health professional educators and practitioners) (Miller Tate, 2019, p. 97). When applied to the findings of this study, we see that the potential for the perpetuation of contributory injustice is both complex and insidious. This is because not *all* service user educators' stories are barred from inclusion in health professional education.

The sharing of personal illness stories upholds appearances that service user educators are increasingly engaged in SUI and thereby *contributing* knowledge (which in and of itself stands to foster social change). However, the way in which service user educators are typically invited to participate (e.g., ad hoc guest lectures), and the *kind* of stories that are solicited (e.g., mental illness narratives), may actually be in tensions with the political aims of broader service user, psychiatric survivor and Mad communities, as stories more closely aligned with these aims are effectively overlooked and/or excluded. As de Bie (2021) has pointed out, some stories are privileged over others, "arbitrating the value of stories based on student enjoyment, prioritising the learning needs of non-Mad students and failing to recognise the contribution of personal narratives to collective Mad/survivor expertise" (p. 9). Stories detailing experiences of 'mental illness' and subsequent recovery are typically told using dominant epistemic resources (i.e., language, concepts, theories) espoused by health professional educators and their students, whereas stories of resistance more often rely on marginalized epistemic resources, (e.g., Mad epistemologies or critical understandings of concepts like recovery), and are less likely to be readily received (or even understood) by health professional audiences.

So, while marginally situated knowers are often able to make sense of and articulate aspects of their experience relatively effortlessly among themselves, they remain unable to communicate these dimensions with the same ease or effectiveness in mainstream discourse (Pohlhaus, 2012, p.722). In other words, some forms of service user knowledge may be suppressed in contexts of SUI under the guise of inclusion (i.e., service users' invited to share stories of 'mental illness' and recovery). Voronka (2015) cautions that when storytelling is approached as an "inclusionary practice" (p. 273), whereby exclusion is positioned as the problem in need of redress, larger structural issues of inequity and injustice are at risk of being left unchallenged.

The findings of this study, as understood through a lens of epistemic injustice, reflect issues raised by de Bie (2021) regarding the legitimacy of service user stories as a source of knowledge as opposed to a complementary perspective or 'view'; and the "degree to which autobiographies are treated as 'individual' stories or as contributing to a collective body of knowledge" (p. 6). Costa et al. (2012) have troubled the "assumptions that individual stories can single-handedly change deeply embedded, oppressive and interconnected powerful social structures" (p.98). They have called for a reclaiming of stories as political knowledge and encouraged those "who reveal their stories to consider doing so in a way that is politically accountable and focused on social justice change" (p. 99). Such accountability may result in storytelling that is more closely aligned with the vast body of work by psychiatric survivors, service users, Mad activists, scholars, and their allies. Informed by individual and collective experiences, this diverse group has worked to advance alternative epistemological bases and approaches to responding to mental distress and diversity (Beresford & Russo, 2016; LeFrancois et al., 2016; Newbigging & Ridley, 2018).

5.4.4 Reflexive prompts for educators

Storytelling by service user educators in health professional education will not inevitably lead to "social justice outcomes," however, thoughtful engagement with the ethical and epistemic complexities of this practice, "may increase this possibility by shifting when, why and how we teach with autobiographies" (de Bie, 2021, p. 1). We propose the following series of critically reflexive prompts for educators looking to attend to the complexities inherent in this work toward greater ethical and political accountability to service user educators:

Table 5: *Reflexive Prompts for Educators*

Aim	**Reflexive Prompt**
Troubling expectations that service user educators should entertain	Is it possible that my motivation for soliciting a service user educator's story is to make for a more memorable or engaging lesson? Is it my expectation that service user educators' contributions will be engaging or entertaining? How might my expectations around service user educators' involvement (regarding performativity) differ from those I have for non-service user educators?
Acknowledging the extent of service user educators' emotional and/or affective labour	How important is it to me that service user educators share intimate personal details, diagnoses, or firsthand accounts of their experiences with mental health services? Is it possible that I am asking service user educators to do the emotional/affective labour of 'humanizing' or presenting themselves as "redeemable subjects" (Voronka, 2015, p. 300)? Has my determination of the remuneration or compensation I am prepared to offer service user educators taken into account the extent of the emotional and epistemic labour involved in their contribution?

Mitigating epistemic injustice	Have I discussed the legitimacy of service user-produced knowledge with students? Have I engaged with the concepts and ideas presented in service user/survivor-produced literature, toward establishing a conceptual foundation which would enable students to *hear* service user educators’ storied knowledge as it is intended? Have I discussed systems of oppression and privilege (e.g., sanism/sane privilege) with students?
Fostering supportive (epistemic) environments	Is my decision to involve service user educators in my [classroom, program, activity] supported by my department? If not, why might that be? What steps might can I take to create safer, more supportive epistemic conditions for service user involvement and storytelling?
Supporting epistemic communities	How can I encourage ‘affinity groups’ among the service user educators in my network? Have I established connections with local service user/survivor collectives or communities to inquire about individuals or groups who may be interested in the role of service user educator?
Critical/Mad (positive) pedagogy and transformative learning	Have I thought about the involvement of service user educator’s in health professional education classrooms as a critical pedagogical method? Is my aim in involving service user educators in [health professional education context] to trouble taken-for-granted knowledge and practices toward transformative learning? Or, to provide students with an exemplar of popular (biopsychosocial) concepts or theories? Am I able to clearly communicate these objectives to service user educators? Am I open to service user educators’ feedback regarding these objectives?

5.5 Limitations

The study was situated in a bounded context, focused primarily on service user and health professional educators from one health profession. While the findings are therefore not generalizable, the insights may hold resonance and be practically transferable to other health professions education contexts. It is possible that the participants involved in this study were over-representative of those who have had positive experiences with SUI. Presumably, those who have enjoyed multi-year tenures with health professional education programs have an experience that differs from those who discontinued involvement soon after initial involvement. As such, it is important to acknowledge that the findings of this study may not be representative of the diversity of experiences of service user educators.

5.6 Conclusion

In this paper, we point to a need for greater critical reflexivity related to *how* and *why* storytelling by service user educators is approached and enacted in health professional education. This work contributes to emerging conversations around the complexities inherent in this work, and supports recent findings in a growing body of literature which suggests that while the inclusion of service user educators' stories can be both important and meaningful, their use in health professional education is not without risk. Our findings trouble the notion that storytelling in the context of SUI is a wholly positive or benevolent endeavour, and offers a set of critically reflexive prompts in hopes of engaging the imaginations of educators interested in more ethical and epistemically just approaches to this practice.

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6 From involvement to partnership: Navigating the risk of tokenism in health professional education

6.1 Introduction

Over the past several decades, health professional education programs have seen greater service user involvement (SUI) in the admission, education and evaluation of students (Arblaster et al., 2015; Beresford, 2002, 2003, 2005; Beresford & Croft, 1993; Happell & Bennetts, 2016; Happell, Pinikahana & Roper, 2002; McKeown & Jones, 2012; McKeown, Malihi-Shoja & Downe, 2011; Repper & Breeze, 2007; Sapouna, 2020; Soklaridis et al., 2020). Despite its growing presence in a range of health and social care contexts around the world, SUI as a concept and pedagogical practice, has been conceptualized and implemented with tremendous inconsistency across health professional programs (Bassett, Campbell & Anderson, 2006; Felton & Stickly, 2004; McKeown et al., 2012; 2014). Interpretations of SUI by health professional educators are wide-ranging, from ad hoc guest lectures – which remain the most common form of involvement – to partnerships between service user and health professional educators.

Various forms of involvement, beyond guest lectures, include participation in curriculum design and delivery, admissions decisions and committees, assessment of students, workshop facilitation, and mentorship of individuals or small groups (Happell & Bennetts, 2016; Sapouna, 2020). It has been suggested that a lack of formal conceptualization or clear definition regarding what SUI actually entails has hindered its development as a pedagogical approach (Lloyd, 2010; McCutcheon & Gormley, 2014; McKeown et al., 2014; McLaughlin, 2007). Such confusion has been influential in the development and adoption of evaluative tools and frameworks for taking stock of levels of service user involvement (McKeown et al., 2014), including Arnstein’s (1969) *Ladder of Citizen Participation*; Tew et al.’s (2004) *Ladder of Involvement*; and Tritter and McCallum’s (2006) *Social Citizenship Mosaic*.

6.2 Conceptualizing service user involvement

Tew et al.’s (2004) *Ladder of Involvement,* is a particularly useful starting point for thinking about the ‘depth’ or level of involvement of service user educators. This framework was developed specifically for application in analyses of SUI in mental health professional education settings, with occupational therapy educators in its target audience. Educators have identified this framework as particularly useful for application in health professional education contexts, as it, “illustrates the integration of service-user involvement into curriculum planning and delivery” (McCutcheon & Gormley, 2014, p.1197). The *Ladder of Involvement* evaluates the extent to which service user educators are involved in health professional education programs, and which tasks they undertake; mapping the progression in depth of involvement across 5 levels, beginning with ‘no involvement’ to involvement of service user educators as consultative partners to that of equitable partnership (See Table 5). This framework also takes into consideration, “policies on payment and reward; training and supervision opportunities for involvement experts; and to what extent people with lived experience are involved in decision-making and in shaping and influencing the course, more widely” (Fox, 2020, p. 4). Evidence of ‘level-5’ partnerships in health professional education settings are reported to be rare, with most SUI initiatives aligning with levels 2 (*limited involvement*) or 3 (*growing involvement*) on the continuum (McCutcheon and Gormley, 2014). This observation also seems to be reflected in the scant body of literature detailing the conceptualization, organization or implementation of SUI initiatives in Canadian occupational therapy education contexts (Morgan et al., 2009; Williams et al., 2007).

Table 6: *Ladder of Involvement (Tew et al., 2004, p. 54)*

Level 1 “No Involvement”	The curriculum is planned, delivered and managed with no consultation or involvement of service users or carers.
Level 2 “Limited Involvement”	Outreach and liaison with local service user and carer groups. Service users / carers invited to ‘tell their story’ in a designated slot, and/or be consulted (‘when invited’) in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity to participate in shaping the course as a whole.
Level 3	Service users / carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery,

"Growing Involvement"	student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecturer rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users / carers are not represented. Some support available to contributors before and after sessions, but no consistent programme of training and supervision offered. No discrimination against service users and carers accessing programmes as students.
Level 3 "Collaboration"	Service users / carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. This is underpinned by a statement of values and aspirations. Payment for teaching activities at normal visiting lecturer rates. Service users / carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users / carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.
Level 5 "Partnership"	Service users, carers and teaching staff work together systematically and strategically across all areas – and this is underpinned by an explicit statement of partnership values. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users and carers to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

6.3 The issue of 'tokenism' in service user involvement

Mention of concern regarding the risk for tokenistic forms of involvement can be found across nearly all SUI literature (Epstein, 2015; Happell & Bennetts, 2016; McLaughlin, 2020; McKeown et al., 2014; Meehan & Glover, 2007; Soklaridis et al., 2020; Tew et al., 2004**)**. Bryant (2020) describes tokenistic involvement as occurring, “where the *presence* of service users is valued above their contribution” (emphasis added, p. 314). As McKeown et al. (2014) have cautioned, uncritical approaches to SUI can result in, “superficial, tokenistic or ‘tick-box’ forms of involvement” to satisfy policy initiatives (p. 1175). However, when employed with intention by critically engaged educators, SUI can serve as a critical pedagogical approach with the capacity to inspire empowered change, and realize “service users’ demands for social justice and change across health care services and wider society” (McKeown et al., 2014, p. 1175).

6.4 Methodology

6.4.1 Theoretical framework

This study is informed by theoretical perspectives drawn from Mad studies; a growing interdisciplinary field of social sciences and humanities education, research, and activism, which positions service users’ knowledge as central and important for understanding all matters related to mental health (Beresford, 2005; Burstow, 2015; Burstow et al., 2014; Castrodale, 2015; Church, 2013; LeFrancois, Menzies & Reaume, 2013; Reville, 2013). Mad Studies has the potential to lend theoretical support to critical SUI approaches, as it represents a “confederacy of academic and service user activists relating to critical understandings of mental health” (McKeown et al., 2014, p. 1177).

This research also embraces Mad (positive) and critical pedagogies as theoretical lenses, whereby SUI is approached as a pedagogical strategy that draws on participatory learning practices to maximize inclusion of a plurality of perspectives (Castrodale, 2017; hooks, 2014; Lather, 1995). Through these lenses, health and social care classrooms are understood as complex discursive environments that shape and reproduce dominant social structures, and service user educators are viewed as “social movement activists” engaging in this work on the politicized and contested territory of professional education spaces (Brown & Zavestoski, 2005 as cited in McKeown et al., 2014, p. 1176).

The research further draws on theories of epistemic injustice (Fricker, 2007; Medina, 2013; Pohlhaus, 2012). Epistemic injustice refers to the distinct wrong done to someone in their capacity as a *knower*; restricting their ability to engage in the basic everyday practices of knowing, conveying knowledge to others, and making sense of personal and social experiences (Fricker, 2007). Epistemic injustice has been applied as a theoretical lens for better understanding the challenges endured by marginally situated communities in their efforts to know, and legitimate this knowledge, within contexts of confluent oppressions such as ableism, racism, sexism, and sanism (Carel & Kidd, 2014; Crichon, Carel & Kidd, 2017; Fletcher & Clarke, 2020; LeBlanc & Kinsella, 2016; Liegghio, 2013; Miller Tate, 2019; Molas, 2016; Newbigging & Ridley, 2018; Scully, 2018; Scrutton, 2017). Attending to the issue of epistemic injustice in mental health professional education involves troubling existing operations of power and knowledge, and questioning: what constitutes valid knowledge, who the legitimate knowers are, and whose knowledge should count (Fricker, 2007; LeBlanc & Kinsella, 2016; Newbigging & Ridley, 2018).

6.4.2 Postcritical ethnography

The findings reported here are from a postcritical ethnographic study into the practice of SUI in mental health professional education. Postcritical ethnography combines tenets drawn from poststructuralism with the critical ethnographic genre, constituting a research methodology that invites audiences to, "consider what could be otherwise (and is not yet) in the everyday lives of people who navigate oppression, inequitable social systems and material conditions, and disenfranchisement" (Anders, 2019, p. 2). Central to postcritical ethnography is a commitment to approaching research as an ethical and political practice, aimed at producing 'justice-centered discourses' (Anders, 2019; Lather, 2001; Noblit, 2004). In clarifying our positionality within this work, our aim is to make it, "more accessible, transparent and vulnerable to judgement and evaluation," and to avoid presenting our interpretation as though it has no 'self' (Olomo, 2006, p.343).

The first author is a maddened woman and scholar who has at various times (and simultaneously) occupied the positions of service user/educator and health professional/educator. and her experiences in these roles provided the impetus for this research. The tensions she perceived between her participants' largely positive accounts of the nature of service user educators' involvement in health professional education contexts and the seemingly limited depth of involvement she witnessed, experienced, and come to appreciate in her close reading of SUI literature provided the impetus for this paper. The second author is an academic whose scholarship takes up critical reflexivity, conceptions of knowledge, and epistemic justice in health professions education; she is committed to the critical pedagogical potential of SUI in solidarity with service user educators. In keeping with postcritical ethnographic methodology, we engaged in critical reflexivity through reflexive journaling, critical interrogation of evolving insights, and dialogic debriefs (Srivastava & Hopwood, 2009). Critical reflexivity was also employed by the first author as a means to navigate her positionality as ‘insider/outsider’ with experiences as service user and health professional/educator.

Two broad aims of the study were to (a) gain an understanding of current practices of SUI, and (b) deepen understandings of the complex and varied experiences of SUI from the perspectives of various stakeholders. The research questions asked: (a) How is SUI being conceptualized, organized, and implemented? (b) How do different stakeholders describe their experiences of SUI? And (c) How does SUI support service user educators’ contributions to the education and knowledge base of health professional students? The perspectives of both service user educators and health professional educators are represented in this study.

6.4.3 Participants

Fourteen stakeholder participants engaged in the practice of mental health SUI participated in this study. All participants had taken part in SUI in health professional education in one of the following capacities: (a) mental health service user educator involved in occupational therapy (n=7) or other health and social care (n=2) professional education program(s) in Ontario (total n=9); or (b) health professional educator who facilitated SUI (n=5). Pseudonyms are used in place of participants’ names (see Table 7). Participants were recruited through the distribution of recruitment materials within four occupational therapy programs in Ontario, accompanied by a request for circulation of materials by educators to known service user educators with current and/or prior involvement in these programs. In addition, service user educators who participated in other health and social care education programs were recruited through an announcement in the Ontario Peer Development Initiative (OPDI) newsletter (considered highly visible to service user educators); and by word of mouth. Potential participants contacted the first author to express interest in participation.

Table 7: *Participant Pseudonyms and Roles in Service User Involvement*

	Pseudonym	**Role**
1	Glen	Service User Educator
2	Kimberly	Service User Educator
3	Heather	Service User Educator
4	Fred	Service User Educator
5	Carmen	Service User Educator
6	Elliot	Service User Educator
7	Joel	Service User Educator
8	Sally	Service User Educator
9	Edward	Service User Educator
10	Nancy	Health Professional Educator
11	Anthony	Health Professional Educator
12	Sara	Health Professional Educator
13	Lindsay	Health Professional Educator
14	Rita	Health Professional Educator

6.4.4 Ethics

Approval to conduct this research was obtained from the Western University Non-Medical Research Ethics Board (NMREB).

6.4.5 Data collection

Data sources included in-depth recorded interviews, participant observation, and the first author’s autoethnographic and reflexive writing. Each of the participants completed an in-depth semi-structured interview that inquired into their experiences of SUI (e.g., their experiences as educators; reasons for becoming involved or soliciting involvement; perceived benefits and challenges), and other pertinent details related to their role(s) and context of involvement (e.g., recruitment/hiring practices; role title; remuneration; involvement expectations or objectives). Interviews took place in locations and/or via communication platforms chosen by participants; 7 interviews were conducted in-person, and the remaining 7 were conducted by telephone. Interviews ranged from approximately 40 to 130 minutes in length (average length was 76 minutes). Participant observation took place during 2 service user educators' guest lectures in 2 separate health professional education programs.

6.4.6 Data analysis

The interviews were audio recorded and transcribed verbatim. Analysis of the interview data was carried out using a reflexive approach guided by Srivistava and Hopwood's (2009) framework for analytic reflexivity, using the following three questions: (1) What are the data telling us? (2) What is it we want to know? And, (3) What is the dialectical relationship between what the data are telling us and what we want to know? The first of these questions was also used to question the role of the researchers as interpreters, by way of asking, "What [are] the data telling [us] that they might not tell someone else"? For Srivistava and Hopwood (2009) this reflexive analytic framework can "offer one of the many ways of writing yourself into the narrative without being self-indulgent or distracting from the purpose of research"; an endeavor consistent with a postcritical ethnographic research methodology.

Quirkos, a qualitative data management software, was used to organize the data into visual and thematic representations (i.e., a colour-coded 'canvas' illustrating connections or relationships between thematic codes, or 'quirks'; See Appendix C). Other data (i.e., participant observation field notes and reflexive journal records) were compiled and referred to regularly to help contextualize and inform interpretations arising throughout the analysis of the interviews. In addition, regular dialogue meetings between the researchers occurred to discuss and explore evolving thematic representations of the data. The reflexive analytic framework (Srivastava & Hopwood, 2009) was used to inquire into participants' responses across and throughout the interviews, and Tew et al.'s (2004) *Ladder of Involvement* was consulted to consider the 'depth' of service user educators' involvement. One paradoxical 'story' that the data seemed to tell was that despite many participants' responses reflecting involvement that was relatively superficial, or "limited" according to Tew et al.'s (2004) Ladder of Involvement (See "Level 2" as outlined in Table 5), most participants described this involvement as meaningful, and decidedly *not* tokenistic. This apparent contradiction sparked several reflexive questions, including:

> *Can meaningful involvement and/or transformative education take place even where depth of service user educators' involvement is 'superficial' or 'limited'? For instance, when SUI initiatives are stifled due to systemic constraints (e.g., limited expertise, time, and/or financial resources)?*
>
> *If so, what factors might shape or influence service user and health professional educators' perceptions and experiences of tokenistic and/or meaningful service user educator involvement?*

6.5 Findings

Participants described a relatively wide range of involvement activities in terms of format or modality, though much less variety in terms of *depth*. Most participants described engaging in or facilitating SUI in the form of ad hoc guest lectures (n=14). Some also described involvement through: short-term, one-to-one (or one-to-small group) mentorship of students (n=7), the role of 'standardized patient' (n=2), and workshop co-facilitation (n=2). One health professional educator reported 'no involvement' of service user educators in one particular mental health-related course they coordinate. Despite participants' reports that the depth of SUI was relatively limited, most participants described their involvement as "meaningful," and decidedly *not* tokenistic. Participants' reported experiences of tokenistic involvement were generally portrayed as exceptions-to-the-rule, standing out against numerous other deeply meaningful engagements. However, this apparent contradiction between participants' reports of limited involvement, and their largely positive accounts of this involvement, raised questions about what factors might be shaping participants’ perceptions of tokenistic and/or meaningful involvement.

The analysis suggested that participants’ reported experiences of tokenism (or lack thereof) seemed to be related to perceptions of whether service user educators and/or their experiential knowledge was valued by/within health professional education programs. Discussions with participants regarding the *value* of SUI flowed organically into conversations about the manner in which this value was acknowledged in a material sense. Participants’ accounts of tokenistic and/or meaningful involvement are presented as ‘two sides of the same coin’ (as signified by our use of demarcated theme headings) in the following distinct, yet overlapping, themes: (a) dis/respect for service user knowledge, (b) dis/connection from the curriculum, and (c) material reflections that de/value service user contributions.

6.5.1 Dis/Respect of service user knowledge: “She absolutely tokenized me; and it was demeaning” / “Expertise is expertise, it’s just coming from a different spot”

Participants who had experienced tokenistic involvement in health professional education programs generally described feeling disrespected, particularly in their capacity as knowers. In Glen’s words:

> The only time I felt tokenized is when I was doing the [standardized patient role] one year...and [the usual course coordinator] wasn't there. So, the professor moderator didn't know my role. And, normally after the role and interview, I take questions. Well, she wouldn't let- she kept interrupting, and dismissing what I was saying, and answering, and interrupting; she didn’t understand that I was *able* to answer. She absolutely tokenized me; and it was demeaning. In my mind, it made my trip …a waste.

This experience contrasted with Glen’s usual experiences with a health professional educator with whom he has worked for a number of years, who he said makes a point of “listening to [his] ideas” and valuing his knowledge and input regarding the content and flow of lectures: “She treats me like an adult professional. And that to me is the ultimate level of real value and fairness.”

Heather reported that her only experience with tokenistic involvement occurred while she served as a board member for a community mental health agency, and much like Glen, her experience was tainted by a perceived lack of respect:

> Anything that I had to say was just... I was just there as a token. You could sense it, you could feel it, I was spoken down to. Anything I had to say was trivial and side passed and whatever. So, I was their token person, so they could say they had somebody with a mental health challenge on their board. And I knew it. And I felt it.

In contrast, in the context of health professional education, Heather stated: “I've always been treated with respect and dignity when I've gone and done my stuff. When I was doing the community thing, it was completely different.” Sally described feeling “appreciated,” and having her knowledge both “valued and validated” in her various service user educator roles. She recalled her particularly meaningful involvement in a research project affiliated with a health professional education program. In her words:

> Any of the papers that we put out, my name was on all of them. My feedback as far as being a consumer and how language was used in the papers and the articles was valued and validated. So, I've never felt, what's the word, that my input was not as good as anyone else. I mean those are people with PhDs, and lots of professors across Canada. [Tokenism] has not been my experience anyway, in any of the work that we've done with [the research project], occupational therapy students, with social work students. I felt appreciated in all of those realms.

Joel explained that, “except for one situation, [he] never felt tokenized.” Of this one instance, he described an interaction with one student who, “was very resistant. The student didn’t understand why [service user educators] were in the program. But everyone else got it.”

Rita explained that for her ensuring that "the students [were] engaged" represented an important part of fostering meaningful SUI and showing respect to service user educators. She explained:

> Whenever a service user does come into the classroom I actually ask students to put their computers away, and for a couple of reasons: one is to protect the confidentiality of what's being said; and two, is to engage and make sure that eyes are on, you know, on the speakers, you know, to show them that respect.

In possible tension with Rita's approach, Glen cautioned against the special or exceptional treatment of service user educators, explaining that the manner in which service user educators' knowledge is introduced to students has the potential to "flavour the whole experience." In his words, SUI should not be presented as something "totally different." He argued that:

> You don't have to rationalize or explain [why it's being done], it's just because it has value… there's a lot of pedestalizing, 'well, we're just going to… they're just service users' [in a mocking tone]. And I mean, it has to be done with a balance, and respect.

Some health professional educators spoke about their efforts to resist tokenism by way of recognizing that service user educators' knowledge constitutes valid knowledge, or 'expertise'. For Sara, this involved working with service user educators as she would, "any other guest speaker." She explained:

> We can't just have people come in and share their experiences. I think we need to treat them like we treat any other speaker. We're asking people who are experts at whatever… and whether they're clinicians- whether it's clinical expertise, or lived experience expertise…

Anthony also recognized service user educators' knowledge as constituting expertise and described the importance of nurturing "supportive relationships;" whether the guest speaker is a service user educator or a therapist. In his words:

> I have come to an awareness that it takes time and effort to develop supportive relationships with people. In any context. Whether you want that to be therapists coming into your classroom, or whether you want that to be individuals with lived experience coming into your classroom. And the expertise is expertise, it's just coming from a different spot. So, in order to do that, you need to be in a position to develop or nurture those relationships…in order for this to really be effective beyond a level of tokenism…

6.5.2 Dis/Connection from the curriculum: “You don’t feel like you’re part of anything” / “To be thoroughly enmeshed”

For some participants, experiences of tokenism were markedly related to a perception of disconnection from the health professional education program; with the inverse – meaningful involvement – related to expressions of “connection,” “integration,” and “relevance.” Glen described most of his experiences in health professional education as *not* tokenistic, when, like “any other adult professional,” he was:

> Not relieved of the societal expectations of respect, staying on topic, quitting on time, and being relevant. I insist on knowing what they studied the class before me, and what they're doing in the next class. Right? To be thoroughly enmeshed, is to have all those societal obligations of, like every other adult professional. That's important.

He contrasted this with an approach to SUI that involves, “just letting the service user do whatever they want,” which he states is “the most common” way of ‘tokenizing’ service user educators:

> You feel like you're floating around in the sky and you walked in and you're in the background. You don't feel like you're part of anything, because you don't have to act like anybody else. Everybody lies to you, and there's the big fake smile, or ‘B-F-S’... You know the people that hold out their hand with a limp handshake and put on a big fake smile when they say ‘hire the mental person’.

Glen explained that:

> It’s really important that the service user be considered a piece of the design machine, and a piece of the delivery machine. Otherwise, you have this amorphous thing – the alien comes in, everybody says, ‘Hey, look at the alien!’ and then the alien leaves.

Perceptions of disconnectedness were often related to not knowing how and where service user educators’ knowledge would *fit* within the program. Heather recalled:

> Well there are times, I don't know [if my involvement was meaningful], because I'm uncertain whether I've met the criteria or not. Unless I'm told what [content] they would like covered, I don't know. So, I think that we could be involved more by giving us more than one visit for instance…

Sally also described knowing very little in the way of context prior to her involvement:

> I don't know where they put us into the program. All I know is we were to come in and tell our story… it's just been a call of ‘will you come in and do the one [talk]? So, minimal discussion, and no, ‘do you think they should have something else? Or, do something else?’ There's been no request for feedback from our end, or... at all.

For Fred, having a sense of where students were in their learning and of where his knowledge was being integrated in the course, meant not – as he put it – “going in blind.” He suggested that this helps service user educators from “getting off on a rabbit trail… and getting off topic,” which was “not beneficial to the curriculum.” From the perspective of facilitating SUI, Sara’s stated, “[SUI] risks being experienced as tokenism if we don't have it interwoven, well-integrated in the curriculum.” She further explained:

> Sometimes we just let service users come in and they can share their story, and I think I'm criticizing myself. I've done that; where I'm like, ‘Ok, we're going to talk about recovery,’ and I just want someone who's recovered to come and talk about recovery, without [deeper consideration]… and I think that can come across as tokenism. Because we're not thoroughly integrating that story into the curriculum.

Sara contrasted this with a description of a more collaborative, “iterative process” whereby service user educators, “carve their story around the learning objectives, and [they] also carve the learning objectives around their story.” Rather than simply saying, “come and share your story,” Sara proposes the following dialogic exchange:

> Here are the learning objectives of the session; do you agree with these learning objectives? Do you have any feedback on the learning objectives? Ok. Now, here's what I'm thinking for the session, and here's where your story will come in. By the way, here's where the students are at in their own learning, this is how many placements they've had. This is what we've done in the course thus far, can you situate your story in that context?’ So, treating them not as just a story, but actually inviting them to be part of the curriculum…in a meaningful way.

Glen described engaging in similar conversations: “We talked about [the course] and I talked about my story… also, what I thought were the key pieces for professionals to know.” Fred recalled that in his experience:

> Often [the course coordinator] would give us an outline beforehand of basically what she was teaching the class, what our purpose there was along with her curriculum, and where we're given leeway to speak and answer questions… Sometimes we would be given three or four questions before we spoke, so it kind of flowed with what she was teaching, and so that the curriculum was followed. You know, it's a short amount of time, and you can get off topic sometimes, and it's good to stay focused on what the students are really needing here.

While several participants’ pointed to the importance of determining the best fit for service user educators’ knowledge in collaboration with health professional educators, it seemed to be more common for service user educators to take it upon themselves to determine the context in which their knowledge would be shared. For instance, some service user educators actively gathered information from course coordinators regarding learning objectives, content previously covered, other guest speakers, etc. in preparing presentations that would be meaningful. Carmen explained:

> I always ask, ‘can you please send me a list of what everyone is going to be doing?’ because I wanted to get a sense of where I'm being slotted; but I also want to know who else is coming in [to speak]. So, then I kind of Google who else is presenting because I want to get a sense of like what the angle is on what they're doing. Then I try and figure out, how do I set up what I'm going to say in a way that's going to allow them to think about it as the [presentations] go on?

Despite making it a practice to ask course coordinators for such details, Carmen also shared:

> I think that being transparent about what it is [course coordinators] are expecting from you when you come in to tell the story is really important; and that onus can't necessarily be on the service user… it has to be on the person who's inviting them in, to really think that through, and to have a framework for what they can expect. Who is in the room? And, why are we asking you now? What is the context of why you've been asked?

Anthony argued that sharing course-related details with service user educators without further conversation, “is a little token.” In his words, “a better approach” would involve saying,

> Alright let’s talk about it… I talk to [them] about the context of the course. What are we teaching? What is that about? Why does this course exist? What is it that I’m doing? Like, why bother? It’s more that discussion, which I think… in any context when someone asks you to guest lecture…like, why do you want me to come? I don’t really care about seeing their course outline…

6.5.3 Material reflections that de/value service user contributions: “thank you very much, here's a gift card” / “It only makes sense to fairly compensate someone for sharing their expertise”

Participants’ discussions of tokenism and the value of SUI often led into discussions of the ways this value is (or is not) reflected. While most participants spoke about the “value” of SUI insofar as it was appreciated, or held in high regard by health professional education programs; others drew attention to the issue of this value not necessarily being reflected materially. For Elliot:

> Lived experience is as valuable as textbook knowledge and should be paid in the same way. I find that often people with lived experience when they're brought in to teach or to help educators and other facilitators or even people with lived experience, they're expected to do so for free.

Elliot described the expectation that service user educators would engage in SUI without fair compensation as:

> An expectation that's stigmatic. With somebody else, if you were bringing in a professor or somebody else who was skipping a day of work, you would compensate them. You wouldn't even *think* about asking them to do it for free. But yet with someone with a mental health disability, you do somehow feel like they could just do it for free. If nothing else, we're compensating someone for sharing very valuable knowledge. It only makes sense to fairly compensate someone for sharing their expertise, because I think that's what it is.

Sally recalled an experience of SUI in which “there was no tokenism,” as reflected through fair remuneration practices. Though she explained that these practices were short-lived, “It was like here's your money go and do your part, and all of the money came... We paid honorariums [to service user educators] before we got in trouble for that.” Glen reflected on his experience with a particular course coordinator, who in his words, “was the first one to pay me *properly*. She gave me $500 bucks for half a day; I just about flew out of my skin.”

Several participants spoke about experiencing tensions related to the compensation of service user educators for their knowledge contributions. For Sara, this tension was related to the uniquely emotional labour required of service user educators and the fairly standard practice of offering compensation in the form of a gift card. She explained,

> My other mixed feeling is… we ask these people to come in and sort of pour their hearts out...and then we say to them, ‘thank you very much, here's a gift card.’

> And, something about that at times can feel quite, I don't know the right word for it, maybe... quite perverse almost.

During the interview, Sara began to brainstorm about alternative compensation practices. She suggested:

> Maybe we need to be thinking about what we're going to *give back* to [service user educators]; that we don't just end after they finish the session, but that maybe there's a prolonged engagement where we train, they deliver a session, and then we give them some sort of certificate that maybe enables them to improve their employability or, you know, something like that. So that there's more of a give and take, and it doesn't *have* to be about money.

Much like Sara, Elliot spoke about the service user educators' emotional labour in relation to remuneration practices: "You're asking people to do things that trigger people, it could actually be detrimental to their health leading up to, and presenting. So that needs to be thought about, and therefore compensated for." Glen also linked emotional labour (and benefits) to the financial impact of SUI, describing how his involvement in health professional education often requires him to take time off work in preparation for his involvement. On the one hand, Glen explains that SUI is, "easy for me to do, because it nurtures my soul in a way" but on the other hand, he says: "I need 4 days off, to get that pumped-up-ness. If I took 4 days off, I'd be so stressed about not being at work for 4 days."

Despite some calling for fairer remuneration practices, not all participants seemed to take issue with the way service user educators are typically compensated for their involvement. Some participants reflected quite positively on the receipt of a "small gift" in return for their involvement. In Fred's experience, "[the course coordinator] was always very appreciative, and the students were too… they had an appreciation night, a get-together [for the service user educators]. We were all given a kind of a certificate and small gift." Edward, expressed appreciation for having received personalized cards as a token of 'thanks':

> I've got some cards; it's about 6-, 7-years-worth, of them writing down what they thought I did, and most of, well, nearly all of it was positive. And I know they were just being nice sometimes, but… So, that was cool. Very cool.

Kimberly recounted, “Well, with the occupational therapists, they’ll give me a gift card… I think it’s $50 dollars, and they’ll ask me what store I want it for. But, I don’t expect to be paid… It’s a gift.” When asked if she would still engage in SUI if it were on a “solely volunteer-basis” she responded with an emphatic: “yes!” In Nancy’s experience:

> [Service user educators] are either willing to come or they're not willing to come. So, I've never had anybody say, ‘I can't come unless I'm getting paid.’ I've never heard anybody ever say that. So, no, I don't really think that's an issue so much…

Within Nancy’s program, it’s standard practice to give, “a gift, maybe a mug or a pen, or, you know, something like that. And, a card. It’s pretty simple.”

There were also participants who spoke about a lack of financial and temporal resources available to support SUI initiatives. On the one hand, Rita identified a lack of, “time and money, and resources” as a barrier to deeper, less tokenistic SUI (i.e., “bringing people in during the planning stages”), and expressed “concerns about not wanting to ask for things that [she] can’t implement.” On the other hand, Lindsay, who also noted that SUI is a resource-intensive endeavour, described that aspect as being a deterrent to pursuing SUI in any way that could be considered tokenistic. She said,

> First of all, it's a lot to organize… a guest speaker; in many ways it’s a lot easier to just lecture yourself. You don't have to you know bring water for somebody, or organize a thank you card, you know, compensation or anything like that. I mean, it's so much easier. So, if I'm going to bring somebody in with the lived experience it's going to be because they are presenting something that I feel like I can't, or that the students will have an experience with them, that they can't have with me. Um, so, I would say that in my experience I would never include somebody from a tokenistic – it would never be a token involvement. I'm just thinking it's actually way too much to organize without having a tangible benefit.

6.6 Discussion

6.6.1 Toward epistemic justice through partnership

The findings offer important insights into how experiences of tokenism in this study were linked to perceptions of respect, recognition, legitimacy, connection and value; often irrespective of the depth or level of involvement, or apparent power imbalances. As such, even within contexts of relatively limited involvement, participants often regarded SUI as meaningful, and decidedly *not* tokenistic, when they felt respected as knowers (e.g., recognized as legitimate knowers, seemingly held in high regard, treated as professionals, listened to, etc.), their knowledge was meaningfully connected to students' learning, and the value of their contributions were reflected materially (e.g., fair remuneration or other expressions of appreciation). In a departure from participants' reports, however, tokenism as it has been conceptualized in SUI literature is often directly linked to unaltered power structures, whereby meaningful involvement, "inevitably requires a shift in power" (Felton & Stickley, 2004, p. 97). While a deeper understanding of the factors contributing to a sense of meaningful involvement is important; by limiting our focus to individualized or personal evaluations of tokenism, we risk neglecting to interrogate knowledge hierarchies and/or power structures at play in SUI within health professional education. Using the theory of epistemic injustice to consider and make sense of the findings, we question the extent to which SUI can truly transcend tokenism if epistemic power disparities or knowledge hierarchies are not disrupted.

Consistent with the findings of this study, reports of SUI across health professional education programs are most commonly described as, "more consultative than partnership-based" (McCutcheon & Gormley, 2014, p. 1197). The involvement of service user educators in this way reflects the individualized 'access' described by disability justice activist, Mia Mingus (2011), with respect to engaging in social justice work, which is "often about granting entrance to one individual or providing inclusion to one event" (as cited in Annamma & Handy, 2020, p. 5). While a single ad hoc guest lecture may be experienced as deeply personally meaningful to service user educators, students, and faculty alike, it is reasonable to expect that this kind of involvement will result in only "a limited shift in power within the collaborative relationship" between service user and health professional educator (Cleminson & Moesby, 2013, p. 7). Mingus (2017) cautions that individualized access, “is a strategy toward assimilation, giving individuals some advantages of the privileged, evidencing why access alone has not engendered justice” (as cited in Annamma & Handy, 2020, p. 5). A more epistemically just conceptualization of SUI, requires us to acknowledge that service user educators may be, “interested in more than just simple involvement and voice,” and rather, in partnership in processes of change and the opportunity to influence priorities, decisions, and outcomes (Gee et al., 2016; McKeown et al., 2014, p. 1177). We argue with others that a shift from service user involvement to service user partnership, whereby inherent power structures are shifted and challenged, holds promise for realizing more equitable and epistemically just conditions in SUI (Duffy & Beresford, 2020; McCutcheon & Gormley, 2014; Soklaridis et al., 2020).

Setting our sights on the joint venture of service user partnership offers a discursive and conceptual shift with generative possibilities for those engaged in SUI, as the term “‘partnership’ has different connotations from those of involvement,” ‘participation’ or individualized ‘access’ (McCutcheon & Gormley, 2014, p. 1197). Theories of epistemic injustice help us to appreciate the subtle yet important distinction between these terms by illuminating the limits or constraints placed on service user educators as knowers (or epistemic agents) when involved in health professional education as participants, rather than partners. Partnership stands to afford service user educators power to influence decisions and outcomes, whereas involvement positions them as ‘participants’ offering (at times, critical) commentary on the work of health professionals (Gee et al., 2016). According to McCutchen & Gormley (2014), failure to involve service user educators in all aspects of education delivery and development, “is in itself tokenistic in approach” as “the decision of when and how service users are involved [remains] firmly with the academics” (p. 1198). Indeed, as elaborated in an earlier chapter (see discussion of epistemic objectification in Chapter 2; revisited in Chapter 7), even when knowledge contributions are solicited from marginally situated knowers – in this case, service user educators – there is a risk that they will be undermined in their capacities as knowers and constrained as givers of knowledge, “at the service of the inquirer’s epistemic agency” (Medina, 2012, p. 92). In other words, “centering oppressed groups is very different from giving them a seat at the table" (Annamma & Handy, 2020, p. 5). Without disrupting epistemic power disparities through purposeful centering of service user knowledge – as is the aim of genuine service user partnership - service user educators remain effectively isolated, with their knowledge at risk of erasure, "even when they are invited to deliberate" (Annamma & Handy, 2020, p. 5).

At its core, service user partnership stands to trouble taken for granted assumptions about who the legitimate knowers are/can be, and whose knowledge should count. Participants in this study acknowledged that service user educators' knowledge indeed represents, "expertise […] just coming from a different spot" (Anthony), and as such, should be included without having "to rationalize or explain [why it's being included]" (Glen), as this knowledge is valid, legitimate, and coming from a credible source. As Annamma and Handy (2020) point out, "when we transcend boundaries of whose knowledge is valid we allow ourselves to build knowledge with marginalized communities" (p. 7). While the inclusion of service user educators' knowledge in health professional education may seem like progress – and may be viewed favourably by various stakeholders – without the re-distribution of epistemic power required for genuine partnership, current approaches to SUI risk reinforcing unequal power relations; further marginalizing service user educator knowledge (Collier and Stickley, 2010, p. 4).

We contend that a more clearly established conception of tokenistic involvement amongst health professional educators stands to offer a promising way forward. In particular, one which acknowledges that involvement that is more than tokenistic is dependent upon epistemically just conditions, whereby in addition to perceptions of respect, recognition, connection and value, service user educators are regarded as active epistemic agents or partners in co-producing health professional education. Such non-tokenistic (or meaningful) involvement would be evidenced by service user educators' engagement in a range of educational activities, such as: curriculum design and delivery, student selection and evaluation. To this end, adoption of a formalized framework, such as Tew et al.'s (2004) *Ladder of Involvement,* for conceptualizing, organizing and implementing SUI could support health professional educators in discerning, "their level of commitment and progress towards the implementation of service-user partnerships" (McCutcheon & Gormley, 2014, p. 1198).

6.6.2 Toward epistemic justice through fair remuneration

The issue of remuneration in SUI has been highlighted in recent literature as a priority area in need of further research (Campbell & Wilson, 2017; Unwin et al., 2018). The findings of this study align with literature suggesting that remuneration reflects, or is at minimum related to, broader matters of respect, recognition, value, power and justice (Campbell & Wilson, 2017; Soklaridis et al., 2020; Towle & Godolphin, 2015). Much like the practice of SUI itself is carried out in varied and inconsistent ways across health professional education programs, so too are approaches to remuneration. The range of payment or compensation models may include (but is not limited to): no payment, gift cards, cash honorarium, expenses only, expenses plus honorarium, or an hourly rate (Towle & Godolphin, 2015). Fair and appropriate remuneration for SUI is typically understood as one way of acknowledging and valuing service user educators' expertise and epistemic contributions, and recognizing the emotional labour involved (Repper & Breeze, 2007; Soklaridis et al., 2020). However, as was highlighted by participants in this study, and has been taken up in SUI literature, the issue of remuneration is fraught with complexity, tensions, and differences of opinion both across, and within, stakeholder groups (Campbell & Wilson, 2017; Repper & Breeze, 2007; Soklaridis et al., 2020; Towle & Godolphin, 2015). For instance, while ultimately in support of paid SUI, Soklaridis et al. (2020) described tensions surrounding the notion that payment can "erode the uniquely critical stance that service users bring to education," or that "paying off" service user educators may, "be used as a way of limiting [ethical] obligations to them" (p. 165).

Some occupational therapy education programs in Ontario – the primary ethnographic context in which this study is grounded – have conceptualized SUI through a lens of volunteerism, as evidenced in the development of the *Volunteer Experience Model* (Morgan et al., 2009). Indeed, service use service user educators are referred to as 'volunteers' in publications outlining SUI initiatives developed by prominent health professional education programs in Ontario, which engage a transformative approach to learning about disability (inclusive of ‘mental illness’) through the matching of students with community members with ‘lived experience’ (Morgan et al., 2009; Williams et al., 2007). Within the field of occupational therapy education specifically, volunteerism as it is enacted through engagement in SUI has even been theorized as a form of *meaningful occupation* for service user educators (Morgan et al., 2009).

This conceptualization is contrasted with the position taken by Soklaridis et al. (2020), who discuss the complexities of remuneration within the landscape of SUI, and conclude that, “asking for and accepting unpaid labour” risks, “perpetuating the marginalization of people with disabilities by reducing the value of their labour and, ultimately, their knowledge and skills” (p.164). They argue that fair remuneration for service user educators’ epistemic contributions is ethically imperative (Soklaridis et al., 2020). The findings of this study lend support to the latter of these two perspectives. While volunteerism likely holds immense value for many, the unpaid epistemic and emotional labour of service user educators may contribute to tokenistic involvement, exploitation, and further marginalization – epistemically, socially, and economically – of this community (Soklaridis, 2020, p. 165). Our findings also resonate with the contention that the role of service users as legitimate knowers and educators will remain limited unless remuneration is ultimately connected to a larger goal of achieving epistemic and social justice (Soklaridis et al., 2020).

In keeping with this broader aim of achieving epistemic and social justice through SUI, we take caution not to view the imperative of remuneration as a reason to exclude the knowledge contributions of service user educators in health professional education; for instance when a program lacks sufficient funding or infrastructure to support such payments (Soklaridis et al., 2020). We acknowledge that there are numerous other ways to recognize and/or compensate service user educators for their valuable contributions. Many participants in this study spoke fondly of other forms of recognition offered alongside or in lieu of payment, including: personalized letters, ‘thank-you’ cards, recognition events, academic memorabilia (e.g., mugs, lanyards, pens), university library privileges, and honorary academic appointments; all of which have been identified in SUI literature as important (Towle & Godolphin,2015). One participant (Sara) suggested a "giving back" that might involve offering formalized training and mentorship for service user educators, which would result in their receipt of a certificate toward improving their overall employability. A similar ongoing practice of training and supervision is outlined in levels 4 (*collaboration*) and 5 (*partnership*) of Tew et al.'s (2004) *Ladder of Involvement* framework.

6.6.3 Epistemic justice through transformative praxis

As has been suggested by McKeown et al. (2014), "when certain conditions are optimized, activism for progressive change can come to the fore" and "critically engaged academics are well-placed to support such praxis" (p. 1177). We offer the following reflexive prompts (Table 6) for critically engaged health professional educators seeking to support a SUI practice oriented toward epistemic and social justice. An approach grounded in transformative praxis strives to depart from tokenistic forms of involvement, and instead, espouse genuine partnerships that centre (in both their conceptualization and practice) recognition and respect for service user educators and their knowledge.

Table 8: *Reflexive Prompts for Educators*

Context / areas of involvement	In what way(s) and/or areas do you envision service user educators and their knowledge fitting into your program, course, or curriculum? According to your conceptualization of SUI, will service user educators' knowledge complement, influence, or be centered in, the education of your students?
Depth of involvement	If service user *partnership* is not (yet) feasible, what incremental steps can you take to ensure that service user educators' involvement represents a departure from tokenistic, or solely consultative involvement? For example, you might consider providing opportunities for collaborative development of learning objectives; or solicitation of service user educators' feedback for shaping future iterations of course material(s).
Planning / evaluating involvement	Have you considered using a particular framework to conceptualize, organize, implement, and evaluate SUI in your program (e.g., Tew et al.'s (2004) Ladder of Involvement, or Arnstein's (1969) Ladder of Citizen Participation)? Where

	would your current (or conceptualized) SUI practice be ‘located’ within one of these frameworks?
Respect and recognition of service user educators as knowers	How might you approach introducing service user educator(s) and/or their knowledge to students and other faculty in a way that prioritizes respect and recognition for their capacity/status as valid knowers (e.g., roles/titles or verbal introduction), and avoids presenting their knowledge as *less than*, ‘alien,’ or Other?
Sensitizing concepts / laying an epistemic foundation	Has a foundation been laid within your classroom in the form of priming or sensitizing concepts that will enable students to ‘hear’ service user educators’ suppressed knowledge and/or stories? That is, have you discussed the legitimacy of service user-produced knowledge; engaged with concepts and ideas presented in service user/survivor literature; and discussed systems of oppression and privilege (e.g., sanism/sane privilege) with your students?
Remuneration	Do you have a predetermined budget and/or access to funds that will allow for the fair and ethical remuneration of service user educators? If fair remuneration is not (yet) feasible, what can you do to ensure that service user educators’ epistemic and emotional labour, and other contributions to your program receive appropriate recognition (e.g., a written letter of appreciation, thank you cards, library privileges, or recognition events)?

6.7 Limitations

This study was situated in a bounded context, focused primarily on the experiences of service user and health professional educators from one health profession. As such, the findings are not generalizable, however, the insights may hold resonance and be practically transferable to other health professional education contexts. It is possible that the participants involved in this study were over-representative of those who had positive experiences with this practice. Presumably, those who have enjoyed multi-year tenures with health professional education programs have an experience that differs from those who discontinued involvement early following initial involvement. As such, it is important to acknowledge that the findings of this study cannot be read as representative of the experiences of all service user educators.

6.8 Conclusion

> *I don't just want technical and logistical access. I don't just want inclusion, I want liberatory access and access intimacy. I want us to not only be able to be part of spaces, but for us to be able to fully engage in spaces. I don't just want us to get a seat at someone else's table, I want us to be able to build something more magnificent than a table, together with our accomplices. I want us to be able to be understood and to be able to take part in principled struggle together—to be able to be* human *together. Not just placated or politely listened to."* (Mingus, 2018, Another term for love).

This study has shed light on epistemic issues that may be overlooked by health professional educators due to individual evaluations of meaningful SUI, and supports a revisioning of SUI toward a practice less likely to fall into the trap of tokenistic involvement. The findings resonate with service user-produced literature in suggesting that SUI initiatives should be designed and fostered with careful consideration given to *how* service user educators and their knowledge are recognized, respected, connected, valued, integrated and embraced within health professional education. Furthermore, the valuing of service user educators' knowledge contributions should be reflected in fair and ethical remuneration or compensation practices. We have identified the importance of attending to the uniquely epistemic dimensions of SUI, and the limits placed on service user educators as *knowers* (or active epistemic agents) when constrained in their involvement as 'participants' rather than partners. At minimum, our findings point to the importance of fostering more epistemically just conditions for involvement, particularly where greater 'depth' of involvement is not (yet) realizable, and service user partnership, or co-production, remain unattainable goals (e.g., due to systemic constraints). Approaches to SUI oriented toward epistemic justice should prioritize in-depth and wide-ranging involvement of service user educators (i.e., through partnerships and co-production) and fair remuneration, and require ongoing critical reflexivity and other actions oriented toward transformative praxis in this domain.

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7 A Reflexive Account of *Doing* Service User Involvement

> *"If we do teach about disability, upon whose voices and knowledge(s) do we draw? Upon which model(s) of dis/ability do we draw? And, how are dis/ability and madness represented through our teaching?"* (Castrodale, 2018, p.190)

7.1 Introduction

In this chapter I present a reflexive examination of my experiences as a sessional health professional educator to further explore the practice of involving service user educators in health professional education. This inquiry was born out of my reflexive journaling and participants' accounts, and my aim to present a layered account of a multitude of perspectives and understandings related to *doing* service user involvement (SUI). My interpretation of the experience of being a health professional, and service user educator involving other service user educators in the classroom is presented in 'conversation' with insights garnered throughout this research (i.e., direct quotes from my participants' interviews, or my interpretation of findings), and with formative and contemporary service user-produced and/or SUI-focused literature.

With my data collection and preliminary analysis well underway, I found myself jumping at an opportunity to develop and instruct a health professional education course, which would allow me to try my hand at facilitating SUI. This course was to be delivered as an elective to a small cohort of graduate students in the Spring term of 2018 at a prominent Canadian University. The overarching objective of the course – as defined by the department – was to deepen students' understandings of 'mental health,' its study, and practice, in order to better prepare them for entry into the profession. For the first time since I had begun to think critically about SUI in health professional education, I occupied the role of *health professional educator* tasked with the conceptualization, organization and implementation of the practice that I had set out to study and better understand through this research. Without prescriptive guidelines or any concrete sense of direction for how I *ought* to go about beginning this work, I found myself looking inward (e.g., what wisdom had I gained through my previous experiences as a service user educator?); to the literature (e.g., what had I read about *doing* SUI thus far, and what were some of the gaps in my knowledge?); and, to my research participants (e.g., what was I hearing in participants' interviews, and what interpretations was I beginning to construct from these?).

Through this reflexive account I attempt to make visible the *why* and *how* behind my development of a health professional education course, wherein SUI – as a tool or practice – was central to my pedagogical approach. These reflexive musings offer generative possibilities about what the *doing* of SUI might actually look like, and the tensions that may emerge for critically engaged educators attending to the complex issues inherent in and external to its practice. I have organized this reflexive account around pedagogical, ethical, epistemic, and economic considerations, which are closely aligned with both the findings of this doctoral research and my vision for SUI practices informed by principles of epistemic and social justice. These considerations include: (1) adoption of a Mad (positive) pedagogical approach; (2) recruitment of service user educators; (3) diverse representation; (4) establishment of clear expectations; (5) epistemic considerations for incorporating service user educators' knowledge; and (6) provision of fair remuneration.

7.2 Theoretical framework

This research is theoretically informed by *Mad studies*, a growing interdisciplinary field of social sciences and humanities research, which positions Mad, consumer/survivor/ex-patient (c/s/x), or service user knowledge as central and important for understanding all matters related to 'mental health' (Beresford, 2005; Burstow, 2015; Burstow et al., 2014; Castrodale, 2017; Church, 2013; LeFrancois, Menzies & Reaume, 2013; Reville, 2013). Mad Studies has been identified as a site with potential to lend support to SUI, as for some it represents a "confederacy of academic and service user activists relating to critical understandings of mental health" (McKeown et al., 2014, p. 1177). This research also embraces *Mad (positive)* and *critical pedagogy* as theoretical lenses. Through these perspectives, SUI is approached as a strategy which draws on participatory learning practices to maximize inclusion of a plurality of perspectives (Castrodale, 2017; hooks, 2014; Lather, 1995). Furthermore, classrooms are understood as complex discursive environments that shape and reproduce dominant social structures, and service user educators are viewed as “social movement activists” engaging in this work on the politicized and contested territory of health professional education spaces (Brown & Zavetoski, 2005 as cited in McKeown et al., 2014, p. 1176). The research further draws on theories of *epistemic injustice* (Fricker, 2007; Medina, 2013; Pohlhaus, 2012) to explore issues related to knowledge and justice as these play out in SUI in mental health professional education.

7.3 Methodology

This reflexive account is situated in a postcritical ethnographic study into SUI in mental health professional education. Postcritical ethnography combines tenets drawn from poststructuralism with the critical ethnographic genre (Lather, 2001; Noblit, 2004). This research methodology is used to produce “justice-centered discourses,” and invites audiences to, “consider what could be otherwise (and is not yet) in the everyday lives of people who navigate oppression, inequitable social systems and material conditions, and disenfranchisement” (Anders, 2019, p.2). There is no *one* way to define postcritical ethnography. However, Noblit (2004) contends that there are important tenets that all approaches to postcritical ethnography should consider; namely: “positionality, reflexivity, objectivity, and representation” (p. 198).

This move for researchers to contextualize their positionality, is congruent with approaches to Mad/service user-produced research, which foreground experiential knowledge (through approaches such as reflexive writing, autoethnography, and storytelling) as a means to “interrogate the *I* and its interconnections not just with the experiences of others, but also with broader institutional, societal, and theoretical levels of understanding” (Sweeney, 2016, p. 39). This interrogation of the *I* is central to postcritical ethnography, in its commitment to approaching research as an ethical and political practice, and helps to avoid presenting interpretations as though they have no ‘self’ (Anders, 2019; Olomo, 2006).

Within this chapter I further unpack my positionality within this research in an effort to make it, “more accessible, transparent and vulnerable to judgement and evaluation” (Olomo, 2006, p.343). I employed critical reflexivity throughout the research process as part of navigating my liminal positionality as ‘insider/outsider,’ ‘service user educator/health professional educator,’ and ‘service user/service provider.’ I have also drawn from Lather’s (1995; 2007) work to use reflexivity as a means to interrogate the emancipatory aims of this research. Lather (2007) writes, “postcritical methodologies are *hinged* on self-reflexive, double(d) practices of representation that both problematize emancipatory research aims and the production of essentialized and romanticized subjects” (p. 347). Toward problematizing emancipatory research, Lather (1995) proposes that researchers foreground the reflexive poststructural question: “how do our very efforts to liberate, perpetuate the relations of dominance?” (p.169). This question, and others like it, underpin this reflexive account.

Data sources informing this reflexive inquiry include, my reflexive journal entries written between 2017-2021; email correspondence with service user educators, administrative staff, and course coordinators (note: only those written by myself are included here); my course outline; the course ‘Call for Proposals’ from 2018/2019; and participant interviews. In the interests of confidentiality and privacy, contextual details of the course including the particular field of health professional education, the academic institution at which this course was delivered, and any individuals potentially implicated in this recounting have been anonymized. Pseudonyms are used in place of participants’ names, and any other potentially identifying information has been redacted or removed.

7.4 Conceptualizing, organizing and implementing SUI: Six considerations

As sessional instructor of a new course I was given significant leeway in terms of its content, format, and mode of delivery, and was therefore able to centre SUI in my approach to its development. The following section explores some of the important considerations and deliberate pedagogical and/or ethical decisions I made throughout the process of developing and realizing this course; how I came to make these decisions; and, finally, what I learned through this *doing*.

7.4.1 Adoption of a Mad (positive) pedagogical approach

My approach to the development of this course was guided in part by Castrodale's (2017, 2018) conceptualization of *Mad pedagogy* and his call for "more 'socially just' critical pedagogies that recognize Mad and disabled subjectivities" (Castrodale, 2017, p. 50). Mad pedagogical approaches to teaching about disability and madness demand that we ask ourselves: "whose voices and knowledge(s) have spaces to be acknowledged, valued, and understood;" and "how [are] disability and madness represented through my teaching?" (Castrodale, 2017, p. 51). Mad pedagogy was translated through this course in multiple ways. First, involvement of service user educators as a deliberate pedagogical approach aligned with Castrodale's (2018) assertion that "drawing directly on the lived experiences of disabled and Mad persons represents a means to challenge ableist/sanist discourses" (p. 190).

The involvement of service user educators in the classroom was politicized by acknowledging their positions as "social movement activists," (Brown & Zavetoski, 2005 as cited in McKeown et al., 2014, p. 1176) as well as the historical marginalization and exclusion of their knowledge from health professional education spaces (Fabris, 2011, Reaume, 2006; Russo & Beresford, 2015; Wolframe, 2013), where psy- discourses and a predominantly biomedical models of understanding experiences of mental distress or diversity continue to dominate (LeBlanc & Kinsella, 2016; Newbigging & Ridley, 2018). The concept of 'mental health' was also politicized (Voronka & Grant, 2021) as we considered evidence of this dominance in: our use of the term 'mental illness' as a signifier to describe human experiences of emotional distress and diversity; our reliance on diagnostic categories outlined in the DSM-V; and in the absence of concepts including 'Mad Pride,' the psychiatric-survivor movement, or survivor-led/produced responses to madness (e.g., the Soteria House/model, or the 'Hearing Voices Network') in most health and social care professional curricula (Crichton et al., 2017; Groot, 2020; Kidd & Carel, 2017; Newbigging & Ridley, 2018).

By extension, respect for 'alternative' ways of knowing mental distress and diversity was a value I sought to uphold in the course design (LeBlanc & Kinsella, 2016). I centred service user, c/s/x and Mad knowledge to support 'unlearning' in the way that Snyder et al. (2019) describe it, as “questioning what we think we already know, and making room for multiple ways of knowing” and in particular as “troubling the dominant understandings of madness that abound in higher education” (p. 2). Health professional students were introduced to service user, c/s/x, and Mad perspectives through assigned readings and in-person engagement with service user educators. Service user-produced literature was used to ‘prime’ students to hear service user educators’ knowledge contributions through a politicized or justice-oriented lens, rather than as individualized recovery narratives. Service user-produced knowledge was also regularly revisited throughout the course to reinforce this stance (see also section on *Epistemic Considerations for Incorporation of Service User Educators’ Knowledge* for elaboration; Voronka & Grant, 2021).

My Mad positionality was intentionally disclosed to students during our first lecture, and in more subtle ways as the course progressed (e.g., in the sharing of firsthand experiences or anecdotes). I also disclosed the same to service user educators prior to their agreement to become involved in the course. My decision to do so was both personal and informed by Mad and service user-produced literature (Castrodale, 2017; Snyder et al., 2019; Wolframe, 2013). As a Mad scholar and health professional educator, I viewed this disclosure as an opportunity to support students in their un/learning related to false dichotomies of us/them, well/unwell, and mad/sane. Furthermore, my disclosure represented resistance to the erasure of Mad people/knowers in academic spaces, and challenged (potential) pre-conceived notions about *who* can be a professor (Snyder et al., 2019). I also disclosed to further emphasize the importance of centring lived experiences and Mad knowledge (Castrodale, 2018).

I disclosed with the belief that sharing begets sharing, openness begets openness, and vulnerability begets vulnerability. In this way, I hoped to offer students a sense of ‘permission’ to begin unpacking and embracing historically marginalized or stigmatized aspects of their own identities, as this permission (and representation) is something that I so desperately longed for as a health professional education student just years prior. As a student, I instead received repeated, tacit messages which suggested that the roles of *service provider* and *service user* were mutually exclusive. As a key part of this Mad-positive pedagogical praxis, I also raised awareness that Mad and disabled students are always present in health professional education classrooms (Snyder et al., 2019). Students' sharing of experiential knowledge or personal anecdotes were welcomed and honoured, with the understanding that our course was operating as a 'brave space' (Arao & Clemens, 2013); a framework I was introduced to during my participation in a *Service User Educator* training course.

The concept of brave spaces offers an alternative to the 'safe spaces' paradigm and was developed for use in facilitating difficult or controversial conversations for the purpose of social justice education. Brave spaces, "emphasize the need for courage rather than the illusion of safety" (Arao & Clemens, 2013, p. 141). This small but important linguistic shift from safe to brave spaces acknowledges that, "learning necessarily involves not merely risk, but the pain of giving up a former condition in favour of a new way of seeing things" (Boostrom, 1998, p. 399 as cited in Arao & Clemens, 2013). Toward establishing this course as a brave space, we negotiated common 'ground rules' as a group using those offered by Arao and Clemens (2013) as a starting point) (e.g., 'controversy with civility,' 'own your intentions and your impact,' or 'no personal attacks'). Finally, teaching through a Mad pedagogical lens meant continually reflecting on my, "onto-epistemological frames, positionality, truth(s), and justifications to make increasingly socially just pedagogical decisions" (Castrodale, 2018, p. 190). Such reflections found a home within the pages of my reflexive journals, which were already being used to navigate similar issues or questions related to my research.

7.4.2 Recruitment of service user educators

An interesting finding from this research is that the involvement (or recruitment) of service user educators in health professional education appears to be a largely relational endeavour. That is, with two exceptions, my research participants did not describe any structured or formalized means of recruitment (e.g., public call for service user educators; recruitment or job ad; or even by interview). Instead, (health professional educator) participants reported drawing primarily from their personal and professional networks, inviting contributions on a 'who you know' basis. For instance, as Lindsay recalled: "Within the mental health courses that I coordinate, I usually have… he's actually a friend of mine who has [a psychiatric diagnosis]… so, I asked him if he would like to come in... And that's a whole session.” She also described reaching out to a regional peer support network as a means for recruitment, as she knew several of their peer support employees personally.

Anthony similarly described drawing from his personal contacts; he explained that there are, “a couple of individuals who come into my classroom who I discharged like a decade ago, and then didn’t see them for five years.” He also described inviting,

> …certain individuals who have historically had at least some interest in [service user involvement], or who have a unique story or have a real desire to get out some messaging, and help people understand them in a context that’s perhaps different.

Sara described her approach as occurring, “probably more [by] word-of-mouth,” which sometimes included, “service users coming to us as saying, ‘I’d love to speak about my experiences’.” For Rita, recruitment was often rather serendipitous. In her words, “sometimes I hear them speak, and I approach them… based on what they do, what their skills are, and how they are experts on the things that they’re experts on; and we just modify [their contribution] accordingly.”

My approach to recruitment for this course, by default, was much the same. I turned first to three individuals in my personal and professional networks whom I knew had both experiential knowledge related to mental distress, diversity and/or encounters with the mental health system, as well as a desire to share this knowledge with health professional students. Two of these individuals had a wealth of experience with public speaking in this area, whereas the third had reached out to me months prior to my knowledge of this course, and asked me to contact him should I hear of any opportunities to share his experiential knowledge with students. Much like some of the participants in my own research, I reached out to a local service user-run organization to inquire about whether they might have an interest in becoming involved in this course. Below is one of my initial emails to the director of this organization:

> “…I'm emailing to follow-up with you about our brief phone conversation in November. I am a PhD student at Western University, as well as an occupational therapist, and mental health service user. I am putting together an elective mental health course for [redacted] titled *Critical Approaches to Mental Health*, and I am hoping to connect with individuals at [redacted] who may be interested in teaching or consulting on the development of the module. The course will run from March 2nd to April 6th 2018 on Friday afternoons from 1:00-4:00pm.
>
> Here is a brief outline of the course:
>
> Students will explore a range of complex psychosocial issues in various occupational therapy practice contexts, taking into consideration the ways social, economic, political, and historical practices impact mental health and wellbeing across the lifespan. Throughout this intensive, students will have an opportunity to learn about these issues from the unique perspectives of consumer/survivor/service user educators, practicing occupational therapists and other allied health professionals. Topics including, but not limited to, the following will be explored:
>
> - Trauma and trauma-informed approaches to care
> - Addiction and harm-reduction strategies
> - Suicide, crisis assessment and services
> - Sanism, stigma, and discrimination
> - Recovery, peer support, and other peer-led mental health initiatives
> - Intersectionality (e.g., LGBTQ, gender, racialization, disability, class)
> - Housing, homelessness and street involvement
> - Psychiatric survivor and Mad movements (radical perspectives, history, rights)
> - The importance of narrative and story within the therapeutic relationship
>
> If you're interested, I would love to sit down with you to chat about the module, and potential ways you might like to be involved.”

I also emailed the individual I described earlier as having particular interest in SUI, though much less formally:

> I hope that this email finds you well!
>
> I'm emailing because I recall you telling me that you'd like to be able to share your story someday, and I have a potential speaking/sharing opportunity for you - I'd love to know if you're interested.
>
> I am putting together a mental health course [redacted] this Spring. As you know, I strongly believe in centring the voices of those with lived experience of madness or alternative mental states in educating health professionals; and I think that an important way to do that is to have individuals with lived experience come in and share their perspectives and parts of their experiences with the students themselves.
>
> If you're at all interested and want to talk more about what this might look like, please let me know and maybe we can chat over coffee.
>
> I look forward to hearing from you.

In the end, 6 service user educators, and 4 practicing health professionals (many of whom also shared their experiences of distress/mental health system encounters), were involved as guest lecturers in this course. Although this largely relational and informal manner of ‘recruitment’ was accessible and timely, upon reflection I am able to see that this practice *can* be problematic. As I see it, its problematic nature is related to issues of *epistemic objectification* and (mis/under)representation (the latter is elaborated in the following section on *Diverse Representation;* McGlynn, 2019). I am referring to the Nussbaum-inspired epistemic objectification recently detailed by McGlynn (2019), which I believe offers some insight into the ways that my/our attitudes and behaviour can be epistemically objectifying. In a critique of Fricker’s popular conception of epistemic objectification (which tends to focus on the ‘inertness’ and ‘instrumentality’ of knowers), McGlynn (2019) draws from Nussbaum’s analysis of objectification as, “a very rich, multi-faceted cluster concept” which encompasses “no fewer than seven ways that one can treat someone as an object” to demonstrate the ways epistemic objectification is similarly complex (p. 12). According to Nussbaum (1995, p. 257), *someone* can be treated as *something* in the following seven ways:

1. *Instrumentality*: the objectifier treats the object as a tool of his or her purposes.
2. *Denial of Autonomy*: the objectifier treats the object as lacking in autonomy and self-determination.
3. *Inertness*: the objectifier treats the object as lacking in agency, and perhaps also in activity.
4. *Fungibility*: the objectifier treats the object as interchangeable (a) with other objects of the same type, and/or (b) with objects of other types.
5. *Violability*: the objectifier treats the object as lacking in boundary-integrity, as something it is permissible to break up, smash, break into.
6. *Ownership*: the objectifier treats the object as something that is owned by another, which can be bought or sold, etc.
7. *Denial of Subjectivity*: the objectifier treats the object as something whose experiences and feelings (if any) need not be taken into account.

As far as ‘recruitment’ of service user educators is concerned, one particular facet of this cluster concept stands out to me – *fungibility*. Epistemic fungibility involves “treating members of a certain social group as interchangeable for epistemic purposes; testimony from one member of the group (on the subject at hand, at least) is as good as any other” (McGlynn, 2019, p. 13). Sara, a health professional educator, offered some insight into our tendency as solicitors/facilitators of SUI toward epistemic fungibility: “I'm like, ‘Ok, we're going to talk about recovery,’ and I just want someone who's recovered to come and talk about recovery, without [deeper consideration]… and I think that can come across as tokenism.” My own limited experience with the recruitment of service user educators, combined with the findings of my research, tells me that Sara’s approach is not anomalous, nor is it typically done with intent to objectify. However, it is in this instance that I am reminded of Lather’s (1995) question: “how do our very efforts to liberate, perpetuate the relations of dominance?” (p.169).

It is possible that in our commitment to service user *inclusion* and prioritizing a plurality of knowledges – and in particular, suppressed knowledges – we neglect to adequately attend to the always present risk of epistemic objectification, and end up (re)producing unequal relations of epistemic power. Resisting the perpetuation of epistemic fungibility requires interrogation of the very conditions of SUI which make it so easy to perpetuate. First, SUI rests on an assumption that ‘service user educator’ or ‘mentor’ or ‘person with lived experience’ constitute *essential*, stable, and coherent identity categories, and that these identifiers can be used to “organize widely heterogenous bodies of experience together” (Voronka, 2016, p. 190). We must acknowledge that service user educators’ interests are wide and varied, and as such, service user educators cannot be regarded as interchangeable subject matter experts. As Voronka reminds us, “some of us as ‘experts by experience’ want more of the same; some of us want to transform systems; some of us want to tear them down” (2016, p. 198). In acknowledging that ‘service user educator’ as an identity is not representative of a homogenous community or some universal standpoint, and that “lived experience in and of itself does not dictate our approach to the topic at hand” (Voronka, 2016, p. 198), it becomes easier to see how regarding service user educators as epistemically interchangeable (or fungible) may very well constitute epistemic objectification.

7.4.3 Diverse representation (or lack thereof)

In addition to fungibility, SUI which depends on an essentialized view of ‘service user educators’ as constituting one cohesive identity category raises questions about representation, and about which ‘members’ of these identity categories gets “recognized as a viable ‘lived experience’ subjectable to work within mental health assemblages” (Voronka, 2016, p. 197). At the time of this course development, I was beginning to better appreciate the various debates around representation. In particular, debates which centred around an undermining of service user educators’ ‘legitimacy’ as knowers by way of suggesting that those involved in health professional education could not possibly represent ‘real’ or ‘typical’ service users, and/or were in some way exceptional or remarkable (Beresford & Campbell, 1994). As Beresford and Campbell (1994) have explained, it is paradoxically the very act of becoming ‘involved’ in health professional education, that renders service user educators ‘unrepresentative’ (read: “confident, experienced, informed, and effective”) in the eyes of some service providers and professional educators (p. 315). Informed by this debate, I sought to share a multiplicity of voices, perspectives, and experiences of distress or mental health system encounters with students through the involvement of multiple service user educators (to speak to each topic). However, it is now abundantly clear that my focus was on engaging with a diversity of experiences/encounters with various facets of the mental health system, rather than ensuring that service user educators' experiences were also representative of multiple, confluent experiences of privilege, pride, oppression, or marginalization. As a result, my approach to SUI was demonstrative of Beresford and Campbell's (1994) criticism of health professional educators' "frequent failure to involve Black people and minority ethnic groups effectively" (p. 317), and of Voronka's (2016) observation that 'viable' lived experience subjects (in this case service user educators) tend to occupy bodies that are, "by and large ones recognized as able to perform White civility, comprehensibility, and [to] self-manage unruliness" (p. 197).

The diversity of sociopolitical identities represented across service user educators involved in this course was regrettably limited. Service user educators occupied predominantly white and cisgender bodyminds. Half of the service user educators were women, and only half identified having disability experiences (external to their experiences of mental distress, diversity or madness). This form of diverse representation was not something that I deliberately prioritized during recruitment, and in my neglecting to do so, I denied students the opportunity to learn from service user educators occupying (and speaking from) varying sociopolitical locations. For instance, while I spoke to students about how sanism is experienced along a continuum depending on one's experiences of privilege or oppression (Meerai, Abdillahi & Poole, 2016), I did not provide students with an opportunity to learn from people whose experiences of *anti-Black sanism* have shaped their encounters/collisions with the mental health system. One of my research participants, Carmen – a service user educator with experience in recruitment and hiring for SUI – spoke to the complexity of this very issue of 'representation' (or lack thereof). She said:

> I'm really aware of who is not in the room. I'm really aware of when we have *one* individual who represents a certain viewpoint, that that's a very alienating place to be, even though in many ways we are all similar. When you have for example, one person of color, or one trans person, or one person who is a minority religion,

> or who identifies as being homeless or whatever, being in the criminal justice system; I'm just pulling social determinants out of the air… That's a very lonely place to be, and we can't have a group that is only homogeneous to one or a few of those pieces. So, how do you maintain diversity in a pool of let's say 15 people, and also look for someone who has really strong verbal communication skills, and is going to be reliable and show up, and has an analysis beyond their own experience? Right? We're looking for multiple different things at the same time.

When I engage once again with Lather's (1995) question (i.e., "how do our very efforts to liberate, perpetuate the relations of dominance?") I can see the ways that my efforts toward an anti-sanist praxis reinforced functions of racism, colonialism, ableism, and heteronormativity. By not centering issues of collective liberation (Berne et al., 2018) and confluence (Joseph, 2019) in my approach to SUI, this 'perpetuation of relations of dominance' manifested in the near total exclusion of non-white, queer, trans, and disabled service user educator voices (Voronka, 2016). Given a 'do-over,' my recruitment of service user educators would (at minimum) prioritize involvement from BIPOC, Disabled, Deaf, and LGBTQIA2S+ communities, as well as those with a self-identified alignment with c/s/x and Mad constituencies. Moving beyond diverse representation, and inspired by the principles of *disability justice*, my recruitment would prioritize leadership by those 'most impacted' by our mental health system, for their ability to radically disrupt dominant ways of knowing and doing (Berne et al., 2018; Voronka, 2016).

7.4.4 Establishment of clear expectations and sense of 'context'

My research findings, which also resonated deeply with my own experiences, informed my commitment to establish clear expectations and objectives with service user educators and to clarify (as much as possible) the context in which their knowledge contributions would be shared. Recognizing that it is the norm for service user educators to be invited to share their 'recovery stories' in health professional education contexts (Voronka & Grant, 2021), I explained during our preparatory meetings that I was seeking knowledge contributions related to service user educators' unique expertise and/or activism (e.g., service user/survivor-led responses to distress; Peer Support work); or a generative systemic critique they had developed from their experiences (e.g., of involuntary hospitalization or student health services). In other words, I discouraged service user educators from *solely* sharing ‘mental illness narratives’ (de Bie, 2021) or ‘from tragedy to triumph’ stories (Voronka & Grant, 2021) which tend to be individualizing, apolitical and centered around psy- conceptions of ‘recovery’ and/or ‘overcoming.’ Several service user educators involved in this course later shared with me that this was the first time their experiential knowledge had been sought by a health professional educator as it related to their activist, advocacy, or vocational work, as opposed to a retelling of their symptomology, diagnosis and subsequent ‘recovery’. As they described it, this was a heartily welcomed change.

While in the role of service user educator myself, I have struggled with an overwhelming sense of not knowing where or how my knowledge was going to fit in the context of the program, or which of my experiences/stories was going to ‘land’ with students. My own desire for a clear sense of relevance and ‘connectedness’ between my knowledge and the professional education context was also echoed by nearly all of the participants in my research project (see Chapter 6 for elaboration). I aimed to establish a sense of clarity and transparency around expectations and context in multiple ways. Prior to any in-class involvement, I shared my course outline and course readings with service user educators and we met (at their convenience) to review these and other expectations and/or details of their involvement. During these meetings we discussed our shared (or diverging) visions for the course and their involvement in it, and how our collective vision could be realized. In addition to clarifying role expectations and context by way of email and in-person meetings, I built the following ‘conversation’ into the design structure of the course in the form of evaluated student participation. I did this in an effort to ensure that service user educators had an opportunity to gauge how and where their knowledge contributions might be most relevant with respect to meeting the learning needs and objectives identified by the students. Students’ weekly participation involved the submission of ‘pre-class’ questions to be shared anonymously with service user educators one week prior to class.

Pre-Class Questions (20%)
In preparation for class, students are asked to formulate and electronically submit **one** question relevant to the topic(s) being discussed in the upcoming class (see question submission schedule below). Student questions will be shared anonymously with the guest speaker(s) prior to class.

The purpose of submitting pre-class questions is to:

- Give students an opportunity to engage in self-reflection about their current learning needs and interest(s) prior to engaging with class material;
- Give both the guest speaker(s) and the course instructor an opportunity to tailor class materials, activities and discussion to meet the learning needs and interests of the students.

7.4.5 Epistemic considerations for incorporating service user educators' knowledge

As I engage deeply with theories of *epistemic injustice* in my doctoral research (Dotson, 2011; Fricker, 2007; McGlynn, 2019; Medina, 2012; Pohlhaus, 2012; See also Chapters 2, 5, 6 and 8) I have been sensitive to the susceptibility of service user educators (and their knowledge) – as a consequence of sanism – to discrediting, invalidation, quieting, dismissal and exclusion from health professional education settings (LeBlanc & Kinsella, 2016; Sapouna, 2020). As I have detailed in an earlier chapter (see Chapter 5), one barrier to the uptake of service user educators' stories of resistance is that these narratives typically rely on marginalized epistemic resources (e.g., alternative epistemologies of mental distress, or critical understandings of concepts like 'recovery'), and are less likely to be readily received – or even understood – by health professional student audiences (Voronka & Grant, 2021). As such, I dedicated a portion of each class to laying important 'groundwork' by way of introducing and unpacking sensitizing concepts (e.g., sanism, Mad Studies/Pride, intersectionality/confluence, anti-oppression, etc.) in an effort to prime students to be able to truly *hear* the service user educator perspectives as politicized knowledge contributions oriented toward social justice (LeBlanc & Kinsella, 2016; Voronka & Grant, 2021). My hope was that addressing extant hermeneutical lacunae (i.e., the absence or suppression of language and concepts necessary for understanding one's own, or others' experiences) important for understanding service user educators' contributions would serve to resist 'discursive confinement' (Voronka & Grant, 2021). As Voronka and Grant (2021) have explained, "systemic criticism is often literarily unhearable" (p. 7) because, "while peers may understand their stories as narratives of oppression and resistance, when they speak them, their stories are conditioned by institutional context, and available language" (p. 12). Put simply, I was trying to *add* to the language, concepts and theories available to students to make sense of what they would hear from service user educators throughout this course.

I also let service user educators know which sensitizing/priming concepts I would be sharing throughout the course prior to their involvement in an attempt to mitigate *testimonial smothering*. Testimonial smothering refers to the truncating of one's own testimony so that it contains only content for which one's audience is (perceived to be) willing and able to receive (Dotson, 2011). In other words, we tend to *only* tell the stories and share the knowledge that we know the contexts in which we tell them are equipped to *hold*. We tell stories in ways that we believe they will be understood, embraced, appreciated, or viewed as relevant. In doing so, certain kinds of knowledge, or parts of stories, are smothered and left unsaid. Along these lines, Mia Mingus, a disability justice activist, describes a set of epistemic resources as, "all the things needed to hold [her] story" (2018, paragraph 14) In her case, she explains that in order for her story to be 'held' and heard as intended, someone needs to (at least) have a basic understanding of:

> "disability, ableism, abled supremacy; the medical industrial complex, histories and notions of cure, ugliness and the myth of beauty; race, white supremacy, orientalism, adoption, transracial adoption, transnational adoption, the commodification and ownership of children, immigration, forced migration; korea [sic], diaspora, US imperialism, war, borders; the Caribbean, colonization, the US South, anti-black racism, slavery and the US slave trade system; misogyny, patriarchy, sexism, gender, domestic and sexual violence, child sexual abuse; feminism, queerness, queer people of color; rural lands, islands, rural communities. *And how all of these intersect with each other"* (Mingus, 2018, paragraph 14).

I question whether health professional education classrooms – with their espousal of dominant psy-discourses for interpreting distress and mental health system encounters – are even (epistemically) equipped to ‘hold’ service user educators’ resistance narratives. In my experience as a service user educator I have tended to shy away from sharing about instances in which I experienced sanism, for example, if I have not had the opportunity to first detail and describe the concept of sanism to students. This said, I do not believe that the onus for ‘priming’ students with hermeneutical resources required to hear and hold resistance narratives and critique should be on service user educators. ‘Setting the stage’ for SUI – by way of ensuring that students have critical epistemic/hermeneutical resources at their disposal – should be understood as part of the process. We cannot expect service user educators to necessarily disrupt the status quo, if their knowledge contributions can only be interpreted according to mainstream, psy-dominated knowledge frames (e.g., clinical recovery, deficit focused ‘intervention’) or a ‘psychiatric gaze’ (Voronka, 2019). As Mingus (2018) asserts, “it is not enough for us to simply get to share what’s important to us (though I know that many times we don’t even get to share that), if no one knows how to hold […] to understand and fully engage with what we are sharing” (paragraph 23).

I was also aware of the importance of *epistemic credibility* – or perceptions of knowers as trustworthy and reliable – toward having service user educators and their knowledge contributions regarded as valid and legitimate (Fricker, 2007). Informed by my research findings, I aimed to reinforce service user educators’ epistemic credibility by way of *normalizing* their involvement as ‘experts’ or knowers in the course; regarding and introducing them, “like any other [non-Mad] guest speaker” (Sara). One manner in which I attempted to do this, was to present the names and affiliations of service user educators in the syllabus in the same way that I presented all other guest lecturers. While this practice may seem rather insignificant, some of my research participants spoke about a sort of “pedestalizing” (Glen) or ‘Othering’ that can occur in the introduction of service user educators to students, and I wished to avoid this practice where possible. I had also witnessed this sort of ‘pedestalizing’ practice, as I understand it, during my participant observation (i.e., during ad hoc service user educator-delivered guest lectures). That is, where health professional educators seemed to heavily emphasize service user educators' 'redeeming' or other humanizing qualities (e.g., service user educator is described as a friend, having a spouse, being employed, etc.) during their introductions, and to a greater degree than one would typically expect from the introduction of a health professional speaker, for instance. My impression has always been that this is a subconscious attempt toward bolstering service user educators' epistemic credibility, rather than an intentional 'Othering' or 'pedestalizing'.

7.4.6 Provision of fair remuneration

Around the time I was developing this course, my early research findings, which were paralleled by conversations I was having with fellow service user educators, were highlighting complex issues related to remuneration in the context of SUI. Until this point, my expectations related to remuneration were largely limited to my own experiences as a service user educator. Compensation or 'thanks' for my involvement had typically been in the form of a thank-you card and/or small token of appreciation (e.g., a mug, $10 coffee shop gift card, lanyard, water bottle, etc.). Through speaking to my research participants and other service user educators I began to better appreciate remuneration as an important service user educator-identified issue; a topic that has been raised by several others (Campbell & Wilson, 2017; Soklaridis et al., 2020; Unwin et al., 2018).

The issue of remuneration overlaps in important ways with the previous section related to validating service user educators' knowledge. That is, fair and appropriate remuneration for SUI is typically understood as one way to acknowledge and value service user educators' expertise and epistemic contributions, and to recognize the emotional labour underpinning their contributions (Repper & Breeze, 2007; Soklaridis et al., 2020). However, as it is taken up in SUI literature and as was highlighted by participants in this study, the issue of remuneration is fraught with complexity, tensions, and differences of opinion both across and within stakeholder groups (Campbell & Wilson, 2017; Repper & Breeze, 2007; Soklaridis et al., 2020; Towle & Godolphin, 2015). As pointed out by Voronka and Grant (2021), some service user educators have come to view their experiential knowledge as ‘economically valuable,’ and a potential source of income (Voronka & Grant, 2021, p.7).

While a case has been made for viewing the payment of service user educators for their epistemic contributions as ethically imperative, to my knowledge there was no infrastructure set in place for this particular course to support compensation of service user educators (Soklaridis et al., 2020). I emailed the department requesting that I be “supported” in my commitment to reimbursing service user educators for their contributions. I explained that I planned to provide each service user educator with an honorarium of $50, and outlined my rationale for doing so. I expressed my preparedness to use my own funds for these honorariums if necessary, however, inquired about the availability of funding in the department to support this remuneration practice. My ‘backup plan’ at the time was to use my instructor stipend to pay service user educators for their epistemic contributions; some of which I did end up using to reimburse out-of-town guests for their travel.

Fortunately, the Administrative Coordinator and the Director of [redacted] [redacted] collectively agreed to “provide funds towards this compensation” (Email excerpt). It was communicated to me that this compensation would have to be in the form of a gift card, as cash compensation, “can only be done following an appointment/contract as per a call or posting” (Email excerpt). While I was disappointed about the gift card stipulation, I was thrilled about the department’s willingness to support remuneration for SUI. My proposed compromise was that we offer *Visa* gift cards in lieu of cash. In the end, I was able to offer service user educators a modest (indeed, inadequate) $50 *Visa* gift card – and where appropriate, travel expenses – for their contributions, which typically involved up to one hour (sometimes individually, or as part of a panel) of in-class time. I discussed the method and details of service user educators’ payment with them prior to their involvement. My inability to offer cash honorariums is a common constraint faced by health professional educators facilitating SUI; and one that I have now run into repeatedly. This is a well-documented issue in SUI literature (Soklaridis et al., 2020) and is something that was echoed by several participants involved in this research project. One research participant, Sara, even described this common practice as “perverse” in its insufficiency considering the emotional nature of service user educators’ contributions.

I witnessed what I perceived to be a subtle cultural shift reflected in the course *Call for Proposals* the following year. Where it had not been at the time of my application in 2018, was now a subsection on the 2019 proposal application form which read:

> “*Compensation for service users/guests: (please outline whether you expect to include service users or other guest lecturers that would require compensation and the anticipated compensation amount)*.”

My initial reading of this change was one of optimism. I felt hopeful that this might be one small, yet promising, sign of a shift in institutional culture toward expected or accepted remuneration for service user educators. This was also what I perceived to be the first tangible ‘fruit’ of my labour with respect to this doctoral research. That is, this subtle change in the proposal form seemed to me, to be directly related to my application of the insights I had garnered from my initial interviews the previous year. I thought to myself, “could this be the beginning of a shift toward more equitable SUI practices in this health professional education program?”

As more time has passed, and I have read the important work and critiques of service user educators (Soklaridis et al., 2020), I acknowledge that it is within the realm of possibilities that the dollar amount indicated by applicants on these forms could very well be a deciding factor – for a program with limited funding to allocate to these courses – in whether or not to accept particular course offerings. That is, where remuneration for SUI is viewed as an ethical imperative, insufficient funding to support this practice might actually result in the exclusion of service user educators from our programs (Soklaridis et al., 2020). An alternative practice might involve infrastructure which supports remuneration for guests *built into* the application form. For example, a clear indication of how much funding the program has available to allocate to service user involvement, so that successful applicants might determine how many service user educators could reasonably, ethically be involved and paid appropriately for their time and labour.

Students' evaluations of the course were resoundingly positive, with an overall course rating of 6.8 out of 7. In their anonymized course evaluations several students commented positively on the practice of SUI. For example, one student commented:

> "Stephanie was an engaging, passionate and clearly knowledgeable professor. I significantly enjoyed her teaching style that was open to suggestions and cared about the interests of the students, had a focus on transparency and the emphasis on lived experience and practical application. Sharing her lived experience and the lived experience of her guest speakers was a fantastic learning opportunity and I really appreciated it as a student and as a future [health professional]."

On the Mad pedagogical approach more broadly, another student shared:

> "Stephanie was an amazing instructor for this course! She designed the course to help us really be critical thinkers about mental healthcare. She always went above and beyond to provide us with resources and provide us with information to answer our questions. She is a very respectful and approachable instructor which made this course even more enjoyable."

Some students also offered constructive feedback regarding SUI such as, "perhaps giving the guest lecturers a few points to focus on each would be useful learning for me" and "maybe less guest lectures as I found that regular classroom lectures/discussion would have sometimes been more targeted and effective." Despite being highly rated and originally developed in response to students' requests and a recognized gap in the curriculum, this course was not selected to be offered the following year. While any number of reasons could have led to the department not choosing to offer the course a second time, one cannot help but wonder if the financial 'burden' of reimbursing service user educators may in some way be implicated.

7.5 Discussion: Exploring the (constraining) role of academic capitalism in *doing* SUI

7.5.1 Time pressures: No time and the efficient use of time

Time (or a lack thereof) was perhaps the most constraining variable in terms of my ability to realize a course that was co-produced or reflective of true service user educator partnership, as I have come to appreciate that establishing and nurturing meaningful relationships requires plenty of it. As discussed earlier (see section on *Diverse Representation*) my decision to adopt a more relational or informal recruitment strategy (i.e., drawing on the modest network of service users and service providers I had at least some relationship with) was ultimately related to a perceived lack of time; or framed differently, a perceived time pressure (Walker, 2009). In relying on *who* and *what* I knew, I neglected to prioritize diverse representation, and in particular, the perspectives of members of LGBTQIA2S+, Disabled, Deaf, Black, Indigenous, and other non-white sociopolitical communities. Participants in this study – specifically, health professional educators – also regularly cited time as a constraining variable related to the involvement of service user educators. Sara, for instance, explained that (saving) time is often an important consideration with respect to inviting service user educators back. She said:

> My strategy to date has really been, 'oh, this is tough. I don't really have the time to do this, maybe I just ask this person back again' and I'll ask someone who I know has that [public speaking] training or support or skill.

In Lindsay's experience, timing was also further complicated by institutional/administrative procedures which required – for remuneration/honorarium purposes – instructors to have the specific names of guest lecturers submitted prior to the onset of the course. As she explained:

> Like I said, you're contacting someone in August for a talk in November. Sometimes, [service user educators] don't even remember. There's all this background work that you need to do, and sometimes they reschedule sessions because they're not available at that time, because it was organized back in August, and then you're switching all your sessions around to accommodate. You

> can reschedule your own sessions, but you can't reschedule a guest speaker very easily. And, sometimes people cancel as well. So, if I could contact somebody a bit closer to the date, and then follow some administrative process after the fact that would be lovely. Or, if we could easily draw… if we had to include somebody at the last moment, and we could draw on this funding sooner, like within the week or something.

Rita cited insufficient “time and money and resources” as perceived barriers to deeper SUI, highlighting the issues of inflexible timing (much like Lindsay) and scarcity of free time. In Rita’s words,

> I think there could be deeper, and more, opportunity [for SUI] for sure. I think bringing people in, in the planning stages would be ideal. It's been really time and money and resources, and all of that, that have stopped me… as well as some concern about not wanting to ask for things that I can't implement… We have a very full, and tight, schedule that the students are on. So, scheduling is always an issue, I only have so many hours that I have at my fingertips, and I have to fill it with a lot of different things. So, I don't have flexibility in timing. I don't have flexibility in the amount of time I can spend on things.

For Nancy, “timing makes [SUI] extra challenging,” beyond the time it takes to recruit service user educators. She explained that SUI itself can add to the already very limited time she has to devote to covering course content:

> We have such a limited time in the curriculum, that we have to be very targeted, make sure it's not redundant, make sure it's on topic, that [SUI is] going to add to what [students] already have. For me, it's quite often more just an efficiency thing; of how to get through so much content, so quickly, and to get to my learning points in a way that I need to. I may only have 10 minutes to [cover a topic], I may have an hour to [cover a topic].

Although I experienced time as a constraining factor in achieving meaningful SUI much like my research participants did, my experience undoubtedly differed in that my sessional role offered me a far greater degree of flexibility than instructors operating on a full-time basis and in accordance with a structured (even rigid) or set curriculum. I have come to appreciate that this flexibility (regarding course content, timing, and structure) afforded me a unique and privileged position as a health professional educator seeking to engage critically in the practice of SUI. It is clear to me that a more just SUI does not simply require the heroic efforts of individual health professional educators, but meaningful change and support at systemic, institutional levels.

7.5.2 Commodification of higher education – Balancing commitment to students and service user educators

Academic capitalism (Slaughter & Leslie, 1997; Walker, 2009) – and in particular, the commodification of knowledge and education – increasingly prioritizes students' needs and wants, constructing them as 'customers' or consumers of educational products delivered by universities (Kauppinen, 2014; Sappey, 2005). In this way, I recognize this course as a product for student consumption. It was their 'consumer perspectives' which would ultimately determine the success or failure of the course (in one sense). As I was developing the course I recall feeling that students' positive evaluations of the first iteration of this course was incredibly important. That is, I believed that it would be tremendously helpful to have 'proof of concept,' so to speak, to support my future applications to offer this course. I felt constrained or bounded by the pressures of academic capitalism in ways that were previously unknown to me. I began to realize that my commitment to service user educators would have to co-exist with my commitments to other stakeholders (e.g., students, other faculty, and our department) in complex, and sometimes competing, ways.

My use of weekly 'pre-class' questions serves as one example of where I sought to balance commitments to both service user educators and students. My objective was (at least) twofold. On the one hand, a better sense of students' interests and knowledge gaps would enable me to tailor the lecture materials to their unique and evolving learning needs. On the other hand, this same knowledge could be shared with service user educators to give them a better sense of where students were 'at' in terms of their learning, as well as the opportunity to modify or tailor their contributions should they wish to do so. From my perspective, this weekly exercise would help to ensure that (a) students were engaged and experienced this course as valuable to their growth as future professionals, and (b) service user educators' knowledge contributions were appreciated, 'relevant' and connected to students' learning objectives. To this second point, I wanted to ensure that when service user educators concluded their involvement in this course that they were not left wondering *how* their knowledge would be taken up by myself and the students. I know firsthand how deeply unsettling the ask to 'tell your story' can be; particularly when it is meant to be done in the context of a course which you know next to nothing about. I suppose that my hope was that this 'pre-class' engagement with students would help to alleviate service user educators' feelings of uncertainty in this regard.

While I do not know when, or in which areas, my focus on student engagement might have infringed on my commitment or ability to involve service user educators in this course in respectful, ethical, equitable and just ways, I want to acknowledge its likelihood. For instance, I have no doubt that my desire to produce a course that students would find value in, tacitly guided precisely *whom* I invited to speak to the class. I had heard many of these service user educators speak; I knew their 'stories' and approaches, and as such, I could envision their involvement in this course producing positive learning experiences. In doing so, I (again) neglected to attend to important issues of representation, diversity, equity and justice.

7.6 Conclusion

> *"My lessons are local, situated, and still unfolding, and I invite readers to ask questions about what is not here."* (Anders, 2012, p. 105)

This experience instilled in me a deep appreciation for the uncertainty that comes with attempting to facilitate SUI in health professional education. While my approach and execution were not without flaws, what I was able to achieve was done from a position of scant resources (e.g., financial, relational, and otherwise), power, and time. I was a junior, sessional instructor without any substantial power or influence over the health professional education department, nor did I have a vast personal or professional network to draw upon in 2018. However, in reflexively attending to the inherent complexities of SUI, my account of this experience stands to offer generative insights toward doing this work in a manner that is ethical, and works toward both epistemic- and social justice. Much like Anders (2012), my lessons are, “local, situated, and still unfolding,” (p. 105) and my thinking around the practice of SUI will surely continue to evolve so long as I am engaged in its doing.

7.7 References

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8 Discussion & Conclusions

This chapter provides a brief overview of each of the integrated articles comprising this dissertation and engages a discussion around the scholarly contributions of this work. In this chapter I also revisit an important ‘unifying thread’ in this work, *epistemic injustice*. Here, I elaborate on why this concept featured so prominently in this project and offer reflexive insights on affordances as well as my potential shortcomings or oversights. In this chapter I also discuss how I have come to a more politicized understanding of mental distress – or madness – through the course of this research. The chapter concludes with a discussion of the implications of, and future directions for, this research and plans for its dissemination.

8.1 Integrated articles

The body of this integrated article style dissertation is comprised of four manuscripts; one centred around theoretical perspectives of significance to this work, two empirically-based, and a final reflexive chapter about my experiences of *doing* SUI. Each of these manuscripts is formatted so that they may stand alone, however, they are woven together using theoretical, epistemological and methodological threads (e.g., epistemic injustice, Mad studies, Mad/critical pedagogy, postcritical ethnography, and reflexive analysis/interpretation). Each manuscript plays an important role in comprising a bigger picture, which aims to deepen and complicate current understandings of the many ways SUI is experienced, as well as to imagine what could be otherwise (but is not yet) in the practice of involving service user educators in health professional education.

The first manuscript (Chapter 2, titled *Toward Epistemic Justice: A Critically Reflexive Examination of ‘Sanism’ and Implications for Knowledge Generation)* is a theoretical chapter aimed at elucidating the links between epistemic injustice and sanism in considerations of the marginalization of the knowledge of people/communities who have firsthand encounters with the mental health system, or who are otherwise deemed Mad. In this chapter, I engage with theories of epistemic injustice described by Fricker (2007) and Medina (2012), and draw illuminating examples from Mad and other critical scholars to demonstrate the way that sanism – as an underpinning *negative identity prejudicial* *stereotype* – upholds the suppression, dismissal and exclusion of Mad and related experiential knowledges from mental health education, research and practice. As my understanding of epistemic injustice, oppression, and violence has deepened, I recognize in retrospect that other theories – that I was previously unaware of – offer important contributions to thinking through these issues. These include elaborations on Fricker's (2007) conceptualization of epistemic injustice by Dotson (2011), Pohlhaus (2012, 2014), and McGlynn (2019). Their writings on contributory injustice, testimonial quieting and smothering, and epistemic objectification, respectively, were taken up in subsequent chapters, and are discussed briefly below.

The second manuscript (Chapter 5, titled *"Come and share your story and make everyone cry": Complicating Service User Educator Storytelling in Health Professional Education*) reports on findings related to the practice of storytelling in SUI, which I identified as a central theme in my analysis of how service user educators' knowledge is conceptualized and shared within health professional education spaces. The findings presented in this chapter help to illuminate a range of complexities related to storytelling within these spaces. The discussion adds to the literature that problematizes uncritical solicitation of service user educators' stories in health professional education using the concepts of epistemic injustice and emotional/affective labour. In this chapter, I endeavour to complicate the popular practice of solicitating service users' 'life stories,' and discuss how this might constitute a form of *contributory injustice* in light of calls for broader conceptualizations of service user educator knowledge (e.g., Costa et al., 2012). The findings also point to a need for consideration of the uniquely emotional and epistemic labour required or expected of storytellers (i.e., service user educators). Drawing from Voronka's (2015, 2019) earlier work in this area, I discuss my findings in relation to emotional and affective labour, emotional pornography, and the commodification of service user educators' Othered knowledge. This paper concludes with generative recommendations and reflexive prompts for educators seeking to engage service user educators in health professional education through the practice of storytelling.

The third manuscript (Chapter 6, titled *Toward service user educator partnerships: Navigating the risk of tokenism in health professional education*) explores one of the most commonly cited risks or concerns related to engaging in SUI: tokenism. This chapter reports on service user educators' and health professional educators' understandings and experiences of tokenism (or lack thereof) in SUI. The findings suggest that stakeholders' experiences of tokenism are linked to a failure to recognize the value of service user educators and/or their knowledge (e.g., experienced as perceptions of disrespect, disconnection, and inadequate remuneration). Stakeholders' experiences of tokenism – or the converse, meaningful involvement – are explored as 'two sides of the same coin'. This paper engages a discussion around epistemic considerations for SUI as these relate to tokenism, and explores a potential shift in discourse and conceptualization from 'service user *involvement'* to 'service user *partnership.'* Possibilities for redress and potential issues in realizing such change are also explored.

The fourth manuscript, (Chapter 7, titled *A Reflexive Account of Doing Service User Involvement*), the last of the integrated articles, offers a reflexive examination grounded in my firsthand experiences as a service user educator and sessional health professional educator, in conversation with data from the empirical study. This inquiry centres around a pivotal experience during the course of my doctoral research and was born out of my ongoing reflexive journaling and insights drawn from participants' interviews. This chapter also offers insight into the examination of my liminal positionality within this project. I framed this chapter around six decisions and/or considerations I made in my *doing* of the work of SUI: (1) adoption of a Mad (positive) pedagogical approach; (2) intentional recruitment of service user educators; (3) diverse representation; (4) establishment of clear expectations; (5) epistemic considerations for incorporating service user educators' knowledge; and (6) provision of fair remuneration. This chapter concludes with a discussion of pressures associated with academic capitalism and how such pressures might influence health professional educators' abilities to realize the aforementioned considerations. In particular, I discuss my experience in navigating a balance between (at times seemingly competing) commitments to service user educators and health professional students in relation to the commodification of higher education.

8.2 Why epistemic *in*justice?

A move *toward epistemic justice* is proposed in each of the integrated articles comprising this dissertation, and is perhaps even the particular (re)imagining I had in mind at the outset of this research. While a move toward epistemic justice may be an aim of this work, I would like to revisit why the language of epistemic *in*justice is more prevalent throughout. As Fricker (2007) explains, a "focus on justice creates an impression that justice is the norm and injustice is the unfortunate aberration" (p. vii), however, there are many spheres where injustice is the norm owing to issues of social identity prejudice and power imbalance. Fricker's (2007) examination shifts our focus to the "negative space that is epistemic injustice" as the "only way to reveal what is involved in epistemic justice (indeed, even to see that there is such a thing as epistemic justice)" (p. viii). By this logic, to focus this postcritical ethnographic examination solely on epistemic *justice*, would risk being "quite false" (Fricker, 2007, p. vii).

8.3 Disrupting the status quo

I propose epistemic injustice as a generative theoretical lens for thinking about the work of service user educators. SUI is understood within this research as a largely epistemic practice, whereby health professional education spaces serve as contested sites of knowledge production and translation. I have been operating from the assumption that epistemic injustice is likely to be the norm in the practice of SUI in health professional education contexts, where 'objective,' 'professional,' and 'expert' ways of knowing are typically privileged over firsthand or experiential knowledge. Indeed, in the context of health professional education – with its foundations deeply rooted in biopsychosocial ways of knowing, relating, and responding to madness, mental distress and diversity – many service user educators experience epistemic marginalization related to both their knowledge, and their status as *knowers*. Service user educators' knowledge (often shared through story or consultation) has yet to be regarded as equal to, or *as* legitimate as, professional, expert knowledge, and its exchange occurs between knowers with unequal epistemic power.

As I see it, neglecting to thoughtfully consider the way service user educators and health professional educators are socially situated in this realm, as well as the epistemic power relations between and around them, is to be complicit in maintaining the status quo. My contention that epistemic injustice represents the status quo in current approaches to SUI is informed by the imbalance of epistemic power and marginalization of service users' knowledge described in SUI-focused and Mad Studies literature (Felton & Stickley, 2004; Newbigging & Ridley, 2018), which resonate with my own experiences of SUI, and the findings of this research. As such, this research has aimed to highlight seemingly overlooked injustices played out in the epistemic activity of involving service user educators in health professional education, whilst stressing the importance of carefully attending to the uniquely epistemic dimensions of this practice. While epistemic justice may not be an entirely realistic destination, a move *toward* epistemic justice stands to foster more ethical and equitable conditions for various stakeholders involved in health professional education (i.e., service user educators, health professional educators, and students).

When we take into account the weight of social identity and power in the production, sharing, and acceptance of knowledge, we are able to better appreciate that while gaining access to health professional education spaces is an important first step for service user educators, this 'access' does not guarantee uptake of knowledge(s) in these contested epistemic spaces. This is, again, in part because health professional education spaces typically espouse dominant epistemic resources for understanding 'mental illness', privileging professional knowledge (at the expense, or in place of, experiential knowledge). As such, even when invited to be involved in the education of future health professionals, service user educators must contend with the objectification, dismissal, and self-smothering of their knowledge. This marginalization extends beyond contentions around the nature of service user educators' *knowledge*, as even those whose knowledge aligns closely with dominant psy- paradigms have historically been relegated to the fringes as unreliable, irrational, invalid *knowers*.

8.4 Following the theoretical thread

Epistemic injustice is first introduced and elaborated in Chapter 2 (*Toward Epistemic Justice: A Critically Reflexive Examination of 'Sanism' and Implications for Knowledge Generation*) and revisited in chapters 5, 6 and 7. Despite its fruitful contributions to a wide range of conversations (e.g., Brosnan, 2019; Brown, Johnstone & Ross, 2021; Newbigging & Ridley, 2018; Sinclair, 2018; Spencer, 2021), one notable shortcoming of the first manuscript is its omission of relevant concepts and conversations that I have become aware of following publication of this paper. These include the concept of contributory injustice, which departs from hermeneutical injustice in important/significant ways; a richer, more nuanced discussion of epistemic objectification (as seen in McGlynn, 2019); and deeper engagement with intersectionality and/or confluence (Joseph, 2015) in discussing the ways we might approach 'consciousness raising' around the concept of sanism. These, and other important concepts, are taken up in subsequent chapters, offering a more comprehensive linking of epistemic injustice to the work of service user educators.

As posited in the discussion of Chapter 5 *("Come and share your story and make everyone cry": Complicating Service User Educator Storytelling in Health Professional Education),* Mad epistemologies – a growing body of critical experientially-based knowledge, often communicated through Mad or resistance narratives (de Bie, 2021) – are vulnerable to *contributory injustice* despite practices of service user inclusion. That is, when service user educators' 'life stories' or 'mental illness autobiographies' are uncritically solicited, a body of more critical (and further marginalized) knowledge remains unable to gain access to health professional education spaces. Broader conceptualizations of service user knowledge, and in particular, intentional/thoughtful engagement with Mad Studies, may help to mitigate such instances of contributory injustice, and in effect move us toward a more epistemically just SUI.

In Chapter 6 (*Toward service user educator partnerships: Navigating the risk of tokenism in health professional education*) this conversation is extended to consider the necessity of realizing a shift or redistribution in epistemic power through service user partnership (as opposed to ‘involvement’), toward what Mingus’ (2018) refers to as ‘liberatory access.’ As Mingus asserts:

> It is not enough for us to simply get to share what’s important to us (though I know that many times we don’t even get to share that), if no one knows how to hold what we are sharing; if no one knows how to understand and fully engage with what we are sharing (2018, symposium).

Acknowledging the importance of ‘priming’ health professional education students with the (marginalized) epistemic resources required for hearing the knowledge of service user educators holds yet more promise for imagining a move toward epistemic justice (Voronka & Grant, 2021).

Finally, in Chapter 7 (*A Reflexive Account of Doing Service User Involvement*) injustice born from epistemic objectification is explored using McGlynn’s (2019) elaboration of Fricker’s earlier theorizing. The issue of epistemic fungibility is taken up here to complicate – yet again – the uncritical inclusion of service user educators in health professional education, which often translates to involving any/one service user educator to speak on behalf of an (imagined) essentialized, homogenous socio-political group. The conversation around the use of priming epistemic concepts is extended in this chapter, revisiting Mingus’ (2018) discussion of what is required to ‘hold’ a story, Voronka and Grant’s (2021) discussion of ‘discursive confinement’, and engagement with Mad epistemologies through the use of a Mad-positive pedagogical approach to teaching about ‘mental health’.

At the outset of this project my thinking about epistemic injustice in the context of SUI was far too simplistic. I now know that access and inclusion through an invitation to share one’s story and/or the absence of censorship (or ‘sanitization’) by health professional educators cannot guarantee epistemic justice, or even adequate uptake of service user-produced knowledge. Because, underlying epistemic injustice is not simply a lack of access or opportunity for involvement; but sanist discrimination and oppression, and thus, the deeply ingrained discrediting of an individual or group by virtue of their mental health system encounters. Thus, it is not sufficient to offer individuals the opportunity to share their knowledge, without first ensuring that the audience (i.e., students) is willing and able to receive the knowledge as just that: knowledge (as opposed to fictional accounts, or a rare glimpse into the unintelligible ramblings of the Other).

What I am suggesting, is that inaccessibility or exclusion are not the only issues we must contend with; we must also acknowledge the presence of and work to address discriminatory attitudes and sanism-fueled negative identity prejudice. Critical reflexivity in educational contexts may be productive in this regard. We might start by asking ourselves:

> What measures can we employ to ensure that the knowledge contributed by service user educators is regarded in a manner consistent with knowledge delivered by health professional educators, or found in textbooks?
>
> What can we do to guard against, or counter, sanism as an insidious form of negative identity prejudice?
>
> What might a (more) epistemically just approach to involvement look like?

8.5 Perpetuating epistemic injustice in the *doing* of postcritical ethnography

I have been simultaneously writing this concluding chapter and editing Chapter 3 which details my methodological approach to this research using postcritical ethnography. I was reminded of the necessity of engaging in a ‘critique of the role of the researcher’ as I wrote the above section on epistemic injustice. It dawned on me that despite my earnest belief that experiential knowledge constitutes a legitimate source of knowledge or that service user educators are indeed valid knowers, that through the doing of this research project I may have unintentionally perpetuated epistemic injustices in my own right. Informed by postcritical ethnographers before me, the findings of this research, and theories of epistemic injustice guided my reflexive questioning (Dotson, 2011; Fricker, 2007; McGlynn, 2019; Medina, 2012; Pohlhaus, 2014).

I asked myself variations of the following: Were there moments throughout the research process where my actions may have contributed to the (epistemic) objectification of my participants? Did the participants in this study receive fair remuneration for their knowledge contributions to this study (See chapters 3 and 7 for discussion)? In what way(s) could my language, in/actions, or approach to this research have prompted participants to engage in testimonial smothering? In what ways might I have been complicit in contributing to testimonial quieting (i.e., where I failed to identify certain individuals or communities as *knowers*)? How might my commitments to social justice have influenced my ability to truly hear the range of my participants' experiences?

In Chapters 3 and 7 I have discussed my regret in having only offered research participants very modest – indeed, inadequate – compensation for their contribution of knowledge to this research. Here I will revisit issues of contributory injustice, testimonial smothering, as well as epistemic isolation or the missed opportunity for supporting epistemic communities. My commitment to social justice and focus on the legitimacy of experiential knowing surely shaped my ability to hear participants' knowledge. In particular, these commitments may have limited my ability to hear participants' accounts of the value inherent in sharing their experiential knowledge; that is, the value in the process over just the product of SUI. In privileging my critical analysis I may have perpetuated a sort of contributory injustice, whereby aspects of my participants' perspectives were not given as much attention as perhaps they deserved.

Dotson (2011) described testimonial smothering as the truncating of one's own testimony so that it contains only content for which one's 'audience' is willing/able to receive. I described my own tendency toward testimonial smothering as a service user educator in health professional education in the introduction to this dissertation, but I have only more recently begun to consider the way my role (as researcher) and positionality (in this research) may have contributed to my participants' testimonial smothering throughout the research process. I began each of my interviews by briefly sharing my position (as a service user educator, Mad scholar and occupational therapist) in relation to this research with my participants. While I cannot presume to know exactly how my role influenced participants' testimonies, I wonder things like: did my roles as Health Science researcher and occupational therapist cause participants' to shy away from sharing critiques of their past experiences with researchers or health professionals? Could my self-identification as a Mad woman have been off-putting to service user educators whose understandings of their mental distress were not necessarily politicized? Or to health professional educators unfamiliar with the terminology? Did my outspoken critical stance and approach to this work push participants to share perspectives in *defense* of SUI for fear that my research findings might result in a dismantling of this practice? Was this stance interpreted by health professional educators as a personal criticism or attack?

I have also been reflecting on whether through my methodological design I missed an important opportunity for supporting service user educators' in establishing epistemic community. Throughout the interview process my sense was that most service user educator participants did not belong to a broader epistemic community engaged in the work of SUI. Data collection took place prior to the onset of the global Covid-19 pandemic, and as such, was primarily carried out in person. Because data was collected from participants in various cities across Ontario, the idea of facilitating focus group interviews or discussions seemed neither feasible nor realistic. Following our worldwide move toward virtual connection raises questions for me about how participants' perspectives might have been constructed in the context of (virtual) epistemic communities. Would such connection have led to communities of support and knowledge generation that continued on long after the conclusion of this research?

8.6 On un/learning madness and becoming politically Mad

> *"Poststructuralist theory allows me to write about my subjectivity in the context of both previous theoretical ideas and new theoretical ideas, where I can re-create myself in process and acknowledge that the research practice is 'an emotional, personal journey'* (Mahipaul, 2015, p. 23).

Prior to beginning a PhD in Health Professional Education I met with my (at the time, prospective) supervisor, Dr. Elizabeth Anne Kinsella, to discuss my research-related aspirations and determine if this program, and more specifically, this academic partnership would be the right ‘fit’ for me. I had travelled to London, Ontario for a sit-down meeting, which seems so bizarre now that all of our connection over the past two years has been virtual. During our meeting I made the decision to disclose my (then) psychiatric diagnosis as I knew then that I wanted my ‘lived experience’ to shape, inform, and perhaps even feature prominently in my research project; whatever it may be.

I attended a guest lecture on the topic of ‘sanism’ during my first term as a doctoral student, which was being delivered in the department of Women’s Studies by a visiting scholar from Ryerson University – Dr. Jennifer Poole. Some of Poole’s (2012, 2015) scholarship was circulated prior to the lecture. What I read and heard would dramatically change the course of my doctoral studies, and in many ways, my life. Dr. Poole’s writing on sanism resonated deeply, and for the first time ever I had language at my fingertips for describing my personal experiences and encounters with the ‘mental health care’ system. Experiences that while often degrading and shame-inducing, up until this point, felt ‘normal,’ acceptable, even justified. Reading this literature and attending this lecture was my entry point to the field of Mad Studies and broader Mad activist community.

Mad studies has given me a theoretical lens for thinking about and approaching this research project, but on a much more personal level, a Mad Studies lens has helped me in unlearning and reimagining (or ‘re-creating’) my own Mad subjectivity. Mad Studies scholars and activists were the first to introduce me to the notion that there are ways of knowing (and experiencing) madness, mental distress and diversity that exist outside of the language and theorizing of psy-dominated disciplines. In fact, the more I learned from Mad and c/s/x scholars and activists, the more disillusioned I became with all that I had previously known about myself and my ‘illness.’ This sparked the beginning of a process of distancing myself from psy- disciplines and ways of knowing, whilst simultaneously trying to find my place in the Mad movement and Mad Studies project.

Aligning myself with the Mad Studies project has not simply been an ideological or epistemological endeavour. It has been undeniably personal, material, political, practical, and messy and there have been many times throughout this process that I have felt like a hypocrite or imposter; not quite sure where my knowledge fits in all of this. In earlier stages of my unlearning and re-creating, I struggled immensely with pressures to write and produce, whilst simultaneously putting distance between myself and the medicalized and individualizing approaches to 'wellness' I had become so accustom to (read: withdrawal). Reframing my understanding of 'mental illness' toward something that I now more critically and broadly understand as Madness, has also meant reframing my understanding of *my* madness. Coming to learn about psychiatric oppression has meant coming face-to-face with my own psychiatric oppression and complicity in the psychiatric oppression of others. These have been the source of some of the many pains I have experienced in my growth toward a politicized understanding of Madness.

I have found Mingus' (2010) conceptualization of the difference between being 'descriptively disabled' and 'politically disabled' to be particularly useful in making sense of my experiences, and for thinking about the knowledge and perspectives represented in the practice of SUI. Mingus (2010) uses 'descriptively disabled' to refer to:

> someone who has the lived experience of being disabled. They may not talk about ableism, discrimination or even call themselves 'disabled,' but they know what it feels like to use a wheelchair, experience chronic pain, have people stare at you, be institutionalized, walk with a brace, be isolated, etc. (paragraph 4).

In contrast, Mingus (2010) uses 'politically disabled' to describe, "someone who is descriptively disabled and has a political understanding about that lived experience. I mean someone who has an analysis about ableism, power, privilege, who feels connected to and is in solidarity with other disabled people" (paragraph 4).

For many years I was – to use Mingus' (2010) language – 'descriptively' Mad. That is, I knew what it felt like to be Mad, or mentally distressed or diverse; I knew what it felt like to sit in the oversized chair across from a psy- professional rolling Kleenex around in my palms (but not in a manner obvious enough to warrant documentation in the 'presentation' section of my chart notes); to take medications that flattened me; to feel Other; to be paranoid that someone might find out that I shouldn't be in any one of the many spaces I occupied – academia, health care provision, marriage, etc.; or to have my legitimate concerns (physical health-related and otherwise) dismissed on account of them being ‘all in my head.’ My introduction to sanism and the field of Mad Studies represented a hermeneutical triumph in that I no longer had to rely on ill-fitting language and concepts to make sense of my experiences. This introduction inspired a profound shift in my subjectivity from descriptively to politically Mad and I began to “think of [madness] as a political identity/experience, grounded in [my] descriptive lived experience” (Mingus, 2010).

8.6.1 When a politicized madness leads to epistemic exclusion

One of my roles as a service user educator familiar with health professional education involved sitting on a committee to discuss the development of a post-graduate health professional education course. When other committee members began discussing the use of standardized patients to ‘play’ the role of persons experiencing mental distress, I steered the conversation toward the possibility of SUI. The conversation quickly turned into a discussion of the usual culprits cited as reasons for the exclusion of service user educators: too unpredictable, too much money, too time intensive, too great a liability, not representative enough, etc. I suggested that engagement with the critical knowledge base of Mad activists and service user educators held potential for the development of this course. Another member of the committee used the new-to-me term *prosumer* (a play on words between ‘professional’ and ‘consumer’) to dismiss my suggestion, contending that Mad-identified and other service users with critical orientations were not representative of the *average* service user.

Critical reflexivity (typically engaged through reflexive journaling) has helped me to appreciate the way terms like *prosumer* can be creatively – though perhaps unintentionally – weaponized against those who have received psy- services *and* hold professional designations or engage in SUI professionally, to alienate them from their sense of connection to particular sociopolitical communities. Prosumer comes with the insinuation that my experiential knowledge – being that it represents a politicized understanding of my experiences – does not reflect the knowledge and perspectives of those whose understandings are merely descriptive; and as such, must be invalid. The term also falsely implies that service user/provider represents a stable, mutually exclusive binary with impenetrable borders. This interaction was deflating as I was struck with the realization that there can be no 'winning' for service user educators without permission from the health professions. Service users unable to articulate their experiences and understandings using mainstream epistemic resources (e.g., language, concepts, theories) risk being deemed a liability. Conversely, service users who articulate their knowledge *too well*, or *too critically*, risk being slapped with the label 'prosumer.' Each of these scenarios represents (seemingly reasonable) grounds for the exclusion of service users and their knowledge. So long as health professional educators maintain the epistemic power and authority to define the *real/authentic* service user experience, I fear this will always be so…

…But, what if rather than dismiss the knowledge and perspectives of *prosumers* as misrepresentative or 'rare,' we broadened our conception of the range of valid service user standpoints. While my thoughts around the 'prosumer' designation are still in their infancy, I do wonder if there is potential in reclaiming and politicizing this identity too. Perhaps prosumers, given their familiarity with the epistemic and paradigmatic terrain of the health professions, might be well-positioned to point out generative theoretical footholds and/or epistemic wiggle room, which might offer promising inroads for service users' experiential knowledge. The politicized prosumer is also likely to be attuned to issues of co-optation, exploitation, and tokenistic involvement, and better able to identify SUI practices which risk perpetuating these.

8.6.2 A note on crip time and slow scholarship

> *"Caring for [oneself] is not self-indulgence, it is self-preservation, and that is an act of political warfare'"* (Lorde, 1988, p. 131 as cited in Jones & Whittle, 2021, p. 382).

Rather than the prescribed 12 full-time academic terms, this endeavour has taken me something closer to 14 full-time, 3 part-time, and one 'defense-only' academic term to complete. I have thought long and hard about why this might be, and I believe the answer lies somewhere in the realm of crip time, slow scholarship, and a radical interpretation of self-care (Jones & Whittle, 2021). Like many, my approach to scholarship was once steeped in, and shaped by, an institutional culture of hyper-productivity, competition, and perfectionism. This began changing for me when I was introduced to the concepts of crip time (Kafer, 2013) and slow scholarship (Mountz et al., 2015) by some colleagues in the field of Disability Studies. Price (2011) describes crip time as “a flexible approach to normative time frames” (p. 62), and slow scholarship has been described as working, “for deep reflexive thought, engaged research, joy in writing and working with concepts and ideas driven by our passions,” leaving us space to care for ourselves and others (Mountz et al., 2015, p. 1253).

These concepts spoke loudly to me and opened my eyes to just how intricately intertwined my academic and (self) care work are. In other words, my scholarship (the political) could not be separated from my madness (the personal). Slowing down and ‘cripping’ my approach to normative timeframes enabled me to realize a more intuitive, embodied approach to rest, care (for myself and others), scholarship, and productivity in general. In this flexing and slowing I have found ways to live ‘well’ on my own terms, engaging in care practices which resist and subvert the powers of psychocentrism and normative temporalities. Embracing crip time and slow scholarship have allowed me to continue my activism, conduct this research, and engage in ‘care-full’ work in a way that has not also meant my undoing (Mountz et al., 2015).

8.7 Implications

This research stands to inform a range of stakeholders involved in health and social care professional education (e.g., service user and health professional educators, curriculum committees, administration, policy makers, researchers, etc.) who may be interested in critically engaging in the practice of SUI. While this work was never intended to be prescriptive, it has the capacity to inform practice and inspire a reimagining of SUI through its illumination of complexities, ethical and epistemic tensions, and other *instructive complications* (Lather, 2017). This work contributes to important ongoing conversations around service user-produced knowledge and its uptake by/within the health professions. The findings highlight some of the ways in which service user educators’ knowledge continues to be subjected to epistemic injustices in health professional education, and points to a need for thoughtful consideration of the epistemic dimensions of this work.

This work adds to ongoing conversations in the field of Mad Studies around epistemic injustice (upheld by sanism) and the importance of centering experiential knowledges in all matters related to ‘mental health’. Ultimately, my hope is that this work will offer Mad scholars-activists-folks (inclusive of service user educators) language to supports them in their advocacy for greater recognition of experiential knowledge and Mad knowers as *valid* within the context of health professional education and beyond.

8.8 Strengths and limitations

Attention has recently been called to the still “limited crossover” between Mad studies and educational research in health professions, medical humanities, and other disciplinary-based education (de Bie, 2021, p. 2). One strength of this research lies in its contribution to this ‘crossover.’ It is anticipated that the findings will contribute to the innovation and development of pedagogical practices that aim to foreground service user educators’ knowledge within professional education. In this way, this research stands to appeal to a wide range of stakeholders interested in increasing engagement with SUI in professional education, with broad relevance to the health and social care professions. This research has also engaged with and presented a multiplicity of perspectives related to the practice of SUI.

As this study was situated in a bounded context, focused primarily on service user educators and health professional educators from one health profession, its findings are not necessarily generalizable. However, the insights may hold resonance and be practically transferable to other health professions education contexts. While I have already acknowledged that this research presents only partial knowledge, it is still worth noting that the participants involved in this study were over-representative of those who have had positive experiences with the practice of SUI. Presumably, service user educators who have enjoyed multi-year tenures with health professional education programs have experiences that differ from those who have not. This research did not adequately prioritize the inclusion of knowers from diverse sociopolitical locations, and as such, participants in this study were predominately white and cisgender. Thus, the findings of this research may not be representative of the experiences of the many service user educators whose experiences with the mental health system (and health professional education) have been shaped by confluent forms of oppression.

8.9 Plans for dissemination

The findings of this research have, and will continue to be disseminated through publication in scholarly venues, including: (i) peer-reviewed (and where possible, open-access) journals in the areas of health professional education, Disability studies and Mad studies, and social justice research; and (ii) local, national and international conference presentations. Findings will also continue to be presented to program coordinators, curriculum committee members, policy makers and administrators, service user educators, and others through research briefings, presentations at conferences and in community, with the hopes of influencing future development of SUI practices, guidelines and pedagogical materials.

8.10 Directions for future research

As was suggested in Chapter 6, a move toward service user partnership holds promise for realizing approaches to SUI which resist tokenism. Future research might examine the usefulness of adopting of a more formal framework for conceptualizing, organizing and evaluating such partnerships and the depth and range of current approaches to SUI. Several such frameworks have been developed and applied to SUI initiatives, including (but not limited to): Arnstein’s (1969) *Ladder of Citizen Participation*; Tew et al.’s (2004) *Ladder of Involvement*; and Tritter and McCallum’s (2006) *Social Citizenship Mosaic*. Research in the context of occupational therapy education more specifically might consider adopting and/or adapting one of these frameworks for use within the profession. Furthermore, while this research adds to the limited body of OT-specific literature related to the practice of SUI, it does not adopt a uniquely occupational perspective. Future research might explore SUI through a lens of occupational justice.

Consistent with suggestions by de Bie (2021), this research points to a need for further research exploring ways we might bridge the gap between service user educator, Mad, c/s/x, and health professional education communities. Further research that explores what a Mad conceptualization or approach to SUI would entail is warranted. Related to this, research which considers dominant ideologies and contemporary approaches in health professional education, and/or seeks opportunities to increase awareness of Mad studies and critical disability studies would be fruitful. This research points to a need for the development of pedagogical materials aimed at supporting an ethical and epistemically just SUI practice (i.e., intentionally addresses contributory injustice) with a focus on 'priming concepts' drawn from the aforementioned fields.

Future research might explore participants' conceptions of *utopias* – that is, questions which explore stakeholders' visions for SUI 'in an ideal world'. As SUI is not yet mandated in a range of Canadian health and social care professional education contexts, future research might seek deeper understanding of health professional educators' (personal and professional) motivations for engaging in SUI. To this end, future research might also revisit and reimagine declarations prioritizing the inclusion of service user educators, to ensure that SUI reflects *liberatory access* and effective uptake of service user knowledge.

Through this research my interest in the notion of 'epistemic communities,' 'collective knowledge,' and 'shared stories' has grown. Bryant (2020) has suggested that "bringing people together to create shared stories avoids some of [the] risk" of reproducing damaging stereotypes and being misunderstood (p. 317). Although I was not able to attend to it at length in this dissertation, participants spoke about the possibilities of a collective knowledge base, or "collation" (Joel) of service user educator-produced knowledge. Future research might focus on the development and support of service user educator *communities of practice* and establishment of a collective knowledge base. Related to epistemic communities, future research might explore a more formalized, service-user produced/led educational initiative – something along the lines of Disability Equality Training (DET) – wherein the knowledge shared reflects the "collective voice and view of disabled [and Mad] people, not the personal" (Cameron et al., 2020, p. 104).

8.11 Conclusion

The impetus for this research came in part from tensions I observed between my experiences of SUI as a complex and imperfect practice for supporting the knowledge contributions of service users in health professional education, and (more benevolent) portrayals of this educational approach in SUI-focused literature. These tensions aligned with recent calls for closer examination of the risks, challenges and complexities inherent in involving service user educators in health professional education. In attending to these complexities, this research addresses a tension – which I still optimistically view as reconcilable – between an ethical imperative to include service user-produced knowledge in the education of future health professionals and current approaches to doing so which may unintentionally perpetuate injustices.

Whenever I have discussed the findings of this research with health professional educators, I have been met with the question: “So, what should we do then? If this work is fraught with complexity and the risk of harm, should we just stop including service user educators in our programs altogether?” This conclusion could not be further from the one I wish to leave you with. Instead, my hope is that through its illumination of areas begging for closer attention and its opening of spaces for reflexive consideration, that this work engages the imagination of health professional educators (and other critically reflexive stakeholders) committed to the pursuit of SUI practices that are epistemically and socially just. In light of the responses described above and combined with a history of exclusion and suppression of their knowledge contributions, service user educators may rightfully be hesitant to risk jeopardizing their (already limited) access to health professional education spaces in pursuit of an unknown reimagining of SUI.

We must welcome, validate and engage deeply with service user-produced knowledge within health professional education; of that I am certain. What remains less clear is whether our current approaches to SUI – which lack formal conceptualization and clear objectives – are optimally suited to fostering epistemic justice. This said, engaging in this research has only strengthened my conviction that there must be ways to involve service user-produced knowledge in ways that resist and thoughtfully attend to the risks of contributory injustice, epistemic objectification, discursive confinement, exploitation, and tokenism detailed in this dissertation. How we *best* go about doing this remains a matter for debate and necessitates reimagination. So, while I have not – indeed, cannot – offer a prescription for *how* to do the work of SUI, I hope that in reading this work, others will be inspired to reconsider their approach or altogether reimagine SUI as an ethical and epistemically complex, power-laden educational approach; to ask: *what could be otherwise, but is not yet?*

8.12 References

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Appendices

Appendix A. Recruitment Materials

RECRUITMENT AD/BRIEF LETTER OF INFORMATION FOR SERVICE USER EDUCATORS

Study Title: Troubling Service User Involvement in Health Professional Education: Toward Epistemic Justice

We are looking for volunteers to take part in a study that examines the experiences of mental health service users involved in the education of students in the health and social care professions in Ontario, as well as current approaches to service user involvement in professional education.

Who?	Individuals who have (i) used mental health and/or social care services, AND (ii) are involved, or were previously involved, in the professional education of health and social care students in Ontario (e.g., Occupational Therapy, Social Work, Nursing, Psychology, Psychiatry, or other); (iii) are 18 years of age or older; and (iv) speak English.
What?	Your participation would involve one individual interview, and if feasible, one participant observation session. The interviews will focus on your experience as a service user involved in the education of health and social care students (directly and/or indirectly).
How long?	The interview will take approximately 90 minutes to complete. The length of observation sessions will depend on the activity being observed. As a thank you for contributing your time and valuable experiential knowledge to this research you will receive an honorarium of $25 following the interview.
Where?	In four cities in Ontario and their surrounding areas: London, Hamilton, Toronto, and Kingston. The interviews will take place in a location of your choice that is suitable for an audio-recorded interview.
Why?	To help deepen understandings of the experiences of mental health service users involved in health and social care professional education programs.

For more information about this study, or to volunteer for this study, please contact:

Stephanie LeBlanc PhD candidate, OT Reg. (Ont.)
Health and Rehabilitation Sciences Graduate Program
Faculty of Health Sciences, Western University

LETTER OF INVITATION FOR OCCUPATIONAL THERAPY PROGRAM PERSONNEL

Dear [Contact Person],

The purpose of this letter is to inform you of a current research project entitled "Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices" being conducted in the context of Master's level Occupational Therapy programs in Ontario, and to formally invite your participation. For a detailed explanation of the study, please see the attached *Letter of Information and Consent* form.

Participation in this study would involve an individual semi-structured interview lasting approximately 90 minutes. The interview would be audio-recorded. We also invite your support of this research in the following (optional) ways:

- Assisting with circulation of recruitment materials to potential participants (i.e., service users, course coordinators, curriculum personnel). Materials include a brief letter of information detailing: the general purpose of the study; expectations of participation in the study; and telephone and email contact information for interested potential participants to obtain more detailed information.
- Assisting with the identification of textual resources relevant to service user involvement in your professional education program (e.g., curriculum documents, course syllabi, required texts and readings, etc.).
- Assisting with the involvement of the study investigator in service user-related activities for the purpose of participant observation (e.g., service users delivering guest lectures, mental health-related curriculum meetings).

If you require any further information regarding this research project or your participation in the study please do not hesitate to contact Stephanie LeBlanc, the study investigator, or Dr. Elizabeth Anne Kinsella [redacted], the principal investigator. We look forward to connecting with you about this important project in the near future.

Stephanie LeBlanc, PhD Candidate, OT Reg. (Ont.)
Health and Rehabilitation Sciences Graduate Program
Faculty of Health Sciences, Western University

Appendix B. Interview Guides

INTERVIEW GUIDE FOR SERVICE USER EDUCATORS INVOLVED IN OCCUPATIONAL THERAPY PROFESSIONAL EDUCATION IN ONTARIO

Introduction:

Thank you for agreeing to take part in this interview. As stated in the *Letter of Information*, your responses will remain completely anonymous and your name will not be kept with records of the interview. I am interested in hearing your thoughts, opinions, and perspectives about your experiences as a mental health service user educator involved in the education of student occupational therapists in the Occupational Therapy program at [Academic Institution]. I have some prepared questions to help guide this interview, but I would also like this interview to be conversational and to foreground the aspects of your experiences that you feel are most important for me to know. If at any time you feel that I have missed something important please do not hesitate to jump in.

1. Can you tell me how you first became involved in professional education as a service user educator? And, within the Occupational Therapy program at [Academic Institution], more specifically?
    a. How did you hear about this SUI opportunity (e.g., recruitment advertisement, word of mouth, service user organization, etc.)?
    b. Was there a recruitment or screening process involved? If yes, can you describe the process?
        i. Did you participate in an interview or ‘screening’ process?
        ii. What qualities or qualifications, if any, were identified as necessary for this role?
2. What made you want to get involved in Occupational Therapy professional education?
    a. What were you hoping to achieve or gain through your participation in health professional education (if anything)?
    b. Are there other health or social care educational programs or groups that you contribute to?

3. Can you tell me about your role(s) within the Occupational Therapy program at [Academic Institution]?
    a. What are the specific responsibilities or expectations associated with your role(s)?
    b. In what other capacities have you been involved with the program?
    c. What audiences do you share your expertise with in this context (e.g., faculty, students, therapists, community)?
4. Throughout this research we use the signifier ‘service user educator’ to describe individuals who have, or who are, using mental health services, and are involved in health professional education in some capacity. What is, or are, the signifier(s) that you prefer to use in describing yourself (e.g., consumer, survivor, ex-patient, ‘expert by experience,’ peer educator, etc.)?
    a. If applicable, can you tell me about any particular signifiers that you dislike, or that make you uncomfortable (e.g., consumer, survivor, ex-patient, ‘expert by experience,’ peer educator, etc.)?
    b. What is your current title as a service user educator within this program? If you had the opportunity to change this title, what would you change it to?
5. Can you tell me about how you prepared for your role(s) (e.g., formal training, verbal/written instruction, self-directed learning, mentorship)?
    a. How was/were your role(s) negotiated?
    b. What guidelines or parameters were you given regarding what your participation as a service user would consist of?
6. In your opinion, what unique knowledge, expertise or perspectives do you, as a service user educator, bring to students?
    a. How does your knowledge, expertise, or perspective differ from the other form(s) of knowledge students are exposed to?
    b. How have your contributions been received by students, and by faculty, at the university?
    c. Who typically decides what sort of knowledge, experience or input you are able to share?

    d. What aspects of your experiential knowledge were you asked to contribute?
    e. What aspects of your experiential knowledge were you asked to refrain from sharing?

7. Within the literature on service user involvement in professional education, concerns have been raised regarding the *level* of involvement of service user educators. More specifically, critics have suggested that service user involvement can be superficial or even tokenistic, as opposed to being active and meaningful. How do you personally feel about the level, or depth, of involvement you have been afforded as a service user?
    a. In your opinion, is your involvement meaningful?
    b. Can you think of an example of a situation where you felt your involvement in a professional education setting was superficial or not meaningful in nature?
    c. If you could change anything about your involvement in the program, what would it be?
8. If you were to tell a friend about the ‘pros’ and ‘cons’ of contributing to professional education as a service user educator, what would you say?
    a. What has surprised you most about the process of contributing to professional education as a service user?
    b. What do you think are the greatest benefits and challenges of service user involvement in professional education?
9. Can you think of other ways that service user educators could be involved in the education of professional students?
10. Can you think of any other aspects of your experience of being involved in the education of student occupational therapists that have not been covered in this interview?
    a. Is there anything else that you would like to share with me to help me to better understand your experience of service user involvement?

INTERVIEW GUIDE FOR SERVICE USER EDUCATORS INVOLVED IN PROFESSIONAL EDUCATION IN ONTARIO (NOT SPECIFIC TO OCCUPATIONAL THERAPY)

Introduction:

Thank you for agreeing to take part in this interview. As stated in the *Letter of Information*, your responses will remain completely anonymous and your name will not be kept with records of the interview. I am interested in hearing your thoughts, opinions, and perspectives about your experiences as a mental health service user educator involved in health and social care professional education in Ontario. I have prepared some questions to help guide this interview, but I would also like this interview to be conversational, and to foreground the aspects of your experiences that you feel are most important for me to know. If at any time you feel that I have missed something important please do not hesitate to jump in.

1. Can you tell me how you first became involved in professional education as a service user educator?
    a. How did you hear about SUI (e.g., recruitment advertisement, word of mouth, service user organization, etc.)?
    b. What qualities or qualifications, if any, were identified as necessary for this role?
2. What made you want to get involved in professional education?
    a. What were you hoping to achieve or gain through your participation in professional education (if anything)?
3. Can you tell me about your role(s) within professional education?
    a. What are the specific responsibilities or expectations associated with your role(s)?
    b. In what capacities have you been involved with professional education?
4. Throughout this research we use the signifier ‘service user educator’ to describe individuals who have, or who are, using mental health services, and are involved in health and social care professional education in some capacity. What is, or are,

the signifier(s) that you prefer to use in describing yourself (e.g., consumer, survivor, ex-patient, ‘expert by experience,’ peer educator, etc.)?

   a. If applicable, can you tell me about any particular signifiers that you dislike, or that make you uncomfortable (e.g., consumer, survivor, ex-patient, ‘expert by experience,’ peer educator, etc.)?
   b. What titles have you had as a service user educator involved in professional education? What title(s) do you prefer?

5. Can you tell me about how you prepared for your role(s) (e.g., formal training, verbal/written instruction, self-directed learning, mentorship)?
   a. How have your role(s) been negotiated?
   b. What guidelines or parameters have you been given regarding what your participation as a service user educator would consist of?
6. In your opinion, what unique knowledge, expertise or perspectives do you, as a service user educator, bring to students?
   a. How does your knowledge, expertise or perspective differ from the other form(s) of knowledge available through professional education?
   b. What do you believe is the value of service user involvement in professional education?
   c. Who typically decides what sort of knowledge, experience or input is shared?
   d. What aspects of your experiential knowledge are you typically asked to contribute?
   e. What aspects of your experiential knowledge have you been asked to refrain from sharing?
7. Within the literature on service user involvement in health professional education, concerns have been raised regarding the *level* of involvement of service user educators. More specifically, critics have suggested that service user involvement can be superficial or even tokenistic, as opposed to active and meaningful. How do you personally feel about the level, or depth, of involvement you have been afforded as a service user?
   a. In your opinion, is your involvement meaningful?

   b. Can you think of an example of a situation where you felt your involvement in a professional education setting was superficial or tokenistic in nature?
   c. If you could change anything about your involvement in professional education, what would it be?
8. If you were to tell a friend about the 'pros' and 'cons' of contributing to professional education as a service user educator, what would you say?
   a. What has surprised you most about the process of contributing to professional education as a service user educator?
   b. What do you think are the greatest benefits and challenges of service user involvement in professional education?
9. In your opinion, in what ways should service user educators be involved in professional education?
10. Can you think of any other aspects of your experience of being involved in professional education that have not been covered in this interview?
    a. Is there anything else that you would like to share with me to help me to better understand your experience of service user involvement?

INTERVIEW GUIDE FOR OCCUPATIONAL THERAPY EDUCATORS

Introduction:

Thank you for agreeing to take part in this interview. As stated in the *Letter of Information*, your responses will remain anonymous and your name will not be kept with records of the interview. I am interested in hearing your thoughts, opinions, and perspectives around your experiences, as a [Role or Title], with the involvement of mental health service users in the education of occupational therapy students at [Academic Institution]. I have prepared some questions to help guide this interview, but I would also like this interview to be conversational, and to foreground the aspects of your experiences that you feel are most important for me to know. If at any time you feel that I have missed something important please jump in.

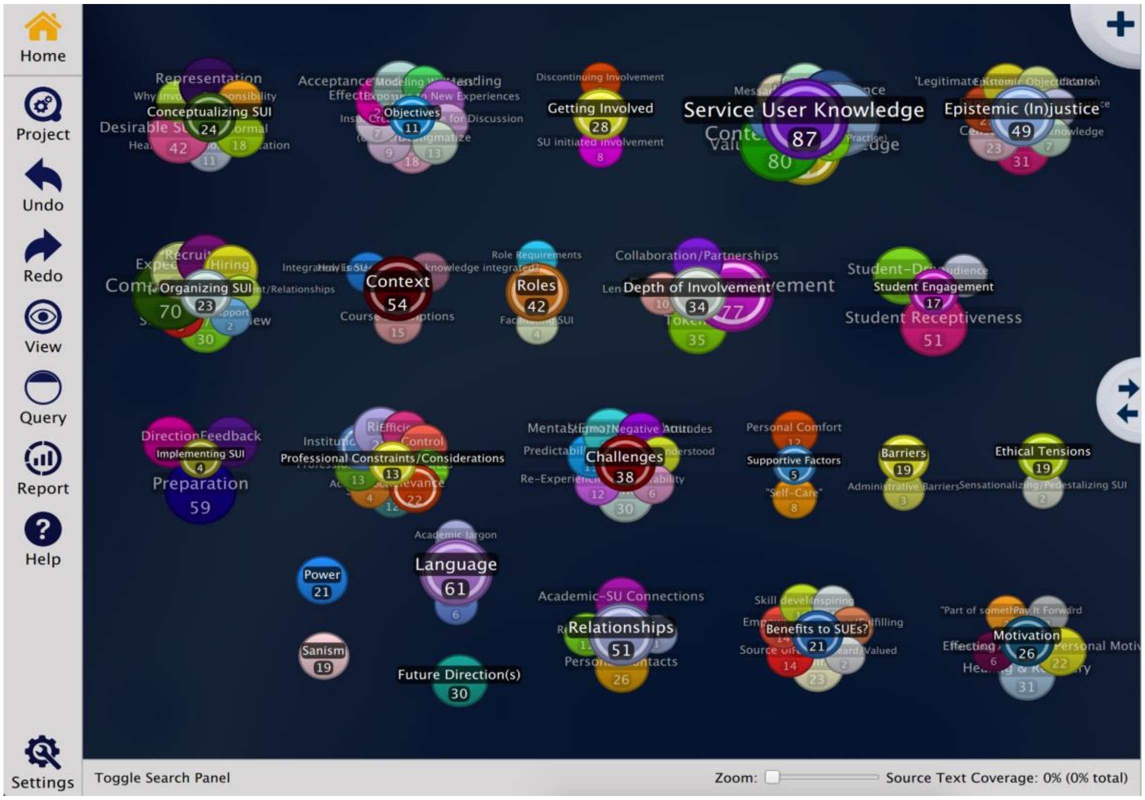
1. Can you tell me about your role(s) within the Occupational Therapy (OT) program at [Academic Institution]?
    a. As it relates to the education of Occupational Therapy students?
    b. As it relates to service user involvement?
2. In what capacity are you involved in organizing, facilitating, overseeing, or advocating for service user involvement in the OT program?
    a. In what ways do you engage with service users directly? Indirectly?
    b. Is there support for SUI in your program (formal or informal)?
        i. If so, what does it entail?
        ii. If not, why do you think that is?
3. In what ways, or at what levels, are service user educators involved within your program (e.g., guest lecturing, course development/instruction/review, curriculum committee member, simulated patient, student evaluation, etc.)?
    a. What do service user educator role(s) typically consist of?
    b. Do service user educators have a well-defined or official role/title within your program?
    c. Is there a 'best practice' approach or set of guidelines that you use to aid in establishing service user educators' role(s)?

4. In your opinion, how do service user educators’ knowledge, expertise or perspectives differ from the other form(s) of knowledge that the students are exposed to throughout the program?
    a. Who typically decides what sort of knowledge, experience or input service user educators share?
    b. What experiential knowledge or insights are service user educators encouraged to share?
    c. What experiential knowledge or insights are service user educators asked to refrain from sharing?
5. How are service user educators recruited for involvement in the OT program?
    a. What specific processes are involved in recruiting or ‘hiring’ service users?
    b. What recruitment strategies are used (e.g., word-of-mouth, advertising, personal contacts, etc.)?
    c. What qualities or qualifications are service users required to have in order to fulfill this role?
    d. Is there a “preferred” or “ideal” type of service user for this position?
    e. Is SUI an educational requirement for your program? If so, where is this mandate documented?
    f. Whose responsibility is it to recruit service users?
    g. Who makes the final decision to involve a service user?
6. Within the literature on service user involvement in professional education, concerns have been raised regarding the *level* of involvement of service user educators. More specifically, critics have suggested that service user involvement can be superficial or even tokenistic, as opposed to active and meaningful. How do you personally feel about the level, or depth, of involvement service users are afforded within the program?
    a. In your opinion, are service user educators actively involved, and in a meaningful way within the OT program?
    b. Can you give me an example of a situation where you felt that service user educators’ involvement within the OT program was, or could be perceived

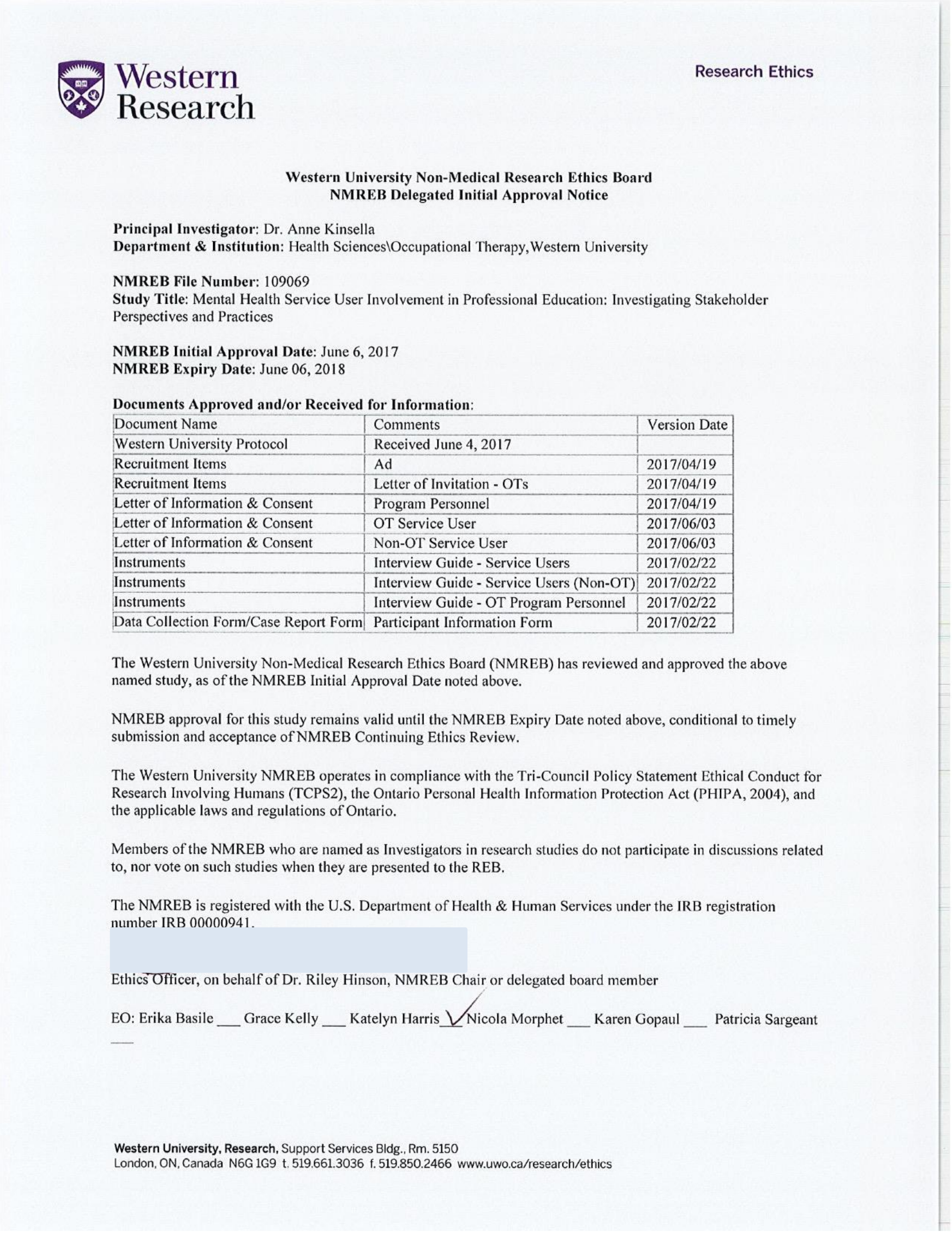
    to be, superficial or tokenistic?
    c. If you could change anything about service user involvement in the OT program, what would it be?

7. What, if anything, has been particularly helpful in fostering active service user involvement in the program?
8. What supports and barriers, if any, have you encountered related to active service user involvement in the program (e.g., administrative support or barriers, financial support or barriers, attitudinal support or barriers, etc.)?
    a. What has enabled SUI involvement
    b. What efforts have been made to address barriers?
    c. What is the general culture in your program with respect to SUI?
9. In your opinion, what other ways should service user educators be involved in the education of student occupational therapists?
10. Can you think of any other aspects of your experience with service user involvement that have not been covered in this interview?
    a. Is there anything else that you would like to share with me to help me to better understand your experience with the practice of service user involvement?

Appendix C. Quirkos Canvas



Appendix D. Non-Medical Research Ethics Board Approval Letters



Western Research

Research Ethics

Western University Non-Medical Research Ethics Board
NMREB Delegated Initial Approval Notice

Principal Investigator: Dr. Anne Kinsella
Department & Institution: Health Sciences\Occupational Therapy,Western University

NMREB File Number: 109069
Study Title: Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices

NMREB Initial Approval Date: June 6, 2017
NMREB Expiry Date: June 06, 2018

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol	Received June 4, 2017	
Recruitment Items	Ad	2017/04/19
Recruitment Items	Letter of Invitation - OTs	2017/04/19
Letter of Information & Consent	Program Personnel	2017/04/19
Letter of Information & Consent	OT Service User	2017/06/03
Letter of Information & Consent	Non-OT Service User	2017/06/03
Instruments	Interview Guide - Service Users	2017/02/22
Instruments	Interview Guide - Service Users (Non-OT)	2017/02/22
Instruments	Interview Guide - OT Program Personnel	2017/02/22
Data Collection Form/Case Report Form	Participant Information Form	2017/02/22

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the above named study, as of the NMREB Initial Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

[redacted]

Ethics Officer, on behalf of Dr. Riley Hinson, NMREB Chair or delegated board member

EO: Erika Basile ___ Grace Kelly ___ Katelyn Harris ✓ Nicola Morphet ___ Karen Gopaul ___ Patricia Sargeant ___

Western University, Research, Support Services Bldg., Rm. 5150
London, ON, Canada N6G 1G9 t. 519.661.3036 f. 519.850.2466 www.uwo.ca/research/ethics

Western
Research

Date: 5 June 2018

To: Dr. Anne Kinsella

Project ID: 109069

Study Title: Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: July 6, 2018

Date Approval Issued: 05/Jun/2018

REB Approval Expiry Date: 06/Jun/2019

Dear Dr. Anne Kinsella,

The Western University Research Ethics Board has reviewed the application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyzynski, Research Ethics Coordinator, on behalf of Prof. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Date: 16 May 2019

To: Dr. Anne Kinsella

Project ID: 109069

Study Title: Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: 07/Jun/2019

Date Approval Issued: 16/May/2019

REB Approval Expiry Date: 06/Jun/2020

Dear Dr. Anne Kinsella,

The Western University Non-Medical Research Ethics Board has reviewed this application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyzynski, Research Ethics Coordinator, on behalf of Prof. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Western Research

Date: 25 May 2020

To: Dr. Anne Kinsella

Project ID: 109069

Study Title: Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: 05/Jun/2020

Date Approval Issued: 25/May/2020

REB Approval Expiry Date: 06/Jun/2021

Dear Dr. Anne Kinsella,

The Western University Non-Medical Research Ethics Board has reviewed this application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyzynski, Research Ethics Coordinator, on behalf of Prof. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Date: 10 May 2021

To: Dr. Anne Kinsella

Project ID: 109069

Study Title: Mental Health Service User Involvement in Professional Education: Investigating Stakeholder Perspectives and Practices

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Date Approval Issued: 10/May/2021

REB Approval Expiry Date: 06/Jun/2022

Dear Dr. Anne Kinsella,

The Western University Non-Medical Research Ethics Board has reviewed this application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

The Office of Human Research Ethics

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix E. Letters of Information and Consent

LETTER OF INFORMATION AND CONSENT FOR SERVICE USER EDUCATORS INVOLVED IN OCCUPATIONAL THERAPY PROFESSIONAL EDUCATION

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, OT Reg. (Ont.)
Health Professional Education Field
Health and Rehabilitation Sciences Graduate Program
Faculty of Health Sciences, Western University
Email: [redacted]

Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Co-Investigators:
Dr. Jennifer Poole, Associate Professor, Social Work, Ryerson University
Email: [redacted]
Dr. Sandy DeLuca, Chair, School of Nursing, Fanshawe College
Email: [redacted]

Invitation to Participate

Thank you for expressing interest in this study. You are being invited to participate in research exploring the involvement of mental health service users in the education and training of future health and social care professionals. You are being invited to participate in this study because you have experience as a mental health service user educator involved in Occupational Therapy professional education in Ontario.

Purpose of this Letter

The purpose of this letter is to provide you with information required to make an informed decision regarding participation in this research.

Purpose of Study

Service User Involvement (SUI) is a practice that refers to the knowledge contributions made to professional education programs by people who have used, or are currently using mental health and social care services. Service user educators are widely regarded as “experts by experience,” with a rich source of knowledge to offer health and social care practitioners. The mental health strategy for Canada, *Changing Directions, Changing*

Lives (2012), has recognized the importance of, and called for, SUI in all aspects of the mental health system, including the education and training of future service providers. Current approaches to SUI in professional education, however, have reportedly been implemented with tremendous inconsistency, and risk becoming superficial-or ‘tick-box’ forms of involvement unless improved practices are identified.

The aim of this research is to deepen understandings of the ways SUI is currently being organized and implemented within health and social care professional education programs, by investigating the perspectives and practices of: (i) service users involved in Occupational Therapy (OT) professional education programs in Ontario, (ii) service users involved in health and social care professional education in Ontario more generally, and (iii) OT educators and administrators who facilitate involvement of service users in their programs. It is anticipated that the findings of this research will contribute novel insights towards the innovation and development of education practices that foreground service users’ knowledge within professional education programs in health and social care.

This study is being conducted in partial completion of the requirements of a Doctor of Philosophy (PhD) degree in the Department of Health and Rehabilitation Sciences at Western University.

Inclusion Criteria

To participate in this study, you must:
be at least 18 years of age;
be able to comprehend and communicate in English;
use, or have used in the past, some form of mental health and/or social care service; AND
have experience in the education of students enrolled in a Master’s level Occupational Therapy program in Ontario.

Exclusion Criteria

Exclusion criteria from the study include: individuals who are not able to communicate in English; individuals who do not have experience with mental health and/or social care services; service users who have not participated in Occupational Therapy professional education programs in Ontario.

Study Procedures

If you agree to participate in this study, you will be asked to take part in one audio-recorded semi-structured interview, and one observation session if feasible. The purpose of the interview is to hear about your experiences as a *mental health service user educator* involved in the education of future occupational therapists. The study investigator will facilitate the interview with the guidance of some pre-planned questions, and you will be invited to share any additional relevant information you wish to contribute throughout the interview. You may decline to answer any questions at any time, and choose to answer only those questions you feel comfortable with. The interview will last approximately 90 minutes and will be conducted at a negotiated location of your choice that is suitable for a recorded interview. Basic demographic data, including the length of time involved in activities related to *service user involvement* will also be collected at that time.

In order to better understand the practices of SUI, you will also be asked to participate in one observation session if timing and schedules allow. The observation session would take place during one of the regular tasks you perform as part of your role in professional education (e.g., giving a guest lecture, attending a curriculum committee meeting, participating in training or mentorship, contributing to course development, etc.). This observation session will be arranged to suit your schedule, and will last for the duration of the chosen task.

Voluntary Participation and Withdrawal from Study

Participation in this study is completely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you decide to withdraw from the study, you have the right to request withdrawal of the information you have provided. If you wish to have your information removed please let the study investigators know.

Possible Risks of Participation in the Study

The anticipated risk associated with participation in this study is extremely low. As in all research, it is possible that talking about your experiences may bring up thoughts and feelings that you find distressing. Should this occur, we would stop the interview until you feel comfortable continuing, cease the interview all together, or re-book the interview for another time. A list of local community resources will be made available should you wish to speak with someone further about memories or emotions that arise in the process.

Possible Benefits of Participation in the Study

Your firsthand experience with service user involvement in professional education is important information that only you have. The information you share throughout this study will be presented to those involved in health and social care professional education, educational administrators and policy makers, service users, and to others through research briefings, presentations at conferences, and publications in scholarly journals. In this way, you may help to influence the future development of mental health service user involvement in professional education. The long-term benefits of the study are unknown, and it is possible that you will not experience any direct benefit from participation in this study. Your identity will never be released in any publication or presentation.

Confidentiality

All information collected during this study is treated in a completely confidential manner. In order to protect your privacy, you will be assigned a study number. A master list linking your study number to your personal information will be kept by the study investigators in a secure place, separate from your study file. The data collected through this study will be retained for 5 years in a secure and confidential location. Only researchers associated with this project will have access to the information. Your personal information will never be shared with fellow participants. You will not be named in any publications associated with the study. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

Compensation

An honorarium of $25 will be provided upon completion of your interview as a thank you for contributing your valuable experiential knowledge to this research study.

Rights as a Participant

Your participation in this study is voluntary. You may decide not to participate in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. We will share with you any new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

Questions about the Study

Thank you for your consideration regarding participation in this study. If you require any further information regarding this research project or your participation in the study you may contact Stephanie LeBlanc, the study investigator [redacted] or Dr. Elizabeth Anne Kinsella, the principal investigator [redacted].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics [redacted], email: [redacted].

This letter is yours to keep for future reference

PARTICIPANT CONSENT FORM

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

CONSENT STATEMENT:
I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this form.

____
Participant Name (Please Print)

____
Participant Signature

____
Date (DD/MM/YYYY)

My signature means that I have explained the study to the participant named above, and I have answered all questions.

____
Name of Person Obtaining Consent (Please Print)

____
Signature

____
Date (DD/MM/YYYY)

LETTER OF INFORMATION AND CONSENT FOR SERVICE USER EDUCATORS INVOLVED IN HEALTH AND SOCIAL CARE PROFESSIONAL EDUCATION

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, OT Reg. (Ont.)
Health Professional Education Field
Health and Rehabilitation Sciences Graduate Program
Faculty of Health Sciences, Western University
Email: [redacted]

Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Co-Investigators:
Dr. Jennifer Poole, Associate Professor, Social Work, Ryerson University
Email: [redacted]
Dr. Sandy DeLuca, Chair, School of Nursing, Fanshawe College
Email: [redacted]

Invitation to Participate

Thank you for expressing interest in this study. You are being invited to participate in research exploring the involvement of mental health service users in the education and training of future health and social care professionals. You are being invited to participate in this study because you have experience as a service user educator involved in mental health and social care professional education.

Purpose of this Letter

The purpose of this letter is to provide you with information required to make an informed decision regarding participation in this research.

Purpose of Study

Service User Involvement (SUI) is a practice that refers to the knowledge contributions made to professional education programs by people who have used, or are currently using mental health and social care services. Service users are widely regarded as “experts by experience,” with a rich source of knowledge to offer health and social care practitioners. The mental health strategy for Canada, *Changing Directions, Changing Lives* (2012), has recognized the importance of, and called for, SUI in all aspects of the mental health system, including the education and training of future service providers. Current approaches to SUI in professional education, however, have reportedly been implemented with tremendous inconsistency, and risk becoming superficial-or ‘tick-box’ forms of involvement unless improved practices are identified.

The aim of this research is to deepen understandings of the ways SUI is currently being organized and implemented within health and social care professional education programs, by investigating the perspectives and practices of: (i) service users involved in Occupational Therapy (OT) professional education programs in Ontario, (ii) service users involved in health and social care professional education in Ontario more generally, and (iii) OT educators and administrators who facilitate involvement of service users in their programs. It is anticipated that the findings of this research will contribute novel insights towards the innovation and development of education practices that foreground service users’ knowledge within professional education programs in health and social care.

This study is being conducted in partial completion of the requirements of a Doctor of Philosophy (PhD) degree in the Department of Health and Rehabilitation Sciences at Western University.

Inclusion Criteria

To participate in this study, you must:
be at least 18 years of age;
be able to comprehend and communicate in English;
use, or have used in the past, some form of mental health and/or social care service; AND
have experience in the education of students enrolled in mental health and social care professional education programs.

Exclusion Criteria

Exclusion criteria from the study include: individuals who are not able to communicate in English; individuals who do not have experience with mental health and/or social care services; service users who have not participated in professional education programs in higher education.

Study Procedures

If you agree to participate in this study, you will be asked to take part in one audio-recorded semi-structured interview. The purpose of the interview is to hear about your experiences as a *mental health service user* involved in the education of future health and social care professionals. The study investigator will facilitate the interview with the guidance of some pre-planned questions, and you will be invited to share any additional relevant information you wish to contribute throughout the interview. You may decline to answer any questions at any time, and choose to answer only those questions you feel comfortable with. The interview will last approximately 90 minutes and will be conducted at a negotiated location of your choice that is suitable for a recorded interview. Basic demographic data, including the length of time involved in activities related to *service user involvement* will also be collected at that time.

Voluntary Participation and Withdrawal from Study

Participation in this study is completely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you decide to withdraw from the study, you have the right to request withdrawal of the information you have provided. If you wish to have your information removed please let the study investigators know.

Possible Risks of Participation in the Study

The anticipated risk associated with participation in this study is extremely low. As in all research, it is possible that talking about your experiences may bring up thoughts and feelings that you find distressing. Should this occur, we would stop the interview until you feel comfortable continuing, cease the interview all together, or re-book the interview for another time. A list of local community resources will be made available should you wish to speak with someone further about memories or emotions that arise in the process.

Possible Benefits of Participation in the Study

Your first-hand experience with service user involvement in professional education is important information that only you have. The information you share throughout this study will be presented to those involved in health and social care professional education, educational administrators and policy makers, service users, and to others through research briefings, presentations at conferences, and publications in scholarly journals. In this way, you may help to influence the future development of mental health service user involvement in professional education. The long-term benefits of the study are unknown, and it is possible that you will not experience any direct benefit from participation in this study. Your identity will never be released in any publication or presentation.

Confidentiality

All information collected during this study is treated in a completely confidential manner. In order to protect your privacy, you will be assigned a study number. A master list linking your study number to your personal information will be kept by the study investigators in a secure place, separate from your study file. The data collected through this study will be retained for 5 years in a secure and confidential location. Only researchers associated with this project will have access to the information. Your personal information will never be shared with fellow participants. You will not be named in any publications associated with the study. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

Compensation

An honorarium of $25 will be provided upon completion of your interview as a thank you for contributing your valuable experiential knowledge to this research study.

Rights as a Participant

Your participation in this study is voluntary. You may decide not to participate in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. We will share with you any new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

Questions about the Study

Thank you for your consideration regarding participation in this study. If you require any further information regarding this research project or your participation in the study you may contact Stephanie LeBlanc, the study investigator [redacted] or Dr. Elizabeth Anne Kinsella, the principal investigator [redacted].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics [redacted], email: [redacted].

This letter is yours to keep for future reference

PARTICIPANT CONSENT FORM

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

CONSENT STATEMENT:
I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this form.

____
Participant Name (Please Print)

____
Participant Signature

____
Date (DD/MM/YYYY)

My signature means that I have explained the study to the participant named above, and I have answered all questions.

____
Name of Person Obtaining Consent (Please Print)

____
Signature

____
Date (DD/MM/YYYY)

LETTER OF INFORMATION AND CONSENT FOR OT PROGRAM PERSONNEL

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, OT Reg. (Ont.)
Health Professional Education Field
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

Co-Investigators:
Dr. Jennifer Poole, Associate Professor, Social Work, Ryerson University
Email: [redacted]
Dr. Sandy DeLuca, Chair, School of Nursing, Fanshawe College
Email: [redacted]

Invitation to Participate

Thank you for expressing interest in this study. You are being invited to participate in research exploring the involvement of mental health service users in the education and training of future health and social care professionals. This study is being conducted within the context of Master's level Occupational Therapy programs in Ontario. You are being invited to participate in this study because you have experience in one (or more) of the following roles within an Occupational Therapy program in Ontario: (1) mental health course coordinator/instructor; (2) curriculum committee representative; or (3) program administrator.

Purpose of this Letter

The purpose of this letter is to provide you with information required to make an informed decision regarding participation in this research.

Purpose of Study

Service User Involvement (SUI) refers to the knowledge contributions made to professional education programs by people who have used, or are currently using mental health and social care services. Service users are widely recognized as "experts by experience," with a rich source of knowledge to offer health and social care practitioners. The mental health strategy for Canada, *Changing Directions, Changing Lives* (2012), has recognized the importance of, and called for, SUI in all aspects of the mental health system, including the education and training of future service providers. Current approaches to SUI, however, have reportedly been implemented with tremendous inconsistency, and risk becoming-superficial, or ‘tick-box’ forms of involvement unless improved practices are identified.

Using Occupational Therapy education in Ontario as an exemplar, the aim of this research is to deepen understandings of the ways SUI is currently being organized and implemented within health and social care professional education. The study investigates the perspectives and practices of: (i) service users involved in Occupational Therapy professional education programs in Ontario; (ii) service users involved in health and social care professional education in Ontario more generally; and (iii) Occupational Therapy educators and administrators who facilitate involvement of service users in their programs. It is anticipated that the findings of this research will contribute novel insights towards the innovation and development of education practices that foreground service users’ knowledge within professional education programs in health and social care.

This study is being conducted in partial completion of the requirements of a Doctor of Philosophy (PhD) degree in the Department of Health and Rehabilitation Sciences at Western University.

Inclusion Criteria

To participate in this study, you must:
be at least 18 years of age;
be able to comprehend and communicate in English;
be employed by any one of the Master’s level Occupational Therapy programs in Ontario;
fulfill a role within said program that is directly (e.g., mental health course coordinator or instructor) or indirectly (e.g., curriculum committee member, administrator) related to mental health education;
have experience with the practice of *service user involvement* in professional education.

Exclusion Criteria

Exclusion criteria from the study include: individuals who are not able to communicate in English; educational personnel who are not employed by a Master’s level Occupational Therapy program in Ontario; educational personnel who are not involved in the organization, coordination, facilitation or provision of mental health education. .

Study Procedures

If you agree to participate in this study, you will be asked to take part in (i) an audio-recorded semi-structured interview. The purpose of this interview is to hear about your experiences working with mental health service users in your health professional education setting. The study investigator will guide the interview with a set of pre-planned questions. You may choose to answer only those questions you feel comfortable with, and you will be invited to share any additional relevant information you wish to contribute throughout the interview. The interview will last approximately 90 minutes and will be conducted at a negotiated location that is suitable for a recorded interview, or at your place of employment. Demographic data, including the length of time involved in activities related to service user involvement will also be collected at that time.

In order to better understand the experience and practice of SUI in professional education, the study investigators are also seeking your assistance to: (ii) identify textual resources relevant to mental health service user involvement in your program (e.g., curriculum documents, course syllabi, required texts and readings, etc.), and (iii) allow the study investigator to be present for the purpose of participant observation during service user activities in your program (e.g., attending service user guest lectures or course instruction, observing curriculum meetings, etc.).

Please note that only the interview outlined above is a requirement for participation in this study. Assisting with access to textual resources and participant observation is optional.

Voluntary Participation and Withdrawal from Study

Participation in this study is completely voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you decide to withdraw from the study, you have the right to request withdrawal of the information you have provided. If you wish to have your information removed please let the study investigators know.

Possible Risks of Participation in the Study

The anticipated risk associated with participation in this study is extremely low. As in all research, it is possible that talking about your experiences may bring up thoughts and feelings that you find distressing. Should this occur, we will stop the interview until you feel comfortable continuing, cease the interview all together, or re-book the interview for another time. A list of local community resources will be made available should you wish to speak with someone further about memories or emotions that arise in the process.

Possible Benefits of Participation in the Study

Your first-hand experience with service user involvement in professional education is important information that only you have. The information you share throughout this study will be presented to those involved in health and social care professional education, educational administrators and policy makers, service users, and to others through research briefings, presentations at conferences, and publications in scholarly journals. In this way, you may help to influence the future development of mental health service user involvement in professional education. The long-term benefits of the study are unknown, and it is possible that you will not experience any direct benefit from participation in this study. Your identity will never be released in any publication or presentation.

Confidentiality

All information collected during this study is treated in a completely confidential manner. In order to protect your privacy, you will be assigned a study number. A master list linking your study number to your personal information will be kept by the study investigators in a secure place, separate from your study file. The data collected through this study will be retained for 5 years in a secure and confidential location. Only researchers associated with this project will have access to the information. Your personal information will never be shared with fellow participants. You will not be named in any publications associated with the study. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

Compensation
While there is no financial compensation for involvement in the study, the researchers are happy to share resources and literature on mental health service user involvement with the participants of the study, as a means of participants to learn and to advance educational practices in this domain.

Rights as a Participant
Your participation in this study is voluntary. You may decide not to participate in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. We will share with you any new information that is learned during the study that might affect your decision to stay in the study. You do not waive any legal right by signing this consent form.

Questions about the Study
Thank you for your consideration regarding participation in this study. If you require any further information regarding this research project or your participation in the study you may contact Stephanie LeBlanc, the study investigator [redacted] or Dr. Elizabeth Anne Kinsella, the principal investigator [redacted].

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics [redacted], email: [redacted].

This letter is yours to keep for future reference

PARTICIPANT CONSENT FORM FOR OT PROGRAM PERSONNEL

Study Title: Troubling Service User Involvement In Health Professional Education: Toward Epistemic Justice

Study Investigator:
Stephanie LeBlanc, PhD Candidate, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]
Principal Investigator:
Dr. Elizabeth Anne Kinsella, PhD, Associate Professor,
School of Occupational Therapy, Health Professional Education Field,
Health and Rehabilitation Sciences Graduate Program,
Faculty of Health Sciences, Western University
Email: [redacted]

CONSENT STATEMENT:
I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this form.

____
Participant Name (Please Print)

____
Participant Signature

____
Date (DD/MM/YYYY)

My signature means that I have explained the study to the participant named above, and I have answered all questions.

____
Name of Person Obtaining Consent (Please Print)

____
Signature

____
Date (DD/MM/YYYY)

Appendix F. Participant Demographic Information and Consent Forms

PARTICIPANT INFORMATION FORM

***Participant code:* __________________**

***Age:* _____________**

Gender: __________

What role do you play in service user involvement in health professional education? (Check all that apply).

Service User Educator [ ]
Course Coordinator/Instructor [ ]
Program Administrator [ ]
Curriculum Committee member [ ]
Other [ ] Describe: ___________________________________

How long have you been involved in this role, or another related to service user involvement in professional education?

____

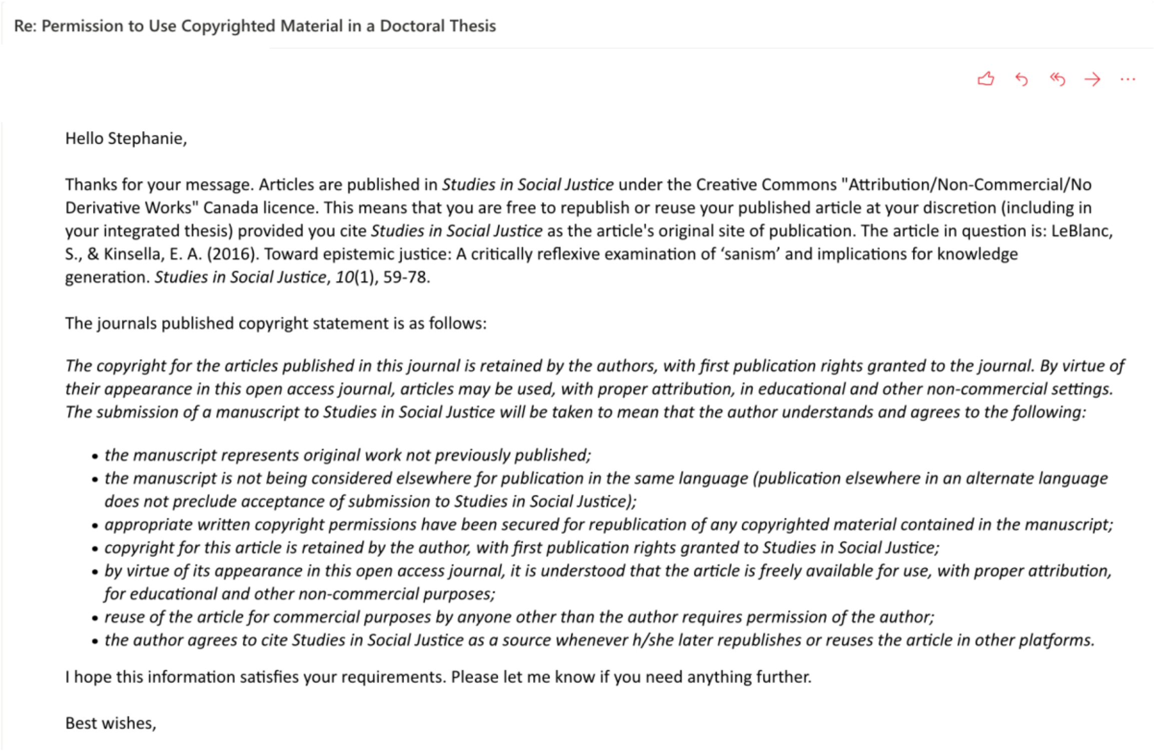
For Service Users Only:

Highest level of education: (circle highest level completed)

Primary School	1 2 3 4 5 6 7 8		
Secondary School	9 10 11 12 13		
College	some	current student	degree obtained
University	some	current student	degree obtained

Other (please specify) ____

Appendix G. Permission to Reproduce Copyrighted Materials



Re: Permission to Use Copyrighted Material in a Doctoral Thesis

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- *the author agrees to cite Studies in Social Justice as a source whenever h/she later republishes or reuses the article in other platforms.*

I hope this information satisfies your requirements. Please let me know if you need anything further.

Best wishes,

Curriculum Vitae

Stephanie LeBlanc-Omstead

1. POST-SECONDARY EDUCATION AND DEGREES

2014-2021	**Doctor of Philosophy**, Health and Rehabilitation Sciences University of Western Ontario, London, ON Supervisor: Dr. Elizabeth Anne Kinsella Advisors: Dr. Jennifer Poole, Dr. Sandra DeLuca
2012-2014	**Master of Science,** Occupational Therapy McMaster University, Hamilton, ON
2008-2012	**Bachelor of Human Kinetics,** Movement Sciences major, Psychology minor University of Windsor, Windsor, ON

2. ACADEMIC DISTINCTIONS, SCHOLARSHIPS & AWARDS

2017	SSHRC Doctoral Fellowship Award, Western University, ($40,000)
2017	Ontario Graduate Scholarship, Western University, ($15,000) [declined]
2016	FHS Graduate Tri-Council Scholarship Incentive ($1000)
2014-2017	Western Graduate Research Scholarship ($14,268)
2015	McMaster Research Plenary Outstanding Achievement Award
2014	Canadian Occupational Therapy Foundation Future Scholar Award ($100)
2014	Mary Tremblay Academic Grant, McMaster University, ($1500)
2013-2014	Ontario Graduate Scholarship, McMaster University, ($15,000)

3. REFEREED PUBLICATIONS

LeBlanc-Omstead, S. & Mahipaul, S. (Forthcoming). Toward More Socially Accountable Service User Involvement in Education: Embracing Critical Disability Studies. *Occupational Therapy Now, TBD.*

LeBlanc-Omstead, S., & Poole, J. (Forthcoming). Sanism: Concepts, contestations and considerations. *In Lewis, B., Ali, A. & Russell, J. (Eds.).* The Mad Studies Reader. Routledge Press.

LeBlanc-Omstead, S. (Forthcoming). Epistemic Injustice and Psychiatric Oppression. *In LeFrancois, B. & Gorman, R. (Eds.) The Palgrave Encyclopedia of Critical Perspectives in Mental Health.*

LeBlanc-Omstead, S. & Kinsella, E.A. (2019). Shedding light on a ‘hidden prejudice’: Considering sanism in occupational therapy. *Occupational Therapy Now, 21*(2), p.15-16.

Katzman, E. & LeBlanc-Omstead, S. (2019). Considering Epistemic Justice in the Quest for Client-Centered Practice. *Occupational Therapy Now, 21*(2), p.9-10.

LeBlanc-Omstead, S. (2019). Book Review – Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies, edited by Jasna Russo and Angela Sweeney. Monmouth, UK: PCCS Books Ltd., 2016. 261 pages, $36.10 (Paperback). *New Horizons in Adult Education and Human Resource Development, 31*(1), p.61-67.

LeBlanc, S. & Kinsella, E.A. (2016). Toward Epistemic Justice: A Critically Reflexive Examination of ‘Sanism’ and Implications for Knowledge Generation. *Studies in Social Justice*, *10*(1), p.59-78.

4. RELATED REFEREED CONFERENCE PRESENTATIONS

LeBlanc, S. (2021). Experts by experience: Service user involvement in occupational therapy education. [Paper presentation]. *Canadian Association of Occupational Therapists (CAOT) Conference.*

LeBlanc, S. & Katzman, E. (2017). Considering ‘epistemic justice’ in the quest for client-centered practice. [Accepted Extended Discussion]. *Canadian Association of Occupational Therapists (CAOT) Conference.* Charlottetown, Prince Edward Island. June 21-24.

LeBlanc, S. & Kinsella, E.A. (2016). Beyond Stigma: Considering ‘sanism’ in occupational therapy. [Accepted Paper Presentation]. *COTEC-ENOTHE Congress.* Galway, Ireland. June 15-19.

Kinsella, E.A., Katzman, E. & LeBlanc, S. (2016). Critical Reflexivity and knowledge generation in professional practice. [Accepted Symposium Presentation]. *COTEC-ENOTHE Congress.* Galway, Ireland. June 15-19.

LeBlanc, S. & Kinsella, E.A. (2016). What lies beneath stigma? Considering 'sanism' in occupational therapy. [Accepted Paper Presentation]. *Canadian Association of Occupational Therapists (CAOT) Conference.* Banff, Alberta. April 19-22.

LeBlanc, S. & Kinsella, E.A. (2016). Busting myths surrounding mental illness: Inspiring dialogue through autoethnography. [Accepted Paper Presentation]. *Canadian Association of Occupational Therapists (CAOT) Conference.* Banff, Alberta. April 19.

Katzman, E. & LeBlanc, S. (2015). Disability Culture: A model for health professional practice. [Poster Presentation]. *Shoppers Health Care Innovations Conference and Trade Show,* Toronto, Ontario. November 17, 2015.

LeBlanc, S. (2015). Communicating Lived Experiences in A Culture of Silence: Using Autoethnography To Inspire Dialogue in Mental Healthcare Contexts. [Paper Presentation]. *Qualitative Health Research Conference.* Toronto, Ontario. October 19-21.

LeBlanc, S. & Kinsella, E.A. (2015). Toward Anti-Sanist Healthcare Practice: A Critically Reflexive Examination of 'Sanist' Discourses and Possibilities for Dialogue. [Poster Presentation]. *Qualitative Health Research Conference.* Toronto, Ontario. October 19-21.

LeBlanc, S. (2015). Mad student meets Mad Studies: An autoethnographic account of 'passing' in a culture of silence and non-disclosure. [Paper Presentation]. *The Making Sense Of: Madness Project: 8th Global Meeting*. Oxford, United Kingdom. September 15-16.

LeBlanc, S., & Kinsella, E.A. (2015). Toward Epistemic Justice in the Mad Community: A Critical Interrogation of Sanist Discourses and Possibilities for Dialogue. *The Making Sense Of: Madness Project: 8th Global Meeting*. Oxford, United Kingdom. September 15-16.

LeBlanc S., Katzman, E., & Tryssenaar, J. (2014). Disability orientation: An exploration of an overlooked component of the therapeutic relationship. [Paper Presentation]. *Canadian Association of Occupational Therapists (CAOT) Conference*. Fredericton, NB.

5. RELATED TEACHING EXPERIENCE

2018	Clinical Educator, [redacted] Instructor: Stephanie LeBlanc-Omstead
2017	Teaching Assistant, Western University, London, ON HS 9730: Philosophical Foundations of Qualitative Research Instructor: Dr. Elizabeth Anne Kinsella
2016	Teaching Assistant, Western University, London, ON HS 9730: Philosophical Foundations of Qualitative Research Instructor: Dr. Elizabeth Anne Kinsella
2015	Teaching Assistant, Western University, London, ON DS 2216A: Disability, Media and Madness Instructor: Dr. Pamela Cushing and Prof. Tobin LeBlanc-Haley
2015	Co-Tutor, McMaster University, Hamilton, ON OT 637: Inquiry and Integration - Problem Based Tutorial Course Coordinator: Jocelyn Harris; Supervisor: Lorie Shimmell

2014 Teaching Assistant, Western University, London, ON
OT 9612a Ethics and Professional Practice in Context
Instructor: Prof. Lisa McCorquodale

6. PROFESSIONAL MEMBERSHIPS & AFFILIATIONS

Current College of Occupational Therapists of Ontario Registration
Registration No.: G1509684

Current Ontario Society of Occupational Therapists (OSOT) Membership
Membership No.: 17813

2015-2016 London and District Distress Centre (LDDC) Board Member

2014/11/01 National Occupational Therapy Certification (NOTC)
Certificate No.: 14578

7. VOLUNTEER ACADEMIC SERVICE WORK

Current Occupational Therapy Program Anti-Racism, Anti-Bias and Anti-Oppression Committee Member
McMaster University, Hamilton, ON

2020-2021 Peer Journal Review:
Hypatia: A Journal of Feminist Philosophy
Studies in Social Justice Journal
American Journal of Orthopsychiatry

2020 CDSA Abstract Review

2018-2021 CAOT Abstract Review