

THE REALITIES OF SCHIZOPHRENIA FOR BLACK AFRICAN FAMILIES NAVIGATING  
GREATER TORONTO'S MENTAL HEALTH SERVICES

by

Dorothy Alvina During, BSW, York University, 2016

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## ABSTRACT

The Realities of Schizophrenia for Black African Families Navigating Toronto's Mental Health Services

Master of Social Work, 2018

Dorothy Alvina During

Program of Social Work,

Ryerson University

This is a qualitative phenomenological (Padgett, 2017) study of how Black African families with relatives diagnosed with schizophrenia navigate and experience mental health systems in the Greater Toronto Area. Data was collected through individual face-to-face interviews with 3 participants who are self-identified adult African family members or relatives of a person diagnosed with schizophrenia. The research draws on the theoretical approaches of Anti-Black Racism (Kumsa et al, 2014) and Anti-Black Sanism (Abdillahi, Meerai & Poole, 2014; Meerai, Abdillahi & Poole, 2016). Participants had an outlet to share their experiences, and a space to share ideas on program development and coping strategies. The findings of this study suggest that Black families need a space where Black and/or African individuals with mental health challenges can safely navigate and share their stories through storytelling, poetry and music, to name a few methods. There is a need for Black and/or African navigating resource services for Black and/or African immigrants diagnosed with mental health challenges and their families. We can conclude that there are a number of areas of research which require more exploration, including the social construction of Black and/or African immigrant families faced with mental health challenges pre- and post-diagnosis and how they navigate mental health systems. It is critical to promote the voices of Black and/or African individuals with mental health challenges and their families in research and practice because “you cannot know about us without us” (Morrow & Malcoe, 2017, p.132).

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## DEDICATION

I dedicate this Major Research Paper to my family, my husband and to all who supported me throughout this process, to the participants in this study, and to all of the individuals who have been told that you cannot, and will not accomplish your dreams. You will, and you can.

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## CHAPTER 1. INTRODUCTION

The purpose of this Major Research Paper is to bring about change. I want to deconstruct experiences around mental health within the Black and African immigrant communities in Toronto. I also want to increase awareness of effective resources and mental health services to Black families and/or African immigrant families with relatives diagnosed with schizophrenia in Toronto and the Greater Toronto Area. This research addresses ways in which Black families and African immigrant families with schizophrenia and their relatives face systematic marginalization, oppression and exclusion. The research question for my Major Research Paper (MRP) is: How do Black families/African Immigrant families with relatives diagnosed with schizophrenia experience the mental health system in Greater Toronto?

Before I continue, let me clarify what I mean by Black, African and ‘schizophrenia’. To me, a 'Black' person is an individual that is black or brown in complexion, from the African diaspora that identifies themselves as 'Black'. The term 'African' “refers to a person with African ancestral origins who self-identifies or is identified by others as African” (Agyemang, Bhopal & Bruijnzeels, 2005, p.1016).

According to the DSM-5, Schizophrenia is defined by “abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behaviour (including catatonia), and negative symptoms” (American Psychiatric Association, 2015, p.1).

Definitions aside, as I continue this journey of my research, the more informed I am about my own personal epistemology, and the more I become aware of the impact it has on my day-to-day activities as an individual and as a researcher. Some of my knowledge is shaped by my community, family values, ethics, and religion, to name a few sources. I was always

connected with my community as a young girl from Freetown, Sierra Leone. From engaging in fictional story telling and personal narratives to being a part of a music and dance culture, all these played a part in constructing my character and forming my own individual epistemology and perception of the world.

However, I have also come to realize that some of my knowledge construction and understanding of the world has also been deeply influenced by colonial Western ideologies. I am now able to reflect on how I, an African woman, have continued to reproduce and perpetuate these oppressive discourses.

For example, as a young child to a youth, my educational experiences were regulated by the English language, and the structure of the educational system was grounded in the British colonial system, even decades after the country gained its independence in 1961. As students, we were punished for speaking our ‘ethnic’ tongue in the school environment. Looking back, in my perception, that was problematic, because essentially it is a form of erasing one's identity and culture. It was in essence, pathologizing one's ethnic tongue as ‘uncivilized’. Fundamentally, speaking English was considered civilized and proper. Even in interpersonal relationships, I could remember this phenomenon manifesting itself, where family members would want to adapt to this culture of Westernization. For instance, some family members would speak English to their children even at home, because they wanted their children to be ‘civilized’.

Growing up, the ideology of language was shaped in the notion that speaking English makes one smart, respected and accepted. Fanon (2008) argues that language is a form of acceptance or entry into a culture, and it makes Black African families feel like they are uncivilized with no history. Even the most common language that is spoken in my native country (Krio) is shaped by a mixture of different languages in an Anglicized format, and politically,

English is the official language of Sierra Leone. Fanon (2008) argues that colonialism has destroyed people's (from all races) ability to grasp the ontology or reality of Blackness, and what it really means to exist as a Black person. This is because of the way colonialism forces Black families to live in relation to white colonizers and their culture.

I believe the strength of my knowledge is grounded on my continual critical reflection, and that “without this critically reflexive journeying, I run the risk of unintentionally reproducing oppression and injustice in my quest to do the opposite” (Sky, 2016, p.622). These different ideologies that have contributed to my knowledge have really taught me the meaning of community. My personal epistemology has played a part in my deep desire for social justice and equality. My different intersectionalities and social locations have also played a part in helping me realize what I know, who I am, where I am from and where I am potentially going – as an individual, a social worker and as a researcher.

The strength of my epistemology has deepened my knowledge that there is no linear way of understanding the world. It has also given me the lens to contextualize how injustice, oppression, colonization and Western ideologies are perpetrated on a daily basis. The knowledge which I gained as a child in my birthplace Sierra Leone, the knowledge which I have gained here in Canada as an immigrant, and the knowledge which I have gained throughout academia have all expanded my horizons, and played a path in assisting me to decolonize some of my possible problematic ways of thinking and knowing.

However, through this process, I have come to the realization that my epistemology has, and continues to, limit me in various ways. In a sense, my identity as a Black African immigrant woman was constructed through the lens of colonization, heterosexuality and heteronormativity. Even through resistance, it is challenging to completely avoid perpetuating these paradigms. And

“when I use these paradigms to frame myself, I tie myself to them and, even though in opposition, I am still perpetuating them; this framing informs not only my practice, but also my experience of the world around me” (Sky, 2016, p.620) because of institutional structures and oppression.

I hope that my personal epistemology continues to evolve in a way that is transformative and inclusive to all knowledge. I am concerned that the dominant discourse of Western colonial ideology will continue to manifest itself in my research, and my hope is to resist that.

It is challenging and also troubling how limited research exists on the topic at hand, especially studies that are authored by (or at least including) Black families/African immigrant families with mental health challenges. However, knowing this further motivates and inspires me to want to continue my research. I believe that contributing our voices and narratives in regard to this topic are a step towards healing and possible change. I certainly believe that there is no research more impactful for Black African families than research done by Black African communities. I believe we can depict our own stories in a way that others cannot, and I also believe this process is a start of decolonizing some of our colonial ways of thinking in research.

This Major Research Paper is about understanding Black African families who have a relative diagnosed with schizophrenia in their own context. As I continue this journey of my research I am weary of implicating oppressive forms of research in my work. As I continue to reflect, I continue to see the implications of my knowledge, and how it is a crisis that needs to be addressed in all levels – micro, mezzo and macro levels.

In the Western world for example, publication of academic journals, magazines and book, are generally tied to a white privileged position in academia. This sometimes makes it

extremely challenging for Black and/or African scholars in the West, as well as researchers in African countries, to move ahead in the world of academic research, especially in the journals, magazines and books that are controlled exclusively by White academics (Baffoe et al, 2014). Part of the problem involves the notion that some academics do not trust those outside of their academic community to have enough insight, enough reflexivity, enough depth, to be able to “see past the traps of ideological discourses”, and to speak beyond their own immediate experiences (Landson-Billings, 2003, p.656). This speaks to the idea that some researchers must believe they can theorize and understand the lives of their participants better than the participants themselves, because of their training and educational background. This further silences, pathologizes and excludes participants from their own narratives. As I continue my research, I am aiming to continue to push against these dominant forms of knowing that affect so much academic literature and marginalized identities.

My response to these epistemological issues involves decolonizing my epistemology and resisting colonial processes by centering the voices of the participants throughout my research. As a social worker, a graduate student, and as a researcher, I have come to the realization that in order to decolonize and de-centre whiteness in my practice, I must first understand that social work as a practice is rooted in a dominant colonial space. This contradicts discourses of “holistic” healing and resistance practices, including those which are common in Indigenous culture (Meerai et al, 2016). And for me to be able to operate in this lens, I must continue to decolonize in my practice through inclusion and centering of Black families/African families’ experiences, pain and knowledge in my practice and my research (Meerai et al, 2016). Like Sky (2016), I believe that instead of perpetuating the ways of oppression, this critical reflexivity journey leads me to a place of realization that I need to liberate my own being from colonization

in order to change the discursive landscapes around me personally, professionally and academically (p.623). I believe these theories are a manifestation and influence from the knowledge gained through my community experiences as well as my academic experiences, which enables me to contextualize problematic and oppressive practices.

It is critical that, as a researcher, I am aware of other alternative ways of research for marginalized communities. Although it is evident that the dominant form of research practice within social work is grounded in Western ideologies, my aim as I do my MRP is to resist those ideologies so that I can better support my participants. This may be done by resisting “social roles, structures, identities and expectations that limit marginalized people” (Baines, 2011, p.216), for example.

Like those described by Sky (2016), the painful task of trying to decolonize my epistemology involves examining my own internal conflicts and peeling apart the layers of my knowledge and how I acquired them (p. 622). Looking through my ‘internalized inferiority’, is allowing me to recognize how deeply my culture, my ancestry and my very being as a person has been impacted by the power of colonization (Sky, 2016). It hurts to know that inadvertently, I have constructed my life and knowledge around the same system I am seeking to resist against (Sky, 2016).

I believe that critical reflectivity is very crucial as a practitioner and as a researcher. The more I critically reflect on what I know, and how I know what I know, the more effective I will be in my work as a social worker and researcher.

## CHAPTER 2: LITERATURE REVIEW

There is limited literature available on this topic, and most of the literature is positivist or quantitative in nature. Some of the themes found in the literature are limited access and stigma towards mental health services in the Black community (Whitley, Kirmayer & Groleau 2006; Steele, Lemieux-Charles, Clark & Glazier, 2002; Eack & Newhill, 2012; Anglin, Alberti, Link & Phelan, 2008; Saechao, Sharrock, Reicherter, Livingston, Aylward, Whisnant & Kohli et al, 2010). These research studies mention the relations between African Immigrants accessing mental health services and the stigma and discrimination that defer this community from accessing care. Another theme is the importance of family involvement in responding to mental health issues (Sandhu, Bjerre, Dauvrin, Dias, Gaddini, Greacen ...& Riera, 2013; Berkowitz, Eberlein-Fries, Kuipers, Leff, 1984; & Knock, Kline, Schiffman, Marynard, & Reeves, 2011). This research suggests that family intervention may reduce the number of relapses and hospitalizations of an individual with schizophrenia (Pharoah et al, 2014), and that family therapy may lower emotional stress (Doane et al, 1986). A third theme is the increase in diagnoses of schizophrenia among African-Caribbean people (Fearon, Kirkbride, Morgan, Dazzan, Morgan, Lloyd...& Mallett, 2006; & Boydell, Van, McKenzie, Allardyce, Goel, McCreadie, & Murray, 2001; Fearon et al, 2006, p. 1541).

However, as mentioned, positivist social science was the most commonly presented paradigm during my research. There were nine examples of positivist research. These research studies were Beiser et al, 2002; Fearon et al, 2006; Pharoah et al, 2014; Boydell et al, 2001; Doane et al, 1986; Guada et al, 2010; Eack & Newhil, 2012; and Anglin et al, 2008. These positivist, quantitative studies included research methods such as surveys, scales, indexes, experimental designs, and randomization in sampling. Neuman explained positivist social

science to be “an organized method for combining deductive logic with precise empirical observations of individual behavior in order to discover and confirm a set of probabilistic causal laws that can be used to predict general patterns of human activity” (Neuman, 2006, p. 95). Positivist social science assumes that “humans are self-interested, pleasure-seeking/pain-avoiding, rational mammals. A cause will have the same effect on everyone. We can learn about people by observing their behavior that we see in external reality. This is more important than what happens in internal, subjective reality” (Neuman, 2006, p. 96). This thinking was present in most of the research found on the topic of relatives who have a family member with mental health or schizophrenia. Most of the research suggested that family members must change their expressive emotions to assist relatives with ‘relapsing’. Overall, positivist social sciences assume that everyone experiences the world in the same way, whereas the interpretive approach questions whether people experience social or physical reality in the same way (Neuman, 2006, p.103).

However, there are some critical studies on the issues faced by African identified people in regards to mental health. In this literature review, there were six research articles that grounded their research paradigm on interpretive social sciences. They are Whitley et al, 2006; Sandhu et al, 2012; Berkowitz et al, 1984; Steele et al, 2002; Knock et al, 2011; and Saechao et al, 2011. The methods used in these research studies are interviews, focus groups, and participant observation. Neuman (2006) explained interpretive social science as how people interact with each other. In general, the interpretive approach is the systematic analysis of socially meaningful actions through the direct detailed observation of people to understand and interpret how people create and maintain their social worlds (Neuman, 2006).

Of the research completed on mental health, schizophrenia and immigrant and families,

the majority of the research found was also constructed with Western ideologies and perspectives. The voices of the writers and researchers were more prevalent than the people being researched. The research conducted on this topic is knowledge that is produced and validated by people with power, people who have a certain academic and educational background, and people who continue to reproduce their authority, especially within the positivist paradigm (Landson-Billings, 2003). Even in the interpretive framework, most of the researchers use a semi-structured approach to attempt to diminish their power dynamic and better understand the experiences of other people (Baffoe, 2014). However, the production of knowledge continues to work within the framework of colonizer/colonized. The colonizer still strives to provide ways of knowing and insists that others use these paradigms, too (Chilisa & Bagale, 2012).

It is important for researchers to work in a decolonizing framework to ensure that the voices of the people are heard throughout the research. Although understanding the voices of the people being researched does not mean that the researchers are rejecting all theory or research from Western Knowledge (Landson-Billings, 2003), it means the researcher also understands the concerns, world views, theory and research from the perspectives of the people being researched (Landson-Billings, 2003).

As a result of using Westernized ideologies and perception in studies of African immigrants and mental health, most of the research studies found were knowledge constructed, reconstructed, distributed and reproduced by Western ideologies and by white researchers, who more often than not, see little or no value in the knowledge base of academics and researchers from African-based research and methodology (Baffoe et al, 2014). This is problematic because it shows that the researchers do not trust the African immigrant participants to have enough

insight, enough reflexivity, and enough depth, “to be able to see past the traps of ideological discourse, [and] speak beyond their own immediate experience” (Landson-Billings, 2003, p.656). Also in Chilisa's research (2003), she mentioned that “concepts, themes, and patterns are developed as researchers read through the data and ask critical questions, which may come from the abstract vocabulary of a discipline or a theory within a discipline” (Chilisa, 2012, p. 214). In other words, the interpretation of the researchers is influenced by their epistemological backgrounds and their practices. The voices of the researchers show that they can theorize about the participants' lives and circumstances better because they are formally trained to do so (Landson-Billings, 2003). Having the voices of the researchers instead of the participants continues to marginalize and silence African immigrants with mental health challenges and their families (Landson-Billings, 2003).

Similarly, the use of tools such as questionnaires and surveys with African participants with mental health challenges displays a top-down method of “collecting data that mirrors the worldview of the researchers or their perception of the topic to be covered, blocking any continuity with the researched people's worldview” (Chilisa, 2012, p.78). Questionnaires and surveys are a popular method used in the positivist paradigm, which is sometimes taken to be the highest measure of truth and knowledge within this form of research (Chilisa, 2012).

Context in a post-positivist framework is important in collecting data and research as it is the mirror of Eurocentric Western epistemologies and realities. However, African researchers are sometimes perceived as “one mass, exhibiting the same characteristics and same behavior, irrespective of geographical boundaries, diverse languages, ethnicity, and institutional practices” (Chilisa, 2012, p. 82). This creates barriers and limitations for African literature.

One alternative and 'Afrikologist' way in which the researcher could have included the

voices of the African immigrants in the data collection process, might have been through the forming of circles, which is also used within the Indigenous community (Chilisa, 2012). In this form of research, individuals are given an opportunity to speak uninterrupted. “The talking circle symbolizes and encourages sharing of ideas, respect of each other's ideas, togetherness, and a continuous and unending compassion and love for one another. The circle also symbolizes equality of members in the circle” (Chilisa, 2012, p. 213). Therefore, there is no power dynamic, and the researcher is not the expert on the participant, but rather the participants are the experts of their own stories and experiences. These ways of knowing form the basis for understanding the participants' perceptions of realities and informing education, communication, and information strategies (Chillisa, 2012) of the mental health system as an immigrant.

Chilisa (2017) also notes that “Afrikology epistemology derived from the African cosmology of connectedness and spirituality, promotes harmony and balance as well as critical inquiry and ‘fearless aspiration for new paradigms’” (Chilisa, 2017, p.328). This shows that there is so much knowledge that can be used within research of African Immigrants communities.

Excluding the voices of the participants continues to perpetuate some of the negative ideologies that have caused psychological harm, embarrassment or humiliation (Chilisa, 2017), shame and reduction of confidence in people's cultures (Chilisa, 2017). Therefore, the engagement of communities in research also “helps the researcher to understand different discourses that can be used to deconstruct some of the socially constructed beliefs” (Chilisa, 2017). For example, Chilisa (2012) has used proverbs to explore community constructed gender ideologies, while Musyoka and Mertens (2007) used proverbs to challenge stereotypes about people with disabilities. “Generally, proverbs can be analyzed to reveal and express social, cultural, natural, and community events and practices. They can form sound theoretical

frameworks that move away from conceiving the researched as participants to seeing them as co-researchers with authentic literature about their communities. Proverbs and languages as theoretical frameworks is now a common practice with research that has decolonization intent” (Chilisa, 2017, p.335).

For some of the reviewed literature, there were very limited recommendations, follow-up or suggestions for action after each research was completed. It was very problematic to review positivist research studies that blamed the family and the individuals labelled and diagnosed with schizophrenia for their relapses without addressing their different Intersectionalities and social locations. There was also no mention of Anti-Black Sanism (Abdillahi, Meerai & Poole, 2014; Meerai, Abdillahi & Poole, 2016) and Anti-Black Racism (Benjamin, 2003; Kumsa et al, 2014) within the research studies. There was no mention of different accommodations for participants, for example an interpreter.

Another limitation of the research studies on African Immigrants with a relative with schizophrenia are the small and non-representative sample sizes used (Whitley et al, 2006; Fearon et al, 2006; Doane et al, 1986; Saechao et al, 2011). One of the studies had only White immigrant participants during their interviews, which would provide a limited understanding of Black immigrants' reluctance to using mental health services (Whitley et al, 2006). These studies were unable to examine differences between ethnic groups in mental health stressors and in the use of mental health services (Saechao, et al, 2011). It is very critical that researchers take into consideration the population of their study to get an accurate and effective result. For instance, if the study is on immigrants, there must be diversity in the study. And if a study is exclusively on Black African Immigrants, the study must be done for Black African immigrants by Black African Immigrants, or from other non-white ethnic or racial groups (Guada et al, 2009).

Turning now to the more critical literature, I found themes such as Black youth violence and healing (Kumsa, Mfoafo-M'Carthy et al, 2014); Anti-Black crisis in mental health diagnosis and care (Abdillahi, Meerai & Poole, 2014; Meerai, Abdillahi & Poole, 2016) and racial 'prejudice' and racism in mental health services (Fernando, 2002; Fernando, 2014). The work on Anti-Black Sanism (Abdillahi, Meerai & Poole, 2014; Meerai, Abdillahi & Poole, 2016) focuses on the discrimination and mental health crisis that is perpetrated on Black bodies on a daily basis (Meerai et al, 2014). It reminds us that Black men are diagnosed with schizophrenia more than any other group (Fernando, 2002), and Anti-Black Racism is the racism that is directly perpetrated against Black people (Benjamin, 2003).

In my research, I take up the theoretical framework known as Anti-Black Sanism (Abdillahi et al, 2014) while addressing Anti-Black Racism (Benjamin, 2003; Kumsa et al, 2014). I examine how these discourses affect the way African Immigrants are diagnosed with schizophrenia and their families navigate the system. I use a phenomenological methodology and an interpretive paradigm using individual face-to-face interviews. Drawing on the critical work reviewed above, I sought to center participant stories, sharing ideas on program development and strategies within our community.

## CHAPTER 3: THEORETICAL FRAMEWORK

The theoretical frameworks on which I draw for this project are anti-oppression (Baines, 2011), anti-Black Racism (Benjamin, 2003) and anti-Black sanism (Meerai et al, 2016). Anti-Black racism in relation to Africans is when racism is perpetrated specifically on Black African individuals (Kumsa et al., 2014). Anti-Black sanism (Abdillahi, Meerai & Poole, 2017; Meerai, Abdillahi & Poole, 2016) is manifested when Black African individuals diagnosed with mental health challenges are isolated, excluded and silenced in various capacities, specifically in the mental health sector. As an anti-oppressive social work student and researcher, my aim is to provide services and collaborate with communities that are oppressed and marginalized. In this research, working with an anti-oppressive lens provides space for Black families/African immigrant families to understand that their problems are not individualized, but linked to social inequality (Baines, 2011), as well as homophobia, transphobia, systemic racism, and systemic sanism.

Secondly, incorporating anti-Black sanism (Abdillahi, Meerai & Poole, 2017; Meerai, Abdillahi & Poole, 2016) within my research gives me a wider lens as to how Black African people with mental health challenges are silenced, shot, over-diagnosed, misdiagnosed, incarcerated and otherwise face physical violence (Meerai et al, 2016, p. 19). According to Poole (2014), Sanism is oppression and it normalizes discrimination, rejection, silencing and exclusion of people. It is a form of violence that makes it possible for psychiatric diagnosis in conjunction with medication to strip away dignity in the name of “health and safety” (as cited in Meerai et al, 2016).

For racialized individuals who identify as Black, African, or of African descent, anti-Black sanism is a crisis that is perpetuated upon Black African bodies on a daily basis. In a white

supremacist system, Black bodies are viewed as intimidating, and make many individuals uncomfortable. Anti-Black sanism creates conformity and a possibility of lost identity; it causes Black people to feel less-than and to be silenced (Meerai et al, 2016).

Anti-Black racism (Benjamin, 2003) is perpetrated on Black families and African immigrants. Kumsa and colleagues (2014) explain how Black African families are affected both within and outside the mould of “anti-Black-African racism, by experiencing subtle and blatant exclusion and marginalization within systems of employment, social services and health care. Within the mental health system, Black families are more likely to be diagnosed with schizophrenia than any other group (Kumsa et al, 2014). I believe it is very important to bring light to this issue because “Black people are disproportionately represented among people diagnosed as ‘schizophrenic’; detained compulsorily in hospital; admitted to forensic institutes; and so on” (Fernando, 2012, p.114). Kumsa expresses that, the “anti-Black racism we experience daily is sharply inflected by the fact that we are Black [folks] from Africa as opposed to Whites and Browns [folks] also from Africa” (Kumsa, p.25). Therefore, there need to be more resources and support in the system to assist Black Immigrant families to navigate. Anti-Black racism (Benjamin, 2003) manifests itself at all levels of Canadian systems, “functioning to preserve systems of whiteness and power and dominance based on a false perception of white superiority” (Meerai et al, 2016, P. 21). This theoretical lens gives me a perception to identify how Black identity is colonized, especially in the psychiatric systems, educational systems and prisons. For instance, “Black identity seemed to be up against a system where only ‘one race’ is visible, accepted and valued” (Abdillahi et al, 2017, p. 7). This invisibility and exclusion further discriminates against black individuals and families with mental health challenges.

When discussing anti-racism, anti-oppression and anti-Black sanism, it is fundamental to

discuss the manifestation and implication of colonialism and White supremacy on mental health diagnosis on Black families and African Families in present time and in history. Fanon (1963) explains how the violence and racism and paternalism was perpetrated upon Algerians all in the name of scientific assessment and facts. Therefore, as social workers and researchers of mental health, mental wellness or psychiatry, it is critical that we first understand the history of psychiatry on Black families—its complexities and the violence perpetuated on Black families and African families on a daily basis—so that we do not continue to perpetuate these forms of violence in our research and practices. This study highlights and addresses some of the continual violence, discrimination, exclusion, colonialism, racism and violence that still present itself within the mental health sector. Our aim as social workers and researchers is to eradicate these violence by first educating ourselves through history.

Mental health in psychiatry began to be studied about approximately 200-300 years ago in post-enlightenment Europe, and often with a focus on social control and social order (Fernando, 2012). Anything that was seen as a problem in terms of mental 'state' and behaviour was seen and classified as 'illness'. Similarly, modern psychiatry came into being as a medical discipline of social control (Fernando, 2012).

If we reflect on this history, we are able to see how many psychiatric aggressions towards Black families have been an ongoing issue. One example is the diagnosis of drapetomania, which was identified as a mental health disorder in 1851 by Dr. Samuel Cartwright (Meerai et al, 2016). Drapetomania was a psychiatric diagnosis or mental illness that was said to cause Black African slaves to flee from their masters in the United States (Meerai et al, 2016). If slaves showed any signs of 'dissatisfied behaviour' they would be whipped, and as a form of early intervention,

slaves were treated like children, with 'care', kindness and attention to prevent them from running away (Meerai et al, 2016).

Similarly, Fanon (1963) highlighted how violence and humiliation was perpetrated on Algerian people through colonial oppression and racism. According to Fanon, prior to 1954, Algerians were considered to be predisposed to criminality and aggressive violence. For French psychiatrists in Algeria, Algerians who were diagnosed with a mental health condition called 'melancholia' created an anomaly. Psychiatrists had been taught that melancholia was a condition given to patients with suicidal tendencies, however Algerians with melancholia killed rather than suffered from suicidal tendencies (Fanon, 1963). This inconsistency is explained by French psychiatrist Porot: "there is no inner life in the North African. On the contrary, the North African rids himself of his troubles by attacking the people around him. He has no sense of analysis. Since by definition melancholia is a disorder of the moral conscience, it is obvious the Algerian can only develop pseudo-melancholias given the unreliability of his conscience and the fickleness of his moral sense" (Fanon, 1963, p. 224). Psychiatry went further to describe Algerians as "mentally retarded" (Fanon, 1963, p. 224) and having the following characteristics:

complete or almost complete lack of emotivity, highly credulous and suggestible, doggedly stubborn, childlike mentality minus the curiosity of the European child, prone to accidents and pathetic reactions. The Algerian is unable to grasp an overall picture. The questions he asks himself are always concerned with details and rule out any synthesis. Pointillistic, attracted to objects, lost in details insensitive to ideas, and closed to concepts. Verbal expression is reduced to a minimum. His movements are always impulsive and aggress. Incapable of interpreting details on the basis of the overall picture, the Algerian absolutizes the component and takes on the part for the whole (Fanon, 1963, p. 224).

Like schizophrenia, many medical diagnoses in past psychiatric history have been constructed to protect White supremacy. According to Fernando, some of the underlying issues of the over-representation of Black people in the mental health system involve the mixture of

'racism' and 'insensitivity' to cultural differences in the system, which is manifested as a form of internalized and structural racism. The way in which our various systems are designed is grounded on Western colonial ideologies, which are very problematic, particularly to Black African families and Indigenous individuals. The truth of this issue is that Black people are "disproportionately represented among people diagnosed as 'schizophrenic'; detained compulsorily in hospital; and admitted to forensic institutes" (Fernando, 2012, p.114), and are more likely to be misdiagnosed.

Marginalization, discrimination and racism also manifested itself in America in the 1920s and 1950s, when schizophrenia, which was considered a middle-class White housewives disease, changed to become a disease known to affect Black men (Metzl, 2013). In the 1960s, several psychiatric journals insisted that schizophrenia was a condition that also afflicted 'Negro men' and that Black forms of the illness were more hostile and aggressive than were 'White ones' (Metzl, 2013), for example. This then transformed schizophrenia "from an illness of White, feminine docility to one of Black, masculinized hostility result[ing] from a confluence of forces" (Metzl, 2013, p.70).

In the mental health field, racism manifests itself in subtle ways that permeate diagnosis, risk assessment, service planning and relationships, to name a few ways. There has not been a satisfactory amount of research done in this area, and limited changes in practice have been observed in this regard. Therefore, we must educate ourselves and study the history of psychiatry on Black bodies as we move towards change in research and in practice. And we must further ask questions like these: does a diagnosis of schizophrenia mean the same thing to everyone? Does Blackness lead to madness?

In this study, I will focus on how anti-oppressive practice (Baines, 2011) allows me to zero in on oppressions of various kinds and how they compound each other. Anti-Black racism (Benjamin, 2003) asks me to complicate the many forms of racism experienced by Black families including those that are laterally violent and those that are directed at these families in multiple systems. Anti-Black sanism (Meerai et al, 2016) asks me to focus on one system, mental health and how, as history has shown, Black bodies are threatened, silenced, isolated and excluded.

## CHAPTER 4: METHODOLOGY

This proposed research utilizes an interpretive phenomenological methodology (Preston & Redgrift, 2017; Creswell & Poth, 2018, Smith et al, 2009). In the interpretive phenomenology method of research, my aim is to investigate and identify a phenomenon (a reality or experience) that can be described as how people “live” the experience (Creswell & Poth, 2018). As the researcher in an interpretive phenomenological method, my role is to engage participants to speak about their truth, and their experiences as they navigate the mental health systems (Creswell & Poth, 2018).

Interpretive phenomenology, according to Creswell and Poth (2018), is a qualitative research framework that is grounded in psychology and influenced by “phenomenology, hermeneutics, as well as idiography” (p.75). Interpretive phenomenology is understood as a particular systematic approach. It is taken from the perspective of particular people, in a particular way or context (Smith et al., 2009). Interpretive phenomenological analysis not only integrates the participant's sense of their lived experience, but also the researchers' attempt in understanding how the participant makes sense of their personal and social world (Smith et al, 2009).

The research question is, how do Black African families with relatives diagnosed with schizophrenia experience the mental health system in Greater Toronto? This question pulls on lived experiences of caregivers and relatives with a family member diagnosed with schizophrenia. The stories shared will be connected to systemic, social, cultural institutional and historical themes.

I sought up to three participants to participate in a face-to-face semi-structured interview that would last no longer than ninety minutes. For an interpretive phenomenology research, 3-5

participants will allow for an in-depth engagement with each individual participant, as well as in analyzing similarities and differences (Smith & Osborn, 2007). According to Smith and Osborn (2007), if the sample size is too big it becomes overwhelming by the amount of data gathered by a qualitative study, which may not be able to produce sufficient analysis.

Interviews were planned to take place at the convenience of the participants, and participants chose the location of the interview. Possible choices were private spaces in their local library, at the Ryerson library or the Ryerson MSW lounge (which has a private interview space) in the basement of Eric Palin Hall. Participants' identities were kept confidential and consent forms were provided ahead of time for the participants' review. Participation in this study was voluntary. If a participant wished to not answer a question, they could skip that question. Participants could stop participating at any time and would still receive incentives and reimbursements. If participants withdrew, they could also choose to not have their data included in the study. Their choice of whether or not to participate will not influence their future relations with Ryerson University or with me and my supervisor, Dr. Jennifer Poole.

I anticipated that participants may receive validation and an increased understanding of how the system plays a part in contributing to various barriers in mental health services. Participants were provided with an outlet to share their experiences, and a space to share ideas on program development and strategies. Overall, the potential risk of this research was minimal. Some of the potential risks of this research included psychological risk by initiating anxiety, or making participants feel upset, or other uncomfortable emotions. To ensure participants were comfortable, interviews took place at the pace dictated by participants. If participants required support, I was set to refer them to Across Boundaries, the 24-hour distress centre phone line and the Family Service Association. To further protect participants, I did not name particular

organizations, programs or their locations in this MRP. Instead, I refer to these as 'Mental Health Organizations' (MHO) in the Greater Toronto Area.

Participants were provided a consent form that indicated that the interview would be audio-recorded. Smith and Osborn (2007) note that it is necessary to utilize an audio-recorder during the interview process. This is necessary so that the researcher does not miss any important nuances, and this will also "help the interview to run smoothly and with establishing rapport" (Smith & Soborn, 2007, p.64). The audio-recording of the interview was stored in a password-locked device. The consent forms were stored in the researchers' locked office at Ryerson University. The audio-recordings were transcribed as soon as possible and destroyed once transcriptions had been verified. Identifiable information was removed during transcription and the password protected encrypted USB was stored in a locked cabinet in the researchers' office. Participants were provided with a resource list including housing, interpreters, mental health services and social service agencies in Greater Toronto, as well as a \$10 Starbucks gift card for their participation. The demographics of the participants who were involved in the study are listed below.

## CHAPTER 5: FINDINGS

This study examines the experiences of Black African families who have a member diagnosed with schizophrenia. Throughout the process of conducting this research, many themes came out and the voices of all participants were centered. The main emerging themes were; relationships; isolation & community; accessibility and race; and lastly, coping mechanisms. I see these themes as related to neoliberalism, socially constructed norms, Western society, anti-Black sanism and anti-Black racism for they all create limited spaces for Black families, African immigrant families with family members diagnosed with schizophrenia to strive, and to be included and represented in various capacities.

The first theme of 'relationships' focuses on love, feelings and family dynamics and some of the challenges and expectations they face as they support their loved ones. In the theme 'isolation and community', participants shared their concerns of feeling alone and excluded on various levels. Participants also mentioned the importance of 'community and representation' as we move towards the process of healing and acceptance. The theme of 'accessibility and race' were also prevalent amongst participants in this study.

The three participants recruited for this study differed in many ways. Participant One identified as a 22-year-old Black African male, non-practicing Catholic, first generation Canadian. Both parents are African immigrants from Central/Eastern Africa. Participant One has a parent diagnosed with schizophrenia. Participant Two identifies as a Black African woman and mother from West Africa. Participant Two shared her son was recently diagnosed with schizophrenia. The final participant, Participant Three, identifies as a Black Immigrant man and father from West Africa and a practicing Christian. Participant Three's son is diagnosed with schizophrenia. All participant quotations are verbatim from all interviews as transcribed in order

to emphasize participants' voices. As such, normative (and white) forms of speech, punctuation and grammar were not imposed.

I began this research study requesting that the participants share with me why they decided to participate in this study and how they understand schizophrenia. When asked why he decided to participate in this research, Participant One explained:

.... you know I mean, it's good to be a part of it. Schizophrenia has affected like my life since the beginning .... since it started you know. So, I would like to talk about the experiences I have had, and especially on the focus on African Immigrants you know, because there is not too much light that has been shone upon issues like that. I am first generation Canadian so I feel like it is important in this sense (Participant 1:30-34).

Participant One also shared his understanding of schizophrenia as, "it just hard to cope with it, and to live with it as well, you know .... just seeing her in a state like that, and having to live life like that, it is tough to see you know".

When asked why she decided to participate in this study, Participant Two explained:

Okay.... so, the reason why I decided to participate in this study is you know, it could be used as an educational tool in the future. At least my experiences would be used to assist other families with the same condition to get the help that they need, you know.... to make it easier for them.... you know, and give them the right path to medication and assistance (Participant 2:5-9).

Participant Two understands schizophrenia as:

...that's a big one. I think schizophrenia is a psychological illness that affects the brain, you know. Wherein the individual doesn't have .... control of his thoughts more or less, and the thought is controlled by whatever is going on in his head. And it can affect his daily life and living his way of life, it affects his way of thinking, the way he .... his day-to-day living will be affected as well. If he does not have the assistance or the medical assistance that he needs, it would go from bad to worst you know, he won't be able to control whatever he does. Even his affect would be affected (Participant 2:12-18).

Participant Three's interest in participating in this study is "to see how people would be able to help come up with some of the new technology" (Participant 3:10-11) in terms of accessibility, and help support "ways of how people will be able to develop new medication" (Participant 3: 12). Participant Three explained their understanding of schizophrenia based on their experiences from West Africa,

back home, some of these people never go to the hospital for whatever it is, once they come around they would continue you know, but normally it's like umm, what you would say ... like not taboo, not the word I am looking for, it kind of like once that happens to you... once it happens to someone they always tend to look at that person like, oh he is like .... we should not touch him, because if you touch him, you also .... I don't know how true ... but it's like once you are a candidate or somebody, you are labelled as that and people always tend to push you away, and then they become a little isolated. People make fun of them, people bully them .... you know, because they will see them like they are just sick in society (Participant 3:38-47)

As the interviews continued to unfold and evolve, it was evident that each participant wanted and were willing to share their stories. Participants wanted their voices as a Black, immigrant person with a relative diagnosed with schizophrenia to be heard and understood. Often in research, the conversation on caregivers and relatives with a family member diagnosed with schizophrenia are excluded or limited to some capacity. It was evident that all participants wanted to express the impact their circumstances had on their development and growth on an individual and a systemic level. The findings section of this research is grounded in the words of the participants interviewed. The first theme discussed below is relationships.

## Theme 1 – Relationships

In their experience of being in relation to a loved one with schizophrenia, participants expressed many different feelings including frustration, shame, embarrassment, toughness, distancing and sadness. They talked about the consequences, the hardships, the time spent apart, the marginalization, family disruption and micro-aggressions. Participants also expressed some reflection on their experiences of supporting their loved ones, as well as the challenges that they face as they continue to journey through this path of healing with their relatives. To better centre participants' voices and experiences in this MRP, I have chosen to quote deeply from each individual interview as I work through the themes. My intent with this is for the reader to feel each participant's experience in a more fulsome way. In line with my theoretical and methodological goals, I also want to de-center my own voice.

Participant One gave an overview of his family dynamic and the impact social structures and expectations of the 'diagnosis' has had on him and his family.

I think with my mom's schizophrenia affected everyone in the household, you know ....we all left at like.... I left at like 16 .... my sister left at 13, my mom left when I was 9 you know.... with him (dad) it's like, he suffered like a Rwandan. My parent were born in Rwanda, I feel like he's had trauma already from experiences in Africa. And when he came here he thought 'I'm going to make it.... I had made it already', he has a job, he had this, had that and then he brought my mom over. It was... yea, he brought my mom over, after that things just.... then I was born in 1995, and then after that things weren't the same. He lost his job, I felt like he was really defeated, like he lost. He felt like he lost everything he came here for .... Everything he came here for didn't happen. Wife is not mentally stable. 'I lost my job, can't really provide' and he just....he fell into slight ....I would say moment like alcohol addiction. There are points when he would say 'I am not doing that' and then there are lows and point when he was so low that every day he would just consume alcohol you know. I would not call him an addict but he was .... he was using that as a coping mechanism and he was very negative.... he was negative, he was very negative. He wasn't physically abusive, but emotionally and mentally he was terrible. And that, like, I'm not saying that it was my mom's fault. but that's what breathed....but that's what breathed it kind of spread and transformed into different ways and affecting other people you know and umm yea (Participant 1: 157-177). With

my mom, visually you can't tell that she is 'schizophrenic'; you can't tell, she is working now, you know, like she can be with other people she can be with other people. One thing that sucks is, I don't know who my mom is, I don't know what's her favorite colour, what her favorite food is. She doesn't talk about that stuff, she doesn't talk about her childhood she doesn't talk about that stuff. She is just very mute. And I think that's more of a personality thing and... umm that's why she hasn't been able to navigate at all" (Participant 1:494-500).

Participant One further discussed his relationship with his sister within their family dynamic,

I only have one sister, she tries to ignore it, and she tries to just keep herself busy, and she is a girl, you know, I don't know, I can't even speak for her, because it's probably so much different. You know when your mom is like not all together, yea they had a really good relationship and then it fell apart, she is like really broken. I just learned that last year she had PTSD from like experiences and group home and foster homes like that. So, she have....she didn't tell me, my dad told me you know and.... right now our relationship is good, but it was never like that. I hated my sister, I hated her you know but it just came to the point where I was like there is only four of us and life is short, life is short, life is so short. (Participant 1:195-203).

Participant One continued:

My parents always told me the good things, like the things that I needed to know, but I feel like the action wasn't implemented. Like they weren't doing it, you know. And I felt like a kid, kids they see what other people do, you can just talk about it all you want but ... action is key. I feel like action is way more important. I feel like action you see the result from it, and if you like it, you know what to do to get it. I feel like, in that sense my parents .... they said everything I needed to hear, but they just weren't doing it (Participant 1:419-424). I feel like, for my mom it was difficult. I can't lie, there was a period she motivated me, just in her own way, even though she wasn't, like, working... but she, she maintained that, the best way she could while she was there. I was eating, I was. After she left I was not eating three times a day, I was not doing that you know. Like the one period where I saw a proper family structure, was when I went to a foster home and they were black, that was so big, that was huge. And I have heard a lot of horror stories from foster homes. They were black and I got to see like you know, what a family was really, really like. It was good man, but my dad stopped it, he stopped it, he... umm it was a pride thing, because they were willing to provide even after I was....even when me and my

sister were not there anymore, you know.... 'you'd rather have no food in the fridge than go to a food bank', you know.... and it was like....those things you know.... those things (Participant 1:427-440).

Participant One expressed his relationship with his mother and how support was managed from a young age to adolescence and adulthood. When asked, how do you support with this diagnosis? Participant One explained:

To be honest I wasn't, when I was younger and even during my adolescence .... like I wasn't supportive. I thought like I was really selfish you know, I was really selfish .... because I wanted someone to care for me, you know. It's crazy how the tables have turned so quickly. Like I have to provide for her, take care of her and stuff like that. But now I don't mind it you know, like in the past it was frustrating and I didn't get it. After 9 years old I didn't live with her, I went to a foster home and stuff like that, I had to leave. I am just finding new ways .... it's more about being with them like on an emotional level, even though they like to be....like they are just not umm expressive you know. Well I can't say everyone but my mom as an example, she excludes herself from family, friends and .... and she is just by herself you know. And when it comes to that point, I think reaching out is the best thing to do, even though I have things that I am doing day-to-day, I may not have the time even to just hang out with her for 30min. I try to find time now to do that and she appreciate it. (Participant 1:53-66)

As the interview continued, Participant One shared how impacted he was when he was excluded from information regarding the wellbeing of his mother. He shared that his father claimed to keep some information away from him, because at the time his father wanted to protect him as a child. Here is Participant One's experience:

I feel like that was so dumb because I am going to end up figuring out regardless - it's just time, it's just time .... like you know....protect me from what? He would say that but I never understood that, that way of thinking you know. It was still bad regardless, it was still bad you telling me and not telling me it wasn't really like a game changer, you know, I felt like I didn't want to be in the dark (Participant 1:85-91). When I was younger I didn't even know she was ill. My dad wouldn't tell me. When I would ask doctors they wouldn't tell me.... umm so I am hearing from everybody that she is not okay. Like how....like when I was younger I really really, I really love....not to say I don't love her now, I do but like I really really love her like I really did. and when

people where telling me that she is not normal I didn't understand what that meant ....and .... umm .... actually... and then I found out at 16... I found out that, you know. I actually forced my dad to tell me and he said you know this is what she is dealing with and that's it's been happening ever since I was born, you know, and err... yea. (Participant 1: 75-82)

When asked, how have these experiences impacted you mentally, physically, and/or spiritually? Participant One explains:

I think that's why I need therapy, I feel like it really fucked me up. Like I'm noticing to a point where I feel like these feeling are like haunting me. I feel like, I don't want to blame, because I have full control of who I want to be but I just feel like ah.... you know. Just what happened, I see myself doing the things that I would see my mom do or my dad do that I hate, you know (Participant 1: 147-151). It's quite scary. This is direct lineage, it's my mom and she has it and my biggest fear is me being like that, and I have no control over that. If the gene is triggered and these are the years now for me, early adulthood .... where most people develop schizophrenia. Like I did a lot of research on it and then... umm it would scare me you know (Participant 1: 121-126) But umm I feel like, I realized that I kind of.... Like I never wanted to be like my dad because I feel like he didn't handle the situation like he should have you know. But I see myself like him. Like a lot of traits. That's something I want to eradicate....and that's something I have seen when I was young, just seeing all the time. you know and its .... I don't want to be like. I want to talk to somebody who is black, this is very important though. It's not a racist thing. It is comfortability thing, it's just a deeper connection, understanding you know. So...that's what I am really looking for (Participant 1: 151-158)

Participant One also explained how different factors, like medication for example, affect his mother.

I mean it's been tough for her, she's been .... she is able to work though ....yea she is able to work. The only thing I don't like is her medication, you know. I feel like she is given drugs that dull her and numbs her. I have seen that throughout the years. The person who she .... when I was a child is the exact opposite, like in her personality. Like before, even though she was aggressive, she was very active, like she was .... like she is from....my mom is like a villager, she never went to any big cities, all she did was just wake up or cook.... and that's all she knows right. She was doing that in the house hold.... that was her way of making food and like.... cleaning up. Like I cleaned the house... but she was like always doing something. But then now it's like the exact opposite like

she just stays in bed, she would sleep the whole...sometimes the whole day. And she just... she looks just like lifeless, you know, and it is sad (Participant 1:95-106). That's what affected me emotionally, right? .... so like .... I could .... my mom I feel like if she wasn't 'schizophrenic' .... she was still like a loving person but I still couldn't receive it because she left when I was younger and my dad was very like, very cold, very cold you know and then umm that would that would just be like a lot of insecurity issues, you know? Just....just lot of, what else, insecurity, developing bad habits, you know.... umm....yea (Participant 1:182-187). Me and my dad, I don't even... it's to the point where I can't be with him for long period. I have to see like, you know, I have to see him like every two weeks... So back there I don't think I could ever (Participant 1:189-191).

As part of his relationship experience with his Mom, Participant One also spoke of spirituality;

Spiritually man, oh my God like, like spiritually my mom was really into God, she was really into Jesus Christ and then umm... I never, for some reason I dunno.... I just never, I never liked going to church. I hated it. But I'm Roman catholic and it's really boring, it's terrible service and she will always like, she just, she had this extreme sensation of like, Jesus you know? and it was umm it was weird, it was like it was embarrassing, like whenever we will shop at Sears, you know like randomly she will just started praying and a thing call the 'rosary'.... you have like rosary and you just do the beads. She would just sit on the couches and do that, and we will just have to stay there. It was so embarrassing and umm it .... you know I am too young i'm like 8.... I wanted to just go home, couldn't go home, she would just take us around to different churches and it was just like....it just made me uhh not an atheist, but I just don't like, I feel like it really scared me spiritually, I don't want anything to deal with Jesus none of that, I don't want to hear it, I don't care... it just made me ... bad taste in my mouth... umm... like Christianity in particular, yea... I hated it..... the distaste is strong, strong, its strong, its strong. I don't like it you know. and my whole family .... and its crazy it comes from her side of the family—really religious. In Rwanda, they come from a line of priests and archbishops and stuff like that so it's like when I went there .... and I....they saw that I wasn't with it, it was surprising to them but.... (Participant 1: 290-329)

In terms of being impacted physically, Participant One shared,

Physically, like I dunno, there are some rumors in my family that like she tried to like kill us when we were younger you know and then umm ... uh for example when I hear those stories on the news about mom that 'kill off' their kids, I kind of relate to that. I know that she is 'schizophrenic', I know she is doing it out of

protection for 'those kids' ....it's weird but.... In her mind, she is doing it out of protection, not out of spit or anger, she thinks. She is so paranoid like she thinks the only way to save these kids is to come with, to you know, wherever she is going, I don't know man. I wasn't... I wasn't... I wasn't surprised, I remember like it was yesterday, I was like 3 years old. I wasn't told, but I remember I didn't feel safe. I was young, I was like 3, I got out of day care early, and then, my dad told .... I just pieced it together and my dad just told me. When I was in day care my mom was going into an episode.... she was saying they were trying to kill us, he said that she snapped and she just left.... and the first thing that was on his mind was, she is going to.... she is going to go to the day care and get these kids. And that's what she did. She did that, and I remember crossing the street, I just felt, I felt .... I don't remember anything from that time. I remember I felt nervous, I felt scared, I felt scared and I felt like this wasn't right because I was leaving earlier and I remember the police came and then they got out, and they had to put her in the back of the car with me as well. And I then, I remember they drove us home and they...."when am I going to see my mom"? and they said "tomorrow". I remember I stayed up the whole day, the whole night, I didn't see her for like .... I think it was six months, you know. I didn't see her for six months. And when she came I see her six months after, then she was like taking medication, so she was different. And she wasn't as aggressive. She kind of .... aside of the medication - kinda numbs her, she was just there, she was kinda complacent.... yea.... but after hearing that I wasn't surpr-- I wasn't mad at her though. It wasn't out of spite though because I know .... I wasn't mad at her because I know she loves me. I know definitely, definitely I know she loves me. I asked her though, she said no .... I know she was lying, says no I would never do that. I know she was lying I never brought it up after that. I asked her, err... you know, if you really tried to end our lives, you know. [Pause] ... she said no. But I know she is lying, because I know what I know. But errr... never brought it up after that I just .... it never really affected me.... it was like she can't do it to me now, you know.... it's over for that. Yea.  
(Participant 1: 445-480)

Because of these experiences, Participant One believes that relationships with other people outside the family, including romantic relationships, are really hard:

umm, I think like the relationship to other people, I feel like that's really like mess me up.... umm like especially romantic relationships. In terms of me wanting to be with a woman, it's a .... I definitely had to learn .... no not learn,... learning now, I'd have to do this like on my own. I never used my parent as an example.... I never even, I never even thought of having like kids, being married, I like kids, but I dunno. My dad told me that when he had us, like his like just .... it was not the worst thing, but a lot of bad things came after that, you know, so I was like holy shit I don't want that, you know. And seeing them fighting all the time and I was like, I don't want that. I don't want that you know. And it is really

hard for me to like open to like.... to be open to like to a woman. Like emotional, emotionally available all the time. I kind of find it taxing sometimes, you know, umm... because I've just always like been on my own and for me now like, caring about somebody else you know, it's hard to do that.... I realized that this year, I realized that this year. It's really affected me with relationships with women that I like but I don't know if I can love them you know? It's a lot of things, sometimes it about trust, sometime insecurity. Not with them committing infidelity, but with myself you know and it's like .... 'm even kinda surprise you want to be with me, dang'? and I'm like, like I will have strokes of that, sometime those thoughts will come, but it is not all the time....umm and they want to meet my parent if it's like serious...oh no I could never do that, I don't ever want.... if I have kids I don't even think they will see my children. I don't even think they will make it to see my kids. I don't think they would. But no, I will never want my girlfriend to see my parents (Participant 1:337-361).

On this topic, I asked if the participant would tell the person you are in a relationship with about your family dynamic? Participant One responded;

I tell them, but they just don't understand it though, you know .... like the last person I was with, this is actually the first person I've been with. When I took that chance and it was umm like they understood, but it was just something they didn't want to accept you know....errr 'I don't think you can ever see my parents you know'. I barely see them, you know, so it's like... no. And you know, like, if they were to really see my parents, I'll have to marry them, you know. Like I can't just keep with new girls to see my parents. I feel like it's like a, kinda like a cultural thing, my dad, if my dad saw the girl I was with you know, he'll be like, okay this is the one.... you know so that too. I don't wanna you know. That's kind of the obligation if I yea .... if I show him, it's for real. So... (Participant 1: 364-373).

#### Participant Two

On the theme of relationships, Participant Two discussed their relationship with their son and their family dynamic as well as the difficulties of his relationships with others;

The thing is with my son now he's, he has a developmental disability and with this kind of disability with age it becomes stressful because he want to be like the other teens (peers), he can't express himself you know, so he get stuck in his head. Most of his friends that he grew up with, they are going to university, they are going to college, to secondary school, he loses most of those friends, and

now it's difficult for him to make friends he can't express himself. He knows within himself that he is a grown man... that he is a grown boy but he can't express himself, so he is just stuck in there...the condition he has now, it comes with schizophrenia later that's why at the age of 15, 13/15 year that when we started experiencing this change in him, you know. He became withdrawn, you know just started err... laughing to himself you know, you know, come up with, you know, fake stories that are not there you know. So that's when I observe that (Participant 2: 622-74).

Participant Two continues -

...Sometimes when he is in that state you know, it affects the entire family, you know the entire family is affected. Even his, he has a little brother that it affects so much, you know sometime he asks questions, why is he behaving like this? Why is he doing this and he can't expre-... even when you explain to him, he doesn't seem to grasp what's going on, and that's where the frustration is. Like, because you can't explain to him that's why, this is why your brother is behaving this way because he can't understand it. He understand that he should help his brother all the time. You should....I help him I am the little one, he should be helping me'.... but he doesn't understand that. So it affects him psychologically too, and there is stress on him too you know... and even when he sees his brother having lots of attention you know.... he is having most of the family members giving attention to this person .... he lacks the affection, it affects him too, because he needs that attention too, you know. So that's where the conflict comes in you know (Participant 2:38-50). So... This is a stressful situation though, because when he is in that condition, you know, and you know he can't help him, he can't express besides his...his....umm he has a learning disability, he can't express himself he is just withdrawn, he is just in his head (Participant 2:35-38).

Turning to Participant Three, the relationship is also affected by their son being 'diagnosed' with schizophrenia.

He (son) was recently just been diagnosed, added to what he's being going through, because they (doctors) were not really sure whether it was schizophrenia, because the first test we did, he didn't, they didn't come out like it's schizophrenia but then as we continued to do more tests... umm I think the last time we went to the doctor, they were talking about schizophrenia. They were concerned about some of the episodes he was having, because he was getting a little bit of hallucination at some point, and then he started getting the psycho-medication to help him...(Participant 3: 71-77).

When I asked about the impact of this, Participant Three explained;

well mentally of course, a little bit, because I am always thinking of ways you know, to help, to help him whichever way is convenient for him whether physically or even getting a job, being able to do something for himself or get what he needs because .... so that he is part of society, he is involved. Even at work I am always thinking about how... how do we do this? Recently he just had his phone, because he would be asking like I want a car... how am I going to explain to him that, you know .... At one point we were at the doctors and the doctor told him "you can't drive my boy". But you don't want him to feel like I am not part of society, what other people .... why I can't.... but at the same time you want him to understand that his condition is.... so that kind of affects me a lot of time mentally. That's why I decided to give him the phone, just so that he feels like he is part of us. He wants to be texting, in fact as soon as he got his phone yesterday, the first text he sent to me was..."dad are you going to buy me a car?" I said well we just got a phone for him, now he is asking can I get a car. So like how am I going to reply to that? But again of course all over spiritually does affect us right because you don't know whether this has to do with spiritual things, sometimes because when we started we said we were casting binding the devil taking control, but is that really a spiritual thing or you know so you begin to wonder how spiritual... how... how spirituality is in this and how much is just medical or physical thing. So but we don't lose any faith in it, we still trust God and his spiritual plan of it, but it just takes a toll spiritually on us, taking a toll on us physically. Having to go downtown every time, try to make him happy at home and keeping him safe because that is very important because I will be at work those days when mom is at work and he is all by himself, I will be thinking about him, I will be calling him. I will call him, and if he doesn't answer I will have to leave work (Participant 3: 144-167).

## Theme 2 – Isolation & Community

Isolation and community building was a dominant theme throughout this research. Two participants articulated their experiences of feeling alone and isolated within their self and with their families in a neoliberal system. There were feelings of social isolation, exclusion as well as discussions on a need for community building. Participants expressed the importance of community and community building for their wellness and for the wellness and support for their relative diagnosed with schizophrenia. Here are some of the experiences shared by participants in regards to isolation and community.

I dunno, I just feel like, when you have something like schizophrenia, there is just like no hope ....I always felt like, once you have it, you are gone. Just because I have just seen it, I just I dunno man, it was just us, you know, I felt like there is nothing I can do, like “what would help this?” you know (Participant 1:215-219). The isolation can be so difficult, so that’s the thing ... breaking out of that box that you think you are in that .... it’s just you. Also, I think after that it’s just building like a system, just for Black, because I feel like it’s a different experience. I feel like it is really different (Participant 1:267-270)

Similarly, Participant Two expressed feelings of isolation too;

stress, helpless, sometimes you feel alone, you know, there is no one that you can talk to. You can't talk to anyone, there is no one to help you out. You are just in the big sea all by yourself, to fend for yourself you know .... you know, you can't do anything to help, sometimes it brings water to your eyes, what can you do?.... so.... (Participant 2: 52-59)

Participants spoke about how systems played a part in creating this isolation. Expressing her frustration, Participant Two said;

at school, the teachers, some of them they don't understand what's going on you know, even when you explain to them that this is what's going on, you know, they just go according to what they have in the book for these kids, but they

don't know what you are going through. Even when you explain to them this is what's going on, they don't listen, I don't know, I don't know what it is. Even if you ask them to .... sometimes I ask them to umm help him you know... do certain stuff to help him, but what they have down in their policy that's what they go by, they don't... you know.... they don't deviate or make room for this person, you know. If they can do that probably it will help, just make a little room for this person, or listen to the parents, everybody is different you know. So that's one thing we went through, so you just have to go and stick with what the school have. Although at one point they provided us with a social worker that was helping us, but she did not do much though, they did not do much. What she did was, most times she would be, probably in the meetings and at the end .... at the age of 16, that's when she gave us address and people to contact you know for health, for ... [mental health services] and all those places, and yea. So then she gave us those addresses and, to make calls and that's how we got some help for him after age 18, when he turned 18. Before then, we've been trying to get help for him, it was tough, you know to take care of him, with the little finances we have as a family and we have other kids. Sometimes the other kids go without you know so it.... and yea I don't wanna (teary eye) its hard....(pause). (Participant 2:74-97)

I supported Participant Two during this time of pause. She was reminded she could stop the interview at any time and did not need to continue if she does not feel like. She took a pause and decided to continue the interview.

Mentally, it is draining, it's draining, it drains you. Sometimes you want to do stuff but you can't, you want to help your kid but you can't, you know. It drains you physically. Spiritually, you know we go to church, but after church, what happens we come back home the same situation, the same thing is going on. At church no one knows what he is going through, only sometimes the pastor would know what you are going through, and sometime would counsel you and talk to you about it. There is no one to go to, you don't have anyone. It's just you, your kids and your family. And when he has the attack, you call 911, sometimes if you can't control him in the house, they send police. (Participant 2:154 - 160)

When asked, "what happens when you a call 911?" Participant Two respond by saying,

It's scary because you see the police cars and the police came, you know. It's scary you don't want everybody to know what is going on in your house. They can make it a little bit less alarming you know. It's shameful, you know.... So if he has the attack next time, do you want to call the police? Do you want to call

911? Even though they come, they will be polite, but you don't want that. Not everybody should know what's going on in your house. At the moment it's good, but when they leave, they don't care, when they leave they don't care, at the moment that's why they are there. After, they don't do follow up or nothing, they leave you to your own devices. They will come when you need them, but yea, they are there for assistance, but you don't get as much support as you know, they can do more. Just sometimes to call and see how this person is doing could be appropriate, because the family is going through a lot. It's a lot we are going through. Just with that one person, you know. You don't have the social support, you don't have the financial support. It's not a road to walk alone you know. You need a community behind you with that (Participant 2:161-181).

When asked what kind of changes you would like to see so that folks don't feel so alone,

Participant One shared;

I feel like people need to talk about it more and not just as a whole, it needs to be specific with like Black people because I believe that it is widespread within Africans. Mental health is something that you don't talk about. You don't talk about, and then you are coming from Africa where like a lot of things that happens over there and a lot of traumatic.... like my dad would tell me .... and there is no way, like, you do not have problems. You know mentally, you know. I just feel like yea, the first step is talking about it, but I don't want to talk about it and nothing happens, you want to talk about it .... and that just grows the community, like when people talk about it, people are open and are expressive about the experiences they've had or that they have and built community for one and other. Like when I was going through this, I really thought that I was alone. I really thought like yo this is really like ....I am the only one going through this. Nobody in school, nobody in school nobody...you know like. and then I meet ... what made it real for me was, even though he wasn't black, he was my best friend at the time. And I went to his house and then I saw his brother and his brother was 'schizophrenic' and his girlfriend later on was 'schizophrenic' you know. And I started getting much more comfortable, and started hearing at their end, what did you do....I can't lie what he was doing was way better than what my family was doing. My family were trying to ignore, trying to deal with her. With him they were much more supportive and patient and mostly there for him and them ... umm .... I was able to pick up on those things... We were able to talk and support, the most important thing is knowing that you are not alone and there are lots of people actually going through this you know. That's the biggest thing, the isolation can make you feel like... wow (Participant 1:237-265).

Similarly, Participant Three spoke to the positive experiences they have encountered with

community services and other families with similar circumstances.

Well I would say, positively in one way, in one sense, because I know, like, for example this year we were not able to attend a [mental health organization] seminar and umm... something like day out ... you know with other families, but I remember we did it once when we went to the zoo with other family members with the same issues. We were able to sit down and learn from other people what they are going through and getting resources and that kind of thing and um-mm, share our commonality... where we are having issues.... that kind of thing, and differences. So that really helped us positively because also, we do attend some of this community like umm ... what do you call it?.... community ... they would have like umm.... what is it? outreach or information session for individuals like my son, where you get to meet and greet other people.... of course there would be lectures, but you are able to meet different lecturers, meet families. So I think positively, it's been a positive experience, navigating and connecting with other individuals with similar circumstances. (Participant 3:352-364)

#### Theme 3 - Accessibility and Race

While navigating various social, community and medical or health systems, most of the participants had experienced barriers to access. These are highlighted below. In addition, they linked these barriers to race and what they would like to see change for a more accepting and effective ways of accessing and navigating systems. Participant One discussed,

I feel like she has a doctor, and the doctor knows that she is ill, this is someone she likes .... I believe she trust him, she's been with him for a long time and he is African, but he hasn't really like put the initiatives or taking the steps for her to seek help other than medication, you know, which is just sad (Participant 1: 503-507). I need to go to the next visit and really talk to them. Like she's been taking medication for x number of years. What else can be done for her to live her best life? And again that's the support, you know, me being there with her. Maybe she wants to say these things but she doesn't know how to or she doesn't know if she should, you know. I think I should do that, I am going to do that. It's just family being there man. I think that's the worst .... that's the thing I regret, like casting her away, because I was kind of embarrassed (Participant 1: 518-524)

For Participant Two:

He was referred to this psychologist by a family doctor or someone and then

when he turned .... when he became a teenager, this pediatric psychologist referred us to a MHO (mental health organization) in Toronto, so we've been with this [MHO] for a few years now, and they have been assisting us you know, with nutrition—they have a nutritionist there, a social worker there that sometimes assists us, but they are limited to what they can do. I think it is the policy, they just give you a few addresses to call, and some of these people, you call them you need finances, and if you don't have the finances you are left out. And most of the time we don't have the finances to continue. There is a lot I would like to do, but I don't have the money to do it. Like I said there is a limitation, I don't know what they can do, I don't know if it's because of my son's limitation as well, I am not too sure about that because even with the school, you know, with his, my son was graded as a, as a grade 4, grade 4 student, can only participate as a grade 4 student, so umm... so I don't know, with the school now, there are other kids, by the time he was graduating some of the kids were going to homes, they had a job, but not for my son. So I had to fend for my son you know, I still have to navigate for my son by myself. And some of the programs I was looking into placing him, I can't afford them. Right now I am not working the way I should, I am working part time or casual because I have to stay at home with him, you know. So it's tough. It's a vicious circle, you don't have the money to do certain things, you don't go to work, and when you don't work you don't get the finances for your family the way you want to. There was a point when we had financial support for him, but it was limited. A few bucks for a few minutes. And when the money runs out, that's the end of it. There is no continuation you know. So what do you do, you know? Most of these places I feel like they are money making .... even though they say they are non-profit, they need money too, but if you don't have it they don't help you (Participant 2: 110-146)

Participant Two's wish was;

With the dual diagnoses, they should have a community, you know, where they can go and be themselves right, communicate with one another, in a way that is affordable. Like with my son now.... we live in [GTA] but we have to travel to Downtown Toronto for doctors' appointments and it should not be, we should be able to have these facilities, they should be accessible wherever you are. Also, I don't know if it's the colour of my skin that is causing this. When you meet, it's always the same thing you know, it's always the same thing when you apply for support I don't know if it's the colour of our skin that we don't have the support that we need. Even with the health system it is difficult .... when you go to the hospital... the colour of your skin, you are being discriminated against (Participant 2: 192-206)

When asked, "how are you being discriminated against? Can you please give an

example?" Participant Two replied by saying;

Some of the people, the people that would attend to you, some of them would be disrespectful, some of them won't talk to you nicely, just be respectful, even navigating he is a friendly boy. Sometimes when we go out when he will say "hi", they will turn their nose, sometimes I'll have to say, 'did you hear this boy say hi, can you say hi back?'. That simple decency, you know (Participant 2: 208-212)

With respect to change, Participant Two would like more access;

You know, just for a day, they don't have to live there or stay there, just for a day, make a facility be accessible to them by promoting it, they can promote it through the media, yea more or less the media, social media, they can just add, or tweak the policy a little so that immigrants like myself have easy access to all of these things, because some of these things that are going on, we don't even know that they have. Just the privileged few knows about some of these things that are going on. If you don't know, you don't know—you are left out. I think they should have policies that would include everybody you know, easy access to some of these facilities and stuff (Participant 2:218 -239)

Participant Three further explains their challenges with accessibility while navigating various mental health organizations;

Well a little bit challenging, number one, commuting with my son downtown Toronto all the time, you know, is not very convenient. Number one, because sometimes he does get the episode when we travel, so it's a risk like you have to travel 40 to 50 minutes or even an hour to get down to Toronto, and that can be a challenge. We've discussed that with the doctors, so what she's being trying to do at times - we will have video chat, where we would go somewhere in Durham region here (MHO).... like mental health organization in [GTA] region and umm .... where we can be able to communicate back and forth, which is one way she's being trying to help us. Even other times when we might have to do a test, like a blood test or something you know, the availability might not be what the test requires, even like Wednesday we have to go down to another specialist you know to .... so this commuting back and forth can be a bit challenging, even though there are mental health organizations [in the GTA] Region, they don't provide all the necessary services that we might need for him. And I am sure that a lot of the times, they have a policy like you don't ask we don't tell .... certain things like if you don't ask they won't tell you. They will give you the general stuff.... yea check this, check that but then you would check those stuff

that they would give you but you would not get much from it. They would give you information to just get you off their back.... because they know even if you get that information it's not going to be like an easy kind of thing.... and even the people who provide this information, once they know who you are, your colour or whatever, who knows, it's like they might not provide you with the information. Then sometimes, you wonder if race plays a part in all of this (Participant 3: 100-120)

When asked, "can you please explain what kind of changes you would like to see put in place to bring visibility to these concern?" Participant Three responded by saying transparency.

Well, transparency is one thing. A lot of times we think that, we... I mean transparency, what I am saying is the colour doesn't matter number one..... there should be that transparency when people are able to accept one another and say, you know, what the outside is different but the inside is basically the same red blood (Participant 3:317-326). And trust, because they would think that certain information if we give to this black man, they might not use it, or they might misuse it because it just feels like the 'Black man is down there'...so it's going to be a waste of time, so that kind of thing (Participant 3:344-346)

## CHAPTER 6: DISCUSSION

Social workers are prominent in the lives of individuals 'diagnosed' with schizophrenia and their families. They are also their intake workers, counsellors, educators, advocates and group facilitators. Despite the prominence of these roles, there is alarmingly little literature written by social workers on how Black African families with relatives diagnosed with schizophrenia experience the mental health systems in the Greater Toronto Area. In response, I crafted this study, which was informed by a theoretical framework of anti-Black racism (Benjamin, 2003; Kumsa et al, 2014), anti-Black sanism (Abdillahi, Meerai & Poole, 2017; Meerai, Abdillahi & Poole, 2016), and anti-oppression practice (Baines, 2011). An interpretive phenomenology research (Padgett, 2017) project was conducted, including three qualitative interviews with Black families/African Immigrant adult persons. I asked them questions about their experiences navigating the mental health systems in the Greater Toronto Area. This is considered preliminary interpretive phenomenological theory research, because with only three participants, this is a micro-level study which explores narratives in detail, but cannot be representative of the issue in its entirety. It is my hope that this research may form the basis of a larger, interpretive phenomenological pool of literature to determine what Black families/African Immigrants can contribute to change within the mental health sector. The experience of being Black and loving someone diagnosed with schizophrenia is very hard-- not impossible, sometimes lovely, but hard. It is so very complex, influenced by material and emotional factors, systems, communication, colonialism and sanism. This chapter will discuss the limitations of this study, my research process, and lastly, ways of informing social work knowledge.

### ***Limitations of the study***

During this research process, I had the opportunity to reflect deeply on my role as a

researcher, social worker, and as an individual with a family member 'diagnosed' with schizophrenia. I had to be reflective on the power dynamics throughout the research process and during this writing by surfacing the voices of the participants, utilizing their text from the transcript verbatim and unaltered, and describing themes based on participants' chosen words and experiences. However, I was limited by time and the requirements of my program. This study was completed in a limited period of time for recruitment and data collection. I was able to recruit participants for approximately a month and a half, and conduct data collection for another period of the same duration. As an alternative, having a year for recruitment and data collection would have increased the number of participants and amount of analysis the study. Additional time and additional participants would have provided me with the opportunity to further engage with my analysis and data. However, the participants provided me with rich insight and knowledge.

### ***Research Process***

The phenomenological analyses of this study were coded using the method "horizontalization" (Padgett, 2017, p. 159). During this process I read through the transcribed interviews repeatedly, identified significant statements, wrote them down and grouped them into the above themes (Padgett, 2017, p.159). All three participants identified as a Black, African Immigrant person with a relative 'diagnosed' with schizophrenia.

At the beginning of each interview, participants and I introduced ourselves to each other. Participants were given a \$10 Starbucks gift card at the start of the interview, and at the end of each interview participants were given a list of resources as an incentive for participating in this study.

As the interviews continued, it was clear that participants specifically wanted to share their experiences with relationships as well as experiences of isolation, community, social exclusion, and unparalleled discrimination in terms of accessing support, economic opportunities and health services. The conversation around relationships was especially important to one participant. For instance, as we were concluding the interview, they suggested that I ask more questions around 'relationship with others'. For this participant, designated anonymously as Participant One, relationships with others was highlighted for them throughout their life trajectory, and they wanted to share some of the complexity of developing meaningful relationships when faced with multiple setbacks and challenges systemically and socially.

As I reflect back to my research question, 'How do Black African families with relatives diagnosed with schizophrenia experience the mental health system in Greater Toronto?', it was evident that many of my participants experience difficulties with relationships as well as isolation and barriers to access because of sanism (Poole, 2014) and especially anti-Black sanism (Abdillahi, Meerai & Poole, 2017; Meerai, Abdillahi & Poole, 2016). Participant Two addressed being discriminated against socially and within the health system. For example, Participant Two shared; "even with the health system it is difficult ... when you go to the hospital, the colour of your skin... you are being discriminated against." Another example Participant Two shared was, "some of the people, the people that would attend to you, some of them would be disrespectful, some of them won't talk to you nicely ... Sometimes when we go out when he will say hi, they will turn their nose, sometime I'll have to say, 'did you hear this boy say hi? can you say hi back?'" In this example, and in other circumstances in this study, sanism and anti-Black sanism were manifested in various forms through practices of discrimination, silencing, exclusion, low-

expectation and violence perpetuated on individual with mental health challenges (Meerai et al, 2014).

During this study, there were observations of lateral sanism, as it was manifested through the interview with Participant One. Participant One expressed some of his feelings of sanism are different now as he is more comfortable and understanding to his mother's circumstances, after meeting with a friends' family in a similar situation. Here is Participant One's narrative;

yea, you know, and I started getting much more comfortable, and started hearing at their end, what did you do... I can't lie, what he was doing was way better than what my family was doing. My family were trying to ignore, trying to deal with her. With him they were much more supportive and patient and mostly there for him and them ummm... I was able to pick up on those things...we were able to talk and support. The most important thing is knowing that you are not alone and there are lots of people actually going through this, you know (Participant 1: 258-264)

There were feelings and attitudes of shame, embarrassment and disconnection expressed by Participant One to his mom. This form of sanism within and on families is powered by colonialism, whiteness and white supremacy. During this study there was a clear manifestation of how colonialism and whiteness continue to perpetuate sanist ideologies within some of the African families in this study. Two of the three participants express their understanding of how individuals with mental health challenges are treated with sanist ideologies within some African context. Participant Three expressed;

like back home, some of these people never go to the hospital for whatever....umm it's like taboo. It's kind of like once that happens to someone, they tend to look at that person like..."oh he is like, we should not touch them because if you touch him you also... It's like once you are a candidate or somebody, you are labelled as that and people always tend to push you away, and then they become a little isolated, people make fun of them, people bully them you know...because they will see them like they are sick in society" (Participant 3: 38-47).

Ibrahim (2017), noted “the discourse that shapes African approaches of psychosocial disability is substantially influenced by the continent’s colonial history” (Ibrahim, 2017, p.113). This is because, “in most African Countries, laws pertaining to mental health have been inherited from colonial governments, which drafted them, in part as a powerful mechanism for controlling the African population politically and socially, perpetuating oppression and protecting White settler rule. In effect, these laws promoted gross human rights violations, social exclusion, and excessive restriction of personal liberties” (Ibrahim. 2017, p.113). Participant One and Participant Three expressed being African and having a mental health issue to be tabooed. In these circumstances we could see the continual violence being placed on Africans with mental health challenges. To resist, we must continually decolonize and enhance human rights and social justice for African Immigrants with mental health challenges ( Ibrahim, 2017) as we center traditional forms of healing and practices. Those with lived experience with schizophrenia and their families should be welcome as equal members of society and should be treated with dignity and respect.

Reflecting on this study there is a clear manifestation of how Black families/African families with mental health challenges continue to be pathologized and marginalized. For example, Participant Two shared her experience of continually having to fight for her son, and how “it's tough. It's a vicious circle, you don't have the money to do certain things, you don't go to work, and when you don't work you don't get the finances for your family the way you want to.”

This participant and their relative diagnosed with schizophrenia identified as Black, and also African, with limited resources. This example illustrates a representation of anti-Black and anti-African racism (Benjamin, 2003; Kumsa et al, 2014), sanism (Poole, 2014) and anti-Black

sanism (Abdillahi, Meerai & Poole, 2017; Meerai, Abdillahi & Poole, 2016). The participant had to continually advocate for her son while they are being excluded from services and opportunities, and even then, as a Black individual/African immigrant, their voices are not being heard and listened to.

Those with lived experience should be welcomed as equal members of society and treated with respect and dignity regardless of their race, ability and socio-economic status. Oftentimes when Black Africans families and individuals affected by schizophrenia are excluded from services, it is due to anti-Black racism (Benjamin, 2003; Kumsa et al, 2014) and sanism (Poole, 2014). For instance, Participant Three addresses this issue; “And I am sure that a lot of the times, they have a policy like you don't ask we don't tell ... certain things like if you don't ask they won't tell you. They will give you the general stuff... yea check this check that but then you would check those stuff that they would give you but you would not get much from it. They would give you information to just get you off their back... because they know even if you get that information it's not going to be like an easy kind of thing... and even the people who provide those information, once they know who you are, your colour or whatever, who knows, it's like they might not provide you with the information”.

Throughout this research, participants' voices are prominent in articulating the challenges that they have faced navigating the mental health systems in the Greater Toronto Area, and their experiences and feelings of isolation and hopelessness. Overall, some of the participants expressed that the services that are supposed to help them only give them a pamphlet and send them on their way with very limited assistance. They addressed not having their voices heard and listened to, and their overall experiences of sanism (Poole, 2014), in a Western Colonial system.

Participants want to be respected and treated with dignity, they want to be a part of community and assisted by those who understand.

When addressing mental health, it is very critical to understand sanism (Poole, 2014), anti-Black sanism (Abdillahi, Meerai & Poole, 2014; Meerai, Abdillahi & Poole, 2016), and anti-Black racism (Benjamin, 2003; Kumsa et al, 2017) in relation to Black African families in the mental health system. Sanism is a form of oppression that normalizes discrimination, rejection, silencing and exclusion of people (Poole, 2014). It is a form of violence that makes it possible for psychiatric diagnosis and medication to strip away dignity in the name of 'health and safety' (Meerai, et al, 2016). As a form resistance, many Black African individuals use their stories of anti-Black racism (Benjamin, 2003) as a way of healing and performing their anti-oppressive practice that prompts action for social justice (Kumsa et al, 2014). According to research on youth violence and healing, studies have shown that many Black African youth who encounter marginalization on a daily basis use storytelling as a strategy of healing. It is especially notable that "storytelling is particularly poignant for Black African individuals from deep-rooted rich oral cultures" (Kumsa et al, 2014, p.24). For many Black African families' storytelling connects them to places of dignity, communities, and is a process of healing and belonging (Kumsa et al, 2014). In this research, I was honoured to listen to so many stories of experience.

### ***Informing Social Work Knowledge***

The data suggested that social workers need to be more aware and knowledgeable about the harm and violence that they can possibly inflict on families affected with schizophrenia.

Having an anti-oppressive (AOP) lens and understanding and reflecting on one's social location, Intersectionalities and power is very important in collaborating with and meeting the needs of

Black families/African families affected by the diagnosis of schizophrenia. Such a lens links personal problems to social inequality, different kinds of oppression and change (Baines 2011).

However, despite the increasing use of AOP and intersectionality, social workers still contribute to further marginalize and pathologize the views of individuals who have mental health challenges and their families. Some practitioners may treat or perceive individuals that act or behave differently from the 'norm', or take individuals against their will to the hospital because their actions may be considered out of the norm, based on our social location, gender, race, class and sexual orientation (Poole et al, 2012, p.23).

According to Massaquoi, "many have critiqued Eurocentric theories for the way they erase and marginalize the experiences of communities of colour (as cited in Baines 2011, p.221). Therefore, "in order for the field of social work to address the needs of people in the African diaspora, AOP needs to draw on the rich tradition of Indigenous practice knowledge and theory that has assisted in the survival of African communities under a range of experiences of colonialism, neo-colonialism" (as cited in Baines, 2011, p.221).

As a form of resistance it is critical to incorporate Black Africans' traditional forms of healing in relation to mental health, especially in our present society where mental health and well-being are "applied through the imposition of western categories and concepts of diagnosis and treatment" (Fernando & Weerachody, 2009, p.196). Additionally, "notions of 'madness' and 'abnormal psychology' on which mental health systems in the west are based are linked to Western ways of thinking, and these conflict frequently with worldviews of non-western culture" (Fernando & Weerackody, 2009, p.196). Therefore as social workers we must engage, learn and work with Black African families and their perceptions of well-being in understanding their mental health needs. I believe that mental health services that are being developed or

implemented for Black African individuals with mental health challenges must be appropriate for the community, especially because the meaning of mental health differs in different cultures and communities.

Another important form of resistance is the community itself and the possibility for dialogue and communication between Black people. bell hooks in (Jackson, 2002), noted that it is important that Black people talk to one another, “that we talk to friends and allies, for telling of our stories enables us to name our pain, our suffering and to seek healing” (Jackson 2002, p.17). Talking to each other and community building were both deemed very important by participants in this study. Participants also mentioned the use of storytelling as a form of connecting with others, especially with the feelings of hopelessness and isolation that most of them faced during their journeys. They didn't want others to feel as though they were alone.

bell hooks in (Jackson, 2002) is an “outspoken advocate of the need for African-Americans to engage in psychological healing to address the legacy of slavery and the ongoing traumas related to being marginalized in American society. She recognizes that the connections we can make with each other and the repeated telling of our truths are forms of emotional healing. The collection of oral history puts the power to heal in all of our hands” (Jackson, 2002, p17). Therefore, we must create a community of support and activism to help support one another, and to voice our concerns of marginalization, discrimination and racism within our society. For examples of how to do this, we can look to activist/education groups such as Black Lives Matter, which is against violence and system racism towards Black people.

According to Fernando (2012), some of the underlying issues of the over-representation of Black people in the mental health system involve the mixture of 'racism' and 'insensitivity' to cultural differences in the system, which is manifested as a form of internalized and structural

racism. The way in which our various systems are designed is grounded on Western colonial ideologies, which are very problematic, particularly to Black Africans and Indigenous individuals. The truth of this issue is that Black people are “disproportionately represented among people diagnosed as ‘schizophrenic’; detained compulsorily in hospital; and admitted to forensic institutes” (Fernando, 2012, p.114), and are more likely to be misdiagnosed.

Sunera Thobani (2007) noted that if one does not conform to the ideal construct of what a good immigrant is, then one is excluded in various capacities, consciously or unconsciously. When encountering many services, African immigrants may face isolation, marginalization, pathologization and racism. In her work, Thobani argues that the Canadian national identity has constructed and conceptualized policies, laws and ideologies that have constituted immigrants as the “other” in relation to white Canadians or what she called the “exalted subject”. Immigrants are therefore considered as a class of second citizen (Thobani, 2007).

Massaquoi (in Baines, 2011) noted that mainstream social work has historically focused on assisting, integrating, and reconstructing those living in the margins. However, through the mainstream social work “helping” process, oppressed people were often objectified and repeatedly scrutinized so that they could be understood, assisted and controlled within existing systems. In contrast, anti-oppressive social work practice recognizes that world reality is defined through “daily experiences of systemic oppression, including racism, sexism, homophobia, ageism, ableism, classism, and so forth, as they interact in the structural level of society” (Baines, 2011, p.217)

As social workers, when working with individuals from different backgrounds or communities, especially in the Black African community, it is essential that we consider not only how we, as social workers, facilitate acceptance and belonging, but also the larger narrative of

how African subjects negotiate their identities and politics across diasporas (Baines, 2011, p.221). As social workers, it is very critical that our practice doesn't further marginalize and pathologize individuals with mental health challenges. One thing we must consider as we engage in support of (or to join in resistance with) Black African families is to be conscious of understanding our social locations in relation to our service users, especially when we work with our clients in a collaborative way, in order to reduce the power relation disparity between client and worker.

## CHAPTER 7: CONCLUSION

In this interpretive phenomenology study, I endeavored to learn from the experiences of other people like myself, who are Black and African with relatives 'diagnosed' with schizophrenia. In order to carry out this qualitative research, I conducted face-to-face interviews. As a result, different findings emerged pertaining to both the major research question as well as through the data collection method.

The findings suggest that Black folks need a space where Black and/or African individuals with mental health challenges can safely navigate and share their stories. There is a need for Black African navigators to assist Black African people diagnosed with mental health challenges and their families. Participants in this study suggested more transparency, trust and support accessibility, regardless of their race, ability and socioeconomic status. The findings of this study also suggest that people working in the mental health field including psychiatrists, nurses, counselors and social workers as well as community workers and volunteers, must improve their knowledge and understanding of communities and the well-being and mental health-related issues of families with relatives affected by mental health challenges. Practitioners must apply a 'bottom up' approach, in which people working in the field are helped to engage in dialogue and consultation with communities. To challenge these medical discourses as an act of resistance and development, social workers must find alternative ways of knowing that can empower them to develop practices that help people overcome their marginalized status within the larger oppressive society (Baines, 2011, p.216). Practitioners can be considered to be "doing" "Anti-Oppressive Practice not only when they include resistance in their social work practice but also when they interrogate how dominant forms of knowledge affect service-users and frontline workers and when they question how much knowledge is passed on to student" (Baines, 2011,

p.216). As social workers, we can also do this by resisting social roles, structures, identities and expectations that limit marginalized people.

I completed three face-to-face interviews with participants for this research. Emergent recommendations for change include a conception of social work practice that resists the implication of Western ideologies in practice and research; centers Black African voices in practice through collaboration and partnership with them; and resists dominant culture and knowledge systems that create, isolation, exclusion, discrimination and systems that create race, gender, sexuality and class oppression.

I agree with Massaquoi (in Baines, 2011), that self-exploration is key to understanding how power is held over oppressed groups and how to empower others to seek alternative strategies that challenge the status quo (p.217). I also believe that finding understanding, focusing on, and sharing my experiences with others is at times difficult, but also empowering. Like Massaquoi, self-exploration highlights for me the fact that the most effective means of resistance can come from my own identity and from struggles, opportunities, and barriers that society puts in front of me because of who I am (Baines, 2011, p.217) as a Black African woman.

Future areas of research to consider may include an exploration of the social construction of Black African families faced with mental health challenges pre- and post- diagnosis and how they navigate mental health systems. I also want to explore the notion that schizophrenia itself is a social and political construction used to benefit white rationalities. It follows that it is critical to promote the voices of Black African individuals with mental health challenges and their families in research and practice because “you cannot know about us without us” (Morrow & Malcoe 2017, p.132).

As I continue my journey as a researcher in this topic, there are much more to learn including the work of scholars such as Barrington Walker, Paul Gilory, Dubois, Huston, Michalko, Hartmen, Walcott, Metzl, Chapman and Yong to name a few. In terms of my learning about anti-Black racism and mental health, this is just the beginning.

## Appendix A: Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions you may have to be sure that you understand what your participation will involve.

### The Realities of Schizophrenia for Black African Immigrant Families Navigating Greater Toronto's Mental Health Services

**INVESTIGATORS:** This research study is being conducted by Dorothy During, MSW student, who has no affiliation with the mental health system, and supervised by Dr. Jennifer Poole, Associate Professor and Graduate Program Director at Ryerson's School of Social Work.

If you have any questions or concerns about the research, please feel free to contact Dorothy During at d2during@ryerson.ca.

**PURPOSE OF THE STUDY:** The purpose of this study is to shed light on the experiences of self-identified Black and/or African folks when they have a family member diagnosed with schizophrenia using mental health services in the Greater Toronto area. Up to 5 participants are being recruited for a face-to-face interview for this study. Eligibility includes identifying as a Black and/or African immigrant person ages 18 years and older, with a relative diagnosed with schizophrenia who is using mental health services in the Greater Toronto area (including York Region and Durham Region). These results will be used for the Major Research Paper of Dorothy During in completion of her Master of Social Work degree.

**What You Will Be Asked to Do:** If you volunteer to participate in this study, you will be asked to do the following things:

- Provide consent by signing this form after being informed of confidentiality and the researcher answering any questions or concerns you may have
- Provide information such as ethnicity and e-mail address
- Answer open-ended questions from your own perspective and based on your own experiences

- o Questions include: Please explain what your experience has been like navigating mental health systems in Toronto with your relative who has been diagnosed with schizophrenia.
  - o How have these experiences impacted you mentally, physically, and/or spiritually?
  - o What are some of the concerns you have regarding existing systems in place for mental health services, as a Black and/or African Immigrant with a relative diagnosed with schizophrenia?
  - o Please explain what kind of changes you may like to see put in place to bring visibility to these concerns.
- You may withdraw from the study at any time. There will be no consequences for doing so and your information will be erased immediately.
- The interview should last no longer than ninety minutes.
- The face-to-face interview will be audio-recorded and transcribed for research purposes.
- After your participation, you can contact Dorothy During for any follow-up question you may have.
- Research findings will be available to participants through Ryerson University's Master of Social Work MRP database.

Potential Benefits:

- You may experience validation for your experiences and further your understanding that the system, rather than individual actions, are contributing to various barriers in mental services.
- You will be provided with an outlet to share your experiences.
- You will be provided a space to share ideas on program development and strategies.
- Researcher will provide space to provide personal ideas on key concerns regarding existing system as well as strategy or program development.

What are the Potential Risks to you as a Participant:

Risk exists in sharing and reflecting upon negative experiences with a researcher, as it may cause oneself to feel vulnerable and could potentially be a psychological risk by initiating anxiety, or

making one feel upset, or other uncomfortable emotions. If this happens, participants are always able to choose not to answer any questions or stop an interview either temporarily or permanently. To ensure participants are comfortable, interviews will take place at the pace dictated by participants. Interviews can also be paused and resumed another day if the participant wishes to do so. Participants are also permitted to stop and withdraw from the study. If participants require support, they will be referred to Across Boundaries, the 24-hour distress centre phone line and the Family Service Association. To further protect participants, the researchers' will not be naming particular organizations, programs or their locations in the report. They will refer to these as 'Mental Health Organizations' (MHO) in the Greater Toronto Area.

Confidentiality:

Only the two researchers involved with this project will have access to this information. The audio-recording of the interview will be stored in a password-locked device. The consent forms will be stored in the researchers' locked office at Ryerson University. The audio-recordings will be transcribed as soon as possible and destroyed once transcriptions have been verified. Identifiable information will be removed during transcription and the password protected encrypted USB will be stored in a locked cabinet in the researchers' office. All data will be destroyed upon completion of the study in August 2018.

Incentives for Participation: Participants will be provided with a resource list including housing, interpreters, mental health services and social service agencies in the Greater Toronto as well as a \$10 Starbucks gift card.

Costs to Participation: There should be no costs to participation, as interviews will be scheduled based on mutual availability and at the convenience of the participant, in a quiet room at a public library for a face-to-face interview.

Compensation for Injury: By agreeing to participate in this research, you are not giving up or waiving any legal right in the event that you are harmed during the research.

Voluntary Participation and Withdrawal:

Participation in this study is completely voluntary. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time and you will still receive incentives and reimbursements described above. If you withdraw, you may also choose to not have your data included in the study. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigators Dorothy During and Dr. Jennifer Poole.

Questions about the Study: If you have any questions about the research, please contact:

Dr. Jennifer Poole, MSW, PhD.  
Associate Director  
Graduate Program and Associate Professor

School of Social Work, Ryerson University  
350 Victoria Street  
Toronto, Ontario  
Canada M5B 2K3  
Tel. (416) 979 – 5000 ext. 6253  
email: [jpoole@ryerson.ca](mailto:jpoole@ryerson.ca)

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Research Ethics Board  
c/o Office of the Vice President, Research and Innovation  
Ryerson University  
350 Victoria Street  
Toronto, ON M5B 2K3  
416-979-5042  
[rebchair@ryerson.ca](mailto:rebchair@ryerson.ca)

Project: The realities of schizophrenia for Black African families navigating Toronto's mental health services

**CONFIRMATION OF AGREEMENT:**

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to participate in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement. You have been told that by signing this consent agreement you are not giving up any of your legal rights.

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Name of Participant (please print)

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Signature of Participant

---

Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

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Signature of Participant

---

Date

## Appendix B: Recruitment Flyer

### Participants Needed For Research on: The Realities of Schizophrenia for Black African Families Navigating Greater Toronto's Mental Health Services

If you self-identify as a Black and/or African immigrant with a family member diagnosed with schizophrenia using mental health services in the Greater Toronto area, you are invited to participate in this study.

This is a qualitative study of how Black families and/or African immigrant families with relatives diagnosed with schizophrenia navigate and experience mental health systems in the Greater Toronto area. This study is being conducted by Dorothy During, a Master of Social Work (MSW) student at Ryerson University who has no affiliation with the mental health system. It is being supervised by Dr. Jennifer Poole, Associate Professor and Graduate Program Director at Ryerson's School of Social Work.

Potential participants would be required to participate in a face-to-face interview that should last no longer than ninety minutes. Interviews will take place at the convenience of the participants, and participants will choose the location of the interview. The choices are private spaces in their local library, at the Ryerson library or the Ryerson MSW lounge (which has a private interview space) in the basement of Eric Palin Hall. Your identity will be kept confidential and consent forms will be provided ahead of time for your review.

In appreciation of your time, a \$10 Starbucks gift card will be provided to you.

Participation in this study is voluntary. If any question makes you uncomfortable, you can skip that question. You may stop participating at any time and you will still receive incentives and reimbursements described above. If you withdraw, you may also choose to not have your data included in the study. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigator, Dorothy During and supervisor, Dr. Jennifer Poole.

The research findings will be included in the Major Research Paper, a requirement for the completion of the MSW degree at Ryerson University.

If you are interested in learning more, please contact: Dorothy During, MSW student, at [d2during@ryerson.ca](mailto:d2during@ryerson.ca)

\* This research study has been reviewed and approved by the Ryerson University

Research Ethics Board

The Realities of Schizophrenia for Black African Families Navigating Toronto's Mental Health Services

Questions Include:

1. Tell me why you decided to participate in this study?
2. How do you understand schizophrenia?
3. Who do you support with this 'diagnosis'?
4. Please explain what your experience has been like navigating mental health systems for this person in Toronto.
5. How have these experiences impacted you mentally, physically, and/or spiritually?
6. What are some of the concerns you have regarding existing systems in place for mental health services, as a Black and/or African Immigrant with a relative diagnosed with schizophrenia?
7. Please explain what kind of changes you would like to see put in place to bring visibility to these concerns.

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