



ORIGINAL ARTICLE

## **Maddening Research Ethics:** Challenging Sanism and Biomedicalism in Institutional Ethics Discourses and Policies

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### **Abstract**

This article details the issues I encountered when seeking ethical approval for my doctoral research which engaged with people who self-harm. Drawing from mad, feminist, and Indigenous perspectives which problematize institutional ethics discourses and policies, I demonstrate the extent to which the problems I encountered with my institution's research ethics board (REB) were more reflective of institutional risk management strategies than they were of a commitment to the ethical treatment of research participants. In this work, I offer detailed explanations of the disagreements that occurred between myself and the REB regarding the level of risk to participants, and biomedicalized strategies that I was urged to implement to mitigate and address these risks. I highlight the mobilization of sanist and biomedical discourses by the REB and argue that it is necessary to problematize the ways in which these discourses were activated to legitimize "ethical" decision-making via both the devaluation of psychiatric survivor knowledges and the active endangerment of psychiatrized people through an imposed reliance on carceral interventions to potential crises. I conclude this article with a discussion of how we might approach research ethics differently. Ultimately, I call for a "maddening" of research ethics that values and integrates psychiatric survivor knowledges and which attends to hierarchies of power and oppression as they are enforced through ethics policies.

### **Keywords**

Research ethics; mad ethics; biomedicalism; sanism

### **History**

Received 2 June 2025  
Revised 4 Dec 2025  
Accepted 3 Feb 2026

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### **Introduction**

In 2020, I began my doctoral project that was inspired by my experiences with mental health care systems as someone who engages in self-harm.<sup>1</sup> Having had a series of

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<sup>1</sup> I use the term "self-harm" here as an alternative to the more biomedicalized term "self-injury" (as used in the term "nonsuicidal self-injury disorder," a condition for future study in the Diagnostic and Statistical Manual of Mental Disorders). However, I also recognize that self-harm is also a term that is used in biomedical spaces. In

confusing and disorienting interactions with various mental health professionals, I sought to understand how other people who self-harm experience mental health care services through a series of semi-structured interviews. Part of this project necessarily involved receiving approval from my institution's research ethics board (REB) to involve human participants in my research. What I anticipated to be a straightforward exercise – albeit with some pushback – became an arduous process imbued with sanism and biomedical bias. This paper offers a critical, autoethnographic account of my ethics approval process, within which I challenge the REB's notion of "ethics" using feminist, mad, and Indigenous research that has pushed back against institutional REB processes.

Specifically, I problematize the framing of prospective research participants as inherently vulnerable and "suicidal", the insistence that I adopt clinical assessment tools to determine research participants' eligibility to participate, and the insistence that I involve emergency medical and police services should a participant disclose intent to harm themselves or others. Drawing from my situated knowledge as someone who was engaging in self-harm, I show how the policies and tools which I was being asked to adopt to minimize harm to participants are more reflective of biomedically-informed risk management strategies than of an ethical commitment to the safety and wellbeing of prospective research participants.

Ultimately, I argue that my experience with REB approval was complicated by a "knot" of sanism, biomedicalism, and risk management that challenged my ability to begin my research and which compromised my personal ethics as a mad researcher, which are grounded in the principles of epistemic justice and anti-carceral<sup>2</sup> approaches to mental health crises.

Sanism, which I conceptualize in this work as the oppression of people who are labelled by psychiatry and/or those who appear to be "mentally ill," particularly their lived and experiential knowledges (LeBlanc & Kinsella, 2016; Poole, 2024; Poole et al., 2012), emerged within the context of my ethics approval process in several ways, largely through the failure to recognize and affirm the agency of people who self-harm, and to discount experiential knowledge as being valuable in the consideration of what is truly "ethical."<sup>3</sup> Sanism was also

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choosing to use self-harm as an alternative to "self-injury", I align myself with Angelotta (2015), who argues that self-harm is a term that has changed over time based on "changing cultural norms" (p. 75) and that this term "occupies the fuzzy border" (p. 75) between what psychiatry deems "normal" or "abnormal" behaviour. In addition, self-harm is a term that I use to refer to my own coping skills. I recognize that others may prefer to use other terms to describe their embodied experiences and that language is deeply personal and ever-changing.

<sup>2</sup> Anti-carceral approaches to mental health challenge carceral practices such as the involvement of police in mental health crises, involuntary psychiatric hospitalization, and the forensic "mental health" system (see Ben-Moshe, 2020; Carlton & Russell, 2018; Kilty & Lehalle, 2019). In the context of my work, I considered my rejection of the involvement of policing as a potential crisis response as part of a commitment to anti-carceral approaches to mental health.

<sup>3</sup> To be more specific, I experienced my REB process as sanist because it assumed that the knowledge of prospective participants was illegitimate due to their experiences of "mental illness" or madness. There was also an interesting dynamic at play in the context of my work, whereas I had disclosed my lived experiences as part of my REB application, to demonstrate that I had valuable experiential knowledge (although I would soon

compounded by biomedicalism – the prioritization of medical perspectives on madness – through the insistence that prospective participants require medical assessments to participate and medical and carceral interventions in the event of a “crisis” – claims that I strongly challenged.

Drawing from LeFrançois and Voronka’s (2022) conceptualization of a mad “ethics of unruliness” (p. 106), and Tynan’s (2021) and Martin’s (2017) conceptualizations of relationality as an ethical research process, I demonstrate how mad researchers might approach doing “ethical” research differently so that we can create space for research within mad studies that is protective of research participants in ways that are in alignment with the principles of the mad and psychiatric survivor communities, including epistemic justice, wherein lived experience is considered a legitimate form of knowledge (see Liegghio, 2013), and the promotion of anti-carceral policies and practices (see Ben-Moshe, 2020). As such, I also argue that institutional ethics review boards are a crucial site of interrogation for mad studies researchers who seek to challenge sanism and biomedicalism in their work.

### **Critiquing Institutional Ethics**

Qualitative, critical, and interpretive researchers have been particularly outspoken about the problems associated with institutional ethics review policies and discourses (Cannella & Lincoln, 2007; Haggerty, 2004; Halse & Honey, 2005, 2007; Holland, 2007; LeFrançois & Voronka, 2022; Lincoln & Tierney, 2004; Pitt, 2014; Tolich & Fitzgerald, 2016). For example, Haggerty’s (2004) concept of “ethics creep” offers up language that lends to a particularly strong critique of institutional ethics processes. Defined as “a dual process whereby the regulatory system is expanding outward to incorporate a host of new activities and institutions, while at the same time intensifying the regulation of activities deemed to fall within its ambit” (Haggerty, 2004, p. 391), ethics creep tackles how REBs have expanded notions of harm, arguing that “[t]he range of potential research related harms envisioned by REBs at times seems to be limited only by the imagination of different reviewers” (Haggerty, 2004, p. 400). Anything that might disrupt a research participant’s condition or routine, or which “poses a greater risk than what a person might encounter in his/her daily life” (Haggerty, 2004, p. 400), may come under scrutiny as a potential harm that a researcher must mitigate, or else the research cannot move forward (Haggerty, 2004, pp. 398–399). For Haggerty (2004), this poses a problem, particularly in the context of qualitative research, as the increasingly bureaucratic nature of measuring risk can stall or even prevent certain research from happening (p. 392–393).

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realize that this was not seen as something that would reduce the level of “risk” within my project). Interestingly, the REB was still able to see me as a rational person who was “sane enough” to conduct this research, even though I disclosed my psychiatric labels and coping mechanisms. I contribute this affordance of rationality to my privileged position within academia, which I believe granted me more legitimacy as a “knower” as opposed to prospective participants. I was not at risk of distress because I was a researcher (with assumed rationality).

One example of how research with mad people can be prevented from happening is laid out in Holland's (2007) article, "The Epistemological Bias of Ethics Review: Constraining Mental Health Research." Within, Holland (2007) details the experience of their attempt to have their research working with people diagnosed with a mental illness approved by their institution's REB. The problems that Holland (2007) faced in their work, including concerns about the safety of participants, their lack of clinical expertise, the need for emergency preparedness, and screening participants for their wellness and ability to give informed consent (p. 895) were all problems that I faced when trying to receive approval for my project. Fortunately, my research was not completely barred from proceeding.

In many ways, my paper builds on and reinforces Holland's work to demonstrate how wide-reaching these epistemological biases are. My paper also builds upon feminist critiques of ethics review processes, including Halse and Honey's (2005) critique of the discursive power of biomedicalism in their research with girls who were diagnosed with anorexia, and Cannella and Lincoln's (2007) critique of ethics review boards as exceedingly neoliberal. More specifically, I build upon Halse and Honey's (2005) critique of the positivist model of research ethics which has been imposed upon disciplines in the social sciences, even though these disciplines "employ radically different epistemic frames and forms of data collection and analysis" (p. 2153). In their work, Halse and Honey (2005) were faced with the contention between their personal ethical and moral desire to not frame girls as "anorexic," grounded in a refusal to pathologize and define girls' experiences without their consent. This refusal not respected by Halse and Honey's (2005) ethics board, who asserted that their research could not be possible if they were unable to clearly define their study population (p. 2146). This policy reinforces the idea that human experiences can be easily categorized and studied in an objective sense, ignoring the inherent differences and among people, and, in this case, ignoring Halse and Honey's attempt to respect the situated knowledge of the girls that participated in their research.

This idea, as well as the idea that research is constituted by purely objective and experimental inquiry (Halse & Honey, 2007), and the assumption that all research can be completed sequentially and predictably (Halse & Honey, 2007), are positivist modes of thinking. In a positivist, quantitative research project, the research trajectory is largely known in advance and researchers can point to a set of participants and research questions that are set and determined (Wynn, 2018). Qualitative research, particularly ethnographic research, is more dynamic, adapting and shifting over time as new study information unfolds, making it difficult for researchers to sufficiently describe their research and its potential risks before the fieldwork is permitted to commence (Truman, 2003, p. 4). In these instances, ethical approval becomes less about the production of ethical commitments to research participants and more about asking qualitative researchers to performatively abide by these institutional rules to answer predictive questions about their work before it has even begun.

The notion of a universalized ethics, which subsumes a universality of human experience, has also been challenged by Indigenous scholars who have been rightfully critical of institutional ethics processes, particularly given how these formalized and universalized structures reinforce racial hierarchies and colonial logics and practices. Given the historical exploitation and violence against Indigenous communities, national ethics boards, such as *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* in Australia and the second edition of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*<sup>4</sup> in Canada have attempted to establish universal ethics protocols for the conduct of research with Indigenous communities. And while these guidelines are well-intended, and while these national-led policies recognize that consent to participate in research depends on the nature of the project as well as the “ethics and cultural sensitivities” (Hawkes et al., 2017, p. 19) of the communities to be involved in the research (Ibid.), the inflexibility of their application at the level of the neoliberal university nevertheless “often undermine[s] ethical research practice” (Hawkes et al., 2017, p. 18) and “imposes a neopaternalist relationship of assumed ‘white’ ‘Western’ superiority of the researcher as communicator and keeper of the researched ‘Indigenous subject’” (Hawkes et al., 2017, p. 19).

For example, Tauri (2014) argues that Eurocentric conceptualizations of what does and does not constitute ethical research is cause for concern in the context of conducting research with Indigenous peoples (p. 137). Tauri (2014) critiques REBs for prioritizing Eurocentric ways of knowing and doing ethics, which often become problematically synonymous for the “right” way of doing research (p. 135). Furthermore, Tauri (2014) argues that these ways of doing research often work within a framework that assumes an “autonomous research subject” (p. 14) in ways that “sideline the importance of the social context within which ‘real world’ research takes place” (p. 14). Similarly, Grenz (2023) writes that although they do support some form of ethical structures for research with Indigenous Peoples due to the “history of extractive and harmful research on Indigenous Peoples” (n.p.), they nevertheless critiques REBs for creating barriers to research. As Grenz (2023) continues, although some ethics boards are making efforts to decolonize, their processes and rules remain oriented toward non-Indigenous researchers. More specifically, Grenz (2023) writes that REBs “don’t account for our years of developing trust and nurturing relationships... nor do they respect the extensive knowledge and cultural awareness we bring to our work with Indigenous peoples” (n.p.). Institutional failures to respect these relationships and cultural awareness leads to the impositions of ethics and research protocols that can alienate Indigenous researchers from their own peoples.

In the context of mad studies research, we can learn much from the above critiques. To ensure that critical research can move forward, and to prevent the alienation of mad

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<sup>4</sup> Guidelines for engaging in research with Indigenous communities is specifically outlined in “Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada” (Social Sciences and Humanities Research Council, 2012).

academics from the people and movements upon which our discipline is founded, it is important that we adopt critiques of research ethics processes that challenge colonial, biomedical, and sanist logics embedded in these institutional processes. In what follows, I detail my experiences with my REB to reveal the extent to which dominant discourses of Western, universalized ethics appear in institutional ethics processes and to underscore the importance of challenging biomedical institutionalized ethics processes.

### **The Making of “Vulnerable” Populations**

One of my REB’s major concerns with my research ethics proposal was that I did not have a clearly defined plan for how I would assess and support research participants who either arrived at the interview in distress or those who might experience distress as a product of the interview. My REB was particularly concerned that my research participants would disclose the intent to self-harm or to die by suicide, before, during or after their interviews; while they did recognize that the likelihood of such a crisis was extremely low, they nevertheless asserted that I must have a plan for how I would approach such a situation, given the “vulnerable nature” of the proposed research population. Although I understand that REBs were initially designed, in part, to protect folks who are made marginalized and vulnerabilized from being harmed by research, the way in which my potential research participants were being framed as “vulnerable” was used as a justification for enforcing biomedical evaluation and intervention strategies, should any research participants experience distress before, during, or after their interviews – a framing which I argue directly compromises participants’ experiential knowledge, agency, and personal safety.

Within this process, there is an assumption being made by my REB about my potential participant pool – an assumption grounded in the biomedical model of mental disorder which narrowly views self-harm as a pathological, suicidal gesture. Interestingly, in the process of conducting my research, I found that for most people, self-harm was *not* a suicidal gesture and that many found comfort in self-harm as a tool that they could use to cope with intense emotions, including *averting* thoughts of suicide. The assumptions of my REB are therefore troublesome in part because they misrepresent and override the lived experiences of people who self-harm, and in part because this logic then facilitates the mobilization of clinical tools that may cause more harm than good.

I initially proposed to my REB that participants would not be at any greater risk of experiencing distress than do in their daily lives, arguing, as does Holland (2007), that many people talk about their mental health with the people in their lives every day, and that voluntarily participating in a research project that they could withdraw from at any time would hardly be different. My REB did not agree. To assuage their concerns, I cited research that highlights the benefits of participating in mental health research, including research about trauma and suicide. For example, I cited Deprince and Freyd (2006) who found that people who participate in mental health research appreciate being asked questions about past traumas (p. 24). I also cited Cromer et al. (2006), who argue that talking about difficult

or traumatic experiences poses a low risk to research participants, that participants often see the benefit of participating in research dealing with trauma, and that participants generally described positive experiences (p. 348).<sup>5</sup> Finally, I cited Cukrowicz et al. (2010) who found that participants in their study who were experiencing “major depression” and “suicidal ideation”<sup>6</sup> reported less frequent suicidal ideation following their participation in a study about suicide which included suicide-related images, and that their participants exhibited zero self-harm or suicidal behaviour in the three months following their initial participation (p. 353). There are numerous other studies that reach similar conclusions. However, it was the decision of my REB that these references were not “directly applicable to the current situation” because these studies were conducted by clinical researchers and neither I nor my supervisor had clinical expertise. Insisting that the evidence presented about the benefits of participating in research were not relevant due to my lack of clinical experience upholds problematic assumptions that clinicians are better positioned to do “mental health research” and that they are better positioned to support people in crisis, even when we know that clinical crisis intervention strategies can lead to psychiatric harm (Marcus & Stergiopoulos, 2022; Skeem & Bibeau, 2008). Such an argument also negates the importance and role of peer support systems that have been integral to mad and psychiatric survivor movements (Adame et al., 2017; Evans, 2023), although these systems are becoming increasingly formalized, professionalized in ways which “actually cooperate with psy regimes of governance” (Voronka, 2017, p. 333) rather than challenging them.

Because I could not prove that risk to participants would be minimal, I had to devise a detailed plan for how I would assess risk to participants before, during, and after each interview. Ironically, this plan necessarily involved the adoption of clinical texts and tools. The text I was asked to draw from for my risk assessment strategy was the University of Washington’s Rapid Assessment Protocol (UWRAP). The UWRAP is a document used by mental health professionals to assess whether one is “at high risk for imminent suicide or intentional self-harm” (Linehan, n.d.). The document asks a range of questions, including questions about whether someone has taken any substances, their level of stress and anger, desire to self-harm, intent to kill themselves, and desire to hurt another person, all rated on a scale of 1 to 7 (“low” to “high”). My REB strongly encouraged that this tool be used to assess a participants’ level of risk for self-harm or suicide prior to, during, or following an interview. I was required to develop a “decision tree” – a document that would explain how I would aid participants who received certain scores, ranging from helping them with their coping strategies, helping them connect with a loved one, or calling emergency services if it was determined that a person had intent and the means to harm themselves. To me, this constituted a form of suicidism, a term used by Baril (2020) to describe the oppression experienced by suicidal people. As Baril (2020) writes, suicidism is “an oppressive system

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<sup>5</sup> Interestingly, Cromer et al. (2006) criticize institutional review boards for treating research about trauma as higher risk than other forms of psychological research, such as research about body image or sexual behaviours.

<sup>6</sup> As per biomedical language.

(stemming from non-suicidal perspectives) functioning at the normative, discursive, medical, legal, social, political, economic, and epistemic levels in which suicidal people experience multiple forms of injustice and violence” (n.p.). The conflation of self-harm with suicidality and the insistence that potential “suicidal” participants needed to be formally, biomedically assessed constituted a form of oppression that could potentially produce physical and emotional harm – actions which I refused to induce or replicate.

It was also initially proposed to me by my ethics committee that I use this tool prior to asking for informed consent – I was to use this tool to determine whether a participant was calm enough to participate or not. Fortunately, I was able to demonstrate how using the UWRAP as a screening tool prior to the interview was inappropriate, given that I am not a mental health practitioner (as my REB had previously pointed out to me), and given my assertion that people with mental health concerns can still make an informed decision to participate in research which they feel may be beneficial to them.

Although I understand that these suggestions were being presented to me as a means to avoid or mitigate harm, when examined from a mad perspective – which I define as recognizing the historical imposition of harm and violence against mad people by biomedical institutions – these suggestions ultimately come into question. Importantly, many of my research participants disclosed having had negative experiences with mental health care providers, including psychiatrists, counsellors, and nurses. Many were assumed to be suicidal when they were not. Others were accused of attention-seeking and manipulation. Others did not have their experiences of trauma considered or validated when seeking out care. For many, this led to unhelpful or harmful treatment practices, ranging from inadequate therapies to involuntary hospitalizations. On the opposite end of the spectrum, for some participants, medical professionals acted as gatekeepers to care, denying them care when they needed it the most.

Being asked to use clinical tools to evaluate the ability for someone to participate in my research project would have unnecessarily/harmfully (re)created a power imbalance wherein I would be positioned as holding more epistemic power over the people who participated in my research. I fought against my REB knowing that acting as a gatekeeper to participation could harmfully recreate the types of power imbalances that mad people often experience when trying to access mental health care, which my participants would ultimately confirm in their interviews with me. Thus, I would like to assert that the REB’s assertion that I use clinical evaluation tools reflects sanist assumptions about people who self-harm. More specifically, sanism emerged in this context through the assumption that people who self-harm are unable to make rational decisions<sup>7</sup> in the context of their own lives, such as through participating in research about their lived experiences. As Liegghio (2013) argues, “psychiatrized people are disadvantaged against constructions of ‘normal mental health’ and experience their identities as pathologized and devalued, and their

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<sup>7</sup> Perhaps, as Perlin (1992) argues, it sanism that is irrational.

humanity is denied” (p. 123). For Liegghio (2013), this constitutes a form of epistemic injustice, whereby psychiatrized people are “disqualified as legitimate knowers at a structural level” (p. 123) specifically through “the treatment of their knowledge and ways of knowing as something other than knowledge and something other than legitimate” (Liegghio, 2013, p. 125). In my engagements with my REB, I asserted that it is not the researcher’s decision whether it is reasonable for the research to proceed based on a set of formulaic questions. Research participants can make that decision for themselves, and to suggest otherwise is to buy into the sanist logics that govern medical and social attitudes about self-harm, which include the belief that people who self-harm are inherently suicidal (Brown et al., 2002; Chan et al., 2016; Kiekens et al., 2018; Klonsky, 2007) or “personality disordered” (Krysinska et al., 2006; Steggals, 2015) which can sometimes lead to their psychiatric incarceration, even if a person’s experience of their self-harm does not align with these narratives. There has been some recognition in recent years that self-harm can occur within a non-suicidal context, with the introduction of nonsuicidal self-injury disorder (NSSID) being introduced in the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5) in 2013 as a “condition in need of further study” (Zetterqvist, 2015, p. 1). However, the stories of my research participants affirmed that the professional interpretation of self-harm as a suicidal gesture is still prominent. For example, many of the people who participated in my research were assumed to be suicidal, even though their experiences and motivations for self-harm were not rooted in a desire to harm, but rather a desire to live. Indeed, Shaw (2016) challenges dominant framings of self-injury as a suicidal act, arguing instead that self-injury can represent a “decision to stay alive” (p. 77). Similarly, Redikopp (2021) frames self-injury as a “politics of survival” (p. 21), and problematizes the dominant categorization of self-injury as a symptom of mental illness. My REB’s decision to ask me to utilize the UWRAP assessment form was likely conducted outside the knowledge of these alternative perspectives, which speaks to the hegemony of biomedical perspectives of self-harm that place it within a risk paradigm.

In addition, using clinical assessment tools may have also unknowingly (re)created a harmful dynamic whereby the people who participated in my research may have felt that their participation in my project may have been predicated on “good behaviour” – a dynamic which they may have experienced in mental health care settings. For example, one of the people who participated in my research told me that it was important for her to have a therapist who did not make assumptions about her mental state when talking about self-harm. She said it was important that mental health professionals are “aware that [self-harm is] not always an impulsive thing and you’re not necessarily going to find somebody was in a full-blown panic attack or something while engaging in that behavior.” Should I have been required to use the UWRAP as a tool for evaluating this participants’ fitness to participate in her interview, I may have unknowingly reproduced this same dynamic. Making assumptions about participants’ emotional states denies and undervalues experiential knowledge, which was the foundation of my ethnographic research. My REB’s insistence that I use clinical assessment tools contradicted by own ethics as a mad person and a psychiatric survivor,

which are grounded in epistemic justice and the belief that psychiatric incarceration can be a source of trauma, especially for people who are made-marginalized by carceral and biomedical systems, including Black, Indigenous, and People of Colour (BIPOC), Two Spirit, lesbian, gay bisexual, trans, and queer (2S/LGBTQ+) people, women, and/or disabled people.

Fortunately, and perhaps not unexpectedly, none of the people who participated in my research became distressed before, during, or following their interview. Most expressed gratitude to be able to have a space to talk about their experiences and the knowledge they hold. Others found the concept of being distressed to the point of an intervention during or following their interviews was illogical. Others stated that they were living with people who could support them should they become distressed but assured me at the end of their interviews that they did not find the content of their interviews to be distressing. This feedback from participants affirmed my perspective that the forced integration of the UWRAP into my ethics proposal was overbearing. In what follows, I discuss how sanism and biomedicalism occur within broader matrix of risk aversion that overshadows what is ethical from a mad, anti-racist, and anti-carceral standpoint.

### **Ethics or Risk Management?**

In addition to requiring me to have a clearly defined crisis plan, my REB also required me to clearly state the limits to confidentiality in my combined letter of information and consent form which I read to participants via screen share at the beginning of each interview. More specifically, I had to tell participants that if they expressed an intent to die by suicide, I would have to call emergency services. For those of us with lived experience of madness, and/or those of us with expertise in mad and psychiatric survivor studies, we know that the involvement of emergency services in the context of a mental health crisis can lead to harm, including physical violence, physical and chemical restraint, and in some cases, even death, especially if the person in crisis occupies a marginalized identity.

In the process of conducting my doctoral research, I learned that people who self-harm are more likely to be treated negatively by health care providers, particularly nurses (Commons Treloar & Lewis, 2008; Mandal & Kocur, 2013; D. G. Shaw & Sandy, 2016; Woollaston & Hixenbaugh, 2008). For example, some nurses view people who self-harm as “time wasters and unworthy of treatment” (D. G. Shaw & Sandy, 2016, p. 407) while Woollaston and Hixenbaugh (2008) argue that nurses see “borderline” patients – who often self-harm – as “destructive whirlwinds” (p. 703). According to survivor perspectives, this is certainly true in many emergency departments, and the idea that people who self-harm are unworthy of treatment is evidenced by mockery, physical abuse, and neglect. Some survivors report having their wounds stitched without painkillers (Pembroke, 1994) because it is believed that they can’t feel pain. Others are denied treatment altogether because they are seen as attention-seeking and manipulative, “a thorn in the flesh” of many clinicians (Royal College of Psychiatrists, n.d.). Knowing this, was my REB’s insistence on involving emergency

services in the event of a crisis a truly “ethical” decision? Or does it better reflect an institutional risk management strategy that is imbued with sanist and biomedical discourses of self-harm that are based in the protection of the university from liability? Such a policy seems designed more to punish non-normative behaviour rather to protect.

Luckily, no one who participated in my research was concerned when I told them that emergency services would be required to intervene should they disclose an intent to die by suicide before, during, or after our interview. In fact, many of them were confused as to why it was necessary. One participant even laughed at the thought. No one who participated in my research indicated signs of distress during my interactions with them and I luckily did not have to break confidentiality at any stage of research. Yet, I wonder how my interviews may have gone differently should I have not had to make such a statement. Would people have been more open with me about their experiences? Would they have felt safer? What would have happened if I did need to call emergency services? Would that decision, as enforced by my REB, still be ethical should someone be harmed in police custody or in the hospital? What might happen to participants who are more likely to experience police and psychiatric violence, such as racialized people, queer and trans people, Mad and disabled people? My research included queer, trans, and disabled participants. Evidently, there are areas for improvement when considering what is “ethical” and what is not in the context of mad and psychiatric survivor research, which I expand upon below.

### **Toward a Mad Ethics**

Thus far, I have problematized how my REB approached my proposal to do research with people who self-harm, pointing to issues of biomedicalism and sanism. But what would an ethics that centres the reality of people who self-harm look like? What would such an ethics provide, not just in terms of addressing the issue at hand, but in terms of the types of institutional disjunctures that I have described in the social processes of diagnosis and treatment? How might we think about doing ethics differently?

#### *Mad Methods and Epistemology as Ethics*

LeFrançois and Voronka (2022) offer one helpful framework through which we might imagine doing ethics differently. Drawing from mad studies and critical disability studies, LeFrançois and Voronka’s (2022) approach to thinking about research ethics centres mad people and mad epistemologies. The authors call for a fundamental reimagining of research ethics – what they call an “ethics of unruliness” (LeFrançois & Voronka, 2022, p. 106) – which “argues for a radical departure from the urge to make mad subjects both knowable and governable, or to *make sense* of that which cannot and should not be reduced to the rationalist’s desire for uniformity, consistency, universality and conformity to the dominant logics of the sanestream” (LeFrançois & Voronka, 2022, p. 108).

LeFrançois and Voronka's (2022) call to depart from "the urge to make mad subjects both knowable and governable" (p. 108) aligns closely with the arguments made in my work more broadly. As I showed, people who self-harm do so for various reasons, many of which counter dominant biomedical discourses that try to make people who self-harm knowable through certain labels such as "attention-seeking" and "manipulative," or through the diagnoses of borderline personality disorder or depression, for example. It is difficult to know and make sense of self-harm in any uniform way because people who engage in self-harm do so for myriad reasons, including to cope with sadness, to communicate distress, and even to elicit pleasure. There are certainly patterns that can be detected, but there is no such thing as a universal "self-harm" subject. This poses problems in the context of institutional ethics processes that operate on positivist logics, such as biomedical discourses of mental illness. These biomedical discourses, when treated as irrefutable facts, can lead to certain forms of medical interventions that can be more harmful than helpful. The same is true of research ethics when these discourses are uncritically applied. If institutional ethics boards are relying on these same biomedical logics to inform their decision-making about how to regulate mad research – research that is by and for mad people – it makes sense that the potential for harm in a research setting is also possible. Resisting the urge to make mad subjects knowable through dominant discursive frameworks would be a step in the right direction toward a mad ethics.

Another important aspect of LeFrançois and Voronka's (2022) conceptualization of a mad ethics is the adoption of transnational feminist, critical race, and postcolonial theories, which they mobilize to unsettle "the dominance of the (white) academy as the hegemonic source of knowledge production" (LeFrançois & Voronka, 2022, p. 106) and to destabilize formulaic, rules-based, and biomedicalized approaches to ethical approval (LeFrançois & Voronka, 2022, p. 108). Tackling mad ethics from a transnational, feminist, and critical race perspective is paramount given the intimate relationship between sanism and racism, and the role that both play in the regulation of who is seen as mad and who is not. Building on this assertion, I also argue that integrating the concept and practice of relationality is a useful tool for reshaping institutional research ethics processes.

### *Relationality*

As Grenz (2023) writes, there must be "reflexivity and relationality" (n.p.) in the development of Indigenous research ethics, particularly for research that is proposed by Indigenous researchers. Campbell et al. (2020) define relationality as "a philosophy that describes the interconnections between all of creation and kinship consists of family, community, and all extended human and more-than-human relations" (p. 8) and describe relationality as being "built upon interconnections and interrelationships" (Campbell et al., 2020, p. 9).

Tynan (2021) writes that relationality is practiced as an "ethic of responsibility" (p. 604) to help avoid an extractivist mindset when doing research with Indigenous communities. In

speaking to the importance of relationality here, and in advocating for its practice in psychiatric survivor research, I am mindful of the ways in which Indigenous knowledges and practices have been extracted by white western researchers and used in ways which do not honour Indigenous ways of knowing and being in the world. At the same time, I believe that relationality is paramount to conducting ethical research in mad studies, particularly given that colonialism and sanism are so deeply intertwined.

Martin (2017) outlines ways of doing ethics that are grounded in an “Indigenous way of relationality” (p. 1399). This way of doing ethics includes considering the position of both the researcher and the participants, whereby the researcher situates themselves in relation to the research participants and whereby participants are positioned as co-producers of knowledge and a subject rather than a mere object of the research (p. 1399). Martin’s (2017) relational approach to research ethics includes recognizing that:

- the nature of the participant is in relation to Country and other entities;
- the importance of lived experience and its relation to use value in research;
- the location of the research needs to be paramount in terms of whether the community approves the competency of the research;
- the participant reserves the right to consent orally;
- principles need to be negotiated and are not necessarily binding because lived experience and actuality of relationality is ever moving. (p. 1399)

While these guidelines are paramount to the development of relational ethical research, of these guidelines, the recognition that lived experience is valuable in the context of research –and the recognition that lived experience and the actuality of relationality are ever-moving – stand out to me as principles that should be integrated into ethics approval decision-making processes. Adopting a relational approach in the context of research ethics would aid in recognizing that each participant brings their own unique experiences to the research, and therefore that REBs cannot appropriately create universalized standards of engagement, if we are to engage respectfully and fairly with research participants.

A relational approach to conducting ethical research in the context of my project may have looked like creating the terms of engagement – what ethics calls a letter of information and consent form – together at the outset of the interview. Such an approach would not assume certain emotional reactions to the interview but would instead ask participants what their triggers and boundaries are. The participant would be the one in control of determining how they would like to engage, and at which point they would wish to terminate their participation. This approach is more respectful of participants’ experiential knowledge and agency and is a less paternalistic approach to trying to “protect” mad people from research which may be beneficial to them. At the same time is it important to remember that:

Relationality is not easy, especially when living in a settler-colony. It means sometimes we are out of practice or taught by the university to research in non-relational and extractive ways, using strict time frames, restrictive academic writing styles, hierarchical notions of expertise and colonial discourses of “discovery,” “finding the gap” and “collecting data.” (Tynan, 2021, p. 599)

Importantly, I found it difficult to make the decision to go forward with this research project because of the pushback I was getting from my REB because I was being encouraged to act within hierarchical notions of expertise and in non-relational ways. My institution’s way of doing things was compromising my relationships with my research participants in the name of “ethics” by forcing me to adopt clinical tools that may have replicating traumatizing power relations experienced in mental health care systems, and by potentially putting them in harm’s way by involving emergency services. A more relational approach may have been to allow me to talk to people about their relationships with policing and psychiatry and to explore other relationships in their lives that have provided them with the best support, outside of carceral institutions.

Here, it is also important to think about REBs as being in relation, both with my research participants and myself, and not just as an external agency which has no bearing on the researcher-participant relationship. As Juritzen et al. (2011) argue, “ethics committees [are] one among several actors that exert power and that act in a relational interplay with researchers and participants” (p. 640). Notably, at no point during my engagement with my REB did they see themselves as a potentially unethical actor. In my interactions with them, it was clear that it was difficult for the REB to see their policies as problematic and potentially harmful, even when I cited research that contradicted their concerns. This lack of attention to power mirrors that of psychiatry and other mental health professions, which play into the regulation of people who self-harm – both of which operate on unquestionable assumptions of epistemological validity and superiority disguised as ethical and effective processes. Thus, challenging the epistemological biases of institutional ethics review processes is paramount to ensure that mad, psychiatric survivor research within the academy can be conducted safely and in relation.

## **Conclusion**

In this work, I have drawn attention to how the knot of sanism, biomedicalism, and risk management created an environment wherein it was extremely difficult for me to receive ethics approval for my research with people who engage in self-harm. In the context of my engagements with my REB, biomedicalism emerged in the form of assuming that people who self-harm must do so because of severe mental disorder. This framing of self-harm thus justified my REB’s assertion that they could ask me to conduct clinically informed assessments with participants to determine whether they were stable enough to partake in

an interview. This intersected with sanist attitudes toward my potential participants – a subjugation of their experiential knowledge and a form of epistemic injustice.

In the absence of contextually-specific approaches to research ethics, particularly the management of risk, and in the absence of a more reciprocal dialogue with qualitative researchers and alternative epistemologies, current institutional ethics discourses, policies, and processes will continue to construct and maintain barriers to mad studies research and may jeopardize the safety of research participants through their mobilization of biomedical narrative of madness and coercive and harmful forms of intervention.

These barriers to research by and for mad people have a broad impact on our knowledge of emotionality, madness, and “mental illness,” given the power that ethics boards hold over the production of academic research. Anything other than contextually specific approaches to mad research, and qualitative research more broadly, are merely the mobilization of dogmatic, sanist, biomedical discourses that do more to uphold the status quo than they necessarily do to protect mad people from harm in psychiatric survivor-based research.

Madness, as a different way of knowing and being, can be easily ignored as a source of information for framing research populations and ethical modes of engagement. That is why approaches to doing ethics differently should include mad epistemologies, methodologies, and insights from psychiatric survivor research. In framing mad populations as inherently vulnerable, REBs are putting these populations at risk, as once this group is identified as such, REBs put into motion the types of policies that I have problematized in this paper, many of which are biomedical and carceral, and which place mad participants into forms of danger that they may not have otherwise been subjected to. People who self-harm deserve to have spaces where they can talk about their experiences free of carceral rules and logic – without any fear that they are going to have their rights taken away from them in the name of “safety.” The idea that calling emergency services on a distressed participant would have been a “safe” intervention shows just how far-removed institutions like REBs are from the realities of mad people, especially racialized mad people, who are at much greater risk of experiencing psychiatric violence and abuse.

Ultimately, to receive approval for my project, I compromised with my REB because I believe more research on self-harm from a mad studies perspective is needed. I also decided to make a compromise because living in a colonial, neoliberal, and sanist society requires all of us to make compromises to survive. For example, I am a very outspoken critic of psychiatry, yet I engage with it because there is little alternative; in the absence of adequate community care, medications are one of the only fixes that I can rely on. In contending with these types of contradictions, it is important not to lose sight of the ways in which we can and must challenge them. As others have shown, there are ways that we can go about doing research ethics differently, such as through integrating mad methods and epistemologies, psychiatric survivor perspectives, collective action, and including communities in the development of research and ethical protocols. After all, as Halse and

Honey (2005) remind us, we are morally and ethically responsible to our research participants, and part of that process of accountability and responsibility necessarily involves pushback. In the context of my work, I felt that I had a moral and ethical responsibility to my research participants to create a space where they did not have to exist under the threat of violent mental health intervention strategies, but I was unable to fulfill that responsibility within the constraints of the current system. I decided I would do my best to play by the rules while making my position on these policies explicitly clear to participants. I made sure they understood that the limits to confidentiality clause in the letter of information and consent form was an institutionally mandated policy, and not a policy that was reflective of my politics. This was my form of resistance.

Through examining my experiences with my institutional REB, I have demonstrated how sanism has been integrated into intellectual institutions. It is my hope in that exploring these discourses outside the original context of my study, future research in this area, and in mad research more broadly, will think more expansively about sites of engagement and will consider the extent to which the psy complex and sanist forms of regulation exist all around us, not just within traditionally defined mental health institutions such as hospitals and therapy clinics. The university is but one additional site where sanist, colonizing and biomedical discourses operate. Disrupting institutional knowledges that forward dominant discourses of madness or “mental illness” is therefore a critical strategy in ensuring that critical, mad and psychiatric survivor research can be produced in ways that uplift and amplify mad people and psychiatric survivors, instead of positioning them in harm’s way.

**Acknowledgements** - I am grateful to Dr. Samantha King for her guidance throughout my doctoral research, upon which this article is based, and to Dr. Karen Lawford for her assistance in helping me navigate the ethics approval process.

**Integrity Statement** - I certify that this work this manuscript is original and has not been published elsewhere nor is it currently under consideration for publication elsewhere.

**Conflict of Interests Statement** - I declare no conflicts of interest.

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