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Desiring a balanced identity : a Heideggerian phenomenological inquiry into the pregnancy experiences of newcomer women to Canada living with HIV

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DESIRING A BALANCED IDENTITY: A HEIDEGGERIAN PHENOMENOLOGICAL INQUIRY INTO THE PREGNANCY EXPERIENCES OF NEWCOMER WOMEN TO CANADA LIVING WITH HIV

by

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ABSTRACT

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The pregnancy experiences of newcomer women to Canada living with HIV is an important area within maternal health research which to date has been unstudied. Hence, the purpose of this study was to explore the meaning of pregnancy for newcomer women living with HIV. Heideggerian phenomenology was used as the methodology and guiding framework. Five women living in an urban setting in Ontario, Canada were interviewed. Through data analysis and using the four existentials of human existence *Desiring a Balanced Identity* emerged as the overarching theme of the pregnancy experiences of the five women. This overarching theme was intimately connected with the four essential themes which were uncovered during data analysis. These themes were *The Situational Self*, *Living with the Good and the Bad*, *Support and Acceptance*, and *The Future Seems Brighter*. Recommendations and implications for education, practice and organizational policy, and research are provided in light of the study findings.

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DEDICATION

This thesis is dedicated in memory of my grandmother, Marilyn Kennedy. My Grammy possessed the most accepting, warm, loving spirit. Thank you for sharing your many lessons with me about hard work, the importance of laughter, and loyalty. Keep track of my stars for me!

This thesis is also dedicated to one mother who I met while working as a Registered Nurse whose journey taught me more than she will ever know about resilience, perseverance, and finding light at the end of a long, dark tunnel. I think of her often and wish her great hope and happiness for her future.

Finally, I dedicated this thesis, with a great deal of admiration, to the five women who selflessly shared their stories of triumph, tragedy, and hope with me. I thank you for your courage and willingness to speak with me.

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CHAPTER 1: INTRODUCTION TO THE STUDY

Introduction

This chapter is intended to set the stage for the reader by beginning with a narrative presentation of my personal context within the study's topic. This is followed by a brief introduction to the study population, *pregnant newcomer*[1] *women to Canada living with HIV*. The chapter concludes with the purpose and the research question that guided this study. Throughout this thesis, several terms are defined in footnotes.

Personal Context

This study was conducted in the tradition of Heideggerian phenomenology which is discussed in Chapter 3. In this tradition, the researcher is seen as the tool of interpretation and as a co-constructor of the findings (Benner, 1994; Leonard, 1994; van Manen, 1997). Therefore, it is necessary that I make my social positioning and sense of self transparent to allow readers to examine my work critically.

Unlike the participants in this study, I am a Canadian-born woman. I have not experienced immigration or life as a woman living with HIV. Instead, my evolving understanding of the social complexities of women's health is the result of nursing education. As a nurse, I have learned about the broader context within which women and their families experience health and illness. Further, my desire to conduct this specific study is connected to my experiences working with women living in socially constructed HIV-related risk conditions[2].

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[1] In this study, newcomer refers to anyone who has come to reside in Canada during the last ten years. Family class immigrants, skilled-worker class immigrants, business class immigrants, undocumented or precarious status immigrants, and refugees or refugee claimants are all included in this broad definition (Citizenship and Immigration Canada, 2008; Guruge, 2007). The inclusion of women who have been in Canada for up to ten years is intended to acknowledge the lengthy process of integration following migration.

[2] Socially constructed HIV-related risk conditions are the externally created living conditions that place certain women at increased risk of HIV infection. These include but are not limited to poverty, lower educational status than men, the gender gap, power differentials, and the prevalence of abuse (Leonard, Navarro, Birkett, & Remis, 2004; World Health Organization [WHO], 2009).

In 2005, I spent five weeks in Zimbabwe as a volunteer at a hospital. I witnessed suffering and social devastation in Zimbabwe due to political instability, absolute poverty, and high prenatal HIV infection rates. I observed firsthand the negative impact that HIV was having on the women of childbearing age in Zimbabwe. For every day I spent in Zimbabwe I have a corresponding memory of a mother whose health was slipping away because of an untreated HIV infection. During this experience I learned that equality and social justice are crucial in the fight against HIV amongst women. I knew that I wanted to remain committed to achieving equity and justice for women.

For the past five years I have endeavoured to continue this work as a labour and delivery nurse in a large urban hospital. I have learned from my colleagues that limited knowledge of, and experience with, certain groups of women creates uncertainty. In practice, this uncertainty impacts care and creates barriers in the development of therapeutic relationships. Simply put, I have observed that nurses and other allied healthcare professionals feel as if they 'don't know what to do with' women from certain groups. What has also had a strong impact on me is the dearth of knowledge that exists regarding the socially constructed experience of living with HIV. In completing this research, I set out to contribute to our understanding of how the experiences of being a newcomer and living with HIV impact a women's journey through pregnancy.

Study Context

Canadian Immigration Policy Regarding Applicants Living with HIV

In recent years, there have been changes to Canadian immigration policy with regard to mandatory HIV testing. These changes have resulted in public confusion about the admissibility of immigrant and/or refugee applicants living with HIV. Mandatory immigration HIV testing of all applicants began in 2002 with the enactment of the *Immigration and Refugee Protection Act*

(IRPA) (Krentz & Gill, 2009; PHAC, 2007). HIV is one of many conditions that can render an applicant inadmissible based on "the excessive demand clause" (Citizenship and Immigration Canada [CIC], 2008b; PHAC, 2007). Excessive demand is defined as:

> Demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the medical examination, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than 10 consecutive years...or....a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of the denial of or delay in the provision of those services to Canadian citizens or permanent residents. (CIC, 2009b, Annex 5)

Refugees and protected persons, as well as spouses, common-law partners, and dependent children of Canadians are exempt from an excessive demand assessment[3] (CIC, 2009a; Krentz & Gill, 2009). According to CIC (2011), spouses, common-law partners, and dependent children of Canadians, as well as refugees accounted for 68,401 of the 280,636 new permanent and temporary residents in Canada in 2010. As such, nearly one quarter of applicants is exempt from an excessive demand assessment. This means that while they will be tested for HIV, they cannot be denied immigration based on the financial costs associated with HIV infection. This data in no way implies that CIC has an open-door policy for people living with HIV; in fact, three quarters of applicants are assessed for excessive demand. It does, however, negate the prevailing

[3] An excessive demand assessment is conducted by a designated medical practitioner. This assessment, which includes testing for HIV, except for the individuals listed above who are exempt, is intended to identify applicants who are likely to create an excessive burden on health or social services. This is a cost-based analysis that is determined by an immigration official and the designated medical professional (CIC, 2009b).

assumption that any immigrant or refugee claimant who is living with HIV will be denied.

Women represent a considerable proportion of these exempt applicants. Between 2004 and 2008 women accounted for 39.8% of family class and 51.4% of protected persons (CIC, 2011). This data suggests that a significant proportion of newcomer women do not undergo excessive demand assessments. In fact, fewer women than men may actually be deemed inadmissible because of an HIV infection. Nevertheless, it is instructive to examine how our limited knowledge of this population may limit our ability to provide appropriate care, in particular maternal health care.

Canadian Public Health Data on Women Living with HIV

By 1998, the proportion of people living with HIV in Canada who originated from HIV-endemic countries was significant enough to warrant the creation of a new exposure category[4] within the Public Health Agency of Canada (PHAC, 2007). The creation of the heterosexual/endemic exposure category was intended to capture new HIV infections that have no risk of transmission other than by the carrier being from, or having a sexual partner who is from, an HIV-endemic country[5] (PHAC, 2007). Data from the heterosexual/endemic exposure category currently estimates that the new infection rate amongst people from HIV-endemic countries is 8.5% higher than other Canadians (PHAC, 2008). Women represented more than half of the infections in the heterosexual/endemic exposure category in 2008 (PHAC, 2011).

The growing number of women living with HIV in Canada has drastically changed the nature of HIV in this country (Loutfy et al., 2009). One particularly important implication of this change is the increasing number of babies born to women living with HIV. According to PHAC (2008), more than half of all the infants that are prenatally exposed to HIV in Canada annually

[4] An exposure category is "the most likely way a person became infected with the HIV virus" (PHAC, 2007, p. 91).
[5] For a complete list of PHAC's HIV endemic country list, visit http://www.phac-aspc.gc.ca/publicat/epiu-aepi/epi-1205/app_a-eng.php

are born to women from endemic countries. It should be noted that this statistic does not capture children born to newcomer women who are not from endemic countries, nor does it account for those born to undocumented women. Therefore, this number may be an underestimation of the number of women living with HIV who are giving birth in Canada each year. The study of lived experiences for newcomer women and how experiences may relate to health outcomes is crucial. Findings related to pregnancy amongst newcomer women to Canada living with HIV will be vital to maternal health in the context of HIV as this population continues to grow.

Newcomer Women to Canada

Newcomer women to Canada come from all over the world. They are diverse, their histories are complex, and their new lives in Canada remain connected with the past (Llácer, Zunzunegui, del Amo, Mazarrasa & Bolůmar, 2007). Newcomer women are disproportionately impacted by structural inequalities[6]. These inequalities result in economic disadvantages, limited social support, various experiences of stigma[7], and barriers to culturally appropriate health (Best Start, 2009; Boyd & Pikkov, 2005; PHAC, 2007).

Foreign-born women in their reproductive years (15-44) are over-represented in Canada's HIV statistics (PHAC, 2007; WHO, 2009c). Furthermore, while the HIV seroprevalence[8] of women seeking prenatal care in Canada is between 2 and 9 in 10,000, newcomer women from endemic countries have 13% HIV seroprevalence than Canadian-born women rates during pregnancy (PHAC, 2007). The disparity in the rates is thought to be attributable to increased access in Canada to antiretroviral treatment that reduces the risk of maternal-to-child-

[6] Structural inequalities are the systemic biases that remain pervasive in government, organizations, and institutions which disadvantage groups of marginalized people (Galabuzzi & Labonte, 2002).
[7] In the broadest sense, stigma is the experience of social exclusion because of an attribute that is deemed outside of social norms (Goffman, 1963). The various attributes that may result in stigmatization of newcomer women may include, but are not limited to, race/ethnicity, being a visible minority, language proficiency, gender, socioeconomic status, and culture. Women living with HIV have the additional experience of HIV-related stigma.
[8] Seroprevalence is the prevalence of those living with HIV (PHAC, 2007).

transmission of HIV to less than 1% (Carvalhal, 2010; CIC, 2008a; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009; Llácer et al., 2007; Statistics Canada, 2007; Türmen, 2003). As rates continue to increase, understanding subjective experiences will become increasingly essential in order to optimize care. And yet, little is known about the relationship between recent migration and pregnancy for women living with HIV in Canada.

Study Purpose and Research Question

The purpose of this study was to explore and interpret the meaning of pregnancy for newcomer women living with HIV. I hoped that by exploring women's experiences I would be able to highlight the complexity of pregnancy for newcomer women living with HIV. I used the question "What are the pregnancy experiences of women living with HIV who are newcomers to Canada?" to guide this study.

Studying human experiences is a conducive approach to knowledge development in nursing given the balance between nursing art and science (Lopez & Willis, 2004). Nurses endeavour to respond to the individualized needs of their clients. In doing so, an understanding of context and subjective realities is essential if care is to be meaningful, appropriate, and sensitive to a person's needs (Lopez & Willis, 2004). Researching lived experience provides the unique opportunity to explore multiple realities of human existence.

Summary

Chapter 1 has introduced this study regarding the pregnancy experiences of newcomer women living with HIV. By providing my personal context and the study context, this chapter has captured why I feel this topic warranted further investigation. In the second chapter, I will provide a critical synthesis of the literature on pregnancy and newcomer women living with HIV.

CHAPTER 2: LITERATURE REVIEW

Introduction

The purpose of this chapter is to present a critical synthesis of the literature regarding the pregnancy experiences of newcomer women to Canada living with HIV. This synthesis is intended to (a) provide a critical perspective regarding the main areas of research that have been conducted to date and (b) discuss the gaps in the literature and explore how this study addresses these gaps. The chapter concludes with the rationale for and significance of this study.

Critical Review of the Literature

Over the past decade, the volume of literature on pregnancy and HIV has grown. Additionally, several new themes have emerged in this body of literature ranging from bio-medical research on the prevention of maternal-to-child-transmission of HIV and the medical management of HIV in pregnancy to HIV counselling and testing in pregnancy (Hahn, Rasch, Chi & Gammeltoft, 2009; Flake, 2000; Tudor Car et al., 2011). The challenge is that over the past ten years, as science has been engrossed in the well-being of the infant, medical advances, and testing, research has overlooked the connection between the medicalized experience of pregnancy and the subjective human phenomenon of women living with HIV.

In my experience, no published health research is available on the specific topic of pregnancy for newcomer women to Canada living with HIV. Therefore, I conducted a review of related literature: (a) reproductive decision making and pregnancy intentions, (b) stigma, (c) accessing appropriate prenatal care, and (d) support for newcomer women living with HIV. I also confined my review to literature that focused on women's emotional, psycho-social, and cultural experiences of pregnancy. The review does not include biomedical aspects of pregnancies in the context of HIV infection, pregnancy prevention, or healthcare providers'

attitudes since these topics were not used to inform this study. The majority of the identified literature was not based on Canadian data. While non-Canadian literature is included in this synthesis, we should be cautious as the immigration and healthcare systems in other countries may be different than in Canada. These differences may have significant impacts on the immigration process and accessibility of services after migration.

Reproductive Decision Making and Pregnancy Intentions

An emerging theme in the literature is reproductive decision making[9] among women living with HIV. This body of literature defies the prevailing assumption that women with HIV do not desire a family because of their HIV infection. The current focus on reproductive decision making is likely in response to the belief that since women have greater access to treatment to maintain their own health, and to prevent the vertical transmission of HIV from mother to child[10], more will decide to become pregnant (Carvalhal, 2010; Cooper, Harries, Myer, Orner & Bracken, 2007; Finocchario-Kessler et al., 2009; Loutfy et al., 2009; Wesley et al., 2000). By extension, with greater access to treatment in Canada, newcomer women living with HIV may have a renewed interest in becoming pregnant and having children.

For women living with HIV, the decision to become pregnant carries characteristics unique to their HIV status (Ingram & Hutchinson, 2000). And while HIV status does appear to have some influence on decisions about pregnancy, it has not been found to dissuade women living with HIV from considering and becoming pregnant (Cooper et al., 2007; Ingram & Hutchinson, 2000; Finocchario-Kessler et al., 2010; Loutfy et al., 2009; Wesley et al., 2000). Some of the other major factors, which have been identified as influential in the reproductive

[9] This term, often interchangeable with pregnancy intentions, has slightly varied definitions among authors but generally refers to the decision-making progress regarding the desire to plan a pregnancy (Cooper et al., 2007; Finocchario-Kessler et al., 2010; Gruskin et al., 2008; Loutfy et al., 2009; Wesley et al., 2000).

[10] Vertical transmission of HIV is the direct transmission of HIV from mother to infant during pregnancy, birth, or through breastfeeding.

decision making of women living with HIV, were: (a) the anticipated joys of motherhood, (b) the personal needs a pregnancy fulfills, (c) the normalizing experience of pregnancy, (d) their partner's desire to have a family, and (e) cultural or social pressure to become a parent (Cooper et al., 2007; Ingram & Hutchinson, 2000; Finocchario-Kessler et al., 2009; Wesley et al., 2000).

Cultural expectations[11] may be one of the most salient factors for newcomer women. In a quantitative, retrospective chart audit, Blood, Beckwith, Bazerman, Cu-Uvin, and Mitty (2009) used descriptive statistics to describe the pregnancies within a group of mostly West African refugee women in Rhode Island, United States, as compared to non-immigrant women at the same clinic. This study posited a link between culture and pregnancy rates for women living with HIV. Despite only representing 16% of the women within the clinic, their sample of newly arrived refugee women accounted for 27% of the pregnancies documented during the audited period. In fact, 50% of the HIV-positive refugee women in the study became pregnant within an average of 16 months of arrival in the United States. While the findings from the Blood et al. study generated statistical information about a group of refugee women living with HIV, its purpose and research question were situated within the dominant biomedical discourse of HIV research focusing more on outcomes than experience. As such, the results did not provide knowledge about the lived experiences of the women in their study.

While the foregoing literature provided some general findings about the pregnancy intentions of women living with HIV, a smaller subset of literature surfaced that shed some light on the reproductive decision making of newcomer women to Ontario living with HIV. In a cross-sectional survey study of 490 women of reproductive age living with HIV in Ontario,

[11] Throughout the world, motherhood is highly valued. So much so that in some instances to remain childless is perceived as socially deviant. It is well documented, however, that certain cultures place a high expectation on motherhood (De Souza, 2004). This often translates to heightened personal desires to become mothers as a result of such socialization (De Souza, 2004).

Loutfy et al. (2009) found that three of the important demographic predictors of pregnancy intention amongst Ontarian women living with HIV were: (a) African, (b) not born in Canada, and (c) shorter time since migration to Canada. This sample matched Ontario's ethnic distribution of women living with HIV in the province, with 61% of participants being born outside of Canada.

Loutfy et al. (2009) underscored the need for Canadian research on women living with HIV. While American publications are more widely available, Loutfy et al. suggested that an understanding of the characteristics, intentions, and experiences of women living with HIV in Canada cannot be achieved by comparing our population with American research. In Canada the population of women living with HIV is disproportionately that of immigrants, while the United States' population is predominantly comprised of the American-born (Loutfy et al., 2009). Thus, it was notable that the reported rates of pregnancy intention in Loutfy et al.'s study were closer to rates of pregnancy intention in a cited Nigerian study than in other American literature. The association between being African and higher pregnancy intention rates were believed to be connected to the high cultural importance placed on motherhood in developing countries (Loutfy et al., 2009). The findings of this study affirmed the aforementioned position that cultural expectations play an important role in reproductive decision making for women living with HIV. While this study alluded to the correlation between being African and higher pregnancy intentions, it did explore the experience of pregnancy for newcomer women to Canada.

Substantiating Loutfy et al.'s (2009) claim that ethnicity is connected to pregnancy intention, Cooper et al. (2007) identified a strong connection between reproductive decision making and societal expectations in a grounded theory study of 40 HIV positive women and twenty HIV positive men in South Africa.

The women in Cooper et al.'s (2007) study reported strong social pressure to produce a child for their husband's families but only if they had not disclosed their HIV status. When they had disclosed it, women "perceived that communities disapproved of reproduction in these circumstances" (Cooper et al., 2007, p. 278). This substantiates the connection between pregnancy intention and cultural expectations. It also creates a question of how these expectations change or influence pregnancy for immigrant women from "pro-natal" societies (Cooper et al., 2007, p. 275). Cooper et al.'s study offered important insight for healthcare professional and policy makers about the influence of culture on reproductive decision making. Newcomer women may experience similar pregnancy intentions, societal expectations, and double binds; however, the complexity of migration may add an additional layer of decision making for newcomer women and this is as yet undocumented.

Other studies found that HIV status, despite not always being the deciding factor, did play a role in women's reproductive intentions. According to Ingram and Hutchinson's (2000) qualitative, grounded theory study of 20 women, which explored the reproductive and mothering experiences of women with HIV, decisions about pregnancy and parenting essentially became a double-edged sword. This double-edged sword, or conflict, existed because while the women in the study acknowledged their socially normative desires to become pregnant, their diagnosis of HIV created a double bind[12]. The woman indicated that the mixed messages they were receiving made pregnancy an extremely stressful time. Ingram and Hutchinson's study produced informative knowledge about the double bind that women living with HIV experience with regard to reproductive decision making. However, this study did not capture the experiences of

[12] A double bind refers to the women's experiences of feeling socially compelled to have a child because they were women while also being "haunted by social and personal messages about the evils of childbearing when HIV positive" (Ingram & Hutchinson, 2000, p. 122).

pregnancy for newcomer women which are further influenced by culture, migration, accessibility of healthcare, and limited social support (Boyd & Pikkov, 2005; PHAC, 2007).

Women in a number of studies also reported fears about their child's health, their own health, and about potentially orphaning the child (Cooper et al., 2007; Finocchario et al., 2009; Wesley et al., 2000). Another dilemma for women was a sense of disapproval from healthcare professionals regarding reproduction due to their positive HIV status (Cooper et al., 2007; Wagner et al., 2010).

HIV-related Stigma

A common theme in HIV research is stigma as it relates to living with HIV. While HIV-related stigma has been widely researched, it remains poorly understood (Parker & Aggleton, 2002). As it sounds, HIV-related stigma is the social exclusion and inequality experienced by people based on their HIV status (Parker & Aggleton, 2002). HIV-related stigma is perpetuated by all levels of society from government down to individuals (Parker & Aggleton, 2002). The origins of HIV-related stigma are believed to be in the condemnation and dislike of already marginalized groups (Gonzalez, Miller, Soloman, Bunn & Cassidy, 2009; Morrison & Guruge, 1997). These aforementioned marginalized groups of people were already subject to stigmatization based on sexuality, gender, ethnicity/race, socioeconomic status, and other behavioural attributes such as injection drug users (Gonzalez et al., 2009; Morrison & Guruge, 1997; Parker & Aggleton, 2002).

While men living with HIV also experience HIV-related stigma, women are thought to have a distinct experience of HIV-related stigma (Sandelowski et al., 2004; Wagner et al., 2010). This distinct experience of HIV-related stigma is described as the intersection[13] of several types

[13] The concept of intersectionality refers to the "interaction of multiple identities and experiences of exclusion and subordination" (Davis, 2008, p. 67).

of stigma (Sandelowski et al., 2004). Women living with HIV are "located at different intersecting points on key axes of differences" (Sandelowski et al., 2004, p. 125). They are disproportionately stigmatized for other attributes such as gender, being from a marginalized racial/ethnic origin, and low socioeconomic status (Sandelowski et al., 2004; Wagner et al., 2010). Some literature has also suggests that women living with HIV are targeted based on issues of morality (Morrison & Guruge, 1997). It is often assumed that women living with HIV became infected through intravenous drug use or promiscuity (Mill et al., 2009; Sandelowski et al., 2004). It is the combined experience of these types of stigma and discrimination that creates HIV-related stigmatization that is distinct to women.

HIV-related stigma in pregnancy. In a meta-synthesis of 93 publications, Sandelowski et al., (2004) concluded that pregnant women living with HIV are vilified for their biological ability to give birth to a child since children represent innocence and women living with HIV are socially constructed as sinful. The potential of infecting a child with HIV is believed to contribute to the stigmatization of women living with HIV (Morrison & Guruge, 1997; Sandelwoski et al., 2004). According to Morrison and Guruge (1997), society sees this as another example of irresponsible behaviour on the part of women with HIV. Ingram and Hutchinson (2000) also discussed how "social stigma…exists for mothers whose life experience falls outside of culturally accepted norms regarding motherhood, such as…[women] who are HIV-positive" (p. 118). In fact, Ingram and Hutchinson state that women who are living with HIV and who choose to have a child are often seen as "cruel and uncaring" (p. 118). Thus, it appears that HIV-related stigma may in fact intensify during pregnancy. This body of literature provides important information in terms of the intensity of HIV-related stigma for women during

pregnancy. However, there is still a lack of knowledge regarding how this influences pregnancy experiences for newcomer women living with HIV.

Studies have also found that HIV-related stigma continues to be a problem for pregnant women within healthcare settings and not just in society at large (Cooper et al., 2007; Ingram & Hutchinson, 2000; McGuire Bunting & Seaton, 1999; Sanders, 2008). Women have been found to avoid discussing pregnancy with healthcare providers for fear of discrimination and the perception of negative attitudes from healthcare providers regarding pregnancy (Cooper et al., 2007; Ingram & Hutchinson, 2000). In an interpretive hermeneutic study of 18 perinatal women living with HIV, McGuire Bunting and Seaton (1999) further identified ethnicity as an added layer of stigmatization in healthcare. The findings of this study suggest that two of the African-American women felt they received inferior care to the white women living with HIV. McGuire Bunting and Seaton incidentally discovered this finding. Their focus on accessing perinatal healthcare services limited their ability to examine the layering effect of stigma for ethnic minority women living with HIV. Nonetheless, this finding was valuable since it demonstrated that the experience of HIV-related stigma for women may also be connected to their social positioning based on race/ethnicity. There is however, still a lack of knowledge about how the social positioning of newcomer women intersects with HIV-related stigma.

Research has also shown that immigrant women in general may experience stigma associated with pregnancy which is related to cultural practices around motherhood (Davies & Bath, 2001). Particularly, Davies and Bath (2001) suggested that the high fertility rates amongst certain groups of immigrant communities are perceived as a drain on, and economic abuse of, the healthcare system. The findings point to an important consideration of the intersection of 'newcomer-related stigma' with the aforementioned HIV and gender-related stigma. It is also

important to note that the Davies and Bath (2001) study was conducted ten years ago which may necessitate a more current investigation to explore if 'newcomer-related stigma' remains pervasive in Canadian society.

Pregnant newcomer women to Canada living with HIV likely face a multiplicity of stigmas. This intersection of key points of difference becomes a cause for concern. While each marginalizing characteristic contributes an element of stigma, it is the cumulative or combined effect that makes poor, minority women with HIV the most vulnerable and stigmatized (Mill et al., 2009; Sandelowski et al; Wagner et al., 2010). Wagner et al. (2010) found that HIV-stigma was higher for women born outside Canada than for those women in their sample who were Canadian-born. They found a significant positive relationship (p=0.0015) between women's reports of having been judged by a physician inside Canada for trying to become pregnant and whether or not she had been born in Canada. However, the subjective experience of this stigmatization was not captured by Wagner et al.

Wagner et al. (2010), who recruited participants from the larger HIV Fertility Survey (Loutfy et al., 2009), also found that "being born in Canada significantly moderated the relationship between having been judged by a health care provider inside of Canada for trying to become pregnant and HIV stigma" (Wagner et al., 2010, p. 210). In fact, Sandelowski et al. also (2004) identified that women who were able to mitigate the effects of being stigmatized for being HIV positive were able to do so merely because they were White and middle-class.

Over 86% of the women in the HIV Fertility Survey (Loutfy et al., 2009; Wagner et al., 2010) were not born in Canada and were sub-Saharan African or Caribbean. This demographic distribution is representative of Ontario's population of immigrants and refugees living with HIV (Wagner et al., 2010). Wagner et al. (2010) further found "distinctly different models" of HIV-

related stigma for women born in Canada as opposed to non-Canadian born women. Qualitative studies that elicit data on the lived experience of HIV-related stigma for non-Canadian born women are still needed to understand how the subjective experience of pregnancy is different for distinct groups of women.

Accessing Appropriate Prenatal Care

In reviewing literature on newcomers, as well as women with HIV, some of the common barriers in accessing prenatal care were: (a) precarious immigration status, (b) fear of deportation because of HIV status, (c) language barriers and lack of culturally appropriate services, (d) challenges with navigating a new healthcare system, (e) poor management and follow up by CIC, (f) perceived and/or experienced HIV and newcomer-related stigma, and (g) financial and cost constraints (Davies & Bath, 2001; Mill et al., 2009; Ndirangu & Evans, 2009; Reitmanova & Gustafson, 2008; Reynolds, 2008; Sohler et al., 2009; Tharao et al., 2005; Wagner et al., 2010). In Canada, research has claimed that the current maternal health services do not meet the needs of women from diverse cultural backgrounds and therefore, their access to prenatal care is inferior to that of Canadian-born women (Reitmanova & Gustafson, 2008). While the factors listed above are common challenges for pregnant newcomer women, the implications may be more significant for those living with HIV, particularly in the context of HIV-related stigma (Ndirangu & Evans, 2009).

Migration status and positive HIV status were found to come together and present barriers to care in Ndirangu and Evans' (2009) qualitative study of eight African women. This study was based on a convenience sample in which all eight women had been in the United Kingdom for less than five years. The authors identified that stigma was a major barrier to accessing appropriate care for newcomer women living with HIV in the United Kingdom. They

also acknowledged that while all migrants face challenges in accessing care, "migrants living with HIV...face a dual challenge in terms of coping with a life threatening chronic illness and adjusting to a new country" (Ndirangu & Evans, 2009, p. 112). The findings of this study are particularly salient to the current study population of pregnant newcomer women to Canada living with HIV. While it broadly captures the barriers to appropriate care for newcomer women living with HIV it lacks the central focus on pregnancy. Newcomer women of reproductive age are amongst the highest new infections in Canada annually (PHAC, 2011). Knowledge of their experiences will be essential to creating responsive maternal health services in Canada.

Support for Pregnant Newcomer Women Living with HIV

In light of the numerous challenges pregnant newcomer women living with HIV face because of (a) conflicting messages about reproductive decision making, (b) pervasive social stigma, and (c) obstacles in accessing prenatal care, a discussion of support available to them is imperative. In a Canadian commentary, Tharao et al. (2005) suggested that despite the fact that African and Caribbean women represent an increasing proportion of the population of people living with HIV in urban Ontario, organizational support services available to them are limited and do not meet their needs. In a second Canadian commentary, Reynolds (2008) also addressed some poignant concerns about the current supports available to female immigrants and refugees in Canada living with HIV. Reynolds contended that CIC is ill equipped to address the complex social, emotional, and medical needs of newcomers living with HIV who are entering Canada. As a result, AIDS service organizations (ASOs) are required to fill the gaps that are created by this poor preparation by CIC. However, the author did not allude to the specific gaps that exist. While this commentary is provocative in its strong condemnation of CIC, it did not

provide any new insight into lived experience. Drawing from this commentary, we must be cautious in assuming how these service gaps impacted lived experience.

Other findings on support also indicate that newcomer women, particularly those living with HIV, struggle to access sufficient social/community support (Ndirangu & Evans, 2009; Reitmanova & Gustafson, 2008). Reitmanova and Gustafson (2008) concluded that isolation and lack of social/community support was a challenge for pregnant and parenting newcomer women to Canada. The women in their study stated that they had weak social supports to draw upon. From this Reitmanova and Gustafson concluded that there was a need for more attention on the emotional needs of pregnant newcomer women to Canada. While physical health needs were being met, as non-Canadian-born women, the participants felt they had significant emotional needs that were unmet. These unmet needs were found to have negatively influenced the participants' experiences with maternity care services in Canada.

Living with HIV appeared to add an additional layer to the challenge of accessing support for newcomer women. As in other studies about women with HIV who are not newcomers (Sanders, 2008), Ndirangu and Evans' (2009) examination of African immigrant women in the United Kingdom identified non-disclosure of HIV status as a barrier to social support. Newcomer women under-reported their HIV status to friends which limited their willingness to draw on these friends for emotional and psychosocial supports (Ndirangu & Evans, 2009). A number of the women noted that because of the HIV-related stigma in many African communities, they were reluctant to disclose their status. This often prevented them from participating in any formal support systems with other African women living with HIV for fear that news of their diagnosis would be spread around their communities in the United Kingdom as well as back home (Ndirangu & Evans, 2009). The authors observed that this seemed to lead to

an immense sense of isolation (Ndirangu & Evans, 2009). How this lack of social support impacts pregnancy experiences for newcomer women to Canada living with HIV warrants further investigation.

Synthesis

A review of the foregoing literature makes it difficult to envision what the pregnancy experiences of newcomer women to Canada living with HIV might entail. The majority of the literature reviewed was non-Canadian and very few studies focused on newcomers. Those studies that did include newcomers rarely focused on both HIV and pregnancy. Therefore it is challenging to develop an understanding of the pregnancy experiences for newcomer women to Canada living with HIV.

A number of the studies employed qualitative methodologies that are appropriate for studying lived experiences (Ingram & Hutchinson, 2000; McGuire Bunting & Seaton, 1999; Ndirangu & Evans, 2009; Sanders, 2008). By contrast, Blood et al.'s (2009) study, which was the only one that focused on pregnancy in a group of newcomer women with HIV, used a quantitative approach. The use of quantitative methodology and the specific research question limited the understanding of the subjective experience of the participants gained from their study. A number of the studies had a narrow focus; for example, certain studies only examined stigma or healthcare utilization. This narrow focus may have precluded women from sharing the holistic details of their experiences.

The various studies retrieved for this literature review and synthesis provided some valuable insight in developing this current study. What is generally known is that (a) HIV-related stigma is pervasive for HIV-positive women in society and within healthcare, (b) women who were not born in Canada appeared to experience more HIV-related stigma, (c) pregnancy

may be a heightened time of HIV-related stigma, (d) women living with HIV often wish for and plan pregnancies, (e) cultural expectations appear to play a pivotal role in the reproductive decision-making of women living with HIV, (f) newcomer women have unique challenges when trying to access to prenatal healthcare services, and (g) newcomer women tend to report limited social supports during pregnancy, whether living with HIV or not, which have negative impacts on their overall well-being. What is still required, however, is a study that explores the unique meaning of pregnancy experiences for newcomer women to Canada who are living with HIV. A qualitative study of this population could shed light on how lived experience impacts maternal health. Furthermore, it may elicit data that can direct maternal health services in Canada.

Gaps in the Literature

I have reviewed the current state of knowledge regarding pregnancy experiences for newcomer women to Canada living with HIV, and I have revealed several gaps in the published literature. Specifically, these are: (a) a lack of research that was conducted in a Canadian context, (b) outdated literature, and (c) a dearth of qualitative explorations of the lived experiences of pregnant newcomer women to living with HIV which would allow for a subjective, holistic inquiry into these women's complex experiences. These gaps in the literature reflect the present state of knowledge regarding my research topic. Pregnancy, for newcomer women, may already be a challenging experience; especially if a woman has recently arrived in a new country. However, combined with being HIV-positive, there may be several additional hurdles. However, this remains unstudied.

Rationale and Significance of the Study

This study is intended as a beginning step to address the gaps in the current literature by exploring the lived experiences of pregnant newcomer women to Canada living with HIV.

Substantially more research is needed to better understand the pregnancy experiences of newcomer women to Canada living with HIV. As Wagner et al. (2010) suggested, the life experiences of migrant women living with HIV in Canada may differ significantly from those women who were born here. Canadian literature supports the fact that newcomer women living with HIV appear to have higher pregnancy intentions than Canadian-born women (Loutfy et al, 2009; Wagner et al., 2010). Furthermore, pregnancy may be a period of significant stress for women living with HIV that is compounded by recent migration. Consequently, there is an escalating need to better understand the pregnancy experiences of these women in order to develop maternal healthcare services that are sensitive and responsive to diverse needs. This is a crucial are of study as there is scant research assessing the unique experiences and needs of newcomer women to Canada living with HIV during pregnancy.

As nurses, knowledge of lived experiences should inform our care as we endeavour to meet the needs of our clients (Lopez & Willis, 2004). Therefore this study is intended to address the gaps in our current knowledge and inform recommendations for nurses within education, practice and policy, and future research in order to enhance the current care provided to pregnant newcomer women to Canada living with HIV. The topic of this study should be of interest to nurses and healthcare professionals in general. As the front line workers within prenatal care settings, nurses are in a position to positively influence the pregnancy experiences of newcomer women to Canada living with HIV if they are given sufficient information on the women's identified needs. Without a rigorously conducted study that employs an appropriate methodology to uncover the women's subjective and layered experiences, nurses' abilities to improve the pregnancy experience of to Canada living with HIV are limited.

Summary

Ontario receives a large portion of Canada's newcomers (PHAC, 2011). It is, therefore, imperative to have studies that focus on the specific healthcare experiences and needs of newcomer populations in order to meet their diverse needs. The lack of a single study that had Canadian newcomer women living with HIV during pregnancy as the focus reflects the current gap in knowledge on my topic of interest.

In this chapter, I have presented a critical review and synthesis of the limited relevant literature. I intended this study to address the gaps I've identified in the literature. I selected Heideggerian phenomenology as the qualitative methodology to undertake this research study since it allows for a meaningful interpretation of the lived experience of pregnancy for newcomer women to Canada living with HIV. In Chapter 3, I will present detailed information regarding the methodological approach used throughout this study.

CHAPTER 3: METHODOLOGY

Introduction

This chapter describes the qualitative approach I used to conduct this study. I selected Heideggerian phenomenology, commonly known as interpretative or hermeneutic phenomenology (Lopez & Willis, 2004). The philosophical underpinnings of Heideggerian phenomenology are explained to clarify the concepts that guided sampling, data collection, analysis, and choice of rigour criteria. Heideggerian phenomenology is a both a methodology and a philosophical framework (Dowling, 2007; Munhall, 1989). Therefore, my understanding of Heidegger's framework was used to guide this study. According to Sandelowski (1993), theory is broadly defined as that which "direct[s] or inform[s] both the inquiry process, including the presentation of findings…" (p. 214). Theory is used to orient the researcher to the worldview they intend to investigate. Given the existential structure of Heideggerian phenomenology, it was suited for use as the guiding theory behind this study. Methodological rigour is defined and discussed in keeping with the philosophy of a Heideggerian phenomenological study. Finally, limitations and ethical considerations related to this study are presented. Throughout this chapter, I will demonstrate how methodological decisions were congruent with Heideggerian phenomenology.

Rationale for Choosing a Qualitative Methodology

Qualitative research serves to enhance our understanding of human experiences not through the establishment of causality, but through a comprehensive knowledge of the whole (Burns & Grove, 2009). Its disassociation with causality enables researchers to conduct investigations of phenomenon where little is known as formed hypotheses are not required (Creswell, 2007). My intention in conducting this study was to uncover the experiences of

pregnancy for newcomer women living with HIV through a dialogic process between the participants and myself, the researcher. As limited existing research had been conducted on this topic, this study was well suited for a qualitative design (Speziale & Carpenter, 2007).

Phenomenology

Phenomenology is a qualitative research method, with its roots in psychology and philosophy, concerned with lived human experiences (Loiselle et al., 2007). Rooted in the traditions of Edmund Husserl, and later his student, Martin Heidegger, phenomenology has evolved into a number of unique perspectives (Loiselle et al., 2007). However, at the core, all phenomenologists share the goal of exploring lived experiences (McConnell-Henry, Chapman & Francis, 2009). Phenomenology has emerged as a method to investigate subjective phenomenon and reality in the context of the world in which we live (Loiselle et al., 2007; Johnson, 2000).

Heideggerian Phenomenology

Heideggerian phenomenology allows a deeper understanding of existence through attention to the nature of meaning (Johnson, 2000; Heidegger, 1927/1962). Unlike Husserlian phenomenology which focused more on description, Heidegger believed interpretation was the basis for understanding by uncovering subtle realities that were often missed by description alone (Mackey, 2005). Heidegger believed that interpretation and meaning are achieved by setting out to formulate the ontological question of the meaning of Being, or *Sein* (Johnson, 2000; Heidegger, 1927/1962; Speziale & Carpenter, 2007). Ontology, the study of being, existence, and reality creates a distinct experience for human subjects (Johnson, 2000). According to Heidegger (1927/1962), the distinct ability to understand ourselves in terms of existence made human's uniquely ontological. Five major conceptual underpinnings of Heideggerian phenomenology were incorporated during the development of this study, through

data collection, analysis, and during my writing. These concepts were (a) *Dasein's* meaning of Being, (b) "*Being-in-the-world",* (c) the fore-structures of *Dasein*, (d) the hermeneutic circle of understanding, and (e) the four existentials.

***Dasein's* meaning of Being.** In "Being and Time", Heidegger (1927/1962) referred to the ontological entity that is the focus of interpretation as *Dasien*. The German term *Dasein* is central to Heideggerian phenomenology (Heidegger, 1927/1962). *Dasein* is "the entity that each of us is" (Johnson, 2000, p. 27) and is "the kind of Being that belongs to persons" (Heidegger, 1927/1962, p. 27). The existence of each *Dasein* is constructed individually and can only be fully understood through a process of ontological interpretation (Heidegger, 1927/1962; Johnson, 2000; McConnelly et al., 2009). As such, it is *Dasein's* meaning of Being that is the topic of any interpretive phenomenological inquiry (Heidegger, 1927/1962).

Being-in-the-world. While hermeneutics is commonly seen as the "art of interpretation", Heideggerian hermeneutics is the process of self understanding of *Dasein* through an understanding of the world in which we live (Johnson, 2000, p. 16). "*Being-in-the-world"* (Heidegger, 1927/1962, p. 528) signified *Dasien's* involved encounters with the world (Johnson, 2000; Mackey, 2005). According to Leonard (1994) "the first essential facet of a person centers on the relationship of the person to the world" (p.46). By considering *Dasein* in term of his existence in the world, a new level of understanding is achieved as a person's behaviour is put in context (Leonard, 1994; van Manen, 1997). Understanding context, or a person's *Being-in-the-world,* is an essential element of interpretation as the meaning of anyone's experience can vary depending on how that experience is felt by that person in their life (Leonard, 1994). As such, according to Heidegger (1927/1962), interpretation is "rather the working-out of possibilities projected in understanding" (p. 189) to generate an authentic understanding of *Dasein*. Within

the scope of this study, the experience of pregnancy for newcomer women with HIV involves multiple possibilities "that exist…by virtue of" the women existing in a "particular cultural, historical, and familial world" (Leonard, 1994, p. 47).

Fore-structures of *Dasein.* The next major concept of Heideggerian phenomenology that underpinned this study was what Heidegger (1927/1962) referred to as the fore-structures of *Dasein* (Mackey, 2005). Simply put, fore-structure is what is known in advance (Mackey, 2005). It is also the foundation upon which a researcher is able to interpret (Mackey, 2005). Heidegger (1927/1962) stated that all interpretation occurs in light of that which we possess prior to interpreting, *fore-having*, that which we see prior to interpretation, *fore-sight*, and that which we "grasp" prior to interpretation, *fore-conception* (p. 191). The utilization of one's fore-structure is unlike Husserlian phenomenology, which requires phenomenological bracketing, or reduction, to prevent the researcher's existing knowledge from influencing the data (Lopez & Willis, 2004; McConnell-Henry et al., 2009). Heidegger believed that fore-structure was in fact the only means to understanding (Mackey, 2005).

Hermeneutic circle of understanding. The process of interpretation occurs through a "circle of understanding" "whereby the fore-structures of understanding are made explicit, then considered in terms of the whole of the understanding of something, and then re-considered in new ways" (Heidegger, 1927/1962, p. 195; Mackey, 2005, p. 182). In the simplest sense, the hermeneutic circle of understanding is the movement between the parts and the whole of understanding to reach a deeper meaning (Mackey, 2005). This can only be achieved by acknowledging one's fore-structure which allows one to correctly enter the circle of understanding (Dreyfus, 1991; Mackey, 2005; Heidegger, 1927/1962). The circle of understanding allows the researcher to begin their process of inquiry. Without some pre-existing

orientation, a researcher would not know what needed to look at (Mulhall, 2005). Interpretation begins with this preliminary orientation and by working in a circular motion, from the parts to the whole, a deeper understanding that has moved beyond preliminary orientation is reached (Mulhall, 2005). As his deeper level of understanding is achieved, things stand out to the researchers. According to Heidegger (1927/1962), remaining in this circle is imperative in order to interpret. However, even though he accepted the role of fore-structures in interpretation, Heidegger cautioned against allowing them to predetermine our interpretation of the "potentiality-of-Being" of each *Dasein* (p. 195).

Four existentials. Heidegger (1927/1962) developed an "existential analytic of *Dasein*" that allowed *Dasein's* Being to "show itself, in itself and for itself" (Mulhall, 2005, p. 35). In creating this analytic, Heidegger set out to uncover the existential structure of *Dasein* (Johnson, 2000). According to Heidegger, the existence of *Dasein* is understood in four existentials; temporality (lived time), spatiality (lived space), corporeality (lived body), and relationality (lived human relation) (Heidegger 1927/1962; van Manen, 1997). The four existentials are the final major conceptual element of Heideggerian phenomenology that grounded this study.

Temporality. According to Heidegger (1927/1962) "Time must be brought to light-and genuinely conceived-as the horizon for all understanding of Being and for any way of interpreting it" (p. 18). Heidegger distinguished temporality from the way it is commonly understood; he conceived of time not as chronological time but instead considered time as a fluid interpretation of understanding the influence of past, present and future (McConnell-Henry et al., 2009). Johnson (2000) eloquently captured Heidegger's threefold conception of time in the following statement.

> To be human is to be directed towards the future, to always be becoming oneself. However, in moving into the future, our past is always with us. This past is both our individual past and the historical past that has helped form our preunderstandings. In this process of becoming that we already are, we are present. (Johnson, 2000, p. 30)

Heidegger (1927/1962) believed that time has an ontological element and as human existence is so interconnected with time, existence cannot be understood without a consideration of time.

Spatiality. Similar to Heidegger's conceptualization of time, which is not solely chronological, spatiality in Heideggerian phenomenology is distinct from the dimensionality we often consider space to be (van Manen, 1997). "*Dasein's* world is spatial" (Johnson, 2000, p. 19) in that "spatiality is characterized by bringing things close and giving them direction" (Johnson, 2000, p. 19). Heidegger (1927/1962) conceived of space broadly only allowing it to be understood in terms of the world. In Heidegger's work, space was not about the tangible dimensions of space, such as width, but about how we experience the space around us (van Manen, 1997). Regarding Heidegger's interpretation of space, it is also important to consider the physical spaces through which we move, and to understanding how these spaces influence our lived experience (van Manen, 1997).

Corporeality. The lived body is conceptualized as the vehicle through which *Dasein* encounters the world (Johnson, 2000). It is through the functions of this body that we are able to experience space, time, and relationships (van Manen, 1997). Through our physical body we are able to both share and conceal our true existence (van Manen, 1997).

Relationality. Heidegger stressed the importance of human relationships, or relationality in his work (Heidegger, 1927/1962; Johnson, 2000). While Heidegger's work may have focused on *Dasein*, this is not an isolated self but instead the process of being engaged with other humans

in a connected way (Johnson, 2000). These lived relations occur in the physical spaces we share with each other (van Manen, 1997). Our interactions occur in a "corporeal way: through a hand shake or by gaining an impression of the other in the way that he or she is physically presented to us" (van Manen, 1997, p. 105). In "Being and Time", Heidegger (1927/1962) stated "…there is thus a relationship of Being…from Dasein to Dasein" (p. 162).

Heidegger on subject-object dualism. The dualistic separation of subject and object in the process of understanding does not exist in Heidegger's work (Johnson, 2000). The preoccupation with objectivity is inconsistent with the spirit of Heideggerian phenomenology as the act of interpretation through *fore-structures* "transcends in principle the idea of rigour held in the most exact sciences" (Heidegger, 1927/1962, p. 195; van Manen, 1997). In essence, Heidegger believed that the subjective experiences that we bring to research do not allow for the rigourous separation that many methodologies require. The notion of unified subject-object is based on the principle that we come to encounter our world through living (Johnson, 2000). It does not happen separately from our daily existence (Johnson, 2000). I have come to understand that when a person acquires new knowledge through a conversation with another person, that encounter is uniquely their own. The new knowledge becomes a part of the person and also a part of the experience as a whole. As such, one cannot attempt to explain the knowledge independent from the person who knows it. Through using Heideggerian phenomenology, knowledge is generated through an interpretive process. As the interpretive process is a process of co-construction based on the interpreter's *fore-structures,* the knowledge is a reflection of the interpreters knowing. *Dasein* is relational to all things around it; as such its Being-in-the-world is in unity and depends on its interactions with other *Dasein* (Johnson, 2000; Heidegger 1927/1962). This situatedness creates an existential structure of *Dasein* that cannot be

interpreted outside of the world within which it exists and those with whom it interacts (Johnson, 2000).

Rationale for Selecting Heideggerian Phenomenology

I chose Heideggerian phenomenology for my study based on the method's philosophical connections to the meaning of human experience. The use of Heideggerian phenomenology creates "dialectic between question and method" (van Manen, 1997, p. 2). As the purpose of my study was to explore the meaning of the experiences of pregnancy for newcomer women to Canada living with HIV, by guiding me through a hermeneutic circle of understanding, Heideggerian phenomenology allowed me to inquire into the human experience, and not simply observe what was consciously known (Lopez & Willis, 2004). As mentioned previously, the hermeneutic circle of understanding allowed me to engage in a circular interpretation of the data by examining the parts, and then the whole, and then the parts again, all with an understanding that my interpretation is based on my fore-structure. Heideggerian phenomenology allowed me to explore each person's meaning of Being while considering their being through the four existentials that are essential to human existence (Lopez & Willis, 2004; van Manen, 1997).

In addition, I selected Heideggerian phenomenology because of Heidegger's tradition of not separating knowledge from knower (Johnson, 2000). In his philosophy, Heidegger was clear in his conviction that the dualism of subject-object does not add to our understanding of existence (Johnson, 2000). Heidegger's position of rejecting the application of bracketing is rooted in his belief that a researcher's ability to interpret data is dependent on the researcher's knowledge and understanding (McConnell-Henry et al., 2009). Heidegger (1927/1962) conceived of this knowledge as the *fore-structures* of understanding. This is a position I strongly

support philosophically. Lincoln (1995) also promoted this notion that objectivity on the part of the researcher does not add to the quality of the research.

Sampling

Sample Size

Sample size calculation for qualitative research is not prescriptive (Loiselle et al., 2007). According to Walters (1993), the traditional principles that guide sample size calculation apply to objective, positivist truth and are incongruent with the fundamental assumptions of phenomenology. In phenomenology there is fluidity to the structure of understanding based on each *Dasein's* existence (Heidegger, 1927/1962). Therefore understanding can be gleaned from a small number of participants.

In qualitative research, the collection of extensive data from a group of fewer participants than would be conventional in quantitative research can facilitate the researcher's immersion in the data and generate a detailed interpretation of the meaning of Being (Creswell, 2007). As the goal of qualitative research is not to generalize findings to the population as a whole, sample size calculation is dependent on data and themes that emerge throughout the research (Creswell, 2007).

Phenomenological studies have been conducted with as few as three participants (Creswell, 2007). Given practical consideration, such as a limited timeframe for recruitment, and information presented in the literature on sample size for interpretive phenomenology, I decided to recruit approximately five women from one hospital. Eliciting detailed data from those five women allowed me to situate myself within their stories and interpret the meaning of their lived experiences.

Sampling Method

The sampling method used to gather participants for this study was criterion sampling, a form of purposive sampling (Burns & Grove, 2009). Purposive sampling is a sampling method used when a researcher seeks to have a question answered by a group of participants who are experts on the subject (Loiselle et al., 2007). Criterion sampling is the process of gathering participants by inviting all "cases" that meet a certain criteria to participate (Creswell, 2007, p. 127). Criterion sampling was appropriate for use in this study as participants needed to have experienced a certain phenomenon (Creswell, 2007), in this case pregnancy as a newcomer with HIV.

Study Setting

This study was conducted at one teaching hospital in an urban centre in Ontario. After considering a number of sites, this location was selected because there was an obstetrician who specialized in infectious diseases in pregnancy. With a limited timeframe for recruitment (between five and six months) it was determined that this site would provide me with the greatest number of possible participants during my recruitment period. At the time that this site was selected, and throughout the recruitment phase of this study, each month this obstetrician received several new prenatal referrals for women living with HIV each month.

Gaining access to the hospital, the clinic, and participants. I first approached the clinic obstetrician to discuss this study and ensure support. As the recruitment plan required assistance from the clinic's nurse, receiving this support was also necessary. I also felt receiving this support early would strengthen my requests to the other gatekeepers[14] during the Research Ethics Board (REB) submission process. Once the clinic obstetrician confirmed that I could

[14] Gatekeepers are defined as the people who have the authority to permit my entry into the hospital and to access participants (Loiselle et al., 2007). In this study, gatekeepers included the obstetrician, the Head of Obstetrics, and the Senior Nursing Leader.

recruit from the clinic, I pursued formal approval from the REB at Ryerson University as I am a MN student there. The letter confirming ethics approval can be found in Appendix A.

I also required ethics approval from my study setting. As a component of this application process, I required approval from the Head of Obstetrics and the Senior Nursing Leader. I provided both with a letter (Appendix B) as well as a package of information including my research proposal, my REB approval from Ryerson University, and my letter of support from the clinic obstetrician. Once I had gained approval and signatures from both levels of leadership, I requested approval from the hospital's REB through an expedited review. A copy of the letter sent to the hospital's REB can be found in Appendix C. Copies of my research proposal, including the information sheet for participants (Appendix D), the consent form (Appendix E), and the interview guide (Appendix F) were included in the package I submitted to the hospital. I received hospital ethics approval prior to commencing recruitment and data collection. A copy of the hospital's ethics approval letter has not been included to maintain confidentiality as the name of the institution appears on the letter.

Participant Recruitment

The inclusion criteria for this study were women who (a) were currently pregnant, regardless of gestational age, (b) were living with HIV, (c) were newcomers to Canada, and (d) were able to speak English. Women who were postpartum and/or who did not speak English were not eligible to participate in this study.

Non English speaking women were excluded based on the fact that the use of translators in qualitative research can be challenging in the context of doing student research. As a novice researcher, my objective was to remain active in the research process. Therefore, I did not want to use translators that may have distanced me from the interactions with participants (Johnson,

2000; Temple & Young, 2004; van Manen, 1997). I was also concerned that using translators may hinder the willingness of the women to participant and/or to share the personal details of their experience. The development of a relationship between researcher and participants, when working with newcomers, is essential (Ogilvie, Burgess-Pinto, and Caulfield, 2008). I felt that not being able to communicate directly with the women would limit the development of rapport which may have compromised my ability to recruit participants. The extensive literature on the stigmatization of women with HIV (Ingram & Hutchison, 2008; Mill et al., 2009; Ndirangu & Evans, 2009; Sandelowski et al., 2004; Sanders, 2008) made me cognizant of how including another person in the interview may have further stigmatized the participants by requiring them to share private details with an additional person. Furthermore, given unique dialects and the likelihood of needing to have a community member serve as a translator, I elected not to include non English speaking women in this study. My decision not to include interpreters was supported throughout the data collection as all five women discussed an unwillingness to share the details of their HIV status with people from their cultural community. In fact, one participant stated that she preferred struggling with English than having a translator when visiting the doctor.

The recruitment strategy took into consideration the special circumstances of recruiting newcomer women where an awareness of safety, interpersonal relationships, and the potential power imbalances were crucial to ensuring a respectful and inclusive research strategy (Ogilvie et al., 2008). I took particular care in generating a recruitment strategy that would avoid potential coercion of women to participate. Caution was also used not to disclose the women's HIV status during the recruitment process.

The recruitment strategy for this study involved two steps. The first step involved the clinic nurse as an intermediary. The clinic nurse was included as she was known to the participants and had established relationships with them. When recruiting newcomers, strategies that rely on print materials or on people who are unknown to the potential participants are often unsuccessful (Ogilvie et al., 2008). Each week potential participants were identified by the nurse based on her knowledge of their HIV status from being involved in their care. Using an assigned script (Appendix G), the nurse introduced the study and inquired if the woman was willing to meet with me to learn more about the study. During this introduction the nurse did not indicate that this study was for women living with HIV if they were accompanied by another person. This safeguard was implemented to avoid disclosure of HIV status. When women agreed to learn more about the study, I met with them immediately if I was available. Otherwise, the nurse provided forms for the women to complete (Appendix H). This was the end of step one of the recruitment strategy. It was also the end of the involvement of the nurse as an intermediary.

The use of the clinic nurse as an intermediary was limited because of concerns regarding newcomers feeling obliged to participate in research, when recruited by their healthcare team (S. Guruge, personal communication, 2009; Ogilvie et al., 2008). However, I do not believe this was an issue in my study because (a) the nurse only requested permission for me to meet with potential participants and was not involved in the second step of recruitment, (b) approximately five women declined the nurse's invitation to meet with me, and (c) one woman who agreed to meet with me, when approached decided not to participate after I met with her.

The second step was a direct approach to recruitment in which I met with the women personally to discuss the study after they had initially been approached by the clinic nurse and had consented to meeting with me to discuss this study. Including this second and direct step

was based on evidence due to the efficacy of a direct approach in recruiting newcomer participants (Ogilvie et al., 2008). Meeting with potential participants directly fostered the development of a safe, interpersonal relationship between the researcher and the participant (Ogilvie et al., 2008). I felt strongly that by meeting potential participants and allowing them to interact with me on a personal level, where they felt safe, the potential participants would feel comfortable in their decision to participate or not. All of the women who initially agreed to meet with my requested that we meet at the recruitment site. They were aware that I had access to private rooms to discuss the study. I initially met with each of the women during a scheduled obstetrical appointment to discuss the study. Some participants were approached by the nurse and able to meet with me on the same day. In other cases, either because I was not present or because the potential participant requested I meet them on another day, I was provided with their next appointment time to meet with them. I used a standardized script to more thoroughly introduce the study to the women (Appendix J). I also provided a two page written information sheet at the initial encounter (Appendix D). Within the five months I had arranged for recruitment I was able to recruit seven women. One participant later changed her mind and a second was unable to continue in the study for medical reasons. This left me with a sample of five women.

Sample Demographics

Minor demographic details regarding the five participants have been changed and/or omitted to protect their identities. There was heterogeneity in the demographics except for the extensive representation of African women. Each of the five women was from a different country. Their stories pre-migration were complex and contextualized their lives in Canada. Two women shared details of possible trauma prior to coming to Canada that may have

influenced their experiences as newcomer women. In depth pre-migration details were not included in this thesis as they were outside the scope of this study which focused on the post-migration experience. The women's time since immigration ranged from six months to eight years, with an average of four years in Canada. The women spontaneously shared details of their migration histories with me. Two participants had come to Canada via a country other than the country which they referred to as "back home". Two women were refugees, two were family-class immigrants, and one participant did not share her exact immigration status. Four of the women discussed being obligated to come to Canada either to seek refuge or because their spouse was unwilling to return to their home country. The fifth participant did not make specific comments about her immigration status.

For two of the women, this pregnancy was their first child. The remaining three women had previous children. Of the women who had previous children, at least one of their previous children had been born in Canada. Three of the participants were married and lived with their husbands in Canada. The women who were married reported 'supportive relationships' with their husbands. Two women identified themselves as single mothers but had contact with the fathers of the child they were carrying. Three of the pregnancies were described as "planned" while two had been "a surprise". There were incidences of sero-discordance, meaning one partner was living with HIV and the other was negative, amongst the sample[15]. However, all five women reported having disclosed their HIV status to their sexual partners.

The gestational age of the pregnancies ranged from 20 weeks to 36 weeks. All of the pregnancies had been conceived spontaneously through unprotected intercourse. All of the

[15] The exact number of cases of sero-discordance was not included in order to prevent the unintentional identification of participants by sharing unique details of their stories. This decision was made in accordance with the process outlined on page 58 of changing and/or omitting information in order to protect participant privacy.

women reported that they were receiving treatment for their HIV during the pregnancy. The women had differing socioeconomic standings but they all reported some financial concerns.

Data Collection

The traditional source of data collection is in-depth one-on-one interviews (Loiselle et al., 2007). The essential purpose of conducting interviews is to collect data that will generate extensive meaning of the phenomenon (Creswell, 2007; Lopez & Willis, 2004). The type of interview used in phenomenology is referred to as a conversational interview (van Manen, 1997). During conversational interviews the researcher and participant talk together like friends (van Manen, 1997). In conversational interviews, participants and researcher are fully engaged, co-participants (Loiselle et al., 2007). This co-participation, in the interview, creates a fusion of the meanings for the participant and the researcher (Lopez & Willis, 2004). Thus, the meanings that the researcher generates are produced by this interaction. The blending, or common understanding, is metaphorically referred to as the "fusion of horizons" (Lopez & Willis, 2004). This "fusion of horizons" is the process by which two people, coming from different perspectives, are able to understand the other person's perspective (Malpas, 2009). During this fusion, however, the understanding is an interpretation based on the interpreter's own background (Malpas, 2009). For example, as I met with participants and listened to their stories, I came only to interpret the meaning of their experiences through my own experiences and background.

Narrative data was elicited from the participants by allowing them to direct the conversation which focused on their meaning of pregnancy as a newcomer women living with HIV. Encouraging the participants to direct the conversation was done to ensure sufficient meaning of the experience was captured. This was also done to ensure they were able to share

the details they felt were important. In the context of this study, sufficient meaning does not refer to data saturation. This study made no effort to reach the conventional notion of data saturation "which occurs when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection" (Loiselle et al., 2007, p. 61). Interpretive research can constantly open up new horizons, making it impossible to reach absolute completion (Mulhall, 2005). Data is collected through an interaction that occurs in a moment of time. Therefore, even with subsequent discussions between the same two people, the evolving interpretation of the experience can be altered merely by having already discussed the phenomenon.

Participation in this study required at least a single one-to-one interview with me. Together, each participant and I arranged the interview time and location. I asked each participant to select a location for the interview where they felt their confidentiality would be maintained. We also worked together to determine locations where we both felt safe and comfortable and where the women felt open to sharing their experiences. Ultimately, four women requested that I come to their home for the interview and one requested that I meet with her following one of her obstetric appointments. For this interview at the hospital I arranged a private location through the nursing administration to ensure that confidentiality would be maintained.

Before each interview, informed consent was obtained using the consent form (Appendix E). However, verbal agreement was also obtained to ensure that process consent was maintained. "This type of consent is an ongoing consensual process" involving the researcher and participant to ensure that the participant "is kept informed at all stages" of the research process (Usher & Arthur, 1998, p. 692). At the end of each interview, I also asked if the participant would like to

share a telephone number where I could contact her to inquire about any additional information she wished to share and to offer a second interview. The telephone call and possible second interview were outlined in the consent form (Appendix E).

Informal conversation was used at the beginning of each interview to allow the participant and I to become better acquainted. According to Ogilvie et al. (2008) allowing for the continued development of an interpersonal relationship between researcher and participant creates a familiarity for newcomers. While I acknowledged the importance of the development of the interpersonal relationship for the newcomer, I also saw this as an important opportunity for me as the researcher to also become emotionally prepared for the personal nature of my discussions with the participants. Furthermore, it was a chance for me to share select details about my professional background with the women as well as why I was conducting this research. Since the participants knew that the purpose of this study was to interpret the meaning of their lived experiences, I felt it was only appropriate that they be provided with some understanding of the lens through which I saw the world. In other words, I provided them with a sense of my fore-structure. Participants were encouraged to ask any questions they might have before we began. I also used this time to clarify my role as a researcher and explained that I would not be able to provide any nursing/healthcare information to them during the interview. In addition, through structured questions, I used this time to gather socio-demographic information including length of stay, marital status, country of origin, pregnancy history, migration history, and immigration status. This information was also gathered spontaneously throughout the interview and during the informal conversation after the interview was completed as the women continued to share details of their lives with me.

I began the interview with an open-ended question: "As you already know, I am doing this study to learn more about women who are new to Canada and who are living with HIV/AIDS. Can you tell me about how this experience has affected your pregnancy?" (Appendix F). Multiple strategies were used to elicit richness in the data, including silence, probing or clarifying questions, and reframing participants' responses as a question to encourage the participant to elaborate (van Manen, 1997). All interviews were between 90 and 120 minutes and ended when the women felt they had fully shared their stories. The completion of each interview was marked by what van Manen (1997) referred to as the "conversation gradually diminish[ing] into a series of more and more pauses, and finally to silence" (p. 99).

Although verbal communication was recorded, I recognized that "much of the emotional context…as well as nonverbal communication are not captured…so that the audiotape itself is not strictly a verbatim record of the interview" (Poland, 1995, p. 291). In order to capture the nonverbal and contextual elements of the interview, including physical space and location, gestures, distractions, and body language, I used fieldnotes to document my observations (Lapadat & Lindsay, 1999; Poland, 1995). There were two forms of fieldnotes that I used in this study; methodological and descriptive (Loiselle et al., 2007). Methodological fieldnotes are "instructions or reminders" (Loiselle et al., 2007, p. 200) of how an observation occurred. During the interviews I wrote methodological fieldnotes to serve as reminders to myself about things that happened which would not have been captured on the audio recording. I tried to put a key word from the participant's conversation with the observation to remember the context of the observation after the interview. The second type of fieldnotes, were descriptive, which are "objective, thick descriptions of events and conversations" (Loiselle et al., 2007, p. 300). I developed descriptive fieldnotes within 24 hours of each interview with the assistance of my

methodological fieldnotes. Four of the interviews were digitally recorded. One interview was not recorded because of a technical error. This error was discovered immediately following the interview. Comprehensive descriptive fieldnotes were developed from existing methodological fieldnotes that were taken during the interview. The notes were created beginning on the same day as the interview and were completed within 24 hours. I believe I captured the interview data and that the technical error did not detract from the data collection for this particular interview.

There was a month between the first and second interviews which allowed sufficient time for me to transcribe the interview and begin a preliminary analysis. Between the second and three final interviews there was a two month interval. This again allowed for transcription and preliminary data analysis. The final three interviews were all conducted on the same week. This was the result of a sudden surge in recruitment as well as time constraints to complete data collection. As such, I was unable to transcribe the third interview before fourth interview the next day. I had however transcribed elements of both the third and fourth interviews and conducted some preliminary analysis before the fifth and final interview.

Each interview was transcribed and analyzed prior to my follow up phone call. Four of the participants agreed to the phone call while one participant declined. She was provided with my contact information in the event that she chose to follow up. The primary function of the follow up phone call was the opportunity to clarify what was shared with me in the first interview. Participants were offered a second interview if they felt they had additional information they wanted to share with me. No participant accepted the offer of a second interview. Three participants spontaneously told me that I could phone again if I needed any additional information. I did not require additional contact during data collection and analysis.

Terminating data collection does not mean that the research question is fully answered, nor is the aim of the text to reach formal conclusions (Mulhall, 2005; van Manen, 1997). Data collection is terminated when, for the group of participants, the nature of the essential human experience under investigation is understood by the researcher (van Manen, 1997).

Data Analysis

Data collection and data analysis occurred simultaneously in a non-linear process (Speziale & Carpenter, 2007). Data analysis was conducted through my understanding of the hermeneutic circle. I moved from a naïve understanding of the phenomenon, to an explicit comprehension of the meaning of pregnancy for newcomer women living with HIV (Speziale & Carpenter, 2007).

> … by looking and re-looking at the data, searching beneath the words and at what is not immediately obvious, the researcher aims to end up with an ontological perspective of the participant's experiences. By utilizing the hermeneutic circle the researcher attempts to 'read between the lines' and uncover the true essence of the experience. (McConnell-Henry et al., 2009, p. 11)

My experience as a researcher within the hermeneutic circle began before I started data collection. As an entity in the world, I entered this research study with an understanding of the experience I intended to research based on my own lived experiences. Coming to understand what it meant to be in the hermeneutic circle was a journey for me as a novice researcher. In an effort to truly remain engaged within the hermeneutic circle, I elected to perform my own transcription.

Transcription

As I transcribed each interview, I came to a new level of understanding. As Lapadat (2000) stated, the process of transcription creates intense familiarity with the data. I also saw transcription as a chance for me to make a choice about my philosophical perspective of how I wanted the spoken interviews to be captured in text. Transcription is not merely an objective account of the conversation on tape, but is an "interpretive and constructive" re-presentation of the participant's story (Lapadat, 2000; Lapadat & Lindsay, 1999, p. 72). I decided that verbatim transcription of interviews, including pauses, silences, and expressions such as 'like' and 'ah', was the best way to capture exactly what each woman said. If I had not used verbatim transcription, I would have been responsible for selecting what text to include, while trying to maintain the integrity of the woman's story (Lapadat, 2000). Removing verbal cues such as pauses and silences would have limited my ability to interpret the whole essence of the experience as I felt that pauses and silences add context and insight to the data. Once I had used this approach in my transcription of the four available interviews, I was able to move to the next step of analysis which involved reading the transcripts. Following transcription, my use of the hermeneutic circle continued as I utilized the reading approach created by van Manen (1997) to analyze the study data.

van Manen

I decided to use the method created by van Manen (1997) in "Researching Lived Experiences: Human Science for an Action Sensitive Pedagogy" to assist me in my interpretive phenomenological reading of my transcripts. I chose the work of van Manen to guide my data analysis as his approach to uncovering meaning in any form of text is guided by concepts that have underpinned this study; namely, the four existentials, fore-structures, Being-in-the-world,

and meaning of Being. van Manen's approach offered a hermeneutic, or circular interpretive reading of the data which brought me closer to the ultimate goal of communicating my evolving interpretation of the meaning of being a pregnant newcomer woman to Canada living with HIV.

Reading the texts. van Manen's (1997) approach to data analysis uncovers meaning in a three dimensional approach to analysis (Loiselle et al., 2007). First, I read the transcript as a whole to capture the holistic meaning (van Manen, 1997). The objective of this first reading was to discover the fundamental meaning of the entire text and to capture it in a single phrase (van Manen, 1997). Second, I selectively read elements of the text several times to highlight sentences, statements or phrases that seemed essential to the meaning of the phenomenon (Loiselle et al., 2007; van Manen, 1997). During this reading I asked myself, "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen, 1997, p. 93). The third dimension of the hermeneutic reading was completed once a general understanding of the transcript had been reached. In this final reading, the transcript was read line-by-line to explore each detail and uncover what each sentence might reveal about the phenomenon (Loiselle et al., 2007; van Manen, 1997). van Manen noted that during the line-by-line reading "certain experiential themes recur" (p. 93). These recurrences were clustered together which served as the building blocks for my thematic structure. Themes emerged from this reading and re-reading that became the units for reflecting and interpretation (Loiselle et al., 2007).

The Use of Fieldnotes in Analysis

Although the transcribed interviews were the main source of data for analysis, I also used my fieldnotes to provide context and to capture that which was not recordable. The use of fieldnotes in data analysis was supported by van Manen (1997), who acknowledged the

importance of close observation as a means of data collection, as well as the previously discussed work of Lapadat (2000), Lapadat and Lindsay (1999), and Poland (1995). An example of how fieldnotes were used in data analysis was that during one interview, a participant's children were present. Throughout the interview the children approached the table frequently but made no noise that would have been captured on the recording. However this often distracted the participant, resulting in pauses or the loss of a train of thought. By noting when the children approach the table, I was able to identify when pauses caught on the recording were because the participant was taking time to think or if it was because she was distracted. The significance of these pauses could now be correctly interpreted.

Development of the Thematic Structure

When I transcribed the interviews, this was done on a computer. However, for data analysis I elected to use hard copies of the transcripts. After reading each transcript several times in the manner described above, I began to highlight statements and sentences on the hard copies that appeared essential to the experience of pregnancy for newcomer women to Canada living with HIV. I initially colour coded data within each of the four existentials of lived time, lived body, lived space, and lived human relations. I also indicated when pieces of data overlapped several existentials. Following the initial colour coding, I began removing the statements and sentences from each transcript. I manually recopied emerging pieces of data onto new pieces of paper and continued to cluster them together by existential. As I clustered the pieces of data together by existentials, I returned to each cluster of data several times and reconsidered the significance of the data. This continuous reconsideration resulted in several pieces of data moving from cluster to cluster. For statements that seemed misplaced, I created a separate cluster to reconsider once I had developed my thematic structure.

As these clusters of data continued to grow within each existential, I became concerned that I was too focused on maintaining distinct themes according to each existential. As a result, I dismantled the clusters and began regrouping the pieces of data by concepts. As the clusters re-emerged so too did the existentials. It became apparent that the data naturally fit within the four existentials. As the final clusters took shape, each theme or subtheme was located within an existential. At that point, I asked myself what each theme or subtheme said about that existential. Taking each existential apart and considering their holistic understanding resulted in the development of my themes.

This initial process of grouping clusters of data together resulted in twelve preliminary themes. Once I had identified these twelve preliminary themes, I returned to the research question and purpose and asked myself what each theme said about the meaning of the essence of the experience. Then I asked myself what my evolving understanding of the whole experience of pregnancy for newcomer women living with HIV said about that specific theme. The process of moving from the parts to whole is demonstrative of my use of the hermeneutic circle during data analysis. As quotes and data clusters were reorganized throughout the creation of my thematic structure, five themes eventually emerged as being essential to the meaning of the pregnancy experiences of newcomer women to Canada living with HIV.

I was able to identify the overarching theme when I reviewed and reflected on the essential themes, as well as the subthemes, and worked through an interpretive process of understanding what the common essence of the themes and their related subthemes was.

Essential versus incidental themes. According to van Manen (1997), researchers must differentiate "between essential themes and themes that are more incidentally related to the phenomenon under study" (p.106). In order to achieve this distinction, I focused on the purpose

of this study throughout the reading of each transcript and data analysis. I reflected on each developing theme by asking myself if it was an element that made the phenomenon what it was, and if without it, the phenomenon would have been changed (van Manen, 1997). By asking these questions I was able to eliminate incidental themes and develop a final thematic structure that captured the essence of the participants' experience. This thematic structure is presented in Chapter 4.

Establishing Rigour

The debate around rigour in qualitative research continues. In Heideggerian phenomenology evaluating rigour can be even more problematic. van Manen (1997) cautioned against the conventional preoccupation with method and technique, while acknowledging that the researcher or "guardian" must defend the true nature of the story being told (p. 20). In Heideggerian phenomenology, researchers must be cautious when making theoretical and methodological decisions to avoid creating inconsistencies that will influence findings (Lopez & Willis, 2004). In a review of the literature regarding rigour in interpretive phenomenology, de Witt and Ploeg (2006) determined that the generic criteria that have been used to judge rigour in qualitative research are not well suited for interpretive phenomenology. In conducting interpretive phenomenological studies, researchers have historically ascribed to the traditional assumption that it is possible, and desirable, to reach a valid interpretation of the human experience (Walters, 1993). Much of the language used for the criteria for appraising rigour in qualitative research, such as the criteria of credibility found in Sandelowski's framework, creates "philosophical inconsistencies" with interpretive phenomenology (de Witt & Ploeg, 2006, p. 221). The underpinnings of these criteria are positivist and not congruent with Heideggerian philosophy (de Witt & Ploeg. 2006). In order to evaluate rigour, in a manner that was congruent

with the philosophical underpinnings of Heidegger's work, I used a twofold approach in my work. First, I will describe how the use of the de Witt and Ploeg framework served as a measure of rigour in my study. Second, I will describe my experience of reflexivity as a novice researcher and my use of reflective journaling as a strategy to develop an accurate reflection of the meaning of Being for the women in this study.

The de Witt and Ploeg Framework

de Witt and Ploeg (2006) generated a framework to enhance rigour in an interpretive phenomenological study which I used in this study. The framework contains five unique expressions of rigour for interpretive phenomenological studies that address limitations which were evident when using standard rigour criteria for qualitative research (de Witt and Ploeg, 2006). These five expressions of rigour are (a) balanced integration, (b) openness, (c) concreteness, (d) resonance, and (e) actualization. The framework generated by de Witt and Ploeg was also in keeping with my method for data analysis as de Witt and Ploeg used the work of van Manen (1997), among other sources, to inform their framework.

Balanced integration. Balanced integration is achieved when the readers are able to identify a clear "articulation of the general philosophical theme and its fit with the researcher and the research topic" (de Witt & Ploeg, 2006, p. 222). Next the reader must be able to identify integration and synthesis of philosophical concepts within the study methodological decisions and presentation of findings (de Witt & Ploeg, 2006). Finally, an effective balancing of the narratives of study participants and the philosophical explanations must be provided (de Witt & Ploeg, 2006).

Throughout the planning and implementation of the study design, I worked toward achieving balanced integration. I needed to first ensure that my research question and purpose

was suitable for inquiry with Heideggerian phenomenology. Based on my review of the literature in Chapter 2 and my understanding of the philosophical underpinnings of Heidegger's work which I have presented in this chapter, I believe the reader can identify the suitability of this method for my study. Next, as the reader continues into Chapters 4 and 5, they will see that I have achieved balanced integration by weaving my findings into the four existentials of lived time, lived space, lived body, and lived human relation.

Openness. The expression of rigour referred to as openness is the process of being accountable for decisions throughout the research process and allowing decisions to be scrutinized (de Witt & Ploeg, 2006). The need for the expression of openness is well documented in the literature (de Witt & Ploeg, 2006).

In order to achieve openness in this research study I relied on several strategies. The first strategy I used was based on the reality of this as student work. As a graduate student, and novice researcher, I worked closely with my Supervisor and thesis committee members throughout the development of this study, as well as throughout data collection and analysis. Being open to this relationship required a willingness on my part to be scrutinized. I also had the experience of several changes in the membership of my thesis committee. This experience facilitated openness as I was exposed to new and different perspectives that added depth and breadth to my critical interpretation of the data. I also maintained openness in the research process by keeping a reflective journal. The journal of my methodological decisions and the processes that had lead to my decision making created a record that can be used as a form of auditability for those who were not actively involved in this study. I have also included my personal experience as the researcher in Appendix K for the reader. I believe sharing this

personal writing creates a sense of openness by allowing the reader to experience my lived experience and understand how this may have contributed to the co-construction of this thesis

Concreteness. A reader can identify concreteness if "study findings are written in such a way that examples are given that situate the reader concretely in the context of this phenomenon" (de Witt & Ploeg, 2006, p. 225) and are linked to a person's experiences in their world (de Witt & Ploeg, 2006).

In order to truly give meaning to this work, concreteness was essential. As Heidegger (1926/1962) believed, meaning can only be understood in the context of each person's experience. As the writer of this re-presentation of the stories of the five participants in this study, I tried to ensure that the readers were situated in the experiences of each woman. I have tried to achieve concreteness by using quotes throughout my Findings and Discussion chapters. In addition, I have provided many quotes to enable readers to link this work back to their own lived experiences.

Resonance. Resonance is the effect or feeling that is left after reading an interpretive phenomenological report (de Witt & Ploeg, 2006). Like the fusion of horizons between researcher and participants, according to Ray (as cited in de Witt & Ploeg, 2006) this impact or effect occurs when the study findings are "juxtaposed with self-understanding" (p. 226).

As stated throughout this thesis, the interpretation presented in this study is mine, based on my fore-structure of understanding, and is not intended to signify a conclusion or an absolute understanding. In an effort to create a text that could resonate with readers, I tried to leave the findings open for further interpretation. In fact, I have noted in Chapter 4 that I encourage readers to draw their own connections between the existentials and to further develop the interpretation of the findings of this study based on their fore-structures. This continued

interpretation opens the way for deeper understanding that will resonate with individual readers on a personal level.

Actualization. The final expression of rigour that is proposed by de Witt and Ploeg (2006) is called actualization. According to the framework, the concept of actualization is reminiscent of the work that I have previously mentioned by Mulhall (2005) which suggested that the conclusion of an interpretive phenomenological study is merely symbolic and is not in fact an end to what is interpretable. Actualization addresses the idea that interpretation of data does not end when the study is complete (de Witt & Ploeg, 2006). The researcher must realize that readers will continue to interpret the data and findings long after study completion (de Witt & Ploeg, 2006). According to de Witt and Ploeg, actualization is the greatest means of affirming the data interpretation.

I have used the same strategy to achieve actualization in my study findings as I did to achieve resonance which was to leave this study's findings open to continued interpretation. While I have presented my evolving interpretation of the data, I have been transparent in my belief that this is not symbolic or a finite conclusion. I have encouraged readers to continue to interpret the data presented in this study and hope that continued interpretation, by people with unique fore-structures, will achieve a new and deeper level of understanding.

Reflexivity

Reflexivity is the process used by researchers to actively engage in a critical self-reflection of how their preexisting knowledge, values, and experiences, as well as their interactions with participants may have influenced data collection and analysis (Finlay, 2002; Loiselle et al., 2007). The integration of reflexivity into qualitative research has not been static. Reflexivity has evolved from simply recounting one's experiences as a researcher to a deliberate

means of diminishing the patriarchic relationship between researcher and participant (Finlay, 2002). In both of the above instances, the objective of reflexivity has always been to examine what may be influencing data (Finlay, 2002).

While my decision to use Heideggerian phenomenology legitimized the influence that my existence had on the data collection and data analysis, it did not allow me to ignore how this influence may have occurred (van Manen, 1997). In order to be self-aware of how my own values may have influenced data collection and analysis, I engaged in reflexivity. Acknowledging that my work was impacted by my role as data collector and analyst allowed for transparency in my interpretation and added rigour to the findings (Finlay, 2002).

For me as a novice researcher, the role of reflexivity seemed daunting. Fortunately, I was provided an article by one of my thesis committee members that allowed me to better articulate how reflexivity allowed me to engage in critical self-reflection. Reflexivity allowed me to "examine the impact of the position, perspective, and presence" I have as a researcher, it has facilitated my exploration of how my interactions with participants and how my reactions may have influenced data collection, it has opened me up to "unconscious motivations" I may have had in the research process, and it has forced me to "evaluate the research process, methods, [and] outcomes" (Finlay, 2002, p. 225). I have achieved a new appreciation for reflexivity by seeing my role as the interpreter of the data. I have come to learn that merely my way of thinking and how I developed the research question and designed this study has "shaped and fore[told]" how the participants were able to provide answers (Benner, 1994, xix; Mackey, 2005). In agreement with Benner, Mackey, and Maton (2003) I believe my epistemological[16] way of seeing the world has shaped and directed this study in many ways.

[16] Epistemology "is the theory of knowledge" (McEwan & Wills, 2007, p. 12). It establishes our criteria of knowledge, how we know what we know, and what we know (McEwan & Wills, 2007). While Heideggerian

Reflective journaling. As a form of reflexivity, reflective journaling allowed me to document how I may have influenced the research process i.e. data collection and data analysis, but also how it influenced me. The use of reflective journaling was in agreement with the de Witt and Ploeg (2006) concept of openness. According to de Witt and Ploeg, the objective of achieving openness is not to document every step and/or decision made during the research project; it is a record of accountability and creative energy used to complete the research. Reflective journaling was used to record events or experiences that may have affected how I collected, analyzed, and interpreted the data. As qualitative writing is, to some degree, a reflection of our own interpretation, it has become common practice for qualitative investigators, especially phenomenologists, to keep reflective journals (Creswell, 2007; Loiselle et al., 2007). My decision to keep a reflective journal was not to eliminate the possibility that my evolving interpretation of the data was influenced by my culture, social class, gender and personal politics (Creswell, 2007). Instead, reflective journaling served as an opportunity for me to record and reflect on the presuppositions that may have influenced my work as these are uncovered during the research process (Creswell, 2007).

As I become more engrossed in data collection and analysis, I was also encouraged by members of my thesis committee to use my journal as a place to document how my interactions with the participants were impacting me. Keeping this reflective journal of my own experiences allowed me to textually capture my existence while keeping it separate from the essence of the participants' experiences. I felt this separation was important because although the "inclusion of the subjective experience of the researcher" is present in qualitative researcher, I wanted to avoid

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phenomenology is about ontology, or the meaning of being, understanding the researcher's epistemology, or theory of knowledge, is essential if the reader is to understand the context of the co-construction of the ontological findings.

my voice overshadowing the stories of the women who participated in my study (Fine, Wei, Weseen & Wong, 2006, p. 107).

Limitations

Although this study had many strengths, it is not without limitations. Four methodological limitations and two researcher limitations have been identified. The first limitation was the limited transferability of my study findings beyond newcomer women to Canada who are pregnant and living with HIV/AIDS. In general, transferability is a limitation of interpretive phenomenology as the everyday experiences of one person will not necessarily apply to others (Walter, 1993). This limitation was addressed by focusing on generating findings that would best serve this specific group of women.

The limited demographic data collected from participants is a limitation of this study. I acknowledge that there are many contextual factors relevant to developing a deeper understanding of lived experience. Only details that were spontaneously shared were used to contextualize and interpret participants' narratives. Therefore, certain data which may have provided additional context to the women's experiences here in Canada, such as socioeconomic status, were not included.

The third methodological limitation existed in the sample. For reasons of feasibility, the sample of women was recruited from one site. Despite being from one site, the sample recruited represented a heterogeneous group of women. They were from diverse ethnic/cultural groups, they had varying migration histories, their previous experiences with pregnancy and birth ranged from being nulliparous to grand multiparous[17], they had distinct marital histories and statuses,

[17] A nulliparous woman has not previously given birth to a viable or live child. A woman who is described as a grand multiparous woman has given birth more than five times (Society of Obstetricians and Gynaecologists of Canada, 2011).

and their lengths of stay in Canada had a wide range. According to Burns and Groves (2009), this type of heterogeneity in a sample is the objective of qualitative research.

The final methodological limitation of this study was the exclusion of non English speaking women. As described in the section on Participant Recruitment in this chapter, the inclusion of only English speaking women was based on my choice not to use translators. To my knowledge, no woman was denied participation or chose not to participate in this study because of a language barrier. However, based on this limitation, I would encourage continued research opportunities for non English speaking women by researchers who speak the women's preferred language.

The first of the two researcher limitations in conducting a Heideggerian phenomenological study was my inexperience as a researcher. To compensate for this limitation, I sought out literary resources and research mentors on my thesis committee to provide guidance both methodologically and in conducting research with newcomer women.

The final limitation that was identified for this study was my position as a Canadian, white, middle-class, Registered Nurse, and educated researcher working with newcomer women. For researchers who come from a different background than participants, be it racial, ethnic, religious, cultural, or social class, critical reflections on power relations and the role that our personal identity as the research plays in our work are necessary (Nelson & Gould, 2005). With the support of my thesis committee I used reflexivity to minimize the impact that this limitation had on the findings by examining both how I was influencing data collection and analysis and how it may have been influencing me. To further minimize the potential impact that power relations had on data collection, I also tried to develop a personal rapport with each participant through our initial contact and the informal discussion prior to the interview. I also provided

information about me that I felt would minimize the gap between myself as a researcher and the participants as newcomers. For example, I shared my experiences of volunteering in Zimbabwe with the participants. This strategy created a sense of familiarity and an atmosphere where participants felt safe and comfortable for their interviews (S. Guruge, personal communication, July 7, 2010).

Ethical Considerations

Ethical considerations for my study included (a) informed consent, (b) confidentiality, and (c) potential risks and benefits.

Informed Consent

Each potential participant received an explanation of the nature and purpose. For those who were interested in participating, an information sheet was provided for their consideration (Appendix D). It was written at grade 6 level in accordance with institutional policies. I also read it verbally to participants in the event that their literacy level was low but they did not wish to disclose this to me. Women were given the opportunity to ask questions and to have these questions answered prior to consenting to participate by signing the consent form (Appendix E).

Women were ensured that their participation was voluntary and that they were free to withdraw without affecting their care at the hospital. A number of additional considerations were discussed with participants including: (a) participants were ensured that the clinic staff, including physicians, nurses, and additional healthcare professionals were not informed of their participation or non participation[18]; (b) participants had a complete understanding that they had the right to withdraw from the study at anytime and or to pause or terminate the interview if they

[18] For the one interview that took place at the hospital, I independently arranged for a private room. I met the participant away from the prenatal clinic at a place she indicated she was comfortable meeting in order to maintain her confidentiality from those involved in her care.

became upset; (c) participants were reminded of their right to refuse to answer any question during the interview yet remain in the study.

Confidentiality

In the context of research, confidentiality implies that researchers' protect participants' identities (Speziale & Carpenter, 2007). As a researcher, I was obligated to ensure that by maintaining confidentiality I would do everything I could to protect the identity of the participants in this study (Loiselle et al., 2007). This meant that I had to create a system to ensure that data could not be accessed by other people nor could the data presented in this thesis and any report or presentation associated with this research be linked back to the participants (Loiselle et al., 2007). Measures were used in the writing of this thesis to maintain confidentiality. First, I used numbers in my coding system throughout data analysis to identify each participant. The numbered coding system was changed to pseudonyms only during the writing of my Findings chapter. With the guidance of my thesis committee I also changed/omitted minor demographic details to protect the identities of the women. The changes in the demographic details had no impact on the results of this study. In working with a population of newcomer women who are pregnant and living with HIV, the protection and respect for confidentiality were paramount.

To also maintain confidentiality the clinic nurse, who acted as an intermediary, was asked to identify at least10 potential participants. As such, the nurse did not know who participated in the study. Second, the nurse was not notified that the clinic was the only site for recruitment. This was done at the suggestion of the Ryerson University REB as a means to further maintain participant confidentiality.

All material associated with my study, including consent forms, digital audio files, transcripts, reflective journal entries, and fieldnotes were kept in a locked cabinet to which only I had access. Digital audio files were immediately moved from the recording device to my non networked computer where files were protected by password access and firewalls. Any confidential information participants provided during the interviews was erased from the digital audio files and was not included in the transcripts. I developed a coding system to track data from each participant. This coding system was only known to me and was also kept locked in a cabinet to which only I had access. Furthermore, the coding system was kept in a separate drawer from the transcripts and other study materials. Upon completion of my thesis, the coding system was destroyed and other materials such as the digital audio files were erased.

Potential Risks

It was possible that participants could experience emotional discomfort because of the personal nature of the questions asked. If needed, participants were encouraged to pause or terminate the interview if the felt upset during the interview and wished to consider withdrawing from the study. I also accessed contact numbers of crisis personnel at the recruitment site in the event that a participant became extremely upset during the interview and required assistance. If needed, these numbers were available to the women to ensure that they were given options for safety if they felt they required support. None of the women required this support.

Potential Benefits

Before the women agreed to participate in this study, I explained that they may not receive any direct benefit from their participation. However, it was stated both verbally and in the consent form (Appendix E) that they may find it helpful to talk about their experiences. The

women were told that the information gathered during this study may help to improve the care of pregnant women who are newcomers to Canada and living with HIV.

Summary

This chapter presented a detailed account of how I conducted this study. I provided my rationale for choosing a qualitative methodology, specifically Heideggerian phenomenology. The philosophical concepts underpinning this study were described. Methodological decisions were presented and methodological coherence was demonstrated. Sampling, data collection, and data analysis were described. de Witt and Ploeg's (2006) framework, as a measure of rigour that is congruent with Heideggerian phenomenology, was presented. Limitations and ethical considerations were also discussed. Chapter 4 will present the findings of this study.

CHAPTER 4: Findings

Introduction

In this chapter I present the pregnancy experiences of the five women in this study. The results are based on my understanding of the philosophical underpinnings of Heideggerian phenomenology and the research question. Four essential themes and their subthemes are identified and are captured within Heidegger's four existentials. I also present the overarching theme. While I present each essential theme separately within the four existentials, the four existentials are deeply connected (van Manen, 1997). This connection is captured throughout this chapter. I encourage the reader to move through their own interpretation of how the themes, subthemes, and existentials are connected and give meaning to the lived experience of pregnancy for newcomers living with HIV.

Researcher as the 'Tool' of Interpretation

The meaning that I have derived from the narratives is a blending of what was shared with me by the participants and my own understanding (Lopez & Willis, 2004). As the tool of data interpretation, my social position, the knowledge I possess, and my personal horizon of experience is intricately connected with the results. The interpretation is a fusion of my personal history and the narratives of the participants. Therefore, the findings are not an exhaustive interpretation of pregnancy experiences for all newcomer women to Canada living with HIV.

The Use of Quotes

Lapadat (2000) suggested that "spoken language is structured and accomplished differently than written text" (p. 206). Therefore, I have made minor revisions to the verbatim transcritions to: (a) facilitate the understanding of this thesis, and (b) reduce the possibility of stigmatizing the women based on their articulation style and/or their language fluency.

Thematic Structure

The findings of this hermeneutic inquiry capture commonalities, differences, and ambiguities about the participants' experiences of pregnancy. The objective in sharing these findings is to uncover how the individual lifeworlds of the five participants have contributed to the complexities that emerged within the thematic structure. Through data analysis, five essential themes were identified from the participants' narratives. These themes represent the women's "fundamental structure of existence" (Johnson, 2000, p. 21). The meaning of the pregnancy experiences of the five newcomer women in this study was captured in four essential themes and their respective subthemes. The essential themes are: (a) Lived Body: *The situational self,* (b) Lived Space: *Living with the good and the bad,* (c) Lived Human Relations: *Support and acceptance,* and (d) Lived Time: *The future seems brighter.* Although these four themes were fundamental to the meaning of pregnancy for the women in this study, one theme, *Desiring a Balanced Identity,* eventually emerged as the overarching theme. In the discussion of the four essential themes I describe the narrative accounts of the participants through their quotes and my fieldnotes. By presenting an overarching theme, I have endeavored to capture the essence of the meaning of the women's experiences.

Overarching Theme

The overarching theme is the major finding of a Heideggerian phenomenological study. Arriving at the overarching theme requires an abstract understanding of the pregnancy experiences of the study participants. The overarching theme synthesizes the essential themes and serves to move beyond the conscious descriptions offered by participants. Therefore, the overarching theme "focus[es] on describing the meaning of the individuals' being-in-the-world and how these meanings influence the choices they make" (Lopez & Willis, 2004, p. 729).

Desiring a Balanced Identity

The overarching theme *Desiring a Balanced Identity* emerged from my conversations with the women that alluded to their desires to be seen as 'normal' pregnant women. The women implied over and over again that they did not want to be seen just as newcomers, or just as women living with HIV. They wanted to find balance between their multiple social identities. In particular, they were striving for their identities as pregnant women to fall within this balance. The desire for a balanced identity is what I came to understand as the hidden meaning of the women's individual narratives about being pregnant newcomer's to Canada living with HIV.

The narratives that were shared conveyed a perception that being in Canada made this balanced identity more achievable. For example, Jamila described her experience of pregnancy in Canada as very normal in spite of the fact that she was living with HIV. During this discussion, it appeared that she attributed her successes in living a balanced identity to her physical location in Canada:

> I think, if I say normal…I mean someone who is walking just like any other person without the virus, without any other sickness. That's how I see myself here…yeah but back home you think about it more than when you are here…All you think about it, "I'm HIV positive"…It is like a different thing all together [here].

Blessing alluded to her balanced identity in these terms: "… here [in Canada] they will encourage you that you are…still the best. You are even still healthy…They are not putting a special stigma on this, you know…It makes you feel that you can worry much less about HIV here". Worrying less about her HIV allowed Blessing to focus on other aspects of her life, such as her pregnancy. Not always being focused on their HIV status was perceived by all of the women as helping them achieve their desired balance. Furthermore, it is important to note that

while achieving a balanced identity was dependent on lived space, as previously described by Jamila, Blessing also eluded to the role of human relations in supporting her desire for balance.

Desiring a Balanced Identity was strongly linked to their lived body, lived space, lived human relations, and lived time. Each of the four essential themes, and their respective subthemes, that will be discussed in this chapter presented challenges that hindered living a balanced identity. In addition, each theme described aspects of life in Canada that the women perceived as helpful and protective.

The concept of *Desiring a Balanced Identity* as the overarching theme of this study provides a holistic interpretation of the meaning of pregnancy for the five newcomer women living with HIV who participated in this study. While the women were all pregnant newcomers living with HIV, they were not defined by just one aspect of this imposed identity. Instead, they were actively making choices and resisted these imposed identities in order to live a life in Canada that empowered them to balance these intersecting identities during pregnancy.

Themes

Lived Body

Our experience of being-in-the-world depends on our body (van Manen, 1997). Our lived relations and lived space are strongly connected to our lived body as our body serves as the vehicle through which we encounter the world (van Manen, 1997). Pregnancy is a powerful bodily experience that gives life. HIV, regardless of how it is conceptualized, whether as an illness, as a disease, or as a chronic condition, is often socially perceived as a destructive power within the body (Vahabi, personal communication, June 15, 2011). However, it is the perceived bodily experience that is most meaningful in Heideggerian phenomenology. Hence, the essence of the lived body for the women in this study was *the situational self*.

The situational self.

Idai came to Canada six months ago. Upon immigration she learned that she was pregnant with her first child. The experience of the imposed identify as a woman living with HIV has been a struggle for Idai. However, over time she has tried to compartmentalize her bodily experiences. When necessary she focuses on being a newcomer woman living with HIV. However, primarily she tried to maintain her personal focus on the experience of pregnancy. Idai's story of a situational self was echoed by the other women. The experience of compartmentalizing different bodily experiences was described by Blessing as "feeling like you are divided". The division was not of the physical body. Instead it was a dissonance between the physical and the perceived bodies. The subthemes that illustrate the corporeal experience of *the situational self* were (a) bodily dissonance and (b) focusing on the pregnancy.

***Bodily dissonance*[19]. ** Most of the participants discussed the negative experience of being reminded by others that they were living with HIV despite their bodily perception of wellness during pregnancy. In my conversation with Idai, she repeated several times that this had been a challenge for her. Idai explained that even though she knew she was "sick", because that is what the "numbers say" [referring to lab test values], it was not something she wanted to discuss because her lived bodily experience was not about sickness. It appeared that there was dissonance between her real or physical body and her perceived bodily experience. This lack of agreement was perpetuated by biomedical technologies, such as blood tests. Hence, an important aspect of *bodily dissonance* was the experience of physical bodies being defined by others based solely on HIV status.

[19] Dissonance is defined as a lack of agreement (Merriam-Webster, 2008). Definitions often suggest that dissonance is uncomfortable and an experience of personal inconsistency.

When I spoke with each of the women I observed that the essence of *bodily dissonance* was the disconnection between the physical body and the lived body. For example, Blessing, who was 26 weeks pregnant with her second child, ascribed her negative experience of bodily dissonance to certain interactions with healthcare professionals "…you feel healthy, your body feels healthy, but these numbers [referring to lab values], everyone is talking about sickness... they are telling you that you are not okay…So you feel disconnected". Throughout our conversation, Blessing appeared quite upset by her adverse encounters with healthcare professionals that had negatively impacted her lived experience of pregnancy. The impact that human interactions had on the women's bodily experiences was an important example of the connection between the four existentials. These adverse encounters are described in greater detail in the Lived Human Relations section of this chapter.

The experience of *bodily dissonance* appeared to affect certain women more than others. Anna, who had been in Canada for seven years and lived here with her other children and her husband, spoke differently about the connection between her physical body and her lived body. Anna expressed that her bodily experience was more integrated than the other participants. She talked about her personal journey of an integrated body since learning about her HIV status in a previous pregnancy:

> I accept the disease right now. But the first time the doctor told me, when I found out [about] the disease, I couldn't accept it…I was sad and angry…But now I'm sharing my life with the disease. I have learned that we have to share my life...right now I have peace in my life.

Through our conversation, and during two follow up phone calls, Anna personified the peacefulness she described. She spoke about her identity as a woman living with HIV with a certainty that I did not observe amongst the other participants.

Focusing on the pregnancy. Focusing on the pregnancy contributed to the bodily experience previously described as *the situational self*. The participants appeared to define themselves by three distinct identities: (a) as a newcomer, which is situational, (b) as pregnant, which is both situational and bodily, and (c) as a woman living with HIV, which is also both situational and bodily. The clear preference articulated by the women was to experience pregnancy separately from their HIV status. They also spoke about pregnancy separate from being a newcomer.

Some of the women stated that they were not thinking about their HIV at all during their pregnancies. This was illustrated by Anna in the following statement: "No, no, I don't worry about the disease at all right now [during pregnancy]…I have to take medications to keep my viral load at a good level but the pregnancy has nothing to do with that". As previously noted, Anna indicated that she was fully sharing her life with HIV. Jamila, who was in her late thirties echoed that her pregnancy was her focus:

> I don't think about the HIV. All I think about is when my alarm blinks for me to take my medication. That is when I know I have HIV…But otherwise my life is just like a normal pregnant human being.

While focusing on their pregnancies added to the experience of separating their bodily identities, it was perceived by the women as a positive separation, unlike the experience of bodily dissonance created by the comments of others. By focusing on their pregnancies, the women

expressed to me that they had experienced typical emotions associated with pregnancy such as "joy", "excitement", and "happiness".

Like the previous subtheme, *bodily dissonance*, the participants described the intimate connection that their focus on pregnancy had with their interactions (lived human relations). The participants indicated that the biggest obstacle in focusing on their pregnancies was when they had medical appointments. The women preferred when healthcare professionals made an effort to separate the issues of pregnancy and HIV as this enabled them to focus on their pregnancies during prenatal visits. While it was previously mentioned that Jamila was focused on her pregnancy, she did explain that the only situation that did not allow her to maintain this focus was during her medical appointments: "My experience now is only about the pregnancy…Only when I have appointments lined up do I have to think about it [HIV]".

Blessing expressed frustration that at prenatal appointments she was required to get HIV related blood work done when it had already been done by her infectious disease specialist at another hospital. She felt like the discussion of her HIV, which was well controlled, took away from the enjoyment of prenatal visits:

> … when you're pregnant, every day that you come [to the obstetrician], they send you here, they send you there…I am telling you that it does not make me happy…Especially when I'm pregnant…It would be better if, the doctor [obstetrician] got anything about my HIV from my doctor [infectious disease specialist]…when you are pregnant, that is the only time when they [healthcare providers] keep on mentioning the HIV, HIV, HIV.

I observed Blessing becoming quite animated as she discussed her frustration. Her voice became louder. During the interview I wrote that she was "suddenly more passionate about what she was discussing".

The women also perceived that their ability to focus on their pregnancies was linked to living in Canada[20] (lived space). While being a newcomer presented challenges in the women's lived space, which are discussed next in this chapter, some of the women perceived that being in Canada allowed them to focus on their pregnancies more than they felt they would have been able to had they been elsewhere. Jamila spoke of her bodily experience as a woman living with HIV before immigration and compared this to her current experience of pregnancy in Canada: "…It is a different thing all together here…Here you go freely…It has made me feel normal…It makes me feel like everything is good".

Lived Space

Lived space is not about physical dimensions, it is about the experience of felt space (van Manen, 1997). Space is the landscape through which we move that influences how we bodily encounter time and others (van Manen, 1997). A significant element of the women's pregnancy experiences was their situational identity, their 'lived space' identity as newcomers. As such, the women's lived space was deeply embedded with meaning for their pregnancy experiences.

Living with the good and the bad.

Relocating to a new country is challenging for most newcomers. The way of life in Canada was seemingly different from what the women recalled of their home countries. And while life as a newcomer presented challenges, the women in this study perceived a number of supportive factors about life in Canada. They were *living with the good and the bad* in Canada. Participants described the dominant Canadian culture as being "open". They valued this openness in their everyday lives. Lydia, who was already a single mother to a four year old son

[20] In the context of the study findings, the discussion of Canada was related to the social context of the country and not the physical location.

and three year old daughter, shared that despite the challenges she had experienced with integrating into a new country, she was happy living in Canada:

> Knowing that you are not from here, like knowing that your family is not here to stand by you, it is really, really hard. And now you are having a baby...There is nobody here… But then, on the other hand, it is good because it's Canada. Like, if something happened to me on the road, someone would help me here.

However, the narratives of the women presented several ambiguities about their experiences of life in Canada. As such, the subthemes of "*living with the good and the bad*" were (a) navigating a new world, (b) giving birth in a new country, and (c) maintaining privacy.

Navigating a new world. As newcomers, the women in this study felt like they were *navigating a new world*. For two of the women, whose pregnancies occurred within a year of arriving in Canada, there was urgency in their need to familiarize themselves with Canada in order to access appropriate care. Idai[21] recalled what she went through in her first weeks in Canada having just learned of her pregnancy and her HIV status. She sounded very proud when she spoke about her journey. She explained that she knew very little about Canada before arriving. Idai had to quickly learn a lot about Canada when she arrived because she discovered she was pregnant and also that she was living with HIV. She felt that it had been necessary to learn these things much quicker than if she had not been pregnant when she arrived.

From different appointment locations and the structure of the Canadian healthcare system, to the city's transit system, Anna recalled her own experience of navigating a new world when she first arrived in Canada. Though each woman's experience varied, they each identified the fast pace at which they had had to learn all about their new city and country.

[21] Idai had been referred to the specialized obstetrician by the physician who conducted her immigration physical and discovered that she was pregnant.

In addition to the basic navigating that the women described, they also identified challenges that were specific to their experiences as newcomer women living with HIV. Jamila recalled her experience of only being able to access prenatal care with a specialized obstetrician: "Going to the prenatal clinic was a problem from the beginning because I didn't know much about the country…I didn't know where to take the transit, where I was supposed to stop". The women in this study were obligated to travel to a specific hospital, sometimes at great distance, to access specialized services. In addition, Idai discussed having to go to one hospital for her HIV, one hospital for her prenatal care, and one hospital where the baby would receive care after delivery. Blessing described this as a challenge because there was limited coordination in their care. Even for participants who knew of their HIV status before coming to Canada, none of the women had experienced multisite healthcare services before immigrating.

While navigating the system was a challenge, the women pointed out that their obstetrician had assisted them in accessing resources available in Canada. These resources were the formal supports that many of the women had not previously accessed post-migration. Lydia told me that during her first pregnancy her doctor had encouraged her to access resources for mothers living with HIV. However, she explained that during her first pregnancy, as a very recent newcomer, she had not had the opportunity to explore those resources prior to beginning prenatal care. She indicated that having these available to her at the beginning of her current pregnancy had helped her manage her uncertainty about the pregnancy.

Length of stay in Canada appeared to moderate the impact that navigating a new world had on the pregnancy experience for other participants. The women who had previously given birth in Canada expressed familiarity with the Canadian healthcare practices during with pregnancy, labour, and birth. Having already given birth in Canada, Lydia had experienced

fewer challenges in navigating the system than some of the other women. She commented on how she was feeling about her interactions with the healthcare system during this pregnancy:

> So far, I think it's going just fine this time. Because I have been through it…You know the procedure they will take and what you are supposed to get…So you have some idea what you need…but before, I didn't know…I was scared…

Giving birth in a new country. The women spoke about the complexities associated with *giving birth in a new country* that they did not recognize as their home. One challenge that several of the women discussed was the dominant, Western medical birthing practices in Canada. Anna identified some of the difficulties she faced by giving birth outside of her home country:

> It's not, you know, like when you are having the baby back home. In Canada, it is different. After [you give birth back home]…the people support you and help with the baby…to raise the baby. But here, the day you come home from the hospital you have to start to cook. It is different.

The physical space between the women and their families was a common uncertainty that several of the women expressed about giving birth in Canada. As in the case of Anna, being in a new country meant that she had limited informal support throughout her pregnancy. The other participants also conveyed that had they been pregnant back home, they would have valued the informal social support that their families would have provided. Lydia, who was a single mother, found being in Canada particularly difficult because "you don't have your family around…so it's pretty hard".

Despite the uncertainty that came with being away from their families during pregnancy, I observed that the women had also discovered many advantages to their new lives in Canada. The women's "absorption in the world" was deeply connected with their bodily experience of

living with HIV (Johnson, 2000, p. 19). The complexity of being a woman living with HIV appeared to add a uniquely positive perspective to giving birth in Canada for the participants. As Lydia reflected on her entire experience of being a pregnant newcomer living with HIV, she explained to me "I would be scared having my kids [in my home country] knowing I'm HIV. Because there are no medications there. I could not deal with them being sick…But here it is good. I think it's still okay".

Access to medical treatment emerged as a major benefit of giving birth in Canada. The women perceived that in Canada they could access the services and treatments needed to maintain their health and preserve the health of their unborn child. Lydia's appreciation of access to medical treatment during her pregnancy was echoed by other participants. Jamila explained:

> When I had just come to Canada, I was so surprised by the pregnancy. In the beginning I asked myself why am I pregnant? Why? With this sickness [HIV] and all of that. But then I had my first appointment and they explained the advantages and disadvantages [of being pregnant with HIV]... Here it is not a big problem…Here, I was relieved.

Idai conveyed her belief that coming to Canada had been a "blessing" for her. She felt that coming here to give birth would allow her to live and her daughter to be healthy. It was the access to treatment that made Idai feel blessed to be in giving birth in Canada.

Despite the desire to be closer to family during pregnancy, some participants expressed concern about how they would have been received by other people if they had been pregnant back home. The desire to be close to family, and yet the fear of disclosure if they had been home, emerged as the most ambiguous findings of this study. While the participants lacked informal support here, they shared many stories of how they valued the formal support they had

received in Canada during their pregnancies. When the women discussed their experience of felt space, in reference to the people they encountered in Canada, they all became emotional. Idai had a particularly strong emotional reaction about her experience as a pregnant newcomer. She looked around the room at all of the things, including baby clothes and supplies that had been given to her by formal support services[22], including support groups and a social worker at the hospital where she was receiving prenatal care. "Nobody expects all of this" she told me with tears in her eyes and her hands pressed against her heart. For the women in this study, coming to Canada had offered them an unexpected "humanity", "caring for others", and "acceptance".

Maintaining privacy. Based on my conversations with the women, privacy emerged as another subtheme of lived space. While most of the participants wished they could be near their families for informal support, they also described how distance was a benefit of being in Canada because they had a greater sense of privacy. Some of them felt that being in Canada enabled them to conceal their HIV status from friends and family back home. They also indicated that, in the broader social context of life in Canada, protecting the privacy of their HIV was easier here than back home. Anna told me what privacy meant to her here in Canada:

> Privacy, I like the privacy I have here. Nobody in my family knows I have HIV...Because that's my privacy. If I tell anyone back home, people will start talking about it and I don't want to be discriminated against.

All five women said that despite other challenges, they preferred being here, where nobody in their closest circle knew or could learn of their HIV status. Having only her husband with her, Blessing preferred "that I am here in Canada so that nobody knows…[because] back

[22] In order to contextualize the women's reactions to formal support services, it is essential to acknowledge their migration to a high income country (Canada). All five of the participants had come from low income countries where access to formal support services is limited due to economic constraints.

home they will scandalize you and kill you….I don't want anybody to know. Because my dignity will be dimmer, my respect won't be there".

In addition to comments on privacy in Canadian society at large, I observed that the women also valued having their privacy maintained in healthcare settings. I understand this as privacy in their immediate or intimate lived space. Lydia shared her beliefs about maintaining privacy in the Canadian healthcare settings as opposed to her home country, "…if you are going to get them [medications and HIV related services], the whole world is going to know. So it's not like here, like you get your medicines and nobody particularly knows exactly what's going on". As someone who had accessed HIV healthcare services before immigrating to Canada, Jamila shared her experience of attending prenatal appointments as a woman living with HIV in Canada, "appointment to appointment nobody knows what you are coming to do…there is nobody around you who knows this girl is going to the HIV doctor or anything. It [the prenatal clinic] is like a different thing all together here". Anna had a similar experience, "when you go to see Dr. [name removed], no one knows who you are, what you have, what you don't have". Blessing's comments were also in agreement:

> You don't know whether that [HIV] is the reason why I am here or whether I have even another pregnancy disease. Or maybe I have diabetes or I have hepatitis or maybe I have one thing or another. You don't know the particular one I have.

The women had a common vision of how important it was to have their privacy protected. And while they shared stories of positive encounters, they were also discouraged by healthcare settings in which their privacy was compromised. Participants seemed to feel that certain, specialized providers did a superior job of maintaining their privacy while other

healthcare professions lacked the necessary sensitivity. Blessing identified her interactions with laboratory technicians at the recruitment site as having compromised her privacy at times:

> …[the lab tech] was calling the other lady across the room, asking how you do a viral load. She was shouting! I was upset…[and] I don't like the lab here because you are always seeing different people. When they see you, they think "oh this one is this and this one is that". You don't feel happy. Especially now that I'm pregnant, I would prefer to keep it [HIV blood work] separate.

Blessing's observations of non-specialized care providers were echoed by Anna. Anna described an experience during a recent hospitalization when personal health information regarding her HIV status had been disclosed unnecessarily. Our discussion was deeply embedded with emotion. I asked Anna to explain to me how that experience had made her feel:

> At first, I felt very sad. It made me cry…I felt discriminated against… Everyone needs to have their privacy. They don't have to go around telling everybody what you have. At the hospital some of the people are wonderful. But others don't understand. They don't understand what I am feeling. I like it better when I have privacy.

While the women perceived that their ability to maintain privacy was related to being in Canada, a place that they suggested respected the need to maintain personal privacy, I also observed that maintaining privacy was deeply connected to the women's experiences of lived human relations. As I reflected on this connection in light of Heideggerian phenomenology, I remembered that it is through our lived space, our being-in-the-world, that we come to encounter others (Heidegger, 1926/1972; van Manen, 1997).

Lived Human Relations

According to van Manen (1997) lived human relations are those which "we maintain with others in the interpersonal space we share with them" (p.104). As each person's existence is centered within their world, it is undeniable that the relationships and human connections we experience leave an impression on our existence (Leonard, 1994). For the women in this study, their experiences of pregnancy were significantly enmeshed with how they perceived their interactions with other people in their world.

Support and acceptance.

For many of the women, receiving *support and acceptance* regarding their pregnancies from others in their lifeworld was encouraging. The *support and acceptance* that the women had received since coming to Canada was an experience that had positively influenced their pregnancies. Each of them described having felt uncertain about how they would be treated in Canada as newcomer women living with HIV. Experiencing *support and acceptance* in their lived human relations had liberated the women from those feelings of uncertainty. However, not all of their lived human relations were supportive and accepting. While the essential theme of lived human relations for the women was *support and acceptance* the layers of support they discussed emerged as the four subthemes: (a) cultural support, (b) "because he's there", (c) "being cared for", and (d) "I'm not the only one".

Cultural support. Being in a new country, most of the women relied on their existing cultural community for certain types of help and support during their pregnancies. Several participants expressed interest in opportunities to engage with other people in Canada who had emigrated from their home countries. Jamila talked to me about the supportive relationships she had established with other newcomers since her arrival in Canada less than twelve months ago:

> We have other friends that are from our country that are here [in Canada]…We can get together and just talk. Knowing other people from your country, here in Canada, is good. …It feels like you know him already or you know her already.

Jamila explained that this support was important as she awaited the birth of her child: "Because you know after you come home from the hospital that you will have more support from your friends". Idai, who had come to Canada alone, also spoke favourably about the new relationships she had created with other people from her country in Canada as well. Idai explained that since she was pregnant when she arrived, finding cultural support was very important for her. The support of people from her home country had enabled her to access cultural foods that she considered very important in pregnancy.

Because the women did not perceive any change in cultural stigma associated with HIV following migration, none of the women had disclosed their HIV status to members of their cultural community. This was previously discussed in the subtheme "maintaining privacy". All of the women felt that given their fears of discrimination, they preferred to keep their HIV status private. Unlike the other women, Lydia and Blessing even stated that they avoided new relationships with people from back home to prevent disclosure of their HIV status. Both stated that they did not want to risk people learning about their HIV status, particularly during pregnancy, as they feared discrimination.

In addition to new relationships, the women relied on people back home for support. They were often ambiguous about whether they preferred being away from home, in order to protect their privacy, or whether being far from friends and family was a challenge during pregnancy. Regardless of how much the women appreciated privacy, being away from family during pregnancy was emotional for some. This was never more apparent than during my

interview with Lydia: "...knowing that your family is not here to stand by you, that's the most difficult thing for me". Anna also spoke of wishing her family was here, especially during her pregnancy: "Especially when you have a baby, you need your family…I would do everything to have my family here. But I can't have it. I'm lying to myself". The challenge created by the physical separation from family was another example of the close connection between the lived space and lived human relations for the women in this study.

"Because he's there". Some of the women discussed how challenging it would have been to be in their current situation if they had not been supported by the father of their child. The support and acceptance of either their husbands, or for the single women, the father's of the babies, appeared to have a unique significance. Jamila spoke of her personal experience of acceptance and support by her husband through her diagnosis with HIV and their mutual excitement about the pregnancy. She stated "My husband has helped me a lot, a lot, 100% percent… Because nobody would expect him to accept somebody with this kind of situation. Because he's [HIV] negative..."

Blessing also pointed out that she appreciated how her husband had continued to support and accept her throughout this pregnancy. Her husband was also HIV negative: "Yeah, it's [referring to her husband's support] everything to me. Because he's there. You know some people, this type of thing used to separate the marriage…he is strongly behind me". While each of the women appeared excited about their pregnancies on a personal level, I observed the importance of having the support of the baby's father given their situational identity as a newcomer living with HIV.

Lydia, who was a single mother, discussed her experience of being supported by the father of her child. Before the interview, Lydia mentioned that he knew of her HIV status. His

support had continued even after this unplanned pregnancy. She found great comfort in knowing that the father of her child continued to be supportive. Lydia described what it was like for her here in Canada on her own, knowing he had promised to support both her and the baby:

> This pregnancy just happened… Eventually I had to tell him that I was pregnant…And he just accepted it…For him to stand up for me when I needed him, it was really helpful…It's something good. At least somebody is there.

"Being cared for". "Being cared for" signified the helpful relationships that the five participants had with their prenatal healthcare professionals. While not all interactions with healthcare professionals had been positive, overwhelming the women focused on these interactions. All of the women were attending the same specialized prenatal clinic during their pregnancies. They identified that the specialized prenatal care clinic had created supportive, accepting relationships with healthcare professionals that made them feel the same as all of the pregnant women in the clinic. Each woman spoke about the positive effect of being supported and accepted during pregnancy by the doctors, nurses, and social workers that cared for them. Blessing shared how her obstetrician had positively impacted her experience of pregnancy. She smiled and laughed when she talked about this in our interview:

> You know, the way [the doctor] treats people, the way [the doctor] will hold you, everything. [The doctor] makes you feel at home. It makes you feel like you are being cared for, you are being loved. It has a lot of impact in making me happy right now.

Jamila was moved by the "kind of medical people I have seen here with the loving and caring…" as were Idai, Anna, and Lydia. Anna spoke about her general experience during her prenatal visits: "…I feel grateful for the way they treat me and support me when I go there…"

Although the women generally felt cared for in their interactions with healthcare professionals specializing in pregnancy and HIV, all five women had examples of unpleasant encounters within the unspecialized providers. Idai spoke of her frustrations with healthcare providers who did not see her as a whole person. She told the story of a physician coming in to the room to assess her early in the pregnancy. She acted out how he kept flipping through notes and turning back to his pages as if he knew nothing about her except that she was living with HIV. She perceived that his attitude towards her had been "negative". She told me she found this "too hard" being that she was new to Canada and was dealing with her HIV diagnosis and pregnancy.

Jamila's initial encounter with a physician during her pregnancy had also been very unsupportive for her:

> I went there just to check if I was pregnant. So [the doctor]…said I was pregnant. [The doctor] said I had to go through the lab work…[the doctor] detected I had HIV...The doctor was like, I'm scared! I've never seen somebody with this sickness before...[That doctor] didn't want to continue to be my doctor…I felt very bad...I didn't even want to go to any more doctors… I was surprised that [the doctor] was doing this to me here.

Despite acknowledging that there were imperfections within the Canadian healthcare system, "being cared for" presented itself as the resounding echo of the women's experiences with the majority of their healthcare providers. It appeared that the amount of *support and acceptance* that the women received in their current specialized care had safeguarded them against the emotional upset caused by the occasional unpleasant encounter with healthcare professionals.

"I'm not the only one". Meeting or hearing about other women in the same situation as them gave the women a truly normalized experience of pregnancy. In some cases, the women were being accepted and supported by people who understood what they were going through. For others, merely hearing stories from their physician was sufficient. For many of the participants, their identities as a person living with HIV, as a newcomer, and as an expectant mother were all relatively new. Lydia described her positive experiences of getting to know other mothers living with HIV.

> I remember with my first pregnancy, when I found out, it was pretty hard. Like what am I going to do? And then I went to this group, they introduced me to [support group name removed], and there I met all the moms who have HIV and who are dealing with it. And that gave me a sort of, I'm not the only one who has it [HIV], who is going to have a kid.

These relationships were all the result of support groups and programming arranged by local ASOs. Jamila explained that being connected with these resources and other mothers gave her a sense that "it was normal to talk about this stuff [living with HIV] here". The women suggested that these types of formal support would not have been available to them back home. There was one specific support group that the women repeatedly identified as having been the most supportive, and which had resulted in their friendships with other mothers living with HIV. It specifically focused on mothers and their children who are affected by HIV.

Jamila expressed her positive attitude towards attending this support group: "you are happy you have met them [the other women] and they are also looking very healthy…seeing them [other mothers who are living with HIV] has given me courage". Lydia echoed Jamila's positive sentiment about her experiences within the group: "It's pretty good because they understand what you're going through, because…they are going through the same thing". It

appeared that the unique support of other women living with HIV, many of whom were also newcomers, was significant because it gave the women a truly specific sense of normalcy that other supportive relationships could not; the sense of normalcy that comes along with knowing you are not the only one.

Like Jamila and the others, Anna reflected on the fact that her relationships with other women similar to herself were important to her during pregnancy. Having already given birth since coming to Canada, Anna knew how important formal support was during a pregnancy. To a great extent, being part of this group gave the women an additional sense of belonging. However, Anna and Lydia found it challenging to attend support groups because these services were far away and required money for transportation that they did not have. Anna explained why she made the effort to go to the group even though it was far for her to travel by public transit with her other children:

> The [support group name removed] has helped me a lot with my kids. It gives me support…It is far away for me but it is good…It is good to get involved with the mothers. We can talk about our lives. Talk about our [long pause], situation. We talk about what it is like to be in Canada and what it would be like if we were back home. We talk about a lot…Because most people don't understand what is going on.

Not all of the women, however, embraced these support networks. For some, their fear of being "outed" regarding their HIV status, should they meet another woman of a similar cultural background, limited their willingness to attend. Blessing explained: "I don't go there [referring to the support group]. Because I don't want anybody to know [that I have HIV]". However, she did state that hearing about other pregnant women living with HIV from her obstetrician was a positive experience in consonance with the subtheme *"I'm not the only one"*.

Lived Time

Just as Heidegger's (1926/1972) philosophy suggested, when the experience of time was discussed, the women's present existence appeared intimately connected with their past and their lives pre-migration. However, the temporal theme that emerged as essential to the experience of pregnancy for newcomers to Canada with HIV was the brightness of the future.

The future seems brighter.

"…When the baby comes, he will also be okay. Like the way I am now...With him around me, I am sure I will be happier than when he is not with me…" (Jamila)

The future seems brighter represented the women's "hopes" and "dreams" for their lives after the birth of their child. In the temporal sense, having a baby was seen as hope for the future. The subthemes were (a) "children, a treasure you have tomorrow" and (b) waiting for a cure.

"Children, a treasure you have tomorrow". Despite the challenges and obstacles the women discussed in regards to navigating a new world, to not always being able to focus on their pregnancies, and to experiencing negative interpersonal encounters, the participants always returned to their anticipated joy with the birth of their child. The women in this study displayed a common cultural expectation of motherhood. Jamila explained to me that as a woman and wife she had been expected to have a child: "You know Africa, they have this mindset that something is wrong with you if you can't give birth…So I feel very fortunate about this pregnancy".

For several of the women, the cultural norm of motherhood seemed to have translated into a personal sense of fulfillment associated with their impending motherhood. Already having one child, Blessing explained to me that as she thought about the birth of a second child, it gave her a sense of normalcy as a woman:

> Children are treasure, you know… if I don't have money, I can do with not having money. But if you don't have a child I don't think I will be normal. Having children, when you see them, they give you joy…. *children, a treasure you have tomorrow*.

While motherhood had cultural significance for each of the women, being in Canada had a unique influence on the pregnancy experiences of the participants. As women living with HIV, the participants expressed reassurance about the probability of having an HIV negative child because they were in Canada. This was very important to each of them.

In the current study, the focus on the future was not associated with chronological time. It was about the possibility of *Being-with* their children. Pregnancy enabled the women to have a positive outlook on the future in the midst of much uncertainty as newcomers and as women with HIV. The discussion of raising children also suggested that despite fears about HIV transmission, the women had hopes that their children would be healthy and continue to grow. This was exemplified in statements by Jamila: "It is like the child is going to be here when I am not here".

It seemed that having a healthy child to treasure also meant a time when the women could focus on something other than their HIV status. The participants acknowledged that having a healthy child was not an end to their disease. At the same time, they would not allow the life experience of being a pregnant woman to be defined by their HIV status. Blessing explained: "Children are treasures you have tomorrow. I will feel the joy of having another baby. That is it. So when the issue of the HIV will try and come up, I just say no." Even though Blessing described the most adverse experiences in regards to being a pregnant newcomer woman living with HIV, it appeared that she continued to struggle towards a future that was more joyful. Anna, who appeared the most at peace through her interview, explained that life was brighter

with the promise of a baby: “When I look to the future I think about having a baby and enjoying my life”.

However, some of the women’s narratives still suggested ambiguous feelings between their anticipation of the birth of their child and their continued worry of the unknown. The unknown that the women feared was whether or not their child would be born with HIV. For Jamila, prayer helped her manage this ambiguity:

> I’m just waiting for the day to come [when I learn if the baby is healthy]…I will see what God will do for me. I pray it will be the same [as the other women who have healthy babies]…[But] with the medication they are going to give you for the first 6 months…I hope the baby will be okay

For some participants, the fear of having a child born with HIV, quelled some of the joy of pregnancy. Despite speaking positively about their pregnancies, Lydia’s and Anna’s anticipation was tempered by their fears of HIV transmission to their unborn babies. Simply having increased access to HIV treatment in Canada was not enough to subdue their worries. Lydia found waiting to find out if her baby would have HIV particularly difficult, “My kid might have the same thing I have. That was my main worry when I had my first one. Well I have got the same worries with this one too right. It’s, it’s not 100 percent right?” Although hesitant at times, like Lydia, even when the other women described their stress about the possibility of transmission, there was a sense of overall optimism for the future. According to the data, this optimism was greatly influenced by a hope for a cure.

Waiting for a cure. *Waiting for a cure* was the subtheme that was the most connected to life after pregnancy and yet it was intimately a part of the women’s pregnancy experience. Becoming mothers signified that the women in this study were making ties to ‘time’ in the future

sense. Yet, they were also challenged by the dominant discourse of HIV as a death sentence. The pervasiveness of their fear associated with HIV meant that the women's freedom to be excited about motherhood was not absolute. Although the women expressed confidence in their current health status, they knew that overtime their health could deteriorate. Their futuristic Being-in-the-world was uncertain. As such, some of the women discussed the future with trepidation. I was touched by the emotions the women shared with me about their fears. I could feel that the women were conflicted between their excitement and their fears. While the future *seemed* brighter, nothing was for certain.

Perhaps the only solace the women discussed from their fears and uncertainty were their hopes for a cure. The women each described their specific thoughts about a cure. These individualized accounts appeared to have been influenced by the women's cultural beliefs, religion, Western medicine, and the experiences that had been shared with them by others. Anna shared her specific belief regarding a cure:

> ...soon there is going to be medication to the kill the disease. Someone has found the cure in Africa...I have just heard that lots of people with the disease have taken it and they never come back positive. One day we are going to get the cure…maybe.

Jamila also believed a cure was coming: "in the future there is going to be a medication that is going to cure it, we don't know. So, let me just take it [the medications] for now and see". Blessing's beliefs about a cure were connected to her faith: "Even before you were born, God knew everything about you…I keep on believing that one day I will get over this [HIV]…".

The women were empowered by their ability to have hopefulness for the future. In the process of experiencing a pregnancy that had presented challenges, awaiting a cure allowed the women to take "each day as it comes" as Lydia stated. Waiting for a cure contributed to the

women's positive pregnancies experiences because they were able to think beyond their HIV status. By believing in a cure, the women's futures seemed brighter as they would no longer have to worry about living with HIV.

Summary of Thematic Analysis

Desiring a Balanced Identity emerged as the overarching theme of the pregnancy experiences of the five newcomer women to Canada living with HIV who participated in this study. This overarching theme was intimately connected with the four essential themes which were uncovered during data analysis. These themes were: (a) Lived Body: *The situational self*, (b) Lived Space: *Living with the good and the bad*, (c) Lived Relations: *Support and acceptance*, and (d) Lived Time: *The future seems brighter*. Within each theme, the women discussed complexities of both the positive and negative elements of their experiences. At times they were ambiguous about how challenges and benefits conflicted with one another. And yet, the underlying meaning in their experiences was that as pregnant newcomer women living with HIV in Canada, they were living more of a balanced identity than they would have back home. And while this balance was the result of certain systemic benefits, it was largely the result of the active choices the women made about how they lived their lives and how they were socially defined. The women resisted imposed identities. Instead they actively constructed their situational selves in order to live with the good and the bad, to access the support and acceptance they desired, and to focus on a brighter future. Through these actions they worked towards their desired balanced identity. Their experiences were multifaceted, consisting of a wide array of emotions, events, and personal relationships.

Although each theme has been captured separately within an existential for the purpose of presenting the study findings, I have noted the intricate relationships between the four

existentials throughout this chapter. For example, the narratives highlighted how lived human relations had, at times, negatively impacted the women's lived bodily experiences. Lived space was also intricately connected to lived human relations. Such as, the women described how living far from their families enabled a greater sense of privacy but was also an emotional challenge. These two brief examples exemplify how all four themes and existentials intertwined to form the overarching experience of *Desiring a Balanced Identity*.

Summary

This chapter presented the findings of this study based on my interpretation and my understanding of Heideggerian Phenomenology. As the objective of Heideggerian Phenomenology is to move beyond description, in the next Chapter I will present an interpretive discussion of the salient themes/subthemes that emerged throughout data analysis.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

Introduction

This final chapter includes an interpretive discussion of the findings of this study. The four essential themes and the overarching theme are discussed in consideration of my understanding of Heideggerian Phenomenology and relevant literature. I present the implications and recommendations for education, practice and organizational policy, as well as future research. Lastly, I provide my concluding thoughts to symbolically bring this study to a close.

Discussion

Desiring a Balanced Identity: Interrogating the Hidden Meaning

We are often socially defined by identities that others ascribe to us. For the purpose of this study, the identity 'pregnant newcomer women living with HIV' was created to define research participants. But 'pregnant newcomer women living with HIV' was merely a descriptor used by me, the researcher. During data analysis, I began to critically examine the social identities that exist within this single descriptor: (a) pregnant, (b) newcomer, (c) woman, (d) living with HIV, and (e) any combination of these identities. Balancing the elements of this complex social identity emerged as the essence of the lived experiences of pregnancy for the women. Therefore, it is imperative that this discussion include a critical exploration of how the five participants projected themselves in the world and why they chose to conceal elements of their social identity.

Amidst the inherent complexities in the women's lived experiences, how they were perceived socially seemed to be the essential component. However, in order to ontologically[23]

[23] As defined in Chapter 3, ontology is the study of being, existence, and reality (Johnson, 2000). Therefore, the ontological meaning of *Desiring a Balanced Identity* lies in the reality of everydayness of the five participants as

understand the meaning of *Desiring a Balanced Identity*, the hidden meaning must be uncovered (Johnson, 2000). In order to interpret the abstract concept of *Desiring a Balanced Identity*, the unconscious social suggestions and implications became paramount. *Desiring a Balanced Identity* suggested a situational sense of being. At times participants described their situational focus on their identity as newcomer women living with HIV. However, their dominant focus was on their social identity as pregnant women. I contend that by defining themselves situationally, the women were not passively defined by imposed identities. The women in this study resisted social judgment and oppression associated with being a newcomer woman living with HIV by constructing their own situational identities.

The question remains why the women actively focused on pregnancy. It is a heteronormative[24] expectation of the female body to reproduce. As such, within the descriptor 'pregnant newcomer women living with HIV' there is averageness in being identified as a pregnant woman. Johnson (2000) introduced the concept of averageness in his writings about Heidegger. According to Johnson, "we get entangled in the world and sucked into the averageness of the 'they' " (p. 23). Averageness is the socially desired norm amongst our peers and society. Heidegger (1927/1962) wrote extensively about the everyday self which he conceived of as the '*they-self*'. Heidegger suggested that Dasein's *Being-in-the*-world resulted in the authentic self being taken hold of by the averageness of others. As discussed in Chapter 2, pregnancy and mothering have been found to have significant meaning for other women living with HIV because they are perceived as universally normal female roles (Ingram & Hutchinson, 2000; McGuire Bunting & Seaton, 1999; Sanders, 2008; Wesley et al., 2000). For women living

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beings (Johnson, 2000; van Manen). Ontological meaning is not concerned with simply being (what Heidegger conceived of as ontic) (Johnson, 2000). Ontological meaning is the meaning ascribed to Beings (Johnson, 2000).

[24] Heteronormativity is defined as the perpetuation of cultural and social rules, beliefs, and expectations that privileges the dominant discourse on the preference of heterosexual men and women producing and raising heterosexual children (Hudak & Giammattei, 2010)

with HIV, in particular newcomer women, the identity 'pregnant woman' arguably appeals to the inauthentic '*they-self*'.

The significance lies in an interrogation of why the women in this study, and society at large, legitimize pregnancy over the other elements of identity in the current study. These other elements include being a newcomer and being a woman living with HIV. I posit that the unconscious implication of this divergence in personal identity is a perpetuation of the stigmatization and invisibility of people living with HIV in this country; particularly people who are new to Canada. To the unknowing eye, HIV is less visible than certain other diseases and stigmatized identities. While surveillance systems are in place to track and monitor HIV infections, the virus itself is more easily concealed from society at large. This 'social invisibility' appeared to positively contribute to the notion of living a balanced identity for the women in this study. As they did not want their HIV status openly disclosed, being able to conceal it was important. Through concealment, the women resisted stigmatization.

For the women in this study, concealment as an element of *balanced identity*, is a mode of living that shapes a 'normalized' experience of pregnancy. Pregnancy becomes the focus of a *balanced identity* as being a newcomer woman living with HIV is a socially deviant identity (Hoffmaster & Shrecker, 2006). This evolving interpretation of a *balanced identity* conveys that despite what was consciously articulated by the participants, stigma and discrimination do covertly affect their lives and the meaning that is associated with their experiences of pregnancy. Their narratives described acceptance and understanding. However, their actions were suggestive that HIV-related stigma remains a problem in this country. As the women described, being in Canada was about living with the good and the bad. In the process of discussing the 'good' elements of life in Canada, it would be remiss to ignore the 'bad' that exists as well.

I contend that the meaning of *Desiring a Balanced Identity* suggests the insidious dominant discourse that renders HIV a shameful and stigmatizing social phenomenon. While it is important to recognize that stigmatization does impact all women living with HIV (Sandelowski et al, 2004; Wagner et al., 2010), social stigma and shame is likely magnified for newcomer women because of the intersection of several layers of stigmatization. Like all women living with HIV, the participants in this study were vulnerable to gender-based and HIV related stigma. However, they had the added complexity of 'newcomer-related' stigma. The intersection of stigma based on race, gender, HIV status in the context of being a newcomer to Canadian society created a different lived experience for the women in this study as compared to previous literature. Identifying as a newcomer living with HIV, who is pregnant, creates a distinct category of 'otherness'. Because we as human beings are "entangled in the….averageness of the 'they' ", it is natural to resist otherness (Johnson, 2000, p. 23).

The individual experience of 'otherness' was magnified by being a pregnant *newcomer* woman living with HIV. As discussed by Hoffmaster and Shrecker (2006) there continues to be social resistance to the provision of care for newcomers to Canada living with HIV. This is complicated by the fact that women living with HIV have historically been vilified as vectors of a contagious disease for their unborn child (Ingram & Hutchinson, 2000; Morrison & Guruge, 1997). In the context of pregnancy, the 'otherness' created by being a newcomer living with HIV appeared to be a subconscious concern for the women in this study. The women frequently mentioning wanting to be treated, seen, and cared for like a "normal pregnant women". It is possible that all women living with HIV want balance in their identities during pregnancy. There is little previous research on this topic. However, for the newcomer women in this study, balance appeared to have critical significance. Being a newcomer is itself an experience of

‘otherness’. Adding the complexity of living with HIV only heightens the ‘otherness’. The women in this study implied a social desire to be perceived as ‘normal’; in the sense of both their status as newcomers as well as women living with HIV. *Desiring a Balanced Identity* seemed to be something the women aspired to in order to experience this ‘normalcy’.

Furthermore, given that other literature has emphasized the embedded cultural significance of pregnancy (Cooper et al., 2007; De Souza, 2004; Finocchario-Kessler et al., 2010; Ingram & Hutchinson, 2000; Wesley et al., 2010), I argue that the *desire to live a balanced identity* was a unique experience for the women in this study. Based on what the participants described as considerable social expectations in their cultures to reproduce, the ability to identify as a pregnant woman appeared particularly important to the women in this study. It did, however, result in somewhat of a double-bind, which is discussed later, because of mixed social messages based on their HIV status.

The women in this study discussed normalcy pertaining to being treated like “any other human being who was pregnant”. Normal is defined in many ways. In its current colloquial sense signifying the standard, or usual, the word normal only emerged in the 19th century (Word Origins, 2011). Normalcy has also been highlighted as an important concept in research on minority groups living with chronic illnesses (Mammah Popoola, 2005). Normalcy is also a prevalent concept in HIV related literature (Chenard, 2007; Mallinson, Relf, Dekker, Dolan, Darcy & Ford, 2005). And while normalcy is often referred to, it is rarely well defined in the context of identity for people living with HIV. The women in this study had a specific focus on a normalized social identity in the context of being a pregnant newcomer living with HIV. I contend that ‘normalcy’ is a phenomenon that is imposed by the world. It only exists because there is a notion of ‘abnormalcy’. As the researcher I was disheartened by the perpetuation of

the dominant discourse of HIV as 'abnormal' that I observed in the participants' narratives. It suggested to me that the women in this study were experiencing internalized stigma as they had begun to see themselves as falling outside of the socially imposed construct of 'normal'. There is a documented connection between the stigmatization of women and their social subjugation and oppression (Heatherton, Kleck, Hebl, & Hall, 2000). Further, Caplan (1992) suggested that social oppression has a negative consequence on women's mental health. Given the adverse consequences of stigmatization, it is imperative that the dominant discourse of HIV as an 'abnormality' in society by redirected.

While striving for a 'normalized' experience within the confines of social judgment may have immediate social fulfillment, it is not without long term social consequence. The consequence of resisting 'otherness' is that we "conceal the possibilities" for ourselves futuristically (Johnson, 2000, p. 23). As the women in this study collectively envisioned their futures as 'normal' women and mothers by balancing their identities, it is important to recognize the possibilities that were concealed. Essentially what was gleaned from the narratives was that while the women had disclosed themselves as newcomers within cultural settings, and as women living with HIV in support groups, their preferred social identity was simply as pregnant women. By losing their actual self in the pursuit of the '*they-self',* the women concealed the possibilities of deconstructing the dominant discourse on HIV as a shameful, 'abnormal' identity. I argue that this identity can only be deconstructed by reducing the social invisibility of HIV in Canada.

UNAIDS (2007) provided a policy statement on the Greater Involvement of People Living with HIV. In the policy statement it was written that "openly acknowledging one's HIV-positive status demolishes myths and misconceptions about HIV and people living with HIV. Disclosing one's status can be an empowering process if it starts by combating internal stigma

and shame" (UNAIDS, 2007, p. 1-2). Disclosure is a process that begins at the individual, or micro level. However, these micro level changes could potentially have a cumulative effect. This effect would remove the shroud of secrecy that currently exists around people living with HIV and may affect larger social or meso level changes. Removing the secrecy around HIV might dispel common misconceptions about people living with HIV. Ultimately, openness about HIV status may reduce the stigma and discrimination people living with HIV fear and experience.

While the limited data from this study cannot be used to draw conclusions, it does suggest the magnitude of how *Being-in-the-world* influences how we perceive ourselves. Prior to this study, little was known about how pregnant newcomer women living with HIV negotiated the layers of their social identity. Knowledge in this area is important because it is essential that healthcare professionals and social advocates understand how newcomer women living with HIV negotiate their complex social identities in order to ameliorate social and healthcare services.

Lived Body: The Situational Self

In *Being and Time*, Heidegger (1926/1972) described his perspective on the body. He advocated for a departure from investigating the physical body in the pursuit of an ontological understanding of the meaning of Being. In keeping with this departure, the essence of the current inquiry was not of the "material body" but the experience of the "lived body" (Aho, 2010, p. 14). *The situational self* alludes to a symbolic experience of a lived body that is situationally defined. It is only within the context of the social structures that infringed on the women's willingness to experience their bodies wholly that *the situational self* becomes critically meaningful.

I propose that what made the corporeal experience particularly complex was the ambiguity between the positive and negative reactions to *the situational self*. In their own words, the women stated that they were not thinking about HIV during their pregnancies; they were focused on their pregnancies. However, the data suggested that there were a number of relational, structural, and organization factors in their lives following migration that hindered the women's ability to situationally focus on pregnancy.

One of these hindrances was the negative impact of the intrusiveness of their HIV status into their prenatal care. According to the participants, this was negatively perceived because the women rejected being reminded of a physical disease when they were living a bodily experience of wellness. As pointed out by Sanders (2008), women living with HIV often express a negative relationship between their lived experience of pregnancy and mention of their HIV diagnosis. Even though the women suggested that they had been able to focus on their pregnancies, social biases and healthcare practices did not fully allow that focus to be realized. By discussing their HIV status during pregnancy they were reminded of the social judgment and stigma they feared. The women in this study were constantly negotiating their situational sense of bodily being in order to compensate for social judgment.

Verschüttet was the term Heidegger (1927/1962) used to describe the process of burying a phenomenon. Heidegger suggested that burying is at times accidental and at other times necessary. As the women in this study experienced pregnancy, it appeared they were burying their other social identities of being newcomer women living with HIV to achieve their socially desirable bodily identity. Aho (2010) suggested that the meaning ascribed to us by others often influences how we experience our bodily existence. The findings of this study suggested that the women sought 'averageness' through this concealment. The women only rarely situationally

defined their bodily experiences as newcomers and/or women living with HIV. Several studies have suggested that concealment of HIV status is a common phenomenon for people living with HIV (Alonzo & Reynolds, 1995; Ndirangu & Evans, 2009; Sanders, 2008). However, only a limited number of studies have begun to examine how this bodily concealment influences experiences for newcomer women living with HIV (Ndirangu & Evans, 2009). Through personal choice, the women in this study often concealed their HIV status. And while they consciously perceived concealing HIV status and focusing on pregnancy as positive, I argue that it is strongly indicative of personal shame. As previously discussed, this shame has damaging consequences for mental health and limits social changes on how HIV is perceived.

Unlike other literature which explored pregnancy experiences for non-newcomer women living with HIV (Sanders, 2008), the participants in this study had the additional context of being a newcomer. Being a newcomer added an additional layer of social/historical context to the women's experiences of concealment. It is important to recognize that the women's perception of shame associated with HIV was largely influenced by their past, including negative encounters in Canada. While the women were encouraged to discuss their HIV status with other women living with HIV through support groups since arriving in Canada, in the larger social context, the women remained largely undisclosed. Their preference to conceal their bodily experience as a woman living with HIV was not simply about their past experiences of HIV-related stigma. It is suggestive that the women had experienced nuances of HIV-related stigma in their lifeworlds (lived space) following migration. If they had not perceived a risk of social discrimination, it is arguable that they would not have avoided disclosure.

Lived Space: Living with the Good and the Bad

Heidegger (1926/1972) wrote that "Dasein's own spatiality is essential to its basic state of Being-in-the-world" (p. 148). He argued that *Dasein*, as an entity, is concerned with nearness (Heidegger, 1926/1972). It is important to keep in mind that the spatiality of the women in this study represented uncertainty and distance from their families. The process of relocating to a country had been problematic for several of the participants because it added several uncertainties to their everyday lives. While many people living with chronic illnesses experience uncertainty about prognosis, support, and identity (Brashers, Neidig & Goldsmith, 2004), being a newcomer contributed to uncertainty for the women in this study.

The first aspect of uncertainty that impacted some of the women's experiences of pregnancy was regarding their acceptance in Canada as migrants living with HIV. As discussed in Chapter 2, several studies have identified that women living with HIV fear being rejected by family, friends, and healthcare professionals during pregnancy (Cooper et al., 2007; Ingram & Hutchinson, 2000; McGuire Bunting & Seaton, 1999; Sanders, 2008). In addition, many of the women in this study indicated that their uncertainty about support and acceptance was exacerbated by their status as a newcomer woman living with HIV. For example, Idai emphasized that she had feared deportation when she tested positive for HIV during her immigration physical. The fear of deportation suggested an expectation of rejection. I contend that this expectation of rejection was the result of the historical oppression and discrimination that women living with HIV have experienced globally. Without any knowledge of Canadian immigration policies pertaining to HIV, the women made assumptions that their HIV status would be unacceptable. As a result of not being rejected by CIC, the women in this study experienced acceptance in their lived space. When the women discussed space, they highlighted

the positive influence that this acceptance had had on their pregnancies. Furthermore, this acceptance was positively perceived because it suggested to the women that they were not being defined by their HIV status within the context of the Canadian governmental structure. Given their pursuits of a balanced identity, not being defined by their HIV status as a newcomer was an empowering experience for the women.

In addition to overcoming their uncertainty about being accepted as newcomers in Canada, participants discussed uncertainties about navigating their new world and preparing to give birth in a new country. As some of the women had only been in Canada for less than a year, they described their urgent need to familiarize themselves with their new lived space. Reitmanova and Gustafson (2008) and Gagnon et al. (2007), in two Canadian studies of postpartum newcomer women, also identified that women had challenges in navigating the new healthcare system in Canada. The current study's participants had the added navigational complexity of accessing specialized prenatal services for women living with HIV. However, it appeared that as the women began to connect with formal social supports through specialized healthcare professionals and ASOs these supports were in fact used to manage spatial uncertainty. Brashers, Neidig, and Goldsmith (2004) suggested that social supports are commonly used to manage emerging uncertainties for people living with HIV. When the women shared their pregnancy experiences with me, it was evident that their ability to manage spatial uncertainty was deeply impacted by supportive human relations. Through the sharing of knowledge, information, and instrumental supports, the women in this study were enabled to navigate the necessary services in Canada and focus on maintaining a healthy pregnancy.

Another important outcome of data analysis was the conflicting data on distance from family yet the desire for privacy. The women discussed their experiences of being far from their

families during pregnancy. For many of them, this distance from family was described as the hardest part of being a pregnant newcomer. However, they also expressed a preference to remain here in order to maintain privacy regarding their HIV status. I also noticed ambiguous data regarding the challenge of being far from family support and the valued privacy of HIV status as a migrant in Ndirangu and Evans's (2009) study on Somali women living with HIV in the United Kingdom. Thus the ambiguous experience of being away from family yet being able to maintain one's privacy regarding HIV status may be common for migrant women living with HIV. I did inquire in two follow up calls about how the women reconciled this ambiguity but neither phone call provided a clarifying response. I suspect that this ambiguity was the result of conflicting sociocultural message that become deeply engrained through a person's *Being-in-the-world.*

I argue that the importance of this ambiguity was less about the individual narratives and more about the social meaning of this ambiguity. The women in this study acknowledged the benefit of the privacy they had experienced following migration. However, they expressed a strong desire to remain connected emotionally to their lives back home. This ambiguity is likely the consequence of conflicting social pressures given the women's complex identities. It is important to recognize that the women in this study had been socialized in cultures where having family in close proximity during pregnancy was highly valued. It was this historically embedded valuing of family proximity that created the challenge of being a newcomer to Canada.

However, the inherent complexities in living with HIV somewhat changed the women's attitudes about distance from family. The literature suggests that women living with HIV experience many other "double-binds" because of conflicting social messages (Ingram & Hutchinson, 2000, p. 117). For the women in the current study, the conflict was between being

close to family and maintaining privacy. I argue that the experience of privacy facilitated the experience of living a balanced identity as it allowed the women to control who knew about their HIV status. Being away from their support structure and family back home allowed a physical distance that enabled the women to keep their HIV status private. The realities of 'lived space' in Canada are markedly different than the social and spatial organization of the countries these women had migrated from. For example, in Canada, we are not socially organized to share our 'lived space' with extended family members as is customary in many other countries and cultures. We are not even necessarily expected to remain in our home town. As such, the difference in physical and social space that the women had experienced following migration was well received. Being away from family back home allowed a physical distance that enabled the women to keep their HIV status private.

There was however a continued desire by the women to maintain strong emotional connections to their home countries. The desire to remain connected to their communities back home is suggestive that as newcomers, the women were lacking certain social connections in their lives in Canada. The examples of Lydia and Anna's longing for their families back home were presented in Chapter 4. If they had been completely socially supported and fulfilled they would not have longed for their homes. Without a greater understanding of the women's desire to stay connected to their community back home, it is difficult to ascertain what supports could be put in place to minimize the negative impact of remoteness from family that is created through migration.

Socio-cultural expectations become a fundamental part of each of us because *Dasein* is part of their world and cannot be separate from the world (Johnson, 2000). As previously mentioned, the world is experienced in terms of the way that it is determined for us by those

around us (Johnson, 2000). In this study, the women voiced social desires to be close to family during pregnancy which was a consequence of their being-in-the-world historically. The ambiguity arose as a consequence of tension between their historical meaning of being and their contemporary experiences as pregnant newcomer women living with HIV. The women discussed a conscious awareness of HIV-related stigma and discrimination "back home". However, HIV-related stigma exists everywhere. Johnson (2000) wrote that "out of our fearful disposition we project possibilities for ourselves" (p. 21). I believe that the narratives implied that out of fear of discrimination, the women in this study placed a higher value on being in a lived space where they believed they could conceal their HIV status and balance their identities over their socialized desire to be close to family. The benefit of this choice, while it was somewhat externally driven, was that the women described their ability to have control over who knew about their HIV status based on the choice to be in Canada. In their daily encounters with other people, the five women in this study used personal agency to choose when to disclose. They were not passive beings controlled by social practices. Instead they used their knowledge to make informed choices that better ensured their privacy.

As the researcher I was deeply saddened by this realization. For women from cultures that place a high value on family and community to desire separation suggested enormous fears of social judgment. More importantly, while the women spoke more openly about concealment from community members back home, they also indicated fear of disclosure in their new lived space. If Heidegger (1926/1972) made a call for people to live their authentic self, social reflexivity is necessary to eliminate the vilification of women living with HIV. Only then can women living with HIV feel free to live holistic lives. A holistic life would be one in which elements of social identity were not concealed for fear of discrimination.

In addition to a fearful disposition, the women in this study personified Heidegger's concept of "situated freedom" (Lopez & Willis, 2004, p.). Lopez and Willis (2004) wrote that situated freedom is "a phenomenological concept that means individuals are free to make choices, but that their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives" (p. 729). Our daily lives are in many ways defined by the social identities ascribed to us within our lived space. The women's desire to be close to their families was usurped by their fear of discrimination. Embedded in this perceived personal preference was the notion of situated freedom. Indeed them were actively making choices. However, their freedom to choose their lived space was situated within their social identity as women living with HIV. Since the women believed they could better conceal their HIV status in Canada, thus living a more balanced identity, they expressed a situated preference to be in Canada. The women in this study demonstrated strength in their extensive efforts and abilities to move beyond their HIV status and continue to lead their lives in ways that they perceived as fulfilling. Despite 'situated freedom', the five participants in this study used their own agency to make informed choices.

Lastly, the data collected during this study demonstrated a unique finding regarding social isolation. The literature documents that newcomer women to Canada often experience social isolation because of the distance from their families (Reitmanova & Gustafson, 2008). At the same time, literature also suggests that pregnant women living with HIV report social isolation because of their fears of discrimination (Sanders, 2008). I believe that this isolation is connected to the experience of otherness or 'abnormalcy'. Despite their experiences of 'otherness' by being a pregnant newcomer woman living with HIV the women in this study did not discuss feeling isolated. While they stated that they missed their families, it appeared that they had developed additional layers of social support post-migration. This new support

network, which is discussed in the next section, appeared to mitigate the impact of social isolation. I argue that this positive experience of lived space as a newcomer woman living with HIV was largely attributable to the women's physical location in a large urban city.

Over the past 30 years, the composition of Canada's immigrant communities has changed drastically. The most notable change is the continued decline in the percentage of newcomers from Europe with marked increases in migrants from Asia, Africa, and the Caribbean (Statistics Canada, 2006). This change in the Canadian immigration pattern is attributed to legislative regulations implemented in 1967 that placed more emphasis on educational and occupational level than country of origin (Department of Justice, 2010).

Another important immigration pattern is the distribution of newcomers within Canada. Statistics Canada (2006) indicates that the vast majority of newcomers chose to live in urban centres, with Ontario cities being the first choice. These patterns of urbanization influence the health and composition of urban cities (Vlahov et al., 2007). Social exclusion has been identified as a factor contributing to health inequity and maladjustment among immigrant communities in Canada (Bryant, Raphael, & Travers, 2007). Furthermore, previous literature has pointed to the relative deprivation[25] of migrant communities compared to their non-migrant counterparts (Quinn, 2001). The women in this study did not perceive, or at least did not discuss, relative deprivation.

The women in this study reported accessing specialized HIV services and being directed to ASOs for further support. The emergent perception in the data was that the participants were 'satisfied' with this level of support. This finding should be contextualized in regards to the women's experiences prior to migration. While they reported 'satisfaction' with their

[25] Relative deprivation is the term used to describe the experience of being denied something to which you are entitled. Relative deprivation is often the result of discrimination based on a personal or demographic characteristic (Quinn, 2001). Relative deprivation is common amongst migrant communities (Quinn, 2001).

experiences of formal support, this perception was in comparison to the deprivation they had experienced back home. Further, while the women reported access and availability to these types of specialized services, even in Canada they are primarily available in urban centres (Bryant et al., 2007; Vlahov et al., 2007). Additionally, access to specialized healthcare services is only one element of social capital that newcomers rely on for successful integration. While the current study did not include newcomer women in non-urban centres, the findings suggest that expanding the availability of social support services, within and beyond urban centres, may decrease the experience of social exclusion and relative deprivation for newcomer women to Canada and women living with HIV in non-urban centres. The expansion of social supports would require access and availability of diverse services and not just healthcare.

Lived Relations: Support and Acceptance

Despite not having disclosed their HIV status, it appeared that the support of their cultural communities during pregnancy gave the women a sense of belonging. Connections to their past was an essential element of integration for the women in the current study. Given the women's situational identities as newcomers, this cultural support seemed to be vital in providing this sense of belonging during pregnancy in a new country. This cultural support was a positive experience in the lives of the women in this study following migration.

The narrative accounts of the women suggested that their *Being-in-the-world* was truly an existence of being-with others. As pointed out by Johnson (2000), "Dasein is not an isolated self, but is always absorbed in relationships with others" (p. 20). Unlike previous literature on women living with HIV and newcomer women (Ndirangu & Evans, 2008; Ndirangu & Evans, 2009), most of the women in this study maintained that they had a relatively substantial social support network.

In their own words, the women identified several layers of human relations with others. These others were indeed the people with whom the women shared their world both spatially and temporally (Johnson, 2000). Blessing described her husband's support and acceptance; Anna spoke about how her prenatal care providers had not treated her differently than other pregnant women; Jamila talked about how her decision not to disclose her HIV status amongst friends had led to essential cultural support as a pregnant newcomer; and Lydia shared that having support from other mothers living with HIV made her feel like she was "not the only one" having to balance this complex social identity. Without these various lived human relations the women in this study could not achieve a balanced identity. Instead they situationally defined themselves. I argue that through these situational identities, the women in this study had not experienced a sense of isolation or immense stigmatization because they had constructed complex social networks for themselves from which they accessed support.

One of the best known conceptual models of social support was created by Lazarus and Folkman (1984). Within this model, three levels of social support exist; informational which broadens the knowledge base, emotional which addresses the human need for affection and understanding, and instrumental which assists people in meeting their needs for daily living (Dageid & Duckert, 2008). In the context of pregnancy and prenatal care, the women in this study voiced feeling supported in their human relations. I believe that the women's perception of support and acceptance in their everydayness was because they believed they had access to all three levels of support. Brashers et al. (2004) pointed out that social support is often used by people living with HIV to manage the layers of uncertainty that accompany their diagnosis. Given the unique social identity of the pregnant newcomer women living with HIV in this study,

it is imperative to recognize how accessing social supports enabled them to reconcile uncertainty and live a balanced identity.

Brashers et al. (2004) identified the importance of informational support for people living with HIV. In the case of the five women in this study, they perceived that informational support regarding pregnancy and HIV was provided to them through their relationships with specialized healthcare providers as well as other women living with HIV. The current study did not evaluate the accuracy of the information being communicated and/or the knowledge level of the women. However, the women did express feeling that they had some knowledge about the risk factors associated with maternal HIV in pregnancy and the services available to them in Canada. Specifically, Jamila talked about how her doctor had provided her with all the "advantages and disadvantages" of pregnancy and birth options for women living with HIV. The experience of having this knowledge appeared to empower the women to make informed choices about pregnancy.

A limited number of Canadian studies have suggested that women living with HIV in general had limited knowledge about the risks associated with maternal HIV (Finocchario-Kessler et al., 2009). However, the findings of this study suggested that the women were informed about the risks. Again, this finding is limited by the lack of data on the quality of information that they women were receiving. However, the value that the women placed on having informational support was congruent with Loutfy et al.'s (2009) recommendation that educational services be increased for pregnant women in Canada. Specifically, Loutfy et al. information should be more available in areas that are densely populated with African immigrants and refugees, who required further information on HIV and pregnancy. The women in this study discussed at length how receiving informational support about pregnancy and HIV

made them worry less, feel more joy, and focus on their pregnancies. Knowledge in this area decreased the amount of uncertainty the women were living with in their everyday lives, thus enabling them to focus on their pregnancies as they desired.

Emotional support has also been cited as very important in other studies of people living with HIV (Dageid & Duckert, 2008; Ndriangu & Evans, 2008; Reynolds, 2008), as well as in studies about newcomer women to Canada who are mothers (Reitmanova & Gustafson, 2008). The women in this study received emotional support through their cultural communities both in Canada and back home, through the commitment of their spouses, by experiencing caring relationships with specialized healthcare providers, and by belonging to support groups for mothers living with HIV. Emotional support from cultural communities and support groups require further analysis because of the nuances of social judgments hidden in the narratives.

Although their interactions with partners and healthcare professionals provided important emotional support for the women in this study, they appeared to highly value emotional support from their cultural communities and support groups respectively. It appeared that the women's stories supported Dagedid and Duckert's (2008) finding that emotional support provided through support groups gives women living with HIV a feeling of "not being the only one" (p. 186). Similarly, in a study about women only support groups for women living with HIV, Lennon-Dearing (2008) found that this type of emotional support decreased women's sense of shame and expanded their network of friends to rely on. Understandably, having this outlet to discuss the experience of pregnancy for women living with HIV reinforced the women's experiences of normalcy, acceptance, and support during their pregnancies. It gave them a collective identity so they no longer felt like "the only one".

In their interactions with other mothers living with HIV, the women in this study revealed their authentic selves. The women did not feel the social pressure to project themselves in a 'normalized' manner. Heidegger (1926/1972) cautioned that when we become absorbed in the inauthenticity of the *'they-self'* we limit ourselves according to others. In the context of support groups, the women made no effort to conceal layers of their complex social identities. In essence, they rejected the need to exist according to diverging identities. Thus, they disclosed themselves as authentic. I observed that the participants who did not feel comfortable in attending support groups appeared to struggle more with their identities as women living with HIV. These women described that by attending these groups they would have risked disclosing their HIV status to community members. As such, their meaning of pregnancy was complicated by making additional efforts to conceal this layer of their identity. In light of this data, I argue that support groups not only created a safe spatial, relational situation for the women to present their authentic self holistically and provided the women with a sense of belonging but that they also gave the women a sense of empowerment. For the women in this study, meeting with other women living a similar social identity provided a sense of community that created a sense of confidence and limited uncertainty about the future.

Paradoxically, in order to balance their identities, and receive the cultural support they required, the women discussed their non-disclosure amongst their cultural communities. In fact, several women also indicated that they were very cautious not to disclose their HIV status to community members and neighbours in Canada. However, while my intention is not to re-present a narrative that marginalizes the women's cultural communities, the participants did appear to struggle particularly with the fear of disclosure within their cultural communities. While HIV-related stigma and discrimination is insidious in all communities and Canadian, for

the women in the current study, who had barriers integrating into the Canadian society, protecting their engagement with their cultural community was critical. Being new to Canadian society meant that the women relied heavily on their cultural communities for support. The fear of disclosure to their cultural communities was not because HIV-related stigma only exists within certain groups. It was based on the emotional value of these relationships.

Dasein chooses how it is disclosed in the world based on a fearful disposition (Johnson, 2000). Non-disclosure suggests that the women in this study had perceived their HIV status as socially unacceptable. As such, they had not disclosed it. Brashers et al. (2004) suggested that when accessing support, people living with HIV are often confronted with dilemmas of support. These dilemmas are based on the knowledge that some support may come at a cost. I argue that the women in this study had consciously negotiated the cost of disclosing their HIV status to their cultural communities. What was hidden in the women's stories was their apprehension about disclosure to anyone other than specialized healthcare professionals or another woman living with HIV. However, given that they appeared satisfied with the informational and emotional support they received regarding their identity as women living with HIV, the women negotiated non-disclosure as a means to access cultural support and access support related to their cultural identities.

In the case of the newcomer women in Ndriangu and Evans' (2008) study, the participants struggled with the isolating impact of non-disclosure of their HIV status to community members. When newcomer women living with HIV have access to emotional support regarding their HIV status, non-disclosure to their cultural community does not appear to have such an isolating impact. I argue that several of the women in this study were able to use non-disclosure as an adaptive coping strategy. Examples of emotional support that the women

discussed despite not disclosing their HIV status were involvement in religious communities and support in adjusting to life in Canada. Dagedid and Duckert (2008) also found that non-disclosure, an emotion-based coping strategy which is commonly perceived as maladaptive in Western cultures, can be adaptive in certain situations for people living with HIV. The participants in Dagedid and Duckert's study also actively resisted discrimination and abuse through the used non-disclosure. The women in the current study were not passively defined by their HIV status. Instead, they actively decided how they would be defined in order to access support and services they required for successful integration into Canadian society.

For the five women in the current study, instrumental supports became available to them through specialized prenatal care providers. Ndriangu and Evans (2009) suggested that specialized services helped to meet the needs of African women living with HIV in the United Kingdom. While Brashers et al. (2004) suggested that access to instrumental support is an important coping strategy for most people living with HIV, I argue that needs are often different for newcomer women. Further, I contend that access to instrumental supports had a different meaning for the women in this study. The availability of instrumental supports was directly connected to the women's uncertainty about being accepted in their lived space. However, the women reported satisfaction with their access to instrumental supports. This access was largely attributed to their prenatal care clinic. It is crucial to acknowledge that the five women in this study were all accessing the same specialized services. Therefore, the differences that exist between care providers were not captured in this data. Hence, it is difficult to determine if all newcomer women to Canada living with HIV have access to instrumental supports during pregnancy.

The women had accessed other sources of instrumental support as well. Being relatively new to Canada at the time of their first pregnancies, the women described that initially they had insufficient information about the instrumental support that was available to them. Through their own agency and efforts, from contacting lawyers, MPs, and support groups, the women in this study learned how to access a number of instrumental supports. Through these efforts they learned about the services they required and what services were available to them as newcomers. However, one woman described her frustration at being denied certain instrumental supports such as subsidized daycare because she was a newcomer. This denial had significant meaning for her as a newcomer woman living with HIV because it created a painful experience of 'otherness' that she believed was contingent on her status as a newcomer. This finding highlights how achieving a balanced identity also entailed limiting adverse social rejections of being a newcomer. I argue that the meaning of not being perceived as a newcomer was again related to the desire to avoid social 'otherness' and the desire not to be discriminated against.

In the context of pregnancy and prenatal care, the women in this study appeared to be satisfied with the support and acceptance they had experienced in Canada. As previously discussed, if interpreted through a critical lens, the 'satisfaction' must be considered in light of the historical deprivation of the women in this study. In highlighting the situational support and acceptance I aimed to accurately represent the overall experience of lived human relations. However, I do not contend that the women were not spared entirely of fear, dilemmas of support, discrimination, stigmatization, disempowerment, and oppression. The women described examples of begin rejected by care providers, having health related information disclosed inappropriately, and their intentionality in avoiding disclosure of HIV status to certain support networks and others in their lifeworlds. However, as I moved through the hermeneutic circle of

understanding, these adverse encounters did not define the women's meaning of being pregnancy.

Lived Time: The Future Seems Brighter

Despite their common challenges as newcomer women to Canada living with HIV, the joy associated with being pregnant and the promise of a brighter future was what the women treasured. This had a positive influence on their experiences of pregnancy as they were able to overlook the challenges they also experienced. The participant's focus on parenting, even during their pregnancies, was an important finding as it substantiated the women's connection to the future.

The women in this study conveyed a directed hopefulness for their futures. This hopefulness was connected with their lived space because of access to treatment and reassurance that they would have healthy children. The belief that the future would be brighter was largely contingent on a cure for HIV. By possessing the hope for a cure and reassurance of a well child, the women were better able to balance their identities and focus on their pregnancies in a joyful way.

While the essential theme of time in this study was directed towards the future, I am reminded by the writing of Heidegger (1926/1972) that our everydayness indeed reveals all three ecstases[26] of temporality. The three ecstases of temporality, past, present, and future, are in unity (Johnson, 2000). Heidegger pointed out that as members of communities, understanding is passed down to us through history (Johnson, 2000). As such, Heidegger suggested that the meaning of Being can only truly be understood temporally. All five women who participated in this study, described their past experiences with HIV-related stigma prior to their own diagnosis.

[26] Heidegger resisted the use of the simple language past, present, and future in his writings on time. Instead he developed the terminology "ecstases of temporality" to define a primordial sense of time (Johnson, 2000, p. 30).

As noted by Morrison and Guruge (1997) and Sandelowski et al. (2004) there also appears to be a heightened experience of HIV-related stigma during pregnancy because of the socially perceived immensity of the risk of maternal-to-child-transmission. Based on historical knowing, it is plausible that a fear of stigmatization might develop. This fear allows the past to be projected into a present by limiting choices and actions. Heidegger argued that we repeat the past by limiting our present possibilities (Johnson, 2000). Repetition does not mean one literally lives the same reality as someone before them (Johnson, 2000). It is the notion that we project the possibility of our own existence based on history (Johnson, 2000). While the notion of repetition is present throughout the data collected in this study, there are also several contradictory examples. An example of repetition is that the women had embraced the cultural, heteronormative experience of pregnancy and motherhood as their own bodily possibility. However, their experience of pregnancy was complicated by their historically rooted awareness of the social disapproval of women living with HIV. As such, if they were completely confined to possibilities of repetition, the women may not have embraced their pregnancies. I argue that the present was as much influenced by the unknown possibilities of the future as it was by the past. There is no one possibility for the present as defined by the past. The lived human experiences in this study present multiple realities based on personal, historical, and social context as well as personal agency and choice. While history may have influenced some choices made by the women in this study, their choice to carry their pregnancies and dream of a brighter future was of their own ability and will.

The women also demonstrated that the socially projected image of ‘normalcy’ defined how they wished to be perceived both presently and futuristically. Consequently, the emergence of their authentic self was denied through concealment of ‘otherness’ as defined historically.

Their projected possibilities changed slightly when the women explored the future. Johnson (2000) explained that as humans it is natural to be directed towards the future. Despite our awareness of our own mortality, we continue to think of the future (Johnson, 2000). I argue that the future becomes even more focal when the past and present represent socially constructed judgment, 'otherness', and situated freedom.

Despite the dominant discourse of HIV as deviant and the social and economic challenges of being a newcomer, the women perceived that their futures were hopeful. The women in this study, as in others (Ingram & Hutchinson, 2008; Sanders, 2008), expressed hope for HIV negative children. Their hope was also in a cure; a cure that would eliminate their socially ascribed 'otherness'. The data from this study have contributed to understanding how possibilities of time are contingent on being redefined socially as 'normal'. However the limited narrative data specific to the women's experiences of time does not facilitate the formation of conclusions. Without a greater understanding of how present identity was connected to the women's hopes for the future, it is difficult to ascertain if time supported the women in their desire to live balanced identities.

New Insights

"Never be bullied into silence. Never allow yourself to be made a victim. Accept no one's definition of your life; define yourself" (Harvey Fierstein).

The voices of the five women in this study have generated a new and insightful perspective on the pregnancy experiences of newcomer women living with HIV. In the co-construction of this thesis, I have been through a journey of learning about the immensity of the social pressure that exists that confines human experience. Despite a perception that life in Canada offered the women many opportunities for a less situated freedom, the women's

experiences here and ‘back home’ were not binary opposites. This study uncovered a hidden fear of stigmatization and discrimination that was pervasive in the women’s everydayness before and after migration. Previous studies have shown that pregnant women living with HIV often have a heightened fear of social rejection during pregnancy (Bunting & Seaton, 1999; Cooper et al., 2007; Ingram & Hutchinson, 2000; Sanders, 2008). This current study added to our evolving understanding of the role that fear of social rejection plays in the pregnancy experiences of newcomer women living with HIV. The participants’ narratives indicated that the added intersection of being a newcomer woman added to the fear of social rejection. Based on this insidious fear, the women in this study desired a balanced identity; one where their social positioning was not defined by their ‘otherness’. They actively resisted socially imposed identities. Instead, they constructed their own experiences as pregnant women.

As mentioned in Chapter 2, no previous literature had provided an understanding of how pregnant newcomer women to Canada living with HIV negotiate the complexities in their lives. While this study has only begun to uncover the meaning in this complexity, it has highlighted how these five women negotiated the layers of their identities by trying to achieve a balance between the composite layers of their identity.

Unlike other studies of pregnant women living with HIV, this study explored the lived experiences of a group of newcomer women. The women’s experiences of immigration, integration, navigation, and socialization have added a new perspective to the challenges faced by pregnant women living with HIV. I also believe it is important to discuss the commonalities between newcomer and non-newcomer women who are pregnant and living with HIV. In fact, Leonard (1994) cautioned against the tendency to focus exclusively on differences when researching a person or a group. In re-presenting these narratives, it has not been my intention to

contribute to the experience of 'otherness' as I believe the commonalities in the lifeworlds of all pregnant women living with HIV should inform social change. Therefore, while this study focused on newcomers, there is value in comparing and contrasting aspects of the newcomer women's experiences with those of Canadian born women and women in other countries living with HIV. Like other literature (Cooper et al., 2007; Ingram & Hutchinson, 2000; Finocchario-Kessler et al., 2009; Wesley et al., 2000), the findings of this study suggested that in managing the uncertainty of living with HIV, pregnant women require social support, specialized care, and hopefulness. The women in this study also echoed previous literature on the personal value placed on the normalized role of motherhood (Cooper et al., 2007; Ingram & Hutchinson, 2000; Finocchario-Kessler et al., 2009; Wesley et al., 2000).

In this study, the use of Heideggerian phenomenology has generated a critical perspective on the impact of the socially imposed construct of 'normalcy'. Because the women in this study existed at the intersection of several axes of differences and stigmatization, they were not free to project their authentic selves into the world. The adverse consequences of social concealment can be isolation, impaired mental health, social oppression, and disempowerment. Fortunately, the narratives of the five women suggested their strong abilities to avoid these adversities. Furthermore, for several women, by choosing to access support groups, they could project their authentic selves. In addition, multiple layers of social support were discussed that each provided the women with a unique element of support and acceptance. The need for social support specific to being a newcomer and also to being a pregnant women living with HIV was a new finding uncovered by this study.

Through the use of Heidegger's four existentials, additional insights have been gleaned through this study on the lived experience of the body. Findings from this study indicated that

the women's bodily experience was situational. Previous literature related to pregnancy and HIV has not discussed this situational self. The participants' experiences of the situational self were neither entirely positive nor negative. Rather, it was a complex human experience, consisting of personal experience and adverse encounters with people in their lifeworlds.

This study also shed light on the unique experience of being a newcomer woman living with HIV in Canada. While previous literature focused on groups of migrant women outside of Canada (Blood et al., 2009; Ndirangu & Evans; 2009), this was the first study to inquire into the lives of Canadian newcomer women living with HIV. Participants' experiences of life following migration consisted of positive and negative factors that influenced their everydayness in the world. However, overall the findings appeared to indicate a certain level of comfort regarding being in Canada due to the increased access to treatment, specialized care providers, formal supports for women living with HIV, and most importantly privacy. Unlike previous Canadian literature (Reitmanova & Gustafson, 2008; Gagnon et al., 2007) the women in this study did not report a sense of social isolation as newcomers during data collection. The current study did not present an exhaustive assessment of social support and social capital available to all newcomer women to Canada living with HIV. However, the data that emerged pertaining to social support generates questions about how ASOs and support groups may have mitigated against social isolation that many women have reported in other Canadian studies.

Overall, the findings of this study have provided a new perspective into the unique experiences of pregnancy for newcomer women to Canada living with HIV. The essence of this experience emerged as the women desiring a balanced identity between their multifaceted social identities. Although the women in this study shared stories that were similar to other non-

newcomer women living with HIV who have been the subjects of previous research, the added complexity of being a newcomer woman was evident throughout the data.

In consideration of the final section, which presents the implications of this study, it is important to consider what is within the reach of these five women. While they described a positive lived experience, the implications are intertwined with social judgment. It may not be achievable to completely eradicate the presence of HIV stigma in society. This is a challenge that advocates have been working towards for decades. However, healthcare professionals are in the unique position to advocate for organizations to integrate the following implications and recommendations. The women described the positive experiences of being supported and accepted within specialized healthcare settings. But support and acceptance is not widespread, even within healthcare. Until social stigma and the perpetuation of 'normalcy' is absent in society, pregnant newcomer women living with HIV will continue to strive for *Desiring a Balanced Identity* to avoid stigmatization, oppression, and disempowerment.

Implications and Recommendations

Implications and recommendations for education, practice and organizational policy, and research will be provided in light of the study findings and the preceding discussion.

Education

The findings of this study highlighted adverse encounters with healthcare providers. One explanation for these adverse encounters is limited knowledge, experience, and unfortunately society's disapproval of pregnancy amongst women living with HIV.

The women in this study described a need for greater understanding from all healthcare providers. In consideration of this need, the following recommendations for education are

intended for all healthcare providers, including specialists. As specialized care providers are often consider the experts in certain fields, they are in a unique position to influence change.

1. Enhancing Inclusive Practices in Healthcare Professionals: Based on the five narratives collected in this study, the women valued their cultural experience and expectations surrounding pregnancy and birth. They echoed one another in their need for understanding and informational support that was contextualized to their lived experiences of pregnancy as newcomer women living with HIV. The data collected in this study illustrated the significance of pregnancy and motherhood for the five women who each described their culture's value on motherhood. They also described practices and traditions regarding pregnancy and motherhood that were different from Canadian approaches. If nurses and other prenatal care providers had increased awareness of the inclusive needs of women during pregnancy, the negative aspects of giving birth in a new country may be less ominous for newcomer women living with HIV. These inclusive needs include, but are not limited to, access to cultural appropriate foods and emotional support during pregnancy and following birth as described by the participants.

2. Implementing Comprehensive Training on HIV: One of the strengths of the pregnancy experiences for the five women in this study was the preparedness of their prenatal care team. However, it is imperative that we recognize that throughout the pregnancy, birth, and postpartum process, these women will encounter many less specialized care providers. We must also recall that the women in this study, as well as in several other studies, reported adverse encounters with professionals in the context of their prenatal care. Continuing education training sessions need to prioritize enhancing all healthcare professionals' comprehensive knowledge of HIV. A comprehensive training session on HIV would go beyond providing biomedical knowledge of the disease and would include the psychosocial and human experience of living with HIV.

Based on the data, important topics in comprehensive training might include the sociocultural experiences of women living with HIV, the experiences of HIV-related stigma for pregnant women, the need for privacy and sensitivity, and the value of increased communication and coordination. The data from the current study suggests that this training is particularly important for unspecialized care providers who are likely to encounter clients similar to the participants in this study. These providers would include, but are not limited to nurses, physicians, social workers, laboratory and ultrasound technicians, and administrative staff. While education may not immediately produce systematic changes, it does empower individuals to integrate evidence into their practice. With comprehensive knowledge of HIV, some providers may engage in a more critical reflection of how their misconceptions negatively impacted pregnant newcomer women living with HIV and other populations.

Practice and Organizational Policy

The women in this study reported both challenging and positive aspects of their prenatal care environments. While the data collected during this study was from a single prenatal care environment, and while practice changes take a considerable amount of time, the following implications of the data and recommendations might be useful:

1. Reorienting Services to a Wellness Model of Care: The women in this study objected to the intrusiveness of their HIV infection during prenatal care visits. We need to work to create prenatal care environments that do not emphasize the 'sickness' associated with HIV. The women in this study suggested that when disease management of HIV was the focus of prenatal appointments being a woman living with HIV overshadowed their pregnancies. A wellness model could be achieved by reorienting prenatal care services to focus on the healthy state of pregnancy for women who are asymptomatic and/or who have uncomplicated HIV. This would

require better coordination and communication between care providers. While the participants discussed a preference for centralized care, which may in turn facilitate communication, a more feasible recommendation is the improved coordination between prenatal care and HIV-related care. Through coordination, prenatal care providers would have increased access to HIV-related medical information and would not have to rely on client reports. Thus, HIV infection would not be a focus at prenatal visits.

2. Emphasizing Client-Centered Care by Focusing on the Pregnancy: To truly engage in client-centered care, the client must be empowered to direct the focus of clinical interactions. As discussed in Chapter 4, the women preferred interactions with prenatal care providers that focused on their pregnancies. Until the social stigma associated with being a pregnant woman living with HIV is eliminated, it is likely that pregnant women will continue to prefer a separation between the two. This recommendation is not intended to diminish the importance of close monitoring of HIV infection during pregnancy. It is instead indicative of the need for increased communication between interdisciplinary and inter-specialty team members.

3. Increasing the Accessibility of Specialized Care Providers: Four of the women in this study had to travel beyond their local hospital for prenatal care with an Obstetrician who specialized in infectious diseases in pregnancy. Jamila described an adverse encounter with an Obstetrician at her local hospital who was not comfortable in providing care to a woman living with HIV. Evidence supports that increasing numbers of women living with HIV will decide to become pregnant (Loutfy et al., 2009; Wagner et al., 2010). As such, expanding the accessibility of specialized services, both in the number of providers and the geographic distribution, is recommended. Based on the findings of this study, as well as the recommendations by Loutfy et al. (2009), it is a recommendation that the accessibility of specialized care providers be expanded

into all healthcare centres that provide prenatal and intrapartum care. While the women in the current study reported positive experiences with their specialized prenatal care providers, they were required to travel great distances into the core of an urban city to receive this care. Further, this was based on the practices in one clinic. Appropriate prenatal care should be accessible to women regardless of their geographic location in Canada. Increasing the accessibility of specialized care providers may: (a) decrease the adverse encounters that women have with unspecialized providers when a specialized provider is unavailable, and (b) increase access to health-related information if specialized care providers understand the informational needs of pregnant newcomer women to Canada living with HIV.

4. Coordinated Services: The women in this study discussed the challenge of having to navigate healthcare services that are dispersed across several hospitals. While there may be fiscal and practical constraints, nurses should advocate for centralized prenatal and HIV services. The WHO (1998) defined advocacy for health as "a combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or progamme" (p. 5). Centralized services would not include HIV and prenatal care being provided in the same clinic but would have these clinics housed within the same hospital. Centralized services could strengthen the existing links and interactions between infectious disease and prenatal care providers.

In the absence of centralized services, it is recommended that the pregnancy experiences of newcomer women living with HIV could be positively influenced through expanded utilization of information and communication technology to improve service delivery. Coordination of care is essential. Blessing described the unnecessary duplication of services at her prenatal appointments related to the management of her HIV. She suggested that having

blood work done repeatedly made her feel different than other women and risked her privacy because of adverse encounters with laboratory staff. Repeated blood work is also an unnecessarily intrusive procedure. If coordination was ameliorated between members of women's healthcare teams, women may experience a greater balance between their social identities because they would not have to discuss their HIV status at prenatal appointments. It would also reduce overall expenditures as expensive laboratory fees would be reduced by eliminating the duplication of services.

5. Social Advocacy through the Greater Involvement of People Living with HIV: The greater involvement of newcomer women living with HIV merits further attention in policy. Personal experiences of people living with HIV should shape the creation of policy, practice settings, and supportive programming (UNAIDS, 2007). Newcomer women need opportunities to be involved in practice and policy decision making, public advocacy, and programme development (UNAIDS, 2007). History has demonstrated that marginalized communities that have experienced oppression cannot be emancipated by others. They must experience community empowerment. The Greater Involvement of People Living with HIV would draw attention to the inaccuracies in societal conceptions of people living with HIV. Exposing the myths could lead to changes in social judgment which would ultimately establish a society were one's authentic self could be disclosed.

Future Research

This Heideggerian Phenomenological study was the first to explore the pregnancy experiences of newcomer women to Canada living with HIV. It was intended as an exploratory study with a sample of five women. This phenomenological study has contributed new

knowledge to this research topic and has uncovered different perspectives that can provide direction for future critical methodological research.

1. Understanding Identity: This phenomenological study focused on the pregnancy experiences of newcomer women to Canada living with HIV. The overarching theme of this study was *Desiring a Balanced Identity*. The concept of identity was interpreted within the social, political, and historical context of the lives of the five women in this study. However, continued exploration of how socially imposed identity may influence experiences may produce new and informative knowledge. In particular, it would be beneficial to have a greater understanding of the factors that contribute to a balanced identity and what factors impede a balanced identity. A follow up study would create the possibility of learning more about these factors. In turn, this expanded knowledge could be used to better inform practice by promoting the positive factors and minimizing the negative factors.

2. Labour and Birth and Early Motherhood Experiences: Through this phenomenological study, new insight has been gleaned into the pregnancy experiences of a group of newcomer women to Canada living with HIV. The decision to conduct a study on the prenatal period was made in accordance with the natural progression from pregnancy, to labour and birth, into early motherhood. While this study provided new insight into the pregnancy experiences, research on the lived experience of labour and birth and early motherhood has not yet been published. I propose that in order to achieve an integrated approach to research, policy, and practice, continued inquiry into the phase of labour and birth and early motherhood are necessary. Data for the current study supports this recommendation as the women's positive experiences of pregnancy were strongly linked to the future. Furthermore, exploring the lived experience of labour and birth should be of particular significance to nurses as we are the primary care provider

during hospitalization. In order for nurses to better inform their intrapartum care of newcomer women to Canada living with HIV, a study of the lived experience of the client is recommended.

3. Quantitative Research: This phenomenological study has provided new perspectives. However, the undertaking of a large-scale quantitative study would provide knowledge in this research topic that this qualitative study has failed to address. Two examples have been selected for future research. The first recommendation for quantitative research is that a larger scale study be conducted in order to achieve generalizability of the current study's finding. Secondly, as the purpose of the current study was not to measure and/or evaluate the knowledge level regarding HIV and pregnancy of the five participants this was not collected. As each woman discussed her positive experience of receiving information, it would be valuable to have a greater understanding of the quality of knowledge the women possessed. Therefore, a recommendation is to conduct a quantitative study incorporating an instrument to assess HIV/AIDS related knowledge i.e. the DiClemente's AIDS Inventory (Wesley, 2000). Knowledge gained from this quantitative study would be informative in the creation of educational sessions for women living with HIV and their care providers.

Summary

This chapter has described how the findings of this study have contributed new perspectives into the lived experiences of newcomer women to Canada living with HIV. Through a critical discussion of the four essential themes and the overarching theme I believe this chapter accomplished what this study aimed to achieve by highlighting the complexity of the phenomenon of pregnancy for newcomer women living with HIV. This chapter also provided implications and recommendations for education, practice and organizational policy, and future research.

Final Thoughts

In keeping with the position I have espoused throughout this study, I will provide no formal conclusion to this study, as interpretation can never be concluded. The purpose of this study was to explore the pregnancy experiences for newcomer women to Canada living with HIV. I set out to conduct this study so that I could use my position as a graduate student to generate new knowledge that I believed would inform practice, education, policy, and future research in order to improve the care we provide**.** I believe this study has achieved this original goal**.**

I chose Heideggerian phenomenology as my research method because of the goal of hermeneutics is to "understand everyday…experiences" and to find "commonalities in meanings" (Leonard, 1994, p. 56). Heideggerian phenomenology allowed me to inquire into the lives of people (Leonard, 1994), specifically into the lives of pregnant newcomer women to Canada living with HIV. Through the design of this study, data collection, data analysis, interpretation, writing, and discussion of my findings, I have strived to ensure methodological coherence. I believe that from start to finish, this study has been grounded in my understanding of the Heideggerian concepts of the circle of understanding and the four existentials of lived body, lived space, lived human relations, and lived time. In using the Heideggerian phenomenological approach, I have reached a new and deeper level of understanding of the pregnancy experiences of newcomer women to Canada living with HIV.

The women's experiences were about *Desiring a Balanced Identity*. Like other women, the participants in this study wanted to focus on their pregnancies. However, because of their social identity as pregnant newcomer women living with HIV this was often a challenge. As such, these women lived a bodily experience that was situationally defined. They acknowledged

challenges and barriers as well as benefits to life in Canada in regards to their pregnancy experiences. Support and acceptance emerged as important concepts in the women's lived human relations. In light of the balance they desired, the women enjoyed thinking about a brighter future.

The five women in this story shared their triumph over the challenges and adversity they faced since arriving in a new country. While their social, political, and historical contexts as pregnant newcomer women to Canada living with HIV often infringed on their freedom, they never failed to use their own agency to make choices about their lives. Each of the women demonstrated immense perseverance, resilience, and personal strength. It is my hope that the findings and recommendations from this study will support newcomer women to Canada who are living with HIV to achieve balance in their identities during pregnancy.

Appendix A: Ryerson University Research Ethics Board Letter Confirming Approval

RYERSON UNIVERSITY
RESEARCH ETHICS BOARD

To: Victoria Kennedy
Daphne Cockwell School of Nurses
Re: REB 2010-225: Pregnancy experiences for newcomer women who are living with HIV/AIDS
Date: August 29, 2010

Dear Victoria Kennedy,

The review of your protocol REB File REB 2010-225 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2010-225) on future correspondence.

Congratulations and best of luck in conducting your research.

Nancy Walton, Ph.D.
Chair, Research Ethics Board

Appendix B: Letter Requesting Leadership Support at Recruitment Site

Dear …….;

My name is Victoria Logan Kennedy. I am a Registered Nurse currently enrolled in the Master of Nursing Program at Ryerson University's Daphne Cockwell School of Nursing. As a requirement of the Master's Degree, I am planning to conduct a study under the supervision of Dr. Susan Bishop, Assistant Professor, Daphne Cockwell School of Nursing, Ryerson University. The study is titled, "The experience of pregnancy for newcomer women to Canada who are living with HIV/AIDS". There appears to be a number of different factors that can influence a woman's pregnancy experience. I am trying to learn more about how women, who are living with HIV/AIDS, and who are newcomers to Canada experience pregnancy.

I am writing to request your support and permission to conduct a qualitative, phenomenological study within the Department of Obstetrics, in the prenatal Clinic of Dr. _____, a physician in the _____ Program. I have requested and received written support from Dr. _____. Enclosed, please find documentation confirming her support for my study. In accordance with protocols at Ryerson University and _____ Hospital, I am seeking your permission to conduct this study prior to applying for Ethics Approval from _____Hospital.

I have conducted an extensive review of the literature and have found that very little is known about the experience of pregnancy for women who are (a) new to Canada and (b) living with HIV/AIDS. In conducting this study, I hope to speak directly to women who can share their experiences that may assist me to improve nursing practice and education, as well as suggest recommendations for those healthcare providers who work with pregnant newcomer women with HIV/AIDS.

I have submitted my request for Ethics Approval from Ryerson University and would be pleased to provide you with a copy of my approval upon receipt.

I would like to take this opportunity to thank you for your time and consideration. I look forward to hearing from you at your earliest convenience.

Sincerely,

Victoria Logan Kennedy, RN, BScN, MN (Student)

Appendix C: Letter Requesting Ethics Approval at Recruitment Site

Dear .....;

My name is Victoria Logan Kennedy. I am a Registered Nurse and a master's student at Ryerson, presently enrolled in the MN-Master of Nursing, Thesis Stream. As a requirement of the program, I am planning a research study under the supervision of Dr. Susan Bishop, Assistant Professor, in the Daphne Cockwell School of Nursing. The study is titled "Pregnancy Experiences for Newcomer Women who are Living with HIV/AIDS". There appears to be a number of different factors that can influence a woman's pregnancy experience. I am trying to learn more about how women, who are living with HIV/AIDS, and who are newcomers to Canada experience pregnancy.

I have conducted an extensive review of the literature and have found that very little is known about the experience of pregnancy for women who are (a) new to Canada and (b) living with HIV/AIDS. In conducting this study, I hope to speak directly to women who can share their experiences that may assist me to improve nursing practice and education, as well as suggest recommendations for those healthcare providers who work with pregnant newcomer women with HIV/AIDS.

As required, I have written support from several individuals at _____ Hospital. Dr. _____ has agreed to fulfill the role of site Principle Investigator, Dr. _____has provided departmental support, and as a nurse I have support from _____. I have also provided written confirmation of my Research Ethics Approval at Ryerson University.

In advance, I would like to thank you for your time and consideration of my proposal. I look forward to hearing from you at your earliest convenience.

Sincerely,

V Logan Kennedy, RN, BScN, MN (student)

Enclosure: Complete Copy of Application for Expedited Review

Appendix D: Information Sheet for Potential Participants

Title of Research Project: Pregnancy experiences for newcomer women who are living with HIV

Hospital Principle Investigator: Dr. _____
Telephone:

Investigator: Victoria Logan Kennedy, R.N., B.Sc.N., M.N. (Student)
Telephone: xxx-xxx-xxxx

Ryerson University Supervisor: Susan Bishop, R.N., M.Sc., Ph.D.
Assistant Professor
Daphne Cockwell School of Nursing, Ryerson University
Office: (416) 979-5000 ext. ___

Purpose of Research:

My name is Victoria Logan Kennedy. I am a Registered Nurse and a master's student at the Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario. I am doing a study on the experience of pregnancy for newcomer women to Canada who are living with HIV. I hope that the results from this study will help nurses and other healthcare professionals to improve care.

Procedure:

You have been selected as a possible participant. If you participate in my study, I will interview you privately on at least once. The interview will last about two hours. I would also like to follow up with you once after the interview. Together we can decide where we can privately do the interview. The interview will be tape-recorded and I will also take notes. During the interview you will be asked to share your feelings and experiences of pregnancy. At the end of the interview, I will ask you if I can call in again. If you agree, approximately one week after our interview, I will contact you by telephone (at the number you give to me) to see if you would like or agree to a second interview. If you do not want a second interview, this telephone call may also be used as a chance for you to share more with me. The second interview or telephone call will be used to make clear the things we talked about in your first interview.

If you do participate, all private information will be kept confidential to me. Your name and private information will not be in the report of the study. I will do my best to protect your identity. At the end of the study, all materials that may link you to the data and reports will be destroyed. If you would be interested, a summary of the study results will be sent to you at the end of the study.

Potential Benefits to Participants and/or Society:

You may not receive any direct benefit from participating in this study. However, you may find it helps to talk about your experiences. Information from this study may help change nursing practice and education, and may improve health care for pregnant women who are newcomers to Canada and living with HIV/.

Potential Risks and Discomforts:

Being in this study may cause you some emotional upset because of the personal questions you will be asked. You may refuse to answer any questions or ask to stop the interview if you feel upset. I have access to helpful people, like Social Workers, and phone numbers if you need them.

Your participation in this study is your choice. Although Dr. _____ is the Principle Investigator at _____ Hospital she will not have access to information on who is in the study. She will only know if you contact her directly about the study. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass". If you decide to stop being in this study I will ask you for permission to use your data and will respect your choice.

Sincerely,

Victoria Logan Kennedy RN, BScN, MN (Student)

Appendix E: Consent Form

HOSPITAL PRINCIPLE INVESTIGATOR: Dr. _____
INVESTIGATOR Victoria Logan Kennedy
My name is Victoria Logan Kennedy. I am a Registered Nurse and a master's student at the Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario. Under the supervision of Dr. Susan Bishop (Daphne Cockwell School of Nursing) I am planning a research study as part of the work for my program.

TITLE Pregnancy Experiences for Newcomer Women who are Living with HIV

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask me, the study investigator, Victoria Logan Kennedy, to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

PURPOSE
The purpose of this research study is to look at the experience of pregnancy for newcomer women who are living with HIV. Even though we know more about HIV in pregnancy now, it is not known very much about how this experience feels for newcomer women. I am trying to learn more about how women, who are living with HIV, and who are newcomers to Canada feel emotionally in pregnancy.

PROCEDURES
You are being asked to participate in this research study. If you would like to participate, you will be asked to take part in at least one private interview with me. It will last about two hours. Together we will decide on a private place to do the interview. The interview will be tape-recorded and I will also take notes.
During the interview, an example of a question you might be asked is "How has being a newcomer living with HIV made you feel in your pregnancy?"
At the end of our interview, I will ask you if it is alright if I call you in one week.
If you say I can call, about one week after our interview, I will contact you by telephone (at the number you give to me) to see if you would like or agree to a second interview. If you do not want a second interview, this call may also be used as a chance for you to share more with me. The second interview or telephone call will be used to make clear the things we talked about in your first interview.
If you would be like, a summary of the study results will be sent to you at the end of the study.

POTENTIAL RISKS AND DISCOMFORTS
Being in this study may cause you some emotional upset because of the personal nature questions you will be asked. You may refuse to answer any questions or ask to stop the interview if you feel upset. I have access to helpful people, like Social Workers, and phone numbers if you need them.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY
You may not receive any direct benefit from participating in this study. However, you may find it helps to talk about your experiences. Information from this study may help change nursing practice, education, and policy and may improve health care for pregnant women who are newcomers to Canada and living with HIV.

VOLUNTARY PARTICIPATION
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass". If you decide to stop being in this study at any time, your data will not be included in the study unless you tell me I may use it.
I will give you new information that is learned during the study that might affect your decision to stay in the study. If you become very upset during the interview, I will pause and give you an opportunity to decide whether you would like to withdraw from the study.

PAYMENT FOR PARTICIPATION
You will not be paid to participate in this study. In order to compensate you for your time and participation, you will be offered a gift card to a local coffee shop for $15. You will be given this gift card at the start of our interview.

EXPENSES ASSOCIATED WITH PARTICIPATING INTHIS STUDY
You may have travel costs from being in this study. Together we will decide where to meet for our interview so you do not have to pay much to get there.

CONFIDENTIALITY
Only I will know who has agreed or not to participate in this study. Interviews will be conducted privately.
All information collected during this study, including your personal health information, will be kept confidential and will not be disclosed to anyone outside the study without your permission or as required by law.
You will not be named in any reports, publications, or presentations that may come from this study. A pseudonym (a made up name that will be used to hide your identity) will be used instead of your name. Although reports from this study will include quotes from the interview, you will not be identified. Audio tapes, field notes, transcripts and research codes with identifying information will each be stored separately in a locked cabinet. Only I will have access to these materials.
Representatives of the _____ Hospital Research Ethics Board may look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.
No new information will be collected without your permission.
At the completion of the research study, the codes with verifying information will be destroyed and the audio tapes will be erased.

QUESTIONS ABOUT THE STUDY

If you have any questions, concerns or would like to speak to the study investigator for any reason, please call: Victoria Logan Kennedy at xxx-xxx-xxxx or Dr. Susan Bishop at xxx-xxx-xxxx ex.xxxx.

If you have any questions about your rights as a research participant or have concerns about this study, call _____, Ph.D., Chair of the _____ Hospital Research Ethics Board (REB) or the Research Ethics office number at xxx-xxx-xxxx. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

CONSENT

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

_____ _____ _____

Print Study Participant's Name Signature Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

_____ _____ _____

Print Name of Person Obtaining Consent Signature Date

☐ The consent form was read to the participant. The person signing below attests that the study as set out in this form was accurately explained to, and has had any questions answered.

_____ _____

Print Name of Witness Signature Date

_____

Relationship to Participant

Appendix F: Interview Guide

Opening Question

"As you already know, I am doing this study to learn more about women who are new to Canada who are living with HIV/AIDS. Can you tell me about how this experience has affected your pregnancy?"

Follow-up Question

"Have there been situations that have had an impacted on your pregnant as a newcomer living with HIV/AIDS?"

Clarifying Questions and Probes

"Can you think of an example?"

"How did that experience make you feel?"

"What has that been like for you?"

"Can you explain what that means to you?"

"In what way?"

"Can you tell me more about that experience/feeling?"

Questions used to Probe about Previous Participants' Responses

"Some of the other women I have spoken with have told me…… Have you felt this way in your pregnancy?"

Appendix G: Recruitment Script for Intermediary

Hello, I wanted to tell you about a nursing research study that is currently underway here in our clinic. It is being conducted by Victoria Logan Kennedy, a registered nurse, who is presently enrolled in the Master of Nursing program at Ryerson University. In the past she has worked with many women like you.

In her study, Victoria Logan is hoping to speak with newcomer women who are pregnant to gain a better understanding of the experience of pregnancy for newcomer women to Canada. The information gained from this study may assist nurse and other members of our team to provide more sensitive and supportive care to women such as you.

Victoria Logan would like the opportunity to call you or meet with you here in the office to tell you more about the study. I would like to emphasize that you do not have to agree to speak with Victoria Logan and the even if you agree to speak with her you are not obligated to be in the study. If you agree to speak with her, you are only agreeing to learn more about her study.

(if answers "yes"): Thank you. In this envelope is a form that you can fill out with your preferred method for Victoria Logan to contact you. Once you have filled it out, please seal the envelope and give it back to me so I can pass it along to Victoria Logan.

Or

Victoria Logan is here today if you would be willing to speak with her.

(if answers "no"): Thank you for taking the time to listen to this explanation.

Appendix H: Contact Information Forms for Potential Participants

I agree to be contacted by Victoria Logan Kennedy to learn more details about the study she is conducting here at _____ Hospital about the experience of pregnancy for women who are newcomers to Canada.

Option 1:
I wish to be contacted by telephone at _____.

The best time to contact me is _____.

Option 2:
I wish to be contacted at my next visit on _____(date) at _____(time).

_____ _____
(Full name)

Appendix J: Recruitment Script for Researcher

Hello, Mrs/Miss/Ms..... My name is Victoria Logan Kennedy. You may recall that you that you have your contact details to the nurse in Dr._____'s office so I could contact you. Thank you for agreeing to hear more about my study. I am a registered nurse presently enrolled in the Master of Nursing program in the Daphne Cockwell School of Nursing at Ryerson University. As a requirement of the program, I am conducting a research study exploring the experiences of pregnancy for newcomer women to Canada living with HIV/AIDS. My supervisor is Dr. Susan Bishop. She is a professor in the Daphne Cockwell School of Nursing at Ryerson University.

If you participate in my study, I would like to interview you, at least once, privately in a location we both agree upon. The interview will last up to two hours and will take place during a convenient time for you. During the interview, you will be asked to share your thoughts, feelings, and experiences of pregnancy as a newcomer living with HIV/AIDS. You can share whatever you wish during this interview. I will contact you by telephone approximately one week following our interview to inquire if you would like or agree to a second interview. If you would prefer not to take part in a second interview, this telephone call may also be used as an opportunity for you to share further comments with me. The second interview or telephone call will be used to clarify what you shared with me in your first interview.

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying "pass". If you decide to withdraw from this study I will ask you for permission to use your data and will respect your choice. The decision to take part in this study is entirely your own.

Do you have any questions related to this study? Have I provided you with a clear answer to your questions? Would you be willing to participate in this study? Would you like to take some time to think about your participation? Might you be willing to provide me with a telephone number so I can follow up with you?

If "Yes, I know I would like to participate": Thank you. Can we discuss a location where you would feel comfortable to conduct the interview? When would be a convenient time for us to meet?

If "Yes, I would like to think about it and have you call me later": Thank you. When would be a convenient time for me to call you?

If "No, I'm not interested in being in the study": Thank you for listening to my explanation.

Follow up telephone call: Hello. This is Victoria. I am calling to see if you have had enough time to consider whether or not you wish to participate in my study.

Appendix K: Lived Experience of the Researcher

"Remember for just one minute of the day, it would be best to try looking upon yourself more as God does, for She knows your true royal nature" (Hafiz of Persia).

Doing this research has truly represented my own journey that has required me to look within myself probably more than ever before. Not only have I come to learn a great deal about the experience of pregnancy for newcomer women to Canada, I have also learned about myself; about how I think, the types of knowledge I value, and I how I interpret the world around me. In Chapter 1, I began this thesis by sharing my context within this topic with the reader; what Maton (2003) called autobiographical reflection. To continue the pursuit towards a deeper, more critical engagement in reflexivity, I will use this section to explore my lived experience as the researcher.

I am the co-creator, interpreter, and writer of this work. For many months now, as a novice researcher, I have struggled to come to terms with what that truly means. I am sure I wrestled with my authorship of this work because I felt vividly that this work belonged to the women whose stories it contains. In reading an article provided to me by a thesis committee member, I was reassured to learn that this discomfort with authorship and creative influence is a common challenge in reflexivity. I have learned that the true essence of reflexivity is being able to respectfully acknowledge one's role as the author of a thesis, while avoiding the narsacistic tendency to make the findings more about the researcher than the subjects of the study (Maton, 2003).

I have had the great fortune as a novice researcher to be encouraged by my committee supervisor and members to move beyond this uncomfortable no man's land and embrace my journey to a deeper understanding of myself through reflexivity. I still find it difficult to articulate what my journey of reflexivity has entailed. My biggest focus has always been to tell

the stories of the five women who so generously agreed to share their lives with me. However, I was encouraged to examine how my existence runs parallel to the women in this study and to consider the significance of how our lives have come together.

Even though my existence has little in common with the women in this study, as I become immersed in their stories I found myself becoming very protective of the stories they have shared with me. Because the women wanted to be treated the same as other women, I found myself emotionally blocking certain words the women had used as I was developing the thematic structure. As I have learned over the years, the word 'normal' can have negative connotations. I seemed to be apprehensive about including the word normal for fear that I would somehow contribute to the stigmatization of the women in this study by suggesting that they were not normal. I had a number of meaningful conversations with my thesis supervisor and she kept encouraging me to look deeper, to go deeper into the essence of the women's stories. For many weeks I found myself facing a brick wall. I could see the importance of the good and bad aspects of the women's journey, but I resisted the significance of normalcy. It was only after these repeated conversations with my thesis supervisor that I was able to realize that the essence of the women's experiences was truly about wanting to be normal.

My learning experience went beyond the women in this study and extended to how I wrote about my colleagues. Through writing this thesis, I have learned the power I have to uncritically present my own preconceptions through my writing. For instance, I had made language choices specific to other healthcare professionals that created a situation of 'me against them'. I suppose that this was, again, related to the fact that the women shared their desire to be seen as normal with me. On a personal level I was hurt by the stories of the women who had been discriminated against in healthcare settings. These emotions were influencing how I was

writing. With the support of my committee, I have come to a deeper place of understanding. As I listened to the women and engaged in reflexive dialogue with my thesis committee members, I uncovered the importance of challenging the knowledge that we use to create opinions. I had created my own preconceptions of other healthcare providers based on my emotional reaction and not on a critical evaluation of what influences other people's attitudes. It has been enlightening to explore the power I possess through my thoughts, opinions, and writing.

As my writing comes to a close, I often find my mind drifting to the women who participated in this study. After listening to interviews and reading transcripts over and over, I am left wondering what has become of the five women whose lives intersected with my own so briefly yet so powerfully? I am so fortunate to have experienced their presence, their resilience, their kindness, and their truth. One interview left me feeling raw for a week. I was like an exposed nerve. It was very difficult for me to transcribe this interview as I did not want to relive the pain of her story. With the passing of time, the rawness of my emotions has faded, and yet I am left feeling that much is unfinished.

While this study has taught me a great deal about the pregnancy experience of newcomer women to Canada living with HIV, it has undeniably taught me a number of personal lessons. The women in this study have reminded me what it means to be resilient. The spirit with which they overcome the challenges in their lives is a lesson for us all that nothing is insurmountable. They have also reminded me what a privilege and honor it is to be a woman in Canada. I sometimes forget that the freedom, acceptance, and support I have to live my life as I choose, is largely contingent on my lived space. Finally, having the privilege of conducting this study has taught me that each of us has many gifts in our life and that true blessings can only be seen when we open our hearts up enough to accept them.

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