

Relationship between Socio-Demographic Factors and Familial and Partner Pressures to
Conceive in HIV-Positive Women in Ontario

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ABSTRACT

This study examined the relationship between socio-demographic factors and family and partner pressure to conceive in women living with HIV in Ontario, Canada. A total of 490 women, aged 18-52 years were included in the study. The HIV Pregnancy Planning Questionnaire was used to collect data on socio-demographic, medical, and pressure variables. Multivariate logistic regression analysis suggest that increased age, years lived in Canada, and living in Toronto were associated with lower odds, and being married and having 0-1 lifetime births were associated with higher odds of family pressure to conceive. Increased age was associated with lower odds, and being married and living in Toronto were associated with higher odds of partner pressure to conceive. Findings suggest that socio-demographic factors influence the fertility decision-making process. Health care providers should consider socio-demographic factors along with medical factors when assisting women living with HIV and their partners to make informed reproductive decisions.

Key words: HIV, Women, Children, Family Pressure, Partner Pressure

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LIST OF ABBREVIATIONS

95% CI – 95% Confidence intervals

AD – Anderson-Darling

AIDS – Acquired immunodeficiency syndrome

ART – Antiretroviral therapy

HAART – Highly active anti-retroviral therapy

HIV – Human immunodeficiency virus

KS – Kolmogorov-Smirnov

OR – Odds ratio

SW – Shapiro-Wilk

CHAPTER 1. INTRODUCTION

1.1 History of HIV

The first appearance of acquired immunodeficiency syndrome (AIDS) was seen in men who have sex with men in the United States in 1981 (Weiss, 2008). In 1983-1984, French and American researchers suggested that AIDS was caused by a retrovirus known as the human immunodeficiency virus (HIV) which attacks the immune system, and impairs its functions (Wainberg & Jeang, 2008; WHO, 2011). This infection leaves people more susceptible to opportunistic infections. Without treatment, the infection can progress into a disease known as AIDS (WHO, 2011). HIV infection can be transmitted through unprotected sexual intercourse and making contact with an infected person's blood through blood transfusion and sharing needles. The virus can also be transmitted from mother to the child during pregnancy, child birth, and through breast feeding (WHO, 2011).

It is estimated that approximately 25 million people have died of AIDS and about 33 million people are living with HIV worldwide (Public Health Agency of Canada, 2008; Wainberg & Jeang, 2008). Unfortunately, about 50% of the people infected with HIV get this infection before the age of 25 years and die from AIDS before the age of 35 years (Wainberg & Jeang, 2008). Further, statistics suggest that 95% of the new infections occur in underdeveloped or developing countries where people are less likely to have access to or afford antiretroviral therapy (ART) (Wainberg & Jeang, 2008). In fact, only 7% of people in the developing countries have access to ART (Wainberg & Jeang, 2008). While sub-Saharan Africa is considered to be the world's most affected region, the number of HIV infections is also increasing in East Asia, Eastern Europe, and

Central Asia (Public Health Agency of Canada, 2005). During the time period from 1980 to 1995, the median survival time was 12.1 years for patients in the United States and only 37.2% survived 15 years after seroconversion (Coutinho, 2000). Similar results were also reported in a study that compiled data from other studies conducted in Europe, North America, and Australia (Coutinho, 2000). AIDS survival rate was found to be lower with increase in age. Survival rate was 11.0 years in individuals aged 15-24 years and 7.7 years among those aged 45-54 years (Coutinho, 2000). Further, annual mortality rate increased by 1.5 times per 10 year increase in age at seroconversion (Coutinho, 2000).

Considering the deadliness of this disease, development of effective ART has been the most important advancement in the field of HIV. Various types of antiretroviral drugs are available based on the enzyme or cellular drug targets (Wainberg & Jeang, 2008). These drugs are categorized into nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, protease inhibitors, entry inhibitors, fusion inhibitors, and integrase inhibitors (Wainberg & Jeang, 2008). Introduction of protease inhibitors in 1995 contributed to significant improvements in disease progression and mortality (Perno, 2011). Combination of three or more reverse transcriptase inhibitors and protease inhibitors resulted in the introduction of highly active anti-retroviral therapy (HAART) in 1996 (Weiss, 2008). After the development of HAART, the mortality rate for AIDS dropped by almost 70% and HIV infection was started to be considered as a treatable condition (Weiss, 2008).

1.2 HIV in Canada

Although several measures are available to prevent HIV infection, the incidence rate of HIV infection is increasing in Canada. The number of people living with HIV in

Canada has increased from 64,000 in 2008 to 71,300 in 2011, an 11.4% increase (Public Health Agency of Canada, 2011a). In Canada, men who have sex with men is considered to be the most affected group accounting for 46.7% of all HIV infections (Public Health Agency of Canada, 2011a). This is followed by injection drug user group which represents 16.9% of all HIV infections (Public Health Agency of Canada, 2011a). A higher number of HIV infections are also reported in Aboriginal people and immigrants (Public Health Agency of Canada, 2011a). Further, women represent 23% of the HIV cases and 28% of all new HIV cases are found in women (Public Health Agency of Canada, 2012). In Canada, 80% of women diagnosed with HIV are of reproductive age (Loutfy et al., 2009). In a study of women living with HIV in Ontario, it was found that 69% of women wanted to have children and 57% of them intended to give birth in the future (Loutfy et al., 2009). These results were obtained using the same dataset as the one used for the current study. It is known that 38% of the general Canadian female population of reproductive age intended to have children in the future (Payne, 2004). Comparing the rates between the general women population and the population of women living with HIV suggests that women living with HIV have similar or even greater desire to have children.

1.3 Why do Women Living with HIV have Increased Desire to Become Pregnant?

It is possible that women living with HIV have higher rates for desiring to have children due to better access to treatment and reproductive services, importance of motherhood in some cultures, and demographic factors. Public Health Agency of Canada (2011b) estimated that about 87% of women living with HIV use combination ART.

Widespread use of combination ART has resulted in reduction in morbidity and mortality, and improved quality of life (Loutfy et al., 2009; Ogilvie et al., 2007). Widespread use of combination ART along with improvements in obstetric practices and replacement feeding has also reduced the risk of vertical transmission to less than 1% (Loutfy et al., 2009). Increased life expectancy, better quality of health, and reduction in vertical transmission rates may explain why increased proportions of women living with HIV desire or intend to have children in the future. Results from a systematic review suggest factors such as age, gender, race/ethnicity, number of children, parenthood, risk of vertical transmission, stigma, availability of social support, and family, partner and cultural expectations influence the decision to have children (Nattabi, Li, Thompson, Orach, & Earnest, 2009). These factors are interrelated and they may have an influence on each other as well.

1.4 Familial and Partner Expectations to have Children

Traditionally, women had a defined social role of bearing and raising a child and taking care of the household. In the North American society, there is no one defined social role for women, but women still experience the social, familial, and societal pressure for childbearing. In women living with HIV, these pressures and expectations may affect their reproductive decisions. Although women may desire to have children, studies conducted in various countries and cultures show that they also experience significant pressure from their partner, family, and the community (Beyeza-Kashesya et al., 2010; Chi, Rasch, Hanh, & Gammeltoft, 2011; Cooper, Harries, Myer, Orner, & Bracken, 2007; Kanniappan et al., 2008; Ko & Muecke, 2005). Research has shown that

women's decision to have children is based on the circumstances of their lives (Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002). Studies have shown that factors such as cultural customs, continuing the lineage, a man's status in society, family formation, strengthening the relationship between the couple, avoidance of stigma and discrimination, fear of infidelity and abandonment, violence, and women's financial and emotional dependency on the partner and family may provide some explanations as to why women experience pressures to have children or why they may comply with the demands of their partner and family (Aka-Dago-Akribi et al., 1997; Chi et al., 2011; Copper et al., 2007; Doyal & Anderson, 2005; Oosterhoff et al., 2008; Siegal & Schrimshaw, 2001; Simbayi et al., 2007; Sowell et al., 2002). Due to these factors, it may be difficult for many women living with HIV to make reproductive decisions without consulting their partner and family members. The strong desire of individuals living with HIV to have children in the future increases the risk of transmission of the infection to the sexual partner as well as to the new born child, especially if the woman is unaware of her HIV status or not receiving ART. Therefore, it is important to identify the factors associated with familial and partner expectations and pressures so that appropriate measures can be taken to understand and help women living with HIV make fertility decisions that are in their best interest.

1.5 Conclusion

In conclusion, significant numbers of women are diagnosed with HIV each year. Specifically, women account for 47% of all HIV cases worldwide (Public Health Agency of Canada, 2005). Women living with HIV of reproductive age have similar desire to

have children as compared to women without HIV. Use of combination ART and advances in pregnancy care practices have improved quality of life, and reduced morbidity, mortality, and risk of vertical transmission. As a result, more women living with HIV desire and intend to have children in the future. These women's decision to have children may also be influenced by various factors including demographics, psychological, social, economic, and cultural. However, there is limited research examining the relationship between these socio-demographic factors and family and partner expectations and pressures to have children. Previous studies were predominantly conducted before the widespread use of ART or included a small sample size. The relationship between socio-demographic factors and family and partner expectations and pressures to have children in women with HIV has not been investigated in a large multi-ethnic population such as Ontario. Due to the large number of immigrants and ethnic diversity in Ontario, the results obtained from this study can also be generalizable and can provide insight for other similar places around the world that has a large immigrant and refugee population. Therefore, the purpose of this study is to examine the relationship between socio-demographic factors and family and partner expectations and pressures to have children in women living with HIV.

1.6 Study Purpose and Research Questions

The purpose of this study is to examine the socio-demographic and biological factors associated with familial and partner expectations and pressures in women living with HIV in Ontario, Canada.

The following research questions were examined:

1) Do socio-demographic factors including age, ethnic background, religion, country of birth, region in Ontario, marital status, annual household income, education, number of lifetime births, number of years lived in Canada, hepatitis C infection, ever taken HIV medications, current intake of HIV medications, CD4 counts, and viral load have an effect on familial expectations and pressures in women living with HIV in Ontario, Canada?

2) Do socio-demographic factors including age, ethnic background, religion, country of birth, region in Ontario, marital status, annual household income, education, number of lifetime births, number of years lived in Canada, hepatitis C infection, ever taken HIV medications, current intake of HIV medications, CD4 counts, and viral load have an effect on partner expectations and pressures in women living with HIV in Ontario, Canada?

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

Over the last several years, antiretroviral therapy (ART) and prevention of vertical transmission programs have improved quality of life, minimized vertical transmission, and reduced mortality and morbidity in women living with HIV (Loutfy et al., 2009). In the past, individuals living with HIV were discouraged from having children due to the concern of vertical transmission or parental death, but more flexible and effective reproductive methods are now available (Nattabi et al., 2009). Availability of assisted reproductive techniques for people living with HIV has significantly reduced the risk of sexual and fetal transmission (Cooper et al., 2007). As a result, many women living with HIV desire to have children. Therefore, it is important to understand the factors associated with fertility desires so that health care providers can assist women meet their fertility goals as well as protect the health of the women, her partner, and her child.

This chapter will review the literature on unplanned pregnancy and factors associated with the desire and intention to have children including age, gender, ethnicity, number of living children, parenthood, prevention of vertical transmission, health status, stigma, and cultural influences. This chapter will also review the literature on family and partner expectations and pressures experienced by women with HIV. In doing so, studies conducted in Canada as well as in other countries will be examined. Ontario has a large multi-ethnic immigrant population and majority of women living with HIV in Ontario are of African descent. The estimated prevalence of people living with HIV in Ontario has increased significantly, from 15,904 in 1999 to 26,627 in 2008 (Ontario Ministry of Health and Long-term Care, 2012). This represents a 67% increase in the prevalence rate.

In Ontario, the proportion of African individuals living with HIV increased from 22.5% in 2009 to 29.4% in 2011-2012 (Public Health Ontario, 2012). Specifically, the proportion of African women living with HIV in Ontario increased from 54.7% in 2009-2010 to 67.1% in 2011-2012, while the proportion of Eastern and Southeastern Asian women living with HIV decreased from 5.2% to 0.46% during the same time period (Public Health Ontario, 2012). In Toronto, 71.5% of all HIV cases in women were diagnosed among women of African ethnicity and majority of these women were immigrants from HIV endemic countries (Public Health Ontario, 2012). Since majority of women living with HIV in Ontario are of African descent, it is important to review international literature, particularly studies conducted in the African countries to gain further insight into the cultural and societal factors that may affect the reproductive decision-making process of individuals who have immigrated to Ontario.

2.2 Unplanned Pregnancy

It is estimated that about 90% of HIV infection in children result from vertical transmission (Kikuchi, Wakasugi, Poudel, Sakisaka, & Jimba, 2011). Therefore, unintended pregnancies among individuals living with HIV should be prevented in order to prevent vertical transmission. Preventing unintended pregnancies is also known to be a good approach in lowering the incidence rate of HIV infection in children (Sweat, O'Reilly, Schmid, Denison, & de Zoysa, 2004). Preventing unplanned pregnancies also helps in lowering the health risks associated with unsafe abortion, and reduces negative effects of pregnancy on maternal health, especially in women with low CD4 cell counts (Schwartz et al., 2012). Although there are several benefits associated with preventing

unwanted pregnancies, the rate of unwanted pregnancy is relatively high among people living with HIV. For instance, 43% of the pregnancies were unplanned in Uganda, 50% of the pregnancies were unplanned in Cote d'Ivoire (Desgrées-Du-Loû et al., 2002), and 63% of the pregnancies were reported to be unplanned in South Africa (Schwartz et al., 2012). Such high rates of unintended pregnancies may be explained by several factors. Like other women, women living with HIV may also want to plan pregnancy or avoid pregnancy to limit their family. Appropriate use of contraception will help women make these reproductive choices. Various contraception methods including condoms, hormonal contraception, emergency contraception, intrauterine device, and sterilization are available. However, there is a large difference in contraception use in women aged 15 to 49 years with 8% in Western Africa to 78% in Northern Europe (Mitchell & Stephens, 2004). Therefore, lack of contraceptive use is a significant factor contributing to the high unintended pregnancy rates. In addition, use of less effective family planning methods such as condoms, withdrawal, rhythm, and lactational amenorrhea may also be responsible for unintended pregnancies (Schwartz et al., 2012; Wanyenze et al., 2011). Wanyenze and colleagues (2011) also found that the use of highly effective contraceptive methods such as implants and sterilization was low. Further, using inappropriate contraceptive methods or irregular use of contraceptive methods may also be responsible for increased rates of unintended pregnancies (Wanyenze et al., 2011). Another study also found that women with lower self-efficacy were less likely to use contraceptives or request their partner to use condoms (Kikuchi et al., 2011). In this study, women indicated that they were economically dependent on their partners and had to comply with their partner's requests to engage in sexual activity without use of a contraceptive

(Kikuchi et al., 2011). Therefore, financial dependability may be another reason why women fail to request their partner to use contraceptives, thus resulting in unintended pregnancy.

2.3 Desire and Intention to Have Children

Although a considerable proportion of pregnancies are unplanned, studies have shown that people living with HIV desire and plan to have children regardless of their HIV status (Nattabi et al., 2009). Those infected with HIV after the year 2000 have an additional 35 years of life expectancy, allowing enough time for women living with HIV to have children (Finocchario-Kessler et al., 2010). In fact, the incidence rate of pregnancy in women living with HIV is similar to the general population rate of 36% (Finocchario-Kessler et al., 2010). Pregnancy rates after diagnosis of HIV range from 30% to 55% in the U.S. (Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005; Craft, Delaney, Bautista, & Serovich, 2007) and 15% in Brazil (Nobrega et al., 2007). However, some studies have shown that women living with HIV are less likely to desire having a child after HIV diagnosis. In Kenya, HIV-infected women had eight times lower risk to have children compared to healthy women (Nattabi et al., 2009). Therefore, it is important to determine the factors influencing fertility desire and intention to have children among people living with HIV.

2.3.1 Factors Positively Influencing Desire and Intention to Have Children

2.3.1.1 Age

Various studies conducted in people living with HIV/AIDS have shown that

younger age was significantly associated with a desire to have children. Results from studies conducted in several countries including Brazil (Nobrega et al., 2007; Santos, Ventura-Filipe, & Paiva, 1998), Uganda (Nakayiwa et al., 2006), South Africa (Myer, Moroni, & Rebe, 2007; Peltzer, Chao, & Dana, 2008), Canada (Loutfy et al., 2009; Ogilvie et al., 2007), and the U.S. (Bedimo-Rung et al., 2005; Chen, Phillips, Kanouse, Collins, & Miu, 2001; Stanwood, Cohn, Heiser, & Pugliese, 2007) have shown that increase in age is negatively associated with desire to have more children. Adjusted odds ratios range from 0.3 in Canada (Loutfy et al., 2009) to 0.94 in South Africa (Myer et al., 2007; Peltzer et al., 2008). In contrast, a study conducted by Sowell and colleagues (2002) did not find a significant association between age and desire to have children.

2.3.1.2 Gender

Several studies have examined the fertility desires of both males and females with HIV. A study conducted in the U.K. found that 44% of men living with HIV desired to have children in the future (Sherr & Barry, 2004). A study in South Africa reported that males are approximately 2.5 times more likely to desire having children compared to women (Myer et al., 2007). Similar results were found in studies conducted in Brazil (Paiva, Filipe, Santos, Lima, & Segurado, 2003; Santos et al., 1998). Another study conducted in Uganda also showed that men are more likely to desire children compared to women (Nakayiwa et al., 2006).

2.3.1.3 Ethnicity

In a multicultural study conducted in the U.S., ethnicity was found to be associated with the intention to have children (Chen et al., 2001). In Canada, earlier analyses of the data used for current study showed that women of African descent were

more likely to intend to become pregnant (Loutfy et al., 2009). Similarly, African men and women living in France were also more likely to desire children compared to European men and women (Beyeza-Kashesya et al., 2010). These results emphasize the importance of parenting in the African culture. Several reasons can be proposed to explain these findings. Compared to other cultures, parents from the African culture may value children more as source of income and companionship (Hollos & Larsen, 2008). Individuals from non-white communities may also desire to have children because they provide assistance with daily chores, take care of aged parents, and provide help with taking care of younger siblings (Hollos & Larsen, 2008). In the African culture, children are viewed as a connection to their ancestors and birth of a child is seen as a continuation of the family and its traditions (Hollos & Larsen, 2008). Further, having a child may also be used as a method of coping with the loss of another child, perhaps due to HIV (Chen et al., 2001). Some individuals also associate pregnancy and having children with high self-esteem and may consider children as a source of motivation to live a “normal”, stigma-free life (Chen et al., 2001). Chen et al. (2001) suggested that these reasons may explain why women with poor health and functioning have a greater desire for children. It implies that individuals in non-white communities consider infertility to be a concern. Therefore, deciding against having children as a result of HIV infection may not be considered acceptable. On the other hand, some studies have suggested that ethnicity was not associated with the desire to have children or continuing pregnancy after being diagnosed with HIV (Chen et al., 2001; Standwood et al., 2007).

2.3.1.4 Number of Living Children and Having Previous Children

Results from cross-sectional studies conducted in different countries have shown that number of living children was associated with the desire to have more children in people living with HIV. In South Africa, a study conducted among people living with HIV showed that those having at least one child had 0.32 lower odds of desiring to have more children compared to those without children (Myer et al., 2007). Studies conducted in Uganda (OR: 0.82; Nakayiwa et al., 2006), and Brazil (OR: 0.26; Nobrega et al., 2007) also support this finding. In Canada, having no more than one child was associated with increased desire to have children in the future (OR: 1.9; Loutfy et al., 2009). A qualitative study conducted in Cote d'Ivoire found that having three or less children is associated with having a higher desire to have children compared with those who have three or more children (Aka-Dago-Akribi, Du Lou, Msellati, Dossou, & Welffens-Ekra, 1999). In other words, having three or more children was not associated with a desire to have more children in the future. In contrast, another study found no association between the number of living children and the desire to have more children in the future (Peltzer et al., 2008). This study concluded that increased desire to have more children was found only among women not living with HIV.

2.3.1.5 Parenthood

In Canada, earlier analyses of the data used in this study found that younger women, recent immigrants, and women who had previously given birth viewed motherhood as highly important (Kennedy et al., 2014). A Nigerian study suggested that marriage and parenthood are important irrespective of HIV status (Smith & Mbakwem, 2007). Similar results were reported in a study conducted in India (Kanniappan, Jeyapaul,

& Kalyanwala, 2008). In people living with HIV, one reason for this finding maybe due to the improvements in their health as a result of using ART. Being on ART gives them an opportunity to reassess their possibilities of having children in the future. Further, a study conducted in the U.S. showed that motherhood has even a larger influence on perspective child bearing compared to the health risks to mother and her child (Siegel & Schrimshaw, 2001). Another study has shown that women living with HIV are interested in having their own children and felt encouraged after observing other women living with HIV giving birth to healthy babies (Oosterhoff et al., 2008). Women identified several reasons to justify their strong desire for parenthood. Some women desired parenthood because they wanted to have a son to continue their family name (Kanniappan et al., 2008). Women who had at least one child desired to have another child so that the children can support and comfort each other after their death (Kanniappan et al., 2008). Some women also indicated that having their own children will give them a reason to live and a hopeful future (Kanniappan et al., 2008). Further, some women underwent depression after the loss of their first child and wanted to have children to fill the void created by the loss of their child (Kanniappan et al., 2008). In some cultures, motherhood is considered as a form of self-expression and self-esteem (Sowell et al., 2002), and is considered to be important for married women's identity and social status (Kisakye, Akena, & Kaye, 2010).

2.3.1.6 Prevention of Vertical Transmission

Several studies have shown that programs and therapies for prevention of vertical transmission are positively associated with reproductive decision making in women living with HIV (Copper et al., 2007; Kanniappan et al., 2008; Peltzer et al., 2008). A

study conducted by Copper and colleagues (2007) showed that men were more likely to desire children than women after information about the benefits of prevention of vertical transmission was provided. Moreover, men did not consider the availability of ART whereas women's decisions to have children were influenced by ART availability. Similar findings were also reported in a study conducted in India (Kanniappan et al., 2008). Individuals believed availability of ART would improve their health and thereby enable them to take care of their children (Oosterhoff et al., 2008). The importance of ART was also noted in South Africa. In comparison to women who had been on ART for less than a year, those who had been on ART for more than a year had higher odds (OR: 3.52; CI: 1.44-8.60) of desiring children (Myer et al., 2007).

2.3.1.7 Health Status

An individual's relative health status is also known to be positively associated with the desire to have children. Women living with HIV who considered themselves to be "healthy" were more likely to have children. This may be associated with being on ART. Studies conducted by Panozzo, Battegay, Friedl, and Vernazza (2003) and Smith and Mbakwem (2007) support this explanation. Further, in addition to health improvements, some women also considered their husband's health status when making reproductive decisions. Women living with HIV in India viewed their husband's health as an important determinant because this would ensure support in caring for the child (Kanniappan et al., 2008).

2.3.1.8 Family, Society, and Cultural Influences

Expectations from family and society also play a crucial role in reproductive decision making for people living with HIV. In South Africa, women living with HIV

were under more pressure from the family and the society to have children compared to men (Cooper et al., 2007). On the other hand, in Vietnam, both men and women were pressured by family members to have children since they do not make reproductive decisions on their own (Ko & Muecke, 2005; Oosterhoof et al., 2008). A multi-ethnic population study in the United States found that women who reported a more traditional gender role were more likely to want a child (Sowell et al., 2002). This suggests that traditional beliefs have a significant influence on reproductive decisions made by individuals living with HIV. Childbirth is viewed as fulfilling the demands of producing an heir to the family as well as strengthening the relationship between the couple and his family. For example, in the Vietnamese culture, women's lives are considered to be incomplete if they do not have children, especially male children (Oosterhoff et al., 2008). In Vietnam, women who marry the only son in the household are highly pressured to have male children to continue the family name (Oosterhoff et al., 2008). In fact, in some cases if a woman is infertile or does not give birth to a son, she is divorced and is expected to find a second wife for her husband (Oosterhoff et al., 2008). Social and cultural norms also support childbearing in sub-Saharan Africa (Kisakye et al., 2010; Myer, Morroni, & El-Sadr, 2005). In Uganda, family and societal expectations to have a child had a positive influence on women's reproductive decisions to the point that it outweighed the fear of HIV-stigma as a discouraging factor for having children (Kisakye et al., 2010). In Uganda, older women believed that their extended family members will take care of their children if their health deteriorated or in case of their death (Kisakye et al., 2010). However, some younger women believed that every family cared for itself and that

extended family members will not support or care for their children in case of their death (Kisakye et al., 2010).

2.3.1.9 Partner Influence

Kline, Strickler, and Kempf (1995) reported that a partner's desire to have a child was more important than the woman's desire. In the U.S., women living with HIV believed that having a child will strengthen their relationship with their partner (Siegel & Schrimshaw, 2001). In India, women made reproductive decisions after having discussions with their husbands (Kanniappan et al., 2008). A study from Taiwan reported that women were expected to obey their husbands regardless of their fear and doubt about transmitting the infection to the child (Ko & Muecke, 2005). These results suggest that a partner has a strong influence on the reproductive decisions made by woman living with HIV especially in the African (Beyeza-Kashesya et al., 2010; Cooper et al., 2007), Asian (Chi et al., 2011; Ko & Muecke, 2005), and Indian cultures (Kanniappan et al, 2008).

2.3.1.10 Stigma

In people living with HIV, stigma can influence fertility desires in both directions. In order to avoid being stigmatized, women living with HIV hide their HIV-positive status by continuing to have children (Cooper et al., 2007). A study conducted by Craft et al. (2007) found that women who have negative self-image and experienced stigmatization or fear of rejection are more likely to get pregnant. For these women, having more children will allow them to conceal their HIV-positive status and avoid stigmatization. Further, women with higher levels of disclosure and concerns about society's attitudes towards HIV-infected people were less likely to become pregnant or desire more children (Craft et al., 2007). This will allow them to avoid being criticized

for having a child despite of being infected with HIV and being aware of the risks of transmission to the child.

2.3.1.11 Geographic Region of Residency

Studies conducted in Ontario, Canada using the same dataset as the one used in the current study found that women living with HIV in a large urban area of Toronto were more likely to intend to become pregnant (Huynh et al., 2012; Loutfy et al., 2009). This may be because individuals living in urban areas may have easy access to health information, as well as health care and family planning services. Therefore, women living in urban areas may be more likely to be aware of the fertility options available to them.

2.3.2 Factors Negatively Influencing Desire and Intentions to have Children

2.3.2.1 Health Concerns

Studies conducted in several countries and different ethnic backgrounds have suggested that women living with HIV were worried about transmitting the infection to their partners and future children (Cooper et al., 2007; Craft et al., 2007; Kanniappan et al., 2008; Oosterhoff et al., 2008; Richter, Sowell, & Pluto, 2002; Siegel & Schrimshaw, 2001). Some women did not think vertical prevention programs were effective and thought that they would not be able to bear if their child was infected. This is supported by the findings of a study conducted by Aka-Dago-Akribi and colleagues (1999), where women experienced guilt for giving birth to a child infected with HIV. Women living with HIV were also concerned about the effects of prospective pregnancies on their own health. Some women reported that becoming pregnant would have a negative effect on their health and thought it was more important to take care of the children they already

have rather than having more children (Kanniappan et al., 2008). However, some women had intentions of having more children even after considering the risks to themselves, their partner, and future children (Aka-Dago-Akribi et al., 1999). This may be explained by their relatively good health and their confidence in the effectiveness of ART.

2.3.2.2 Attitudes of Health Care Workers

Women living with HIV of reproductive age continue to express the desire to become pregnant. However, a considerable proportion of women do not discuss their reproductive plans with health care providers. In addition, many health care providers do not incorporate discussions about gender-specific issues and reproductive issues in their patient visits. A cross-sectional study conducted by Squires and colleagues (2011) in the United States pointed out that less than 50% of participants discussed gender-based issues with their health care providers. Majority of the women denied having any discussion about their reproductive desires because they feared negative attitudes from the provider regarding their reproductive decisions. Some women reported that they received comments from providers meant to make them feel guilty (Gogna, Pecheny, Ibarlucia, Manzelli, & Lopez, 2009) and that their health care provider disapproved of their pregnancy and suggested that they should get an abortion (Cooper et al., 2007; Craft et al., 2007). Similar results were also reported in women receiving ART. Some participants reported that the nurse told them to not have any children and complained of not receiving any support or encouragement (Cooper et al., 2007). Women living with HIV in the United States obtained fertility-related information from other women living with HIV because their health care providers did not provide them with sufficient information

for them to make informed reproductive decisions, but on the contrary provided information to discourage them from having more children (Sowell & Misener, 1997). Another study conducted by Tyer-Viola (2007) examined nurses' attitudes and willingness to care for women living with HIV. The results of this study showed that nurses who knew more than four people affected by HIV had positive attitudes. Nurses with positive attitudes were less likely to discriminate and were more willing to care for pregnant women with HIV. However, overall, nurses were more likely to discriminate and less willing to care for women living with HIV than women living without HIV. The negative attitudes of physicians and nurses toward pregnancy desires of women living with HIV can be explained by several possible explanations. Medical personnel's greater influence on terminating pregnancy may be related to specific medical information told to the women. Also, women may be more influenced by personal opinion, beliefs, and values of the medical personnel. Further, it may also be possible that care providers may not anticipate discussing pregnancy and family planning with their patients because of lack of focus in this area or that they expect these issues to be addressed by other health care providers. There are also other issues that may contribute to lack of communication and appropriate health care in women living with HIV. A study interviewed nurses, midwives, physician assistants, and obstetrician-gynecologist specialists and the results suggested that HIV/AIDS has many negative effects on maternity care providers including increased work load, burnout, reduced availability of services, difficulties maintaining confidentiality, and care provider's fears of becoming infected with HIV and the discrimination and stigma associated with it (Turan, Bukusi, Cohen, Sande, & Miller, 2008).

2.3.2.3 *Stigma*

Although several research studies have suggested that pregnancy in women living with HIV is associated with successful outcomes and low risk of vertical transmission, there is a strong social stigma surrounding this issue. Many women living with HIV fear that the disease will have a negative impact on their ability to raise their children. Women reported that they felt stigmatized by people in the society and have fears about losing their children or their children being discriminated and excluded if their HIV status was to be disclosed (Brickley et al., 2009; Oosterhoff et al., 2008; Squires et al., 2011). Some men and women living with HIV reported that their community and family would not approve of them having more children and that it is socially unacceptable for people living with HIV to have more children (Beyeza-Kashesya et al., 2010; Cooper et al., 2007). A previous study utilizing the same dataset as the current study found that lower education level, higher anxiety level, and being judged negatively by a physician in Canada for trying to conceive are some of the factors associated with the experience of higher HIV stigma (Wagner et al., 2010). HIV stigma is known to have a negative impact on quality of life, accessing health care services, and psychological well-being of women living with HIV (Wagner et al., 2010). In order to lower the negative effects of stigma, health care providers should provide effective care, encourage non-judgmental discussions, and be supportive of the fertility decisions made by women living with HIV.

2.3.2.4 *Child Mortality due to HIV/AIDS*

Experiencing a child's death due to HIV/AIDS can negatively influence the infected parent's desire to have more children in the future. For instance, a study done by Kannappan and colleagues (2008) reported that mothers who had experienced their

child's death due to AIDS did not desire to have any more children due to the fear of the future children being infected as well. Some women felt that they were responsible for their child's death and even went to the extent of getting an abortion in order to avoid similar incidents.

Conversely, experiencing a child's death from HIV/AIDS may also have a positive influence. One study found that some parents wanted to replace children who died from HIV by having more children (Nakayiwa et al., 2006).

2.3.2.5 Potential for Children to Become Orphans

Studies have shown that some women are concerned about not having anyone to look after their children in case of their early death (Kanniappan et al., 2008). Many women expressed desire to take care of their own children because they were worried that their family members might not care for their children (Nattabi et al., 2009). Women were also worried about leaving behind HIV-infected orphans who will be even more vulnerable. These factors deterred them from having more children in the future.

2.4 Familial Expectations and Pressures

In individuals diagnosed with HIV, planning a pregnancy can be a great concern due to the risk of infecting the partner and the child. However, availability of combination ART and assisted reproductive technologies have provided options for individuals living with HIV to become parents. Several studies have examined pregnancy desires and intentions in women living with HIV. Among other factors, family expectations and pressures have been identified to have a significant influence on pregnancy decisions. Some studies have shown that women living with HIV experience

pressures to abort their pregnancy, while other studies showed that women living with HIV are pressured to have a child (Chi et al., 2011). In a study, sero-discordant couples reported that 55% of their relatives wanted them to have children (Beyeza-Kashesya et al., 2010). However, 82% of these participants stated that if their relatives were aware of their HIV status, they would not want them to have children (Beyeza-Kashesya et al., 2010). It is important to note that the rate of disclosure of HIV status is generally quite low and ranges from 16.7% to 86.0% depending on the population (Makin et al., 2008; Kilewo et al., 2001). Studies have shown that younger age, being married, lower socioeconomic status, lower education level, longer duration of relationship with a partner, and report of love and trust in the relationship is associated with higher odds of disclosure to partners (Antelman et al., 2001; Farquhar et al., 2001; Galliard et al., 2002; Issiaka et al., 2001; Makin et al., 2008; Sigxashe, Baggaley, & Mathews, 2001; Stein & Samet, 1999). Conversely, fear of being accused of infidelity, neglect, rejection, discrimination, isolation, violence, shorter duration of relationship with a partner, having multiple sexual partners, and loss of financial support from the partner is associated with lower odds of disclosure (Antelman et al., 2001; Gielen, O'Campo, Faden, & Ake, 1997; Gielen, McDonnell, Burke, & O'Campo, 2000; Makin et al., 2008; Mamam, Mbwambo, Hogan, Kilonzo, & Sweat, 2001; Sigxashe, Baggaley, & Mathews, 2001; Stein & Samet, 1999). The stigma associated with HIV also has a negative influence on disclosure (Mahajan et al., 2008; Makin et al., 2008). In the African and Asian cultures, some people are more concerned about the social consequences of the HIV infection rather than the infection itself (Lie & Biswalo, 1994; Yoshioka & Schustack, 2001). A research study in the United States found that stigma associated with HIV status disclosure is responsible

for an 18.6% decrease in the odds of women deciding to become pregnant (Craft et al., 2007). This suggests that some women are influenced by the negative comments from family members which discourage them from trying to have children. However, family members being aware of the HIV status of the couple and discouraging or criticizing them for having children did not have an effect on some men's desire to have children. For example, a man in a sero-discordant relationship stated: "It does not affect my thoughts at all. My thoughts are mine and their thoughts are theirs" (Cooper et al., 2007, p. 278).

In contrast, other studies have shown that women living with HIV are pressured by their family members or partners to continue on with their pregnancy (Chi et al., 2011; Kanniappan et al., 2008). After adjusting for covariates, sero-discordant couples had 6.8 times higher odds of desiring children if they were pressured by their family members and relatives (Beyeza-Kashesya et al., 2010). Several explanations can be proposed to explain these results. First, according to family members, there is a social value for married couples to have children. Not having children after marriage is considered to ruin the family name. In some cultures such as African, Asian, and Indian culture, motherhood is viewed as a social and cultural part of women's lives and therefore it is difficult for these women to express their desire to not have children regardless of their HIV status (Doyal & Anderson, 2005; Dyer, Abrahams, Hoffman, & van der Spuy, 2002). In a study by Cooper and colleagues (2007), married women believed that they have to give into the family pressures of having children. In this study, a married woman admitted: "Before I got married I was not thinking about having a child. [Now] I do want to have at least one child because it is a disgrace not to have a child..." (Copper et al., 2007, p. 278). It has

been shown that married women's desire to not have children contradicted with the views of their partner, family members, cultural customs, and rules of family formation (Aka-Dago-Akribi et al., 1997) which expects women to reproduce. For instance, a woman said "...my parents-in-law said that many children who were born by an HIV infected mother were still HIV negative. They wanted me to have a child for them. So I decided to continue my pregnancy" (Chi et al., 2011, p. 321).

Continuing the lineage may be another reason why family members pressure women to have children. A study in Vietnam found that the entire family is involved in pregnancy-related decisions (Oosterhoff et al., 2008). When making reproductive decisions, special consideration is given for the family's need to have a male child. Oosterhoff and colleagues (2008) found that mothers-in-law pressure their daughters-in-law to have a child with the intention to continue their lineage.

Another explanation as to why women agree with the decisions made by their family members is financial dependency. A study found that women with low or no income found it difficult to voice their opinions compared to women who were employed and receiving a good income (Chi et al., 2011). Lack of income made women feel weak, helpless, and dependent on their family members (Chi et al., 2011). In a study, some Vietnamese women living with extended family members stated that they lacked control and power to make any decisions (Klingberg-Allvin, Binh, Johansson, & Berggren, 2008). Women in a study conducted in India experienced similar feelings (Suryavanshi et al., 2008). In this study, women living with HIV experienced three times more pressure to reproduce compared to women living without HIV (Suryavanshi et al., 2008). Women in Taiwan also felt that they lacked power to make reproductive decisions (Ko & Muecke,

2005). Women in this culture are required to comply with their father's decisions before marriage and husband's decisions after marriage (Ko & Muecke, 2005).

Further, some women living with HIV may also decide to have children due to the pressure they face from the community, especially if they have not divulged the information about their HIV status to the community members. For instance a woman living with HIV said: "When I am married I will have to have a baby because...only I and my boyfriend are aware that I am HIV positive and people will ask why am I not becoming pregnant in marriage" (Copper et al., 2007, p. 278). Although, it should be noted that family members are usually not aware of a couple's HIV status (Bunnell et al., 2005). It is known that individuals living with HIV, especially women are less likely to disclose their HIV status to their relatives in order to avoid stigma (Simbayi et al., 2007; Wolfe et al., 2006). For example, in the African and Asian cultures, women are expected to have children after marriage in order to continue the lineage (Heys, Kipp, Jhangri, Alibhai, & Rubaale, 2009; Oosterhoff et al., 2008). These cultures place high social value in the women's ability to have children (Heys et al., 2009; Oosterhoff et al., 2008). Due to these cultural values and expectations, women may decide to have children regardless of their HIV status. These women typically feel pressured to have children due to fear of stigma, discrimination, and isolation from the community. They want to be accepted by their culture and not be labelled as infertile (Heys et al., 2009; Myer, Morroni, & Cooper, 2006). Some women may choose to have children so that they can live a normal life and prevent people in the community from being suspicious about their HIV status (Cooper et al., 2007; Heys et al., 2009). Some women also reported that if the family members were aware of their HIV status they would criticize them for having children because of their

status. They feared the community would judge them negatively for having HIV and for taking unnecessary risks of transmitting this infection to their partner or children (Cooper et al., 2007).

Some studies have also reported that family did not have a significant influence on women's pregnancy decisions (Sowell & Misener, 1997). Therefore, some serodiscordant couples decided to have children regardless of their family member's opinions. In fact, some couples believed that family members will care for them during their pregnancy. For instance, in one study, 69% of serodiscordant couples believed that their family members will care for them during childbirth even if they were aware of their HIV status (Beyeza-Kashesya et al., 2010). Some women living with HIV also received assurances from family members to care for their children in event of their death (Kanniappan et al., 2008).

2.5 Partner Expectations and Pressures

In addition to familial and cultural pressures, expectations and pressures from the partner is another crucial factor which influences the reproductive decision-making process. A qualitative study examining the reasons for why women desire to have children identified partner's expectations and pressures to be one of the important factors in the pregnancy planning process (Siegal & Schrimshaw, 2001). Women's desire to have a child was largely dependent on her partner's wish to have a child (Nobrega et al., 2007; Beyeza-Kashesya et al., 2010; Cooper et al., 2007; de Silveira, Fonsechi-Carvasan, Makuch, Amaral, & Bahamondes, 2005; Nakayiwa et al., 2006). For some women, their HIV status did not discourage them from having children, especially if their husbands or

partners desired to have children (Beyeza-Kashesya et al., 2010; Chi et al., 2011; Cooper et al., 2007; Siegal & Schrimshaw, 2001). In serodiscordant couples, the desire to have children was 24 times higher in men living with HIV and 26 times higher in women living with HIV if their partner expressed the wish to have children (Beyeza-Kashesya et al., 2010). These results emphasize the strong influence partners' opinions have on the fertility decisions. Further, a study in Uganda reported that men living with HIV were more likely to desire children compared to women (Heys et al., 2009). Similar findings were also reported in Nigeria, where men desired to have multiple children in the presence of HIV (Oladapo, Daniel, Odusoga, & Ayoola-Sotubo, 2005). Partner's expectations to have children can also be seen in a large study conducted in the United States. Of the 2,864 people living with HIV, 59% of men expected to have a child in the future whereas 20% of their women partners did not expect to have a child (Chen et al., 2001). It was also found that men living with HIV desire to have children regardless of their country of origin (Cooper et al., 2009; Heys et al., 2009; Myer et al., 2007; Paiva et al., 2003; Paiva et al., 2007; Sherr & Barry, 2004).

Several reasons can be proposed to explain these findings. First, factors such as fertility, a man's status in society, and inheritance may influence the fertility desires in men. In addition, knowledge of which partner is HIV-positive also influences whether a man desires to have children (Sherr, 2010). For example, a study conducted in Africa found that 67% of women living with HIV in a serodiscordant relationship stated that their partner wanted to have children (Beyeza-Kashesya et al., 2010).

The importance of family formation may be another explanation for why partners pressure women to have children. Family formation is seen as an essential part of

marriage. Therefore, women believed that having a child is necessary in a loving relationship. For instance, a woman living with HIV stated “My husband told me to keep the fetus. Whether it would be born with HIV or not, he felt we must keep it. He said our life together would be insignificant if we did not have a child. I obeyed him and did not terminate my pregnancy” (Chi et al., 2011, p. 320). Some women also indicated the desire to provide a son to their partner (Siegal & Schrimshaw, 2001) to perhaps carry forward his family name. However, in some instances the pressure that the partner placed on the women to have a child caused problems in their relationship. Regardless of their HIV status, married women reported that they faced pressure to have children because otherwise their husbands may abandon them and find other women who will provide them with children (Cooper et al., 2007). Although women were concerned that their child would be born infected, they felt guilty and were ready to give into their partner’s pressures (Siegal & Schrimshaw, 2001). Further, research suggests that women living with HIV believe they have fewer opportunities for a relationship with a man and will settle down for a poor relationship due to their illness (Siegal & Schrimshaw, 2001). Chi and colleagues (2011) also found that lack of income made women feel helpless, and dependent on their partner or family members. As a result, women may be emotionally and/or financially dependent on their partner which may add more pressure to oblige to their partner’s wishes to have a child.

Violence and stigma experienced by women living with HIV may be another reason why women comply with their partner’s wishes. Many women are known to experience violence from their husbands, partners, or family members. Domestic and intimate partner violence is most common in women of reproductive age and those who

are pregnant (Sowell et al., 2002). The stigma associated with HIV infection, and the close association between violence and risky practices in individuals living with HIV may place women living with HIV at a high risk for violence. Several studies have estimated the prevalence of violence in women living with HIV to be between 15% and 68% (Cohen et al., 2000; Sowell, Seals, Moneyham, Guillory, & Mizuno, 1999; Sowell et al., 2002; Zierler et al., 2000). A possible explanation for this violence may be the environment that these women live in. Seal (1996) suggests that poverty, HIV infection, and substance abuse are interrelated with violence. Another explanation may be that HIV-related violence may be associated with the disclosure of the HIV-positive status to the partner or to the family members (Rothenberg & Paskey, 1995). It may also be possible that women living with HIV face violence if they do not agree with the partner's desire to have children. A study by Sowell and colleagues (2002) found that women living with HIV who have three or more children or an intention to have another child were factors that were significantly associated with violence. It may be possible that these women stayed in abusive relationships in order to provide for themselves and their children. It may also be possible that women wanted to have a child to depend on and add value to their lives (Sowell, Phillips, & Misener, 1999). Another explanation may be that these women may have thought that violence from partner and family member would stop if she were to have a child. However, the high level of violence in women living with HIV is a concern because it has the potential to be an obstacle for HIV prevention programs and further deteriorate the health of these women as well as compromise the health of their partner and the child.

Often time studies have shown that men make the final decisions in sexual and reproductive matters (Cubbins & Tanfer, 2000; Gomez & Marin, 1996; Ko & Muecke, 2005). A possible explanation from the men's perspective as to why they may put pressure on women to have children may be to secure their relationship with the women. In a qualitative study, a man expressed fear that his partner would leave him because they had no children together (Beyeza-Kashesya et al., 2009). Further, having children is important to men to ensure that their lineage is carried forward. Some societies are male dominated and have specific beliefs. For examples, in Uganda, there is a belief that "a man is considered to be man if he produces a child..." (Beyeza-Kashesya et al., 2009, p. 10).

Some women living with HIV do not desire to have children but their opinions are outweighed by their partner's expectations to have children (Aka-Dago-Akribi et al., 1997). Such strong desires to have children can be a potential concern since serodiscordant couples are at a risk of transmitting and acquiring the infection. In circumstances where couples have increased desire to have children, the risk of infecting the partner may not be given enough importance (Beyeza-Kashesya et al., 2009). It is already known that individuals on ART have a better quality of life and live longer. As a result, many individuals living with HIV desire to have children because they feel they will be able to raise their children. People on ART who desire children also use more of a temporary method of contraception or use contraception measures irregularly (Beyeza-Kashesya et al., 2009). Although ART is known to reduce the viral load and the risk of HIV transmission, use of irregular or temporary contraception by individuals living with HIV increase the risk of transmission of the infection (Elford, 2006). Therefore, health

care workers should provide information on conceiving to individuals on ART. The fact that ART does not totally eliminate the risk of HIV transmission should also be explained. Based on the findings reported above, it can be suggested that health care providers should provide guidance and assistance to serodiscordant couples regarding fertility decisions and assisted reproductive technologies. These results also emphasize the importance of involving men in the prevention of HIV infection and successful operation of fertility related programmes and initiatives.

2.6 Summary of the Literature Review

In summary, wide availability of combination ART and prevention of vertical transmission programs have reduced mortality and improved quality of life of people living with HIV. With these advances, more and more women living with HIV and their partners are deciding to have children or carry unplanned pregnancies to term. Several factors including age, gender, race/ethnicity, number of children, parenthood, risk of vertical transmission, stigma, availability of social support, and family, partner and cultural influences are known to be associated with the desire to have children in the future. Due to various reasons, women are often expected and pressured to comply with the wishes of their partners and family members. In addition to the fact that women desire to have children, research suggests that some women living with HIV fear stigmatization, violence, infidelity, and abandonment and give into the expectations and pressures of their partner and family. It is also known that some serodiscordant couples engage in unsafe sexual behaviours (Mitchell & Stephens, 2004). The desire to have children, fear of stigma of HIV and infertility, pressure from the partner, and expectations from the

family and society also put pressure on individuals living with HIV to engage in risky sexual behaviours in order to have a child. The strong desire of individuals living with HIV to have children in the future has several implications including the transmission of infection to the sexual partner as well as to the new born child. Although ART can reduce the risk of vertical transmission, vertical transmission does account for new infections in children. The risk of transmission of the infection to the sexual partner also increases as more serodiscordant couples desire to have children, especially if women are unaware of their HIV status and not receiving ART. Therefore, it is important to identify factors associated with family and partner expectations and pressures so that appropriate information can be provided to people living with HIV and their partners who desire to have children, so that their health, the health of their partner, and the health of the child is protected.

2.7 Rationale

Socio-demographic and biological factors are known to be associated with the desire and intention to have children. Family and partner expectations and pressure, and stigmatization of both HIV and infertility are also known to influence the desire to have children among individuals living with HIV. However, it is not known if family and partner expectations and pressure are associated with socio-demographic and biological factors. Also, a strong desire to have children combined with expectations and pressure from family and partner may increase the risk of both horizontal and vertical transmission. Therefore, it is important to identify the socio-demographic and biological factors associated with family and partner expectations and pressures so that health care

providers can help individuals living with HIV and their partners make informed reproductive decisions.

Further, research examining the factors associated with familial and partner expectations and pressures is lacking. Most previous studies designed to understand pregnancy desires were conducted before the widespread use of ART or included a small sample size. Further, the relationship between familial and partner expectations and pressures, and socio-demographic and biological factors in women living with HIV has not been investigated in Ontario (large population based). Ontario has a large number of immigrants and ethnic diversity, and therefore the results obtained from this study may provide insights for other similar places around the world.

CHAPTER 3. METHODOLOGY

3.1 Introduction

Data from the HIV Pregnancy Planning questionnaire was used to examine the relationship between family and partner expectation and pressure, and socio-demographic variables including age, gender, race/ethnicity, marital status, education, socioeconomic status, partner and cultural influences, and family size. This chapter describes the variables included in the analyses and the statistical procedures used to analyze the data.

3.2 Study Participants

A cross-sectional study was conducted in Ontario, Canada to collect data regarding fertility desires, intentions, actions, and knowledge of fertility options of women living with HIV. In this study, the following inclusion criteria were implemented: 1) HIV-positive, 2) biologically female, 3) of reproductive age (18 to 52 years old), 4) living in Ontario, Canada, and 5) ability to read English or French (Loutfy et al., 2009). A sample size calculation was performed before initiating recruitment of participants. According to the sample size calculation, a total of 525 participants were required. However, 493 participants were recruited of which 490 met the inclusion criteria.

3.3 Recruitment Process

Participants were recruited from October 5th 2007 to March 31st 2009 from 28 AIDS service organizations, 8 primary care and HIV clinics, and 2 community health centres from Ontario. All AIDS service organizations in Ontario, all clinics and community health centres providing care to women living with HIV were sent an email

inviting them to participate in the study. An invitation email was sent to a total of 56 organization sites of which 18 sites refused to participate (Loutfy et al., 2009). The response rate was calculated at 68%.

After verifying the inclusion criteria, recruitment was done by research staff at each site. Participants were recruited consecutively during the study period. Stratified sampling method was used to recruit participants into the study. Participants were stratified based on geographic region. This method ensured that the study sample was representative of the women living with HIV in Ontario (Loutfy et al., 2009).

3.4 The HIV Pregnancy Planning Questionnaire

The HIV Pregnancy Planning Questionnaire consisted of 189 items. This questionnaire was created based on four validated surveys including the Contraceptive Decisions of HIV Positive Women, HIV Cost and Services Utilization Study, Center for Special Studies, and the Pregnancy Planning Instrument used for non-pregnant women (Loutfy et al., 2009). The questions of the survey were categorized into 12 sections which are as follows: 1) desire to have children in the future 2) intention to have children in the future 3) measures taken to become pregnant 4) questions related to use of birth control, menstrual cycle, and sexual history 5) pregnancy and birth history 6) support from friends, family members, and health care professionals for becoming pregnant 7) satisfaction with health care professionals 8) assessment of resources 9) HIV medical history 10) demographics 11) anxiety and depression 12) HIV stigma (Loutfy et al., 2009).

Face validity was assessed by using two focus groups which consisted of a total of 20 women living with HIV. These participants verified that the survey questions measured what they were designed to measure for the 12 different sections (Loutfy et al., 2009). These women were instructed to review each item to ensure that the items were comprehensive, clear, and relevant. Pilot testing of this questionnaire was conducted using 52 women who met the selection criteria. Content validity was established by using questions from four previously verified surveys including the Contraceptive Decisions of HIV Positive Women, HIV Cost and Services Utilization Study, Center for Special Studies, and Pregnancy Planning Instrument used for non-pregnant women (Loutfy et al., 2009). In addition, items were also created based on identification of factors associated with fertility decisions in women living with HIV, and discussing the items with health care providers, HIV experts, and people from the community (Loutfy et al., 2009). For some components of the questionnaire, factor analysis was used to test the reliability, validity, and items' correlation with their domains. Cohen's kappa statistic was used to measure internal consistency of the questionnaire.

3.5 Measurement of Study Variables

3.5.1 Dependent Variables

3.5.1.1 Family Expectation and Pressure

One of the primary outcomes of interest is family expectation and pressure. The questions used to represent this outcome were: "My family wants me to become pregnant" and "If I had a child, it would make my family happy". The responses to these questions range from 1=strongly disagree, 2=disagree, 3=neither disagree nor agree,

4=agree, and 5=strongly agree. For the purpose of this study, family expectations and pressures was grouped into 1=disagree (including responses 1, 2, and 3), and 2 = agree (including responses 4, and 5). This variable was dummy coded and the ‘disagree’ category was used as the reference group.

3.5.1.2 Partner Expectation and Pressure

Another primary outcome of interest is partner expectation and pressure. The questions used to represent this outcome were: “My partner wants me to become pregnant” and “If I had a child, it would make my partner happy”. The responses to these questions range from 1=strongly disagree, 2=disagree, 3=neither disagree nor agree, 4=agree, and 5=strongly agree. In this study, partner expectations and pressures was grouped into 1=disagree (including responses 1, 2, and 3) and 2=agree (including responses 4 and 5). This variable was dummy coded and the ‘disagree’ category was used as the reference group.

3.5.2 Independent Variables

3.5.2.1 Age

Age of the participant was obtained by asking the participant to record their age in years on the survey. In the analysis age was used as a continuous variable.

3.5.2.2 Ethnic background

Ethnic background was obtained by asking the participants to check as many categories that apply to them. These categories included 1=African, 2=Caribbean, 3=Asian, 4=Middle Eastern, 5=European, 6=British, 7=French, 8=Hispanic or Latina, 9=Aboriginal (First Nations, Inuit, Metis), and 10=Other race. In the analysis, ethnic

background was introduced as a dummy variable. ‘African’ category was used as the reference group.

3.5.2.3 Religion

Participant’s religion information was obtained by asking them to check the appropriate category that applied to them. These categories included 1=Catholic, 2=Protestant, 3=Christian (if not Catholic or Protestant), 4=Jewish, 5=Muslim, 6=Hindu, 7=Sikh, 8=Buddhist, 9=Eastern Orthodox, 10=African Traditional, 11=Aboriginal Traditional, 12=New Age, 13=Agnostic, and 14=None/Atheist. Participants were also given the option to write down their religion if they cannot identify themselves with any of the given categories (15=other). In the analysis, religion was introduced as a dummy variable. ‘Christian’ category was used as the reference group.

3.5.2.4 Country of Birth

Country of birth was obtained by asking the participant to record what country they were born. In the analysis, country of birth will be introduced as a dummy variable. ‘Africa’ category was used as the reference group.

3.5.2.5 Region in Ontario

Participants were asked to write the name of the city they lived in when they filled out the questionnaire. Their responses were grouped into the following regions: 1=Toronto, 2=Ottawa, 3=Central West, 4=Central East, 5=Southwest, 6=Northern and 7=Eastern. This variable was dichotomized into 1=Toronto and 2=Non-Toronto (responses 2-7). In the analysis, this variable was dummy coded and ‘Non-Toronto’ category was used as the reference group.

3.5.2.6 *Marital Status*

Marital status was obtained by asking the participants to check as many categories that applied to them. These categories included 1=divorce, 2=widowed, 3=never married, 4=living with a partner, 5=married, and 6=common-law partner. In this study, the groups were re-coded as 1=never married (response 3), 2=living with a partner (responses 4, 5, and 6), and 3=divorced or widowed (responses 1 and 2). In the analysis, marital status was introduced as a dummy variable. ‘Never married’ category was used as the reference group.

3.5.2.7 *Annual Household Income*

Annual household income was obtained by asking the participants to indicate their income. Options included 1=\$0-19,999, 2=\$20,000-39,999, 3=\$40,000-59,999, 4=\$60,000-79,999, 5=\$80,000-99,999, 6=\$100,000-119,999, 7=\$120,000 or more, and 8=I do not know. In this study income was grouped into 1=<\$20,000, 2=\$20,000-40,000, and 3=>\$40,000. Annual household income was introduced in the regression model as a dummy variable. Income group ‘>\$40,000’ was used as the reference group.

3.5.2.8 *Education*

Education level of the participants was obtained by asking them to indicate the highest level of education they have completed. Options included 1=Did not attend high school, 2=Some high school education, 3=High school diploma, 4=Some university, college, or technical school education, 4=College diploma or technical certificate, 5=Bachelor’s degree, 6=Some graduate or professional school, and 7=Graduated graduate or professional school. Education was grouped into ‘high school education’ and

‘high school or higher education’. In the analysis, education level was dummy coded. ‘High school or higher education’ category was used as the reference group.

3.5.2.9 Number of Years Lived in Canada

Number of years lived in Canada was obtained by asking the participants to indicate the number of months they have lived in Canada. Number of months was divided by 12 to obtain number of years. This variable was used as a continuous variable in the analysis.

3.5.2.10 Number of Lifetime Births

The number of lifetime births was obtained by asking the participant to circle the number that answers the question “How many times have you given birth ever in your lifetime?”. Participants were asked to indicate a number ranging from 0 to 8 or 9 or more. Number of lifetime births was grouped into ‘less than 2’ and ‘2 or more’. In the analysis, ‘2 or more’ group was used as the reference group.

3.5.2.11 Hepatitis C

Information on hepatitis C co-infection was obtained by asking the participant to indicate if they had the infection or not. In the analysis, not having hepatitis C infection was used as the reference group.

3.5.2.12 Recent Viral Load

Participants were asked to report their most recent viral load count. In the analysis, this variable was used as a continuous variable.

3.5.2.13 Recent CD4 Count

Participants were asked to report their most recent CD4 cell count. CD4 counts were grouped into ‘less than 200 cells/mm³’ and ‘200 or more cell/mm³’. In the analysis, ‘less than 200 cells/mm³’ group was used as the reference group.

3.5.2.14 HIV Medication

Participants were asked to report whether they had ever taken any medications for HIV. Responses were coded as ‘No’ and ‘Yes’. ‘Yes’ group was used as the reference group in the analysis.

3.5.2.15 Current HIV Treatment

Participants were asked to report whether they were currently receiving any treatment (ART) for HIV. Responses were coded as ‘No’ and ‘Yes’. ‘Yes’ group was used as the reference group in the analysis.

3.6 Ethics Approval

Ethics approval for the entire study was received from the Women’s College Research Institute Research Ethics Board. Ethics approval was also obtained from each site’s research ethics board before recruiting participants into the study. Written informed consent was also obtained from each participant before starting any data collection. After completing the survey, participants were given contact information for counseling in case it was required.

For this study, approval from the Research Ethics Board at Brock University was obtained for secondary data use.

3.7 Statistical Analysis

3.7.1 Univariate Analysis

Descriptive statistics including means (standard deviations) for continuous variables and frequency (proportions) for categorical variables were performed to get an overview of the entire cohort.

3.7.2 Logistic Regression

Regression analysis is a technique used for prediction, hypothesis testing, and modeling the relationship between dependent variable and one or more independent variables. Specifically, regression analysis is used to understand the change in dependent variable with regards to change in the independent variable, while other independent variables are held constant. Logistic regression is used when the dependent variable is dichotomous. The independent variables can be continuous or categorical variables. Logistic model is based on the logistic function which describes probability. The probability can range between 0 and 1, providing an estimate of the risk of getting the outcome (Norman & Streiner, 2008). The logit values from logistic regression can be interpreted in the same way as linear regression. The values vary between 0 and 1 and the logit changes probabilities into odds. Odds ratio greater than 1 indicate higher odds of the outcomes and odds ratio less than 1 indicate lower odds of the outcome. Odds ratio of 1 indicates no association between the risk factor and the outcome.

3.7.3 Bivariate Analysis

Unadjusted logistic regression models were created for family expectation and pressure, and each of the independent variables including age, ethnic background, religion, country of birth, region in Ontario, marital status, annual household income, education, number of lifetime births, number of years lived in Canada, hepatitis C infection, ever taken HIV medications, current intake of HIV medications, CD4 counts, and viral load. Similarly, logistic regression models were also created for partner expectation and pressure and each of the independent variables. The unadjusted odds ratios were reported with the 95% confidence intervals.

3.7.4 Multivariate Analysis

Multivariate logistic regression with progressive adjustment was used to examine the relationship between family expectation and pressure, and the socio-demographic variables. Predictors showing statistical significance in the unadjusted regression analysis were considered as potential independent variables associated with family expectation and pressure to have children. The final multivariate logistic regression model predicting family expectation and pressure included predictors that are significant at $p < 0.2$ in the unadjusted bivariate logistic regression analysis. Based on literature, variables including ethnic background, marital status, region in Ontario, and CD4 counts were included in the model a priori. Similar approach was used for predicting partner expectations and pressures. The adjusted odds ratios were reported with the 95% confidence intervals. All statistical analyses was performed using SAS 9.3 (SAS Institute Inc. Cary, NC) set for a two-tailed test and a statistical significance level set at $p < 0.05$.

3.7.5 Missing Data

Missing values were examined for family pressure and partner pressure. Generally, missing data for less than 10% of the observations can be ignored (Hair, Black, Babin, Anderson & Tatham, 2006). For family pressure, less than 1% of the data were missing. However, for partner pressure 31% of the data were missing. Comparisons for key variables including age (p-value: 0.1373), race (p-value: 0.1667), education (p-value: 0.8848), lifetime births (p-value: 0.9997), region in Ontario (p-value: 0.5137), recent CD4 count (p-value: 0.2541), and number of years lived in Canada (p-value: 0.0927) were made between participants who provided responses to the partner pressure questions and those who did not provide responses to these questions and no significant difference was found.

3.7.6 Tests for Assumptions

The Student's t-test was used to examine if the means of the key explanatory variables differed between women who experienced pressures and those who did not. The Student's t-test has three assumptions: (1) the two samples are independent, (2) normality, and (3) equality of variance. The assumption of independence requires that the response of participants in one group is independent and does not influence the response of the participants in the other group. The normality assumption can be confirmed through examining the measures of central tendency (mean, median, and mode), the results of the Shapiro-Wilk (SW), Kolmogorov-Smirnov (KS), or the Anderson-Darling test (AD), as well as by having a large sample size (larger than 30). The results of the

SW, KS, and AD tests were significant suggesting a deviation of the distribution from normality. However, the Central Limit Theorem states that if the sample size is larger than 30, the normality assumption for all variables is considered to be met. The sample size for variables in this study was larger than 30 and therefore the variables were assumed to be normally distributed (Norman & Streiner, 2008). Finally, the equality of variance assumption requires that the variance of the response variable between the two groups is approximately equal. Levene's test was used to test this assumption. Results of the Satterthwaite test were reported if Levene's test indicated unequal variances. Satterthwaite test calculates the t-statistic and p-value taking into consideration that variances between groups were unequal (Norman & Streiner, 2008).

Chi-square test of independence was used to examine if there was a significant difference in proportions of the key explanatory variables among women who experienced pressures and those who did not experience pressures. The chi-square test requires that the expected frequency in all cells is greater than 5 (Norman & Streiner, 2008). This requirement was met for all chi-square tests performed in this study.

Logistic regression was used to examine the association between family and partner pressures, and socio-demographic and biological factors. Unlike linear regression, no assumptions are made about the distributions of the variables in logistic regression (Norman & Streiner, 2008). However, multicollinearity among the independent variables was examined using the 'Tolerance' and 'Variance Inflation Factor' statistics. Low tolerance values indicate high multicollinearity. In the presence of multicollinearity, the standard error values are overestimated (Norman & Streiner, 2008). Variance inflation factor scores is a measure of how much the standard error of the coefficients are inflated

as a result of multicollinearity. While strict cut-off values are not available for tolerance scores, variance inflation factor scores above 10 correspond to the presence of multicollinearity (Norman & Streiner, 2008). In the analysis, tolerance values were high and all variance inflation factor scores were below 10 suggesting that multicollinearity has not occurred.

CHAPTER 4. RESULTS

4.1 Data Analysis

The purpose of this study was to examine the socio-demographic and biological factors associated with family and partner pressure to conceive in women living with HIV. Several statistical tests including Student's t-test, chi-square test, and multivariate logistic regression with progressive adjustment were used to analyze the data. This chapter discusses the results obtained from analyzing the data.

4.2 Descriptive Analysis

The HIV Pregnancy Planning Questionnaire was used to collect the data. The study included 490 participants. After excluding participants who did not provide information on family pressure and partner pressure to conceive, the sample size was reduced to 486 participants and 336 participants, respectively. Among 486 participants, 247 (50.8%) indicated having family pressure and 239 (49.2%) indicated not having family pressure to conceive. Among the 336 participants, 165 (49.1%) indicated having pressure from partner and 171 (50.9%) indicated not having pressure from partner to conceive. Among women who indicated not having partner pressure, 49.4% had a partner, and among women who indicated having partner pressure, 64.3% had a partner. The mean age of the participants was 37.5 (SD=7.5) years.

Student's t-test and chi-square test were used to compare the means and proportions of key variables among the pressure groups. Characteristics for the study variables for participants by family pressure groups are reported in Table 1. Women who reported pressure from the family to conceive were younger (36.0 vs. 39.0, p-value:

<.0001), spent fewer years in Canada (14.0 vs. 24.2, p-value: <.0001), and had higher proportions for African race (58.0% vs. 32.2%, p-value: <.0001), born in Africa (57.0% vs. 30.0%, p-value: <.0001), married or in a common-law relationship (42.2% vs. 30.2%, p-value: 0.0093), living in Toronto (57.3% vs. 45.4%, p-value: 0.0497), less than two lifetime births (57.3% vs. 47.5%, p-value: 0.0321), were not positive for hepatitis C (92.3% vs. 78.7%, p-value: <.0001), and had a higher CD4 count (93.7% vs. 86.2%, p-value: 0.0196) compared to women who did not report pressure from family. There was no significant difference in the mean viral load count and the proportions of annual household income, education, ART, HIV medication between women who reported pressures and those who did not report pressure from family.

Characteristics for key study variables for participants by partner pressure groups are reported in Table 2. Women who reported pressure from their partner to conceive were younger (35.4 vs. 38.4, p-value: 0.0002), spent fewer years in Canada (15.2 vs. 24.3, p-value: <.0001), and had higher proportions of African race (52.2% vs. 32.5%, p-value: 0.0005), born in Africa (52.2% vs. 28.1%, p-value: <0.0001), living in Toronto (61.9% vs. 41.4%, p-value: 0.0004), and had a higher CD4 count (95.0% vs. 87.7%, p-value: 0.0436). There was no significant group difference in mean viral load count and the proportions of religion, marital status, annual household income, education level, number of lifetime births, hepatitis C infection, ART, and ever received HIV medications.

4.3 Unadjusted Logistic Regression Analysis

Unadjusted logistic regression analysis was performed to identify variables that are significant at $p < 0.2$ to be included in the multivariate logistic regression analysis. Results for the unadjusted odds ratio and 95% confidence intervals are reported in Table 3. Results from the unadjusted regression analysis showed that older age, increased number of years lived in Canada, women of European-British and French-Canadian races, and women born in Canada or Caribbean had lower odds of family pressure to conceive. Women of Muslim religion, had hepatitis C co-infection, lived in the Toronto region, had less than two lifetime births, and had a CD4 count that was greater than 200 cells/mm³ had higher odds of family pressure to conceive. For partner pressure, older age, increased number of years lived in Canada, women of European-British and French-Canadian races, women born in Canada, and women of protestant religion had lower odds of partner pressure to conceive. Women who were married or lived with a common-law partner, lived in the region of Toronto, and had a CD4 count greater than 200 cells/mm³ had higher odds of partner pressure to conceive.

4.4 Multivariate Logistic Regression Analysis

Multivariate logistic regression analysis with progressive adjustment was used to identify the socio-demographic and biological factors associated with family and partner pressure to conceive. Results for the multivariate logistic regression analysis for family and partner pressures to conceive, adjusted for covariates are presented in Tables 4 and 5, respectively. Variables that were significant at p-value of 0.20 in the unadjusted analysis were included in multivariate logistic regression. Age, race/ethnicity, marital status,

region in Ontario, number of years lived in Canada, number of lifetime births, CD4 counts, and country of birth were the covariates included in the model for family pressure to conceive. After adjusting for covariates, on average, every one year increase in the number of years lived in Canada was associated with a 0.97 (95% CI: 0.93, 1.00) lower odds of family pressure to conceive. Also, women who lived in Toronto region had a 0.44 (95% CI: 0.24, 0.82) lower odds of family pressure to conceive. Women who reported less than two lifetime births had 2.07 (95% CI: 1.17, 3.68) higher odds of family pressure to conceive. Further, women who were married or living with a common-law partner was associated with a 2.05 (95% CI: 1.04, 4.07) higher odds of family pressure to conceive. There was no significant effect of race or CD4 counts on family pressure to conceive.

Age, race/ethnicity, marital status, region in Ontario, number of years lived in Canada, number of lifetime births, CD4 count, education level, ever taken medications for HIV, co-infection with hepatitis C, and country of birth were the variables included in the model for partner pressure to conceive. On average, every one year increase in age was associated with 0.95 (95% CI: 0.90, 0.99) lower odds of being pressured by their partner to conceive. Women who were married or living with a common-law partner had a 2.50 (95% CI: 1.06, 5.89) and those who lived in Toronto region had a 2.18 (95% CI: 1.14, 4.17) higher odds of partner pressure to conceive. CD4 count was not significantly associated with partner pressure to conceive.

Model fit statistics for family and partner pressure to conceive are presented in Table 6. This table should be interpreted in the following manner: For family pressure, when years lived in Canada was entered in the model, the AIC score was 379.369. When years lived in Canada and number of lifetime births were entered together, the AIC score

was 375.300. When years lived in Canada, number of lifetime births, and region in Ontario were entered in the same model, the AIC score was 371.652 and so forth. Lower AIC scores indicate that the model has a better fit. For family pressure it can be seen that the model including years lived in Canada, region, marital status, race, recent CD4 count, and age provided the lowest AIC score (364.225), and for partner pressure, the model including marital status, age, region, recent CD4 count, and years lived in Canada provided the lowest AIC score (239.540). For family pressure, the Wald Chi-square value was 45.10 (p-value: <.0001), and for partner pressure, the Wald Chi-square value was 18.02 (p-value: 0.0062) suggesting that both these models have a good fit.

Table 1: Descriptive characteristics of the participants by family pressure status

| Variables | Family Pressure | No Family Pressure | p-value |
|---|-------------------------------|-------------------------------|----------------|
| | Mean (SD) or n (%) | Mean (SD) or n (%) | |
| Age (years) [mean (SD)] | 36.0 (7.1) | 39.0 (7.5) | <.0001 |
| No. of years lived in Canada [mean (SD)] | 14.0 (14.1) | 24.2 (1.2) | <.0001 |
| Race [n (%)] | | | |
| African | 138 (58.0) | 73 (32.2) | <.0001 |
| Caribbean | 26 (10.9) | 25 (11.0) | <.0001 |
| European-British, French-Canadian | 28 (11.8) | 78(34.4) | <.0001 |
| Other | 46 (19.3) | 51 (22.5) | <.0001 |
| Country of Birth [n (%)] | | | |
| Africa | 138 (57.0) | 69 (30.0) | <.0001 |
| Canada | 64 (26.5) | 122 (52.8) | <.0001 |
| Caribbean | 25 (10.3) | 24 (10.4) | <.0001 |
| Other | 15 (6.2) | 16 (6.9) | <.0001 |
| Religion [n (%)] | | | |
| Christian | 71 (29.5) | 65 (28.0) | 0.0010 |
| Catholic | 56 (23.2) | 64 (27.6) | 0.0010 |
| Protestant | 29 (12.0) | 43 (18.5) | 0.0010 |
| Atheist | 8 (3.3) | 15 (6.5) | 0.0010 |
| Muslim | 18 (7.5) | 3 (1.3) | 0.0010 |
| Aboriginal | 6 (2.5) | 10 (4.3) | 0.0010 |
| Other | 53 (22.0) | 32 (14.0) | 0.0010 |
| Marital Status [n (%)] | | | |
| Never married | 71 (30.6) | 64 (28.8) | 0.0093 |
| Married or common-law partner | 98 (42.2) | 67 (30.2) | 0.0093 |
| Divorced or widowed | 50 (21.6) | 68 (30.6) | 0.0093 |

| | | | |
|--|------------|------------|--------|
| Geographic Region [n (%)] | | | |
| Northern | 8 (3.4) | 10 (4.4) | 0.0497 |
| Eastern | 1 (0.4) | 8 (3.5) | 0.0497 |
| Central East | 2 (0.85) | 1 (0.44) | 0.0497 |
| Central West | 18 (7.69) | 17 (7.49) | 0.0497 |
| Southwest | 18 (7.69) | 32 (14.1) | 0.0497 |
| Ottawa | 30 (12.8) | 30 (13.2) | 0.0497 |
| Toronto | 134 (57.3) | 103 (45.4) | 0.0497 |
| Annual household income [n (%)] | | | |
| \$0-19,999 | 91 (46.4) | 98 (47.1) | 0.6358 |
| \$20,000-39,999 | 63 (32.1) | 59 (28.4) | 0.6358 |
| >\$40,000 | 42 (21.43) | 51 (24.5) | 0.6358 |
| Education [n (%)] | | | |
| Did not attend high school | 11 (5.0) | 9 (4.4) | 0.7747 |
| High school or higher education | 210 (95.0) | 196 (95.6) | 0.7747 |
| No. of lifetime births [n (%)] | | | |
| 0 or 1 birth | 138 (57.3) | 112 (47.5) | 0.0321 |
| >=2 births | 103 (42.7) | 124 (52.5) | 0.0321 |
| Hepatitis C [n (%)] | | | |
| Yes | 18 (7.7) | 49 (21.3) | <.0001 |
| No | 215 (92.3) | 181 (78.7) | <.0001 |
| Antiretroviral therapy [n (%)] | | | |
| Yes | 184 (76.0) | 169 (72.5) | 0.3826 |
| No | 58 (24.0) | 64 (27.5) | 0.3826 |
| HIV medication [n (%)] | | | |
| Yes | 207 (85.5) | 203 (85.7) | 0.9710 |
| No | 35 (14.5) | 34 (14.35) | 0.9710 |
| CD4 counts (cells/mm³) | | | |
| <200 | 11 (6.3) | 24 (13.8) | 0.0196 |
| >=200 | 164 (93.7) | 150 (86.2) | 0.0196 |
| Viral Load [mean (SD)] | 2.9 (1.0) | 2.8 (1.0) | 0.2508 |

Table 2: Descriptive characteristics of the participants by partner pressure status

| Variables | Partner Pressure Mean (SD) or n (%) | No Partner Pressure Mean (SD) or n (%) | p-value |
|---|--|---|----------------|
| Age (years) [mean (SD)] | 35.4 (6.6) | 38.4 (7.9) | 0.0002 |
| No. of years lived in Canada [mean (SD)] | 15.2 (14.1) | 24.3 (16.9) | <.0001 |
| Race [n (%)] | | | |
| African | 84 (52.2) | 52 (32.5) | 0.0005 |
| Caribbean | 18 (11.2) | 16 (10.0) | 0.0005 |
| European-British, French-Canadian | 26 (16.2) | 54 (33.8) | 0.0005 |
| Other | 33 (20.5) | 38 (23.8) | 0.0005 |
| Country of Birth [n (%)] | | | |
| Africa | 85 (52.2) | 46 (28.1) | <.0001 |
| Canada | 50 (30.7) | 88 (53.7) | <.0001 |
| Caribbean | 20 (12.3) | 15 (9.2) | <.0001 |
| Other | 8 (4.9) | 15 (9.2) | <.0001 |
| Religion [n (%)] | | | |
| Christian | 52 (32.0) | 45 (26.8) | 0.0822 |
| Catholic | 38 (23.6) | 47 (28.0) | 0.0822 |
| Protestant | 15 (9.3) | 30 (17.9) | 0.0822 |
| Atheist | 7 (4.35) | 11 (6.6) | 0.0822 |
| Muslim | 11 (6.8) | 6 (3.6) | 0.0822 |
| Aboriginal | 5 (3.1) | 7 (4.2) | 0.0822 |
| Other | 33 (20.5) | 22 (13.1) | 0.0822 |
| Marital Status [n (%)] | | | |
| Never married | 31 (19.8) | 43 (27.2) | 0.0648 |
| Married or common-law partner | 81 (51.6) | 62 (39.2) | 0.0648 |
| Divorced or widowed | 25 (15.9) | 37 (23.4) | 0.0648 |

| | | | |
|--|------------|------------|--------|
| Geographic Region [n (%)] | | | |
| Northern | 7 (4.5) | 7 (4.3) | 0.0004 |
| Eastern | 2 (1.29) | 6 (3.7) | 0.0004 |
| Central East | 2 (1.3) | 0 (0) | 0.0004 |
| Central West | 11 (7.1) | 13 (8.0) | 0.0004 |
| Southwest | 4 (2.6) | 26 (16.1) | 0.0004 |
| Ottawa | 16 (10.32) | 23 (14.2) | 0.0004 |
| Toronto | 96 (61.9) | 67 (41.4) | 0.0004 |
| Annual household income [n (%)] | | | |
| \$0-19,999 | 53 (38.4) | 66 (46.2) | 0.3510 |
| \$20,000-39,999 | 46 (33.3) | 38 (26.6) | 0.3510 |
| >\$40,000 | 39 (28.3) | 39 (27.3) | 0.3510 |
| Education [n (%)] | | | |
| Did not attend high school | 5 (3.3) | 9 (6.3) | 0.2404 |
| High school or higher education | 145 (96.7) | 135 (93.8) | 0.2404 |
| No. of lifetime births [n (%)] | | | |
| 0 or 1 birth | 90 (56.3) | 81 (47.9) | 0.1311 |
| >=2 births | 70 (43.8) | 88 (52.1) | 0.1311 |
| Hepatitis C [n (%)] | | | |
| Yes | 19 (12.2) | 29 (17.7) | 0.1682 |
| No | 137 (87.8) | 135 (82.3) | 0.1682 |
| Antiretroviral therapy [n (%)] | | | |
| Yes | 123 (75.9) | 125 (75.8) | 0.9716 |
| No | 39 (24.1) | 40 (24.2) | 0.9716 |
| HIV medication [n (%)] | | | |
| Yes | 137 (85.1) | 152 (90.5) | 0.1353 |
| No | 24 (14.9) | 16 (9.5) | 0.1353 |
| CD4 counts (cells/mm³) | | | |
| <200 | 6 (5.0) | 16 (12.3) | 0.0436 |
| >=200 | 113 (95.0) | 114 (87.7) | 0.0436 |
| Viral Load [mean (SD)] | | | |
| | 2.9 (1.0) | 2.9 (0.9) | 0.9986 |

Table 3: Unadjusted logistic regression results for family and partner pressure to conceive

| Variables | Family pressure with “neutral” grouped as “disagree” n = 486 | | Partner pressure with “neutral” grouped as “disagree” n = 336 | |
|----------------------------------|---|-------------|--|------------|
| | OR | 95% CI | OR | 95% CI |
| Age (yrs) | 0.95 | 0.92, 0.97 | 0.95 | 0.92, 0.97 |
| Years in Canada | 0.96 | 0.95, 0.97 | 0.96 | 0.95, 0.98 |
| Race | | | | |
| Caribbean | 0.55 | 0.30, 1.02 | 0.70 | 0.33, 1.49 |
| European-British/French-Canadian | 0.19 | 0.11, 0.32 | 0.30 | 0.17, 0.53 |
| Aboriginal/Other Race | 0.48 | 0.29, 0.78 | 0.54 | 0.30, 0.96 |
| African | 1.00 | | 1.00 | |
| Hepatitis C co-infected | 3.23 | 1.82-5.75 | 1.55 | 0.83, 2.90 |
| Annual Household income: | | | | |
| \$0-19,999 | 1.13 | 0.69, 1.86 | 0.80 | 0.45, 1.42 |
| \$20,000-39,999 | 1.30 | 0.76, 2.23 | 1.21 | 0.65, 2.25 |
| >\$40,000 | 1.00 | | 1.00 | |
| Birth Place | | | | |
| Canada | 0.26 | 0.17, 0.40 | 0.31 | 0.19, 0.51 |
| Caribbean | 0.52 | 0.28, 0.98 | 0.72 | 0.34, 1.54 |
| Other | 0.47 | 0.22, 1.00 | 0.29 | 0.11, 0.73 |
| Africa | 1.00 | | 1.00 | |
| Religion | | | | |
| Catholic | 0.80 | 0.49, 1.13 | 0.70 | 0.39, 1.26 |
| Protestant | 0.62 | 0.35, 1.10 | 0.43 | 0.21, 0.90 |
| Atheist/none | 0.49 | 0.19, 1.23 | 0.55 | 0.20, 1.54 |
| Muslim | 5.49 | 1.55, 19.50 | 1.59 | 0.54, 4.63 |
| Aboriginal Traditional | 0.55 | 0.19, 1.60 | 0.62 | 0.18, 2.08 |
| Other | 1.52 | 0.87, 2.64 | 1.30 | 0.66, 2.54 |
| Christian | 1.00 | | 1.00 | |

| | | | | |
|---|------|------------|------|------------|
| Marital Status | | | | |
| Married or Common-law partner | 1.32 | 0.83, 2.09 | 1.81 | 1.03, 3.20 |
| Divorced/Widowed | 0.66 | 0.40, 1.09 | 0.94 | 0.47, 1.86 |
| Living with a partner (neither married nor common-law) | 0.51 | 0.24, 1.09 | 1.73 | 0.78, 3.87 |
| Never married | 1.00 | | 1.00 | |
| Region | | | | |
| Toronto | 1.73 | 1.20, 2.47 | 2.17 | 1.40, 3.36 |
| Non-Toronto | 1.00 | | 1.00 | |
| Education | | | | |
| Less than high school | 1.14 | 0.46, 2.81 | 0.52 | 0.17, 1.58 |
| High school or higher | 1.00 | | 1.00 | |
| Lifetime births | | | | |
| 0-1 | 1.48 | 1.03, 2.13 | 1.40 | 0.91, 2.16 |
| ≥2 | 1.00 | | 1.00 | |
| Ever taken HIV medication | | | | |
| No | 1.01 | 0.61, 1.68 | 1.66 | 0.85, 3.26 |
| Yes | 1.00 | | 1.00 | |
| Currently taking HIV medication | | | | |
| No | 0.83 | 0.55, 1.26 | 0.99 | 0.60, 1.64 |
| Yes | 1.00 | | 1.00 | |
| Recent CD4 count | | | | |
| CD4 ≥ 200 (cells/mm ³) | 2.39 | 1.13-5.04 | 2.64 | 1.00, 7.00 |
| CD4 ≤ 200 (cells/mm ³) | 1.00 | | 1.00 | |
| Viral Load (log₁₀copies/ml) | 1.11 | 0.93, 1.33 | 1.00 | 0.80, 1.25 |

Table 4: Multivariate logistic regression model for family pressure to conceive

| Variables | OR | 95% CI | Beta Estimate | Standard Error | p-value |
|---|-----------|---------------|----------------------|-----------------------|----------------|
| Age (yrs) | 0.97 | 0.93, 1.00 | -0.03 | 0.02 | 0.1806 |
| Race | | | | | |
| Caribbean | 0.74 | 0.29, 1.92 | -0.30 | 0.49 | 0.5377 |
| European-British/French-Canadian | 0.46 | 0.17, 1.25 | -0.79 | 0.51 | 0.1267 |
| Aboriginal/Other Race | 1.48 | 0.55, 4.00 | 0.39 | 0.51 | 0.4401 |
| African | 1.00 | | | | |
| Marital Status | | | | | |
| Married or Common-law partner | 2.05 | 1.04, 4.07 | 0.71 | 0.35 | 0.0394 |
| Divorced/Widowed | 0.90 | 0.41, 1.96 | -0.11 | 0.40 | 0.7838 |
| Living with a partner (neither married nor common-law) | 0.68 | 0.25, 1.87 | -0.39 | 0.52 | 0.4525 |
| Never married | 1.00 | | | | |
| Region | | | | | |
| Toronto | 0.44 | 0.24, 0.82 | -0.82 | 0.32 | 0.0098 |
| Non-Toronto | 1.00 | | | | |
| Years in Canada | 0.96 | 0.93, 0.99 | -0.04 | 0.01 | 0.0030 |
| Lifetime births | | | | | |
| 0-1 | 2.07 | 1.17, 3.68 | 0.73 | 0.29 | 0.0126 |
| ≥2 | 1.00 | | | | |
| Recent CD4 count | | | | | |
| CD4 ≥ 200 (cells/mm ³) | 1.97 | 0.82, 4.71 | 0.68 | 0.45 | 0.1294 |
| CD4 ≤ 200 (cells/mm ³) | 1.00 | | | | |

Table 5: Multivariate logistic regression model for partner pressure to conceive

| Variables | OR | 95% CI | Beta Estimate | Standard Error | p-value |
|---|-----------|---------------|----------------------|-----------------------|----------------|
| Age (yrs) | 0.95 | 0.90, 0.99 | -0.05 | 0.02 | 0.0234 |
| Marital Status | | | | | |
| Married or Common-law partner | 2.50 | 1.06, 5.89 | 0.92 | 0.44 | 0.0361 |
| Divorced/Widowed | 0.99 | 0.35, 2.81 | -0.01 | 0.53 | 0.9894 |
| Living with a partner (neither married nor common-law) | 2.64 | 0.89, 7.83 | 0.97 | 0.56 | 0.0811 |
| Never married | 1.00 | | | | |
| Region | | | | | |
| Toronto | 2.18 | 1.14, 4.17 | 0.78 | 0.33 | 0.0179 |
| Non-Toronto | 1.00 | | | | |
| Recent CD4 count | | | | | |
| CD4 \geq 200 (cells/mm ³) | 2.76 | 0.77, 9.93 | 1.02 | 0.65 | 0.1191 |
| CD4 \leq 200 (cells/mm ³) | 1.00 | | | | |

Table 6: Model fit statistics for multivariate logistic regression models for family and partner pressure to conceive

| Variables Entered | AIC Scores for Family Pressure to Conceive |
|--|--|
| Years lived in Canada | 379.369 |
| Lifetime births | 375.300 |
| Region | 371.652 |
| Marital status | 368.045 |
| Race | 364.530 |
| Recent CD4 count | 364.230 |
| Age | 364.225 |
| Variables Entered | AIC Scores for Partner Pressure to Conceive |
| Years lived in Canada | 243.095 |
| Marital status | 241.686 |
| Age | 241.216 |
| Region | 240.512 |
| Recent CD4 count | 240.241 |
| Years lived in Canada (Removed) | 239.540 |

CHAPTER 5. DISCUSSION

5.1 Introduction

The purpose of this study was to examine the socio-demographic and biological factors associated with familial and partner expectations and pressures to conceive in women living with HIV in Ontario, Canada. Data obtained from the Pregnancy Planning Questionnaire were used for this study. Multivariate logistic regression analytical technique was used to analyze the data. The results of the multivariate analysis found that women who reported family pressure to conceive were younger, spent fewer years in Canada, were not living in urban area, had less than two lifetime births, and were in a married or in a common-law relationship. Further, those women who reported partner pressure to conceive were younger, were married or living with a common-law partner, and were living in urban area. This chapter discusses the results by providing possible explanations for the findings. This chapter also discusses the significance of the study findings, strengths and limitations of the study, as well as implications for future research.

5.2 Family and Partner Pressure to Conceive in Women Living with HIV

Different cultural backgrounds assign different level of importance to the role of motherhood and family structure. Therefore, cultural background of an individual has a significant influence on their reproductive decision-making process. According to Statistics Canada, in 2011, Ontario received 43% of Canada's immigrant population, and 61% of the minority population were of South Asian, Chinese, and Black ethnic origins (Statistics Canada, 2014). Research suggests that generally individuals identifying

themselves with these ethnic origins hold motherhood in high importance. The results of the current study will be interpreted keeping in mind the demographics of the population of Ontario.

The results of this study showed that younger women reported increased pressure to conceive from their family as well as their partner. This finding is consistent with previous studies that examined desire and intention to have children in individuals living with HIV (Kakaire, Osinde, & Kaye; 2010; Standwood et al., 2007). A possible explanation for this finding is that perhaps older women with HIV are more likely to have an advanced form of the disease compared to younger women. According to Ross and colleagues (2004), women with advanced stage of the disease have lower ability to reproduce and increased fetal loss. Although it did not reach statistical significance, in this study, women aged older than 35 years had lower CD4 counts and higher viral load than women aged 35 years or younger. It is perhaps due to this reason that older women living with HIV experience relatively lower pressure to conceive compared to younger women. Another explanation for this finding may be that older women may have already achieved their reproductive goals and therefore their family and partner may not pressure them to have more children. It is also possible that pressure to conceive is lower in older women due to social expectations. Some people believe that there is a moral duty to conceive within an “appropriate” timeframe so that the mother is around to take care of the child (Bonte, Pennings, & Sterckx, 2014). Late motherhood is also unfavorable because increased age is associated with an increased risk of adverse health outcomes for both mother and the child (Delpisheh, Brabin, Attia, & Brabin, 2008).

Further, as expected, the results of this study showed that women reported having increased family pressure and partner pressure to conceive if they were married or in a common-law relationship. This finding is in agreement with the results reported by previous studies (Cooper et al., 2007; Kakaire et al., 2010; Kirshenbaum et al., 2004; Oosterhoff et al., 2008). According to Oosterhoff and colleagues (2008), couples do not make reproductive decisions by themselves but instead these decisions are made after discussing with their family members. There are several possible explanations for why married women or those living with a common-law partner experience increased pressure to have children from their families. First, in many cultures motherhood is considered as a norm for married women (Myer et al., 2005). For many women, motherhood provides a reason to live, a positive self-esteem, a sense of well-being, and a source of love and support (Sandelowski & Barroso, 2003). In some cultures, women who have children are given a higher status in society compared to women who are unable to have children (Beyeza-Kashesya et al., 2009). Although this may not apply to all women living with HIV in Ontario, Ontario does have a large immigrant population and majority of the women living with HIV are immigrants from countries that have a high prevalence of HIV. It is estimated that African and Caribbean Black women comprise 55% of women living with HIV in Ontario (Public Health Ontario, 2012). Similar rates have been found in this study where 59% of women living with HIV are of African and Caribbean ethnicities. It is possible that women who have recently immigrated to Ontario from parts of the world where HIV is prevalent may still experience this type of discrimination from their families and local communities. In many societies, women that are unable to bear a child experience negative social consequences including stigma and humiliation (Doyal

& Anderson 2005; Dyer et al., 2002; Papreen et al., 2000; Santos et al., 1998; Sonko, 1994). Another possible reason why family members pressure women to have children may be to continue their family lineage. Women living with HIV are expected to have a child while they and their partner are still alive. In some cultures, there is an emphasis to have a male child to continue the family name (Oosterhoff et al., 2008). Inability to have a child is associated with a lot of stigma and discrimination and is considered to be sad and disgraceful to the family (Handwerker, 1998; Oosterhoff et al., 2008). It is possibly due to this reason that family members also encourage women living with HIV to have a child by assuring them that they will support and take care of the child in case of the woman's death (Kanniappan et al., 2008; Sowell et al., 1999). Another reason why women living with HIV feel pressured to have a child is that having a child not only strengthens their relationship with their partner but also with the partner's family members (Oosterhoff et al., 2008; Siegel & Schrimshaw, 2001; Sowell et al., 1999).

In addition to increased pressure from family, women who were married or in a common law relationship also reported increased pressure to conceive from their partner. This is consistent with previous studies that found that women are influenced by their male partners to conceive. Studies have reported an increased desire to have children if an individual believed their partner also had a desire to have children (Nobrega et al., 2007; Beyeza-Kashesya et al., 2010, da Silveira Nakayiwa et al, 2006). Further, women may feel pressured to provide their partner with a son to carry forward his family name due to the fear of infidelity, abandonment, and divorce (Cooper et al., 2007; Oosterhoff et al., 2008).

This was the first study to show that geographic region of residence was a predictor of both family and partner pressure. It was found that women living with HIV in Toronto experienced lower pressure to conceive from family but higher pressure to conceive from their partner. The reason for this finding is unclear. However, it can be hypothesized that social and environmental changes in urban regions may play a role. Chi and colleagues (2011) suggested that women who are financially dependent on their family members are more likely to agree with the decisions made by their family. Lack of income may make women feel helpless and they may not be able to express their opinions in front of their family members. Urban areas present more job opportunities as well as opportunities for women's empowerment. Women in urban areas may be financially independent and may be able to voice their opinions in front of their family members, hence reporting lower pressure from their family.

Another explanation is that extended family is important in rural areas but is considered to be more of an independent unit in urban areas (Key, 1961). According to Key (1961), people in urban areas are more independent, have less time to spend with family members, as well as engage in fewer activities involving extended family members compared to individuals in the rural areas. Perhaps, little or no contact with family members may explain why women residing in urban areas experience lower family pressure to conceive.

However, in this study, women reported experiencing higher pressure to conceive from their partner. Perhaps, this may be due to the relatively easy access to health care services and fertility clinics in larger urban areas such as Toronto (Ontario Ministry of Children and Youth Services, 2010). Assisted reproductive technologies and approaches

to reduce viral load in genital secretions has led to significant reductions in rates of horizontal transmission. This may be because assisted reproductive technologies have shown to increase the chance of conception per menstrual cycle and decrease the number of unprotected intercourse needed to conceive (Al-Khan, Colon, Palta, & Bardeguet, 2003). Many assisted reproductive technologies are available for people living with HIV including intrauterine insemination, in vitro fertilization, intracytoplasmic sperm injection, and sperm washing (Al-Khan et al., 2003). According to the Ontario Ministry of Children and Youth Services (2010), most of the assisted reproductive services in Ontario are located in larger urban areas such as Toronto, London, and Ottawa. A study done in Ontario found an association between living in an urban center and desire in obtaining more information on assisted reproductive technologies (Zhang et al., 2012). Increased interest in obtaining information about assisted reproductive technologies indicates a higher intention to have a child in the future. The study also stated that many women living with HIV do not perceive information regarding reproductive technologies to be easily accessible (Zhang et al., 2012). However, in urban areas, fertility clinics and information on assisted reproductive technologies is easily accessible and since its use provides for a relatively safer pregnancy planning option, women may experience desire or pressure to have more children.

Previous research has suggested that race and ethnic background also influences fertility decisions made by women living with HIV (Chen et al., 2001; Loutfy et al., 2009). In this study, a significantly higher proportion of women of African (58.8% vs. 30.5%) and Caribbean (16.3% vs. 5.0%) ethnicity were living in urban area compared to non-urban area. A higher proportion of women living in urban area were also born in

Africa or Caribbean. Both these cultures are known to give high importance to motherhood and on average report a higher number of children per family (Bongaarts, 2011; Kennedy et al., 2014). Therefore, the demographic characteristics such as ethnic background and country of birth of women residing in urban regions may also be associated with the pressure they report.

Another unique finding of this study is that increase in the number of years spend in Canada is associated with a decrease in family pressure to conceive. According to the findings obtained from previous studies, cultural and societal influences have a significant impact on HIV-positive individuals' desire and intention to have children (Kanniappan et al., 2008; Ko & Muecke, 2005; Nattabi et al., 2009; Oosterhoff et al., 2008). Generally, when individuals emigrate from another country to Canada, they experience a change in the cultural and societal norms and expectations. Some individuals may experience language barriers and some may not have the financial stability when they first arrive in the country, forcing them to live with family members who may already be living in Canada. In such situations, family members may play a more influential role in deciding whether to have a child or not. However, with increasing number of years spent in Canada, immigrants may learn to integrate and adjust to the Canadian culture, become more financially independent, may not be living with families, and hence family may play a less dominant role in the fertility decision-making process. Also, as individuals adjust to the Canadian culture, influence of traditional views and fear of stigma associated with not having a child may be relatively less. Therefore, women may experience lower pressure from family members and be able to make their own fertility-related decisions. In a study done by Sowell and Misener (1997), African-

American women living in the United States stated that the decision to have a child was their own and that partner and family members had little influence on their reproductive decisions. Perhaps, most of these women were able to make their own decisions because they were living independently, had no language barriers, majority had high school or higher education, and most likely have lived in the United States for considerable amount of time although this information was not explicitly provided in the article.

This study also found that having less than two children was associated with increased odds of family pressure. This finding supports those from other studies, which have examined factors associated with reproductive decision making process (Heys et al., 2009; Paiva et al., 2007). On average, women in Asia and Latin America report two births and women in Africa report five births (Bongaarts, 2011). According to Statistics Canada (2013), among families who have children, higher proportions have two or more children compared to one child (32% vs. 24%). Therefore it is possible that individuals having no children or only one child may not have achieved their desired family size and therefore experience increased pressure to have more children. Also, widespread availability of ART is known to reduce mortality and improve quality of life (Kisakye et al., 2010). Therefore it can be hypothesized that availability of ART and improvement in individuals' health status combined with the importance of motherhood in African and Asian cultures may be the reason why they may desire more children despite the death of previous children. Also, for many women living with HIV, having at least one child may provide them with hope and a reason to live (Kanniappan et al., 2008; Paiva et al., 2003; VanDevanter, Thacker, Bass, & Arnold, 1999). Myers and colleagues (2005) indicated that these feelings are likely to be particularly prominent in couples who do not already

have children of their own. Family members may also pressure or encourage women to have children by offering to take care of the child in an event of parental death (Kanniappan et al., 2008). Finally, as discussed earlier, family members may pressure a woman who has only one child, especially a female child to have more children in the hope to have a male child who would continue their lineage and carry forward their family name after the death of the parents (Cooper et al., 2007). Families may also want to continue their lineage so that the male child can pay respects to the ancestors, provide care for parents, inherit the family wealth and carry forward the family traditions (Ko & Muecke, 2005; Oosterhoff et al., 2008).

Disclosure of the women's HIV status is also important when examining family and partner pressure to conceive in women living with HIV. Rate of disclosure is usually low, ranging from 16.7% to 67.0% and varying by population sampled (Makin et al., 2008; Kilewo et al., 2001; Wagner et al., 2010). Fear of stigma and experience of violence were the primary reasons cited for not disclosing HIV status (Makin et al., 2008; Kilewo et al., 2001). Some studies have shown that individuals living with HIV are criticized by the family and society for trying to conceive a child (Copper et al., 2007; Feldman & Maposhere, 2003; Sherr & Barry, 2004). Therefore, disclosure status should be taken into consideration when examining pressure to reproduce.

Finally, although important, none of the HIV-related factors such as recent CD4 counts, viral load, and HIV treatment were significant in the adjusted regression analysis. This finding is supported by other studies that have examined factors influencing the intention to have a child (Chen et al., 2001; Green, 1994; Kline et al., 1995, Sowell et al., 2002, van Benthem et al., 2000). Studies by Kline and colleagues (1995) and van

Bentham and colleagues (2000) found social and cultural factors, and studies by Chen and colleagues (2001), and Ahluwalia and colleagues (1998) found demographic factors such as age, ethnicity, number of children, and marital status as important variables in the fertility decision-making process.

5.3 Study Strengths

This study has several strengths. First, the HIV Pregnancy Planning Questionnaire was found to have good face and content validity and internal consistency. Second, this study included a population-based sample unlike many previous studies that have included a clinic-based sample. Further, stratified sampling method was used to recruit participants. Participants were stratified based on geographic region. This method ensured that the study sample was representative of the women living with HIV in Ontario. Third, a comprehensive set of socio-demographic variables were included in the study. Fourth, the study included a large sample size which enhances the study power.

5.4 Study Limitations

There are limitations that will need to be addressed in future work. First, selection bias may have occurred because the survey used in this study was available in only English and French. Therefore, participants who did not understand these languages were excluded from the study. Also, women who participated in the study were required to have high literacy levels. Second, the questionnaire was self-administered by the participants and therefore information bias may have occurred. Participants did not answer some questions leading to missing data. Also, it is possible that participants were

unable to accurately recall information on biological and medical variables such as recent CD4 count and viral load or did not provide an honest response to some of the questions in the survey and therefore recall and social desirability bias may have occurred. However, since participants completed these surveys in complete privacy and were assured anonymity for the information they provide, social desirability bias should be minimal. Third, population of Aboriginal women living with HIV that may be on reserves were not included in this study. Finally, this was a cross-sectional study and therefore causality between the independent and the dependent variables cannot be established.

5.5 Significance of the Study Findings

The results obtained from this study have scientific as well as clinical significance. This study explored the association between socio-demographic and biologic factors, and partner and family pressure to conceive using a large population based sample. Further, Ontario has a large number of immigrant and refugee populations and the population is also ethnically diverse. Therefore, the results obtained from this study may be generalizable to other areas having similar demographics such as Quebec, U.K., and Western Europe. Clinically, the results obtained from this study will help identify the factors associated with pressure to conceive in women living with HIV. It is important to provide appropriate information to all women living with HIV who desire to have children and particularly to those women who feel pressured to have children and have difficulty expressing their opinions. Identification of these factors will help health care professionals, counselors, and researchers to better understand fertility decision-

making process involving women living with HIV and assist them in making proper decisions. When assisting women with HIV, health care professionals should provide non-judgemental information on reproductive health including fertility options and information on minimizing the risk of transmission. Health care providers should not only consider medical factors but also social and demographic factors that may influence women's decision to have a child. Finally, the results of this study indicate a need for services that offer appropriate support to these women. Support programs that help women cope with family and partner pressure are also needed, especially for women who do not want to have a child.

5.6 Directions for Future Research

The current study was a cross-sectional examination of factors associated with family and partner pressures to conceive. Future studies should examine familial and partner pressure in women living with HIV using a prospective study. A prospective study in this area would help determine a temporal relationship between pressure to conceive and decision made by the women. Also, the relationship between socio-demographic factors and the pressure to have a child should also be examined in HIV-positive male populations. Future studies should also consider the influence of HIV disclosure status when examining this relationship. Finally, studies should be carried out to understand how an individual's area of residence affects pressure to conceive among women living with HIV.

5.7 Conclusion

In summary, women living with HIV of reproductive age desire or are pressured to have children at levels that are similar to the general population. This study examined the relationship between socio-demographic and biological factors associated with family and partner pressure to conceive in women living with HIV in Ontario. The results suggest that age of the woman, living with a partner, and living in urban areas were significantly associated with both family and partner pressure to conceive, while number of years lived in Canada and number of lifetime births were only associated with family pressure to conceive. Factors related to HIV were not found to be significantly associated with pressure to conceive in this population. These results suggest that socio-demographic factors should be taken into consideration when assisting women meet their reproductive goals. Increased pressure on women to conceive can be a potential concern since there is an increased risk of infecting the partner and the child. Health care providers should also explain that receiving ART does not completely eliminate the risk of HIV transmission. Women who experience pressure may not be able to freely express their opinions and therefore appropriate measures need to be taken to help these women make independent fertility decisions and have healthy pregnancies.

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