Perspectives on HIV Care and Support Services for African, Caribbean and Black Women living with HIV in Winnipeg, Manitoba

By

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Abstract

Introduction: African, Caribbean, and Black (ACB) women in Manitoba are overrepresented in HIV infections relative to other racial groups. Yet, there are no community-based or participatory studies that have explored the stories of these women. The goal of this study was to explore how ACB women living with HIV in Winnipeg experience care and support to call attention to their lived realities, including highlighting the historical and cultural oppressions. Several research questions guided this process, including (1) how ACB women describe ACB and HIV care and support programs in Winnipeg; (2) how ACB women living with HIV assess HIV care and support services, health care staff, and operations; (3) what are health providers' perspectives about HIV care and support services provided in Winnipeg; and (4) are there any gaps in services or areas of good practice?

Methods: Study participants were ACB women living with HIV (n=10) in Winnipeg, as well as care and support staff (n=12). The qualitative research design was informed by critical race and feminist theoretical frameworks, incorporating intersectionality and constructivist grounded theory methodology for data generation, organization, and analysis. This study was also community-based and collaborated with several HIV-focused clinics in Winnipeg. The study focused on providing insight and developing a theoretical lens into the experiences of HIV care and support by ACB women living with HIV through in-depth, semi-structured face-to-face and phone interviews.

Results: Study findings revealed the specific life histories and themes of ACB women in Winnipeg, particularly highlighting trauma that informs and shapes their experiences. ACB women with HIV in Winnipeg and their care staff also expressed a lack of cultural care and support, how ACB women bear multiple loads, face language problems, experience long waiting times, and do not feel welcomed, including dealing with the cost of HIV medication. Findings show that the difficulties ACB women face involve multiple intersecting forms of oppression within social and health services and are at various levels (individual, community, and structural). At the same time, ACB women also commit to using HIV care, self-accepting their HIV-positive identity, connecting with religion and spirituality, and creating a stronger sense of themselves in order to live well with their condition.

Implications: This study generates new knowledge and understanding of the experiences of ACB women living with HIV in Winnipeg, Manitoba. Study participants indicated a demand for consideration of the holistic needs of ACB women, which may include their cultural, linguistic, religious, and racial or ethnic characteristics. Stories from these women can inform future public health practices and interventions regarding HIV care and support in Winnipeg and across Canada.

Keywords: ACB women, HIV, HIV care and support, intersectionality, feminist, critical race, Winnipeg, Manitoba

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Contents

CHAPTER ONE

INTRODUCTION

Introduction

The thesis focuses on African Caribbean and Black women living with HIV in Winnipeg, Manitoba, to improve our understanding of how these women perceive and experience HIV care and support services in Winnipeg, Manitoba. My main objective in conducting this study was to explore the stories of ACB women living with HIV from the perspectives of the women and their care providers. ACB women living with HIV are considered racial minorities in a dominant Western-centric society and are often marginalized and relegated (Gardezi et al., 2008; Logie et al., 2013). ACB women with HIV have also been found to be significantly impacted based on the influence of broader external factors such as marginalization, reduced employment, the criminal justice system, as well as sexual and cultural norms (Gardezi et al., 2008; Logie et al., 2013). ACB women living with HIV's vulnerable positions in society are rarely the result of one disadvantage but an intersection of multiple vulnerabilities. Despite the challenges ACB women with HIV face, relatively little is known about how these women perceive HIV care and support in the province, and research focusing specifically on ACB women living with HIV in Winnipeg, Manitoba, particularly relating to HIV care and support, is scarce and not as available. The lack of attention to ACB women living with HIV research in the Manitoba context is a concern considering the growing size of African, Caribbean, and Black communities.

Situating the study within a social constructionism epistemological perspective and drawing on feminism and critical race theory, I examined experiences of HIV care and support by ACB women living with HIV as racial minorities. Considering the uniqueness and complexity of health and social challenges facing ACB women with HIV, this doctoral research, therefore, explored systems of societal interlocking oppression experienced by ACB women living with HIV and how these multiple systems of oppression might simultaneously corroborate and shape

ACB women's experiences about HIV care and support. Through the use of face-to-face and telephone interviews, I created meaningful constructions of service providers and ACB women's narratives and accounts of experiences of HIV care and support and how ACB women living with HIV "made sense" of the support and care that they receive and their life situations in relation to HIV care and support.

In this first chapter, I have provided an overview and rationale of the study. I also provided background information relating to the African, Caribbean, and Black populations in Canada and HIV, as well as described ACB women in Manitoba and HIV. HIV, particularly within the ACB community, is a continuing multi-layered public health concern; therefore, I included an overview of the women's background to ensure a better understanding of the ACB women's context. Within this chapter, I also included descriptions of HIV care and support, a literature review, and the research questions and objectives, and then proceeded to make a reflexivity statement that highlighted my social position and personal motivation in undertaking this study. As researchers, reflexivity remains crucial as a process of examining oneself and the research relationship to provide a more effective and impartial analysis.

Background and Literature Review

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) are a continuing international public health concern that affects many people from around the world (Bourgeois et al., 2017; Mondal & Shitan, 2013; Haddad et al., 2018). Studies show that HIV first began infecting humans in the 1970s but did not come to the public's notice until the early 1980s (Sharp & Hahn, 2011). Scientists trace the origin of HIV back to chimpanzees. HIV most likely jumped from chimpanzees to humans when chimpanzees' infected blood got into the wounds of hunters (Sharp & Hahn, 2011). Early diagnosis of HIV is critical to successful linkage of care, support, and treatment (Nanditha et al., 2019; May 2017). However, HIV, if not detected early and managed, practically always results in increased disease burden, a decline in immune function leading to opportunistic infections, rare malignancies, and early death from AIDS (Nanditha et al., 2019; May 2017). Since its first identification almost three decades ago, recent evidence points out that about 79.3 million people have been infected with HIV worldwide, and over 37 million have already died from AIDS-related illness (UNAIDS, 2021). Developing countries remain mostly hit and have experienced the most significant HIV morbidity and mortality (Grant & De Cock, 1998; Kerr, 1989; Yousaf et al., 2011).

In Canada, HIV also remains an issue that has not gone away over the years, and in many places, there has been an increase in HIV prevalence (PHAC, 2014). The Public Health Agency of Canada (PHAC) estimated that some 63,110 people were living with HIV in Canada at the end of 2016, representing an increase of 2,945 people (5%) since 2014 (CATIE, 2013). In 2017, a total of 2,402 new HIV cases were also reported, representing an increase of 17.1% since 2014 (Haddad et al., 2018). HIV continues to pose a significant public health threat.

Across provinces and territories, Manitoba has the second-highest reported diagnosis and incidence rates of new HIV cases in the country (Government of Manitoba, 2018). Manitoba is also a Canadian prairie province where annual rates of new HIV infections are consistently higher than the national average, with the majority of cases occurring in Winnipeg (81%) (Government of Manitoba, 2018; McClarty et al., 2021). Women are accounting for an increasing proportion of new HIV cases and continue to drive the shift in new HIV cases identified in Manitoba. The rate among women in 2019 remained the highest in the last five years (Government of Manitoba, 2020). The number of women living with HIV in Manitoba continues to increase due to ongoing transmission as well as the advent of antiretroviral therapy

(ART). Once considered universally acute and fatal, the evolution of antiretroviral therapy has transformed HIV into a manageable chronic condition, consequently resulting in increased longevity for people living with HIV (Haddad et al., 2018). These advances, in turn, have allowed people living with HIV to experience a higher quality of life and a longer lifespan than in the earlier phases of the HIV pandemic (Nanditha et al., 2019; Women and HIV Initiative, 2020; Grant & De Cock, 1998; Sharp & Hahn, 2011). Despite these improvements and medical advances in the treatment of HIV, the brunt of the HIV epidemic continues to disproportionately affect specific populations, particularly the African, Caribbean, and Black (ACB) communities (Government of Manitoba, 2018; Nine Circles, 2017).

African, Caribbean, and Black Population in Canada and HIV

Due to the composition of Canada's Black population, the term African, Caribbean, and Black (ACB) is used to recognize ethnic diversity and racial identity and refers to persons self-identifying as a black visible minority (PHAC, 2013; Baidodonso et al., 2013). Canada's Black population dates back to the 1600s but has grown substantially over the last 50 years (Shimless et al., 2011). The Black population in Canada is a collection of ethnically, culturally, and linguistically diverse communities comprised of people of Black descent who were born primarily in Africa, the Caribbean, or Canada, and some of whom have resided in Canada for many generations (African and Caribbean Council on HIV, 2013; Etowa et al., 2022). However, most Black people have their origins in HIV-endemic African or Caribbean countries (PHAC, 2013). HIV-endemic countries are defined as those where "HIV prevalence in the general population is 1% or greater, and where heterosexual contact accounts for more than 50% of infections" (ACCHO, 2013, p. 7). The majority of the countries are located in sub-Saharan Africa or the Caribbean, and, thus, in epidemiologic research on HIV in Canada, the terms "HIV-endemic" and "ACB" are often used interchangeably as a term because the two overlap substantially (Baidodonso et al., 2013; PHAC, 2013).

People from ACB communities are overrepresented in Canada's HIV epidemic (CATIE, 2013). While ACB people make up about 3.5% of the Canadian population, they account for 14% of HIV infections (OTHN, 2014). More so, ACB people are 12.6 times more likely to contract HIV through heterosexual exposure than other adults in Canada (Baidoononso et al., 2013). Similarly, in Manitoba, nearly two in three people with new infections self-reported being of African, Caribbean, or Black ethnic origin in 2016 (Nine Circles, 2017; Government of Manitoba, 2018). This represents an increase of 16.2 percentage points in the proportion of new HIV cases for individuals who self-identified as African, Caribbean, or Black. HIV vulnerability is associated with migration from areas where HIV is more prevalent, but it is also shaped by social drivers of health (Nine Circles, 2017; Government of Manitoba, 2018). Published studies also demonstrate that social drivers are intersectional; thus, ACB people face intersecting and overlapping forms of stigma, discrimination, and oppression, including multi-layered barriers to accessing related health services (Baidodonso et al., 2013; Antabe et al., 2021: Archibald, 2010).

African, Caribbean, and Black Women in Manitoba and HIV

ACB women in Manitoba, as part of Canada's Black population, form a diverse community that largely came to Canada through the immigration waves of the last five decades (PHAC, 2014; CATIE, 2013). Whereas there are more than 170 different places of birth for the Black population in Canada, the main birthplaces for ACB women in Manitoba include Nigeria, Ethiopia, Jamaica, Somalia, and Eritrea (Statistics Canada, 2017). English is known as the first language of most ACB women, followed by French. However, there are still those with a non-official mother tongue, for example, Somalians, and this group represents 35.7% of the Manitoba

Black population (Statistics Canada, 2017). While it is difficult to say precisely the number of ACB women residing in Manitoba since this data is scarce, census data shows that the Black population is increasing faster than the overall population and is distributed among Canada's provinces (PHAC, 2013).

In Manitoba, for example, which is among the fastest growing in terms of the black population, black people tripled in size between the periods 1996 and 2016, and as of 2016, they represent 2.4% of the Manitoba population, with Black women being more (18%) than men (Statistics Canada, 2017). Heterosexual contact, including coming to Canada from an endemic country with higher HIV prevalence, remains the most common self-reported risk category (Nine Circles, 2017; Government of Manitoba, 2018). While data is available for identifying vulnerability among ACB women living with HIV (PHAC, 2014; CATIE, 2013; Nine Circles, 2017; Government of Manitoba, 2018), data specifically about ACB women living with HIV in Manitoba and experiences of HIV care and support programs for these women is not as available.

Nonetheless, among Manitoban women populations, women of ACB descent are increasingly affected and account for 51% of all women's HIV infections (Government of Manitoba, 2018). ACB women also represent a much more significant proportion of individuals entering care with the Manitoba HIV Program in comparison to all previous years (Nine Circles, 2017). Notably, the cases in ACB women were also immigrants from HIV-endemic countries to Canada, with over 95% of these women testing positive for HIV prior to immigrating to Canada or within one year of immigration (Government of Manitoba, 2018). Despite this evidence of disproportionately high rates of infection among ACB women, little is known about ACB women living with HIV in Manitoba, and Winnipeg in particular, even though they are a priority group for HIV prevention and intervention services in Canada. Notably, there is a specific lack of published research focusing on ACB women living with HIV in Manitoba (Mc Clarty et al., 2021), resulting in persistent gendered and racial health inequities. The lack of attention to ACB women living with HIV research in the Manitoba context is a concern considering the growing size of African, Caribbean, and Black communities. ACB women with HIV have been found to be significantly impacted based on the influence of broader external factors such as marginalization, reduced employment, criminal justice involvement, difficulties with negotiating the health care system, including the fear of contamination, homophobia, religious beliefs, and ignorance. (Worthington et al., 2013; Gardezi et al., 2008; Baidanonso et al., 2013; Logie et al., 2013).

ACB women also face barriers relating to sexual and cultural norms, language and communication styles, social support, and a lack of adequate programs, policies, and curriculum (Etowa et al., 2022; Ukoli et al., 2018; Gardezi et al., 2008; Blot et al., 2013; Archibald, 2010). Additionally, since most ACB people in Canada, including ACB women, are immigrants, factors related to migration—such as immigration status, loss of social status, unemployment, and racism—also play vital roles and put ACB people at increased exposure to HIV infections (Blot et al., 2013). There are also issues related to settlement and acculturation, securing housing, language, access to health services, and culture (Ukoli et al., 2018; Gardezi et al., 2008). ACB women's heightened vulnerability is situated in structural contexts of social, economic, political, gender, and racial inequities, cultural differences, and the creation of social hierarchies of power, which often leave these women in relatively disadvantaged positions in terms of accessing HIV-related services (WHIWH, 2007; Logie et al., 2016; Worthington et al., 2013).

ACB women also face multiple forms of stigma and discrimination. By being women, ACB women experience several unique issues that potentially contribute to stigma. For example, in the global context of HIV and ACB settings, when a family member falls ill with HIV, ACB women living with HIV, as women, owing to their place in society, as those who bear and rear children and who are seen to uphold the moral and spiritual values of society, carry the overwhelming majority of the burden of care (Gahagan & Ricci, 2012; Land, 2017; ICAD, 2006). ACB women living with HIV provide home-based care, tend to the family's fields, find income-generating activities, and perform ongoing household duties supporting the family. Despite all the hard work, they bear enormous HIV-related stigma and are often left to battle discrimination alone, with little or no emotional and social support (Land, 2017; ICAD, 2006). Social norms about women’s sexuality, including discriminatory laws, make it difficult for ACB women living with HIV to protect themselves from the stigma they often experience. Stigma also makes it hard for ACB women living with HIV to talk openly and honestly about HIV (Mihan et al., 2016; Gardezi et al., 2008; Logie et al., 2013; Archibald, 2010).

This is further complicated because, unlike their men counterparts, ACB women have less power and control and limited access to productive resources (Paudel & Baral, 2015; Corbin, 2012; Jewkes & Morrell, 2012). ACB women also lack education, both in terms of general schooling and knowledge of HIV transmission, and also face oppression from broader gender inequities in relation to their sexuality and religion (Gahagan & Ricci, 2012). The convergence of external structural factors, gender inequities, race, and stigma influence ACB women living with HIV's response to HIV disease and prevention practices and operate distally to reduce access to HIV testing, treatment, and support services (Gardezi et al., 2008; Logie et al., 2016; Worthington et al., 2013).

More so, as mothers, the life of ACB women living with HIV is never easy (Paudel & Baral, 2015). Balancing treatment with other family responsibilities is complex and a significant commitment, particularly for women who are living in poverty and dealing with mental health or immigration issues (WHAI, 2020). As mothers, ACB women living with HIV experience elevated levels of caregiving stress, fears of infecting the baby, internalized stigma, and other mental health concerns. As such, for many ACB women living with HIV, motherhood is characterized by emotional anguish and enormous stress, which puts women at a higher probability of severe mental illness requiring social support and counseling (Etowa et al., 2022).

Notwithstanding, stigma prevents ACB women living with HIV from disclosing their status and talking about their issues, compromising their care and social support (WHIWH, 2007; WHIWH, 2003; Loutfy et al., 2012). HIV stigma, intersecting with other social drivers of health and condition, adversely impacts the well-being of ACB women and undermines HIV care, treatment, and support (Gardezi et al., 2008; Archibald, 2010). An Ontario study by Women's Health in Women's Hands Community Health Centre demonstrated that ACB women living with HIV experience limited access to appropriate services and support, particularly for those whose primary language is not English (WHIWH, 2006). These ACB women also reported a lack of emotional and mental support despite facing emotional trauma and experiencing side effects from their HIV medication, which in turn created barriers to treatment and disrupted their daily function.

Similarly, in the CHIWOS (Canadian HIV Women Sexual and Reproductive Health) study, Canada's largest ongoing community-based study that enrolled over 1,400 women living with HIV in British Columbia, Ontario, and Quebec, findings showed that women who identified as ACB experienced significant levels of racist events in their day-to-day experiences as compared to those identified as other or multiple ethnicities (Kerkerian et al., 2018). Experiences of racial discrimination, in turn, led to and accounted for a very significant decrease in HIV care. This study also found that beyond racial discrimination, the environments within which ACB women live, interact with daily, and seek care also shaped their engagement in the HIV care cascade. The HIV care cascade, or continuum, is a model that begins with HIV testing and diagnosis, followed by engagement in care and treatment and support while in care in order to achieve viral suppression and an undetectable HIV viral load (MacCarthy et al., 2015).

In another Ontario study, Louty et al. (2012) also showed that women of non-White ethnicities, such as African, Black, and Caribbean women, experienced more HIV-related stigma than White people living with HIV. Gender and ethnicity worked together to increase the stigma experienced by ACB women, which adversely influenced HIV care use. Despite the challenges ACB women with HIV face, relatively little is known about HIV care and support programs that are available and attend to the diverse needs of these women in Winnipeg—women do not only belong to socially and economically marginalized populations but also face several inter-connecting determinants of health that adversely impact their exposure to HIV infection and experiences accessing diagnosis, care, treatment, support, and preventive services. Notably, no community-based or participatory studies have explored the stories of these women.

Meaning of HIV care and support

UNAIDS (2016) refers to HIV care and support as critical non-antiretroviral therapy clinical services, the treatment of HIV-related infections, and non-clinical services that, in combination with antiretroviral therapy, contribute towards the reduction of rates of ill health and AIDS-related deaths among people living with HIV. HIV care and support encompass a comprehensive set of services, including medical, psychosocial, physical, socioeconomic, nutritional, and legal support, extend beyond medicines and formal healthcare systems and consider the different needs of people living with HIV (Croxford et al., 2018; UNAIDs, 2016). HIV care and support remain important to enhance immediate access to treatment for persons diagnosed with HIV, to prevent infecting other people with HIV, to enhance the prevention and management of HIV-related infections, and to enhance coping with the challenges of living with HIV (Croxford et al., 2018; UNAIDs, 2016). HIV care and support programs are essential to meet the increasingly complex needs of people living with HIV and ensure they live long, healthy, fulfilling, and independent lives (UNAIDs, 2016).

Statement of the Problem

The health of ACB women in Manitoba continues to be threatened by the high incidence of HIV, as the number of new cases within this population continues to increase. It is also well documented that ACB populations have poorer access to patient care, more negative experiences in healthcare settings, and worse HIV health outcomes in comparison to the majority of Canadian populations (Etowa et al., 2022; Antabe et al., 2021). ACB people living with HIV are also often stigmatized beyond their race or ethnicity and experience a greater magnitude of HIV stigma when compared to their White peers (Gardezi et al., 2008; Archibald, 2010; Gilreath, 2015). Race and ethnicity among minorities, including the stigma associated with poverty, social class, and racial minority status, affect the likelihood of acquiring HIV infection, the opportunity for access to healthcare, and healthcare outcomes (Freeman et al., 2017; Kelly, 2012). This is further complicated in ACB populations from lower socioeconomic backgrounds, evidencing higher morbidity and mortality rates (Gardezi, 2008; Freeman et al., 2017). The disproportionate representation of ACB women in new HIV infections reinforces the need to closely look at and examine not only broader external factors that create and perpetuate inequities in HIV infections but, crucially, HIV care services and associated support networks that are in place for ACB women living with HIV. However, there remain gaps in knowledge about care programs, support services, and networks focusing on ACB women living with HIV in Manitoba and their assessment of these services. Nine Circles Community Health Centre (Manitoba HIV lead site) and Sexual Education Resource Centre (SERC) provide supportive services for people living with HIV in Manitoba to enable clients to remain engaged in HIV care as well as facilitate the development of safe and non-judgmental environments for all clients seeking HIV care (Nine Circles, 2017: 2019; SERC, 2019). Despite the existence of HIV care services and capacity-building initiatives, it is unknown how many women living with HIV are aware of and assessing services. Much also remains unknown about how those assessing HIV care are currently using HIV care services. HIV surveillance data for people living with HIV in Manitoba are usually aggregated, thus masking variations in not only exposure to HIV but also how HIV care and support use is distributed among HIV persons, even for ACB women living with HIV (Baidoononso et al., 2013).

Additionally, Nine Circles Community Centre, in a conference presentation shared at the 28th Annual Canadian Conference on HIV Research, identified other areas of need for people living with HIV in Manitoba, including access to peer and other support groups, employment resources and opportunities, safe and affordable housing, recreation programs, public education, advocacy, and support for people living with HIV to meet personal and daily needs (Ukoli et al., 2018). However, it is unknown if these services exist for people living with HIV, including ACB women living with HIV in Manitoba, since there are no published studies in this area. Additionally, many studies have equally failed to adequately examine the socio-demographic characteristics, health profile, and outcomes of ACB women living with HIV in Manitoba, as well as study HIV care and support services in the context of historical, structural, and sociocultural factors related to the vulnerable position of ACB people living with HIV in Winnipeg, Manitoba.

Purpose of the Study

The overall purpose of the doctoral research was to engage care providers and ACB women living with HIV as racial minorities to critically explore ACB women's experiences of HIV care and support and co-design care recommendations to improve primary care and support for ACB women living with HIV in Winnipeg. Four key objectives guided this work and are as follows:

1. To learn about what ACB means, and the life history of ACB women living with HIV in Winnipeg in order to better understand women's context.
2. To explore, from the perspectives of ACB women living with HIV and care providers, knowledge, attitudes, feelings, and interpersonal experiences related to HIV care and support services, as well as the use and perceptions of these services.
3. To highlight perceived barriers, unmet needs, and facilitators to HIV care engagement among ACB women living with HIV.
4. To develop recommendations for future improvement and learning based on health care supports for ACB women living with HIV in Winnipeg.

Research questions

The central premise of this research is that the health of ACB women living with HIV can be enhanced through the provision of HIV care and support programs that attend to and adapt to the changing and diverse needs of ACB women living with HIV in Winnipeg. Therefore, the key research questions asked were:

- What are the socio-demographic characteristics of ACB women living with HIV who are receiving care and support services in Winnipeg?
- How do ACB women living with HIV and service providers describe and understand the meaning of African, Caribbean, and Black communities in Winnipeg?
- What are ACB women's experiences before and after diagnosis with HIV?
- What are ACB women's experiences of HIV care and support? How do ACB women living with HIV assess HIV care and support services, including health care staff and operations?
- What are health providers' perspectives on HIV care and support services?

Reflexivity and situating self

At the core of qualitative research is reflexivity, a strategy health and social science researchers use to understand and improve research practices and outcomes (Darroch & Giles, 2014). It is important for context to note that I am a Black African woman born and raised in Nigeria with relevant background, knowledge, and significant interest in the topic. My social positioning as a Black African woman guided this research, including its topical focus, epistemological framework, and methodological choices. I desired to conduct this inquiry because I care about ACB women living with HIV community and in order to establish a working relationship in which these women's interests, needs, and values are more authentically represented in this research. I also chose to conduct this study to help give ACB women living with HIV a voice and raise awareness of the issues these women face in society.

Growing up as a Black African woman, I experienced many struggles. Born and raised in a culture where girls' education was not a priority and was often not prioritized compared to boys, I struggled to go to school. My parents were small-scale business owners who were formally educated but not beyond high school, and as such, they did not see the need to educate a girl child who would be married off and whose place is believed to be in the kitchen. As I think of this experience, it reminds me of ACB women living with HIV and all the hardships that they face, yet they are still relegated and marginalized. I eventually made it to elementary school, then college, and then university, after which I proceeded to work as an outreach worker at a renowned public health government agency. Despite daily struggles, public health was a part of me, particularly as it relates to the health inequity of marginalized and underserved populations, particularly women and people living with HIV. Earlier, I had assumed and thought of HIV as a deadly disease without remedy, and as such, I had feared HIV. This assumption developed from misinformation and a lack of understanding about the virus. With more exposure and learning, I have been focused on interacting and supporting people who live with HIV, creating more public awareness and acceptance, dispelling myths about HIV, and facilitating greater involvement of people living with HIV, to improve the relevance, acceptability, and effectiveness of HIV programming as well as in ensuring their wellbeing.

Since moving to Canada and starting my Ph.D. program in 2017, I have been involved in the HIV community and discourse through interactions with HIV care providers, volunteering, and attending workshops, conferences, and events. I have also been involved in facilitating video presentations geared toward supporting people living with HIV, keeping abreast of recent happenings, and building relationships with People living with HIV, including ACB women, since I want to learn from their point of view how best I can assist and contribute to addressing several issues that they face.

Thus, my research study was born out of my identity development process, personal conversations with HIV care staff about the ACB community, and my keen interest in addressing disparities in health and social services and improving community health, especially among vulnerable women like ACB women living with HIV. I believe my identification as a woman of African descent, ACB women with HIV were able to see me as a fellow ACB compatriot who is capturing their voices, views, thoughts, and opinions. This awareness and understanding worked to resolve unequal power relations due to differences in social identities that often exist between researchers and participants. I so long for a time when women and people living with HIV can reach their goals and lead full lives.

As a result, I chose to explore ACB women's subjective experiences of HIV care and support in Winnipeg for my research topic in order to address knowledge gaps in the existing literature and build knowledge relating to unmet needs and preferences for HIV care services by ACB women living with HIV, as well as areas of good practice. Learning about how ACB women living with HIV perceive such services is important not only for patient empowerment but will also help to better inform HIV interventions for ACB women and allow health staff to provide quality and optimum care. (Plot et al., 2016; Baidobonso et al., 2013). Additionally, as noted by UNAIDS (2016), HIV care and support programs remain essential to meet the increasingly complex needs of people living with HIV and to ensure they live long, healthy, fulfilling, and independent lives.

Significance of the Study

While there have been some research studies focusing on HIV and women in Canada (Loutfy et al., 2021; Women's Health in Women's Hands [WHIWH], 2003; WHIWH, 2007; Richard, 2019; Baidanonso et al., 2013), ACB women with HIV in Manitoba, and Winnipeg in particular, have not received much attention. There is a shortage of research focusing on HIV in ACB communities in Manitoba. Similarly, there is a scarcity of HIV-related published research on ACB women in Manitoba in general and Winnipeg in particular. Viewing published literature in the area of HIV care and support programs for ACB women living with HIV, research is literally non-existent, as ACB women in Manitoba are grossly under-researched. The few studies that were conducted in other provinces found that there is racial discrimination and stigma attached to HIV in the ACB community, which influenced engagement in HIV care (Kerkerian et al., 2018; MacCarthy et al., 2015; Louty et al., 2012; Shimless et al., 2011).

Notably, the doctoral study is the first of its kind to my knowledge that provides important information regarding how ACB women living with HIV talk about HIV care and support programs in Winnipeg, Manitoba. More importantly, this study fills a critical knowledge gap on ACB women's assessment of services, including health care staff and operations. A greater understanding of how ACB women living with HIV perceive HIV care and support programs is indeed essential in planning current and future interventions that address the HIV epidemic in the ACB community.

Additionally, this work also highlights structural, racial, systemic, and interpersonal forces implicated in the use of HIV care by ACB women living with HIV and helps better understand the needs of the ACB community. This study also provides critical information on how the HIV care system operates and the impact of individual and structural factors on ACB women's health and well-being. The knowledge gained from this research will inform service providers, such as Nine Circles, Manitoba Health, the Sexual Education Resource Centre (SERC), social care providers, ACB-serving organizations, and non-profit governmental organizations working on settlement and policymakers. Additionally, study findings will also be used to develop recommendations for future improvement and learning based on health care support for ACB women with HIV in Winnipeg and Manitoba in general.

Chapter Summary

ACB women living with HIV Winnipeg, Manitoba, are an important group to study. The reality of having high HIV rates among Canadian immigrants, along with the increasing size of African, Caribbean, and Black communities in Manitoba, including in Winnipeg, makes this group a priority group for HIV prevention and intervention services in Canada. Based on scholarly and community-based research in the ACB community in Canada, it is clear that there are a number of factors that increase vulnerability and poor health outcomes, which in turn shape HIV care use among ACB women with HIV. Ultimately, there is a dearth of published work relating to HIV care support and ACB women with HIV in Canada, particularly in Winnipeg. Learning about HIV care and support, including how ACB women perceive such services, remains key to promoting the voices of ACB women living with HIV and understanding how best to structure an efficient and sustainable response to the epidemic among ACB populations (Plot et al., 2016; Baidobonso et al., 2013). Additionally, understanding the impact of individual and structural factors in relation to care use remains key to ensuring optimum HIV support and care. To address these gaps is the goal of this thesis.

In conclusion, within this chapter, I outlined the introduction and rationale for the study, including the positionality statement. Additionally, I laid the foundation of this dissertation and highlighted the background to the study. I also described the concept of HIV care and support and justified its importance for people living with HIV, like ACB women living with HIV in Winnipeg, Manitoba, and also described this study's significance. The following chapter will present the study methodology and theoretical frameworks.

CHAPTER TWO

THEORETICAL FRAMEWORK, METHODOLOGY, AND METHODS

Research Design and Theoretical Frameworks

In this chapter, I include a discussion of the research design and paradigm, epistemological orientation, and theoretical frameworks, including critical race and feminist theory, the intersectional approach, the community-based participatory research approach, and the grounded theory methodology. This chapter provides an introduction to these overarching foundations for my research and illuminates how each approach or framework informed particular aspects of the research process.

Research Paradigm

As Guba and Lincoln (1994) explain, the research paradigm constitutes the basic set of beliefs or worldview that shapes research action or an investigation. As such, the research paradigm inherently constitutes the abstract beliefs and principles that shape how a researcher sees the world, interprets it, and acts within it (Kivunja & Kuyini, 2017). Thus, as researchers, it represents the conceptual lens through which to examine the methodological aspects of our research to determine the research methods that will be used and how the data will be analyzed (Kivunja & Kuyini, 2017; Khaldi, 2017). As a researcher, I began my project with definite theoretical and ideological assumptions concerning how and what I would be learning during my investigation. These took the form of paradigms and philosophical and epistemological assumptions (Creswell, 2003; Guba & Lincoln, 1994).

Epistemological Orientation

The notion of epistemology owes its etiology in Greek, where the word episteme means knowledge. Put simply, in research, epistemology is used to describe "how we come to know something; how we know the truth or reality. Kivunja & Kuyini 2017, p. 27), or as Cooksey and McDonald (2011) put it, what counts as knowledge within the world. It focuses on the nature of human knowledge that a researcher can possibly learn so as to be able to broaden and deepen their understanding in any chosen area of research.

As I explore throughout the dissertation, the research was situated within a social constructionist epistemological perspective and employed a qualitative approach informed by critical race theory (CRT) and feminist methodological research design, incorporating intersectionality (Freeman et al., 2017; Ford & Airhihenbuwa, 2010) and constructivist grounded theory methodology for data organization and analysis (Charmaz, 2006; Charmaz, 2014).

Constructionist epistemology holds as its core assumption that reality is socially constructed and multiple and emphasizes knowledge generation from the dynamics within the interaction of relationships (Creswell, 2009; Losantos et al., 2016; Room, 2013). In other words, from a constructionist epistemological perspective, “knowledge and all meaningful reality as such are contingent upon human practices, being constructed in and out of interaction between individuals and their world and developed and transmitted in an essentially social context” (Broido & Manning, 2002, p. 436).

Therefore, in constructionism, such an inquiry aims to move away from discussions on the contestation of truths. Rather, knowledge is understood as something not one possesses or is out there in the world, but instead knowledge is something that is constructed between those involved (Kivunja & Kuyini 2017). The emphasis is thus placed on understanding the individual and their interpretation of the world around them—and the meaning s/he is making of the context (Kivunja & Kuyini 2017). A social constructivist perspective also recognizes subjective experiences and looks for the complexity of views, in contrast to positivist research that reduces meanings into categories. Additionally, in constructionism, people’s social world is (re)created through engagement in social interactions and processes and influenced by broader external factors (McNamee, 2012; Crotty, 1998; Broido & Manning, 2002). I am aware that my work generally fits within a social constructivist paradigm, also referred to as the interpretivist paradigm by Guba and Lincoln (1989) and Kivunja and Kuyini (2017). From my perspective, situating my work within social constructionism was crucial, as I was able to gain an in-depth understanding of the subjective world of ACB women and make sense of how ACB women living with HIV experience HIV care and support in Winnipeg (Creswell, 2003; Guba & Lincoln, 1989). By analyzing the social world of ACB women living with HIV, I was able to understand how women's lives are externally organized and influenced by existing social and cultural structures. As such, I moved beyond mere description to a critical interrogation of ACB women living with HIV's experiences and focused on how the broader context, perceived gender differences, distribution of wealth and power, and cultural beliefs shape the women's experiences, constrain care use, and define ACB women's behaviour.

Indeed, following a social constructionist paradigm allowed me to create meaningful constructions of what ACB women with HIV said they experienced and uncover social phenomena in the context of historical, structural, and sociocultural factors related to the vulnerable position of ACB people living with HIV in Winnipeg. Therefore, the use of a social constructionist approach ensured I applied a holistic socio-cultural, political, and economic analytical approach in examining women's issues, and I was able to learn how ACB women living with HIV in Winnipeg actually live and embody the experiences of HIV care and support. In doing so, I introduced a number of theoretical frameworks and methodological tools to undertake a critical inquiry.

Critical Race Theory

This doctoral thesis was rooted in critical race epistemology. Critical race theory (CRT), as described by Gilreath (2015) and Freeman et al. (2017), is an interpretive framework used to explain the position of marginalized groups from the viewpoint of the participants and is most applicable in population health investigations where ethnic identity is associated with the health outcome, like ACB women living HIV and HIV care and support service concerns. Developed from legal studies in the mid-1970s, CRT seeks to challenge and transform racial hierarchies, illuminate contemporary racial phenomena, and expand the discourse about complex racial concepts (Ford & Airhihenbuwa, 2010; Howard & Navarro, 2016). Thus, CRT reminds us to look beyond the dominant group's acceptance of what is known to be true in order to accept other ways of knowing, and it also understands knowledge as embedded in social, economic, historical, and cultural processes. CRT provides an important framework that researchers can use to recognize, analyze, and change power dynamics that maintain institutional racism and reinforce racial inequality.

Delgado and Stefancic (1993), Ford and Airhihenbuwa (2010), and Howard and Navarro (2016) discuss principles and ideas that characterize CRT: a critique of liberalism, storytelling, or counter narrative that brings forth and explores racial oppression and people's experiences in that context. CRT also focuses on the centrality of race and racism, including intersections with other forms of subordination such as gender, class, and citizenship, and challenges the dominant narratives while re-centering marginalized perspectives. Additionally, CRT is deeply rooted in the promotion of social justice, valuing experiential knowledge, which is a way of knowing that results from a critical analysis of one's personal experiences (Ravitch & Carl, 2019). Consistent with the interpretive paradigm, the ontology and epistemology of critical race theory are grounded on the assumption that the world is multidimensional, and similarly, research about the world should reflect multiple perspectives (Mills & Unsworth, 2018; Gillborn, 2015).

CRT informed the focus of my doctoral research on the experiences of HIV care and support for ACB women living with HIV in Winnipeg. In applying CRT, I was able to elucidate and ascribe meaning from ACB women living with HIV and their care givers' narratives and learned how structural level factors as well as individual factors influence HIV care use and behaviour of ACB women. Understanding that ACB women living with HIV's behaviour is nested within larger social interactions across ecological levels, applying CRT helped me to understand how larger social interactions and realities influenced their personal decisions about HIV care use.

Employing CRT also helped me to uncover and legitimize the knowledge and lived experiences of ACB women in the context of the dominant cultural orientation of ACB women living with HIV (Freeman et al., 2017; Gillborn, 2015). Understanding HIV care and support services from ACB women living with HIV's context and perspective and that of care providers provided an opportunity for discussing sensitive issues of race as well as diverse challenges facing ACB women living with HIV in society. Additionally, applying CRT helped to decentralize dominant knowledge and practices, shifting the focus to that of ACB women living with HIV, experiencing the world, and navigating HIV vulnerability. CRT influenced my interpretation of the use of care behaviours and views and experiences about HIV care and support services as a by-product or influence of the historical roots and cultural treatment of the social position and identities of ACB women living with HIV. Thus, the use of CRT contributed to a nuanced understanding of how peers of ACB women with HIV talk about HIV care and support programs.

Employing a CRT approach also afforded me a unique opportunity to examine and explicate the mechanisms by which ACB women's race, structural racism, and other external factors might shape and influence ACB women's relationships with HIV care settings and health decisions, particularly within the context of HIV care and social service use, while also attending to intersections of other frequently marginalized social categories (Freeman et al., 2017; Howard & Navarro, 2016). In other words, CRT privileged the knowledge of ACB women living with HIV as racial minorities and drew attention to structural, systemic, and interpersonal forces implicated in ACB women's experiences of HIV care and support, as well as areas of good practice. Therefore, CRT highlighted the multiplicity of issues related to the intersectional impact of racism and discrimination on ACB women living with HIV in Winnipeg (Mills & Unsworth, 2018).

Feminist Theory

Feminist theory is another important theoretical framework that I used to frame this study and guide the research process. Like CRT, feminist theory is an interpretive framework devoted to the tasks of critiquing women's subordination and gender-based relations of domination (Allen, 2014; Opara, 2018; Gentry, Elifson, & Sterk, 2005). Based on the assumption that men are the dominant social force in most aspects of life while women are being denied a voice about issues relevant to them (Lay & Dale, 2007; Allen, 2014), feminist theory focuses on giving women a voice. Notably, a feminist perspective calls for centering gender and consideration for how gender differences affect human behaviour in the context of historical, political, social, and cultural concerns (Marindo, 2017; Allen, 2014). Recognizing that women's oppression is not simply related to one social relationship, such as a class system, but rather a unique constellation of social problems that has to be understood in itself, feminist theorists place an emphasis on examining the multifaceted oppressions of women. Feminist theorists also investigate the ways different power systems—global, local, patriarchal, and family—interconnect and create vulnerability among women, who not only have less power but are poor and resource-limited (Corbin, 2012; Marindo, 2017; Lay & Dale, 2007; Gentry et al., 2005), such as African, Caribbean, and Black women living with HIV.

Olesen (2005) identified three elements of feminist qualitative research as “research that problematizes women’s issues within a framework of social and historical structures; research that focuses on social justice for women; and research that creates knowledge of the marginalization of women” (p. 236). The ontology and epistemology of feminism assume that gender is a socially constructed, historically changing reality and emphasize that any particular view of reality or truth can only be understood in the context of the social constraints under which it was constructed and within the history and subjective lived experiences of gendered oppression (Hesse-Biber, 2017; Carastathis, 2014; Broido & Manning, 2002). Thus, feminist theorists assert that knowledge from a woman’s perspective is a truer form of knowledge, and the larger premise of feminist theory is grounded in a “politics of empowerment” that demands action at the individual (agency) and systematic levels (Harding, 2020).

Similar to critical race theory, feminist theory also informed the focus of the study and was an ideal fit for the research purpose. For ACB women living with HIV in Winnipeg, their vulnerable positions in society are hardly the result of one drawback but an intersection of multiple vulnerabilities that include lack of education, belonging to a minority group, lack of information, lack of financial resources, patriarchy, culture, and oppressive political systems (Marindo, 2017). Moreover, navigating health systems and structural barriers to overcome HIV care access remains daunting for most ACB women living with HIV (Antabe et al., 2021).

In applying feminist theory, I was able to centre ACB women living with HIV's experiences of HIV care and support, their diverse issues, situations, embodiments, contexts, and institutions that frame their lived realities (Kelly, 2012; de Souza, 2010; Parikh, 2012). Through personal stories shared by ACB women living with HIV and their caregivers, I was able to gain an in-depth understanding of how social, political, and economic factors, including cultural norms, social determinants of health, and institutions, impact ACB women with HIV and shape their experiences of HIV care and support.

Feminist theory also helped to extend my knowledge about the meaning of HIV care and support programs in the lives of ACB women living with HIV, as well as the relationships these women have with HIV care and support organizations and health staff that provide care, including their perceptions of the care services they receive. The use of feminist theory allowed me to consider the differences in the experiences of women based on their multiple identities and diverse needs and afforded me a distinctive opportunity to produce a comprehensive view of women’s multiple realities (de Souza, 2010; Lay & Daley, 2007). Applying feminist methodology thus exposed the formal and informal ways in which gender inequality manifests in health care access and delivery, as well as the role this system of power plays in impacting HIV care and support programs for women living with HIV.

ACB women living with HIV are also often marginalized and relegated (Gardezi et al., 2008; Loutfy et al., 2012; Gupta, 2000). More crucially, applying a feminist worldview allowed me to engage in research partnerships with minority and marginalized ACB women living with HIV populations and the inclusion of stories of these women. Collaborating with ACB women living with HIV was really empowering for most women who felt strengthened to share their stories. Notably, a feminist worldview allowed this study to give the voices of ACB women living with HIV with HIV a primary place in the research results (Harding, 2020).

When the conceptualization of ACB women's health is framed following critical race and feminist theory worldviews, ACB women's health is treated as distinct from men and other ethnicities' due to gender and race influences and includes a totality of ACB women living with HIV's issues rather than providing a narrow focus on their HIV care and support concerns. Both CRT and feminist theories, including the constructionist paradigmatic approach, informed the manner in which this study was conducted. These theoretical frameworks and paradigms influenced my adoption of a community-based participatory approach to ensure representation of ACB women perspectives and an intersectional approach to embrace a broader scope for investigating the intersections of race, gender, and other social identities of ACB women living with HIV and the effects of the multiple intersecting social identities and oppressions of ACB women living with HIV on care and support use. Essentially, it ensured the inclusion of stories of ACB women living with HIV in Winnipeg and provided an opportunity to extend ACB women living with HIV's knowledge into dialogue and action for social change. To address the Manitoba HIV epidemic and also ensure representation and inclusivity within research and HIV program delivery for individuals living with HIV, we must look for the silences and pockets of exclusion by actively considering whose voices are missing, such as those of low-income HIV-positive African, Caribbean, and Black women, what barriers to participation exist, and what methods can be used to address these factors (Lay & Dale, 2007).

Intersectionality

I chose to draw upon an intersectional approach given the overall purpose of my research to engage ACB women living with HIV as racial minorities, including their caregivers, to understand the complexity of the women's issues and to improve the comprehensive HIV care and support for ACB women living with HIV in Winnipeg.

The term "intersectionality" originated from the Black feminist movement and highlights the mutually constitutive forces of gender, sex, race, class, and disability that jointly shape group members' perceptions, behaviours, and outcomes within socio-environmental contexts defined by power and privilege (Puar, 2012; Sutherland, 2016; Hankivsky, Cormier, & De Merich, 2009). Coined by feminist legal scholar and activist Kimberle Crenshaw in 1989, intersectionality moves beyond single or typically favoured categories of analysis (e.g., sex, gender, race, and class) to consider simultaneous interactions between different aspects of social identity (e.g., race, ethnicity, indigeneity, gender, class, sexuality, geography, age, ability, immigration status, religion) as well as the impact of systems and processes of oppression and domination (e.g., racism, classism, sexism, homophobia) and how they affect a person's life.

The importance of the intersectional approach within HIV research has been an undisputable part of the HIV response. As Women's Health in Women's Hand (WHIWH, 2021) pointed out, applying the concept of intersectionality to research prompts researchers and scholars "to conceptualize and analyze social inequities in complex and multidimensional ways that mirror the experiences of populations for whom adverse health outcomes are most disproportionate" (p. 11). In an era where the HIV epidemic disproportionately compromises the health of ACB women living with HIV, an intersectionality approach is best suited to achieve a better understanding of the needs of ACB women living with HIV and to reduce or eliminate disparities.

Just like CRT and feminist theory, intersectionality remained integral as an important framework for examining and understanding experiences of HIV care and support concerns among ACB women living with HIV (Henry, 2021). ACB women living with HIV in Winnipeg may not only experience exclusion from appropriate health care research but are also hesitant to socialize and talk openly about HIV support services due to multiple interlocking oppressions and for fear of being further stigmatized (Taylor & Richards, 2019; WHIWH, 2007). ACB women living with HIV in Manitoba are not also a homogenous group. They are people of race as well as women with particular social determinants of health such as class and culture (Taylor & Richards, 2019; WHIWH, 2007). Moreover, HIV itself is an extremely serious social illness, with its causes, impacts, and consequences profoundly rooted in social, economic, cultural, and political processes (Henry, 2021; Kippax et al., 2011; National Research Council, 1993).

Intersectionality, as applied in this doctoral research, considered the impact of race, gender, class, and other social categories on ACB women living with HIV, including social, cultural, historical, and economic contexts, and examined systems of societal interlocking oppression experienced by ACB women living with HIV and how these multiple systems of oppression simultaneously corroborate to shape ACB women's experiences in relation to HIV care and support (Taylor & Richards, 2019; Sunderland, 2016; Wilson et al., 2016). Using this theoretical framework, we highlighted the salience of gender, race, age, racism, ethnicity, and other social categories that affect both behaviour and access to HIV care resources. The use of intersectionality allowed for an examination of the multilayers that structure women's lives and served to disrupt linear thinking that prioritizes any one category of social identity over others (Verjee, 2012). It also provided a social and political context through which to understand women with HIV day-to-day experiences of HIV care and support and opened up different ways of looking at women's issues.

Community Based Research

Throughout the research process, I utilized a community-based research (CBR) approach. This study addresses a gap identified by Nine Circles, as not much is known about ACB women living with HIV in Winnipeg, particularly in regard to HIV care and support services. Therefore, in my initial research protocol, I proposed that the present study be a collaborative work between myself as the researcher, ACB women living with HIV, and Nine Circles, and thereby would adopt a community-based participatory research (CBPR) process.

The term community-based participatory research (CBPR) is increasingly being used across many diverse community settings and is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings (Duran et al., 2012; Hacker, 2013). CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate social disparities (Duran et al., 2012; Muhammad et al., 2015; Jane, 2016). Thus, a community-based participatory research approach is built on a foundation of social justice and empowerment of the oppressed and shares central principles of collaboration and power-sharing, including a commitment to research (Hacker, 2013). Notably, CBPR is unique given the heavy emphasis placed on genuine community engagement throughout the process and the use of findings to help bring about changes in programs, practices, and policies that can in turn help to improve health outcomes within the affected community (Jull et al., 2017; Minkler et al., 2012; Rhodes et al., 2010).

In applying the CBPR process, I initially set out to form a community advisory committee (CAC) composed of members (n = 4) from agencies providing health and social services to ACB women living with HIV and ACB women living with HIV (n = 6) to provide additional consultation on research design, implementation, interpretation and dissemination of results, and application of the results [action] (Minkler et al., 2012; Rhodes et al., 2010). However, with the onset of COVID-19 in early 2020, I struggled with enrolling CAC members, particularly ACB women with HIV, in Winnipeg, except for two ACB women living with HIV who accepted to be on the CAC. However, as COVID persisted, I continued to struggle with recruiting CAC members, including care and support staff. I was unable to connect with care providers supporting ACB women with HIV, who had initially agreed to be on my CAC group, to meet in a group with other identified community members. Consequently, I could not actually form a CAC group and have consistent meetings with members.

However, I did draw upon community-based research principles to guide the research process, even though my doctoral research is not itself a community-based participatory research project, as the research decisions, development, and conduct of the research were ultimately my own. Hacker (2013) states that CBR is dependent on partnerships. In establishing CBR in this study, I built relationships with some Nine Circles and SERC staff and connected with these community members and partners through a number of email correspondences and telephone discussions throughout the research process. As described in the first chapter, Nine Circles in Winnipeg is a foremost HIV treatment centre that offers a wide range of social support, preventive counselling, and education to Manitobans. Likewise, SERC supports community members, including people living with HIV in Manitoba, through education and organizing regular workshops (SERC, 2019). The meetings with Nine Circles and SERC underscored a deeper understanding of ACB women's unique circumstances and highlighted additional recommendations on best practices, strategies, and approaches to enrolling and collaborating with ACB women living with HIV in research. Hence, in this doctoral research, the principles of

CBR informed the engagement of community stakeholders like Nine Circles Community Health Centre and SERC staff in providing guidance on the research process. Additionally, the overall purpose of this doctoral research stemmed from a number of consultations, advocacy, and meetings with social and health organizations supporting people living with HIV, in which Nine Circles health staff described exploring perspectives on HIV care and support programs for ACB women living with HIV as a huge gap that needs to be addressed as the data is hugely lacking (S. Vanhautte, personal communication, May 6, 2019). CBR fostered co-learning and also ensured the study's rigour, validity, and trustworthiness (Minkler et al., 2012), as this doctoral research was grounded not only in the researcher's perspectives but in the exchange of knowledge, skills, and capacity among community partners. Strong community input by community stakeholders thus enriched both the quality and the outcome of the study.

Furthermore, "the goal of a community-based research approach is to produce research that is relevant to the life circumstances of communities and the people who reside within them" (Viswanathan et al., 2004, p. 12). Additionally, in a CBR approach, affected communities' want to have their voices heard. As such, it was important that I conduct this research, prioritizing the ACB women living with HIV as racial minorities, whose perspectives appear less present within healthcare decision-making and whose HIV care and support needs my research aimed to address. Even though ACB people with HIV are a priority group for HIV prevention and intervention services in Canada, reviewing published literature, much remains unknown about HIV care and support services for ACB people, including women living with HIV in Manitoba and Winnipeg in particular. Still less is known about how many ACB women with HIV are aware of HIV care services and how those accessing care are currently using services. Research is literally nonexistent, as ACB women are grossly under-researched. This doctoral research responded to support care and research needs, including highlighting the historical and cultural oppression of ACB women living with HIV in Winnipeg. CBR ensured that this doctoral research included ACB women living with HIV's wealth of knowledge and lived experience from a cultural, local, and historical lens that in turn provided important insider information that is typically unattainable by an outside scientific researcher (Minkler et al., 2012; Rhodes et al., 2010).

Study Site/Location

The project was conducted in Winnipeg, the largest and capital city in the Prairie province of Manitoba, spanning 464.1 km2 (City of Winnipeg, 2016). According to the 2019 Manitoba Health Population Report, Winnipeg has a city population of 749,534 and a metropolitan population of 889,872 people, a 23% increase from 1991 (City of Winnipeg, 2016). Continued international immigration remains the single largest contributor to population growth. As such, Winnipeg is culturally diverse and home to increasingly diverse populations and nationalities, including the ACB community. Winnipeg has the most, new cases of HIV infection (78%) compared to other regional health authorities (Government of Manitoba, 2020). African, Caribbean, and Black (ACB) women in Winnipeg have become increasingly more impacted by HIV (Haddad et al., 2018; Nine Circles, 2018; Government of Manitoba, 2018).

Since 2007, the Manitoba HIV Program has been the primary provider of specialized, evidence-informed HIV care and treatment for people living in Manitoba, including ACB women living with HIV (Nine Circles, 2019). As such, in Winnipeg, HIV care is primarily provided through the Manitoba HIV Program at two clinic sites: the Nine Circles Community Health Centre and an ambulatory clinic at the Health Sciences Centre. Outside of Winnipeg, there is the 7th Street Health Access Centre in Brandon, Manitoba.

However, Nine Circles Community Health Centre is the community lead site for the Manitoba HIV Program (Nine Circles, 2019; Woodgate et al., 2017). As noted earlier, Nine Circles is a community-based, non-profit community health organization and a foremost HIV treatment centre that offers HIV care and a range of social support and services, preventive counselling, and education specifically to people living with HIV in Manitoba (Nine Circles, 2019).

Recruitment process and sampling technique

Given (2021) defined participant recruitment as a process whereby a researcher identifies and enlists participants to join the study. In other words, it entails reaching out to the population of interest, making a connection with community members who have relevant lived experience, and them consenting to share their experience (Bonestill et al., 2021). To recruit ACB women living with HIV and care staff to answer the questions asked in the study, a number of sampling techniques were employed to be able to reach as many potential participants as possible. Unlike in quantitative studies, qualitative research uses non-probability sampling methods for selecting participants for study (Ritchie et al., 2013; Sargeant, 2012). As such, participants are selected based on who can best inform the research questions and enhance understanding of the phenomenon under investigation.

Considering the culture and diversity of ACB women living with HIV, I proposed to use a combination of purposeful sampling and snowballing, also known as word-of-mouth or "chain referral" sampling, to recruit ACB women with HIV, including their service providers (Verjee, 2012). Purposive sampling involves "selecting specific participants by virtue of their capacity to provide detailed insights and richly textured information relevant to the phenomenon under study" (Vasileiou et al., 2018, p. 2). Likewise, snowballing is also a non-probability sampling method, but it is based on referrals from initial known subjects to recruit new additional subjects (Shaghaghi et al., 2011).

Bonestill et al., (2021) and Shaghaghi et al. (2011) underlined the importance of using a range of sampling techniques involving those sub-groups of the population that may be difficult to reach, as well as members of cultural communities, to recruit isolated or vulnerable immigrant groups. The effectiveness of these strategies depended upon my years of experience as a volunteer engaging in HIV research and interacting with health and community-based organizations supporting people living with HIV, which included ACB women, my identity as an African Black woman, knowledge about specific characteristics of the ACB community, and also the flexibility and availability of the researcher.

In recruiting participants, I shared my study flyer or poster with community stakeholders: Nine Circles Community Health Centre, where persons with HIV, including ACB women, receive care, and the Sexual Education Resource Centre (SERC), which supports Manitobans, including people living with HIV in Manitoba, through education. As key stakeholders, Nine Circles and SERC agreed to provide support with participants' recruitment, including recruiting members of the lived advisory committee, informing research design, analysis, and dissemination of study results.

With the help of the MB HIV program development officer at Nine Circles, my research poster was posted on Nine Circles' website by Nine Circles' Community Engagement Coordinator. Similarly, this doctoral research flyer was also posted on Nine Circles' premises and clinic space, and an email was sent to Nine Circles teams and staff to encourage recruitment. Since I also approached and consulted with SERC about the study at the beginning of the project, I also shared the doctoral research flyer with SERC through the Knowledge into Action (KIA) coordinator and evaluator. Additionally, information about my research was shared by SERC staff in their workshops to ensure wider publicity of my doctoral research to be able to reach as many potential participants as possible.

Despite making these efforts, I was unable to recruit participants after months of effort. It was really challenging for me to enrol any participants, especially ACB women living with HIV, due to HIV stigma and the COVID-19 situation. Consequently, I resorted to word of mouth and writing personal emails to key representatives on social and community networks of ACB women living with HIV, like the African Communities of Manitoba (ACOMI) and the Kenyan Association of Manitoba. I also spoke about my research to folks from the ACB community I met at the shopping malls and at the church just in case they might know anyone who might be interested. Additionally, being a volunteer with Nine Circles and the Winnipeg Regional Health Authority (WHRA) at the time, I mobilized my existing network and leveraged relationships built when volunteering, engaging in workshops, and facilitating video presentations. I connected with the Winnipeg Regional Health Authority, the Manitoba HIV program clinic at Health Sciences, the Manitoba Interfaith Immigration Council (Welcome Place), as well as various members of staff at SERC and Nine Circles, and other public health staff and student colleagues through several emails and telephone conversations. To enrol ACB women living with HIV, I relied on referrals from staff of health and community-based agencies serving ACB women living with HIV. Particularly, I relied on referrals from the laboratory specialist at Nine Circles.

The laboratory technician at Nine Circles made the initial contact with ACB women living with HIV who met the study criteria. This laboratory technician, who self-identified as an African Black woman, had knowledge of key aspects of the project, including having previous experience working with the ACB community and people living with HIV.

Some of the ACB women living with HIV approached disagreed to participate due to confidentiality. For ACB women consenting to take part and sharing their contact information, the laboratory technician communicated their contact phone number without disclosing any real names. I then made follow-up phone calls to these women to further share information about the research and to schedule an interview at a mutually acceptable place and time.

Just like ACB women living with HIV, in recruiting service providers, I used purposive sampling in combination with word-of-mouth and snowball sampling techniques. I also leveraged on relationships built as a Nine Circles volunteer, and personally connected with some Nine Circles staff (through, phone calls, and text messages) since they provide care and support for people living with HIV, including ACB women living with HIV, and as such would be able to provide insights regarding the area of interest for the study. In this case, I made the initial calls to care staff and introduced the doctoral research. Then, if the care staff agreed, I scheduled a convenient day and time to have an interview. Alongside, the lab technician also helped to recruit some of the care staff. But then in general, given the recruitment difficulties I faced, coupled with the COVID-19 situation, recruitment, and consequently data collection took a full year, from August 2020 to May 2021.

Study sample and sample size

Unlike quantitative research, sample size in qualitative studies depends on the number of participants who are able to inform all key aspects and perspectives related to the study focus (Young & Casey, 2019; Sandelowski,1995; Ritchie et al., 2013; Sargeant, 2012). The sample size for my doctoral research study was ultimately determined by how many ACB women living with HIV and service providers I could recruit, how many of the women and care staff who agreed to participate and met the inclusive criteria for the study, how many of the women and health staff who were available, that I could interview within a specified time frame, and also the point I reached saturation. Participants comprised10 ACB women living with HIV who are adults 18 years of age and older, residing in Winnipeg, and who self-identified as African Black women living with HIV, who have ages ranging from 25 to 54 years old. Study participants also included 12 HIV care and support staff providing care to ACB women living with HIV in Winnipeg, whose ages ranged from 38 to 59 years old.

Originally, I intended to enrol a total of 30 participants (15 ACB women living with HIV and 15 care providers) to take part in the study. However, when I found it difficult to find participants, especially ACB women living with HIV willing to participate, I made a substantial effort to enrol ACB women with lived experience of HIV as well as their service providers. This was to ensure I included stories of ACB women and gave them a voice. I was still unable to recruit Caribbean women living with HIV, which is a limitation of my study, even though I did have one health staff member who was of mixed race from the Caribbean. Considering the nature of the study and HIV being a sensitive topic or issue, one of the ACB women living with HIV dropped out of the study following her recollection of her past experiences in answering interview questions around how she became HIV-positive. For this doctoral research, I enrolled a total of 22 participants beginning in August 2020. This number of participants recruited for this study was deemed adequate for critical race and feminist analysis and the scale of this study. Also, for a constructivist grounded theory study, sample sizes may range from 20 to 30 participants (Creswell, 2012).

All the women were immigrants to Canada. All the women could also speak English, so there was no need for translation, although for four of the women, I had to probe sometimes and re-ask questions to fully understand participants' responses. One of the women did ask for her daughter to be present to translate during the interview because she did not feel her English was ‘good’ enough for her to be interviewed on her own. ACB women living with HIV were excluded if they were aware of HIV care programs but not engaged in HIV care programming. The study also excluded ACB women living with HIV in Winnipeg who practice self-care and access medications outside of Winnipeg since they may have unique experiences and different service providers.

For health care participants, all could speak English. Eight care staff self-identified as African/Black, three as White, and one as Biracial. I terminated my sampling owing to the depth and duration of interviews, the richness of the data, and when no new ideas emerged with additional interviews (Vasileiou et al., 2018; Bonisteel et al., 2021). I sensed that I had collected enough information to support my analysis. Young and Casey (2019) highlight that determining an adequate sample size in qualitative research is ultimately a matter of judgment and experience in evaluating the quality of the information collected. Likewise, theoretical saturation occurs when gathering fresh data no longer sparks new theoretical insights. Critical race and feminist studies as part of qualitative research typically benefit from a concentrated focus on a smaller number of subjects in order to create a rich, robust, diverse data set and to conduct a comprehensive analysis of the data sets, with the goal of developing an understanding of the experiences of interest from the natural and real-world settings where the ‘phenomenon of interest unfolds naturally’ and where the researcher does not attempt to manipulate the phenomenon of interest (Vasileiou et al., 2018; Young & Casey, 2019; Verjee, 2012). Table 1 shows the demographics of the participants. Also, see Appendix 3.

Study participants

Table 1 shows demographic information of participants that took part in the study

Category	Number of Participants (n=22)
ACB women living with HIV (n=10)	
Women	10
25-34	2
35-44	5
45+	3
Married or common law	3
Single (Never married, separated, widowed	7
Full-time	3
Part- time	2
Unemployed	5
West Africa	2
East Africa	5
Central Africa	3
Higher than secondary	4
Below High school	4
High school graduates	2
Service Providers (n=12)	
Men	4
Women	8
Age	
35-44	7
45-54	4
55+	1
Married or common law	11
Single (separated)	1
Full-time	10
Part- time	2
West Africa	1
Central Africa	4
East Africa	3
South America	1
North America	2
Black African	8
Caucasian White	3
Biracial	1
Unsure	1
Higher than secondary	12

The participants in the study have varied characteristics based on their country of origin, age, education, and employment. The ACB women participants ranged from the ages of 25 to 54 years old, while their service provider counterparts were aged between 38 and 59 years old. In terms of formal education levels, only four ACB women living with HIV had attended higher-level secondary education, such as university education, while the remaining six ACB women either had below-high school education or were simply high school graduates. Informal education for care staff differed greatly, as all health and support staff had attended beyond secondary education that included post-secondary training and/or varying degrees. One health staff member had attained two master's degree honours.

The participants also ranged in employment level. For ACB women living with HIV, a good number (n = 5) were unemployed and were searching for jobs or going to school to acquire additional requisite knowledge needed to strengthen their employability, while the rest of the ACB women were working full-time or part-time positions. One ACB woman was on her maternity leave but had worked a part-time position prior to going on leave. For service providers, all health care staff were employed, doing part-time and full-time jobs. Service providers' roles included medical lab scientists (2), certified primary care nurses (2), outreach workers (2), family physician, medical director, and primary care lead (1), sexual reproductive health educator (1), health education facilitator (1), project coordinator (1), coordinator program evaluation and research (1), and settlement advisor (1). They are also ranged in terms of their professional experience and work for HIV from 9-21 years.

The participants also ranged in marital status from married to divorced to separated to single and common-law partnered. In terms of ethnicity and gender, all ACB women living with HIV self-identified as women and Africans, while for service providers, the majority were women (8) and men (4). They were also primarily Black identifying (8), 3 Whites and 1 Biracial. Participants also differed based on their nationalities or countries of origin, including Nigeria, Rwanda, Burundi, Eritrea, Brazil, Canada, the Democratic Republic of Congo, Ethiopia, and Uganda (see table 2).

Data Collection

As mentioned earlier, data collection took place through face-to-face or telephone (online) interviews with each study participant, spanning from 2020 to 2021. Interviews were conducted separately for ACB women with HIV and their care staff. For ACB women living with HIV, interviews were completed in two sessions. This approach ensured ACB women with HIV had adequate time to reflect and share their stories. The first interview reviewed the life histories of ACB women and how they developed HIV, while the second interview posed questions about their support and treatment access within Winnipeg. The second interview proved highly effective for building rapport and trust with ACB women, which is essential for a constructive qualitative research encounter), allowing women to open up to me in greater detail and allowing me to gather thick descriptions of ACB women living with HIV's experiences and detail-rich, contextual data.

Interviews for service providers were only done in one session. Three of the service provider interviews were face-to-face and was conducted at Nine Circles premises, while the remaining nine interviews took place over the phone and online as health staff worked, either from their home residences or the office. For ACB women living with HIV, only two of the interviews occurred face-to-face. One of the in-person interviews took place in the Nine Circles meeting room reserved by the lab technician staff at Nine Circles, while the other face-to-face interview occurred in the comfort of the participant’s home, where the ACB woman participant preferred that we meet for the interview. The remaining interviews with ACB women living with HIV took place over the phone, as women were in their homes, sitting inside their cars, in a park, or taking a walk. I was not able to complete a second session interview for one of the ACB women living with HIV I met in person, as she was no longer available. After several phone calls and text messages, when I didn't hear any response from the participant, I stopped trying.

The use of interviews ensured that this doctoral research was rooted in ACB women's lived experiences, in line with my chosen theoretical perspective of critical race and feminist worldview. While the use of interviews was appropriate in addressing the research questions, it also allowed for and supported the gathering of detailed and rich accounts of ACB women living with HIV's specific views, experiences, and practices in relation to HIV care and support use. To arrive at a deeper understanding of the phenomenon under study, an open-ended, semi-structured interview technique was employed.

Semi-structured interviews helped to promote in-depth probing and were particularly appropriate for understanding how ACB women with HIV and their care providers interpret their experiences. Such an approach gave study participants the opportunity to discuss what they deemed important, have greater control in the interview process, and tell their stories. Therefore, allowing "opportunities for clarification and discussion" and "active involvement in the construction of data about ACB women's experiences" (Reinharz, 1992, p. 18). As noted by DeJonckheere and Vaughn (2019), semi-structured interviews are a part of most interpretive and qualitative studies like CRT and feminist research as a key way of accessing the interpretations of participants in the field. If using other approaches like focus group discussions, ACB women living with HIV may be uncomfortable and hesitant to participate and share their personal stories or narratives as regards HIV care programs due to HIV-related stigma. Notably, the use of semi-structured interviewing aligned with my goals: to facilitate giving voice to ACB women living with HIV and to understand their social world from their diverse perspectives, as well as the complexities characteristic of their everyday lives. In conducting semi-structured interviews with participants, I prepared a flexible interview guide that explored a variety of issues, including personal background, experience of, thoughts and feelings about HIV care and support, frequency of use of care, perceived facilitators, and barriers to HIV care and support use (see Appendix 1 & 2).

My first interview commenced with a health care staff. As an interviewer, this, was my first interview, and I felt a bit uneasy and nervous. Despite having generated the questions, I pondered the following: should the questions follow a certain chronological order? What question should follow after the introductory statement? Do I need to present the questions in a certain way to elicit the responses that I need? Despite this shortcoming, the interview guide remained a very useful instrument in knowing what to ask about, in what sequence, how to ask your questions, how to pose follow-ups, and in guiding the interactions with participants (Kvale & Brinkman, 2015). Additionally, for four years, I have worked as a graduate research assistant at the University of Manitoba, Department of Community Health Sciences, and for about three years at the Department of Social Work, where I conducted interviews with ACB women living with HIV in Winnipeg and, as a Nine Circles volunteer, interacted with folks living with HIV and did some work in the area of HIV self-testing. The training and skills acquired through engaging in these activities, including my supervisor's enormous support, remained particularly useful in conducting the interviews.

As I began the interview, I started with an introduction, highlighting the purpose of the study. Consequently, I proceeded with reviewing the consent forms and seeking participants' consent to record interviews. The consent form explained the purpose of the study, outlined any possible risks and benefits of the study, and gave information about confidentiality and the role of the participant. I obtained either verbal or signed consents, depending on whether the interviews were conducted in person or over the phone. Given the COVID-19 situation and restrictions, only five interviews were held face-to-face while the rest were conducted online. Basic sociodemographic questions, such as date of birth, gender, nationality, educational levels, employment status, ethnicity, and marital status, were asked at the beginning of the interview. Prior to asking interview questions, participants were reminded that they could refrain from answering any questions that made them feel uncomfortable and that participation was voluntary. They were also informed of their right to withdraw from the study at any time without any consequences. Thereafter, I acknowledged my professional and personal background, including my motivation and rationale for conducting the study. Sharing my personal background and reasons for the study was beneficial and helped to establish a good rapport with participants.

Additionally, my ethnic identity and personal history also contributed to the ACB women's comfort level and to building trust. Most ACB women living with HIV in Winnipeg are unwilling to socialize and connect freely in society due to the stigma associated with HIV. However, being that the study was being conducted by an African woman just like them, ACB women felt strengthened and at ease airing their voices and narrating their experiences, facilitating good rapport and the free flow of information. For one ACB woman living with HIV, even though she mentioned lacking trust in the system, in health care staff, and in research based on her past experiences, she felt encouraged to participate in the study and share her stories with me, which she has held in for a long time. As such, at the beginning of her interview, she personally urged that I publish the findings from the study.

To achieve a positive research environment during the interviews, I was patient and sensitive in my approach, giving participants time and space to respond to questions asked and soliciting answers in a respectful way. I also strived to address each of the questions included in my initial semi-structured interview guide; thus, interviews with participants were highly conversational rather than checking off an ordered list of questions. After listening, I often reiterated statements I had heard in order to keep the conversation moving forward and to confirm participants' responses. I was not focused on the technique but rather on the task of listening to stories of ACB women living with HIV, including their care providers, to gather knowledge sought and, as well, use my personal judgement to discern which question to raise and, in the order, which it should follow.

To elicit more and deeper knowledge of participants’ responses, I used open-ended topical prompts and probes. Probing of certain responses (e.g., please, can you tell me more about that?) was done to stimulate further knowledge, obtain more specific or in-depth information, fully understand shared experiences, and ensure quality data. Questions included in the interview guide were reordered or rephrased when the flow of the conversation necessitated making the changes. This flexibility allowed me to obtain rich, robust, and detailed accounts from the participants. Then I worked conscientiously with the participants to integrate the information shared into findings that were useful and credible.

The process of conducting interviews varied depending on specific situations and the availability of the participants. For instance, for most health care staff, the interview was set as a specific appointment, taking place within a 45- to 90-minute time period, except for two health support staff, where interviews occurred over a two-day period since health staff needed to attend to work calls. Consequently, I had to reschedule their interviews to another convenient date and time suggested by health staff. In another instance, interviews were conducted around midnight and on weekends, which was when health staff were available. Also, for ACB women living with HIV, both first and second session interviews combined took over for over 3 hours, sometimes up to 4.5 hours, but some of that time was also allowing ACB women time to share their stories, to unfold the meaning of their experiences, and to uncover their lived world.

During interviews, I was very mindful of the hierarchical relations of power and power imbalances between myself as the researcher with access to certain means, and the ACB women I interviewed, some of whom faced challenging life circumstances such as lack of adequate medication coverage, rejection from family, friends, and partners, unemployment, language issues, overlapping forms of stigma, discrimination, and oppression limiting their freedom and autonomy. Academic researchers represent centres of power, privilege, and status within their formal institutions as well as within the production of scientific knowledge itself (Muhammad et al., 2015; Janes, 2016). Researchers also have power and privilege from their class, education, or other identity positions.

I strived to avoid reinforcing my privileges, which differed from those of ACB women living with HIV. As noted by Karnieli-Miller et al. (2009), rebalancing power in the researcher-participant relationship necessitates creating a welcoming, non-threatening, non-hierarchical atmosphere, and environment in which the qualitative researcher and participants establish their relations in an atmosphere of power equality. A non-threatening environment, as described by scholars, entails creating “a feeling of empathy for informants” (Karnieli-Miller et al., 2009, p. 4) and building considerate and sympathetic relationships that are inclusive of warmth and care.

To reorient the power relations during the interviews, I maintained a warm and conversational tone rather than a repetitive, question-answer approach. I meticulously made use of language tailored to the ACB women's intonations, capabilities, and life experience, adopting a causal and familiar approach during the interviews, and ensuring I was not too formal. I re-visited questions previously asked to ensure participants' understanding of the information sought (particularly for ACB women living with HIV, some of whom struggled with communicating in English) and, in turn, affirmed my understanding of the participants' responses. There were times ACB women broke down in tears, recollecting past experiences and all they had been through, especially how they got infected with HIV. These are women living in panic, women who bear a ‘triple jeopardy’ impact of HIV: as people infected with HIV, as mothers of children, and as carers of partners, yet their voices remain unheard (Paudel & Baral, 2015, p. 2). I applied and showed empathy, using warm and overt body language as well as adopting a friendly and non-judgmental attitude. Brinkman and Kvale (2005) and DeJonckheere & Vaughn (2019) point out that the warm, caring, and empowering character of qualitative interviews not only might conceal huge power differences but also enable participants to open up about their feelings and elicit more details needed to understand the topic, consequently resulting in robust findings.

Ideally, the process of conducting interviews varied and depended on participants’ specific needs and circumstances. Due to ACB women living with HIV’s busy schedules, work, schoolwork, family, personal, and health needs, in some instances, some interviews took place at different times and moments throughout the day or over days. In some other cases, interviews occurred at night, during the weekend, or in secluded spaces where ACB women living with HIV felt safe having the interviews. Some other times, interviews were rescheduled by ACB women, and some other time, after the first interview, the second interview occurred several days later as ACB women living with HIV were unavailable. My flexibility ensured that I was successfully able to include the voices of ACB women and gather a wide range of experiences from a diverse range of ACB women living with HIV. Health staff received a $20 honorarium for participating in the study to compensate them for their time, while ACB women living with HIV were given $40, $20 for each session of interviews attended, except one ACB woman who was not able to complete her second session interview.

As soon as the first interviews began, data analysis occurred concurrently, which created an iterative process for the interpretation of the study data. As the interview progressed, I modified my questions and data collection procedure when the results of the analysis suggested a modification of the questions. Interviews were audio-recorded. I also took notes as I discussed with participants. For face-to-face, in-person interviews with participants, I also noted any social and non-verbal cues, including body language, gestures, and intonations. Following the completion of interviews, I reflected on both the process and the content of the interview. I wrote notes or summaries that captured learning points from the data, including my first perception of the interview itself, the key concepts and issues discussed, and any applicable contextual features of the interview. The notes proved immensely useful for improving the quality of subsequent interviews. The field notes including all interview data from ACB women and health staff were stripped of identifying information within a week after their production. The de-identified interview data was stored on a password protected computer of the researcher.

Data Analysis

All interviews with ACB women living with HIV and service providers were conducted and audio recorded by me. In preparation for analysis, audio recordings were transcribed verbatim to protect the words of the research participants and also allow me to analyze the material after the interviews had taken place. Transcriptions of ACB women interviews and care staff were done separately using Otter software subscribed to by my academic supervisor. Potentially identifying information (such as name, address, or contact information) was removed from the transcripts to protect confidentiality. For the analysis, I adopted a constructivist grounded theory approach, as described by Charmaz (2006), as its focus on “views, interpretations, beliefs, feelings, assumptions, and ideologies of participants” corresponded with my research aims and is considered suitable for social constructionist, community-based, critical race, and feminist research.

Grounded theory is generally referred to as an inductive research process that leads to the systematic development of a theoretical model to explain behavioural patterns and processes in social settings linked to the phenomenon under study (Thapa et al., 2018; Malagon, Huber, & Velez, 2009). In other words, rather than begin with a theory and attempt to prove it, a grounded theory researcher begins with an area of study, a phenomenon is studied, and theory emerges from the data (Creswell, 2012; Konkle-Parker et al., 2018). Charmaz’s (2006) constructivist revision of Glaser and Strauss’s (1967) classic grounded theory suggests that human relations (including racial and gender relations) and interactions are guided by thoughts and ideologies that are rooted in their historical and social context. Therefore, constructive grounded theory research acknowledges researchers’ active role in shaping data and analysis and departs from purely descriptive accounts of a phenomenon to building a framework about a process, an action, or an interaction that all the participants have experienced (Creswell, 2012).

As an exploratory method, grounded theory was particularly well suited for studying ACB women living with HIV's and service providers’ perspectives in relation to HIV care and support services in Winnipeg. The use of a grounded theory approach helped to identify new themes relating to experiences of HIV care and support that evolved in the data, as well as explored themes identified by the intersectional theoretical approach guiding the study (e.g., sexism, racism, gender, HIV-related stigma). The emergent, inductive, and comparative nature of grounded theory made it particularly well-suited to uncover processes by which factors related to gender and racial/ethnic diversity influence ACB women with HIV's experiences and decisions in relation to HIV care use. Within the CRT and feminist lens, grounded theory ensured that the background, experiences, and perspectives of ACB women living with HIV and care providers were foregrounded in theories about HIV care and support programs (Charmaz, 2014).

In applying the grounded theory approach, analysis occurred in stages, with coding as the main tool of analysis (Corbin & Strauss, 1990; Hussein et al., 2014; Charmaz, 2006). Analysis commenced immediately after each interview and involved continual reflection on the data, writing notes throughout data collection and beyond (Creswell, 2003; Charmaz, 2006; Miles & Huberman, 1994). After an interview was completed, I listened to the audios and created memos that contained thoughts about the interviews. I developed a summary document that described the main themes of the interview, experiences with HIV care and support, selected social characteristics, and the researcher’s impression of the interview, including any new concepts participants may have mentioned and points to consider for subsequent interviews. After subsequent interviews, memos were reviewed for any recurring concepts. After all the interviews were conducted, additional memos were written, which captured ideas for analysis.

As earlier mentioned, interview data was transcribed using Otter software. With the support of my academic supervisor, transcribed interview transcripts were entered into Dedoose, an online qualitative data management software. I analyzed ACB women's and care staff data in a separate document in Dedoose, and the two have distinct themes. The ACB women's data took precedence, while the care staff data were there to inform and give further insights into women's experiences. During the analysis, I read all the transcripts and conducted preliminary coding of the text based on interview topics and themes that were identified through the reading of the transcripts). I also reviewed all the notes to ensure all previous codes and ideas were integrated. I worked from the transcripts to develop codes that were aggregated into core themes and sub-themes. Emerging codes were also refined throughout the analysis (Charmaz 2006; Chun Tie et al., 2019; Heydarian, 2016). In attempts to find meaning through themes, interview transcripts, summaries, and notes were reviewed and read repeatedly for significant statements. According to Saldana & Omasta (2018), several readings of the data are recommended so as to gain holistic and intuitive awareness of their contents.

Congruent with the constructivist ground theory approach, the core themes that emerged from the first interviews helped shape subsequent data collection (Charmaz, 2014; Heydarian, 2016). During coding and throughout the process of this doctoral research, I connected with my academic supervisor. He examined the transcripts, as well as the emerging themes, and offered his feedback and his own perceptions of the emerging themes. This check was done as an objective second review of the emergent codes and themes. Following the generation of core themes, member checking was also done with participants to help clarify the data. The final themes were presented in the narrative using verbatim quotations within the findings section of the study. In organizing findings, I utilized the pre-HIV diagnosis experience, post-HIV diagnosis experience, and HIV illness experience as an additional analytical framework. This framework was found useful for analysis of ACB women care experiences. It served to provide further contextual information for understanding ACB women's lived experiences relating to HIV care and support in Winnipeg.

Ethical Considerations

This project was approved by the Research Ethics Board of the University of Manitoba (S23689 (H2020:099)) and, as such, was deemed to have met their required ethical standards (see Appendix 4 for University of Manitoba ethics approval). I also received approval from Nine Circles Community Health Centre as a study collaborator and was issued a letter of support (see Appendix 5 for the Nine Circles support letter).

A potential risk that was considered for ACB women living with HIV was any emotional distress related to the conversation topics that may come up during the interview. For some ACB women living with HIV, reflecting on their experiences could contribute to, arouse emotions, or trigger memories of a traumatic event that may potentially cause distress or result in traumatization. The strategy was that ACB women living with HIV didn’t have to answer any questions that made them feel uncomfortable. Also, ACB women living with HIV can be linked to services, resources, supports, and other assistance if needed and may be taken off the study if it becomes apparent that the interview conversation appeared harmful to them. I was proactive and discussed with some Nine Circles staff about possible resources for ACB women living with HIV. I came to each interview with a list or link to possible mental health support and services, should ACB women living with HIV need to access them; however, none of the women needed the extra support. In the event that ACB women experienced emotional distress or perhaps some grief during the interview, I responded with empathy and politeness and asked whether they would like to stop. Where ACB women needed a break from the interviews, I remained respectful of ACB women’s decisions. Every effort was made to ensure that the interview process was comfortable, empowering, and non-threatening.

Another potential risk was the confidentiality and privacy of participants with HIV if interviews were conducted in open and public spaces. All possible steps were taken to protect the privacy and confidentiality of ACB women with HIV. For health care staff, the risk of participating in the study was minimal. I did not anticipate any foreseeable risk.

However, in terms of potential benefits to participants, there was a short-term benefit of participants having the opportunity to express their thoughts, views, and feelings about the experiences of HIV care and support and those of African Caribbean descent. Particularly for ACB women living with HIV, this doctoral research created an opportunity for women to talk about their experiences, which they had held in. In the long run, I hope that the information learned from this study will inform improved services and programs for ACB women living with HIV. With the new information made available by the study, ACB women with HIV in the community will benefit because the needs of ACB women living with HIV might be known and gaps in services might be identified, which could provide justifications for more funding being appropriated to support ACB women with HIV.

Additionally, the new information made available by the study will also inform service providers, ACB serving organizations, and non-profit governmental organizations to better support ACB women living with HIV in Winnipeg, including other ACB populations. This is possible since I will be able to develop recommendations for future improvement and learning-based care supports for ACB women with HIV in Winnipeg.

Study Strength: Quality

Quality in research design entails the adoption of a critical methodological approach to the research that seeks out and creates conditions that allow researchers to do justice to participants’ experiences and pushes against the kinds of research design and data analysis that assume the researcher as the knower or lone interpreter of reality (Johnson et al., 2020).

As a volunteer in an HIV care organization in Winnipeg (Nine Circles Community Health Centre), who had participated in a number of HIV discourses and workshops, I knew roughly half of the care staff interviewed, albeit only in the broad professional context. Leveraging care staff relationships was useful, as I was able to enrol health staff participants who could provide answers to the phenomenon under study. The use of these subjects, who were suitable and could inform the research, ensured quality in carrying out this study and in reporting rich findings, and particularly allowed me to gather robust data and report findings that were based on narratives of ACB women living with HIV and care providers in Winnipeg.

Furthermore, in this doctoral research, in-depth interviews were used, as earlier mentioned, as part of data collection, and in-depth interviews were semi-structured. The use of a semi-structured interview method with open-ended questions afforded participants the opportunity to elaborate in a way that is not possible with quantitative methods such as survey research, allowing participants to open up about sensitive issues and share their views and perspectives in their own words rather than attempt to fit those perspectives into the perhaps limited response options. Thus, employing the semi-structured interview technique allowed me and supported the gathering of rich accounts of ACB women living with HIV and caregivers' specific views, experiences, and practices of ACB women living with HIV. The data gathered was helpful in enriching both the quality and outcomes of this study.

Likewise, the semi-structured interview schedule allowed me to be flexible, examine unforeseen issues as they arose, and assess the deeper truth of participants experiences. This flexibility might not have been possible if I had employed more structured questioning methods.

Being that I conducted the interviews myself, I was also able to make observations of the verbal behaviour of the participant beyond what the participant was orally reporting, such as body language, and use that information in the analysis of the data.

Also, in analyzing interview data, grounded theory methodology was utilized, as noted above. Grounded theory does not start with testing an existing hypothesis but uses empirical data to generate concepts and theories (Strauss & Corbin, 1994). The use of this methodological approach allowed me to move through a process of discovery whereby themes and interpretations naturally emerged from the data, thus allowing this doctoral research to derive meaning from the data and analysis using creative, inductive processes, which, in essence, allowed me to report findings based on participants' views (Hussein et al., 2014). Demonstrating that findings accurately represent participants' narratives is a means to promote credibility, thus ensuring the authenticity of the findings and of the study. My commitment and involvement at every stage of the research—the planning, recruitment, conducting the interviews, transcribing, and analyzing the data—helped me to understand the data more closely and to discern the strengths and weaknesses of the data collection process and analysis.

Interpretive research and qualitative methods must also follow standards of methodological rigour and meet quality best practices for ensuring rigour and trustworthiness (Johnson et al., 2020; Kivunja & Kuyini, 2017). Lincoln & Guba (1981) outline four criteria for establishing the overall trustworthiness of qualitative research results, namely credibility, dependability, confirmability, and transferability.

Credibility, as one of the central critiques in qualitative methodologies, is similar to internal validity in quantitative research (Johnson et al., 2020; Forero et al., 2018; Kivunja & Kuyini, 2017). The criterion of credibility evaluates whether or not the representation of data fits the views of the participants studied, whether the findings and data analysis hold true, and whether they are believable and authentic (O’’reilly & Kiyimba, 2015). In qualitative research, credibility can be achieved by providing thick descriptions, using verbatim quotes, and having participants validate their findings through member checks and peer debriefing (Lincoln & Guba, 1985; Tracy, 2010; Spencer et al., 2003). Member checks essentially involve returning to the participants and asking if the data collected is actually reflective of what research participants talked about during the interviews (Birt et al., 2016; Kovach, 2009). Thus, giving participants an opportunity to provide feedback on the accuracy of the researcher's interpretations of their experiences. On the other hand, peer debriefing involves asking peers experienced in qualitative analysis to review and assess the coding process, including the final themes or findings of a given study (Janesick, 2015; Guba, 1981).

In order to establish the credibility of the results, member checking occurred following data collection, as mentioned above, since some participants agreed to be contacted for follow-up conversations and to receive a summary of the research findings. I asked two health care staff individually to review their respective interview transcript data to check resonance with what they shared during the interviews. I also requested feedback on their original responses, on the interpretation of the findings, and occasionally on the interpretations and perceptions shared by others. While some researchers have questioned the merit of the member checking process, viewing it as not congruent with qualitative research in that it assumes that participants’ experiences are objective and finite (Birt et al., 2016; Ravitch & Carl, 2019), member checking remained a key technique as a means of enhancing rigor and credibility of this study.

Crucially, it also provided an opportunity for participants to reflect on their personal experience, add on, and reconstruct their narratives, thereby co-constructing new meanings and enriching the findings of this study. Member checking conforms with the interpretivist, critical race, and feminist theoretical positions of this doctoral research and was also appropriate for the epistemological stance of the study. But given the difficulty in recruiting ACB women living with HIV, it was hard for me to get back to ACB women living with HIV to discuss study findings.

Notwithstanding, to enhance credibility, I also checked each transcript for accuracy against the digital recordings and afterwards performed preliminary analysis of the transcripts. Consequently, I also consulted my thesis advisor. He provided valuable feedback on the emerging themes in the study. I worked closely with my thesis advisor to refine my themes, and his role was instrumental in shaping the final analysis presented in this thesis. Credibility was also achieved given my prolonged engagement and extended meetings with the participants, particularly ACB women living with HIV (Lincoln & Guba, 1985). To further achieve the credibility of study results, in applying codes to study findings, I used the real words of the participants, as is common in interpretative qualitative and methodological studies, to ensure that participants' perspectives and experiences are represented meaningfully and accurately within the study and that the voices of the participants are faithfully captured within the write-up and not lost through the process of interpretation (Ravitch & Carl, 2019; Forero et al., 2018; Smith, Flowers, & Larkin, 2013).

Using verbatim quotes and extracts from participants' interviews in the presentation and discussion of findings was also a means to boost transparency and ensure that each interpretative claim made is supported by excerpts directly from the participants interviews (Smith, Flowers, &

Larkin, 2013, p. 110). Transparency, another important criterion, assesses honesty about the research process and involves auditing and researchers providing a methodologically self-critical account of how the research was done (O'reilly & Kiyimba, 2015; Tracy, 2010).

Transferability is equally one of the central critiques of qualitative methodology. The criterion of transferability is related to external validity in quantitative terms (; Spencer et al., 2003; Lincoln & Guba, 1985; Kivunja & Kuyini, 2017). Transferability assesses whether research findings can be applied or generalizable to other settings, populations, situations, and studies (Lincoln & Guba, 1985). This is extremely crucial in this study, given the goal that these research results will be applicable to the development of programs for ACB women living with HIV, for members of other minority groups, and for the support and care of women with HIV in general.

To establish transferability, I provided a descriptive detail of the study participants with basic demographics and geographic settings of the study, including thick descriptions of research findings. This informed how the qualitative study may apply to practice while also facilitating readers' understanding of the study population. But given that interpretivist and qualitative research is context-specific in relation to settings and participants, the generalizability of research might be practically impossible ((Kivunja & Kuyini, 2017; Forero et al., 2018) As such, this study makes no broad claims of transferability to ACB women living with HIV in other contexts. This doctoral research was, by design, Winnipeg area specific. But it is hoped that the findings may be useful and inform health care practice for the ACB women with HIV population at large, including non-ACB women groups.

Confirmability as another important criterion is similar to objectivity in quantitative studies (Lincoln & Guba, 1985; Guba, 1981; Moon et al., 2016). It refers to the degree to which the findings of the research are the result of the experiences and ideas of participants rather than a product of the researcher's biases, preferences, and prejudices. A strategy that I followed to ensure confirmability was to be reflexive. The concept of reflexivity as described by Probst (2015) is “referred to as a process of self-examination (exploring one’s assumptions, emotional reactions, cultural positioning) through specific actions (keeping a journal, debriefing with others, and so on) within a field of inquiry that is also an object of awareness” (p. 2). In order to achieve reflexivity, I maintained a reflexive journal that captured personal feelings, biases, and insights. I was also mindful of my personal preconceptions and how that might influence the research process. Additionally, I was conscious of my social positioning and strengths, and as such, I tried to foster a welcoming environment with participants, particularly ACB women living with HIV, and encouraged the collaborative construction of knowledge with participants who are experts on their experiences.

During the interviews, being an African Black woman, engaging with ACB women living with HIV was not a problem, as women saw me as a fellow ACB compatriot with shared understanding. As such, ACB women felt comfortable and were interested in talking about their experiences, resulting in genuine data that was reflective of the women’s realities in Winnipeg. Many stated at the end of the interview that they felt happy that the research was being conducted, as it presented an opportunity for their voices to be heard. Some other ACB women stated that they felt relieved having shared their stories, which they had held in for some time. My self-reflexive practices were present throughout the research process, from the early stages of research design to data collection, analysis, presentation, and dissemination of findings.

Audit trail was also another technique used to establish the confirmability of study research findings (Ravitch & Carl, 2019; Lincoln & Guba, 1985; Forero et al., 2018). I detailed the process followed to collect data and how the data was analyzed, including providing interpretations of the analysis. I also noted my thoughts about coding and what themes meant. As widely documented, the hallmark of high-quality qualitative research is marked by confirmability, credibility, transparency, and the transferability of the research to other settings, including dependability (O'reilly & Kiyimba, 2015; Kivunja & Kuyini, 2017; Moon et al., 2016).

Dependability is similar to the quantitative concept of reliability (Ravitch & Carl, 2019; Moon et al., 2016). It refers to the extent to which the research procedures are documented so that any external person can follow and critique the research. Thus, dependability occurs if another researcher can follow the decision trail used by the original researcher. In this doctoral research, I included an audit trail, as earlier mentioned, that described the specific purpose of the study, how the participants were selected, how the data was collected, and for how long (Lincoln & Guba, 1985). The audit trail also encompassed how the data were analyzed, the interpretation of the analysis, and the techniques used to determine the credibility of the data (Ravitch & Carl, 2019; Moon et al., 2016; Lincoln & Guba, 1985).

To establish dependability, I documented my research design. I provided sufficient information and a critical account of the research methods, including the rationale for the choice of methods. Providing this information was useful not just for the light it casts on the circumstances that shaped interaction during data gathering and the data obtained but also in enriching the study and relating the study to another context. However, Lincoln & Guba (1985) assert that because interpretivist research deals with human behaviour, which is by its very nature continuously changing, contextual, and subject to multiple interpretations of reality, researchers might not be able to replicate exactly the same results.

Summary

To sum up this chapter, I described the methodology and methods used in this research to explore ACB women living with HIV and their care providers' perspectives of HIV care and support services in Winnipeg. I also described an overview of the rationale for the method used, including details about the data collection and analysis and the steps taken to ensure the quality of the work. I also described some challenges and study limitations. Finally, I provided a socio-demographic profile of the participants I collaborated with in this doctoral research to help put the analysis into context.

CHAPTER THREE

DESCRIPTION OF ACB AND ACB WOMEN LIVING WITH HIV IN WINNIPEG

Findings Introduction

Chapters 3–7 deal with the research findings, first presenting findings from ACB women's and service providers' descriptions of ACB and ACB women living with HIV (Chapter 3). To present the study results on how African, Caribbean, and Black (ACB) women living with HIV in Winnipeg experience HIV care and support, I utilized the pre-HIV diagnosis experience, post-HIV diagnosis experience, and HIV illness experience as the analytical framework. The pre-HIV diagnosis experience of ACB women (Chapter 4) served as further background information about ACB women living with HIV in Winnipeg, in addition to the socio-demographic data highlighted in the method section in Chapter 2. Remarkably, it provided useful information that evidenced the history of ACB women's experiences as well as ACB women living with HIV's own constructed accounts of their everyday lives before HIV diagnosis. It is hoped that presenting the pre-HIV diagnosis experience of ACB women living with HIV will illuminate the themes generated in this study and provide contextual information for understanding ACB women's lived experiences relating to HIV care and support in Winnipeg.

Similarly, sharing post-HIV diagnostic experiences (Chapter 5) revealed ACB women living with HIV's immediate experiences following their diagnosis and how women engaged with HIV care and support. Equally, the HIV illness experience (Chapters 6 and 7) described ACB women's experiences living with HIV over time and accessing related HIV care services in the province. In chapters 6 and 7, the results of my in-depth interviews designed to investigate ACB women living with HIV's experiences of HIV care and support and the interactions of these women in relation to HIV care and support use are described. Chapter 6 presented findings from ACB women living with HIV's perspectives, while Chapter 7 detailed findings from service providers' perspectives. Here, I delve into findings from ACB women's reported accounts of their experiences and service providers' perspectives to reflect how ACB women living with HIV's experience HIV care and support, as well as reveal overlapping intersections of multiple factors impacting these women's use of care, health, and well-being.

There were many similarities and differences between the stories shared by participants. Several core categories with supporting themes were also developed from the data. Accordingly, my interpretation of accounts of ACB women's and health staff's narratives formed the basis of the key themes and sub-themes generated in the study. Subsequently, participant quotes included in the discussion of each overarching categories and their respective subthemes illustrate the interactions between and among the themes. A theme is understood to represent some level of patterned or meaningful response that is informed by the research questions. I have chosen to use pseudonyms for ACB women when sharing their stories because I want the readers to connect more with their lived experiences of reality. This is a women-centred project focused on their world and experience, and I really want the women's voices to remain at the core. With service providers, that motivation is less important, and I did not use pseudonyms for them.

ACB women's and service providers' narratives added to the information provided by the review of the literature earlier and led to a greater understanding of how folks from the ACB community, particularly ACB women living with HIV, experience HIV care and support—including highlighting gender relations in the ACB women's community in Winnipeg. In what follows, I present an overview of organizing categories (i.e., chapters), and supporting themes derived from the use of the grounded theory analytical approach detailed in the methodology chapter of this thesis (see table 2 below). However, first, I include themes on the meaning of African, Caribbean, and Black, which capture descriptions of how participants in this study have described the ACB community and ACB women living with HIV in Winnipeg, Manitoba.

Table 2: Mapping of Overarching Categories and Supporting Themes

Description of ACB and ACB women living with HIV in Winnipeg (Chapter 3)
• Relating to ACB women’s ethnicity and land status • Questioning ACB identity, politics, and relations • Struggling and surviving • Connecting with religion and spirituality
Women’s experiences before HIV diagnosis (Chapter 4)
• Just living life: feeling free, connecting socially, and living carefree • Gender and local economic situations • Lacking guidance and education related to HIV and sexual health • Experiencing war and civil unrest • Dealing with sexual assault and trauma
Experiences following an HIV diagnosis (Chapter 5)
• Feeling scared, broken, wanting to give up and feeling of losing everything • Being mindful, caring about safety of self, others, and the community • Becoming closed Avoiding relationships Isolating, keeping to self, and hiding • Feeling loved
Women’s experiences of HIV care and support (Chapter 6)
• Committing to HIV care • Load bearing “Killing confidence” in women’s future The “work” of protecting others Maintaining care: just being Black • Waiting • Dealing with language • Feeling a lack of safety, cultural sensitivity, and awareness • Lacking medication coverage • HIV self-acceptance • Treating differently or with dignity
Service providers’ perspectives on women’s experiences of HIV care & support (Chapter 7)
• Valuing care • Cultural care is for Indigenous, not Black • Preferring services in own language • Waiting again • Connecting to religion and spirituality • Dealing with the cost of HIV medication and treatment

This section includes a critical examination of the themes relating to how ACB women diagnosed with HIV define themselves and the ACB community in Winnipeg. This section also captures service providers' meaning of ACB and ACB women living with HIV. When ACB women and care staff were asked to describe the ACB community, five main themes emerged from my analysis: 1) relating to ACB women's ethnicity and landed status; 2) questioning ACB identity and relations; 3) struggling and surviving; 4) connecting to religion and spirituality. In this thesis, care staff are often used synonymously with health staff and service providers.

Relating to ACB women's ethnicity and landed Status

A key theme extracted from women's narratives regarding the meaning of ACB and the ACB community was related to ACB women's ethnicity and landed status in Canada. As care staff outlined, the ACB community includes people and their offspring with African ancestral roots who migrated from Africa and other parts of the world to Canada, including from the Caribbean. Even though some ACB persons might identify and live in different countries before arriving in Canada, for the most part, ACB people in general, including ACB women living with HIV, were described as immigrants to Canada. Participants also pointed out that some ACB people, particularly Africans, are new arrivals to Canada, while others have lived in Canada many years ago, and included people born here in Canada by parents having African roots. As care staff narrate, "African, Caribbean, and Black in Winnipeg, it's people that came from their countries from Africa and from the Caribbean living in Winnipeg." (59-year-old African man, care staff). Other service providers note, "I'll describe African, Caribbean, and Black women as people who actually have their full or partial ancestry from Africa. There are a lot of people I've seen. So, they're from Africa and could be through immigration or being born here by African parents" (38-year-old African woman, care staff-a). "I can say some of them have stayed for many years, even for like 10 generations. But for some also, they're new arrivals; they came some months ago or some years ago, so the year of stay differs from person to person" (38-year-old, African, woman, care staff).

While corroborating these descriptions by care staff, ACB women living with HIV also noted that the ACB community in Winnipeg includes ACB people that are mostly Canadian citizens. Most of them, who are likewise settled here in Manitoba, have families and kids. ACB women living with HIV also described the ACB community as being generally Black people. But then, regardless of how long ACB people have lived in Manitoba and Canada, they still identify as being Black and immigrants. As ACB women living with HIV explain,

> I have come in contact with a good number of Africans and Caribbean some of them are my friends, you know. I will say that, as much as we have a lot of immigrants, a lot of them are also born here; they're citizens here (Emma, 44-year-old ACB HIV woman).
>
> They are immigrants, but they have family here, you know. Just married here, just born kids, they made a family, but no matter how many years, they are Black and immigrants. I have met people from Ethiopia, Eritrea, Sudan, Egypt, and Morocco, you know, yeah. (Linda, 45-year-old ACB HIV woman).

Here, participants' stories reveal the meaning of ACB in relation to persons having ancestry from Africa and also being immigrants and Black people, as well as Canadian citizens. For ACB women living with HIV in Winnipeg, the idea of a Black African immigrant heritage means that they may face challenges that Caucasian and Canadian-born women do not. Many participants are also aware of the long struggle for the immigrant Black community in society, layered on top of their experience as immigrants. This also means that ACB women can face the discrimination and marginalization that Black immigrants deal with based simply on their features or skin colour, which can be traumatic and detrimental to their health and wellbeing. But then, notably for most participants, being Black was particularly important to ACB people's sense of self and personal identity. As one care staff explains,

> Interviewer: Based on what you shared; I get the sense that the African Caribbean community here would mean people that've immigrated from various countries of the world to Canada?
>
> Participant: No, no, no! Just people who are Black, yeah, that's what it means. (49-year-old, African man, care staff).

Extending the meaning of ACB people as being Black and immigrants, participants further discuss ACB in terms of ACB people's immigration history to Canada and particularly highlight the diversity that exists among Black populations such as ACB people. One care staff explains,

> We have different languages, cultures, dialects, laws, lifestyles, and health interpretations. I cannot generalize all African countries as having the same or homogeneous communities. I can say it's because of our differences in duty. That is a beauty. I'm not scared of our differences because the difference is the strength that I see (38-year-old, African, woman, care staff).
>
> So, it's tough for me to describe because it's not my community, but I try to learn from people who identify as African, Caribbean, or Black. And so, everything I know is what I hear from them. For example, I hear that the communities are diverse, speak different languages, and have different traditions and beliefs. So, if I were to say a few words about these communities, that's what I would say. (40-year-old, woman, care staff).
>
> In terms of migration experience, another care staff adds,

> Caribbeans may be in their second or third generation if we compare their immigration history to Canada. But Africans are really in their first generation; they still newly arrived. They're still settling down; they have come with their children. Unlike the Caribbeans, they are not the generation where the children of immigrants are, the second generation (38-year-old, African man, care staff).

From the above accounts, ACB women and health staff specifically add and point out how ACB people are diverse, which was centred around migration history and experience, culture, ethnicity, languages, lifestyles, and health behaviour, and was also in turn perceived as a strength. Defining ACB in relation to their ancestral origin and being diverse means having racially, culturally, and economically diverse communities that benefit the society at large. This also means having multiple voices, perspectives, and personalities bouncing off one another especially as it relates to issues that borders on ACB peoples' health. Notably, a multicultural and diverse community such as ACB as participants have noted can help a society thrive and breed creativity and innovation. It is from this perspective that ACB women living with HIV and health staff conceptualize the ACB community in general and in Winnipeg. While a multi-cultural ethnic origin is a valuable asset, there can be a challenge of integration and communication across languages and cultures. There is also the tendency to face negative cultural stereotypes that can be detrimental to one's health.

Questioning ACB identity, politics, and relations

Another important theme that emerged from ACB women's and service providers' conceptualization of ACB was questioning ACB identity and relations. This means participants disputing the use of the term ACB to refer to African and Caribbean communities while also questioning the relationships that exist between Black Africans and Black Caribbeans. ACB women living with HIV in this research and their care providers therefore challenge the appropriateness of the term ‘ACB as one community” since Africans and Caribbeans bear a wide range of ethnic and cultural backgrounds and have a distinct history of heritage and migration experience. There is also a huge social distance between Africans and Caribbeans. Therefore, for participants, the ACB community represents and includes two separate communities, the African and Caribbean Black communities, instead of the African and Caribbean Black community. The implications thereof means that Africans and Caribbeans may have different needs specific to each community. Combining both Africans and Caribbeans as one ethnic group leads to differences between them, their cultures, and a multifaceted set of issues related to group identity being ignored.

As described in the previous section, African-descent populations, which include ACB community members in Canada as a whole and in Manitoba in particular, are diverse. Additionally, for most participants, the African, Caribbean, and Black communities do not have that much of a connection in Manitoba since African and Caribbean communities have different histories of heritage. Even in terms of migration, their experiences are so different, as earlier mentioned. So, as was common in participants’ stories, the Caribbean community has been in North America for ages, but in Manitoba, African immigration is quite recent.

And for one care staff, even when conversing with people who had immigrated to Canada earlier, there were a few people from Africa in Manitoba during the late 80s and early 90s. The bigger wave of African immigration to Canada and Manitoba started in the mid-2000s, unlike Caribbean immigration. Also, particularly for this care staff who self-identified as an African, sharing his experience when he is socially connecting with Caribbeans, there is hardly an African in their midst practically all the time. He remains the only African when hanging out with

Caribbeans. This is important to know considering that Africans and Caribbeans are continuing to be combined and referred to as one community. And while there've been some efforts to bring African and Caribbean communities together, as a reality, it is not the same. The Caribbean community experience is more like that of a Canadian because they have been in Canada for centuries. Given these variations and the lack of connection within the African Caribbean community, participants felt it made no sense to describe and lump ACB as one homogenous ethnic group. As one care staff illustrates,

> You know what? For the African Caribbean community, putting them together makes no sense to me because they don't have that much of a connection in Manitoba. They have two different histories of heritage, and their experiences differ. I understand both communities have African roots, but if you take that, the Caribbean community has been in North America for centuries. But in Manitoba, African immigration is recent. So, when you put Africa and the Caribbean together again, it's confusing to me (49-year-old, African man, care staff).

Further demonstrating the relationship between Africans and Caribbeans, one ACB woman living with HIV explains,

> Some of the Caribbeans don't want to be called people coming from Africa, so they don't accept Africans as brothers or sisters. They're thinking they are closer to the Whites. So, they feel much closer and more accessible to the Whites than the Black Africans, perhaps because they were enslaved when there was war, and someone was trying to get them to become a country (Daniella, 59-year-old, ACB HIV woman).

Care staff continue to question the use of the term ACB as one community, considering the social distance that exists between African and Caribbean communities. As one care staff narrates,

> It's people who came from their countries, Africans and Caribbeans, living in Winnipeg, but we are trying to get them to be one community. These people are two communities: Caribbeans and Africans. I've realized there is a gap; it looks like a conflict. Caribbeans, until now, have had a concern that African people sold them to America. As a sociologist and counselor, this is a genuine concern for me. The gap is like a big social distance. I want to say that we call ACB 'a community', African Caribbean community, but instead, we should be saying African Caribbean communities (60-year-old, African, man, care staff).

Another ACB woman re-iterates the gap and social distance between Africans and Caribbeans. As she narrates, “I don't know about them. I've never been with Caribbeans. I may talk too much about Africans just because I've never been with Caribbeans. So, I don't know their culture. But, African culture, yeah, I may talk about it, because I've been there since my childhood” (Theresa, 38-year-old, ACB HIV woman).

In the lives of ACB women, this notion of distance signifies little or lack of relationships between Africans and Caribbeans. It also demonstrates a tendency to have reduced communication between the two communities. In fact, the notion of distance can hamper any form of idea sharing, idea building and collaborations that could take place especially as it relates to ACB peoples’ health and wellbeing. Even though, both communities have the same Black identity and are diverse, social distance stalls communal relationships, creativity and any opportunities for innovations and development and can also contribute to the isolation ACB women living with HIV face. There is also a possibility of mental detachment in how ACB women might interact with each other, and African and Caribbean women with HIV may not get along.

Also, even in terms of HIV, participants illustrate how Africans and Caribbeans have different experiences. As such, combining African, Caribbean, and Black as one community and simply assuming that Africans and Caribbeans are the same seemed racist and inaccurate. As one care staff narrates,

> Yeah, but in terms of HIV, when we are trying to address that issue, when you look at different studies conducted, they tried to look into how HIV impacts the various communities. You have the Caucasians, heterosexual, or homosexual females, and then you have Asians, Africans, and Caribbean; the experiences are so different. In truth, up until now, we don't have much in common regarding our recent history or even our immigration experience. I can't find a better way to address it than to say that it's racist, just assuming that Africans and Caribbeans are the same. We have the same roots, but our history is different (49-year-old, Black, man, care staff).

As observed here, as much as Africans and Caribbeans both have African heritage, as earlier outlined, African-Caribbean relations are such that there is a lack of connection between both communities and a social distance between both communities. Africans and Caribbeans are socially and culturally distinct and also have different experiences, including HIV disease experiences, with Caribbean experiences likened to being similar to those of Canadians.

Struggling and Surviving

The theme of ‘struggling and surviving’ is another important notion that was associated with the meaning of ACB. This theme of struggling and surviving was also particularly dominant in the narratives shared by participants and remained part of the participants’ stories. While acknowledging ACB people as being immigrants to Canada, most care staff and ACB women living with HIV highlight the harrowing struggles of ACB people as they navigate life on a daily basis. Notably, participants mention how ACB people face a number of intersecting problems, mostly associated with being people of color. More so, even for those who were born here and are Canadian citizens, they still face some form of difficulty. The challenges facing ACB people that participants mentioned include structural inequalities, barriers to acceptance and full assimilation into Canadian societies, racism, socio-economic marginality, equal opportunity, and participation in many institutional spheres and activities, particularly in the area of employment, which is a significant indicator of socio-economic status as well as a major channel of mobility in any industrial society. Even after acquiring additional educational qualifications, as participants point out, ACB people continue to struggle and experience extreme difficulties, especially as it relates to finding jobs in their chosen line of work. As one ACB woman narrates,

> I am an accountant; I have a degree in it. However, finding a job was difficult because my diploma or degree was not recognized in Canada. I had to take more English classes. I had to retake some tests for my papers to be qualified here. I did that but still couldn't find a job in that industry. I'm working now. I'm in a different sector, which is unrelated to my accountant status. It's just not easy as an immigrant in general to find a job, specifically when you're from Africa (Flora, 36-year- old, ACB HIV woman).

Relating to issues of racism, this ACB woman further narrates,

> As a Black person, there's a lot of racism, and I have had three incidents that happened to me. One time, I was at the park with my kids. A guy came up to me; he was White, back in 2016 or 2017. I was in the park in the East Kildonian area of Winnipeg. He told me that I was not allowed, as a Black person, to go there; that was what he said. This area is not for Black folks; we never had Black folks here; we don't want to start having them, he

> said. My kids are half White, but I had a nephew who is 100% Black. So, I took him out of there, and we went away (Flora, 36-year- old, ACB HIV woman).

Recollecting her next experience of racism, she adds,

> The second time, it was in Superstore, and the guy told me, well, why don't you return to Africa? He said, go back to your fucking country. He said that to me. He was yelling and screaming. This is a very well-dressed person; he's not crazy. You can never say he's mentally ill or anything like that. He was well dressed, he was shopping, he was fine, and he was mentally stable, as far as I understood. He told me to go back to your country (Flora, 36-year- old, ACB HIV woman).

Racism is one of the struggles of ACB women as the quote above indicates. But despite these challenges ACB people face, ACB women living with HIV and care staff note that ACB people are strong people who keep working hard and striving to build their lives and those of their families and future generations. Notably, for people from the ACB community, there is a strong will to survive, to provide lifelong and unlimited support to their respective families, and also to achieve set goals. Therefore, in spite of the external stressors and daily struggles, it is the desire to achieve goals and support their family that allows ACB people to withstand adversities and try to live normal lives like everyone else. As participants narrate,

> Describing the African, Caribbean, and Black communities in Winnipeg, as much as we have a lot of immigrants, the majority are also born here; and are citizens. And the truth is, those born here still face some form of difficulties, mainly because of their colour. Regardless of the language or accent, even if their way of speaking sounds Canadian, I still feel that look of, okay, this color, phew! However, for me, I've noticed that Africans and Blacks generally are strong people and don't stop at anything until they have attained

> whatever it is their goal or what their mindset set on achieving (Emma, 44-year-old, ACB HIV woman).
>
> What I see is people coming here trying to survive or live, working hard, some working two jobs, working tough jobs. Some are educated but can't get a job in the area of education, but others have completed their education here and got a job. So, I see a community of strong people with goodwill to live and have a normal life like anybody else (41-year-old, African, woman, care staff).

The next data extract is from an ACB woman living HIV who also shares her account of the meaning of ACB in relation to the theme of struggling and surviving. She particularly stressed how the ACB community is an under looked community, having limited opportunities, information, and resources for them to be successful. In addition, Black people, including ACB people, also experience racism. However, regardless of the issues that ACB people face, ACB people are very quick to adapt. As she explains,

> I feel like they're an under looked community, meaning they don't have enough resources to succeed. Yes, we are a very under looked community because, regarding opportunities, even if you're a Canadian citizen, you are like a second-class citizen. You don't get the opportunity as easily. You don't get any information; it is almost like you are kept in the dark. And if you are an HIV person, especially if you have a family that does not know your situation, if you don't have anybody to talk to, there's not enough information and resources, unless only a doctor's office will tell you to take your medication. I was very confused about where to go and whom to talk to (37-year-old, ACB HIV woman).

Further narrating the struggles of ACB people particularly ACB women living with HIV, this ACB woman continues,

> I don't also think there is any group of HIV women or women HIV groups that could check on each other, be there, and support each other. I don't think there is one. Being HIV, when I think of it from my own experience, is abuse, honestly! I had an incident of not getting accepted for a job because you have to disclose your HIV status. There are certain jobs that you're not allowed to have. It's heartbreaking! ACB also means people who have been attacked by racism, including me. We're the minority. But, notwithstanding, they're a very united community and very quick to adapt (37-year-old, ACB HIV woman)

While one care staff agrees, he further underlined the specific struggles of ACB women living with HIV. As he narrates,

> Apart from being HIV-positive, they are just alive with a life that has a lot of layers of stigma: there are integration problems, there are social inclusion problems, there are racial problems, problems of race and minorities, employment problems, and on and on, when we add the gender problem of HIV. However, the thing you'll notice with clients is that they keep striving to build their lives for the lives of their future generations (38-year-old, African, man, care staff).

From the above accounts, several of the participants describe the meaning of ACB, and ACB women living with HIV, linking ACB as people who face significant struggles in their everyday lives, but yet they try to survive and continue to build their lives. People from the ACB community find it difficult to find employment in comparison to others, and in addition, they have fewer opportunities and lack information and resources in relation to HIV. Worse still, for ACB women living with HIV, the issues they face are multi-fold, including stigma, social discrimination, racism, employment, and gender problems. However, notwithstanding, ACB women living with HIV and ACB people in general remain resilient even as they live their lives with HIV. Resilience is part of what being an ACB is all about, which helps women cope with their everyday struggles. For one ACB woman living with HIV, in staying resilient she does not let her HIV-positive status bother her. And even when she attends her dental cleaning (appointment), she feels confident, carries herself with such an aura, and doesn't also leave room for people to look down on her.

As she narrates,

> Irrespective of my status as a person living with HIV, you can not intimidate me. I never let that get to me. For instance, when I go for my dental cleaning, I carry myself with such an aura that you can't help but notice me and seeing me does not mean you should look down on me. On the contrary, you want to do my bidding. HIV is just like someone living with syphilis. If someone has syphilis and can live the fullness of life and eventually get through it, how much more HIV? (Emma, 44-year-old, ACB HIV woman)

Here, this ACB woman narrates how she deals with the struggles of living with HIV. Surviving and being resilient for her means resisting bad treatment and having agency and ownership of her own life. But notwithstanding, the intersection of the various struggles ACB people face outlined above, including ACB women with HIV, makes a compelling narrative that necessitates the need for intervention strategies to focus on ACB people in general while also paying attention to the needs of ACB women living with HIV.

Connecting to Religion and Spirituality

Another key theme that emerged in ACB women's and care staff descriptions of ACB is connecting to religion and spirituality. As participants outlined, religion is to keep friendship with God and to be associated as a child of God, as well as showing connection to a higher power or supreme being. Religion also meant one's commitment to an organized religious institution and engaging in religious activities and practices. ACB was described as people who connect to religion and spirituality" For example, one ACB woman illustrates,

> I'm a Christian., and my church is Pentecost. Since they told me I'm HIV, I pray. I didn't go to any bars; I didn't go outside to get HIV. I got this disease in the house of marriage. So, I can't die; I'll die on my own. I go to church because my God is wonderful; he listens to me (Linda, 45-year-old ACB HIV woman).

According to most participants, religion and spirituality was described to be major forces in the lives of ACB people, including women living with HIV, in the attainment and maintenance of health and well-being, as well as in promoting their resilience. Connecting to religion and spirituality was also linked to, as a mechanism by which ACB women cope with living with HIV, relieving pain that they feel as well as surmounting different challenges they face in society. One service provider adds,

> As I work in the church, I've seen people coming over there in that dock and counselling with some of them. They think that it (HIV) is witchcraft or poison. But all the time I talk to such people, I tell them to go do a test. Some of them are now taking medications and are kind of ashamed of themselves; they don't want people to know that they're sick. They go to prayers; they believe God is going to help them (59-year-old African man, care staff).

ACB were described as people who connect to their religion and spirituality. ACB people's religious involvement and spiritual practices also provide that sense of meaning in their daily lives and in living with HIV. Hence, given ACB's people's religious affiliations, engagement, and participation in religious and spiritual activities, most participants in this study define the ACB community, making links to ACB people's connection to their religion and spirituality. As participants further narrate, “But for sure, ACB women have beliefs. African people believe in something. Some are Christians, and some are Muslims. They are people who believe. So, their belief for sure gives them more strengths than barriers to care” (38-year-old Black man, care staff). Illustrating the belief of ACB women and how women value religion and spirituality, one woman adds,

> Yeah, I believe that if you don't have religion, if you don't have God in you, you do things anyhow you want. But with religion, if you have God, everything is easy. You do things that are right to be done. You can't just wake up in the morning; you cut somebody. You can't just wake up in the morning and make other people feel pain, like give them pain. So, I am one of them. I don't do things that God doesn't allow us to do (Rachael, 40-year-old ACB HIV woman).

For this ACB woman living with HIV named Racheal, further sharing how religion impacts her life, she explains,

> For me, it helps a lot. Because, even when my husband passed, I used to cry and think a lot. But when I overthink, I get my prayer mat, perform my ablution, and pray. This calms me down, and then I will go and sleep. So, my religion helps me so much to calm down. Every day then, I used to think and ask myself what happened or why my husband died, but I know God has a reason. I wish he could show me that reason. (Rachael, 40-year-old ACB HIV woman).

Another ACB woman living with HIV also narrates her own story relating to connecting to religion and spirituality. As she explains,

> Yes, before now, I didn't change my character. I do not go to church; I go to parties, and I drink beer. I had too many friends in my house. People are gossiping about me. My children are not happy because it wasn't my character. Back home, I only stay home, watch TV, read the Bible, and go to church. But when I got here, oh! I'm not working; the government supports us. Everything was terrible for me. But when I realized it, I had to start to pray again. I followed the prayer on the internet and YouTube. There was a significant change—a big total change—until God helped me buy my own house with four bedrooms (Linda, 45-year-old ACB HIV woman).

Here, religious affiliations moderate ACB women's relationships with others and the way these women would behave or tend to carry on with their lives. Religion and spirituality remain that which helps to keep women committed to improving themselves for their family, and for social and personal development. Therefore, generally, for most ACB women living with HIV, they have the belief in the presence of God (a higher being) in everything that they go through, and that's happening in their lives. Religion and spirituality are integral to healthy living, in promoting their wellbeing and navigating through the struggles and pain of daily living. Another ACB woman living with HIV illustrates,

> I believe God is walking with me behind everything I'm going through. At my workplace, I was only scheduled for six days of work in two weeks and got $600 on my paycheck. I'm going mad. The money needs to be more. Later, my manager called me and offered me another shift of eight days in two weeks, which I accepted because I needed money. That is not me; that is God. How can somebody be helping you at work?

> Moreover, she's your manager; she doesn't even know you. She doesn't even want to know you. She wants her job done. These things happening feel like God made everything (Rachael, 40-year-old ACB HIV woman).

The next extract is from another ACB woman living with HIV. Narrating through her daughter, she particularly stressed how connecting to religion and her faith is a source of strength for her to keep living and pushing, despite feeling isolated and facing difficulties. As she narrates,

> You know, religion is a big part of my life, and my faith is big for me. It's what I have had all my life. I get comfort from God in my times of distress. When I'm anxious or stressed, I also find comfort in that. God is my comforter and my strength. He (God) is the one person I can go to in times of isolation, and he's trustworthy. Because of my religion, my faith has been of immense help to me. I find comfort and strength in my faith to keep going, to keep pushing, and I pray daily as well, and I fast too (Christy, 50-year-old, ACB HIV woman)

Other ACB women with HIV corroborates,

> You see, I am happy and grateful for my religion; it keeps me going and me stronger. Having faith helps me a lot being with HIV. Because if I did not have faith, I don't know how I would cope with HIV. I don't know how to make sense of it. I wouldn't have an answer for everything that is happening to me. Having my religion is the best thing, being HIV positive. If I wasn't, I don't know what I would have done (Theresa, 36-year-old, ACB HIV woman).
>
> Okay. I'm a Muslim. It (religion) makes me strong every single day. You know, when I have a stressful event, when I become, sometimes lonely, I pray, and I feel okay. My

> spirituality has just become stronger even now, especially here without family (Flora, 38-year-old, ACB HIV woman).

Although women discussed these benefits, connecting to religion and spirituality was also described to be problematic. ACB women often have to hide their HIV status to be accepted in the religious community. As one care staff illustrates,

> For some, they say I can go to church, but I do not disclose my status because stigmatizing is also there. And some feel stigmatized and judged because of some religious leaders' approach. They approach it as if like they do not see it (HIV) as an element of a person but like lots of judgment. We have heard like, oh, I do not want to go to that church anymore because I have heard enough (37-year-old African woman, care staff).

ACB people were described as deeply religious, as outlined here, going by how ACB women with HIV connect with, involve, and engage in religious activities as a means to support their day-to-day living. Moreover, for ACB women with HIV, connecting to religion and spirituality plays vast roles, including allowing ACB women participants to make sense of their HIV-positive status and as a coping strategy. On the other hand, connecting to religion and spirituality appears to be a source of stigma and religious judgments and women are afraid to disclose any health. Based on the linkages and ACB people's religious and spiritual relationships, ACB was described as people who connect to religion and spirituality.

CHAPTER FOUR

WOMEN'S EXPERIENCES BEFORE HIV DIAGNOSIS

This section describes in detail key themes identified from the interviews that described various life experiences and histories of women before diagnosis with HIV. Five themes emerged from the analysis, which, along with quotes, form part of the structure of the findings and the discussion. The themes are: (a) Just living life: feeling free, connecting socially, and living carefree; (b) Gender and local economic politics: the structural determinants of HIV; (c) Lacking guidance and education related to HIV and sexual health; (d) War and civil unrest; and (e) Dealing with sexual assault and trauma.

I begin with women's accounts of living freely, doing what they want, and associating with others without fear or undue or unjust constraints. On the other hand, women's lives before HIV were also saddled with challenges and difficulties, including facing trauma. These issues women experienced before HIV diagnosis occurred concomitantly and in tandem with each other, crystallizing into the sharp, hard surfaces of individual women suffering, constraining agency, and ultimately leading to HIV for these women.

“Just living life”: feeling free, connecting socially, and living carefree

All ten women in the study expressed how unrestrained their lives were before the diagnosis of HIV because they could easily connect with others, live life “so nice," "carefree,” and “just doing young people's stuff,” and not try to distance themselves and withdraw from other people and their community. Notably, these women emphasized how they could freely socialize with their family members, hang out with friends and peers, and engaged in relationships without feeling bothered by what people would say, how people would react towards them, or if they would be gossiped about. For the women, coming from an African context where HIV remains highly stigmatized with consequent isolation and exclusion of folks that are living with HIV and where most still believe infection with HIV meant a rapid and disabling death, life before HIV meant freedom, freedom to mingle, and the ability to live a full life with confidence. More importantly, for these women, they didn’t also have to deal with the loss of relationships with family members and friends, especially the physical separation and emotional distance, which are usually very difficult. The women also narrated not having to deal with the personal thoughts about having a shortened life expectancy, the reluctance and anxiety to disclose HIV-positive status, and the continuous fears of being rejected and discriminated against, which are evidence of the persistent nature of AIDS-related stigma in communities and households. Rachael explained her experiences of feeling free, connecting socially, and living carefree.

> Life was so nice (laughter). My life was "so nice," but I wasn't that girl who likes boyfriends. I was a person who wanted to hang out with my brothers, like my real big brothers and cousins. Everywhere we could go, like we went to clubs, bars, and the beaches, but with my people. Always. I'll be going with somebody, not a boyfriend or a man. Yeah. But when I knew this (my HIV-positive status), my life changed for real. (40-year-old, ACB HIV woman).

Natalie, another woman aged 25, who migrated to Canada with her eight siblings and both parents at the age of 6 years, reflects a similar story. As a young girl in Congo, she barely could recollect what her life was like at the time. However, living in Canada and reminiscing about her experiences before HIV, she narrates:

> Like before I had HIV, I was living life. I was doing whatever I wanted—just doing young people's stuff. I liked hanging out, going out with friends, and drinking as much as possible. I was having sexual activity with people, but not with several people, but with 2 or 3 people. Now, it's different. I must be careful who I do it with; they're protected. I am

> also protected. I have to keep them safe. It's different because I feel like whenever I want to have sex with somebody, I have to tell them I have HIV. Oh, this is different; it's weighing me out. I was enjoying my life before this thing happened (25-year-old, ACB HIV woman).

For Natalie, who least imagined that she could never contract HIV, life before HIV was described as fun, “just doing young people’s stuff," like socializing, reaching out and connecting with others freely and sexually, without being burdened by what she has and what “weighed” on her, or the need to disclose her status to sexual partners, or also the fear that she might be rejected.

Theresa, who worked in an HIV organization in Ethiopia before relocating to Canada, also narrated her life experiences before her HIV diagnosis, similarly describing herself as a “free person,” someone who was “just living life" who was full of confidence like every other person. For Theresa, she freely supported people living with HIV, spending time with them too. Growing up in a ‘good’ family that supported each other in everything, she easily connected with her family members every other week. She least expected that she would get infected with HIV, just as most other ACB women, given that she was always mindful of herself and her lifestyle. However, since living with HIV, she wishes that no one should “notice her disease” and, as such, distances herself, especially from her peers and community. She describes:

> At the time, I was a free person. I was full of confidence, like other people. I couldn't expect to have HIV in my life because I just took care of it. I was living with my husband and my kids. My family was also good—not just a good family; we supported each other in everything. We discussed every other week at the end of the week, but contracting HIV has been so stressful that I lost my confidence. I just closed myself off (hiding and

> distancing myself from friends and her community) (Theresa, 38-year-old, ACB HIV woman).

Theresa's freedom has really been affected since she was diagnosed with HIV, isolating, and hiding herself. Christy, Emma, and Rachael also share similar experiences.

> You know, at least it (life before HIV diagnosis) was more peaceful. I could live among others, among my peers and the community, without carrying, in a way, the burden of knowing what I have and the ostracization that comes with it. Yeah, so it was more peaceful, I guess. (Christy, 50-year-old, ACB HIV woman).
>
> So, before I was diagnosed as a young kid, a young teenager, and growing into a young adult, I just wanted to enjoy life. So, I love fashion, and I love to fix nails. I love to fix my hair. I usually have a new hairstyle every two weeks. And I can go into any home, as long as you can make my hair nice the way I want, get in any way, and get my hair done. Even while I was married, I could travel anywhere to get my hair done. I could get into any hole to look good (Emma, 44-year-old, ACB HIV woman).

"Before I found out, I had HIV; I was free; I have a free mind (not burdened); and I breathe right. I also worked back then; I'm happy, I'm young, and I laugh" (Rachael, 40-year-old, ACB HIV woman).

Here, the women discuss how easily, prior to diagnosis, they could move around, engage in any activity they so desired, bond with their families, and interact with others without reservations or nursing fears. The notion of freedom, which women particularly describe is about the possibility of acting—or the fact of acting—in such a way as to take control of one's life and realize one's fundamental purposes. To be free is about living life defined by authenticity, joy, and self-acceptance. Therefore, in the context of women's lives, freedom remains important to enable women to truly be themselves, act or change without constraints, associate with others, and make their own decisions and choices. More importantly, freedom also gives women the right to free expression, which is particularly important for a long and happy life.

Gender and local economic situations

Standing at the intersection of ‘being Black’, ‘from Africa’, and being a woman, a common theme also emerged, centering on the suffering that these women faced while living in their home countries, including financial hardship, shouldering responsibilities, and fending for family members that are typically seen as a woman’s responsibility. Notably, two interrelated social structures were of particular importance in shaping women’s experiences before HIV: gender and economic situations. These prevent women from reaching their full potential and restrict their agency. These social processes are structural because they shape how people act and live and set the context for individual and group behaviour. These social structures also elevate exposure to HIV for these women.

For most women in the study, there is a sense of duty and caring responsibilities, particularly towards siblings and family members in general, even at the expense of women’s own health, comfort, and happiness. Particularly, these women, unlike their men counterparts, bear the larger burden of family members’ responsibilities and the need to contribute to their household financially, emotionally, and physically.

Most women also describe struggling with finances and high unemployment in their home countries, which deprived them of opportunities to get primary and further education at the time since their parents couldn’t afford to pay their fees and send them to school. Even when these women were educated, many still struggled to find work, make a living, and provide for their families. The combined effects of being a woman and the financial impact influenced women's experiences and their sense of agency. Crucially, it provided a general stimulus that prompted ACB women to seek better opportunities and a better quality of life abroad and also included movements within and from their countries of origin to other neighbouring countries where they lived and as refugees. Particularly, the interaction of the issues women faced prior to HIV diagnosis was instrumental in ACB women getting infected with HIV.

Similar to how previous authors described the lives of women on the Hattian plateau, these ACB women narrated how they experienced different forms of challenges, such as lack of education and inadequate employment opportunities, that occurred concurrently and in interaction with each other, crystallizing into the sharp, hard surfaces of individual women's suffering, constraining agency, and ultimately leading to the women's HIV positive status.

For one woman, Linda, the difficulties, and struggles spurred her to seek ways to meet her family needs, which included remarrying against her will following her initial divorce with her first husband and consequently getting infected with HIV. For Linda, who got married at a young age, life before her HIV diagnosis was tough and saddled with a lot of family responsibilities as she was the first child of the family. Also, being, a married woman, life was also difficult given the inability of her spouse to secure a job and the lack of financial means. As she described:

> You know, in Africa, life wasn't good. It wasn't good because my husband married me; he finished his studies at the university but didn't find a job. Until we divorced, he didn't find a job. We divorced because life was difficult. I was responsible for our three kids—my two younger sisters and brother. I was the first kid in the family. But my husband decided that if I wanted my siblings to stay with me, I could care for them in my own family. For that problem, we got a divorce only because it was tough for us. I divorced my first

> husband at the age of 22 after being married for five years (45-year-old, ACB HIV woman).

Linda, following her initial marriage divorce, wanted to be able to support her family and meet their family needs, so she started a business, while her mom helped her out with raising the kids. Due to these restrictions on her agency and the financial difficulties she faced with her first husband, she entered into a second marriage as advised by her mom, who maintained that she would not be able to run her business without being married. The outcome of that second marriage was that she contracted HIV from her new husband. Similarly, for Linda, navigating daily life was challenging, and learning about her HIV status was also devasting. It presented an additional layer of stress in her life as she was constantly concerned about her status and also had to deal with keeping her HIV-positive status a secret from her mom, who was not only a widow but was also sick with blood cancer. Consequently, Linda arranged with her husband, as she stated, because they were both sick, not to gossip but instead to strive to live a ‘good’ life and pray earnestly to see if God would help them. With the hardship that she faced, as she mentioned, and when the second husband began hiding and dating different women and a particular lady, she became fed up. She initiated a second divorce process, finalized it, divorced her husband, and then came to Canada. As she explains,

> I didn't want to get married again because of the initial divorce. It was a huge disappointment. My mom said you're still young—22 years old. You have to get married. My mom forced me. Oh, you have to get married because of your business. I find one man in our house. I didn't know who the husband was. But my mom said this man needs you. After several persuasions, I accepted, but that man was living with HIV, and we got married I didn't know. I only slept with him, and I tested positive. We made a divorce,

> and I went to Namibia thereafter because life wasn't good in Zambia. Life was just brutal! What can I do? I had to go to be a refugee in Namibia for five years. UNCR helped me, and I came to Canada after five years (45-year-old ACB HIV woman).

This woman revealed the varying degrees of difficulties she faced based on the evidence presented and her experiences before HIV diagnosis. Although Linda experienced restrictions on her personal agency, her quest to surmount her financial difficulties and support her family was greatly instrumental in her acquiring HIV.

Another woman named Danielle also spoke about the lack of parental support and care, her hard living condition, not having finances, fending for herself, and needing to support her younger siblings as her experiences before learning about her HIV-positive status. As such, in a bid to overcome her challenges and survive, a combination of these factors ultimately contributed to her acquiring HIV. As Danielle outlines,

> Growing up, life was difficult. My father married four wives, my mom included, and I had two brothers and three sisters. At 11 years old, my mother went missing. I cannot say if my mother is dead or not since it's been over 50 years. Living with my family afterward, along with my other siblings, we were not brought up so friendly. After we spent two weeks in our house, they also took us to live in one of the wife's houses. While there, my father's other wives did not treat us kindly. My father was not also kind to us (Danielle, 58-year-old, ACB HIV woman).

For Danielle, considering the harsh treatment from her family, coupled with the disappearance of her mother, she felt unhappy not being cared for by her own family. While she attended primary and secondary school, she dropped out of class 4 (Grade 7) of her secondary school education. Since she was not happy at her father’s house, when she attended a classmate’s party, she seized the opportunity to meet with a guy and later moved in to live with him when asked. Consequently, in their first month of living together and still in class 4, she became pregnant. However, she had to return to her father's house eight months into the pregnancy since the unmarried father lost his dentist job and was asked to leave the staff apartment where they both lived.

Seeing Danielle in that condition was disheartening for her dad, who felt unhappy that she failed to complete even class 4. Following the birth of the baby, her father took the baby when he turned four months old since he wanted her to go to continue her education up until university. However, after about seven months, Danielle took in again to have a second child with the partner. This time, her father requested that the baby father come to take Danielle away from his house. For Danielle, living with her partner was not easy given the hard economy, and he had no job anymore. She was also unable to secure a job. As such, to make ends meet and to be able to take care of her children, including her siblings since she was the first child, and heeding advice from friends, Danielle, residing in Nigeria, relocated alone at the age of 17 to live in another African country, Togo, to seek job opportunities and a better life. In the new country, with her secondary school French education and previous experience, she landed a job as a bar attendant at the Sheraton hotel. This was a huge relief, as she needed to pay her bills and send money to her brothers and sisters back home in the country. Starting work, she was introduced to a man from Belgium, whom she assisted with language translation. They soon became friends and began dating. The White man supported her financially, even with house accommodations and monthly upkeep allowances of USD 2000. They toured the world together, visiting several countries such as Belgium, France, and Switzerland. However, after Danielle returned back to Togo, the partner ended things abruptly which was truly shocking for her. Danielle thinks that she may have acquired HIV from her partner, given the way he ended the relationship and was also unwilling to share why he broke up with her. As she narrates.

> We didn't have any problems. He can't tell me what happened; he only knows the relationship is over. He was done with me. I went for a checkup afterward at the hospital, and I got to see that I had HIV. I just made up my mind that he was the one who gave me HIV before he said we should stop. I traveled to Venezuela afterward for better opportunities as I did not have sufficient funds. I went to the United Nations Office for assistance. After two months, I was told that the Canadian government had accepted me to come to Canada. The UN office brought me to Canada. It was good (Danielle, 58-year-old, ACB HIV woman).

While there were other intersecting factors at play (e.g., lack of parental affection, care, and support) that influenced Danielle's life before HIV diagnosis, economic hardship right from her early years and having to fend for herself and her siblings remained a key influence. Entrenched economic difficulties and gender inequities operated cyclically: the myriad manifestations of economic issues—insufficient income, lack of accommodation, difficulty in fending for children and access to labor markets, reinforced Daniel's lower social and economic status and increased the likelihood of HIV infection. Economic hardships were fueled by inequities in gender-based norms and values and led to the precarious sexual practices that resulted in acquiring HIV. ACB women have increased exposure to HIV as a result of structural pathways, that stem from the interactions between economic hardships and entrenched gender power inequities.

Indeed, the stories of ACB women exemplify how the challenges and difficulties women faced prior, particularly suffering from the economic crisis, led to their getting HIV. With the economic hardships, women sought different ways to survive and to meet their daily needs and, in the process, acquired HIV. Herein, the social and economic forces that dictate life choices in every sense, helped to shape women's susceptibility and acquisition of HIV.

Lacking guidance and education related to HIV and sexual health

Lacking guidance and education related to HIV and sexual health was also another theme that emerged as ACB women living with HIV described their life experiences before HIV diagnosis. Sexual health education is about creating awareness and enlightening individuals, couples, families, and communities with the information, motivation, and behavioural skills needed to enhance sexual health and avoid negative sexual health outcomes. Lack of guidance and education on HIV was a common theme among ACB women living with HIV in this study.

Growing up, most women express concerns about lacking direction and counsel from their parents, particularly around sexual education. The lack of guidance and counsel meant that women grew up without much awareness or education, particularly around sexually transmitted diseases such as HIV. Not having HIV information remarkably allowed the women to live freely without taking any required steps to protect themselves against HIV and keep themselves healthy. Notably, the lack of HIV education and guidance prevented the women from making safer choices and taking all the necessary precautions before engaging in a sexual encounter, and as a result, getting infected with HIV. One Congolese woman, Joan, illustrates, "Yeah, I was not doing any protection. You know, I didn't know anything. So that's why I was saying that I got infected with HIV, maybe from someone else. Yes, I think I got HIV from someone else" (30-year-old ACB HIV woman).

Racheal is another woman who narrates her experience of lacking guidance on relationships and information about HIV growing up. She notably highlights how not having any guidance or education from her mother was particularly instrumental in her acquiring HIV. As she states,

> You know, in my life, I was trying my best. I used to fear HIV so much just because I didn't have guidance. That was my problem. My mother is about 60 to 64 years old, and she can't express herself, telling me about relationships, oh, if you have a boyfriend…. She'll be hiding things. So, I didn't get that chance to talk to somebody. And just because I was young, I didn't know back then about checkups if I needed to check up on somebody. If she were talking to me, I would have been wise. I wasn't too jumpy. I was so careful with my life (Rachael, 40-year-old, ACB HIV woman).

Based on Racheal’s experience, she makes it a duty to educate her children on sexually transmitted and blood-borne infections to keep them well-informed and also empower them to be able to make safer choices. Additionally, rather than dwell on the past and how she became HIV-positive, she makes meaning of her HIV-positive status, attributing it to being the handwork of God. For another woman, Emma, having been through the loss of her mother at an early age, the loss of her brother, the loss of her father, and even the loss of their home, she similarly explained how there was not much information, guidance, and awareness related to HIV. She stated,

> I grew up, there were eight of us in the family. My eldest brother passed away. My mother also passed very early, shortly after my brother passed. Smitten, my father, too, passed. It became crystal clear that I had to ensure I didn't lose focus. I love fashion, and I usually have new hairstyles every two weeks. Where I come from, we use needles to weave wigs into our hair, and we all share needles. You're finishing this and hopping on another person's hair with the same needle. However, the lack of knowledge of what

> exposure to these things could cause was not there at the time (Emma, 44-year-old, ACB HIV woman).

The women's narratives showcase the lack of guidance and HIV education among women that led to women acquiring HIV. Women noted that if only they were more informed about HIV and better equipped with its several modes of transmission, they would have been more watchful as well as taken all the steps to protect their health. When a person, particularly women, miss out on sexual health education and lack guidance, they are put at an increased likelihood for sexually transmitted infections, including unplanned pregnancies and sexual violence. As the quotes from Rachael and Emma say, many of the women lacked education and guidance relating to HIV. This prevented women from building and maintaining healthy and safe relationships as well as practicing healthy sexual behavior and consequently contracting HIV, that in turn creates hardship in their lives. The women's stories particularly highlight the need for HIV awareness and sexual education within the ACB community and at large.

War and Civil Unrest

Many women were exposed to war in their youth and childhood. Fighting and chaos were happening within their home countries. Consequently, these women express multiple adverse events and intersectional experiences, such as homelessness, where many were trying to find a place to live and running away from everything that was going on, losing family members, migration, seeking asylum, relocating to other neighbouring countries, and eventually migrating to Canada. As one woman, Joan narrates:

> I came to Canada. The reason was that our Congo was not a safe country there. There was a lot of fighting, like gun shooting. Oh, yeah, all of us were running, everyone going their separate ways and running for safety, and we couldn't see each other. I had seven siblings;

> however, two brothers passed because of the violence and fighting. But I ran away with my only surviving brother to Uganda. Even there, it wasn't easy. I didn't know that I had HIV. It was just mentioned to me when we were about to come to Canada from Uganda during medicals and check-ups. I didn't know where it came from, but they just found it in my blood. I don't want even to remember this (participant crying). (Joan, 30-year-old ACB HIV woman).

As the woman above explains, the violence of war caused her emotional suffering and also exposed her to enormous challenges, such as losing family members. Additionally, the terror and horror spread by the violence of war also disrupted her life and severed her relationships and connections with her family, leaving her emotionally distressed. Violence is destructive as Joan shows; on the one hand, it destroys necessary health and has a severe impact on individuals, especially on public mental health, while on the other hand, it damages the development of a peaceful civil society. The combined effects of the wars Joan faced, and the unrest warranted her migration to other countries, seeking a safe place but eventually relocating to Canada. Additionally, for Joan, the wars and fighting that she experienced remained a huge influence in her life and also greatly exposed her to acquiring HIV. In a war situation as commonly known, wars destroy social and physical infrastructure, resulting in untreated poor health and malnutrition and, as a consequence, an increased exposure of transmission in the event of viral exposure. More so, war shocks can weaken an individual’s ability to avoid HIV exposure or infection (vulnerability).

For another woman, Natalie, she mentions not recollecting much about Africa, as she and her family were running away from the war happening in her country. Just like most other ACB women living with HIV, the violence of war exposed her and her family to life-threatening situations, continuous disruptions of daily living, economic hardships, and geographic displacement. As a result, along with her family members, she relocated to Canada, and she wishes not to visit home as a result of her early childhood experiences. As she outlines,

> I work with the City of Winnipeg. I engage with and play with kids and ensure they have fun with me or other staff. About going to Africa, no. I told myself I'd never. I don't remember much about Africa because we fled war when I came here. Being only six years old, I don't remember much. But I remember that after Congo, we went to Zimbabwe. We stayed there for a few years, and then we came here. It wasn't easy then, as my parents noted (Natalie, a 25-year-old ACB HIV woman).

As a physical consequence of the war, another woman, who is a mother of three children and narrating through her daughter, mentioned seeking asylum in another country where she could be safe. She lived largely in the refugee camp for 10 years due to the civil war and unrest in her home country at the time. While living life as a refugee in another country had its stresses, as she notes, she felt peaceful residing therein. The experiences and exposure to war created significant social and psychological distress, including anxiety and depression, which caused much morbidity and retarded socio-economic development within the community. She eventually relocated to Canada afterwards. She was diagnosed, even before she knew she had the disease, during the medical examinations and check-ups before she came to Canada in 2010. As she explained,

> You know, before I was diagnosed with HIV, there was a civil war. There was civil unrest in my country at the time, and the war ended in 1991. Life during the war was brutal. Then, I just got out, sought asylum in Kenya, and was registered as a refugee. I lived predominantly in a refugee camp, but, in a way, it didn't seem much different because

> there wasn't much to celebrate there, and I often felt isolated. I was in Kenya on asylum for 20 years and in a refugee camp for ten years before we came here (Christy, 50-year-old, ACB HIV woman).

Here, women describe their experiences of war and civil unrest that resulted in women's migration to other countries, while at the same time increasing their exposure to and acquisition of HIV. Living before HIV and during war, women lived in a state of fear and psychological trauma, scampering for safety. The horrors of war heightened women's responsibilities and domestic hardships and disrupted the development of the social and economic fabric of women. Women also faced social, economic, and cultural disaster, and were like as hapless victims unable to act on their environment. Based on how ACB women discussed populations in war and conflict situations, an understanding of women's war experiences, including the psychological consequences of the wars in their lives, is of great importance and could add new understandings and solutions to the care needs of women.

Dealing with sexual assault and trauma

These women were also affected by conflicts and situations of political instability, which resulted in increased levels of gender-based violence, including sexual assault, torture, and arbitrary killings. Gender-based violence, such as sexual abuse, undermines women's sense of self-worth and self-esteem and adversely affects women's physical and mental well-being, including depression. For example, Flora was kidnapped at the age of 12 as a target to capture her parents, who were involved in politics and were labelled as rebels going against the government. Thrown into a prison where she was held for 4 years, she was given the option to either be a sex slave and sleep with men working at the prison or be killed. She chooses to be a sex slave rather than be killed. As this woman notes, even though she has undergone therapy and counselling in order to heal from the traumatic experiences and the sad ordeal, she contacted HIV in the process. With all that this woman faced and being forced into sex slavery, she mentions not being able to recall her childhood life before HIV like some other women. As she explains:

> I don't remember my life or childhood before my HIV diagnosis. I don't remember it because I was a sex slave. I was taken away from my parents at the age of 12 until 16 and held captive in one place. Yeah, four years in one prison. They kidnapped me, my sister, and my two cousins because they couldn't find my dad in the house. My sister was 14, and my two cousins were 8 and 9 years old. They're all dead other than me; I'm the only one here. The option for me was to have sex with the people who served there, or I was going to be killed. I would rather be sleeping with men than be dead. I took it, and the result was HIV. (Flora, 36-year-old, ACB HIV woman).

For Flora, she points out how challenging it was for her given what she went through and witnessed, particularly the mass killings of people and her family members. She felt helpless and powerless, and this also produced a wide range of negative emotions including the thought that she could die. But she feels thankful that she made it alive. As she further states,

> Oh, I went through a lot. It was not only torture; it was like hell! I cannot describe them as people; they're animals. But then, some people had worse. Some lost their entire family; they just put them in the house and let the fire on, and everybody died. I lost six friends in front of me, which was traumatizing. My older sister died because they put her in a barrel of cold water overnight, and she just froze. So, I had the option of being a woman, which saved me then. But then they left me with an ultimate lifetime thing

> (HIV), but I'm alive. There's a reason why I'm here (Flora, 36-year-old, ACB HIV woman).

Another woman reports also experiencing rape and sexual assault before HIV diagnosis. Thinking back, she feels that it was during this time that she acquired HIV after being raped by someone well-known to her. This woman further explains how she didn’t know she could be treated in that way (being raped) and, worse still contracting HIV in the process. As she points out,

> Yeah, you don't expect these things to come to you, but you know, I was raped by someone I know. Yeah, I know him. I didn't think he would do this; that's why. My brain didn't tell me I would be sick because I didn't know. After I found out, I knew how I got this HIV (Sophie, 39-year-old, ACB HIV woman).

The torture, insidious assaults on women’s dignity amounted to women’s sufferings, and everyday life felt like war as women struggled to navigate the traumatic experiences. Sexual assault negatively affected women's physical, and mental health, and subsequently, women contracted HIV, a condition one of the women termed an ‘ultimate lifelong thing.’ Herein, the incident of sexual assault and trauma involved elements of control, power, and domination and women faced extremely difficult and painful emotions. The sexual abuse, trauma along with the financial situation, cultural and local pressures, and stresses that women faced are considered structural violence because they put women in harm’s way. They are structural because they are embedded in the political and economic organization of women’s social world, the structures of their culture, the way they get their meals, and their world in general. They are also violent because they caused injuries to women and led them to develop HIV in their bodies. Getting HIV because these women were forced into suffering and poverty is a form of violence. Albeit this violence is hidden; we can't see it, and it's different from getting shot with a gun.

Therefore, understanding structural violence in women's lives is indeed important to make sense of women's current experiences with HIV in Winnipeg and to learn how social forces beyond the control of women come to impact women's experiences in Winnipeg, including their use of care. It has long been clear that many medical and public health interventions will fail if we are unable to understand the contexts of trauma and social determinants of disease.

CHAPTER FIVE

EXPERIENCES FOLLOWING AN HIV DIAGNOSIS

This chapter presents findings on ACB women's immediate experiences following a positive HIV diagnosis. Primarily, this chapter brings to the fore the reactions, actions, thoughts, behaviours, and feelings of women right after their initial diagnosis and delineates women's initial response to their diagnosis and how they navigated life after they learned that they had contracted HIV. The notion of immediate experiences here refers to the first time a woman was informed of her HIV-positive status. I draw on women's post-HIV diagnosis experiences to further offer a nuanced account of women's context and also to help make sense of women's experiences of HIV in Winnipeg.

In the preceding chapter, which dealt with women's experiences before HIV diagnosis, I described women's lives before HIV-positive diagnosis, including their social relations and relationships with the different structural forces, as well as the weight of social structures in their lives. In this chapter, four main themes were generated from the analysis: (a) feeling scared, broken, wanting to give up, and feeling of losing everything; (b) being mindful and caring about the safety of self, others, and the community; and (c) becoming closed. (d) feeling loved. Although presented separately, women often describe their experiences of these themes as overlapping.

Feeling scared, broken, wanting to give up, and feeling of losing everything

A key theme extracted from women's narratives upon receiving a diagnosis of HIV is 'feeling scared', 'feeling broken', and 'wanting to give up'. Other reactions triggered by the diagnosis included women having the feeling of "losing everything." and a 'feeling of dying'. Women express these deep negative reactions, feelings, and emotions, given their familiarity with the negative experiences of other people living with HIV. More so, the fear of spreading the virus to others was ever present. Considering that HIV is an incurable ailment, women also felt down knowing that they would have to use medication for the rest of their lives. Consequently, most women choose to accept their new condition as they perceive there was nothing they could do, and moreover, their HIV status was never going to change. As a way forward, therefore, women set out to protect themselves, their families, and others. One ACB woman, Joan, describes,

> I felt scared because this is something in your life, right? Other people don't have it, but you have it. I felt it was not good. Sometimes, I sit down and think about it, and I stress and stress. But other times, I felt like, you know, this is my life right now, which will not change anymore. I have nothing else to do about my HIV-positive status. I need to protect myself and my family (Joan, 30-year-old, ACB HIV woman).

Sophie, Theresa, and Racheal described similar experiences, respectively.

> When we went for a test for the refugee process to immigrate to Canada, they said I was HIV-positive. So, my brain winked (terrified) after I found out. My whole world was broken. I thought I was going to die right away. That was how I pictured it in my mind. As a woman, you dream of a good marriage life, and the key is a happy life, right? All my dreams crashed (Sophie, 38-year-old, ACB HIV woman).
>
> Yeah, I felt that I might die within a short period because of the HIV diagnosis. Even though I know that I'm working with people who live with HIV back home (Ethiopia), when it came to me (became HIV-positive), I was like, I lost everything. It's not just the same when you live with HIV and when you support others (Theresa, 38-year-old, ACB HIV woman).
>
> It was tough for me. My whole life, I felt like I was going to die in a very short period. I didn't know; I'll be here today. I thought of many things. I was overthinking; if I die now,

> my siblings are going to die. If my mom knows now, she's going to die. I had too many problems in my head. I was super scared about it (Rachael, 40-year-old, ACB HIV woman).

Natalie also describes how badly she wanted to give up following her HIV diagnosis. Not knowing how to handle the new diagnosis, she felt really infuriated. She also felt burdened considering that nobody in her family has HIV besides her. As a result, her social bond and connections became severed and she felt scared to socialize,

> Yeah, I went there (clinic) to do a checkup to find out my health status. I didn't have anything; they said, you're negative for this and that, except for one thing that came back positive: HIV. I wanted to give up so badly. I was so frustrated; I was angry. I was cursing; I was just angry with God; I was furious with everybody. To crown it all, I had TB along with HIV. I was only 18 years old then. I told myself, why can't you give up like you already have this, like you're going to die anyway? What's the point? (Natalie, 25-year-old ACB HIV woman).

Unlike before HIV, wherein women lived life “so nice” and “carefree” without carrying in a way the “burden of knowing what they have," since diagnosis, women have been really affected. Women feel more burdened by HIV and experience the most negative psychological effects of an HIV diagnosis. The women are no longer “just living life. Women described how their HIV-positive status shaped notions of loss, particularly, loss of opportunities in life. Women also have worries about dying and never being able to have a family and live a happy life and this put strain on ACB women. The stress is also compounded by the thought of being different form others, and facing rejections, all of which can create a vicious cycle of increased depression and fear. Deep negative emotions characterize women’s feelings after HIV diagnosis. As a result, psychological support, including counseling services and emotional support from family and loved ones, should be an integral part of HIV treatment,

Being mindful, caring about safety of self, others, and community

Being mindful and caring about the safety of self, others, and the community is another experience women reported following a positive diagnosis of HIV. Unlike before HIV, women mention not taking life seriously and paying much attention to themselves, their health, and that of others. While referring to themselves as normal, some women also report caring less about the world, including people suffering from chronic conditions such as HIV, as long as they are not living with the condition. However, since being diagnosed with HIV, women reveal taking all the necessary steps to care for and protect themselves, their family members, and the community. Women continuously self-monitor their own health and develop strict self-discipline when associating with others and interacting with family members in order to limit the chance of HIV transmission. Since being diagnosed, the safety of self and others has become women’s priority. The importance of avoiding transmissions of HIV to others is widely known. It promotes safe living within the community, which can translate into positive long-term health outcomes. Similarly, close self-monitoring and maintaining good overall health remain key in order that women can spot early signs of possible infection, as it can help prevent a range of complications. Women can also expect to have a high quality of life, managing the challenges of living with HIV easier. Natalie illustrates how her life has changed after the HIV diagnosis as she begins to care more about others.

> Like before, I didn't care about the world. I didn't have HIV; I couldn't care. I didn't care about people who had cancer, HIV, or hepatitis B. I didn't care as long as I didn't have it. I didn't take my life seriously. But once I found out that I had HIV, my life changed. I

> started looking at my life. I started taking my life and the world more seriously. I had to look at things differently. For example, I had to look at guys differently when I had this. If I want to have fun, how will I protect them and me at the same time? (Natalie, 25-year-old, ACB HIV woman)

Herein, Natalie, just like other women, feels more responsibility, sensitivity, and concern regarding the transmission of the disease to others. Women are afraid and most concerned about exposing others to their blood, given that HIV is a terminal illness. Women, therefore, make a special effort to care about others, set household rules and take precautions in order to reduce the chance of HIV transmission. Women are mindful and even going so far as to take exaggerated hygiene measures and use different nail kits or sharp objects from the rest of the family. Another woman, Emma, who has lived with HIV since 2001 and got to know about her HIV-positive status during her antenatal, shared her experience following her HIV diagnosis as she stated,

> Since I learned my status, I have tried to be more careful and protective of myself and others, ensuring that everyone is good and that nothing happens or falls through the cracks due to my careless acts. For instance, I took more cautious steps to ensure I attended to every detail that concerned sharing sharp objects. I have three children and a husband, all negative to date. I decided to have my nail cutter, which is kept aside; nobody touches it. I also reduced my interactions with certain kinds of places to go to limit possible transmission. I've been more cautious, and that has kept me safe (44-year-old, ACB HIV woman).

Similarly, Linda noted, "For me, when they tested us, they said we were positive, and I started to protect my life and my health" (45-year-old, ACB HIV woman). Women feel obliged to take necessary precautions in their day-to-day interactions with others to avert the spread of

HIV, especially to their children. For Theresa, HIV remains the gift and curse in her life that she never expected. While it forced her to live in concealment and solitude, it also gave her the opportunity to be her own personal doctor and care for her health better than before her HIV diagnosis. She outlines,

> Before HIV, when I did have a headache, I said it was okay; it was just a headache, and I wouldn't bother. But now if I have a headache, I say, where is this headache from? Could it be stress or lack of sleep, or maybe I didn't drink water? For me, my HIV diagnosis makes me run my life in good quality because I'm now watching everything in my life since I don't want to become ill. I am my doctor. I might not be prescribing medication to myself or know about my illness. I might not support others or give this information or that to others. I'm professional for my health because I watch everything in my life. I'm so proud of myself, no matter what. I lived a quality life after I became HIV positive (38-year-old, ACB HIV woman).

Based on stories women shared earlier, women considered the positive test results to be a limitation and contributing to a life filled with the fear of stigma and isolation; however, on the other hand, a positive diagnosis of HIV caused them to change their attitude about themselves and towards others, tending to protect themselves and others. HIV represents a gift as women start to care more about their own health. Previously, health and wellness were not something that took up women’s thoughts and attention, whereas after diagnosis, thinking about health took on a more central and conscious aspect of their lives. Women act cautiously, adopt prudent self-care measures, and set out to lead quality lives.

Becoming closed

Becoming closed’ is another unpleasant event that women shared after receiving positive HIV test results. In the context of this study, ‘becoming closed’ often means "hiding," “distancing oneself," “staying alone,” and choosing not to connect with people in order that they do not “expose one’s status and lives." This experience was manifested in two ways: avoiding relationships and isolating, keeping to self, and hiding.

Avoiding relationships. Avoiding relationships is specifically about women's relationships with the social world, especially intimate partner relationships. This became closed after women found out they were living with HIV. Women stated that after facing a positive diagnosis, they often choose not to engage in a relationship, including sexual relationships, or even getting married. They feared that people would gossip and talk about them if they found out that they were HIV-positive. Additionally, considering the stigma associated with HIV, women also feared that people would discriminate against them if they heard about the news of the positive diagnosis. Women perceiving, themselves as sick also mention that they do not want to get married in order to not be a burden to their partner. There is also the fear and likelihood of infecting their partner if they are married or in a relationship. As such, some women prefer to “stay alone," distancing themselves. As Racheal and Theresa narrate,

> When I knew about my HIV, my life changed for real because I was like, I don't want to date anymore. I don't want it, even now. My husband passed away in a car accident. Everybody tells me, oh, you have to get married. And I'm like, no, I can't. Because I know I don't want to do anything stupid. Anybody who knows my status will run, and other people will talk about you. You know Winnipeg is very small. So, I'm like, I'm better staying alone. I don't want to get married so that nobody can expose my life. I don't

> want a husband; I don't want to overwhelm anyone with my HIV diagnosis. (Rachael, 40-year-old, ACB HIV woman).
>
> I don't want a marriage for myself. No, I don't like it! I don't have any plans to get married at this time. But my friends ask, why can't you get married? They even pray that I get a husband. I say no; I don't want to. They say we know someone who needs just a wife—a good wife. You have to meet together. For me, I'm not comfortable with that because they don't know about my HIV. Now, if I marry someone and tell him, maybe he will become disappointed or talk with others. So, I don't want to go public with my HIV (Theresa, 38-year-old, ACB HIV woman).

Flora, another woman who arrived in Canada in 2013, further narrates her experience with how she turned down her date invitation because of her HIV-positive diagnosis. “He asked me out for dinner, and I said no, I can't because I have HIV. I don't want to kill anyone. I'm like, how can somebody be accepting if he's not HIV positive already? Why would he be accepting me? That's what I thought." (Flora, 36-year-ol, ACB HIV woman). Women are afraid of contagion in the uninfected population and revealing their HIV status to others and as a result tend to avoid relationships. In fact, the act of receiving a positive HIV diagnosis was shrouded with lack of interest in relationships, especially intimate partner relationships in order to manage to manage anxiety around transmitting HIV to others. Although women have the negative thoughts related to their HIV diagnosis and avoid relationships, at the same time, they note that they are trying to protect themselves and others. Women further attribute reasons for avoiding relationships because they perceive themselves as not being ‘normal’ like other women who are not living with HIV. With that perception and seeing themselves as different, women do not want to connect with people in a relationship. For example, Linda is a single mom of four kids. As much as she would love to be in a relationship and be married again, she sees herself as ‘not normal’. She also fears being refused and gossiped about if she discloses her HIV-positive status. She outlines,

> I am not normal again like other ladies. Even though I'm beautiful, I'm not beautiful again because I'm unlike before. Before, if men needed to marry me, they could marry me. But I'm scared because I'm now positive. I am not happy to accept men because of what I have; I have a limit. Since I came to Canada, many men have followed me in getting married. I refuse because I think about that problem (my HIV identity). How can I share that with someone who came to marry me? Maybe when I shared with him, he refused me, and he is going out now to tell all the people. That's why I'm good on that side (about marriage). That limit (my HIV positivity) gives me stress. I'm not happy because of that (Linda, 38-year-old, ACB HIV woman).

Natalie, on the other hand, narrates how her sexual relationships have been affected because of her HIV diagnosis. Unlike before HIV, as she earlier noted, wherein she was ‘just living life’ like all the other women and doing young people's stuff, since being diagnosed, her sexual relations with friends have been greatly affected. She describes being scared to connect with others sexually and therefore limits her sexual interactions and connections for fear of facing discrimination.

> I wasn't so worried about having sex, but after my diagnosis, I became so concerned. Because whenever I tell them I have HIV, they get scared; that is why I'm afraid to have sexual intercourse with somebody. So many things run through their heads, like HIV. It's a disease, but it's not curable, but it's treatable. Also, whenever I say, oh, I have H (HIV), automatically, what I see is discrimination and stigma; they always think negative things.

> And I used to think that too; I remember, I used to think that way before I had this (Natalie, 25-year-old, ACB HIV woman).

Women narrate how the diagnosis of HIV infection has far-reaching implications for their lives. HIV restricts and disrupts women's desire to connect with others, be in and nurture relationships, and even build a family with their partners. Notably, women's sense of self, attractiveness, and relationships with others are affected because women see themselves as different and are wary of being contagious, therefore choosing to distance themselves and withhold interactions and physical affection. Their fears related mostly to disclosing their HIV-positive status and getting rejected, as well as the loss of their social position, including being disgraced. Therein, HIV diagnosis distorts 'just living life'.

Isolating, keeping to self and hiding. Isolating, keeping to self, and hiding is another aspect of becoming closed women described in this study. Women stated that after receiving the first positive diagnosis of the disease, they thought they should keep to themselves, conceal their status, and thus avert incidents of stigma and enacted discrimination. Isolating, keeping to self, and hiding appear different from 'avoiding relationships' Herein, this is focused on the women and their being alone and not wanting to reach out to friends, family, or their community. In other words, this theme extends beyond intimate family relationships into friendships and community. Women are afraid of disclosing their HIV diagnosis based on personal negative experiences and because they have seen other men and women with HIV face discrimination and stigma, as noted earlier. Women thereby internalize the negative ideas and stereotypes about people living with HIV and start to apply them to themselves. Women particularly feel that the stigma and views of other people would hurt them more than the actual HIV. Additionally, women do not also feel the need to burden family members with their problems, knowing that they too might have their challenges. Similarly, there is also a lot of ignorance and a chronic lack of information and awareness about HIV in the community, as women further noted, often leading to negative value judgments about people who are living with HIV. As a result of fears of stigma, rejection, and shunning, including the possibility of being uninvited from social functions and barred from public places, many women choose to hide their HIV status and close themselves. Theresa, who is a mother of two children outlines,

> When I found out I was living with HIV, uh, I hid; it was so hard to believe I was living with HIV (crying). And it was even harder to continue my diagnosis. I just wanted to die at that time because I lost my husband accidentally. Everything that'd happened made my life a mess. I lost lots of stuff (tearing up again). I didn't have any hope for the future (Theresa, 38-year-old, ACB HIV woman).
>
> But now that I live in Canada,
>
> I couldn't expect that when I came here, I would still hide just behind the people and my community. I expected to become freer—not like hiding behind my friends or my status. In Ethiopia, for example, if you say I am HIV-positive, no one could want to become close to you, your friends, family, and other acquaintances, no matter what you know. Now, I feel the same here as back home. I couldn't get good feedback when we discussed HIV is like any other illness. They couldn't agree with me. (Theresa, 38-year-old, ACB HIV woman).

For Theresa, hiding and self-isolation were seen as a way to allow her to avoid shame and save face. She ‘closes herself’ and withholds her HIV diagnosis from friends and the community due to fear that disclosure may cause her distress and add to psychological burden, especially for her children. Theresa also sees no difference between living back home and in Canada because her life continues to be a struggle, as she constantly has to hide herself and distance herself from others. She feels she can't still talk about HIV and her HIV-positive status with others. In fact, based on her experiences, being in Winnipeg appears to not be ‘good’ for her. Similarly, for Christy, she narrates her own experiences,

> I often hear them (acquaintances) talking about other people, people who have HIV and AIDS, and they'll say, oh, so and so has HIV, oh, so and so has that. They talk about and gossip about them. So, often, I isolate myself, stay at home, and don't mingle because I'm afraid they might also be talking about me. Because of that, I do not participate in the community as much as I would like to. I also do not feel comfortable hanging out with people. I'm all by myself and isolated. This causes me a lot of stress and anxiety, and it causes me depression, too (Christy, 50-year-old ACB HIV woman).

The consequences of self-isolation can be devastating as Christy described, depriving people living with HIV of major sources of support and social connection and potentially compromising their mental health. Living in silence without disclosure puts an individual in a condition of emotional drain, imposes more stress and psychological burdens, and can also thwart HIV self-management and engagement in medical care, in addition to heightening the chances of health disparities. Rachael, who got infected though her husband shares her own experience of distancing herself from her parents because of her HIV diagnosis,

> By that time, after I knew my HIV status in Uganda, it was hard. …. When I went to my mother's house with my newborn, she'd say, you have to feed the baby. In the hospital, they tell you to breastfeed for six months straight. So, you have to breastfeed. It was tough because I didn't want her or anybody else to know. To maintain secrecy, my husband had to travel and take me away from my parent's house to bring me back home.

> In Winnipeg, I feel much better not exposing myself because I know they will stigmatize me, and I'll not want to go outside, talk to people, or go to work. Why do I have to? (Rachael, 40-year-old, ACB HIV woman)

For Rachael, due to her HIV diagnosis, she had to cut short her stay at the parents' house for fear of them finding out about her status and being negatively labelled, avoided, rejected, and excluded within her family and possibly her community. The implication thereof is that her HIV-positive status deprived her of access to the maternal care and support she required at the time as a nursing mother. She closes herself, creating a distance between her parents and herself. Indeed, there is an everyday struggle for women to conceal their HIV status, which poses tremendous psychological burdens on women.

Some other women did not share their HIV-positive status with anyone. In an emotional narrative, Flora, who was kidnapped at the age of 12 to work as a sex slave as earlier discussed, narrated her experience of hiding her status as well as revealed the consequences of HIV disclosure. This woman drove home the point that she would rather be found dead than disclose her HIV-positive status to others, particularly her community. She attributes her reasons to stigma and discrimination, just like other women. She further explained how, particularly, her community would not accept her but instead spread news of the illness. She narrates,

> I did not disclose it to anyone; even my mom, grandmother, and family didn't know. In Uganda, to have HIV and tell people you can't, you hide until you die. Until you fall sick, people will know. Yes, it is the stigma. So, instead of talking about themselves, people will talk among themselves and will mentally destroy you. Your people will not accept you, trust me, if you have HIV. From that experience, I decided to keep it to myself. If I had not found Nine Circles when I arrived in Canada, I wouldn't have gone anywhere

> else; I wouldn't have called a doctor; I wouldn't have told anyone; I would have just kept it that way. They would have found out, and I would have been dead or mentally incapacitated actually to live life. (Flora, 36-year-old, ACB HIV woman).

Flora chooses to 'close herself' from her family members and community. This was a common sentiment shared among women. The anticipated stigma and fear of 'not being accepted' informed her decision to hide her diagnosis, 'keep it to herself' and keep safe from discrimination by adopting mechanisms of concealment. For Flora, living with HIV isn't a separation from her sex slavery experience. It's a continuity with the violence and struggles of her life, as well as a constant reminder of the hostility and cruelty that she suffered. The violence she experienced has driven her to become infected with HIV, an ultimate lifelong disease' as she described, brought on her due to sexual assault. Now she has to live with HIV for the rest of her life and also deal with challenges associated with HIV non-disclosure, separation, and disconnection with her family members, coupled with living with HIV. These afflictions were not caused by accident or force majeure (natural and unavoidable catastrophe); they were direct consequences of structural violence and restrictions on her agency.

Joan is another woman, a mother of five children who relocated to Canada as a result of war and civil unrest. She shares her own experience and explains,

> When I heard I had HIV, I did not tell anybody. I just kept the information to myself because I am an adult. Also, coming from Uganda to Canada, nobody in my family knew anything about my HIV-positive status. I didn't want them to know because sometimes they, too, have their feelings. They may be worrying too much. They're going to be thinking about me a great deal. How did I get it? How do I feel about it? I know, it's good

> to tell them. But for me, I think I don't want to say anything except to keep quiet (Joan, 30-year-old, ACB HIV woman)

Here, Joan, while in Congo during the war, was living in fear, burdened, hiding, running away from war, avoiding chaos, and seeking a safe place. Now, living with HIV, she hides her HIV-positive status from her family; that's a fundamental unit, just like other women, avoiding any situations for possible disclosure, keeping to herself, and navigating life with HIV all by herself, and crucially, also losing a valuable form of social support from her family. Joan keeps away from her family in a bid to maintain the secrecy of her HIV-positive status and for fear of being devalued and shamed. She is particularly wary that her disclosure may upset the feelings of her family members, add to their struggles, and affect their psychological wellbeing. For her and other women like her, living with HIV appears to be like living in war and living 'not in a safe country' as she is still hiding, nursing fears, and avoiding disclosure of her status. Facing war is synonymous with hiding and being burdened, just like HIV. Joan and other women tried to escape war, but because of their illness, the war followed them.

Notably, in this section, women reveal a range of forms of 'closing self' behaviours as part of their experiences immediately following HIV diagnosis. The reactions of women are prompted given the social image of HIV as an incurable disease and, more crucially, as a result of the negative reactions from the community and the stigma that is attached to the disease. Women following HIV diagnosis seem to experience a continuation of their struggles where daily living feels very challenging since women need to do all they can to maintain secrecy of their status even at the detriment of their health and also have to deal with the struggles associated with non-disclosure such as hiding, loneliness, and social isolation. Women no longer feel free to interact and go about their activities freely, but rather choose to live in seclusion.

Notably, ‘becoming closed’ impacted ‘just living life', and they were no longer just living life. Life ‘became closed’.

However, on the other hand, for women, life before and after HIV appear not to be so different. The challenges that women face following receiving a positive test result is like a kind of war and more intense fear that puts them in harm’s way, as noted earlier. Although, living with HIV, women do not have to deal with guns, bombs, and ammunition every day like in actual war, what women have narrated since living with HIV is like a kind of violence coupled with constant fear. As a result of fear and knowing how others will treat them after they find out they have HIV, women tend to live in seclusion, closing themselves and trying to be in a safe space. Living with HIV appears to be synonymous with living in fear, hiding, distancing oneself from harm, heartache, and trauma, avoiding psychological burden, and trying to find a safe place to be. It's like that in war; it's like that in HIV. HIV-positive diagnosis for women is like living in war.

Feeling loved

Despite feeling down after the diagnosis, women also particularly acknowledge the support of their family members, spouses, care providers, and counsellors. Four women reported that their family members, spouses, care providers, and counsellors were helpful in many ways after learning about their HIV-positive diagnosis, such as providing more emotional support as well as counselling and constantly reminding them about taking medication to help protect and preserve women's health and help them stay long and healthy lives and keep an undetectable viral load. As much as being diagnosed with HIV presented women with life-changing news, they felt loved following the support they received, reassuring them that HIV is a manageable health condition. At the same time, women also felt ‘thankful’ and ‘grateful’ as they began to cope with their illness, particularly knowing that their children were healthy and HIV-negative.

Even though women have an understanding of HIV as an ailment that has no cure, the support of their family and staff gave them hope. They hope for a miracle and believe that some day they will be cured. Women also hoped that they wouldn't have to continue to take the medication as food every day. As Joan narrates,

> After I found out, I thought I was going to die right away. But he (my unmarried father) brought back my brain. He gave me hope; that's why I owe him so much. So, he asked me to calm down. I calmed down. I didn't care what others said after that because of the way he supported me (Joan, 38-year-old, ACB HIV woman).

Similarly, for Theresa and Racheal, the reassuring support and encouragement derived from family members and counsellors eased concerns about the lethality of HIV and the challenges of accepting a new diagnosis. They both added,

> My family, yeah! They reminded me about my medications, my meals, and my water. They say you have to drink water now, even just one glass. You have to eat something, too, and sometimes they say you have to rest now. Generally, they just followed up on me and watched my blood pressure. My mom also took off my kids and started caring for them. I don't know how to explain it; they were more supportive than anyone, spiritually and physically; they supported me economically too (Theresa, 38-year-old, ACB HIV woman).
>
> [The counselor said] Don't mind about anything; I'll just be here, and you'll be here and may even go up 100 years. There has been HIV medication for over 30 years. I thought she was lying. But I thanked God, and after 12 years, I started coping because my counselor was there for me. She was nice. My husband was my best friend, too (Rachael, a 40-year-old ACB HIV woman).

Natalie, just like other women, also got comfort from the advice and counsel of her parents as well as from care providers. As she described,

> Nobody in my family—my twin sister, my two other sisters—has it. I am the only one who has it, and it bugs me. But my family was my support system, and my doctor and nurse worked; they were part of it, too, especially my parents. The nurse said, don't worry, it will be fine, and my parents gave me hope. They said you're not the only one who has this, and you're not going to be last. So, you have to keep going. That's what they said. They were so supportive. If it weren't for them, I don't know what I would have done (Natalie, 25-year-old, ACB HIV woman).

The women demonstrate the importance of family and emotional support in the lives of people living with HIV. Family members and health staff engaged women in understanding about living with HIV and in demystifying and de-stigmatizing the virus, thus regaining women's hopes for the future. Family members and care staff encouraged women to seek care and treatment and being there for the women and showing them that life is worth living. The dimensions of family members and care staff support included counselling, daily activities, educational and psychological support. Women therefore feel loved and important following the emotional, moral, and physical support they received from their family and care staff. Women also feel loved hearing those powerful counsel from family their and staff, particularly learning that certainly, being HIV positive isn't a reason for them to stop living life and quit progressing. This counsel and advice gave the women hope.

CHAPTER SIX

WOMEN’S EXPERIENCES OF HIV CARE AND SUPPORT

This chapter explores the experiences of ACB women living with HIV interacting with the Winnipeg health care and available support systems. Many themes emerged in the interviews as outlined in Table 2.

Here, the focus is on the eight main themes above, including: (a) Committing to HIV care; (b) Load bearing; (c) Waiting; (d) Dealing with language; (e) Feeling a lack of safety, cultural sensitivity, and awareness; (f) Lacking medication coverage; (g) HIV self-acceptance; and (Women's experiences with the healthcare and support system are largely diverse, but also overlap and reflect their interactions with the care environment itself or providers across a continuum of care. Notably, layering through women's experiences, is the trauma from structural violence women experienced before their HIV diagnosis described in the previous chapter. That structural violence means that women live with trauma that colours, informs and shapes all of their experiences. Unfortunately, trauma experiences of different forms were in the background of all the women's lives.

Committing to care uptake

Committing to care uptake involves the women devoting time and actively and continuously participating in care appointments and other related or referred services. The concept of "care" as described by participants includes providing physical, psychological, social, emotional, and mental support to patients to enable them preserve or improve their health, live well and be independent. In other words, the notion of care has an intrinsic meaning in terms of caring about an individual, providing physical comfort, mental, emotional, spiritual support as well as meeting other needs that they may have.

Therefore, for the women in this study, care is about caring, lending a listening ear, showing empathy, not judging and being compassionate. That embodies being friendly, courteous, interested, and concerned. Care is also about giving hope and providing moral support, considering that people living with HIV have to deal with not only mental health conditions, but crucially their daily interaction with the social environment —how people look at them and how they perceive themselves. Therefore, for women, aside from medications and effective treatment that helps to alleviate physical discomfort of living with HIV, care also encompasses social support to help people living with HIV solve their life difficulties and relieve their trauma. Showing care along with social support plays an important role in coping with the disease and in moderating the negative effects the women face due to their HIV-positive identity.

Migrating from their home countries, where most women have experienced turbulent times, African women living with HIV desire a chance to get improved health care and support and not have their whole lives impeded by their illness. Prioritising their health as key, women therefore often value going for their appointment to be in top health and to stay alive over other engagements and struggles that they face as they navigate daily life. Notably, women set out to preserve their health, to be there for their loved ones and families. As such, there is a commitment to engage in care and use care as prescribed. As several women described,

> It's (care) vital for me because it's my life. Nothing can stop me from going to the clinic for my health. No, I have to fight that because that's where I am getting my pills to become okay. I can then go to work for my kids. So, I believe it's the best place for me. I don't know about others, but it's the best place because they give me what I'm looking for. They're making me feel okay because if I wasn't accessing care and getting the excellent service, I think I'm getting, I wouldn't have been the same (Rachael, 40-year-old ACB HIV woman).

> So, when it comes to my care, for instance, I don't play with that. No matter how busy I am, I can attend my clinics. And if I can't make my clinics, I communicate with my doctors to reschedule. I don't trade those appointments for anything else except when the timing is inconvenient because of work. If I can't make it on a particular day or time, I am always free to reschedule, and I will always take into cognizance the importance of making sure I don't push it later than I should (Emma,44-year-old, ACB HIV woman).

> Oh! For me, my health matters. My health is my number one priority. It is a priority. No! Culture, whatever, doesn't affect me; if I am sick and I need care, I will go for care. It won't matter if I go to Nine Circles or anywhere else. It doesn't matter if I'm sick; I will go to any hospital (Natalie, 25-year-old, ACB HIV woman).

Here, women highlight how much they value using care in order to live with their diagnosis. Women also ascribe other reasons for committing to care uptake: they want to learn about HIV, how they are faring with their condition, and how they are responding to treatment. As such, to remain healthy, women regularly visit Nine Circles, or other local clinics, for care because they feel that they wouldn't be the same if they weren't receiving care and taking medication. Moreover, local clinics, like Nine Circles, are places they could meet with others like them, connect, and share their thoughts and expressions about how they feel without being judged. The need to better support themselves to live well and to know about their health therefore keeps women dedicated to using care. As Joan and Theresa noted,

> I really just want to make sure I know everything—how it (HIV) is in my body (the viral load), how I'm doing during and following after the blood work. How my body is functioning according to the care I receive. That's why I like to go to the appointment (Joan, 30-year-old, ACB HIV woman).

> I like going for care; you can meet people like you, and we can talk about ourselves. All of us are the same. We are the same under one umbrella. I don't know how they feel, but no matter where they came from, I don't care. Whenever I go there, I'm so happy. I can share my ideas and what I feel, and they can share their ideas and how they think without judgment. So that's why I like going to care. The most significant time in my life is when I go there; I relax afterward. Maybe if I have some issues, I could get some support from them (Theresa, 38-year-old, ACB HIV woman).

Most women feel at ease using and committing to care considering the way they are cared for. They feel that they are treated normally and like any other patient with some disease. For example, Danielle and Rachael illustrated,

> I didn't want HIV, but I contacted it. I wasn't happy about it. But I always go for my HIV treatment. I am pleased about the care and the way they treat me. Yeah. I have good medication treatment here in Canada because if I were back home, maybe I would be dead by now (Danielle, 58-year-old, ACB HIV woman).
>
> The support and care, oh! I feel so good. They make you feel as if you're home. I can't even move from Winnipeg to anywhere because of them (Nine Circles). Like I get everything I want. And when I feel like something is bothering me, even if it's not about medication or I have a problem, I call and talk to them, and they will find a way for me. They give me that moral support. It is the best place to be for me because they care. They always ask how you are feeling. You feel like you're in safe hands, which I always appreciate (Rachael,40-year-old ACB HIV woman).

Women feel happy with the care, with some women finding a sense of home and safety within the confines of Nine Circles. But then, as much as women commit to care, for one woman, attending care appointments and support programs remains a constant reminder of who she is—her HIV positive identity. As Sophie adds, “Sometimes, it's better not to go, I say. Because when I go there, I know who I am: I am living with HIV” (39-year-old, ACB HIV woman). Visiting the clinic for care also reminds women of the sad events they have experienced in their lives. Nonetheless, the goal of keeping alive, staying healthy, and being there for their loved ones surpasses the sad thoughts and feelings, and women in this study largely commit to accessing health care. As Emma also outlined,

> Generally, I'm not too fond of hospitals. It's just something about me; it didn't start today. I lost my mother at the hospital. For a long time, I didn't want to know about anything that would take me to the hospital, but when I did not have a choice, I had to attend—my health and care matter (Emma, 44-year-old, ACB HIV woman).

Because HIV requires lifelong treatment, women commit to care and regularly visit support and health care providers to preserve their health and to be there for their loved ones. Ongoing medical care and treatment with HIV medicines is indeed important in women’s lives and make sure women's HIV treatment regimen keeps the virus under control. Likewise, HIV medicines can also help women live longer, healthier lives and, more importantly, reduce the likelihood of HIV transmission.

Load bearing

Load bearing is another way women described their experiences of HIV care and related support in Winnipeg. Load bearing here is all about women’s work. It refers to all the different demands and burdens in women’s lives that they juggle and face while living with HIV and trying to take care of their health. Women bear the load of maintaining their own HIV care, and at the same time need a job, to take care of their children and uphold family responsibilities, alongside pursuing academic studies. Women also need to navigate work, surmount family issues such as finding day care and at the same time attend appointments and do blood work as prescribed. Given that HIV is a terminal illness, blood work and attending appointments are constant and not one-off activities. As such, these women are constantly tasked with finding daycare for their children in order that they can attend their appointments and related support programs. Women also need to deal with differing mental health conditions such as depression, mood disorders that often happens with people living with HIV, and likewise have to bear the load of seeking resources and necessary support in order to live well with their conditions. Women also continuously bear the load of protecting others from acquiring HIV. These loads women bear have “no end in sight” and form a chronic background to their lifelong struggle with illness.

As the women have described, there is always that constant interchange of their different worlds, for example, being mothers and living with HIV. Life, indeed, for women seems to be challenging. These loads women bear often impact the way they use care. The women’s experiences are illustrated through three primary cross-cutting sub themes; a) “Killing confidence” in women’s future; b) The “work” of protecting others; and c) Maintaining care: just being Black.

“Killing confidence” in women’s future. This theme is one of the ways women described their experiences of load bearing. This is about others, particularly women’s spouses, killing women’s confidence as well as maltreating and discouraging women from having hope for the future simply because they are living with HIV. Some women have supportive partners, but sometimes women get partners who question their point of going to school, working or even dressing nice given that they are HIV-positive. In fact, the spouses feel there is no point for the women in putting in an effort. It is just over.

Women therefore narrate their stories and how some of their spouses just ‘look down’ on them and see them as slaves whose position in the house remains in the kitchen and in manning the house chores and taking care of the children. Women also mention, facing neglect and chronic emotional disturbances that characterise their everyday lives. These women also had to listen to the demeaning utterances and treatments from their spouses, and still had to wake up the next day and to fight. It takes strength to then get up and go take their medication, go take care of their children and go back to work.

Rachael illustrated this experience of “killing confidence” since as much as she didn’t want to be a single mom, following the ill treatments, she experienced living with her spouse, she had to quit her marriage. She was constantly abused verbally, and neglected, and the spouse felt there was no need for her to improve herself or even leave the house as she was HIV-positive. As she narrated,

> Before coming here, I lived with my spouse for almost two years in Ethiopia. He was supportive, just understanding, and always appreciated my contributions and ideas. Sometimes, even when I feel bad, he supports me in feeling good. But, after I came here, he started to use me because I have HIV. He always looked down on me and tried to kill my confidence, just making me feel down. I'm HIV positive, so he thinks I don't have any dreams for the future. When I asked him to go to school to take an English class since English is not my first language, he said, oh! What do you need it for? I'm just HIV positive (Rachael, 44-year-old, ACB HIV woman).

Rachael continued to recount the sad and ugly experience living with her husband which took a toll on her mental wellbeing, As, she further adds,

> And when I asked him to let me find a job, he said, no, you don't need it. You're not as good as other people. He looks at me with negativity, not like a wife but as an enslaved person at home. He does not want me to contact and connect with anyone. I didn't want to have a baby at that time. I needed time. He tried to get me pregnant because he thought if I became pregnant, I'd just not be going anywhere. He couldn't even care about my medication, my health, and my nutrition. It was the worst time I ever spent in Canada. I couldn't imagine that people lived that kind of life without food. Oh! It was a hard time. He makes me not have thoughts about the future at all (Rachael, 44-year-old, ACB HIV woman).

Rachael had ‘good’ expectations about life, and didn’t want to kill her hope, she needed to live as she further adds,

> I wanted to live. A few months later, my doctor figured out what was going on in my marriage. She asked me with an interpreter, and I told her what was happening in my life. They connected me with support in family dynamics, followed everything about me, gave me advice every time, and even built my confidence. They took me out of his home; they just sent me a shuttle. Yeah, it surprised him. I separated from him because of my HIV status, and legally, we divorced last year (Rachael, 44-year-old, ACB HIV woman).

Rachel had to leave her husband to rebuild her life due to his maltreatment simply because of her HIV-positive identity. Her spouse cared less about her condition and her health, whether she had something to eat or not or even the kind of food she ate, considering that people who live with HIV need to eat healthily to preserve their health and also be able to take their medications. Not wanting to kill her hope about the future, her confidence, and to remain in control of her agency and social life, she had to fight. These challenges Rachael faced have severe implications not only for her health but also for her care and life. In fact, that's dangerous, because if there's no future, one can be plagued by thoughts of ending his/her life and that's where suicide comes in. Rachael hearing those hurtful statements from her spouse who ought to be supporting towards her, that is traumatizing. Even still, the restrictions Racheal would have faced in wanting to leave the house, to attend her HIV care appointments and blood work at the clinic, or even in adhering to her medications, that is also distressing and obstructing to Rachael to living a healthy and productive life.

Theresa also added how it isn't the same when a woman is living with HIV compared to men living with HIV. Women tend to suffer more than men. As she stated,

> As a woman, you'll have more challenges, and people will judge you quickly, like it's her fault she got HIV. But when men get HIV, they feel like they have the right, even though people know about their HIV status. For example, a man who has HIV can marry anyone, like a girl, if she's willing to marry him with his HIV. It doesn't matter if she doesn't have HIV. But when it's a woman, just a woman living with HIV, she doesn't have any right even to marry someone who does not have HIV (Theresa, 38-year-old, ACB HIV woman).

ACB Women draw out the differences and freewill men do have over women and the violence against women when living with sero-discordant partner. Women often face harsh treatments, unequal power relations, and also have less privilege than men, which not only affects their autonomy, but compromises women's safety, increases their burden and makes them disproportionately vulnerable to health and mental health problems. This reflects women's experiences in Winnipeg and what they go through. Women's lives continue to be a struggle and they also face trauma even as they navigate HIV care and support services in Winnipeg.

The 'work' of protecting others. This is another way women illustrate the load that they bear. This 'work' signifies protecting others and making sure that the women do not pass HIV to their spouses, children, and other persons within the community. Women set out to protect others from the transmission of HIV and also for their peace of mind. Protecting others involves women not having to breastfeed their newborns, but instead using formula. Women also need to exercise a lot of caution and effort, practice safer sex while engaging in sexual activity, especially in a sero-discordant relationship, that is a sexual relationship in which one partner is HIV-positive and the other is HIV-negative. Protecting others also entails that they not only apply the utmost care during sexual intercourse but also have to disclose their HIV status to partners before having the sexual intercourse. In other words, women's 'work' also involves avoiding criminalization. Being mothers and wives, women talk about how hard it is to be a woman with HIV, protecting lives and the toll it takes on them, their mental health, their care, and wellbeing in general. Flora, who works full-time and is married to a White man, illustrated,

> Yeah, my husband doesn't have HIV; he is HIV-negative. We have been together for almost eight years. Every time we have to have sex, we need to be thinking wisely; it has to be like you feel like doing it. If we have to have sex all the time, we have to be using a lot of caution for us to have sex. He knew that I had HIV when we met, but still, I wouldn't feel comfortable with him getting it. I can't live with it if he catches HIV from me. It will kill me. We must be careful; let alone the person you built your life with. You know that you have this deadly disease on your side; you have to be very careful when

> you have intercourse with people who do have HIV (Flora, 36-year-old, ACB HIV woman).

Rather than being an enjoyable, intimate experience, for Flora, knowing that she is HIV-positive, engaging in sexual activities with her husband appear to be a lot of work and burden. She constantly has to deal with the thought of protecting him from getting infected with HIV. She further also describes the load, the trauma and agony she also bears in a bid to protect her newborn from also getting HIV. As she further described,

> Being a woman is very hard, especially being a mother. But having HIV and being a mother is one of the things that gets me emotional. You're not able to breastfeed your kids if you're living with HIV, no matter what, even if your CD4 count is very low, like I have a better count than a normal person who is HIV negative. My virus is undetectable. But, still, I couldn't breastfeed my kids. My breasts, I have never experienced that with my kids. That is very traumatizing. It’s like the worst feeling you could ever have. It is hard; to this day, it is the hardest thing and heavy on me. Mentally, it is hard. Physically, it is hard. I feel like it is hard either way. It has been the hardest time of my life (Flora, 36-year-old, ACB HIV woman).

Flora expresses her agony at not being able to breastfeed her baby in a bid to avert mother-to-child transmission of HIV. Even though, also, she feels the need to breastfeed her baby as breastmilk is a free source of nourishment that facilitates bonding with the baby, also, among people of African and Black descent, there is also the cultural expectation for a mother to breastfeed her infant. However, she finds herself in another world of being, wherein that challenges her core identity as a woman, and mother, thereby limiting her sense of self-worth and identity simply as a person living with HIV, and not fully experiencing the joys of motherhood.

For Flora, the work of protecting her family weighs heavily on her, causing her serious emotional distress. She feels like she is "carrying a lot," like a "heavy load" is on her shoulders, in addition to the work of protecting her family and others, there is also her full-time job. Similar to her life before the HIV diagnosis, she continues to experience trauma, which is kept alive or worsened by her deeply disturbing or distressing experiences.

Maintaining care: 'Just being Black'. Maintaining care is also another way women illustrate their load-bearing experiences, and it also has to do with all the hurdles women face and have to surmount while trying to maintain care and retain HIV services. As much as women narrate about committing to care, earlier mentioned, maintaining care is not an easy task but instead is, encumbered with different struggles in which women's lives intersect. Women emphasize the lack of a support system for ACB women living with HIV, particularly being in a setting where most women do not have access to the support traditionally provided by family members. The lack of support thereof makes daily living and maintaining care often challenging for women. As Flora again narrated,

> Africans who live with any transmission disease, like HIV, don't have support; they don't have such. They don't have an interpreter for you. I volunteer as an interpreter, sometimes at regular hospitals. There is no (interpreter). Finding these kinds of things is challenging and bothers me a lot. Women would need to get their meds and struggle with that still. No group can find an interpreter for me. No group would take care of my baby so that I could find a job. And she can't trust her community because they talk, and there is a stigma associated with HIV. For women like me with HIV, it's hard (Flora, 36-year-old, ACB HIV woman).

Being Black and living with HIV and maintaining care is permeated with cutting-across issues such as dealing with language and child care, including stigma. These issues appear complex and are interwoven and often difficult to unravel. The multiple demands of living with HIV and maintaining care add to the already stressful HIV experience. Women further outline about the lack of resources and support.

> There are also no resources. When I say resources, no company or organization would be there to explain things to you. There's also no support group one can reach out to. Some people have trauma over getting HIV because people get it in different ways—trauma, rape, and a lot of other connections, and not certainly by sleeping around. However, there are not enough resources to express that. I feel like Caucasian people with HIV would have more resources to be treated better. There may be a support group for people from here, but we don't have a support group for immigrants. Just being black, yes, in Canada is different (Flora, 36-year-old, ACB HIV woman).

Women also describe concerns about discrimination in the care environment because of the widespread prejudicial attitudes toward people living with HIV, and especially Black women. Although discrimination was often times not visible for women, for some, it was felt. Christy described her experience participating in one of the support programs at the clinic and how she felt discriminated against. While trying to maintain care use, that discriminatory experience harmed rather than helped her. She therefore questions the need for her to continue using such services. As she outlined,

> I used to go to the clinic for a support program. However, I noticed that every time I went, one woman from the US facilitating the group would have her utensils. She will use her kettle to make her tea and wouldn't share the same kettle with us. That hurt me

> and affected my esteem and humanity because I felt, oh! Suppose this facilitator, who is supposed to be educated, doesn't want to share something as simple as a kettle. Why should I even participate in anything like the program or with other educated people? This harmed me more than helped me and is one of the main reasons I stopped going. I just felt less than human because of that experience, and isolated and unwanted in a way. I also ceased attending the clinic for in-person interpretations (Christy, 50-year-old, ACB HIV woman).

Here, this experience specifically is more about HIV related discrimination and stigma, but Christy being HIV and Black, the intersection of these identities is an added weight that she is experiencing, feeling uncomfortable because the lady wouldn't share a kettle with them in the group because of being HIV-positive. Explicitly, this experience adds to other experiences that she and other women face in terms of being a Black women. Women gets discriminated in various ways. Race isn't the only thing but stigma being a woman. Consequently, the impact of this experience is an added layer of load on Christy's life that now shapes the way she uses care. She also struggles internally, feels like an outsider and not like others, and suffers emotionally.

Women also talk about other issues which they face trying to maintain care, including difficulty accessing care due to lack of financial means and transportation, and women also have busy schedules. As Joan described,

> They told me they have a food bank program, but I just went once. I did not go again. I had no time to go. I was busy schooling and working. I had no help, too, so these problems made it hard for me to go to the food bank program. We had no car since I live far from there (Nine Circles). When it was wintertime, it was even more challenging for

> me to pick up the food, and I just decided not to go anymore until now. Yeah, I feel like the food bank) helps, but it's far from me (Joan, 30-year-old ACB HIV woman).

Theresa also shares a similar experience,

> They have a lot of programs, but I was only sometimes there. I just participated in the One Feel Better Together and Coffee Time program. We are running another program where we meet monthly to discuss and learn from everyone's experiences because we have different experiences. But I missed it every time because I was busy. Since it was a night program, I usually went with my kids to play soccer and basketball at that time. So, I was busy, and I missed that program (38-year-old, ACB HIV woman).

Here, as much as women would love to maintain their care use and attend support programs and continue to live well with their condition, they have busy schedules and also face accessibility issues. Even still, juggling work and at the same time maintaining care feels also ‘stressful’ and burdening as they strive to maintain secrecy of their HIV diagnosis even at their workplace, and also constantly have to miss out or encroach into their work time in order to attend their appointments. Being absent from work not only does affect women’s productivity but can also result in disengagement and loss of pay, which in turn impact women’s ability to pay for their medications, since HIV meds aren’t free. Flora illustrated,

> When I have an appointment, they take my blood work today, and three weeks after, I have to get my results. They have to check my thyroid three or four days after that. So, for people with this disease, there are constant doctor appointments. Like, they send you everywhere. So, if you have a job, you need to take a week off to organize that and get all that done. So, taking that time off is stressful. It's very stressful, especially if you don't want to talk about it, and if you tell them about it, you'll lose your job. So, women are just

> very stressed out! Stressed about working and missing their work time to go to their appointments, You could only say so much about taking off so many days (36-year-old, ACB HIV woman).

Similarly, Christy highlights the anguish she bears at having to get her blood work. The frequency of visits and the constant strain on her body affects her mental wellbeing. As she explained,

> Ever since I've been diagnosed, having my blood drawn, like, every so often, that's one of the things that get to me and causes me psychological and mental health issues because it's always that persistent strain and stress about having my blood drawn every single time and I feel like am not living because of that (Christy, 50-year-old, ACB HIV woman).

Christy feels like she is not living, having to give blood over and over again. Although more frequent blood testing may confer better outcomes, the repeated blood testing can cause progressive scarring to the veins, and in some cases, lead to damaging the veins over time, causing swelling and pain, that in turn severely impact individuals' quality of life. Additionally, the 'feeling of not living' presents serious health implications. It can contribute to poor treatment adherence, and an increase in other maladaptive behaviors. However, given that HIV is a lifelong infection and maintains such a permanent presence in the body, Christy is compelled to bear the load and burden of that constant drawing of her blood and the consequent psychological and acute mental health distress with no end in sight. Maintaining care remains such a huge task and more so emotionally distressing.

Additionally, in trying to maintain care, women also worry and fear about being seen by others at the clinic, such as Nine Circles, particularly folks from their community. As Linda notes, “For the programs, I can attend when I can, but if there are too many African people, I can't be seen because of the stress. I don't like to be stressed again. I thought that life is good, but I don't like to be stressed because of HIV” (45-year-old, ACB HIV woman). For Linda, based on previous experiences, she is okay missing out on care and support programs, rather than face the stress of being seen and consequently gossiped about. Indeed, maintaining care seems to be burdening considering the very many hurdles’ women have to navigate and surmount, which remain loads in women’s lives, increase their burden, contribute to trauma and also shape the way women use and maintain care.

Waiting

Weaved throughout women’s interactions with the Winnipeg health care and available support systems were experiences of waiting. Waiting was about women sitting in a clinic and waiting to be called to see their doctor. It was about feeling disrespected with their time. Waiting is also about women not being able to get an appointment when they need to meet with their doctors. Women expressed how their personal effort to maintain care is jeopardized due to long wait times and inability to see their specialist, particularly when they need care the most. When women are not able to secure an appointment to see their doctors, they don't get to express the concerns which they may have. These experiences of waiting are disturbing considering that these are women who face daily struggles, are often overwhelmed with fear, and whose everyday lives also feel like war and burdened with trauma.

The consequences of long wait times (between booking and appointment and seeing a doctor) compromises women’s health due to delayed utilization that defers appropriate treatment, and also increases the sufferings in these women’s lives and women feel frustrated. Long wait times also disrupt women’s schedules such as work and other things they could be doing, decreases their satisfaction and adversely affects their willingness to return to the clinic, which could greatly reduce the utilization of HIV care and support services. Indeed, as much as women set out to use care, excessive waiting remains a barrier to their care continuum.

Emma, who typically uses her 15-30 minute break time at work to attend her appointments, describes the awful experience of waiting at the clinic to see her doctor. Although it was more important to her to maintain care and stay healthy, with the waiting and long delays to receive HIV care, she felt disrespected with her time and abandoned, even to the point of questioning how one could just literally forget her at the clinic. As she narrated,

> I look forward to my appointment; it's a good environment, and every other interaction has been quite cordial. However, I arrived at the clinic (Nine Circles), but then the front desk didn't attend to me or notify the nurse that I had arrived and was there for a while. Even though calling her attention and mentioning that I was supposed to be seeing the nurse at such a time and that I needed to get back to work, she just said, oh, yes, I know, the (nurse) is attending to somebody else. She will come out to get you and roll her eyes when she's done. The body language generally told me she was not in for me at all, twice. I don't know what or why that happened (Emma, 44-year-old, ACB HIV woman).

Here, Emma noted how she was treated by the front desk staff and how unprofessional the front desk staff acted in terms of handling clients' arrivals. Even with her constant reminders and mention that she needed to return to work, the front desk staff made her wait, encroaching on her work time and also making her spend more time waiting than actually consulting with her care provider. Emma recalls also that it was not her first encounter with that front desk staff. It happens many times with the staff.

Flora, similarly, also describes the difficulty of getting an appointment with her doctor at Nine Circles. As a result, she was unable to see her doctor, particularly at the time she needed care and also didn't get to 'express her concerns'. When people bottle-up their concerns, it can impact mental energy and endanger health, both physically and psychologically, including general wellbeing. Further not expressing ones' concerns can increase stress in the body and lead to depression and reactive outbursts. Likewise, the inability to secure an appointment also amounts to stress and disruption in the continuity of treatment and care, which can in turn negatively impact women's outcomes. As Flora shared,

> Getting an appointment when you need your doctor is very hard at Nine Circles, that's for sure. I remember, like so many times, I tried to get hold of my doctor, Dr. (xxxx). I tried so many times to make an appointment. Sometimes, it takes a month or two. His availability and mine sometimes do not work. So, we don't get to see each other. I don't get to express my concern, and it remains like that. When I was pregnant, I had to make my pap appointment with my gynecologist, and she could see me, even though my doctor at Nine Circles could not see me. Yeah, it's a hard thing (Flora, 36-year-old, ACB HIV woman).

Waiting is one of the ways women describe that shapes their HIV care experiences in Winnipeg and also determines their quality of healthcare and support services. When women do not receive timely access to care, they are likely to experience a decline in their condition. It can also create the impression that their health concerns are not significant, exacerbating discomfort and pain, particularly for those who are unwell. As the women have stated, waiting for an extended period disrupted their daily schedules, causing inconvenience and potentially impacting their work time and overall experience.

Dealing with language

Women also narrate their experiences of HIV care and support experiences in Winnipeg, including dealing with and facing language barriers. Language barriers refer to linguistic barriers in communication between individuals that impede understanding and can also result in miscomprehension or complete loss in communication. The language barriers affect women's access to care and how HIV care and support services are understood. Women also point out how their lack of understanding of the language necessitates that they use an interpreter in order to attend care appointments. Women feel uneasy and concerned considering that they have to meet with different interpreters all the time, and more so, Winnipeg is a small city. This poses significant worry for women who fear their confidentiality as well as about people finding out about their status. As Flora explained,

> One of the issues remains that there's a different interpreter from the community at every meeting I attend. Even though they say it's confidential, I do not have confidence in it. Different people come in from the community every single time. It's a small community in Winnipeg, and everybody knows my business; I do not find it okay. If it were to be a doctor or healthcare professional, that is one person consistently doing it, then I guess that would make a difference. But the fact that different people come in to translate doesn't sit well with me (Flora, 36-year-old, ACB HIV woman).

Christy further expresses concerns about how the language barrier impacts her ability to work. As she adds, "I do want to work, I have a desire to work, but the issue is due to the language barrier and then the education level that I have, there's not a lot of work that I can do. It's mostly contained within cleaning services. Oftentimes I pick up cleaning jobs, but I've not been able to really work at any job that I want" (Christy, 50-year-old, ACB HIV woman).

Theresa has a similar experience, highlighting how difficult it is for immigrants generally, which includes ACB women living with HIV because of the language. She also points out how the problem of language personally affects her. As she described,

> It's hard because of the language. It was hard to start here because I was settled in my country. I had a job and income. I also had my own home and business. But when we came here, I had to start from scratch. You have nothing; you have to find a job, pay rent, and even do that, especially for a woman, a Black woman; even without HIV, it's hard. With HIV, look at that; it's just hard. Language is a huge barrier. I might not engage more or be found in the community, society, or social service because of my language. I'm afraid of explaining myself. I don't have enough vocabulary or grammar to explain, and people might not just understand me even if I explain in different ways (Theresa, 38-year-old, ACB HIV woman).

Whereas back in her home country as mentioned previously, where Theresa worked in an HIV organization supporting people living with HIV in the community, due to the issue of language, she prefers not to connect with others in the community as she feels people may not understand her. The lack of understanding of the language limits her involvement and engagement with social and support services the way she ought to. Due to the language difficulties, her social life is also affected, and she mentions not having social peers, isolating self, and choosing not to go public. Consequently, she feels like she doesn't have anything. Also, given that language is a crucial means of expression and communication, she battles with finding a job. This has serious implications not only for her physical health and well-being, but being unemployed also takes its toll on her mental health and increases the stress she faces daily as a woman living with HIV and also a single mom of two children navigating the world and HIV care and support all by herself. Indeed, the problem of language impacts women’s lives as well as their care use. Language affects employability, which prevents women from sharing any ideas, thoughts, feelings, experience, information, expectations, and giving feedback. Employment is also a setting in which many people express and achieve competence, receive positive feedback, advance their abilities, and experience a sense of achievement. As such, it may be a uniquely important anchor while dealing with a disease such as HIV.

Feeling a lack of safety, cultural competence, and sensitivity

Women further shared their experiences of HIV care and support services, highlighting feelings of lack of safety, cultural competence, and sensitivity in care delivery. Safety is about creating an environment that is safe for African, Caribbean, and Black people and it focuses on prevention of harm and adverse effects that occur during provision of health care. Cultural competence, on the other hand, refers to the ability of providers and organizations to effectively deliver care services that meet the social, cultural, and linguistic needs of patients. At the same time, cultural competence also entails care providers acquiring skills, knowledge, and attitudes to work in more respectful ways with people of different cultures. Cultural sensitivity similarly refers to providers' appreciation and respect for the cultural diversity of clients. Culturally competent, sensitive, and safe care, focuses therefore on making spaces, services, and organizations safer, considers the social and historical contexts of people’s condition and health care inequities, and as well results in an environment where people feel safe and there are no challenges to their identity or to who they are.

As racialized women with HIV, women talk about the lack of safety, cultural competence, sensitivity, and awareness in the care delivery. Navigating the world where most women do not understand the language (English), women highlight how the whole program is set up and centered on the culture and understanding of the West. And so, being an ethnic minority, coming in with a different language, it doesn't feel like a safe space because they do speak the language fluently. It also doesn't feel safe, because there are different people coming in to interpret, and it also doesn't feel safe because it's not approached with their cultural understanding in mind and so, all these things definitely happen and affect them because they come from an ethnic minority. For women, therefore, the lack of safety remains a huge gap and indeed affects the way they use and receive care. As Christy described,

> The way the programs are set up is geared toward English-speaking people. It's English-speaker-friendly, more so than people like me, an ethnic minority. Most programs, if not all, are not designed with people like me in mind. It's generalized, designed for the general public, predominantly Western-centric and English-speaking, friendly, and oriented. So, it doesn't feel like a safe space. Yes, it does affect me because I am African, and I am Black. So, because of those reasons. Given how they set it up, the thinking is, oh! for one to constantly need an interpreter or someone to relate with you. It doesn't feel safe. It feels like injustice with the system being designed, not considering me in mind (Christy, 50-year-old, ACB HIV woman).

Christy further highlights how there's also a lack of cultural awareness and cultural competence when it comes to the healthcare that is provided to her, not just at Nine Circles but also in other places/areas. Due to lack of cultural competence from health care providers, she mentions that she doesn’t end up getting the appropriate care that she needs. She doesn’t also feel taken care of and seen as it should be. As she added,

> A lot of times, I find that other healthcare providers, whether they're nurses or doctors, often lack that cultural competency. They often lack that sympathy of, you know, as a

> racialized woman with HIV and AIDS, and I'm navigating the world where I don't understand the language. They don't consider all these things, and the things that they do can often come off as offensive or sometimes just downright not dignified (Christy, 50-year-old, ACB HIV woman).

In terms of cultural sensitivity, coming from a cultural background, where there's a lot of stigma, Christy also mentioned how one care staff at Nine Circles openly and loudly blurted out her HIV-positive status at the reception area. As she outlines, “Some of the things that I have endured, someone from Nine Circles blurted out my HIV and AIDS status out loud. You know that was, such a humiliating moment for me” (50-year-old, ACB HIV woman). Disclosing HIV status to friends, family, and sex partners is often stressful, let alone to the public and more so even without the person’s consent. Publicly disclosing her HIV status increases the likelihood of being alienated by others who were previously unaware about her status. This can have serious negative effects on her self-esteem and social support. Also, because HIV is often negatively perceived by the public, that public disclosure carries greater perils and threats of harassment, rejection, humiliation, and even violence. It takes strength then for Christy to visit the clinic again and attend her next appointment.

Flora also mentioned how women face cultural barriers in accessing care because women lack understanding of how things work and even also lack access to information as earlier discussed. As she pointed out,

> Women have a problem with cultural things; they need to understand how things are done here. And to be honest, maybe 70% of the time, we don't have information, I could say, to live life the way we anticipated, the way it was promoted to us when we were in Africa (Flora, 36-year-old ACB HIV woman).

The lack of cultural competence, sensitivity and awareness by care providers hinders women interactions and how they engage with HIV care and support system. It may make women reticent to seek care, delay seeking and obtaining care or engage deeply with their provider. When women are engaged, they are better able to make informed decisions about their care options. Additionally, they can also inform HIV care education and policies, as well as enhance HIV care and support delivery. The lack of cultural competence, sensitivity and awareness may also affect communication with women and make them uneasy and reserved in their interactions with their care providers. This creates situations where women may not feel free to share crucial health information and also not fully disclose their concerns, creating additional burden for the women.

Lacking medication coverage

Lacking medication coverage is another way women describe their experiences of HIV care and support in Winnipeg. This means women having no HIV drug coverage and therefore having to bear the burden of paying for their HIV medications, which comes at a huge financial cost, especially since HIV is a lifelong illness. The high cost of HIV medications is a huge concern since most times women have no job (largely due to language barrier and women's HIV positive identity) or even work lower-paid jobs. Even for those that work, they also share a similar concern. Therefore, women rely on private insurance, public funders like the Manitoba Pharmacare Program, out-of-pocket payments, or a combination of these to pay for their medications.

When using the Manitoba Pharmacare Program, in order to be eligible, a deductible has to be paid, which is usually based on an individual's adjusted family income. Paying this deductible most times is a struggle for women. Unlike in selected provinces in Canada such as in

British Columbia where all medically eligible persons at risk of and living with HIV have access to antiretroviral therapy at no cost, in Manitoba, the situation is different and people living with HIV, including ACB women, continue to account for a disproportionately greater burden of care and costs. The disparity in HIV medication coverage results in unequal costs for women when compared to other people living with HIV in Canada with the same prescriptions, impeding health equality across the country.

Sophie shared about the stress she feels having to pay deductibles for her medication along with her husband who is not living with HIV, and because of the medication payments, they had to divorce. As she explained,

> We are husband and wife, but I am the one who has a problem. I am living with HIV. I work three days a week as a cleaner, and he used to work five days at the post office as a cleaner, too. We have the same rate (pay). We got to spend money on my medication. When he paid for the deductibles, I asked myself how I would live like this. I got stressed and even cried. Even though I thought we would live like this, with my health condition, it became a less valid problem. He doesn't talk to me or tell me anything, but behind in his brain, he needs to be free to live. So, that's why we divorced, that's why he married another woman (Sophie, 39-year-old, ACB HIV woman).

For Sophie, even though the husband contributed to paying for her medication, deep down she sensed he wasn't happy, needed to be free. He ceased communicating with her and bothered less about her HIV condition. Even though she was married with two beautiful kids, she decided to divorce her husband to make him free, free from contributing to paying for her medications and deductibles. Sophie's family became broken due to the issue of medication coverage because she is living with HIV.

Sophie also ponders about other women like her that are living with spouses who are not HIV-positive, stressing on how HIV medication shouldn't have to be a hitch for families and ultimately, asking (wishing) that HIV medication is made free for people living with HIV. As she added,

> It was me, for example. Now I'm single. What about others? One person has HIV, and the other doesn't; they have kids and bills, and on top of that, there is a medication problem. Are they going to live a happy life? No!! Yeah, this (HIV medication, no coverage) is not good for families. It breaks up and separates families, but the government likes to support only single parents. Families don't have to divorce because of this kind of stress. One person earns more, and another earns like this. HIV medication doesn't have to be an issue for marriage. Yeah! It doesn't (Sophie, 39-year-old, ACB HIV woman).

The lack of HIV medication coverage has serious consequences for women's lives. Sophie wouldn't have had to divorce her husband if only there was full coverage for HIV medication, and she didn't have to pay for the deductibles, regardless of her income. The lack of HIV coverage and having to pay for HIV medications adds on to the loads women already bear, increasing their sufferings and trauma. Likewise, lack of HIV medication coverage could also affect treatment adherence, viral suppression, and related health outcomes.

Flora also describes how she had to stop taking medication because she couldn't afford to pay for it. As she explained,

> I did not take medication for the entire year because I couldn't afford it. I couldn't afford it. They said you have to pay the deductibles, and I said I can't. Like, I feel if HIV medication is very, very expensive, there should be a program that covers it besides the pharmacare (Flora, 39-year-old, ACB HIV woman).

When women are not able to get on HIV medication, they are less likely to achieve viral suppression. More so, stopping treatment allows HIV to actively replicate and circulate in the blood and this is associated with increased inflammation in addition to increased exposure of kidney and liver problems including heart attacks. Additionally, discontinuing HIV medication also predisposes women to becoming more vulnerable to serious infections and therefore, they are likely to become ill. This can put their health at stake and also endanger their lives. Furthermore, discontinuous antiretroviral therapy can also result in drug resistance, increasing costs associated with care. In fact, women will continue to face a range of challenges including difficulties accessing HIV medications if the issue around HIV medication is not addressed. Having stable coverage and uninterrupted access to HIV medication remains key for improving health outcomes for women and others living with HIV.

HIV self-acceptance

HIV self-acceptance is another way women describe their experiences of HIV care and support in Winnipeg. Living with HIV, for many women, has meant adjusting to life with a stigmatised condition—that affects how women connect to care, and also prevents women from taking an active role in society, isolating, and preventing women as well from living a full and enjoyable life. In addition, worries about the future, health, and feeling ashamed about their HIV-positive status as well as low esteem also remain. This in turn often also makes women feel that they are somewhat different than everyone else in society.

HIV self-acceptance therefore involves women looking within and accepting themselves and their HIV-positive identity and also building a positive outlook that helps them to live well with their condition, and also allowing them take important health decisions such that benefit their health and promote positive health outcomes. Women seeing how far they have gone and survived living with HIV, create a stronger sense of self, unlike when women were newly diagnosed with HIV, wherein most felt scared learning about their status and thinking they will die in a short time. HIV self-acceptance allowed women to have a solid grasp on their sense of identity, accepting their new identity and having positive feelings about themselves. Rather than being afraid and pigeonholing themselves, women value and believe in themselves, understand their needs and desires and tend to care for their health. This understanding and self-acceptance gave women the peace of mind and renewed strength to continue seeking treatment and adhering to antiretroviral therapies (ARTs). Women are also able to progress with their lives and have more control over their lives, having more understanding of HIV over time, living with HIV.

Linda shares her experience, describing how her acceptance of her HIV-positive identity helped her to cope well with her illness. Being aware of her HIV status, it would have been expected that she would be downcast and emotionally impacted. Rather than let her HIV positive status weigh her down, depress her or make her feel defeated and give up, —over time, living with HIV and having gained more understanding about HIV, Linda fully embraces her condition, recognising that full acceptance of her HIV status will help her cope better and access care and support as needed to be able to live a full life. Linda, therefore, takes her health and care as priority and sets out to achieve her dreams. As she explains,

> For me, I have already learned. (HIV) is a part of my life. I can't run again. I have come to accept the way I am. People run; I don't know why. When you accept, you forget and continue to speak only positively. Since I got this disease, I've never gone to the hospital to sleep for emergencies because I accept the condition of HIV. You'll forget the name, HIV, but you know you're sick; you seek help and take your medications and put a schedule of the time to take the medication. It's like a person that has diabetes and high

> blood pressure. They take their medication daily. So, we are the same, no different. When you forget and continue your life, you'll stay longer and do what you can do (Linda, 45-year-old, ACB HIV woman).

With Linda's self-acceptance, she sees the need to keep up with care and take her medications in order to live well, regardless of the stigma that comes with the status. She also exudes a positive energy and mindset that can relieve stress, depression, and anxiety — all of which in turn strengthen her immune system and make it easier for the HIV medications to be effective. Indeed, HIV self-acceptance and controlled "forgetting" really matters to Linda as she feels free rather than trapped in her illness and she sets out to manage her health properly. Linda's experience reflects other women's experiences, who also self accept their new identity, having understood more about HIV and knowing they can live long, healthier lives with their HIV condition so long as they remain committed to care.

Treating differently or with dignity

Women further narrated their experience of HIV and care and support, to include treating differently or with dignity. Everyone, in spite of who they are, including people living with and affected by HIV, has a right to health, and to make decisions about their health and to be treated with dignity and without judgement, discernment and prejudice. To treat someone with dignity means to treat them with courtesy and as being of worth, in a manner that is respectful of them as valued individuals. It is also about giving them freedom of choice and listening and taking into consideration what they say. Hence, the dignity of an individual is reached when such a person is treated ethically and with 'good' manners. When one is valued and treated with respect, one's health can actually improve, and one can manage their health and cope better with illness, leading to a better quality of life. On the other hand, when people are treated differently and without dignity, it makes them feel worthless, and this can have tremendous negative consequences for their physical and mental and their overall wellbeing.

Christy recalls her first experience accessing services at the Mission of Welcome place, an organization that provides support services for newcomers to assist with settlement in Canada. Being already aware of her HIV status, she narrates how she was treated differently by the Welcome place staff. Compared to how she was treated before knowing she had HIV, it was the first time for her to experience how people looked down on those who have this disease, and whether they were White or Blacks, or Asians, it didn't matter. She noted she felt less than, and also felt like she was ostracized. She also even considered suicide but couldn't bear the thought of leaving her three children behind. But then, she felt grateful knowing that her kids were healthy, and as such wouldn't have to deal with what she, was dealing with and that gave her some joy in the whole situation. As she described,

> There's a way they treated me differently than others. At least I could realize that I was being treated differently than before I knew I had the disease. So, I considered suicide. I would instead have taken my own life rather than live with that kind of treatment. But I continued and endured because of my kids. They were younger then, and it was just hard for us. I kept pushing on despite not wanting to continue living because of the way I was being treated and the different treatments I experienced (Christy, 50-year-old, ACB HIV woman).

Christy felt dehumanized and her dignity was violated. No person deserves to be treated disrespectfully on account of living with HIV, and worse still, even contemplating committing suicide. In fact, treating with dignity remains of great essence for women whose self-identity and worth has been and continues to be threatened through fear, and the attitudes of others towards them within society. If women are not treated with dignity, that could discourage them from engaging more and connecting to care. Christy also shared her experience accessing care at Nine Circles clinic. Although, a lot of the time she feels that dignity is gone, she's not treated with dignity, which is so harmful to her mental health and overall health. In fact, she also feels that a holistic approach is lacking. However, she recounts an experience of where a specific doctor treated her with dignity and went above and beyond to make sure she felt heard. As she further added,

> He was kind and compassionate, basically putting himself in the shoes that I was in, as someone who's struggling with HIV, and would make sure that my concerns were addressed. He was also able to understand where I was coming from, sympathized with that, and gave me treatments and health care from that understanding. And when he treated me, he wasn't also like the other care staff who would have an aversion to the way they would even approach me or others living with HIV. I appreciated that, above all else (Christy, 50-year-old, ACB HIV woman).

Christy outlined what it meant for her to be treated with dignity. Three key things stand out in relation to treating women with dignity: sensitivity, equality, and empathy. Women want care and support staff to be sensitive to their needs and do one's best for them. They also want to be treated the same as everyone else and also with empathy, while respecting their individuality. Meeting these needs not only amounts to real quality of life for women but can also lead to improved use of services.

Conclusions

As much as women mention about being treated with dignity, however, in general, women's experiences of HIV care and support in Winnipeg remain such that is largely rooted in different struggles and sufferings as described in this chapter. While women commit to using care, they are often made to wait to see their doctor and to book their appointments. Women are being discriminated against in the Winnipeg health system by waiting. Women are also often treated differently, and worse still, bear multiple loads that remain barriers in accessing care including also being maltreated. Even though women sometimes receive support from their family members, they also have to deal with the problems of medication, having no coverage and paying deductibles. Women experience different barriers in accessing, maintaining, and keeping up with care, all of which affect their physical, emotional, mental health and overall wellbeing. But then, women continue to fight to live well, and they self accept their HIV-positive identity and create a stronger sense of themselves in order to live well with their condition.

CHAPTER SEVEN

SERVICE PROVIDERS' PERSPECTIVES ON WOMEN'S EXPERIENCES OF HIV & CARE

This chapter outlines service providers' perspectives in relation to how women experience HIV care and related support services in Winnipeg. Twelve interviews with service providers were conducted with individuals from three organizations: Nine Circes Community Health Centre, Sexual Education Resource Center, and Welcome Place. Six key themes stood out in the interviews (also see figure 2), including: (a) Valuing care; (b) Cultural care is for Indigenous, not Black; (c) Preferring services in own language; (d) Waiting again; (e) Connecting to religion and spirituality; and (h) Dealing with the cost of HIV medication and treatment. The views of health care and support professionals reinforced many of the views expressed by women. However, oftentimes, it varied, and care staff tended to emphasize a lack of trust in the health care system and how women feel uncomfortable, do not feel safe and welcomed because care is not culturally informed and fail to attend to the needs of women as racialized population.

Valuing care

Valuing care is one of the ways service providers described women's experiences of HIV care and support, as seen above one of which included valuing care. The notion of "value" means something of worth or significance, or something people attach importance to, while the concept of 'care' as described in the previous chapter includes providing holistic support to patients to enable them to meet their personal needs and live healthy fulfilling lives. In this paper, valuing care means women taking care services as crucial and deciding to use HIV services in order to live well with their condition. Many service providers described that ACB women living with HIV in Winnipeg value care in terms of attending their medical appointments, and not wanting to miss their appointments except in serious situations. Service providers mainly attributed the reason to women coming from their home countries, where many lacked access to HIV medication and treatment. As such, women feel lucky that they can access HIV care and therefore make judicious efforts to regularly visit the clinic for their care to improve their daily life.

Service providers also perceived that women value care because most of the women diagnosed in their home countries are already on medication and are also pretty knowledgeable about HIV. Hence, they will go to the clinic, not an issue, and continue with care and be careful. Service providers also pointed out that women come to Canada with a goal (reason), as previously stated in the earlier chapters—to better their lives and those of their families and children. Based on their mindset, HIV is not going to stop them. Women will connect to care to preserve their health, so that their lives can just go on as if they were not carrying the HIV virus with them. When these women value care and remain connected to care, they avoid potential imminent health deterioration and improve their individual health outcomes. In fact, ongoing participation in HIV medical care and support leads to reduced morbidity and mortality associated with HIV and infection progression. In two illustrative examples, service providers describe how women are valuing care:

> Like I said, when they come from Africa, they value the care they get here. In endemic countries, an HIV-positive diagnosis is a death sentence. Then, they get to Manitoba, where they can access treatment; the idea is to pursue their dream of building a healthy life for themselves and their children. So, I always see them; they will attend the appointments. As much as resources are offered, they will use them medically and socially for support and counseling. The greatest advantage that they have over other patients is that we don't see them involved in addictions like drug abuse. They come to

> Canada to better their lives and their families and children. So, they have nothing to do with drug abuse (49-year-old, care staff, man)
>
> Yeah, ACB clients are often up to date with their health. I find that African, Caribbean, and Black women usually show up to their appointments, book ahead, and then show up to those appointments as well. They adhere to their appointment and come in at the time they need to come in (42-year-old, care staff, woman).

Service providers also attributed reasons for women valuing and using care to the fact that women see HIV care support organizations such as Welcome Place and Nine Circles as their "second family," being their first point of contact and place of care contact since they arrived in Canada. That gives women confidence in the care and support that they receive, and as such, they value and therefore use care. As another service provider illustrates,

> Oh no! They feel comfortable because most of them—the majority of them—have been with us since the day they landed at the airport. So, we are like their second family. Because they have known us since they landed, we are the only ones who welcome them, put them in a temporary shelter, move them to their temporary accommodation, and then move them to their permanent address. So, they feel comfortable and prefer to keep coming back here (50-year-old, care staff, man).

Here, the idea of 'second family' for the women represent the trust they have not only in service providers but crucially in HIV care and support organizations such as Nine Circles and Welcome Place, being a place, they have been receiving care since their arrival to Canada. Based on having a history and connection to services in these organizations and also because women feel comfortable, women tend to value care and want to constantly visit these organizations to obtain HIV services. Perceiving these organizations as a 'second family' remains beneficial in women’s care. People living with HIV often experience better clinical benefit if they perceived available social and family support such as support from service providers.

Notwithstanding, as much as women value and regularly show up for care, service providers also mention not knowing the number of ACB women living with HIV currently accessing care in Winnipeg. Additionally, some service providers report contrary views regarding women’s use of care, noting that care use by women is often dependent on the individual’s interest and how they perceive the place of care. As one care staff member adds,

> Sometimes, some African people will not attend their appointment because they perceive Nine Circles, of course, as known as the HIV clinic. So, if you go there, the meaning is that you have HIV. That shouldn't be so; even the people we see don't all have HIV; some of them just come for primary care because their doctor is there at Nine Circles (38-year-old, care staff, woman).

Even though women have earlier described Nine Circles as a safe haven in the previous chapter, for health care staff, some women do not feel comfortable being seen at Nine Circles, having been labeled as the HIV place. This is a barrier to women accessing and committing to care.

Service providers also mentioned how there is prejudice, so women will not attend the clinic because of that fear of seeing someone from the community. Thus, as much as women value care, they are afraid to access health care and for people to know their status because they feel that people are going to breach their confidentiality, and women do not also want to be marginalized. And particularly when it comes to other facets of care beyond direct medical services, ACB women will also rarely attend. This presents serious implications in terms of enhancing women’s health and advancing their coping and wellbeing. When women do not visit the clinic for social support and care, this presents further implications in terms of women having less participation in HIV programming, not hearing the voices and experiences of these women, and not learning about the issues that they face, including their preferences for HIV care. As one female service provider explains,

> When it comes to engagement with other programs within HIV, I'll say it's pretty unfortunate that you'll hardly see people from the Black community, Black women, participating in the programs. They need these people to be involved to voice their concerns. But when it comes to that, maybe one or two that I've seen—yeah, so long as they have their medications and no concerns. The reason, I believe, has to do with discrimination and stigmatization. People are still very much discriminated against internally; women feel guilt, shame, and anger, and that limits their involvement (38-year-old, care staff, woman).

Here, care staff perceptions of women's experiences of HIV care and support suggest that women value care. Additionally, when service providers are working well, they are like second family to the women which in turn has positive effects with respect to women's use of care. However, at the same time, women are faced with different barriers such as stigma and discrimination that impede how care use.

Waiting Again

Waiting again is another way service providers described women's experiences of HIV care and support in Winnipeg. Similar to how the women defined and expressed the experiences of waiting, service providers also describe waiting in terms of women taking a longer time to book or rebook an appointment, particularly a missed appointment for any reason. Although it should not be much of a challenge to see a doctor, often times when people, including women, show up for care, it gets to a point where they call in but cannot see the doctor for a period of time because the appointment has been fully booked. Even though there is triage, which is certain and handled by nurses with added time in the schedule to see people who are walking in, there could be miscommunication —such as when nurses fail to notify doctor about a patient's arrival or when clients lack information and do not know that they could walk in any day and see a doctor that happens, that is then perceived as a barrier to getting in quickly for care.

The service provider's descriptions of waiting was similar to that of the women's but also different. It is similar because clients, including women, still have to wait for care regardless, and at the clinic, and women may also experience delayed appointments that prevent them from seeing their doctors at the time they need care most. On the other hand, the care staff's depiction of waiting is also different. For care staff, waiting mostly occurs when women miss their appointment and, therefore, have to wait longer to be rebooked. Women missing their appointments and having to wait present significant setbacks in terms of their health. Treatment delays and waiting can compromise women's health and increase the chance of transmission to others. Additionally, missed HIV medical care visits and having to wait are linked with deleterious clinical outcomes, including virologic failure, thereby increasing morbidity and mortality. As one service provider explained,

> You know, we are dealing with marginalized populations, for example, drug users. So, if somebody has been using the previous day of the appointment, they get hung up and decide not to attend. They are taking their chances. But then that means they will have to wait three to six months to attend the same appointment. Yeah, because of the limited number of doctors that we have here. But then you can think about when people miss that appointment, not sure if they've taken their medications; the viral load can increase,

> increasing the chances of infecting others. So that's a vicious circle (49-year-old, care staff, man).

Although, ACB women are not primarily to my knowledge part of the drug using community, they are still impacted by a culture of care of drug users that are seeking support from clinics like Nine Circles. The women's world remains negatively impacted by drugs indirectly. Service providers also reinforce how waiting occurs because there are mostly part-time doctors at Nine Circles, and as a result, women have delayed appointments, which pose huge barriers to their care. As a service provider further narrates,

> Yes, only one (doctor) probably works full-time, and she's passionate about this field. But the rest of them are part-time. It is an issue in terms of access. Because if they're part-time, booking an appointment with them comes with some obstacles. If you miss an appointment with them, you will have to wait six months. It's a political and systemic issue. Because if the system views it as a big issue that needs to be given some priority, then that would work. But if they think that they're doing okay so far, they're not going to add any more funds to improve the system (49-year-old, care staff, man).

Waiting here is also viewed as an issue influenced by systemic and political forces. Other than women having to wait for care only when they miss an appointment, another care staff describes how clients, including ACB women, generally feel that they have to wait a long time to assess care and see their specialist, and not only when they miss an appointment due to the doctor's non-availability. As she outlines,

> I think clients might say they would get an appointment later than they'd like. If you want to see your doctor, you'd have to wait a few months to get an appointment. This is

> because we can only afford a few full-time doctors here. We only have one full-time doctor, and the others are part-time (42-year-old, care staff, woman)

Here, service providers indicated that waiting does occur at the clinic, which is often exacerbated due to limited healthcare providers' availability. Long waiting hours and delays at healthcare facilities affect not only the access and quality of service rendered to the clients but also the motivation of the patients on antiretroviral therapy to continue with their care. Waiting and having deferred appointments and treatment also put women at an increased exposure higher of harming their immune systems, transmitting HIV to others, getting sick, and developing AIDS.

"Cultural care is for Indigenous, not Black"

This theme speaks to another way service providers perceive HIV care and support services in Winnipeg. The concept of culture has been widely described. As participants imply, culture includes values, beliefs and rules and customs shared by a group and used to interpret experiences and direct patterns of behaviour. In other words, culture is considered a central concept that encompasses learned patterns of perceiving, interpreting, and adapting to the world.

Consequently, the notion of "cultural care is for Indigenous, not Black" is when women feel unwelcome and excluded as they visit the clinic for care because services lack cultural support, while only Indigenous populations are targeted for specific cultural engagements. Explicitly, the idea of "cultural care is for Indigenous, not Black" refers to health provision that fails to attend to cultural concepts of care that may improve health outcomes for members of minority groups, like ACB women. Such cultural concepts of care entail acknowledging clients' cultural identities and taking their beliefs, norms, and values into account in interventions, and one service provider working with ACB community illustrate,

> For example, when we have workshops with people who are Muslims, we don't set our sessions during Ramadan. Is it a normal time? No! Because women cannot talk about sexuality during that time. Instead, we try to ask them when the normal time is. Women prefer gender-based training. So, we don't discuss together (men and women). We set the workshops according to women's needs and have to start with some traditional way of starting an event. We accommodate their way of starting and follow a culturally responsive approach because different groups have different needs, cultures, and practices (38-year-old, care staff, woman).

Essentially, cultural concepts of care means considering clients' cultural characteristics and resources as key references in HIV care planning and in building sustainable actions in HIV care and support. Adopting a cultural approach also involves respect and an understanding that socio-cultural issues such as race, gender, disability, social class, and status can affect health beliefs and behaviours.

When providers, organizations, and systems lack cultural support and fail to provide culturally competent and responsive care, patients remain at higher exposure of having negative health consequences and being dissatisfied with their care. However, on the other hand, when care is welcoming and culturally informed, this can help improve individual wellbeing, including the quality of care, and also contribute to the elimination of racial and ethnic health disparities. In the realm of HIV care, as much as Nine Circles offers great programming, including expanding care, service providers narrate how HIV and support services, although, generalized, Indigenous populations remain targeted for specific cultural engagements but not ACB populations. In fact, particularly, as some service providers describe it, there's not necessarily anything that speaks directly to the population of ACB people. As a results, this affects women’s use of care and women feel they can cope and live with their condition on their own. As two service providers describe,

> For the most part, I feel like there might be more services for the Indigenous community specifically, but not really for any other individual community. Otherwise, services are all just grouped for people living with HIV. Unfortunately, because of that, when I am participating in or witnessing any of these programming, it's the people from the Black community that don't access the program very often (50-year-old, care staff, man).
>
> Yeah, I don't know off the top of my head, but nothing really speaks to women's culture. I don't know of or have seen any program specifically for folks living with HIV who are part of the Black community here. There's nothing there for them. A lot of stuff is geared around substance use, and I don't know if those types of things speak to that population (ACB). ACB people feel that they can manage on their own. I don't know the word like it's not for them, and they'll continue with their daily lives (49-year-old, care staff, woman).

Particularly, service providers illustrated how at Nine Circles, there is only an Indigenous cultural support worker given the huge disproportionate Indigenous population affected by HIV, but the primary focus of that position, its actual title and job description, is about providing cultural safety and care and connecting people to a cultural resource that might be available in the community, and not just Indigenous. But then, that position gets confused because it's got an Indigenous focus, as the important worker in that position is Indigenous. Because it gets packaged more or seen more as an Indigenous support worker, which it's not really meant to be, service providers therefore acknowledge the gap in service regarding cultural support. As one service providers explained,

> That could be something that I say is lacking. That position is meant to provide broader cultural support. Even though they are Indigenous and might be familiar with drumming in the round room, we are meant to build the capacity for that support worker to connect with people of any ethnicity or background with cultural support in the community. So that would be like someone or a staff member that should have the information to link people to if there was a support group for African Caribbean and Black women, to be the one that pulls that knowledge. (48-year-old, care staff, woman).

Cultural support is for only Indigenous group and not for any other community like ACB populations. The drumming in the round room, and the offering of smudge, that's like very traditional pan Indigenous form of honoring culture and creating safety is done very much for Indigenous populations. Whereas for ACB women, as one service provider indicate, "they want to do some gathering together, engaging in activities like sewing, painting, learning together and, supporting each other, which they plan in such a way that it allows everybody to be involved" (38-year-old, care staff, man). ACB women might also want to bring and burn incense. Like Eritrea and Ethiopian women, when they get together, they make coffee, like burn coffee which is actually a ceremony that's shared among them.

Culture can't be synonymous for Indigenous. Because care is structured based on the understanding of the White, women feel they are not understood, lack trust in the health care system, and feel uncomfortable and unsafe. As one service providers outline,

> There is a White way of how care is organized, which affects the understanding between health care professionals and women during all aspects of care. It leads to a poor understanding of diagnosis and treatment. Based on their experiences, women usually share that they are uncomfortable when they receive medical care. They feel they are not

> understood because they have their own cultural beliefs and expectations, whereas there is the medical culture (38-year-old, care staff, man).

HIV care realities of women are formulated in care settings heavily influenced by its own culture, that is different from that of the women and includes, its, language, codes of conduct, expectations, and methods. As a result, women do not feel safe when accessing care. As such, for service providers the absence of cultural support for communities, other than Indigenous populations is a gap in service and can paralyze attempts at identifying problems ACB women face and developing plans for solving them. Likewise, service providers perceive HIV care to be unwelcoming for ACB women. As one service provider further describe,

> So there, I get the sense that some of what Nine Circles has done over the years might not be as welcoming as our population is changing. You know, HIV affects a lot of people with different experiences and backgrounds. So, I can tell for sure (48-year-old, care staff, woman).

In discussing perceptions of HIV care and support for women, service providers particularly feel that the support women might be needing is different. Women lack cultural support, that in turn impacts their access to care, and cause women to feel unsafe. Even though there is a women's cultural group at SERC, service providers mentioned how what exists in terms of care is not really something that's officially known as a service. It's more or less like mutual support services started by people given the different hurdles ACB women face in society. As participants earlier outlined, women experience a great deal of sufferings, face trauma, rejection, and isolation on a day-to-day basis and shoulder the emotional burden of living with HIV, as well as associated health and wellbeing impacts. Consequently, following these issues women face, the group was started as a platform where women can meet with and interact with others like them, share their challenges, empower, and support each other, understanding that they are not alone. However, the group remain such that is not open and known to everybody and that people can access. It is only known by a small number of people that have that openness, and supports that mutual support, and there is no published information about the group, even on SERC's website. Service providers therefore continue to emphasize the lack of cultural support groups, care, and services specifically for ACB people, including women. As another service providers shared,

> From my experience, there are no cultural services for ACB women. ACB women have a lot of struggles and face layers of isolation outside of HIV. Some have language issues, suffer from social program harassment and exclusions, and then you add the issue of HIV. All these are like wounds on wounds, and women need people who can help them put dressings on those wounds. But there is no support group for HIV in Manitoba or Winnipeg, No! The women's group in SERC is just a small group for people who have identified themselves with the community and need some support, like a social network to talk among themselves. There is nothing official or published for women who have HIV from Africa or Caribbeans (38-year-old, care staff, man).

To better support women living with HIV, this care staff further adds,

> We want services ACB knows are central, like this, the center for all African women who have moved to Canada. In Toronto, there are things like that. We don't have any of these services here for ACB. People can certainly get out of their minds the fear of someone who has HIV. They can accept the center, learn, and do different activities, such as sharing and playing, that will help them. The one at SERC needs to be more advanced. It may help as a model to initiate something great but to say there are services, I don't even

> know if I can say that there are services for ACB folks outside of medical services and springing support services for social life like food banks and other places they can go (38-year-old, care staff, man).

The lack of cultural care, services and support for women is a topical issue as most care staff illustrate. Care staff also highlighted concerns about the lack of cultural responsiveness within healthcare and among service providers. One service provider outlined,

> There is a gap in the approach, and that's about cultural responsiveness and care staff having more awareness and learning more about their own biases to break some of the assumptions. We know that the topic is very sensitive for many communities. Still, starting this conversation and creating a safe environment to understand a bit of women's culture without being judgmental is critical. Cultural responsiveness is very important (40-year-old, care staff, woman).

Providing care with awareness and knowledge of women’s cultural norms and differences and bidding to accommodate those differences can contribute to shaping the health-related values, beliefs, and behaviors of women towards care use. The likely satisfaction of women with culturally responsive care can result not only in adherence to treatment protocols, but also in retention and understanding of relevant information necessary to improve their health. Service providers therefore note that to address the issues around cultural support and responsiveness and further involve and engage ACB women in HIV care, specific support programming is needed beyond medical services: Women has to be involved in programming, just as they do for Indigenous people in order to better understand women’s culture and their needs. One service provider describe,

> It would be important for Nine Circles and anywhere else to offer specific programming. We all want to be united, anyway. But sometimes, you must reach out to the different communities as individuals to bring them all together. That's how you gain that trust and know how to speak with them and hear their needs, typically for them as individuals, and then once you attain that trust, you can bring everybody together. But as you welcome everybody, people feel you're not speaking directly to them, they won't come. Yeah, we need to have direct programming specifically for communities, the same as they do for Indigenous folks, and to learn even some of their customs and culture because you don't find that here (49-year-old, care staff, man).

This care staff further elaborates,

> Essentially, I know nothing of African culture or any of that. I may be looking in the wrong places. ACB people do not feel safe when they're going to attend anything. It would also be good if the people presenting these programs were people from their community, or even if somebody from that community could bridge that gap and welcome people and let them know that this is safe, is positive, and will be helpful. Because to have someone who doesn't look like you, doesn't sound like you, and doesn't have your experiences come and tell you, hey, listen to me, I'm going to help you, it doesn't make sense (49-year-old, care staff, man).

Another care staff who is an educator also adds,

> Yes, (ACB people) must be engaged from the start to the end of any program, and services must also engage communities. It's about more than asking them to come to the organization; it's about reaching out to them; that's what works because we need to reach them to come to us (38-year-old, care staff, woman)

Service providers overwhelmingly highlight the importance of engaging women and integrating their culture into health care delivery. Although it may be difficult for care staff to be completely aware of all cultural nuances unless they've grown up in the particular culture, it’s imperative to strive to accommodate the cultural needs of service users and, in this paper, ACB women.

Preferring services in own language

Preferring services in one’s own language is another way health staff described their perspectives on HIV care and support for ACB women in Winnipeg. Women come from incredible linguistically diverse countries and sometimes speak languages other than English that reflect their preferred language for communication. Preferring services in own language means women choosing to have HIV care and care support services in their native or official language for ease of access to care, specifically for women who do not speak English. Although there are often interpretive services made available by the Winnipeg Health Region Authority (WHRA), as service providers noted, called the Language Access Program, which has been created to provide face-to face interpreter services for individuals with limited language. Nevertheless, women have concerns about involving interpreters due to confidentiality and misinterpretation issues.

When care is not provided in women’s preferred language and women cannot safely understand and communicate in English, which is the dominant language in Manitoba, the quality of patient-provider interactions is lower, which in turn can lead to lower overall satisfaction with health care. Women can also experience less participation in medical decisions regarding their care and health, posing threats to their lives, use, and continuity of care. Most of the service providers interviewed shared experiences where they perceived that those women felt comfortable accessing care when it was provided in their preferred language. One support staff member who is a settlement advisor illustrated,

> Regarding language, not only women but also ACB people feel more comfortable when they get services in their language. I have been interpreting in medical settings. Often, some are less open than required. They think this person might share my life with others outside, even though you have openly stated that this will be confidential. So, there is some hesitation in being 100% open with the story and getting enough help. This is an issue because if they could do it without any interpretation, they may be more open than depending on an interpreter (50-year-old, care staff, man).

In further demonstrating how women prefer to have services in their own language, service providers also point out how clients, including women, often discontinue language interpretation services during medical consultations as they have concerns about confidentiality. As this service provider further added,

> As an interpreter, you have nothing to do with their lives. You are there only to interpret, but you will see that sometimes women will say okay, you know what, I don't need this person anymore because I am hungry. But then we found later that the reason is that you are from the same community, and they do not want you to keep listening to their life (50-year-old, care staff, man).

Women do not feel as comfortable accessing services, even when interpretation is put in place. Hence, when provision of care and services in women's preferred official language is not possible, women’s interactions with the health care system and use of care are affected, and women’s lives also remain at stake. One service provider described how miscommunication in language nearly cost one woman her life. As he narrated,

> Yeah, there was a woman from Ethiopia referred to have HIV and some mental health stuff. She was getting care from HSC and was told she was in denial about her HIV status. She was placed on HIV meds without her knowledge. She was also given some heavy medicines for mental health. When transferred to Nine Circles, where she accessed a nurse from Africa, we discovered she was not in denial. Every piece of information about her turned out to be false. The heavy medication she was getting from the psychiatrist was having side effects. She was in her early 40s but was already displaying the symptoms of an early stage of Parkinson's disease. There was a big misunderstanding between the woman and HSC; until now, when I think about it, this is how we made a difference. The patient would have died (49-year-old, care staff, man).

For service providers, the issue of language presents a severe concern for women, including a threat to their lives. Language barriers also prevent women from communicating and mingling with others in the community, and women are afraid to ask for help, as another service provider adds, "So, it's difficult for them. It's also difficult for others to know what they really need. It’s complicated" (38-year-old, care staff, man). Additionally, comparing ACB women with other populations, care staff point out how people from Indigenous communities have been putting in the effort to sort of be heard and noticed, not only with HIV but with everything, and so the government and the community have to respond to that. However, with the ACB community, it’s different. Women's language ability is often a barrier. As another service provider further illustrated,

> With HIV in the Black communities here, I feel it is still underground and more hidden. In many cases, a language barrier prevents people (ACB) from speaking out and putting in those requests. And when I also look at the people, I feel like the White people and the

> Indigenous people kind of can mix, but yet the Africans or the Black community here is separate. You won't know what's being offered if you can't read the posters. That's a big part of the problem (53-year-old care staff, woman).

The problem of language affect different aspects of women’s life and how interact and engage within society and programming. Due to language limitations, ACB women face difficulties in their lives, in accessing care, and in having their voices heard while seeking care and attending programs. Language barriers significantly impede women’s participation and effective involvement while also impacting their ability to identify and communicate the services needed. As a result, women may be unable to access services promptly and therefore experience delayed access to available HIV care and support services. This also means women are left to manage care on their own. Living with a chronic disease such as HIV requires continual monitoring through regular clinic and care support appointments. It is challenging for women to navigate care on their own.

Connecting to Religion and Spirituality

Connecting to religion and spirituality is another way service providers described women’s experiences of HIV care and support in Winnipeg. Broadly speaking, religion can be viewed as an outward form of belief in a supernatural or divine force, including an organized system of worship, rituals, and creeds, and a church affiliation. In other words, religion represents the external expression of faith, comprised of institutionalized beliefs’ practices and rituals related to the sacred. Spirituality, on the other hand, represents the inward, individual experience and is concerned with an individual’s connection with a sense of a higher power or supreme being like God, searching for a sense of meaning and purpose in life. Spirituality is therefore associated with that cordial interconnectedness to God, self, and others, built on a personal belief and faith in God, and is also that which helps individuals make meaning of life and circumstances.

In the context of this research, connecting to religion and spirituality refers to women's connectedness and devotion to their religion and spirituality and how that impacts their decision to use HIV services. Religion and spirituality may be particularly important in general for many living with HIV in terms of survival and coping. Just like ACB women with HIV in Winnipeg, health care staff describe how spirituality and a connection to religion significantly shape these women's outlooks on living with HIV and the way they engage with HIV and support services. Notably, women view religion as a source of support and control that empowers and propels them to engage in HIV care and support programming. Conceptualizing their infection as a path chosen by God, women turn to religion to make sense of and come to terms with being HIV-infected. Women appear to use prayer, going to church or mosque, meditation, reading the holy book (Bible or Quaran), faith in God, and other forms of religious participation to overcome the sadness and anger knowing that they are living with HIV, and they just feel like they are in a 'better place'.

Women's spirituality, beliefs, and connection to religion through engaging in religious activities frame their daily behaviors and attitudes towards care use, and they feel safe to use care and visit the clinic for their appointments. Religiously motivated behaviors practiced by women and a connection to spirituality empower self-reconstruction and remain favorable for engagement with HIV care and support, and women have a sense of peace. As one service provider outlined,

> I had a woman who liked attending church and always talked about God. God will help me do this and that. So, because of her belief, she feels she's in a better place. She's okay

> to take the medications and attend appointments because it is all God helping her. God has sent her good nurses, God has sent her good doctors, and God has provided her medications (41-year-old, care staff, woman).

Here, spirituality and a connection to religion offered women an opportunity to develop meaning and perspective-taking, to have a source of support, and to have control through a more powerful being. Women feel that God, the higher being, is just inspiring them and helping them connect to care, take their medications, and feel well. When religion empowers and strengthens women to make decisions that support their health, that kind of religion tends to be helpful. Consequently, women take care of their general health and well-being and adopt behaviors that do not put their health in jeopardy while actively participating in care programs.

While service providers mentioned how ACB women are religious people, on the other hand, they also noted how connection to religion and spirituality can go both ways in women's lives and constrain their agency to engage in HIV care and support services. Particularly ill-advised religion can be detrimental and catastrophic to women's health such as the loss of life. Ill-advised religion is when religion takes that power away from ACB women and women feel that is all up to the higher forces and they do not have a role in their care, that is it is all preordained by the higher being. As much as it's important to acknowledge the spiritual world and the higher powers of God, when women's agency, power, decision making ability and freewill is gone, it doesn't matter to them if they take their medication or not. Contrary to when religion is helpful, women experiencing ill-advised religion tend to engage in behaviours that prevent them from using care and greatly endanger their health, as well as increase their exposure to transmitting HIV to others. Service providers shared experiences of ill-advised religion in women's lives and care use. As one care staff describes,

> I encountered one case of a lady from Sierra Leone who ended up dying because she was in denial for religious reasons. So, she refused treatment. The people who surrounded her had some radical views about religion. So, they kept telling her they would pray for her, and she believed that. I supported that one woman, and yeah, I saw her decline gradually, and eventually, she died (49-year-old, care staff, man).

Sadly, this woman lost her life because she was ill-advised and consequently felt it was all God's will and the responsibility of the higher forces to take care for her health. She therefore neglected her medications. This service provider shares another experience, as he adds,

> Then, I had a young man from Congo who was diagnosed at a very young age before even becoming sexually active. But, because of the HIV stigma, he thought what was happening to him was unfair because HIV is always associated with sex as a transmission mode. I remember encouraging him to stay on treatments: you're going to be okay; this is how it works. It's not a death sentence. So, he gets into his mid-20s, he stops taking medication, and he goes, my family has been praying for me. The pastor has confirmed that I'm HIV-free. That was heartbreaking (49-year-old, care staff, man).

This care staff further narrates his encounter with the ACB patient. As he adds,

> I saw him declining. But then I explained to him that God does not teach people to be idiots. You need to understand the blessings of God. In this situation, the blessing is that he brought you to Canada, where you can access your medication. This is how you can be healthy. I support your family and church, praying for you; it is perfect. But your pastor is no expert to decide that you're HIV-free. It would help to see a doctor and be tested again for confirmation. I had to work with his mother. It took us two years to convince that young man that he needed to go back to treatment (49-year-old, care staff, man).

Religious beliefs about HIV can lead to fatalistic, laid-back attitudes and passive resignation that stalled participation in treatment. Yet, connecting to religion and spirituality can also play crucial roles in women's lives and can help support women to live well, uptake HIV services, and adhere to treatment. However, when women choose to disengage from HIV care due to their spirituality and religious beliefs about HIV, as service providers noted, this challenges adherence to antiretroviral treatment programs and notably puts women's health at peril, in addition to undermining the medical community's evidence-based effort to initiate and retain people living with HIV on antiretroviral therapy. Health care staff therefore strongly highlighted the effectiveness of treatment and promoted HIV treatment as mutually beneficial, particularly as there has been sustained scientific evidence that it works. Service providers notably highlighted that African people that includes ACB women are religious people and do have beliefs. While some are Christians, others are Muslims. But then their belief for sure gives them strengths than barriers to care.

Dealing with cost of HIV medication and treatment

Just as women noted in the previous chapter, service providers also describe their perception of HIV care and support services in Winnipeg in relation to clients, including ACB women, dealing with the cost of HIV medications and treatment. In this paper, dealing with the cost of HIV medication and treatment refers to women having to bear the responsibility of the cost of their HIV medications, especially for those who are not on social support or assistance from the government. ACB women, as part of the people living with HIV in Winnipeg, require HIV care and treatment that typically involves regular visits to a doctor to monitor the progress of the treatment and particularly taking antiretroviral medications daily to help slow disease progression caused by HIV, preserve, and extend the lives of women, and also help prevent the transmission of the HIV virus.

As service providers explained, like every province, Manitoba's medication coverage is different. HIV medication is covered for individuals on employment and income assistance (EIA), disability, or social assistance. In that case, the province bears the cost of the medication, and individuals do not have to pay when they go for medication pick-up. However, when individuals work or start to work, they are required to apply for pharmacare and contribute towards their medication. Consequently, folks are expected to pay a deductible, which is usually calculated based on an individual's annual salary, as stated in the previous chapter.

Service providers, just as women narrated how HIV medications come at a high cost. This presents a significant financial burden for women, especially for those who work and have to pay deductibles and incur out-of-pocket drug-related expenses. As service providers notes, ACB people, generally including women as immigrants, can hardly access good-paying jobs except for minimum wage types or kinds of work, which makes it extremely difficult for them to be able to afford HIV medications. The implications of having to deal with the cost of HIV medication and out-of-pocket costs for women can be prohibitive, creating a barrier to the initiation and continuation of antiretroviral therapy. Women are also more likely to indulge in prescription abandonment at the pharmacy, have decreased adherence, and have more frequent drug discontinuations. Two service providers who are nurses by profession shared their perceptions regarding the issue of high HIV medication costs in the province. As they outlined,

> In Manitoba, there is a gap in access to medication because people still have to pay 10% of the cost, even if there is pharma care. That's a big issue. I know Nine Circles advocated universal access, but people still need universal access. People don't have to choose

> between eating breakfast or buying meditation. That's not right. We know that. That must be changed because many provinces are already ahead of Manitoba (37-year-old, care staff, woman).
>
> HIV medications are very, very expensive and can go up to $1,000 in a month. So, working people must pay deductibles based on salary and what they make. So, I've seen people have a very high deductible of $10,000 or $3000, and not everybody can afford to pay the deductibles. It's a significant barrier for everybody—the African community and the Whites. It's very stressful. In other provinces like BC or Alberta, HIV medications are covered, and people don't have to pay (38-year-old, care staff, woman).

As one can infer, the effect of the high cost of HIV medications and treatment is especially severe on people living with HIV, including ACB women, who are already burdened, bear multiple loads, face stigma, trauma, and various challenges as they navigate their lives on a daily basis. Notably, having to deal with the cost of HIV medication and treatment worsens already pre-existing difficulties in women’s lives.

Aside from the trauma women tend to face, service providers also mention how women are left to make hard choices. This includes choosing to live on social assistance and disability in order to be able to access free medications since if they choose to go to work, they have to pay the deductibles, which is mostly expensive for women. While reinforcing the issue of the high cost of medication and treatment in the province, one service provider illustrated,

> The only issue we have in Manitoba, specifically, is that medication is not free, and HIV treatment is costly. It is very, very expensive. So, what kind of problem does it cause? It's tricky. The thing is, if someone who's HIV positive, as an African, decides to be professionally active, meaning going to work, yeah. I think they have to pay for

> deductibles. It isn't easy to access medications if the government does not support one (49-year-old, care staff, man).

When women choose to live on government support rather than work to earn a living, there are catastrophic consequences. Living on disability resources alone is an ongoing concern for women and tend to evade personal financial security that contributes to survival and an improved quality of life. Additionally, women's self-esteem, self-worth, or reason for existence may be utterly undermined by unemployment and if they are living on disability—and women may also miss out on opportunities to build a social support system and socially interact with others, in contrast to the isolation many experience because they are living with HIV. As much as living on disability and not engaging in employment may allow women to have free HIV medication, it presents dire challenges in women's lives that can compromise their health and wellbeing. Service providers therefore add that women consider relocation in a bid to have free HIV medication, seeking to be in provinces where HIV medications are covered, where they can live at peace with their condition without being burdened and bothered with paying for HIV medications. As an outreach service provider added,

> Yeah, I remember that a family from Congo decided to leave Manitoba, and they moved to Nova Scotia because the government supported the medication. So, whether you work or don't work, if you're HIV positive, treatment is supported by the government and is free. So, yeah, however, this (HIV medication) is a big issue in Manitoba (49-year-old, care staff, man).

Indeed, the problem of HIV medication and women and others living with HIV having to deal with the cost of medication and treatment is a huge gap in service, as care staff describe it, necessitating immediate and urgent attention.

Conclusion

In general, and similar to the women’s stories, interviews with service providers relating to their perspectives on HIV care and support for ACB women living with HIV in Winnipeg highlighted different meaningful insights and views. ACB women living with HIV in Winnipeg are not only a culturally diverse group with various spoken languages and strong religious connections, alongside, these women face layers of issues including rejection, stigma, discrimination, isolation, and trauma, which one service provider termed as ‘wounds on wounds’. Women value and use care as service providers indicated, in order to live well with their condition, lead full lives and achieve set goals. But then, being a culturally, ethnically, and linguistically diverse group, women particularly lack cultural care and support that influence their access to HIV care and support, inhibit trust and satisfaction with services. Women also face the problem of language, experience long waiting times, do not feel welcomed, including dealing with the cost of HIV medication. Having to bear the burden of HIV medication increases women’s suffering and entrench existing social inequalities, while intersecting with other issues in women’s lives. Indeed, these issues women encounter impact different facets of their lives, causing significant financial, economic, emotional, mental health, and psychological burdens. Health care provision must hence consider the holistic needs of these women, which may include cultural, linguistic, religious, sexual, and racial or ethnic characteristics of these women.

CHAPTER 8

DISCUSSION

In this chapter, the results of this research and its contribution to the literature are discussed, weaving together findings from both ACB women and service provider interviews. I discuss how this research advanced our understanding of gaps in care for ACB women living with HIV and delineate key strategies and recommendations that emerged in the ACB women's and service providers' interviews. Together, study findings explicate how ACB women's HIV care and support delivery may be improved to address persistent gaps between women's care needs and care provision, thereby addressing the research questions. In an effort to enhance understanding of the study, findings relating to women's life before and after HIV and how ACB women experienced HIV care and support in Winnipeg are synthesized with other relevant studies. This discussion also includes a limitation section and the implications for theory, policy, practice, and health care research. Finally, recommendations for changes to policy and practice are also outlined.

Summary and discussion of key findings

There is a dearth of research regarding Africans, Caribbeans, and Blacks with HIV infection in Canada. Previous research with ACB populations has revealed multi-level barriers to engagement in HIV care, treatment, and support programs, and these included a lack of understanding regarding biomedical concepts, fear, stigma, language barriers, discrimination, racism, sexism, and a lack of culturally appropriate information (Etowa et al., 2022; Medeiros et al., 2023; Etowa et al., 2021; Blot et al., 2013; Etowa et al., 2017; Ukoli et al., 2018; Etowa, 2016).

There have been no studies that have looked at how African, Caribbean, and Black women living with HIV in Winnipeg experience HIV care and support. Limited research into ACB women with HIV in Winnipeg makes it difficult to assess how healthcare deficiencies impact ACB women’s HIV care continuum. Understanding current experiences of HIV care and support from the perspectives of ACB women themselves and their service providers remains essential for targeting services that meet women’s needs and therefore improve access to care and women’s health. The findings from the interviews shared by participants in this study offer such a contribution.

By adopting critical race and feminist theory and incorporating intersectionality into a constructive grounded theory analysis, this study highlighted ACB women’s voices on their experiences of HIV care and support services. This study unveiled context-specific complexities and challenges experienced by ACB women living with HIV in Winnipeg. It helped to better identify criss-cross problems associated with the intersection of HIV care and ACB women, including the inadequacy of resources, all of which affect HIV care use and limit optimal engagement along the HIV care continuum (Hankivsky et al., 2009; Caldwell, 2016; Watkins-Hayes, 2014; Graham et al., 2011). Notably, this study highlighted the structural, social, systemic, and interpersonal forces implicated in women’s HIV care use and was the first to look at how ACB women living with HIV talk about, experience, and engage in HIV care and support services in Winnipeg. Indeed, this thesis contributes to efforts to improve ACB women living with HIV’s comprehensive care by elucidating, from the perspectives of women and their service providers, the needs of ACB women, what gaps exist, and which HIV care and social service improvements would be most suited and valuable in current contexts of care. Asghari et al. (2016) points out that efforts to enhance health care will be wasted unless they reflect what clients want from the service, in their own voices, and their own perspectives.

Since there is minimal research on ACB women’s HIV care experiences in Winnipeg, Manitoba, most previous studies have focused on ACB populations in provinces like Ontario and

British Columbia (Antabe et al., 2021; Baidanonso et al., 2013; Logie et al., 2016; Women's Health in Women's Hands [WHIWH], 2003; WHIWH, 2007; Richard, 2019; Baidanonso et al., 2013). This dissertation contributes to the literature on ACB women's health in Winnipeg by broadening the scope of the analysis to understand the constitutive nature of their care experiences as racial minorities. Study findings revealed the meaning participants ascribed to ACB, specific life histories of ACB women in Winnipeg, their contextual background, and the structural forces in their lives, particularly trauma that informs and shapes all of their experiences, deters access to health care, undermines women's health, and reduces their opportunity. Findings show that the difficulties ACB women face involve multiple forms of oppression within social and health services and are at various levels (individual, community, and structural)—due to ACB women's positioning at the intersection of several categories of oppression such as HIV, gender, racism, unemployment, and ethnic minority status.

Meaning of ACB and ACB women living with HIV. Few studies have described the term ACB (Cénat, 2022; Agyemang et al.,2005; Mental Health Commission of Canada (MHCC), 2024). In research evaluating the health of Black people in Canada, the term ACB has been used when referring to the diaspora or people grouped under the heading "Black" (Cenat, 2022; Rahemtulla & Bhopal, 2005). Various other expressions have also been used to define who ACB is. These included people of Black and Caribbean descent (Agyemang et al., 2005; Cruickshank et al., 1991), people of either West African or Caribbean descent (Cappuccio et al., 1998; Chaturvedi et al., 1993), Black Canadians (Bhopal & Donaldson, 1998) and Individuals or people with African descent and diverse cultural differences (Agyemang et al., 2005; Lyold et al., 2021).

In line with the literature by Agyemang et al. (2005), Cruickshank et al. (1991), and Lyold et al. (2021), this study found one meaning of ACB to refer to people with African ancestral origin who migrated from Africa and the Caribbean Islands and are also Black people bearing distinct and diverse ethnic and cultural backgrounds. While the different expressions ascribed to ACB advance a deeper understanding of the ACB community in general, on the other hand, it does mean that ACB, as a Black ethnic group, is not a homogenous community. The idea of a Black ethnicity also means that ACB people can face various oppressions and marginalization that Black people deal with based simply on their skin color. Notwithstanding, Agyemang et al. (2005) indicate that in classifying populations of different African descent, ethnicity provides a powerful approach that captures the key facets of race within a broader framework.

Questioning ACB identity, politics, and relations was another term participants used to define ACB. This theme highlighted a contradiction of the normative view of ACB people guiding and dominating Canadian policy and practice, everyday conversation, and political exchange, as well as being entrenched in epidemiological and public health language (Agyemang et al., 2005; Thornton et al., 2017). For example, in the available Canada HIV and AIDS status report, Africans and Caribbeans are continuously grouped as one community (ACB) and used interchangeably with the term 'Black' to represent racial identity, ethnocultural diversity, origin, and history of immigration (Odhiambo et al., 2022; Statistics Canada, 2019; PHAC, 2012; CATIE, 2013). Additionally, in reporting the Manitoba HIV Program update by Nine Circles, Africans and Caribbeans continue to be combined under a single label of ACB, even though African Caribbean people have cultural values that are different from those of African Black populations in terms of language, beliefs, customs, and migration history (Nine Circles, 2017).

The Manitoba HIV program report furnished information on the proportion of individuals who self-identified as ACB, with no specific breakdown relating to this ethnic group. However, given the ascendancy of race categorization in Canada and across provinces, including Manitoba, Africans, and Caribbeans continue to be combined under a single label of ACB without reference to their distinctive cultures, histories, and countries of origin. More so, research into the health of ACB people also has yet to capture the heterogeneity of ACB populations.

According to the study results, participants counteracted these frequent narratives in the literature that mostly suggest and categorize ACB populations under a single label of ACB instead of two separate communities, African and Caribbean communities. Although both groups have African heritage, combining heterogeneous African and Caribbean communities as one homogenous ethnic group reinforces racial stereotypes and masks a remarkable heterogeneity of cultures among diverse ACB populations. Notably, it leads to differences between ACB being ignored and creates practical problems of comparability between places and times. This study's findings, questioning ACB identity and noting the distinctiveness of African and Caribbean communities, aligned with earlier studies such as Cross et al., 2018. Cross and colleagues reported that in the US, Black immigrants from the Caribbean region and native-born African Americans are typically subsumed within the larger racial category of 'Black' even though the two groups differ substantially by culture, history, and immigrant origin. Likewise, Jackson and Cothran (2003) and Cox and Tamir (2022) noted that ACBs are so different culturally, socially, and intellectually that they should be considered entirely separate people. Agyemang et al. (2005) reported similar findings, stating that the common practice of classifying people of diverse African descent as ACB or Black needs to be reviewed. Otherwise, these populations will remain hidden when policy on ethnic diversity is made. Therefore, rather than attempting to explain ACB women's experiences of HIV care from a homogenous perspective, accounting for the heterogeneous make-up of the ACB women population can better explain their access and use of HIV care services and how Black Africans might experience HIV care differently from Black Caribbeans. These hold profound implications for researchers and professionals working in the field of ethnicity, HIV, and health, as they need to understand and acknowledge the massive diversity within the populations of African descent and avoid implying that they all share unique characteristics in common. Otherwise, in epidemiological and public health research, ethnic classifications for ACB populations may remain vaguely defined, and the concepts underlying them may be poorly understood. Although ACB has the same roots, there are differences in experience and perceptions between a multigenerational African, Caribbean, and Black community, who may share nothing more than the origin of heritage and skin color (Cenat, 2022; Charmaraman & Grossman, 2010).

Most participants also described ACB and ACB women with HIV as struggling and surviving. ACB women and their care staff emphasized how the ACB community is overlooked, with limited opportunities, information, and resources to succeed, when compared to Indigenous patients, for example, who benefit from regular cultural programming, Elder services, smudging, and other community engagements. Gebremeskel et al. (2022) shows that men and youths from the ACB community have limited access to support necessary for survival and good health. ACB individuals are affected by systemic and embedded discriminatory policy and practice in Canada that downgrades, disregards, and discredits academic credentials—especially from Black majority countries. To survive and fend for themselves and their families, ACB men, particularly immigrants, are confronted with the dilemma of working low-paying jobs, enrolling for further studies, and taking educational loans without assurance of rewarding employment upon graduation. For those living with HIV, their struggles are heightened. A lack of financial security often dictates their possibilities and life choices around fulfilling basic needs such as food. It also impacts their mental health by reducing their sense of control and agency over one's life. According to Gebremeskel et al. (2022), these individuals also have limited access to health and HIV-related information, which has consequences for their well-being and health outcomes.

A similar finding was expressed by Hibbert (2008) and Minority Rights Group (2023). For the most part, Canadians of African and Caribbean descent have been marginalized in poorly remunerated and insecure sectors of the economy. Racialized immigrant women such as ACB women often suffer from the double negative effect because of intersections of race and gender and grapple with high levels of underemployment, unemployment, and significantly lower income levels than their White peers. Yet, these racialized immigrants, like ACB women, continue to endure financial difficulties and everyday struggles that increase current poverty and jeopardize future development (Hibbert, 2008). In another study by Gibbs (1996) entitled Triple Marginality, the Case of Young Caribbean Women in Toronto, the study detailed the magnitude of marginalization against racial minorities in Canada. Young African Caribbeans encounter significant barriers to total acceptance and incorporation into Canadian societies. Among young Africans-Caribbeans, the authors reported that job discrimination is widespread and results in negative consequences for the women's economic and general well-being. These findings were similar to mine and reflect the presence and deep rootedness of systemic and economic forces in ACB peoples' lives. In the current study, for ACB women living with HIV, the issues they face are exacerbated, as the study indicated, since women also deal with HIV and gender issues, including multilevel forms of stigma. The combination of race, gender, and HIV status amplifies these women's challenges.

Connecting to religion and spirituality was also found to be another meaning participants ascribed to ACB. As the study results suggested, religion and spirituality are major forces in the lives of ACB people, including women living with HIV, in the attainment and maintenance of health and well-being, as well as in promoting their resilience and identity. Several studies have also emphasized how ACB people, including women, are religious and grounded in sacred scripture and teachings that provide meaning and purpose to their lives and a moral code that guides their behavior (Arrey et al., 2016; Dalmida et al., 2012; Este & Bernard, 2006). The findings from these authors have shown that connecting to religion and spirituality appears in the form of praying, attending church or mosque, and reading a holy book, and affects their health outcomes, including disease progression, physical, emotional, psychological, and mental health, and quality of life. Likewise, studies conducted by Medved Kendrick (2017) in the US document that religion and spirituality have since played a significant role in the lives of ACB people. Frequent religious engagements for many ACB religious adherents provide these individuals with constant social interactions with others and community support. However, continued research and a deeper understanding of what dimensions of religion and spirituality are associated with health outcomes for ACB communities may be required to guide programs that incorporate religion and spirituality. Participants' descriptions of ACB were associated with ACB peoples' religious beliefs and practices, ethnic identity, race, diversity, marginalization, struggles, and resilience. These descriptions provided deeper insights about ACB, helping us understand what the community needs, which is important in tailoring services to address the impact of the intersecting issues.

The pre-HIV diagnosis experience of ACB women. In this study, I also explored ACB women’s various life experiences and histories before HIV diagnosis to provide further sociocultural backgrounds on the women. Based on the perspectives of ACB women and care staff, a number of key themes were obtained.

First, it was stated that women were living life, feeling free, connecting socially, and living carefree before diagnosis with HIV. In this regard, Pierret (2007) mentions that being socially integrated is very common among people who are not living with HIV. The participant's experiences have shown that this social integration appears in the form of interacting freely and working, which meant maintaining continuity with life. In fact, for these individuals, life before HIV meant the continuity of everyday life, thriving and relishing life, the one that is fulfilling and exciting for the individual without fear of judgment from others and without consideration for the long term.

Some other studies reported findings on peoples' experiences before HIV diagnosis. Pienaar and Visser (2012), in a qualitative social constructionist narrative study conducted with young adolescents, pointed out that being HIV-free meant living a normal life and not being different. The idea of normality, which these authors describe, typically entails having friends and participating in social events such as sports. Essentially, life with no HIV is not feeling trapped and isolated and having the liberty to do what one wants, socialize, and pursue life plans, for example, starting a business and buying a house. Pierret (2007) also showed that life before HIV still meant being free, socially and occupationally integrated, which represented the meaning and condition of a normal life. These authors mainly describe the notion of freedom, which is synonymous with Miller's (1983) concept of freedom. According to Miller (1983, p. 3), being free is “to be able to act according to your autonomous will in consequence of not being dependent on the will, and hence on the mere goodwill, of anyone else.” In other words, being free is the possibility of acting—or the fact of acting—in such a way as to take control of one's life and realize one's fundamental purposes (Carter, 2003). However, unlike Pienaar and Visser's (2012) and Pierret's (2007) study, the current study adds that being free is about having complete confidence like others, which gives courage, resilience, motivation, and a belief in one's ability to succeed. Life before HIV is also about living a peaceful life that is not burdened with thoughts of knowing what one has and the ostracization that comes with it.

Another experience of ACB women before HIV diagnosis, focused on gender and local economic situations. This phenomenon appeared in ACB women in the form of facing financial hardship and shouldering responsibilities, including fending for family members. These social forces occurred concurrently and in interaction with each other, crystallizing into the sharp, hard surfaces of individual women's suffering, constraining agency, preventing women from reaching their full potential, and ultimately leading the women to contract HIV, a chronic disease marked a break from the previous life. In this regard, research on socio-economic status and HIV by Riley et al. (2007), Farmer (1996), and Pellowski et al. (2013) has shown that a person's socio-economic standing may affect their likelihood of contracting HIV and developing AIDS. Crucially, Pellowski and colleagues show that a lack of socio-economic resources has been linked to the practice of perilous health behaviours, such as exchanging sex for money, drugs, housing, food, and safety, which can lead to the contraction of HIV. Herein, the social and economic forces that dictate life choices in every sense, as Farmer (1996) notes, helped to shape women's susceptibility and acquisition of HIV.

Some women also mentioned inadequate parenting, early experiences of neglect, and lack of love, care, and support, which were central to their lives before their HIV diagnosis and made their lives hard and marked by an unhappy childhood. Notwithstanding, economic hardship right from an early age and having to fend for themselves and their siblings remained a key influence and increased women's vulnerability to HIV. Using a descriptive approach, Charles-Eromosele et al. (2022) and Sia et al. (2016) found that women face gender-related constraints compared to men. Women are significantly more disadvantaged financially and socially, more likely to be uneducated, unemployed, and therefore poorer than men, which puts them in the position of being exposed of acquiring HIV. Limited control of resources decreases women's ability to protect themselves against disease transmission and negotiate safe sexual practices (e.g., condom use) with their partners. Economic hardships are fueled as a result of structural pathways that stem from the interactions between economic inequality and entrenched gender power inequities.

Likewise, a study by Sherafat-Kazemzadeh et al. (2021) noted that in Africa, poverty and gender inequality underlie enormous challenges facing women, and this puts women in a particularly vulnerable position and increases the probability of HIV infection. All three studies, Charles-Eromosele et al. (2022), Sherafat-Kazemzadeh et al. (2021), and Sia et al. (2016) and the current study described sociocultural forces, gender and economic disparities in women's lives. However, unlike these published studies, the current study added and delineated how the early experiences of neglect and lack of love and support intersected with gender and economic situations and aggravated the likelihood of acquiring HIV among ACB women. Sherafat-Kazemzadeh et al. (2021) stated that the risk is significantly higher for women who are poor and lack agency.

Another experience of ACB women before the positive diagnosis of the disease was lacking guidance and education related to HIV and sexual health. The women expressed concern about not having direction and counsel on HIV and sexual education, which played a role in women acquiring HIV. The experience of the women shows that if they were educated and well-informed about HIV and sexual health, they would have been more alert and able to make safer choices regarding their health. Earlier studies have revealed that without sex education, women and girls lack basic information about sexual health and HIV transmission, and this affects HIV risk behaviour (Pomeroy, 2008; Sherafat-Kazemzadeh et al., 2021). Likewise, when women lack maternal guidance and counsel, Goodwin et al. (2005) and Sooki et al. (2016) noted that it affects daughters in specific ways and has negative consequences. However, suppose women are empowered and have an awareness of HIV; in that case, it has been shown to be an apparent protective factor for women and is associated with better overall sexual behavior, higher condom use, and testing for HIV (Pomeroy, 2008; Sherafat-Kazemzadeh et al., 2021). Hence, sexual health education is deemed vital to the social and personal empowerment of women and plays an important role in curtailing the acquisition and transmission of HIV.

According to ACB women, war and civil unrest were other phenomena they experienced before the diagnosis of HIV. This phenomenon occurred in women as fighting and chaos happened within their home countries, leading to multiple adverse events and intersectional experiences such as homelessness, consequently increasing women exposure of acquiring HIV. The experiences and exposure to war created significant social and psychological distress, including anxiety and depression, which caused much morbidity and impacted socio-economic development within the community. In this regard, Mock et al. (2004) state that in war situations, for example, wars destroy social and physical infrastructure, resulting in untreated poor health and, consequently, an increased exposure to transmission in the event of viral exposure. More so, war shocks can weaken an individual's ability to avoid HIV exposure or infection (vulnerability).

Similar to how Mock et al. (2004) discussed populations in war and conflict situations, ACB women experienced the violence of war, which caused them emotional suffering and trauma. Huesmann et al. (2023), Musisi & Kinyanda (2020), and Murthy & Lakshminarayana

(2006) have also shown that chronic exposure to war violence has deleterious effects on health and HIV care. Generally, it takes a more significant toll on civilians, creates extensive emotional and psychological stress, and has significant indirect negative consequences on public health provision, infrastructure, and social order.

Another experience of ACB women prior to their HIV diagnosis was dealing with sexual assault and trauma. Women were affected by gender-based violence, including sexual assault, torture, and arbitrary killings. Sexual abuse particularly undermined women's health caused injuries to their bodies and led them to contract HIV. Studies have shown that sexual violence and rape affect a large proportion of girls and women in Africa (Ajayi et al., 2021; Dartnall & Jewkes, 2013; Montesanti, 2015). Such gender-based violence is deeply rooted, particularly in social norms that devalue women and girls, as well as in unequal power dynamics between men and women that are created and maintained through gender stereotypes (Ajayi et al., 2021; Montesanti, 2015). The idea of violence, as evidenced by women's experiences, is linked very closely to social injustice and the social machinery of oppression (Farmers, 1996). Men, particularly those in the military, are deemed untouchable, while women are subjected to structural violence, which results from rape, sexual abuse, and other acts of violence (Farmers, 1996; Hourani et al., 2021; Sinha et al., 2017). Being victims and survivors of sexual violence, women have several devastating mental, physical, and social effects, as well as increased exposure to sexually transmitted infections (STIs), including HIV.

Post HIV diagnosis experiences of ACB women. The diagnosis of HIV was a life-altering event. Most ACB women reacted negatively to their HIV-positive diagnosis by feeling scared and broken. Findings reported by Senyeurek et al. (2021) showed that with a positive diagnosis of HIV, HIV-positive African American and African Caribbean childbearing women in the US reported a wide range of negative experiences, ranging from shock, anger, disbelief, fears, and fear of dying, both for themselves and their unborn child. Likewise, according to Ribeiro Nobre et al. (2012), participants' experiences related to shock, thoughts about death, and fear of others knowing about their HIV status. These findings reflect the result of the present study, and participants in Ribeiro Nobre et al. (2012) and Senyeurek et al. (2021), including ACB women in the study, stated that they never thought they would have HIV. However, unlike findings in Ribeiro Nobre et al. (2012) and Senyeurek et al. (2021) study and research by Cain et al., 2013 where participants' emotions started with an initial shock, in this study, ACB women's adverse reactions largely stemmed from fear and being scared. In this regard, Imani et al. (2021) showed that fear and anxiety in HIV patients is a psychological complications.

In addition to feeling scared and broken, wanting to give up, and feeling like losing everything were other adverse reactions shared by ACB women. Women suffered these negative expressions based on personal past negative experiences of other people living with HIV and fear of the consequences of losing family members and of a wider disclosure causing discrimination. Women's negative reactions also stemmed from recurring thoughts about death and the possibility of dying since HIV was incurable. Women also feared infecting others and having to take HIV medications for an indefinite time. These findings partly coincide with those of Iman et al. (2021) on the lived experience of HIV-infected patients in the face of a positive diagnosis of HIV. Similar to some respondents of the studies of Imani et al. (2021), two ACB women from the study thought that their dreams and goals had vanished and that they had reached the end. These reactions were partly due to the lack of sound information on HIV and also not knowing how to handle the new diagnosis. However, different from the Imani et al. (2021) study, the findings of this study added that being diagnosed with HIV steered feelings of loss of everything (like ACB women's life achievements and accomplishments), which can decrease motivation and interest in life activities

Being mindful and caring about the safety of self, others, and the community was another way women described their experience when they first learned of their HIV status. The analysis showed that life changes after receiving an HIV-positive diagnosis were also assessed more positively. Women revealed taking all the necessary steps to care for and protect themselves, their family members, and the community. Women also reported continuously self-monitoring their health and developing strict self-discipline when associating with others and interacting with family members in order to limit the probability of HIV. Many studies also reported the same situation, especially when it came to taking precautions against HIV transmission (Li et al., 2006; Xie et al., 2017; Senyurek et al., 2021; LaGrange et al., 2012). Participants with HIV applied strict hygiene rituals if they could not isolate their physical selves in order to minimize the possibility of infecting others. Being diagnosed as an HIV-positive individual living with HIV has led to an inner desire to help others by protecting and mentoring others. In this regard, based on the findings of a descriptive qualitative study carried out in the US in 2012, upon receiving a positive diagnosis of HIV, one of the self-care techniques adopted by African American women was being an advocate to prevent HIV transmission in others (Webel et al., 2012). This was described as a positive strategy, providing women a sense of personal reward, and was also a way to reduce negative emotional states associated with living with HIV. Ribeiro Nobre et al. (2012) noted that when individuals found positive meanings in living with HIV, they were usually more able to develop suitable coping mechanisms to tackle daily life-changing occurrences.

Becoming closed was also described by women after facing a positive diagnosis of HIV. In the context of the study, becoming closed was manifested through avoiding relationships and isolating, keeping to self, and hiding. Women feared that people, including family members, would gossip, discredit, and discriminate against them if they learned about their diagnosis. As a result, most women choose to close and distance themselves and avoid relationships. Nije-Carr et al. (2012) state that the biggest hurdles people living with HIV faced were being subjected to stigma and discrimination and difficulty in communicating their HIV-positive identity with others.

Consequently, similar to this study's results, participants tended to hide their HIV status to avoid negative reactions from people and protect themselves against adverse consequences of the disease. Participants in the Nije-Carr et al. (2012) study also attributed reasons to hiding self as they do not want to upset their families. When persons with HIV hide and isolate themselves and have reduced or no social interactions, this significantly affects their feelings, goals in life, and relationships with their immediate environment and social life (Nasir et al., 2023). For ACB women, the isolation most faced was more self-imposed. Some took it upon themselves to cut ties with family and community based on familiarity with harmful and harsh treatments meted out to people living with HIV. Others cut contact, expecting rejection from their community and family members. Isolation deepened and compounded pre-existing difficulties, stressors, and traumatic events in women's lives and increased their psychological burden. Likewise, Syneurek et al. (2021) corroborate, adding that grappling with the lifestyle changes caused by HIV, such as avoiding close connection with people and not being able to discuss freely one's HIV status with families or friends, can put enormous pressure on people living with HIV that included Black women. ACB women's decision to evade relationships and close self also self stemmed from women's desire to protect others from contracting HIV. This finding is also well supported in the literature, as noted earlier. However, unlike the current study, Syneurek et al. (2021) did not particularly discuss people living with HIV closing themselves and evading relationships due to their HIV-positive identity. Similarly, Imani et al.'s phenomenological study conducted in Iran did not also describe HIV patients avoiding relationships when they faced a positive diagnosis of the disease. Additionally, the reasons participants in Syneurek et al. (2021) and the current study alluded to hiding after facing a positive diagnosis of HIV slightly varied.

Another experience of ACB women post HIV diagnosis was feeling loved. Despite feeling devasted, some women particularly emphasized the support of their family members, spouses, care providers, and counsellors. This support and education from these social support networks gave women hope and helped them understand the need for medication adherence and to reframe HIV as a manageable chronic condition. Li et al. (2006) showed that family support benefited people living with HIV in many different ways. With family support, HIV individuals expressed positive behavioral and attitude changes in their lives, including making important medical and treatment decisions, having a positive outlook toward life, and regaining hope for their future. This reflects similar findings in this study. Like the participants in Li et al.'s (2006) study, ACB women got comfort from their families and care providers' advice and counsel. Consequently, women felt loved to have the support of their family and service providers in their lives and help them reduce the negative consequences of stressful events related to the disease. Silva and Tavares (2015) also reported the same situation, especially when it came to how HIV persons felt satisfied having the support of their care providers in dealing with HIV diagnosis. This suggests that family members and service providers of people living with HIV could likely be a good target audience for HIV interventions and programming. However, contrary to the findings of Derlega et al. (2003), ACB women in the current study were more disposed to seek support from their parents and health staff while distancing themselves from their friends and acquaintances to save face and avoid discrimination. Derlega and colleagues explored the topic of HIV and social support and how individuals with HIV, including women recruited from a clinic and HIV service organizations in Virginia, US, seek and receive social support in relationships with peers versus parents. These authors found that participants reported seeking more support from a friend than from parents and were more persuaded to talk about their HIV diagnosis. In this study, most ACB women connected with their parents and health staff for social support, which is a significant buffer in coping with HIV-related stressors.

ACB Women's experiences and service providers perspectives on HIV care and support

Women's experiences of HIV care and support on the basis of race, gender identity, and HIV status were complex. Their interactions with the healthcare systems and their capacity to obtain equitable healthcare services were affected by complicated power dynamics created by these intersecting identities and persistent systemic and structural inequities in their daily encounters. In this regard, ACB women and service providers described interactions and reinforcement of factors impacting women's experiences of HIV care and care. On one hand, ACB women experienced factors that posed access issues and made it difficult for them to access care. On the other hand, women also experienced factors that facilitated their care use and impacted their general health and wellness. The findings indeed show that there is an intersectionality of barriers to how women's care use was shaped by individual, community, and societal/systemic factors. These barriers were seen as issues in women's lives and gaps in HIV services that necessitate specialized solutions.

Barriers to the use of HIV care and services. Some studies in and outside of Canada have examined existing gaps in HIV care access by minorities living with HIV to expose the reasons for healthcare disparities faced by these individuals (Djiadeu et al., 2020; Orza et al., 2017; Asghari et al., 2016). Access remains a huge issue in health care policy and programming and is one of the most commonly used words in discussions of the health care system. Women, including ACBs, living with HIV continue to face widespread access issues in health care settings after their diagnosis. In their global review of HIV care and treatment access, Orza and colleagues (year) discussed key facilitators and barriers to access to HIV treatment and adherence from women's own perspectives and was the first peer-led global study involving focus group discussions and interviews with nearly 200 women living with HIV from 17 countries (Bolivia, Cameroon, Nepal, Kenya, and Tunisia). In particular, barriers included violence from family, community members, and healthcare professionals, whereas the authors reported supportive friends and family as important facilitators.

There were certain similarities among women in Orza et al.'s (2017) research study and the ACB women in the present study. In both groups, participants were concerned about the issue of transportation and distance to the clinic, childcare, and having to take permissions to attend appointments. These concerns represent the different struggles women face and contend with while living with HIV and trying to take care of their health. Being women, mothers and living with HIV, they have increased physical needs that call for them to escape from their competing demands and find time to care for themselves (Orza et al., 2017). Additionally, in both groups, women also faced complex experiences in accessing and continuing to use care and take treatment. In particular, aggression and maltreatment from society, internalized stigma, and being ostracized by community members were seen as barriers that impacted women's care use and health-seeking behaviours, including HIV treatment access. Women also experienced depression, pain, agony, low self-esteem, and other mental health problems, coupled with oppression and verbal abuse from their husbands, causing women to live in a state of terror and fear. Similar to the current study, Orza et al. (2017) described violence at the clinic, otherwise referred to as structural violence, which included general human rights abuses such as violations of rights to privacy, and confidentiality.

There were also some differences between the two studies. Orza et al.'s (2017) study also highlighted key facilitators, including friends. In this current study, ACB women reported being supported mainly by their parents and care staff. Orza et al.'s (2017) study did not particularly discuss the cost of HIV medication and coverage and also did not include references to culture—such as highlighting whether service providers practiced cultural competency and sensitivity and how that shaped women's experiences of HIV care and support. Notwithstanding, in the present study, considering the history of ACB women as people living in war and experiencing trauma, the ill-treatments, and the lack of support from their spouses lead women to continue to endure episodes of terror and hardship. These experiences serve as systemic barriers and disincentives to the uptake of HIV care services in the Manitoban context.

Djiadeu and colleagues (2020) also examined existing gaps in HIV care delivery to HIV-diagnosed Francophone ACB in Canada and the condition of this population's HIV care continuum. This study was a systematic review that spanned nine different databases, such as Scopus, PubMed, Global Health, PsychInfo, and Web of Science and eventually included only two eligible qualitative studies from two provinces in Canada—Ontario and Manitoba.

In the Ontario study, Djiadeu et al. (2020) found issues relating to language barriers, the non-availability of bilingual care services, and shortages of HIV organization staff, which posed difficulties for health care professionals to provide quality healthcare to Francophone patients. Specifically, service providers experienced problems conversing with patients who speak French when that was not the provider's first language (Djiadeu et al., 2020). Similarly, in the Manitoban study also described by Djiadeu et al. (2020), the situation is no different. The authors reported how new Francophone ACB immigrants to Manitoba had difficulties accessing specialized services such as counselling on HIV and mental health and were also more likely to experience delays for bilingual healthcare services and interpreters. Djiadeu et al. (2020) also found a lack of cultural awareness and sensitivity among healthcare providers in the Manitoban study.

Both Djiadeu et al. (2020) and the current study acknowledge and emphasize the issue of language and having bilingual services—that is, services in participants' own language—as a priority in accessing HIV care services, keeping in mind the huge importance of a common language in patient-provider interactions. For ACB women who do not speak English, as participants indicated, the system has been structured such that women would require interpretation services in order to access care, which women strive to avoid for fear of confidentiality. This finding shows that systemic and embedded inequitable policy and practice, persist in the healthcare system as an impediment to access health and HIV care for ACB women (Gebremeskel et al., 2022). But, if patients' language preferences are factored in and there is language-concordant care—that is, clinical encounters in which the service user and care providers speak the same language—Molina & Kasper (2019) point out that could enhance trust between patients and care staff, optimize health outcomes, and advance health equity for diverse populations like ACB women. More importantly, People living with HIV can feel at ease, be more open, and not be afraid to share any concerns that they may have regarding their care and health and get the help they need (Odhiambo et al., 2022; Molina & Kasper, 2019). Similarly, integrating clients' language preferences into care delivery affords an opportunity for service providers to offer safe and high-quality care while also helping to address women's language needs and cultural aspects of clinical care.

Both Djiadeu et al. (2020) and the current study also highlighted the importance of culturally appropriate and sensitive HIV treatments and interventions within the health system, which is an as important resource to access health and HIV care among ACB people. ACB people in general are known to face a number of intersecting problems, mostly associated with being people of colour (Djiadeu et al., 2020; Odhiambo et al., 2022; Gebremeskel et al., 2022). Likewise, the current study also noted that ACB women continue to experience layered or intersectional oppression and lack resources that impact HIV care utilization and complicate their health and wellbeing. Being immigrants, ACB women also struggle to get professional jobs because their credentials are often not recognized in the Canadian/Manitoban market, as earlier stated. Consequently, women settle for minimum-wage jobs, which appear to be barely sufficient for women to pay their bills. ACB women in Winnipeg are also facing higher levels of discrimination from society because they are racialized women. While this evidences the meaning ACB women and service providers alluded to, 'struggling and surviving', both Djiadeu et al. (2020) and the current study have shown that there exists an interconnectedness of marginalization, discrimination, and various forms of structural, economic, and physical abuse in the lives of ACB people, which are made natural and consequently accepted as everyday trauma and normalized violence. In fact, these findings showed unjust life situations for ACB women, which coupled with the lack of cultural competency and sensitivity in care, and language barriers, adds significant burden to ACB women's lives, to their health and well-being, and to accessing HIV services. and yet, there are no studies that have managed to expose the pain, trauma, and suffering of ACB women living with HIV in Winnipeg.

The study's findings further identified the gaps in ACB women's care and individual healthcare encounters with service providers and in accessing non-HIV-related health services. These were related to waiting, being treated differently, lacking medication coverage, and dealing with the cost of HIV medication. These realities for ACB women are supported by the literature and has the potential to lead, and continues to lead, to profound harm for ACB women who access and use care within the health care system. In this regard, a prior study conducted by Wallach & Brotman (2010) that explored the perspectives of both older adults living with HIV (OAHIV) and their healthcare providers in order to document gaps in service delivery, found that participants reported long waiting times across the health network, whether it entailed access to medical examinations or scheduling medical consultations with specialists. In fact, in these participants, the issue of long waiting times was exacerbated not only because OAHIV suffer from various health issues associated with the interaction of HIV and aging but also due to the differential treatment by healthcare professionals due to their infection status (Wallach & Brotman, 2010). Consequently, long wait times ultimately affected the prognosis of OAHIV, ultimately leading to the loss of patients.

Both Wallach and Brotman's and this research described several challenges faced by people living with HIV in accessing care and reported how participants faced multiple and complex challenges that undermined their efforts to remain actively engaged in HIV care. Specifically, both studies narrated the problem of long waiting times at clinics and being treated differently while noting that these barriers to HIV care engagement are largely underpinned by HIV-related stigma.

Previous researchers have discussed the impact of waiting time on patients (St Clair-Sullivan et al., 2019; Reichert & Jacobs, 2018; Chu et al., 2019). Although it's more important to stay healthy, longer waiting times and delays within the health service system can impede the patient's utility gain from the treatment, contribute to worse overall patient care experiences, and cause a deterioration in patient outcomes. Difficulties in accessing health care services create exceptionally detrimental repercussions for people living with HIV due to their significant health needs, especially for those experiencing multiple comorbidities (Wallach & Brotman, 2010). Likewise, relating to findings on treatment of women living with HIV, in previous studies, women, including ACB people living with HIV, have also been negatively affected by discrimination and being treated differently without dignity, lacking resources, and support while being frequently referred to as ‘HIV carriers', 'vectors', ‘diseased’ and ‘prostitutes’ (Paudel & Baral, 2015; Gardezi et al., 2008; Etowa et al., 2022; Lawless et al., 1996; Logie et al., 2018; Gebremeskel et al., 2022). As these different authors note, for women just like ACB women living with HIV, living with HIV meant living with panic, fear, and the hurtful effects of stigma and discrimination—which is the act of treating people living with HIV unfairly and differently than those without HIV (Taylor et al., 2020; George, 2019). Various studies have revealed that one of the consequences of AIDS/HIV that women will suffer from is discrimination and prejudices because of the non-acceptance of the others (Paudel & Baral, 2015; Gebremeskel et al., 2022). Consequently, women living with HIV experience rejection, ostracism, isolation, and even violence in family and within the community, and women's lives seem difficult. This discrimination extends to treatment by health care professionals. These overlapping, multilevel forms of issues are demonstrative of the intersectional forces in women's lives. In accordance with the research by Paudel and Baral (2015), Gebremeskel et al. (2022), Lawless et al. (1996), Taylor et al. (2020) and George (2019), these dynamics are tied to long histories of colonization, racism, gender inequity, unequal power structures between men and women, structural inequality, and social exclusion. Women's role in the community, low standing in the social hierarchy, subordination of women in society, low control in decision-making, financial dependence, and low levels of literacy have made them more susceptible to stigma and discrimination at the community and family level, as well as by health personnel (Paudel & Baral, 2015; Gebremeskel et al., 2022; Lawless et al., 1996; Taylor et al., 2020; George, 2019). In turn, discrimination and social exclusion affect the emotional well-being and mental health of women living with HIV and reinforce structural inequalities in accessing social and material resources and, more importantly, health services (George, 2019; Gardezi et al., 2008). This discrimination and social exclusion are particularly amplified by the intersections of women's race, gender, and HIV status (Ojukwu et al., 2022).

In this study, it was also uncovered that ACB women lack medication coverage and have to deal with the cost of HIV medication, that in turn impacts their HIV care experiences. This finding is also consistent with results from a descriptive study in Canada where authors reported that patients spend up to several thousand dollars annually on HIV medications depending on their income (Yoong et al., 2018). According to Yoong et al. (2018) and Gupta et al. (2018), ideally, the costs of HIV medication should not limit HIV care for people living with HIV; however, in contemporary health care, they are a factor and consequently poses an enormous obstacle for people living with HIV while affecting patients' annual out-of-pocket expenditures. For ACB women in the current study, this is a similar experience, and women face different negative consequences including having to stop their medications and divorce their spouses due to the high cost of HIV medications. As earlier noted, studies have shown Blacks, including ACB women, experience a higher rate of unemployment and are more likely to work in minimum-paid jobs and sectors that do not provide health insurance (Couch & Fairlie, 2010; Nnaji & Ojikutu, 2022). Furthermore, particularly for new immigrants of color, as Antabe et al. (2021) assert, navigating systemic and structural barriers to surmount financial and economic challenges to improve health remains daunting.

ACB women living with HIV have to deal with the cost of HIV medication in addition to these many pressing and conflicting needs in their lives, causing disruptions in women's families, increased their financial burden, and increased stress, which in turn could affect treatment adherence, viral suppression, and related health outcomes. The effect of cost-related HIV medication nonadherence has been well documented (Beer et al., 2019; Holbrook et al., 2021; Law et al., 2012; Yoong et al., 2018; Nicolas et al., 2006). Nonadherence to antiretroviral therapy can lead to unrestrained HIV replication and, consequently, increase the probability of disease progression, drug resistance, and HIV transmission. Therefore, Yoong et al. (2018) suggests the critical need to provide accessible antiretroviral therapy for all persons living with HIV, as this has been shown to be a fundamental component of a public response to the HIV epidemic.

According to the study results, it was also shown that while living with HIV and accessing care services, women experienced load bearing. Research evidence has also revealed that women from African countries suffer the heaviest burden of living with HIV compared to their men counterparts (Ramjee & Daniels, 2013; Girum et al., 2018; Logie et al., 2016). Through gender power dynamics, these women living with HIV are embedded in relationships that worsen their health (Ramjee & Daniels, 2013). Women are being saddled with the tasks of fulfilling family and community responsibilities while trying to take care of their health. The social and familial burden women bear along with living with HIV and ethnic and gender disparities contribute to women's trauma and limit their access to HIV care and treatment. These findings are similar to the current study, wherein participants described ACB women's experiences of HIV care and support, including the idea of load bearing. ACB women juggle intersecting issues while living with HIV and trying to care for themselves and live well with their condition. The implications of these loads and burdens in women's lives form a chronic background to their lifelong struggle with illness, and as a result women carry the highest burden of AIDS-related mortality (Ramjee & Daniels, 2013).

The intersectionality of the diverse issues ACB women face, the convergence of women's many identities and social settings means that the HIV care experiences of ACB women cannot be understood in isolation. The concept of intersectionality illuminates the description of the multiple levels of determinants of ACB women to access HIV care.

Facilitators for the use of HIV care and services. Notwithstanding the barriers ACB women face, women also shared positive factors that shaped care use in their lives. One of such key theme that emerged in ACB women's and service providers' discussions was committing to and valuing care. ACB women and service providers highlighted how HIV care and treatments are often not readily available or are so expensive that they are unattainable in ACB women's home countries. Therefore, for ACB women living with HIV now residing in Canada, these dynamics mean they can now access HIV care, and so ACB women tend to value care and commit to using HIV services. Both ACB women living with HIV and service providers identified this theme of valuing and committing to care as an important factor in ACB women's experiences of HIV care and support. The anticipated positive outcomes associated with HIV treatment and the goal to be healthy and lead full lives keep ACB women committed to using

HIV care. This finding reflects the effect of ACB women being exposed to HIV care and support services after immigration. In fact, many ACB women stated that, even with the struggles that they faced, nothing could prevent them from committing to care and adhering to the prescribed medication regimen. It is well known that accessibility of antiretroviral therapy and factors related to medicine, such as the availability of drug stocks, help individuals remain committed and engaged in HIV care and treatment (Nimwesiga et al., 2023; Hlongwa et al., 2022). Indeed, Manuel (2021) showed that migrants who were living with HIV in the UK were more motivated to remain in care to suppress their viral load for health reasons despite experiencing significant barriers to accessing HIV treatment.

Self-acceptance of HIV positive status was also another theme that emerged in the study as a facilitating factor that helped ACB women have a positive outlook, try to avoid mental strain, and connect with HIV care services. ACB women who accepted their status saw the need to link to and utilize care and were receptive to the advice and medical counsel provided by service providers about the importance of engaging in HIV treatment and adhering to care. The findings of a previous study by Hlongwa et al. (2022) were similar, and these authors highlighted the importance of accepting one's HIV-positive status compared with denialism or struggle accepting their diagnostic identity. Similarly, Nasir et al. (2023), in their interpretative phenomenological analysis supported the results obtained in the research about self-acceptance, as this is a foothold to better adapt to the virus or to the disease. These authors deemed self-acceptance to be a positive attitude in the lives of people living with HIV, helping to calm these individuals down, and also adopt new roles that in turn influence successful living with HIV. While corroborating that self-acceptance is a better strategy for coping with HIV, on the other hand, Ribeiro Nobre et al. (2012) confirmed in their study that when people living with HIV are able see HIV as a small part of their identity, that manifest hopefulness and a successful internal decentralization of HIV from self.

ACB women and care staff also expressed women's connection to their religion and spirituality as part of women's care experiences. Previous studies have shown how important religion and spirituality are to HIV care among ACB populations (Szaflarski, 2013; Este & Bernard, 2006; Arrey et al., 2016; Dalmida et al., 2012; Fante-Coleman et al., 2023; Taylor & Chatters, 2010). Although religion can be a hindrance to accessing care, particularly when people living with HIV feel that is all up to the higher forces and they do not have a role in their care (Kremer et al., 2009; Arrey et al., 2016), on the other hand, religion and spirituality also play key roles in coping, survival, and maintaining overall wellbeing and remain an enabler to accessing HIV care among ACB people living with HIV (Este & Bernard, 2006; Arrey et al., 2016; Taylor & Chatters, 2010). Indeed, a long tradition of research and scholarship details the salient and focal role of religion and spirituality in the lives of Black people, including Africans, Caribbeans, and Blacks. In this regard, Arrey et al. (2016) note that strong reliance on spiritual beliefs and faith in God to help through HIV experience are very common among sub-Saharan African migrant women with HIV. The experience of the participants has shown that majority stated being more spiritual or religious since being diagnosed with HIV, while also reporting that using spiritual or religious strategies, like prayer, meditation, and engaging in religious activities, helped them to cushion life struggles and pain caused by HIV and to adhere to antiretroviral therapy.

In living with HIV and accessing care, ACB women described belief in the power of God in their HIV care treatment and particularly believed that using antiretroviral therapy is a way God uses to heal them through the wisdom of the care providers. As a consequence, these women developed positive health behaviours, self-image, self-esteem, and self-care. But, due to pressure from women's pastors, religious leaders, and partners, some women disengaged with ARTs because they felt their religious and spiritual beliefs were not compatible with conventional medicine. Moreover, they also believed the situation was beyond their control, so they placed their fate in a higher power. The current study's findings relating to the connection with religion and spirituality were similarly nuanced. Religion was helpful and remained favorable for ACB women's engagement with HIV care and support, and ACB women mentioned having a sense of peace. ACB women's religiosity and spirituality allowed them to adopt behaviours that do not put their health at danger.

On the other hand, ill-advised religion constrained some ACB women's agencies to engage in HIV care and support services and stay on medications. Ill-advised religion, as previously described, is when religion takes that power away from ACB women, and women feel that it is all up to the higher forces and they do not have a role in their care; that is, it is all preordained by the higher being. As Cole et al. (2003) and Arrey et al. (2016) found, when people living with HIV adopt negative spiritual or religious beliefs in preference to traditional treatment, that may be damaging to not only the individual's health-seeking behaviours and treatment adherence but, crucially, their survival and quality of life. This was evidenced in the present study, and in previous research in the UK, where the authors reported the deaths of three sub-Saharan African women who stopped their HIV medications on the basis that they thought prayers had cured them of HIV (Dangerfield, 2011). When spirituality or religiosity becomes a barrier to HIV treatment adherence, service providers can use examples of patients who combine spirituality, religious beliefs, and practices, and conventional treatment to convince and counsel patients to stay on treatment and continue with medical care (Arrey et al., 2016). Although religion can be harmful, remarkably when it is ill-advised, overall, in this study, connecting to religion and spirituality enabled ACB women with HIV to cope better despite the various struggles, difficulties, and trauma these women face. This study finding demonstrates the necessity for service providers, HIV specialists, and policymakers to acknowledge the meanings and importance attached to spirituality and religiosity by ACB women living with HIV in the Winnipeg context.

The findings from the study suggest that women experience complex and diverse challenges as a racial minority regardless of the setting. Findings also showed that there is an intersectionality of barriers that are embedded in systemic discriminatory policies, practices, and inequities. In other words, being an ACB person is comprised of intersecting social identities that contribute to HIV menace and access to health services. Therefore, addressing interacting issues of ACB is crucial using appropriate multi-level and intersectoral approaches.

Implications for theory, practice, and policy

Structural challenges, lack of access, abuse, and neglect ACB women face all stem from trauma. Critical race and feminist theories remain useful vehicles in trauma narrative (Quiros et al., 2020), and ACB women with intersectional identities suffer more and have an added layer of complexity regarding trauma. *Trauma* is an important thread that ties all three theories and positions together. Moving forward, an important implication for theory is that trauma should be considered part of CRT and feminism work and intersectionality. Trauma adversely affects a person's mental, social, emotional, physical, or spiritual health. Considering trauma in these previous theories will deepen an understanding of the totality of individual (culture, ethnicity, gender, sexual identity) and structural vulnerabilities that expose a person to trauma. In the context of this study, ACB women experienced sexual, emotional, physical, and structural violence. Including trauma as part of the theoretical frameworks and providing trauma-informed care support for ACB women would be essential for their HIV health to visit the clinic for care and take their medications, including counseling, peer support, and social, financial, and nutrition support. This also allows ACB women to fully engage in their health care, build and sustain a trusting relationship with their provider and social environment, and improve long-term health outcomes. However, without incorporating trauma, there is a likelihood of failure to capture untreated past trauma of an individual, which can have a significant impact on their future health. Again, another implication for theory, given that being an ACB person is comprised of intersecting social identities that contribute to HIV vulnerability and access to health services, the concept of intersectionality should also be considered always in studies involving ACB populations.

In envisaging a racialized women-centred approach to HIV care, ACB women living with HIV and service providers offer clear narratives for improving policy and practice to meet ACB women living with HIV's care needs. Perhaps the most important finding that deserves urgent policy attention is ACB women’s trauma from structural violence experienced before and after their HIV diagnosis, which layers through women’s experiences. Prior to HIV diagnosis, ACB women reported experiencing significant traumatic experiences such as sexual assault, living in war and fear, being greatly burdened, hiding, running, avoiding chaos, and seeking a safe place. Even now, living with HIV, women continue to encounter diverse forms of trauma, confronting interlocking barriers and dealing with disruptions in their family units due to the high cost of HIV medications—being treated without dignity, facing long wait times, and language barriers, bearing enormous loads, feeling a lack of safety, cultural sensitivity, and awareness. Therefore, women keep to themselves, largely navigating life with HIV all by themselves and losing a valuable form of social support from their family that’s a fundamental unit. Trauma negatively affects a person’s overall wellbeing and has been associated with reduced HIV care engagement and treatment adherence and worsening HIV outcomes (Stockham et al., 2023).

Strategies targeted at improving HIV care and alleviating ACB women living with HIV’s heightened burden, emotional torment, and increased exposure of a variety of mental and physical health problems need to be centred on trauma-informed HIV interventions. According to Stockman et al. (2023), providing trauma-informed HIV care services is a critical approach to boost HIV care outcomes and promote uptake of HIV care and ancillary support services among ACB women populations. Grounded in the core principles of safety, respect, empowerment, choice, transparency, and collaboration and individually tailored in line with gender issues as well as historical and cultural issues, trauma-informed care and practice are crucial for HIV health. For instance, empirical research shows that trauma-informed HIV care interventions are associated with a number of positive outcomes for women living with HIV, including enhanced quality of life, health access, and antiretroviral therapy adherence (Deering et al., 2019; Sikkema et al., 2018; Sales et al., 2016).

ACB women appear increasingly committed to care in order to preserve their health, lead full lives, and reach their goals. Although committing to care and taking this precautionary measure is recommended and highly beneficial, the disproportionate burden of HIV care and support issues facing ACB women living with HIV is complex and worrisome and points to the need for more targeted interventions. In fact, even though HIV and primary care organizations such as Nine Circles have made efforts in recent years to provide group programming and support services such as the coffee talk, standing strong, food bank program, and meeting clients where they are, the significant barriers to HIV care access that ACB women face mean that more needs to be done, particularly for the ACB population. Policies on access to HIV health services among ACB women living with HIV need to take into consideration the nuances in this study. It is therefore more and more important to have culturally inclusive and safe spaces where ACB women feel welcomed and have a sense of connection and trust when accessing HIV and support services. Service providers, policymakers, and other public health stakeholders need to give priority to culturally appropriate health services (addressing the needs of ACB women, including language) to address health inequalities and the rights of racialized populations who are disproportionately impacted by HIV.

Covering HIV medication costs, just like in provinces such as Nova Scotia, removing barriers to government assistance programs, prioritizing efforts to lower HIV prescription prices, and reducing out-of-pocket costs for ACB women and others living with HIV are important strategies for policymakers to consider in improving the HIV health of people living with HIV—and in achieving Canada's commitment to meet all of the United Nations Programme on HIV (UNAIDS) 90–90 targets (Yoong et al., 2018; Holbrook et al., 2021). Policies are also required that recognize the distinct heterogeneity of Black African and Caribbean communities, including anti-racism policies to dismantle discriminatory treatments ACB women suffer in the job market, educational sector, and health institutions.

The findings of this study also demonstrate the need for service providers and policymakers to recognize the several meanings and importance alluded to spirituality and religiosity by ACB women living with HIV. Even though there is also the possibility of high spirituality or religiosity as a barrier to treatment adherence among ACB women, notwithstanding and despite the diversity of faiths, service providers should strive to learn and acquaint themselves with the details of specific religious perspectives by conversing and listening to ACB women with HIV and consequently working to integrate religiosity and spirituality in HIV care.

This study's findings also suggest the need to provide an HIV centre for ACB women similar to that in Toronto in order to provide quality care for ACB women affected by HIV. Implementing policy changes and clinical practices will serve as structural-level interventions that will increase access to care and help inform the needed changes to the treatment guidelines for the effective care of ACB women living with HIV.

Limitations and strengths

Given that HIV is highly stigmatized, most ACB women living with HIV in Winnipeg were hesitant to come forward to be interviewed about their HIV care and support-related experiences. This certainly did prove to make recruitment difficult. In order to surmount this challenge, I approached some Nine Circles staff, including the lab technician, to brainstorm on the best strategies to recruit ACB women with HIV and also sought their assistance in promoting the study with their ACB women clients. I also reached out to other service providers, ACB community groups, and colleagues. Despite my efforts at recruitment, the sample size was still limited. I was unable to recruit specifically Black Caribbean women living with HIV in Winnipeg. HIV-positive Caribbean women might have had different stories to tell. Nevertheless, I felt gratified that I was able to recruit 10 African Black women participants with HIV, including 12 service providers, and achieved saturation during data collection. I was also content with the depth of information shared among participants in my sample.

Another limitation of this study was that the majority of ACB women living with HIV interviewed visited and utilized HIV care services at Nine Circles. ACB Women with HIV who access care at Health Sciences might have had different perspectives. Additionally, given the lack of empirical evidence on HIV care experiences and racial health disparities, it was also challenging to provide critical discussion and evidence of the need to develop specific health and HIV care policies for the ACB population. Moreover, ACB men may have different experiences of HIV care and support than the women whom I worked with in the study.

As strengths, the study contributed to ACB and HIV care knowledge by providing evidence about the experiences of ACB women living with HIV in Winnipeg. This study represents one of the first studies that specifically included ACB women in Winnipeg and discussed their unique care experiences, including exposing the histories, pain, trauma, and suffering of these women. This is particularly important as the voices of these women remain unheard in Winnipeg. Another important strength of the study lies in the meaning participants ascribed to ACB, providing rich insights and questioning the use of ACB as one community instead of African and Caribbean communities. Additionally, the study collaborated with HIV-focused clinics in Winnipeg, such as Nine Circles. Care staff from the clinic provided meaningful and extensive input throughout the study. This collaborative approach between the researcher and the clinic staff enriched the study's design and outcomes.

Directions for future research

The conspicuous gap in research undertaken among ACB populations in Winnipeg when compared to other community groups highlights the urgency of conducting large-scale studies that take into account both Black Africans and Black Caribbeans' experiences as people living with HIV to investigate racial experiences. There is also a need to explore the experiences of men living with HIV in Winnipeg. These experiences are important to know because men and women supposedly differ in the course of accessing HIV care services, their uptake of care, and their response to treatment, all of which are exacerbated by social, structural, and behavioural factors. Consequently, I recommend critical qualitative studies to examine the HIV care experiences of ACB men and women in Winnipeg, the effect of structural violence, and unequal gender relationships between men and women, exploring the socio-cultural, political, and economic dimensions that shape care use and make men and women susceptible to gender-based violence. Additionally, more culturally responsive research is also needed to explore the impact of intersecting gender-based violence on HIV care use and address the critical knowledge gap of ACB people's experiences and poor clinical outcomes across the HIV continuum of care in this priority population. Additionally, data on the impacts of antiretroviral medications on ACB men and women is limited and undoubtedly also requires further research and an enhanced understanding of what ACB populations need in terms of the management of co-morbidities associated with living with HIV.

Dissemination of findings and Knowledge Translation

Since the goal of this study was to generate knowledge that informs service providers, social care, and the development of policies and/or interventions for improving and expanding HIV care and support for ACB women with HIV in Winnipeg, it is important stakeholders learn of the study and its findings. Additionally, dissemination of research results remained important, to give voices to ACB women living with HIV, whose voices remain unheard, create a greater awareness of issues ACB women living with HIV face, and also ensure that ACB women and their care providers see that their contribution created practical knowledge for change. CRT and feminist theory methods emphasize the importance of ensuring that research results are shared with all stakeholders and not restricted to academia (Leininger, 1992).

After the initial analysis, preliminary results from this study were shared with the organization collaborating in the research process (Nine Circles), that included members of ACB community. I presented preliminary findings from this doctoral research at the webinar presentation organized by MB HIV-STBBI Collective Impact Network and Nine Circles. Disseminating this initial research findings presented a unique opportunity for ACB women living with HIV, collaborating organization and community stakeholders to respond to the study findings and interpretations and support the development of recommendations and deliverables of the project. Following this community consultations, feedback from stakeholders and community were integrated in my final research.

In disseminating final research reports and in knowledge transfer, I intend to involve my thesis advisor and committee members, Nine Circles, and SERC in information dissemination in the form of presentations at conferences, small group presentations, community forums, posters, reports, and publications in peer-reviewed journals.

The new data resulting from this study will be essential, to help close the gaps in knowledge particularly relating to perspectives on HIV care and support among ACB women living with HIV in Winnipeg (Harding, 2020; Muhammad et al., 2015). This doctoral work will inform, service providers, such as Nine Circles, Manitoba health, SERC, social care providers, ACB serving organizations and non-profit governmental organizations working on settlement and policy makers.

Conclusion and Recommendations

ACB women living with HIV in Winnipeg face significant barriers to HIV care access, despite Canada's commitment to facilitate equitable access to health services to residents of Canada without financial or other barriers. The challenge of HIV care problems among ACB women is intertwined and complex and is rooted in culture, trauma, structural violence, and community. In summary, key strategic directions should include the initiation and establishment of multi-level strategies to address the HIV care needs of ACB women and the priorities of ACB communities, addressing these needs along with other service priorities of ACB women living with HIV. Indeed, community-based education, health system, and novel inter-sectoral strategies are necessary. Service providers, policymakers, and organizations supporting ACB women need to be cognizant of the various challenges faced by ACB women living with HIV, the context leading to the problems, and the recurring and intersecting effects of social, cultural, biomedical, economic, and structural factors affecting the health and wellbeing of ACB women living with HIV. In order to address the barriers, gaps, and hurdles to better support ACB women living with HIV in Winnipeg and the planning and delivery of quality HIV care programs to these women, several actions were identified. Table three provides an overview of all the recommendations provided by the participants.

Table 3: Recommendations from Participants

Recommendations	Number of participants (ACB women and Care staff)
Manitoba should craft and implement anti-stigma, racist, and discriminatory policies, and protocols.	ACB women (10); Care staff (6)
Changing and creating policies that are responsive to science and having policies around HIV disclosure are important.	ACB women (0); Care staff (2)
Manitoba should create an HIV centre specifically for the ACB community (similar to the Black Coalition for AIDS Prevention (Black CAP) that serves Toronto's diverse African, Caribbean, and Black (ACB) communities.	ACB women (0); Care staff (2)
Service providers should adopt a hope-centred and holistic approach to providing healthcare to ACB women living with HIV.	ACB women (8); Care staff (4)
Counselling should be readily available and free for ACB women to help them cope with their HIV-sero status and reduce trauma and its impact on wellness.	ACB women (9); Care staff (3)
Continuing HIV education and awareness and creating capacity-building programs would be helpful for ACB women.	ACB women (9); Care staff (5)
Service providers and health care organizations should ensure HIV literacy around U=U with the sample population and larger ACB communities to reduce stigma	ACB women (0); Care staff (2)
ACB women should be encouraged to participate in care and support programs	ACB women (3); Care staff (0)
Manitoba to provide and increase funding support for addressing HIV among ACB communities and for community-based HIV programming.	ACB women (10); Staff (8)
Creating childcare spaces within the clinic would be helpful for ACB women with children	ACB women (6); Care staff (4)

ACB women should be supported to acquire job opportunities and/or set up a business.	ACB women (2); Care staff (0)
Physicians and non-HIV specialists should be trained and incorporated to provide HIV services in order to expand HIV care, reduce wait times, and allow ACB women to access HIV services in close proximity to their residence.	ACB women (7); Care staff (4)
Service providers should provide culture-informed care and be trained on cross-cultural issues to increase cultural awareness, cultural sensitivity, and cultural safety, knowledge, and skills.	ACB women (10); Care staff (12)
Culture and religious-specific activities and values should be incorporated into HIV care and support programming for ACB women.	ACB women (9); Care staff (7)
More ACB staff, including physicians who speak multiple languages, should be recruited and retained in health care to bridge trust issues, provide language support, reduce wait times, and encourage care use.	ACB women (10); Care staff (8)
Peer-to-peer support groups should be created and made easily accessible as a source of solid support for ACB women affected by HIV.	ACB women (4); Care staff (5)
More collaborations between service providers, public health, and social services administrators are required.	ACB women (4); Care staff (6)
Service providers need to engage more with the ACB community, resource persons, religious leaders, and community leaders.	ACB women (5); Care staff (6)
Transportation tickets should be provided for appointments.	ACB women (7); Care staff (1)
HIV medication should be free, fully covered, and made easily accessible for all to reduce the burden on ACB women.	ACB women (10); Care staff (12)

Service providers should cut down on wait times. Beyond incorporating modern technology and online patient portals, care and support staff should be effectively trained on how to provide prompt care that contributes to addressing intersecting needs of ACB women.	ACB women (5); Care staff (4)
Work organizations should avoid asking questions relating to HIV status as part of pre-screening questions for employment.	ACB women (2); Care staff (0)
Access to ACB women living with HIV as peer support would be helpful for ACB women who have been newly diagnosed with the disease.	ACB women (4); Care staff (5)
Involving ACB women in HIV decision-making and planning would be beneficial and would support creating policies that are effective.	ACB women (5); Staff (7)

The recommendations range from practical advice for policy makers and the Manitoban government, such as creating an HIV center specifically for the ACB community to ensure that ACB women have an inclusive space where they feel welcomed and can access diverse culturally adapted services, to health sector-level interventions, such as giving ACB women access to a counselor to help them cope with their HIV-sero status, reduce trauma, and reduce their impact on wellness.

There were a number of recommendations that were unanimously agreed upon and recommended by both ACB women living with HIV and service providers: physicians and non-HIV specialists should be trained and incorporated to provide HIV services; Manitoba should provide and increase funding support for addressing HIV among ACB communities and for community-based HIV programming; peer-to-peer support groups should be created and made easily accessible; service providers should provide culture-informed care; HIV medications should be free and fully covered; involving ACB women in HIV decision-making and planning would be beneficial to support creating policies that are effective; more ACB staff, including physicians who speak multiple languages of ACB people, should be recruited and retained in health care, etc.

The participants noted these recommendations as being key to addressing the interlocking issues faced by ACB women living with HIV when accessing care in Winnipeg. Even so, each recommendation listed was made with enthusiasm and certitude in the hope that it might help ACB women living with HIV in several ways. With increased ACB migration and the number of ACB women living with HIV in Winnipeg, it's imperative for the Manitoban government, policymakers, service providers, and all other stakeholders supporting ACB populations to consider implementing recommendations in order to expand the provision and uptake of HIV care and support among ACB women, which in turn will contribute to reducing the high burden of HIV in this priority community.

In conclusion, within this chapter, I provided a discussion that explored the findings of the study, situated the findings within the previous research, and investigated how the results inform and build on existing work. Within this chapter, I also explored the potential implications of the findings as well as described the study strength and limitations and the recommendations thereof.

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Appendix 1

Interview Guide for ACB women with HIV

Start by giving an introduction:

Thank you very much for taking this time to speak with me. I have invited you to participate in this study because we are interested in learning more about you and your experiences, opinions and views about HIV care and support services in Winnipeg. I'd like to remind you that your responses will be anonymous and used as data for this research study only. There are no right or wrong answers in this interview. Also, please keep in mind that you do not have to answer any questions that make you feel uncomfortable. Just let me know if you feel uneasy, and we can move on to another question. We are interested in hearing about your experiences and opinions. Do you have any questions at this time? [Wait for verbal affirmation.]

Participant ID_____________

First Interview Sessions for ACB women with HIV: Opening and Demographic Questions

To begin, are you fluent in English? If otherwise, which language do you feel most comfortable speaking on a regular basis?

Please can you tell me a bit about yourself?

1) Age____
2) Year of birth____
3) Employment status
    a. Self-employed -
    b. Employed
    c. Unemployed

    If employed, what is your occupation?

4) Education
    a. No education
    b. Primary
    c. Secondary
    d. Higher than secondary
5) Marital status
    a. Single
    b. Married
    c. Living with partner

6. How would you describe African, Caribbean and Black community in Winnipeg?

Probes: What does ACB mean to you?

7. Can you please tell me what life was like before and after being diagnosed with HIV?

8. From your personal perspectives, how do ACB women living with HIV compare to Canadians born persons (Indigenous & non-Indigenous) with HIV in terms of socio-demographics characteristics?

9. Would you say there are differences/similarities, from being an ACB woman with HIV in Winnipeg?

a. If different, could you describe in detail these differences?

b. If similar, could you describe in detail these similarities?

Second Interview Session with ACB women with HIV

Now, I would like to start asking you a few questions relating to HIV care and support services.

10. How would you describe HIV care and support programs in Winnipeg?

Probes:

What do you know about HIV care and support programs for people living with HIV?

Are you aware of HIV care and support opportunities?

11. Tell me what happened or how you came to be involved in HIV care and support programs?

Probes: Since being diagnosed, what made you involved in HIV care and support programs?

Were you referred by someone?

12. Can you please share your experiences of HIV care and support services?

i. When did you first experience HIV support programs?

ii. Describe the events leading up to and surrounding your experiences.

iii. Does being an ethnic and racial minority impact decisions regarding HIV care use and care received? in what way? Also, do social, political, and economic factors, including cultural norms and institutions shape your experiences of HIV programs, how?

iv. Considering that spirituality/religion is an important cultural strength within ACB community, and is particularly relevant to health and well-being, including health promotion, what is your current state of knowledge on spirituality/religion in HIV as a means to cope with HIV illness and support wellness outcomes for ACB women with HIV?

13. What is your assessment of HIV care and support programs?

Probes: How do feel about HIV care programs in Winnipeg? What goes through your mind when you think about HIV care and support services for ACB women with HIV?

14. Can you also share your assessment of service providers and their mode of service delivery?

Probes: How do health and social support staff treat you? How do you feel about HIV care and support experience? Would you go back for subsequent appointments in the future?

15. Do you have any reported outcome regarding HIV care and support?

Probes: Do services allow you to live well with HIV or are there other services HIV-positive you require to lead full lives?

Does HIV care programs work or not work for you? If otherwise, how do you think HIV care services can be improved.

16. Is there something else, you wish to share with me that you perhaps did not think about during the interview?

17. Is there something else you feel is important for me to know to understand your experience?

18. Is there anything you would like to ask me before concluding the interview?

Appendix 2

Interview Guide: Healthcare and Support Staff

Start by giving an introduction:

Thank you very much for taking this time to speak with me. I have invited you to participate in this study because we are interested in learning more about you and your perspectives, opinions and views about HIV care and support services in Winnipeg. I'd like to remind you that your responses will be confidential and used as data for this research study only. There are no right or wrong answers in this interview. Also, please keep in mind that you do not have to answer any questions that make you feel uncomfortable. Just let me know if you feel uneasy, and we can move on to another question. We are interested in hearing about your experiences and opinions. Do you have any questions at this time? [Wait for verbal affirmation.]

Participant Code_____________

Opening and Demographic Questions

Please can you tell me a bit about yourself?

6) Age____

20–29 years

30–39 years

40–49 years

50+ years

7) Year of birth____

8) Employment status

    d. Self-employed -

    e. Employed

f. Unemployed

If employed, what is your occupation?

9) Education

e. No education

f. Primary

g. Secondary

h. Higher than secondary

10) Marital status

d. Single

e. Married

f. Living with partner

6. How would you describe ACB community and ACB women living with HIV in Winnipeg?

Probes: What does ACB mean to you?

7. Are you aware of HIV care programs for ACB women living with HIV in Winnipeg?

8. Can you describe the process of accessing HIV care? How does the HIV care system operate? What is the context of care?

9. What are your views, opinions and perceptions relating to HIV care and support services for ACB women with HIV?

10. What is the frequency of use of HIV support programs by ACB women?

11. What do you think are the barriers/factors influencing HIV care and support use among ACB women living with HIV?

12. How would you assess HIV services and care staff?

i. What are the approaches to care?

ii. Are there any gaps in services and areas of good practice?

13. How do you think challenges and issues has to be intervened at all levels, policy, health sector and community?

14. What are your recommendations for improving and expanding services?

15. Is there something else, you wish to share with me that you perhaps did not think about during the interview?

16. Is there something else you feel is important for me to know to understand your experience?

17. Is there anything you would like to ask me before concluding

Appendix 3

Socio-demographics of participants

Health and Support Staff

HS	Age (yrs.)	Employment status	Education	Marital Status	Gender	Ethnicity	Nationality	Religion	Time of Diagnosis
HS1	38	Full-time medical lab scientist at Nine Circles (NC). Has 9 years' experience	Higher than secondary school, Bachelor holder	Married	women	African	Nigerian	Not Applicable (NA)	NA
HS2	42	Partially part-time or full-time lab technician. Has 9 years' experience	Higher than secondary school	Married	women	Caucasian White	Canadian	NA	NA
HS3	38	Full-time primary care nurse, has 10 years with NC	Higher than secondary school. B.Sc.	Married	women	Black African	Canadian	NA	NA
HS4	49	Full-time outreach worker, has worked for 13 years with NC	Higher than secondary school. BSc.	Separated	Man	African	Burundi	NA	NA

HS5	48	Full-time, Family physician, medical director & primary care lead for the HIV program at NC. Has roughly 11 years' experience	Higher than secondary school. Post-graduate	Married	Woman	White Caucasian	Canadian	NA	NA
HS6	53	Full-time outreach worker. Has worked 20 to 21 years at NC	Higher than secondary school, has post-secondary training in medical assistant	Common Law	Woman	Biracial		NA	NA
HS7	41	Full-time certified, registered nurse at NC Has11 years' experience	Higher than secondary school, B. A	Common Law	Woman	African	Rwandan	NA	NA
HS8	38	Full-time, health educator, has 10 years' experience	Higher than secondary school	Married	Man	African	Demographic Republic of Congo	NA	NA

HS9	59	Part-time, permanent health education facilitator at SERC and pastor at the church	Higher than secondary school, B.Sc.	Married	Man	African	Demographic Republic of Congo	NA	NA
HS10	37	Full-time Project coordinator at SERC. Years of experience not specified	Higher than secondary school, B.Sc.	Married	Woman	African	Newcomer Canadian, originally from Eritrea	NA	NA
HS11	40	Full-time Co-ordinator program evaluation and research at SERC. Years of experience not specified	Higher than secondary school, has two masters	Married	Woman	Not sure, born in Brazil, family immigrated from Italy	Not sure	NA	NA
HS12	50	Full-time Settlement advisor at Welcome place. Years of experience not specified	Higher than secondary school, B.Sc. and also, interpretation training	Married	Man	African	Burundian		
AFRICAN CARIBBEAN AND BLACK WOMEN									

ACB1 Emma	44	Full-time, temporary, or causal	Higher than secondary school, has a B.Sc. and health care aid certificate	Married	Woman	African	Nigerian	Christianity	2001
ACB 2 Sophie	39	Unemployed, Job hunting	Grade 7	Divorced	Woman	African	Ethiopian	Christianity	2007
ACB 3 Theresa	35-40 (38)	Unemployed	Grade 12	Separated	Woman	African	Ethiopian	Muslim	2013
ACB 4 Linda	40-45 (45)	Part-time employed	Grade 12 graduate, also had 8 months of health care aide training	Single	Woman	African	Democratic Republic of Congo		2001
ACB 6 Rachael	40	Full-time, employed	Grade 7	Widowed	Woman	African	Ugandan	Muslim	2004
ACB7 Daniella	58	Unemployed, on disability	Grade 7	Single	Woman	African	Nigerian	Christianity	2001
ACB 8 Joan	30	Unemployed on maternity leave. Before worked a part time job	Grade 12, has health care aid certificate and planning to	Married	Woman	West African	Congolese	Christianity	2008

			study nursing						
ACB 9 Flora	36	Full-time employed	B.Sc. Accounting	Married	Woman	African	Ugandan, originally from Ethiopia	Muslim	2003
ACB10 Christy	50	Unemployed, on income assistance	Below high school or middle school. After grade 7	Separated, now Single	Woman	Black African	Ethiopian	Christianity	2010
ACB11 Natalie	25	Part-time employed, intend to stop work the next day	Grade 12	Single	Woman	Black African	Congolese	Christianity	2015