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Constituting "Lived Experience" Discourses in Mental Health: The Ethics of Racialized Identification/Representation and the Erasure of Intergeneration Colonial Violence

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Abstract

The term "lived experience" has been used widely in mental health literature and research to claim a proximity to authority and authenticity in relation to voice and identity. Through an examination of literature from the perspectives of Critical Mental Health, Mad Studies, and Critical Disability Studies, "people with lived experience" discourses are contested for perpetuating social relations of white supremacy. The ethics of "lived experience" discourses are questioned for their role in (re)positioning of modernistic ideas of experience and Eurocentric systems of identification as dominant. "Lived experience" in mental health research is often understood as inseparably connected to those who have used or been coerced by Western models of mental health services, often those specifically formed by or with biomedical psychiatry. This omits appreciations of the over-criminalization and dehumanization of racialized people and indigenous peoples who struggle with distress and suffering. Racialized and indigenous peoples often find themselves at the mercy of criminal justice and immigration systems, while mental health services are differentially accessed or imposed. Mental health for racialized and indigenous peoples is often referenced to support prosecution, to establish threat, risk, biomedical inferiority, and ideas of dangerousness. While contributions from Mad Studies and Critical Disability Studies have helped many to appreciate the value of the voices of those who have experienced the effects of services and systems, the ethics of self-identification alongside systemic and structural analyses of identification/representation for racialized and indigenous peoples are often inadequate. The divergent identification/representation processes, practices, and technologies that essentialize criminality, alienism, and biological inferiority for racialized and

indigenous peoples are analyzed through an attention to the erasure and devaluing of the repercussions of intergeneration colonial violence and subjugation. An appreciation of identity and experience as a social, historical, and political confluence is offered as an ethical response to the technologies of identification/representation that order hierarchies of voice and agency and attempt to silence ongoing practices of racist and eugenic colonial violence.

Keywords: lived experience, ethics, Critical Mental Health, Mad Studies, racism, eugenics, colonization, confluence

Introduction

I often feel pressured to respond to the unsolicited question, 'whose lived experience counts and what counts as lived experience?' Who are we talking about and what experiences are legitimated? These questions are central to the issues raised for this special issue of the *Journal of Ethics in Mental Health* as many struggle to appreciate the ethics and historiography of political identities related to lived experience discourses. Contributions from Mad Studies and Critical Disability Studies have helped and continue to demonstrate the need to appreciate the value of the voices of those who have experienced the effects of mental health services and systems. One of the major contributions from Mad Studies and Critical Disabilities perspectives is the acknowledgment and respect for the knowledge of those affected by, surveilled, taxonomized, and essentialized via their proximity to mental health, psychiatric, and medicalized services. These perspectives have been historically and systemically undermined if not entirely dismissed from consideration within dominant psy-professions and disciplines that maintain a hegemonic position of authority within policy, practice, knowledge, law, and service for those who use mental health and disability services. These hegemonic authorities affect those found at the confluence of juridical medical systems that govern mental and physical distress and suffering as anomalous pathology, threat, and deviance.

One of the primary concerns for critical perspectives is an attention to and respect for critique that can recognize and then amplify that which has been historically left out. Critiques themselves can also re-inscribe foundational, irreconcilable problematics via their contributions. However, congruent with the critical project is the ethical responsibility to consider that knowledge and those perspectives

that are indeed systemically, discursively, and structurally undervalued and subjugated while adding to existing valuable praxis. In this paper, I will suggest that the attention to the ethics of self-identification alongside systemic, discursive, and structural analyses of identification/representation for racialized and indigenous peoples are often fundamentally inadequate within Mad Studies and Critical Mental Health literature in their (in)attention to intergenerational forms of colonial violence and the impacts of "lived experience" identities as an access point to community and justice.

In this paper, through an examination of literature on lived experience from the perspectives of Critical Mental Health, Mad Studies, and Critical Disability Studies, "people with lived experience" discourses are contested for perpetuating social relations of white supremacy. The divergent identification/representation processes, practices, and technologies that essentialize criminality, alienism, and biological inferiority for racialized and indigenous peoples are analyzed through an attention to the erasure and devaluing of the repercussions of intergeneration colonial violence and subjugation. These processes and practices are critically important for how we consider (or erase) how racialized and indigenous peoples differentially inherit and live the intergenerational effects of colonial violence, and what this means for lived experience discourse. An appreciation of identity and experience as a social, historical, and political confluence is offered as an ethical response to the technologies of identification/representation that order hierarchies of voice and agency and attempt to silence ongoing practices of racist and eugenic colonial violence.

A site of ethics: Whose lived experience?

The term "lived experience" has been used widely in mental health literature and research by scholars and activists in the United Kingdom, North America, Australia, and Asia to claim a proximity to authority, expertise, and authenticity in relation to voice and identity, while challenging the dominant systems of biomedical pathologization of human suffering (Barker, 2001; Van Lith, Fenner, & Schofield, 2011; Pattadath, 2016). As Bindhulakshmi Pattadath (2016) has commented, "Although we argue for political solidarity among survivors, the specific experience of going through the mental health system cannot be the only determining identity for forming any sort of collectivities" (p. 205). Much of the recent literature on Mad Studies and lived experience in mental health systems and services has come out of Canada, the United States, and the United Kingdom. Much of the literature

review in this paper draws on that growing body of literature in relation to themes of identity, ethics, and social relations that can be considered and applied in other global and local contexts.

As a movement, the demand for attention to the lived experiences of those who encounter mental health systems and services raises ethical questions about knowledge production and the productions of professions and disciplines (Sweeney, 2016). Many have focused on lived experience discourse to recognize that lives are involved, affected, are not just diagnoses and illnesses to be cured, surveilled, and coerced but people to be heard to improve systems and services (Bradstreet, 2016; Deegan, 2007; de Jager et al., 2016). The people with lived experience (PWLE) discourses become murky and opaque as they have been engulfed by pathologizing biomedical psychiatric discourses to rationalize these services, reinforce notions of personality disorder and chronic illness, while sometimes even reverting the focus back onto the mental health professionals themselves or to rationalize coercion and violence (Eakes, 1995; Fallon, 2003; Drury, Francis, & Dulhunty, 2012; Light et al., 2014).

PWLE discourses in mental health literature and elsewhere are often fashioned to both constitute what perspectives can be considered valid and to legitimize these avowals in relation to existing and co-constituted, historical Eurocentric/American, colonial systems of biomedical, criminal, and immigration identification/representation. Shaindl Diamond (2013) has shared reflections on what the language of identify might mean for solidarity. Specifically, what and who does psychiatric survivor or the Mad constituency community attend to or include? "Lived experience" in mental health research is often understood as inseparably connected to those who have used or been coerced, encapsulated, defined, or "served" by North American and European models of mental health services, often those specifically formed by or with biomedical psychiatry. While this has been resisted, the attribution of what constitutes lived experience regularly omits appreciations of the over criminalization and dehumanization of racialized people and indigenous peoples who experience distress and suffering. Also obscured is the tendency for racialized people and indigenous peoples to find themselves within the dominion of criminal justice and immigration systems while mental health services are differentially accessed or imposed. When race is commented on within PWLE discourse, it presents a need for North American and European psychiatric models of mental health services and relies on individualized psy-pathological constructs (Smedley, 2012). Others have critiqued the racism within psychiatry without focusing on lived experience, while leaving systems of identification,

taxonomization, and essentialization intact (Fernando, 2010). In a somewhat rare study of the lived experiences of mental and emotional distress of twenty-seven racialized African, African-Caribbean, and South Asian women, "Many participants felt that mental health services and recovery frameworks did not account for their experiences of racism and other discrimination, essentially failing to address a significant part of their distress" (Kalathil, Bhakta, Daniel, Joseph, & Trivedi, 2011, p.3).

As Jijian Voronka (2016) has proposed,

> as 'people with lived experience' becomes a new identity category to organize widely heterogeneous bodies of experience together, we need to start marking and making connections across some philosophical and practice-based issues that arise in reifying 'people with lived experience' as an undisputed and cohesive category. (p. 190)

This difficult task of appreciating the position of the experiences, voices, and knowledge of those who live out the effects of psychiatrization or pathologization carries with it the problems and ethics of representation (how we portray, depict, or talk about experience and symbols), technologies of subjectivity (how we come to be made as subjects, identities, etc.), alongside calculated spaces for resistance relying on strategic essentialism and self-governance to challenge modes of regulation as they are linked to operations and relations of power. Voronka (2016) describes that, while scientific and biomedical explanations have contributed to subjugating and constricting people's experiences and identities, "such explanations create opportunities for resistance by offering openings to construct counter identities against this defining norm" (p. 193).

The constructions/constitutions of counter identities and the positions of resistance that have resulted from psy-interactions have had to continually respond to the neoliberal mechanism of cooption and appropriation (Beresford and Russo, 2016). Specifically, concepts of recovery and peer support have been appropriated by psy institutions in tokenistic ways to convey an attention to the oversimplified idea that people can recover from experiences of distress and that service-user experiences are valuable to services. Within psy institutions, these (re)processed versions of recovery have come to mean you still are a biomedical problem but you can live a dreamy neoliberal existence achieving "satisfying and productive lives", "with a message of individualism, empowerment and choice" (Sowers, 2005, p. 757). These contributions that recognize the value of service-user voice, Mad voices, and alternatives to biomedical psychiatry have been, in some instances, appropriated

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and co-opted by traditional biomedical psychiatric institutions that add peer-support roles to current services in ways that counter the work of resistance. The cooption of user involvement has been (re)positioned such that a service-user can provide "peer support" in ways that assist people in accepting psy-institutional services (Dennis, 2003). However, Solomon (2004) for one has described that the necessary ingredients of "peer support" include "peer delivered services" and "peer run and operated services" (p. 393). Personal stories of lived experience with psy institutions, suffering, and distress have also been appropriated by the psychiatric system as "disability tourism" or "patient porn" to "bolster research, education, and fundraising interests" (Costa et al., 2012, p. 85). Relying on lived experiences and stories for marketing purposes repositions and recreates social relations of exploitation that also feed progress discourses that transformation is occurring.

As counter identities have emerged, they too have been ordered and stratified in ways that subjugate and constrain notions of lived experience. *If* a decolonized idea of lived experience that values the perspectives of those who encounter psy institutions or experience distress is to be constituted, it must be done in ways that recognize how racialized and indigenous people heterogeneously, intergenerationally, and differentially inherit and live the effects of colonial violence and dehumanization that also stratify contemporary legitimization criteria within lived experience discourses. Here, we must also appreciate that this project is and should be continually dedicated to understanding the confluence of historical processes of identity formation and stratification and how these discursive products frame experience. Recognition alone can be a problematic ethical demand as it can reproduce cultural hierarchization that repositions dominant groups as distinct fixed identities (Cornell & Murphy, 2002).

As Carla McKague discusses in issue #1 of *Phoenix Rising: The Voice of the Psychiatrized* (1980 to 1990), the myth that people diagnosed with "mental illness" are dangerous or violent is a falsehood that is exacerbated by sanism within the media and within biomedical psychiatry and its affiliated or allied disciplines. McKague notes that "every single study" demonstrates that rates of violence are lower among the psychiatrized than the general population and psychiatrists "grossly over predict" dangerousness among those diagnosed with "mental illness" (McKague, 1980). This theme of analysis is heavily drawn upon within Critical Mental Health literature. This position is often employed to convince the "general public" that people diagnosed with "mental illness" are not dangerous while simultaneously the disproportionate use of incarceration, coercion, and the discourse

of dangerousness to criminalize racialized and indigenous people in mental health systems proceeds relatively untouched.

As Frank Keating has outlined, scholars have repeatedly noted that how we talk about race and madness has been inadequate. Specifically, authors such as Patel (2014), who demonstrates through a depiction of the/a "Mad Muslim terrorist" in Canadian media how racial ideas are imbricated in the popular understanding of madness; Louise Tam (2013), who explores the gap between race and madness vis conviviality; Nadia Kanani (2011), who argues that "race and madness have been mutually socially constructed in Canadian and American Society" (p. 1); and Rachel Gorman (2013, cited in Keating, 2016) who comments that a lack of critical race analysis exists within Mad Studies and there must be a more intentional connection between the psy-survivor movement and those of racialized groups. Asylum magazine published *Mad People of Colour: A Manifesto* to highlight many of these concerns; specifically, the authors note that, "We write this manifesto because we know that racism, sexism and oppression circulating in the system are also circulating in the mad movement*" (*Gorman, Saini, Tam, Udegbe, & Usar, 2013).

Kanani and Tam suggest that in order to appreciate how Mad identities are complicated by race, we need to appreciate how they are co-constituted historically and how these ideas are manifested in contemporary experience.

As I have commented elsewhere, mapping of critical race theory onto Critical Disability Studies or Mad Studies precludes an ability to appreciate the confluence of racial, sanist, eugenics, and ableist ideas as they have proceeded from historical constructs such as *undesirability* and *prohibited classes* that intersectional approaches and analysis of interlocking systems of oppression have historically left out (Joseph, 2015). This is an ethical problem. The values, principles, and standards for appreciating lived experience within Critical Disability and Mad Studies have (re)produced a general neglect for the kinds of dehumanization and violence experienced by racialized and indigenous groups.

The politics of lived experience: Race, hierarchy, erasure

Without specifically remarking on the effects of systemic and intergeneration racism, a study with 755 Aboriginal Australian participants revealed, "Experiencing interpersonal racism in health settings is associated with increased psychological distress over and above what would be expected

in other settings" (Kelaher, Ferdinand, & Paradies, 2014, p. 44). Williams and Williams-Morris (2000) have pointed out from the lived experience of African Americans that racism as a system and structure can limit socioeconomic mobility and it can affect access to resources and living conditions while inducing "physiological and psychological reactions that can lead to adverse changes in mental health status" (Williams & Williams-Morris, 2000, p. 243). These arguments or positions convey the message that racism produces "objective" Westernized conceptualizations of harm (such as post-traumatic stress disorder (PTSD), for example) that we should all be concerned with (Williams, 2013). This is, in effect, a recognition claim and a claim to recognize that racialized minorities are affected by racism while simultaneously demanding recognition of the issues of disproportionate access to mental health systems and services for racialized people. What these positions inadequately consider most often is that mental health systems and services have historically been fashioned for Othering, nation building, and segregating purposes that targeted people based on race (Metzl, 2009, McLaren, 1990). These systems produce harm to racialized groups as well as further experiences of racism today as they continue colonial relations and projects (Heaton, 2013; McCulloch, 1995; Smith, 2014; Vaughan, 1991).

Prior to the American Civil war, black men were often depicted in docile terms, rationalizing slavery. After the Civil War, during what is referred to as the period of reconstruction (1865-1877), freed black slaves were feared as legitimate threats to white supremacy (Smiley & Fakunle, 2016). "This fear was met with a shift from Black people being viewed as compliant and submissive servants to savages and brute monsters" (Smiley & Fakunle, 2016, p.5). The fear of blackness over time was associated with a direct threat to white women, rationalizing the criminalization and persecution of black men while positioning defenders of white supremacy (including the Ku Klux Klan) as "heroic and honorable" (Smiley & Fakunle, 2016, p.6). Within contemporary mental health systems and services, "black and minority ethnic groups are less likely to be offered psychotherapy, more likely to be offered drugs, and more likely to be treated by coercion, even after socioeconomic and diagnostic differences are considered." (McKenzie & Bhui, 2007, p. 650).

Often the racism within mental health systems and services is analyzed as an effect of racial profiling. In 2003, the Ontario Human Rights Commission published a report as a result of an inquiry into the practice and effects of racial profiling. They defined racial profiling as,

any action undertaken for reasons of safety, security or public protection that relies on

stereotypes about race, colour, ethnicity, ancestry, religion, or place of origin rather than on reasonable suspicion, to single out an individual for greater scrutiny or different treatment. (Ontario Human Rights Commission, 2003, p.6)

The inquiry found that most people who shared experiences of racial profiling were identified as "Aboriginal, African Canadian, Arab, Chinese and South East Asian, Latin American, South Asian and Muslim" (Ontario Human Rights Commission, 2003, p. 7). The report notes that racial profiling causes much harm, making people fearful and anxious through intimidation with increasing feelings of hopelessness. These harms manifest in "tearfulness, nightmares, difficulty sleeping, suicidal thoughts, depression and drug abuse. Several participants reported seeing, or having their child see, a psychologist or therapist to cope with the mental aftermath of racial profiling" (Ontario Human Rights Commission, 2003, p. 47). In 2017, the Ontario Human Rights Commission published another report entitled, *Under suspicion: Research and consultation report on racial profiling in Ontario.* Fourteen years later, many of the experiences were similar. The report added much needed detail to the 2003 inquiry confirming for many that racial profiling is experienced across services and sectors including*:* "Police", "Courts", "Corrections", "Child Welfare", "Transportation", "Education", "Health Care", "Private Businesses/Retail Sector/Private Security", "National Security", "Government and Social Services", "Housing", and "Employment" (Ontario Human Right Commission, 2017, p.1).

The Health Care section of the report notes significant dehumanizing racism generally and within the mental health system. One vignette offered from a participant identified as "Black female, age 25-34" described being forced into isolation for coughing (which was not the reason for her visit to hospital) rationalized with concerns about "Ebola", while her daughter, "identified as white" who "presented with more symptoms of possible Ebola (including fever)" was not isolated (Ontario Human Right Commission, 2017, p. 64). The Canadian Mental Health Association of Ontario is referenced in the report for submitting that "racialized individuals with mental health disabilities may be profiled based on their race, mental health, or both" and "that the use of force by hospital security staff against racialized people with mental health disabilities is an issue of significant concern, and that the use of physical and chemical restraints may also be a problem" (Ontario Human Right Commission, 2017, p. 65).

The report also references Rachel Spector, Arthur Whaley, and Eric Jarvis, who state that in the United States and the United Kingdom, dangerousness is more likely to be erroneously attributed

to black males (Spector, 2001; Whaley, 1998), and in Canada, race plays a role in the use of restraints on those admitted to hospital and "other control mechanisms for patient**s** with psychosis", i.e. "Black patients were chemically restrained and secluded more often than White patients" even after "controlling" for other variables (Jarvis, 2002; Ontario Human Right Commission, 2017, p. 65-66). These attributions of dangerousness and aggression to racialized and indigenous people has historically been supported by Western biomedical psychiatry to align with nationalist ideas, nation building, and colonization (Dowbiggin, 1997; Metzl, 2009; McLaren, 1990; Yellow Bird, 2004). These ideas were historically consolidated through the processes of dehumanization attached to colonial, national building projects that attached notions on incivility, savagery, criminality, deviancy, and madness directly to black and indigenous bodies (Dowbiggin, 1997; Metzl, 2009; McLaren, 1990; Yellow Bird, 2004).

For racialized and indigenous people who have lived experience, often experiences with the criminal justice system, child welfare, and immigration system may be more immediately proximal (Primm, Osher, & Gomez, 2005; Taylor, 1991; Pon, Gosine, & Phillips, 2011). For racialized and indigenous academics, this can limit the inclusion of these groups without medical and professional diagnoses that constitute Western notions of lived experience and thereby render them primarily persons who are a danger, criminal, or illegal. Intergenerational forms of lived experience are also underappreciated for how they are *lived* by racialized groups and people of colour. This can contribute to resistance to disclose suffering and struggle to conventional mental health systems and services. Often resistance to disclosure is also connected to the idea of internalized sanism, shame, or the effects of "stigma" (Corrigan, 2004; Sartorius, 2007). I am a descendent of indentured labourers from India, brought by colonizers to toil in sugar plantations in Guyana alongside a rum industry which was also used to effectively sedate the labouring populous. This context brought with it experiences of extreme poverty, poor living conditions, alcoholism, and violence that have affected my people intergenerationally. As a racialized person who has experienced racial profiling by police, I also know the effects of being more likely to encounter criminal justice systems. I may be less likely to disclose my own personal encounters with social work and psychiatry as these were complicated by a confluence of factors: specifically, being perceived with suspiciousness and inferiorizing judgments about my family, concerns about associating with "the wrong crowd", and being preemptively "treated" for "drug use" based on who I am. This is also complicated by my work later in life inside psy systems as a social worker. Without sharing my entire life story, these experiences were/are imbricated with

histories which cannot be separated from histories of colonial subjugation and viewed solely through my proximity to mental health systems and services. My experiences also positioned me to be profiled in terms of race, criminality, and inferiority (in terms of behaviour and parenting) more so than "mental health". These experiences also may more likely be associated with aggression and dangerousness, and affect my access to social mobility. This is neither about sanist, racial or criminal, colonial, and eugenic ideas nor systems individually, but about all of them as a confluence.

These contexts convey the need for a greater appreciation of complexity, when poverty, low levels of access to education, high unemployment, lack of housing, differential access to healthcare, racial profiling/criminalization, incarceration, and other effects of colonial histories are experienced within contexts of domestic violence, substance abuse, trauma, and the trauma of racist systems and services. The idea of lived experience is further unraveled for its stratifications and associations with inadequacy or lack.

Mental health for racialized and indigenous peoples is often referenced to support prosecution and to establish threat, risk, biomedical inferiority, and ideas of dangerousness (Keating, 2016, Joseph, 2015). The effects of this are widely permeating and proceed from a complex confluence of historical factors. Specifically, racialized people and indigenous people do not attain the same value of voice from disclosure nor are respected for *their* lived experience as others who have had interactions with mental health systems. When dangerousness is assumed, tropes of incivility, savagery, and madness are often relied upon to distance, dehumanize, and delegitimize the lived experiences of racialized people and indigenous people. These divergent identification/representation processes, practices, and technologies work to essentialize criminality, alienism, and biological inferiority for racialized and indigenous peoples.

Eurocentrism, and the erasure of intergenerationally lived experiences of colonized, indigenous and racialized people

Early Mad Pride activists in the 1970s gained momentum alongside black pride activism, women's movements, Lesbian and Gay rights activism, and disability activism. As Bradley Lewis (2006) has described,

The key experience that motivated Mad Pride activists was their negative treatment within the psychiatric system. Early founders of the movement shared common experiences of being treated with disrespect, disregard, and discrimination at the hands of psychiatry. Many also suffered from unjustified confinement, verbal and physical abuse, and exclusion from treatment planning. (p. 188)

Beyond some notable progress in Mad activism and theory, in "the United Kingdom, the United States, Canada, and Australia, service users and survivors continue to represent a tiny fraction of the overall research and evaluation workforce in academia, service delivery organizations, and the community." (Kalathil & Jones, 2016, p.183). However, as Kalathil and Jones have explained, "With some key exceptions, both user/survivor research and 'mad theory' remain Euro-American phenomena" (Kalathil & Jones, 2016, p.183). As Joseph (2015) has discussed at length elsewhere, this trend within Critical Mental Health and disabilities literature is not an accident but a continuing trajectory based on "a Eurocentric conceptualization of history within articulations of struggle and when attending to the political and social contexts of critique" (p. 1021). The result is "often an inattention to the complicit influences of colonial and imperial projects on the practices and technologies of dehumanization, taxonomization, and the establishment of human hierarchies to rationalize violence through the implementation of racial and eugenic rationale" (Joseph, 2015, p. 1021).

These contexts support the scaffolds that underpin how people have come to understand the rise of Mad activism in the West, value Western Mad activists for their voice, while positioning the voices of racialized and indigenous groups as somehow outside the purview of what is considered valid experience. There are examples of where this trend has been breached. For one, the May 1989 issue of *Phoenix Rising* (a renowned publication by Mad activists that ran from 1980-1990) was a special issue on prisons entitled, "Prison: Voices from the Inside". The issue attempted to bridge the analysis of mass incarceration across psychiatric institutions and prisons to also name the violence and maltreatment that people in prisons experience. In the issue, Fran Sugar, who describes herself as "an angry, young, poor, uneducated Native woman!!!" shares the complexities of her anger (Sugar, 1989, p.5). Sugar describes how unemployment, lack of education, alcoholism, infant mortality, death from violence, and crime are the major ways "native people lead the country in statistical categories":

When we come to prison we need to adjust to greater and greater violence in our lives. We adjust to increasingly deadly conditions, and come to accept them as "natural." We

adjust to having freedoms stolen away from us, to having fewer and fewer choices, less
and less voice in the decisions that affect our lives. (Sugar, 1989, p.5)

Fran describes issues of suicide, abuse in foster care, child welfare, sexual assault, and the experiences of a "battered wife". She continues:

I am your typical Native woman and one who has survived the Criminal Just-Us System.
When I think about the time I've spent in prisons, I wonder how I maintained my sanity.
I never conformed in my heart or in my mind, but my body danced. I learned how to
cope with lies. I believe justice does not exist for Native people. (Sugar, 1989, p.5)

In this example, both Fran Sugar and the editors of *Phoenix Rising* are positioning her commentary not as an experience of madness itself but as an example of maltreatment within a system of incarceration. In the issue, Sugar's writings are presented alongside other contributions from the perspective of prison inmates. Often in tellings of stories of the Mad movement, this attention to the confluence of experiences that names the injustice of systemic violence, individual violence, and structural violence for racialized and indigenous people, that also harkens to the realities of intergenerational colonial suffering, is all too often erased (Shimrat, 1997; Starkman, 1981).

Eurocentric perspectives within critical perspectives on disability and mental health have often marginalized the histories and contexts for colonized groups (Joseph, 2015). In conjunction, also marginalized, subjugated, or erased are the intergenerationally lived experiences of colonized, indigenous, and racialized groups. When we examine how these trajectories affect how we talk about lived experience, often hierarchies of value permeate our understandings of what is appreciated as valid forms of knowledge. When lived experiences are taken at face-value,

analyses are permeable to the reproduction of knowledge without critical analyses of
race, ability, sexual orientation or gender and can perpetuate modernist ideas that
knowledge is observable and transparent and (re)institutes Western/Eurocentric
knowledge as dominant/superior. (Maiter, & Joseph, 2017, p. 755)

Postcolonial scholarship has struggled with the ethical complexities of identity and representation in ways that are helpful to this discussion. Specifically, Homi Bhabha provides a valuable set of analyses that have been described as a "dual engagement with social ethics and subject formation on the one hand, and (the representation of) contemporary inequalities and their

historical conditions, on the other" (Bhambra, 2014, p. 116). As Gurminder Bhambra (2014) highlights,

> in Bhabha's words 'we must not merely change the narratives of our histories, but transform our sense of what it means to live'. Postcolonial theory, according to Bhabha, is no longer (if it ever was) simply about the establishment of separatist trajectories or parallel interpretations, but should be seen instead as 'an attempt to interrupt the Western discourses of modernity through … displacing, interrogative subaltern or postslavery narratives and the critical theoretical perspectives they engender'. (p. 116)

What Bhambra via Bhabha is alluding to here is that we need not interject stories of racialized and indigenous people as a challenge to what modernity has done to understandings of lived experience, but rather change how we come to understand lived experience "both in historical terms and theoretical ones—rather than simply renaming or re-evaluating the content of these other 'inheritances'" (Bhambra, 2014, p. 116). For Bhabha, modernity 'is about the historical construction of a specific position of historical enunciation and address' (Bhambra, 2014, p. 116). As I have mentioned elsewhere, Franz Fanon has also shared the critique of modernity and "aimed at considering the effect of social and political reality on mental states, while recognizing the inherent violence within colonial projects that compels, through its very composition, a violent response" (Fanon 1965, cited in Joseph, 2014, p. 279). It is from the critique of how lived experience has been appropriated by psy professions as essentialized narratives that rationalize psy intervention that we can tell another story of lived experience and how its colonization represents a historical continuity, a confluence of historical trajectories that convene in the now, manifesting in a separation, a segregation in thinking and analysis that positions intergeneration forms of lived experience of racism, genocide, and colonialism outside of what should be valued and heard through a system of continuing white supremacy.

Elise Klein and China Mills have examined how psy expertise has become more than that which affects individual lives, professions, and their corresponding disciplines. It also is "increasingly and explicitly shaping international development policy and practice" (Klein & Mills, 2017, p. 1999). Psy expertise can often be positioned and rationalized as beneficial for reducing social ills and improving "economic efficiency" while simultaneously entrenching individualized notions of problems that can and should be understood from a systemic, historical level structurally (i.e., poverty) (Klein & Mills, 2017, p. 1999). This process *fashions* socio-political problems into individual psychopathological ones. Klein and Mills point out how psy knowledge has been used in specific development policy work,

including "child development/developmental psychology, behavioural economics, positive psychology, and global mental health." This historical neoliberal colonial project maps Western psychological knowledge as superior onto the world to promote "a specific mode of being: one that projects the inferiority of subjectivities not subscribing to white liberal norms" (Klein & Mills, 2017, p. 1999). As they articulate,

> Today, with the globalisation of psy-expertise, ever growing populations are codified through psychological vocabularies as in need of 'improvement'. Individualised and reductionist models that are culturally and historically contingent to the global North are being applied globally…that there can be global norms for the treatment of distress; and that certain behaviours and ways of being (including self-governance) are universally normative and desirable (Klein & Mills, 2017, p. 1999-2000).

Psy knowledge, expertise, and its positioning as superior is imbricated with historical colonial projects of white supremacy and has become an overwhelming mode of domination. As Pierre Bourdieu has clarified when we talk about a mode of domination, there are "two extreme forms between which all the possible modes of domination can arise":

> On the one hand, there are the social universes in which the relations of domination form, dissolve, and reform in and through interaction among individuals; here the relations can endure only at the price of personal effort and continual upkeep. On the other hand, there are the social formations in which the relations of domination are mediated by objective and institutionalized mechanisms. Among the latter are those which produce and assure the distribution of aristocratic titles, academic degrees, and money; they are independent of the individual's consciousness and beyond his powers to modify. (Bordieu, 1976, p. 122)

When we talk about lived experience as specifically defined by and made respectable by the individual relationship with psy disciplines - we too participate in the superiorization of this mode of domination. When we valourize the social universes of the experiences of individuals with psy professions and disciplines or maintain an analysis at this level, we can consequently obscure appreciations of the experiences of dehumanization, distress, and suffering of racialized and indigenous groups who do not define themselves or come to be taxonomized primarily through a psy

context. What is at stake is the erasure of considerations of racialized and indigenous experiences of suffering. These experiences are historically and intergenerationally bound to projects of colonization and manifested in the contemporary as that which is less likely to be valued as lived experience due to the tendency of racialized people and indigenous people to be catalogued and surveilled by systems that might not always be primary proximal to psy interventions. These are ethical demands that require careful and respectful consideration for how we participate in the delimiting of what constitutes lived experience and how it is accessed as a pathway to justice and care for racialized and indigenous people. However, if we simultaneously consider lived experience and its social formations of domination, we can appreciate how these social arrangements are produced within a broader system of white supremacy that establishes norms through sanist, racist, and eugenic colonial rationales.

Conclusion: Decolonizing "lived experience" discourses in mental health

When considering the ethics of lived experience, it is important to not (re)produce this colonial dynamic when theorizing. In Charles Mills' paper entitled *Revisionist Ontologies: Theorizing White Supremacy*, he notes that when there are demands for an attention to race, often "what one gets (insofar as any effort is made at all) is an attempt to piggyback the problem of race on to the body of respectable theory" (Mills, 1994, p. 107). Mills suggests as an alternative that we consider race itself as "a political system…as a particular mode of domination". Specifically,

> So we would treat this as a particular mode of domination, with its special norms for allocating benefits and burdens, rights and duties, its own ideology, and an internal logic at least semi-autonomous, influencing law, culture, and consciousness. We could use the term "white supremacy" to conceptualize this system… what I am suggesting is a more latitudinarian conception, encompassing de facto as well as de jure white privilege, that would refer more broadly to the European domination of the planet for the past several hundred years that has left us with the racialized distributions of economic, political and cultural power that we have today. (Mills, 1994, p. 108).

From this perspective, if we look at lived experience as a discourse, as a social, historical, and political confluence of identity that is imbricated in the (re)fashioning of global hegemonic psy modes of domination, then how we talk about lived experience has the potential to resist the effects of

appropriation and colonization. The consumptive neoliberal/neocolonial practices of fetishizing patient stories are historically and ethically critiqued when interrogating discourse that was wielded to depict people as deviant, docile, and aggressive or dangerous whenever politically required. We can use an ongoing scrutiny of the processes of appropriation and colonization of lived experience to attend to the erasure of intergenerational colonial, eugenic, and racialized violence as it manifests in the contemporary experiences of indigenous and racialized people. Via this historical analysis of confluence in application to lived experience discourse, we may also appreciate how the risks of disclosure (of criminalization, deportation, dismissal, social mobility) land in complex ways depending on who you are. Also at stake is the ethical obligation to resist forms of white supremacy that would position lived experience with psy disciplines as more visible, more important, or more noteworthy than the intergenerational forms of suffering, distress, and violence as they are lived by racialized and indigenous people today.

References

Barker, P. (2001). The tidal model: The lived-experience in person-centred mental health nursing care. *Nursing Philosophy*, *2*(3), 213-223.

Beresford, P., & Jasna Russo, J. (2016). Supporting the sustainability of Mad Studies and preventing its co-option. *Disability & Society*, *31*(2), 270-274, DOI: 10.1080/09687599.2016.1145380

Bhambra, G. K. (2014). Postcolonial and decolonial dialogues. *Postcolonial Studies*, *17*(2), 115-121, DOI: 10.1080/13688790.2014.966414

Bourdieu, P. (1976). Les modes de domination. *Actes de la Recherche en Sciences Sociales*, *2*(2-3), 122-132.

Bradstreet, S. (2006). Harnessing the 'lived experience': Formalising peer support approaches to promote recovery. *Mental Health Review Journal*, *11*(2), 33-37.

Bubar, R., Cespedes, K., & Bundy-Fazioli, K. (2016). Intersectionality and Social Work: Omissions of race, class, and sexuality in graduate school education. *Journal of Social Work Education*, *52*(3), 283-296.

Cornell, D., & Murphy, S. (2002). Anti-racism, multiculturalism and the ethics of identification. *Philosophy & Social Criticism*, *28*(4), 419-449.

Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist*, *59*(7), 614.

Costa, L., Voronka, J., Landry, D., Reid, J., Mcfarlane, B., Reville, D., & Church, K. (2012). "Recovering our stories": A small act of resistance. *Studies in Social Justice, 6*(1), 85-101.

de Jager, A., Rhodes, P., Beavan, V., Holmes, D., McCabe, K., Thomas, N., ... & Hayward, M. (2016). Investigating the lived experience of recovery in people who hear voices. *Qualitative Health Research*, *26*(10), 1409-1423.

Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychiatric Rehabilitation Journal*, *31*(1), 62.

Dennis, C. L. (2003). The effect of peer support on postpartum depression: A pilot randomized controlled trial. *The Canadian Journal of Psychiatry*, *48*(2), 115-124.

Diamond, S. (2013). What makes us a community? Reflections on building solidarity in anti-sanist praxis. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies* (pp. 64-77). Toronto: Canadian Scholars' Press Inc.

Dowbiggin, I. R. (1997). *Keeping America sane: Psychiatry and eugenics in the United States and Canada, 1880-1940*. Ithaca, N.Y.: Cornell University Press.

Drury, V., Francis, K., & Dulhunty, G. (2012). The lived experience of rural mental health nurses. *Online Journal of Rural Nursing and Health Care*, *5*(1), 17-27.

Eakes, G. G. (1995). Chronic sorrow: The lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing*, *9*(2), 77-84.

Fallon, P. (2003). Travelling through the system: The lived experience of people with borderline personality disorder in contact with psychiatric services. *Journal of Psychiatric and Mental Health Nursing, 10*(4), 393-401.

Fernando, S. (2010). *Mental health, race and culture* (3rd ed.). Macmillan International Higher

Education.

Gorman, R. (2013). Mad nation? Thinking through race, class, and Mad identity politics. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Mad Studies.* Toronto: Canadian Scholars' Press Inc.

Gorman, R., saini, a., Tam, L., Udegbe, O., & Usar, O. (2013). Mad people of colour: A manifesto by Rachel Gorman, annu saini, Louise Tam, Onyinyechukwu Udegbe & Onar Usar. *Asylum.* Retrieved August 1, 2018, from http://asylummagazine.org/2013/12/Mad-people-of-color-a-manifesto-by-rachel-gorman-annu-saini-louise-tam-onyinyechukwu-udegbe-onar-usar/

Heaton, M. M. (2013). *Black skin, white coats: Nigerian psychiatrists, decolonization, and the globalization of psychiatry.* Athens: Ohio University Press.

Jarvis, G. E. (2002). *Emergency psychiatric treatment of immigrants with psychosis* (Master's thesis, McGill University, Montreal, Canada). Retrieved from http://digitool.library.mcgill.ca/R/-?func=dbin-jump-full&object_id=33785&silo_library=GEN01

Joseph, A. J. (2014). A prescription for violence: The legacy of colonization in contemporary forensic mental health and the production of difference. *Critical Criminology, 22*(2), 273-293.

Joseph, A. J. (2015). The necessity of an attention to Eurocentrism and colonial technologies: An addition to Critical Mental Health literature. *Disability & Society, 30*(7), 1021-1041.

Kalathil, J., & Jones, N. (2016). Unsettling disciplines: Madness, identity, research, knowledge. *Philosophy, Psychiatry, & Psychology, 23*(3), 183-188.

Kalathil, J., Bhakta, R., Daniel, O., Joseph, D., & Trivedi, P. (2011). Recovery and resilience: African, African-Caribbean and South Asian women's narratives of recovering from mental distress. *London: Mental Health Foundation.*

Kanani, N. (2011). Race and Madness: Locating the experiences of racialized people with psychiatric histories in Canada and the United States. *Critical Disability Discourses/Discours critiques dans le champ du handicap, 3.*

Keating, F. (2016). Racialized Communities, Producing Madness and Dangerousness. *Intersectionalities: A Global Journal of Social Work Analysis, Research,*

Polity, and Practice, *5*(3), 173-185.

Kelaher, M. A., Ferdinand, A. S., & Paradies, Y. (2014). Experiencing racism in health care: the mental health impacts for Victorian Aboriginal communities. *The Medical Journal of Australia*, *201*(1), 44-47.

Klein, E., & China Mills, C. (2017). Psy-expertise, therapeutic culture and the politics of the personal in development, *Third World Quarterly*, *38*(9), 1990-2008.

Lewis, B. (2006). A Mad fight: Psychiatry and disability activism. *The Disability Studies Reader*, 339-354.

Light, E. M., Robertson, M. D., Boyce, P., Carney, T., Rosen, A., Cleary, M., ... & Kerridge, I. H. (2014). The lived experience of involuntary community treatment: A qualitative study of mental health consumers and careers. *Australasian Psychiatry*, *22*(4), 345-351.

Maiter, S., & Joseph, A. J. (2017). Researching racism: The colour of face value, challenges and opportunities. *The British Journal of Social Work*, 47(3), 755-772. https://doi.org/10.1093/bjsw/bcw052

McCulloch, J. (1995). *Colonial psychiatry and 'the African mind'*. New York: Cambridge University Press.

McKague, C. (1980). Myths of mental illness. *Phoenix Rising: The Voice of the Psychiatrized*, *1*, 1-14.

McKenzie, K., & Bhui, K. (2007). Institutional racism in mental health care. *BMJ: British Medical Journal*, *334*(7595), 649.

McLaren, A. (1990). *Our own master race: Eugenics in Canada, 1885-1945*. Toronto: Oxford University Press.

Metzl, J. (2009). *The protest psychosis: How schizophrenia became a black disease*. Boston: Beacon Press.

Mills, C. W. (1994). Revisionist ontologies: Theorizing white supremacy. *Social and Economic Studies*, 105-134.

Ontario Human Rights Commission. (2003). Paying the price: The human cost of racial profiling [PDF file]. Retrieved from http://www.ohrc.on.ca/sites/default/files/attachments/Paying_the_price%3A_The_human_cost_of_racial_profiling.pdf

Ontario Human Rights Commission. (2017). Under suspicion: Research and consultation report on racial profiling in Ontario. Retrieved from http://ohrc.on.ca/en/under-suspicion-research-and-consultation-report-racial-profiling-ontario#overlay-context=en/user

Patel, S. (2014). Racing Madness: The terrorizing Madness of the post-9/11 terrorist body. In L. Ben-Moshe, C. Chapman, & A. Carey (Eds.), *Disability incarcerated: Imprisonment and disability in the United States and Canada*, (201-216). Palgrave Macmillan US.

Pattadath, B. (2016). Experience as 'expert' knowledge: A critical understanding of survivor research in mental health. *Philosophy, Psychiatry, & Psychology*, *23*(3), 203-205.

Pon, G., Gosine, K., & Phillips, D. (2011). Immediate response: Addressing anti-Native and anti-Black racism in child welfare. *International Journal of Child, Youth and Family Studies*, *2*(3/4), 385-409.

Primm, A. B., Osher, F. C., & Gomez, M. B. (2005). Race and ethnicity, mental health services and cultural competence in the criminal justice system: Are we ready to change? *Community Mental Health Journal*, *41*(5), 557-569.

Sartorius, N. (2007). Stigma and mental health. *The Lancet*, *370*(9590), 810.

Shimrat, I. (1997). *Call me crazy: Stories from the Mad movement*. Vancouver, Canada: Press Gang.

Smedley, B. D. (2012). The lived experience of race and its health consequences. *American Journal of Public Health*, *102*(5), 933-935.

Smiley, C., & Fakunle, D. (2016). From "brute" to "thug": The demonization and criminalization of unarmed Black male victims in America. *Journal of Human Behavior in the Social Environment*, *26*(3-4), 350–366. http://doi.org/10.1080/10911359.2015.1129256

Smith, L. (2014). *Insanity, race and colonialism: Managing mental disorders in the post-*

emancipation British Caribbean, 1838–1914. Basingstoke: Palgrave-Macmillan.

Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27*(4), 392-401.

Sowers, W. (2005). Transforming systems of care: The American Association of Community Psychiatrists guidelines for recovery oriented services. *Community Mental Health Journal*, *41*(6), 757-774.

Spector, R. (2001). Is there racial bias in clinicians' perceptions of the dangerousness of psychiatric patients? A review of the literature. *Journal of Mental Health*, *10*(1), 5-15.

Starkman, M. (1981). The movement. *Phoenix Rising: The Voice of the Psychiatrized. 2*(3), A2–A15.

Sugar, F. (1989). Voices from the inside. *Phoenix Rising: The Voice of the Psychiatrized, 8(2), p. 5.*

Sweeney, A. (2016). Why Mad Studies needs survivor research and survivor research needs Mad Studies. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, *5*(3), 36-61.

Tam, L. (2013). Whither indigenizing the Mad movement? Theorizing the social relations of race and Madness through conviviality. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies* (pp. 281-297). Toronto: Canadian Scholars' Press Inc.

Taylor, K. W. (1991). Racism in Canadian immigration policy. *Canadian Ethnic Studies/Etudes Ethniques au Canada*, *23*(1), 1.

Whaley, A. L. (1998). Racism in the provision of mental health services: A social-cognitive analysis. *American Journal of Orthopsychiatry*, *68*(1), 47.

Williams, D. R., & Williams-Morris, R. (2000). Racism and mental health: The African American experience. *Ethnicity and Health*, *5*(3-4), 243-268.

Williams, M. T. (2013). Can Racism Cause PTSD? Implications for DSM-5. *Psychology Today*. Retrieved from https://www.psychologytoday.com/ca/blog/culturally-speaking/201305/can-racism-cause-ptsd-implications-dsm-5/

Van Lith, T., Fenner, P., & Schofield, M. (2011). The lived experience of art making as a companion to the mental health recovery process. *Disability and Rehabilitation*, *33*(8), 652-660.

Vaughan, M. (1991). *Curing their ills: Colonial power and African illness.* Cambridge: Polity Press.

Voronka, J. (2016). The politics of 'people with lived experience': Experiential authority and the risks of strategic essentialism. *Philosophy, Psychiatry, & Psychology*, *23*(3), 189-201.

Yellow Bird, P. (2004). Wild Indians: Native Perspectives on the Hiawatha Asylum for Insane Indians [PDF file]. Retrieved from dsmc.info/pdf/canton.pdf