The Lived Experience of Pregnancy among HIV-positive Refugee Women: A Qualitative Study

by

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ABSTRACT

Previous research has revealed that the experience of HIV-positive refugee women arriving from endemic countries is complicated by social, structural, and cultural issues. If and when they become pregnant, HIV-positive refugee women face a unique situation that is poorly understood by health care providers. The intersecting influences of HIV and refugee status in the context of pregnancy have been essentially unexplored in the Canadian context. The objective of this study was to describe the lived experience of pregnancy among HIV-positive refugee women; to explore the meaning of pregnancy from the perspective of HIV-positive women; and to understand the complexity of issues facing HIV-positive refugee women. An interpretive qualitative research design viewed through a critical post-colonial lens guided the study. Women were interviewed using a semi-structured in-depth approach. Four core themes emerged from the phenomenological analysis. The findings suggest that the experience of HIV and pregnancy among refugee women in Canada involves both disconnection and restoration. They must manage the dynamics of pregnancy, the impact of HIV and the cultural, political and geographic 'newness' of Canada. Noteworthy, are the efforts women take to conceal the HIV diagnosis. Additional insight was gained through an intersectional analysis of the data. The findings of this analysis suggest that women: 1) experienced alterations in identity 2) faced significant social disruption, and 3) are impacted by macro-level polices that influence both their initiation and access to the health care system. The lived experience of pregnancy among HIV-positive refugee women in Canada is analogous to moving through a liminal reality. HIV-positive refugee women work to restore a disrupted and "Othered" identity. Pregnancy is integral to that restoration. The results of the study have implications for nursing's ability to support the transformative aspects of the liminal reality of pregnant HIV-positive refugee women. The potential for these transformations draw attention to nursing at practice, policy, education and research levels.

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DEDICATION

I would like to dedicate this thesis to the women I encountered in my clinical practice who were HIV-positive, pregnant and from endemic countries. You caused me to question what I was seeing and to challenge current processes that eventually led me down a path of new learning.

GLOSSARY

Canadian citizenship: A person described as a citizen under the *Citizenship Act*. This means a person who: is Canadian by birth (either born in Canada or born outside Canada to a Canadian citizen who was themselves either born in Canada or granted citizenship) or has applied for a grant of citizenship and has received Canadian citizenship (Citizenship & Immigration Canada, 2015)

Ethnicity: A group of persons who have a common ancestral origin, who have a sense of peoplehood and of group belonging, who are of immigrant background and may have either minority or majority status within a larger society (Ashcroft, Griffiths & Tiffin, 2007).

Landed immigrant: A person who has applied to immigration authorities and has been granted the right to live in Canada permanently (Statistics Canada, 2006).

Permanent resident status: The position of a person who has legally immigrated to Canada but is not yet a Canadian citizen (Citizenship & Immigration, Canada, 2015).

Race: A term used to classify human beings into physical, biological, and genetic categories, which presupposes that humanity can be separated into distinct groups, identifiable by their physical characteristics (Ashcroft, Griffiths & Tiffin, 2007).

Refugee (Claimant): A person who has applied for refugee protection status while in Canada and is waiting for a decision on his/her claim from the Immigration and Refugee Board of Canada (Citizenship & Immigration Canada, 2015).

Refugee (Convention): A person who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country (UNHCR, 2015)

Refugee (Government Assisted Refugee): A person who is outside Canada and has been determined to be a Convention refugee and who receives financial and other support from the Government of Canada or Province of Quebec for up to one year after their arrival in Canada. GARs are selected from applicants referred by the United Nations High Commissioner for Refugees (UNHCR) and other referral organizations (Citizenship & Immigration Canada, 2015).

Refugee (Privately sponsored): A person outside Canada who has been determined to be a Convention refugee or member of the Country of Asylum class and who receives financial and other support from a private sponsor for one year after their arrival in Canada (Citizenship & Immigration Canada, 2015)

Refugeeness: The universal process of becoming a refugee that transcends national origins and boundaries. It includes the crossing of borders, and the uprootedness that is shared by all who are forced out of their countries so that it constitutes an irreversible element in the construction of that person's subjectivity so much so that they become re-constituted as a new kind of person (Lacroix, 2004).

CHAPTER ONE

RESEARCH PROBLEM

This chapter describes the research problem which is located at the intersections between gender, HIV, refugeeness, and pregnancy. The research problem will be divided into two sections. The first section will explore the intersection between gender, HIV and pregnancy, while the second section will look at the intersection between refugeeness, HIV and pregnancy. The objectives and the research questions are also presented, followed by an overview of the epistemological stance that guided the project.

1.1 Intersection between Gender, HIV and Pregnancy

Women make up a substantial proportion of people living with HIV (Joint United Nations Programme on HIV/AIDS, 2013). More than half of the 35.3 million adults who live with HIV are women (Joint United Nations Programme on HIV/AIDS, 2013). Approximately 98 % of women with HIV live within developing countries with about two-thirds of them residing in sub-Saharan African and Caribbean regions (UNAIDS, 2010).

The impact of HIV on women is aggravated by gendered power dynamics and biological factors that are influenced by social, cultural and structural contexts affecting their vulnerability to HIV infection (Higgins, Hoffman, & Dworkin, 2010; Ostrach & Singer, 2012; Turmen, 2003). Women's biological vulnerability, including differences in mucosal epithelium, the modulating effects of semen on the female genital tract, and hormonal influences, can confer a greater risk of male-to-female than female-to-male transmission (Doncel, Anderson & Zalenskaya, 2014; Fox & Fidler, 2010; Kaushic, Roth, Anipindi & Xiu, 2011). In many countries where HIV is endemic, unequal gender relationships make it difficult for women to negotiate safe sex (Holtz, Sowell & Velasquez, 2012; Krishnan et al, 2008; Magadi, 2011), and contribute to women's susceptibility to HIV infection (Campell et al., 2008; Kendall, et al., 2012). As a result of disclosing their HIV status, many women within these same regions suffer physical, sexual and psychological violence (Gielen, Mcdonnell, Burke & O'Campo, 2000). During times of conflict

and displacement, often widespread within endemic areas, HIV has also been used as a weapon of war, where women are purposely infected through rape and sexual violence in order to propagate HIV within a region (Mills & Nachega, 2006). In addition, many of the societies within sub-Saharan Africa have social norms that dictate marriage and childbearing at an early age for women. The result is that younger women may have older sexual partners, affording them an HIV prevalence of three to six times higher than that of young men of the same age (Gouws, Stanecki, Lyerla & Gys, 2008).

Compared to their situation reflected by statistics available at the beginning of the epidemic, women in Canada account for a larger number and percentage of all people living with HIV/AIDS (Public Health Agency of Canada, 2011). Between 1998 and 2009, roughly 25 % of all new positive HIV tests in Canada involved women who were 15 years and older (PHAC, 2011). At the end of 2011, approximately 16,600 women were living with HIV/AIDS, an estimated 23.3% of the national total, and a 12.6% increase since 2008 (PHAC, 2011). Heterosexual vaginal transmission remains a predominant risk factor for women, accounting for infection in approximately 76% of all new cases (PHAC, 2011). When compared to men, women in younger age groups have a higher proportion of HIV/AIDS diagnoses (PHAC, 2012). Women within the 30–39 year age group comprise 37% of the distribution of women living with HIV, while slightly lower proportions of case reports have been documented in the 15–29 year old age group (32.5%) (PHAC, 2012). AIDS diagnoses for women in Canada have also increased over time. In 2008, women accounted for 24.7% of all new AIDS cases, an increase of 18.9% from the previous year (PHAC, 2010). Women within the 30–39 year age group represented 39.9 % of the total accumulated cases over the last 10 years, while those in the 40–49 year range represented an increase of 28.3% (PHAC, 2010). A quick view of these figures reveals that approximately 66%–80% of women who have HIV are of childbearing age (PHAC, 2010, Loutfy, 2009).

New infections continue to rise in Canada with women accounting for 24% of all new infections (PHAC, 2011). Of these new cases, women from endemic countries account for approximately 55% (PHAC, 2011). In Ontario, HIV prevalence for women of African and Caribbean origins has increased 85% since 1996 (Remis, Major, Wallace, Schiedel, & Whittingham, 2001). From 1984 to 2008, 137 infants with HIV were born in Ontario with 54% of the infants born to mothers who came from countries where HIV is endemic (PHAC, 2012). More recently, Forbes and colleagues (2012) conducted a national review of vertical HIV transmission, and found that, within Ontario, many of the women with HIV had emigrated from African and Caribbean countries where HIV is endemic.

Gardezi and colleagues (2008) have provided much of what we know about women with HIV from endemic countries in Canada. Many of the women who participated in this study stated that there was a lack of information about HIV in Canada, compared to what their country of origin supplied (Gardezi et al., 2008). A significant number reported reluctance to access health services for fear of racist perception that African or Caribbean people are carriers of HIV and other diseases (Gardezi et al., 2008). For many, HIV was low on their list of priorities while they dealt with other issues more important to them, difficulties such as familial conflicts, problems their children faced in schools, unemployment and settlement issues (Gardezi et al., 2008). They described the vulnerability of being an immigrant and talked about the lack of family support networks because they felt uncomfortable disclosing their situation to family members who lived far away (Gardezi et al., 2008). Some women also had trouble accessing HIV-related support services because of opposition from their partners (Gardezi et al., 2008).

Other studies have highlighted the effect of HIV-related stigma, gender discrimination and racial discrimination that present barriers to treatment, care and support, and often contribute to mental health problems (Logie, James, Thaoro, & Loutfy, 2013). The few studies in Canada that have addressed the needs of women with HIV from endemic countries have called for more culturally specific support services, greater sensitivity and knowledge on the part of

health care providers, increased community development and awareness within the endemic communities, and enlarged efforts to address housing, poverty, racism and settlement issues (Gardezi et al., 2008). Many of the studies within this population in Canada have been conducted within the Toronto or Montreal area (Adrien et al., 1999; Gardezi et al., 2008; Thaoro, Massaquoi & Telcom, 2006). One study looked at the prevalence of four preventable and treatable diseases among newly arrived refugees to Ottawa (Pottie, Janakiram, Topp & McCarthy, 2007). The researcher found no qualitative studies that looked at the concerns of refugee women with HIV within the National Capital region of Ottawa.

A study by Loutfy and colleagues (2009) demonstrated that significantly more is needed to support HIV-positive women to have healthy pregnancies and families. With reference to HIV-positive women's intent to have children, this study indicated that 69% of the women wanted to have children, and 57% fully expected to conceive one day (PHAC, 2010). Sixty-one percent of women included in this study were born outside of Canada, with 47% of them defining themselves as being of African ethnicity (Loutfy et al., 2009). Fifty-eight percent of the women who had fertility intentions expected to give birth in the future, with half of the women stating that they had taken action to become pregnant: 39% of women expected to be pregnant within the next one to four years (Loutfy et al., 2009). Characteristics of HIV-positive women who intended to have children included a younger age (than Canadian counterparts), having African ethnicity, being a newcomer to Canada, having a short duration of occupancy in Canada, and having a shorter duration of antiretroviral therapy (ART) (Loutfy et al., 2009).

The present study aims to build on the research conducted by Loutfy and colleagues (2009) by examining the intersecting influences of HIV and pregnancy for refugee women in Canada. It also draws on previous research within Ontario demonstrating that, with respect to women, four major, sometimes counteracting forces–including contextual conditions, constraints, barriers and deterrents–shape access to health care (Angus et al., 2013). In looking

at populations that are new to Canada, studies have revealed that participants experience geographic, socio-cultural and economic barriers that affect their accessibility to health care (Asanin & Wilson, 2008; Donnelly, 2006). Other studies have examined the settlement challenges, which usually include difficulties encountered in securing access to employment, housing, as well as experiences of discrimination with the Canadian host context (Danso, 2001; Gabriel, Morgan-Jonker, Phung, Barrios, & Kaczorowski, 2011; Gushulak, Pottie, Roberts, Torres, & DesMeules, 2011). With reference to pregnancy, a few authors have examined the experience of pregnancy within specific immigrant populations (Chalmers & Omer-Hashi, 2000, 2002; Higginbottom et al., 2013).

Canadian studies examining HIV and pregnancy have largely focused on HIV prenatal screening, fertility among HIV women, mothering issues, and the type of ARV therapy used for virologic suppression at birth (Kaida et al., 2009; Loutfy et al., 2009; Money et al., 2009; Wang, Larke, Gabos, Hanraham, & Schopflocher, 2005). None have specifically looked at the woman's experience of pregnancy and HIV. Yet it is known that a diagnosis of HIV in pregnancy has an impact on the physical, mental, social and spiritual well being of the mother which in turn has implications for the infant's and family's well-being (Bansil, Jamieson, Postner & Kourtis, 2007; Carolan, 2010; McIntyre, 2005; Ross, Sawatphanit & Suwansujarid, 2007).

Likewise, a similar lack of studies of pregnancy and HIV in the context of refugee status in Canada indicates a need for research that looks at the lived experience of pregnancy among HIV-positive refugee women. With the aim of providing valuable insights into issues surrounding their physical, mental and social well-being, such research would also illuminate current practices that either promote or hinder the woman's ability to access health care. Knowledge gained in such studies may be used to promote and maintain the health of refugee women with HIV when they become pregnant and deliver their babies in Canada. Studying the lived experience of pregnancy within this population will give health care providers valuable knowledge about the issues that are important to pregnant refugee women at a time when they

will be encountering major life transitions (pregnancy), in addition to a diagnosis of HIV. As we gain knowledge about what is both useful and problematic for pregnant women with HIV we will be better able tailor practices, supports, programs, policies and institutional contexts that foster good nursing care. This is especially important for refugee women with HIV who are also pregnant, whose experience may be altered by the processes of migration within the social context of Canada.

The interplay of HIV, pregnancy and refugee status represents a unique interaction that has not been explored within the social context of Canada in the National Capital region. While previous research tells us that the experience of refugee women is complicated by various social, structural and cultural issues (Gardezi et al., 2008), studying their lived experience will serve to increase our understanding of how women from HIV endemic countries experience pregnancy and a concurrent diagnosis of HIV within the social, political and institutional context of the National capital region in particular. By describing their experiences, the participants in the study will provide valuable insights to how refugee women bring meaning to and make sense of the experience of HIV and pregnancy (Smith, Flowers, & Larkin, 2009). By exploring the complexity of issues facing this group of women, we hope first to provide a space that affirms the lived experience of pregnant refugee women with HV, who, up until this time, may have been silenced or rendered invisible within the social and institutional context of Canada. Secondly, we hope that narration of their experiences may begin to unveil barriers that limit their care and ability to access health services as they attempt to care for themselves.

1.2 Intersection between Refugeeness, HIV and Pregnancy

Canada ranks seventh as a country receiving asylum claims, and the first part of 2011 saw four percent more asylum claims than the first half of 2010 (UNHCR, 2011). Between 10, 000 and 12, 000 refugees, representing nearly 70 different nationalities, resettle annually in Canada, with approximately 70% of them originating from sub-Saharan Africa and the Caribbean (Citizenship & Immigration Canada, 2010; Statistics Canada, 2009). Since 2002, Canada implemented a

mandatory HIV testing policy for all permanent and some temporary applications for Canadian residency (Bisaillon, 2010). This screening takes place during the medical examination that is carried out either in federally designated foreign or Canadian sites (Bisaillon, 2010). Refugee women often discover their positive HIV serological status either immediately before, or shortly after their arrival into Canada. On arrival, they have a high incidence of infectious diseases such as tuberculosis, syphilis, hepatitis B and gastrointestinal parasites (Beiser, 2005). Prior to resettlement, refugees may have been victims of physical and sexual violence, economic distress, conflict, oppression, discrimination, exploitation, gender bias and socio-political marginalization (Beckwith et al., 2009; Berman, Giron, Marroquin, 2006). Upon arriving in host countries, they often experience welfare dependency, psychiatric disorders, mistrust, demoralization, poorer health status and poor responses to “Western medicines” (Briggs, 2011; Westermeyer, 2011; Wong et al., 2011).

The Interim Federal Health Program (IFHP) that provides limited and temporary coverage of health care benefits to resettled refugees and refugee claimants in Canada is challenging and complex for clients and providers alike (McKeary & Newbold, 2010) . To add to this complexity, the federal government, as of June 2012, instituted cuts to the program that resulted in effectual removal of health care coverage for many refugees and refugee claimants and decreased access to health care for most (Baines, 2013). Subsequently, a July 4, 2014 federal court decision ruled that these cuts were contrary to the Canadian Charter of Rights and Freedoms in that they imposed cruel and atypical treatment on refugees (Canadian Council for Refugees, 2014). Effective November 5, and pursuant to ministerial authority under the Department of Citizenship and Immigration Act, the Minister of Citizenship and Immigration implemented temporary measures while appealing the July 4, 2014 Federal court decision (Citizenship & Immigration Canada, 2014). All of this magnified the confusion around the Interim Federal Health program creating further barriers to care and contributed to an aversive social environment for refugees.

Being displaced from one's country of origin has an enormous impact on a refugee's life as well as upon the lives of people within host communities (UNAIDS, 2010). In the case of refugee women, their gendered experiences during war and escape, in conjunction with the stressors they encounter in exile, result in their needs being qualitatively different from those of men (Deacon & Sullivan, 2007). During war, women are at an increased risk of sexual assault and more vulnerable to attacks while involved in gender specific duties: they may face sexual exploitation at the hands of border guards, armed forces men and refugee camp officials (Hynes & Cardozo, 2000; Miller et al., 2002). While in refugee camps, women may have limited access to health resources, and suffer disproportionately from health problems, such as poor nutrition, when gender norms dictate that male family members eat first (Hynes &Cardozo, 2000). Resettlement challenges, which include securing shelter, food and employment security, often consume the bulk of their energy, leaving little time left to attend to health care needs until an emergency arises (Asgary & Segar, 2011). Lack of second-language skills may act a significant barrier to accessing health care, and, at times, leads to miscommunication, misdiagnosis, and lack of suitable follow-up (Kemp, 1993; Moreno, Piwowarczyk, & Grodin, 2001). In addition, inadequate interpretation makes it difficult to navigate and understand the workings of an unfamiliar and complex health care system that offers limited community support (Asgary & Segar, 2011). Furthermore, health care professionals in host countries often have insufficient skills to detect and manage unfamiliar diseases among refugees (Weinstein, Sarnoff, Gladstone, & Lipson, 2000). There is a significant gap in service provision affecting pregnant women living in communities (Harris & Telfer, 2001).

Previous studies have attested to the lack of Canadian data on refugee health (Gabriel, Morgan-Jonker, Phung, Barrios & Kaczorowski, 2011; Gagnon, 2002; McKerary & Newbold, 2010). Despite Canada's assurance to relocate refugees and the identified barriers faced by refugees in accessing health care, there is a surprising lack of longitudinal data on the health of refugees (Gabriel et al., 2011). In addition, there is scarcity of evaluation of the efficacy of

interventions designed to meet refugee health care needs (Gabriel et al., 2011). The accessible studies are usually external to Canada, often examine only one ethnic group, and neglect the study of local areas or communities (Gabriel et al., 2011; Wood & Newbold, 2012).

This study will remediate the paucity of research that is currently available in Canada surrounding the health of refugees. By adopting a post-colonial perspective, it will seek to describe and explore the complexities inherent in the experience of HIV-positive refugee women who are also seeking maternal care. According to previous studies, the barriers refugees encounter translate into decreased utilization of needed health care services (Fenta, Hyman, & Noh, 2007). This is particularly important to recognize in dealing with HIV-positive refugee women who are also pregnant, since barriers to health care may cause them to present late in pregnancy, creating a crisis management approach to care and resulting in less than optimal health care for them. By studying the experiences of pregnant HIV-positive refugee women, the hope is to discover gaps and barriers within our health care system and in Canadian society in general. Such barriers shape the woman's experience and have implications for the meanings she attaches to her pregnancy. Knowledge generated in this study could be useful to policy makers in designing health policy, programs and services for refugees. It may also assist health care providers who have felt overwhelmed and identified the need for training to deliver culturally appropriate care to refugee populations (Lamb & Smith, 2002; Miedema, Hamilton & Easley, 2008).

In addition to a lack of research on refugee health, there are few studies that explore a woman's experience of being pregnant while being a refugee and living with a diagnosis of HIV. No studies of a qualitative nature were identified within the Canadian context; one quantitative study examined pregnancy outcomes of HIV-infected refugees in the United States (Blood, Beckwith, Bazerman, Cu-Uvin & Mitty, 2009). This study, a retrospective chart review, looked at a population of 28 HIV-infected women between the years of 2000 – 2006. During this time frame, there were 20 pregnancies among 14 women, with 9 deliveries, 5 terminations, and 3

spontaneous abortions. One child was born with HIV. The results of the study confirmed that we need to gain a better understanding of the social and cultural issues and the potential barriers to care that are involved in the reproductive health of this unique and growing group of women (Blood et al., 2009).

Such understanding is best achieved with qualitative research. Qualitative studies are undertaken when some aspect of a phenomenon is poorly understood and there is a need to develop a rich, comprehensive and context bound understanding of it (Creswell, 2007; Polit & Beck, 2008). They also serve to heighten awareness and create dialogue about a phenomenon (Creswell, 2007; Polit & Beck, 2004). As a unique and growing population within host countries, HIV-positive refugee women who are also pregnant represent a phenomenon about which little is known, especially in the Canadian context.

Previous authors who have examined the experience of HIV and pregnancy have identified a 'double bind' for many women. On the one hand these women view pregnancy as integral in achieving a complete and fulfilling life, a view that corresponded to the social and cultural norms of their society. The addition of HIV links their pregnancy to an aura of deviance associated with the potential harm to the fetus resulting in social and personal messages about the "evils" of childbearing when HIV-positive(Ingram & Hutchinson, 2000; Sanders, 2008). Stigma is inherent in a diagnosis of HIV (Barroso & Powell-cope, 2000), and this is amplified for women who are pregnant (Ingram & Hutchinson, 2000; Ross et al., 2007; Sandelowski & Barroso, 2003). These women often receive negative judgement about becoming pregnant, and they are often excluded from discussions surrounding breast-feeding with its relationship to transmission of HIV (Sanders, 2008). Relationships with health care providers are often problematic, and have considerable influence on shaping the meaning of the pregnancy. Women often feel that they are seen only as HIV-infected women obscuring those aspects of the pregnancy that were typical and enjoyed by women during that time (Ingram & Hutchinson, 2000). As such, as women who are perceived to deviate from an ascribed norm of maternal

identity, they often receive lack or recognition and support for the experience of pregnancy (Ingram & Hutchinson, 2000). Most of the studies within the literature review have discussed either pregnancy and HIV, or pregnancy within a refugee population, or the general needs of refugees. There were no studies that specifically looked at the effect of a pregnant woman's being HIV-positive in the context of coming to Canada as a refugee.

Nursing as a discipline has a social mandate to develop knowledge for practice aimed at the good of both the individual and society (McCurry, Hunter, Revell & Roy, 2009). Several studies have shown that refugee claimant women have a high number of pregnancy and post-partum health and social concerns that are not being addressed (Gagon, 2002; Gagnon, Dougherty, Platt, Wahoush & George, 2007; Loutfy et al., 2009; Merry, Gagnon, Kalim, & Bouris, 2011). This study is significant in its focus on exploring how refugee women make sense of their experience in the context of HIV and pregnancy. The information generated will assist in developing nursing knowledge of interventions that recognize the complexity of issues facing this population. Describing the experiences of pregnant refugee women, who also have a diagnosis of HIV, will advance nursing knowledge by attuning practitioners to the multifaceted concerns facing this group of women, and assist in addressing gaps to care that currently exist within the social, political and institutional context of Canada. By exploring the meaning of pregnancy and HIV within the lifeworld of refugee women we come closer to understanding the issues that are relevant to this population. We can then move closer to being able to develop and design health care interventions that are pertinent and supportive to their care.

Further research is also necessary in order to provide insight to our present processes, illuminating gaps and providing guidance for improvement. Previous authors have advocated for programs that acknowledge the centrality of motherhood for pregnant women who have HIV delivered within an interdisciplinary holistic model of care (Barroso & Powell-Cope, 2000; Sandelowski & Barroso, 2003). The knowledge generated in this study may provide insights towards developing such programs and the policies and systems that can support them.

Information gained may be utilized to design educational programs for all disciplines working within the context of HIV, including nursing, medicine, social work, nutrition, pharmacy, research and community advocacy. Cultural stigma and lack of particular cultural knowledge have been cited as important concerns of pregnant refugee women (Bulman & McCourt, 2010; Bunting and Seaton, 1999). Insight to these phenomena within the Canadian context is particularly valuable in order to promote health care contexts that are culturally and emotionally safe.

The proposed project addresses a gap in Canadian studies on pregnancy and HIV that have largely overlooked the lived experience of refugee women. Health care professionals have a limited understanding of pregnancy as it relates to the many realities of HIV-positive refugee women. This inquiry aims to acquire a deeper understanding of the experience of pregnancy and HIV among this group of women. The hope is to explore and shed light on how the intersection of HIV, gender and refugee status shape the experience of pregnancy with relevance to the woman's well-being, her social relationships, and her interactions within health care institutions in Canada. By paying attention to the "story" revealed in the lived experience the researcher hopes to be able to focus on how various dimensions of a refugee woman's social identity–such as race and class, as well as education, citizenship and geographic location–overlap to influence health. In so doing, we hope to move beyond the individual experiences of health and illness, and acquire a more meaningful understanding of the social, cultural, economic and political aspects of their lives. Such knowledge has the potential to bring us closer to healthcare that is more equitable, culturally safe, and socially just.

1.3 Research Objectives

The current study has three objectives:

- Describe the lived experience of pregnancy among HIV-positive refugee women;
- Explore the meaning of pregnancy from the perspective of HIV-positive refugee women;

- Explore the complexity of issues facing HIV-positive refugee women in the context of pregnancy at the micro, meso and macro levels.

1.4 Research Questions

- What is the lived experience of pregnancy among HIV-positive refugee women?
- What is the meaning of pregnancy for HIV-positive refugee women?
- What are the issues facing HIV-positive refugee women at the micro, meso and macro levels?

1.5 Epistemological Stance

1.5.1 Critical theory paradigm

The approach of critical theory has much to offer the current study. The following paragraphs will discuss the ontology, epistemology and methodology related to critical theory. Its use in nursing inquiry and the relationship to this study will be highlighted. Finally, the goal of critical theory within this study will be pointed out.

In critical theory, ontology is viewed as critical realism. Social, political, economic, cultural, ethnic and gender influences merge together in a virtualized crystallized form that is taken for 'real' (Ford-Gilboe, Campbell & Berman, 1995; Guba & Lincoln, 2005). This "reality" remains hidden, based on assumptions and values that are taken for granted, culturally marked and historically situated (Darlington, 2011; Guba & Lincoln, 1994). How each of these contexts and processes intersect to form reality is never static; rather, contexts and process are always evolving in light of new theoretical insights and social circumstances (Kincheloe & McLaren, 2005). New interpretations of meaning are generated by recognizing the importance of historical influences and how such influences continue to affect social, cultural, political, psychological and educational consequences (Kincheloe & McLaren, 2005).

The critical theorist adopts a transactional and subjectivist stance towards epistemology (Darlington, 2011; Guba & Lincoln, 2005). Interactions between the investigator and the

participant create a dialectic that results in a quest towards making sense of what has been observed (Guba & Lincoln, 1994; Kincholoe & McLaren, 2005). No one pure interpretation exists, but what ensues is a form of cultural criticism that reveals power dynamics within cultural and social contexts, linking historical contexts with present circumstances (Kincholoe & McLaren, 2005). New knowledge is dual: a social critique that results in raised consciousness and a possibility for constructive, transformational social change at the individual and structural level (Guba & Lincoln, 2005).

The methodology of critical theory is dialogic/dialectical (Guba & Lincoln, 2005). The goal is to make connections that link the present day experiences of the subject to historical and subjugated knowledges that may have influenced their experiences of collective struggle, suffering, and conflict (Guba & Lincoln, 1994). This methodology digs beneath surface appearances, with intent of exposing unequal societal, power and ideological structures, in order to embrace a political aim that combats oppression and effects change. The dialectic challenges the status quo with oppositional thinking, dialogue and analysis, while asking the questions “Who benefits from this situation?”, and “How is this situation maintained?” (Fontana, 2004). Critical theory situates truth as partial, identity as fluid, language as an unclear referent system, and method and criteria as potentially coercive (Guba & Lincoln, 2005). A researcher using the methodology of critical theory seeks to explore the way in which discourses influence power, and how power and knowledge dialectically interact to substantiate what is considered plausible and true (Kincheloe & McLaren, 2005). The researcher confronts injustice, is inherently political, and becomes a partner in transforming and empowering individuals towards a more socially just world (Kincheloe & McLaren, 2005).

Critical theory has been increasingly used in nursing inquiry, theory and practice to inform oppressive socio-political conditions influencing health, health care, and human perceptions of the social world (Boutain, 1999; Browne, 2000). As such, it is also useful in the study of this refugee group of HIV-positive, pregnant women. Refugee women, often travelling

alone, represent a special class of displaced populations who are forced to leave their countries and cross international borders to seek refuge from persecution related to race, ethnicity, religion or political affiliation (Baird, 2012). Potential citizens with HIV represent a distinct class of immigrants that sets them apart from other newcomers who are HIV negative (Bisaillon, 2011). Racial and ethnic disparities continue to exist for women in initiation of both routine and specialized prenatal care services (Gavin et al., 2004). Critical theory recognizes that these imposed social oppressions experienced by refugee women are not natural, but occurred as a result of historical, political, economic and social conditions that contributed to their production (Davis, 1995). In addition, it interrogates the power relationships that maintain the conditions (Calhoun, 1995). A critical dialogue opens up a space wherein the voices of those who have been silenced throughout history may become central in the social production of contextualized knowledge that may provide the basis for ethical and socially just action (Anderson et al., 2009). It contributes to advancement of social justice for this group of women, by linking knowledge and theory development to practice-relevant social and political actions aimed at improving health, health care and social conditions (Maxwell, 1997).

The goal of critical theory within this inquiry will be to question the assumptions upon which reality is based, to provide insights to the power influences that affect that reality, and to construct a reflection of women's lives that have been influenced by those historical, cultural, political and social circumstances. While critical theory provides a suitable paradigm from which to examine the power dynamics that influence inequities in people's access to health, a post-colonial perspective alerts us to colonizing and racializing practices that contribute to the gap between social justice and socially just action. (Anderson et al, 2009).

1.5.2 Post-colonialism

Post-colonialism is one of the critical theories that provide a theoretical lens allowing access to the everyday experiences of marginalization as structured by the micropolitics of power and the macrodynamics of structural and historical nature (Kirkham & Anderson, 2002). This approach

is the theoretical and empirical work that centralizes the issues arising from colonial relations and its after effects (Cashmore, 1996). It seeks to unveil the harmful effects of racialization in everyday life, while illuminating the unpredictable and changeable operation of intersecting oppressions (Kirkham & Anderson, 2002). It is interdisciplinary in character, comprising several themes, including race, ethnicity, nation, subjectivity, identity, power, subalterns and hybridity (Kirkham and Anderson, 2002). By challenging the idea of a universal standpoint for knowledge development, it suggests that we learn our most enduring lessons from an inter-related historical analysis of subjugation, domination and displacement (Anderson, 2002).

Others have utilized this framework to devise a research methodology and to examine cultural safety in health care practice (Kirkham & Anderson, 2002; Kirkham et al., 2002). In addition, post-colonial theory has been combined with feminist theory to provide explanations regarding theory and methodology in nursing scholarship, policy research and exclusionary effects of healthcare systems (Anderson, 2000; Anderson, 2004; Blackford, 2003; Racine, 2003). Its pertinence has been demonstrated in the work of Guruge and Khanlou (2004) who established that the individual health concerns of refugee and immigrant women are embedded within the complex socio-economic, historical, political, and institutional structures and dynamics of the pre- and post-migration context. The social identities of their race, class, gender, citizenship and geographical location not only interconnect and shape their experience of health and illness, but become transformed into hierarchies and built into institutional structures, that legitimize inequalities and access to health care. Guruge and Khanlou (2004) maintained that a post-colonial perspective creates a space for looking at how these various dimensions of social identity place women in various social locations that inadvertently affect their health.

The approach of post-colonialism is pertinent to the current study, which is designed to describe the experiences of pregnant refugee women who also have a diagnosis of HIV. Marginalization, influenced by the intersecting influences of power, race, racialization and culture, has traditionally dominated the lives of women in minority situations and patients living

with HIV (Anderson, 2002; Guruge & Khanlou, 2004; Mill et al., 2009). Post-colonialism contextualizes the individual health experiences of pregnant refugee women with HIV, by examining their experiences at the micro, meso and macro levels of analysis (Guruge & Khanlou, 2004). Instead of viewing race as denoting biological origin, post-colonialism recognizes that races are socially represented and embedded in a process of racialization (Barker, 2000). Instead of viewing culture as a static entity, it embraces an understanding of the processes that contribute to culture and the way in which discourses of culture are used by colonial systems to obtain and maintain the power of the dominant culture (Downing & Kowal, 2011). In these ways, post-colonialism can help us understand how refugee women's views are shaped by experiences in their own countries, their lives during displacement and their interactions within the host Canadian country. It recognizes that immigration laws, Western health policies and settlement experiences interconnect with Canadian health strategies to create a complexity in experience that is unique for refugees, influencing how they comprehend and address their health and settlement concerns within the hierarchical social space of Canada (Guruge & Khanlou, 2004; Oxam-Martinez et al., 2005).

Post-colonial theory is particularly applicable to the current study. The participants within this research project comprise a population of women from countries that have been historically dominated by a colonial force. They may have been subjected to a variety of racisms, both personal and organizational, which may impact their health condition, their entry into health care, their beliefs about using health services, and their exchanges with health care providers (Culley, 2006). By providing a reference point from which to examine the after-effects of an empire and experiences of colonization, post-colonial theory challenges nursing's traditional notions of transcultural care and points to a more intricate configuration of culturally safe nursing practice that considers how social and cultural contexts, race and gender intersect to impact non-Western populations' health (Racine, 2009). Such an analysis is essential if we

are to comprehend, and eventually transform the dramatic disadvantages in health that exist for non-Western populations within Canada (Anderson et al., 2009; Racine 2003).

CHAPTER TWO

LITERATURE REVIEW

A comprehensive review of the literature was conducted to establish the evolution of the research that has looked at the experiences of pregnancy for HIV-positive refugee women. Across multiple disciplines, including medicine, nursing, social work, anthropology and psychology, a search was conducted using various databases including CINHAL, Scopus, Psychoinfo and Proquest. Keywords utilized included HIV, pregnancy, refugee, Canada, barriers, and access. Since there was limited research available on the three particularities of refugees, pregnancy and HIV, the literature review was drawn from various sources. The search began with an exploration of the experiences of refugees within the host context of Canada. The focus was then directed to the particular issues facing HIV-positive refugee women. Since there was a paucity of literature that specifically explored the experience of pregnancy among HIV-positive refugee women, literature that looked at HIV in the context of pregnancy was examined first, followed by literature that looked at pregnancy in the context of refugee status.

The chapter begins with a discussion of the experiences of refugees in Canada, followed by a pertinent breakdown of the mandatory HIV testing policy. The particular experiences of HIV-positive refugee women will then be examined, followed by literature on HIV and pregnancy, and a final section that looks at the issues facing refugee women who are pregnant.

2.1 Experiences of Refugees in Canada

Studies looking at the experience of refugees in Canada have been diverse. These examine: initial settlement experiences (Danso, 2001); mental health (Anderson, et al., 2010; Beiser, 2009; Donnelly et al., 2011; Fenta, Hyman & Noh, 2004; Wilson, Murtaza & Shakya, 2010); the status and models of refugee health (Beiser, 2005; Greenaway et al., 2007; Maximova & Krahn, 2010); the impact of policy changes (Arya, McMurray & Rashid, 2012; Bassel, 2010; Steele, Lemieux-Charles, Clark & Glazier, 2002); and challenges and barriers to providing and receiving health care for refugees (Caulford & Vali, 2006; Crooks, Hynie, Killian, Giesbrecht & Castleden,

2011; Miedema et al., 2008). However, the distinctive experiences and consequences confronting refugee populations in Canada remain poorly understood (Edge & Newbold, 2013). These are a complex interplay of environmental, economic, genetic and socio-cultural factors related to when refugees arrive in Canada, where and how they lived in their home countries, and the process of migration (Carranza, 2008; Gushulak et al., 2011; Hopkins, 2010). Once refugees are in Canada, their experience will also be influenced by the structural and cultural differences of their particular host city (Castles, 1998; Danso, 2001). In addition, the widespread diversity among refugees' encounters makes their pathways to relocation and integration divergent and varied (Danso, 2001). In spite of these contrasting experiences among refugees, Lacroix (2004) argues that they share universal elements that transcend national origins and boundaries. These elements include the crossing of borders, disturbing uprootedness, and a sense of loss and dislocation, which are fundamental when a person is forced to take flight from their own country (Jorden, Matheson & Anisman, 2009; Lacroix, 2004).

2.1.1 Refugeeness

Refugees have no choice but to exit their country (Carranza, 2008). They very often retain a strong attachment to their home country, where they were established with their families, jobs and homes. Leaving is viewed as accepting defeat and as giving up on an ideal that has fuelled their life, with the sense that who they are is diminished as a result (Lacroix, 2004). From this place of no choice, individuals in the process of becoming a refugee catapult into situations where many decisions are forced upon them: from the route they take to exit, to their choice of a lawyer who assists in the immigration process, to where they live in Canada (Lacroix, 2004).

A refugee's self-identity is seriously disrupted by their geographical and social relocation. Refugees are persons with an identity, a past, a history and a cultural legacy (Lacroix, 2004). Escaping persecution restricts their movements, and once they enter resettlement areas, they are often cast into a state of limbo for many years (George & Ramkissoon, 1998). The resulting process impacts "who they were, who they are, and who they will become" (Lacroix,

2004, p. 147). By virtue of becoming a refugee, a person is re-signified as a new kind of person through a fragile relationship between the individual and the sovereignty power of the nation state within the host society (Hopkins, 2010; Lacroix, 2004). A previously cohesive identity becomes fragmented, and a new identity becomes imposed and defined by others (Dyck & McLaren, 2004; Wilcke, 2006). Some refugees constitute their formulation of self as two states of being: one that looks backward that involves retaining a cohesive sense of self from a fragmented society, and one that looks forward creating a sense of self in a new society (Connor Schisler & Polatajko, 2002; Dossa, 2008; Wilcke, 2006).

Refugeeness begins with the particular incident that forces the individual to escape and exit from their country (Bokore, 2013; Dossa, 2008; George, 2008). Once the person arrives in Canada, the refugee assignment process is drawn out and unclear, and it is often described as a "state of limbo" (Bassel, 2010; George, 2008; Lacroix, 2004). For applicants who apply for permanent status within Canada, the processing time is approximately 22 months, taking up to 42 months for humanitarian and compassionate cases (Citizenship and Immigration Canada, 2015). During this period, when they have limited access to work and social assistance, claimants are also generally separated from their families (George, 2008; Lacroix, 2004).

The refugee is constructed at macro, meso and micro levels. The macro level, the dominant discourse of construction, originates from the international refugee organization with its categories, classifications and rules that label someone as a refugee within the Western world. Meso level effects are enacted within different nation states through restrictive policies and administrative appraisals that constitute the refugee as the "Other,' who becomes excluded from full participation in host societies. The micro level occurrences involve each individual refugee's experience and the impact that Canadian refugee policy has on their lives including their work and family life (Hopkins, 2010; Lacroix, 2004).

Many refugees have described their decision to become a refugee as a "point of rupture," a severance from their previous environment, with resultant confusion as to how to

represent themselves (Lacroix, 2004, p. 156). Traumatic events that precipitate their decision to leave shatter their assumptions that the world is a predictable and meaningful place and cripple their sense of community and meaning of self (Carranza, 2008; Jorden et al., 2009; Wilcke, 2006). In this state of trauma and resultant confusion, people are made to feel guilty for who they are rather that what they do, resulting in tremendous shock to their identities (Talebi & Desjardins, 2012; Wilcke, 2006). Becoming a refugee includes rebuilding the person's sense of who they are, not only rebuilding their lives but also rebuilding their subjectivity (Dossa, 2008; Hopkins, 2010; Lacroix, 2004). There is no direction or framework for this rebuilding. The refugee experiences the feeling of being "led," and of not knowing what to do or where to go, rather like "not knowing where to put one's feet" (Lacroix, 2004, p.157). This whole process involves leaving the old person and becoming someone else for a time, even to the point that the refugee no longer knows who they are (Lacroix, 2004).

Gender constitutes a major variable in the refugee experience (Dossa, 2008; Hyndman, 2010; Hopkins, 2010; Lacroix, 2004; Oxman-Martinez, Abdool & Loiselle-Leonard, 2000). Refugee women are often expected to alter aspects of their identity in order to "fit" into health and policy interventions that may be designed for Canadian women or immigrants in general (Hopkins, 2010; Oxman-Martinez et al., 2000). They do not claim this imposed subjectivity, and affirm that they will discard it at the end of the process (Lacroix, 2004).

2.1.2 The influence of bureaucracy

A refugee's destination is largely determined at the visa post-interview, when staff makes destination decisions for refugees based on unclear and inconsistent practices that are affected by social conditions within Canada (Canadian Council for refugees, 1996). Typically most refugees are asked if they have family or friends in Canada as staff attempts to send them to places where they will have the support of someone they know (Citizenship and Immigration Canada, 2010). However, refugees identify risks in indicating their destination of preference. Some refugees have stated that asserting their desire to join family may undermine their

refugee claim, that such a declaration could detract from government assistance, or that their claim for refugee status may be negated altogether (Simich, 2003). Still others have stated that cultural norms about what constitutes a close relationship is often not authenticated in the host Canadian culture, limiting verification of a choice as a reasonable destination (Simich, 2003). Time pressures are real and expediency is a priority for visa officials who work under extreme demands to process the large numbers of refugee applications. The discussion about destination could be short and brief. Thus, destination desirability is not always honored in the final decision about re-location.

The selection and destination interview is a high-stakes negotiation process (Simich, 2003). These pressures determine the rest of refugees' lives, determining whether one is able to seek refuge or not. The transaction occurs within bureaucratic constraints, which in turn are based on larger domestic political negotiations. Targets that have to be filled are set for a number of cities (Simich, 2003). In Canada, Toronto is a popular destination point. The process becomes a constant juggle, attempting to honor family reunification requests with federal-provincial regulations that have set targets according to the infrastructures for refugee assistant program income support. Thus, predetermined refugee targets for various provincial communities sometimes take precedence over meeting refugees' needs for social support (Simich, Beiser, & Mawani, 2003). It becomes necessary to send people all over the country because that is the policy of immigration. A large majority of refugees (60%) who move within the first year are those who stated a destination preference but were not relocated accordingly (Simich, 2003). Based on political agendas, bureaucratic endeavours to control refugee resettlement de-emphasize the needs of the refugees and compel refugees to engage in secondary migration in order to sustain meaningful social support.

The process of selecting and bringing refugees to Canada "positions" them in assigned geographical regions that are politically determined according to provincial and national jurisdictional agreements. As a consequence, the importance of social ties most relevant to

refugees is often underestimated or unseen. When lack of social ties adds to the already present stresses of migration, refugees assert their needs to establish ties through the process of secondary migration, despite the definition imposed by those within the bureaucratic structure from “above.” Viewed in this light, secondary migration may be seen as a form of resilience that refugees exhibit in order to sustain the social support that is so important to health and adaptation.

2.1.3. Dissonance

Many refugees coming to Canada express a dissonance between what they expected to find in Canada and their actual experiences (Anderson, et al., 2010; Dyck & McLaren, 2004; Simich, Este & Hamilton, 2010; Simich, Hamilton & Baya, 2006; Talebi & Desjardins, 2012; Walsh & Krieg, 2007). One woman from Somali commented, “When we come to Canada, we start all over again, we start from zero, and it’s very difficult to start your life from zero” (Anderson et al., 2010, p.101). Others are chiefly concerned with securing physical protections from persecution. One Ethiopian woman commented, “All I want is safety and protection for my children and me” (Danso, 2001, p.6). Many have high hopes that they will be able to reassemble the pieces from their splintered lives and reconstruct them within the politically stable environment of Canada. They have hopes of a fulfilling, productive existence that allows them to reclaim their lives and self-dignity (Anderson, et al., 2010; Danso, 2001).

For some, this optimism was founded on the belief that they would be attaining more than political asylum and they had confidence that they would be able to obtain jobs and continue in their areas of professional training (Danso, 2001). They assumed that their skills, knowledge and past work experience would be transferrable into the Canadian job market (Danso, 2001). Others believed that they would have access to opportunities such as higher education that could improve their circumstances (Danso, 2001). Simich, Hamilton and Baya (2006), while interviewing Sudanese refugees and family class immigrants, found that they anticipated prospects for work and study that would assist them in achieving an improved and

easier life. Some of these hopes were also based on images put forth by Canadian visa officers abroad, where Canada is promoted as a land of opportunities and equality (Danso, 2001). Due to distinguishing circumstances that included escape from persecution, and as new members of society, many refugees also safe-guarded the hope that Canadians would be empathetic and co-operative in accommodating them: such are the values incorporated within African culture, where the inclination is to assist persons in need without regard to their country of origin (Danso, 2001).

Despite high hopes of betterment, 71% of respondents in one study felt that whatever expectations they had entertained prior to coming to Canada, these had been diminished since arriving and living in the new country (Danso, 2001). This was echoed in the study by Simich and colleagues (2006), in which 75% of Sudanese refugees and some immigrants stated that Canada was not what they thought it would be. Many felt that there was a huge gap between what they were told about life in Canada, and their own real-life personal encounters during resettlement (Anderson et al., 2010; Danso, 2001). Those who felt that their expectations were met had as their sole migration concern the escape of persecution within their own country (Danso, 2001).

When things do not evolve as anticipated, a sense of despair and despondency sets in for many refugees. They become very uncertain about their opportunities for a fresh life in Canada. Their hopes become eroded with the emergence of pessimism and insecurity regarding their future in the adopted homeland. Hope gives way to a pervasive uncertainty as to whether things will ‘‘turn around” for them, or if they must accept the reality that they will continue to be marginalized and treated as “unwanted additions” within an already established order (Danso, 2001; Dyck & McLaren, 2004). Simich and colleagues (2006) found that unmet expectations of life in Canada were clearly associated with psychological symptoms that contributed to a decrease in overall health.

Many newcomers also report a desire to return to their home country permanently should the conditions that transformed them into refugees alter for the better (Danso, 2001). Their physical presence is located in Canada, but more often than not, their emotions, thoughts and cares are directed towards their homeland (Dossa, 2008). They are “here,” but think about “there,” where they believe they essentially belong (Danso, 2001; Dossa, 2008). Sometimes this translates into “biding their time,” until the state of affairs in their homeland returns to a more “normal” state. They treasure the idea of returning to their homeland, and sometimes entertain the prospect of re-migration to settle in another country that is linguistically, culturally and geographically more similar to their own (Danso, 2001).

2.1.4 Reception and welcome

Research has shown that the kind of reception an immigrant group receives and the context within which that reception occurs are essential in determining the arrangement and resulting integration of that group within the new society (Gold, 1992; Wood, McGrath & Young, 2012). This reception is instrumental in affecting the life chances of those coming to the new country. If refugees are regarded as “unwelcome others” rather than as full members of the new society, this may create a condition of social exclusion leading to dysfunctional integration for the refugee community (Danso, 2001). There is a well established link between the long-term stability of host societies and the sense of belonging that refugees encounter (Ali, 2001). Because this experience of belonging is socially constructed, host communities must confront the task of building civil and cordial societies where rights are honored and differences are acknowledged and known (Ali, 2001).

Studies have examined the kind of reception afforded to refugees in Canada. The varieties of reception have ranged from a friendly encounter (50%), to one that is non-descript or not entirely genial (49%) (Danso, 2001). Some Somali refugees reported that their status as refugee claimants perpetuated the idea that there were in some way manipulating the system, and they were labelled as “queue jumpers” as a result. They felt that many mainstream

stereotypes contributed to their unfriendly welcome as refugees (Danso, 2001). Further investigation into the reception provided to refugees, especially those from a black ethnic heritage, showed that Canadians displayed friendly attitudes, but only as an obligatory gesture or as a matter of propriety (Danso, 2001). One Somali women from Toronto related how her children were excluded from playing with other Canadian children because of their skin color and because “black people were bad to associate with” (Danso, 2001). Richmond (2001) identified a hierarchy of “social distance” in Canada that places British, French and other western European peoples high on a preference scale, with blacks, Asians, and other “people of color” placed low. Although explicit racism is rejected in Canada, physical differences are still relevant in the discernment of groups. Subtle “polite racism”’ exerts an effect that denies minority association full acquisition of membership rights in egalitarian Canada (Danso, 2001).

2.1.5 Initial settlement experiences

2.1.5.1 ***Employment***

An essential step to successful resettlement is the establishment of stable and meaningful employment (George & Chaze, 2009; Henin & Bennett, 2002; Lamba, 2003; Sherrell, Hyndman & Preniqi, 2005). Many refugees encounter difficulties in the job market (Chapra & Chatterjee, 2009; Connor Schisler & Polatajko, 2002; Danso, 2001; George, 2008; Henin & Bennett, 2002; Husni, Koye, Cernovsky & Haggarty, 2002). Despite the fact that many refugees have high levels of education, they encounter limited access to employment opportunities due to devaluation or lack of recognition of credentials and experience obtained outside of Canada, and to lost documentation verifying occupational and educational status (Bokore, 2013; Creese & Wiebe, 2012; Crooks et al., 2011; George, 2008; Kopinak, 1999). For many, this leads to loss of status due to either unemployment, under employment, or “survival” employment, resulting in excessive workloads and loss of control within places of work (Danso & Grant, 2000; Henin & Bennett, 2002; Lamba, 2003; Oxman-Martinez et al., 2000). In addition, immigrant women are less likely to be employed than immigrant men (CRIAW, 2003). “Accent discrimination” and

Canadian employers' refusal to accept foreign-earned qualifications are major barriers that influence the adjustment and integration process for refugees new to Canada (Creese & Wiebe, 2012; Danso, 2001; George & Ramkissoon, 1998). Inadequate employment is also related to systemic discrimination and stereotypes that are associated with racialized groups in Canada (Crooks et al., 2011; Ng, Wilkins, Gendron & Berthelot, 2005).

As a result of these high levels of unemployment, refugees often report insufficient incomes to meet the demands of everyday living, leading to frustrations and disenchantment with life in Canada (Bokore, 2013; Connor Schilser & Polatajko, 2002; Creese & Wiebe, 2012; Dyck & Dossa; 2007; Dyck & McLaren, 2004). Only a small percentage of refugees reported job security (Danso, 2001; Sherrell, Hyndman, & Preniqi, 2005). Those who are able to secure employment are frequently hired into blue collar job positions that are often under-related to their current qualifications, providing limited opportunities for advancement, leading to experiences of downward mobility socially and economically, with subsequent degradations in mental health (Chen, Smith & Mustard, 2010; Creese & Wiebe, 2012). Most refugees find their first job between one and six months of arriving in the host city, with the average length of time being approximately seven months (Danso, 2001).

2.1.5.2 ***Housing***

Housing that is safe and affordable is the foremost concern for refugees, and is an essential first step in the resettlement and integration process (Francis, 2010; Carter & Osborne, 2009). Access to housing constructs and sets in motion a particular set of circumstances that have an unequivocal influence on the overall living experiences of newcomers (Danso and Grant, 2000). Secure housing acts as both a pivotal and congregating point that serves to orient all of the other activities in which refugees engage within the acculturation process, and provides a basis from which to look for jobs, language training and other services that assist in resettlement (Carter & Osborne, 2009). Attaining suitable housing has long-term implications, influencing access to other resources, including occupations, educational, medical, and recreational and

leisure facilities (Kearns & Smith, 1993; Francis, 2010). Without adequate housing there is no security, employment opportunities are diminished, health is compromised, education is put at risk, and social life is often chaotic (Danso & Grant, 2000; Carter & Osborne, 2009).

Refugees find their ability to find adequate housing is constrained by many factors, with resultant fears of homelessness (Carter & Osborne, 2009; Chapra & Chatterjee, 2009; Francis, 2010; George 2008; Kisson, 2010; Teixeira & Li, 2009). Although affordability was cited as the biggest housing-related barrier, other difficulties were attributed to factors related to general racism, discrimination, county of origin, ethnicity and neighborhood safety within government housing (Bokore, 2013; Danso, 2001; Teixeira, 2011; Wayland 2010; Weerasinghe, 2012). Studies that look at how Blacks and Whites are treated while seeking housing have discovered that there are notable differences (Hulchanski, 1993). Caucasians are often provided more information about housing markets, while blacks may be racially "steered," directed to all-black or largely black neighborhoods (Skaburskis, 1996). Institutional barriers in the host society, especially government policy and actions of "gatekeepers"–real estate agents, mortgage financiers, insures, and house owners–often make it difficult for racial minorities to obtain housing. Discrimination has compelled many immigrant groups within Canada to accept housing that is substandard (Danso & Grant, 2000). Other studies have shown how fragmentation of refugees' immediate households results in household extension, in which additional members (relatives or friends) are brought into the household, in order to facilitate economic adaptation to the new environment (Miraftab, 2000). This may have the effect of creating additional stressors attributable to overcrowding and congestion (Danso & Grant, 2000).

In essence, the experience of attaining affordable and accessible housing among refugee populations in Canada is a complex web of inter-related factors ranging from social, cultural and personal factors, such as intent to stay, and specific cultural and personal values. In addition, several other factors shape the newcomer's ability to secure housing, including their race, socio-economic status, income, age, gender, education and language. Also important are

their length of time in Canada, their immigration status, and government policy (Danso & Grant, 2000).

2.1.5.3 ***Family re-unification***

A particular stress in the initial settlement experience is refugees' attempts to have family members join them in Canada (Danso, 2001). Fleeing a homeland country disrupts relations within families and often gives rise to new forms of independence, dependence and identities with individuals (Danso, 2001; Oxman-Martinez et al., 2000). In order to reclaim family ties, many refugees attempt to reunite with their families by assisting them to come and live alongside them in Canada. This process is often complicated by bureaucratic red tape, lengthy immigration procedures, and refugees' insufficient financial resources (Danso, 2001). These difficulties can have a deleterious effect on the economic and psychological well-being of families, which in turn affects their ability to integrate as Canadian citizens (Jorden, et al., 2009; Wilson, Murtaza & Shakya, 2010).

Once families are united, refugees' social networks are improved assisting them to solve economic and social problems that are addressed insufficiently or not at all by public programmes (Danso, 2001). Both social networks and public institutions are instrumental in providing assistance for problems that refugees typically encounter during the course of initial resettlement (Danso, 2001).

2.1.5.4 ***Social Exclusion***

Social exclusion, often based on discrimination related to race, ethnicity, gender and religion, situates them as "unwelcome others," and has been cited as major source of difficulties encountered in refugee resettlement (Chapra & Chatterjee, 2009; Danso, 2001; Dyck & Dossa, 2007; Galabuzi & Teelucksingh, 2010; Hynie, Crooks & Barragon, 2011;Talebi & Desjardins, 2012; Teixeira & Li, 2009). The resulting isolation leaves them with little external social support and little understanding with respect to their trauma and losses, affecting their physical and mental health (Bokore, 2013; Carranza, 2008; Dossa, 2008; Oxman-Martinez et al 2000;

Stewart, Simich, Shizha, Makumbe & Makwarimba, 2012; Wilson, Murtaza & Shakya, 2010). They must work to rebuild their wellbeing and to restore social networks that have been ruptured as a result of their dislocation (Shellenberg & Maheux, 2007). In order to alleviate this exclusion many refugees maintain and develop various relationships both between and within host and home countries (Dossa, 2008; Sherrell & Hyndman, 2006; Walsh & Krieg, 2007).

Participants in some studies attributed downward socio-economic mobility and loss in status to pure discrimination (Stewart et al., 2012). While Canada offers protection to political migrants, locally communities may be less willing and prepared to accept refugees from African societies (Danso, 2001). Respondents in one study stated that they believed that black Africans were not welcome, nor would they ever be accepted by whites as equal members of Canadian society (Danso, 2001). The effects of omnipresent institutional and everyday racism may perpetuate the social isolation and contribute to the social anguish of many minority groups within Canada (Danso, 2001; Walsh & Krieg, 2007).

Exclusion is also augmented by policies that prevent recognition of credentials obtained outside of Canada (Li, 2001; Wilson et al., 2010). Many newly arrived refugees are further excluded by having to adjust to occupations that have fewer financial returns and less prestige than what they had been accustomed to in their home country (Connor Schisler & Polatajko, 2002).

2.1.5.5 ***Secondary migration***

Finding themselves within situations lacking social support, many refugees initiate a process of secondary migration and co-ethnic peer support in order to construct a sense of belonging that acts a springboard to other basic needs (Hynie et al., 2011; Kopinak, 1999; Simich et al., 2003). Within the first year after arrival at their destination in Canada, a significant number of refugees move to another province or city (Simich, 2003). Between the years 1999 to 2001, approximately 1,000 refugees relocated from the Prairies and nearly 700 moved from the Atlantic provinces. Most relocate to Ontario, which, on a yearly basis, receives half of all

Canada's refugees (Simich, 2003). This secondary migration seems to be part of a larger transitional phenomenon of re-establishing social ties based on family relations and cultural affiliations, and of mediating the pressures of the bureaucratic process (Simich, 2003).

Refugee resettlement is supposedly a negotiated process, although parties are initially unequal (Simich, 2003). Broader power structures have an influential effect in the evolution of migrant social networks (Simich, 2003). Immigration and resettlement officials make the plans that dictate the migration process for refugees, including their arrival and resettlement in Canada (Simich, 2003). However, once arrived in Canada, refugees customarily exercise increased self-determination in order to navigate their social environment to locate and sustain familiar sources of support, independent of the original destination plans set out by immigration (Simich, 2003). These social supports are vital to refugee migration and early resettlement not only assisting with the adaptive stressors imposed by migration but also in securing the social capital and resources that are essential in resettlement (Simich, 2003; Stewart et al. 2012).

Refugees make their decisions as members of extended social networks that include family, friends and ethnic community members (Simich, 2003). These decisions often take into consideration advice and information surrounding housing, securing a job, information about potentially useful health resources, and they involve emotional support and affirmation (Wahoush, 2009; Stewart et al. 2012). Through secondary migration, refugees maximize their ability to secure social support, irrespective of the logistical problems that are incurred as a result of the resettlement arrangement (Simich, 2003). An example of this is illustrated by a Bosnian refugee woman who moved closer to her brother in Toronto when her son suddenly became ill. Her need for social support during a crisis made clear to her the necessity of living in proximity to someone who was available for help (Simich, 2003).

Among refugees who have been settled for several years, the search for employment has also been cited as a significant reason for migrating. This has also been especially true for government assisted refugees whose income support is terminated after one year (Dossa 2008;

Simich, 2003). Job-hunting is one of the "push" factors that drive the secondary migration process. However, "pull" factors account for a large amount of secondary migration, and include moves not only towards access to jobs, but more importantly, to social support that reconnects refugees with family and friends in the crucial first year of resettlement (Simich, 2003). These support systems are critical in helping them meet their most essential needs, such as housing, and child care.

2.1.5.6 ***Health care experiences***

With regard to health care delivery, the experience for refugees who come to Canada varies from province to province (Miedema et al., 2008). In Ontario, new persons arriving to the area are required to wait three months before they are eligible for benefits under the provincial health insurance program (Goel & Beder, 2012). Most women learned to obtain their health insurance card through friends, family, social networks, as well as through health and social service organizations (Crooks et al., 2011). Since many refugees are not capable of securing private insurance, finding affordable health care becomes a significant stressor for many women (Crooks et al., 2011; Miedema et al., 2003; Stampino, 2007; Wahoush, 2009; Walsh & Krieg, 2007). The "healthy immigrant effect"* that has been cited in newcomers to Canada is not evident in the refugee population, with many of them rating their health as poor or fair (Walsh & Krieg, 2007). Their health insufficiencies are often related to pre-migration experiences, including their living conditions in refugee camps (Miedema et al., 2003; Wilson et al., 2010). Refugees often experience barriers accessing health care services that then translate into decreased utilization of needed services (Fenta et al., 2007; Kiss, Pim, Hemmelgarn & Quan, 2013; Walsh & Krieg, 2007). The result is a lower utilization rate of both physicians and hospital services in a population that has high health needs, leading over time to a decline in that population's health status in Canada (Gabriel et al., 2011; Newbold, 2009).

* "healthy immigrant effect" – the phenomenon where the health of new immigrants is known to be better than that of their Canadian counterparts (Goel & Beder, 2012).

The Interim Federal Health program (IFH), which provides coverage for “emergency and essential” services, is a complex system that is difficult to navigate and to interpret for clients and providers alike, and it often acts as a barrier to health care services (Miedema et al., 2003; Wales, 2010). Family physicians, who are often solo fee-for-service practitioners, do not recognize the IFH program certificate due to their unfamiliarity with the program (Miedema et al., 2003; Wahoush, 2009). The reimbursement requirements are usually cumbersome, and a physician must often complete a great deal of paperwork in order to receive compensation for services provided (Edge & Newbold, 2013; Miedema et al., 2003; Wales, 2010). In addition, once forms for reimbursement have been submitted, there are often lengthy delays in receiving payment (Miedema et al., 2003). As a consequence, many family doctors are frequently unwilling to accept patients utilizing IFH program coverage (Edge & Newbold, 2013; McKeary & Newbold, 2010; Pollock, Newbold, Lafreniere & Edge, 2012; Wales, 2010). This results in many refugees, especially pregnant women, presenting to walk in centers or to emergency departments for non-urgent conditions (Gabriel et al., 2011; Kiss et al., 2013; Meidema et al., 2003; Wahoush, 2009). Hospital authorities usually accept IFH certificates more readily, since they have more manpower to process billing forms, and the payment to the attending physician does not depend on whether costs are recouped from IFH (Miedema et al., 2003).

Additional issues exist with billing and referral to the IFH program. Problems arise if refugee patients seen in emergency require follow-up care with specialists, since these doctors typically do not recognize the IFH form: this results in incomplete follow-up for patients and further potential for complications (Miedema et al, 2003). Since the IFH program only covers “essential and emergency” health services for the treatment and prevention of serious medical conditions, this interpretation is often left up to settlement workers, who must have the patient medically assessed in order to determine eligibility for a service (Miedema et al, 2003). When IFH payments are delayed, family physicians sometimes resort to billing refugees directly. The results of this are both frustrating for the medical provider and stressful for the refugee patient

who, more often than not is without the financial means to provide payment (Miedema et al., 2003; Pollock et al., 2012).

Interpretation and language issues, discrimination, lack of cultural competence, incomplete medical histories and a shortage of health services all interact to make clinic visits problematic and less than satisfactory for refugees and health workers (Crooks et al., 2011; Dossa, 2008; Edge & Newbold, 2013; Fung & Wong, 2007; Hrycak & Jakubec, 2006; McKreary & Newbold, 2010; Oxman-Martinez et al., 2000; Wahoush, 2009; Walsh & Krieg, 2007; Weaver, 2005; Weerasinghe, 2012). Refugee women often face the dual challenge of adjusting to a differently organized health care system while attempting to heal from pre-migration losses and violence (Bokore, 2013; Crooks et al., 2011; Hrycak & Jakubec, 2006; Kopinak, 1999). They often experience feelings of depression affecting body, mind and spirit, that are not "given voice" by health professionals, who may be at a loss as to how to account for their unarticulated symptoms (Dossa, 2008; Edge & Newbold, 2013; Fung & Wong, 2007; Hrycak & Jakubec, 2006). This may result in women being re-traumatized and experiencing increased anxiety in a context where they expected to gain safety, support and respect (Hrycak & Jakubec, 2006).

Refugee women's lack of awareness of their context leaves them feeling devalued, dissatisfied and mistrustful about the care they receive (Edge & Newbold, 2013; Hrycak & Jakubec, 2006; Walsh & Krieg, 2007; Weerasinghe, 2012). They have difficulty in securing a doctor, in getting to see specialists, in obtaining mental health services, and they experience financial stresses and limitations in accessing extended health services, such as psychologists (Crooks et al., 2011; George, 2008; Schellenberg & Maheux, 2007; Wood, McGrath & Young, 2012). Women expected to have appointments with family doctors lasting longer than 5 to 10 minutes that is typical within the Canadian system (Crooks et al., 2011). Distrust of health care personnel, perception of decreased right to use, and lack of knowledge in steering their way through the health care system limit refugees willingness to engage with the health care system,

while the realities of transportation and economic concerns erect formidable barriers to care (Chapra & Chatterjee, 2009; Gabriel et al., 2011, Gagnon, 2002; Wahoush, 2009).

2.2 Mandatory HIV Testing Policy

The work of Bisaillon (2010; 2011; 2012; 2013) has been integral to our understanding of the mandatory HIV testing policy and the immigration medical exam. Since there has been limited research within this area, her findings are essential to understanding the experiences of refugee women who come to Canada and who, for the first time in their lives, may face testing for a highly stigmatized and chronic illness that will have ramifications for the rest of their life.

2.2.1 Mandatory immigration HIV screening

As of January 15, 2002, all individuals aged 15 years and older who request permanent residence in Canada are required to undertake HIV testing (Canadian HIV/AIDS Legal Network, 2011). In addition, all persons who self-declare that they have received blood products, or anyone who is born to a mother living with HIV, regardless of their age, also engages in a screening test (Bisaillon, 2011). Attached to the HIV screening test is a physical medical examination conducted by Designated Medical Practitioners (DMPs) who are staff of Citizenship and Immigration Canada. The intent of this immigration medical assessment is to determine medical inadmissibility (Gushulak & Williams, 2004). This testing may be done outside Canada or within the country at the city of application. The authority for determining a refugee person's inadmissibility to Canada on health grounds is explicated in the Immigration and Refugee Protection Act and its Regulations. It is noteworthy that neither of these documents specifically mentions HIV/AIDS (Bisaillon, 2011). Most immigrants with HIV who are allowed to stay in Canada are persons who cannot be excluded under the law which includes individuals who have applied for refugee status (Bisaillon, 2011).

The HIV test plays an important role in the social organization of the everyday activities of someone who is diagnosed positive. The aim of the test is to detect the presence or absence of a blood born pathology that, to this date, has no cure. It does this by detecting the presence

of antibodies that the HIV-infected person's body has produced in response to contact with the virus. It does not detect the disease specifically, but checks whether an immune response has been mounted in order for the body to protect itself. Once a person is labelled as positive, the diagnosis also activates a network that involves and connects people living with HIV—a network that includes physicians, laboratory technicians, nurses and other clinical personnel, and that extends over time and place (Bisaillon, 2011). In the name of supervision and management of the person's health, the HIV test and other tests associated with it, such as CD4 and viral loads, become a set of technologies that will exert considerable influence throughout an HIV-positive individual's life (Bisaillon, 2011).

The detection of HIV brings under societal scrutiny an illness that is otherwise hidden in the most private and intimately accessible parts of a person's body (Bisaillon, 2011). Very often border and government officials look suspiciously upon immigrants and refugees during their encounters with them (Bisaillon, 2011). A diagnosis of HIV intensifies this attention, and follows newly diagnosed persons as they navigate the complex maze of health professionals with which they become connected as a result of a HIV diagnosis (Bisaillon, 2011). The HIV test becomes a permanent "mark" of social identification on a refugee or immigrant person with HIV. It is first recorded in government documents where, upon the immigrant's diagnosis, an official institutes a paper trail that associates the person with the "truth of their diagnosis": this, in turn, attaches them to a process of surveillance whereby they are managed, referred and monitored for the duration of their life (Waldby, 1996). One woman compared the process to being a prisoner, due to the fact that she had a permanent file at public health (Bisaillon, 2011).

In most Canadian provinces, a newcomer who tests positive for HIV will have her status communicated to provincial authorities. In Ontario, results are linked to a provincial database that informs public health nurses of new persons who have HIV within their area. Once received, public health nurses initiate a "home visit" to the HIV positive person to inform them that they have a legal obligation to disclose their status before having sex with a person, even

when the sex is protected. They want to make sure that the person understands they are responsible to not spread the virus. Waldby (1996) describes this as a process whereby individuals engage in the “economies of institutions” so that the invisible elements of the infection are made visible in regular and quantifiable ways that can be communicated between organizations. Quebec has no comparable tracking system, and no meeting between public health officials and infected persons.

According to current guidelines, people living in Canada who are stable with the illness, are generally asked to see their HIV physician three to four times a year, with blood work done approximately two weeks prior to the appointment (Bisaillon, 2011). The social structure of the HIV-positive person’s life is often dominated by their efforts to take antiretroviral medication, a course of treatment that has been influenced by physician practice that, in turn has been influenced by the pharmaceutical industry and the entire biomedical apparatus. Thus, the person’s health becomes medicalized and embedded in socially constructed, instutionalized practice of surveillance, whereby the discovery of HIV infection is the gateway to medical intervention (Bisaillon, 2011).

2.2.2 Immigration and medical examination

The immigration medical examination is a pivotal moment in the refugee/immigration process (Bisaillon, 2011; Bisaillon, 2013). Reports from refugees have claimed that this part of their immigration process was particularly challenging and problematic leading to both contradictory and negative effects (Bisaillon, 2011). The organizational features of this mandatory examination are significant in that it constitutes HIV as an exceptional disease category with an attached moral judgement. This in turn affects how the person living with HIV is understood and managed by state doctors working for Citizenship and Immigration Canada (Bisaillon, 2011). The Designated Medial Practitioner (DMP) acts as an administrative person whose function is to identify potential immigrants who may be a threat to public health, safety or health care costs as determined by the Canadian state (Bisaillon, 2013). Viewed in this light the DMP becomes a fact

finder for the Canadian government rather than a therapeutic liaison, a role that would be typical of most doctor-patient relationships (Bisaillon, 2013). Applicants to Canada who are HIV-positive do not initially know that the Immigration medical exam is conducted in the interests of disease detection. This disease detection has the potential to make them inadmissible to Canada (Bisaillon, 2013).

The immigration medical exam necessitates that persons who are non-citizens have no choice but to participate in a diagnostic blood test whose sole purpose is to exclude a diagnosis of HIV. This procedure would be considered unacceptable if carried out on Canadian citizens without their prior consenting knowledge (Canadian HIV/AIDS Legal Network, 2007). HIV often has no visible symptoms and can be present for long periods of time. The discovery of HIV totally alters the path of an individual's life, whether or not the person knew or suspected their seropositive status prior to the immigration medical exam. (Bisaillon, 2011). Potential citizens with HIV occupy and come to experience a distinct social location that sets them apart from other refugees and immigrants. This occurs as a result of the many government policies developed specifically for HIV, all of which are developed specifically for non-citizens living with a diagnosis who are looking to reside in Canada (Bisaillon, 2011).

Reports from women who have undergone mandatory HIV testing with a resultant positive HIV outcome have noted the particular effect of a positive HIV status within the application process (Bisaillon, 2011). They identified an ever-present tentativeness about the way decision-makers perceived their HIV, giving these women the impression that their diagnosis of HIV activated particular processes that HIV-negative people attempting to come to Canada did not encounter. They were cognizant of the deviation from routine practice that their diagnosis generated, including interactions with federal agents, provincial institutions of employment, and non-profit organizations (Bisaillon, 2011). As people living with HIV, these refugee claimants, as people living with HIV, were often unclear and uncertain as to how their application was being processed.

Bisaillon (2011) reported how one woman learned about her HIV diagnosis. She described a phone call with the physician who had seen her during the immigration medical exam. The doctor first informed her that there was a problem, and then proceeded to report her newly diagnosed HIV status. Bisaillon (2011) noted that the woman remembered feeling depressed, shocked, and in denial. According to this woman's account, she did not receive any pre-or post-test counselling, despite the fact that this is mandated as part of the practices of Designated Medical Practitioners within the immigration process. Many clients report being given the diagnosis and then being left with no idea of where to go (Bisaillon, 2011). What follows is their "going underground" instead of proceeding with a positive orientation towards referral resources that may prove useful (Bisaillon, 2011).

This gap between policy and what happens practically in the context of people's lives has been reported since the early days of the HIV epidemic in North America (Macpherson, 1993). Since the screening test is mandatory, the meaningful consent practice falls by the wayside (Bisaillon, 2011). The phenomenon of HIV becomes abstracted, as does the social organization and experience of testing. The result is the alienation of the people undergoing the testing without full realization of how the testing may affect their everyday lives (Mykhalovshiy & McCoy, 2002). Deficiencies in care and service that state representatives convey to newcomers with HIV in turn create problems for this group of people (Bisaillon, 2011).

The linkages within the institutions that carry out the mandatory HIV screening policy organize the everyday activities and circumstances of refugee and immigrant persons living with HIV often in difficult and contradictory ways (Bisaillon, 2011). According to Bisaillon (2011), some lawyers who have particular experience in immigration laws with HIV-positive refugees think that it is particularly important for immigration officials to have awareness of the social character of HIV. They observe issues of discrimination, and consider that people with HIV might access social services in particular ways that people without HIV might not. Which types of social services people draw on, and how they draw on them, mean different things for

different immigration application procedures. This in turn affects the type of decisions that Immigrations and Refugee Board agents can make about applicants with HIV (Bisaillon, 2011).

Once diagnosed with HIV, the person is conferred admittance into the social milieu of the Canadian AIDS organizational network. This set of connections is a strong transmitter of information and education to persons living with HIV, through which they receive education on immigration and HIV, the law, and research approaches among people living with HIV. These organizations provide a context for persons to discover, perceive, and identify themselves as "being HIV positive" in Canada (Bisaillon, 2011). As they learn about their civil rights and responsibilities as a person living with HIV, they are quickly socialized and guided towards a particular frame of reference. Being an HIV-positive refugee positions that person in a specific societal station that Canadian-born clients within the AIDS service organizations do not occupy. Although the diagnosis of HIV brings refugee applicants together in a collective way, there is no uniform or distinct way that refugee persons with HIV experience this new social location. They become engaged with specific social relations that come to organize people's activities across the country at various points in time.

The HIV test becomes a defining relation for people who are positive, producing a specific set of concepts, theories, classifications and technical language (Bisaillon, 2011; Smith, 1996). The revelation of HIV antibodies, followed by the person's awareness of their virus, alters their positionality within society and channels them according to certain forms of institutional organization. Whether the applicant is external to Canada or within the country, he or she comes to be represented, understood and regulated through membership in an assortment of non-mutually exclusive categories that include disease, transmission, infectivity, immigration and sexuality (Bisaillon, 2011). This process of classification is catalyzed by the diagnosis generated in the mandatory HIV antibody test (Bisaillon, 2011).

2.3 Refugee Women and HIV

The following section will provide information about HIV-positive refugee women. Specifically, it will look at their socio-demographic factors, their physical health, their utilization of health care and the barriers they experience in accessing that health care.

2.3.1 Socio-demographic factors

Refugee women represent a diverse group of women who originate from a variety of countries, and who have different experiences and expectations of health and health care (Burnett & Peel, 2001; Krentz & Gill, 2009). The country of origin and cultural background of women have implications for understanding the experience of HIV for each woman, since various cultural beliefs about HIV and treatment may affect engagement and utilization of treatment for HIV (Cavaleri et al., 2010). Several studies have noted that a large percentage of these women originate from sub-Saharan Africa, the Caribbean, (in particular, Haiti), or Mexico (Ankouad, et al., 2007; Krentz & Gill, 2009). Heterosexual acquired HIV is the usual mode of transmission (Beckwith, et al., 2009; Krentz & Gill, 2009). There was almost no reported intravenous drug use among the refugee population (Beckwith et al., 2009). Most women had completed high school, with the majority identifying English as their second language, and a small percentage naming French as their second language (Krentz & Gill, 2009). Most women were married or living in a common law relationship (Krentz & Gill, 2009).

2.3.2 Physical health

Refugee women with HIV tend to engage in care having lower states of immunity as identified by the CD4 count which is a measure of HIV health status (Krentz & Gill, 2009). This indicates that they are likely to be diagnosed at a later stage of disease than non-immigrants (Krentz & Gill, 2009). In addition, a large percentage of the women are identified as late presenters, when the initial CD4 count is less than 200 (Krentz & Gill, 2009). At this level of immunity the person is significantly more at risk for acquiring additional illnesses, and requires additional medication to

prevent the occurrence of opportunistic infections that result when a person has a decreased level of immunity (MacLaren & Imberg, 1998).

A large percentage of patients that emigrate from countries where HIV is endemic have different subtypes of HIV virus. HIV viral subtype may influence disease evolution and management (Krentz & Gill, 2009). Viruses from some subtypes and /or geographical regions may have a greater inclination to cultivate resistance against certain medications. In addition, variations in regard to replication capacity or fitness may exist among a range of HIV subtypes. These variations may become amplified during conditions of drug resistance. Pressures exerted on immunity may also influence the evolution of viral subtypes which may, in turn, also affect drug resistance profiles (Spira et al., 2003). Drug resistance profiles impact the clinical care afforded to patients.

Refugee women from countries where HIV is endemic have higher rates of previously rare co-morbidities (Krentz & Gill, 2009). Latent tuberculosis, hepatitis B, positive toxoplasmosis serology, malaria, hepatitis A antibody, and parasitic infections were some of the more frequent co-morbidities cited (Beckwith et al., 2009; Costa, 2007; Krentz & Gill, 2009; Moreno et al., 2003; Pottie et al., 2007). Attention to latent tuberculosis in this population is particularly important as there is an increased risk of latent tuberculosis converting to active tuberculosis in persons who have HIV; therefore, completion of treatment for latent tuberculosis is of the utmost importance (Beckwith et al., 2009).

Hepatitis C is another co-morbidity that has been cited in some studies (Ankouad et al., 2007). This is often related to the country of origin. Women originating from sub-Saharan Africa, where hepatitis C is prevalent (Madhava, Burgess & Drucker, 2002), have a higher incidence than women from West Africa, particularly Liberia, where the disease is still widespread but presents with a lower prevalence than in sub-Saharan Africa (Mboto, Davies, Fielder, & Jewell, 2006). Co-infection is characterized by a more rapid progression towards end-stage liver disease, leading to increased rates of disability and death (Dodig & Tavill, 2001). Hepatitis C

viral load is significantly affected by HIV co-infection, with hepatitis virus levels up to 10 times higher than in immunocompetent patients, and virus replication occurring 8 times faster (Cribier et al., 1995). In addition, treatment for HIV with antiretroviral therapy may induce hepatotoxicity at the beginning of therapy, necessitating closer monitoring and special drug regimes to facilitate the patient being able to continue with treatment (Dodig & Tavill, 2001).

Anemia was another presenting comorbid illness found to be particularly common in women (Ankouad et al., 2007). In the context of HIV infection, anemia and iron deficiency are highly prevalent and are independent predictors of mortality and HIV disease progression (Levine et al., 2001; O'Brien et al., 2005). HIV along with anemia also has implications during pregnancy affecting both the health of the mother, the fetus and potentially the health of the young child (Isanaka, et al., 2012).

These refugee women also present with physical injuries incurred as a result of trauma, torture and the difficulties of the refugee journey, as well as low rates of preventative care such as cervical cancer screening (Costa, 2007; Dolma et al., 2006; Pottie et al., 2007).

2.3.3 Health care utilization

As stated earlier, most refugees present to clinics for care already with advanced HIV infection (Ankouad et al., 2007; Krentz & Gill, 2009). Despite this fact, one study showed that an average of 24 weeks between engaging with a clinic and starting antiretroviral therapy (Ankouad et al., 2007). This reluctance to engage in therapy was due to financial difficulties, immigration difficulties, religious beliefs, fear of side effects, and fear that treatment would require disclosing their HIV infection (Ankouad et al., 2007; Beckwith et al., 2009). Response to antiretroviral therapy for refugee patients with HIV is generally favorable, and similar to the Canadian population (Krentz & Gill, 2009). When clients are initiated and supported on antiretroviral therapy, they tend to remain on therapy and achieve viral suppression within the first year (Krentz & Gill, 2009). This response has been observed despite the possibility that different

responses to treatment might occur due to the variant in HIV sub-types in patients who come from endemic countries (Spira et al., 2003).

Refugees with HIV have more clinical encounters per year than Canadian counterparts: an average of 8.1 clinical encounters in one study (Krentz & Gill, 2009). In addition, consultations with social workers are particularly prevalent, with one study citing a doubling of visits in the refugee population (Krentz & Gill, 2009). Laboratory testing also is more frequent, as are referrals for neurologic issues (Krentz & Gill, 2009). Refugee patients with HIV are underrepresented in visits to the emergency departments (Krentz & Gill, 2009). An exception to this is during pregnancy and childbirth, when hospital and emergency department use increases by 38% for issues attributable to pregnancy and child-birth-related events (Krentz & Gill, 2009).

Refugee women with HIV often become pregnant without any pre-pregnancy planning (Beckwith et al., 2009; Westoff et al., 2008). The ad hoc nature of the pregnancy creates a "crisis management" approach to care by their need for urgent clinical evaluations, for beginning antiretrovirals and for social work engagement (Beckwith et al., 2009). Unintended pregnancy for refugee women often results in pregnancy termination within less than optimal circumstances (Austin, Guy, Lee-Jones, McGinn & Schlecht, 2008).

2.3.4 Barriers to care

Access to care is complicated by perceptual and cultural barriers (Murray & Skull, 2005; Nyagua & Harris, 2008), fatalistic and religious views, the experience of living with HIV, and unfamiliarity of HIV support services that facilitate access to care (Othieno, 2007).

2.3.4.1 ***Perceptual, cultural and religious barriers***

Perceptual barriers included negative beliefs about the quality of care being received and inaccuracies about HIV and treatment (Cavaleri et al., 2010; Tompkins, Smith, Jones & Swindells, 2006). Cultural barriers include folk beliefs about HIV causes and cures, and utilization of indigenous providers who are not knowledgeable about Western treatments for HIV (Conviser, 2007). As a result, various terms for the disease have evolved: the "curse from God",

“slimming disease”, “disease with no cure”, “gay man’s disease” and the “shameful disease.” Within African communities, HIV is associated with depraved behavior, and people living with HIV are automatically presumed to have engaged in promiscuous behavior. The disease is “God’s way of punishing them for bad behavior” (Othieno, 2007). This judgement is particularly severe for women, who are expected to be a virgin at the time of marriage according to the law of God. If this law is broken, she loses God’s protection and is punished with HIV/AIDS. (Othieno, 2007). For women who have been subject to the atrocities inflicted by war, HIV is seen as “sexual humiliation” (Othieno, 2007).

Certain myths have been perpetuated surrounding the transmission and “cure” of the disease. Some Ethiopian societies believe that eating hot peppers could prevent HIV. Muslim societies, such as Somalia, perceive it as a “foreign disease” obtained from a non-Muslim person, while other African communities believe that HIV is contracted through witchcraft or “being given the evil eye” (Othieno, 2007). In regards to the “cure” for HIV, some traditional doctors advocate “sleeping with a virgin” to cleanse HIV. Somalian remedies focus on the use of “habaa-sooda” (flax seeds) to treat various ailments, while other religious leaders recommend the use of “holy water” and prayer, religious rituals or spiritual healing, such as “wallah” in the Muslim tradition. Within this framework, specific verses of the Koran are written, washed and then consumed by the infected person in an effort to eliminate the virus (Othieno, 2007).

Conspiracy theories propagate the myth that AIDS is an overseas disease created by the white man to discourage Africans from having sex and that governments are intentionally infecting people with HIV (Othieno, 2007). Related to this, is the negativity perpetuated about HIV within African media. This includes painting HIV as a “dangerous and incurable disease” that portrays Africa as “the dark continent” that is the sole place affected by HIV disease, rather than referring to the global extent of the illness. As a result of these myths, people all too often ignore any HIV-related information and the idea that whole countries are HIV positive becomes perpetuated (Othieno, 2007).

HIV is also associated with other highly stigmatized illnesses within African culture, such as mental illness and tuberculosis (Othieno, 2007). This is especially true for countries within West Africa, as well as Somalia. It is considered shameful to have a mental illness, and people with the illness often do not marry (Othieno, 2007). Patients commonly decline to see a mental health counselor or receive psychiatric medication, despite the fact that they may acknowledge significant psychological difficulties to a health care provider (Moreno, Crosby, Labelle, Sullivan & Samet, 2003). Along with certain illnesses having negative stigma is the belief among young people that HIV strikes mostly the older generation, creating a culture of risk within younger populations (Othieno, 2007).

Many African cultures have taboos against drawing blood, talking about sex and not getting married (Othieno, 2007). Not marrying and not having children causes women to be more stigmatized than men. Many women may be forced to leave their homes if their HIV status is disclosed, whereas a women will likely stay with an HIV positive man (Othieno, 2007). Women have fewer options than men: they fear being rendered unmarriageable if they have HIV, and are often rejected and condemned (Othieno, 2007). Since discussing sexual matters, even between a husband and wife, is also considered taboo, it is very difficult to discuss prevention of HIV or to educate children about HIV (Othieno, 2007). In these ways the lives of HIV-positive refugee women from African countries are often affected by the interaction of stigma, gender, religion and/or faith.

Within these cultures, once a person's HIV status becomes known they are treated differently by both family members and members of the community at large. How they are treated is determined by the gender of the HIV-positive person, the family's and community's assessment of that person and the person's past sexual behavior. In addition, the route by which the person acquired the infection and the progression of the illness also determine their treatment (Othieno, 2007). It is not considered appropriate to directly address an individual regarding their HIV status, but evidence of the infection can be surmised in that HIV-positive

persons are not allowed to touch children, require specific kitchen utensils, and require special cleaning procedures with regards to bathroom appliances (Othieno, 2007). A more extreme case would necessitate that an HIV-positive person be evicted from their home (Othieno, 2007). All of these realities encourage the HIV-positive person to keep their status secret from family and close friends.

Isolation is also perpetuated by certain religions, including Islam and Christianity that maintain that isolation is essential as a form of punishment for "living in sin": it is also an essential means of preventing infection. Because people believe that a woman who has HIV has engaged in promiscuous behavior, women are often treated more severely than men. They are susceptible to domestic violence, and they face more discrimination than their male counterparts, for example, being denied access to transportation, such as taxi rides (Othieno, 2007).

2.3.4.2 ***Unfamiliarity with HIV support services***

Refugee women with HIV are often not familiar with health and support services in the new country, and this lack of knowledge, combined with the apprehension and stigma associated with HIV, affects their ability to seek out and remain in care (Othieno, 2007). It manifests in various forms, from not understanding the concept of service and service systems to issues related to self-disclosure of their HIV status (Othieno, 2007).

Many refugees originate from countries where services are very limited. The concept of having service is thus foreign and very new. With no frame of reference regarding what a service may offer, many refugee women with HIV do not know what to ask for. It is a reality that they may not be aware of potentially available and accessible HIV-related services (Othieno, 2007). Fear that others may find out about their status limit discussion about HIV services, lest this arouse suspicion. (Othieno, 2007). Thus, lack of knowledge about available services and fear associated with disclosure surrounding the illness intersect to influence initiation into care, causing delays for treatment and service for refugee women with HIV.

Lack of understanding regarding the health care system leads many refugee women to incorrectly believe that all information is reported to immigration. For those women who have precarious status or are awaiting the results of their claim, this may create fears about deportation. Someone who has come from a place and situation where there has been massive mistrust and corruption may lack confidence that she can be open and safe (Othieno, 2007). Many refugees with HIV are also not aware that there are programs to assist with payment of their medication (Othieno, 2007). Even though this may be understood as a benefit, the refugee fears that this required disclosure to the payee may "leak" their HIV status, and in other areas of their life cause harm such as loss of employment (Othieno, 2007).

Their unfamiliarity with Western style health services is reflected in the brief time refugees spend with physicians, the subject matter of assessments, and the doctor's role and authority. Often, this results in distrust that has arises from lack of clarification regarding the roles of specific health providers, lack of system knowledge, and differences in communication styles (Othieno, 2007). Some asylum seekers do not trust professionals within their home countries, and their attitude transfers to their encounters with professionals in the host country.

The brevity of time that physicians spent with HIV-positive refugees was thought to affect their quality of care. Following a doctor visit in their country of origin, these refugees were accustomed to seeing a nurse who would ensure that all the information was explained adequately (Othieno, 2007). Another unfamiliar practice is "team care," where information is shared among a group of professionals; patients may also be uncomfortable with this, and believe that other providers "talk about them," especially when they have explicit privacy concerns surrounding their HIV status (Othieno, 2007). They are often not aware of privacy and confidentiality guarantees that prohibit release of their information.

With regard to medical assessments, most refugees originating from African cultures are unaccustomed to having explicit conversations about sexual issues, and doing so results in avoidable discomfort for the patient (Othieno, 2007). This is especially true when discussion

occurs in the presence of one's spouse, since some topics–sexual activity, for instance–are particularly uncomfortable to address in this situation. Efforts to educate patients about condom use may be met with arguments. Patients often state that they did not need this type of information, since they now practice complete abstinence following the diagnosis of HIV (Moreno et al., 2003). Eliciting a history of substance abuse was also upsetting for refugee women with HIV (Moreno et al., 2003). They found these questions insulting due to the fact that such behavior is perceived as immoral (Moreno et al., 2003). Discussing the appropriateness of antiretroviral medication has also been found to create suspicion among refugees. When patients do not meet the criteria for starting antiretroviral therapy, providers may be accused of barring patients from therapy because of ethnic or discriminatory reasons (Moreno et al., 2003).

Several factors contribute to the difficulty of women refugees, who may also be young, to ask directly for what they need from their health care professional, especially from their doctor: services and care may be very limited in their home countries; they are not aware of existing services in the new country; and they have different cultural traditions surrounding the doctor-patient relationship (Othieno, 2007). The concept of preventative care may also be new to refugee women with HIV. Within Africa, people often seek care only when they are sick, and they do not go for check-ups. In addition, their first choice for care may often be a spiritual provider of other alternative medicine (Othieno, 2007). Older persons often engage with care more readily than younger people. The Western concept of emotional support is also unfamiliar to African persons living with HIV. Support groups within their countries of origin are often linked to income-generating activity: "merely talking" about problems is viewed as a strange notion (Othieno, 2007). Thus, the refugee woman, who is young and HIV positive but "physically well" may be a reluctant to engage with and participate in care because of cultural and traditional beliefs about health care that she has learned in her home country.

2.4 HIV and Pregnancy

The following section will explore the literature that describes the experience of pregnancy and HIV together. Here we focus on the emotional feelings that women experience, the stigma imposed as a result of the HIV diagnosis, as well as the effects of HIV on the pregnancy outcomes of women.

2.4.1 Distress, fear, loss and depression

Emotional distress related to the HIV diagnosis, with feelings of shock and fear, along with anger directed towards their current partner, was a universal finding (James, 1988; Stinson & Myer, 2012). Many women described the diagnosis as a life altering event that caused them to be forever changed: some women experienced long-term emotional effects (Sanders, 2008). Processing the knowledge of an HIV diagnosis and grappling with decision-making surrounding antiretroviral therapy often led to a psychological crisis for many women (Sanders, 2008).

"Struggle" was descriptive of the women's emotional distress. When they learned about their HIV diagnosis, they were often ashamed and unsure about whether to disclose their status. The associated stigma left them alone as though they were "living in the darkness" (Ross, Sawatphanit, Draucker & Suwansujarid, 2007). Women often sought out other HIV-positive women with whom they could "share their struggle" (Ross et al., 2007). They "struggled for the baby" by attempting to take good care of themselves, taking the antiretroviral medication and suffering its side effects, in the hopes that this would significantly reduce the risk of HIV transmission to their newborn (Jones, 2008; Ross et al, 2007). "Struggling through the ups and downs" was evident as women also coped with added stressors such as poverty, inadequate support and weakened health (Ross et al., 2007). Shame, uncertainty, isolation and added stress intersected to define the prenatal experience as predominantly one of struggle**.**

Fear also characterized the women's emotional distress. Paramount was their fear of transmission of the HIV infection to the baby (Ingram & Hutchinson, 2000; Ross et al., 2007; Stinson & Meyer, 2012). Mothers were acutely aware of the potential risks of perinatal

transmission, and they also worried about the safety of antiretroviral drugs (Sandelowski & Barroso, 2003; Sanders, 2008). Protecting the child from contracting HIV became one of the primary goals (Bunting & Seaton, 1999; Sandelowski & Barroso, 2003). Having an HIV positive baby was a critical factor as to whether or not a woman would have more children (Ingram & Hutchinson, 2000). The uncertainty produced by having a chronic illness with the possibility of life-threatening complications made them wonder "Would my baby drain me?" or if they would be around to raise their baby (Sanders, 2008). In addition, many women voiced fear that their families would reject them once their HIV status was disclosed (Bunting & Seaton, 1999). Combating fear manifested itself in their adherence to HIV medication, their self-care during pregnancy and their relationships with family (Psaros, Geller & Aaron, 2009). Unacknowledged fear often led to depression which in turn had implications for adherence to antiretroviral medications (Psaros et al., 2009**).**

Youngwanichsetha and colleagues (2010) detailed how HIV-infected Thai women make decisions surrounding the management of their pregnancy. "Weighing distress" related to initial ambivalence about continuing the pregnancy, the exploration of alternative paths, and the determination of an appropriate choice (Youngawanichestha, Isaramalai, Songwathana, & Wiroonpanich, 2010).

The presence of their own HIV infection caused women to re-examine their desire to have a child. Ambivalence as to whether to continue the pregnancy was largely related to the concern accompanying transmission of the virus to the fetus; 63% of women considered an abortion after they learned of their HIV diagnosis. They did not want to give birth to an HIV child. (Youngawanichsetha et al., 2010). In cases where the pregnancy was unplanned, the woman's decision to proceed with it ultimately resulted from the realization that it was possible to eliminate HIV transmission to the baby, and from the family's desire to have another child (Youngawanichsetha et al., 2010). Women who automatically proceeded with their pregnancy, despite the realization that HIV might be transmitted to the fetus, had an exceptionally strong

desire to have a child, had planned the pregnancy and had less concern over mother-child-transmission. Some women knew other women who were HIV positive and still able to give birth to non-HIV-infected babies.

Minnaar and Bodkin (2009) likened the experiences of HIV and pregnancy to Kubler-Ross's conceptualization of the death and dying process that comprises five stages: denial, anger, bargaining, depression and acceptance. In the first stage, denial, the woman is shocked and overwhelmed with the diagnosis. She is unable to believe it, and often this belief extends to the woman's partner who may accuse her of lying. Denial is protective and emerges as a way to avoid thinking about the diagnosis, erasing a reality in order to control the strong emotions associated with the disease. Many women during this stage tell themselves repeatedly, "I'll be fine", "I am o.k.", "I do have a future", in order to protect themselves and enable them to move forward.

Inherent in the process are considerable feelings of anger fuelled by the contradictions within the woman's experience. On the one hand, they are carrying a new life that holds the promise for happiness and new possibility; conversely, they face prospects of change in function associated with a chronic illness that is associated with death (Minnar & Bodkin, 2009). Many women express this anger through a rejection of any sort of pity that is offered them. Pity implies that they are being viewed as "different," and they want to be treated in the same way as other pregnant women (Antle, Wells, Goldie, DeMatteo & King, 2001; Minnaar & Bodkin, 2009). One woman commented that she "just wanted to be treated like she was negative," while others directly demonstrated anger toward their caregivers (Minnaar & Bodkin, 2009 p.11). Thus, women experienced both shame and anger but most often their behavior towards their caregivers remained submissive and subdued (Minnaar & Bodkin, 2009).

Bargaining was exhibited when women made statements like "I don't want to die; I want to see my baby first" (Minnaar & Bodkin, 2009 p.11). It was as though they were pleading for extra time, promising to either change certain behaviors or asking for more time should their

wishes be granted. Conversations surrounding death and dying are not typical for women who are of childbearing age and experiencing pregnancy. However, concerned about their own possible early death in relation to HIV, they often had questions during antenatal exams that related to life expectancy. They asked about mortality rates and life expectancy of patients with HIV and whether they would live to see their baby (Minnaar & Bodkin, 2009).

Depression sometimes overtakes the bargaining process, and the negative consequences of the disease dominate the woman's everyday thoughts (Minnaar & Bodkin, 2009). Women often exhibited despair, which was echoed in such phrases as "There is nothing I can do" (Minnaar & Bodkin, 2009 p.12). Despair was often associated with loss of hope and loss of self-worth, and was accompanied with frequent bouts of crying. Longing for the "normalness" of health also became apparent. Women were fearful of the inevitable "sickness," the loss of body image and the shame accompanying the later stages of the disease, when they would no longer be able to conceal their illness (Minnaar & Bodkin, 2009). During this stage, they often had questions about the progression of the disease and how it would affect their physical presentation and overall well-being. During this time, women might lose a sense of purpose in their lives, putting both themselves and their baby in particular jeopardy of failing health. Health care professionals are particularly needed at this time in order to assist women to focus on their own health along with that of their baby (Minnaar & Bodkin, 2009).

Noteworthy in the study by Minnaar and Bodkin (2009) is the finding that, once women had accepted their diagnosis, they did not anticipate any "right drug" to cure or ease the disease. They instead attempted to focus on sustaining their health by attending to good nutrition and other aspects of good self care. Minnaar and Bodkin (2009) also noted that not all women reach this stage during their pregnancies.

According to Minnaar and Bodkin (2009), HIV-positive pregnant women mourn their circumstance of being pregnant and HIV positive. Sadness over the diagnosis permeates their experience, yet stigma often prevents them from disclosing their status to family and friends

(Kohi et al., 2006; Minnaar & Bodkin, 2009). What was most important for women who were pregnant and HIV positive is that they be treated like other pregnant women in ways that allowed them to focus on preparations for the baby rather than on trying to stay alive (Minnaar & Bodkin, 2009). These researchers' acknowledgement of the grief associated with HIV and pregnancy is significant: grief changes a person and affects his or her self-esteem, and it often leads the person to find new ways of adapting that result in lifestyle changes (Minnaar & Bodkin, 2009). Listening to their stories and acknowledging the losses that pregnant HIV women experience, as well as focusing on routine activities that "normalize" their pregnancy, tend to be the most helpful strategies for HIV-positive pregnant women (Minnaar & Bodkin, 2009).

HIV-related worry, shame and disclosure issues caused many HIV-infected pregnant women to experience anxiety and depression, both during pregnancy and post-partum (Blaney et al, 2004; Bennetts et al., 1999; Kapetanovic et al., 2009). This risk is present even when women have access to highly specialized HIV care. Depression was found to be associated with poor self-care and inadequate resourcefulness during pregnancy, decreased adherence to antiretroviral medications, poorer obstetrical outcomes, and poorer maternal fetal-attachment (Boonpongmanee, Zauszniewski & Morris, 2003; Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000; Lindgren, 2001). Blaney and colleagues (2004) found that psychosocial factors were important predictors for the level of prenatal depressive symptoms. Untreated depression during pregnancy had important implications for the well-being of the mother, newborn and family (Lindgren, 2001).

2.4.2 Stigma

The stigma inherent in a diagnosis of HIV, a stigma that is amplified for women who are pregnant, is often operative in a woman's experience of health care providers. Some women reported that professionals made them feel uncomfortable "just by the way they looked at them" (Sanders, 2008). Others stated that they believed that health care providers viewed

reproduction as “bad” because of the HIV infection. They were hurt and angered by the negative social messages condemning pregnancy in HIV-positive women (Ingram & Hutchinson, 2000).

Tyer-Viola (2007) found that nurses were significantly more judgemental and more reluctant to care for women who were pregnant with HIV. She suggests that this might be related to the nurse’s perception of the patient’s responsibility in acquiring their infection along with the nurse’s attitudes towards certain lifestyles, such as prostitution and intravenous drug use. The mode of HIV transmission to the mother affected the degree of sympathetic attitude provided by the nurse (Tyer-Viola, 2007). Women reported that, during their encounters with nurses, they were not seen as being well-informed about their needs, were not respected and were marginalized (Tyer-Viola, 2007). This translated into women’s poor attendance at prenatal care because they feared being discriminated by health care providers (Minkoff, 2003).

In some ways, impending motherhood positively affected the identity of HIV-positive women. For many women, childbearing not only enhanced their self-esteem and identity, but was also a means of survival, giving them a reason to live and fight the infection (Ingram & Hutchinson, 2000, Nelms, 2005). They wanted to do the “good” work of mothering by preventing transmission of HIV to the baby, and by preserving a positive maternal identity (Giles, Hellard, Lewin & O’Brien, 2009). They engaged in surveillance and safety work to prevent the spread of infection, and they worked to stay adequately informed to make good decisions regarding care for their physical bodies and the demands of HIV infection.

However, an HIV diagnosis can negatively affect the self-identity of a pregnant woman. Valencia-Garcia, Starks, Strick and Simoni (2008) likened the change in identity for HIV-positive mothers to a “fall from grace.” For instance, women in Peru typically learn about their HIV diagnosis during pregnancy (Valencia-Garcia et al., 2008). HIV infection converts the social identity from that of the idealized *mariana* (the epitomized female gender role within Latin culture) to that of a promiscuous woman, placing her at the opposite end of the social spectrum from where the woman ideally positions herself (Valencia-Garcia et al., 2008). This social

standing leaves her little room in which to reconcile her reality, since it is assumed that she is the source of infection rather than her husband (Valencia-Garcia et al., 2008). If the knowledge of her HIV status becomes public, it may eventually affect her work life, limiting possibilities for employment. As well, people then feel free to invade the privacy of the woman regarding her sexual practices, asking her questions that otherwise would not have been posed (Valencia-Garcia et al., 2008). Pregnant women with HIV risk losing social benefits and financial support that they would normally be afforded as a wife and mother. If they disclose their HIV status, they could risk being rejected and abandoned by their husband, and find themselves living without the traditional support offered by in-laws (Valencia-Garcia et al., 2008). In order to reconcile the situation, these women often adopt an attitude of fatalism and make the best of their circumstances in their culturally defined roles of wives and mothers (Valencia-Garcia et al., 2008).

Within Latin culture, childbearing when infected by HIV is deemed an immoral act (Valencia-Garcia et al., 2008). As a result, for some women, their HIV status often becomes a defining element in whether they decide to have more children. Sometimes women are told directly by their doctors that they cannot have more children: others report feeling pressured into signing consents authorizing a tubal ligation (Valencia-Garcia et al., 2008). Uninfected women often viewed HIV-positive women as selfish, and question the HIV-positive woman's desire to have additional children. In extreme circumstances, an HIV diagnosis may provide a socially sanctioned reason to deny a woman's right to mother the children she already has. In such ways, an HIV-positive woman's identity is reconstructed from a loving, caring and capable mother to one that is inept, terminal and ill (Valencia-Garcia et al., 2008).

Women in this situation sometimes make efforts to reclaim their fallen identities by disclosing their status and relating their stories about how they have been physically altered by medication and isolated by their families. This seems to occur only when they feel that they have nothing else to lose after having been identified as "fallen women"; such efforts are

exceptional in a woman's struggle to regain her identity, social rights and position (Valencia – Garcia et al., 2008).

Experiencing HIV infection in the context of pregnancy moves a woman to another place in the identity spectrum, shifting and trapping her in an "'identity game" without providing instructions about an optimal course of action, and depriving her of the recognition and respect that are otherwise dictated by her cultural norms.

2.4.3 Pregnancy outcomes

HIV/AIDS continues to be a cause of maternal mortality, especially in areas where there is a high burden of HIV infections, such as sub-Saharan Africa (Moodley, Pattinson, Baxter, Sibeko, & Karim, 2011). In addition, HIV positive women may be more vulnerable to direct or obstetric causes of maternal mortality, such as post-partum bleeding and other infections during pregnancy that could be related to AIDS-related anemia or severe immune deficiency (McIntyre, 2005). Subsequently, HIV- infected women have been found to have longer hospitalizations and more likely to be hospitalized for a variety of other complications including bacterial infections, sexually transmitted illness or liver disorders (Bansil et al., 2007). Several authors have noted the risk of pre-term delivery. Haeri and colleagues (2009) found a twofold increase in the odds of spontaneous pre-term birth for HIV positive women, while Martin and Taylor (2007) found an association between preterm delivery and the initiation of ART's during pregnancy.

The risk of complications for HIV-infected women increases for those women who undergo Caesarean delivery (Legardy-Williams, Jamieson & Read, 2010). HIV-infected women who deliver by this method are at a higher risk for both major complications, such as peritonitis and minor problems such as urinary tract infections (European HIV in Obstetrics Group, 2004). This association is further linked with the degree of immunosuppression present during the delivery (Rodriguez, Spann, Jamieson & Lindsay, 2001). Similar findings have been reported during the post-partum period. When compared to HIV-positive women who deliver vaginally, those women who undergo the operative procedure incur more pneumonia and wound

complications, as well infective blood complications that include fevers and chills (Read & Newell, 2005).

The infants of mothers who have HIV have increased incidence of low birth weight, putting them at risk for short- and long-term complications, as well as perinatal mortality (Carolan, 2010; Haeri et al. 2010) Thus, the addition of HIV to the pregnancy imposes unique and complex circumstances that have implications for the mother's well-being as well as that of her infant.

2.5. Refugee Women and Pregnancy

The following section will outline the experiences of refugee women during pregnancy. Specific topics will include the mental health of refugee women, cultural aspects relevant to pregnant refugee women, obstetrical care, and finally, barriers they confront in obtaining health care during pregnancy.

2.5.1 Mental health

Refugee women in a new country may have been through a range of experiences including trauma, torture, deprivation, abuse, poverty, and loss and separation from family members (Carolan & Cassar, 2007; Kahler, Sobota, Hines & Griswold, 1996). They may arrive in a place having lost everything they value, putting them at risk for depression, post traumatic stress disorder, schizophrenia and other mental health issues (Beiser, 2005; Bhui et al., 2003; Kitzinger 2004). The asylum-seeking process itself can be damaging to a woman's mental health and depressive symptoms have been shown to be related to country of origin (Miszkurka, Goblet, & Zunzunegui, 2010; Reynolds & White, 2010). Resettlement in the host country is often fraught with increased social stressors and isolation (Essen et al., 2000; Kitzinger, 2004). This, along with the fact that these refugee women may be moved at very short notice, places them in a marginalized and disadvantaged situation. Increased domestic violence during pregnancy has also been reported (Hammoury, Khawaha, Mahfoud, Afifi & Madi, 2009). In light of all the stressors refugee women experience, pregnancy with its additional changes and challenges

make refugee women particularly vulnerable to developing depression during the perinatal period (Ahmed, Stewart, Teng, Wahoush & Gagnon, 2008).

2.5.2 Culture

Lack of understanding of cultural differences was also cited as problematic for many women (Bulman & McCourt, 2002; Chalmers & Omer-Hashi, 2000). An important concern for Somali women is female genital circumcision. Women who had experienced this in their country of origin expressed dissatisfaction with the care they received in their host country: some sustained severe perineal tears while in labour. With infibulation, women typically experience severe perineal trauma with resultant physical discomfort post-partum, making getting out of bed to attend to the baby more difficult. A study done in Canada found that most Somali women desired more help with the care of their newborn (Chalmers & Omer-Hashi, 2002). Women also experienced hurtful and degrading remarks surrounding the appearance of their genital area; they would have preferred to have more caring, respectful, and supportive staff (Chalmers & Omer-Hashi, 2002).

Women's views of nursing care were not favorable, since they thought that nurses were generally insensitive to their post-partum pain or were not knowledgeable surrounding the fact that women with female genital circumcision can go through especially severe post-partum throbbing and soreness (Chalmers & Omer-Hashi, 2002). They longed for caregivers to be trained in the needs of women with female genital circumcision presuming that, because of the way they were treated during pregnancy and childbirth, caregivers were ignorant about this (Chalmers & Omer-Hashi, 2002). With reference to labour and delivery, women sometimes felt pressured to have their partner accompany them when they would have appreciated the choice of having a female companion instead, a situation that would have been culturally more acceptable (Chalmers & Omer-Hashi, 2002).

Because many Somali women associate a Caesarean with death, this surgery is a topic that creates fear and apprehension (Brown, Carroll, Fogarty & Holt, 2010; Herrel et al., 2004).

Associated with Caesarean section were concerns about future infertility as well as fears of persistent disability, of decreased ability to participate in the care-giver role at home, and of the hazards associated with anesthesia (Brown et al., 2010). Some thought that, after a Caesarean, they would never be able to get pregnant again. They also viewed the surgery as limiting their ability to lift their child or perform tasks that required extra physical effort. Women understood that, compared to other women who had not undergone the surgery, they would lose their ability to do things (Brown et al., 2010). Some women also reported concerns about being able to work after a Caesarean section. They knew of women who could perform a variety of tasks ten days after delivery, and they also knew that a Caesarean section could limit a woman's activity for more than four months (Brown et al., 2010). In Somalia, women who delivered by Caesarean section had the delayed recovery experience of 40 days (Brown et al., 2010). General anesthetic that was associated with the operation also instilled fear in many Somali women, and some women believed that doctors in the new country "practiced" Caesareans on Somalis. One Canadian study found that less than 1% of women desired a Caesarean section, but more than 50% received one (Chalmers & Omer-Hashi, 2000).

Many women believed that doctors rushed the experience of labour, specifically the induction of labour, and the augmentation of active labour. They compared this to their home country's practice, in which it was common for a woman to seek hospital care only after a three- or four-day labour (Brown et al., 2010). Because of this dissonance, some women in labour would delay entry to the hospital preferring to wait for the spontaneous rupture of membranes and/or the beginning of very strong labour before medical intervention. A large percentage of women also opposed induction, since the acceptable norm in Somalia was to have an extended gestation, with delivery occurring between 9 ½ to 10 months. They said that, regardless of the due date, it was normal to stay home and wait for labour to begin (Brown et al., 2010). Women justified their actions according to a strong belief in God and the assurance that everything would be done in its time. They wanted a natural child birth without using any medication, and

accepting certain interventions, such as a Caesarean section, sometimes represented not waiting for God's help (Brown et al., 2010).

Despite many women's preference for a birth free of "medicines," they were nevertheless concerned about the failure of health care professionals to discuss any form of pain control during the labouring process. They believed that stereotypes related to cultural differences about pain contributed to certain groups of women not receiving information about the various forms of pain relief available to them (Bulman &McCourt, 2002).

2.5.3 Obstetrical care

When women were able to access care for pregnancy, they often presented late in the pregnancy with no blood work, no obstetrical scans, and with undiagnosed complications (Barnes & Harrison, 2004; Lalchandani, MacQuillan & Sheil, 2001; Reynolds & White, 2010). A large percentage of woman in one study (74.4%) reported dread and worry in seeking prenatal care. In the beginning months, most women sought care from family and friends (46%), although most did consult a family doctor (63%), a walk-in clinic (38%) or a specialist (31.9%). The first prenatal visit usually took place at approximately 20.1 weeks gestation (Chalmers & Omer-Hashi, 2000; Chalmers & Omer-Hashi, 2002). All of the women were identified as "high risk," since they had many conditions that affected their physical health, including high parity, HIV/AIDS, communicable diseases, anemia, dental problems, and injuries that were a result of torture (Carolan, 2010; Correa-Velez & Ryan, 2012; Reynolds & White, 2010). Once in care, many of these women were lost to follow-up, experienced poor continuity, poorer obstetrical outcomes, and sometimes presented only in labour (Edmondson, 2009; Iliadi, 2008; Johnson, Reed, Hittis, & Batra, 2005).

2.5.4. Barriers to care

Language barriers were cited as a significant problem in accessing any services (Bulman &McCourt, 2002; Carolan & Cassar, 2007; Reynolds & White, 2010). This included securing access to food, communicating with health professionals, and the ability to seek out information in order to make choices regarding antenatal care. One study reported how the availability of an interpreter made it easier for women to attend an antenatal clinic (Carolan & Cassar, 2007). Some pregnant women had been subject to communication that was both insensitive and cruel. When they were unable to communicate, their care was often remote, confusing and sometimes frightening (Bulman & McCourt, 2002). Communication was seen as fundamental to good care, and a pre-requisite to quality (Bulman & McCourt, 2002).

Discrimination and injustice were often blatant, creating further barriers to accessing care (Davies & Bath, 2001; Kitzinger, 2004; Naab, 2006). Marginalization and disadvantage, exacerbated by language barriers, lack of social support and complicated re-imbursement issues, made access to health care complicated and confusing (Merry, Gagnon, Kalim & Bouris, 2011; Reynolds & White, 2010). Lack of understanding of cultural differences was problematic for many women and caused delays in women seeking care as well as limiting women's ability to negotiate good care for themselves (Bulman & McCourt, 2002; Brown, et al., 2010; Chalmers & Omer-Hashi, 2002, Herrel et al., 2004).

The preceding sections have shown that the experiences of HIV-positive refugee women who become pregnant are complex and multi-faceted. Their initial settlement experiences to find housing, employment and secure health care are fraught with dissonance and influenced by bureaucratic processes in Canada. The mandatory HIV testing policy and immigration medical exam act as pivotal points in their journey to Canada. As refugee women with HIV, their health is often strained by other medical conditions or conditions that have resulted from their travel or time in refugee camps. They experience perceptual, cultural and religious barriers to health care and lack of familiarity about HIV support services. The addition of HIV to pregnancy often cause

women to experience distress, fear, and loss as they manage the associated stigma of HIV and possible outcomes of the pregnancy. These challenges often exert its toll on their mental health as they deal with cultural encounters that influence both their access and experience of obstetrical care.

CHAPTER THREE

CONCEPTUAL FRAMEWORK

The focus of this chapter will be a discussion of the conceptual framework. The first section will discuss the nature of post-colonial theory, with an explanation of the key concepts and how they have implications within this research project. The second section will describe the framework and its application to nursing scholarship. Finally, there will be a discussion that illustrates how the concepts of post-colonial theory are incorporated into the research process.

3.1 Post-colonial Theory

Post-colonialism embodies a critical perspective about the harmful effects of racialization in everyday life, while illuminating the unpredictable and changeable operation of intersecting oppressions (Kirkham & Anderson, 2002). It is interdisciplinary in character, comprising several themes—including race, ethnicity, nation, subjectivity, identity, power, subalterns and hybridity—as a result of contributions from sociology, anthropology, literary and cultural critics, as well as from political activists and analysts (Kirkham & Anderson, 2002). It provides insight into the nature of colonized subjectivity and illumination of the various forms of cultural and political resistance (Kirkham & Anderson, 2002). In this study, it allows a more in-depth analysis of culture by deflecting attention away from essentialist constructions to a scholarship that provides a framework of understanding culture and identity as multifaceted and fluctuating, historically situated, and linguistically and socially constructed (Mohammed, 2006). Homi Bhabha is a leading author among post-colonial theorists, and his writings on post-colonial theory provide a useful framework for this project.

3.1.1 Key concepts

Homi Bhabha's book, *The Location of Culture,* is considered a seminal work in discussions about culture and post-colonialism. Others in the field of nursing have cited his work in discussion of post-colonial scholarship (Anderson, 2002; Browne, Smye & Varcoe, 2005; Racine, 2003), hybridity (Kirkham et al., 2002; Racine, 2009; Sochan, 2011), cultural difference

(Racine, 2009) and Third space (Chulach & Gagnon, 2015– see Appendix A; Kirkham et al., 2002; Racine, 2009). We begin with a discussion of the concept of post-colonialism, with close attention to the insights provided by Homi Bhabha. Once that has been accomplished, we will look at the concepts of cultural difference, Othering, hybridity, and agency, which are particularly pertinent in this project's development, undertaking and analysis. The goal is a thorough understanding of a concept that is useful in providing insightful connections throughout the course of the project.

Throughout this chapter, I will make frequent reference to Bhabha (1994) in order to illustrate how ideas adapted from his theoretical constructs of post-colonialism and culture are integral to the project. Direct quotes will be utilized to illustrate specific ideas. Bhabha asks the very important question of whether theory is simply another power tactic that re-entrenches the power–knowledge symbiosis. From his standpoint, the true intent of theory is to scrutinize power and knowledge so that "truth" may be informed and signified. The language of critique is effective only to the extent that it opens up a place for translation that establishes a relationship between knowledge and theory, which not only clarifies theory's intention but also directs its political objectives. In the process the notion of binary polarities present within systems and structures is challenged leading to conversion and transmission in meanings. With reference to culture, this conversion can only happen if we refocus our theoretical perspective on culture from one of diversity to one of difference. The premise of Bhabha's analysis is that "cultural difference is the process of enunciation of culture as 'knowledgeable,' authoritative and adequate in the construction of systems of cultural identification" (Bhabha, 1994, p.50). This enunciation occurs in a "non-fixative," "Third space," where the production of meanings and symbols are appropriated, translated, rehistoricized and re-interpreted. This space, void of the politics of polarity, but rife with the uncertainty and instability of change and negotiation, generates substance in the meaning of culture, and allows emergence of more complete identities.

3.1.1.1 ***Cultural difference***

Homi Bhabha (1994) makes a profound statement by inviting us to a different way of thinking with regard to cultural differences:

> What is theoretically innovative and politically crucial is the need to think beyond narratives of originary and initial subjectivities and to focus on those moments or processes that are produced in the articulation of cultural differences. These "in-between" spaces provide the terrain for elaborating strategies of selfhood – singular or communal – that initiate new sights of identity, and innovative sites of collaboration, and contestation, in the act of defining the idea of society itself (p.2).

Bhabha elaborates by reminding us that the terms of cultural engagement, whether unreceptive or engaging, are produced performatively. Contrary to any pre-given, social articulation, culture is a "complex, on-going negotiation of historical transformation" (Bhabha, 1994, p. 3). The place of this reconstruction occurs in a borderline space that entertains the possibility of a "cultural hybridity" where difference is conceived without an enforced or presupposed hierarchy. The boundary translates into the place from which something begins its presencing (Bhabha, 1994). Increasingly, national cultures are being produced from the perspective of disenfranchised minorities (Bhabha, 1994). The established associations of capitalism and class no longer provide an organizational structure for cultural identification and political affect (Bhabha, 1994). With reference to the issues of race, feminism, the lifeworld of refugees, and the social destiny of persons with AIDS, the traditional modes of representation are particularly ineffectual (Bhabha, 1994).

Cultural difference is not a free play of polarities and pluralities in a homogenous national community. Its interpretation is a process wherein meanings are conflicted and values are generated as a result of living in the visible spaces of a national group. Cultural differences, as knowledges and practices, exist beside each other in constant negotiation, and are antagonistic to current social discourse. The aim of this difference is to rearticulate the sum of knowledge from the perspective of the minority. It disturbs the control of power and knowledge, producing other spaces of subaltern signification. It is dialogical and transferential, while at the

same time signified in a process of substitution, displacement or projection. It questions forms of identity, and because of its continual implication of other symbolic systems, it is always incomplete and open to translation.

It is not enough to recognize the signs of cultural difference. The true challenge is to interpret the present, inclusive of diverse disciplinary discourses and institutions of knowledge that constitute the condition and contexts of cultures. It requires a cultural temporality that recognizes forms of activity that are both ours and theirs. Interdisciplinary is the acknowledgment of the space of cultural difference in the ambivalent movement between instruction and performance. It is perpetual movement towards a hybrid meaning site, a borderline moment that articulates incommensurable differences in the act of cultural translation.

In his discussion of cultural difference, Bhabha makes a unique contribution to the understanding of culture. Instead of adopting a multicultural view, he positions culture as a multi-faceted existence that is best understood in the context of “time.” He positions minorities as cultures who shape their individual, community and national identities within state civilization, integrating what is adaptive, and retaining that which is incommensurable. The “Third space” is the proclaimed site of negotiation; it is the borderline area where the substance of culture is renewed and repeated in the complex process of everyday living.

3.1.1.2 ***Identity***

According to Bhabha (1994), when one is confronted continually with one’s “difference,” identity presents as a persistent questioning in the structure of representation. The subject is apprehended from its historical space, made invisible, and seen and heard from where it is not. A person’s space is cross-examined and marked, placing them in simultaneous, contradictory contexts in which stereotype is both created and erased at the same time. What is negated is the aspect of depth and dimension that authenticates any representation (Bhabha, 1994). The signifier pre-determines the identity of the signified, visually, objectively and conceptually within

Western perspectives. It eliminates the self and autonomy of the subject, leaving behind residual resistance within a problematic identification. It negates originality, portraying only a barely perceptible and "less than" place that has been inscribed by authority. This crisis in representation of personhood, initiated by invisibleness and erased self-presence, creates a subaltern existence (Bhabha, 1994). In response to this, the subject circulates without being seen, seeking to open up a space where the subject can speak. In this space, the subject manipulates their representation of identity, re-shaping the past within the race, racism, colonialism and cultural identity of the present.

Bhabha's discussion of identity and stereotype from the post-colonial perspective provides insight into the construction of identity as it evolves within colonial discourse. He illuminates how this construction is something that is never an affirmation of a "pre-given" identity, but always a production of an image that is constructed as an "Other." Its impact on the subject comprises a range of effects from self-erasure to political subversion (Bhabha, 1994).

The discussion of identity within the framework of post-colonial discourse has direct applications to this research project. The participants' status as refugee women positions them as a group that has historically been dominated by a colonial force. Previous studies have identified how refugees have been subject to discrimination and injustice that is often based on cultural and ethnic stereotypes (Bulman & McCourt, 2002; Kitzinger, 2004). Knowledge regarding the nature of colonized subjectivity and attunement to the various forms of cultural and political resistance will alert the researcher to the societal, institutional and political forces that have shaped the woman's experience and its subsequent effects on how she may define herself. Such information will be useful throughout the research process, as it may influence locations and methods in data collection and recruitment strategies. Knowledge will also be useful in data analysis of narration of the lived experience of women, possibly bringing forth scenarios of discrimination and other forms of colonial discourse that may have shaped their identity and well-being.

3.1.1.3 ***Otherness***

Linked to the concept of identity is the concept of Otherness. As a sign of cultural/ historical/racial discrimination, Otherness is a paradoxical mode of representation that produces a “probabilistic truth” that can never be substantiated. It depends on fixity and symbolizes rigidity, turmoil, immorality and evil repetition. It strategically uses stereotype to maintain a regime of truth that purports a certain knowledge and identification. Bhabha (1994) maintains that it is important to focus on the process of subjectification that occurs with stereotypical discourse. Colonizer and colonized are constructed through a process of dominance and dependence navigated by the interplay of power and resistance inherent to the particular regime of truth. This construction creates space for subject peoples only within a surveillance system that stereotypically categorizes the knowledges of colonized and colonizer. It serves as a form of governmentality that marks, directs and dominates the subject, resulting in a colonized “Other” that is only recognizable and knowable according to the dominant force. Subjects are constrained within that apparatus of power that “contains” their “Other” knowledge. The effect creates mummification in individual thinking that is maintained by an acceptance of that which is visible as natural and by the omission of any working-up of difference. The subject becomes “fixed,” inhabiting only a visible “Otherness” that becomes the point of identity. Institutionalization entrenches the process when ideologies that are prejudicial, discriminatory, archaic and mythical are seen as appropriate. The result is marginalization and hierarchization that obscures the “Othering” and subjectification process with its attention to objectification, normalization and discipline.

Bhabha’s analysis of “Othering” and its relationship to stereotype and discrimination is useful in illuminating it as a significant and powerful strategy in maintaining an established order of colonial power. Enhanced understanding of the colonial power’s regime of truth assists in uncovering the process of subjectification within that order. The metaphor of mummification that describes the profound effect on the subject provides insight into the behaviour of subjects

affected by the colonial process. Canales (2000) has offered further insights into the concept of Othering, distinguishing between Exclusionary and Inclusionary types. Exclusionary Othering, which utilizes the power dynamics within relationships for domination and subordination, is related to Bhabha's concept of Othering (Weiss, 1995). Processes such as vulnerability, stigma, and racism are seen as components of Exclusionary Othering (Canales, 2000).

The concept of "Othering" as described by Bhabha has specific implications for this research project. I will be engaging with a group of women whose physical presence may subject them to the process of "Othering." As refugees within Canada, they may be subject to particular stereotypes or stigmas as a result of that classification. It will be imperative that I maintain an awareness of the Othering process. Canales (2000) relates that consequences for those who experience Exclusionary Othering are often alienation, marginalization, decreased opportunities, and internalized oppression. When this occurs within the context of health care delivery, potential negative consequences exist for human development, maintenance of self-esteem, and health promotion and restoration (Hall, Stevens & Meleis, 1994). Increased knowledge of the conceptual underpinnings of Othering will allow me to be attuned to its presentation. Lastly, the research process itself focuses on the lived experience of participants. It is hoped that the increased understanding resulting from becoming more intimately knowledgeable of their experience will affirm rather than "Other" that experience.

3.1.1.4 ***Agency***

In his discussion of agency, Bhabha (1994) calls for a radical revision of social temporality. Such a revision alters cultural identities by creating space for historical narration and self-determination as the "sign" of cultural presence. Space that illuminates the agency of those who have suffered the effects of subjugation, domination, diaspora, marginalization and displacement brings to light a culture of social survival, displaying the "selfhood" of those who are in the midst of incommensurable demands and practices (Bhabha, 1994). It brings to the forefront uneven, incomplete meanings and values emanating from that struggle for survival.

Actions of agency denote transitional, transnational and transformational aspects of culture. Culture viewed in this light affirms and extends a collaborative dimension, constructing identity through a process of alterity. In this enunciative site, objectified others become subjects of their history and experience, and they emerge relocated and re-signed. A contingent structure of agency allows polarities to be replaced with truths that are partial, limited and unstable. In this light, agency is both the dialogue of historical narrative and the creation of history itself. Both subaltern and dominant cultures are affected, reflecting a change in configuration to both.

Bhabha's discussion of agency in the context of cultural survival, cultural translation and cultural displacement offers an encompassing view of the process of agency. His focus on signification points to the "signs" of agency that contribute to the macro process of cultural transformation. Tomlinson (2010) provides insight into the micro-process of agency when she demonstrates how refugee women in the United Kingdom use different identity markers not only to give meaning and significance to their experiences as outsiders, but also to contest and resist limitations and negativities associated with their refugee status. They also use these markers to suggest possibilities of inclusion across the boundaries of being a refugee. This is similar to Canales concept of Inclusionary Othering (Canales, 2000).

The concept of agency has important implications for this research project. As I explore the lived experience of pregnant refugee women living with HIV, it will be important to be attuned to those experiences in which they have been able to exercise agency in their day-to-day lives. Such feedback may provide useful information with regard to systems and processes that are helpful to them. Stories about experiences in which their agency has been prohibitive or restrictive will also be informative. These stories may uncover processes, policies or systems that are particularly problematic for this group of women. Of particular interest will be the exploration of their ability to exercise agency within the health care and social systems. Their agency within these systems will shape their experience and determine their access to care while they are pregnant with a chronic diagnosis of HIV.

3.1.1.5 ***Newness in the world: becoming minor***

In his treatise on how newness enters the world, Bhabha (1994) describes the experience of colonialism as living at the centre of the incomprehensible. “Becoming minor” communicates different ways and standards that have been forced into a negative, generic, subject location. In a minority community, the oppressed person transforms it into a positive one, substantiating cultural difference and territory where collective identification is negotiated. Culture becomes a site of solidarity. Bhabha calls for a global analysis of culture, with more attention to a new international culture and less emphasis on “local” space. In his quest for survival, the migrant’s experience is both a transitional and a translational one. Cultural difference, the foreign element in the midst of translation, appears as the stubborn chunks, the element of resistance that does not lend itself to the process of transformation (Bhabha, 1994). Such an analysis destroys an assumption of cultural supremacy, and calls for contextual specificity and historical differentiation within minority positions. Persons living on the borderlines and in the midst of the incomprehensible demand an agency of initiation that is constantly in translation and transformation, in perpetual movement toward a culture of belonging.

3.1.1.6 ***Hybridity***

Hybridity, another key concept in post-colonial theory, recognizes a cross-cultural exchange that makes any form of cultural purity untenable (Ashcroft, Griffiths & Tiffin, 2007; Kirkham & Anderson, 2002). Most third-world countries do not share a single common past or a single common condition; nor do cultural groups exist as singular entities or in a binary form (Kirkham & Anderson, 2002; Kirkham et al., 2002). Cultural systems are constantly changing and are contextual according to their particular time and location (Kirkham et al., 2002). In light of this constant fluctuation, Bhabha coined the term “hybridity” that employs a Third Space where identities are recast, negotiated, and reorganized (Kirkham et al., 2002). The result is a constructed culture in an “in-between space.” Hybridity within a “Third space” engages resistive agents to mobilize “incommensurable” forms of culture to bring about something new and

unrecognizable; combined partial cultures construct new visions of communities, new political initiatives and versions of historic memory (Kirkham & Anderson, 2002).

Bhabha (1994) also introduces hybridity as a necessary counter-strategy to colonial authority. In order to sustain itself, colonial authority depends on the "immediate – unmediated – visibility of rules of recognition as the unmistakable referent of historical necessity" (Bhabha, 1994, p. 157). These rules articulate the signs of cultural difference and implicate them in the deferential associations of colonial power through a process of hierarchization, normalization and marginalization. By disclaiming its part in this dislocatory process, colonial domination is strategically achieved and preserved. It exercises authority through modes of subjection and discriminatory practices that section off subject populations, producing various differentiations, individuations and identities, and disclaiming any stable unitary assumption of collectivity. Hybridity is the strategic reversal of this process of domination. It disavows the assumed colonial authority and intervenes to indicate not only the possibility of identity but also the unpredictability of its presence.

The concepts of "hybridity," "Third space" and cultural differentiation have important implications for this research project. It will be important to discover what aspects of their cultural identity women have incorporated into their life in Canada, and how this contributes to their overall health and well-being. What space allows them to freely articulate that identity? What space is problematic for them as they navigate and negotiate life in a new country, attending to their lives a pregnant refugee women living with HIV? Hybridity is also useful to this research project, as it dispels the traditional "myths" associated with culture and names the space for dialogue between the researcher and participant. It lends a cautionary note to the researcher to avoid homogenizing the experience of the refugee women, but rather to seek with them shared meanings that emanate from their position as pregnant women with HIV in a new land.

3.2 Post-colonial Framework and Nursing Scholarship

Post-colonial theory brings focus to our research method as an angle of inquiry (Kirkham & Anderson, 2002). It is like a tool set that includes provisional strategies, protocols and concepts that are utilized when recognizing a historical and intersecting approach to difference. Calling on their disciplinary and hybrid nature, these tools get adapted and reconfigured according to the time and place during which they are used (Dutton, Ghandi, & Seth, 1999). Five particular features of post-colonial nursing research have been identified. These include the way the research is framed, the contextual relationship between the subject and society, giving voice, intersectionality, and an orientation toward praxis (Kirkham & Anderson, 2002).

3.2.1 Political lens

When utilizing post-colonial theory, the entire research project is viewed through a political lens that attends to the micropolitics and large-scale dynamics of power (Radcliffe, 2005). Post-colonial theory directs our attention to how intercultural health-care exchanges at the individual, organizational and societal level oscillate in a pattern of authority and resistance (Blix, Hamran, & Normann, 2012). Race and power are foremost themes of post-colonial theory's focus, its process, and in its analysis. One intent of the research is to unveil how contemporary constructions of race, ethnicity and culture continue to perpetuate colonialist images leading to patterns of inclusion and exclusion in health care settings. This is best achieved within a researcher–participant relationship in which freedom is created for questioning taken-for-granted assumptions. In addition, the researcher acts as an analyst, bridging the everyday experience with larger societal influences, while at the same time maintaining a reflexive standpoint between theory and research (Kirkham & Anderson, 2002). The current project invites a group of refugee women to share their stories. A post-colonial perspective will help us understand how their views are shaped by their experiences in their own countries, their lives during displacement, and their interactions within the host Canadian country. It will illuminate

how their health and settlement concerns are shaped by their location in a hierarchical social space (Guruge & Khanlou, 2004).

3.2.2 Relationship between self and society

Another salient feature of post-colonial research is situating the human experience of everyday reality into the larger social contexts of social, economic and political influence (Kirkham & Anderson, 2002). The starting point for this type of inquiry is the everyday world of people that is then linked to larger economic and authoritative associations. It recognizes the inter-related social construction of knowledge and experience, while at the same time maintaining a person's agency and voice without objectifying them (Kirkham & Anderson, 2002).

The chosen methodological framework for this study is an interpretive phenomenological philosophical inquiry with special application of critical theory. It aligns well with post-colonialism in its focus on common life experiences (Lopez & Willis, 2004). Interpretive phenomenology views humans as embedded in their world and inextricably linked to their social, cultural and political contexts. Post-colonial research shares this belief, but stretches this stance to an explanation, questioning and critiquing of those forces. The rich description of everyday living integral to the interpretive phenomenological approach leads to complex, in- depth descriptions that provide fertile ground for post-colonial analysis and understanding.

3.2.3 Giving voice

De-centering the dominant culture's worldview is an important characteristic of post-colonial research (Kirkham & Anderson, 2002). The worldview of the marginalized person becomes the reference point for knowledge construction. This significant aspect of "giving voice" is essential to developing scholarship that does not continue to silence or render invisible perspectives of people who have been diminished by the sequel of colonization. An essential feature of post-colonialism is that people exercise the right to speak, rather being spoken for, the right to represent oneself, rather than being represented, and the right to be seen, rather than being entirely erased (Kirkham & Anderson, 2002). The population included in this study will be one

that has borne the burden of history through their experiences of displacement and colonization. A diagnosis of HIV may have subjected them to the damaging effects of stigma. It is imperative that the research process does not vicariously repeat these experiences. Giving voice in a respectful and mindful way is an important responsibility for nurse scholars as we seek to illuminate nursing knowledge that is representative of all peoples, including those who have found themselves on the margins of society. Kirkham and Anderson (2002) have offered strategies for achieving this, including purposive sampling, careful listening, verbatim narratives, and critical examination of the structures that influence their lived experience. As a Caucasian researcher, it is imperative that I remain particularly wary of knowledge production from a dominant position, and work to uncover ways that marginalization and racism operate in health care to impact the health of refugee women with HIV.

3.2.4 Intersectionality

The intersectional analysis of post-colonialism sets it apart as uniquely positioned when interacting with a group that has historically been exploited (Mohammed, 2006). The tyrannies of classism, racism and sexism become intertwining influences in analysis (Kirkham & Anderson, 2002). The presentation of oppression becomes an atmosphere of domination where the fields of economics, politics and ideology are continually in motion and interacting with one another. Thus, at any point in time, depending on the context, an individual may be both and oppressor and oppressed (Kirkham & Anderson, 2002). Unless this intersectional analysis is accomplished, the risk is to overlook issues of primary health care, health promotion, discriminative immigration laws and health policies, and settlement patterns that also influence non-Western peoples' health (Racine, 2009). Focusing on race, gender and social class, without attending to the environments of oppression and marginalization, threatens to isolate these factors form the broader socio-political and ecological contexts within which domination and marginalization occur (Racine, 2009).

An intersectional analysis of influence moves beyond traditional ways of conceptualizing research. It considers the location of subjects by analyzing the forces of oppression and privilege (self and other), acknowledging that categories of identity are unstable, dependent, relational and inseparable (Hulko, 2009). Social processes that are involved in constructing identity vary according to time and place. Systems of oppression, such as heterosexism and ageism, are historically and culturally positioned (Hulko, 2009). Acknowledging this intersection of identities and the process by which value is placed on them not only reflects the socially created nature of reality but also identifies the processes that may inadvertently serve to enhance or diminish a person's identity (Hulko, 2009). In this research, intersectional study will create a venue for illuminating how the various dimensions of social reality such as race, gender, class, education, citizenship and geographic location converge and are legitimized into inequalities in institutional structures to impact the health of refugee women with HIV (Guruge & Khanlou, 2004). Previous authors have shown how, as a framework, intersectionality extends understanding and provides significant meaning and usefulness when addressing health issues for populations such as pregnant HIV-positive refugee women (Chulach & Gagnon, 2013 see Appendix B).

3.2.5 Orientation toward praxis

A final but important feature of post-colonial research is its commitment to critique the status quo and to build a more just society (Kirkham & Anderson, 2002). This type of research is committed to social change by critiquing misdistributions of power and resources in order to enable a more just society. Research that produces knowledge is the best way to challenge hegemony and the status quo, and knowledge for action can be a cornerstone for praxis (Racine, 2009). Thus, research becomes the vehicle for social activism, and the researcher becomes transformed into a social activist (Racine, 2003). The researcher has the social responsibility to take forward the resultant knowledge into community, clinic and policy arenas in crucial dialogues where structural inequities and their resolution remain a top priority.

Relationship between community, policy makers and researcher should be established prior to the start of the research project, and should be maintained through continuous connection and ongoing communication (Anderson, 2002). Post-colonial theory opens the door to social and political activism in order to achieve nursing's social and moral mandate in addressing health disparities and social inequities. Engagement with grassroots organizations and advocacy groups decentres knowledge production and promotes structural and institutional change (Racine, 2009).

Praxis begins with a reflexive critique throughout the research process. Thoughtful contemplation regarding the relationships formed with participants, the influence of the researcher's strong positionality, the dynamics of power at play, and the nature of knowledge being constructed lead to a social construction of knowledge rather than knowledge in the traditional factual sense. Change occurs for both the researched and the researcher. The possibility for emancipation is achieved as the researcher seeks changes in social attitudes, re-structuring in organizations and adaptations in public policy. For the research participant, there is hope for increased self-reflection and deeper understanding with a more attuned consciousness (Kirkham and Anderson, 2002).

The hallmark of post-colonial study is a firm research–theory dialectic that provides a specific interpretive lens that views each life as shaped by history. The context of each life is important and is framed by how race, gender, class and historical positioning intersect at that given moment in time. This lens frames how questions are formulated, who is included in the study, how the data is interpreted, how meanings are derived and how research knowledges are disseminated (Kirkham & Anderson, 2002). It is defined by its inclusivity and its commitment to social justice for all. It challenges and repositions the boundaries between the social and empirical sciences, between qualitative and quantitative methods, providing a release from traditional dualistic thinking. Its rigorous scrutiny of dominant discourse makes it an unsettling discourse in many health care settings. Yet it is this very disruption that has the potential to

transform health care settings into the equitable and socially just environments that provide health care for all.

3.3 Doing Post-colonial Research

Mohammed (2006) offers a useful illustration of how post-colonial theory can be utilized to influence every step of the research process from participant inclusion criteria through to dissemination of results. It will be utilized as a guide to explore how post-colonial theory will be incorporated into this research project.

Research incorporating a post-colonial perspective must begin with the experience of those who are willing to share their narratives of histories and interactions, and then works backwards to illuminate the context of those experiences (Anderson, 2002). A mainstay of post-colonialism is its recognition of past injustices and its commitment to non-replicate them (Mohammed, 2006). Researcher preparation includes familiarization with destructive practices that the participant may have endured, including religious persecution, rapid relocation, trauma, torture, isolation and stigma (Beiser, 2005; Danso, 2001). Mohammed (2006) recommends extensively reading historical literature of the participants. In this study, it will be important to have historical knowledge related to the participants' lives in their home countries, with particular attention to their diagnosis of HIV. As well, it will be important for me to be familiar with various accounts of the refugee process in Canada. An extensive literature review did provide insight and allowed me to be attuned to issues that arise within the conversations with participants. Mohammed (2006) also recommends building trust through affiliations with community organizations. These associations allow the researcher to link with key community members and demonstrate commitment and collaboration. This is done by investing time in relationships as well as acts that exhibit a willingness to give back to communities and organizations (Mohammed, 2006). Possible associations include linkages with refugee associations and local advocacy groups for persons with HIV.

Mohammed (2006) conceptualized the research with four central suppositions informed by post-colonial theory. Along similar lines, I have formulated assumptions that are important for this project. First, it is important to recognize that not all refugee women with HIV who are pregnant are the “same.” Although they may share similar experiences of racism, pregnancy, stigma, displacement, and associated struggle, each experience is “their own” and will be shaped by their particular nationhood, class, education level and social circumstances. Second, it will be important for me to recognize that both “refugee” and “HIV” are not neutral terms, but that both of them have been subject to stereotypical connotations. Third, HIV will be recognized not only as a biological entity, with specific immunology, signs, symptoms and courses of treatment, but also as a social construction with the added associations of stigma. Some clients incorporate folk beliefs surrounding HIV’s causes and cures (Conviser, 2007). This way of thinking decentres the assumed hegemony of the Western medical belief system, and opens dialogue for a more expansive exploration of the diagnosis. Finally, the objective of this research project is to explore the experience of what living with HIV is like for refugees who are also pregnant, with its intent being to advocate for systems and processes in health care that are transformative and equitable. As a nurse practitioner, I am partially located within Western biomedical culture. It will be important that the women involved in the study remain at the centre of knowledge production, and that the resultant meanings comprise a hybrid and shared nature.

Mohammed (2006) utilized self-identification and chose not to recruit from hospital or clinic sites in order to reduce an impression of coercion and to mitigate the effects of past colonial processes. Informal communication provided the avenue for snowball sampling, and flyer advertisements revealed her non-Caucasian identity and acknowledged past researcher exploitation within the population (Mohammed, 2006). This concept, as it is related to post-colonialism, provided guidance in the recruitment process; it impressed upon the researcher the

importance of establishing the voluntary nature of the study and the need to be mindful that methods do not essentialize or re-enforce already existing stereotypes.

Post-colonial data collection requires that the focus be determined by the participant, with interviews that are loosely structured, with open-ended questions, and narratives that tell about their background (Mohammed, 2006). Inquiry must be dialectical and reciprocal (Anderson, 2002). In this study, such a process would provide a space for each person to tell their story about having HIV while being pregnant and a refugee new to Canada. Mohammed (2006) viewed participant observation as especially useful for the post-colonial approach. It facilitated greater understanding of the contexts of the participants' everyday lives as they reside among the dominant society, and allowed a profound view of the interactions of class and ethnicity.

Post-colonialism provides a forum from which to address health problems related to race, class, and gender within their larger socio-historical and cultural contexts, while centering its analysis on issues of power (Mohammed, 2006). The analysis often evokes a contrast between the researcher and participant, and brings to light colonial influences that have affected patterns of immigration, division of labour, and gender relations, which in turn affect admittance to health services (Racine, 2003). In this study, field notes and interview transcripts will help unravel the interconnection of HIV with historical, social, economic and political forces that position life for the pregnant refugee woman. Reflexivity is crucial in post-colonial research (Mohammed, 2006). In this project, I will constantly face my identity as a Canadian, middle-class nurse. This must be constantly kept in mind in an effort to equalize power differentials through dialogue and debriefing, to incorporate researcher bias, and to negotiate and create meanings with participants (Racine, 2003).

The way that results are constructed is particularly important when utilizing a post-colonial framework in research. Avoiding reproduction of post-colonial portrayals is paramount and requires attentiveness as to how representations are created. Since a goal of both the

research project and post-colonial theory is to move towards enhanced social justice, it is relevant that complexities illuminated drive this agenda forward. Mohammed (2006) recommended avoiding essentialisms, highlighting intricacies, and articulating significant and considerable portions of participants' narratives in order to validate construction of findings. My goal will be to provide a more complex understanding of culture, identity, ethnicity and diagnosis for pregnant refugee women with HIV as they navigate a land that is both politically and socially foreign, economically challenging and laden with stigma surrounding their HIV and refugee status (Anderson & Doyal, 2004; Beiser, 2005; Danso, 2001; Ingram & Hutchinson, 2000).

Post-colonialism calls for a change in societal structures and attitudes (Mohammed, 2006), and therefore demands a dissemination strategy that is both broad and directed, along with a commitment on the part of the researcher to remain engaged (Mohammed, 2006). This includes sharing results with research participants and people who work with populations that have participated in the research (Mohammed, 2006). Within this study, it will be important for me to offer results to participants, to remain engaged with advocacy organizations and interested professionals at the sites where the research has been conducted, as well as to continue to work with patients with HIV in my clinical practice.

A post-colonial framework is useful to address some of the proposed solutions to the research problem. Previous researchers have recommended the need for increased accessibility, equity and continuity, with a reduction in institutionalized racism (Bulman & McCourt, 2002; Carolan & Cassar, 2007; Reynolds and White, 2010). Because post-colonial theory links the health of women to the social, cultural, economic, historical and political contexts of their lives, it points to these areas to provide solutions aimed at addressing the health of pregnant refugee women with HIV (O'Mahony & Donnelly, 2010). Instead of viewing each woman as being totally responsible for her health care, it redirects the attention to health care institutions and policies that influence the processes of care and women's health (Donnelly & McKellin, 2007). Hybridity as a central theme of post-colonialism assists in creation of

solutions as it recognizes a “Third space” where cultural identities are negotiated to produce more empowering hybrid cultures. This opens the door to new possibilities for providing care, to transformative knowledge necessary for health care delivery, and to empowering positions for the client.

Post-colonialism as a theoretical framework is particularly important to this study. It brings to the surface the ethical and moral problems of cultural representation, exposing the politics of research and the hegemony of Western policies. It positions nursing research in a context of understanding in which questions of cultural identity are complicated and fluid, and it recognizes Western biomedicine as a cultural construction. It fuels discussion surrounding culture and health inequities by moving the emphasis from individualistic models to a model in which history, politics, economics and cultural aspects of care are as important as the physiological processes. By reflecting on race, class, and gender discriminations, post-colonialism uncovers exclusionary effects of mainstream practices and brings us closer to the goal of socially just health care for all.

CHAPTER FOUR

METHODOLOGICAL CONSIDERATIONS

This chapter will begin with a brief presentation of the research design followed by a description of interpretive phenomenology. The data collection and analysis process will be described, along with the ethics approval process. Lastly, the rigor criteria will be identified and explained.

4.1 Research Design

Since there is a paucity of research that looks at the intersection of HIV, pregnancy and refugee status, it is fitting that a qualitative approach was utilized for this project. Qualitative research is used when a problem or issue needs further examination (Broussard, 2006; Creswell, 2007; Stewart, Gill, Chadwick & Treasure, 2008). It is also beneficial when there is a need to study a specific population or to hear silenced voices (Creswell, 2007). The literature has identified that refugee women and women living with HIV tend to be marginalized in society, resulting in a loss of that population's voice (Moussa, 1998; Valencia-Garcia et al., 2008). For this reason, the research design was chosen to provide participants with a space in which to share their experience. Furthermore, qualitative research is appropriate when we seek a complex, detailed understanding of an issue for which context is important (Creswell, 2007; Draper, 2004; Morse, 2003). The intersection of HIV, pregnancy and refugee status presents a complexity that can only be revealed by speaking directly with those who have lived this experience. By creating an opportunity for women to speak about their experience, this project provided a unique opportunity for the researcher to gain an in-depth understanding of that intersection.

A qualitative design that incorporates explorative and interpretive aspects was chosen for this research project, particularly because one of the study's objectives was to explore the meaning of pregnancy from the perspective of HIV-positive refugee women. By incorporating the explorative and interpretive aspects associated with this design, the researcher was able to make sense of and interpret phenomena as described by participants (Denzin & Lincoln, 2005; Gelo, Braakamann & Benetka, 2008; Polit & Beck, 2008; Stewart et al., 2008; Vishnevsky &

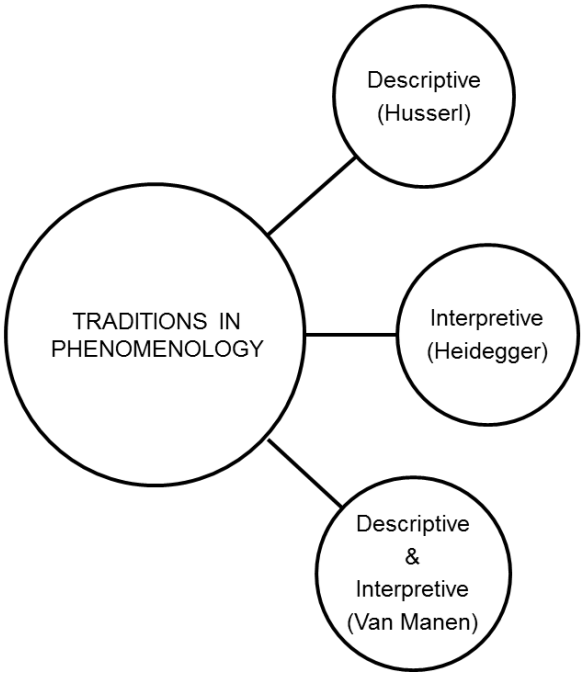
Beanlands, 2004). From these interpretations, new knowledge was generated that stayed close to the in-depth stories of participants (Creswell, 2007; Vishnevsky & Beanlands, 2004). The participants' stories represented a diversity of experience that could be honoured only with qualitative research. Their stories had the ability both to represent the multiple realities exemplified by each participant and, at the same time, to illuminate the intersection of HIV, pregnancy and refugee status, which is often intricately connected to the political, social and cultural contexts of the participants (Creswell, 2007; Draper, 2004).

Application of an intersectional lens to the interpretive phenomenology approach provided insight and a depth of understanding that could only be gained by looking at the power influences affecting the lived experience of HIV-positive refugee women. Intersectionality is concerned with simultaneous intersections between aspects of social difference and identity (such as race, ethnicity, gender, migration status, religion) and modes of systemic oppression (racisms, stigmas) at macro and micro levels that are multifaceted and interdependent (Hankivsky & Cormier, 2009). By examining the lived experience of HIV-positive refugee women at individual, social and structural levels, we gain an enhanced level of comprehension that captures the multiple contexts that shape their experience of pregnancy. Such understanding is both useful and necessary in generating action sensitive knowledge.

4.2 Interpretive Phenomenology

Many traditions of phenomenology exist (Dowling & Cooney, 2012). A summary of these traditions is provided in Figure 1 (next page).

Figure 1. Traditions in Phenomenology



The tradition of eidetic or descriptive phenomenology is grounded in the work of Husserl, the founder of phenomenology as a branch of philosophy (Mackey, 2005). A further tradition is inclusive of hermeneutics, also referred to as interpretive or existential phenomenology, and guided by the work of Heidegger and Gadamer. A third tradition encompasses the Dutch (Utrecht) philosophy that claims to include a combination of descriptive and interpretive elements, drawing mostly from the work of van Manen. According to Thomson and colleagues (2011), this classification is also adaptable in that it is able to incorporate recent developments in phenomenological research approaches such as the “lifeworld” (Dahlberg, Drew, & Nystrom 2001) and interpretive phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2009).

The methodology adopted in this research project is interpretive phenomenology. While the general tenets of the interpretive approach have guided the methodology, the specific work of van Manen (1990) has been incorporated, as well as that of Smith, Flowers and Larkin (2009). This is fitting, as there is no one way to do a phenomenological study (Dowling & Cooney, 2012). The choice of approach is largely related to the nature of the research question

(Hein & Austin, 2001). In fact, a unique feature of research with a phenomenological orientation is its freedom from prescriptive methodology (Garza, 2011). This particular aspect of interpretive phenomenology was important for this study because of the need to present a more complex picture of the experience under examination (Whitley & Crawford, 2005). As such, it became possible to study the experience of pregnancy from the perspective of HIV-positive refugee women, while also using a critical lens to explore the interplay of factors and influences that contribute to the complexity of this experience (Conklin, 2007; Creswell, 2007).

A key tenet of interpretive phenomenology is that it begins in the lifeworld, the natural world of everyday life (van Manen, 1990). Researchers look for meanings embedded in this "everyday life" by studying common life practices and experiences (Lopez & Willis, 2004). Interpretive phenomenology recognizes that such practices and experiences are influenced by a broader context (Tuohy, Cooney, Dowling, Murphy & Sixsmith, 2013). Yet, they are not expected to study that context in great detail or to incorporate that context in their analysis. The decision to add a critical (post-colonial) approach to the interpretive design of this study allowed for a fuller appreciation of the complexity of the lived experience described by the participants (Gillis & Jackson, 2002). This decision was important to the study for several reasons:

First, adopting such an approach gave voice to a group of culturally diverse women who occupied a precarious social location at the time of the study, and whose points of view have not traditionally been heard in the clinical setting. Second, it provided the necessary tools to fully recognize power issues embedded in personal stories. Using a post-colonial framework to analyze these stories provided an opportunity to reveal how historical, relational, cultural, social, economic, and political influences manifest themselves in the lived experience. Third, it assisted the researcher in linking the macro (social and political), meso (community) and micro (identity) within the experience of pregnancy as opposed to locating them as external influences. Finally, it redefined the role of the researcher (as a transformative agent) and the outcomes of the study.

Listening to participants and their stories is essential to interpretive phenomenology (Koch, 1999; McConnell-Henry, Chapman & Francis, 2011; Smith et al., 2009). As such, researchers are expected to remain attuned to what is said during the interview and to monitor for what is remotely present or unsaid (Naden, 2010; Vandermause & Fleming, 2011). Both the descriptions and understandings about their reality that participants bring are accepted and valued by the researcher (Koch, 1999). At the same time, it is recognized that researchers bring prior awareness about the phenomenon and prior exposure to the study population, clinical practice, research, and theory (Kumar, 2012; Tuohy et al., 2013). In interpretive phenomenology, researchers are not expected to "bracket" this prior awareness and exposure (Koch, 1999; Heidegger, 1996; McConnell-Henry, Chapman & Francis, 2009). Instead, they are expected to use it to enrich the analysis (Kumar, 2012). As a result, the analysis process produces a "blend of meanings" articulated by both the participant and the researcher. This is referred to as a "fusion of horizons" (Gadamer, 1990; Lopez & Willis, 2004), reflecting that there is no one true meaning but, rather, multiple meanings that emerge from the coming together of both participants and researcher. This is unique to interpretive phenomenology, and is consistent with critical theory (and post-colonial) epistemology (Scotland, 2012).

Studying the complexity and depth of human experiences is integral to the interpretive phenomenological approach. In nursing, this approach has been used to study the experiences of caring, healing, and wholeness (Abedi, Babamiri & Rostami, 2012; Healey-Ogden & Austin, 2011; Wojnar & Swanson, 2007). By accessing the "everyday lives" of nurses or of people who receive care, researchers gain awareness of the significant in the taken-for-granted and of the meanings assigned to particular kinds of experiences (Coventry, Dickens & Todd, 2014; Davies, Jenkins, & Mabbett, 2010; Mackey, 2005; Reiners, 2012). The whole process cultivates one's ability to be thoughtful, tactful, and insightful about one's own experience and the experience of others (van Manen, 1990). According to van Manen (1990), the "story" in lived experience

broadens the existential horizon and allows us entry into a world of situations and vivid emotions that would not otherwise be possible.

For the purpose of this study, it was important to use a research methodology that pays attention to the "story" that van Manen (1990) describes – the "story" that reveals everyday realities of refugee women in Canada, as they navigate their social location within a new country while, at the same time, attempting to attend to their health care needs in the context of HIV and pregnancy. Yet, it was important to remain cognizant of the fact that this "story" is always more complex than the study can reveal (van Manen, 1990).

The study of lived experience undertaken in interpretive phenomenology has a temporal structure (Heidegger, 1962, 1996; Mackey, 2005; van Manen, 1990). It begins in the lived experience and reflects back to it, hoping to arrive at the fundamental nature of the phenomenon (van Manen, 2014). It focuses on understanding the phenomenon in context at that particular point in time (Wojnar & Swanson, 2007). Both participants and researchers are situated in time in order to reveal and search for understanding (Flood, 2010). The participants' rich descriptions situate the participant in the world, allowing them to recognize significant involvement in the world (Starks & Trinidad, 2007). The uniqueness of each situation is limited by its temporal horizon that determines the range of possibilities for the experience being narrated at that time (Mackey, 2005). The attentiveness of the researcher and the awareness of this temporal determinateness are intrinsic to the interpretive process, and are elicited in the discussion of the phenomenon (Vandermause & Fleming, 2011). With its focus on temporality that is cognizant of past, present and future orientations, interpretive phenomenology is the most appropriate methodology for capturing an experience in time – an experience such as being pregnant for an HIV-positive refugee woman (Mackey, 2005, van Manen, 1990). As such, temporal (as well as spatial) considerations were helpful in generating an interpretive understanding of the research phenomena.

The following sections will provide a more detailed account of the interpretive phenomenological dimensions of the project and the application of the critical lens at different stages of the project, with a clearer emphasis on the process of analysis.

4.3 Research Context

Refugee women in Canada represent a diverse group. The National Capital Region accepts refugees from a variety of countries, and in 2005 it was the fourth most popular city for newly arriving refugees to Canada (Pottie et al., 2007). A study done at one of the clinics providing care to refugees in Ottawa found that between December 2004 and November 30, 2005, 98% of refugees originated from sub-Saharan Africa, from north Africa or from the Middle East, with the remaining individuals coming from North Eastern or Central Europe (Pottie et al., 2007).

The current study was conducted exclusively in the National Capital Region. Since the goal of the study was to understand the experience of pregnancy from the perspective of HIV-positive refugee women, a particular country of origin was not selected prior to recruitment. Extending the recruitment for this study to women from a variety of cultural backgrounds provided additional breadth to the analysis, offering insight and understanding into how the intersection of HIV, pregnancy and refugee status is experienced differently (and similarly) across different cultural backgrounds. It was crucial to involve women capable of sharing their story and willing to take part in the study. This was a significant challenge, considering both the sensitive nature of this topic for many women living with HIV as well as the precarious status of refugee women in the National Capital Region.

4.4 Recruitment

Participants were recruited from two community-based organizations and from one outpatient HIV clinic using recruitment posters (French and English) (see Appendix C). These sites were specifically selected since they provide services to women living with HIV and to refugee women in the National Capital Region. The recruitment posters clearly indicated the title of the study, the objective of the study, and contact information of the researcher. This contact number

provided potential participants with a means to join the study, and also offered them an opportunity to seek further information about the study before deciding to fully engage. It was considered important that the recruitment posters stress the voluntary nature of the study. The posters were displayed after ethics approval and required permissions were obtained.

The researcher worked closely with a support worker at a one of the community-based organizations. Prior to recruitment, the researcher met with the support worker to inform her about the nature of the study, to discuss how confidentiality would be maintained, and to talk about the logistics of data collection. The discussion also included how the researcher could give back to the organization. Subsequent to this, and prior to data collection, the researcher provided a presentation to potential participants on the benefits of cervical cancer screening for HIV-positive women. Once ethics approval and the organization's letter of support had been obtained, the support worker at this community-based organization distributed the recruitment posters. Participants recruited through this organization called the researcher directly or gave their consent to the support worker for the researcher to contact them.

Recruitment took place from July 2013 until May 2014. In this study, as in most qualitative research, data collection and analysis processes were concurrent, with analysis beginning after the first interview. Due to the sensitive nature of the research topic, the women's fear of disclosure, and contextual factors – including recent changes in federal immigration policy – recruitment posed a challenge. All participants who were interested in participating in the study were included. A description of the research sample is provided in the next section.

4.5 Sample

In a phenomenological study, where there is a large amount of data for each participant, sample sizes are typically small (Morse, 2000). Smith and colleagues (2009) suggest sampling between three and six participants. With interpretive phenomenology, the primary concern is to gather a detailed account of individual experience in order to reveal the complexity of the phenomena, with a focus on quality, not quantity (Smith et al., 2009). Participants were eligible to engage in

this study if (a) they were more than 18 years of age, (b) they had a diagnosis of HIV, (c) they arrived to Canada as a refugee, (d) they could communicate in English, and (e) they experienced a pregnancy within the last five years. In this study, a refugee was defined as

> a person who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country. (UNHCR, 2015)

The sample for this study consisted of four women. A pseudonym was assigned to each participant to make these stories more personal and at the same time, to protect confidentiality. It is important to note that participants defined the experience of pregnancy as the period of time between learning about confirmation of the pregnancy up to and including the post-partum period (often referred to as the pueperium). Pueperium is usually defined as a 6-week period, but for this study we will extend it up to 12 months to reflect how participants talked about their experience of pregnancy, as an experience that continued after the baby was born and during the time they were adapting to being a new mother as well as living with HIV in a new country.

4.6 Data Collection

Interviewing is the primary data collection tool used in interpretive phenomenology (Smith et al., 2009; van Manen, 1990). For the purpose of this study, a face-to-face, semi-structured interview was conducted with each participant. The researcher made every effort to accommodate the participant's choice of interview location, with close attention paid to both participant and researcher safety. All the participants chose their home as the site for the interview. Each interview lasted between 45 minutes to 60 minutes. Three interviews were conducted in English. One interview was conducted in English and simultaneously translated from French to English by the researcher's supervisor who took part in the full interview.

Prior to the interview, the researcher explained the nature of the study and gave the participants time to ask any questions. Participants were informed about their right to withdraw at any time, as well as their right to refuse to answer any particular question. Privacy and

confidentiality were emphasized. Before beginning the interview, each participant completed a socio-demographic questionnaire (see Appendix D) and was provided with a list of resources in case they required extra support after the interview was over. Additionally, every participant was provided with a $40 compensation for their participation in the study. After completing the consent process described above, each participant was asked to describe their own experience of being pregnant while living with HIV and being new to Canada. The researcher began each interview by making the following comment, and proceeded with the interview guide (see Appendix E):

> I'm interested in knowing what it is like to be pregnant, while having HIV and also being new to Canada. I'm particularly interested in your experience. So, maybe if you could begin by thinking back, to a time that stands out for you, when you think about what it is like to be pregnant and have HIV.

All but one of the interviews were audio-recorded. For the participant who did not want to be audio-recorded, notes were taken by the researcher during the interview. The researcher transcribed all of the interviews, excepting the interview that was simultaneously translated. This interview was transcribed by a bilingual transcriptionist to capture both French and English parts of the interview. Each transcription was verified to ensure accuracy with the audio file prior to the analysis.

Throughout the data collection process, field notes were taken after each interview. As noted by Patton (2002), insights and interpretations described in field notes begin the process of analysis. Patton (2002) also noted that the interval period after the interview is critical to the rigor and validity of qualitative inquiry, and should include descriptive observations of what the physical stetting was like and what social interactions occurred. For this reason, the researcher for the most part completed field notes as soon as possible following the termination of the interview. These field notes included observations and annotations about the physical location (both inside and outside), about who was present at the interview, how the participants

presented themselves, the seating of participants and researcher, as well as insights, feelings and reflections that the researcher formulated as part of the interview process.

Throughout the research project, the researcher used a journal of reflections to keep an audit trail of methodological decisions, emerging ideas, experiences in the field, and items to consider for the analysis. In this journal, the researcher documented one particular experience that was revealing of the sensitive nature of the research topic. During a meeting at a community-based organization, a nurse told the researcher that a woman who heard about the objective of the study reacted by saying, “Oh, I don’t want to talk about that [pregnancy]!” This information collected in the field proved to be very helpful to understand the challenges many women face when asked to talk about their pregnancy (ies), and to reflect on the reasons why some women were not willing or able to speak about that experience in the context of the study.

4.7 Data Analysis

The analysis of this study included two separate yet complementary dimensions. First, a phenomenological analysis was conducted and led to a set of themes (and sub-themes) that summarize the lived experience of the participants. Second, an intersectional analysis was undertaken to look at this experience from a micro, meso and macro perspective. The two analyses together provide a fuller exploration of the experience of pregnancy among HIV-positive refugee women.

4.7.1 Phenomenological analysis

The fundamental nature of interpretive phenomenological analysis lies in its analytic focus that directs attention towards the participants’ efforts to make sense of their experiences (Smith et al., 2009). According to Smith and colleagues (2009), this is a set of common processes that moves from the particular to the shared and from the descriptive to the interpretative. Through this dynamic and fluid process, the researcher uncovers common meanings and describes shared practices (Polit & Beck, 2008). The goal is convergence of the participant’s generated data with the researcher’s understanding of the phenomenon being studied (Draucker, 1999). In

this study, the goal was the convergence of the participants' and the researcher's understandings of the experience of pregnancy.

A key tenet of interpretive phenomenological analysis is its iterative nature, with movement back and forth between different ways of thinking about the data (Smith et al., 2009). The hermeneutic circle is a useful way of understanding this process. It is concerned with the dynamic relationship between the part and the whole, such that, to understand any given part, one looks to the whole, and to understand the whole, one looks to the parts. This illustrates the continuous, non-linear style and inherent circularity in interpretative phenomenological analysis. As one moves back and forth throughout that analysis, one's relationship to the data shifts according to the hermeneutic circle. Engagement into the meaning of the text can be made at a number of different levels, all of which relate to one another, and many of which provide different perspectives on the part-whole unity of the text (Smith et al., 2009).

The following paragraphs will provide a detailed account of the phenomenological analysis. The process is described as follows. First, it entailed a reading and re-reading of data that included each interview and field notes. Second, initial coding was done. Next, emergent themes were developed. Each interview was like a new case, such that the above process was repeated for each interview. Finally, the researcher looked for patterns across themes in order to conceptualize the "whole" lived experience of the phenomena.

Reading and re-reading: In line with Smith and colleagues (2009), the first step of the interpretive phenomenological analysis involved the researcher becoming immersed in the data. Liamputtong (2009) also supported this approach in an attempt to understand what data has been collected. Smith and colleagues (2009) have also recommended listening to the audio-recording at least once while reading the transcripts, so that the researcher is able to imagine the voice of the participant during subsequent readings. In this study, the researcher transcribed all of the interviews except for one, allowing for a complex engagement with the data. The aim during this first stage was to ensure that the participant became the focus of analysis. Once the

interviews were transcribed, the researcher furthered the analysis by reading the text in its entirety, thereby entering the participant's world by actively engaging with the data.

As recommended by Smith and colleagues (2009), repeated reading allowed a model of the overall interview structure to develop, and permitted the researcher to gain an understanding of how narratives connected particular segments of the interview together. The chronological accounts that provided the framework of an interview made it possible to discover patterns that highlighted the particular rather than the generic, and made it possible to locate richer, more detailed sections. This was also recognized by Smith and colleagues (2009), who found that interviews often begin with broad and general information, moving to specific micro-details of events (towards the middle), and ending with some kind of synthesis or "wrapping up." Thus, the first step towards analysis in this study was to read the transcript as an individual whole in order to gain an understanding of the woman, her life and her situation.

Initial coding: According to Smith and colleagues (2009), this part of the analysis looks into semantic content and language use in the transcripts at a very exploratory level. They assert that attention to language provides insight into the ways content and meanings are presented. During this phase of the current study, the researcher noted anything of interest within the transcript, enabling the researcher to become more familiar with the participant's thinking on certain issues. In accordance with Smith and colleagues (2009), the aim during this part of the analysis was to produce a comprehensive and detailed set of notes and comments on the data. This initial, exploratory commentary looked at the experiences the participant described as well as the language used to describe these experiences. The descriptions provided an account of processes, relationships, and places that mattered most to the participant. Smith and colleagues (2009) made note of how it is important to attend to any use of metaphor at this stage, as well as to pronoun use and to laughter. What was noted at this stage in the current study was the repeated us of emphasis on feeling verbs such as "worry," "happy"

and “scared.” Participants also avoided using the word “HIV”. Instead, HIV was referred to as “having it” or “the diagnosis.”

The third level of initial note taking is more interpretative and deals with the transcript data at the conceptual level (Smith et al., 2009). The interpretation developed at this stage draws on the researcher’s own experiential and/or professional knowledge, a type of Gadamerian dialogue between the researcher’s pre-understandings and the newly emerging understandings of the participant’s world (Smith et al., 2009). Here, note was made of such phrases as “they find out” or “happy/worried.” Conceptual annotation at this stage in analysis is about the opening up of a range of provisional meanings (Smith et al., 2009). An example of this is the range of possible meanings that were formulated from the first interview, including “belonging,” “rebirth” and “new beginning,” as well as “keeping it hidden.” According to Smith and colleagues (2009), although initial notes may feel very loose, open and contingent, comprehensive, initial note taking retains a strong link to the original transcript and, if done well, facilitates the next stage in data analysis.

Developing emergent themes: Both the transcript and the initial note taking comprised the data set during this stage of the analysis. The task here was to begin to map the interrelationships, connections and patterns between exploratory notes (Smith et al., 2009). Attride-Stirling (2001) also recommends that the way to uncover themes is by extraction from coded sections. Here, there is an analytic shift that focuses attention on the exploratory comments that are particular to a specific section of the transcript, along with a global recall of what was learned throughout the entire process of initial coding. This process involves breaking up the narrative flow of the transcript, and represents a manifestation of the hermeneutic circle. The original whole of the interview becomes a set of parts as the analysis is conducted, only to be re-connected in a new whole at the end of the analysis in the write-up (Smith et al., 2009). Thus, this stage of the analysis had the effect of temporarily taking the researcher away from the participant. It was important to recall that, as the researcher, I was instrumentally involved in

the lived experience of the participant as part of the research process. As such, the resulting analysis was a product that was a collaborative effort of both parties (Smith et al., 2009).

Preliminary themes were derived from notes by producing a concise statement of what was relevant in the comments and from initial coding that was attached to the manuscript. As suggested by Smith and colleagues (2009), comments and codes were selected that spoke to the psychological essence of that part of the transcript. The aim was for these portrayals to exemplify concrete particularity, as well as conceptual abstraction (Smith et al., 2009). The selected emergent themes reflected not only the participant's original words and thoughts but also the researcher's interpretation, which resulted in synergy of description and interpretation. Examples of emergent themes were "making up stories" and "disconnected." In line with Smith and colleagues (2009), such themes are meant to draw together understandings that relate unequivocally to both the participant and the researcher.

Searching for connections across emergent themes: As recommended by Smith and colleagues (2009), the next step in the analysis involved charting or mapping how the themes fit together. What was noticed during this part of the analysis was that not all emergent themes were incorporated; what was retained depended upon the overall research question and its breadth. The aim was to discover a way of bringing together emergent themes in order to produce a structure that drew attention to the most significant aspects of the participant's account.

Several methods were utilized to uncover patterns and connections between emergent themes. Abstraction involved developing a sense of what can be called a "super-ordinate" theme, bringing together "like with like," and developing a new name for the cluster. When groupings such as "here and there" were abstracted to "being in–between" is an example of this. The super-ordinate theme appears at a higher level as a result of putting themes together (Smith et al., 2009). Subsumption is similar to abstraction, but differs in that an emergent theme automatically assumes a super-ordinate status in its ability to organize other related themes. An

example of this was the eventual theme of “making up stories” that was prevalent throughout the interviews and organized other themes. Using polarization transcripts were scrutinized for their differences as opposed to similarity. By contextualizing, the researcher identified thematic elements that were representative of temporal and cultural aspects. Numeration was useful to make note of the frequency of a theme, and it provided insight regarding its relative importance. Thus, in this analysis, the researcher utilized a number of tactics in order to reveal prototypes as well as relationships between emergent themes.

Moving to the next case: In phenomenological analysis, it is important to treat the next case on its own terms and to do justice to its own individuality (Smith et al., 2009). It is inevitable that the researcher will be influenced by what had been discovered in the previous analysis. To use hermeneutic terminology, the researcher’s “fore-structures” will have changed. However, interpretive phenomenological analysis must allow new themes to emerge with each case. In this study, the researcher began the analysis after each new interview through the process of transcription, but this also occurred when the researcher wrote field notes. For each interview, the researcher repeated steps one to four, as above, intending to treat each new case as its “own,” while, at the same time, being cognizant of changes in preconceptions.

Looking for patterns across cases: In this level of analysis, the researcher posed several questions in order to discover the patterns and connections that emerged from each of the individual interview transcripts: What were the associations across cases? How did a theme in one case relate to a theme in a different case? Which themes were most compelling? In accordance with Smith and colleagues (2009), the final set of themes sought to capture the participants’ most vital representations in a manner that was truly reflective of their experience.

The goal during this stage of analysis is to move to a deeper level of interpretation, moving from the whole to a more meaningful understanding of the parts (Smith et al., 2009). The discovery of a constitutive pattern forms the highest level of hermeneutic analysis (Draucker, 1999). This pattern expresses the relationship among relational themes, and is

present in all the texts or interviews. It gives actual content or style to one's self-understanding or one's way of being in the world. In this study, the search and discovery of a constitutive pattern uncovered the way that the experience of pregnancy among HIV-positive refugee women shaped their lives and personal meanings. Final stages of the analysis included an iterative examination of texts, field notes and writing in an attempt to identify crucial responses and suggestions that were relevant to the final draft. Draucker (1999) has highlighted that reflection regarding social forces may be particularly important to interpretation. Such was the case in this analysis. As a result, an intersectional analysis was also undertaken in order to bring to light those social forces that affected the pregnancy experience of HIV-positive refugee women.

4.7.2 Intersectional analysis

O'Mahony and Donnelly (2007) argue that, to respond to the needs of refugee women, nurses must be able to recognize the complexity of their individual experiences and to acquire a more meaningful understanding of the social, cultural, economic, and political aspects of their lives and their subsequent health effects. For this reason, an intersectional analysis was conducted in order to better understand the experiences of pregnant, HIV-positive refugee women and the impact of these experiences on their health and well-being. Drawing on the work of Guruge and Khanlou (2004), and Chulach and Gagnon (2013), the researcher explored the individual stories of the participants to examine their identity influences (micro-level analysis), their social locations and social relations (meso-level analysis), and the complex historical, political, cultural, and socioeconomic factors that impact their access to equitable and quality health care (macro-level analysis). In keeping with Guruge and Khanlou, this three-level analysis operationalized intersectionality and provided a structure with which to examine the complex issues of participants at the intersections of gender, refugeeness, HIV, and pregnancy.

Intersectional analysis considers the social location of women. It critically examines the various influences of oppression and privilege (self and other), acknowledging that identity

categories are unstable, dependent, relational, and inseparable (Shields, 2008). It also takes into consideration that social processes involved in the construction of identity vary according to time and place (Weber & Parra-Medina, 2003). By taking a closer look at the everyday life and social practices of women, intersectional analysis directs us to explore the construction of identities, as well as the structures, standards, and customs these identities draw on. Important questions to be addressed in relation to women's health are as follows: Which identity categories do women relate to? Which customs, values, and belief systems affect them? How do women formulate and navigate different social identities in ways that maintain (or not) their health? Which contexts support their health and identities, and which intersections place them at a disadvantage? Are there additional factors that have multiplicative negative effects on the health and well-being of women, and so forth (Hulko, 2009)?

At its most basic level, intersectional analysis draws attention to the interactions between identity categories and how these categories influence the way women define themselves and are defined by others (Oleksy, 2011). At its most complex level, however, it moves the focus of the analysis beyond the person to see broader issues (such as access to health care), and considers other aspects that shape individual's lives (such as family relations, social networks and communities, relationships, etc.) (Guruge & Khanlou, 2004).

For the purposes of this analysis, the researcher focused on the micro-level processes that included the participants' identity as a mother, as a refugee woman, and as an HIV-positive woman. Meso-level analysis examined informal and formal social networks that are closely linked to the experience of pregnant, HIV-positive refugee women. As part of this analysis, and in line with Guruge and Khanlou (2004), pregnancy is seen in a framework of interactions with others—interactions with family members, relatives, community members, health care providers, and with other social networks (school, neighbourhood, workplace, etc.). This type of analysis allows us to examine the relational processes that are inherent in understanding the experience of pregnancy for HIV-positive refugee women. Macro-level analysis critically

examines the structures, organizations, and policies that affect the experience of pregnancy for HIV-positive refugee women. This type of analysis looked at the access to health care services as well as the effect of policies that impacted the experiences of the participants while they were pregnant. Two policies in particular affected the experiences of participants. These were the HIV mandatory testing policy and the Interim Federal Health program. The analysis of these two policies at the macro level provided a more complex and nuanced understanding of the experience of pregnancy for HIV-positive refugee women.

4.8 Ethics

The following sections summarize the ethical considerations of the study, including the position of the researcher, the consent process, the ethical dimensions (confidentiality and anonymity, equal and fair participation, support), and the ethical approval of the project.

4.8.1 Position of the researcher

As a Nurse Practitioner working within a tertiary care centre HIV clinic, I witnessed the complexities of care among refugee women and how these complexities intensified during pregnancy. I began to wonder if the needs of the women were truly understood. I wondered if the health delivery system that they were entering as potential mothers, patients, refugees and women was particularly attentive to their needs. In undertaking this study, my aim was to increase understanding of the multiple realities that confronted pregnant refugee women with HIV, and in so doing, to increase my ability to advocate for their care at the personal, institutional, community and societal level. As a White nurse having more than 25 years experience, I embarked on this research journey knowing that I must be continually reflexive regarding the privilege and power afforded to me as a result of my professional, educational, economic and Caucasian status. Using a post-colonial framework to guide this project kept me “in check” as a researcher, and allowed me to deepen my appreciation for what this framework allows us to do as nurses.

4.8.2 Consent process

Consent was obtained from participants prior to conducting the research. The aim of the consent was that it be free, voluntary and ongoing. This means that individuals who consented were choosing to participate in the research process according to their own values, preferences and wishes (Tri-Council policy statement, 2010). Every effort was made for this process to begin at recruitment and to carry on throughout the research process to the end of the participants' involvement in the project. How, when and where participants were contacted, and who engaged with them were important facets in guaranteeing voluntariness (Tri-Council policy statement, 2010). To uphold the condition of voluntariness, participants were free to remove their consent to participate in the research at any time, without any obligation to disclose their reason for doing so (Tri-Council policy statement, 2010).

The researcher provided potential participants with all necessary information to facilitate their ability to arrive at an informed decision to participate in the research process. This included the stipulation that they were being invited to participate, a statement outlining the purpose of the research, the identity of the researcher, the funder or sponsor, a description of research procedures, and the expected duration and nature of participation along with clarification of the responsibilities of the participant (Tri-Council policy statement, 2010). Potential participants were given adequate time to absorb the information and to put forward any questions or concerns with reference to their participation. Participants were also provided with a reasonable explanation of the efforts and channels that would be utilized to advance societal knowledge through the publication and distribution of results (Tri-Council policy statement, 2010).

Participants engaged in the research only after providing their consent and signing the consent form (see Appendix F). This validated that their participation was based on evaluation of the risks and potential benefits of the research (Tri-Council policy statement, 2010). Evidence of consent was documented in a signed form, and in the case of one person, audio consent was received. Participants were offered a copy of the information explained in the consent process.

In this study, one of the participants chose not to retain a copy of the consent form. This document provided participants with written agreement of their engagement in the research process. It gave them access to the terms of the research project, allowing them to consider and reconsider these terms at any time during the research process (Tri-Council policy statement, 2010). Women were assured that there would be no negative consequences if they decided not to participate in the study. Once an interview began, they also were made aware that they could stop the process at any time. They were also informed that they did not have to disclose anything that made them feel uncomfortable.

4.8.3 Confidentiality and anonymity

In keeping with the ethical practices recommended by Polit and Beck (2008), information participants provided was not made accessible to others and was not publicly reported in a manner that identified them. The information provided to the researcher by participants was not shared with others. Throughout the research process, all identifying information was kept in a locked file and no identifying information was entered into computer files. As per Polit and Beck (2008), all identifying information will be destroyed as quickly as is practical.

To ensure confidentiality, any contact information obtained during the interview process was destroyed immediately after the interview, and unique, alpha-numerical codes were randomly assigned to participants. These codes replaced names on the audio files and in the transcripts. Only the researcher and the supervisors, Dr. Dave Holmes and Dr. Marilou Gagnon, had access to the files that contain the names of participants (i.e., consent forms). Any identifying information (places, names, etc.) that might be mentioned during the interview will be automatically removed from the transcripts by the researcher.

Anonymity is the most secure means of protecting confidentiality and is best achieved when researchers cannot associate participants with their data (Polit & Beck, 2008). Given that anonymity is almost never possible in qualitative studies, additional confidentiality measures were implemented (Polit & Beck, 2008). Since there was a small sample size, extra precautions

were taken to safeguard the identities of individuals. This included the use of pseudonyms. Morse (2007) has suggested that, if a participant wants their name used, they may sign a release to have their name associated with the data. In this study, no participant chose to have their real name utilized, and they were re-assured by the efforts directed towards confidentiality. In addition, as recommended by Polit & Beck (2008), anonymity was further ensured by using general descriptions and by slightly altering identifying information when deemed necessary. Individual and institutional privacy was enhanced by avoiding specific details about the setting of the study.

4.8.4 Equal and fair participation

Fairness and equity in research participation insures that participants will not be excluded on the basis of any attributes such as culture, language, religion, race, disability, ethnicity and linguistic proficiency (Tri-Council policy statement, 2010). The researcher in the current study was English-speaking and unilingual. Prior to the beginning of the study, and in the event that a French-speaking woman wished to engage in the research process, provision was made to either utilize a translator, or to engage a francophone research assistant who would be able to conduct the interview. In this particular case, one participant wanted her interview to be conducted in French. Accommodations were made to maintain inclusivity of this client by utilizing French language translation.

Throughout history women have unjustly and erroneously been prohibited from participating in some forms of research (Tri-Council policy statement, 2010). The inclusion of women in this research project advances the commitment to justice and contributes to the advancement of knowledge so that both men and women may benefit from research. Women should not be inappropriately excluded from research solely on the basis of their reproductive capacity, or because they are pregnant or breast-feeding (Tri-Council policy statement, 2010). This study was directed at uncovering a phenomenon that is inclusive of pregnancy. Thus, including participants in the research process promotes the principle of fairness and equity in

research. At the same time it recognized that pregnant women may be considered a vulnerable group, worthy of special attention that ensured minimal risk to the woman and the fetus.

4.8.5 Availability of resources

The researcher recognized that pregnant women, refugee women and women with HIV qualify as vulnerable groups (Polit & Beck, 2008), and that medical/emergency care had priority over research activities (Morse, 2007). A list of available resources (Appendix G) was made available to women if they desired it. In addition, all of the women were engaged in ongoing care at a clinic.

4.8.6. Ethical approbation process

Written ethics approval was obtained from the University of Ottawa Research Ethics Board (REB) (see Appendix H) and The Ottawa Hospital REB (see Appendix I). This ethics approval continued throughout the life of the project. During the research process, the researcher was aware of the need for timely reporting to the REBs of any unanticipated issues that could increase the level of risk to participants, or of any other ethical implications. However, the researcher is pleased to report that no issue had to be raised, and the study was conducted as originally planned. It is important to point out that the researcher requested an extension of the REB to ensure inclusivity of possible participants throughout the recruitment period.

4.6 Rigor

Ensuring rigor was handled according to the criteria as described by Whittemore, Chase and Mandle (2001). These researchers identified primary criteria (credibility, authenticity, criticality and integrity) as well as secondary criteria (explicitness, vividness, creativity, thoroughness, congruence, and sensitivity) (Whittemore et al., 2001). The primary criteria focus on those aspects that are important for all qualitative inquiry, while secondary criteria allow for flexibility and creativity in the research process by encompassing criteria that are particularly suited to that method of inquiry. The following sections will provide an overview of these criteria and how

they were used in the context of this study. It is important to point out that these criteria were adapted to meet the design of the study and the epistemological position of the researcher.

4.9.1 Primary criteria

Whittemore and colleagues (2001) identify four primary criteria:

Credibility is the effort to establish confidence in an accurate interpretation of the meaning of the data. Throughout the analysis, the researcher constantly engaged in a reflexive dialogue to ensure credible results. Reflective questions included: Do the results reflect the experience and context of the participants? Do the explanation and interpretation fit the description? Credibility is also enhanced through researcher self-awareness (Koch, 1994). As suggested by Koch (1994), keeping a journal in which the content and process of interactions is detailed provides material for reflection to enhance self-awareness. Such was the case in this study, where the researcher recorded feelings about each interview, insights obtained, as well as what appeared to be most significant to the participant.

Authenticity is the ability of the research to reflect the meanings and experiences as lived and perceived by the participants (Sandelowski, 1986). Specifically, authenticity allows the multiple voices and realities in an interpretive inquiry to shine through, illuminating the person, phenomenon and situation (Whittemore et al., 2001). As suggested by Lincoln (1995), the best way for the researcher to achieve this is through mindful attention to the researcher's prior understandings and influences, along with an astute awareness of the subtle differences in the voices of participants (Whittemore et al., 2001). In line with both of these recommendations, the researcher noted in the field notes and reflective journal the particularities expressed by each participant. The researcher also engaged in thoughtful reflection about previous knowledge and assumptions that might have been formulated from previous professional experience or literature reviews.

Criticality is achieved through reflexivity, open inquiry and critical analysis of all aspects of the inquiry. Attention to alternate interpretations, and recognition of uncertainties all assist in

maintaining criticality. In line with this, the researcher considered alternative interpretations and themes while doing the analysis. As suggested by Whittemore and colleagues (2001), the researcher worked to show evidence of critical appraisal throughout the entire project.

Integrity is achieved if investigators are self-critical, with recursive and repetitive checks at each stage of the inquiry (Whittemore et al., 2001). This is best maintained by close attention to the scientific process of inquiry in conjunction with humility during the presentation of findings (Whittemore et al, 2001). The researcher was cognizant of her novice status as a researcher, and consulted with an experienced qualitative researcher (thesis supervisor) throughout the project. In addition, the literature was consulted wherever possible when questions arose regarding methodology. The researcher recognized the subjective nature of the interpretive process, and for that reason, every effort was made to base the interpretation in the data, recognizing both discrepant and alternate findings, in order to lead to illuminations and understandings that were responsible, upright and forthright.

4.9.2 Secondary criteria

Whittemore and colleagues (2001) identify six secondary criteria:

Explicitness is demonstrated by detailing the interpretive effort of the investigator. It refers to the ability to follow the interpretive effort of the investigator (Whittemore et al., 2001). As recommended by Whittemore and colleagues (2001), this was achieved by use of an audit trail that consistently and conscientiously documented methodological decisions, interpretations, investigator bias and representation of results. In line with Sandelowski (1986), this explicit presentation of results provides evidence and support for inferences and conclusions drawn by the investigator. As a result, research judgements were made available.

Vividness is demonstrated by the use of thick, rich and authentic descriptions that articulate clear and striking themes (Whittemore et al., 2001). In line with Whittemore and colleagues (2001) and with Sandelowski (1986), the researcher endeavoured to do this artfully, and with imagination and clarity in order to portray the fundamental nature of the phenomenon.

Quotes and descriptions were chosen to evoke a sense of the phenomenon and to make visible new meanings and understandings. In addition, quotes that reflected the participants' voices, feelings and actions were selected in order to evoke emotionality and self-feelings from the reader.

Creativity is demonstrated through flexibility within the inquiry process as well as through imaginative ways of organizing, presenting and analyzing data (Whittemore et al., 2001). Flexibility was incorporated when adaptations had to be made in sampling and data collection. An example of this was when accommodations were made for the participant who spoke only French, even though the researcher was unilingual. The researcher adopted a flexible approach in order to ensure inclusivity. Van Manen (1990) has recommended an eclectic approach to both analyzing and writing a research study. Imagination in analyzing the data was achieved in this study by the addition of an intersectional analysis that was able to shed additional light on the experience of participants, and to provide further understanding of their experience. This analysis was also useful in structuring the final chapter of the research study and the organization of the discussion.

Thoroughness is achieved when there is adequate sampling and data collection, comprehensive analysis, and connection between themes that illustrate full development of ideas so that the full scope of the phenomenon is explored (Whittemore et al., 2001). Throughout the project, the researcher maintained an orientation toward the research questions and objectives. The intersectional analysis and phenomenological analysis provided a meticulous inquiry so that the wide-spread influences on the phenomenon could be demonstrated at micro, meso and macro levels. As suggested by Whittemore and colleagues (2001), the researcher questioned, Do the findings fully present a complete and plausible exploration to the research question?

Congruence is evidenced by connection between the research question, method and findings (Whittemore et al., 2001). In this study, congruence was demonstrated by linking the

research question, which focuses on “lived experience,” with the interpretive phenomenological methodology that leads to enhanced understanding. Congruence is also achieved when there is a clear relationship between previous studies and the current study (Whittemore et al, 2001). This study is novel in that it addresses the lived experience of pregnancy among HIV-positive women in the Canadian context, but it is linked to other studies within Canada that have looked at the health of refugees or vertical transmission of HIV (Beiser, 2005; 0’Bryan, Jadvji, Kim & Gill, 2011). Interviewing was in line with the philosophical and methodological traditions on which the study is based, and worked well with the data analysis method that is interpretive in nature. A critical lens applied to the interpretive phenomenological approach establishes the connection between methodology and the theoretical stance, and allows for an in-depth exploration of the interpretation, an important element in congruence (Burns, 1989).

Sensitivity is attention to the human, cultural and social context of the research (Whittemore et al., 2001). Prior to conducting interviews with a participant, the researcher attempted to sensitize herself to the some of the possible historical, political and cultural contexts of the interviewee. This was also done as the research process evolved. During the study, the researcher made note of literature that described the experiences of participants in their home countries. This was undertaken with attention to the experiences of stigma, HIV and childbearing that were integral influences throughout the study. A post-colonial framework assisted in theorizing the concept of culture in ways that took into account history, politics, and economics that are inherent in any cultural representation (Mohammed, 2006). The researcher was mindful of her representation as a researcher. Every effort was made to engage with participants as a learner, in the hopes of dispelling any association with a colonial culture. By listening to participants from a variety of geographical, cultural and religious backgrounds, the researcher was able to honour multiple voices and perspectives, another way of affirming sensitivity. According to Whittemore and colleagues (2001), ensuring that the research benefits the community helps to maintain respect and concern for human dignity. It is my hope that

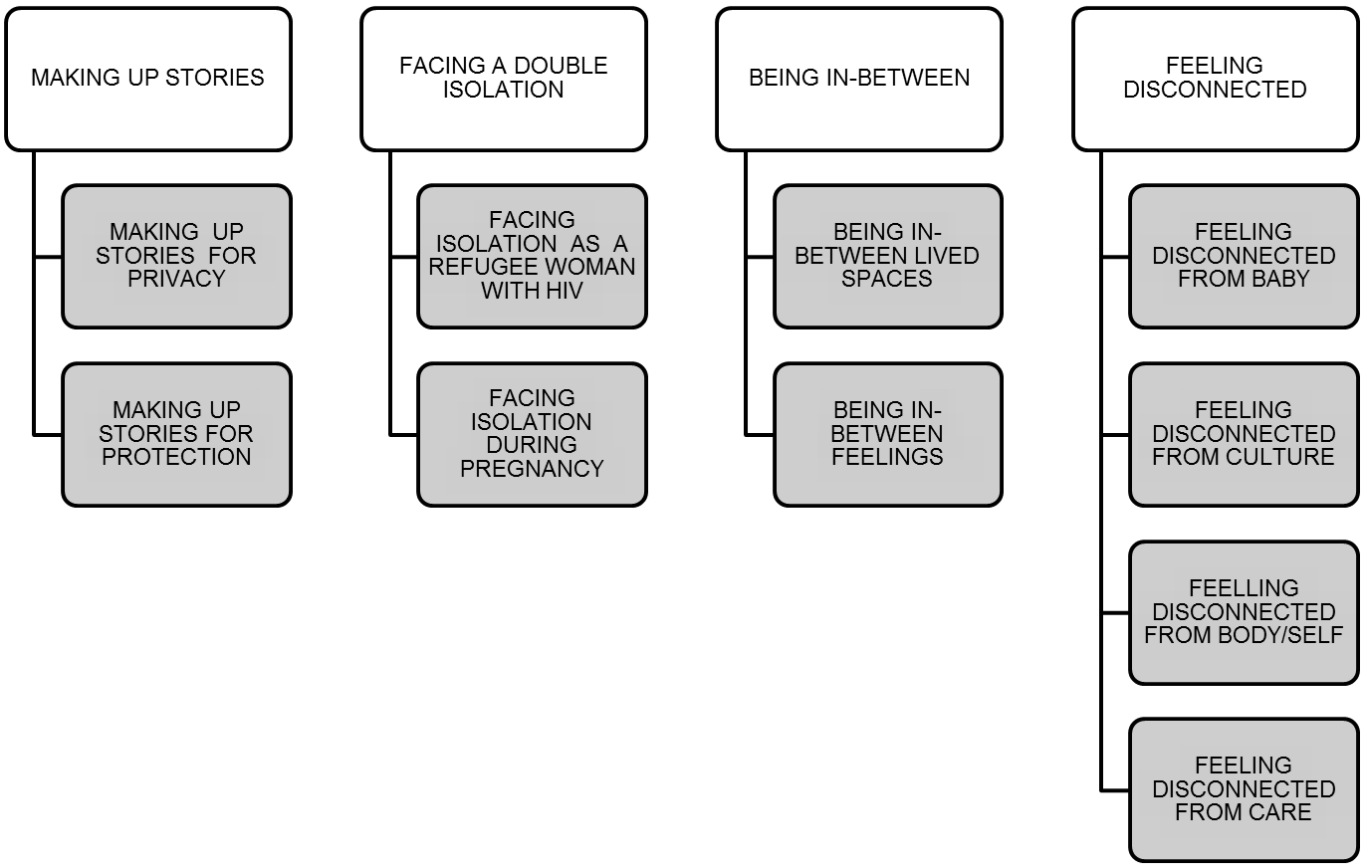
results of this research may assist health care providers to engage with pregnant HIV-positive refugee women at a more healing level.

CHAPTER FIVE

RESEARCH FINDINGS: PHENOMENOLOGICAL ANALYSIS

Attending to the individual stories gathered for this study, the findings presented in the following sections will provide an in-depth understanding of the experience of pregnancy from the standpoint of refugee women who are HIV-positive. During the analysis, four main themes and a number of sub-themes surfaced. These are outlined in Figure 2.

Figure 2. Overview of research findings



5.1 Making up Stories

The theme, “making up stories” emerged almost immediately during the analysis when participants discussed their experience during pregnancy, the factors that influenced it, and how the experience changed over time. It became especially evident as a dominant theme when participants were asked to think back to a particular time in their pregnancy that stood out as being difficult or negative. This theme was so prevalent that sometimes they explicitly stated that they had to “make up a story,” while at other times, it was referred to as “having to lie” or “make things up”. The theme “making up stories” most aptly described the creative thought and narrative process that women engaged in over the course of their pregnancy. The women used these stories when they were confronted with circumstances that could lead to the disclosure of their HIV status, a disclosure that had the potential of subjecting them to feelings of shame as well as to experiences of disconnection associated with HIV-related stigma.

“Making up stories” enabled women to navigate their experience of HIV and pregnancy while encountering people from their countries of origin while in Canada. For example, when women interacted with people from their countries of origin, the theme “making up stories” occurred in response to circumstances that could arouse suspicion about the woman’s HIV status. These stories provided a plausible explanation for their actions, especially when their behavior was contrary to the expectations of their cultural and historical contexts. For example, in African countries and cultures, breastfeeding with very early mixed feeding (giving little bits of food to the baby) is widely practiced and remains the traditional and cultural norm (Buskens, Jaffe & Mkhatshwa, 2007; Doherty, Chopra, Nkonki, Jackson, & Greiner, 2006). As described by participants from these countries, feeding exclusively with formula deviates from this norm and has the potential to arouse questions or suspicions about their mothering practices and maternal health. Because it is common knowledge in African countries that HIV is a contra-indication for breastfeeding, exclusively feeding infants with formula may arouse questions or suspicions specific to the mother’s HIV status.

In general, participants disclosed that they used stories in these and other circumstances that made reference to any decision or action that could potentially reveal their HIV diagnosis. This included decisions and actions surrounding the feeding of the baby, the birth (i.e. which hospital was chosen and why), and the delivery process (i.e. admission to the hospital, pre-and post-delivery care). The theme of making up stories can be divided into two sub-themes: 1) making up stories for privacy, and 2) making up stories for protection. The following section will address the first sub-theme of making up stories for privacy, a privacy that was especially salient during the experience of pregnancy.

5.1.1 Making up stories for privacy

Women made up stories to keep their HIV status private. All of the participants originated from countries where HIV is associated with significant stigma. Fear of letting the diagnosis "out" was mentioned by the following participant:

> I am scared of "letting it out." I am terrified. People are so rude. It has been there for so long ... we still feel ashamed (Chidimma, p.19)

This quote illustrates the fear that Chidimma experiences should her HIV diagnosis become public. Her desire not to "let it out" or be known is reflected in her efforts to contain her serological status, keeping it hidden from view, confined within her body and mind. During the interview, she spoke to the need to keep her diagnosis to herself, thereby protecting her from the associated stigma, people's ignorance about the infection, and any anticipated offensive, disrespectful or jarring behaviour that could follow once her status was revealed. She also spoke to the historical and cultural nature of the interpretation of HIV as something "bad" and "shameful," attesting to its longevity and persistence in her country of origin as well as in Canada. This entrenched attitude was clearly displaced onto her own feelings and emotions, resulting in a condition of shame as she talked about her experience. For Chidimma, that feeling of shame and the need to keep her HIV status hidden, or "not letting it out," supported her decision to make up stories during her pregnancy.

Participants also made up stories to maintain their privacy around the time of the birth. They did not want their friends to know the hospital where they were going to deliver. Nor did they want anyone other than their husband and their other children to accompany them to the hospital. As part of their birthing preparations, women were instructed to present to the hospital where HIV and obstetrical specialists practiced and there was only one place that could provide these services. When friends asked why they were going to that hospital, especially if it was located far from their household, women found that they had to make up stories to explain their choice. One participant commented that this was particularly salient during the last trimester of pregnancy. She knew that she would need to have antiretroviral prophylaxis medication four hours prior to her delivery. If visitors came then, they would see that she was receiving intravenous medication, and she would risk disclosing her HIV status. At one point during the interview, she said:

> *"You have to think more...You spend a lot of energy keeping things private."* (Mageti, p.5)*

This statement illustrates how "thinking" seems to be part of the HIV-positive woman's everyday experiences in the context of pregnancy: during the time of her impending delivery, it is intensified (i.e. thinking more) to "keep things private." Women must constantly attend to everything surrounding their HIV status, considering, pondering and anticipating circumstances that might be necessary for them to navigate. "Spending a lot of energy," also illustrates the encompassing, and potentially exhausting nature of the endless anticipation and planning that the pregnant woman must undertake in order to secure privacy.

"Making up stories" is twofold: it expends energy that could be otherwise directed, while at the same time safeguarding and positively supporting the experience of pregnancy by "keeping things private" during the third trimester, labor and delivery. "Making up stories" also helps the woman to maintain an image of normalcy, and averts any questions or explanations

* The quotes of Mageti are in italics to indicate that this interview was not audio-recorded. Notes were taken.

that may have to be given surrounding unusual procedures, such as medicines that are given intravenously four hours prior to delivery.

"Making up stories," or the potential to have to make up stories, was also a notable theme that emerged from women's descriptions of visits they received in the hospital during the early post-partum phase, after the delivery. For example, one participant described a situation in which her doctor inquired about her next infectious disease appointment in front of family members. In this particular instance, the brother of the participant was visiting her in the hospital and had no knowledge of her HIV status. While her brother was in the room, the participant, conscious of her risk of involuntary disclosure, tried to signal to the doctor, not to say anything. During the research interview, she explained how she later confronted the doctor about his actions, asking him why he mentioned the infectious disease appointment in front of her brother without considering the implications this could have for her. Such incidents are illustrative that the potential to have to make up stories is ever-present in the context of pregnancy: this intensifies in health care settings when providers don't reflect on the implications of what they say and do in front of family members.

"Making up stories" was particularly relevant to the issues surrounding breastfeeding. All of the women came from cultural contexts where breastfeeding is the expected and normal way of feeding a newborn baby (For references on this particular topic, see Maman et al., 2012; Greene et al., 2014; and Tuthill, McGrath & Young, 2014.) Since breastfeeding is the accepted cultural norm, formula feeding may be interpreted by family members and community members as an indicator of a woman's HIV status (Doherty et al., 2006). The story of "why they were not breastfeeding" was especially dominant throughout the interviews. Participants explained that women who do not breastfeed are questioned by other women in their community. They then need to create stories to justify why they are not giving breast milk to their baby. As one participant mentioned, women have to "make things up." Another participant made up this story:

> *I breastfeed only at night, and give formula during the day" and "Breastfeeding is hard on me.* (Mageti, p.3)

By stating that she only breastfed during the night, Mageti was able to normalize her feeding practices and maintain the cultural expectation around breastfeeding. As such, she was able to provide a credible explanation (i.e. breastfeeding is hard on her) to justify her choice of limiting the breastfeeding to night time and using formula during the day. This explanation was considered necessary for her to meet the cultural expectation reinforced by women in her community, while at the same time allowed her to maintain her privacy and to avoid disclosing the real reason for her choosing not to breastfeed.

Both at home and in their communities, women encountered the need to make up stories. While women were in the community, many friends would comment on their decision not to breastfeed saying:

> *... You are not nice ... You don't give her your body ... You don't breastfeed her...* (Mageti, p.3)

The church was another communal location where women often found they had to make up stories. The following quote illustrates this clearly:

> Even at Church ... We go ... We have a room where you can breastfeed ...You find 3 or 4 moms who are breastfeeding ... Just women … (Chidimma, p.9)

That the Church had a room dedicated to breastfeeding was a reminder of the cultural significance of this feeding practice and what is considered "normal" behaviour for new mothers. Being in that space with other mothers was particularly unsupportive for the participants who could not breastfeed because of their HIV status. It also exposed them to the scrutiny of other people in their community. Chidimma felt stressed and fearful when she could not breastfeed within the confines of that space:

> Oh my God ... I was ... In my mind ... Everybody was looking at me ... Every time I'm giving the bottle ... You know ... I was ... Back in my mind ... I was scared ... Maybe I don't know what they are thinking ... (Chidimma, p.9)

Chidimma's words also reveal her hypervigilance about what others might think of her practice of bottle-feeding, and how those thoughts have the potential to "out" her as a woman living with HIV.

While in their homes, women received comments about breastfeeding from their immediate family members, including their children, as well as from friends who came to visit. One participant states that she needed to make up a story when her son asked: "*Mom, why don't you breastfeed? ... You do not like her*?" (Mageti, p.3) This sort of questioning illustrates how the expectation to breastfeed exists in the private, domestic space of women living with HIV, thus, creating the need to make up stories even for those closest to her, people she should be able to rely on for support. During the interview, Mageti explained that her son did not know about her serological status at the time because she felt he was too young to know that she was HIV positive. However, based on his observation of Mageti's formula feeding her infant, the boy was nevertheless alarmed that something was wrong with the way his mother was acting or feeling toward the baby. This is a potent illustration of how formula feeding is viewed as something "'out of the norm," resulting in questions or suspicions even from family members. It also suggests that the need to "make up stories" in the community settings extends into the family units of women living with HIV and homes of women living with HIV. This was clearly explained by Chidimma when she described her experience of friends visiting her home following the birth of her baby.

> I remember I had a best friend ... Every time she come for a visit ... She would say "breastfeed the baby" ... I'd say "No" ... I don't like her to breastfeed during the day because I'm looking at daycare for her ... I want her to be used to the bottle ...Yeah ... At night ... I am ok ... But during the day, I just give her the bottle" ... So ... Sometime I find myself in the position where I am lying ... I'm not telling the truth, but I have to ... So that ... I don't want a lot of questions ... For them to ask a lot of questions … Why ... Why ... I have to lie ... It's not a good feeling ... But there's no other way ... You have to do it. They'll keep asking ... Asking ... Just to avoid all that ... Just give them short answer like "she'll be going to daycare," "I want her to use the bottle" ... That's straightforward and move on. (Chidimma, p.9)

Another participant used a straightforward and direct strategy to divert questions surrounding breast-feeding: “I would say “No” and that’s it” (Baako, p.3)

These quotes illustrate the social pressure that women living with HIV experience when they are not breastfeeding. This theme recurred throughout the interviews. Though breastfeeding was not the focus of this research, it was consistently mentioned when women described situations where they had to make up stories to ensure their HIV status remained hidden in the context of pregnancy.

5.1.2 Making up stories for protection

During the interview, women explained that they made up stories for protection as well as for privacy. The analysis revealed that “making up stories” for privacy had more to do with their status as HIV-positive women while “making up stories” for protection had more to do with their status as refugees in Canada. Women considered that it was important for them to keep their HIV status hidden. As refugee women with HIV, they feared that they might be unable to stay in Canada if immigration officials knew their HIV status. They also realized that, as newcomers, they were situated within a particular close-knit cultural community in Canada. News of their HIV status within this new community could lead to their exclusion within that community or travel back to their homelands and could inadvertently reveal their HIV status to family and friends. Making up stories for protection allowed them to stay psychologically safe. The following section of the findings is brief, but it provides additional context for why “making up stories” is something women feel they must do when they are HIV-positive refugee women who are pregnant.

During the interview, participants commented on their experience of coming to Canada as refugee claimants. They provided important information about their social location as refugee women and how this impacted their experience during pregnancy. They explained how “making up a different story” about their health when they first came to Canada was important for them to retain or regain control of their life circumstances as refugee women. For Mageti, going through

the medical examination process involved making up a different story about her HIV status to immigrate and stay in Canada. Underlying the story of Mageti is her fear of deportation should her HIV status became known to immigration officials. When her HIV status was "revealed" at the immigration medical examination, Mageti commented:

> *I told him that I couldn't tell him, because I was scared that if immigration know, they gonna take me out of this country.* (Mageti, p.2)

Although the immigration process was not the focus of this research, and not discussed by all participants, it is relevant as it speaks to the precarious situation of refugee women within the current context in Canada. It also speaks to the context in which women experience pregnancy and to their efforts to protect themselves as refugee claimants. During the analysis, it was found that making up stories for protection became necessary when HIV had the potential to alter the course of participants' lives by jeopardizing their application to Canada and dislocating them to another country.

5.2 Facing a Double Isolation

As indentified by one of the participants, women who took part in the study faced a double isolation: isolation as a refugee woman with HIV and isolation during the pregnancy. During the interviews, they described the isolation experienced as a result of their HIV status and also the isolation that was related to their journey as refugee women in their re-location to Canada. The other type of isolation that was particularly dominant within the interviews was the experience of isolation during the pregnancy. This type of isolation became especially salient since for many of the women, this was a stark contrast to what they had experienced in their countries of origin. The following section will address the first sub-theme of facing isolation as a refugee woman with HIV, and show how the two positionalities of HIV and refugee intensified their isolation.

5.2.1 Facing isolation as a refugee woman living with HIV

This study revealed that, for refugee women living with HIV, their serological status and their experience of coming to Canada as a refugee influenced their social interactions with people

and often led to a state of isolation. Women explained that their HIV status influenced interactions with members of their new communities, with individuals who had migrated from surrounding countries of origin or their country of origin, and with individuals of similar ethnic background who they encountered in various settings. In this section, the quotes illustrate how their HIV status and the influences of their immigration journey often led women to limit interactions with others, resulting in a state of isolation. Mageti's story is the first illustration of how women living with HIV who come to Canada as refugee claimants hesitate to meet new people, even when these "new" people are from similar ethnic backgrounds.

During the interview, Mageti mentioned that she was "afraid to meet people" when she first arrived in Canada. Even when directed to a support group for people living with HIV, she explained that she was "so scared." The process evolved until finally she was able to make contact with the group:

> *It took me one month to call the support worker. I was so scared. I was afraid to meet people. She gave me an appointment to see her. I told her that I couldn't go and meet her ... That I couldn't come. This happened a few times. Then I told her again, I can't come today … She told me ... You have to come today ... Tomorrow, we are having the meeting ... so I go.* (Mageti, p.2-3)

Mageti's fear of meeting new people identifies the state that women living with HIV find themselves in when they first arrive to Canada as refugee claimants. Her statement illustrates the ambivalence, fear, and concerns that other participants also experience in meeting new people, and shows how they were caught in a state of isolation when they arrived in Canada: for some, this state of isolation still described their lives at the time of the interview. Mageti finally broke out of that isolation through back-and-forth negotiations with an Aids Service Organization (ASO) worker who eventually encouraged her to "go" to the meeting. Through the persistence on behalf of the ASO worker and right timing, Mageti was finally able to reach out.

During the interview, Tulun shared the experience of having someone from her country of origin disclose her HIV status upon her arrival in Canada. As a result of this disclosure, Tulun quickly re-located to a place where she knew no one, leaving behind the little support she had

acquired in Canada, including some of her family members. Because of this betrayal of her HIV status, she did not want to make new contacts or friends in the new location. The previous experience of being “exposed” or “outed” as a woman living with HIV made her want to protect herself. In the process of protecting herself from others, she isolated herself and had little relational support at the time of the interview.

> I don’t want to have a friend ... My problem I don’t have friends ... I never call someone and say “hello” ... Or he call me and say “hello” ... Because I don’t want to have problems again ... Africa people ... If you have friends ... They also want to know your problem ... When they’re going to see ... Ah! This is HIV ... I don’t want to have this problem again ... For that ... I don’t have a friend ... No ...I don’t have a friend. (Tulun, p.9)

Tulun firmly asserts her intention to avoid friendship. The experience of having friends makes her feel vulnerable to the potential rejection that she sees would be inevitable should her HIV diagnosis be revealed. She admits that the lack of friends is a problem, which seems to create a state of dissonance: friendship is both longed for and potentially harmful. She recognizes the value of relational support within a friendship, but this is also potentially not a “safe space” because of her HIV status and her refugee status. She is unwilling to risk the combination of exposure, rejection and dislocation she experienced previously. For the time being, she has resolved this dissonance, deciding to have no friends.

The isolation that often occurred as a result of the participant’s HIV status and refugee status often took its toll on their relationships with their husbands. For some women, previous experiences of abandonment, rejection or stigma made it difficult to trust and to hope for the possibility of an enduring and long-standing relationship. For others, the isolation placed an additional burden on the marital relationship, making it necessary for them to shoulder many of the responsibilities that normally would be shared with other women in communities’ countries of origin. For example, when discussing her experience of isolation, Tulun explained that this had placed an added pressure on the relationship, often leading her to doubt the relationship’s endurance and longevity. While living in a refugee camp during her time of transit, Tulun was

abandoned by a former husband when he discovered her HIV status. The memories of that previous experience had travelled with her to Canada causing her to wonder about the living situation with her present husband, and creating a state of insecurity about her future. At the time of the interview, she was considering the possibility of leaving her husband to live, on her own with her children. The following quote illustrates her state of mind with respect to her relationship.

> ...My husband too ... For now ... I don't know ... I want to move ... I'm going to move with my kids ... and ... I live alone. (Tulun, p.9)

For Tulun and other women in her situation, relationships located at the nexus of past and present experiences with HIV, displacement and so forth were difficult to negotiate.

Women who took part in the study reported a sense of isolation because of the limited number of people–especially within their family–who knew their HIV status. One participant illustrated the situation the following way:

> *No one knows in my family. Nobody knows. My parents do not know. For them, it does not make sense to tell them. HIV means death [in my country]. It means bad things: if you have this, you are not blessed*. (Mageti, p.8)

During the interview, Mageti made special reference to her parents and explained her reasons for not telling them about her HIV status. Her story suggests that refugee women carry with them from their country of origin the stigma associated with HIV. This stigma can become part of their present day rationale for keeping the information from others, especially family members. In Mageti's country, HIV means death. Her parents, who have remained in her country of origin, have already "lost" their daughter to another place. During the interview, she explained that HIV would further intensify that loss. She also stated that HIV means "bad things" in her country of origin: HIV is associated with disobedience, and an HIV-positive person is considered disagreeable, unpleasant, unhealthy or diseased. These "bad things" are so morally objectionable, she explained, that to disclose her HIV status would leave her without reverence or honour, a state that is not blessed. She made reference to Allah during the course of the

interview, affirming her identification with the Muslim religion. Thus, not telling her parents affirms Mageti's life and keeps her blessed, even though her secret contributes to her sense of isolation.

When sharing her story, Chidimma made a similar comment:

> My family, they don't know ... They don't know. It has been 14 years ... We are positive [my husband and I] ... And they don't know ... I just ... I just don't know how to tell them ... I just don't know ... My kids don't know that we are [HIV] positive ... But I don't know how I am going to tell ... I just don't have the courage ... I don't know. (Chidimma, p.18)

Here, Chidimma refers to the fact that her family "doesn't know'. The lack of informed, supportive family was an important factor that contributed to the sense of isolation among the study participants, particularly during their pregnancies (see section 5.2.2). To be part of a family usually means that members experience a close relation with those who share common characteristics and values. The family is considered to be a unit that provides a link to one's ancestry and lineage, which in turn anchors and contributes to one's identity, representation and place in the world. Families can be a source of fellowship, a source of support and community that often acts as a buffer to the stresses incurred in day-to-day existence. The fact that women did not want their families to know, or did not know how to tell their families about their HIV status, limited the type of relationships they were able to construct with them, and caused the women to conceal a significant part of themselves. Because they had to hide part of who they were, these women did not feel they could expect the same type of recognition and understanding that one could commonly look forward to within the family network. This created a social void that was a poignant theme in their discussion of the sense of isolation they experienced around being HIV-positive and not being able to tell anyone. The result of 'keeping this secret' often exerted a heavy weight on participants:

> Sometimes I feel that it is 'too much'... Keeping it to yourself. (Chidimma, p.19)

Baako, another participant, explained how she never disclosed her HIV status, and subsequently had to shoulder all responsibilities related to her health. Her description shows

that she has been influenced by her country of origin's view of HIV which subsequently influenced her decision to keep her status to herself:

> It's hard because I've never talked about it (HIV status)...I'm like that, I have to keep my health (private)...Because people have not been open up to now...It's a sin...No one knew (Baako, p.1)

The analysis revealed that for some women, the experience of having a baby and creating their own family alleviated the sense of isolation described above:

> It's not easy ... It's good ... It's good to have a baby. Me for my experience ... Today ... I have 2 ... And if I don't have love ... I have no friend ... I don't have family ... I have my kids ... I have someone to talk to ... And it's good. (Tulun, p.21)

In cultures that are largely based on oral traditions, having "someone to talk to" is of particular significance, as reflected in Tulun's comments. Even though this participant acknowledges that having a baby "is not easy," she also highlights that "it is good" because it breaks her isolation.

In this study, the idea of children acting as a source of support and forming a new family network was mentioned by all participants. The analysis revealed that the experience of pregnancy and the arrival of a baby offered women an opportunity to restore some of the alterations in identity that had been disrupted by their HIV diagnosis, and provided a way for them to develop new family ties here in Canada. For women in this situation, becoming and being a mother became their *raison d'être* – a way to make sense of who they are and where they belong. This relieved some of the isolation they experienced while living in the intersection between HIV and refugeeness.

5.2.2 Facing isolation during pregnancy

Women experienced isolation during every stage of their pregnancy. Their husbands and possibly one friend were the only supports identified by those who took part in the study:

> [During the pregnancy], the support was only my husband ... By then ... I didn't know anybody ... Like just a few friends I met from the apartment ... I remember ... I used to have a good friend from XXX. She came sometimes ... She can keep my kids ... They can go there to play ... Apart from that ... There was nothing else ... Nothing. And it was very stressful on [the children] (…) They wanted to have

> somebody ... Like family they related to, but that was not the case so ... It was also very difficult on them. (Chidimma, p.4-5)

This illustrates the singular nature of the support available to women in the context of pregnancy. The isolation faced by women and their husbands can also impact other children in the family, as suggested by this participant who highlighted the challenges of coming to Canada as a refugee and living far from family members.

Analysis of the interviews revealed that the isolation reported by participants was somewhat alleviated during their pregnancy through a support group offered by a local ASO. One of the women commented on her experience as follows:

> *It was good to be in the company of other women living with HIV. There are women who had babies who are in the group. When someone is having a baby, it feels like everyone is having a baby. There is a lot of experience in the group. You learn ... How it is going to be with the baby.* (Mageti, p.1).

The sense of community and sharing, illustrated by the statement, “When someone is having a baby, it feels liking everyone is having a baby,” gave participants an invaluable sense of belonging and place. It was also a useful source of information, providing skill, practice and knowledge of what to expect about the experience of pregnancy from the standpoint of women living with HIV. In this rich contextual space where women not only broke the pattern of isolation, but they were also able to expand their relational supports and enhance their experiential knowledge of pregnancy, labor, delivery, location and place, resulting in invaluable insights into the processes, expectations and norms that were particular to their new context. In many ways women in the support group were thought of as providing the support that had customarily been provided by family, mother-in-law or other relatives or friends in their country of origin. The fact that their HIV status was known within the group was also significant, since many women kept their status hidden elsewhere (as described in section 5.1). This was found to alleviate the emotional isolation felt by women, like Tulun, Mageti, and Chidimma (see previous section) during their pregnancies.

In this study, the post-partum stage was considered to be the time of greatest isolation. When talking about their post-partum experience at home, participants described feeling isolated because they had no one to help them. Many of them found the pain after Caesarean very difficult to manage, and it was challenging to mobilize and take care of themselves at home. This meant that they often went without eating.

> For me it was tough ... I have no help at home ... It was tough ... I had no one ... I had no one at that time ... It was very tough. I could remain upstairs ... And I was hungry ... but I could not come downstairs ... So I just slept ... I remember I even lost 8 or 10 pounds ... Just there's no one there to give me maybe something to eat. I waited until my husband came back and fix something ... It was very tough ... Very tough ... It's like "double," you know? Double pressure ... You are going through pain and no one is there. It's too much ... Too much to take in. (Chidimma, p.7-8).

Baako echoed this description when she talked about the pain she experienced after her Caesarean section. In this particular instance, she was able to obtain medication by talking to a nurse at the hospital. While her baby was doing well, she was in need of more care and support.

> When I came home after having the baby, I was in a lot of pain but the baby was doing well. I was in a lot of pain, but I talked to a nurse and she gave me medication. The first week, I was really, really sick, but the baby was doing good. (Baako, p.3).

These descriptions illustrate the extreme difficulty that women experience when trying to cope alone with very little support during the post-partum period. Chidimma's and Baako's stories suggest that this experience can be intensified when women are recovering from a Caesarean at home and lack additional support. When she says there is "no help" at home, she speaks to the absence of support to make the transition to motherhood easier, to assist with the baby, and to alleviate some of her basic needs, like eating. Her isolation is reflected in her words "no help," no one to give assistance in order to make the situation more pleasant or bearable. Chidimma's post-partum experience was "tough" because of her isolation, but it was also "tough" because of pain caused by her Caesarean. During the interview, she described this experience as a "double pressure." She also commented on the fact that she felt overwhelmed--"too much"--

which echoed what other participants indicated when they spoke of their post-partum experience.

When women talked about their experience of feeling isolated during the post-partum stage, they explained how that feeling translated into a sense of rejection. Particularly telling is Chidimma's description:

> ... We don't have no one ... There's no one here! We need people to be there ... You know ... Just to say ... How is your day? I'm talking on behalf of other women like me because we are coming from ... We have large family members. Here it is like you are "rejected," especially if you don't have no one ... And also if it is your first child ... It's like "killing people alive" oh yes ... It's killing us alive ... Oh yes ... It's killing us alive. (Chidimma, p.14)

Chidimma highlights the stark contrast between the meanings of pregnancy where she came from and where she is now. Her culture of origin would place her within a context where pregnancy and motherhood would be supported, and the new mother would be surrounded by family members who could help with the baby. In contrast, her experience in Canada, her HIV serological status, and her refugee experience, placed her in a context where pregnancy is lived alone (i.e. you have no one) and in isolation. She experienced this as a form of rejection. The intensity of that experience is evident in Chidimma's choice of words. She used the metaphor "killing us alive" to depict a struggle between two contexts where pregnancy has very different cultural and social meanings for the participants: in one, pregnancy brings "life," but in the other, pregnancy is accompanied with a form of "social and cultural death" that results from their refugee and HIV-positive status. This type of struggle during the post-partum pregnancy period highlights the kind of challenges faced by refugee women who are living with HIV. It also illustrates the stressful and destructive effects of being isolated, especially from women who come from collectivist cultures. Chidimma went on to explain that:

> A lot of people are in deep deep stress ... And the culture is different ... You feel like you are rejected ... The stress from having only a baby ... It's enough ... It's enough ... And no one is there. (Chidimma, p.15)

Interestingly, one participant framed her isolation during the post-partum in a positive light, especially when it came to breastfeeding. She viewed her lack of friends as protection from potential disclosure of her HIV status. She explained it in the following way:

> ...The people don't know you have HIV ... They are going to see if you give breast to it ... If you do not give ... They automatically ... This woman have something ... But I have luck ... Nobody I know ... Come to my house ... Just 3 people come here. Nobody come to see me you ... It's good for me ... I have no have family or friends here. (Tulun, p.13)

While this was not consistently mentioned by participants, it is important to recognize that women often reported mixed feelings about their experience during pregnancy, including mixed feelings about the double isolation they faced as refugee women and women living with HIV. These will be further explored in the following sections.

5.3 Being "In-Between"

The experience of HIV, pregnancy and their journeys to Canada as refugee women situated women in an in-between state that brought to light the third main theme. They talked about how their experiences of pregnancy, while HIV positive in Canada meant they were physically and socially interacting in their new environments but simultaneously retaining strong emotional and verbal connections to people and places in their home countries. This was evidenced when they contrasted the cultural practices surrounding pregnancy in their countries of origin with those of North America to which they were now subject. In addition, their serological status led to mixed feelings and concerns associated with the pregnancy. As a result of this, two sub-themes emerged within the main theme of "being in-between": being in-between lived spaces and being in-between feelings.

5.3.1 Being in-between lived spaces

During the interviews, women sharply contrasted the way they experienced pregnancy in their country of origin and how they experienced it in Canada. These in-between lived spaces were experienced from the time women first learned they were pregnant, during the birthing process and also in the post-partum phase.

Baako explained how her thoughts were influenced by practices in her country of origin when she first learned she was pregnant. She later learned of different practices in Canada that were able to alleviate some of the fears and anxieties that had caused her inital concern:

> At the beginning, I was surprised because I was thinking "How am I going to feed my baby?" In my country, a baby that is born (with HIV)...You have to spend a lot of money to buy milk for the baby to make sure he doesn't become ill (...). I was really surprised. Oh yes...But after that, I realized that the hospital would give me milk. They gave me many, many, boxes of milk. This way there are no health problems with the baby...Yes...And it's good for the baby that way. (Baako, p.1)

Despite the fact that Baako was delighted to learn about the supply of milk that would be provided by the hospital, she still experienced difficulty in making the transition from breastfeeding (there–country of origin) to bottle feeding (here–Canada):

> When I had my baby [here], to give him milk, you have to lose a lot (of sleep)...You cannot sleep because he misses the breast. When you give breast [milk], you can sleep and it's not a big deal. With the bottle, you have to be awake and sit to give milk to the baby so it's difficult. (Baako, p.3)

Another difference that women noted was the number of appointments that were arranged during the course of their pregnancy. Despite the fact that this often meant spending long days at the hospital, they viewed these appointments as a safeguard for their health and that of their babies, providing them with more protection than what was afforded in their countries of origin. This was especially true in cases where women were followed, not just for HIV, but for other health conditions related to the pregnancy. Baako commented:

> Some days I would spend the whole day at the hospital because of the different appointments. They helped me to get transportation to go to the appointments but nothing else. It wasn't like this before (with the other babies). I had to go to a lot of appointments...Here, I don't know why... At home... I know that if I go to the clinic, I come back after. There's no one that follows me, follows me for the appointment. That's the difference, but I see this as something to protect my health and that of my baby. (Baako, p.2)

In addition to the difference in infant feeding practices and the number of clinic appointments that many of the women in this study experienced, being pregnant in their

countries of origin often meant that they were surrounded by people and with special rituals and practices, both at the time of the baby's birth and in the post-partum phase.

> I remember when I had my first baby, and I am coming from a family of seven people ... I was the first one to have a baby in my family ... Everyone was there ... I remember for four months ... I could not change my baby's diaper ... I could just sleep, eat ... Life. It was so amazing. Now ... To find myself in my bed where there is no one ... I look at myself and these scars (referring to the C-section scar) ... It's like "Oh my God" ... I am going to die ... What kind of life is this? You cannot compare ... Back in Africa ... Just to have people ... The atmosphere ... People are there ... Support is there ... Even if you don't eat ... Even if you don't have much ... That support is there emotionally, physically. (Chidimma, p.10)

Contrary to the experience she had with her first pregnancy in her country of origin, Chidimma's experience in Canada was markedly different. She found herself confined to her bed in a place, where there was "no one" to take care of her and assist with the baby. This is echoed in Tulun's story.

> ...In my country ... You have a baby ... You are a princess (smacks lips) ... The people are going to give you, the family, everybody ... It's my food you're going to eat it ... Money ... At night everybody came with the food to help you to take the baby ...everything. (Tulun, p.16)

Baako also described the experience of pregnancy in Canada, comparing it to her home country and noting the lack of social contact that she experienced while living in Canada.

> At home, when I was pregnant, someone would come to help me wash, to do the dishes...Here, in Canada, it's difficult. Over there, we had people; people were sociable. Here people are not sociable...That's it. My neighbour does not wonder if I'm doing well...offering to help. [There] My neighbour would come into my house, but here no. It's you, it's you. Sometimes when you're pregnant ...You feel weak and you sleep. Your neighbour would come in and help, but here, no. No one comes here to see me. There's not a lot of support. There's no help. (Baako, p.2-3)

Their stories reveal a tension that was common to all participants, a tension between "here' (Canada) and ''there'' (country of origin). It suggests that women have an understanding and a lived experience of what pregnancy is like in their country of origin (there) that is not reflected in their experience in Canada (here). This situates them in an "in-between" state – *neither here nor there* – that is not at all satisfying, sustaining or healing for women.

Looking specifically at cultural and birthing practices within former lived spaces and present lived spaces, an analysis of Chidimma's story shows that the tension between "here" and "there" is palpable as she goes back and forth between them. She articulates what is important to her and what she might need in her present state by re-counting her experience in her home country. Thinking back to her earlier experience of giving birth, she describes the environment, atmosphere, and the people around her. The people "there" were able to provide the support that 'here' and now she experiences as a greater need. She examines herself and her situation, and she sees "scars" from the Caesarean. These "scars" do not make sense to her. Scars on her abdomen are not something she has previously associated with having a baby, and bewilder her. Quite possibly, she sees these scars as symbols of a lasting cultural or emotional injury, scars from loss of her family, scars from dis-location, or the scars imposed by her HIV status. During the interview, the intensity of these feelings arising from beholding her scars and not having anyone to help with the baby was so great that she was questioning how meaningful this "in-between" life was for her.

The experience of having a Caesarean, especially in an emergency situation, situated women within an "in-between" place, since Caesareans in their countries of origin have negative implications. For many women coming from African countries, Caesareans are associated with a high rate of maternal death. Even though participants realized that this is not true here their residual fears from the experience in their countries of origin carried through to their and their husbands' current experience in Canada. As Tulun explained,

> In my country, to have a C-section ... Is a 'BIG PROBLEM' ... Dangerous ... Because many women with babies ... 50% of them who get the operation can die ... But here ... It's not like that ... My family was afraid ... When my husband came ... C-section ... I know ... It's like ... he's going to lose you. (Tulun, p.15)

To this participant, a Caesarean section meant distress, harm, something mysterious that had the potential to cause injury or even death and thrust her into a state of pain. This was related to meanings that were carried over from her country of origin (there) to Canada (here). Even

though she realized that Caesareans have different meanings and outcomes ‘here’, she was aware how she had transported this fear from her former experience and how this caused apprehension and fear for herself and her family. When Tulun discussed her experience of having a Caesarean, she positioned herself in her country of origin. Although she was aware that things were different “here” in Canada, the long held associations between Caesarean as a birthing practice and mortality became figural when she was told she would need a Caesarean. During the analysis, this was identified as a position between two worlds: being physically here within the boundaries of a Canadian hospital and medical practices, but also being cognitive of what these practices mean in her home country.

Similarly, the experience of not being able to breastfeed situated women in another “in-between” state. The following participant described her experience of going to church, where she met many women from an ethnic background similar to her.

> Back in Africa, once you don’t breastfeed, everyone knows [that something is wrong] ... That there is something going on ... There is something ... Why is she not breastfeeding? There’s something going on ... So it was in my mind here like ... Maybe they’re suspecting ... Maybe they are talking ... They think something ... Even if they cannot come and ask you ... Inside their head they might be saying “Why is she not breast-feeding? Is she positive? Is she what?”... Stuff like that. (Chidimma, p. 9)

When Chidimma participated in her Canadian community among people from her own culture reflections about the way breastfeeding was perceived in her country of origin permeated her thoughts. During the interview, she explained that, back in Africa, not breastfeeding one’s child could transmit personal information – the knowledge about one’s status as a woman living with HIV. As such, she was keenly aware that not breast-feeding here in Canada spoke volumes about her serological status, even though no word had been uttered. Other participants clearly expressed this understanding. For women who took part in the study, though church had the potential to become a place of community and support, formula feeding made them different from other women there. During the analysis, it was noted that the practice and meaning of breastfeeding in Africa (there) was displaced to their current situation in Canada (here). Church

was a space of discomfort for Chidimma, an “in-between” place in Canada that operated by the same cultural norms, perceptions and judgements she experienced when living in Africa. This seemed to contribute even more to her isolation, even though she was now living in Canada.

The HIV status itself also seemed to situate women in an “in-between” place, even when they had come to “accept” their status through a somewhat transformative process. Women saw themselves differently and believed other women shared this view as well. Because of this, they did not feel as connected to their own culture (see section 5.4.2) and other pregnant women. During the interviews, women explained that HIV separated them from other women who were pregnant and other women who had come to Canada as refugees, all potential groupings of women with whom they would have at least one thing in common, and who could provide a potential source of support. Not “fitting” in either group of women affected them a great deal. As pregnant women with HIV, they had to take medications every day, which situated them in a space where they could never forget about the HIV diagnosis, knowing, at the same time, that they would not be accepted by those around them. One woman made the following comment to this effect:

> You can accept HIV ... Me today ... I know I accept ... Before I didn’t want to ... If I am here ... I don’t want to tell nobody I have HIV … But today it’s not my problem ... I accept ... But you cannot forget ... Every day, when you take your medicine ... Everything comes back ... How you have HIV ...Comes back ... You’re going to think about it ... Now you will be positive ... It is different ... After to accept it ... It’s not easy ... But if you accept ... You can never forget ... Every day it is there with you ... You’re going to be ‘dirty’ ... Because it’s not ... Not everybody accept the positive people ... Yah ... You’re not accepted. (Tulun, p.13-14)

Here, Tulun explains how she has come to accept her HIV status. However, because of her HIV status, she is aware that she does not “fit” among other women. She also acknowledges that she is located somewhere between her own acceptance and the acceptance of others (or lack thereof). This is yet another “in-between” state that was identified in the data. The way Tulun spoke about this phenomenon resonated with other participants who also shared similar thoughts during the interviews.

5.3.2 Being in-between feelings

During and related to the pregnancy, women experienced a host of conflicting and polarized feelings that often situated them in an "in-between," wavering and capricious state. This is reflected in the following quote:

> *When I was newly pregnant, I was happy to have baby. Of course I was worried about the situation, the new baby, all those things. I used to go to the hospital and worry about the baby being infected*. (Mageti, p.1)

This quote illustrates the joy that this participant experienced when she learned of her pregnancy and the prospect of having a baby. However, it also illustrates another side of the pregnancy that gives rise to some concerns. She talks about "the situation," not specifically mentioning her HIV status, which caused her to worry. During the interview, she goes on to articulate the context and focus of her worries: her health, the hospital, and the health of the baby. As with the other women who took part in the study, worrying about the baby becoming infected with HIV was also part of Mageti's experience of being pregnant. This experience was often located in between positive feelings and negative feelings. Throughout the pregnancy, women were never in a state of total well-being or happiness, but experienced a constantly shifting state from being "happy to have a baby" to worrying "about the baby becoming infected."

During the interview, Baako echoed similar thoughts about her pregnancy and told the story of how her husband came to accept the pregnancy. She had previously practiced contraception while living within a refugee camp, and had conflicting feelings regarding the reality of another pregnancy:

> I went to see the nurse and the doctor because I thought I was pregnant. She did the test and told me I was pregnant. But I was worried...Of not being able to give milk and other things ...I was angry. (...). After that, I came home and I talked to my husband, I told him I was pregnant. My husband said o.k. He didn't have a choice to accept it because I could not terminate the pregnancy. In my religion, this is not good. After that, I looked after my health. (Baako, p.1)

When sharing her story, Chidimma described having mixed feelings as the pregnancy progressed. For her, this occurred with the realization that there was still a very small probability that her baby could become infected with HIV. At the outset of the pregnancy, Chidimma had not been too worried about her baby becoming infected, and this seemed to ameliorate her experience as suggested by the following quote:

> We knew the risk, we had a little bit of information from the doctors ... And also because one of my friends went through the same thing ... She was positive ... And she had a baby ... So I was really comfortable with it since I knew the risk ... And prevention ... And I was comfortable with it. (Chidimma, p.2)

So it seems that, for some women, worry over the baby's health was not so apparent upon the initial confirmation of the pregnancy. However, this concern fluctuated over the course of the pregnancy. Chidimma's comments elsewhere in the interview illustrate this particular point:

> ... But there was always that thought ... You don't know ... Because they say [the medication] is not 100% ... So you don't know the outcome. (Chidimma, p. 2)

Despite the fact that she had come to have "comfort" with her decision to have a baby, while she was HIV positive, Chidimma still entertained persistent thoughts about the "outcome" of that pregnancy. This outcome, although not articulated in the quote itself, referred to the possibility of transmitting HIV to the baby with the resultant diagnosis of her newborn. The uncertainty of this was with her at all times during the pregnancy. Because there was no certainty her baby would not become infected with HIV, its possibility was ever-present in her mind, resulting in mixed feelings about the pregnancy.

Another participant also described in-between feelings surrounding the health of the baby, as well as feelings concerning herself, should she become sick and possibly die from the effects of HIV. She worried that her baby and her other children would be without a mother:

> There is a difference, when I think of my other pregnancies...The ones that I experienced with HIV (...). After HIV it is hard. You first think of the baby; is the baby going to be infected? What am I going to do? Will I lose my baby? ...That is the difficult part. Or, if I have my baby, and after that I become sick and die. How are my children going to live? So, a lot of worries ... A lot. (Baako, p.3).

Tulun expressed this in the following way, showing the polarization of her feelings during her pregnancy and also the “in-between” position in which it situated her. On one hand, the pregnancy provided her with the possibility for a “new life” with HIV, but at the same time, it raised questions about the idea of having a baby while living with HIV. The following quote supports this:

> I feel happy and afraid. Happy is ... I never knew that if you have HIV, you can have a baby ... In Africa, [HIV] will kill you, I don’t know ... It’s like for me ... It was finished ... I’m so happy (about the pregnancy) ... But I ask myself ... How? To have a baby with no HIV ... How? I need to go see the doctor ... I have many questions to ask. (Tulun, p.1)

During the interviews, women explained that they felt both happy and afraid while pregnant: happy, because they felt fortunate to be able to have a baby while HIV-positive, and afraid, because they were concerned about the health of their baby and worried about potential complications, such as the baby acquiring HIV at some point during the pregnancy or the delivery. Previous knowledge about HIV and HIV in the context of pregnancy was often combined with new knowledge about HIV treatment and HIV transmission, which contributed to their mixed understanding of their experience. Over the course of the interview, Tulun went on to explain that family members also displayed mixed feelings about the pregnancy when she first made the announcement. Here, she draws on new knowledge acquired in Canada to address these feelings:

> I just called my family to say that I was pregnant ... But my brother ... He said ... No, you can’t ... You’re going to have a sick baby ... I said no ... The doctor said no ... I am going to have this baby. (Tulun, p.1)

The positive re-assurance offered by doctors was particularly helpful in these types of situations, alleviating some of the worry associated with the possibility of transmitting HIV to the baby.

> *At the appointment at the hospital, the doctor was so positive. Every time, he said that he knows that for sure [if I take the medicine], there is no chance that the baby is going to be infected.* (Mageti, p.1)

Women managed their “in-between” state by listening to the reassurance of their physicians. This reassurance gave women hope, and alleviated some of the worries associated with HIV in the context of pregnancy. The knowledge that physicians were able to impart, linking medication, adherence, and the baby “not getting infected,” provided women with a course of action for their pregnancy and a sense that could protect their unborn child by taking their medications as prescribed.

Women also managed their “in-between” state through a belief in God, by praying, and by drawing on previous experiences of being pregnant in their country of origin while being HIV positive. They also bargained with God, wishing for the diagnosis of HIV to be only on them and spare their unborn child.

> Since I am a Christian ... I look at that baby and say ... Please God ... If it is a kind of punishment, just let it be on me ... And I pray ... Once I pray ... I feel much better. (Chidimma, p.2-3)

Here the participant affirms that praying made her feel better during the pregnancy. This is important to recognize, because part of the way women viewed and coped with mixed feelings during their pregnancy was through the lens of spirituality. It was also considered an important source of power in influencing the fate of their unborn child. While the meaning assigned to HIV was not the focus of this study, it is important to point out that women ascribed to the idea that HIV was a “kind of punishment,” a punishment that they did not want extended to their baby.

5.4 Feeling Disconnected

The fourth main theme that emerged from the data was “feeling disconnected.” During the interviews, participants were asked to think back to a time during the pregnancy that perhaps was not so positive for them. This theme surfaced and was further divided into four sub-themes. The first sub-theme, “feeling disconnected from baby” pertained to those experiences when participants were not feeling connected to the baby after the birth. This was especially prevalent in relation to not being able to breastfeed, as all the women in the study were discouraged to breastfeed their baby in order to prevent the transmission of HIV to their newborn. The second

sub-theme, “feeling disconnected from culture,” presented when women made contrasts between cultural practices pertaining to pregnancy, childbirth and the post-partum period and differing practices in Canada. “Feeling disconnected from self/body” was identified as the third sub-theme when women talked about the physical and emotional symptoms during the pregnancy, experienced in part because of the HIV medications and the interrelated psychosocial stressors that they faced every day. Finally, sub-theme four, “feeling disconnected from care,” emerged when they discussed their interactions with the health care system and health care providers.

5.4.1 Feeling disconnected from baby

Not being able to breastfeed left women feeling disconnected from their babies, placing them in an untenable situation, since they knew that there were legal repercussions if they did in fact decide to breastfeed. As suggested by the following quote, this feeling of being disconnected was very real for women who couldn’t breastfeed:

> In our culture ... Once you are breastfeeding, you are feeling like you’re more connected to your child ... But ... Once you are not breastfeeding ... You ... It’s like ... Wow ... You don’t know that child ... You are like strangers ... You are like strangers ... Not breastfeeding is a HUU...UUGE problem for us ... So if you are not breastfeeding ... I felt like I was completely disconnected to my babies ... Like lost ... And sometimes I was condemning myself. (Chidimma, p.8)

Chidimma clearly explains that breastfeeding is not only about feeding one’s child, but it also is a way of connecting to one’s child, on both a physical and emotional level. It is a way of establishing a relationship, a bonding that allows mother and child to get to know each other. This was consistently mentioned throughout the interviews. Without that connection, women felt that their children were like “strangers”. In their minds, the pair became like two people who were foreign or did not belong together. For women living with HIV, the fact that they were discouraged from breastfeeding to prevent the transmission of the virus interfered with their ability to become acquainted with their child in the normal way. This was a radical shift from their way of being and understanding their role as women and (new) mothers.

The fact that participants described formula feeding as a “HUGE” problem denotes the enormity of the implications for women who consider this feeding practice not to be consistent with their culture and with their own views on motherhood. The analysis suggested that women who are HIV-positive and new to Canada are required to learn new ways of being as mothers. As indicated by the findings, these new ways often collide with cultural norms and representations of good motherhood. Hence, these new ways of being could create a strong sense of disconnectedness between the mother and her baby. This phenomenon had implications for the emotional well-being of mothers who internalized the inadequacy and the guilt of not being a “good” mother. Going back to the story of Chidimma, we see that her inability to breastfeed contributed to her feeling “completely lost” as a new mother and to her lack of self-confidence. This was also the case for women who had other children, because they could not necessarily draw from past experiences with breastfeeding.

> I felt completely lost ... But there’s no other way ... It’s against the law [to breastfeed] ... You cannot ... You can be charged ... And something like that ... Once something happens ... It’s like you’re tied somewhere ... That’s the feeling. (Chidimma, p.8)

Here, Chidimma refers to her lack of options and choices. This also refers to the risk of HIV transmission to the baby that is associated with breastfeeding. In addition to the risk of transmission, she is also aware of the potential of criminalization, should she be accused of transmitting HIV to her newborn. She also experiences the practice of formula feeding as a legal obligation rather than a personal choice.

For Tulun, breastfeeding was also equated to “giving love” to her baby. This was embedded in her culture and was considered to be what “good” mothers do:

> Just one worry I have again ... I cannot give my breast to my baby.... In Africa, if you don’t give your breast ... It’s like you refuse to give him love ... From my country ... If you don’t give ... its like something is broken between you and the baby ... I cried many, many times for that.(Tulun, p. 12-13)

To her, formula feeding is like a “refusal to give love,” something that totally contradicts the concept of caring for her child in her culture. Refusing to breastfeed her baby is like a form of

non-acceptance of her child, almost like a form of rejection or disconnection. Tulun explains that it is like something is “broken between you and the baby”. This expression evokes a connection or process that is shattered or interrupted. In Tulun’s mind the bond that would normally be established through breastfeeding is damaged, altered or reduced, so that she feels cut off and disconnected as a mother. The grief and loss induced by this is reflected in her report of “crying many, many times.” This is not unique to Tulun’s story. It is an experience that was shared among participants.

During the interviews, women described how they attempted to re-connect with their baby. Increasing opportunities for physical proximity was one of the methods mentioned by women who took part in the study. The next quote describes this in more detail:

> Every time, I put the baby beside me [in the bed] ... To know that he is there ... I don’t want to put him in the crib ... If they (the children) are far away ... So ... I remember it took me a long time to let them out of my bed ... So I could feel that sense of connection ... They were beside me ... I want the baby to be there ... Just to feel that connection. (Chidimma, p. 8)

Here Chidimma explains how she made the attempt to intensify physical proximity by co-sleeping with her baby during the post-partum period. This proximity with the baby helped her to re-establish the bond that she perceived had been severed by her inability to breastfeed. Another participant related a similar story, but also told of how the local municipality had created a novel situation to support her ability to re-connect with her baby.

> I just slept with my kid ... For that ...The city gave me like the double bed ... And something ... The baby has one pillow for the head place ... It can help ... When sleeping so you can’t smother ... So I sleep with my baby. (Tulun, p.13)

Here, Tulun also refers to her attempt to increase physical proximity by co-sleeping with her baby during the post-partum period. In this instance, assistance was provided to help her achieve this objective. In Canada, most public health departments discourage mothers from sleeping with their babies because of the perceived risk of suffocation. However, in this case, accommodation was provided for this mother to regain a sense of connection with her baby. During the analysis, this was identified as a good example of how creative and culturally

responsive solutions can be offered to HIV-positive mothers who feel disconnected from their baby because they cannot breastfeed.

5.4.2 Feeling disconnected from culture

As described in the previous section, women felt disconnected from their babies due to their inability to breastfeed. This also contributed to the feeling of being disconnected from their culture. Thus, these two sub-themes overlapped. To reduce repetition, the following paragraphs will focus specifically on the feeling of disconnection that women reported when they talked about their experience with HIV, while their experience of pregnancy acted as a way to reconnect with their own culture.

For women who took part in the study, living with HIV made them feel disconnected from their culture and their relationships (as described in section 5.2). Living with HIV had led to their abandonment by their husband and family members, thus situating them alone in a culture where gendered roles, social status and identities for women are very much circumscribed around child-rearing as well as around the responsibilities and rewards associated with being a mother (For example of research on this, see Cooper et al., 2007; Sofolahan & Airhihenbuwa, 2013.) Living with HIV had also led them to believe that they would never be able to fulfil this role of childrearing that is so central to their culture. The experience of being pregnant and having a baby re-connected them with this traditional role, and allowed them to carry out the cultural expectation of being / becoming mothers. While they did not experience a “traditional pregnancy,” so to speak, this experience meant that they could re-establish a sense of positive connection with their culture. One participant explained it this way:

> I forget if I am going to have a baby again in my life ... But I have HIV ... I lost my husband ... But after ... Another man accepted me like that ... And I never planned for the baby ... And the baby came ... One and two ... Three ... Here (in Canada), I had 2 pregnancies ... 2 babies ... It’s positive. (Tulun, p.7)

The experience of being pregnant and also having a baby provided reconnection to culture and also re-connected these women to a new place. This experience was situated at a particular

point in a journey that was often marked by multiple losses, including the loss of cultural schemes of reference, relationships, roles, and identities as women and mothers- to-be.

One participant, whose husband had passed away in her country of origin, described the experience of pregnancy as one that created more disconnection in her native country because of the level of necessary secrecy around her HIV status. She became disconnected from her culture, country and locality during this experience, and subsequently made the decision to come to Canada.

> *Back home, having the baby while HIV positive, the experience was finding a way to hide when you are going to deliver the baby. You don't want people to come around. I came here (to Canada) because of the 'situation'. I decided to travel because there is more here. There were rumours back home (about my HIV status). When I came here, I expected that I would not have more babies and have another life. Then I found out how I can have a husband and kids together. If I have the baby here, the baby will be a citizen of the country. The baby is not a refugee. Even if I move, my daughter is from the people here. The meaning for this is positive.* (Mageti, 1, 5-6)

During the interview, Mageti described her experience of pregnancy while living in her country of origin. She had to find a way to hide her pregnancy, a process that was physically and emotionally isolating. Having to hide her HIV status and running the risk of being exposed as a woman living with HIV created a disconnection for her. She sought re-connection in a different location, because, from her view, there was "more here." Her expectations were for "another life," one that was distinct from her previous one. As suggested by the quote, she did anticipate that this "other life" would include a husband and having more children. Finding out that that she could have a husband and more babies while in Canada was a way of connecting her back to life as she knew it – a life that made sense for her. It is important to note the special meaning of "having the baby here" in Canada. This gave her a new sense of belonging and connection.

Another participant talked about feeling disconnected from others and disconnected from her culture in which women "NEED to have babies." She saw her pregnancy in Canada as an opportunity to regain a sense of connection that had been previously lost. She offered the following explanation during her interview:

> With HIV, you lose everybody ... Friends ... Family ... When HIV came ... My husband moved ... I don't know for the Canadian people ... But the people that come from the Caribbean's or Africa ... We are the same ... You have HIV ... You lose everything ... Everybody. If a woman with HIV wants to have a baby ... I can never say no ... Because we know it's different ... We NEED to have baby ... If you have HIV ... For that woman who has HIV ... You want to have ... a baby ... Go to see your doctor ... Do it ... Do it ... It's good ... It's not in our country ... Our family ... You have nobody there ... You're going to have maybe small problems ... But after you have the baby ... You know you have 99% ... You're going to have your baby ... No HIV ... If you have HIV ... And you decide to have baby ... Go to your doctor ... If everything is o.k. ... Have your kids ... It's good ... It's for you. (Tulun, p.19-20)

Tulun articulated the loss imposed on her by HIV and the cultural expectations surrounding motherhood in her country of origin. She articulated that "'here," in Canada, women living with HIV have an opportunity to reconnect by fulfilling these expectations.

5.4.3 Feeling disconnected from body/self

The analysis revealed that HIV medications made women feel somewhat disconnected from their "normal" body and "normal" selves during the pregnancy. For example, signs, symptoms, and feelings usually associated with pregnancy took on a particular significance, because they interfered with women's ability to take these medications as prescribed. The fact that they had to take HIV medications during their pregnancy also created a situation where symptoms and feelings were hard to interpret: Were they related to pregnancy, or were they caused by the medications themselves? During the interview, women located their experience at the intersection between the baby and the virus. At times when they developed side effects from the HIV medications, women were reminded of that intersection. They were also reminded of that intersection during interactions with health care providers as suggested by the following quote:

> I vomited the medicine ... For the virus ... Everything ... It's not good ... And I stayed in the hospital ... And the doctor saw me ... And after he tried to ... The first time I took ... Yah one medicine for the vomiting ... It did not work ... He changed for 3 times ... It did not work ... I tried another (medicine) ... But (the medicine that can help) for the people who have cancer ... It was expensive ... but ODSP said no (...). Finally they accepted to buy the medicine ... And this one helped ... I took 2 ... It worked ... But it just worked for 3 hours ... In 3 hours the medicine work ... No problem ... That is good ... In 3 or 4 months I was going to have the baby ... I lived 3 or 4 hours without vomiting ... It was very good for me. (Tulun, p. 10-11)

Women experienced severe nausea and vomiting upon taking HIV medications during their pregnancy. They also experienced other symptoms that were clearly not related to the pregnancy.

For some women, these symptoms created a sense of disconnect from their "normal selves" while for others, it had the opposite effect. When Tulun talked about her insomnia, it was clear that sleeping well during the pregnancy was seen positively and offered a way to reconnect with her "old self":

> Since the day they told me I have HIV ... My problem is no sleep (…). No sleeping ... It's a strong problem ... No sleep ... And I live like that ... I never sleep ... And when I was pregnant, I slept well. I slept ... slept ... slept, and when I had my first kid ... I slept well ... And when I had another pregnant ... I slept ... After 3 months ... It start again ... I don't sleep ... Now I'm not sleeping. (Tulun, 11-12)

For Tulun, not sleeping had become part of her every day existence. As such, pregnancy was restorative for her. It connected her back to her "normal self."

Chidimma also spoke of how the practice of taking HIV medications disconnected her from her "normal" self. For Chidimma, the practice of taking pills made the pregnancy more difficult and stressful, and always occupied a central place in her mind. An example of this is illustrated in the following quote:

> Taking those pills...Oh my God...Huge pills...You have to take them the same time every day...Its stressful...It was always in my head...Even if I was somewhere else, I was always thinking...I need to take those pills...Because, I'm not good at taking medication...It was quite a challenge for me. (Chidimma, p. 3)

Women were able to re-connect back to themselves with the support of their husband or partner, who often was the one reminding them to take their medication.

5.4.4 Feeling disconnected from care

Women reported feelings of being disconnected from care on various occasions during their pregnancy, including times when health care providers refused to touch them or when they faced difficulties accessing care.

During the interviews, women described situations where health care providers did not want to touch them. Tulun experienced this during the birth of her baby at the hospital.

> He didn't want to touch me ... Because I have HIV ... He say ... We are born ... but the patient has HIV ... He did not touch me ... And one other girl did not want to touch me. (Tulun, p. 7)

This experience of health care providers refusing to touch them was extremely distressing to women, especially in the context of pregnancy. For women who faced this type of experience during labour or after birth, it was even more distressing. In addition to creating a sense of disconnect with health care providers, the memories of that experience became a permanent part of what they hoped to be a joyful moment. However, in other instances, HIV care clinicians were considered to be helpful in reconnecting women to care and advocating for change in practice.

The experience of feeling disconnected from care was also encountered by one woman during her experience in the emergency department when she had symptoms that required immediate attention. On presenting to emergency she encountered difficulty in gaining access to examination and admission. This experience led to anxiety and worry about the loss of her baby, should something happen. It also caused her to wonder if underlying discrimination or stigmatization related to her HIV status or her status as a refugee were at play. Reconnection to care was established in the subsequent response of nurses and physicians within the health care setting on this particular occasion, which led to the eventual birth of her baby.

> For the second baby, the term pass ... No baby ... And the doctor gave me appointment ... I went to the hospital ... They said we have no place ... The first day ... We came and the day after I started to have pains ... But it was not too much ... And we went ... No place ... We came back ... And in the night ... I just had pain for 3 days like that ... We went ... And I said ... Is it because you don't want to do a delivery on people who have HIV? Or is it because I'm black? ... I said o.k. ... Just give me paper ... You say you have no place ... See in this paper? ... I'm going to go to the house ... If something bad happens … It's you. (Tulun, p.14)

Tulun required numerous visits to the emergency department before she was eventually admitted to the hospital. As a pregnant woman with HIV, who was also new to Canada and had

limited knowledge of the Canadian health care system, she felt disconnected to care: she felt ignored, pushed aside, and discriminated against. It was a distressing care experience for her and this raised questions about her HIV status, her status as a refugee, and her needs as a pregnant woman living with HIV.

During the interviews, women explained that they were concerned about their health and also the health of their baby during labour, a time of extraordinary physical and mental expenditure. On presenting to the hospital, women in labour are very often in a vulnerable state. Finding the energy and resources needed to advocate for oneself during labour takes extra effort, and often leads to distress during a time that is already filled with apprehension and worry. When refugee women felt disconnected from care in emergency situations, this resulted in feelings of anxiety, fear, and anger as suggested by Tulun:

> He said, “OK ... Wait” ... And he turned around ... And maybe half hour after ... He came back ... He said, “Come ... (…) You don’t have the time ... If we don’t do something ... We are going to lose the baby because her heart is not good ... Operation ... You don’t have time ... You don’t have place ... Because the heart of the baby is so bad ... It’s an emergency ... And he prepared ... They took out the baby... Ah ... AH ... Ah ... It was so difficult ... But my baby was alive ... I was so angry ... Because if I say if I go to hospital 3 times ... Maybe I would have lost my baby ... If I didn’t ask for the paper ... If I didn’t ask for the paper ... He would have said to go again ... And come back ... But my baby is alive ... Good. (Tulun, p. 15)

Women also felt disconnected from care during the post-partum stage. Reconnection to care was achieved when health care providers were able to recognize and respond to the women’s unique situation. Tulun provided an example of this. When she developed a complication after her Caesarean, necessitating her to go to the hospital every day for follow-up, arrangements were made to provide the care in the home setting rather than in the hospital setting.

Participants emphasized the difficulty of getting to appointments: they all commented that, if help were to be offered to women living with HIV, it would be especially beneficial if assistance could be provided for them to attend health care appointments, thereby maintaining a connection with care.

> If an organization or a government want to do something ... It's good to help people who have HIV to go to their appointment with the doctor ... This is a big problem for us. (Tulun, p. 20)

Participants also emphasized the importance of continuity in the connection to care, and how care in the home would have helped both pre-and post-delivery.

> To come to the house, because people don't want to go in the hospital. Come to the house ...1 hour every week ... After you are pregnant ... The baby is born ... To see how you're feeling and if you are ... You have something in the week ... Same people ... They come in the week ... To talk to you ...See if everything is o.k. ... It's the same people take you to your appointment … It would be their job. (Tulun, p. 21)

Tulun's comment establishes further connections with the findings presented in section 5.2. She implies that there is a need for social connection and support as well as the need for re-assurance, and awareness that someone else is "there," and is attentive to her experience of pregnancy. She also identifies the need for continuity to establish, ensure and facilitate connection to care. Connection was an important element that participants mentioned during the interviews. The recommendation that visiting persons not be of the same ethnic background as those who would require this type of service initially seemed surprising, because the opposite is often recommended for culturally safe care. However, the findings presented in section 5.1 help to contextualize this recommendation. In general, participants felt that having a Caucasian person visit would protect them from stigma and disclosure within their community in Canada. As previously described, they felt they could be potentially alienated if their HIV status became "known" in their own local community.

Finally, disconnection from care was reported when services that had previously been provided were suddenly stopped. One participant described how, during a first pregnancy, a social worker came to her home and assisted her with getting to her health care appointments. This same person also came to the house to talk to her, and assisted her with obtaining food and other supplies. The participant explained that all of these visits suddenly "stopped," and she was never told the reason for this. Being suddenly disconnected from these supportive services

caused her to re-evaluate her needs and seek alternative methods to try to manage her family's situation: some of these "solutions" led to more re-location and the need for further adaptation, with possible further isolation. The subsequent experience and its effect are described below:

> With the first pregnancy, I had (someone) ... He came to pick me up ... He came to the house to talk to me ... And if I had an appointment at the hospital, he took me ... If I wanted to buy food or something ... Every appointment with the pregnancy or if you have the baby ... He came ... But when I had my second baby, everything stopped, stopped just like that ... Now we suffer ... Now I'm going to move long place ... I think ... How am I going to go to the appointment with 2 kids? (Tulun, p. 8-9)

Tulun's experience of connection to care during her first pregnancy in Canada completely contrasted to that of her second. During the first pregnancy, she had the benefit of transportation assistance, a visitor or counsellor in her home, as well as someone to assist her with acquiring basic necessities, such as "'food or something." With her second pregnancy, she "suffered" from being disconnected from support services. At the time of the interview, she could not comment on the reason why "everything just stopped": it is possible this was related to changes in health policy and expenditures at both the federal, provincial and local levels. Her disconnection to care remains and creates increased anxiety for this woman as she wonders how she is going to manage. Such anxiety and lack of resources can limit rather than aid her in her ability to maintain her health as well as that of her children.

5.5 Summary

The personal narratives from the four participants reveal the lived experience of pregnancy among HIV-positive women who have come to Canada as refugees. Their experience involved a complex and intricate process of managing the dynamics of pregnancy, and the social, cultural, physical and emotional impacts of HIV, while they cope with the "newness" they encounter when adapting to a country that is culturally, politically and geographically different from their country of origin. Four themes emerged that were central to this experience. These included "making up stories," "facing a double isolation," "being in-between" and "feeling disconnected."

Making up stories involved two sub-themes: making up stories for privacy and making up stories for protection. Making up stories for privacy was done in order to maintain an appearance of the “normal pregnancy” and to avert any possible disclosure of the HIV status. Women were acutely aware that any revelation of their HIV status before and during their pregnancy would expose them to stigma that could negatively affect their personal circumstances: who they knew, who they related to, where they lived, and how they were perceived. The need to make up stories for privacy was experienced to varying degrees throughout the pregnancy, but was especially important before and during the time of delivery when they were linked to a particular hospital for their care and the delivery, during the immediate post-partum period in the hospital when friends and family customarily visit, and during times of infant feeding, both within the home and in the community. Women made up stories about why they were delivering at a particular hospital and why they were not breastfeeding. The story of “why they did not breastfeed” was especially dominant for women since breastfeeding was the accepted norm of feeding a baby within their cultural traditions. Women made up stories for protection in an attempt to secure their status as refugees in Canada and this was also closely linked to issues around privacy.

The second main theme, “facing a double isolation,” encompassed two sub-themes: facing isolation as a refugee woman with HIV, and facing isolation throughout the pregnancy. As refugee woman with HIV, participants were afraid to meet new people. This fear both intensified and maintained their isolation, since the lack of social support exerted effects on both their physical and emotional health, in turn influencing both present and future relationships. Breaking the isolation often required a back and forth testing process that allowed women to transition out of this isolation. Their isolation was also amplified by the associated stigma of HIV, which prevented them from disclosing their diagnosis to friends or family, leading to emotional isolation and strain. The fact of their isolation during pregnancy was reinforced as women identified their husband or one friend as their only support. A predominant time of isolation

during the pregnancy was the post-partum period when women were attempting to heal from the stresses of childbirth, which often included a surgical intervention, along with the demands of caring for a newborn baby and managing their own illness from HIV. The isolation was alleviated if women were able to access local ASO support groups for HIV women.

The third theme, “being in-between,” comprised two sub-themes, including, being in-between lived spaces and being in-between feelings. The theme of being in-between lived spaces captured the contrast that women experienced as they compared being pregnant in Canada with being pregnant in their countries of origin. This situated them in a liminal state, as they remembered previous birthing experiences “‘there,” where they were allowed to rest and recuperate in accordance with the cultural rituals attached to birthing, compared to “here,” where it was necessary to be independent in the care of one’s newborn, one’s family and one’s own physical healing. They also experienced being in-between lived space when giving birth in Canada included the surgical intervention of Caesarean section, eliciting concerns and fears associated with that procedure in the country of origin. Being in-between feelings was illustrated by the joy that women experienced upon learning they were pregnant, especially in light of their HIV diagnosis. At the same time, they constantly worried about the baby becoming infected. They also experienced conflicting reactions from family that situated them in an in-between state.

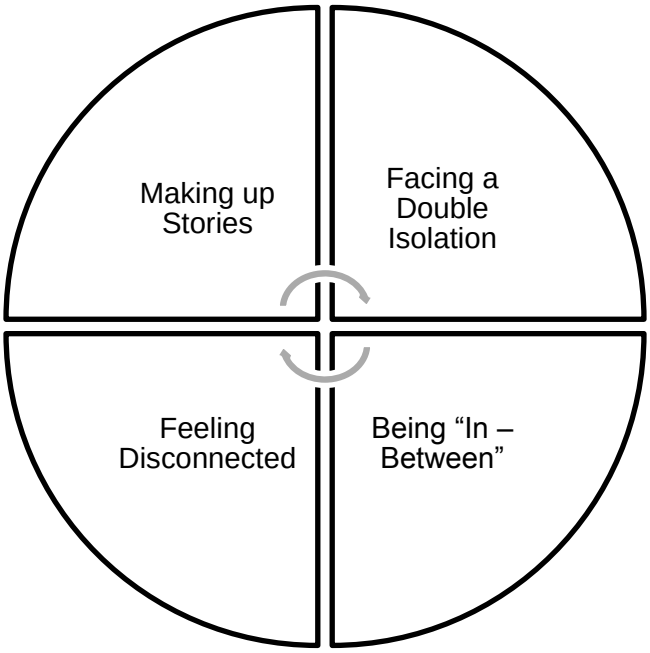
Feeling disconnected was the fourth dominant theme. This main theme included four sub-themes: feeling disconnected from baby, feeling disconnected from culture, feeling disconnected from self/body, and feeling disconnected from care. Feeling disconnected from the baby happened when women practiced bottle feeding (as opposed to breastfeeding). This practice made women feel disconnected from their newborn, limiting their way of getting to know and attach to the baby. Re-connection to the baby was accomplished by keeping the baby close by and making sure that they were physically close at all times. The diagnosis of HIV made women feel disconnected from their culture. Within their communities and in Canada generally,

they realized that this diagnosis subjected them to varying degrees and types of stigma. This stigma subsequently led to various losses and abandonments, including previous husbands, as well as by friends and family. They experienced this disconnection when this stigma led to rapid re-location, when they suffered separation from family and friends, and when they were unable to practice some of the tradition cultural rituals of pregnancy, especially those that were afforded during the post-partum period. Re-connection was accomplished with the birth of the baby, which allowed them to assume their traditional gender roles as mothers, and to move past some of the losses that were inflicted upon them as a result of their diagnosis of HIV.

The theme of the feeling of being disconnected from their body/self was experienced during those times when women were extremely isolated, causing them to endure periods of emotional lows and stress. They felt physically unwell as they dealt with the stress and effects of anti-retroviral medication along with the physiological symptoms and changes associated with pregnancy. Feeling disconnected from care was a distressing theme for woman. This occurred if they were unable to access care when needed, if they had emergency situations that caused increased worry or distress, if they were subject to perceived systemic and environmental discrimination related to their racial or immigration status, or if they experienced being perceived as contaminated when a health care provider was unwilling to touch them. Re-connection to care was accomplished when they had those special moments of “good care,” when health professionals extended extra efforts of advocacy of their behalf, and when transportation assistance made it easier for them to attend their appointments.

In summary (Figure 2), the lived experience of pregnancy and HIV among refugee women in Canada is a complex process that requires energy, persistence and agency on the part of the woman in order to navigate the intersecting influences of HIV, citizenship status and pregnancy.

Figure 3. Lived experience of pregnancy among HIV-positive refugee women



During the pregnancy, women endure a double isolation related to their immigration status and HIV diagnosis. They are often situated “‘in-between,” physically, emotionally, and culturally, as a result of their refugee status, their rooted cultural origins, and transitional states in coming to belong in Canada. Making up stories turns into a finely developed skill, utilized in order to avert the stigma associated with HIV, and, in turn, ensuring one’s privacy and protection. All of the above can result in a feeling of disconnection. The diagnosis of HIV and its overarching stigma disconnected them from members of their cultural communities. The resulting emotional isolation, along with the physical symptoms of pregnancy and side effects of anti-viral medication often led to a disconnection from body/self. Disconnection to care was extremely distressing to women, especially if it was exacerbated by perceptions of discrimination, or perceptions that health care providers did not want to touch them. Finally, the most distressing disconnection was the disconnection from their newborn baby that was experienced when

women elected not to breastfeed in order to protect their newborn baby from acquiring HIV infection.

CHAPTER SIX

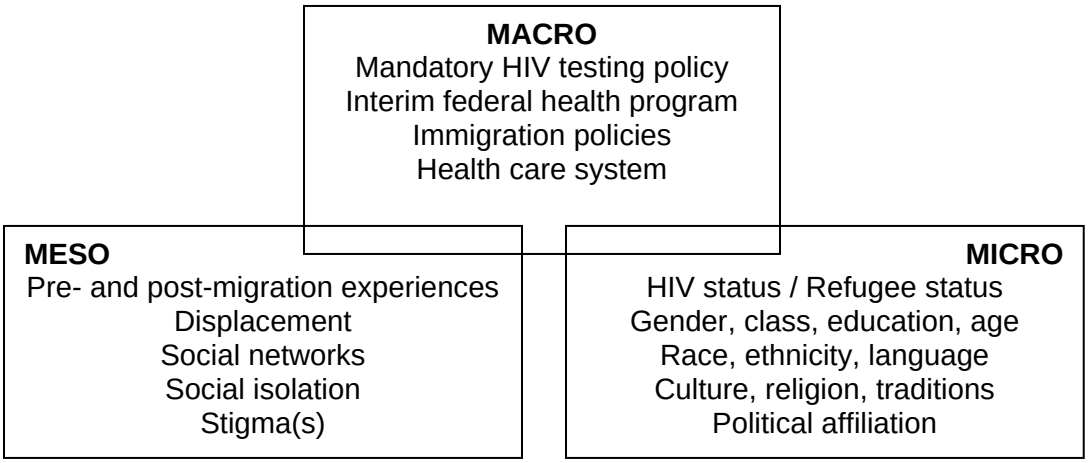
RESEARCH FINDINGS: INTERSECTIONAL ANALYSIS

This chapter will summarize the findings of the intersectional analysis conducted along with the phenomenological analysis presented in Chapter 5. The data for this analysis was primarily drawn from the interviews. Additional information was also pulled from scholarly and grey literature. This literature will be used throughout the chapter to illustrate and support the findings.

6.1 Intersectional Analysis

The aim of this analysis is to further illustrate how the experiences of participants as pregnant HIV-positive refugee women shaped their identity (micro-level analysis) and their social locations and social relations (meso-level analysis), and how they were influenced by complex historical, political, cultural, and socio-economic factors (macro-level analysis) – all of which have also impacted their access to health care and their relationships with health care providers. A summary of these three levels is presented in Figure 3. Since much of the previous chapter has focused on the individual stories of women, the objective here is to explore these stories further in order to shed light on how their experiences as pregnant, HIV-positive refugee women have shaped the construction and reconstruction of their identity. The analysis will also draw attention to the meso and macro influences that structured their experience and their access to resources.

Figure 4. Intersectional Analysis: Three Levels



6.1.1 Micro-level analysis

At the individual level, refugee women define themselves in ways that reflect their heritage and that recognize, to divergent grades, their race, ethnicity, class, gender, age, language, education, citizenship status, biology, and genetics. Within the context of this study, all of the participants were women who identified African countries as their geographical area of origin. They ranged in age from 30 to 44 years and all had an education level equivalent to a high school diploma. At the time of this interview, their immigration status was variable, although all of the women left their countries of origin as refugees. The variability in their age, countries of origin, and immigration status resulted in similarities as well as differences among this group of women.

Rather than focusing solely on gender, which views all women as the same, intersectionality assumes dynamic variability and looks to other aspects of individuality – such as the ones listed above – that more aptly illustrate the unique situation for each woman. This approach recognizes that a refugee Sudanese woman who was previously a teacher in her home country, is partly English-speaking and is now unemployed and alone in a new country, will experience different alterations in identity formation than an immigrant woman from the United Kingdom who is employed at a daycare. Although they may experience some of the same transitions in adapting to a new country, the woman whose experience is shaped by her loss in income, language disparity, and lack of social support may have significant challenges that not only affect her health in the present but also may have persistent effects over time. For the purposes of this discussion, the focus will explore participants' identities as mothers, their identity as refugee women, and their identity as HIV-positive women.

6.1.1.1. ***Identity as a mother***

As stated above, all of the participants within the current study identified countries in Africa as their homeland. Their specific countries of origin will not be mentioned here in order to protect the confidentiality of the participants. Within these societies, the role of the mother is seen as

central to African life (Muwati, Gambahaya & Gwekwerere, 2011). All of the participants identified strongly with this role, and saw it as important to their identity. This was evidenced by the following quotes drawn from several of the interviews:

> *Back home, you get married. It is normal to have children... it made it special.* (Mageti, p.6)

Similarly, Tulun made a comment that illustrated the value she placed on mothering and having children:

> (Back in Africa) I want to have another child...I just have one...I LUVE children...I want to have four...Here (in Canada) I have 2 pregnancies...2 babies... it's positive. (Tulun, pp.6-7)

The identity as "mother" and the experience of being a mother brought meaning to their lives, and also became a bridge to integration within Canadian society.

These women also experienced a shift in their identity as mothers. This was evident in how they described the experience of pregnancy in their home countries, where their communities conferred an elevated status on them, as opposed to their experience in Canada, where no such status was bestowed. This was illustrated by the following quote:

> ...In my country...You have a baby...You are a princess...The people are going to give you, the family, everybody... food... to eat...Money...At night everybody came with the food to help you to take the baby. (Tulun, p.16)

This identity is contrasted with the status granted in Canada, where they experienced a void in such recognition due to the absence of extended family members and different post-partum practices that were reflective of the change in culture and context. This comment was made by one of the participants who referred to her post-partum time at home after the baby was born:

> To find myself in my bed where there is no one...it's like "Oh my God ...I am going to die...What kind of life is this?" (Chidimma, p. 10)

Thus, the intersection of culture, social support and gender influenced their identities as mothers, and was particularly important for participants because of the complex political and social contexts in which they lived.

The politics and relationships they encountered in their new environments influenced whether they felt they could belong. Similarly, their social context defined the type of relationships they found themselves in, whether it was in the community, at home or in health care settings. For example, Settles (2006), in an intersectional analysis of race and gender, found that, although black women hold other identities that may impact their daily lives (e.g., those related to their social class, age, employment status), their unique experiences as black women lead them to be especially conscious of their racial and gender associations. Black women's varied experiences may present both opportunity and barriers. Commonalities associated with their race and gender group memberships may provide the opportunity to experience positive and uplifting experiences. An example of this within the current study was the participants' attendance in a group inclusively for HIV-positive black women from African and Caribbean countries. Conversely, their race and gender may also make them subject to difficulties and obstacles associated with the various racisms and sexisms within society. For example, when Tulun presented to the emergency department, she suspected her reception there resulted from the intersection of her gender, HIV status and racial origin. As a black woman who presented with what seemed to her to be labour pains, she wondered why she could not be admitted to the hospital, and questioned whether it was related to her HIV serological status or her "black" racial origin.

Furthermore, meanings women attach to their different racial and gender identities may influence psychological outcomes. An example of this within the current study was the importance of breastfeeding to the participants' identities as black women and as mothers who came from African countries. For this group of women, not being able to breastfeed led to

psychological distress and to questioning their identity as mothers. This was noted in the following quote by Tulun:

> It's like something is broken between you and the kids...I'm crying many, many times for this. (Tulun, pp.12-13)

Similarly, Chidimma talked about how the experience altered her perception of herself as a mother, since it was so contrary to what was expected within her culture. She found the experience overwhelming in that it produced a feeling of separation between her and her child.

> Back in Africa ...there is no way you could have a child without breastfeeding...Once you are not breastfeeding, you don't know that child ...you are like strangers.(Chidimma, p. 8)

For refugee women, the experience of racialization intersects with their status in a new country, as will be illustrated within the following section.

6.1.1.2. ***Identity as a refugee women***

An intersectional approach is particularly relevant in regard to refugee women who are displaced because of threats often related to race, ethnicity, and religion, or because of political affiliation and pre-migration experiences that may have included trauma or torture. This displacement frequently involves disruption in geography, resources, social supports and networks, and socioeconomic status, leading to both loss and adaptation. New identities, complex and multi-faceted, often emerge in the context of constrained resources, disruptive transitions, unfamiliar settings, and additional stressors that, in turn, impact the health (and well-being) of refugee women. The particularity of migration is that it leaves participants confused about their sense of self and with feelings of ambiguity about their personal identities, which are subject to the forces of constructed stereotypes. For the women in this study, many of their experiences involved re-asserting and redefining who they were and who they wanted to become, and doing so in the midst of dominant discourse influences.

Migration and identity are related. The prevailing ideology has been to view migration as a single movement in space (Benmayer & Skotnes, 1994). However, a more nuanced understanding of migration recognizes the link between migration and identity. Especially for marginal racialized groups, this understanding of migration views it as a life-long process of negotiating identity, difference and the right to flourish in a new context (see Benmayer & Skotnes, 1994).

As refugee women, all of the participants in the current study were displaced several times while en route to Canada. Three women spent time in refugee camps in another country bordering their homeland, while one of the women spent time in another North American country. This displacement as migrants conferred upon them a shift in identity – from full citizenship in their home countries to transitional status within the bounds of a refugee camp. Their final destination, a Western industrialized nation, categorized them as someone who did not fully belong, based on their asylum, refugee or other immigration status.

There were considerable differences in their migratory pathways that influenced their sense of belonging and integration into the new context. Within the context of the current study, participants spent between three to five years within the confines of a refugee camp, which often bordered their homelands. Presumably, they were assigned the status of refugee women within the camp, and likely were racially, ethnically and culturally similar to their hosts. Once arriving within the North American context of Canada, their immigration statuses became more amplified and salient, since other aspects of their identity such as race, religion (as Muslim women wearing the hijab), and French language dialect potentially situated them as racially, culturally and ethnically "different." It is known that all of these identities intersect with their refugee status and influence their ability to adapt and belong in the new environment. Not only is individual health compromised by the uptake of new identities—such as refugee status, HIV status, social assistance status and so forth—each of these identities come to act as pathways

by which systems of inequality place them at a disadvantage, and in turn, influence their health outcomes (Weber & Parra-Medina, 2003).

In studying refugee women who also became pregnant in their new environments, an intersectional analysis draws attention not only to the transitional circumstances of pregnancy and its impact on identity but also recognizes the effect of pre- and post-migration experiences. These may include trauma or torture (pre-migration) and changes in employment and socioeconomic status (post-migration) that also can influence and shape their identities as pregnant women. An example of this among the participants in this study was Tulun. During the pre-migration phase, her identity changed from that of a married woman to that of a single mother, after her husband abandoned her while living in the refugee camp. Similarly, Mageti's husband became sick and died prior to her journey to Canada. At a relatively young age, her identity changed from married woman to widow. Both women subsequently migrated to North America on their own as single mothers with children.

For refugee women, the task of re-establishing identity is compounded by the addition of newfound rights and privileges granted to women in their host culture (Smith, 2013). As a result, during the transition and adjustment process, refugee women often reformulate cultural patterns as they interact with others in the new environment. At the same time, they retain strong ties with their homelands. As such, their adjustment to a new country cannot be fully understood without an appreciation of the continuing kinship links across national borders, as well as the new and familiar relationships formed within the new context. Intersectionality scholars understand that each woman's experience is unique and is affected by changes in context that give rise to new identities and transform old ones (Samuels & Ross-Sheriff, 2008). The reality for many refugee women is that they experience both belonging and Othering as they attempt to reconstruct their identities in the new environment. The following paragraphs will examine how social connection or a lack thereof, within the new context impacted participants' ability to reconstruct and reformulate their identities.

The dynamic interplay between belonging and Othering is illustrated in Mageti's case. As a refugee claimant, Mageti was still waiting to receive confirmation of her immigration status. The fact that she had not received valid status positioned her in a state of limbo, and socially located her as "the Other" within her host country. "Other" in this context refers to someone who is not from Canada, and who can be perceived as being different and not belonging. However, she reconstructed her identity as a woman in Canada when she remarried, became pregnant and delivered her baby in the new context. In this way, she affirmed her identity as a mother. She also assured a place and identity for her newborn, who, she stated, "will be a citizen of the country" and who belongs to the people of Canada (Mageti, p.1). Likewise, Baako continued to affirm her identity as a mother when she delivered her fourth child in Canada.

Tulun experienced a significant shift in her identity as a result of her migration. As a refugee woman in Canada, she faced a significant shift in social status, from that of a woman who had gainful employment and access to resources in her country of origin to a person requiring social assistance and additional supportive services. She had attempted and wanted to work in Canada, but degradations in her health status prevented her from sustaining any meaningful employment. Such changes in employment and social status would influence how she viewed herself and what resources were available for her to look after herself and her family. Tulun maintains connections with her family in Africa, along with other relatives in North America, affirming and sustaining her cultural identity within the new context.

Chidimma's alterations in identity formation took a different pathway. By the time of the interview, Chidimma had obtained her landed immigrant status. This enabled her to attend school, and she was in the process of formulating a new identity that might not been available to her in her home context. Married, with four children, she was continuing to affirm her identity as mother, while at the same time obtaining an additional identity that would enable her to establish herself in the workplace of the new context.

Religious identity for women arriving to Canada in diasporic flows cannot be separated out into a private sphere of activity (Reimer-Kirkham, 2014). For the participants within this study, religion encompassed a core part of their whole identity, integrating, informing and influencing both the public and private sphere of their lives. As a complex set of social practices, religion often influenced the choices and actions of participants, in addition to serving as a reference point from which they made decisions. Spirituality, a less institutionalized and more individualized expression of values and beliefs, often occurred concurrently with religious practices, but both religious and spiritual practice depended on the social milieu that could either hinder or enhance its practice. The discussion of religion and spirituality finds its way into the intersectional analysis, as the participants in this study made reference to religious influences several times. Overlooking the importance of these two influences as aspects of their identity produces incomplete accounts and possible misrepresentations or their lived realities. An intersectional analysis demonstrates the hybridity of the participants' identities and brings to light how aspects of their identities may be pathways to inclusion, enhancing possibilities for health. Alternately, the identities may position them in marginalized spaces that become pathways for social and health inequalities (Reimer-Kirkham & Sharma, 2011).

At the individual level, religion can affect health by influencing the system of meanings, and by providing feelings of strength to cope with the stress and adversity of other intersecting influences. As an integral aspect of their total identity, religion often defined many of the participants' social practices both at home and within the community. Mageti identified herself as a Muslim woman, and spoke of how some things were "up to Allah." Another example of this was provided by Chidimma, who indentified with the Christian faith, and utilized its associated practices of prayer as a way of coping with the difficulties and stressors that she encountered during her pregnancy and in her new life in Canada.

> I can say that I used to pray. We are still praying. There is something which I cannot describe...Once I pray ...I feel much better...So I used to pray...And it helps. (Chidimma, p. 3)

Religion also played a part in the lived experiences and health of another participant by directly influencing her decision to continue with an unplanned pregnancy. In the previous chapter, Baako became pregnant in Canada after ceasing to use contraception in a refugee camp. She asserted her religious identity within her marriage in the following quote:

> I came home and talked to my husband. I told him I was pregnant. My husband said o.k. He didn't have a choice to accept it because I could not terminate the pregnancy. In my religion, this is not good. (Baako, p. 1)

The previous examples illustrate what intersectionality asserts about the numerous influences that are always at play, affecting the physical, mental, and spiritual health experiences of women (Hankivsky & Christoffersen, 2008). We move now to a discussion of identity of participants as HIV-positive women.

6.1.1.3 ***Identity as an HIV-positive woman***

For each of the participants in this study, the process of becoming a woman with a serologically positive HIV identity cannot be separated out from what it means in their social world to be HIV-infected. In this study, the social world includes both their pre-migration contexts of their homeland, their cultural communities in the host context, and the larger socio-political and economic climate of Canada (Soskolone, Stein & Gibson, 2003). As mentioned in chapter two, numerous studies have documented how the serological status of HIV is highly stigmatized and affects the identity of a woman (Wingwood et al., 2007). Other authors have also revealed how women in many parts of Africa have been blamed for the cause and spread of HIV/AIDS (LeClerc-Madlala, 2001). This understanding is based on the notion that a woman is naturally "dirty" and contaminates others through sexual fluids (LeClerc-Madlala, 2001). For the participants in this study, experiences of stigma were both formulated and influenced by the prevailing concepts about the illness at the time they lived in their countries of origin. They experienced HIV-related stigma in both pre-migration and post-migration contexts. However, the dynamics between stigma and other factors such as culture, race, gender, citizenship status,

class, and socioeconomic status (just to name a few) translated differently in the lives of women (Reidpath & Chan, 2005). It has been shown that the identities that flow from stigma do not necessarily compound one another, but interact in complex ways, depending on the individual's access to social resources (Goudge, Ngoma, Madnerson, & Schneider, 2009). This was evidenced within the context of the current study from the following comments provided by the participants.

Mageti talked about the gossip that circulated in her country-of-origin community when her husband displayed visible signs of HIV and AIDS. Such speculation about the illness had the effect of discrediting and devaluing her as a woman and a mother.

> *Back home, I was pregnant with my son. We both found out we were positive* (my husband and me). *We were sick, he was sicker. He passed away. There are rumours back home* (about the HIV diagnosis). (Mageti, pp. 5-6)

Tulun talked about the perception of being "dirty," and about the experience of abandonment by her former husband when he learned of his own HIV diagnosis. She supposed he blamed his illness on his wife. She also carried from her country of origin expectations about the terminal nature of her illness. This had the possibility to influence her expectations of her own health with respect to her own identity. In her own words, "In Africa ...it will kill you" (Tulun, p. 1).

Chidimma internalized some of the messages surrounding HIV from her home country; when she was first diagnosed, she blamed herself and saw HIV as a kind of punishment. Her words reveal a concept of stigma as formulated from her country of origin. She previously had distanced herself from ever being identified as an HIV-positive woman, and she describes the difficulty she had incorporating this identity into her own self-image:

> It did not cross my mind that one day I'll be in that situation...I thought maybe somebody else. I lived my normal life...as a teenager. That's because in Africa...once you have it...people think you are sleeping around and having that kind of life. It was not my case ...so I thought ...Why? ...I didn't deserve this...It made it very tough on me. I lived a really pure, I can say respectable life, and to be in that position was really tough. It was like unfair...In Africa, you have it ...you deserve it. (Chidimma, p. 1)

Post-migration and post-diagnosis, the participants incorporated their identity as HIV-positive women in various ways, depending both on other aspects of their identity and on their particular social contexts. The decision of how to manage information about HIV status, including when and to whom to disclose it, was found to be central to how they managed their identity post HIV-diagnosis. Often, the process began with non-disclosure and secrecy related to fear of stigma and discrimination. This was the case for Mageti, Baako and Chidimma, who, upon learning about their diagnosis, kept the knowledge hidden from others and discussed it only with medical personnel. This non-disclosure protected them from the damaging effects of stigma and allowed them to carry on with re-establishing and reformulating new identities in their post-migration contexts.

The process of disclosure was entirely different for Tulun. Her identity as an HIV-positive woman intersected with her identity as a black woman from an African context. She experienced forced disclosure of her HIV status upon her arrival in Canada. Revelation of this part of her identity within her cultural community made her vulnerable to the social devaluations and discriminations that were applied to persons with HIV from her original racial and cultural background. As a woman from her cultural background, her positive HIV status conferred on her the identity of being promiscuous and immoral. With this aspect of her identity no longer protected and private, she did not feel emotionally safe within her post-migration location. The distress it caused her is evident in the following quote:

> I can't do nothing...I can't go out...and depression...my pain...I can't eat...I can't wash...I can't do nothing...just the house. (Tulun, p. 3)

For her own protection, she relocated to another city. This indicates how the decisions and process of disclosure impact the identity of HIV-positive women, and intersect with various other aspects of their identity, such as gender, race and socio-economic status, to influence and shape how they are able to integrate into the new Canadian context. When she relocated in Canada, Tulun left behind a small familial and social network that was able to recognize other

aspects of her identity besides the HIV status. In the new location, however, she became invisible, seen only by the eyes of health care and social service professionals. She talks about her experience in the following quote:

> This problem came ...It's by force...I was separated from my son. I was given a ticket to go to a new city... I see people. They give me house...Like that ... I start a new life...but it is difficult. (Tulun, p. 2)

Previous studies have shown how one's finding a community of HIV-positive people has assisted with integrating the diagnosis with one's identity, and often has acted as a turning point in incorporating the diagnosis with one's sense of self (Baumgartner, 2007). This was the case for all the women in the study when they joined a support group of HIV positive women. Mageti talked about the benefits the group provided her in incorporating her HIV sero-logical status: *"They give me the courage to become positive" (*Mageti, p. 2*).*

Chidimma also talked about the importance of connecting with a group of people who are HIV positive, especially immediately after the diagnosis. Her explanation illustrates the importance of social interaction in the identity process, and how that interaction has the ability to assist the person to incorporate the diagnosis.

> Once they give you that information...You need someone to tell you...There are a group of people who are like you...You can go there...You can talk...Once that person goes there, he will be o.k. Some people it takes a LONG TIME for them to process the information...but if there is a certain group of people...certain workshop somewhere ...They can go there...They will be able to process it faster. If there is not information...You don't know what is next...you don't know where to go ...It becomes very difficult ...very difficult. (Chidimma, p. 17)

Within the context of the current study, the participants' identities as HIV-positive women seemed to be especially salient, although that identity was hidden from visual recognition. For all of them, their HIV serological status was a determining factor of their identity, and it had implications for how they were "viewed" within their own communities, the health care system, and Canadian society in general. However, how that stigma manifested for each participant varied depending on the participant's beliefs, social norms, social roles, community influences,

and practices. As a result, these women experienced HIV-related stigma in multiple ways, ranging from shame, alienation, exclusion and marginalization to poor access to health care, all of which affected their health and well-being.

Previous authors have found that the effects of multiple marginalized identities, such as gender, race, refugee status and socio-economic status, appear not to necessarily compound qualities associated with each identity (Meyer, Swartz & Frost, 2008). Individuals often demonstrate resistance to stigmatizing discourses so as to maintain their health and well-being. This is typically done by finding meaning in other aspects of their lives, whereby they assert social roles that have value (Goudge et al., 2009). This was evidenced in the current study when all of the women actively engaged in becoming pregnant, having children and being mothers. This is corroborated by Awitu Ujij, Ekstrom, Ilako, Indalo and Rubesnon (2010), who found that, for women within African contexts, a way of re-gaining self-status is through motherhood.

Racialization has also been found to be linked to health disparities. Previous authors who have looked at racial, gender and socio-economic status disparities have found that Black women have rated their health as much worse than their White counterparts rate their own health (Cummings & Jackson, 2008). This is significant, as experiences of health and illness are fundamental to how we understand ourselves (Kelleher & Leavey, 2004). For all of the participants in the current study, the addition of HIV to their pregnancy made them feel “more sick.” They also incurred additional health challenges that were related to the pregnancy or to the combination of pregnancy and HIV. Tulun experienced these as persistent nausea and vomiting. For Baako, it was “another condition” related to the pregnancy, along with a low birth-weight baby. This is illustrated in their descriptions.

> I had to be followed for another health condition related to the pregnancy... (...). The baby, his (weight) is very, very low, but he is healthy. (Baako, pp. 1, 2)

Similar comments were echoed by Tulun in reference to her health; she talked about how sick she felt, and how her feeling unwell made it difficult for her to walk:

> With pregnancy, I can't walk...I just walk like this (gets down on the floor, and walks on her hands and knees). It's so difficult. I'm very sick. When I am pregnant with HIV, I see a big difference...weak...more sick. (Tulun, p. 5)

Over time, the participants' construction of illness during pregnancy, which may very well be linked to an intersection of their racial, gender and socio-economic statuses, might in turn influence their perceptions of themselves as "healthy" women and their ability to carry out their roles as mothers and women within their cultural communities.

New social identities—based on refugee status, HIV status, socioeconomic status, and so on—affected and shaped the experiences of pregnant, HIV-positive women. Thus, it is important to consider the interactions between these different identities to better understand these experiences and the multiplicative effects on their health (and well-being) and their access to health care during pregnancy. By rejecting any linear or singular entitlement to any one social identity, intersectionality proposes that what is created at that intersection of gender, refugeeness, HIV and pregnancy is a completely "new" identity. This "new" identity cannot be simplistically evaluated based on the sum of its individual parts. Rather, it is important to consider the various influences that intersect at any one particular point in time. This tells us that intersecting influences may produce an entirely new social identity for pregnant, HIV-positive refugee women in post-migration contexts. However, the ways in which women identify themselves and are identified in the context of pregnancy vary based on refugee status, citizenship status, socioeconomic status, and HIV status in conjunction with other individual factors such as race, ethnicity, age, language, education, and previous life experiences (e.g., previous pregnancies, traumatic experiences, abusive relationships, etc.). Thus, for each of the participants in this study, micro-level forces that contributed to their identity interacted with each other, as did influences at the meso and macro levels, which will be illustrated in the following sections.

6.1.2 Meso-level analysis

Meso-level analysis examines informal and formal social networks that are closely linked to the experience of pregnant, HIV-positive refugee women. Here, it is important to locate pregnancy in a context of interactions with others (Guruge & Khanlou, 2004): interactions with family members, relatives, community members, health care providers, and with other social networks (school, neighbourhood, workplace, etc.). Rather than exclusively locating pregnancy within the individual body, it is important to recognize that interactions with informal and formal networks can have a powerful influence on the health and well-being of HIV-positive refugee women (Guruge & Khanlou, 2004). Interactions with members of social networks can be supportive or not, and can exert beneficial or damaging effects on physical, psychological, spiritual health and well-being. Conceptualizing health and well-being as relational processes, therefore, may assist in better understanding the experience of HIV-positive refugee women, especially in the context pregnancy.

Research has shown that, on arriving in a host country, refugee women are often relocated in physical and geographical spaces where they have no support network and where they eventually feel isolated and outcast (Kitzinger, 2004). Many refugee women are set adrift from their families, and they report a loss of social networks that are known to have a protective effect on women who experience life transitions (e.g., migration, pregnancy, illness) (Donnelly et al., 2011). This was true for the participants in the current study. Despite the fact that some of the participants migrated as part of a family unit, they all talked about the pervasive isolation they experienced as a result of their newness to Canada. This resulting social isolation left them particularly vulnerable to mental health issues, and put them at a particular disadvantage; this vulnerability placed them at greater risk during pregnancy. In this study, Chidimma talked about stress she experienced upon first arriving into Canada. She described it in the following way:

> I remember...when we came...I was really in deep, deep stress. I remember I used to walk and cry by myself. I felt like...We are lost...What kind of life is this... I

> could feel my heart pounding...Like it would explode... The stress... The stress started as soon as I put my feet on this land. (Chidimma, p. 4)

Chidimma migrated to Canada with her husband and family. For women who migrate alone or with their children, the isolation may be intensified further. Relocation stressors (including social isolation) and pre-migration experiences of possible trauma, torture, deprivation and abuse (psychological and physical) often make the situation untenable, and affect refugee women to a point where many of them will develop symptoms of depression, post-traumatic stress disorder (PTSD), psychosis, and suicidal ideation (Beiser, Johnson & Turner, 1993; Carolan, 2010; Reynolds & White, 2010). Tulun talked about the isolation and relocation and how these affected her mental health:

> You don't know nobody...We didn't see one person who spoke my language ...Nobody...We didn't know anybody...School, I can't ...I can't do nothing...I can't go out...and depression...I can't eat...I can't sleep...I can't wash...I can't do nothing...Just (stay) in the house...Alone...Depression is high. (Tulun, p. 3)

As discussed in the previous section, both pre-migration and post-migration experiences are considered relevant here.

For pregnant refugee women who have been diagnosed with HIV—most often upon their arrival to the host country—the situation of social isolation or exclusion may be amplified further. Women living with HIV are often isolated during pregnancy (Ingram & Hutchinson, 2000; Sanders, 2008). They are conflicted by doubts of their "right" to pregnancy and by social messages about the "evils" of childbearing when HIV positive (Sanders, 2008). Their relationships with relatives or friends who are pregnant or with other expecting mothers in their environment may be affected, and they may find themselves excluded from social networks that usually develop throughout the course of pregnancy (e.g., prenatal groups, discussion groups, support groups, social groups) (Ross et al., 2007). The current study found examples of this when women talked about their experiences of infant feeding, especially among those of similar ethnic origins. They felt excluded from these groups that might have been a potential source of

support. They knew that if they did not breastfeed their infant, members of their cultural groups would disapprove, and they would also risk exposure of their serological status.

Relationships with their spouse and family members may also be altered by an HIV diagnosis (Anderson & Doyal, 2004). This is attributed to the stigma associated with HIV, especially within African communities, which could position them as promiscuous or deviant women (Anderson & Doyal, 2004). As a result of this stigma, pregnancy in the context of HIV can lead to rejection by family members, eviction from the home environment, and special precautions (i.e., washing of kitchen utensils) within the family environment, or to other measures that attest to their families' irrational fear of transmission, which leads to limited and decreased contact with children and distancing of the spouse (Anderson & Doyal, 2004).

In this study, participants talked about how they kept the knowledge of their serological status to themselves, shielding it from family members in their country of origin, as well as from family members in Canada. They did not disclose their status to their children. Their spouse was often one of the very few people who knew about their serological status. This imposed emotional isolation exerted extra stresses on the relationships women had with their spouses, as the two of them bore the weight of maintaining the secrecy associated with keeping the diagnosis private. Some relief for this "secrecy" was offered when women were able to join support groups, usually offered by AIDS Service Organizations (ASOs) that provided a community and a place where the woman and her spouse could be open about the diagnosis. These organizations and support groups also provided a venue where they could learn not only about the pregnancy but also about what life would be like with the baby. As well, the groups provided women with information about other aspects of their health, including regular preventative screening measures that might be very different from those in their country of origin. Most importantly, women saw evidence of how one could live a full life while HIV positive. Mageti talked about her experience within the group, when she learned that a baby born with HIV can thrive:

> *I go to the group...I see a boy ...he is fourteen years old...He was born with HIV. I see...These people are living with HIV and no problem. This boy has a whole life and he is going to live. I accept myself.* (Mageti, p.3)

HIV-positive women may experience a double bind when they are pregnant: their pregnancy is filled with anxiety and distrust; yet it is also one that is hopeful about the "normalcy" of motherhood (Ingram & Hutchinson, 2000; Sanders, 2008). On the one hand, many women voice fears that their families will reject them if they disclose their serological status, and they express concerns over the repercussions of the disclosure in their lives (Bunting & Seaton, 1999). As discussed above, many of the participants in this study talked about the few people who knew about their HIV status. They were aware of the stigma of HIV as it was understood within their countries of origin, and they protected themselves from the effects of any disclosure. On the other hand, pregnancy in the context of HIV can have a positive impact on the lives of women who now identify themselves, and are identified by others, as mothers. The social meaning of "becoming a mother" and the fulfillment of this social role have been shown to enhance the self-esteem of women living with HIV (Ingram & Hutchinson, 2000).

Examples of this were evident in the current study. For Tulun, having children while HIV positive meant that she formed a new family in this country, establishing new connections after the many losses imposed by her serological status. Mageti framed it differently, revealing how the experience of pregnancy while HIV positive provided her with a new sense of life and possibility:

> *It gives you stronger power, because you know how much you can do with it. It means power...To take responsibility...To be present...To deal with any risk that you are going to get. It makes me want to have more pregnancies...To love more...to have other babies and other experiences...Back home...it is normal to have children...It made it special.* (Mageti, p. 6)

For Baako, the positive experience of receiving good quality care during her delivery made her optimistic about having other children while HIV positive. This is evident in the following quote:

> It was very good quality, the day of the delivery. Yes. I liked it because there was a lot of doctors and nurses. After I had the baby, they helped me and took care of

> me. It was like ...I told my husband I would be ready to go back again for another delivery. (Baako, p. 2)

The immediate and extended family may have a positive or negative influence on HIV-positive women who experience pregnancy, contributing both to a source of strength and a source of stress (Guruge & Khanlou, 2004; Ingram & Hutchinson, 2000). In this study, Tulun received negative messages from family members when she disclosed the news of her pregnancy. Still others, Baako, Mageti and Chidimma, chose to keep the news within a tightly knit circle of contacts to maintain their privacy and to protect themselves from the judgements that could result from being pregnant and HIV positive. The particularity of HIV-positive refugee women is the fact that they are most often separated from family, and they report an intensification of social isolation during pregnancy (Kitzinger, 2004), hence, the importance of engaging in meso-level analysis of social networks. This was the experience of all the participants in this study.

Intersectionality seeks to uncover the intersecting influences that lead to social isolation, including various forms of discrimination, exclusion, and oppression (Hankivsky & Christoffersen, 2008). Its aim is to discover the impact of social interactions (or lack thereof) on the person, while paying close attention to meso-level structures, networks, and communities that are closely linked to the experiences of health and illness. It provides a lens to better understand the social location of that person and its subsequent effects on health and well-being. In other words, it shows that opportunities to engage in “healthy” practices, to manage illness, or to participate in care are often shaped through interactions with various social networks: workplace (type of occupation, position within the echelons of the workforce, social benefits, precariousness, etc.); day care (costs, location, flexibility, availability); neighbourhood (geographical location, resources, travel costs, transportation methods and costs); family (family support, family members and relatives in host country, family roles and responsibilities); health care providers (approaches to care, services and care provided, delivery of care), and so forth.

This is particularly important for HIV-positive refugee women, who may see their health and well-being significantly impacted by these interactions (Guruge & Khanlou, 2004).

The following paragraphs will examine the journeys through migration, pregnancy and motherhood pathways for each woman in order to determine the intersecting influences that contributed to their social isolation. Their stories will illustrate how intersecting forces at various levels affected their formal and informal networks, which in turn have had implications for their health and well-being. Their stories are important, because they signify that, although the participants were all pregnant refugee women, their stories are both similar and unique, and can provide information on what interventions may best assist them in strengthening their resilience in order to maintain their well-being. The individual stories are also important for illustrating the continuity of experience, and for showing how perceptions and experiences in one context (pre-migration) may influence expectations and well-being in post-migration environments. Significantly, the stories of the participants exemplify how the social identity of HIV serological status and stigmatization both imposed and sustained their isolation as pregnant, HIV-positive refugee women.

Some of the details within these stories have been altered to protect the privacy of participants.

Tulun's Story

> *Tulun came to Canada with her young adult son from West Africa. Prior to her landing in Canada, she spent several years in a refugee camp in a country that bordered her country of origin. Her first husband left her after he learned that he was HIV positive. The only contact she had in Canada was a sister. Eight days after her arrival in Canada, she learned about her HIV-positive status. Subsequent to this news of her serological status, she experienced inappropriate disclosure of her status by a person within her ethnic community. This exposure led to her rapid relocation. Her son did not travel to her new location with her, nor did her sister. She maintained social contact (by phone) with her son and sister in the original point of entry, as well as with a brother in another country, and with family in her country of origin. She did not want to make friends in this new location, since she had experienced being "outed" in the previous setting in Canada. After learning about her serological status, she was unable to sleep, which lead to degradations in her mental health. This has affected her ability to work. As a result, she became dependent on social assistance as her source of*

> *income. This contrasted significantly with her economic and employment situation within her country of origin, where she had gainful employment. During her pregnancy, she experienced perceived stigma and discrimination within the hospital setting, and had many concerns regarding her ability to attend medical appointments without transportation assistance.*

If we examine Tulun's story with an intersectionality lens, we see a clearer picture of all the factors that contribute to her isolation as a refugee woman within Canada. She had pre-migration experiences within a refugee camp. Although Tulun never specifically made reference to these experiences, it has previously been pointed out that many refugee women experience pre-migration trauma that can subsequently affect their mental health, which in turn affects their ability to maintain and sustain social connections. The news of her serological status, and then her subsequent exposure, led to her rapid relocation away from the social support that she had in Canada. In her second location, Tulun had limited formal and informal social networks. She experienced depression and insomnia. Both of these made it difficult for her to maintain employment, further isolating her. Her small income, maintained by social assistance, limited her choices and opportunities for social engagement. It is possible that stigma and discrimination encountered within the health care system made her mistrustful of people, and led to additional isolation within the new context. Limited access to medical appointments made it difficult for her to maintain her health, which in turn affected her ability to engage with others.

Mageti's Story

> *Mageti is a Muslim woman from East Africa who migrated to Canada with her infant son. Her first husband died in her country of origin after becoming sick. There were rumours around the reasons for his death, and she left because of this situation. En route to Canada, she passed through another country, where her residency was prohibited due to entry bans on persons with a positive HIV serological status. She had one relative in that country. When she arrived in Canada, she was afraid to meet new people because of her serological status. Finally, she became connected to a support group for HIV-positive women (who are Black and came from African and Caribbean countries). Through new information acquired at this support group, she met her partner who is HIV positive. She also learned that it is possible to have a baby (who is HIV negative). She has one family member in Canada, but that person does not know her diagnosis, nor do her parents in her country of origin. This means that her husband is the sole family member who is aware of her HIV serological status. During her pregnancy, she received criticism surrounding the choice of the*

> *hospital where she delivered the baby, as well as for her choice to bottle feed rather than breastfeed her infant. She did not want people to visit her in the hospital. She made up stories to keep things private. She took the bus, bringing her school-age son with her, to attend medical appointments at the hospital. At the time of the interview, she was awaiting a decision on her refugee status.*

If we examine Mageti's story with an intersectionality lens, we see that pre-migration and post-migration experiences have affected her social networks. Prior to coming to Canada, she lost her first husband. His death, associated with possible HIV and its stigma, caused her to leave family and friends and to start at new life where she perceived that she could have more opportunities. While en route to Canada, she experienced exclusion related to her HIV status. This led to further displacement. In Canada, her social network is composed of her brother (who does not know her HIV status) and a support group through an ASO. The fact that only a few people are aware of her diagnosis contributes to her emotional isolation. In turn, her isolation means there are limited resources to assist her to maintain her health. As a result, she travels by bus, along with her school age son, to attend medical appointments. As her immigration status is still being decided, there is potential for more displacement, which in turn may also affect her social networks. At the time of the interview, Mageti was also considering leaving her current place of residence.

<u>Chidimma's story</u>

> *Chidimma migrated from Central Africa to Canada with her husband and children. She spent time in a refugee camp in a neighbouring country. This is a second marriage for both her and her partner. She came from a big family in Africa, where she was surrounded by brothers and sisters. The loss and lack of family support she experienced in Canada was an extreme source of stress for her. Since moving to Canada, they have moved from an apartment into a town home. She talked about the shame she felt surrounding her HIV status, and about her fear of disclosure. As a newcomer, she found it difficult to navigate the transportation (bus) system within the city. She also was disturbed by quarantine measures (associated with a possible tuberculosis diagnosis) that were imposed on her husband when they first arrived in Canada. During her pregnancy, she identified her husband as the sole source of her support. She talked about the difficulty of having kids and of being alone, with no friends around. She also revealed the post-partum isolation she endured, sometimes to the point that she did not eat during the day. When she bottle-fed her baby while at church, she experienced perceived stigma from other members of her congregation. She also feared "exposure" and judgment while attending the HIV clinic at the hospital.*

> *She talked about the difference in culture between Canada and her country of origin. At the time of the interview, Chidimma had obtained landed immigrant status. She was attending school.*

If we apply an intersectional lens to Chidimma's situation, we see some of the circumstances that contributed to her social isolation. She had no extended family members in Canada who were able to offer assistance in her transition to a new geographical location. Stigma and shame associated with her HIV status kept her from sharing this information with anyone, limiting the number of people with whom she could discuss her concerns related to her status. This lack of social support intensified during pregnancy and the post-partum period. When she returned home from the hospital, her lack of social support made it difficult for her to attend to her nutrition and to manage the pain she experienced. Thus, pre-migration experiences that associated pregnancy with a supportive familial context intersected with her post-migration context. Decreased community networks in her new context, HIV stigma, displacement and lack of formal networks in the post-partum period intersected to shape her experience of pregnancy, leaving her little relational and social support.

The stories of these women are similar in that they all experienced extreme social isolation as a result of their displacement. Their HIV status was a determining factor in this isolation, as they were aware of its associated stigma, and they took measures to protect themselves by limiting the number of people who knew about their diagnosis. HIV stigma and racial discrimination made them wary of new relationships, thus making their social networks small and homogenous. Because of their social isolation, they experienced increased stress in dealing with their illness and pregnancy, as well as in their adaptation to Canada. Their refugee status, HIV status and processes such as racialization and stigmatization affected both their formal and informal support networks. As will be seen in the following paragraphs, influences at the macro-level were also instrumental in affecting their social networks and their identities in the new country.

6.1.3 Macro-level analysis

Macro-level analysis critically examines the structures, organizations, and policies that affect the health and well-being of pregnant, HIV-positive refugee women, and that impact access to health care and services. The application of intersectionality to this context requires the analysis of macro-level factors (including, but not limited to, economic, political, and social factors) that affect access to health care and services, and of structural barriers that maintain high levels of health inequalities among HIV-positive refugee women who are expecting a baby. Despite the fact that refugee women have high health needs, they typically experience barriers in accessing health care, which translates into declining health status over time (Gabriel et al., 2011). Access to health care and services in the context of pregnancy may be complicated by factors such as (a) ease of use (including locations, hours, language, and consistency and variety of providers), (b) resources to make use of available services (including economic, informational, and practical resources), and (c) suitability of services provided (including gender-specific, needs-specific, and culturally safe care) (Sutherns & Bourgeault, 2008).

Access to health care and services in the context of pregnancy may be further complicated by structural barriers. Several studies have shown how refugee women report considerable difficulties in accessing affordable housing, sustaining sufficient income to meet their most basic needs, and finding employment or training services (Danso, 2001). In the current study, participants discussed how they were provided with recommendations for their health, but at times were unable to carry out those recommendations due to their limited income. An example of this was provided by Baako, when she talked about how nurses made suggestions about how she could enhance her nutritional status with certain foods. However, these foods were not within her financial means to purchase:

> When you're pregnant like me, I didn't eat everything but sometimes the nurse would tell me "You have to buy this," but I don't have the means; yes the means to buy these. I would like to, but I don't have the means and this is hard ...It's true, it's the problem, yes.... And all the other things that are expensive like diapers. (Baako, p.2)

Similar difficulties have been reported by refugee women with respect to accessing health care and services. All of the participants in this study talked about the difficulty of attending their appointments without some kind of transportation assistance. In one jurisdiction, this assistance was provided. In addition, one participant talked about how having another health condition related to the pregnancy made it necessary to attend additional appointments at the hospital. For two of the women, the lack of proximity to health appointments and the lack of transportation assistance made them consider relocating in order to more easily attend health appointments. The importance of this assistance was emphasized by one participant when she declared that, if any assistance were to be offered to HIV persons, transportation assistance to attend appointments would be the most helpful. This difficulty with access may in part explain why HIV-positive refugee women tend to engage in care when they have lower states of immunity, indicating that they are diagnosed at a later stage of the disease and are significantly more at risk for acquiring additional illnesses and opportunistic infections (Krentz & Gill, 2009). In addition, many women present with comorbidities, including latent tuberculosis, Hepatitis B, Hepatitis C, anemia, positive toxoplasmosis serology, malaria, Hepatitis A antibody, and parasitic infections (Pottie et al., 2007). They also present with physical injuries incurred as a result of trauma, torture and the difficulties of the refugee journey, as well as with low rates of preventative care such as cervical cancer screening (Costa, 2007). Thus, it is evident that pregnant, HIV-positive refugee women, often have complex medical histories and experience structural barriers to care that directly influence their health.

Guruge and Khanlou (2004) consider that the interplay of health, immigration, educational, economic, and social policies (and how it operates at various levels) is important to analyze when trying to better understand the experience of refugee women. Expanding on this idea, Oxman-Martinez and colleagues (2005) consider that federal policies constitute an

important starting point to critically examine barriers to health, and recognize that they function as an important framework to structure the experience of refugees.

To illustrate this point, there are two examples that are specific to the Canadian context and that also have implications for countries with similar policies. The first example has to do with the mandatory HIV-testing policy implemented in Canada in 2002. This policy has caused many refugee women to discover their HIV status either immediately before, or shortly after, their arrival into Canada, but it has failed to successfully link them to HIV care (Bisaillon, 2011). This was illustrated in the context of the current study. Participants talked about their experience during the immigration medical exam, when they were administered an HIV blood test in order to determine their status. For some participants, revelation of their serological status was delivered within the first ten days of their arrival into Canada. For others, besides the experience of overwhelming shock, it immediately led them to question the timing of the transmission, and whether this illness had been transmitted to any of their children. Chidimma provides an example of this when she talks about receiving knowledge of her status at the immigration medical exam:

> Oh Wow, it was a shock...it was a shock...by then I had my second child who was only 1 year old...my first thoughts went to him...like, Oh my God...What is this...For me, I thought it was like a kind of punishment...Right away, I just pray and say..Like God, if this is like a kind of punishment, please let it be just on me and not my innocent son. Really...It was very, very tough. (Chidimma, p. 1)

As mentioned in chapter five, for other participants who might have known earlier about their status, the HIV blood test administered in the immigration medical exam created fear and worry about their potential ability to remain within Canada. For example, Mageti did not disclose her HIV serological status freely during this exam due to fear of deportation. This was because she had passed through the United States en route to Canada at a time when the US banned the entrance of persons with HIV, and they were not permitted to stay in the country (Ofori-Asenso, 2013). That ban was subsequently lifted in January 2010, after it was recognized that HIV infection does not pose a risk to the public's health, because it is preventable and is not

spread through casual contact (CDC Fact sheet, 2009). This participant, who already knew her serological status, worried that she might face the same situation in Canada. The memory of the US non-acceptance of HIV-positive persons remained with her. Though Canada allowed her, as a refugee, to remain in the country, she nevertheless seemed to realize that her HIV serological status would subject her to specific forms of investigation, and might influence the decision that dictated whether she could remain in the country, or might affect her introduction and subsequent surveillance within the health care system in Canada. Had she been applying as an immigrant, she might have been subject to additional tests related to her HIV status, tests used to determine "Excessive Demand" within the health care system (Bisaillon, 2012). In any case, the results of the HIV blood test and the delineation of her serological status as positive or negative as part of the admissibility criteria to Canada were part of the series of events that were utilized to assess her right and ability to "belong." This was a determining experience in her access to Canada and also in her connection to future health agencies and social practices within the country.

For another woman, the revelation of her diagnosis at the immigration medical exam led to inappropriate disclosure of her status, and to her subsequent rapid relocation. Tulun talked about her experience of learning she was HIV positive, her lack of knowledge surrounding the diagnosis and her subsequent "exposure":

> This is really, really difficult, because the doctor told me that I have HIV 8 days after I came to Canada...Just one week. And when I got (the news)... And I don't know anything about it...A person came (a volunteer translator) to do the bloodwork...He took me to the hospital... To explain to the doctor....That is so bad for me and my son...This volunteer is African...This volunteer had a sister in the same English school as me....Just 2 weeks (after I came to Canada) EVERYBODY in the school who was an immigrant knew that I had HIV. (Tulun, p.2)

Thus it seems that, although some positively-diagnosed women subsequently were connected to care, others experienced adverse effects as a result of the Immigration Medical exam. From these examples, it is evident that this global screening practice mandated by the

government significantly impacted their experience. This included increased anxiety, worry and fear surrounding deportation, while for others, it led to rapid relocation to another city in Canada where they were alone and isolated.

The second example of a governmental policy that impacts the health of refugee women with HIV who are pregnant is the Interim Federal Health plan, which provides coverage for some "emergency and essential" services. This complex policy is difficult to navigate for refugee women, and it often acts as a barrier to health care and services (Miedema et al., 2008). Although the policy was not specifically mentioned within the current study, both Mageti and Tulun referred to a time when the health coverage changed:

> *Health coverage...Changed some things now as of June. People are not accepting the coverage (...) When things are going good, (you), don't need help. (You) only find out what is needed when things are not going good.* (Mageti, pp.2, 4)

Tulun also echoed concerns about a time when everything suddenly stopped. This meant that she needed to seek out alternate resources and means of support in order to access health services.

It is relevant that the time period referred to in these statements coincided with changes to the Interim Federal Health program that were implemented on June 30, 2012, by the federal government. These changes resulted in the elimination of valuable health care coverage for many refugees and refugee claimants, and they decreased access to health care services for most (Barnes, 2013). The funding cuts on June 30, 2012, amplified confusion and administrative complexity, preventing refugee claimants from accessing health care, even if they had a disease that was a concern for public health (Barnes, 2013; Evans, Caudarella, Ratnapalan & Chan, 2014). For certain refugee populations, it meant that there was little funding for conditions such as pregnancy, diabetes, and mental health.

Attention to systemic barriers is another aspect of macro-level analysis. Here, attention will be given to the analysis of the health care system and health care providers, because

several barriers reported in the literature pertain to ethnocentric and biomedical practices, social norms and expectations in the context of HIV and pregnancy, as well as bureaucratic and administrative processes (Hancock, 2007). An example of this is evident in Tulun's story. She experienced barriers to care when she attempted to access the health care system through the emergency department. She was first told that there was no place for her, and subsequently her experience resulted in a crisis situation. She also experienced barriers to care when it became necessary for her to take a medication in order to relieve the nausea and vomiting that she experienced during her pregnancy. In this case, she finally achieved access to the medicine she needed. However, in the interim, she suffered and experienced a worsening of her HIV illness. This illustrates how access to certain prescriptions affected whether the participant could obtain the necessary assistance to alleviate some of the side effects and symptoms associated with HIV and pregnancy.

Many of the participants experienced barriers related to social norms and expectations. This was illustrated repeatedly in the participants' stories of how pregnancy in their home countries contrasted with their experience in Canada. Here the social norm of independence and self-sufficiency contrasted with their customary social norm of collective support, especially during the post-partum period.

Sometimes the attitudes and practices of their health care providers also create difficult social situations for the women. Research indicates that HIV-positive refugee women often find interactions with health care providers problematic because of the way they impact and transform the meaning of the pregnancy (talking about it as a disease-like experience vs. a natural experience) (Ingram & Hutchinson, 2000; Monticelli, dos Santos & Erdmann, 2007). In other words, women often feel that they are seen only as HIV-positive women and sick bodies, with any sense of normalcy about the pregnancy being lost (Ingram & Hutchinson, 2000). Sometimes health care providers are insensitive to their patients' needs for confidentiality. Mageti was subject to inappropriate disclosure by one of her health care professionals when a

member of her family visited her in the hospital post delivery. This encounter was particularly distressing for her, as it brought HIV to the forefront of her experience when the focus for her visitor should have been the mother and the newborn baby. Some women find the health care regime to be onerous. Baako found that her pregnancy involved more appointments compared to previous pregnancies. Even though she also had an additional condition to HIV that was associated with her pregnancy, she did not really understand the reason for the numerous appointments. Furthermore, many refugee women often report that health care providers lack understanding of cultural differences in their interactions with them (Brown et al., 2010; Chalmers & Omer-Hashi, 2002). This was evident when the women talked about going to the hospital, the number of appointments associated with the pregnancy, as echoed in Baako's situation above, and the isolation that they endured, especially during the post-partum period.

Thus it is apparent that health care providers' lack of sensitivity and shortcomings in communicating effectively with their patients may result in women disengaging from care, because they either wish to maintain a sense of normalcy or to distance themselves from an approach to pregnancy that is disconnected from personal values and cultural beliefs.

Stigma, discrimination, and various forms of disrespectful treatment in health settings are known to act as barriers to accessing care and treatment for HIV-positive women, and, in some cases, cause patients to disengage from care completely (Lindau et al., 2006; Naab, 2006). Some studies indicate that nurses are significantly more prejudiced and less willing to care for HIV-positive women for than HIV-negative women (e.g., see Tyer-Viola, 2007). In the current study, Tulun was extremely distressed when she perceived that health care providers (nurses during delivery) did not want to touch her. She also wondered whether the problems she had with accessing emergency care were related to discrimination associated with her skin colour or her HIV status.

Women who are unfamiliar with the health care system may not be aware of their right to equitable and quality health care, the roles and responsibilities of health care providers, or the

care and support needed during pregnancy (Oxman-Martinez et al., 2005). This can be exacerbated by various factors that make health care complicated and confusing (Merry et al., 2011). Within the context of this study, Chidimma found her first experience of accessing the hospital extremely distressing. Although this visit was related to her husband's health and not her own, she spoke of the feeling of being "separated" by her husband's imposed quarantine and isolation:

> My first experience...It was...because my husband was coughing ...and they were not sure ...You know...Coming from Africa...They are not sure if it is TB or only a pneumonia...But he was put in an isolated room...They come and see him ...The doctors who come into the room wore the mask...You know ...That feeling (of the mask)... did not feel good. (..)..That was an awful experience ...The Mask...It was crazy ...It was crazy. (Chidimma, p. 5)

If we look at Chidimma's reaction to this experience, we see that her feelings of being "separated" were intensified by her husband's isolation procedures. It is also significant that, for persons from her country of origin, tuberculosis is referred to as "the disease of distance" and is described "as a person invading people" (Beenstam, Strandmark & Diwan, 2004, p.299). Chidimma's experience shows how dealings with health care providers interact with cultural associations from her home country.

When issues like the aforementioned arise during interactions with health care providers and intersect with other issues, they result in serious implications for HIV-positive women, who may end up under-utilizing health care and services, or who may be lost to follow-up during pregnancy. This, in turn, may put these women at risk for inappropriate or suboptimal treatment and for complications (Oxman-Martinez et al., 2005).

6.2 Summary

Intersectionality as a theoretical and analytic framework has been utilized as a way to attain further understanding of the lived experience of HIV among refugee women in Canada. The health of pregnant refugee women who have HIV is complex and intricately attached to their social identities, social supports and community. They undergo significant alterations in their

identity that may be attributed to the stigmas imposed as a result of refugee status, HIV status, and the context of pregnancy, as well as to the processes undergone during migration and re-settlement, such as racialization, gender role adjustments and lack of acknowledgment of educational credentials. Social support, an integral determinant of health, is altered, as refugees are so often separated from family and community, leaving them vulnerable to degradations in their spiritual, emotional and mental health. Access to health services is often complicated and confusing. Pregnant, HIV-positive refugee women often experience not only language, discriminatory, financial and transportation barriers when they attend health care appointments, they may also be subject to perceptual barriers regarding their HIV care and to lack of caregiver knowledge concerning particular cultural practices, which directly affects their obstetrical experiences.

For all of the women within this study, the revelation of their serological status during the mandatory immigration medical exam intersected with both the micro and meso levels of their experience. It confirmed an identity that determined pathways along the immigration process, and also affected the social interactions within their ethnic communities and within the larger Canadian society. An identity as a serologically “positive” HIV woman had specific connotations that they carried with them from their countries of origin, which in turn affected their self-concept and movement within the new geographical context of Canada. At times, the HIV serological status made them mistrustful of health care providers or afraid to meet new people, while at other times, the physical effects of the illness left them feeling physically weak. In any case, the overlapping influences perpetuated a persistent isolation, which was very often only interrupted when women were able to connect with other HIV-positive women who were in similar situational contexts. These contexts often became a source of information sharing and mutual support. The HIV serological status connected them to a health care system that identified them as “positive,” assigning them to a process of life-long surveillance. The other macro-level force was the Interim Federal Health program, which determines the type of health coverage that

refugee women with HIV have access to during the course of their pregnancy. As mentioned earlier, this was not the focus of the study, but participants did make reference to some aids that were provided at one point, and then suddenly ceased.

The additional intersectional analysis is particularly important in order to further our understanding of the lived experience of pregnant, HIV-positive refugee women. While a phenomenological analysis provides insight into the phenomenon of HIV and pregnancy for refugee women in Canada, an intersectional analysis is especially useful as a lens for highlighting the inter-related and co-constructed nature of social locations and experiences (Hankivsky & Cormier, 2009). Such an analysis recognizes that the dimensions of social lives cannot be delineated into separate elements (Brah & Phoenix, 2004). An intersectional analysis provides depth to the analysis in order to fully portray the lived experience of participants' lives. It recognizes variance within groups, and views social categories as dynamic, historically grounded, and socially constructed at both micro- and macro- structural levels (Burges-Proctor, 2006). It provides insight as to how various dimensions of social identity such as race, social class, gender and sexuality, as well as citizenship and geographical locations shape and contribute to the complexity of the participant's experience (Guruge & Khanlou, 2004).

Intersectionality brings to the forefront the impact of power and its role in creating and sustaining the person and social structures of discrimination and oppression (Hankivsky & Cormier, 2009). Systems of domination and processes of subject formation are influenced by time and place. An understanding of systems of power, such as racialization, gender, stigmatization and socioeconomic statuses, and the intersecting effects of history, political context and social processes come together in unique ways, affecting peoples' experiences and identities (AWID, 2004). This is particularly relevant in understanding the effects of displacement and the subsequent barriers and facilitators that individuals encounter as they attempt to create places that offer them the opportunity to restore safety, security, a sense of self and social relationships (Sampson & Gifford, 2010). In order to fully understand the experiences of women

with HIV/AIDS care, an intersectional analysis is crucial in recognizing the role of oppression – that is, political, economic and social power processes – based on axes of discrimination (e.g., gender, races, ethnicity, religion, age, sexual orientation, and geography) that impact women's lives (Msimang, 2003). Only then are we able to begin the process of transformation that challenges the status quo and promotes social justice and equity, which may in turn alter, for the better, the experiences of pregnant, HIV-positive refugee women.

CHAPTER SEVEN

DISCUSSION

Chapter seven presents a discussion of the major findings that were revealed in chapter five and in the intersectional analysis that was constructed in chapter six – findings that will allow the lived experience of HIV and pregnancy among refugee women to come to light. The aim will be to link previous knowledge within the field as outlined in chapter two (literature review), as well as to make connections and interpretations through the lens of the theoretical framework as presented in chapter three. Following this discussion, the last section of the chapter will present some novel and potentially beneficial applications for clinical practice, education and nursing research. Finally, limitations of the study will be discussed.

Moving through a Liminal Reality

One of the major themes that surfaced during the phenomenological analysis was “Being In-between.” In this study, two subthemes were also identified: “being in-between lived spaces,” and “being in-between feelings.” This being in-between physically, spatially and emotionally situates pregnant, HIV-positive refugee women in a liminal existence, a border zone where they experience an existential crisis in which they are neither the person they once were, nor yet the person they strive to be (Rainbird, 2014). In response to this in-betweenness, they work to set in motion a course that propels them forward to a future that is crafted in their own understandings of themselves and who they would like to be and to become in the new context of Canada.

In light of this, the lived experience of HIV and pregnancy among refugee women in Canada is analogous to *moving through a liminal reality*. The movement through this liminal reality is both spatial and affective. More than a feeling of being propelled forward in a linear motion, the movement denotes an intentionality and expansiveness that is directed at establishing and promoting one’s “place.” This place attachment involves not only the physical work of establishing a location where one dwells but also includes attachment to a “place identity” that is formulated within the new context, along with the sense of belonging that is

related to “place” attachment. The usefulness of liminality has been noted by other authors who identify it as a pivotal concept in relation to situation-specific theory of well-being in refugee women experiencing transition (Baird & Reed, 2015).

The liminal aspect of this reality describes an “in-between” space in which change and adaptation occurs. Because this study involves women from different ethnic, religious and racial geographical origins, liminality denotes a “transcultural space in which strategies for personal and communal selfhood may be elaborated” (Ashcroft et al., 2007, p.117). Within this reality, pregnant, HIV-positive refugee women engage in a constant process of connection, contestation and appropriation as they seek to find and establish place. As stated by Bhabha (1994), this is the “Third space”: the enunciative site of negotiation where pregnant, HIV-positive refugee women “shape their individual, community and national identities, integrating what is adaptive, and retaining that which is incommensurable.”

In this “in-between” state, pregnant, HIV-positive refugee women negotiate ambiguity. The women strive to settle the ambiguities of their situation between the lived spaces of both their homeland and the new country, as well as the ambiguities of feelings related to their HIV-serological status and the experience of pregnancy in Canada. This state of “in-betweenness” has been noted in other studies that have sought to discover the distinctive realities of women who have been born outside of Canada. Donnelly (2006) used the concept of living “in-between” when she explored how Vietnamese women living in Canada practice health care. She found that it often involved a complex, non-linear process—a process in which women recognized their special sense of being different, and negotiated these differences in order to cultivate contextual solutions according to their unique circumstances. Meleis (1991) also found “in-betweeness” to be a useful descriptor when she advocated for the importance of understanding the delicate interplay between identity, roles and health for immigrant women.

Within this liminal reality, three other aspects came to light as they represented the lived experience of pregnancy for HIV-positive refugee women. The first of these included *restoring a*

disrupted, "Othered" identity that had been imposed as a result of their HIV and refugee status. These identities contributed to the social isolation and disconnection that typically characterizes a liminal space. The second theme that emerged within the liminal reality was *untangling isolation and finding place* as these women worked to interrupt the isolation that characterized their experience. The third aspect of this liminal reality was *traversing a web of systemic barriers* that shaped how participants were able to move through Canadian society, and how they interacted with the health care system. Pregnancy became their reason for being, and empowered them to overcome barriers to health care access in order to ensure safe delivery for their infant. Each of these will be discussed further in the following sections in order to illustrate more fully the lived experience of pregnancy for HIV-positive refugee women.

① Restoring a disrupted identity

Becoming a refugee has been described as a rupture, a cutting from the homeland that involves a traumatic displacement with a resultant loss of who the person once was (Rainbird, 2014). For the women within this study, their HIV serological status further disconnected them from their cultural communities. Thus, these participants experienced a rupture in identity as a result of both their refugee status and their HIV status. Once arrived in Canada, they set about a process of rebuilding that identity. Pregnancy that led to new motherhood was integral to this restoration. It brought meaning to their life, and allowed them to re-establish their identity as good mothers and as women, despite the negative aspersions they were subject to as a result of their HIV status.

The "Other" identities of HIV-positive status and refugee status assigned to the participants within this study contributed to their being positioned as "different" in Canadian society. This is congruent with Homi Bhabha's conceptualization of "difference," what happens when individuals are conferred a stereotyped, pre-determined, "less-than" identity as a result of cultural/historical and racial discrimination (1994). According to Hopkins (2010), refugee status designates an individual as a new kind of person, and confers on them a specific type of

relationship between themselves and the nation state. This observation is also in line with Lacroix (2004), who talks about how becoming a refugee impacted the way women viewed themselves in past, present and possible future contexts. Additional scholars have also explored how this imposed identity crisis catapults refugees into a re-formulation of self with two states of being, one that looks backward in order to retain a cohesive sense of self, and one that looks forward to create a new sense of self in the new context (Connor Schisler & Polatajko, 2002; Dossa, 2008; Wilcke, 2006). Dyck & McLaren (2004) assert that the assignment of the "refugee" identity carries women into an unparalleled state – a doubling of discrimination associated with ethnic, HIV or religious identity, and the refugee category that further marginalizes. These authors describe the process of rebuilding and restoring identity as follows:

> These identities are highly conditioned and negotiated through social and political relations and processes – including representations – that racialize women's bodies and construct an immigrant identity with profound consequences of how "womanhood" is interpreted and lived in "migrant spaces" emerging from places of globalization.... All this is mediated through available hegemonic discourses, including that of "immigrant" and normative "womanhood." (p. 529)

Since this assignment of identity positions refugee women in relation to social and material resources, it puts into play a process whereby each woman sets off to restore the identity that has been fractured, dislocated and Othered. This changing sense of self develops over time and often includes retention and modifications of dress, religious practices and language that help to maintain identity integrity throughout resettlement, but may also take on new significance as refugee women take steps to reposition these identities in the host land (Hopkins, 2010). The process of deciding which customs and practices to retain, modify or add to their identity challenges social categories such as race, class and gender along with some of the taken-for-granted assumptions associated with "cultural difference." It is a dynamic progression rife with tensions, contradictions and resistance, and the process is a "lot of work" (Viruell-Fuentes, 2011). Such was the case in this study, as women "worked" to establish who

they were in spite of limited socio-economic resources, acculturation stressors, precarious immigrations statuses and negative stereotypes.

All of the women relocated from areas in Africa that had been colonized by French speaking countries; thus their French language fluency had the potential to both help and hinder restoration of their identity. Identity was re-enforced and rebuilt when they had effective and satisfying communication with members of their cultural communities as well as with their host context. However, if they became subject to the effects of discrimination related to the "difference" within their French language dialects, they needed to negotiate their identity and right to belong in different ways. Such findings are reiterated in Warriner (2007), who recognized the integral part that language plays in forming identity in a place that is not one's homeland. In addition, all of the women in this study were actively speaking and learning English as an additional way to communicate, adding additional and transformative aspects to their identities.

As illustrated in the previous chapter, religious affiliation was instrumental in both retaining a core aspect of their identity, as well as facilitating identity restoration and adaptation in their new contexts. It helped them to make sense of their circumstances, as well as to develop realistic expectations of life goals. Religious doctrine and philosophy also assisted with their decision-making. In addition, practices such as prayer and rituals associated with a particular religion often provided a sense of self-care and soothing, thereby providing stability and steadfastness to their identity. Some of the women chose to retain aspects of their dress that signified their religion; for example, some continued to wear the hijab, which identified them as Muslim. Other authors have verified that incorporation of a religious identity can provide a system of meanings and offer feelings of strength that are helpful when a person encounters stress and adversity (Reimer-Kirkham, 2014). Dossa (2008) also illustrated how Afghan refugee women utilized prayer for personal and therapeutic time, gaining solace and comfort from this tradition, and how they also used it as a way of passing on that identity to their children.

Gergen (2000) maintains that understandings of our self are inherently rooted in community; so in this discussion, we draw attention to the importance of relationships and social exchange in refugee women's restoration of their identity (Siddiquee & Kagan, 2006). In rebuilding their identities in the new context, all of the women in this study maintained a strong attachment to their home country through phone contact, contact with family members and media presentations surrounding events in their home countries. Such practices helped each woman to retain aspects of her past identity (i.e., as sister or daughter) that might not be available in the new context. In addition, the women in this study retained positive memories of practices belonging to their homelands, especially those practices around pregnancy, birthing and the post-partum phase. This has also been observed in previous studies of refugee experiences: retaining positive memories of their homeland was not only an important way of restoring identity for refugees but also helped them retain connection to the community they lost (Carranza, 2008). Rather than viewing these memories as intrusive, refugees understood that keeping these memories was a way of making sense of past traumatic experiences, and of re-narrating and reconstructing the story of their lives in new contexts (Carranza, 2008). Positive memories connected them to a time that was not associated with migration and relocation, and helped them remember a time of belonging.

The current study found that the women's identity as being HIV-positive disrupted their cultural identities, their identities as women and their identities within the nation state of Canada. This is in line with previous studies that have examined the powerful negative social discourses associated with HIV/AIDS that results in a "spoiled identity" for HIV-positive women (LeClerc-Madlala, 2001; Mupenda et al., 2014; Othieno, 2007; Rohleder & Gibson, 2006). This discourse was transnational, informed by the knowledge and processes they were exposed to in their home countries, as well as new knowledge, practices and relationships encountered in the host environment. Similar findings were present for Cavaleri and colleagues (2010), who found that both the country of origin and the cultural background of women had implications for

understanding their experience of HIV. Similar findings were also noted by Bisaillon (2011), who concluded that being identified through the immigration process as HIV-positive alters the woman's identity so she becomes defined by disease, transmission, infectivity and sexuality (Bisaillon, 2011).

For women in the current study, the addition of HIV to their pregnancy altered their identity as mothers. An existing stigma is intensified in pregnancy when the woman becomes exposed to the surveillance of other community members regarding mothering practices that could be deemed deviant and could inadvertently link them with an HIV diagnosis. This intensification of stigma has been noted in other studies, making the task of restoring identity during this time a complicated endeavour (Giles, Hellard, Lewin & O'Brien, 2009; Ingram & Hutchison, 2000; Sanders, 2008). Previous studies have likened the change in identity for HIV-positive mothers to a "fall from grace" (Valencia-Garcia et al., 2008). Women who become pregnant when they are HIV positive are often viewed as selfish, sometimes leading them to question their desire for children. Their identity is reconstructed from that of a loving, caring and capable mother to one who lacks ability and may potentially not be there for her child (Valencia-Garcia et al., 2008). In summary, HIV infection in the context of pregnancy can impose a move along the identity spectrum for women, shifting and trapping them in an "identity game" without providing them with any instructions to an optimal course of action, and depriving them of the recognition and respect that is dictated by their cultural norms.

Despite the discrediting associated with HIV and pregnancy, all of the women in this study identified intensely with being pregnant and becoming a mother. The importance of this identity has also been recognized in other studies. Fouquier (2011) looked at the concept of motherhood among three generations of African women, and found that motherhood was "a source of power and provides significant meaning, satisfaction and respect within the family and the larger community" (p. 145). Etowa (2012) echoed this finding when she examined the childbirth experiences of African-Canadian women. In addition, Kennedy and colleagues (2014)

identified the importance of motherhood for HIV-positive women, particularly for women who claimed African ethnicity, along with women who had been in Canada for fewer than ten years. This experience acted as a bridge to reconnect them with their original selves that had been fractured and disrupted into an “Other” identity as a result of their HIV and refugee categorizations.

Although this restoration often involved a shift in the conceptualization of what it meant in their home country to be pregnant and a mother, it influenced how they were able to fit in within their new Canadian contexts. Memories of pregnancy, motherhood and the post-partum period represented an aspect of identity that was transformed in the new environment. As refugee women who were HIV positive, they sometimes mourned for the positive memories of family and belonging that were associated with pregnancy and the post-partum period in their homeland. At the same time, they realized that their ability as an HIV-positive woman to have a baby (who would be HIV negative) was an opportunity that might not be available to them in their countries of origin. This is a good example of how the identities of HIV-positive refugee women are altered in new contexts by the availability of opportunities that might not have existed at home (Smith, 2013). Becoming a mother in the host environment allowed them to assert the positive identity of motherhood within their cultural origins. In restoring this aspect of their cultural identity, they also were able to mitigate some of the “spoiled identity” that was associated with the HIV diagnosis. As noted in other studies, child-bearing not only enhanced the self-esteem and identity of women, it also provided them with a reason to be, the will to fight the infection of HIV and a means of social survival (Ingram & Hutchinson, 2000; Nelms, 2005).

Restoring a disrupted identity was not without its ambivalences and ambiguities. All of the women in this study experienced ambivalence at the outset of the pregnancy that situated them “in-between” feelings that fluctuated during the course of the pregnancy. They worried about the baby’s health, how they would feed the baby, about their own health and about its effect on their ability to care for the baby after the birth and in the future. Minnaar and Bodkin

(2009) compared this to a type of grief response that led HIV-positive mothers to think differently about themselves, but at the same time to make accommodations to carry on with the pregnancy. Youngwanichsetha and colleagues (2010) described this as “weighing distress” that was related to initial ambivalence about continuing the pregnancy, to the exploration of alternative paths, and finally to the determination of an appropriate choice. This ambivalence affected their identity as mothers, and is shown to be in line with other studies that have looked at the impact of HIV and pregnancy. Stinson & Meyer (2012) spoke to mothers who revealed their anxiety about their HIV infection and their preoccupation with keeping the child safe and free from the illness. The mothers in Stinson & Meyer’s study described a diminished sense of pride about motherhood that was linked to guilt associated with the newborn’s vulnerability to HIV. Although the women in the current study grappled with worries related to their HIV status, they found joy in their status as new mothers. This difference could reflect variation in context, as Stinson & Meyer’s study took place in a South African context where the prevalence of HIV is much higher and is reinforced by poverty and gender power differentials (Gupta, 2002). In both studies, the HIV infection was seen as something that could destabilize and undermine their identity as mothers. Thus, their HIV serological status added a potentially problematic dimension to the pregnancy.

The experience of being pregnant in the new context often led these women to feel disconnected and to question their identity as a mother when they could not use mothering practices that had been natural to them in their home context. Such was the case for the practice of breastfeeding that was prohibited because of their HIV status; this caused them again to feel disconnected and “Othered.” The disruption to the identity of HIV-positive mothers who do not breastfeed has been noted in other studies. According to Stinson & Meyer (2012), women thought that the practice of “not breastfeeding” diminished their status as a mother; they also thought that not breastfeeding revealed their HIV serological status, which further acted to discredit them. Similarly, Moland (2004) reported how not breastfeeding was recognized as both

a failure of motherhood and as a warning sign about the mother's probable HIV-positive status. In Canada, Greene and colleagues (2014) found that women's identities as mothers were put into question (by both the mothers themselves as well as those around them) when they felt that they were not performing their womanly duties by not breastfeeding (Greene et al., 2014). In the current study, as well as that of Greene and colleagues (2014), women felt that they were constantly being watched to see if they would breast or bottle feed, which could reveal their HIV status.

To resist this threat to their motherhood identity, as well as to avert disclosure of their HIV status, the women engaged in acts of resistance that served to restore and maintain their identity as mothers. They made up stories in order to reconstruct their images and identities as pregnant women and mothers. These stories allowed women to construct and maintain their identities as good women, wives, friends and mothers, and to move through the pregnancy with an intact self. The stories were usually designed to keep the HIV diagnosis concealed. They provided pragmatic explanations for their behaviour so that they could substantiate their actions and, at the same time, put in place images of themselves as responsible and attentive mothers who were acting in the best interests of their children. The practice of making up stories is similar to what Greene and colleagues (2014) found in their study, where women talked about making up "excuses" when faced with interrogations that threatened their identity in the context of motherhood. Similarly, Giles and colleagues (2009) talked about the "work of preparing an alternative story."

Women also worked to restore their maternal identity in the face of HIV infection by concentrating their efforts on protecting the baby from HIV infection. This has been noted in several other studies (Jones, 2008; Ross et al., 2007; Sandelowski & Barroso, 2003). In this study, they endured the side effects of anti-retroviral medication, both physically and emotionally, and worked to ensure that every effort was made to have a healthy baby and safe delivery. Giles and colleagues (2009) described this as the "good" work of mothering. They

described how the women engaged in surveillance and safety work to prevent the spread of infection, and in information-gathering to make decisions regarding care for their physical bodies and the demands of HIV infection. Similar to the finding of the current study, women cared for themselves in order to sustain their health by attending to good nutrition and other aspects of good self-care (Minnaar and Bodkin, 2009). Such efforts helped them to maintain a positive maternal identity.

The challenge to restore their identities was intensified as these women made their way though unfamiliar contexts with constrained resources and unstable immigration statuses; they had to constantly negotiate their right to thrive in the new setting. Danso & Grant (2000) noted this when they discovered how gender intersects with race, class, marital status and immigration category to hamper ethnic minority women's access to needed housing. Other studies have also noted how migrant women, as part of the minority group in society, tend to experience social repression, racial bias and negative interactions with health care providers (Carolan & Cassar, 2008). These types of encounters meant that the women in this study had to make extra efforts to put in place such things as housing and health care that they needed to survive. Their physical health, their immigration status or their need to stay home and look after other children also presented challenges when they attempted to secure employment. This finding is in line with other studies that have shown that immigrant women are less likely than immigrant men to be employed (CRIAW, 2003).

In summary, the experience of pregnancy incorporated not only identity transitions associated with the current pregnancy but also carried with it from their previous lives associations that were connected to their HIV and refugee status. The restoration that resulted from this ongoing negotiation to reconcile their identity as HIV-positive women who were pregnant and mothers in a new context led to a new social identity. This process is also reflective of what Bhabha (1994) considers to be hybridity: the constitution of a "new identity" that is formulated when persons of different cultural systems interact. Such interactions often

combine elements of both cultures, and they lead to a transformation that produces something new and unique. Such was the case in this study when women retained aspects of their identity formulated within their countries or origin, but adapted and negotiated new identities around motherhood and self as they moved through daily experiences, interacting with the host society and members of their cultural community to establish this "new identity." This new identity was a reflection of their place of interaction and was part of the process of establishing "place identity" within the new context. The agency that pregnant, HIV-positive refugee women have is like a type of social survival, whereby they display their own "selfhood" despite being in the midst of contradictory demands and practices (Bhabha, 1994). Such acts are transitional, transnational and transformational. These experiences position them in Canadian society, and are pathways to both inclusion and marginalization, as will be seen in the next section.

② *Untangling isolation and finding place*

The social isolation and disconnection that typically characterize a liminal space defined participants' experience and produced what some authors have referred to as a "social death" (Rainbird, 2014). During this time of uncertainty, reconnection became extremely challenging, as social isolation produced feelings of alienation and suffering (Rainbird, 2014). *Untangling isolation and finding place* became predominant modes of being while they attempted to interrupt the isolation. They engaged in acts of agency by joining support groups, making connections with other women and finding safety in stories and in silence. The imposed identities of HIV-positive status and refugee status cast women adrift and relocated them socially where they experienced loss of social networks and isolation.

The untangling of isolation is about the efforts that women engage in to unravel this isolation and to create a sense of belonging. According to Hout, Dodson and Rudman (2014), belonging is "influenced by processes of mobility, identity and place." It can be understood as "feeling at home," where individuals build attachment to place over time" (p. 330). Viewed in this light, belonging is not just a personal matter but also a social one (Antonsich, 2010). This means

that one's personal feeling of belonging interacts with the discourse and practices of inclusion/exclusion (Antonsich, 2010). The social processes of inclusion and exclusion shape this belonging so that it unfolds as a fluid process that is continually performed through multiple practices in relation to one's body, household, and community (Blunt & Dowling, 2006). In addition, particular places impact belonging through the unique blend of social relations forming within them, making the process of untangling isolation and finding place dynamic and shifting, and something that is negotiated and alterable (Gilmartin, 2008; Hout et al., 2014).

In this study, their identities as black women having different language dialects as well as specific attire that signified their associations to a non-Christian religion positioned the participants as "new" and "minor" in Canadian society; it made them vulnerable to the processes of discrimination and racialization. This finding is in line with other studies that have found that social exclusion, often based on discrimination related to "race," ethnicity, gender and religion, situates refugees as "unwelcome others" (Chapra & Chatterjee, 2009; Danso, 2001; Dyck & Dossa, 2007; Galabuzi & Teelucksingh, 2010; Hynie, Crooks & Barragon, 2011; Talebi & Desjardins, 2012; Teixeria & Li, 2009). According to Danso and Grant (2000), non-English speaking and racial minority women often become constituted as a segmented, gendered and marginalized group. The effects of this omnipresent social exclusion and the absence of protective supportive social relations intensify adaptation processes and contribute to their feelings of being "lost," vulnerable, and weary. Such findings were in line with Walsh and Krieg (2007), who discussed the social anguish experienced by minority groups in Canada, as well as with those of Beiser (2005), who documented that the multiple social losses refugees incur have implications for their mental health and their ability to form new connections.

In spite of such difficulties that have been documented by other research, the findings of this study demonstrated that women persisted and consistently engaged in daily efforts to contest and unravel their isolation. They joined local support groups, attended medical appointments and were visited by various service organizations. This finding is in line with

Shellenberg and Maheux (2007), who found that refugees must work to rebuild and establish new associations that have been ruptured as a result of their dislocation. Danso (2001) illuminated how engagement with these social networks and public institutions was instrumental in providing assistance to refugees during the course of resettlement. In the current study, women formed alliances with other members of their ethno-cultural communities for child-care support and also for the purpose of learning about different opportunities available to them within the new context. Such findings were similar to those of Wahoush (2009) and Simich (2003), who found that these associations helped refugee newcomers make decisions about housing and health care, as well as provided valuable emotional support and affirmation. This re-establishing of new associations also echoes other studies that show that many refugees initiate a process of co-ethnic peer support in order to construct a sense of belonging that acts as a springboard to addressing other basic needs (Hynie et al., 2011; Kopinak, 1999; Simich et al., 2003). As shown in the previous sections, the study observed that women also maintained contact with their home countries. This was another strategy, documented as well in other studies, whereby contact with the home community acted to reduce and ameliorate some of the effects of isolation and to help women retain some sense of connection and belonging to the cultural group (Dossa, 2008; Sherrell & Hyndman, 2006; Walsh & Krieg, 2007).

The addition of HIV to the women's refugee status reinforced their isolation, since stigma translocated from their countries of origin disconnected them from their culture and combined to create a "double isolation" (incurred from their status both as refugees and as HIV positive) that was enacted in the host context of Canada. This is in line with other research findings that HIV-positive women, especially in African contexts, may be forced to leave their homes if their HIV status is disclosed; they fear being rejected and condemned, because once a person's HIV status becomes known, they are treated differently by family members and members of the community at large (Othieno, 2007). Faced with the fear of rejection, the women in this study were wary of interactions even with people whom they knew, and they were hesitant to form

new contacts. This fear of rejection extended to family members, and, as a result, the family support that one normally associates with pregnancy was not available to them. Thus, family relationships were also altered if women sensed disapproval or rejection regarding the pregnancy. Such encounters led them to protect themselves from any judgement by keeping their HIV status private; they took great care not to disclose their status in order to enable and sustain relationships, and to protect themselves from any potential rejection or abandonment that they could have previously experienced in situations related to disclosure. This study found that, because of their need to protect their HIV status, women most often identified their husband as their sole source of support. Brickely and colleagues (2009) shared this finding of the husband being the only source of support, even in cases where the woman's partner did not have HIV.

One of the main findings of the current study relates to the efforts women undertook to avoid the disclosure of their HIV status. The women were well aware of the associated meanings attached to HIV and how the disclosure of their status had the potential to further isolate them and destroy what little social connection they had in their new context. This reiterates what Hardon, Desclaux and Lugalla (2013) emphasized about the social effects of disclosure and its relationship to meanings of HIV in public and private places. What was also notable in this study is the limited number of people to whom women chose to share the knowledge of their HIV serological status. As stated above, their husbands were often the only ones who were aware of their diagnosis. They especially wanted to protect their parents and their children from this information. They used this strategy of "not disclosing" to protect themselves from any possible rejection by others in an effort to sustain their relationships. This strategy mimics tactics found in other studies in which people weighed other people's reactions, anticipating the effects of disclosure on their "targets," and concealing their status to evade negative reactions (Anderson & Doyal, 2004; Hardon et al., 2013).

Women made attempts to untangle the isolation imposed by HIV stigmatization, racialization and refugee discrimination by joining supports groups that were typically offered by Aids Service Organizations (ASOs) and were made available for members of their ethno-cultural communities. Here they were able to reconnect with their culture and to build a sense of community that had been severed through the processes of stigmatization (HIV), discrimination (racial and ethnic) and dislocation (geographical country origins). Such attachments were the beginning of "finding place" within the new context. This finding is in line with other research that showed how connecting and participating in an AIDS support group helped the women reverse the shame and stigma that came with the assignment of HIV by creating a new sense of belonging (Liamputtong, Haritavorn & Kiatying-Angsulee, 2012). In the current study, when they joined AIDS support groups, women learned how to "live positively," a dynamic strategy that is co-created and conveyed in activist organizations and support groups (Levy & Storeng, 2007). Because women in the group shared the condition of HIV, they were able to achieve a form of emotional support and connection that is best received from peers (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009). In effect, they achieved what Alonzo & Reynolds (1995) referred to as a community of "own." Similarly, Seeley and Russell (2010) found that new social relationships women developed through links with HIV-related organizations transformed their lives, and these relationships led to a type of "social rebirth" that provided them with new hope and energy for the future.

When the women became pregnant, their associated HIV status further excluded them from social networks that could have provided a potentially supportive role during the pregnancy. As was noted previously in chapter six, the importance of religion cannot be separated out from the experience of refugee women, since for many of them, socializing founded on religious affiliation has traditionally been a source of social support and interaction (Reimer-Kirkham, 2014). In the current study, women who became pregnant while also HIV positive were subject to exclusion from church networks, largely because of the infant feeding

practices they adopted. Thus, for the women in the current study, a place that normally performed a supportive role leading to a sense of inclusion and belonging became a potential exclusionary space. This has been noted in other studies where women have found themselves excluded from social networks due to the practice of not breastfeeding. During the pregnancy, and especially during the post-partum phase, women found that their social practices attached to mothering (such as infant feeding) came under particular scrutiny, as other members of their community carefully watched and inquired about their behaviour. This finding has resonated with studies done in various locations. Triesman, Jones and Shaw (2014) discovered that a key issue for women was the complexity of not breastfeeding that made their social interactions particularly challenging. The women felt that it aroused suspicions from others because of the value placed on breastfeeding in African culture. Greene and colleagues (2014) found that HIV-positive pregnant women were often caught between the social pressure of “breast is best” and the fear that not breastfeeding would announce their HIV status. Thus, during pregnancy and the post-partum period, isolation often became more intensified as women moved to care for and mother their babies and, at the same time, to protect themselves from the disclosure and stigma of HIV.

In order to avert this potential isolation that could occur with “not breastfeeding” revealing their HIV status, the women created stories to “normalize” their infant feeding practices. Such stories eased and sustained relationships. It allowed them to move about more freely within their current social networks, even though they might be practicing a “mothering role” that could be perceived as “deviant” from expectations. The alternative would render them alone and trapped within the narrow confines of an already limited set of contacts and social supports. These stories were an intricate practice, as they needed to be believable and plausible, something that would satisfy the questioning person’s interrogation and, at the same time, would serve to represent and maintain the woman’s gender role as a caring and responsible mother, a role that would ensure her attachment to social networks. This finding

was also corroborated by Greene and colleagues (2014), who revealed that many HIV-positive mothers began to prepare “excuses” for why they were not breastfeeding. These “excuses” supplied a “convincing answer” that served to justify the choice of infant feeding. The relationships required more emotional energy, as the women were constantly on the “look out” for the need to make up these excuses. In this way, relationships were sustained, but usually required extra efforts and navigations.

Similarly, relationships with health care providers could be both inclusionary and could enhance belonging by providing a sense of safety and reciprocity, or they could be exclusionary so that participants felt they had to overcome obstacles and steer their way to belonging. Women experienced belonging when they had good care from doctors and nurses. It made them feel strengthened within themselves and also helped them adopt a future orientation regarding their life in Canada. Conversely, the perception of health care providers not wanting to touch them, perceived prejudice, stigma, or inappropriate disclosure made participants mistrust health professionals, and caused them to feel unwelcome, confused, angry and frightened about their safety and that of their babies.

This echoes some of the findings in other studies. Bulman and McCourt (2002) related how pregnant women had been subject to communication that was insensitive to the point that care was experienced as being remote, confusing and sometimes frightening. Sanders (2008) found that pregnant women with HIV had experiences of feeling judged and depersonalized by health professionals, which in turn affected their desire to engage with that particular health clinic and the health care system in general. Tyer-Viola (2007) found that care intentions for pregnant women with HIV may be influenced by nurses’ prejudiced attitudes, leading to diminished respect, less support and less sympathetic attentiveness to clients and resulting in women’s marginalization. Minkoff (2003) also documented how women’s fear of discrimination by health care providers translated into women’s decreased attendance at prenatal appointments. The current study found that, when women felt stigmatized or racialized or when

they perceived that their HIV status had been inappropriately disclosed, in some instances they would challenge health professionals by asserting their rights for care and confidentiality, while in others, they accepted feelings of distance and of being “separated.”

A particular area of concern during the pregnancy was the post-partum period. Here the participants experienced extreme isolation. They dealt with the pain related to their Caesarean recovery on their own, or often went for long periods without eating, because they had no one to help them during this time. This finding is corroborated by other studies. Merry, Gagnon, Kalim and Bouris (2011) found that refugee women endured isolation during the post-partum period, with many women having symptoms of post-partum depression and some women skipping meals due to insufficient resources. Similarly, Gardner and colleagues (2014), in a study involving West African mothers, found that the women experienced increased social stress due to lack of practical and emotional support. Chalmers’ and Omer Hashi’s (2000) study of Somali women’s birth experiences in Canada reported insensitivity to women regarding their pain management in the post-partum period. In the current study, the women had little recourse for dealing with their concerns during the post-partum period. Sometimes they were able to call a nurse at the hospital, and when this resource was available, it was particularly helpful to them; others endured isolation during the daytime hours, receiving support only when their husband returned home in the evening. Still other women were left to do “everything” in the post-partum period due to traditional gender norms that dictated the woman cook and clean despite the fact that she was recovering from her delivery. This was especially difficult for these women, since it directly contrasted to practices in their home countries where they would have had social support and sanction for resting. In Canada, they faced a new experience for which they had no frame of reference.

In summary, the experience of untangling isolation was a negotiated and carefully managed process that enabled women to maintain existing relationships, while at the same time ensuring access to the health care they needed in order to ensure the safety and well-being of

themselves and their baby. They used the strategy of making up stories and limiting disclosure of their HIV status in order to sustain relationships. By forming relationships with other women who were pregnant, HIV-positive and new to the country, they strengthened their identities as mothers and found new hope, possibility and “place” as women living with HIV in Canada. Such “place” was not something they arrived at, but was an ongoing process of navigation within the web of services, programs, policies and systems of Canada. This process will be examined in the next section.

③ Traversing the web of structures and systems

The process described above was accomplished by these women while *traversing a web of systemic barriers* that shaped how they were able to move through Canadian society and how they interacted with the health care system. Despite these obstacles, their pregnancy became their reason for being, and led them to overcome barriers to health care access in order to ensure safe delivery for their infant. The lived experience of HIV and pregnancy for refugee women in Canada was akin to traversing a web of structures and systems. This web included, but was not limited to, the crossing of international borders, the bureaucracy of the immigration system, seeking out and connecting with different programs and services that might be available to them in Canada (schools, churches, transit systems, social services), as well as engaging with a health care system that was new and very different from what they would have experienced in their countries of origin. Navigating these systems involved a process that was like weaving through the many barbs, membranes and tissues that construct a web.

For the women in this study, traversing this web began at the moment they exited their country of origin, and continued as they moved into refugee camps and then plotted their course to Canada. The threat of violence and maltreatment that defined their exodus meant that their movements were constrained. Their “refugeeness,” the dominant constructing discourse as determined by the international refugee organization, immersed them in a refugee assignment process that was protracted and unclear. This process has been described in other studies and

has been compared to “a state of limbo” (Bassel, 2010; George, 2008; George & Ramkissoon, 1998; Lacroix, 2004). In the current study, all of the women endured the uncertainty and vulnerability of this “limbo” status. That status was still very much a part of some of the participants’ day-to-day experience in Canada, while other women had moved toward a more stable “place” by attaining their landed immigrant status. Still, both “placements” determined what they were entitled to in Canada, where they would live once in Canada, and how they were able to move through society.

Undergoing the immigration medical exam with its practice of mandatory HIV testing was a seminal incident for the women in this study. This finding echoes that of Bisaillon (2011, 2013), who described the medical examination as a “pivotal moment” in the immigration process. As a tool utilized to determine admissibility and belonging, the medical examination has the potential to influence the women’s ability to enter and stay in the country and to determine their “rights to services” within Canada. An HIV positive test links the person to further government policies and institutions that create a passageway which each HIV-positive person must navigate; it is a difficult corridor that is distinctly crafted for persons who are HIV-positive (Bisaillon, 2011). Though some of the women in the current study may have suspected that they were HIV positive, the verification and announcement of this news became a crossroads in determining their path to “placement” within the new country. It magnified the pressures associated with immigration, since it added another layer of emotions and stressors—including the planned or anticipated exposure of their status—that were specifically related to the HIV diagnosis. Once news of that status was made “public,” they began the process of navigating their diagnosis using strategies that devoted attention and energy to avoiding disclosure and maintaining concealment, a process that Bisaillon (2011) compared to “going underground.” Similar findings have been noted in other studies that have acknowledged the additional psychological stress associated with HIV screening in immigrant populations (Kalengayi, Hurtig, Ahlm & Krantz, 2012).

The women talked about the “shock” of receiving the news of their illness, the proximity of its revelation to their arrival into the country, and their lack of knowledge surrounding the diagnosis. This is significant, as a recent national survey of designated Medical practitioners (medical doctors who order the mandatory testing policy) rated their own knowledge of HIV diagnostics as “fair” (Tran et al., 2014). In addition, the survey found that coping and social support was discussed only slightly more than one third of the time (Tran et al., 2014). Moreover, approximately one third of these examiners felt that HIV-infected individuals were a threat to public health and safety, even though Citizen and Immigration Canada refute this stance (Tran et al., 2014). Similar findings were reported by Bisaillon (2011), whose investigation of the mandatory HIV-testing policy found that a positive diagnosis delivered during the immigration process resulted in feelings of depression, shock, and denial, and that immigrants were given little guidance as to what to do and how to manage this information. Such practices and attitudes mean that, when refugee women encounter the immigration system, the immigration process becomes “intensified” by the addition of mandatory HIV testing. Once they know their status, these women must begin to navigate the difficulties presented by anticipated stigma and, if this is the initial revelation, to deal with potential disclosures. The meanings attached to HIV become foremost in their minds. These new challenges are added to finding their way through the labyrinth of practices that are inherent in the immigration process.

In this study, one of the women attempted to conceal her HIV diagnosis during the immigration medical. She utilized this concealment as a strategy to protect herself and her child from further displacement lest she be deported due to her HIV status. This fear of deportation related to one’s HIV status has been found in other studies, and speaks to the trepidation that individuals experience about disclosing their HIV status. It also speaks to the embeddedness of HIV stigma within government policies and practices. Kalengayi and colleagues (2012) found that fear of deportation affected immigrants in Sweden, and this fear made them reluctant to seek health care. Other studies have found that concerns about deportation following disclosure

of HIV status may encumber contacts with official government agencies, including health care agencies (Amon, & Todrys, 2008). Still other studies and reports have also found that HIV testing related to travel and its associated restrictions has impacts on individual health by augmenting the risk of non-adherence to ARV medications, since patients may stop medications during this time or hide medications to avoid disclosure (Klein, 2001; Salit, Sano, Boggild & Kain, 2005).

The Interim Federal Health program was another web that participants needed to navigate, though in a different way. For the women in this study, changes to the Interim Federal Health policy were important, not only because their benefits decreased during a time that was particularly significant for them but also because such cuts created a national discourse that brought them into the spotlight. According to Olsen and colleagues (2014), these changes led to further construction of "the refugee" as the "Other" and perpetuated an image of "the refugee" as a vulnerable, foreign and potentially threatening individual who is burdensome and dependent on Canada's humanitarianism. It is interesting that participants in this study did not discuss in detail the cuts made to the Interim Federal Health program and how this affected their experience. Participants made comments about how health coverage "changed" or "suddenly stopped." Such realizations usually came about when they were experiencing difficulty and needed assistance. What did transpire is that women in this study carried on despite the negative discourse that was being perpetuated.

As mentioned in chapter two, research has made the link between the kind of reception an immigrant group receives, the context within which that reception occurs, and the resulting integration and life chances of that group within the new society (Gold, 1992; Wood et al., 2012). When refugees encounter a sense of welcome and belonging, these contribute to the long-term stability of host societies (Ali, 2001). Thus, in the case of the Interim Federal Health program and its associated cuts to assistance, a condition of social exclusion was created, having the potential to contribute to dysfunctional integration for refugee communities. This

magnified the effects of social exclusion that were already part of their experience. Danso (2001) documented similar findings with Somali refugees who felt that their status as refugee claimants perpetuated the idea that they were in some way manipulating the system. It also created a state of dissonance: on the one hand, a person is allowed to stay within a country, while on the other hand, policies and structures are erected that make the experience of re-settlement and integration difficult. Such findings of dissonance have been cited in other studies looking at the experiences of newcomers to Canada, and these have reiterated that the gap between what was expected and what actually occurred does exist (Anderson et al., 2010; Simich et al., 2010; Simich et al., 2006; Talebi & Desjardins, 2012)

Access and participation in health services proved to be a challenging experience for all of the women in this study. This finding supports that of other researchers who conclude that refugees' ability to utilize health care services can be difficult; they often face the dual challenge of adjusting to a differently organized health care system, while attempting to heal from pre-migration losses and violence (Bokore, 2013; Crooks et al., 2011; Hrycak & Jakubec, 2006; Kiss, Pim, Hemmelgarn & Quan, 2013; Kopinak, 1999). In the current study, women found it considerably difficult to attend their appointments during the pregnancy. Due to their HIV status (and sometimes other health conditions), they found that their visits to health professionals were more frequent. Their limited social support, child care responsibilities for other children, financial constraints, labile health related to the pregnancy, and HIV and migration issues all presented hurdles to overcome. As a result, "Feeling disconnected from care" was a predominant finding in this study. This disconnection encompassed the treatment they might have received within health care institutions (related to discrimination surrounding their HIV, racial or ethnic status), as well as the isolation they experienced when they were convalescing (from Caesarean section) at home during the post-partum period.

Similar findings have been cited in other studies that have looked at refugee women's access to the health care system. The cost and ability to secure transportation to appointments

has been cited in several studies. Hadgkiss and Renzaho (2014), in conducting a systematic review of barriers to care for asylum seekers, found that the cost of transportation was a significant obstacle to engaging with the health care system. Similarly, Gagnon (2002) and Wahoush (2009) emphasized how transportation concerns present formidable stumbling blocks for refugees new to Canada, and can compound the stresses associated with steering one's way through an unusual health care system. According to Fenta and colleagues (2007), such barriers can become overwhelming, leading to disengagement and decreased utilization of care that is deemed beneficial and necessary. As remarked in this study, other authors have made note of discrimination experienced by refugee women who are pregnant. Naab (2006) looked at the perceptions of maternity service in England for asylum seekers, and found that when they attend clinics, asylum seekers were often subject to hostile reactions from members of the host country. Similarly, Newbold, Cho and McKeary (2013), in looking at access to care for refugee women in a city in Ontario, Canada, found that the women shared stories of mistreatment and perceived discrimination.

Despite these difficulties, the women in the current study demonstrated agency and persistence in navigating the constraints, identity inscriptions and limited social mobilities imposed and afforded by these arrangements. They learned to manage new transportation systems within their new environments, and they had their young children accompany them to appointments if they were unable to solidify other arrangements for childcare. They formed alliances with other women in order to obtain housing that could increase proximity to care, thereby reducing the barrier to accessing that care. They sought out new information from family doctors that enabled them to re-establish a highly coveted and socially important role as a mother. In line with other studies, this research found that the protection of the child from contracting HIV became one of the woman's primary goals (Bunting & Seaton, 1999; Sandelowski & Barroso, 2003). At the same time, this focus propelled them forward, providing them with hope for life and a new beginning. This also echoes the findings of Ingram &

Hutchinson (2000) and Nelms (2005), who found that pregnancy in the context of HIV provided women with a means of survival, giving them a reason to live and determination to fight the infection.

In summary, the web of policies, structures and health care systems was like a maze that women must traverse, balance and navigate. It was fraught with many barbs, obstacles, and entanglements. Various policies and programs, such as the mandatory HIV testing policy and the Interim Federal Health program, as well as other provincial and federal funding programs, determined their "rights to services" within the health care system. Their HIV status determined their immediate as well as future engagements with health care systems, while barriers experienced in accessing these systems caused a feeling of disconnection. During the pregnancy, women became attached to the health care system in a process of surveillance that included daily management of anti-viral medications and pregnancy symptoms. Persistence, agency and a determination to prevent transmission of HIV to their newborn allowed them to find their way through the pregnancy and through a disconnected and painful post-partum course, and then to carry on with life as new mothers.

7.1 Implications of Study Findings

The findings of this research project are important for nurses who are engaged in clinical practice, but also are pertinent for social and service providers who work in both public and other health environments with HIV-positive refugee women who are pregnant or considering pregnancy. The findings also provide significant information for those who are involved in program and policy development affecting this population. In addition, the results point the way for further research and education.

7.1.1. Clinical practice and policy

The results have shown the profound effects that migration, refugee status, HIV and the transitions of pregnancy have on identity, with resultant effects on refugee women's health. Restoring this identity is a multi-faceted process. Nursing first needs to be aware of this

profound dimension that affects the health and well-being of HIV-positive refugee women, and then needs to work in collaboration with other service providers to assist with that restoration. The process of restoring this identity is based on each woman's unique circumstances and individuality. Nursing practice delivered in this manner cultivates a space where pregnant, HIV-positive refugee women's unique cultural, health, and obstetrical concerns may be recognized, respected, and supported. In recognizing this, nurses are well positioned to address and support the physical well-being of HIV-positive pregnant women, and also to be attuned to and aware of the assistance that is needed to sustain emotional well-being when threats to identity are present.

As noted in this study and documented in the literature, for many of these women, religion and spirituality are an integral part of their identity. By incorporating these dimensions into the assessments and care plans of pregnant, HIV-positive refugee women, nurses, as well as other health care providers, are better positioned with knowledge that can assist women in rebuilding and sustaining their health. Given that HIV-positive refugees are constantly negotiating risks to self-identity related to stigma, it is important for health care providers to regularly assess a woman's related risk in this regard, as the effects of this identity negotiation can be time- and context-dependent.

With reference to restoring this population's physical health, nurses and nurse practitioners can work to provide knowledge, assistance, and education based on the unique needs of each woman. In this study, women had varying degrees of knowledge regarding the impact of HIV on pregnancy. Nurses can be integral in assessing this knowledge and providing ongoing education. In addition, they are well suited to assist with management of HIV medications and to discuss ways to promote their general health. This includes linking these women with agencies or nutritional programs that can provide needed assistance in times of financial deficits. Awareness of influence of pre-migration (country of origin), migration and settlement stressors may provide clues to potential degradations in health, assisting nurses and

other health professionals to both anticipate and plan care. Awareness of cultural meanings and practices that the woman attaches to pregnancy and to associated procedures (such as Caesarean section fears) is particularly important, so that the woman's expectations of care will lead her to feel safe and connected.

A particular area of concern noted in this study was care during the post-partum period. Here women struggled with pain management and efforts to restore and maintain their health. Van der Woude, Pijnenborg and deVries (2015) found that Caesarean section affected the health status of post-partum mothers for at least two months after delivery. Nurses are integral to assessing pain, providing therapeutic measures and evaluating the response. In addition, they are well-equipped to care for women in the post-partum period following Caesarean section; nurses may assess the women's physical health and their surgical recovery as well as the emotional challenges they are facing. The Quality Standards for Postnatal Care (National Institute for Health and Care Excellence, 2013) has acknowledged that, for particular women and infants, the postnatal period should be lengthened in order to better meet their needs. Extending postnatal services in the home to promote both continuity in care and continuity in provider would do much to enhance the health and well-being of HIV-positive refugee women, particularly those who are recovering from the effects of Caesarean section and who often lack social support.

An important finding in this research study regards the isolation these women endured and the benefit to them of social support. This has implications within practice settings. It would be an important part of clinical practice to consistently assess and document the social support of pregnant, HIV-positive refugee women. Use of specific tools could be utilized, thus providing both a means of assessment, as well as a means of communication between health and social services representatives. One such scale is the Perceived Social Support in HIV (PSS-HIV). It was specifically developed to assess a person's perceived support provided by a social network. Such tools can provide valuable data that is specific to each person's level of needs

and context, which could then be utilized to devise strategies to enhance social support and decrease isolation (Cortes, Hunt and McHale, 2014).

All of the women in this study encountered a health care system that was very different than the one that they were accustomed to in their country of origin. Richter and colleagues examined the use of peer support for pregnant women living with HIV (Richter et al., 2014). They demonstrated that peer support for an HIV-positive woman who had previously experienced pregnancy especially benefitted maternal and infant health at 1.5 months post-birth (Richter et al., 2014). In the current study, some of the women had access to such support through a support group at a community-based organization that was separate from their clinical care. Such enhanced interventions, if offered as a standard part of care, could prove useful if available to all HIV-positive refugee women.

In this study, as well as in others (Benza & Liamputtong, 2014), access to transportation posed a significant barrier to HIV-positive refugee women's attendance of medical and social service appointments. Viewed in this light, transportation becomes a social determinant of health. Exploration of alternate methods of offering clients health care, such as home visits, could also be explored. This might even be more beneficial to the HIV-positive refugee women, allowing them to maintain their privacy and to avert the stigma they would face in attending an HIV clinic or health care setting.

Another important finding of this study was the difficulty HIV-positive refugee women had in traversing the health care system and social services systems while trying to meet the demands of daily life within the new geographical and cultural context of Canada. The mandatory HIV testing policy and the Interim Federal Health program significantly affected their experience. Klein (2001) recommended that the HIV test be included during the immigration medical exam only if it is clinically indicated. She maintained that there is no reason to require all prospective immigrants to Canada to undergo an HIV test, since allowing people into Canada with HIV would not endanger the health and safety of Canadians (Klein, 2001). As mentioned

previously by Tran and colleagues (2014), the mandatory HIV testing that now occurs is often being done without adequate pre- and post-test counselling. Other countries, such as the US, have revoked their mandatory test, altering the test to be utilized during immigration only if clinically warranted (Tran et al., 2014). Other authors have also argued for the need to avoid conflating migration with HIV/AIDS control issues (Kalengayi et al., 2012). For these reasons, re-evaluation of this policy during immigration to Canada is warranted. Testing that is done only when clinically indicated might enable HIV-positive refugee women to learn of their diagnosis in a more appropriate setting, at a time that is suitable to them, when they may not be experiencing the additional challenges of immigration and entry.

Similarly, changes to the Interim Federal Health program require evaluation; since its imposition, nurses and other professionals have put political pressure on governments to re-instate benefits so as to alleviate current suffering that refugees may experience due to lack of access, as well as to prevent future impediments that could result when one does not have access to health care.

7.2.2 Education

This study points the way for further education with regards to the knowledge that may be integral for nurses to provide care to pregnant, HIV-positive refugee women.

Nurses would benefit from an increased understanding and knowledge development with respect to the relationship between identity and health, as well as to the profound effect that migration, especially forced migration, has on identity and health. One of the main findings from this research study was how forcefully HIV and refugee status disrupt one's identity. Nurses' understanding of this dimension is essential for them to initiate and engage in therapeutic relationships with their clients. Nurses' awareness of the possible trauma and identity transformations as well as the disruption that occur during migration will allow them to be more attentive and empathetic to clients. It might also enable nurses to recognize disruptions that clients may not readily express.

This study also contributes to knowledge development with reference to the cultural meanings attached to pregnancy. Such knowledge is important; while they struggled to adapt to the conventions associated with pregnancy in their new environment, participants continued to long for their experiences of pregnancy in their home countries. The significance of the mothering role was integral in restoring the participant's identity. Not being able to breastfeed their baby was a cultural and personal loss that often left them feeling "disconnected." Participants also incorporated the meanings of stigma that had been conceptualized in their countries of origins. With insight about such important factors in the refugee woman's experience, nurses will be better able to deliver culturally competent and culturally safe care. This information also makes one aware that Western bio-medical approaches to care represent only one paradigm; in order for health care services to be inclusive in this ever-changing global society, it is necessary for health care providers to incorporate other ways of viewing the world.

Some of the encounters that participants experienced with health care providers point the way forward for education on several fronts. In the current study, some participants perceived that, on certain occasions, health care providers did not want to touch them. During another interaction, a participant experienced inappropriate disclosure by one of the health care professionals. This reinforces the need for health care professionals to be knowledgeable not only about the physiological aspects related to HIV but also about the social aspects, such as stigma that are related to the illness, about the need for privacy, and about the efforts that women undertake to protect themselves from the effects of stigma. For nurses engaging with HIV-positive pregnant women, an in-depth understanding of the processes of stigmatization and of the complexity of issues related to disclosure is needed, so they may be empathetic to the needs of clients and provide care that is sensitive to the unique circumstances of the woman.

This study also was useful in illustrating the connection between the micro, meso and macro structures that influence health and access to services. Insight into the mandatory HIV testing policy and the Interim Federal Health program provides nurses with the opportunity to

advocate for change, and to so promote the discipline's social justice mandate. Finally, increased knowledge of theories such as the post-colonial framework and intersectionality enables nurses to examine the interplay of privilege and oppression within the therapeutic encounter between the nurse and client, within the profession itself, and in the practice environment (Van Herk, Smith & Andrew, 2011). The application of such frameworks invites nurses to reflect on their own positionality. Such a reflection is especially important when providing care to women who may face various forms of disempowerment or marginalization, as may be the case with HIV-positive women who are pregnant.

7.1.3 Research

This study has noted that the experience of HIV and pregnancy is a complex and intricate process whereby refugee women exhibit persistence and agency both in resettlement and in an ongoing way throughout the pregnancy. These complex narratives of refugee women call on other modes of research that can provide nuanced understandings of their lived experiences.

One such method is photovoice. According to Plunkett, Leipert and Ray (2013), photovoice is an example of a research method that may be utilized for eliciting data to extend understanding of the lived experience. As a participatory research approach rooted in critical consciousness, it creates spaces and opportunities for voices to be heard (Wang & Burris, 1997). Such methods could bring out vivid understandings of experience by incorporating supplementary visual and narrative data within phenomenological inquiry (Plunkett et al., 2013). Another method that could prove useful is visual ethnography. Lenette and Boddy (2013) used this approach to study the experiences of single refugee women in Australia. They found that the methods of photovoice, photo-elicitation and digital sound transmission enriched the quality and depth of data of refugees' lived experiences. Such techniques could assist researchers to highlight knowledge on resilience and the pathways to well-being for pregnant, HIV-positive refugee women.

More research is needed to understand the concept of place with reference to HIV-positive refugee women who are pregnant. Andrews (2002) has called for more place-sensitivity within nursing research. Still other nursing scholars have recognized the fact that place is not a neutral concept, and they have begun to examine its influence within community nursing (Bender, Clune & Guruge, 2009). Cummins, Curtis, Diez-Roux and Mcintyre (2007) have identified the relational aspects associated with place and health, and recognize how an increased understanding of this enables more contextually appropriate policy interventions. In this study, note has been made of the importance of place identity and finding one's place. Further research could provide insight into which environments are most health enhancing for pregnant, HIV-positive refugee women. Such research would also assist in understanding the importance of "place" and its contribution to health inequalities.

Breastfeeding and infant feeding are additional areas that call for further knowledge development. It is significant that some of the women in this study had breastfed their babies during previous pregnancies, with no resultant transmission to the fetus. Further studies are needed to uncover the factors that influence transmission during breastfeeding for both mother and infant, and whether there are any conditions when breastfeeding may be safe and pose no threat of transmission. Researchers have begun to understand the experience of not breastfeeding for HIV-positive women, but further studies in a variety of contexts, i.e., in both urban and rural settings, would be beneficial.

Further studies are also needed to provide insight about disclosure. A significant finding in this study was how the women safeguarded disclosure of their HIV status. More studies are needed to understand how and when pregnant HIV-positive women choose to disclose their status. Many of the women in this study struggled with how they were going to disclose their HIV status to their children. Qualitative studies would do much to enhance understanding of this process and of the meanings that are attached to it. Further studies are needed in order to

understand what best helps HIV-positive refugee women to navigate the process of disclosure, ensuring a safe context for both the woman and the person to whom she discloses.

Linked to the process of disclosure is the concept of stigma. In this study, women were very much aware of the stigma associated with HIV and its power to discredit them as mothers and women. Further studies are needed in order to understand this very powerful process. Additional studies are also needed in order to uncover modalities and structures that can dissolve and/or interrupt the effects of stigma. Important questions need to be asked. Are there different modalities that should be incorporated when addressing internalized versus anticipated versus enacted stigma? Given that stigmatization is a process that operates at the micro, meso and macro levels (Parker & Aggleton, 2003), what structural interventions are needed in order to alleviate stigmatization at each of these levels? Particular attention needs to be paid to the effects of stigma in the context of health care.

The finding that most of the women in this study knew their HIV serological status prior to becoming pregnant has implications for future research. A few studies have looked at the effect of receiving a HIV diagnosis at the time of prenatal testing; none were known to take place in a Canadian context (Kelly, Alderdice, Lohan & Spence, 2014). During a study conducted in Ireland, Kelly and colleagues (2014) found that an antenatal diagnosis of HIV creates a “sudden disjuncture” and that significant efforts were necessary for women to create a sense of continuity in their lives. More studies are needed to understand this process in different contexts and with women from a variety of cultural backgrounds, so that appropriate interventions may be tailored to specifically address the impact of an HIV diagnosis during the antenatal course of pregnancy.

Adolescent pregnancy with subsequent motherhood is an event with unique bio-psychosocial implications for the adolescent, her newborn, her partner and her families (Vescovi, Pereira & FLevandowski, 2014). More studies are needed to comprehend the nuances that occur when pregnancy and HIV take place in the context of another life transition

such as adolescence. Likewise, many women who acquired their HIV infection perinatally prior to the advent of antiretrovirals are now within childbearing age. Although there have been some studies conducted within this population (Millery et al., 2012), more knowledge is necessary in order to determine the unique needs and experiences of perinatally infected women who then go on to experience pregnancy and childbirth.

In Canada, significant cases of HIV have been documented within Aboriginal populations (PHAC, 2011). Further studies are needed to understand the particular needs of this population of pregnant HIV-positive women. Important questions to be addressed would include: Are their specific cultural needs being met? What are the barriers and facilitators they experience in accessing health care?

Suggestions for research as noted above point the way for answering questions that affect not only pregnant, HIV-positive refugee women but also other populations and cultural groups of women who become pregnant when they are HIV-positive. Only with continued research can we begin to obtain answers to the questions that lead to optimal care for all HIV-positive pregnant women.

7.2 Limitations of the Study

A strength of the study was the use of participants' narratives; narrative provides an important source of data to assist health care workers to obtain greater understanding of the impact of illness from the perspective of the patient's understanding. The intersectional analysis brought to light the influences and affects acting upon pregnant HIV-positive refugee women at micro, meso and macro levels. The post-colonial framework provided guidance at all levels of the research by providing attention to the historical and present day influences of colonization. The research question originated out of clinical practice, attesting to its relevance. However, as with all health research, there are limitations.

Sampling: The response to the purposive sampling method for participation in this study elicited a small, though sufficient, number of participants, despite the fact that the recruitment posters

were provided at one other community-based organization, as well as at a hospital-based outpatient clinic. The study was also conducted only in one area of Canada. It is possible that women from other areas of Canada, or those recruited through different organizations, might have different experiences, so caution must be used in the interpretation of the results. Further, it is possible that the sample may have been skewed towards a particular representation of people, and an alternate sampling strategy might lead to different results. For example, one of the inclusion criteria of this study was that all of the women were currently attached to care. Different results might have been obtained with women who were not attached to care services.

Ethnicity: The participants within this sample all identified Africa as their locale of origin. It is not known if similar results would have been found for women who migrated from different parts of the world or from different cultural backgrounds, such as Asian, Eastern Europe and Middle Eastern.

Methods: Although interviews are recognized as a powerful way to gain insight about an experience, they do have limitations (Patton, 2002; Seidman, 2006). All interview data are subject to personal bias, recall error and reactivity of the interviewee to the interviewer (Patton, 2002). The interview data can also be affected by the emotional state of the interviewee, depending on the time and context of the interview (Patton, 2002). The researcher was unilingual. It was recognized that each language has nuances and certain meanings may be missed in translation when a person communicates with English as a second language. According to Marshall and While (1994), although language may pose as a barrier in research studies when participants speak English as a second language, it is important that these same participants be included in research in order to obtain their unique perspective.

Rigor: Despite these limitations, reflexivity of the researcher and attention to rigour were maintained throughout, leading to an interpretation that is both possible and probable.

CONCLUSION

In addressing the nursing care of pregnant, HIV-positive refugee women, it is essential that nurses move beyond the individual biomedical aspects of health. In order to do this, a deeper level of understanding is required – one that takes into account the social aspects of their lives as well as the historical, cultural and political influences that structure their interactions with health care and host society contexts. For this reason, the aim of this research project was to acquire a more nuanced and enriched understanding of the lived experience of pregnancy among HIV-positive refugee women. An interpretative phenomenological research design was utilized to bring the phenomenon of HIV, pregnancy and refugeenees to light. This methodology allowed participants to describe their experiences, to elaborate on the meaning of pregnancy and to explore the complexity of issues they faced when they were pregnant. Post-colonial theory was particularly relevant to this study, as it guided interpretation of the power dynamics that were inherent in the day-to-day lives of women as they interacted with host society institutions, particularly the health care system.

The findings revealed that, for HIV-positive women, the experience of pregnancy is one that requires determination, attentiveness, and consistent work and action on the part of the woman. These women deal with challenges presented in new geographical contexts, manage the stigma associated with both HIV and refugee status, and interact with a health care system that is complex and is often poles apart from what they are familiar with in their home countries. As a result of these challenges, they often find themselves situated within a liminal reality – a space that is neither here nor there and that is often characterized by isolation, yet is a space that also offers the possibility of transformation and the hope for something “new” to develop. Restoring identity, untangling isolation and traversing a web of systems and structures are the features of this reality.

As HIV-positive refugee women, they work to refurbish their identity that has been disrupted, “Othered” and fractured as a result of their HIV diagnosis, their refugee status, and

sometimes also by their racial or religious status. Pregnancy is an integral part of restoring that identity: for all of the women in this study, being a mother was a way of reclaiming a valued aspect of their gender and cultural identity. Engaging with host societies' various institutions and agencies was a way of untangling isolation, with particular associations such as ACO support groups helping them to rebuild their identity as HIV-positive women and as new mothers. The many policies and programs that determined what they were entitled to in host society contexts constructed the web of their liminal reality. Traversing this web was something they encountered from the moment they started their journeys as refugee women, and they continued this process on a daily basis as they established themselves as new mothers in Canada.

The findings of the study provide insight into the lived reality of HIV-positive women who experience pregnancy. Such knowledge is useful and provides a more nuanced picture that enables nurses to connect with women on a more healing level. The liminal reality of HIV-positive refugee women alerts nurses and health care professionals to the transitional state of this group of pregnant women. It compels the health professional to be cognizant of the different meanings of pregnancy and health for HIV-positive refugee women. It also brings to light the isolation that is part of this experience and how isolation impacts the health and well-being of both mother and newborn. Recognition, assessment and assistance to interrupt this isolation are paramount if the well-being of pregnant, HIV-positive refugee women is to be fostered and supported. Lastly, the study has provided insight into the effects of government policies, such as the Immigration Mandatory HIV testing policy and the Interim Federal Health program. These policies have far-reaching effects for HIV-positive refugee women. The mandatory HIV testing experience was a seminal moment in their lives. To this day, the Interim Federal Health program affects their entitlements to health care in the new context.

These findings have implications for the education and practice of nurses, as well as for other health professionals who work with pregnant, HIV-positive refugee women. This study provides a contribution to the knowledge base that lays the foundation for care provided to HIV-

positive refugee women who are pregnant. In addition, it points the way for further research, so that we can continue to work to provide nursing care that is culturally safe, competent and socially just.

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Appendix A

Feature

Working in a 'third space': a closer look at the hybridity, identity and agency of nurse practitioners

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CHULACH T and GAGNON M. *Nursing Inquiry* 2015
Working in a 'third space': a closer look at the hybridity, identity and agency of nurse practitioners
Nurse practitioners (NPs), as advanced practice nurses, have evolved over the years to become recognized as an important and growing trend in Canada and worldwide. In spite of sound evidence as to the effectiveness of NPs in primary care and other care settings, role implementation and integration continue to pose significant challenges. This article utilizes postcolonial theory, as articulated by Homi Bhabha, to examine and challenge traditional ideologies and structures that have shaped the development, implementation and integration of the NP role to this day. Specifically, we utilize Bhabha's concepts of third space, hybridity, identity and agency in order to further conceptualize the nurse practitioner role, to examine how the role challenges some of the inherent assumptions within the healthcare system and to explore how development of each to these concepts may prove useful in integration of nurse practitioners within the healthcare system. Our analysis casts light on the importance of a broader, power structure analysis and illustrates how colonial assumptions operating within our current healthcare system entrench, expand and re-invent, as well as mask the structures and practices that serve to impede nurse practitioner full integration and contributions. Suggestions are made for future analysis and research.

Key words: advance practice nursing, nurse practitioner, postcolonial, third space, hybridity, identity, agency.

Advanced practice nursing has evolved over the years to become recognized as an important and growing trend in Canada and worldwide (Kaasalainen et al. 2010). We utilize the Canadian situation as an example to illustrate issues and concepts that have international relevance for nurse practitioners as recognized by Kleinpell and colleagues (2014). The Canadian Nurses Association (CNA) (2008) defines advanced nursing practice as:

> An advanced level of clinical nursing practice that maximizes the use of graduate educational preparation, in-depth nursing knowledge and expertise in meeting the health needs of individuals, families, groups, communities and populations. It involves analyzing and synthesizing knowledge; understanding, interpreting and applying nursing theory and research; and developing and advancing nursing knowledge and the profession as a whole (10).

The nurse practitioner (NP) role appeared in Canada during the mid-1960s and 1970s with the emergence of publicly funded medical insurance, a perceived physician shortage, an increased emphasis on primary care and a trend toward increased medical specialization (de Witt and Ploeg 2005). Outpost nurses, originally introduced in Canada in the 1960s, have been recognized as the first Canadian nurses to practice as nurse practitioners (Boudreau 1972; Kaasalainen et al. 2010). They provided basic primary healthcare services in remote Aboriginal communities, while working within an expanded scope of practice, comparable to that of present-day NPs (Browne and Tarlier 2008).

During the 1970s and early 1980s, healthcare planners and politicians identified NPs as a futuristic movement

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within health-care (CNA 2006), and within that timeframe, the first nurse practitioners were introduced within southern urban communities within Canada (Donald et al. 2010). In conjunction with this introduction, two landmark randomized controlled trials, the Burlington trial (Sackett et al. 1974) and the Southern Ontario study (Spitzer et al. 1973) showed that the outcomes of NPs in primary care were effective, safe and improved resource utilization. What followed was an abundance of empirical evidence attesting to the safety, efficacy and acceptability of NP practice (Brown and Grimes 1995). However, despite these endorsements as to their effectiveness, sustainable implementation of the role was halted in the early 1980s due to various reasons including physicians unfavorable perceptions of NPs, lack of legislative and remuneration mechanisms for NPs to practice, lack of support from policy-makers and other healthcare providers, and a perceived oversupply of physicians (Spitzer 1984; Browne and Tarlier 2008; Kaasalainen et al. 2010).

Major primary healthcare reform of the mid-1990s and the early 2000s revitalized the interests of governments in primary healthcare nurse practitioners (PHCNPs) (Romanow 2002) and prompted further role implementation that was supported by legislation, regulation, remuneration mechanisms and subsidized education programs (Donald et al. 2010). In addition, there had been further research that attested to the fact that PHCNPs were safe, effective practitioners who positively shaped patient, provider and health system outcomes (Horrocks, Anderson and Salsbury 2002; Donald et al. 2010). Nurse practitioner roles evolved differently across provinces and territories mostly related to political reasons within the particular jurisdiction (Kaasalainen et al. 2010). Ontario claimed the first legal recognition for NP scope of practice in 1998, with many jurisdictions following (Alberta, British Columbia, Manitoba, Newfoundland and Nova Scotia), each granting and defining the professional scope of practice (Kaasalainen et al. 2010). In addition, the shift toward better integration of primary health-care into the Canadian system supported development of a framework for the integration and sustainability of the NP role in within the healthcare system (CNPI 2006), along with standardized educational requirements for NPs at the graduate level (CNA 2008). Today, all provinces and territories have legislation to support the NP role (Hass 2006).

In spite of sound evidence as to the effectiveness of NPs in primary care and other care settings, role implementation and integration continue to pose significant challenges (Edwards et al. 2011). Many authors have written about these challenges in the Canadian context and how to best address them at various levels (i.e., organization, political, legal, cultural and so forth) (cf. Katz and Macdonald 2002; Reay, Golden-Biddle and Germann 2003, 2006; Schreiber et al. 2005; Gould and Wasylkiw 2007; Burgess and Purkis 2010; Sangster-Gormley et al. 2011; Heale 2012). Similar discussion of these issues has occurred in Australia (cf. Harvey 2011; Lowe, Plummer and Boyd 2013; Schadewaldt et al. 2013); in the Netherlands (cf. van Offenbeek and Knip 2004); in the United States (cf. Miller, Snyder and Lindeke 2005; Villegas and Allen 2012; Hain and Fleck 2014) and in the United Kingdom (cf. Williams and Sibbald 1999; Wilson, Pearson and Hassey 2002; Marsden, Dolan and Holt 2003).

However, few authors have analyzed these challenges from a critical standpoint. Along with Holmes, Roy and Perron (2008), we consider that postcolonial theory provides an interesting starting point for examining and challenging traditional ideologies and structures that have shaped the development, the implementation and the integration of the NP role to this day. For the purpose of this study, we draw on the work of postcolonial scholar Homi Bhabha and, more specifically, his use of the concepts of third space, hybridity, identity and agency. We will discuss each of these concepts and show how they may be useful in articulation of the nurse practitioner role, how the role challenges some of the inherent assumptions within the healthcare system, and how development of each to these concepts may prove useful in integration of nurse practitioners and transformations within the healthcare system.

BACKGROUND

Recent nursing scholarship has moved toward an understanding of identity and culture as concepts that are 'fluid, complex, historically situated and discursively constructed' (Mohammed 2006, 98) an approach commonly identified as postcolonialism. This shift challenges traditional assumptions around health and health-care and offers an alternative way to examine the continuing effects of colonialism on present-day health, healthcare practices and systems (Mohammed 2006). Integral to this approach is an analysis of historically determined social structures in order to promote more equitable, collaborative and interdependent healthcare practices (Mohammed 2006; Browne and Tarlier 2008). Without a postcolonial perspective, stereotypes become fixed and group subjectivities are formed on the basis of hegemonic colonial assumptions that serve the dual purpose of marking off some individuals, while centering others (Mohammed 2006). Postcolonial theory recognizes individual variations, while at the same time acknowledges that historical interactions have constructed and entrenched social power imbalances and infrastructures so that they are made to appear inevitable and natural. It makes available

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ways to re-examine, challenge and resist ideologies and structures of power in order to deconstruct essentialisms and provide a space for reconstruction and agency (Smith 1999).

Postcolonial theory within the nursing literature has been utilized in various ways. Several nursing scholars have examined how it can be useful to further our understanding of cultural safety (Kirkham et al. 2002; Anderson et al. 2003), cultural frameworks (Blackford 2003) and the politics of belonging with reference to intercultural health-care (Kirkham 2003). More recently, nursing authors have utilized postcolonial theory to examine how the biomedical model is a form of colonial patronage that perpetuates powerful discourses in nursing and manifest themselves within institutional practices that serve to maintain the status quo (Holmes et al. 2008). In this article, we build on this argument and attempt to demonstrate how nurse practitioners roles and identities are often constructed by the powerful hegemonic forces of biomedicine which in turn serves to further position nursing within a subordinate role in the health-care system.

Homi Bhabha's book, *The Location of Culture,* is considered a seminal work in postcolonial scholarship. Nursing researchers and scholars have cited his work in discussion of hybridity (Kirkham et al. 2002; Racine 2009; Sochan 2011), cultural difference (Racine 2009) and third space (Kirkham et al. 2002; Racine 2009). While Bhabha's work was originally acknowledged in its contributions to literary, historical, geography, politics and cultural studies, it can offer insights to the identity and role implementation of NPs if we view the biomedical model as a colonial entity, as suggested by Holmes et al. (2008). It can also allow us to better understand the luminal 'in-between space' in which NPs are located (Rashotte and Jensen 2010). This notion of 'in-between space' or 'third space' was first introduced by Bhabha (1994) to describe the phenomenon that takes place when different cultural systems come into contact. Third space is a 'boundary zone in which two cultures meet, hybrid identities take shape, and new discourses are created' (Verbaan and Cox 2014, 2). It is a site of interaction, contestation, tension and transformation between two cultural systems.

In this in-between state, identities are reconstructed as existing cultural relations are transformed and new boundaries are created (English 2005). Those situated within this 'in-between (third) space' become neither this nor that, but often combine aspects of both cultures to create something unique (Jacobs and Brandt 2012). This space, void of the politics of polarity, but rife with the uncertainty and instability of change and negotiation, brings about new meanings to the definition of culture and allows emergence of re-defined or transformed identities. Third spaces can be seen both as an opportunity and a site of struggle (Verbaan and Cox 2014). When operating within a 'third space', traditional views and established ways of doing things come under scrutiny. This can result in both 'cultural clashes' and opportunities for transformation (English 2005; Verbaan and Cox 2014). The latter can contribute to the production of something 'new'—new values, systems of meaning, philosophies, attitudes, practice and structures. As such, those operating within a third space often need to strategize and shift behaviors in order to meet the demands of this unique 'in-between' situation (English 2004a).

Previous scholars have used the concept of 'third space' and applied it to a range of phenomena. Johnston and Richardson (2012) utilized it to examine social studies curriculum studies in Canada, in an attempt to transform the existing liberal Universalist thrust of the discipline. Haig-Brown (2008) found the concept of third space to be useful when interrogating the roles, limits and possibilities for education, and the tensions that arise when indigenous knowledge collide and interact in the discursive spaces of postcolonial universities. English (2005) found it useful to demonstrate how international adult educators challenged existing categories and demonstrated a new 'third-space' way of being in local and global contexts. It was also found to be an informative framework for social work practice when examining the factors that influence the change processes with groups (Keenan and Miehls 2008).

The concept of 'third space' is particularly relevant to this study because it allows us to understand nursing and medicine as evolving cultural systems, with NPs occupying an 'in-between space'. More specifically, it allows us to think about the potential for 'hybridity' between these two cultural systems and its implications for NPs—both in terms of identity and agency. In the following sections, we move toward a more explicit analysis of these three concepts (hybridity, identity and agency). This analysis is almost exclusively informed by the work of Bhabha (1994). While other postcolonial scholars have written about concepts such as identity and agency, we consider Bhabha's (1994) perspective to be unique because it focuses on cultural interactions (and the product of cultural interactions) and requires us to think differently about cultural differences. This is a departure from prevalent views in the literature, which tend to reinforce the divide between nursing and medicine as two separate cultural systems.

HYBRIDITY

Bhabha (1994) makes a profound statement by inviting us to a different way of thinking with regard to cultural differences:

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> What is theoretically innovative and politically crucial is the need to think beyond narratives of unitary cultures and initial points of reference and to focus on those moments or processes that are produced in the articulation of cultural differences. These 'in-between' spaces provide the terrain for elaborating strategies of selfhood—singular or communal—that initiate new sights of identity, and innovative sites of collaboration, and contestation, in the act of defining the idea of society itself (2)

According to Bhabha (1994), these spaces provide the terrain for 'cultural hybridity'—a term he coined to describe situations where elements of different cultural systems come together to form something 'new'. Hybridity, a key concept in postcolonial theory, recognizes a cross-cultural exchange that makes any form of cultural purity untenable (Kirkham and Anderson 2002; Ashcroft, Griffiths and Tiffin 2007). Furthermore, it recognizes the potential for hybrid formulations to emerge when two cultural systems (such as medicine and nursing) intersect. Authors have typically used the concept of hybridity illustrates how these formulations can result in new identities, new visions of communities, new political initiatives and new versions of historic memory (Kirkham and Anderson 2002).

Bhabha (1994) uses the concept of 'cultural hybridity' as a necessary counter strategy to colonial authority. To sustain itself, colonial authority depends on the 'immediate—unmediated—visibility of rules of recognition as the unmistakable referent of historical necessity' (Bhabha 1994, 157). These rules articulate the signs of cultural difference and implicate them in the deferential associations of colonial power through a process of hierarchization, normalization and marginalization. By disclaiming its part in this positioning process, colonial domination is strategically achieved and preserved. It exercises authority through modes of subjection and discriminatory practices that section off subject populations producing various differentiations, individuations and identities, disclaiming any stable unitary assumption of collectivity. Hybridity is the strategic reversal of this process of domination. It disavows the assumed colonial authority and intervenes to indicate not only the possibility of identity, but the unpredictability of its presence.

As early as 2000, Tye and Ross put forth the ideas of hybridity when discussing the role of NPs. They considered that viewing the NP as a replacement for junior doctors was problematic and what was needed was a move away from the artificial distinction between curing and caring, focusing instead on the unique needs of the patient. Tye and Ross (2000) described nurse practitioners as possessing foundational nursing aspects, along with diagnostic capabilities, to advance the health of their patients. The hybrid role of NPs, as one that crosses the traditional boundaries between nursing and medicine, has been documented in research (cf. Murray, Reidy and Carnevale 2010). While hybridity can allow for a unique and differentiated practice to emerge, it implies a significant amount of disruption—the disruption of existing systems (i.e., meanings, roles, identities and so on) and privileges as well as the disruption of boundaries (i.e., skills, competencies, scopes of practice, training, delegated acts and so on). As such, it is important to understand that the hybrid role of the NP is disruptive by nature.

Hybrid existences are not easy places (Bhabha 1994). Any hybridity creates a translation and disruption to any current system. As noted by Homi Bhahba:

> Hybridization is not some happy, consensual mix of diverse cultures: it is the strategic translational transfer of tone, value, signification, and position—a transfer of power—from an authoritative system of cultural hegemony to an emergent process of cultural relocation and reiteration that changes the very term of interpretation and institutionalization, opening up contesting, opposing, innovative, 'other' grounds of subject and object formation… It seeks cultural translation… to assert that there is positive, agential value in the whole process (2000, 370).

This may in part explain many of the barriers that NPs—as hybrid practitioners—have experienced during the course of role implementation, along with some of the resistances, discounting and misidentification that has emerged from nursing, medicine and decision-makers across the healthcare system (Martin and Hutchinson 1999; DiCenso et al. 2007; Martin-Misener 2010). Introducing a hybrid practitioner to any healthcare system signals a change in the way that health-care is organized and delivered. This was demonstrated by Barton and Mashaln (2011) who found that introducing NPs led to unforeseen changes in the relationship with nursing and medical hierarchies. While these changes are to be expected, they are not always planned for or properly addressed in practice. This is often due to the fact that NPs are seen as a special model of nursing or an extension or replacement of medicine—not as hybrid practitioners.

IDENTITY

If we look to Bhabha's postcolonial discussion of identity, we gain a better understanding of the challenges confronting NPs when their role, combing both elements of nursing and medicine, is introduced into the current healthcare system. His work suggests that the NP identity is never an affirmation of a 'pregiven' identity. It is actively constructed within a dominant discourse on knowledge, expertise, autonomy and health-care. As hybrid practitioners, NPs may be perceived as not totally belonging to either nursing or medicine, thus

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resulting in various degrees of isolation and marginalization (Bennett 1984; Bryant-Lukosius et al. 2004; de Guzman, Ciliska and DiCenso 2010). They may also face challenges related to their constructed identity and their ability to make visible aspects of their professional personhood (their particular experiential, clinical and decision-making capabilities) that are essential to the successful implementation of their role (Rashotte 2010). Finally, they may experience essentializing practices that view all nurses and NPs as the same or NPs and medical residents as the same—both contributing to the identity crisis of NPs (Rashotte and Jensen 2010).

The concept of 'Otherness' is particularly salient in Bhabha's work on identity. The process of identifying 'Others' or being identified as 'Other' implies a certain regime of truth through which we come to understand the world we live/work in. This regime of truth informs the way we see ourselves (i.e., who holds knowledge, expertise, status) and how we interact with one another. From this perspective, the colonizer is typically seen as the one that holds the knowledge and expertise. In contrast, the colonized (as the Other) is constructed in such a way as to privilege certain ways of knowing and maintain the status quo. Bhabha (1994) maintains that it is important to focus on the processes that lead and sustain 'Othering'. Characteristically, this involves the colonizer (the biomedical model and its supporting structures) exerting dominance on the 'Other' (in this discussion nurse practitioner roles and identity) in a system of surveillance that categories each other's knowledge and allows the colonizer to mark and direct that of the 'Others'. An example of this is nurse practitioners being supervised by physicians, rather than recognizing their particular knowledge and autonomous practice within the healthcare system (Bailey, Jones and Way 2006). In this way, the colonizer maintains their central, dominant and natural position, while those that are different come to occupy a visible 'Otherness' as their point of identity. This type of hierarchy both obscures and normalizes the othering so that it is made to seem both acceptable and natural. In addition, nurse practitioners have also been subject to the process of 'Othering' within their own profession when their difference from what is regarded as the 'status quo' in nursing is upset (Reay et al. 2003).

According to Bhabha (1994), when one is confronted continually with its 'difference', identity presents as a site of persistent questioning and tension. As 'different' practitioners, NPs' competences are sometimes questioned by both physicians' and nurses (Bryant-Lukosius et al. 2004). Despite the fact that many nurse practitioners bring with them substantial nursing experience (up to 20 years in some environments), lack of physician trust and disrespect from these colleagues has resulted in decreased job satisfaction for nurse practitioners and, in some case, failure of role implementation (de Guzman et al. 2010). This crisis in representation of personhood initiated by invisibleness and erased self-presence creates a subaltern existence (Bhabha 1994). As a result, nurse practitioner knowledge and past nursing expertise becomes unseen and underutilized, and health outcomes related or nurse practitioner practice remain unnoticed and undetectable (Bryant-Lukosius et al. 2004). This act of mis-recognition is harmful in that it has the effect of projected a false distorted identity (Racine 2009).

According to Bhabha, a typical response to this 'erasure' of one's personhood is to circulate without being seen, in order to open up a space where one can speak. In this space, the subject manipulates their representation of identity, reshaping the past within the colonialism and cultural identity of the present. An example of this is when nurse practitioners strategically disengage (withdraw psychologically and/or physically) in situations when they had unequal power (for example physicians or administration) in order to be able to continue negotiating their identities (Martin and Hutchinson 1997). Another example was found among NPs who tried, as much as possible, not to disrupt the established clinic routine so much so that they felt like they were 'visitors' in the practice (Humbert et al. 2007). In their attempt to construct a new identity, what NPs' typically do is rediscovered their sense of self by incorporating their nursing framework of care (their anchor identity) into a new professional world, a space in-between nursing and medicine (Reay et al. 2003; Gould et al. 2007; Burgess and Purkis 2010; Rashotte and Jensen 2010).

Bhabha has highlighted that the place of reclamation of identity is in the 'in-between (third) space'. This space, situated between the cultural systems of nursing and medicine, is where nurse practitioners let go of old ways of being and their old identity, and learn new ways of thinking, acting and relating to colleagues, families and patients (Rashotte and Jensen 2010). It is the enunciative site of negotiation, where the substance of nurse practitioner work is renewed and repeated in the complex process of everyday practice. Such reiteration in performance, along with accompanying dialog leads to the cultural translation that is necessary when an identity that is different is introduced to a colonial space.

What often happens during this dynamic time of identity construction is that nurse practitioner identity becomes assigned and determined by the colonial forces of biomedicine. An example of this was cited in a study by Katz and Macdonald (2002), when medical residents stated, they would collaborate with an NP, but only to the extent that it would allow residents to give up some routine tasks. This

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discursive announcement constructs the NP as someone who can assist with workload, someone who is subordinate, rather than as an interprofessional colleague. Another example of this assignment of identity was when family practitioners' self-defined what they thought was an appropriate NP scope of practice and attempted to determine what the NP 'knew' and whether they functioned appropriately (Bailey et al. 2006). Such examples illustrate how colonial discourses, such as biomedicine, attempt to generate acquiescent subjects who reproduce their own assumptions, habits and value (Ashcroft et al. 2007). Faced with such inscriptions to their identity, the challenge for nurse practitioner is then to interrupt this process, but as previously illustrated, this process always occurs within a network of power relations. Both dialog and performance become the active processes in which nurse practitioners engage in identity re-construction.

Dialog, as a mechanism of change, becomes essential to initiate and propel the transmission of nurse practitioner identity (Whittle, Suhomlinova and Mueller 2011). It helps to restore the qualities of 'fluidity', 'plasticity' and 'pliability' to identity, incorporating reciprocity in social interaction and identity construction (Hirsch and Boal 2000; Whittle et al. 2011). An example of this was cited by Bennett (1984) when nurse practitioners engaged in dialog, which in turn decreased their marginality and resulted in better integration of the role in healthcare systems. Here nurse practitioners sought out feedback regarding their role performance. Such dialog decreased their role strain and resulted in clearer role identity. Role identity was also enhanced if open communication styles were utilized (Bennett 1984). However, this type of style was only possible if a supportive working environment was facilitated that promoted collegial relationships (as opposed to hierarchical) and professional (as opposed to semi-professional) relationships (Bennett 1984).

By illustrating the importance of dialog, and its role in the construction of identity, we view the process of identity formation as something that is fluid and ongoing, something that is conceived in relation to the organizational environment, as well as other healthcare providers, patients and families within that environment (Watson 2008). It acknowledges the effect of context and the particularities of individuals in shaping identities and provides a more full appreciation of the reality of identity construction for nurse practitioners in an social location where role structures that have traditionally been viewed to be static and hierarchical, rather than evolving and changing (Barton, Thome and Hoptroff 1999). Nurse practitioner identity has evolved on the contact zones of nursing and medicine, both professions that are dynamic and changing as is the healthcare environment in which they are situated. Such an identity calls into being different ways of relating between health professionals and is closely linked to the agency that the nurse practitioner is able exhibit within the particular context.

AGENCY

Agency represents the ability to act or perform an action; individuals who have agency autonomously initiate action (Ashcroft et al. 2007). Within postcolonial theory, individual agency is interpreted within the working of power relations and the strategies postcolonial subjects use to engage or resist colonial power (Ashcroft et al. 2007). This demonstration of agency is determined by the way a person's identity has been constructed, the social positioning of the person and the space, that either constrains (keeps the agency hidden or suppressed) or enables the agency (allows it to become visible) (Henry 2007). Actions of agency within a postcolonial framework symbolize transitional and transformational aspects of culture. By enacting these 'signs' of agency, those who have been objectified or subjugated become the actors of their own history leading to alternate cultural identities through the process of re-signing and re-location. Instead of rigid polarities that exist prior to the cultural encounter, meanings become context specific, fluid and flexible.

In his discussion of agency, Bhabha (1994) calls for a radical revision of how people relate to each other. Changing the way that individuals within a given context relate alters cultural identities by creating space (a 'third space') where traditional roles and scripts may be re-formulated. During this time of re-construction, the agency of those who have previously been constrained or dominated comes to light, and in the process traditional relationships and systems are altered. Both subaltern and dominant cultures are affected reflecting a change in configuration to both. This has been confirmed in many reports that have documented how positive working relationships with team members, physician and administrative champions, and NP-physician collaborations facilitated nurse practitioner role implementation (Goss Gilroy Inc. 2001; DiCenso et al. 2003; Martin-Misener et al. 2009). Conversely, conventional and historical relationships, such as those with the physician situated at the top of the hierarchy, overseeing MD–NP working relationship, were cited as a strong barrier to integration (DiCenso et al. 2010).

Autonomy, the ability to exercise agency, is a defining characteristic of nurse practitioner work (Welland 2008; Murray et al. 2010) and, when not achieved, can be a central source of frustration and conflict (Lamarche and Tullai-McGuinness 2009). Nurse practitioners' ability to exercise

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agency shapes their experience and determines their ability to construct and enact their roles, affirming and re-affirming their identity (Chumbler, Geller and Weier 2000; Burgess, Martin and Senner 2011). Agency allows nurse practitioners to develop and exemplify performances that signify their practice as distinct, relevant and contributory to the practice environment. Without agency, nurse practitioner identity remains hidden and invisible. The two are interrelated, as without authority and authenticity solidified in a recognizable identity, it is difficult to exhibit agency (Henry 2007).

Bhabha also offers insight into the concept of resistance that arises out of new acts of agency. These acts of agency can create colonial crisis or panic that serves to unsettle the security of an established colonial authority. It usually happens when an old and familiar symbol develops an unfamiliar significance. In the case of nurse practitioners, we see the familiar symbol of a 'nurse' acting in an unfamiliar fashion. This re-signing of 'nursing identity' displays an altered identity, different from biomedical culture, but similar, in that they were able to diagnose, prescribe and orders laboratory tests. Such agency acts as a form of mimicry to the colonial authority. It disturbs the assumption of the colonial presence as an 'all knowing' and regulatory entity. Within postcolonial discourse, it is the most threatening of representations. It contests the established symbols of authority by challenging the usual social ordering, displacing the usual rules of engagement. Unable to interpret this new 'sign of difference' within established colonial discourse, resistance, often disguised as rumor, surfaces and circulates. Regardless of the outcome, the disruption and displacement create an imprint.

There are many examples within the literature of how nurse practitioner agency has been constrained and resisted by the colonial force of biomedicine. When a 'perceived' shortage of doctors created a 'space' that allowed nurse practitioners to 'emerge' as safe and effective healthcare providers (Sackett et al. 1974; Spitzer 1984), the medical profession lobbied the government to discontinue the NP education programs leading to the end of the first phase of the evolution of the NP identity, eliminating such agency (Angus and Bourgeault 1999). An example of how existing relational practices affected that agency and integration of nurse practitioners into the healthcare system is the fee for service model that forms the pay relationship that most physicians have with the government. Perceived declining physician income, along with a lack of funding mechanisms for nurse practitioners, halted the NP role implementation and limited any demonstration of their professional agency and capabilities (DiCenso et al. 2010). When nurse practitioners lobbied for increases to the scope of practice, they received criticism from organized medicine who maintained that the research used to support NP utilization was flawed (Evans et al. 1999).

Bhabha invites us to pay attention to the 'signs' of agency. In this case, the 'signs' of agency will be those health outcomes that can be directly attributable to nurse practitioner practice. Examples of this are numerous in the literature including decreased wait times in emergency department and high quality chronic disease management (Ducharme et al. 2009; Russell et al. 2009). An example of persistent and strategic agency was when a group of nurse practitioners engaged in intense lobbying to open the first nurse practitioner led clinic in Canada (Heale and Butcher 2010). Here too, colonial opposition was enacted when voices from organized medicine garnered criticisms toward the clinic that resulted in a form of negative backlash (Heale and Butcher 2010; Heale 2012).

Bhabha also invites us to recognize the contingent structure of agency. Acknowledging the dependent and conditional aspects of agency allows us to see that polarities, often viewed as static and unchangeable, are in reality truths that are partial, limited and unstable. Agency viewed within this light is an act and a process that is both creative and transformative. Alternative and new acts of agency create historical transformation and new dialog within a cultural system. This was recognized by Woods (1999) who highlighted the contingent nature of practice for nurse practitioners when they attempted to implement their roles. While attempting to construct their practice according to their professional capabilities, they discovered that the ability to enact their role (agency) was often controlled by key stakeholders within the organization, the most notable being medical practitioners (Woods 1999). Similarly, other authors have made note how the agency of nurse practitioners during role implementation has been influenced by several factors including the setting (current practice and expectations), the longevity of the NP role in that setting, as well as the experience of the nurse practitioner in that role (DiCenso et al. 2003).

IMPLICATIONS FOR NURSING

The concept of 'third space' has implications for nursing in articulating the hybrid nature of nurse practitioners' evolving practice, in depicting the formation of that identity, and in analysis of the agency that nurse practitioners are able to exhibit within the current healthcare system. It situates nursing and medicine as evolving cultural entities, with the nurse practitioner occupying an 'in-between' space. Identities formulated between 'in-between spaces' of cultures, like nursing

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and medicine, become hybrid, combing elements of both. The identity is dynamic, developing and changing, influenced by both the context and the organizational structure that either enhances or hinders the hybrid nature of that identity. As a space of both opportunity and struggle, the 'third space' is a place, both symbolic and concrete, where a 'new' nursing identity is re-formulated and re-signed, as it evolves to bring new contributions and fill gaps within the current healthcare system.

The concept of 'third space' brings understanding to the conflict, ambiguities and contestations that occur as nurse practitioners, especially during role implementation, enact their new hybrid identities (as hybrid practitioners). The presence of these hybrid practitioners challenges existing ways of doing things and leads to transformations to the usual way of doing things. Such transformations often meet with varying forms of opposition and resistance and are often seen as a threat to the existing status quo of both nursing and medicine. Clear articulation of this hybrid identity, through the process of dialog and performance, is important not only during the process of role implementation, but also needs to be ongoing in order to ensure continuing evolution of the role. Such dialog and demonstration of performance may assist other professionals, as well as general public, in understanding the role, leading to enhanced uptake, integration and utilization within the healthcare system.

This study contributes to the state of knowledge regarding the development, implementation and integration of nurse practitioners within the Canadian healthcare system. Postcolonial theory, as conceptualized by Homi Bhabha, offers a unique and critical perspective in our attempts to further understand the complex evolution of the emergence of nurse practitioners with this system. The concept of 'third space', as a site where cultural systems interact, provides an explanation of how the hybrid nature of nurse practitioner identity began, progressed and continues to be shaped by the interaction between the two cultural systems of nursing and medicine. It emphasizes the ongoing and continuous processes that are involved in the social construction of nurse practitioner professional identity. By drawing attention to the relational and contingent aspects of nurse practitioner agency (crucial to the enactment, visibility and establishment of that identity), it provides insight to some of the colonial resistances that surface when the 'signs' of that agency are enacted. Such agency has often been constrained or obliterated, when it is perceived to be too great a threat to assumed, traditional and normative processes (based on taken-for granted power structures) that are characteristic of colonial entities, such as biomedicine.

This postcolonial analysis demonstrates the importance of understanding how traditional power structures and affiliations (maintained within colonial systems) shape healthcare systems innovations, such as nurse practitioner identity and agency. It brings to light the complexity of forces often operate synergistically in order to maintain nursing practitioner colonization. It is crucial to understand these processes, and their relevance to nursing, in order to create the paths that are necessary in order to advance the nurse practitioner role. An intersectional analysis that unveils the macro, meso and micro influences that operate within a particular context could further increase our understanding. Distributed agency is another concept that has been found to useful during introduction of organization innovations. Others have advocated for the case study method of research as practical way to capture the specific impact (agency) of each unique nurse practitioner role (Neville and Swift 2012). Only with continued dialog and research can we bring to fruition the full capabilities of nurse practitioners within the Canadian healthcare system and worldwide.

CONCLUSION

In this study, we have utilized postcolonial theory, as articulated by Homi Bhabha, to examine and challenge traditional ideologies and structures that have shaped the development, implementation and integration of nurse practitioners within healthcare systems. Specifically, Bhabha's concepts of third space, hybridity, identity and agency have been illustrated to enhance understanding about the nurse practitioner role and to examine how the role challenges traditional assumptions and hierarchies within healthcare settings. Although the discussion has been situated with the Canadian context, examples drawn from other countries have illustrated the applicability and relevance to the global milieu. We hope that the discussion with prove useful to health professionals in a wide variety of settings so that nurse practitioners' knowledge, competence and capacities may be fully realized.

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Appendix B

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Rethinking the Experience of HIV-Positive Refugee Women in the Context of Pregnancy: Using an Intersectional Approach in Nursing

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When providing care to HIV-positive refugee women in the context of pregnancy, nurses must be able to move beyond the individual experiences of health and illness and acquire a more meaningful understanding of the historical, social, cultural, political, and structural influences that shape women's health and women's lives. Intersectionality is a framework that focuses on various dimensions of a refugee woman's social identity such as race, class, gender, as well as education, citizenships, and geographic location and how these dimensions intersect to influence the experiences of health and illness. In this article, we present a brief overview of the origins and evolution of intersectionality. From there we describe three distinct levels of analysis: (a) micro-level analysis to examine the influences that impact the social identity and social location of women; (b) meso-level analysis to explore informal and formal support systems; and (c) macro-level analysis to interrogate historical, social, cultural, political, and structural influences that shape health outcomes. Finally, we will examine how this framework may be useful for nursing practice, research, and knowledge development. We hope to illustrate how intersectionality is a useful framework to understand the experiences of HIV-positive refugee women in the context of pregnancy.

Keywords: health; HIV; intersectionality; pregnancy; refugee; women

Biomedical conceptualizations of health, illness, and life transitions (such as pregnancy) have proved inadequate to understand the experiences of refugee women because they fail to bear in mind, or only minimally consider, the social structures, the social contexts, and the social identities that shape these experiences (Rusek, Olesen, & Clarke, 1997). From this perspective, the focus of attention is the individual body and the pathological (or potentially pathological) processes that take

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place within this body (Weber & Parra-Medina, 2003). By focusing exclusively on the individual body, it fails to consider how "various dimensions of social identity such as race, social class, gender, and sexuality, as well as education, citizenship, and geographical locations" may be contributing to refugee women's experiences and subsequently affecting their health and well-being (Guruge & Khanlou, 2004, p. 33). In fact, there is growing recognition that a biomedical approach lacks the necessary framework to incorporate the various distinct and converging influences affecting refugee women's health, and therefore may be limited in its ability to address outcomes of these influences in clinical practice (Guruge & Khanlou, 2004).

O'Mahony and Donnelly (2007) argue that, to respond to the needs of refugee women, nurses must be able to recognize the complexity of their individual experiences and acquire a more meaningful understanding of the social, cultural, economic, and political aspects of their lives and their subsequent health effects. In this article, we build on this argument and attempt to demonstrate that intersectionality can be used to better understand the experiences of HIV-positive refugee women in the context of pregnancy and the impact of these experiences on their health and well-being. This alternative framework is important to nursing practice because it shifts the focus away from a biomedical approach onto the needs of refugee women who face significant challenges in navigating complex socioeconomic, cultural, political, and institutional structures and whose pregnancy is simultaneously constructed as natural and disease-like through interactions with health care providers. We hope to illustrate that intersectionality is a useful framework to shed light on various influences that may be contributing to health disparities and barriers that affect the health and well-being of HIV-positive refugee women in the context of pregnancy.

BACKGROUND

Approximately 16 million women are currently living with HIV/AIDS worldwide and face complex health, interpersonal, family, and social issues (United Nations Programme on HIV/AIDS [UNAIDS], 2010). According to UNAIDS (2010), more than 2 million pregnancies occur each year among this particular population. Although most women living with HIV/AIDS will experience pregnancy and motherhood in their country of origin (most likely in Sub-Saharan Africa, Asia, and the Caribbean), this is not the case for women who migrate to host countries as refugee claimants. Many refugee women arrive to their host country from areas where HIV/AIDS is endemic and come to learn their serological status through medical examinations conducted immediately before or after their arrival to the host country. This is particularly true for women who migrate to countries that require all refugee claimants and prospective immigrants to undergo mandatory HIV testing (for more information on this, see Bisaillon, 2011). Women from endemic countries account for an important proportion of new HIV-positive reports in countries that accept refugees for resettlement and are overrepresented in the perinatal HIV data. For example, women from endemic countries account for 51.3% of new HIV-positive reports in Canada (Public Health Agency of Canada [PHAC], 2010) and have greater intent

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to get pregnant (Loutfy et al., 2009). Based on several studies conducted in the United Kingdom, the United States, Canada, and Australia, we know that the health of pregnant refugee women with HIV may be particularly compromised because of their serological status, their position in society as newcomers, and the wide range of premigration and postmigration experiences (Carolan, 2010; Edmondson, 2009; Gushulak, Pottie, Hatcher, Torres, & DesMeules, 2011; Krause, Otieno, & Lee, 2002). Research indicates that pregnant refugee women encounter many barriers as they navigate the health care system (Reynolds & White, 2010). As a result, they often present late in pregnancy without adequate prenatal care and proper health assessments (Reynolds & White, 2010). Research also indicates that health care providers have a limited understanding of pregnancy because it relates to the many realities of HIV-positive refugee women (Reynolds & White, 2010). We argue that intersectionality offers a new framework for nurses to understand and address the health care needs of refugee women in the context of HIV and pregnancy.

GENDER, "REFUGEENESS," HIV, AND PREGNANCY: AN INTERSECTIONAL APPROACH

We begin our discussion with a brief overview of the origins and evolution of intersectionality. From there we will move to a three-part analysis that highlights the relevance and contribution of intersectionality to provide a better understanding of the experiences of HIV-positive refugee women in the context of pregnancy. Lastly, we will examine how this framework may be useful for nursing practice, research, and knowledge development.

Intersectionality: A Brief Introduction

Intersectionality became popular in the early 1970s in light of the critiques voiced by feminist scholars of color regarding the intrinsic limitations of feminist scholarship at the time (Combahee River Collective Statement, 1977). They argued that conceptualizations of feminist scholarship were inadequate because they were limited to discussions of gender that pertained only to middle-class, White women (Shields, 2008). What was needed was a more inclusive view of women's experiences, one that acknowledged other social identities besides gender. The Combahee River Collective (Combahee River Collective Statement, 1977), a Black feminist collective, acknowledged this need for alternate ways of understanding the experiences of women and introduced an intersectional approach to race, gender, and class. They argued that the lived experience of oppression was not simply the result of one variable (such as gender) but more related to intersectionalities of influences that shape women's lives. Their statement echoed the voices of other feminist scholars who maintained that social positions and social identities intersect in distinct ways to impact women's lives (Shields, 2008).

The term *intersectionality* was officially coined by Kimberley Crenshaw, a professor of Law at the University of California, USA. The concept, although largely North American in origin, has expanded and been used as a framework by others in Canada and Europe (Guruge & Khanlou, 2004; Oleksy, 2011). Arising out of emerging

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critical race theory, Crenshaw's 1989 landmark paper on violence against women of color differentiates between structural and political intersectionality. Structural intersectionality refers to the manner in which various influences (such as gender and race) intersect to make a "common" experience (e.g., the experience of violence) qualitatively different for Black women and White women (Crenshaw, 1989). According to Crenshaw (1991), structural intersectionality allows us to examine situations where care and services that are meant to address the needs of "all" women are supposedly provided but are, in fact, likely designed to meet the needs of a particular group of women thus leading to less than optimal care and services. For example, a rape crisis center for Black women—who are struggling with economic hardship, child care responsibilities, and precarious housing situations—is unlikely to be effective if it is designed according to the needs of economically privileged, educated, and stably employed White women.

Political intersectionality, explains Crenshaw (1991), allows us to understand how women's experiences are often examined through competing and sometimes contradictory frameworks that limit our ability to examine multiple sources of influence that underpin health and social issues. Such is the case for Black women whose political energies are often split between social action agendas based singularly on either race or gender—and not the intersection of both (Crenshaw, 1991). Building on the work of Crenshaw, Collins (1990) insists on the importance of differentiating intersecting and interlocking oppressions when trying to depict the complexity of women's experiences. Intersecting oppressions operate at the micro-level of analysis to locate each woman within a particular social position, whereas interlocking oppressions operate in macro-level social structures (such as race, class, and gender). Together these two types of oppressions provide a useful structure to examine micro-level and macro-level influences that shape women's experiences.

Intersectional analysis considers the social location of women. It critically examines the various influences of oppression and privilege (self and other), acknowledging that identity categories are unstable, dependent, relational, and inseparable (Shields, 2008). It also takes into consideration that social processes involved in the construction of identity vary according to time and place (Weber & Parra-Medina, 2003). By taking a closer look at the everyday life and social practices of women, intersectional analysis directs us to explore the construction of identities as well as the structures, standards, and customs these identities draw on. Important questions to be addressed in relation to women's health are as follows: Which identity categories do women relate to? Which customs, value, and belief systems affect them? How do women formulate and navigate different social identities in ways that maintain (or not) their heath? Which contexts support their health and identities, and which intersections place them at a disadvantage? Are there additional factors that have multiplicative negative effects on the health and well-being of women, and so forth (Hulko, 2009).

At its most basic level, intersectional analysis draws attention to the interactions between identity categories and how these categories influence the way women define themselves and are defined by others (Oleksy, 2011). At its most complex level,

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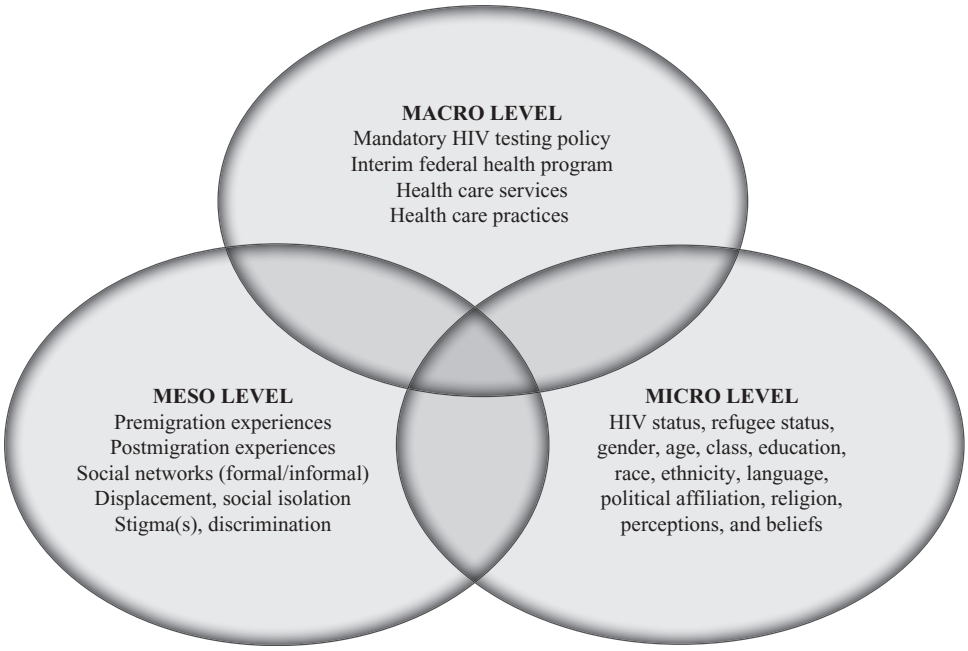

Figure 1. Intersectionality framework for providing nursing care to HIV-positive refugee women in the context of pregnancy.

however, it moves the focus of the analysis beyond the person to see broader issues (such as access to health care), and considers other aspects that shape individual's lives (such as family relations, social networks and communities, relationships, etc.; Guruge & Khanlou, 2004). Drawing on the work of Guruge and Khanlou (2004), the following sections will explore the individual situations of HIV-positive refugee women in the context of pregnancy (micro-level analysis), the social locations and social relations that affect their health and well-being (meso-level analysis), and the complex historical, political, cultural, and socioeconomic factors that impact their access to equitable and quality health care (macro-level analysis). In keeping with Guruge and Khanlou, we consider that this three-level analysis (see Figure 1) helps operationalize intersectionality and provides a structure to examine the complex issues at the intersections of gender, refugeeness, HIV, and pregnancy.

Micro-Level Analysis

At the individual level, refugee women may define themselves in ways that reflect their heritage and recognize, to divergent grades, their race, ethnicity, class, gender, age, language, education, citizenship status, biology, and genetics (Heise, 1998). The intersections of these dimensions, explains Guruge and Khanlou (2004), "create differences both within and between groups of women" (p. 38). Rather than focusing solely on gender that views all women as the same, intersectionality assumes dynamic variability and looks to other aspects of individuality—such as economics, ability, and geography—that more aptly illustrate the unique situation for each individual woman.

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An intersectional analysis recognizes that a refugee Sudanese woman, who was previously a teacher in her home country, partly English speaking, but now unemployed and alone in a new country, will experience different alterations in identity formation than an immigrant woman from the United Kingdom who is employed at a day care. Although they may experience some of the same transitions in adaptation to a new country, the woman whose experience is shaped by her loss in income, language disparity, and lack of social support may have significant challenges that not only affect her health in the present but also may have persistent effects over time.

Intersectionality scholars understand that each woman's experience is unique and affected by the changes in context that shift the meaning of various social identities to give rise to new ones (Samuels & Ross-Sheriff, 2008). This approach is particularly relevant for refugee women who are displaced for fear of threats often related to race, ethnicity, religion, or political affiliation. This displacement frequently involves disruption in geography, resources, social supports and networks, and socioeconomic status leading to both loss and adaptation. The new identities often occur in the context of constrained resources, disruptive transitions, unfamiliar settings, and impose additional stressors that in turn impact the health (and well-being) of refugee women. Not only is their individual health compromised but also the new identities—for example, the imposition or uptake of the identity of refugee status, HIV status, social assistance status, health insurance status, and so forth—come to act as pathways by which systems of inequality place women at a disadvantage, and in turn influence their health outcomes (Weber & Parra-Medina, 2003).

Intersectionality asserts that numerous influences are always at play, affecting the physical, mental, and spiritual health experiences of women (Hankivsky & Christoffersen, 2008). An intersectionality framework assists nurses to take a closer look at the individual circumstances, beliefs, culture, education, class, citizenship, and age of individual women to better understand both their individual needs and the situations of disadvantage, disparity, or advantage that may be impacting their health and well-being (Hankivsky & Christoffersen, 2008). For example, Settles (2006) found that although Black women hold other identities that may impact their daily lives, their unique experiences may lead them to be especially conscious of their racial and gender associations. Along the same lines, Cummings and Jackson (2008)—in their study of the race, gender, and socioeconomic status disparities in self-assessed health—found that Black women rated their health as much worse than their White counterparts. Similarly, it is important to consider how new social identities—based on refugee status, HIV status, socioeconomic status, and so on—affect and shape the experiences of women in the context of pregnancy. It is also important to consider the interactions between these different identities to better understand these experiences and their multiplicative effects on health (and well-being) and access to health care during pregnancy.

With reference to pregnant refugee women, an intersectional analysis would encourage nurses not only to be aware of the life transition of pregnancy and its influence on identity but also to expand that analysis to other influential processes. This would include premigration experiences, which may include trauma or torture, and postmigration experiences that often affect the identity of the woman because

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of changes in employment and socioeconomic status (Guruge & Khanlou, 2004). In both premigration and postmigration contexts, women will experience HIV-related stigma. However, the dynamics between stigma and other factors such as culture, race, gender, citizenship status, class, and socioeconomic status (just to name a few) will translate differently in the lives of women (Reidpath & Chan, 2005). In both contexts, HIV-related stigma will be amplified in the context of pregnancy (Barroso & Powell-Cope, 2000; Ingram & Hutchinson, 2000). However, how that stigma may be manifested in the life of each particular woman will vary depending on that woman's beliefs, social norms, social roles, community influences, and practices. As a result, women may experience HIV-related stigma in multiple ways ranging from shame, alienation, exclusion, marginalization to poor access to health care, human rights violation, and violence: all of which will affect their health and well-being.

An intersectional analysis recognizes that an immigrant woman from the United Kingdom who was diagnosed with HIV and linked to care in her home country, with three children who are HIV negative, and is well underway with her fourth pregnancy will experience different alterations in identity formation than a Congolese woman who was diagnosed upon arrival to the host country and is expecting her first baby. By rejecting any linear or singular entitlement to any one social identity, intersectionality proposes that what is created at that intersection of gender, refugeeness, HIV, and pregnancy is a completely "new" identity. This "new" identity cannot be simplistically evaluated based on the sum of its individual parts. Rather, it is important to consider the various influences that intersect at any one particular point in time. This tells us that intersecting influences may produce an entirely new social identity for HIV-positive refugee women who experience pregnancy in postmigration context. However, the ways in which women identify themselves and are identified in the context of pregnancy will vary based on refugee status, citizenship status, socioeconomic status, and HIV status in conjunction with other individual factors such as race, ethnicity, age, language, education, and previous life experiences (e.g., previous pregnancies, traumatic experiences, abusive relationships, etc.).

Meso-Level Analysis

Meso-level analysis examines informal and formal social networks that are closely linked to the experience of HIV-positive refugee women in the context of pregnancy. Here, it is important to locate pregnancy in a context of interactions with others (Guruge & Khanlou, 2004)—interactions with family members, relatives, community members, health care providers, and with other social networks (school, neighborhood, workplace, etc.). Rather than exclusively locating pregnancy within the individual body, we highlight the fact that interactions with informal and formal networks can have a powerful influence on the health and well-being of HIV-positive refugee women (Guruge & Khanlou, 2004). Interactions with members of social networks can be supportive or not and can exert beneficial or damaging effects on physical, psychological, spiritual health and well-being. Conceptualizing health and well-being as relational processes may, therefore, assist in better understanding the experience of refugee women especially in the context of HIV and pregnancy.

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Inherent to this approach is the idea that social networks (both informal and formal) can affect women both positively and negatively over the course of pregnancy (Guruge & Khanlou, 2004).

Research has shown that on arriving in a host country, refugee women are often relocated in physical and geographical spaces where they have no support network and where they eventually feel isolated and outcast (Kitzinger, 2004). Many refugee women are set adrift from their families, and report a loss of social networks that are known to have a protective effect on women who experience life transitions (e.g., migration, pregnancy, illness; Donnelly et al., 2011). The resulting social isolation may leave them particularly vulnerable to mental health issues and put them at a particular disadvantage—and this disadvantage places them at greater risk during pregnancy (Donnelly et al., 2011). Relocation stressors (including social isolation) and premigration experiences of possible trauma, torture, deprivation, and abuse (psychological and physical) often make the situation untenable and affect refugee women to a point where many of them will develop symptoms of depression, posttraumatic stress disorder (PTSD), psychosis, and suicidal ideation (Beiser, Johnson, & Turner, 1993; Carolan, 2010; Reynolds & White, 2010). As discussed in the previous section, both premigration and postmigration experiences should be considered relevant here.

For pregnant refugee women who have been diagnosed with HIV—most often upon their arrival to the host country—the situation of social isolation or exclusion may be amplified further. Women living with HIV are often isolated during pregnancy (Ingram & Hutchinson, 2000; Sanders, 2008). They are often conflicted by doubts of their "right" to pregnancy, and social messages about the "evils" of childbearing when HIV positive (Sanders, 2008). Their relationships with relatives or friends who are pregnant or other expecting mothers in their environment may be affected and they may find themselves excluded from social networks that usually develop throughout the course of pregnancy (e.g., prenatal groups, discussion groups, support groups, social groups; Ross, Sawatphanit, Draucker, & Suwansujarid, 2007). Relationships with their spouse and family members may also be altered (Anderson & Doyal, 2004). This is attributed to the stigma associated with HIV, especially within African communities, which may position them as promiscuous or deviant women (Anderson & Doyal, 2004). As a result of this stigma, pregnancy in the context of HIV can lead to rejection by family members, eviction from the home environment, special precautions (i.e., washing of kitchen utensils) within the family environment, or other measures that attest to an irrational fear of transmission that leads to limited and decreased contact with children and distancing of the spouse (Anderson & Doyal, 2004). The result of these scenarios is that women often become alienated from partners and family members during pregnancy.

HIV-positive women may experience a double bind in the context of pregnancy: a pregnancy that is not only filled with anxiety and distrust but also one that is hopeful for the "normalcy" of motherhood (Ingram & Hutchinson, 2000; Sanders, 2008). On the one hand, many women voice fears that their families will reject them if they disclose their serological status and concerns over the repercussions of the disclosure on their lives (Bunting & Seaton, 1999). On the other hand, pregnancy in the context of HIV can have a positive impact on the lives of women who can

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now see themselves and be seen as mothers. The social meaning of "becoming a mother" and the fulfillment of this social role has been shown to enhance the self-esteem of women living with HIV (Ingram & Hutchinson, 2000). The immediate and extended family may have a positive or negative influence on HIV-positive women who experience pregnancy, contributing to both a source of strength and a source of stress (Guruge & Khanlou, 2004; Ingram & Hutchinson, 2000). The particularity of HIV-positive refugee women is the fact that they are most often separated from family and report an intensification of social isolation during pregnancy (Kitzinger, 2004); hence, the importance of engaging in meso-level analysis of social networks.

Intersectionality seeks to uncover the intersecting influences that lead to social isolation, including various forms of discrimination, exclusion, and oppression (Hankivsky & Christoffersen, 2008). Its aim is to discover the impact of social interactions (or lack thereof) on the person while paying close attention to meso-level structures, networks, and communities that are closely linked to the experiences of health and illness. It provides a lens to better understand the social location of that person and its subsequent effects on health and well-being. In other words, it provides a lens to understand that opportunities to engage in "healthy" practices, manage illness, or participate in care are often shaped through interactions with various social networks—workplace (type of occupation, position within the echelons of the workforce, social benefits, precariousness, etc.), day care (costs, location, flexibility, availability), neighborhood (geographical location, resources, travel costs, transportation methods and costs), family (family support, family members and relatives in host country, family roles and responsibilities), health care providers (approaches to care, services and care provided, delivery of care), and so forth. This is particularly important for HIV-positive refugee women who may see their health and well-being significantly impacted by these interactions (Guruge & Khanlou, 2004).

Macro-Level Analysis

Macro-level analysis critically examines the structures, organizations, and policies that affect the health and well-being of refugee women in the context of HIV and pregnancy, and impact access to health care and services. The application of intersectionality to this context requires the analysis of macro-level factors (including but not limited to economic, political, and social factors) that affect access to health care and services, and structural barriers that maintain high levels of health inequalities among HIV-positive refugee women who are expecting a baby. Despite the fact that refugee women have high health needs, they typically experience barriers in accessing health care that translates into declining health status over time (Gabriel, Morgan-Jonker, Phung, Barrios, & Kaczorowski, 2011). Access to health care and services in the context of pregnancy may be complicated by factors such as (a) ease of use (including locations, hours, language, and consistency and variety of providers), (b) resources to make use of available services (including economic, informational, and practical resources), and (c) suitability of services provided (including gender-specific, needs-specific, and culturally safe care; Sutherns & Bourgeault, 2008).

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Access to health care and services in the context of pregnancy may be further complicated by structural barriers. Several studies have shown how refugee women report considerable difficulties in accessing affordable housing, sustaining sufficient income to meet their most basic needs, and finding employment or training services (e.g., see the work of Danso, 2001). Similar difficulties have been reported by refugee women with respect to accessing health care and services. This may in part explain why HIV-positive refugee women tend to engage in care with lower states of immunity, indicating that they are diagnosed at a later stage of disease and significantly more at risk for acquiring additional illnesses and opportunistic infections (Krentz & Gill, 2009). In addition, many present with comorbidities including latent tuberculosis, Hepatitis B, Hepatitis C, anemia, positive toxoplasmosis serology, malaria, Hepatitis A antibody, and parasitic infections (Pottie, Janakiram, Topp, & McCarthy, 2007). They also present with physical injuries, incurred as a result of trauma, torture and the difficulties of the refugee journey, as well as low rates of preventative care such as cervical cancer screening (Costa, 2007).

Guruge and Khanlou (2004) consider that the interplay of health, immigration, educational, economic, and social policies (and how it operates at various levels) is important to analyze when trying to better understand the experience of refugee women. Expanding on this idea, Oxman-Martinez and colleagues (2005) consider that federal policies constitute an important starting point to critically examine barriers to health, recognizing that it functions as an important framework to structure the experience of refugees. To illustrate this point, we would like to introduce two examples that are specific to the Canadian context but have implications for countries with similar policies. The first example has to do with the mandatory HIV-testing policy implemented in Canada in 2002. This policy has caused many refugee women to discover their HIV status either immediately before, or shortly after, their arrival into Canada but has failed to successfully link them to HIV care (Bisaillon, 2011). The second example has to do with the Interim Federal Health Plan, which provides coverage for some "emergency and essential" services. This complex policy is difficult to navigate for refugee women and often acts as a barrier to health care and services (Miedema, Hamilton, & Easley, 2008).

Attention to systemic barriers is another aspect of macro-level analysis. Here we wish to expand the analysis to the health care system and health care providers because several barriers reported in the literature pertain to ethnocentric and biomedical practices, social norms and expectations in the context of HIV and pregnancy, as well as bureaucratic and administrative processes (Hancock, 2007). Research indicates that HIV-positive refugee women often find interactions with health care providers problematic because of the way they impact and transform the meaning of the pregnancy (disease-like experience vs. natural experience; Ingram & Hutchinson, 2000; Monticelli, dos Santos, & Erdmann, 2007). In other words, women often feel that they are seen only as HIV-positive women and sick bodies with any sense of normalcy to the pregnancy lost (Ingram & Hutchinson, 2000). This may result in women disengaging from care to maintain a sense of normalcy or distance themselves from an approach to pregnancy that is disconnected from personal values and cultural beliefs. Furthermore, many refugee women often report a lack of understanding of cultural differences in their interactions with health care providers (Brown, Carroll, Fogarty, & Holt, 2010; Chalmers & Omer-Hashi, 2002).

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Looking at the perspective of the health care provider, some studies indicate that nurses are significantly more prejudiced and less willing to care for HIV-positive women than HIV-negative women (e.g., see Tyer-Viola, 2007). Stigma, discrimination, and various forms of disrespectful treatment in health settings are known to act as a barrier to accessing care and treatment for HIV-positive women and in some cases cause patients to disengage from care completely (Lindau et al., 2006, Naab, 2006). Women that are unfamiliar with the health care system may not be aware of the right to equitable and quality health care, the roles and responsibilities of health care providers, or the care and support needed during pregnancy (Oxman-Martinez et al., 2005)—this can be exacerbated by various factors that make health care complicated and confusing (Merry, Gagnon, Kalim, & Bouris, 2011). When issues (such as the ones listed earlier) arise during interactions with health care providers and intersect with other issues, this can have serious implications for HIV-positive women who may end up underusing health care and services or may be lost to follow-up during pregnancy that, in turn, may put them at risk for inappropriate or suboptimal treatment and complications (Oxman-Martinez et al., 2005).

IMPLICATIONS FOR NURSING

Intersectionality has implications for examining the interplay of privilege and oppression within the therapeutic encounter between the nurse and client, within the profession itself, and the practice environment (Van Herk, Smith, & Andrew, 2011). The application of an intersectionality framework to nursing invites nurses to reflect on their own authoritative status, especially when they provide care to women who may face different forms of disempowerment or marginalization. Most importantly, it requires nurses to not only be aware of but also to identify and facilitate those processes that enhance the agency of women and the integration of their perspective in the delivery of care. Nursing practice delivered in this manner cultivates a space where pregnant HIV-positive refugee women's unique cultural, health, and obstetrical concerns may be recognized, respected, and supported. Without careful attention to their position of privilege and authority within the health care context, nurses, despite good intentions, might run the risk of providing care that is disconnected from the needs of this particular group of women or perpetuating processes (such as stigmatization) that influence both health outcomes and access to health care (Van Herk et al., 2011). Intersectionality offers health care providers a more insightful picture of the experiences of refugee women and a better understanding of the social, cultural, economic, and political aspects of their lives in the context of HIV and pregnancy. It may also provide alternative explanations to so-called "resistances" in care practices such as "noncompliance" with medical advice or absences from medical appointments. Within the practice arena, an intersectional tool could be used in assessing factors that need to be addressed regarding a person's health by focusing on individual (micro), social (meso), and system (macro) forces that may impact or limit them in achieving their health goals.

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Intersectionality, with its roots in social justice, can be an effective tool for nursing to advance its social mandate. Social justice is committed to reducing excess burden of ill health among groups most harmed by health and social inequalities (Krieger, 2001). Refugee women constitute a group within society that have both high health needs and low service use, both of which are complicated by a range of barriers to access health care and services (Gabriel et al., 2011). Nurses providing care to this particular group of women could use an intersectional approach to address access issues and health disparities. An example of this is research conducted by Bengiamin, Capitman, and Ruwe (2010) on the use of an intersectionality framework to examine the impact of racial/ethnic, immigration, and insurance differences on the initiation and engagement to prenatal care. Another example is the work of Rogers and Kelly (2011) that used this framework in the context of health disparities to establish links between health research ethics, social action, and social justice. To engage with an intersectional framework, nurses would need to first recognize that the experiences of health and illness are embedded in the social location and the material conditions of women's lives (Pauly, MacKinnon, & Varcoe, 2009). They would also need to examine how these conditions affect women's ability to adhere to a particular therapeutic regimen or nursing recommendation, participate in care, and attend to her health care needs. Such insights may result in increased possibilities for negotiated choices in the delivery of health care and increased agency for women with the resultant possibility of advancement in health outcomes.

Intersectionality encourages researchers to go beyond the individually informed perspective that is typical of nursing scholarship and science (Shields, 2008). Incorporating this framework compels researchers to observe phenomena from the worldview of others and not simply from their sole perspective (Shields, 2008). It is especially pertinent in its ability to explore the ways in which social identities shape women's lives and various levels of influences (micro, meso, and macro) intertwined to impact the experiences of women regarding health, illness, and life transitions (such as pregnancy). Intersectional research and scholarship in nursing has the potential to shed light on areas that have as yet remained unexamined. In the process, assumptions may be unearthed, and the way that research is conducted may be reshaped (Hancock, 2007). Van Herk et al. (2011) point out that incorporating an intersectionality paradigm forces nursing researchers to examine who is being represented and how issues are being examined. This is particularly relevant to research conducted with groups of women whose experiences may not be adequately portrayed if this is not first examined.

Because it has the potential to deconstruct categories and examine the processes and systems that construct various identities, intersectionality becomes an important tool to examine the ways society is organized and the structural conditions that contribute to vulnerability, illness, and health disparities for certain groups within a population. Previous studies have highlighted how intersectional analysis extends our understanding of the social determinants of health and inequalities that impact particular groups such as refugee women. Intersectionality is also useful in identifying the effects of institutional practices on women's lives. With its focus on the institutional structures and processes that shape identities and interlocking

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oppressions, it has the potential to target areas of change needed to address social and health inequities, and point to potential solutions at various levels (micro, meso, and macro; Pauly et al., 2009).

As a method of knowledge development, the intersectional approach has great potential to provide new knowledge that can more effectively guide actions toward eliminating health disparities not only across race and ethnicity but also across gender, sexual orientation, social class, and socioeconomic status (Weber & Parra-Medina, 2003). Knowledge changes over time and reflects the social, political, and professional climate in which knowledge development occurs (Chinn & Kramer, 2008). Intersectionality, with its contextual and time-dependent nature, is particularly relevant in a world where constant change and the effects of globalization are an everyday reality. With its roots in critical theory and its attention to power dynamics, it offers the possibility to make noteworthy contributions toward emancipatory learning. "Epistemic privilege"—knowledge gained from lived experience—may be the best way to gain insight into various influences that shape the lives of women. Intersectional ways of thinking provide an avenue for refugee women to understand their own experiences, and a window for nurses, health care providers, and health care organizations to gain access to this information that can contribute to new theory formation and health care model development.

FINAL REMARKS

The goal of this article was to explore the use of the concept of intersectionality as means to enhancing the body of nursing knowledge and nursing scholarship devoted to examining and understanding the experiences of refugee women in the context of HIV and pregnancy. By discussing the evolution of intersectionality, we have illustrated the changes that have occurred since its inception as a framework for social justice within the 1970s. As a theoretical and analytic framework, intersectionality brings significant values to the body of nursing knowledge as a way of attaining further understanding about refugee women's health, and by its attention to the interplay of various influences within the micro, meso, and macro environments that impact women's lives, health status, and overall well-being. Other nursing researchers have used this framework to bring increased understanding to Aboriginal populations (Van Herk et al., 2011); young males' experience of incarcerated adolescent fatherhood (Shade, Kools, Weiss, & Pinderhughes, 2011); and clients participating in methadone maintenance treatment (Smye, Browne, Varcoe, & Josewski, 2011). Because the framework views categories as changeable and contingent, it has been shown to advance more comprehensive understandings of both men and women's lives (Hankivsky, 2012).

The health of pregnant refugee women is complex and intricately attached to their social identities, social supports, and community. Pregnant refugee women with HIV undergo significant altercations in their identity attributing to the stigmas imposed as a result of refugee status, HIV status, and the context of pregnancy, as well as the processes incurred during migration and resettlement such as racialization,

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gender role adjustments, and lack of acknowledgment of educational credentials. Social support, an integral determinant of health, is altered because they are so often separated from family and community leaving them vulnerable to degradations in their spiritual, emotional, and mental health. Access to health services is often complicated and confusing. For refugee women who are pregnant with HIV, they often experience not only language, discriminatory, financial, and transportation barriers attending health care appointments but they may also be subject to perceptual barriers regarding their HIV care, and lack of knowledge concerning particular cultural practices that directly affect their obstetrical experiences.

Intersectionality offers the possibility of viewing health within a contextual framework to illuminate the host of economic, sociopolitical conditions that impact health. This framework, with its specific attention to how power is exercised in specific locations, may be particularly relevant in understanding the effects of displacement, and the subsequent barriers and facilitators that individuals encounter as they attempt to find places that offer them opportunities to restore safety, security, a sense of self, and social relationships (Sampson & Gifford, 2010). With its emphasis on the individual at the micro-level of analysis, its emphasis on social support at the meso-level, and the systems interrogation at the macro-level analysis, it brings into view the complicated and contradictory forces that shape a woman's health. In so doing, we open the door to health care that is centered within the specific concerns of the individual woman, and move toward a system that is accessible, equitable, culturally safe, and socially just. Most importantly, it can be a starting point to provide tailored obstetrical care for HIV-positive women in an environment that is void of the stigmatizing effects of HIV and newcomer status and at the same time attend to the unique needs of each woman.

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Appendix C

UNDERSTANDING THE EXPERIENCE OF PREGNANCY IN WOMEN LIVING WITH HIV

Are you a woman living with HIV?
Did you come to Canada as a refugee?
Have you been pregnant in the past 5 years?

We are looking for HIV-positive refugee women to take part in a study on the experience of pregnancy (first come, first served).

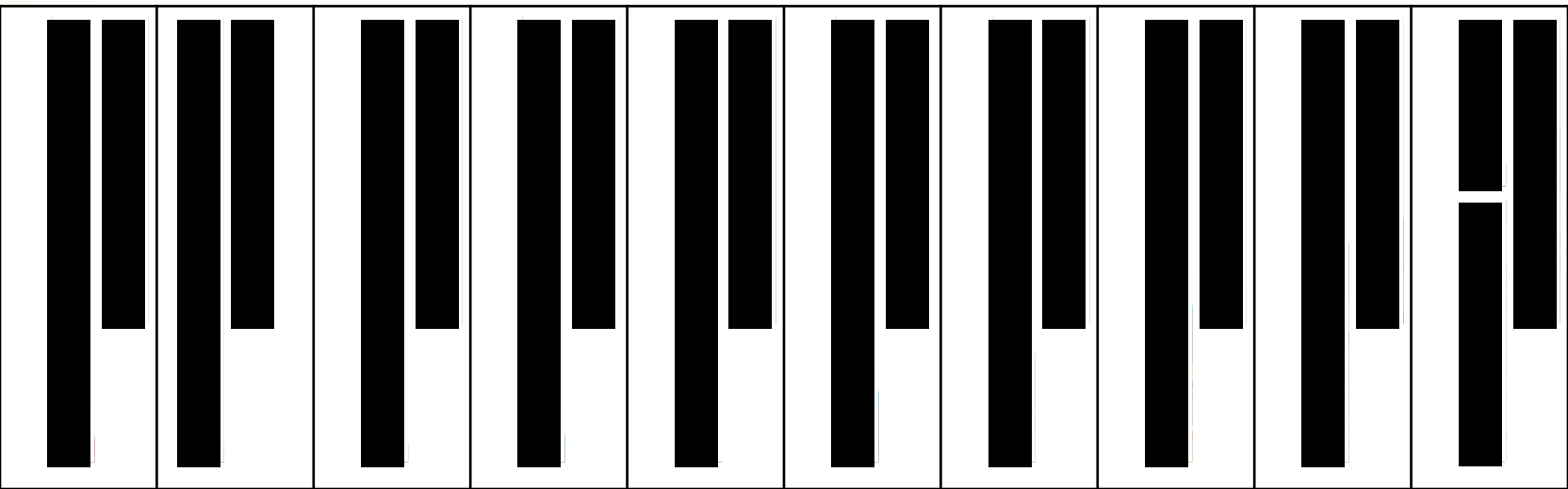
As a participant, you will be asked to take part in a 75 minute interview. This interview will be conducted in English.
In appreciation for your time and contribution, you will receive a 40$ compensation (even if you withdraw from the study).

For more information or to volunteer for this study, please contact :
Teresa Chulach, RN, NP, PhD(c)

[redacted]

uOttawa
Faculté des sciences de la santé
Faculty of Health Sciences

École des sciences infirmières
School of Nursing



UNDERSTANDING THE EXPERIENCE OF PREGNANCY IN WOMEN LIVING WITH HIV

Are you a woman living with HIV?
Did you come to Canada as a refugee?
Have you been pregnant in the past 5 years?

We are looking for 12 HIV-positive refugee women to take part in a study on the experience of pregnancy (first come, first served).

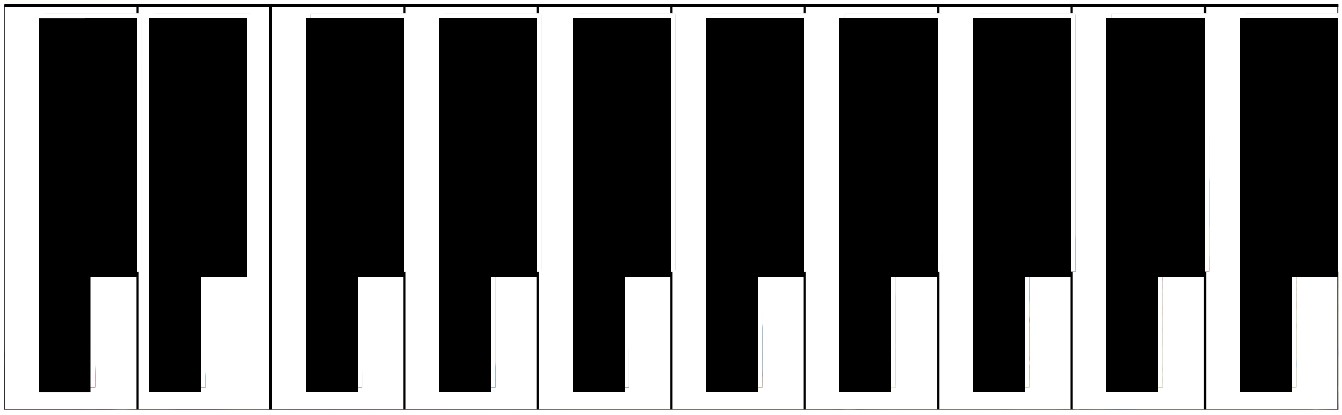
As a participant, you will be asked to take part in a 75 minute interview. This interview will be conducted in English.

For more information or to volunteer for this study, please contact :
Teresa Chulach, RN, NP
[redacted]

uOttawa
Faculté des sciences de la santé
Faculty of Health Sciences

École des sciences infirmières
School of Nursing

This Research Study has been approved by the Ottawa Hospital Research Ethics Board



MIEUX COMPRENDRE L'EXPÉRIENCE DES FEMMES ENCEINTES AUX PRISES AVEC LE VIH

Êtes-vous une femme aux prises avec le VIH?
Êtes-vous venue au Canada à titre de réfugiée?
Avez-vous été enceinte au cours des 5 dernières années?

Nous sommes à la recherche de 12 femmes réfugiées séropositives pour le VIH qui souhaiteraient prendre part à une étude sur l'expérience des femmes enceintes (première arrivée, première servie).

À titre de participante, vous prendrez part à une entrevue de 75 minutes. Cette entrevue se déroulera en anglais.

Pour de plus amples renseignements ou vous porter volontaire, veuillez communiquer avec :

Teresa Chulach, inf. aut., IP
[redacted]

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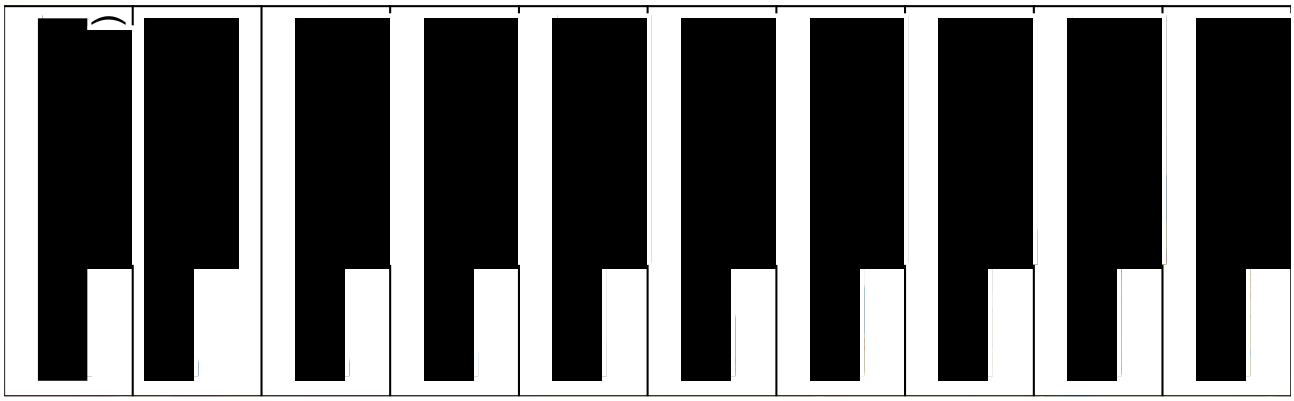
Faculté des sciences de la santé
Faculty of Health Sciences

École des sciences infirmières
School of Nursing

Cette recherche a reçu l'approbation du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa.



Appendix D

Socio-Demographic Questionnaire

Participant Code:

1) What is your age group?
- ☐ less than 20 *
- ☐ 20-24
- ☐ 25-29
- ☐ 30-34
- ☐ 35-39
- ☐ 40-44
- ☐ 45-49
- ☐ 50 and above

* *You must be 18 years old to participate in this study*

2) What is your geographical area of origin?
- ☐ Africa
- ☐ Asia
- ☐ Eastern Europe
- ☐ Latin America
- ☐ Middle East
- ☐ South America
- ☐ Other, please specify _____

3) What is highest level of diploma or degree you have attained?
- ☐ No Diploma
- ☐ High School Diploma (or equivalent)
- ☐ College Diploma (or equivalent)
- ☐ Bachelor Degree (or equivalent)
- ☐ Master's Degree (or equivalent)
- ☐ Doctoral Degree (or equivalent)
- ☐ Other, please specify _____

4) In which year were you diagnosed with HIV?
- ☐ 1980-1984
- ☐ 1985-1989
- ☐ 1990-1994
- ☐ 1995-1999
- ☐ 2000-2004
- ☐ 2005-2009
- ☐ 2010- (…)

5) How many pregnancies have you had? _____

6) State the year of your most recent pregnancy _____

French version

1) Quel âge avez-vous?
- ☐ Moins de 20 ans*
- ☐ 20-24
- ☐ 25-29
- ☐ 30-34
- ☐ 35-39
- ☐ 40-44
- ☐ 45-49
- ☐ 50 et plus

* *Vous devez être âgée de 18 ans et plus pour prendre part à cette étude*

2) Quelle est votre zone géographique d'origine?
- ☐ Afrique
- ☐ Asie
- ☐ Europe de l'Est
- ☐ Amérique latine
- ☐ Moyen-Orient
- ☐ Amérique du Sud
- ☐ Autre, veuillez préciser _____

3) Quel est le plus haut niveau de scolarité ou d'éducation que vous avez atteint?
- ☐ Aucun diplôme
- ☐ Diplôme d'étude secondaires (ou équivalent)
- ☐ Diplôme d'études collégiales (ou équivalent)
- ☐ Baccalauréat (ou équivalent)
- ☐ Maîtrise (ou équivalent)
- ☐ Doctorat (ou équivalent)
- ☐ Autre, veuillez préciser _____

4) En quelle année avez-vous reçu un diagnostic de séropositivité au VIH?
- ☐ 1980-1984
- ☐ 1985-1989
- ☐ 1990-1994
- ☐ 1995-1999
- ☐ 2000-2004
- ☐ 2005-2009
- ☐ 2010- (…)

5) Combien de grossesses avez-vous eues? _____

6) À quand remonte votre dernière grossesse? _____

Appendix E

Interview Guide

During the interview process, participants will be asked to describe their experience of pregnancy and share their feelings about this experience. They will be asked about their experience within the health care system and their relationship with health care providers in the context of HIV and pregnancy. Finally, they will be encouraged to expand on the meaning of these experiences.

Please describe your experience of when you first learned (were told) that you were pregnant.
Emphasis on timing, context and serological status
Probe: What did this mean for you at the time?

- As a refugee?
- As a woman living with HIV?

Please describe your experience during the pregnancy.
Emphasis on experiences over time and various factors that shaped these experiences

Can you think back to a particular time during your pregnancy, a time that might stand out as good or positive?
Emphasis on good or positive experiences and meaning

Can you think back to a particular time during your pregnancy, a time that might stand out as difficult or negative?
Emphasis on difficult or negative experiences and meaning

What supports did you have during the pregnancy?
Emphasis on social network, family unit, relatives, health care providers
Probe: What supports did you feel were lacking?
Probe: How would you describe the meaning of these supports for you?

Please describe the moments leading to the birth of your baby and after the birth.*
Emphasis on the last phase of pregnancy and memories of the events
Probe: How did you feel at the time?
Probe: When you think about this experience, what are your most vivid memories?
* *For women who carried the pregnancy to term only*

How did HIV affect you during your pregnancy?
Emphasis on physical, psychological, emotional, social, legal, cultural and spiritual dimensions

What does having a pregnancy with HIV mean for you today?
Emphasis on the evolution of meaning over time
Probe: Has your perception changed over time? If so, please explain. If not, please explain.

Please describe your experience of receiving care during the pregnancy.
Emphasis on experience with health care providers and with the health care system
Probe: Can you describe an experience that stands out for you (positive or negative)?
Probe: What did this experience mean for you at the time?

Appendix F

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École des sciences infirmières

University of Ottawa
Faculty of Health Sciences
School of Nursing

CONSENT FORM

Project title: The experience of pregnancy among refugee women living with HIV in Canada

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Invitation to participate in this study

You are invited to participate in this study conducted by Teresa Chulach, PhD candidate at the School of Nursing, University of Ottawa. This document will inform you about the nature of the research project and the type of participation required for those who wish to become involved. In addition, the consent form provides you with an opportunity to clarify your rights as a study participant and to understand how Teresa will ensure these rights throughout the study. Please note that she is available at all times to answer questions and if needed, to clarify the information contained in this document.

Goal of the study

I understand that the goal of this study is to explore the experience of pregnancy from the perspective of HIV-positive refugee women in the National Capital region. As a participant, I understand that the aim of this project is to document my own personal experiences on this topic through an individual face to face interview with Teresa.

Participation

In order to partcipate in this project, I need to be 18 years or older. In addition, I need to identify myself as a person living with HIV. I also need to identify myself as a woman who has come to Canada as a refugee and who has experienced pregnancy within the last five years, while living with HIV. In order to participate, I also need to be able to understand and speak English.

As a participant in this study, I will be scheduled to meet with Teresa on an individual basis in order to share my personal experience. One face to face interview will be scheduled and should last approximately 75 minutes. The interview will take place at my home or another location that I prefer. If I do not wish to be interviewed at home or at another preferred location, I will meet with Teresa in a closed office at the University of Ottawa. This interview will be scheduled based on a date and time determined by myself and Teresa. In addition, I will be asked to fill out a short socio-demographic questionnaire.

I am aware that only Teresa will be present during the interview and will be audio-taping my statements unless I am opposed to it. If I do not wish to be recorded, notes will be taken during the interview to capture what I say. The audio-tapes and the transcription of the interview will be identified using a code and will not contain any of my personal information. Following the interview, Teresa will remain available to answer my questions and document my comments.

Compensation

At the time of the interview, I will receive $40 cash for the time required to participate in the study and any related expenses such as childcare, transportation and parking. I will receive this compensation even if I decide to withdraw from the study.

Risks

Psychological: I may feel the need to talk to someone after this interview or wish to receive some form of psychological supprot. Prior to the interview, Teresa will offer me a list of resources.

Social: I may perceive a certain risk associated with the interview since I am being asked to share personal information. In response to this concern, I am aware that the confidentiality of the information shared during the interview will be maintained at all times throughout the study and after (including the publication of results).

Additional resources: My participation in this project may require additional resources such as traveling expenses and/or babysitting fees. However, I will be given $40 to address this potential inconvenience.

Personal schedule: I may also have to change my personal schedule to participate in this study. However, I understand that the researcher will provide me with flexible availabilities to minimize this possibility.

Benefits

By participating in this project, I will contribute to the development of knowledge in the field of HIV. This study is an opportunity for me to share my story as a woman living with HIV and my experiences in the context of pregnancy. By taking part in the study, I will contribute to more

research being conducted on this topic and work toward the improvement of care and services offered to refugee women in the context of pregnancy.

Confidentiality and anonymity

I am aware that the following strategies will be used to ensure the confidentiality of my statements and the preservation of my anonymity:

The nature and content of the interview will be audio-recorded in a way that preserves my confidentiality. My name will not appear on the research material and a code will be assigned to me in order to identify my contribution to the research. This code will prevent any link possible between my statements and my identity, and it will only be accessible to Teresa and the supervisors. In addition, I understand that Teresa will censor any information that may lead to my identification in order to maintain anonymity.

Storage *of research material*

I understand that all of the research data (audio-files, transcriptions, and notes) will be stored in a locked unit within the research space of Dr. Dave Holmes at the University of Ottawa. I am aware that the data collected will be kept as of March 1st 2013 for a period of 5 years in order to be analyzed, after which it will be destroyed. Only the researcher and the supervisors will have access to the research material.

Autorization of the utilization of research results

By participating in this study, I accept that the data collected during the interview will be used for scientific, professional and educational purposes. It is possible that my statements be cited in publications and/or presentations. However, I understand that my confidentiality will be respected at all times. Fictional names will be used in scientific publications and indentifying information will be removed from quotes.

Withdrawal from the study

It is clear that my participation to this project is done on a voluntary basis. I can choose not to answer certain questions. It is also clear that I can withdraw from the research at anytime, without having to justify why I chose to do so. The content of my interview will be destroyed (transcriptions wil be shredded and audio-files destroyed) if I choose to withdraw from the study and the information I provided will not be used in the analysis.

Questions regarding the study

If I have any questions regarding this study (before, during or after my interview), I am aware that I can contact Teresa Chulach at any time by cell phone [redacted] or by e-mail: [redacted].The supervisors may also be contacted at any time. Additional contact information for Teresa and her supervisors are provided on the first page of the consent form.

Ethics

This research project has been approved by the Research Ethics Board at the University of Ottawa. If I have any questions regarding the ethical aspect of this study or my rights as a study participant, I can contact the ethics advisor at the University of Ottawa: University of Ottawa, Pavilion Tabaret, 550 Cumberland Street, room 154, Ottawa, ON K1N 6N5; (613) 562-5387; ethics@uottawa.ca.

Participant consent

This is to state that I agree to participate in a study being conducted by Teresa Chulach at the University of Ottawa.

I have been informed that the purpose of the research is to explore the experience of pregnancy and HIV while being a refugee in Canada.

I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences. In addition, I understand that my participation in this study is CONFIDENTIAL (the researcher (Teresa Chulach) will know, but will not disclose my identity)

I also understand that the data from this study may be published but will remain confidential (fictional names will be used in scientific publications and during the presentation of the findings)

I accept to be audio-recorded: yes ☐ no ☐

I accept to be quoted directly (any identifying information will be removed): yes ☐ no ☐

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

There are two copies of the consent form, one of which is mine to keep.

NAME (please print)

_____

SIGNATURE

_____

VERBAL CONSENT: Audio –recorded ☐

DATE: _____

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Faculty of Health Sciences
School of Nursing

FORMULAIRE DE CONSENTEMENT

Titre du projet : L'expérience de la grossesse telle que vécue par les femmes réfugiées vivant avec le VIH au Canada

Chercheure : Teresa Chulach, Inf., IP, PhD (c)
École des sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa
[redacted]
451 Chemin Smyth
Ottawa, Ontario
K1H 8M5

Superviseurs: Dave Holmes, Inf., PhD
Professeur titulaire
École des sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa
[redacted]
451 Chemin Smyth
Ottawa, Ontario
K1H 8M5

Marilou Gagnon, RN, PhD
Professeure adjointe
École des sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa
[redacted]
451 Chemin Smyth
Ottawa, Ontario
K1H 8M5

Invitation à participer à cette étude

Vous êtes invité à participer à la présente étude qui est menée par Teresa Chulach, candidate au doctorat à l'École des sciences infirmières, Université d'Ottawa. Ce document vise à vous informer de la nature du projet de recherche et de votre participation. Il s'agit d'une opportunité de clarifier vos droits en tant que participant et de vous informer des moyens utilisés par Teresa afin de respecter ces mêmes droits. Veuillez noter que celle-ci est en tout temps disponible pour répondre à vos questions et au besoin, pour clarifier les informations contenues dans ce formulaire de consentement.

But de l'étude

Je comprends que le but de cette étude est d'explorer l'expérience de la grossesse telle qu'elle est vécue par les femmes réfugiées séropositives dans la région de la capitale nationale. En tant que participante, je comprends que cette étude a pour but de documenter mes propres expériences dans le cadre d'une entrevue face-à-face avec la Teresa.

Nature de votre participation

Afin de participer à cette étude, je dois être âgée de 18 ans et plus. De plus, je dois m'identifier comme étant une femme qui vit avec le VIH. Je dois également m'identifier comme une femme réfugiée et avoir vécue une grossesse dans les cinq dernières années. Afin de participer à ce projet, je dois également être capable de comprendre et de communiquer oralement en anglais.

En tant que participante, je serai rencontrée individuellement par Teresa afin de répondre à quelques questions directement reliées à mon expérience personnelle. Une seule rencontre face-à-face est prévue et celle-ci durera environ 75 minutes. Cette rencontre s'effectuera à mon domicile ou dans un autre lieu de mon choix. Si je ne souhaite pas compléter l'entrevue à mon domicile ou autre lieu de mon choix, elle s'effectuera dans un bureau privé à l'Université d'Ottawa. L'entrevue aura lieu à une date et heure qui respecteront mon horaire personnel. En plus de prendre part à la rencontre individuelle, je devrai remplir un court questionnaire sociodémographique.

L'entrevue se déroulera en présence de Teresa. Je comprends qu'elle sera enregistrée sur bande audio. Si je préfère ne pas être enregistré, des notes seront prises durant l'entrevue pour résumer mes propos. Les bandes audio, les transcriptions de mon entrevue de même que les analyses seront étiquetés au moyen d'un code et ne porteront aucune information permettant de m'identifier. Après mon entrevue, Teresa demeurera disponible pour répondre à mes questions et documenter mes commentaires.

Compensation

Dans le cadre de ce projet, je recevrai 40.00$ en argent comptant pour ma participation à l'entrevue et pour couvrir les frais associés au projet comme des frais de gardiennage, de transport ou de stationnement. Cette compensation me sera remise même si je décide de me retirer du projet.

Risques

Psychologiques : Il se peut que je ressente le besoin de parler à quelqu'un après cette entrevue ou que je souhaite recevoir une aide psychologique. Avant l'entrevue, Teresa me remettra une liste de ressources appropriées.

Sociaux : Ma participation à l'entrevue implique que je révélerai des informations personnelles. Cependant, je cromprends que la confidentialité de ces informations sera maintenue en tout temps pendant la recherche et après la recherche (incluant lors de la publication des résultats).

Ressources supplémentaires : Il se peut que ma participation à cette étude exige des ressources supplémentaires comme des frais de transport et/ou des frais de gardiennage. Toutefois, un montant de 40.00$ me sera offert afin de minimiser ce risque.

Horaire personnel : Il se peut que je modifie mon horaire personnel et/ou familial pour participer à ce projet. Par contre, je réalise que Teresa sera en mesure d'offrir une horaire flexible afin de minimiser ce risque.

Bienfaits

Ma participation à cette étude aura pour effet de contribuer à l'avancement des connaissances dans le domaine du VIH/SIDA. Il s'agit d'une opportunité de partager mon vécu en tant que femme séropositive et mon expérience par rapport à la grossesse. En participant à cette étude, je serai en mesure de contribuer au développement de la recherche sur ce sujet et de travailler à l'amélioration des soins et services offerts aux femmes réfugiées qui vivent une grossesse.

Confidentialité et anonymat

Je comprends que les stratégies suivantes seront déployées afin d'assurer la confidentialité de mes propos :

La nature et le contenu de mes propos qui seront enregistrés sur bande audio lors de l'entrevue demeureront en tout temps strictement confidentiels. Mon nom n'apparaîtra en aucun temps dans les données ou les résultats de recherche. Un code me sera assigné afin de préserver mon anonymat et prévenir toute forme d'identification. Teresa s'assurera également qu'il ne puisse pas y avoir de rapprochement entre mes propos et mon identité. Toute information pouvant mener à mon identification sera donc éliminée afin de respecter mon anonymat.

Conservation des données

Je réalise que toutes les données (fichiers audio, transcriptions, notes) seront conservées dans une filière verrouillée dans l'espace de recherche de Dave Holmes à l'Université d'Ottawa. Ces données seront conservées pendant une période de cinq ans à partir du 1er mars 2013 afin d'en permettre l'analyse. Après cette période, elles seront détruites. Seule Teresa et ses superviseurs (Dave Holmes et Marilou Gagnon) auront accès aux données.

Autorisation d'utiliser les résultats de recherche

En participant à l'entrevue, j'accepte que les informations recueillies fassent partie des conclusions de la recherche et conséquemment puissent être utilisées à des fins de communications scientifiques, professionnelles et éducatives. Il se peut que mes propos soient cités de manière intégrale dans des publications ou des présentations. En regard de toutes ces formes de communication, il est entendu que ma confidentialité sera respectée en tout temps. Des noms fictifs seront utilisés dans les publications scientifiques et toute information pouvant m'identifier sera retirée des citations.

Participation volontaire

Il est entendu que ma participation au projet de recherche décrit ci-dessus est tout à fait libre. Je peux choisir de ne pas répondre à certaines questions. Il est également entendu que je peux, à tout moment, mettre un terme à ma participation sans que cela ne me cause préjudice. Les motifs de mon retrait de l'étude sont personnels et n'auront pas à être partagés avec Teresa. Les données amassées lors de mon entrevue seront alors détruites (fichiers audio coupées et transcriptions déchiquetées) et ne seront pas utilisées.

Questions sur l'étude

Si je m'interroge au sujet de cette étude, je peux communiquer (avant, pendant et après l'entrevue) avec Teresa Chulach par téléphone [redacted] Il me sera également possible de contacter ses superviseurs en tout temps. Les coordonnées de Teresa et de ses superviseurs sont indiquées sur la première page de ce formulaire.

Éthique

Ce projet de recherche a été approuvé par le Comité d'éthique de l'Université d'Ottawa. Pour toute question éthique concernant les conditions dans lesquelles se déroule ma participation à ce projet, je peux à tout moment communiquer mes préoccupations au responsable de l'éthique en recherche, Université d'Ottawa, Pavillon Tabaret, 550, rue Cumberland, salle 154, Ottawa, ON K1N 6N5; Tél.: (613) 562-5387; courriel: ethics@uottawa.ca.

Consentement du participant

Par la présente, je déclare consentir à participer à un projet de recherche mené par Teresa Chulach à l'Université d'Ottawa.

On m'a informé(e) du but de la recherche, soit d'explorer l'expérience de la grossesse telle qu'elle est vécue par les femmes réfugiées vivant avec le VIH au Canada.

Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives. Je comprends également que ma participation à cette étude est CONFIDENTIELLE (c'est-à-dire que la chercheure (Teresa Chulach) connaît mon identité mais ne la révélera pas)

Je comprends que les données de cette étude puissent être publiées tout en assurant ma confidentialité (utilisation de faux noms pour la rédaction d'articles scientifiques et la présentation des résultats)

J'accepte d'être enregistrée sur bande audio : oui ☐ non ☐

.

J'accepte que mes propos puissent être cités de manière intégrale (mon identité ne sera en aucun temps révélée): oui ☐ non ☐

J'AI LU ATTENTIVEMENT CE FORMULAIRE DE CONSENTEMENT ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

Il y a deux copies de ce formulaire de consentement. Une de ces copies m'appartient.

NOM (caractères d'imprimerie)

_____

SIGNATURE

_____

CONSENTEMENT VERBAL: Enregistré sur bande audio ☐

DATE : _____

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INFORMATION SHEET & CONSENT FORM

Project title: The experience of pregnancy among refugee women living with HIV in Canada

Researcher: Teresa Chulach, RN, NP
School of Nursing
Faculty of Health Sciences
University of Ottawa

INTRODUCTION

You are being asked to participate in this study because you are a refugee who is or has been pregnant within the last 5 years, while living with HIV. This document will inform you about the nature of the research project and the type of participation required for those who wish to become involved. In addition, the consent form provides you with an opportunity to clarify your rights as a study participant Please ask as many questions as you like before deciding whether or not you would like to participate. While a French Consent Form is available to you, please note that the study will be conducted in English only.

BACKGROUND, PURPOSE AND DESIGN

The proposed project addresses a gap in Canadian studies on pregnancy and HIV which have largely overlooked the lived experience of refugee women. Healthcare professionals have a limited understanding of pregnancy as it relates to the many realities of HIV-postive refugee women. This can be explained in part, by the lack of explorative and descriptive research conducted with refugee women in Canada. Insights in the experiences of HIV and pregnancy are particulary important in order to be able to address the needs of refugee women in clinical practice. The project is designed to describe the experiences of refugee women who also have a diagnosis of HIV; to explore the meaning of pregnancy and HIV within the life of refugee women; and to look at the complexity of issues facing pregnant refugee women with HIV in the social, political and institutional context of Canada.

STUDY PROCEDURES

If you consent to partcipate, you will take part in one face to face interview of approximately 75 minutes in length. The interview will be scheduled between you and the researcher at a mutually convenient time and place, and it will be audio recorded in order to ensure accuracy when later transcribed to a written document. In addition, you will be asked to fill out a short socio demographic questionnaire. You may skip any question you are not comfortable answering and you may choose to not have the interview audio recorded if you wish.

Risks

You may feel the need to talk to someone after this interview or wish to receive some form of psychological support. You will be provided with a list of resources.

Benefits

You may not receive any direct benefit from you participating in this study. Your participation in this research may allow the researcher to describe the experiences of refugee women living with HIV who are pregnant, or have been pregnant which may be of benefit to others living with HIV in the future.

Voluntary Participation and Withdrawl for the study

Your participation in this study is voluntary. If you choose not to participate, your decision will not affect the care you receive at the Ottawa Hospital at this time, or in the future. You will not have any penalty or loss of beneifts to which you are otherwise entitled. You may withdraw from the research at anytime, without having to provide a reason. If you decide to withdraw, the content of the interview will be destroyed (transcriptions will be shredded and audio-files destroyed).

Compensation

At the time of the interview, you will receive $40 cash for the time requried to participate in the study and to help cover any related expeneses such as childcare, transportation and parking. You will receive the compensation even if you choose to withdraw from the study.

Confidentiality and anonymity

All personal health information will be kept confidential, unless release is required by law. Representatives of the Ottawa Hospital Research Ethics Board, as well as the Ottawa Hospital Research Institute, may review relevant study records under the supervision of Teresa Chulach for audit purposes.

You will not be identifiable in any publications or presentations resulting from this study. No identifying information will leave the University of Ottawa. All information which leaves the university will be coded with an independent study number. It is possible that statements you make will be cited in publications and/or presentations. However, fictional names will be used in scientific publications and identifying information will be removed from quotes.

The link between your name and the independent study number will only be accessible by Teresa Chulach and/or her direct supervisor(s). The link and study files will be stored separately and securely. Both files will be kept for a period of 10 years after the study has been completed. Audio files will be deleted immediately upon transcription. All paper records will be stored in a locked file and/or office at the University of Ottawa. All electronic records will be stored on a password protected computer only accessible by Teresa Chulach. At the end of the retention period, all paper records will be disposed of in confidential waste or shredded, and all electronic records will be deleted.

Questions regarding the study

If you have any questions about this study, please contact Teresa Chulach at [redacted].

This research project has been approved by the Research Ethics Board at the University of Ottawa. If you have any questions regarding the ethical aspect of this study or your rights as a study participant, you may contact the ethics advisor at the University of Ottawa: University of Ottawa, Pavilion Tabaret, 550 Cumberland Street, room 154, Ottawa, ON K1N 6N5; (613) 562-5387; ethics@uottawa.ca.

The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at 613-798-5555, extension 14902.

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Consent Form
The lived experience of HIV and pregnancy among refugee women in Canada

Consent to Participate in Research

I understand that I am being asked to participate in a research study about the experience of refugee women who have been pregnant while living with HIV. This study has been explained to me by Teresa Chulach.

I have read and understand this 4 page Information Sheet and Consent Form. All my questions have been answered to my satisfaction. If I decide at a later state in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

I consent to be audio-recorded: Initial yes □ no □

I consent to be quoted directly (any identifying information will be removed): Initial yes □ no □

There are two copies of the consent form, one of which is mine to keep.

Signatures

_____
Participant name (Please print)

_____ _____
Participant Signature Date

Verbal Consent: Audio-recorded □ Documented in field notes □

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing (or verbally consenting to) this consent from understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

_____
Name of Investigator/Delegate (Please Print)

_____ _____
Signature or Investigator/Delegate Date

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FEUILLE DE RENSEIGNEMENTS ET FORMULAIRE DE CONSENTEMENT

Titre du projet : *L'expérience vécue de femmes réfugiées au Canada enceintes et séropositives pour le VIH*

Chercheur : Teresa Chulach, inf. aut., IP
École de sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa

INTRODUCTION

On vous invite à prendre part à ce projet de recherche parce que vous êtes une femme réfugiée, qui est ou a déjà été enceinte, dans les 5 dernières années pendant que vous aviez le VIH. Ce document vous fournira des renseignements sur la nature du projet de recherche et le type de participation requise pour celles qui souhaiteraient se porter volontaires. De plus, ce formulaire de consentement fournit l'occasion de clarifier vos droits à titre de participante à cette étude. N'hésitez surtout pas à poser toutes vos questions avant de décider si vous souhaitez ou non prendre part à cette étude de recherche. Bien qu'il soit possible d'obtenir un formulaire de consentement en français sur demande, il est important de noter que l'étude se déroulera uniquement en anglais.

CONTEXTE, OBJECTIF ET MÉTHODOLOGIE DE L'ÉTUDE

Le projet ci-proposé se propose de mettre en évidence les lacunes relatives aux études canadiennes sur la grossesse et le VIH qui, en grande partie, ont négligé l'expérience vécue des femmes réfugiées. Les professionnels de la santé ont une connaissance limitée de la grossesse en ce qui a trait aux réalités imposées sur les femmes réfugiées séropositives pour le VIH. Ceci s'explique, en partie, par l'absence de recherche exploratoire et descriptive effectuée auprès de femmes réfugiées au Canada. Un aperçu des expériences de femmes séropositives pour le VIH enceintes s'avère particulièrement important si nous souhaitons être mieux à même de répondre aux besoins des femmes réfugiées en pratique clinique. Ce projet a été conçu pour décrire les expériences des femmes réfugiées qui ont reçu un diagnostic de VIH; pour explorer la signification de la grossesse et du VIH en ce qui concerne la vie des femmes réfugiées; et pour examiner la complexité des problèmes auxquels font face les femmes enceintes séropositives pour le VIH dans un contexte social, politique et institutionnel au Canada.

PROCÉDURES DE L'ÉTUDE

Si vous consentez à participer à cette étude, vous prendrez part à une entrevue en personne qui durera environ 75 minutes. Vous et le chercheur prévoirez le rendez-vous en fonction de votre disponibilité, à une date, une heure et un lieu qui vous conviendront. L'entrevue sera enregistrée sur bande audio afin d'assurer l'exactitude de la transcription éventuelle. De plus, on vous demandera de remplir un bref questionnaire sociodémographique. Vous pourrez omettre de répondre à toute question de votre choix et vous pourrez également, si vous le souhaitez, opter pour que l'entrevue ne soit pas enregistrée sur bande audio.

Risques
Vous pourriez ressentir le besoin de vous confier à quelqu'un suivant cette entrevue, ou avoir besoin d'une forme ou d'une autre de soutien psychologique. On vous fournira une liste de ressources à cet effet.

Bienfaits
Il est possible que vous ne retiriez aucun avantage direct en prenant part à cette étude. Votre participation à cette recherche permettrait au chercheur de décrire les expériences des femmes réfugiées aux prises avec le VIH pendant leur grossesse, ce qui pourrait s'avérer bénéfique, à l'avenir, aux personnes séropositives pour le VIH.

Participation volontaire et retrait de l'étude
Votre participation à cette étude s'effectue sur une base volontaire. Même si vous choisissez de ne pas y prendre part, votre décision n'aura aucune conséquence sur la qualité des soins qui vous sont ou seront dispensés à L'Hôpital d'Ottawa. Vous n'encourrez aucune pénalité ni perte d'avantage auxquels vous auriez normalement droit. Vous avez le droit de retirer votre consentement en tout temps, sans devoir fournir de raison. Si vous décidez d'interrompre votre participation, le contenu de l'entrevue sera détruit (les transcriptions seront déchiquetées et les fichiers audio seront détruits.

Indemnisation
Au moment de l'entrevue, on vous remettra 40 $ en espèces pour le temps consacré à cette étude et pour vous aider à couvrir toute dépense associée à votre participation, notamment les frais de garde, de transport ou de stationnement. Vous recevrez cette indemnisation, même si vous choisissez de vous retirer de l'étude.

Confidentialité et anonymat
Tout renseignement personnel sur la santé sera maintenu confidentiel, à moins que la loi n'exige leur divulgation. Des représentants du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa, ainsi que de l'Institut de recherche de l'Hôpital d'Ottawa, pourront procéder à l'examen de vos dossiers médicaux originaux, sous la supervision de Teresa Chulach, uniquement à des fins de vérification.

Aucune publication ou présentation résultant de cette étude ne pourra servir à vous identifier. Aucune information pouvant servir à vous identifier ne sera transmise à l'extérieur de l'Université d'Ottawa. Tout renseignement transmis à l'extérieur de l'université sera codé à l'aide d'un numéro d'étude indépendant. Il est possible que les énoncés soient cités dans le cadre de publications ou de présentations. Toutefois, on fera appel à des noms fictifs dans toute revue scientifique et aucune information pouvant servir à vous identifier ne figurera dans ces citations.

Seule Teresa Chulach pourra accéder au lien entre votre nom et le numéro de l'étude indépendant. Ce lien et les dossiers de l'étude seront entreposés en lieu sûr et séparément. Ces dossiers seront conservés pour une période de dix (10) années suivant la fin de l'étude. Les fichiers audio seront détruits immédiatement suivant la transcription. Tout dossier papier sera entreposé dans un cabinet ou un bureau verrouillé de l'Université d'Ottawa. Les fichiers électroniques quant à eux seront stockés sur un ordinateur et protégés par un mot de passe, auquel seule Teresa Chulach aura accès. Une fois la période de rétention terminée, tous les dossiers papier seront déchiquetés ou jetés aux rebuts confidentiels, et les fichiers électroniques seront supprimés.

Questions au sujet de l'étude

Pour toute question au sujet de l'étude, veuillez communiquer avec Teresa Chulach, [redacted].

Ce projet de recherche a reçu l'approbation du Comité d'éthique de la recherche de l'Université d'Ottawa. Pour toute question au sujet de vos droits à titre de sujet de recherche, veuillez communiquer avec les conseillers en matière d'éthique de l'Université d'Ottawa : Université d'Ottawa, Pavillon Tabaret, 550, rue Cumberland, salle 154, Ottawa (Ontario) K1N 6N5; (613) 562-5387; ethics@uottawa.ca.

Le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa (CÉR-RSSO) a révisé ce protocole. Le CÉR-RSSO est chargé de l'ensemble des aspects éthiques de toutes les études de recherche menées auprès de sujets humains effectuées à L'Hôpital d'Ottawa. Pour toute question au sujet de vos droits à titre de sujet de recherche, veuillez communiquer avec le président du Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa, au 613-798-5555, poste 16719.

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Formulaire de consentement
L'expérience vécue de femmes réfugiées au Canada enceintes et séropositives pour le VIH

Consentement à la participation à la recherche
Je reconnais que l'on sollicite ma participation à une étude de recherche sur l'expérience de femmes réfugiées qui sont tombées enceinte pendant qu'elles étaient séropositives pour le VIH. Teresa Chulach m'a fourni les explications nécessaires au sujet de cette étude.

J'ai pris connaissance des quatre (4) pages de cette Feuille de renseignements et de ce Formulaire de consentement à l'intention du patient. On a répondu à toutes mes questions de manière satisfaisante. Si je décide plus tard au cours de l'étude de retirer mon consentement, il me sera possible de le faire en tout temps.

Je consens volontairement à prendre part à cette étude.

Je consens à être enregistrée sur bande audio : Initiales oui ☐ non ☐

Je consens à ce que l'on me cite directement (toute information pouvant servir à vous identifier sera supprimée) : Initiales oui ☐ non ☐

Il existe deux copies de ce formulaire, l'une d'entre elle qui me sera remise.

Signatures

_____
Nom de la participante (en caractères d'imprimerie)

_____ _____
Signature de la participante Date

Consentement verbal : Enregistrement audio ☐ Documenté ☐

Énoncé du chercheur (ou de la personne chargée d'obtenir le consentement)
J'ai expliqué soigneusement au participant de la recherche la nature de l'étude susmentionnée. Pour autant que je sache, le participant apposant sa signature à ce consentement reconnaît la nature, les exigences, les risques et les avantages que comporte sa participation à l'étude. Je reconnais ma responsabilité envers le soin et le bien-être du participant susmentionné, le respect des droits et des désirs de ce dernier, et le déroulement de cette étude, conformément aux directives et aux règlements relatifs à la bonne pratique clinique.

_____
Nom du chercheur/délégué (en caractères d'imprimerie)

_____ _____
Signature du chercheur/délégué Date

Appendix G

List of resources

If you feel the need to talk to someone after this interview or if you wish to receive some form of psychological support, please refer to the following resources:
Si jamais vous ressentez le besoin de parler à quelqu'un après cette entrevue ou si vous souhaitez recevoir une aide psychologique, vous pouvez faire appel aux ressources suivantes :

Distress Centre of Ottawa and Region
Phone Number | *Numéro de téléphone*: 613-238-3311
Services offered 24 hours a day, 7 days a week (in English): mental help support, crisis intervention, information referral and education services
Services offerts 24 heures par jour, 7 jours semaine (en français): soutien en santé mentale, intervention de crise, services information et d'éducation
http://www.dcottawa.on.ca/

Eastern Ottawa Resource Center | *Centre de ressources de l'est d'Ottawa*
Address | *Adresse*: 2339 Ogilvie Road, Ottawa
Phone Number | *Numéro de téléphone*: 613-745-4818
Services offered 5 days a week services (in English): mental help support, crisis intervention, counselling, legal advice clinic, and support groups
Services offerts 5 jours semaine (en français): soutien en santé mentale, intervention de crise, counselling, clinique d'information juridique et groupes de soutien
http://www.eorc-gloucester.ca/

Mental Health Helpline | Ligne d'aide sur la santé mentale
Phone Number | *Numéro de téléphone*: 1-866-531-2600
Services offered 24 hours a day, 7 days a week (in English): mental help support and referral
Services offerts 24 heures par jour, 7 jours semaine (en français): soutien en santé mentale et référence
* Services offered in over 170 languages | *Services offerts dans plus de 170 langues*
http://www.mentalhealthhelpline.ca/Home/FAQ

Tel-Aide Outaouais (*en français seulement*, in French only)
Numéro de téléphone: 613-741-6433 ou sans frais 1-800-741-6433
Services offerts 365 jours par année: écoute téléphonique et référence
http://www.tel-aide-outaouais.org/index.php

Appendix H

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Dave	Holmes	Health Sciences / Nursing	Supervisor
Marilou	Gagnon	Health Sciences / Nursing	Co-Supervisor
Teresa	Chulach	Health Sciences / Nursing	Student Researcher

File Number: H12-12-03

Type of Project: PhD Thesis

Title: The lived experience of HIV among pregnant refugee women in Canada: A qualitative study

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
05/30/2013	05/29/2014	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

Recruitment can take place within the AIDS Committee of Ottawa (permission letter received March 27th, 2013).

550, rue Cumberland, pièce 154 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
(613) 562-5387 • Téléc./Fax (613) 562-5338
http://www.research.uottawa.ca/ethics/index.html
http://www.recherche.uottawa.ca/deontologie/index.html

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: http://www.research.uottawa.ca/ethics/forms.html.

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.research.uottawa.ca/ethics/forms.html.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Protocol Officer for Ethics in Research
For Chair of the Sciences and Health Sciences REB

550, rue Cumberland, pièce 154 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
(613) 562-5387 • Téléc./Fax (613) 562-5338
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Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Dave	Holmes	Health Sciences / Nursing	Supervisor
Marilou	Gagnon	Health Sciences / Nursing	Co-Supervisor
Teresa	Chulach	Health Sciences / Nursing	Student Researcher

File Number: H12-12-03

Type of Project: PhD Thesis

Title: The lived experience of HIV among pregnant refugee women in Canada: A qualitative study

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
05/30/2013	05/29/2014	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:

Recruitment can take place within the following organizations:

- AIDS Committee of Ottawa (permission letter received March 27th, 2013).
- South East Ottawa Community Health Centre (permission letter received September 5th, 2013).
- The Ottawa Hospital (OHSN-REB approval received November 26th, 2013)

550, rue Cumberland, pièce 154 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
(613) 562-5387 • Téléc./Fax (613) 562-5338
http://www.research.uottawa.ca/ethics/index.html
http://www.recherche.uottawa.ca/deontologie/index.html

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at: http://www.research.uottawa.ca/ethics/forms.html.

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at: http://www.research.uottawa.ca/ethics/forms.html.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Protocol Officer for Ethics in Research
For Chair of the Sciences and Health Sciences REB

550, rue Cumberland, pièce 154 550 Cumberland Street, room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada
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Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
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Marilou	Gagnon	Health Sciences / Nursingy	Co-Supervisor
Teresa	Chulach	Health Sciences / Nursingy	Student Researcher

File Number: H12-12-03

Type of Project: PhD Thesis

Title: The lived experience of HIV among pregnant refugee women in Canada: A qualitative study

Renewal Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
05/30/2014	05/29/2015	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

Université d'Ottawa University of Ottawa
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: http://www.research.uottawa.ca/ethics/forms.html.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: http://www.research.uottawa.ca/ethics/forms.html.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Ethics Coordinator
For Director of the Office of Research Ethics and Integrity

Appendix I

Research Institute
Institut de recherche

uOttawa

UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE

Ottawa Health Science Network Research Ethics Board/ Réseau des sciences de la san d'Ottawa Conseil d'éthique de la recherche

Civic Box 411 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311
http://www.ohri.ca/ohsn-reb

November 05, 2013

Ms. Teresa Chulach
School of Nursing
Health Sciences
University of Ottawa
451 Smyth Road
K1H 8M5

Dear Ms. Chulach :

Re: Protocol # 20130280-01H **The lived experience of HIV and pregnancy among refugee women in Canada**

Protocol approval valid until - November 04, 2014

I am pleased to inform you that this protocol underwent delegated review by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved. No changes, amendments or addenda may be made to the protocol or the consent form without the OHSN-REB's review and approval.

Approval is for the following:
- Research Proposal, version 1, dated March 31, 2013
- English and French Poster, version 1, dated August 06, 2013
- English and French Information Sheet & Consent Form, version 1, dated September 04, 2013
- English Only Interview Guide, version 1, dated March 04, 2013
- English Only Socio-Demographic Questionnaire, version 1, dated March 04, 2013
- English Only Resource List, version 1, dated March 04, 2013

The REB no longer requires a 'valid until' date at the bottom of all approved informed consent forms The consent forms currently approved for use by the REB are listed above.

If the study is to continue beyond the expiry date noted above, a Renewal Form should be submitted to the REB approximately six weeks prior to the current expiry date. If the study has been completed by this date, a Termination Report should be submitted.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) was created by the merger of both the Ottawa Hospital Research Ethics Board (OHREB) and the Human Research Ethics Board (HREB) for meetings held at the University of Ottawa Heart Institute.

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline and the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,

Vice Chairperson
Ottawa Health Science Network Research Ethics Board

/hm