

Running head: THE EXPERIENCES OF NON-WHITE SUBJECTS LIVING WITH
CHRONIC ILLNESS

An Examination of How Dominant Notions of Normalcy Inform the Experiences of Non-
White Subjects Living with Chronic Illness

Practice Research paper

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Abstract

The subject of normalcy within critical disability studies explores the dichotomy of normal and abnormal and how this informs the way disability is discussed within society. Using a post-structural and critical approach, this research has examined the intersections between race and disability within the narratives of non-white subjects living with chronic illness. What this research reflects is a global conversation regarding the ways in which capitalism, whiteness and ability impart limitations upon participants in this study, and how community activism and friendship serve as a form of empowerment and solace while navigating these structures of dominance.

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This Body

I have spent a lot of time thinking of my body
Realizing my body has come in stages
My body feels like another entity that exists apart from me

I know it is mine, but it feels separate from me
This body is decorated with scar tissue that weaves in and out of its skin
It has seen many surgeries and many doctors
Organs have been added, and have been removed

It has survived near death and has adapted to each transformation and circumstance
It has been critiqued, pushed and observed by others and myself
This body has tried to hide; it has been handled, extracted and questioned

It is lumpy, scarred and rigid, but it is also resilient
This body has done things it was never supposed to do
Through the mourning, it danced and soared

Although many saw it as limited, this body has been limitless
There were times when it needed to stop, but it did the best that it could do to move
forward
This body has been looked over but it keeps trying, it keeps dreaming

Chapter 1: Introduction

“I learned in school how to deconstruct—but how do we move beyond our beautiful deconstruction? Who teaches us to reconstruct?” (Brown, 2017, p. 56)

Challenging My Comfort

In my ongoing effort towards being a part of a narrative that dismantles dominant discourses within the field of social work, I have chosen to begin with those that are inherent within myself. This work has brought me outside of academia and other public realms into my own personal exchanges with those that I love and care about. In these private spaces, I have seen how power dynamics, differences in histories and notions of opportunity are taken for granted, and how easy it is to forget the deconstructing we often speak of in academia. As I continue to develop my practice, it has become more challenging to ignore this dichotomy; and while it may be relatively simple to assert the importance of deconstructing oppressive structures, observing my own learned tendencies revealed to me that this work begins with oneself. In my own personal context, it began with recognizing the ease in which I place compassion and empathy for others aside when I am preoccupied with securing my personal comforts. This learning, coupled with its ensuing challenges, contributes to an aspect of the knowledge put forth in this project. Addressing this lesson is not intended to sound self-deprecating. Rather, it is to highlight the importance of acknowledging how arduous it can be to engage in critical self-reflexivity.

Moreover, I am privileged in that I am able to reflect on these experiences within the context of academia and that I can address such complexities in this manner. Embracing my vulnerability and learning is a part of how I have been taught to critically

navigate my own participation in a field entrenched in settler-colonial violence. As I complete my graduate studies in social work, I have realized how automatic and performative situating these lessons and narratives can be. Therefore, this research project is not only a mandatory part of my education, but a method in which I can engage in a practice that can connect me to a reality that feels genuine and empowering.

The development of this project has been guided by many factors, where one of the most significant influences stem from reflections I had in regards to the body. Indeed, the subject of the body is vast and could be taken in a number of directions. Within the framework of this research, I am curious about how ability---or rather, disability---intersects with the various experiences of being a racialized or non-white person within a Western framework. Therefore, the purpose of my Practice Research Paper (PRP) will question how dominant notions of normalcy inform the experiences of non-white subjects living with chronic illness. This topic has been inspired by my own lived experience as a non-white subject living with chronic illness, where the examination of my own body and wondering where I “fit in” has retrospectively caused me to realize that these thoughts reflect how whiteness and disability have intersected in my own life. In an effort to adequately execute the purpose of this research project, I have utilized creative expressions, such as poetry, while also providing insight into the experiences of the participants.

I had encountered many difficulties in ensuring the completion of this project, owing to the fact that my intent was to incorporate various concepts (i.e., sexual orientation, gender expression, queerness in relation to South Asian diasporic identities and cultures, etc.); however, due to such boundaries as timelines and length, I resolved to

limiting myself. Nonetheless, many of my reflections are still ongoing and require further research. In this regard, my goal here is to not introduce or incorporate all of my ideas and thoughts into a project of this size, but to provide the reader with an introduction to the work I hope to contribute to in the future, and to add context to an existing conversation with my own knowledge and work. Being introduced to narratives surrounding normalcy within academia enriched my reflective process. Consequently, this exploration expanded my understanding of how ideas surrounding the “abnormal body” are created (Davis, 1995, p.23). Therefore, although this research subject was inspired by my own personal experiences, I will demonstrate how this topic reflects a global discourse by using literature that discusses the intersections between race and disability.

The following section of this introduction will provide insight into ethical considerations behind my recruitment process, how I recruited participants, the ways in which data was collected and how my data was coded. I will complete my introduction with insight into the theoretical and methodological foundations that guided this research. The second chapter of my PRP will provide further information into the relevance of this research by introducing literature critical to the analysis of the intersections between race and disability. The literature will explore race and disability experientially, in practice and within a global context. Chapter three provides the reader with further knowledge into findings that were collected during the coding phase of my research, which will be analyzed through a major argument and sub-themes related to the argument. Finally, chapter four concludes my PRP with ideas for further research, implications and

recommendations for practice, followed by a summary of findings and personal reflections.

Ethical Considerations

Prior to meeting the participants, I was not exactly aware of each individual's circumstance, and therefore I felt that a part of considering ethics in this study was to make the assumption that although participants had been living with their respective chronic conditions for quite some time, they may still be experiencing the impacts of their diagnosis(es). Furthermore, I could not assume how/whether trauma had manifested and if my study would trigger traumatic incidents. Therefore, in order to prioritize the care of my participants, I wanted to ensure that this piece was discussed. I had initially planned to inquire about support systems in place; however, information regarding support unfolded organically as we began to talk. Another aspect in considering ethics had to do with my own position as someone who was also a subject in the study. Although I shared my identity as someone living with chronic illness with the participants, I needed to acknowledge that our experiences would differ based on our own intersecting identities. Moreover, my position as the researcher in this study would inherently create a power differential, which has historic and colonial implications within the context of research. Knowing this, I wanted each participant to know that these conversations were not solely for my own academic benefit, but also so that they could take up space, interrupt me and we could engage in an exchange of knowledge with one another. This experience varied depending on whom I met. For instance, two individuals who identified as a part of Indigenous communities provided me with knowledge of what they might need throughout our conversation. For example, one of the participants needed to smudge

periodically throughout our interview, as it was a way to reduce her anxiety. Furthermore, a part of acknowledging that I was working with individuals belonging to communities that have been historically disrespected and violated through methods of research was to be clear about my role and that, as a researcher in this project, I am participating in a practice that has taken from groups that have been systemically marginalized. Finally the last ethical consideration I took was to abide by the ethical guidelines as regulated by York University in order to ensure further safety of my participants. I did this by completing ethics review forms, ensuring low risk by confirming that participants fit my criteria for participation and asking participants to sign a confidentiality agreement (See Appendix A).

Research Design: Recruitment and Method of Collecting Data

The method in which I recruited data for this project was through interviews. I went through this process in two ways: through Facebook via an open call-out and through the assistance of friends and colleagues who referred me to participants. Due to the realities of living with chronic illness, many participants requested Skype/audio interviews. Defining chronic illness is essential to this project. Due to the extent to which I was capable of conducting research in conjunction with the time constraints, I intended to only include individuals who identified as having physical chronic illness as I thought it would help specify and narrow down my criteria. However, once I began the recruitment process, it became apparent to me that although I was primarily looking at physical chronic illness, many participants also identified as living with mental chronic illness. In addition, it was brought to my attention that solely looking at physical chronic illness might perpetuate stigma associated with mental chronic illness, or that it would

further silence the realities of living with mental chronic illness. These reflections were essential, as it challenged my own preconceived notions surrounding mental illness and my scope of what was considered to be chronic illness. Therefore, although this study is primarily looking at the body and individuals who were diagnosed with physical chronic illness, many participants revealed other chronic issues that were not limited to the physical. These reflections were an important aspect of how I navigated my research design and the lens in which I collected data.

I managed to acquire seven participants through the recruitment and data collection phase of this project. Out of the seven participants, I only met two individuals in person. The two in-person interviewees I met with were compensated with baked goods and Toronto public transit fare. For the participants that were not able to meet in person, I offered to help support them with other projects/interviews if they wished. My criteria for recruitment involved the following components:

- Participants must self identify as non-white/racialized
- Participants must have lived with their chronic condition for at least 5 years
- Participants must be over the age of 21

Once recruitment was completed, participants from the following *self-identified* ethnic and racial backgrounds emerged:

- Filipino | Cis | Male | Queer |
- Mexican, Native American and White | Cis | Female | Queer
- Indigenous, Ojibway, Mohawk and Chinese | Two-Spirit | Queer
- Jamaican, Black | Cis | Straight
- Indigenous, Ojibway | Two- Spirit | Femme | Trans- Girl

- Tamil, Brown | Queer | Femme
- Indo-Caribbean, Brown | Non-Binary | Masc. | Queer

In order to uncover the common narratives in the lives of these participants, I wanted to use the concept of normalcy as a theme to connect these narratives and to find out what dominant discourses were informing the experiences of participants that joined my study. During our interview process, each participant was asked twelve questions about common ideas surrounding “normal” and how this concept connected to discourse surrounding race and disability. The questions posed to each participant were:

1. Are there aspects of your health that you would like to share with me?
2. What is normal?
3. How have dominant ideas of what consists as normal impacted you?
4. What does your normal look like?
5. Have you ever tried to fit in? How so?
6. How do you feel individuals who do not share your experiences perceive your circumstances/ your identity/ context?
7. What have your interactions with healthcare providers been like?
8. In what ways have healthcare providers attempted to maintain a sense of normalcy for you?
9. How has race informed your experience living with chronic illness?
10. How is race discussed within the context of healthcare?
11. Are there other figures in your life aside from healthcare providers who have informed your experience living with chronic illness?
12. How do you feel your identities are validated?

Coding

Once I had completed transcribing each interview, the coding process revealed 6 main themes:

1. Barriers around accessing employment and education
2. Barriers to navigating healthcare
3. How normalcy informed race and ability
4. The importance of community support
5. Incompetent service & individuals in places of authority controlling the voice of participants
6. Self-Advocacy

As I had expected, analyzing and coding the data proved to be overwhelming, and therefore keeping theory in mind during this process allowed me to hold an academic perspective in mind while I reviewed the themes that emerged.

Theoretical Frameworks

The theoretical frameworks guiding my research are within critical race theory and critical disability studies. The experiences of non-white subjects living with chronic illness is intriguing as racism and disability intersect, adding complexity to the experiences of these individuals. As Titchkosky & Michalko (2009) discuss, the construction of these dominant groups evoke notions of legitimacy associated with certain experiences, which consequently otherizes the experiences of individuals who do not meet the criteria of what is considered normal (p. 6). Furthermore, in using a critical race lens, normalcy can be perceived to be a symptom of colonialism, and, within a Canadian context, begins with the genocide, displacement and appropriation of

Indigenous Peoples and land (Fobear, 2014, p. 49). In considering the experiences of racialized individuals in this country, we must acknowledge how Canada holds a role in their construction through immigration policies and narratives, which inherently otherizes the identities of non-white individuals (Fobear, 2014, p. 49). Within the scope of critical disability studies, further research into the historical contributions of normalcy reveal how this systemic issue was conceived through the eugenics movement and perpetuated through the birth of statistics (Davis, 1995, p. 26). Systemically, normalcy is often placed in a binary, where one group is seen as normal and others are seen as abnormal. According to Titchkosky & Michalko (2009), abnormality exists when one is perceived to exist outside of dominant groups (p. 3). On a micro level, it appears that the impacts of normalcy are experienced through feelings of isolation, self-comparison and striving to fit in (p. 3). Examining dominant notions of normalcy is essential for this research as it allows for the analysis of how abnormality is imposed and constructed onto those that exist outside of whiteness and within disability.

The ways in which I have personally resisted these impositions is by naming my own racialization as non-white versus other designated terms such as “person of colour” or the abbreviated version, “POC”. My self-determination over naming myself has been an intentional way to prohibit whiteness from dictating my colouredness. Instead of embracing colour, I choose to embrace not being white, and therefore I have used non-white in my title. I have also intentionally used non-white to create space for those who identify as “white-passing”, as it has been expressed to me through conversation that much silence exists in the lives of these individuals, especially those that identify as First Nations, Inuit or Métis and who pass as white. However, although non-white is the term I

use, I acknowledge that there are many terms that are used to name racialization, and that empowerment exists through the self-determination of naming oneself.

The significance of this research is relevant to discourse surrounding the delegitimization and erasure of marginalized populations. Using critical race theory and critical disability studies, exploring this research has the potential to provide further insight into this issue and to challenge dominant narratives which reinforce notions of normalcy. This research not only intends to emphasize racist and ableist structures, but also aims to contribute to conversations that politicize the experiences of racialized and non-white individuals living with chronic illness in Canada. These factors are what make my research post-structural and therefore, in accordance, I have chosen to use critical discourse analysis as the method in which I will deconstruct the data I have gathered.

Methodology

Through class discussion, I have learned that critical discourse analysis (CDA) vs. discourse analysis is meant to be critical, post-structural and emancipatory in nature. CDA assumes that there are dominant forms of knowledge informing the subjectivities of individuals (p. 294). Within the context of this research, using CDA allows for the deconstruction of dominant structures within the subjugated experiences of non-white individuals living with chronic illness, thus exposing them and “interrupting” the popular neo-liberalist notion of the individual experience as the only truth or story. This deconstruction is essential as it creates space for multiple meanings to emerge and expose systemic power that are often unnoticed in everyday discourse (p. 23). As it relates to my research, critical discourse analysis provided me with a lens in coding my data. As a student of social work and someone who has been trained in practice to accept speech

discourse as truth, I found it difficult to be critical in my process listening to the experiences of participants in this study. As I had often expressed to my colleagues, I was worried that being critical would disrespect the individuals sharing their knowledge and time with me. As Badwall (2013), mentioned in her doctoral thesis, I similarly would veer towards validating and caring for the individual experiences of the participants (p. 43); however, when it had come time for me to code my data, this was when I found it easier to apply a CDA approach to my research. Additionally, using CDA involved me looking into the ways in which other academics writing about the intersections between disability and race discussed dominant discourses influencing the experiences of this demographic.

Chapter 2: Literature Review

The following chapter will introduce literature that intends to provide academic context surrounding my research, which aims to question how dominant notions of normalcy inform the experiences of non-white subjects living with chronic illness. In order to explore this subject further, I will draw from articles engaging in critical disability studies and critical race theory. Concepts that will be explored will include normalcy, colonial impacts of the Global North over the Global South, racism and healthcare related research. The following will be a critical analysis and review of these articles, demonstrating how my research is situated within critical scholarship.

Davis (1995) provides context surrounding the experiences of racialized individuals living with chronic health needs by stating that in order to understand the disabled body, we must begin by gaining knowledge surrounding the constitution of the able body (p. 23). In his book *Enforcing Normalcy*, Davis (1995) explores the social construction of normal, and how the disabled body is consequently impacted (p. 24). By drawing attention to the birth of statistics, Davis (1995) critiques the idea that there is a certain population who fall within a norm, therefore fostering the creation of a space that deviates from this norm (p. 30). In his discussion of these two spaces, Davis (1995) critiques the dichotomy created between normal and abnormal, and how the danger of this dichotomy is that it homogenizes both these spaces (p. 36, p. 38). Within the context of normality, homogeneity enforces the belief of what humans should look like and be like (p. 34), which additionally creates traits that are desirable and those that are undesirable (p. 35). He builds upon this discussion by problematizing the eugenics movement and the fear promoted by its members, which preaches that allowing space for

difference will influence an entire nation of deviance (p. 36). Although Davis (1995) uses examples of eugenicist ideology concerning the Nazi party or the use of sterilization (p. 38), he argues that the maintenance of normalcy does not have to appear overtly violent, and that ableist attitudes extend itself into seemingly innocent areas, such as in literature, thus illustrating the many ways in which “abnormal” identities are erased (p. 41). In portraying how normalcy is maintained, Davis (1995) signifies how those who fall outside the dominant norm are consistently moulding themselves into the ideal (p. 45). The ways in which the dominant norm transforms in Davis’ analysis is illustrated through the creation of intersectional pathways by extending its impact outside of those who have physical disabilities to other areas of marginalization, such as mental illness, sexual orientation, nationality, race, gender, criminality, etc (p. 24, p. 39). Therefore, Davis’ (1995) discussion regarding the maintenance of normalcy presents a core aspect of this concept, which is to *fix* that which is abnormal.

Titchkosky & Michalko (2009) provide further insight surrounding the symptom of normalcy by discussing how disability is perceived. Their discussion brings forward the general negativity surrounding the subject of disability, which is often interpreted as tragedy (p. 2). The danger in this attitude towards those living with disability is that it allows for this circumstance to be simplified into a problem that requires a solution (p. 2). Titchkosky & Michalko (2009) hold professions such as medicine, rehabilitation and counselling accountable for perpetuating these views in the way of determining how disability and those with disability should be perceived (p. 2). This is most commonly observed within the philosophy of such professions where the primary focus, if not solution, is prevention. These practices within various healthcare professions contribute

towards the notion that there is a disadvantage in being disabled (p. 3). Fixing disability, whether it appears in the form of maintenance or assimilation, implies that achieving normalcy achieves happiness (p. 6). However, what Titchkosky & Michalko (2009) bring forward is that for those involved in disability studies, disability is not synonymous with success, value or positivity (p. 6-7). In questioning what erases these truths, Titchkosky & Michalko (2009) present the involvement of colonialism and how knowledge is co-opted by the dominant group. Incorporating the impacts of colonization supports the validity of expertise brought forth by those on societal margins (p. 6). This discussion is applied to the field of critical race discourse, where the authors include the experience of bell hooks (1990) who demonstrates the colonization of knowledge by emphasizing how those who experience racism, disability or both are placed in situations where their learning experiences are “dominated by those who dominate” (p. 8). The involvement of such dominant discourse within disability studies delegitimizes the experiences and existence of those who do not fit into the norm, and allows for dominant groups to hold expertise over concepts distinguished as needing remedy (p. 4-5).

Titchkosky & Michalko (2009) connect disability to colonization and racism, which provides insight into the systemic implications of my research question. Although they begin this conversation, Meekosha (2011) applies disability studies to global discourses by discussing how disability or impairment has been physically inflicted onto “postcolonial” and settler societies through genocide, war and global capitalism (p. 668-669). Many conversations surrounding disability involve independent living and care, although the gap in these discussions excludes the lived realities of those who have been pushed out (p. 670). Meekosha (2011) reflects upon the ongoing global violence towards

Indigenous communities, specifying those in Australia, where many live in isolation from healthcare services (p. 670). The impacts of colonial violence result in impairment outside of Western notions of disability, which involve poverty, substance use, chronic illness, etc. (p. 670). Meekosha (2011) extends the image of disability into what she refers to as social suffering, which unlike disability, is frequently disregarded as a personal tragedy, and is instead viewed as a choice (p. 671). Neglecting to include the experiences of Indigenous Peoples within disability studies re-creates colonial processes used to dominate and erase these groups (p. 672). The inclusion of these experiences are essential to disability studies and as Meekosha (2011) states, the destabilization of these communities is incomparable to the way disability is portrayed within Western frameworks (p. 672). Meekosha (2011) contends that including the brutalization and displacement of Indigenous communities is essential to de-stabilizing the West within disability studies (p. 677).

Meekosha (2011) further argues that in conjunction with acknowledging atrocities committed by Western and European nations, disability scholars must consider the ways in which knowledge has been colonized, creating a notion that experiences of disability are universal (p. 678). Therefore, she encourages those involved in disability studies to hold the Eurocentricity of disability activism accountable in order to uncover voices that are not centred within these conversations (p. 678). Meekosha (2011) provides a global and systemic context in conjunction to the conversation surrounding bodies within disability studies, by creating significance surrounding the physical mistreatment of those experiencing disability. Her inclusion allows for disability scholars, such as Connell (2011), to assert how the colonization of racialized bodies have also been exploited for

capitalist use, such as in the case of factory workers and agriculture farmers in the Global South (p. 1,374).

In her article *Southern Bodies and Disability: re-thinking concepts*, Connell (2011) demonstrates how global capitalism functions as a tool of normalcy to discern which bodies are capable of generating profit and which bodies are not. This point brings forward the issue of how bodies unable to carry out these tasks are viewed within the context of global capitalism (p. 1,375). Connell (2011) decentralizes capitalism in her discussion by emphasizing how in many cultures, bodies within the context of community serve a purpose; however, within capitalist frameworks, bodies that cannot contribute towards the economy are not conducive (p. 1, 375). The perceived lack of productivity presents another layer to understanding disability, which asserts that those who do not contribute towards the creation of financial gains are abnormal and are further segregated. Connell (2011) advocates for the inclusion of history in allowing disabled groups and those impacted by colonialism to reclaim identities outside of normalcy (p. 1,371).

Within a practice setting, there seems to be an effort in validating the identities of racialized individuals experiencing various forms of disability. However, what occurs is the essentialization of these identities. In her article *Transcending transculturalism? Race, ethnicity and health-care*, Culley (2005) writes that ethnicity and race have become interchangeable within dominant discourse (p. 44). She asserts that the issue with considering racism within healthcare settings is that it becomes homogenized and invalidates the complexity of racialization (p. 45). Similarly to the works of Meekosha (2011) and Connell (2011), Culley (2005) aims to emphasize the correlation between

systemic racism and various health issues. Her article explores the practice of nurses and their consideration of race in working with racialized individuals (p. 45). Culley (2005) introduces the concept of power relations between nurses and hospital service users, and the ways in which acknowledging this power differential critiques the social construction of nursing as a “colour-blind” and “class-blind” caring profession (p. 45). This narrative simplifies the experiences of racialized subjects and shows how concepts of ethnicity, race and culture become universal (p. 45).

Culley (2005) discusses how the notion of cultural competency was created in an effort to understand how to cater to different ethnically diverse populations. She contends that the danger in carrying out practices viewed as being culturally competent, is that it caters to Western structures of placing racialized bodies within guidelines and simplistic frameworks that can be understood by the dominant norm. Therefore, the practice of cultural competency within such organizations still perpetuates the dichotomy of the dominant norm learning about the marginalized other (p. 46). In this regard, the pursuit of knowledge from racialized bodies continues to perpetuate colonization and racism (p. 46). Moreover, Culley (2005) demonstrates how the co-option of knowledge by the dominant group (this case being healthcare providers) allows for the imposition of assumptive notions and opinions onto racialized bodies, which is reflective of practices such as scientific racism, which has legitimized human rights violations such as slavery, eugenics and the Nazi movement (p. 48). Culley (2005) proposes that it is crucial we consider the use of postmodern thought in the discussion of race and healthcare. She presents the notion of cultural hybridity, which argues that ethnicity is constantly evolving based on intersecting identities; therefore, it cannot be contained. In regards to

implications for practice, Culley (2005) encourages healthcare providers to reflect upon ways of responding to the hybridity and fluidity of racialized identities (p. 51).

Similarly to Culley (2005), Johnson et al. (2004) discuss the issue of explanations being essentialized resulting in the othering of healthcare users (p. 255). Aside from the perpetuation of racism within healthcare settings, Johnston et al. (2004) presents the issue of culturalism, which reinforces power differentials between healthcare providers and healthcare users. In order to bring issues of culturalism and racism into the fore, Johnston et al. (2004) interviewed healthcare providers serving South Asian women (p. 258). Their findings included the notion of the “idealized other” (p. 260). For further context of what this means, the idealized other is a patient who is cognizant of what is important and adheres to the advice of the expert (p. 260). Alternatively, those who do not fall into the category of the idealized other are viewed as unable to follow instructions or take responsibility for their health (p. 26). Johnson et al. (2004) include that their sample was a combination of non-South Asian care providers and South Asian care providers where the latter also adhered to the notion of the idealized other (p. 257). This illustrates the ways in which Western ideals are ingrained within the healthcare system (p. 265). In addition, Johnson et al. (2004) discuss how those experiencing otherness within the healthcare system survive. This often results in the racialized other adopting Western identity by attempting to fit in and reject the identity that others them. This is often manifested in service users attempting to avoid burdening the system and their care providers by diminishing the severity of their experience, lowering their expectations, or altering their tone of voice in such interactions (p. 264-265).

As Culley (2005) had indicated, the danger in striving for cultural competency is that it reproduces racism. Additionally, Johnson et al. (2004) submit that one cannot know or fully grasp another culture (p. 267). Furthermore, the issue in attempting to utilize cultural competency with racialized populations is that it ignores the inherent exclusion of non-white voices and identities from health related discourse (Nelson & Macias, 2008, p. 20). Nelson & Macias (2008) provide further insight into this point within their article, *Living with a White Disease: Women of Colour & Their Engagement with Breast Cancer Information*. Nelson & Macias (2008) critique the dominance of whiteness within discourse related to breast cancer treatment, and how much of the information delivered is not relevant to women of colour, consequently resulting in those living with breast cancer ascribing to information that largely ignores their individual realities (p. 20). Nelson & Macias (2008) assert that the de-construction of this issue is complicated by the insertion of race; therefore, what dominates breast cancer discourse is whiteness and services benefiting the needs of white women (p. 26).

The concept of the ideal subject re-appears within this study; in the case of racialized service users living with chronic health needs, the authors bring forward the importance of imagery and its significance in validating the identities of non-white women undergoing breast cancer care. What is emphasized within this conversation is how in an effort to appeal to diverse populations, images continue to be whitewashed and exclusionary of women belonging to different religious affiliations (p. 27). Furthermore, Nelson & Macias (2008) demonstrate how normalcy emerges through the portrayal of bodies undergoing breast cancer treatment. Aside from the whitewashing of images, women are portrayed as possessing conventionally ideal body types, often excluding

images of women who have undergone a mastectomy – a common reality of those experiencing breast cancer (p. 27). Furthermore, the erasure of non-white identities is exhibited through the production of prosthetics, which have been demonstrated as not including black or brown skin tones (p. 27, p. 31). Moreover, Nelson & Macias (2008) insert the intersection of capitalism and disability in the way of discussing how information packages often portray women performing activities or possessing signifiers often accessible to those holding upper-middle class incomes (p. 27). Normalcy is demonstrated in ways that not only extends itself into cosmetic and financial aspects of those undergoing breast cancer care, but also in regards to diet by portraying images of expensive Western foods (p. 27).

As Davis (1995) previously discussed, the moulding of marginalized populations into the dominant norm is a consequence of normalcy (p. 45). Within this article, it is presented through the concept of mimicry, where it was found that although focus group participants within Nelson & Macias' (2008) research were critical of whiteness, many still felt compelled to use the resources provided and to ascribe to normative standards of beauty (p. 31). The concept of mimicry is connected to colonialism by arguing that an aspect of colonialism is for subjects to embrace features of the “colonizing society” (p. 32). This conversation presents another area of this experience, which is that subjects are often caught in between the process of attempting to fit in, and at the same time, not being successful in embodying the dominant figure (p. 32, p. 37). This particular struggle experienced by women of colour illustrates how in experiencing potentially life-threatening illness, these groups are also exhausting emotional energy into conforming to

the dominant norm (p. 32). Therefore, Nelson & Macias (2008) contend that in order to care for women of colour, those involved must attend to systemic inequality (p. 36).

In contrast to the whiteness of breast cancer, Dyson et al. (2007) explore the racialization of the chronic health condition, sickle cell anemia, which has been known to predominantly affect those of African and Caribbean descent (p. 582). Similarly to other articles presented in this review, Dyson et al. (2007) bring forward the tensions in addressing whiteness outside of the medical model of disability in regards to racialized service users (p. 582). In their research of experiences held by those impacted by sickle cell disorder, Dyson et al. (2007) explore how these individuals navigate schooling. The authors indicate how the education system exists as another mechanism of monitoring performance and how the concept of the ideal subject is re-created through the view that those who excel at school while experiencing disability are successful (p. 583). However, the tensions exposed within this research is that what is important to those experiencing sickle cell disorder, especially to children and young people, is the resemblance of being normal (p. 583). Where these populations are concerned, Dyson et al. (2007) discuss how the pursuit of normalcy is interrupted by the involvement of teachers and school staff acting as care providers (p. 583). The power differential between adult school staff and young people experiencing this chronic condition, combined with increased monitoring and a lack of understanding, often leave students feeling socially isolated and different from the rest of their peers (p. 585). Furthermore, the reality of living with sickle cell disorder often subjects students to frequent absences and hospital visits, which not only segregate students from school life, but also impact their academic standing in school (p. 585).

Similarly to Connell's (2001) discussion of how capitalism and disability intersect, Dyson et al. (2007) expose a dichotomy between those who miss school on account of experiencing pain and those who deny the extent of their symptoms, reinforcing the impacts of capitalism (p. 585). This point made by Dyson et al. (2007) is reflective of points brought forward by Johnson et al. (2004), where racialized individuals involved with the healthcare system exert more energy into appeasing the dominant norm. Those who cannot conceal the impacts of sickle cell disorder demonstrate how maintaining normalcy perpetuates anti-black racism. For example, the lethargy associated with this condition, coupled with being Black, stereotype individuals living with this disorder as lazy (p. 589). Furthermore, the treatment of those living with sickle cell disorder is held in low academic standards, and these individuals are often discouraged from having high expectations of their abilities (p. 590). Such practices are reflected in the gaps of anti-discriminatory policies within educational systems and illustrate how those living with sickle cell disorder are forced to conceal their symptoms and respective realities, thus contributing to the erasure of these identities (p. 586).

Additionally, these instances reflect the larger narrative of personal tragedy within disability studies and solution/prevention focused tactics in regards to the maintenance of normalcy. In connection with Meekosha (2011) and Connell's (2011) discussion surrounding colonial based violence in the creation of disability and displacement of communities, Dyson et al. (2007) contend that the importance of knowing history is significant. The narrative of disability as tragic, such as in the case of populations living with sickle cell disorder, bring forward practices such as pre-screening of birth defects in an effort to prevent disability, and how this reflects genocide (p. 588). The extent to

which the dominant norm aims to prevent disability is reflected in the belief that being disabled decreases a person's legitimacy (Procknow et al., 2017, p. 362).

In their article discussing the role of leadership, Procknow et al. (2017) critique the notion of inadequacy surrounding disabled individuals within positions of leadership. The notion of inadequacy can be connected to Titchkosky & Michalko's (2009) argument surrounding the de-legitimization of knowledge and the expertise of those experiencing disability (p. 6). Furthermore, Procknow et al. (2017) exhibit how the disqualification of worldviews outside of the dominant norm is connected to Meekosha (2011) and Connell's (2011) discussion of colonial impacts in relation to disability studies. In addition to the domination of knowledge, connections to healthcare often subject those experiencing disability to being viewed through frameworks of diagnosis and treatment, further discounting knowledge through epistemic violence (p. 365). Procknow et al. (2017) highlight the connection to the ways in which those involved in the healthcare system are viewed to the pursuit of leadership in spaces of employment. They assert that a contradiction exists where healthcare services are formed through neoliberalist policies under the guise of assisting those living with various disabilities (p. 367). However, these ideologies simultaneously reinforce the belief that these groups are incapable of being productive members and leaders of society, reproducing capitalist values (p. 367). Furthermore, those living with disability often conceal their fear of being perceived as unproductive (p. 367).

The discussion of the ideal subject is asserted in Procknow et al.'s (2017) research where dominant groups are responsible of creating a hierarchy of marginalization within the context of disability; often, those with physical disabilities are seen as being more

competent than those with mental illness (p. 368). The hierarchy of disability introduces the concept of those who Procknow et al. (2017) present as “supercrrips”, in which inspiration and standards are held for all people with disabilities to achieve in spite of being “disadvantaged” (p. 370). This standard reinforces the maintenance of normalcy through epistemic violence and implies that those who are not working hard to fit into the dominant norm do not have useful knowledge or expertise.

Phelan’s (2011) article *Constructions of disability: A call for critical reflexivity in Occupational therapy* asks for healthcare providers – in this case, occupational therapists – to hold themselves accountable in practicing epistemic reflexivity in the way of advancing knowledge and connecting larger social systems to the treatment of those living within a framework of disability (p. 165). In line with the previous articles, Phelan (2011) emphasizes the importance in framing disability as a social construction, where those who experience disability are subjects of being in a circumstance that was designed to oppress (p. 165). Phelan (2011) reflects the work of Titchkosky & Michalko (2009), in her discussion of how disability is framed using the medical model, where disability is viewed as a “biological impairment” (p. 165). This reinforces the idea that those outside of dominant ability must be fixed (p. 165). What Phelan (2011) differentiates about disability in comparison to other marginalized groups, is that everyone will experience disability to a certain extent in their lifetime (p. 166). What is then constructed is the notion that disability should be feared, which further segregates those experiencing disability from those who do not (p. 166). Like other disability scholars, she draws attention to the narrative of disability as personal tragedy, helplessness, inadequacy, etc., and advocates for the focus in disability studies to not centre disability, but to centre the

impacts of normalcy (p. 167). As Dyson et al. (2007) had discussed in their article regarding sickle cell anemia and the tendency for those experiencing chronic illness to conceal their ailments, Phelan (2011) draws a similar relationship within her study, as many individuals experiencing disability are often encouraged to deny their experiences (p. 167). What consequently occurs is the tension between owning and denying one's disability and the disclosure surrounding distress related to disability. Phelan (2011) contends that this allows room for those belonging to dominant groups to impose the notion of tragedy and a lack of worth onto those who have been open about their experiences (p. 167). Although this tension exists, many disability scholars argue that having self-determination over one's disability prevents non-disabled individuals from co-opting the experiences of the disabled body (p. 167). However, what should be noted here is that this still places a tremendous amount of responsibility on individuals experiencing disability to educate non-disabled folks.

Procknow (2017) introduces an analysis of hierarchy where the imposition of dominant structures such as the medical profession and able-bodied individuals within these structures creates borders, where the degree to which disability is experienced can be stratified, therefore deciding the amount to which a disabled body experiences disability over another disabled body (p. 167). Phelan (2011) continues to elaborate on the impacts of living in an ableist society where she discusses how this hierarchy is dangerous to those experiencing various forms of disability. She contends that for those who are much more visibly disabled, the issue lies in how these individuals can accommodate normalcy in spite of their disability (p. 168). Phelan (2011) connects this tension to the experiences of those who require added support and how this leads to a

barrier in accessing services (p. 168). Furthermore, she emphasizes how the voices of those experiencing disability are not heard in the midst of able-bodied individuals co-opting these experiences (p. 167); therefore, this leaves room to question how to centre the voices of those involved within the healthcare system.

In an effort to provide context surrounding my research of how dominant notions of normalcy inform the experiences of non-white individuals living with chronic illness, I have drawn upon a series of articles that have explored concepts surrounding normalcy, colonial impacts, racism and healthcare related research. The articles have demonstrated how normalcy extends itself outside of disability and into other areas of marginalization such as within race and class. Furthermore, this review of literature allows for further acknowledgement in regards to the existence of power dynamics, where histories of colonization and exploitation have given way for a dominant discourse to exist and inform the experiences of non-white individuals living with chronic illness. The following chapter will provide more insight into how my research relates and contributes knowledge to the literature reviewed.

Chapter 3: Exposing Capitalism and Colonialism

“How many mornings

you have run out of sick days.

when do you run out of being brown?” (Shraya, 2017, p. 23)

Teaching myself to embrace my body required me to learn how to reject shame associated with the experience of being viewed as abnormal. I learned this lesson through an incident that took place several years ago where I was asked not to reveal too much about the ways in which I was physically different from others. This section is not just a play by play of what I found and how I encountered these findings. Rather, it is a demonstration of how this research provided me with a platform in which I could engage in conversation with people who are a part of a narrative that asks them to hide themselves regularly. This chapter will introduce themes that emerged during my coding process and how they developed into an argument that supported me in answering my research question: how do dominant notions of normal inform the experiences of non-white subjects living with chronic illness. In this section, I will introduce themes that emerged during my coding process and how my analysis of this data led me to my final argument: structures with foundations in global capitalism and colonialism create notions of productivity that delegitimizes the experiences of non-white subjects living with chronic illness.

Data Analysis and Findings

Most of the participants in this study expressed that maintaining work and school while managing the realities of living with chronic illness were challenging. This common theme within my data revealed how accessing education and employment acted

as a barrier for participants in this study. Within the scope of employment, there were a few factors that were challenging to navigate, namely staying employed, accessing medication, and fear of having their chronic illness revealed to others and what that would do to their career. Needing to be employed was a huge source of stress for participants for several reasons. One reason was that many participants expressed concerns about having a means to access insurance for medications that were essential in maintaining their health. Participants revealed that there were many barriers to staying employed; firstly, it was found that the realities of living with chronic illness, which included fatigue and chronic pain, were not synonymous with the realities of what it means to maintain full time employment. What I noticed was that it was not necessarily about trying to find employment that was challenging for participants; rather, it was how they were able to thrive within these pre-determined structures. This had to do with how much participants felt that they were able to care for their conditions while accommodating the demands of employment. Two participants I spoke to, J.E. and Keto, revealed how living with their chronic illness made it difficult for them to maintain work while also trying to care for themselves. “I was working two jobs where I was pushing myself to the max. The last 5 years I couldn’t actually maintain a job, let alone work a full-time job” (J.E.). “I couldn’t hold a job for more than 6 months with my body” (Keto)

These narratives reflect the need for these participants to live outside of their physical means in order to maintain a career. However, these struggles are not limited to them, as they reveal gaps that exist within a capitalist society. Namely, how those living with disability become marginalized due to the inability to perform to the same extent as the majority. As I demonstrated in my review of literature, Connell (2011) exposes this

gap through her analysis of how capitalism constructs an image of bodies that are capable of generating profit and bodies that are not (p. 1,375).

What made J.E. and Keto's respective situations more challenging was that disclosing one's health needs within the workplace was a source of fear as they did not want to complicate their situations further in case their employers were to see them as liabilities. For participants in this study, finding a job involved ensuring that employers could accommodate their lived realities and needs. However, due to the difficulty in being able to find these necessities, participants needed to find other ways outside of employment and education in order to thrive. This poses an additional challenge as living with chronic illness also required participants to pay for medications and treatments, and therefore, accessing insurance was necessary. In this regard, being able to thrive within employment settings not only consisted of whether participants were able to work with their respective conditions, but also whether their places of employment provided insurance to access their medications and treatments.

The issue with not being able to access employment and education is that it offers a means in which participants can access coverage for their medications and treatments. For participants that were able to secure work, it was found that places of employment opted for cheap insurance plans, which barely covered the financial demands of medications on which individuals living with chronic illness depend on. Consequently, participants were left paying for the bulk of their medications out of pocket:

They're just putting limits on us, like 'Oh, you use so many test strips...if you hit your limit we're going to cut you off'. Are you serious?? I need this to live! I need to check my blood everyday... I was looking at my bill...if I have to pay for this

stuff myself, it's like hundreds of dollars every month. That's crazy. That's a huge expense. (J.E.)

For some participants who were younger, relying on youth benefits provided them a lot of support; however, much anxiety still existed surrounding what would happen once these benefits were no longer accessible to them:

I was lucky that my dad had a good job with medical insurance because then none of this would have happened...I'm still on it till I'm 26 so I'm lucky that way...I'm actually in the middle of trying to get disability so I can have some more surgeries without worrying about money. (Keto)

Similarly to employment, participants conveyed having a difficult time managing the realities of living with chronic illness while completing their education. Being in school required participants to be present in order to achieve grades. For many, this was extremely difficult. Keto in particular, a young person living with Pars Defect, had difficulty completing her secondary and post-secondary education, as she required numerous treatments and surgeries over the years of being diagnosed. She spoke to me about how she was almost denied the chance to graduate high school due to having many surgeries and treatments that took her out of class, "...they said I couldn't graduate because I missed too much school for surgeries" (Keto). Frequently being absent from school was a significant factor in how much this participant thrived, especially in comparison to her classmates; therefore, the gap Connell (2011) spoke to surrounding capitalism was illustrated here. Frequent absenteeism placed many participants in situations where they were observed as having circumstances that were not like others, and therefore, they did not fit in.

J.E., a person living with diabetes, discussed his experiences trying to fit in while being someone who immigrated to Canada from Jamaica in his youth. Fitting in within his context involved a conceptualization of what it means to be Canadian. Although he spent much of his youth attempting to fit in, J.E. realized that he was expected to perform in ways that were similar to his peers, thus replicating normalcy within his context. His experience reflects how people living with disability are expected to adjust to the pace of the dominant population, while also not receiving an opportunity that is equitable. These kinds of realities were exhibited in the article written by Dyson et al. (2007), where the experiences of students living with sickle cell disorder were discussed in relation to how well they thrived within the education system. Within this discussion, participants were expected to attend school, engage in various school related activities while also managing the realities of living with sickle cell disorder. However, for many of these students, their illness led to fatigue, absenteeism (due to treatment and hospital appointments), and needing more rest as a result of other symptoms associated with living with sickle cell disorder (p. 589). This study by Dyson et al. (2007) demonstrate how the education system enforces a capitalist structure onto students, leaving little room to care for oneself, an important aspect of living with chronic illness.

What further interrupted their participation in dominant systems were false notions surrounding inclusivity. This led participants to believe that their circumstances were welcome. J.E. and Keto both talked about how they were affiliated with organizations, schools and companies that appeared open to people living with health disparities; however, their experiences proved to be the opposite as they were still expected to produce to the same capacity as those who did not share their circumstances.

Although for some time he had felt that he needed to hide his chronic illness from possible employment situations, J.E. discussed his experience trying to secure work at an organization that catered to individuals living with his condition. J.E. described how he would consistently see individuals with no lived experience, yet notions surrounding higher education combined with these individuals being white or white-passing provided easier access to paid positions. Although J.E. demonstrated knowledge through his lived experience by volunteering, he saw no paid outcome for his efforts. “Jobs were prioritized to white people” (J.E.).

This circumstance introduces an additional aspect to experiences surrounding employment with non-white individuals living with chronic illness. J.E.’s excerpt demonstrates how there is difficulty finding legitimacy in employment and that the ways in which he is invalidated at work are tied to racism. This example introduces how the study of disability can intersect with race. In my analysis of J.E.’s narrative, one of the conclusions I came to was that there is an aesthetic attached to disability, and furthermore spaces that were created to support those living with disability perpetuate this idea. Attaching the systemic issue of capitalism to my analysis brings me to the discourse surrounding the ways in which disability is advertised to our society. This theme surrounding the advertisement of disability came through in my conversation with participants.

In discussing the advertisement of disability, J.E. described the aesthetic attached to those living with his particular chronic illness; among the images of fit white people, J.E. discussed how he felt frustrated that these images did not represent the diverse populations that could be impacted. The whitewashing of images is not uncommon as it is

apparent in the experiences of participants within the study by Nelson & Macias (2008). In their study titled *Living with a White Disease: Women of Colour & Their Engagement with Breast Cancer Information*, participants shared their experiences receiving education related to breast cancer. Because white women are portrayed as the forefront of living with this illness, the needs of racialized individuals are consequently neglected (p. 26, p. 27). What this further speaks to is a larger narrative of how homogenization occurs within the dichotomy of normal and abnormal, reflecting how knowledge from subjugated populations are co-opted by the dominant group (Titchkosky & Michalko, 2009, p. 6). Therefore, when disability is advertised, it is advertised in ways that are meant to be pleasing to dominant populations. In the case of non-white people living with chronic illness, this homogenization further erases their experiences (Davis, 1995, p. 34). In J.E.'s narrative, he felt that the way his disability is advertised was connected to how he was not able to find work, whereas with other participants, it impacted the way they were seen. Keto discussed how no one took her seriously as someone living with disability because she was not in a wheelchair, a common narrative where dominant groups place a hierarchy of what disability should look like. Procknow et al. (2017) speak to the hierarchy of disability where they state how disability is often recognized more with people who look visibly disabled, whereas those who live with invisible disabilities need to work harder to prove themselves. Moreover, the severity to which these individuals live, whether it is mental or physical, often goes unrecognized or is further stigmatized (p. 370). The incorporation of race is relevant here. Similarly to the experiences of women living with breast cancer in the study by Nelson & Macias (2008), whiteness, a global symbol of dominance and power, also contributes to how people's experiences living

with chronic illness are legitimized. “[I] am not a little white boy so I can't possibly have [ADHD] and I also think that definitely shaped how psychiatrists have seen me as well when it comes to diagnosing and assessing these things.” (M.R.)

Notions of a person's race, culture or location inform the chronic illness they have. Through my conversations with participants, certain illnesses could only be advertised positively when white individuals were at the forefront of the ways in which these disabilities were portrayed. Otherwise, people had negative notions of what illness looked like. For instance, participants discussed how it is common for diabetes to be associated with Jamaicans, how heart disease and diabetes were associated with Indigenous Peoples, and how they have often been the target of having people test them for certain illnesses just because of their race or even gender:

[They] want to know whether or not I've had any sexual activity as a way to get me to get HIV testing...they want to know so much of my personal life and the way many doctors are so controlling of me partly has to do with the fact that I'm trans, the fact that I'm part Indigenous. (Kiki)

Being a trans girl, someone who is part Indigenous and white-passing were important factors in how Kiki navigated her experience in healthcare. Similarly to her, many participants navigated other intersecting identities, namely gender-nonconformity and sexual identity outside of heterosexuality. What was common among these participants was a strong tie to community and friendship.

The theme of community and friendship emphasized the importance of creating space for oneself in order to feel validated. When I spoke to Keto, her bedroom walls were covered with rainbow flags and signs that read “Protect Trans Kids” and “Black

Lives Matter”. Her partner, who was present during our meeting, reminded her throughout the interview of the strength she maintained through her struggles navigating healthcare, racism and homophobia. Creating this space for herself was a strong part of her narrative and was what she felt helped her survive. Similarly, activist spaces demonstrated to be helpful for many participants in this study, and furthermore, finding spaces that were created specifically for those living with disability and who are not white. M.R., a queer person living with spina bifida and ADHD, discussed how more space was emerging in Toronto that allowed for those living with disabilities to exist without worrying about barriers to access or being questioned about their disability. Being questioned was a common theme for participants living with physical disabilities; M.R. dedicated time in our conversation to how their friends have helped make spaces safer for them as someone who does not only live with a visible disability, but as someone who has recently come out as non-binary:

[When] someone has invited me to something and they say, ‘Oh, there's a few steps up to the entrance, would that be an issue?’ little things like that. Or in terms of gender, since I’ve come out as non-binary, when people make little changes to how they talk about me or even check in. (M.R.)

Although safe spaces are critiqued in academia and social work, the participants in this study demonstrated how important this idea is for their own well-being. Kiki provided many examples of how gathering with other Indigenous and non-white peoples in community settings provided her with a sense of comfort and connection:

I’ve met some Indigenous people who were labelled with an intellectual disorder and who would also be Two Spirit or LGBTQ...I do really love to be around them.

Some of the Two Spirit young adults I've met at this young adult Two Spirit group that I used to go to...I still talk to them and I'm still friends with them and I feel like I have a very great relationship with many of the Indigenous people who know me from many other spaces that I've been to. (Kiki)

The importance of connection demonstrated through Kiki's narrative not only exposes the isolation experienced by those who have been marginalized, but also reminds us how Indigenous Peoples in Canada and across the globe have been structurally displaced (Meekosha, 2011, p. 670). This excerpt in Kiki's interview is integral to expose the violence rooted in the position of dominance held by the global North, and that encouraging community and connection is a tool that can be used to destabilize structural oppression in the West.

While many participants were determined to find safe spaces outside of dominant systems (such as within community groups) some participants were able to create spaces for themselves by practicing resistance and activism within dominant systems, such as school. J.E. and M., two graduate students with a history in activism and community organizing, discussed how they were using their education to begin conversations to not only expose the barriers of living with chronic illness, but to also create spaces where they can celebrate their identities within academia:

I feel now as an adult...very creative and inspired by my chronic illness, like it's allowed me to embrace this kind of fluidity that is in my life. I've lived my life with so many people trying to place me in a box and try to label me, and I think that in itself is very much a symptom of whiteness...needing to define, needing to state clearly who you are and what you are, so we can identify you. (M.)

Discussion

The findings stated that there were barriers to employment and education, that a structure existed in the way disability is advertised, and that finding space in community and activism helped legitimize the identities of participants in this research. They have led me to conclude that existing structures with foundations in global capitalism and colonialism create notions of productivity that delegitimizes the experiences of non-white individuals living with chronic illness. Being unable to find accommodating employment or education is reflective of how central productivity is within the context of global capitalism. Participants in this study demonstrated this through their employers not prioritizing the medical needs of their chronic illness or viewing them as a workplace liability due to their limitations. These experiences illustrate the extent to which normalcy is valued in our society and that participants in this study were pressured to be resourceful and function in ways that were not “normal” for them in order to thrive.

I have introduced many examples of how capitalism (employment and education) and colonialism (aesthetic) impacted participants at a micro level; however, a much larger conversation exists in regards to how de-legitimization is a global phenomenon, which then informs the experiences of non-white individuals living with chronic illness. Evidence of this was found in my review of Meekosha’s (2011) article discussing how disability is and has been physically inflicted onto the global south through genocide, war and colonization (p. 668-669). Meekosha (2011) reminds us that the introduction of global capitalism has further disadvantaged these populations, namely those that are Indigenous, as we are still not living in a post-colonial society (p. 668-669). The impacts

and effects of colonization remain present within the narratives of those I spoke with, as the image of whiteness continues to colour the lens of disability and chronic illness.

The narratives of participants in this study expose structural oppression in the way of racism, colonialism, ableism and capitalism. Although the effects of this systemic discrimination have deeply impacted participants in this study, I want to convey my intention to celebrate their strength and resistance in this paper. In my conversations with them, I have observed and appreciated how they celebrate themselves, how they surround themselves with people who see them and love them, and furthermore, the incredibly resourceful ways in which they resist.

Chapter 4: Conclusion

...we do not live in the margins, but
at the centre
of this ongoing evolution
we are racial redefinition
in flesh and blood
in celebration
we -
are re-imagining ourselves and what it means to be human
beyond the borders of either / or. (Thompson, 2010, p. 180)

In my completion of this Practice Research Paper, I have demonstrated how race and ability intersect within the scope of my research question: how do dominant notions of normalcy inform the experiences of non-white subjects living with chronic illness. In concluding this research, I have found that structures such as global capitalism and colonialism perpetuate notions around what it means to be productive in our society. This major finding has proved to impact non-white subjects in this study through the extent to which their experiences are legitimized in spaces such as employment, education and by various dominant groups. Capitalism and colonialism were found to be prominent influences, emphasizing that in order for disability to be accepted in our society, an aesthetic has to be attached to the way disability is advertised. The narratives of participants in this study expose how disability is legitimized when it is visible and when it is white. Through my conversations with participants, I have found that destabilizing the co-option of disability by dominant groups can be accomplished through smaller

community spaces and feeling connected to a greater discourse through activism and social justice. Furthermore, my review of literature also demonstrates that an integral aspect of destabilizing dominant notions of normal involve one's development of knowledge, specifically context surrounding the colonization of Indigenous Peoples, and how the concept of "normal" came to be.

Limitations

Addressing limitations within this paper primarily has to do with constraints I experienced while producing this research. Honouring the individuals that were a part of this study was a priority for me, and although I feel I did my best, a major limitation involved the ways in which capitalism impacted how much time I had, how much money I had to sustain my well-being, and how time and financial constraints affected my own mental health. The subject of chronic illness and normalcy is one that is personal to me; however, due to time and financial constraints I found myself feeling quite distant from the subject and also doubting my own abilities as someone who has lived experience within this context. While writing this paper, I found myself identifying with many of the issues surrounding productivity that were discussed by those I spoke with. However, my role as a researcher and a student did not allow much room for me to check in with my own process and care. Therefore, although I have aimed to celebrate those in my study, I feel that as a graduate student in critical social work, it is my duty to reflect upon the gaps that exist in producing knowledge; I will not separate the two.

Another limitation I experienced connected to the length of time I had to complete this research was how much I wanted to elaborate upon a subject that is so vast. A part of what made producing this content difficult was that I needed to remind myself that what I

am providing is merely an introduction to my relationship with this research. Looking back on my work, each finding could have been a separate research study, and although I would have loved to do more, I believe there are many opportunities for further research.

Future Research

The subject of the body in relation to normalcy is vast and can be taken in a number of directions. One area I hope to pursue, and have already started exploring is queerness and the body. As a queer person, and someone who identifies as having a “queer body”, I am interested in how we can talk about the body as a separate entity from one's consciousness and am hoping to incorporate existing research into this idea. Another direction I would like to take this research is by being more specific in regards to the body and its ability, specifically in relation to movement and dance. Apart from my own personal research goals in hopes of celebrating non-white individuals living with chronic illness, I feel that there are many themes within this current study that can be explored further. For instance, producing more research to the subject of employment within the scope of whiteness and disability or contributing to work similar to academics such as Nelson & Macias (2008) by discussing the aesthetic of disability and our society's preoccupation with whiteness. These research ideas are significant and provide many opportunities for those within social work to inspire conversation and facilitate reconstruction.

Implications for Social Work

My research reflects how people are resisting ideologies that are so deeply ingrained in our society and therefore, complex. Although I spoke to many individuals who were critical of how disability is discussed, there was still a consensus of how

hidden dominance is and how it is yet to be acknowledged. In my introduction of this paper, I called attention to how easy it can become to deconstruct, but as Adrienne Maree Brown writes, we must also learn how to reconstruct (p. 56). Therefore, while calling attention to the ongoing violence of global capitalism and colonialism, I also intend to demonstrate how those I have been honoured to speak with find strength in themselves not only through anger, but also through love and community. As social workers, we often encounter this resilience by meeting service users or by engaging in community activism ourselves. However, due to our role and its inherent power, a divide still exists, and we are therefore susceptible to being desensitized to this beauty. I aim to remind myself and my colleagues of the importance of checking in with ourselves and practicing resistance against capitalism to ensure that we can properly assess that we are truly honouring those that we work with. Participants in this study demonstrated how living with chronic illness had made them feel stripped of their self-worth, their humanness and their legitimacy. As a subject in this research, I could identify with these sentiments. Nevertheless, as someone who also has power within the field of social work, I intend to spend time reflecting upon the ways we can facilitate space and celebration in the midst of this violence.

One of the things I feel that we can do is to be engaged with how resistance is being practiced. As a non-white individual living with chronic illness, one of the ways I practice resistance is by actively demonstrating the strength that exists in being vulnerable. As someone who has lived with both invisible and visible disabilities, I began practicing vulnerability by being open about who I am and what my normal is, but I continue to apologize. I have recently reached a place in my life where I choose to be

unapologetic and, like many others inside and outside of this study, I choose to use my body as a way to engage people, legitimize my experiences and resist dominance. As social workers and academics, I feel that we are capable of appreciating these strengths. What I feel should be appreciated more, is the strength of those that stay in bed, and surround themselves with trusted loved ones, their medications, and objects that inspire warmth. As my research demonstrates, society has intended to erase these individuals. I had mentioned several times throughout this paper that honouring the individuals within this study was important to me; I would like to conclude my research paper with a demonstration of my appreciation and gratitude for those that participated in conversation with me.

A Place

There is a place inside my head that I have created at every stage of awareness

Where the words

ACCEPT, EMPOWER, CELEBRATE and EMBRACE

Echo in my ethos and have kept me afloat

I want to feel normal

I want to be normal

My normal

I am normal

It is a place where I can't just dance

I can soar

Swim, even

So I'll show them that I am able

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