

1-1-2009

HIV stigma, psychological distress and social support and their relationship to fertility intentions amongst HIV positive (HIV+) women

Anne C. Wagner
Ryerson University

Follow this and additional works at: <http://digitalcommons.ryerson.ca/dissertations>

 Part of the [Psychology Commons](#)

Recommended Citation

Wagner, Anne C., "HIV stigma, psychological distress and social support and their relationship to fertility intentions amongst HIV positive (HIV+) women" (2009). *Theses and dissertations*. Paper 936.

This Thesis is brought to you for free and open access by Digital Commons @ Ryerson. It has been accepted for inclusion in Theses and dissertations by an authorized administrator of Digital Commons @ Ryerson. For more information, please contact bcameron@ryerson.ca.

HIV STIGMA, PSYCHOLOGICAL DISTRESS AND SOCIAL SUPPORT AND THEIR
RELATIONSHIP TO FERTILITY INTENTIONS AMONGST HIV POSITIVE (HIV+)

WOMEN

By

Anne C. Wagner

Bachelor of Arts (Honours), University of Western Ontario, 2007

A thesis

presented to Ryerson University

in partial fulfillment of the requirements for the degree of

Master of Arts

in the Program of

Psychology

Toronto, Ontario, Canada, 2009

© Anne C. Wagner, 2009

**PROPERTY OF
RYERSON UNIVERSITY LIBRARY**

Author's Declaration

I hereby declare that I am the sole author of this thesis.

I authorize Ryerson University to lend this thesis to other institutions or individuals for the purpose of scholarly research.

I further authorize Ryerson University to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Abstract

HIV Stigma, Psychological Distress and Social Support and their Relationship to Fertility Intentions Amongst HIV Positive (HIV+) Women

Master of Arts, 2009

Anne C. Wagner

Psychology, Ryerson University

The current study examined the relationship of demographic and psychological predictors to fertility intentions in HIV+ women in Ontario. 326 HIV+ women between the ages of 18 and 52 were recruited through 28 AIDS service organizations, 8 HIV clinics and 2 community health centres across the province. 58.6% of the sample intended to become pregnant. African ethnicity, living in Toronto, high social support for having a child, and high perceived HIV stigma were associated with higher fertility intentions. Higher age, and European, Canadian and British ethnicity were all associated with lower fertility intentions. No moderation effects were found in multiple regression analyses, but main effects were found for African ethnicity, lower age, living in Toronto, high perceived HIV stigma and high social support for having a child. The majority of the sample intended to become pregnant, suggesting the need for effective health care support for HIV+ women in Ontario.

Acknowledgements

I would like to thank my supervisor, Dr. Trevor Hart, for his guidance and the opportunity to join this project. I would also like to thank Dr. Tae Hart, my co-supervisor, for her assistance and support, as well as my family and friends for their encouragement. This thesis would not have been possible without the help of Dr. Mona Loutfy and her team at Women's College Research Institute for their enthusiasm and the opportunity to work on this phenomenal project, as well as the Community Advisory Board, the site coordinators, and the amazingly strong and persevering women who participated in the study.

Dedication

To my grandfather, who saw me start, and helped me finish.

Table of Contents

1. Introduction.....	1
HIV prevalence among women in Canada.....	1
The advent of cART – transforming HIV from an acute to a chronic disease.....	2
The impact of cART on vertical transmission of HIV.....	3
Fertility among HIV+ women.....	4
Fertility intentions and desires in HIV+ women.....	7
Psychological variables that may influence fertility intentions.....	11
Purpose and hypotheses.....	16
2. Methods.....	18
Measures.....	19
Statistical analyses.....	20
3. Results.....	22
Descriptive statistics.....	22
Main hypotheses.....	24
Additional exploratory research questions.....	28
4. Discussion.....	30
Unique sample characteristics.....	30
Bivariate associations hypotheses results.....	31
Multiple regression results.....	34
Additional moderation analyses.....	35
Explaining a lack of moderation.....	36
Limitations and future directions.....	36

Implications.....	40
Conclusions.....	41
Appendices.....	42
References.....	49

List of Tables

Table 1: Study population characteristics.....	23
Table 2: Bivariate associations with fertility intentions.....	25
2. Methods.....	29
Measure.....	30
Statistical analysis.....	32
3. Results.....	33
Descriptive statistics.....	33
Main hypothesis.....	34
Additional exploratory hypotheses.....	35
4. Discussion.....	36
Unique sample characteristics.....	36
Important associations by population groups.....	37
Multiple regression results.....	38
Additional moderation analysis.....	38
Exploring a lack of fit.....	39
Limitations and future research.....	39

List of Figures

Figure 1: Proposed model for moderation effect of perceived HIV stigma.....	13
Figure 2: Proposed model for moderation effect of psychological distress.....	14
Figure 3: Proposed model for moderation effect of social support for having a child.....	16

List of Appendices

Appendix A: HIV Fertility Project: Project Advisory Committee Members.....	42
Appendix B: Participant Information and Consent Form.....	44

HIV Stigma, Psychological Distress and Social Support and their Relationship to Fertility

Intentions Amongst HIV Positive (HIV+) Women

The human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) pandemic is a virulent phenomenon, with an estimated 40 million infected individuals worldwide (UNAIDS, 2006). In Canada in 2008, there were a reported 73,000 people living with HIV (UNAIDS, 2008). More than 70% of infected women in Canada are of childbearing age (Public Health Agency of Canada (PHAC), 2007). With the face of the pandemic changing worldwide, the advent of combination antiretroviral therapy (cART), and drastically improved methods of prevention of vertical transmission of HIV from mother to child during birth (Klein, Pena, Thornton, & Sauer, 2003), HIV has become a chronic disease in Western countries. Beyond medical advances, the impact of ongoing issues including the impact of perceived HIV stigma, psychological distress, and social support for HIV+ women prior to conception, during pregnancy and subsequent childrearing and may affect HIV+ women's fertility intentions. The current study seeks to examine the relationships between demographic variables of age, ethnicity and relationship status, psychological variables (perceived HIV stigma, psychological distress and social support for having a child) and fertility intentions for HIV+ women in Ontario.

HIV Prevalence Among Women in Canada

Before 1994, only 10% of HIV cases in Canada were women. By 2004, that percentage had risen to 27% (McWilliam, 2006; PHAC, 2007). Among HIV+ Canadians between the ages of 15 and 29, from 2001 to 2006, 35%- 46% of all new HIV cases were female, a higher percentage than in any other age group (McWilliam, 2006; PHAC 2007). Most (70%) HIV diagnoses in 2004 were due to heterosexual intercourse (PHAC, 2005), with an increasing percentage (33%) occurring among individuals who immigrated to Canada from HIV endemic

countries (i.e., countries where >1% of the population is HIV+). Additionally, between 2002 and 2005, there was a 23% increase in the number of women in Canada with HIV (from 9,600 in 2002 to 11,800 in 2005; PHAC, 2007).

In Ontario, as of 2006, there were 3,895 reported cases of women who were HIV+ (Remis, Swantee, Schiedel, & Liu, 2008). The number of positive first time diagnoses has risen dramatically since 1999 when there were 190 new cases reported, to 356 in 2004 (Remis, Swantee, Schiedel, Merid, & Liu, 2006). The proportion of female HIV+ diagnoses comparatively to the total number of diagnoses skyrocketed from 1.8% in 1985 to 30% in 2006, indicating the changing face of the epidemic in Canada (Remis et al., 2008). Ontario has the largest number of HIV+ women in Canada, followed by Quebec with 2,607 and British Columbia with 1,779 (PHAC, 2007a). Since 1985, legislation in Ontario has required that all positive diagnoses be reported to the provincial government, so underreporting of positive diagnoses is not a concern (McWilliam, 2006). However, the risk still remains that women are not being tested, with estimates that 30% of individuals living with HIV do not know they are HIV+ in Canada, making the reach of the epidemic potentially far greater and with larger impact than originally thought (PHAC, 2003). Additionally, demographic reports suggest that women are being infected at younger ages than in the past, which allows for a greater window for childbearing while HIV+. According to Liu and Remis' ethnicity report of the HIV+ population in Ontario (2007), 55.1% of HIV+ women were black. In the current study, while we categorize ethnicity differently, we anticipate a large proportion of the HIV+ women will identify as being of African ethnicity. Also, according to Remis and colleagues (2008), 49.8% of all HIV+ women in Ontario live in Toronto, which we also anticipate to be the case in the current study.

The Advent of cART – Transforming HIV From An Acute to A Chronic Disease

Since 1996, there has been a revolution in HIV health care. HIV has moved from an acute and fatal infection to a severe but chronic illness in the developed world (Klein et al., 2003). The major reason for this change is the advent of cART, which allows HIV viral loads to remain low enough to be undetectable to medical tests for up to decades and prevents progression of the virus into AIDS, which is defined as the presence of one or more HIV-related opportunistic infections and a CD4 count of less than 200 (Buehler, 1992). cART improves general immune system functioning, known as immune reconstitution, and inhibits HIV-1 cofactors (such as the replication of HIV-1 and intracellular cytokines) which lead to the development of opportunistic infections (Stebbing, Portsmouth, & Gazzard, 2003).

cART has been demonstrated to improve time perspective (the subjective understanding a person holds regarding time flow between the past, present and future, and with HIV in particular, relating to perspective of survival times) and quality of life in individuals with HIV (Preau, Apostolidis, Francois, Raffi, & Spire, 2007). In recent years, the use of antiretrovirals has become widely accepted and cART is integrated into consensus guidelines for the care of HIV+ women who become pregnant (Burdge et al., 2003).

The Impact of cART on Vertical Transmission of HIV

Vertical transmission (the transmission of HIV infection from mother to child) which can occur in utero, during birth, or after birth via breastfeeding, can be significantly reduced using antiretroviral treatment (Klein et al., 2003). Current techniques to reduce vertical transmission include the use of cART during the second and third trimesters, administration of zidovudine (AZT) during labour, and prophylactic liquid AZT for the child after birth (Al-Khan, Colon, Palta, & Bardequez, 2003). It has been demonstrated that belief in the effectiveness of cART is directly associated with its usage, an important relationship to consider when examining fertility

intentions and decisions in HIV+ women. A study was conducted using AZT assessing HIV+ women's intentions to use antiretrovirals during pregnancy (Sowell, Phillips, Seals, Misener, & Rush, 2001). The results demonstrated that intention to use AZT was directly related to beliefs about its effectiveness. Similar results were found by Healton, Taylor, Messeri, Weinberg and Bamji (1999) and Richter, Sowell, and Pluto (2002). Prenatal screening for HIV is extremely beneficial to begin early harm reduction procedures, however, only recommendations, and not screening requirements, are in place in Ontario. Recent reports, however, indicate that 96.9% of pregnant women in Ontario underwent this screening procedure, an increase from 46.1% in 1999 due to the implementation of the screening guidelines (Remis, 2008). A total of 118 HIV+ children have been born to HIV+ mothers in Canada since 1984, but notably only 21 since 1999, and 5 since 2001 (PHAC, 2005). This confirms that the proportion of infants born to HIV+ mothers who were diagnosed with HIV is decreasing, from 26.8% in 1995 to 2.6% in 2006 (PHAC, 2007a). This reduction in transmission is attributed to the introduction of prenatal testing and the use of anti-retroviral medication to reduce viral load and subsequently the risk of vertical transmission in HIV+ mothers (e.g., Forbes, Samson, Alimenti, Singer, Money, & Lapointe, 2006; Hughes, Zuk, Foisy, Robinson, Singh, & Houston, 2009; Klein et al., 2003).

Fertility Among HIV+ Women

As risks of vertical transmission of HIV between mother and child decrease (Klein et al., 2003), and the use of cART increases life expectancy, health status and psychological outlook of HIV+ women (e.g., Preau et al., 2007), the ability to bear and raise children is again a realistic possibility. Thus, new considerations are needed to assist HIV+ women with childbearing, as unprotected intercourse poses a risk of transmission to HIV- partners or cross-infection of either partner.

Reproductive aid in a select minority of fertility clinics has been offered to serodiscordant couples since 1997 in the United States (Klein et al., 2003), however their distribution and capacity across the continent is not widespread (Yudin, Shapiro, & Loutfy, 2008). HIV+ women who want to bear children without putting partners at risk for HIV via unprotected intercourse require medical assistance either via artificial insemination, sperm washing, the “swim up” technique which selects only motile sperm for insemination after washing, or in vitro fertilization (e.g., Al-Khan et al., 2003). Women with other chronic illnesses, such as diabetes mellitus and cystic fibrosis which may be transmitted genetically (Taylor & Arioglu, 1999; Kerem et al., 1989), may be discouraged from childbearing due to medical concerns, but do not have reproductive assistance withheld (Englert, Van Vooren, Place, Liesnard, Laruelle, & Delbaere, 2001; Gilling-Smith, Smith, & Semprini, 2001; Lyrly & Anderson, 2001). Previously, as a vestige of the state of HIV care prior to the advent of cART, the U.S. Centers for Disease Control and Prevention (CDC) guidelines were that HIV+ women should not become pregnant because of concerns regarding vertical transmission and the ethical decision of having a child when the mother’s survival time was unknown (Wesley, Smeltzer, Redeker, Walker, Palumbo, & Whipple, 2000). With the advent of these new treatments, however, this is no longer the case. In Canada, while guidelines for care of HIV+ women include assistance during childbearing (Burdge et al., 2003), not all fertility clinics offer services to HIV+ women (Yudin et al., 2008), indicating the need for stronger policy so that women can access the health care they need.

Access to sensitive and egalitarian health care for HIV+ women, and particularly in regards to sexual and reproductive health, is substantially more difficult than for HIV+ men in North America, and across the world (Davidson, Bertram, Lezotte et al., 1998; Wood & Tobias, 2005; Kebaabetswe, 2007). In Canada, where HIV continues to be most saliently visible in the

gay male community, support networks including AIDS service organizations geared towards gay men, specialized health clinics and community involvement in advocating for HIV+ peoples' rights have developed out of the gay community, whereas such networks are substantially more limited for HIV+ women (e.g., Gurevich, Mathieson, Bower, & Dhayanandhan, 2007). When support networks do exist, they are often centered only in high density urban areas. The reasons why these networks and resources for HIV+ women do not exist may be severalfold – firstly, many of the women in Canada who are HIV+ are from endemic countries (Remis et al., 2008), and are therefore immigrants or refugees. These women may have increased difficulty accessing appropriate health care, and particularly specialized HIV care, due to language barriers and a lack of understanding of the Canadian medical system. Additionally, HIV may not be as visible a concern for women due to current lower prevalence rates and a lack of knowledge that services are available. In male-dominated societies, such as those from which many individuals from endemic countries come, women's health may not be a priority, and women may not be in a position to assert their needs regarding appropriate care, particularly if HIV is seen as taboo or the male partner's status is unknown and judgment could be placed on the woman regards means of contraction and presumed unfaithfulness (Dworkin & Ehrhardt, 2007; Greig, Peacock, Jewkes, & Msimang, 2008; Kebaabetswe, 2007; White, Pope, & Malow, 2008). These cultural attitudes may hold once people immigrate to Canada, and may speak to increased stigma surrounding HIV.

To assess the necessity of increasing the availability of assisted reproductive health services for HIV+ women, the fertility intentions and desires of HIV+ women must first be examined. Intentions are the psychological precursors to behavior, and without intention, desires will not turn into action (Miller, Severy & Pasta, 2004). Additionally, intentions reflect the

reality of the individual's current situation, as opposed to their desired situation. In regards to reproductive decision-making in HIV+ women, the assessment of intentions is particularly relevant to determine whether these women would like, and indeed intend, to have children, and which variables influence this intention.

Fertility Intentions and Desires in HIV+ Women

Generally, results have demonstrated that HIV serodiscordant couples in particular wish to have children (VanDevanter, Thacker, Bass, & Arnold, 1999), and that knowledge of HIV status does not affect HIV+ women's desire (Panozzo, Battegay, Fried, Vernazza, & the Swiss HIV Cohort Study, 2003) and decisions to become pregnant (Smits, Goergen, Delaney, Williamson, Mundy, & Fraser, 1999). Increased desire to become pregnant has been demonstrated to be associated with increased intentions to become pregnant (Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002). In a sample of African American HIV+ and HIV- women, no difference in intensity of desire for children was detected. However fertility intentions, or the intentions to have children, were not assessed (Wesley, 2003).

Few studies have comprehensively examined the fertility intentions of HIV+ women. Several of the studies conducted have either been with small sample sizes, assessing only very basic demographic characteristics, or demographically limited using only one ethnic group (e.g., Aka-Dao-Akribi, Du Lou, Msellati, Dossou, & Welffens-Ekra, 1999; Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005; Cooper, Harries, Myer, Orner, & Bracken, 2007; Craft, Delaney, Bautista, & Serovich, 2007; Fiore et al., 2008; Kanniappan, Jeyapaul, & Kalyanwala, 2008; Myer, Morroni, & Rebe, 2007; Nduna & Farlane, 2009; Nobrega et al., 2007; Richter et al., 2002; Sowell et al., 2002; Wesley, 2003). Three seminal works have been published, however, that have opened the field of research and begun to determine the basic variables

predicting reproductive intentions in HIV+ women that could be moderated by forces such as perceived HIV stigma, psychological distress, and social support for having a child. In a Nigerian sample of 147 HIV+ individuals who were seen at an HIV clinic in Sagamu, 63.3% expressed a desire to have children (Oladapo, Daniel, Odusoga, & Ayoola-Sotubo, 2005). Of the 52 women surveyed, 68.4% indicated they desired children. All female participants who desired children intended to have them, and notably 70.8% of the women who desired children indicated their partners also desired children. Multivariable logistic regression analyses demonstrated that younger age, less time since diagnosis of HIV, having had fewer or no children, and less likelihood of disclosing HIV status to one's partner were predictive of higher fertility desires (Oladapo et al., 2005). Lower desire was associated with higher socio-economic status, longer time since HIV diagnosis, higher recent CD4 count, having attended the HIV clinic for a longer period of time and being on cART. The strong fertility intentions are of particular note in this study, as they indicate the need for specialized care for HIV+ women when they do become pregnant.

In North America, Chen, Philips, Kanouse, Collins and Miu (2001) conducted a study with 1,421 HIV+ individuals who were part of a nationally representative sample of HIV+ adults who were receiving medical care in the United States. Of the 377 women surveyed, 29% expressed the desire to have children in the future. Of the women desiring children, 31% did not expect to have children. Comparatively to the general U.S. population of women, the percentage of HIV+ women who desired children was lower (36% versus 29%, respectively). The desire for children in HIV+ women was found to be associated with being younger, being non-Hispanic, being African American, having fewer children, having better physical functioning and better overall health (Chen et al., 2001). Fertility desires were not related to HIV progression.

Limitations to this study include the consideration that only individuals receiving medical care were included, which could significantly bias the results if the perspective that care is available impacts fertility decision-making, or if those not seeking medical care are exposing themselves to higher risk of becoming pregnant.

In Canada, relatively high fertility intentions were found in one study. Ogilvie and colleagues (2007) conducted a study of HIV+ women's fertility intentions in British Columbia, Canada. Women were recruited from all HIV clinics and AIDS service organizations in British Columbia, and a total of 182 women of childbearing age were surveyed. 25.8% of the sample indicated they intended to have children (Ogilvie et al., 2007), while in the general Canadian population, approximately 37.5% of women indicated they intended to have children (Payne, 2006). In multivariable analyses, being younger, not being aboriginal and being in a stable relationship were associated with higher fertility intentions. Notably, viral load, CD4 count, education level, living conditions, presence of menstrual cycles, status of menopause, drug use and currently taking cART were not associated with fertility intentions.

Few studies have been conducted on the fertility intentions of women living with other chronic illnesses, namely diabetes and cystic fibrosis, however the growing body of literature surrounding the health complications and perspectives about pregnancy of these women before and during pregnancy suggests that intentions and actual behaviours remain significant (Gregory & Tattersall, 1992; Griffiths, Lowe, Boardman, Ayre, & Gadsby, 2008; Janz et al., 1995; Johannesson, Carlson, Brucefors, & Hjelte, 1998; Mulholland, Njoroge, Mersereau, & Williams, 2007). Sawyer, Phelan and Bowes (1995) found that women with cystic fibrosis had high intentions to become pregnant in the near future (51% of the sample), as did Fair, Griffiths, and Osman (2000), with fertility desires at a rate of 72%, lying between the results of HIV+ women

in Nigeria and those in North America. Women with diabetes were found to have fertility intentions to be slightly lower than women without diabetes (Vahratian, Barber, Lawrence, & Kim, 2009). Interestingly, support is not withheld for reproductive aid to these groups (Gilling-Smith et al., 2001) despite the risk of severe medical complications including premature labour and delivery, perinatal death, maternal illness and death (Kent & Farquharson, 1993), and life expectancies only until the fourth decade of life (cystic fibrosis; Boyd, Mehta, & Murphy, 2004). Both HIV+ women and women with diabetes require preconception care and counseling, for HIV+ women to undertake cART and for women with diabetes to regulate their glucose levels (Hawthorne, 2005; Kim, Ferrara, McEwen et al., 2005), demonstrating the similar needs of these groups.

The three studies outlined describe how HIV+ women intend to have children at similar rates to HIV- women, and how therefore specialized services are needed to help facilitate this intention without risk of cross-infection between partners or vertical transmission between mother and child (Oladapo et al., 2005; Chen et al., 2001; Ogilvie et al., 2007). Demographic variables such as age and ethnicity were indicative of fertility intentions across all three studies. However, the influence of psychological variables influencing fertility intentions is unknown. Researchers have suggested that there may be a potential impact of social support for becoming pregnant on fertility intentions, but few studies have examined this relationship empirically (Brickley, Hanh, Nguyet, Mandel, Giang, & Sohn, 2008). Additionally, similar assessments of fertility intentions have not been conducted in other regions of Canada which have significantly different demographic distributions than British Columbia. The current study seeks to fill the gaps in the literature by assessing whether the relationship between the demographic variables and fertility intentions exist in Ontario, and whether those relationships are influenced by three

psychological variables: perceived HIV stigma, psychological distress, and social support for having a child.

Perceived HIV stigma, psychological distress and social support for having a child were chosen as potential moderators for several reasons. First, since HIV stigma is such a salient problem for people living with HIV (Berger, Ferrans, & Lashley, 2001), its impact on fertility intentions was questioned. Secondly, since HIV+ women have high rates of psychological disorders and are also at higher risk of experiencing psychological distress (Cohen et al., 2003; Prachakul, Grant, & Keltner, 2007), it was also deemed important to look at its impact. Thirdly, since social support is also often used as a measure to capture quality of life in the literature (Catz, Gore-Felton, & McClure, 2002), it was seen to be important to examine. Since there is such a dearth of literature on the psychological predictors of fertility intentions, these variables were used as a broad starting point to examine relationships since they are the psychological variables that occur most frequently in the HIV literature in general.

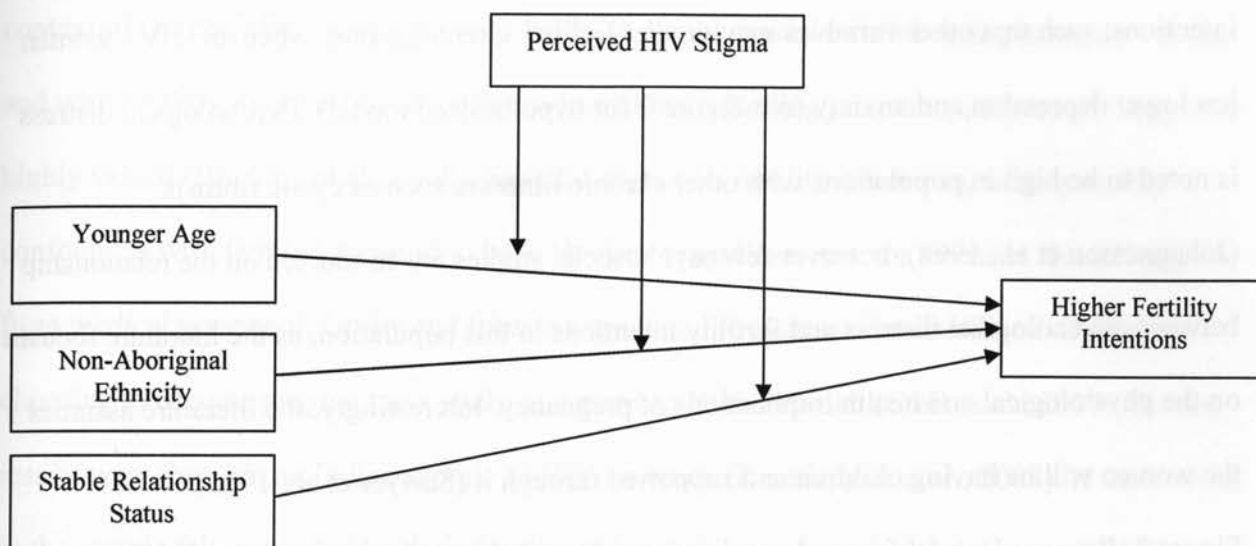
Psychological Variables That May Influence Fertility Intentions

Perceived HIV stigma. Perceived HIV stigma may have a large impact on reproductive decision-making in HIV+ women (see Figure 1 for hypothesized model). Stigma is a socially constructed experience, where the stigmatized individual does not feel wholly integrated or accepted into the culture or society (Goffman, 1963). Conceptualizing stigma, a separation has been made between perceptions of public stigma (general negative public attitudes towards individuals with the defined stigmatizing characteristic) and self-stigma (the personal effect on an individual of having a stigmatized characteristic) (Rusch, Angermeyer, & Corrigan, 1995). Berger and colleagues (2001) have created a model of HIV stigma which examines stigma as the perceptions of societal attitudes towards HIV and personal experience of HIV stigma. The

experience of personal HIV stigma is often associated with low access to health care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007), but while concern with HIV stigma among people living with HIV is widespread, it is not universal (Berger et al., 2001). The experience of personal stigma is associated with decreased self-esteem, lack of self-efficacy, higher rates of depression and anxiety, and hopelessness (Emlet, 2006; Lee et al., 2002; Rao, Pryor, Gaddist, & Mayer, 2008; Riggs, Vosvick, & Stallings, 2007). Regardless of whether the individual has experienced personal stigma, the perception of stigma is what appears to be most strongly related to these negative outcomes (Rao et al., 2008). The experience of HIV stigma is related to increased levels of perceived stress (Remien et al., 2006; Riggs et al., 2007). One study in Vietnam found that stigma experienced by HIV+ women during pregnancy and postpartum significantly impacted their experience (Brickley et al., 2008). The women in the study reported experiencing the moral judgments of their families and communities when they disclosed their HIV+ status, particularly in a cultural milieu in which childbearing is often the decision of elders and not just the partners involved. These moral judgments are due to the intensely negative connotations associated with HIV and prevention campaigns emphasizing death and “social evils” in Vietnam. While women in the study experienced stigma, they also, however, experienced increased social support in some circumstances (Brickley et al., 2008). Craft and colleagues (2007) found that higher levels of public attitudes and disclosure stigma, conceptualized as perceived stigma, were associated with lower fertility intentions. Conversely, higher levels of personalized, experienced stigma were associated with higher fertility intentions (Craft et al., 2007). It would be hypothesized that higher levels of perceived HIV stigma would be associated with lower fertility intentions among HIV+ women due to the increased duress and

personal stress experienced. It is also possible that other variables that predict fertility intentions may only exert their effects when women have lower perceived HIV stigma (see Figure 1).

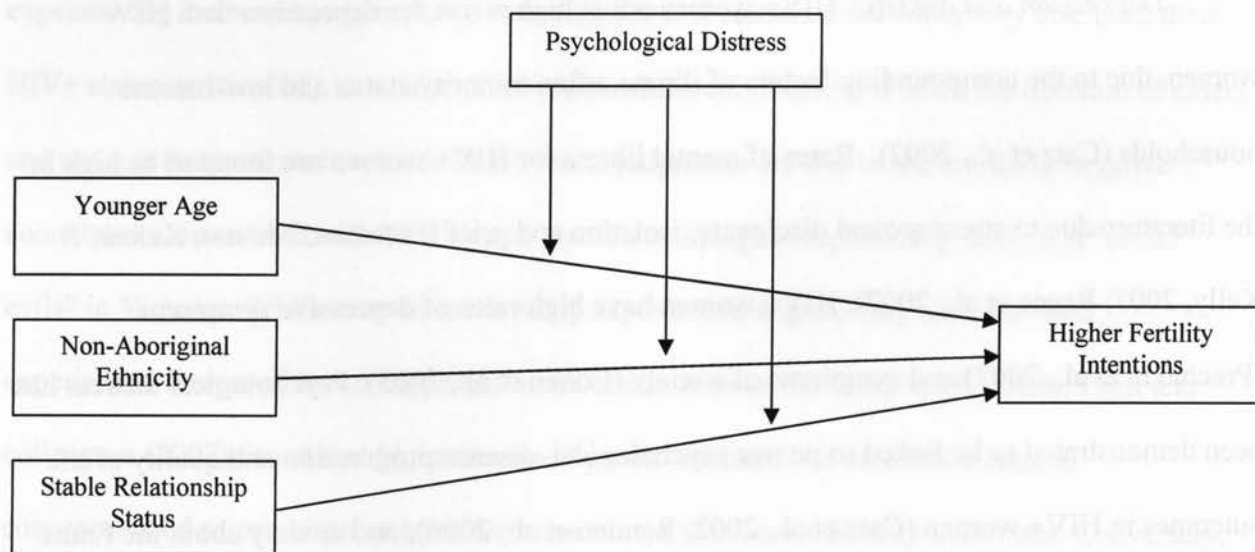
Figure 1. *Proposed model for moderation effect of perceived HIV stigma.*



Depression and anxiety. HIV+ women are at higher risk for depression than HIV- women, due to the compounding factors of illness, often minority status and low-income households (Catz et al., 2002). Rates of mental illness for HIV+ women are found to be high in the literature due to stress around disclosure, isolation and grief (Freeman, Nkomo, Kafaar, & Kelly, 2007; Reece et al., 2007). HIV+ women have high rates of depressive symptoms (Prachakul et al., 2007) and symptoms of anxiety (Cohen et al., 2003). Psychological distress has been demonstrated to be linked to poorer psychological, disease progression and quality of life outcomes in HIV+ women (Catz et al., 2002; Remien et al., 2006), and anxiety about the future have been associated with reduced fertility intentions in HIV+ women in India (Kanniappan et al., 2008). Because psychological distress is so relevant to HIV+ women, and is strongly associated with stigma and social support (Prachakul et al., 2007; Riggs et al., 2007), which have been demonstrated to be associated with fertility intentions, it is hypothesized that higher anxiety

and depression would be associated with lower fertility intentions. This may be due to a poorer quality of life and less drive to accomplish life goals and fulfillment of desires and intentions. Depression and anxiety may also negate the predictive effects of other variables on fertility intentions, such that other variables may predict fertility intentions only when an HIV+ woman has lower depression and anxiety (see Figure 2 for hypothesized model). Psychological distress is noted to be high in populations with other chronic illnesses such as cystic fibrosis (Johannesson et al., 1998), however few psychosocial studies are conducted on the relationship between psychological distress and fertility intentions in this population, as the literature focuses on the physiological and health implications of pregnancy. Interestingly, the literature assumes the women will be having children and supported through it (Sawyer et al., 1995).

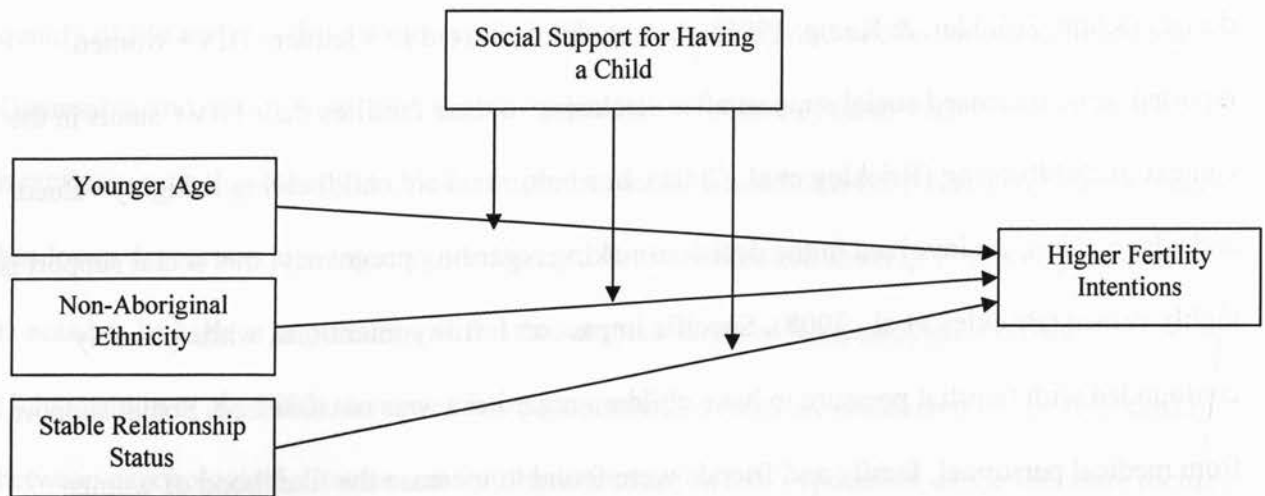
Figure 2. *Proposed model for moderation effect of psychological distress.*



Social support. Generally, social support, and particularly instrumental or functional support, is associated with better quality of life, medication adherence and decreased psychological distress in individuals living with HIV (Catz et al., 2002; Emlet, 2006; Prachakul et al., 2007). Social support, particularly from one's partner, is associated with decision making

to continue with unplanned pregnancies in HIV+ women in line with pre-diagnosis fertility desires (Kline, Strickler, & Kemp, 1995). In a study conducted in Vietnam, HIV+ women reported some increased social support after disclosing to their families their HIV+ status in the context of childbearing (Brickley et al., 2008). In a culture where childbearing is highly valued, and where elders are involved in the decision-making regarding pregnancy, this social support is highly valued (Brickley et al., 2008). Specific impact on fertility intentions, while possibly confounded with familial pressure to have children regardless, was not assessed. Social support from medical personnel, family and friends were found to increase the likelihood of women choosing to become pregnant in a study of American HIV+ women (Craft et al., 2007). Similar results were found in an Indian sample of HIV+ women (Kanniappan et al., 2008). If the women in the sample felt supported by their families to have children knowing that they were HIV+, they were more likely to choose to have children. However, if the women did not feel supported, they were less likely to opt to have a child (Kanniappan et al., 2008). Therefore, it is possible that reduced social support for having a child would decrease fertility intentions as it would be associated with a reduced quality of life and increased stigmatization by others without the positive protective buffer of family, friends and medical professional support. In addition to the possible direct relationship between social support and fertility intentions, other variables that may predict fertility intentions may exert their effects under conditions of higher social support for having a child, implying a moderation effect (see Figure 3 for hypothesized model). While social support is reported to be similar to a normative population for individuals with cystic fibrosis (Shepherd, Hovell, Harwood et al., 1990), social support for having a child has not been examined specifically to our knowledge.

Figure 3. *Proposed model for moderation effect of social support for having a child.*



Purpose and Hypotheses

The study will address the paucity of research on fertility intentions in HIV+ women in Ontario to better inform health care policy and assess the need for assisted reproductive services.

1. The first goal of the present study is to examine the relationship between three demographic variables (age, ethnicity and relationship status) and fertility intentions among HIV+ women in Ontario. It is hypothesized, drawing from Ogilvie et al. (2007), that:

- 1a) younger age will be associated with higher fertility intentions
- 1b) non-Aboriginal ethnicity will be associated with higher fertility intentions
- 1c) stable relationship status will be associated with higher fertility intentions.

2. The second goal of the present study is to examine the relationship between three psychological variables (perceived HIV stigma, psychological distress and social support for having a child) and fertility intentions. It is hypothesized that:

- 2a) lower perceived HIV stigma will be associated with higher fertility intentions
- 2b) lower psychological distress will be associated with higher fertility intentions
- 2c) higher social support for having a child will be associated with higher fertility

intentions.

3. The third goal of the present study is to examine whether the psychological variables moderate the relationship between the demographic variables and fertility intentions. It is hypothesized that:

3a) the relationship between younger age and higher fertility intentions will occur under four conditions: low HIV stigma, low depression, low anxiety and high social support for having a child

3b) the relationship between non-Aboriginal ethnicity and higher fertility intentions will occur under four conditions: low HIV stigma, low depression, low anxiety and high social support for having a child

3c) the relationship between stable relationship status and higher fertility intentions will occur under four conditions: low HIV stigma, low depression, low anxiety and high social support for having a child

Additionally, due to the demographic information suggesting that African women are 55.1% of the HIV+ women in Ontario and data suggesting that Toronto accounts for 49.8% of the HIV+ women in Ontario exploratory analyses will also be conducted examining African ethnicity (hypothesized to be a significant minority of the sample) and location of residence as correlates of fertility intentions.

Methods

The current study is part of a larger, epidemiological study of HIV+ women's fertility intentions and access to care run by the Women's College Research Institute's Women and HIV Program. The larger study comprised 437 participants at time of writing, while for the current study, a sub-sample of 326 participants were used due to incomplete data on the variables of interest. The original study was developed with the assistance of a community advisory committee (see Appendix A for a full listing of community advisory board members). Focus groups were originally run with a convenience sample of 20 HIV+ women to determine what the women would want addressed in such a study, as well as garnering their opinion and support for the questionnaire being developed to ensure face validity. To examine the specific measures in the current study, perceived HIV stigma and psychological distress measures were added to the questionnaire in the fall of 2007. From January 2008 until March 2009, HIV+ women between the ages of 18 and 52 (determined to be the upper limit for conception using assisted reproductive technologies) were recruited from across Ontario to participate in the current study. Women were recruited through 28 AIDS service organizations, eight HIV clinics and two medical clinics (Ontario Community Health Centres; CHCs) specializing in HIV care. The population of participants was stratified to ensure a representative sample of HIV+ women in Ontario consistent with regional location and demographic variables such as ethnicity and age utilizing Remis and colleagues' (2008) report on the demographic distribution of the HIV+ population in Ontario. Participants needed to meet the following inclusion criteria: 1) being HIV+, 2) older than 18 years of age, 3) biologically female, 4) of child-bearing age (between the ages of 18 and 52) and 5) living in Ontario.

Recruitment of the participants was consecutive at each of the participating sites, with staff inviting each eligible participant to take part in the study. Written informed consent was obtained from each participant by the study staff at each location (see Appendix B). Participants were then given a questionnaire package which took approximately one hour to complete. Participants were assigned an identification number based on their location of test administration (the first two numbers of their four digit code were the site numbers assigned to the participating clinics and ASOs). Participants were remunerated \$25 for their time and were given a debriefing sheet and a list of free counseling services by a trained staff member.

Measures

Demographic variables. Participants completed a demographics questionnaire including age, ethnicity, education, income and current relationship status.

HIV stigma. Perceived HIV stigma was assessed using the “concern with public attitudes about people with HIV” subscale of the Berger HIV scale (Berger et al., 2001). This subscale consists of 20 questions assessed on a four-point Likert scale, from strongly disagree to strongly agree (Berger et al., 2001). Sample questions include “Since learning I have HIV, I worry about people discriminating against me” and “I worry that people will judge me when they learn I have HIV”. Cronbach’s alpha is .93 for the public attitudes subscale, indicating excellent reliability.

Psychological distress. Psychological distress was assessed using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The 14-item questionnaire assessed these symptoms using a variable 4-point Likert scale from 0 to 3, with 0 being the lowest endorsement of the question and 3 the highest. The scale is examined as two subscales, the anxiety subscale (HADS-A), and the depression subscale (HADS-D) (Olsson, Mykletun, & Dahl, 2005). Cronbach’s alphas were .89 for the HADS-A and .86 for the HADS-D (Olsson et

al., 2005). The HADS is commonly used in medical populations to assess psychological distress, and is used frequently in HIV+ populations (Chandra, Deepthivarma, Jairam, & Thomas, 2003; Cohen et al., 2002).

Social support. The following questions were created for the present study to assess social support for having a child: 1) Who could you talk to about becoming pregnant?, 2) Who would support you if you wanted to become pregnant?, 3) Who would understand if you wanted to become pregnant?, and 4) Who would accept you if you wanted to become pregnant?, with check boxes indicating whether a friend, a family member, a physician, another health care professional or nobody would support the participant.

Fertility intentions. Fertility intentions are assessed by the question “How many children do you expect to give birth to in the future?”, which was presented with the scale of 0 to 9+, and dichotomized into yes or no answers (0 = no; 1 to 9+ = yes).

Statistical Analyses

The data were assessed for outliers, and the subscales for reliability. Hypothesis 1 posited that the demographic variables of younger age, non-Aboriginal ethnicity and stable relationship status were related to higher fertility intentions. To assess this, logistic regressions were computed to examine associations between a) age and fertility intentions, b) ethnicity and fertility intentions, and c) relationship status and fertility intentions.

Hypothesis 2 posited that high perceived HIV stigma, high psychological distress, and low social support for having a child were associated with lower fertility intentions. Logistic regressions were computed to examine associations between a) perceived HIV stigma and fertility intentions, b) psychological distress and fertility intentions, and c) social support for having a child and fertility intentions.

Hypothesis 3 posited that the psychological variables (perceived HIV stigma, psychological distress and social support for having a child) would moderate the relationships between the demographic variables (age, ethnicity and relationship status) and fertility intentions. To examine moderation by perceived HIV stigma, psychological distress, and social support for having a child, moderation analyses were conducted (Baron & Kenny, 1986). To conduct these analyses, the main effect of each demographic variable and each moderator variable were entered on Step 1, and the interaction between each demographic variable and each moderator variable were entered on Step 2 of the regression. For example, for one regression, age and perceived HIV stigma were entered on Step 1, and the interaction between age and perceived HIV stigma on Step 2. Each significant interaction term was considered support for the hypothesis of moderation. Given that twelve regressions were conducted using this approach, to control for Type I error, α was set to .01.

Results

Descriptive Statistics

326 HIV+ women between the ages of 18 and 52 ($M = 37.62$, $SD = 7.73$) were included in the study. The 111 participants were excluded from the study due to incomplete data. There were no outliers in the data, and normality of dependent variables does not need to be assumed as the regression analyses that were conducted are non-parametric. 58.6% of the sample intended to become pregnant. A total of 60.4% of the sample were born outside of Canada, 55.5% identified themselves as being in a romantic relationship, and 74.1% had previously given birth ($M = 1.77$ births, $SD = 1.64$). In terms of ethnicity, 44.5% ($n = 145$) of the population identified as being of African ethnicity and 8.3% of Aboriginal ethnicity ($n = 27$) (see Table 1 for full descriptive characteristics). The participants had a mean score of 6.65 ($SD = 4.44$) for depression, which is in the typical non-clinical range in a normative population (Zigmond & Snaith, 1983). This finding is contrary to previous literature findings which have reported high levels of depression in HIV+ women (Prachakul et al., 2007). The participants had a mean score of 8.91 ($SD = 4.40$) for anxiety, which is considered to be in the moderate range for normative samples (Zigmond & Snaith, 1983), and consistent with findings of other HIV+ women (Cohen et al., 2003). Participants had a mean score of social support of 7.53 ($SD = 4.50$), which does not appear high comparatively to a total possible score of 16 on this measure developed for the current study. In terms of HIV stigma, the participants had a mean score of 61.41 ($SD = 13.25$) out of a possible score of 80, which is similar to results found by Rao and colleagues (2008) that Black participants had high ratings of concern about public attitudes and discrimination on the HIV stigma scale. See Table 1 for participants' reported levels of perceived stigma, anxiety,

depression, and social support. The participants who were included in the analysis did not differ from the participants who were not included in the analysis on any of the variables measured.

Table 1

Study population characteristics

Characteristic	Mean	SD
Demographics		
Age	37.62	7.73
Number of times given birth	1.77	1.64
Income	2.67	2.31
Education	3.65	1.69
Judged negatively by a physician <i>in</i> Canada	2.10	1.32
Judged negatively by a physician <i>outside of</i> Canada	2.04	1.26
Medical variables		
CD4 count	648.66	334.95
Psychological variables		
Anxiety	8.91	4.40
Depression	6.65	4.44
Social Support	7.53	4.50
HIV Stigma	61.41	13.25
Characteristic	% Yes	
Demographics		

Intend to become pregnant	58.6%
In a romantic relationship	55.5%
Ethnicity ^a	
African	44.5%
Caribbean	13.2%
Asian	0.9%
Middle Eastern	0.9%
European	11.7%
British	7.7%
Canadian	13.8%
Hispanic	3.4%
Aboriginal	8.3%
Other	8.0%
Born in Canada	38.7%
Live in Toronto	50.3%
<i>Medical variables</i>	
Viral load undetectable	56.1%

Note: ^aParticipants may indicate more than one ethnicity.

Main Hypotheses

Logistic regression analyses were conducted to determine which variables were significantly associated with fertility intentions (see Table 2 for a summary of bivariate associations). As hypothesized, age and social support were significantly associated with fertility intentions at $p < .01$. Increased age was associated with lower fertility intentions, while increased social support

were associated with increased fertility intentions. Contrary to the hypotheses, *increased* perceived HIV stigma was associated with higher fertility intentions. Aboriginal ethnicity, relationship status, anxiety and depression were not associated with fertility intentions, contrary to the hypotheses. Regarding the additional research questions, African ethnicity and residing in Toronto were found to be associated with higher fertility intentions, while European, British and Canadian ethnicities were associated with lower fertility intentions. CD4 count, number of times given birth, viral load undetectable, education and income were not found to be associated with fertility intentions.

Table 2

Bivariate associations with fertility intentions

Variable	OR (95%CI)	<i>p</i>
<i>Demographics</i>		
Age	0.85 (0.82 - 0.89)	< .001*
Number of times given birth	0.84 (0.74 - 0.97)	.02
Judged negatively by a physician <i>in</i> Canada	1.13 (0.90 - 1.42)	.29
Judged negatively by a physician <i>outside of</i> Canada	1.24 (0.98 - 1.56)	.07
In a romantic relationship	0.86 (0.55 - 1.34)	.50
Ethnicity ^a		
African	4.97 (3.03 - 8.14)	< .001*
Caribbean	1.37 (0.71 - 2.69)	.35
Asian	1.42 (0.13 - 15.80)	.78

Middle Eastern	0.35 (0.03 - 3.90)	.39
European	0.37 (0.18 - 0.74)	.005*
British	0.30 (0.13 - 0.73)	.007*
Canadian	0.21 (0.10 - 0.42)	< .001*
Hispanic	0.39 (0.11 - 1.36)	.14
Aboriginal	0.63 (0.29 - 1.39)	.25
Other	0.58 (0.26 - 1.30)	.18
Born in Canada		
Live in Toronto	4.50 (2.78 - 7.28)	< .001*
<i>Medical variables</i>		
Viral load undetectable	0.59 (0.37 - 0.93)	.02
<i>Psychological variables</i>		
Anxiety	1.12 (0.90 - 1.40)	.31
Depression	1.18 (0.94 - 1.48)	.15
Social support	1.38 (1.10 - 1.73)	.006*
HIV stigma	1.36 (1.08 - 1.70)	.008*

* $p < .01$.

According to the hypotheses, twelve multiple regression analyses were run to investigate potential moderation effects, with α set at .01.

Younger age. Four hypotheses were delineated for the independent variable age. First, the relation between age and stigma was examined, and a main effect for younger age was found (OR = 0.85, 95% CI = 0.82 - 0.89, $p < .001$). Second, the relation between age and anxiety was investigated, and a main effect for younger age was found (OR = 0.85, 95% CI = 0.82 - 0.89, $p < .001$).

.001). Third, the relation between younger age and depression was investigated, and a main effect for younger age was also found ($OR = 0.85$, $95\% CI = 0.81 - 0.89$, $p < .001$). Finally, the relation between younger age and social support was investigated, and a main effect for younger age was found ($OR = 0.85$, $95\% CI = 0.82 - 0.89$, $p < .001$). Interaction effects were not found for a) stigma, b) anxiety, c) depression, or d) social support. Therefore it does not appear that stigma, anxiety, depression or social support moderate the relation between younger age and fertility intentions.

Aboriginal ethnicity. As for age, four hypotheses were delineated for the independent variable Aboriginal ethnicity. First, the relations between Aboriginal ethnicity and stigma was investigated, and a main effect for higher perceived stigma being associated with higher fertility intentions was found ($OR = 1.37$, $95\% CI = 1.09 - 1.72$, $p < .01$). Next, the relation between Aboriginal ethnicity and anxiety, Aboriginal ethnicity and depression, and Aboriginal ethnicity and social support were investigated, respectively, and no significant main effects were found. Interaction effects were not found for a) stigma, b) anxiety, c) depression, or d) social support. Therefore it does not appear that stigma, anxiety, depression or social support moderate the relation between Aboriginal ethnicity and fertility intentions.

Relationship status. As for age and Aboriginal ethnicity, the same four hypotheses were delineated for relationship status and fertility intentions. First, the relation between relationship status and stigma was examined, and no significant main effects were found. Next, the relation between relationship status and anxiety and relationship status and depression were examined, respectively, and no significant main effects were found. Finally, the relation between relationship status and social support was examined, and no significant main effects were found. Interaction effects were not found for a) stigma, b) anxiety, c) depression, or d) social support.

Therefore it does not appear that stigma, anxiety, depression or social support moderate the relation between relationship status and fertility intentions.

Additional Exploratory Research Questions

As discovered when examining the demographic breakdown of the current population, approximately half of the sample identifies as being of African ethnicity, and approximately half of the sample resides in Toronto. Both were also very strongly associated with fertility intentions (African ethnicity (OR = 4.97, 95% CI = 3.03 - 8.14, $p < .001$) and residing in Toronto (OR = 4.50, 95% CI = 2.78 - 7.28, $p < .001$)). Therefore additional regression analyses were run to explore their relation to fertility intentions, and the impact of the hypothesized moderator variables, totaling a further eight multiple regression analyses. Per previous analyses, α was set at .01 to reduce Type I error.

African ethnicity. First, the relation between African ethnicity and stigma predicting fertility intentions was examined, and a main effect was found for African ethnicity (OR = 4.73, 95% CI = 2.51 - 8.92, $p < .001$). Second, the relation between African ethnicity and anxiety was examined, and a main effect was again found for African ethnicity (OR = 5.22, 95% CI = 2.78 - 9.78, $p < .001$). Third, the relation between African ethnicity and depression was examined, and a main effect for African ethnicity was found (OR = 4.92, 95% CI = 2.63 - 9.17, $p < .001$). Finally, the relation between African ethnicity and social support was examined, and a main effect for African ethnicity was found (OR = 5.35, 95% CI = 3.22 - 8.89, $p < .001$), as was a main effect for social support predicting higher fertility intentions (OR = 1.49, 95% CI = 1.16 - 1.90, $p = .002$). No interaction effects were found, indicating that the variables examined do not moderate the relation between African ethnicity and fertility intentions.

Residing in Toronto. First, the relation between residing in Toronto and stigma predicting fertility intentions was examined, and a main effect was found for residing in Toronto (OR = 3.36, 95% CI = 1.86 - 6.07, $p < .001$). Second, the relation between residing in Toronto and anxiety was investigated, and a main effect was again found for residing in Toronto (OR = 3.38, 95% CI = 1.87 - 6.12, $p < .001$). Third, the relation between residing in Toronto and depression was examined, and a main effect was found for residing in Toronto (OR = 3.39, 95% CI = 1.88 - 6.13, $p < .001$). Finally, the relation between residing in Toronto and social support was examined, and a main effect was found for residing in Toronto (OR = 3.59, 95% CI = 1.97 - 6.52, $p < .001$). Interaction effects were not found for a) stigma, b) anxiety, c) depression, or d) social support. Therefore it does not appear that stigma, anxiety, depression or social support moderate the relation between residing in Toronto and fertility intentions.

Discussion

The current study is, to our knowledge, one of the first to examine the psychological moderators of the relationship between demographic variables and fertility intentions. It is the first to do so with a geographically representative sample of HIV+ women in Ontario, with the sample effectively constituting approximately 7.5% of the entire HIV+ female population of the province. Although several studies in North America, Africa and South America (i.e., Chen et al., 2001; Ogilvie et al., 2007; Sowell et al., 2002; Myer et al., 2007; Oladapo et al., 2005; Nobrega et al., 2007) have investigated predictors of fertility intentions, these studies have not examined psychological variables, such as stigma and psychological distress, as either correlates or moderators of fertility intentions. 58.6% of the sample reported that they intended to have children, which is high compared to rates found in the general Canadian population (37.5%; Payne, 2006). The current study found that higher levels of social support, increased perceived stigma, African ethnicity and residing in Toronto were associated with increased fertility intentions. Increased age, European, British and Canadian ethnicities were associated with lower fertility intentions. Main effects demonstrating an association with fertility intentions were found for higher perceived stigma, younger age, African ethnicity, residing in Toronto and higher social support.

Unique Sample Characteristics

Because the demographic make-up of the HIV+ women in Ontario differs greatly from the HIV+ population in British Columbia, additional research questions were added to the original model to determine the associations between African ethnicity and living in Toronto or not with fertility intentions. Specifically, the number of HIV+ women who identify themselves to be of African ethnicity is far higher in Ontario, making up 44.5% of the entire sample, whereas

participants above and beyond the impact of stigma. It may be that individuals with high fertility intentions may have factors promoting their intentions which outweigh the influence of stigma, even if they do perceive it more than individuals with lower intentions. This may speak to cultural differences, and stronger benefits and obligations associated with childbearing for women of African ethnicity (Aka-Dago-Akribi et al., 1999) as well as increased motivation to become pregnant (Sowell et al., 2002), since women of African descent make up a significant proportion of the sample. Cultural differences are also clearly present with the lower intentions exhibited by individuals of westernized ethnicities in the sample (European, British and Canadian). Additionally, the result that some 58.6% of the sample intend to become pregnant is far higher than the intentions found in the HIV+ population of women in British Columbia (25.8%; Ogilvie et al., 2007), as well as a normative Canadian population (37.5%; Payne, 2006). This finding may be due to the high percentage of women of African ethnicity, who in other samples have indicated higher fertility intentions (Aka-Dago-Akribi et al., 1999; Oladapo et al., 2005). In the current population, women of African ethnicity had higher intentions than the overall sample, while women of European, British and Canadian ethnicities had lower intentions. The overall intentions of the sample were similar to rates of intentions found in HIV+ samples in African studies and follow the fertility intention trends of HIV-negative populations of the same ethnicities, and of normative samples (Aka-Dago-Akribi et al., 1999). These results suggest that HIV+ women intend to have children at the same rate as HIV-negative women of African ethnicity.

Additionally, the unexpected findings of higher fertility intentions being associated with higher perceived stigma are similar to findings found by Craft and colleagues (2007) where higher personalized stigma, where one fears or experiences rejection because of being HIV+,

was associated with higher fertility intentions. Although different subscales were used in these analyses, both used the HIV Stigma Scale (Berger et al., 2001), which may speak to a conflation of the two subtypes of stigma, or perhaps their measurement in these studies. Additionally, it has been demonstrated that Black women score higher on the subscale used in this study (Rao et al., 2008), potentially conflating ethnicity with the scores, or an altogether different experience of stigma in this population. For the findings of higher intentions associated with residing in Toronto, this could be as a result of better access to resources, but also of the relatively higher proportion of women of African ethnicity residing in Toronto.

Multiple Regression Results

It was hypothesized that these psychological variables would moderate the relationship between the demographic variables of the first hypothesis and fertility intentions. Specifically, it was hypothesized that the relationships between younger age, non-Aboriginal ethnicity and stable relationship status would occur under conditions of low HIV stigma, under conditions of low psychological distress (depression and anxiety) and under conditions of high social support.

Younger age. No interactions were found between younger age and any of the potential moderators, however there was a main effect of younger age in every regression. These findings indicate that the age of the participant has a direct relationship to the participants' fertility intentions, regardless of the amount of perceived HIV stigma they have or psychological distress they are experiencing. The main effect of younger age further supports the relationship outlined in the bivariate associations.

Aboriginal ethnicity. No robust interaction effects were found between Aboriginal ethnicity and any of the proposed moderators. There was a main effect of stigma, however, but this effect was independent of Aboriginal ethnicity. The low sample size of Aboriginal women (n

= 27) may have led to Type II error. These findings are in contrast to Ogilvie et al.'s (2007) sample where 35.2% of the sample was Aboriginal, and they did find an association between Aboriginal ethnicity and fertility intentions. There were no main effects for psychological distress or social support.

Relationship status. Contrary to the hypotheses, relationship status did not appear to have significant bearing on fertility intentions in this population. No interactions or main effects were found with any of the proposed moderators. Also contrary to the hypotheses, there were no robust interaction effects that would indicate moderation by the psychological variables of perceived HIV stigma, psychological distress or social support. Notably, there were strong main effects for age, and a main effect for stigma, indicating their impact on fertility intentions nonetheless. The fact that these main effects exist indicates the necessity of their further investigation and consideration in further assessments of HIV+ women's fertility intentions and general quality of life. Relationship status may have been found to be a significant predictor of fertility intentions in Ogilvie et al.'s study (2007) because social support in general was not assessed, and therefore may have replaced the construct of social support as a predictor. Additionally, as has been found in prior literature, being in a stable relationship does not always either have a bearing on fertility intentions due to external pressures (such as extended family desires) or a lack of partner support for becoming pregnant (Brickley et al., 2008; Kanniappan et al., 2008). Here, the relationship does not appear to be significant.

Additional Moderation Analyses

African ethnicity. When examining African ethnicity, again, no robust interaction effects were found, indicating that none of the psychological variables moderated the relationship between African ethnicity and fertility intentions. However, strong main effects for African

ethnicity were found in every relationship, indicating African ethnicity may be an important predictor of intentions to bear children among HIV+ women. As for each of the independent variables examined, there was also a main effect of social support. These results speak to the high fertility intentions found in other samples of HIV+ women of African ethnicity (Aka-Dago-Akribi et al., 1999; Cooper et al., 2007; Myer et al., 2007; Oladapo et al., 2005), and the cultural differences in the importance of having children (Aka-Dago-Akribi et al., 1999; Brickley et al., 2008) comparatively to women of European, Canadian or British descent, as demonstrated in this study and by Fiore and colleagues (2008) in Europe.

Residing in Toronto. No interaction effects were found for residing in Toronto with any of the potential moderators, but main effects for residing in Toronto being associated with higher fertility intentions were found for every analysis.

Explaining a Lack of Moderation

Strong main effects were consistently found, for age, African ethnicity and residing in Toronto. It appears that although psychological distress may impact the experience of HIV+ individuals in other realms of experience, such as seeking social support (Prachakul et al., 2007; Reece et al., 2007; Vosvick et al., 2008), it may not influence fertility intentions. Perceived HIV stigma, however, does appear to be associated with fertility intentions, but does not influence the relationships of age or relationship status, nor African ethnicity or residency in Toronto. Although perceived stigma appears to influence the relationship between Aboriginal ethnicity and fertility intentions, experienced stigma or further stigma related to the health care system may yield further moderation effects for the other relationships in question.

Limitations and Future Directions

One of the major limitations of the current study is that it was cross-sectional in design, and not longitudinal, and therefore actual pregnancy actions (e.g., seeking assisted reproductive services from a clinic) following intentions were not assessed. Intention, while an important component, would be particularly meaningful if found to lead to pregnancy-seeking behaviours, and thus pregnancy outcome. Additionally, while the sample population made up a large proportion of the entire female HIV+ population in Ontario (>7%; Remis et al., 2008), sampling was not random and the women who chose to participate self-selected into the sample. It is therefore possible that the participants may have disproportionately had an interest in fertility or childbearing as they agreed to participate in a study clearly advertising its focus on these topics. The women participating were also already accessing health and support services via AIDS service organizations, community health centres or medical clinics, therefore potentially not representing the same opinions as the women who were not accessed via these sampling methods. The sample collected was also significantly reduced due to incomplete data, which could have been due to the length of the questionnaire and some women may have been completing it in a second language.

The women in the study self-reported their psychological distress, which may not accurately reflect their actual distress levels, which would ideally have been corroborated by objective personality test results and semi-structured interviews assessing psychological distress. The women were also not asked explicitly about their motivations for having a child, which could be useful considering the difference of impact of cultural norms and societal obligations towards childbearing documented in the literature (e.g., Aka-Dago-Akribi et al., 1999). Another significant limitation to the study was the use of some non-validated scales. For example, the questions regarding social support were created for the study, and assessed social support for

becoming pregnant from a variety of sources including friends, family, and one's partner. Additionally, we measured social support by quantity, and not qualitatively, or measuring how satisfied the participants were with their social support. The conceptualization of social support has been source of debate in the literature, however it has been demonstrated that satisfaction with social support may be a better indicator of its beneficial impact rather than quantity (Barrera, 1986; Ducharme, Stevens, & Rowat, 1994). Due to restraints with the questionnaire package, we were unable to add in such a measure, but in the future, that would be preferable. Lastly, to assess perceived HIV stigma, only one sub-scale of the Berger HIV Stigma scale (Berger et al., 2001) was used. Not only was stigma assessed only using one measure, and therefore no confirmatory comparison, or convergent validity, is available, but also only one aspect of HIV stigma was assessed. HIV stigma, while a relatively under-studied area in the psychological literature, continues to have ambiguous conceptual definitions, broadly categorized into perceived and experienced stigma (Mahajen et al., 2008). Only perceived societal HIV stigma was assessed in the present study. Experienced stigma, or direct stigmatizing experiences encountered by the individual, may offer a different picture of how stigma affects the lives of HIV+ women, as well as potentially directly relate to the experiences of the women in the health care system and with their families.

As outlined in the limitations section, conducting a study with the same population with a longitudinal design would allow for an understanding of how intentions translate into actions, and whether or not there is a disparity between the two, and for whom. Further investigation into the relationship between HIV stigma, with its further conceptual definition, and the assessment of both perceived and experienced stigma, is also necessary. Because almost half of the population was of African ethnicity, and over 60% were born outside of Canada, measures of

acculturation would be very informative. How much these women identify with North American culture and the structure within which they now live would be of particular relevance as childbearing is seen differently in various cultures (Aka-Dago-Akribi et al., 1999). In concert with acculturation would be a measure of the perceived benefits of childbearing, which could influence the relationship between the demographic and psychological variables and fertility intentions. A measure of religion may also be of interest to assess its impact on the perceived benefits of childbearing and intentions. And although general psychological distress was assessed using the HADS (Zigmond & Snaith, 1983), specifically assessing distress about childbearing, anxiety about the future as described by Kanniappan and colleagues (2008) and anxiety about disease progression could be very informative.

Because there is very little research on the fertility intentions of women with comparable chronic illnesses such as cystic fibrosis, diabetes and multiple sclerosis, drawing from that literature on pregnancy for potential moderators is difficult. Disease severity and progression appear to play a role in fertility desires and outcomes in some studies of women with cystic fibrosis (Boyd et al., 2001), although not all studies have found them to be significant (Fair et al., 2000). Disease severity and progression have been shown to have some impact on fertility intentions for HIV+ women (Chen et al., 2001; Oladapo et al., 2005), although CD4 count and viral load were not significant in this sample. Investigating them as a future potential moderator coupled with questions regarding the significance of childbearing for the women could be informative.

In the future, conducting mediation analyses could also be helpful. For example, we found that greater social support for having a child is associated with higher fertility intentions, and if we were to find that residing in Toronto was also associated with greater social support for

having a child, we could conduct analyses to determine whether or not social support for having a child is in fact a mediator of the relation between residing in Toronto and fertility intentions. The same could be examined for greater social support for having a child potentially mediating the relation between African ethnicity and fertility intentions, as well as younger age and fertility intentions, should African ethnicity and younger age be associated with greater social support for having a child.

Implications

The results of the current study suggest that psychological variables warrant further investigation when examining the fertility intentions of HIV+ women. Social support and stigma are the two variables which have been demonstrated in this study to potentially impact the women's experience and intention, and should be considered when addressing future research questions, as well as health care delivery and services. These results also demonstrate that certain demographic variables, namely age, ethnicity and city of residence, need particular attention when determining the services needed and intentions of HIV+ women in Ontario. Particular attention should be paid to the changing demographic make-up of Toronto's and Canada's HIV+ populations. HIV+ women in this sample have higher fertility intentions than HIV-negative women, and with women of African descent in particular, these intentions are very high – these findings will have ramifications for the health care system if not addressed swiftly and competently, as HIV+ women will likely be seeking more and more fertility services as the HIV+ population in Canada is particularly growing among women of childbearing age. Finally, the high intentions of HIV+ women in Ontario necessitate safe means of reproduction, and therefore assistance in health care system, to avoid unprotected sex and the risk of cross-

infection. Since these services are not available to HIV+ women across the country (Yudin et al., 2008), policy and implementation of care for the women should be a priority.

Conclusions

Although no moderation of the relationship between demographic variables and fertility intentions by psychological variables was found, strong main effects were for age, perceived HIV stigma, African ethnicity, social support and residing in Toronto. These results speak to the need for health care providers in Ontario who work with HIV+ women to find safe and supportive ways for the women to have children, as becoming pregnant via unprotected sex may pose a risk to themselves and their partners for cross-infection. Additionally, the results delineate which groups of women have the highest fertility intentions, and health care providers should be cognizant of these heightened intentions. With the population of HIV+ women in Ontario growing, the current study results suggest further research on this important group is warranted, and that reproductive supports within the health care system are necessary.

APPENDIX A

HIV Fertility Project Project Advisory Committee Members

Georgina MacDougall **Hospital for Sick Children**
Dr. Trevor Hart **Ryerson University, Department of Psychology**
Dr. Trent Newmeyer **Brock University, Department of Recreation and Leisure Studies in the Faculty of Applied Human Sciences**
Dr. Mark Yudin **St. Michael's Hospital, Obstetrics, Gynecology and Reproductive Infectious Disease**
Jay Macgillivray **Sage-Femme Rouge Valley Midwives**
Doe O'Brien-Teengs **Ontario Aboriginal HIV/AIDS Strategy**
Dr. Gina Ogilvie **Division of STI/HIV Prevention and Control/Family Practice, UBC**
Dr. Peggy Millson **University of Toronto, HIV Behaviours Unit**
Louise Binder **Canadian Treatment Action Council (CTAC) and Voices of Positive Women**
Dr. Gord Arbess **410 Sherbourne St., St. Michael's Hospital**
Fanta Ongoiba **Africans in Partnership Against AIDS (APAA)**
Dr. Sharon Walmsley **Toronto General Hospital, Division of Clinical Investigation and Human Physiology**
Eva Sin **Asian Community AIDS Services**
Randi Reynolds **St. Stephen's Community House, AIDES Program**
Shari Margolese **Voice of Positive Women, Blueprint for Action on Women and Girls & HIV/AIDS**
Dr. Pat O'Campo **University of Toronto, Public Health Sciences, St. Michael's Hospital, Centre of Research on Inner City Health**
John Goodwin **AIDS Bureau/LHIN Liaison Branch/Health and Long-term Care**
Dr. Anita Rachlis **Sunnybrook Health Sciences Centre, HIV Ambulatory Clinic**
Danielle Layman-Pleet **Voices of Positive Women**
Dr. Jim Martin **Southern Ontario Fertility Technologies**
Dr. Kellie Murphy **Mount Sinai Hospital, Division of Maternal-Fetal Medicine**
Esther Amoako **African and Caribbean Council for HIV/AIDS in Ontario (ACCHO)**
Dr. Fiona Smaill **McMaster University, Pathology and Molecular Medicine**
Laura Puri **McMaster University, Pathology and Molecular Medicine**
Dr. Jim Downey **Toronto East General Hospital**
Dr. Kevin Gough **St. Michael's Hospital, HIV Service and Positive Care Clinic**
Khaled Salam **AIDS Committee of Ottawa**
Lena Soje **Black CAP/APAA/ACCHO**
Anne Wagner **Graduate Student, Ryerson University**
Dr. Lindy Samson **Children's Hospital of Eastern Ontario, Division of Infectious Diseases**
Lisungu Chieza **AIDS Committee of Toronto**
Dr. Lynne Leonard **University of Ottawa**
Marvelous Muchenje **Women's Health in Women's Hands**
Dr. Robert Remis **University of Toronto, Department of Public Health Sciences**
Rosemary Eraskine **African Community Health Services**

Sara Merali **St. Michael's Hospital (Resident with interest in HIV and pregnancy)**
 Simone Shindler **The Teresa Group**
 Maureen Ringlein **The Teresa Group**
 Wangari Tharao **Women's Health in Women's Hands**
 Dr. Matt Gysler **Isis Fertility Centre, Medical Director**
 Dr. Hannah Balakier **CReATe IVF Program, Embryologist/Lab Director**
 Deb Davies **CReATe IVF Program, Nurse Manager**
 Ruth Clarke **CReATe IVF Program, Clinic Manager**
 Dr. Cliff Librach **CReATe IVF Program, Medical Director**
 Gail Linklater **AIDS Thunder Bay**
 Sylvie Daviau **ACCESS AIDS Network of Sudbury**
 Ken English **AIDS Bureau/LHIN Liaison Branch/ Health and Long-Term Care**
 Dr. Jonathan Angel **Ottawa Health Research Institute**
 Dr. Jeff Cohen **Windsor Regional Hospital**
 Nancy McFarland **Windsor Regional Hospital**

You are being asked to participate in a research study. This study aims to learn about your desire to have children in the future and your needs to access pregnancy planning and care. We would also like to know if you think the general medical community and your doctor support people with HIV who want to have children. This research study is asking these questions to 525 women who are living with HIV and are living in Ontario. This informed consent letter is designed to inform you about the purpose of the study and your rights if you choose to participate.

Why is the study being done?
 Treatment of the human immunodeficiency virus (HIV) has greatly changed over the past 10 years with the use of combination antiretroviral therapy (cART). Although the rates of infection are higher, more people with HIV are able to live longer now and experience a better quality of life. Within Canada, HIV infection is now considered a chronic disease with management, but no cure. These changes have led many people infected with HIV to consider having a family and to consider issues related to pregnancy.

We would like to know about the experiences and opinions of HIV-positive women who are of child-bearing age. The information collected in this study will be used to better understand the pregnancy planning and fertility treatment needs of women affected by HIV.

What will I be asked to do?

You are eligible to participate in this study if you are:

1. HIV infected
2. 18 years old or older

PARTICIPANT INFORMATION AND CONSENT FORM

Study Title:	Survey to assess the fertility desires and needs of Ontario HIV-positive women of reproductive age	
Study Sponsor:	Canadian Foundation for AIDS Research (CANFAR)	
Study Investigators:	Dr. Mona Loutfy Maple Leaf Medical Clinic 70, Carlton Avenue, Upper Level Toronto, Ontario M5B 1L6 Tel: 416.465.7936	Dr. Trevor Hart Ryerson University Department of Psychology 350 Victoria Street Toronto, Ontario M5B 2K3 Tel: 416-979-5000

You are being asked to participate in a research study. This study aims to learn about your desire to have children in the future and your needs to access pregnancy planning and care. We would also like to know if you think the general medical community and your doctors support people with HIV who want to have children. This research study is asking these questions to 525 women who are living with HIV and are living in Ontario. This informed consent letter is designed to inform you about the purpose of the study and your rights if you choose to participate.

Why is the Study being done?

Treatment of the human immunodeficiency virus (HIV) has greatly changed over the past 10 years with the use of combination antiretroviral therapy (cART). Although the rates of infection are higher, more people with HIV are able to live longer now and experience a better quality of life. Within Canada, HIV infection is now considered a chronic disease with management, but no cure. These changes have led many people infected with HIV to consider having a family and to consider issues related to pregnancy.

We would like to know about the experiences and opinions of HIV-positive women who are of child-bearing age. The information collected in this study will be used to better understand the pregnancy planning and fertility treatment needs of women affected by HIV.

What will I be asked to do?

You are eligible to participate in this study if you are:

1. HIV infected
2. 18 years old or older

3. A biological female
4. Of child-bearing age (18 to 52 years of age)
5. Living in Ontario

This study involves answering a confidential set of questions (a questionnaire). You will be asked about:

- Your knowledge, thoughts and experiences with pregnancy planning and fertility.
- Your opinion on your fertility and pregnancy planning opportunities available from the medical community.
- Some questions about your background and medical history.

The questionnaire will take between 60 minutes to complete.

After you have completed the questionnaire, a research staff member will review some of your medical history with you. This will be done to make sure the information we collect from you is recorded accurately. Your name will never be shared or linked to the answers you provide.

Additional Information You Need to Know:

What risks or benefits could there be from taking part in the study?

There is a risk you may feel uncomfortable answering some of the questions.

No direct benefit is guaranteed to you by taking part in this study. The information you provide may give the medical community some knowledge about education and planning strategies for HIV-positive individuals considering parenthood. The information you provide may also guide future health policies to support pregnancy planning and fertility for people living with HIV. You may request a visit with your doctor to discuss any concerns you have about pregnancy planning and the current treatment strategies that are available.

What will be done with the information I provide?

If you choose to participate, the answers you provide in the questionnaire will be entered into a database. Once all 525 questionnaires have been entered into a database, they will be analyzed to determine the needs and desires related to pregnancy. Study staff will discuss the results of the study with you when they are known. The results may be published in scientific journals and presented at conferences.

Voluntary participation/withdrawal

What are my options if I am not in the study?

You may choose not to join this study. If so, other services you receive at this institution will not be affected. Your participation in this study is completely voluntary. There is no penalty to withdraw, financial or otherwise. If you are uncomfortable answering any of the questions in the survey you may choose to not answer them. You may decide to discontinue the study at any time.

How will my privacy be protected?

Your participation in the survey will remain completely confidential. You are not asked for your name on the questionnaire; it is anonymous. The information you provide will remain under secure lock for a minimum of seven years. The information you provide will only be used for the purposes of this study.

Will I be paid?

You will receive compensation for your time and involvement in the amount of \$25.

Who do I call if I have questions about?

If you have questions about this study you should call the study investigator or the study coordinator at the numbers listed below:

Dr. Mona Loutfy at 416-465-7936
Ms. Saira Mohammed at 416-351-3732 ext. 2324

If you should have any questions regarding your rights as a study participant or any ethical issues, you should contact your family doctor, lawyer or ethics review committee that reviewed the ethical aspects of the study at:

Dr. Miriam Shuchman

Chair, Women's College Hospital Research Ethics Board at 416-351-3732 x2535

Research Ethics Board

c/o Office of the Vice President, Research Innovation, Ryerson University at 416-979-5042

350 Victoria Street, Toronto, ON

M5B 2K3

Study Title: Survey to assess the fertility desires and needs of Ontario HIV-positive women

If you have any questions about your rights as a research subject, or complaints regarding this research study, you should contact your family doctor, lawyer or the ethics committee that reviewed the ethical aspects of this study at: the University of Toronto Ethics Review Office at 416.946.3273 or ethics.review@utoronto.ca.

By signing below, I agree that:

- I have read this consent form.
- I have had the chance to ask questions and they have been answered.
- I understand that taking part in this study is voluntary.
- I give permission to use and share my health data as described in this form.
- I may choose not to be in the study or to leave the study at any time by telling the study doctor. I will not be penalized or lose any benefits to which I am otherwise entitled.
- I do not give up any of my legal rights by signing this informed consent.

I will receive a copy of this signed consent form.

Printed Name of Volunteer

Signature of Volunteer

Date

Printed Name of Person

Signature of Person

Date

Obtaining Consent

Obtaining Consent

Printed Name of Investigator

Signature of Investigator

Date

References

- Aka-Dago-Akribi, H., Du Lou, A.D., Msellati, P., Dossou, R., & Weiffens-Ekra, C. (1999). Issues surrounding reproductive choice for women living with HIV in Abidjan, Cote d'Ivoire. *Reproductive Health Matters*, 7(13), 20-29.
- Al-Khan, A., Colon, J., Palta, V., & Bardeguet, A. (2003). Assisted reproductive technology for men and women infected with human immunodeficiency virus type 1. *Clinical Infectious Diseases*, 36, 195-200.
- Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173-1182.
- Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology*, 14(4), 413-445.
- Bedimo-Rung, A.L., Clark, R.A., Dumestre, J., Rice, J., & Kissinger, P. (2005). Reproductive decision-making among HIV-infected women. *Journal of the National Medical Association*, 97(10), 1403-1410.
- Berger, B.E., Ferrans, C.E., & Lashley, F.R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24, 518-529.
- Boyd, J.M., Mehta, A., & Murphy, D.J. (2004). Fertility and pregnancy outcomes in men and women with cystic fibrosis in the United Kingdom. *Human Reproduction*, 19(10), 2238-2243.
- Brickley, D.B., Hanh, D.L.D., Nguyet, L.T., Mandel, J.S., Giang, L.T., & Sohn, A.H. (2008). Community, family, and partner-related stigma experienced by pregnant and postpartum

- women with HIV in Ho Chi Minh City, Vietnam. *AIDS and Behavior*, [E-pub ahead of print].
- Buehler, J.W. (1992). The surveillance definition for AIDS. *American Journal of Public Health*, 82(11), 1462-1464.
- Burde, D.R., Money, D.M., Forbes, J.C., Walmsley, S.L., Smaill, F.M., Boucher, M., et al. on behalf of the Canadian HIV Trials Network Working Group on Vertical HIV Transmission. (2003). Canadian consensus guidelines for the care of HIV-positive pregnant women: Putting recommendations into practice. *Canadian Medical Association Journal*, 168(13), 1683-1688.
- Catz, S.L., Gore-Felton, C., & McClure, J.B. (2002). Psychological distress among minority and low-income women living with HIV. *Behavioral Medicine*, 28, 53-60.
- Chandra, P.S., Deepthivarma, S., Jairam, K.R., & Thomas, T. (2003). Relationship of psychological morbidity and quality of life to illness-related disclosure among HIV-infected persons. *Journal of Psychosomatic Research*, 54, 199-203.
- Chen, J.L., Philips, K.A., Kanouse, D.E., Collins, R.L., & Miu, A. (2001). Fertility desires and intentions of HIV-positive men and women. *Family Planning Perspectives*, 33(4), 144-152+165.
- Cohen, M., Hoffman, R.G., Cromwell, C., et al. (2003). The prevalence of distress in persons with human immunodeficiency virus infection. *Psychosomatics*, 43(1), 10-15.
- Cooper, D., Harries, J., Myer, L., Orner, P., & Bracken, H. (2007). "Life is still going on": reproductive intentions among HIV-positive women and men in South Africa. *Social Science & Medicine*, 65, 274-283.
- Craft, S.M., Delaney, R.O., Bautista, D.T., & Serovich, J.M. (2007). Pregnancy decisions among women with HIV. *AIDS and Behavior*, 11, 927-935.

- Davidson, A.J., Bertram, S.L., Lezotte, D.C., Marine, W.M., Rietmeijer, C.A., Hagglund, B.B., & Cohn, D.L. (1998). Comparison of health status, socioeconomic characteristics, and knowledge and use of HIV-related resources between HIV-infected women and men. *Medical Care*, 36(12), 1676-1684.
- Ducharme, F., Stevens, B., & Rowat, K. (1994). Social support: conceptual and methodological issues for research in mental health nursing. *Issues in Mental Health Nursing*, 15(4), 373-392.
- Dworkin, S.L., & Ehrhardt, A.A. (2007). Going beyond "ABC" to include "GEM": Critical reflections on progress in the HIV/AIDS epidemic. *American Journal of Public Health*, 97(1), 13-18.
- Emlet, C.A. (2006). An examination of the social networks and social isolation in older and younger adults living with HIV/AIDS. *Health & Social Work*, 31(4), 299-308.
- Englert, Y., Van Vooren, J.P., Place, I., Liesnard, C., Laruelle, C., & Delbaere, A. (2001). ART in HIV-infected couples: Has the time come for a change of attitude? *Human Reproduction*, 16(7), 1309-1315.
- Fair, A., Griffiths, K., & Osman, L.M. (2000). Attitudes to fertility issues among adults with cystic fibrosis in Scotland. *Thorax*, 55, 672-677.
- Fiore, S., Heard, I., Thorne, C., Savasi, V., Coll, O., Malyuta, R., et al. (2008). Reproductive experience of HIV-infected women living in Europe. *Human Reproduction*, 23(9), 2140-2144.
- Forbes, J., Samson, L., Alimenti, A., Singer, J., Money, D., & Lapointe, N. (2006). Perinatal HIV transmission seen in the Canadian Perinatal HIV Surveillance Project (CPHSP) from

1990. *Canadian Journal of Infectious Diseases and Medical Microbiology*, 17(Supplement A), 41A-42A.
- Freeman, M., Nkomo, N., Kafaar, Z., & Kelly, K. (2007). Factors associated with prevalence of mental disorder in people living with HIV/AIDS in South Africa. *AIDS Care*, 19(10), 1201-1209.
- Gilling-Smith, C., Smith, J.R., & Semprini, A.E. (2001). HIV and infertility: time to treat. *British Medical Journal*, 322, 566-567.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, N.J.: Prentice-Hall.
- Gregory, R., & Tattersall, R.B. (1992). Are diabetic pre-pregnancy clinics worth while? *The Lancet*, 340, 656-658.
- Greig, A., Peacock, D., Jewkes, R., & Msimang, S. (2008). Gender and AIDS: time to act. *AIDS*, 22(suppl 2), S35-S43.
- Griffiths, F., Lowe, P., Boardman, F., Ayre, C., & Gadsby, R. (2008). Becoming pregnant: exploring the perspectives of women living with diabetes. *British Journal of General Practice*, 58, 184-190.
- Gurevich, M., Mathieson, C.M., Bower, J., & Dhayanandhan, B. (2007). Disciplining bodies, desires and subjectivities: sexuality and HIV-positive women. *Feminism & Psychology*, 17(1), 9-38.
- Hawthorne, G. (2005). Preconception care in diabetes. *Seminar in Fetal & Neonatal Medicine*, 10, 325-332.

- Healton, C., Taylor, S., Messeri, P., Weinberg, G., & Bamji, M. (1999). Effects of ZDV-based patient education on intentions toward ZDV use, HIV testing and reproduction among a US cohort of women. *AIDS Care*, 11(6), 675-686.
- Hoyt, L. (1997). HIV infection in women and children. Special concerns in prevention and care. *Postgraduate Medicine*, 102(4), 165-6, 169-71, 176.
- Hughes, C. A., Zuk, D., Foisy, M., Robinson, J., Singh, A. E., & Houston, S. (2009). Prenatal Screening and Perinatal HIV Transmission in Northern Alberta, 1999-2006. *American Journal of Public Press*, [E-pub ahead of print].
- Janz, N.K., Herman, W.H., Becker, M.P. et al. (1995). Diabetes and pregnancy: factors associated with seeking pre-conception care. *Diabetes Care*, 18(2), 157-165.
- Johannesson, M., Carlson, M., Brucefors, A.B., & Hjelte, L. (1998). Cystic fibrosis through a female perspective: psychosocial issues and information concerning puberty and motherhood. *Patient Education and Counseling*, 34, 115-123.
- Kanniappan, S., Jeyapaul, M.J., & Kalyanwala, S. (2008). Desire for motherhood: exploring HIV-positive women's desires, intentions and decision-making in attaining motherhood. *AIDS Care*, 20(6), 625-630.
- Kebaabetswe, P.M. (2007). Barriers to participation in the prevention of mother-to-child HIV transmission program in Gaborone, Botswana a qualitative approach. *AIDS Care*, 19(3), 355-360.
- Kent, N.E., & Farquharson, D.F. (1993). Cystic fibrosis in pregnancy. *Canadian Medical Association Journal*, 149(6), 809-813.
- Kerem, B., Rommens, J.M., Buchanan, J.A., et al. (1989). Identification of the cystic fibrosis gene: genetic analysis. *Science*, 245(4922), 1073-1080.

- Kim, C., Ferrara, A., McEwen, L.N., Marrero, D.G., Gerzoff, R.B., Herman, W.H., and the TRIAD Study Group. (2005). Preconception care in managed care: the translating research into action for diabetes study. *American Journal of Obstetrics and Gynecology*, 192, 227-232.
- Kinsler, J.J., Wong, M.D., Sayles, J.N., Davis, C., & Cunningham, W.E. (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care and STDs*, 21(8), 584-592.
- Klein, J., Pena, J.E., Thornton, M.H., & Sauer, M.V. (2003). Understanding the motivations, concerns, and desires of human immunodeficiency virus 1-serodiscordant couples wishing to have children through assisted reproduction. *Obstetrics & Gynecology*, 101(5), 987-994.
- Kline, A., Strickler, J., & Kempf, J. (1995). Factors associated with pregnancy and pregnancy resolution in HIV seropositive women. *Social Science & Medicine*, 40(11), 1539-1547.
- Lee, R.S., Kochman, A., & Sikkema, K.J. (2002). Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior*, 6(4), 309-319.
- Liu, J., & Remis, R.S. (2007). *Race/ethnicity among persons with HIV/AIDS in Ontario, 1981-2004*. Ontario HIV Epidemiologic Monitoring Unit, Department of Public Health Sciences, University of Toronto.
- Lyerly, A.D., & Anderson, J. (2001). Human immunodeficiency virus and assisted reproduction: reconsidering evidence, reframing ethics. *Fertility and Sterility*, 75(5), 843-858.
- Mahajan, A.P., Sayles, J.N., Patel, V.A., Remien, R.H., Sawires, S.R., Ortiz, D.J., et al. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*, 22(Supplement 2), S67-S79.

- McWilliam, S. (2006). Literature review: HIV prevention and women. *Ontario Women and HIV/AIDS Working Group*. Available online at http://www.health.gov.on.ca/english/providers/pub/pub_menus/pub_aids.html.
- Miller, W.B., Severy, L.J., & Pasta, D.J. (2004). A framework for modeling fertility motivation in couples. *Population Studies*, 58(2), 193-205.
- Mulholland, C., Njoroge, T., Mersereau, P., & Williams, J. (2007). Comparison of guidelines available in the United States for diagnosis and management of diabetes before, during, and after pregnancy. *Journal of Women's Health*, 16(6), 790-801.
- Myer, L., Morroni, C., & Rebe, K. (2007). Prevalence and determinants of fertility intentions of HIV-infected women and men receiving antiretroviral therapy in South Africa. *AIDS Patient Care and STDs*, 21(4), 278-285.
- Nduna, M., & Farlane, L. (2009). Women living with HIV in South Africa and their concerns about fertility. *AIDS and Behavior*, [E-pub ahead of print].
- Nobrega, A.A., Oliveira, F.A.S., Galvao, M.T.G., Mota, R.S., Barbosa, R.M., Dourado, I., et al. (2007). Desire for a child among women living with HIV/AIDS in northeast Brazil. *AIDS Patient Care and STDs*, 21(4), 261-267.
- Ogilvie, G.S., Palepu, A., Remple, V.P., Maan, E., Heath, K., MacDonald, G., et al. (2007). Fertility intentions of women of reproductive age living with HIV in British Columbia, Canada. *AIDS*, 21(Supplement 1), S83-S88.
- Oladapo, O.T., Daniel, O.J., Odusoga, O.L., & Ayoola-Sotubo, O. (2005). Fertility desires and intentions of HIV-positive patients at a suburban specialist center. *Journal of the National Medical Association*, 97(12), 1672-1681.

- Olsson, I., Mykleton, A., & Dahl, A.A. (2005). The hospital anxiety and depression rating scale: A cross-sectional study of psychometrics and case finding abilities in general practice. *BMC Psychiatry*, 5(46), 1-7.
- Panozzo, L., Battegay, M., Friedl, A., Vernazza, P.L., and the Swiss HIV Cohort Study. (2003). High risk behaviour and fertility desires among heterosexual HIV-positive patients with a serodiscordant partner-two challenging issues. *Swiss Medical Weekly*, 133, 124-127.
- Payne, J. (2006). Impact of a reduced fertility rate on women's health. *Women's Health Surveillance Report 2003*. Ottawa: Public Health Agency of Canada.
- Prachakul, W., Grant, J.S., & Keltner, N.L. (2007). Relationships among functional social support, HIV-related stigma, social problem solving, and depressive symptoms in people living with HIV: A pilot study. *Journal of the Association of Nurses in AIDS Care*, 18(6), 67-76.
- Preau, M., Apostolidis, T., Francois, C., Raffi, F., & Spire, B. (2007). Time perspective and quality of life among HIV-infected patients in the context of HAART. *AIDS Care*, 19(4), 449-458.
- Public Health Agency of Canada. (2003). Estimates of HIV/AIDS prevalence and incidence in Canada, 2002. *Canada Communicable Disease Report*, 29(23). Available online at <http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/03vol29/dr2923ea.html>.
- Public Health Agency of Canada. (2005). *HIV/AIDS Epi Updates, May 2005*. Ottawa, ON: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control.

- Public Health Agency of Canada. (2007). *HIV/AIDS Epi Updates, November 2007*. Ottawa, ON: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control.
- Public Health Agency of Canada. (2007a). *HIV and AIDS in Canada: Surveillance report to December 31, 2006*. Ottawa, ON: Surveillance and Risk Assessment Division, Public Health Agency of Canada.
- Rabkin, J.G. (2008). HIV and depression: 2008 review and update. *Current HIV/AIDS Reports*, 5, 163-171.
- Rao, D., Pryor, J.B., Gaddist, B.W., & Mayer, R. (2008). Stigma, secrecy, and discrimination: Ethnic/racial differences in the concerns of people living with HIV/AIDS. *AIDS and Behavior*, 12, 265-271.
- Reece, M., Shacham, E., Monahan, P., Yebei, V., Ong'or, W.O., Omollo, O., et al. (2007). Psychological distress symptoms of individuals seeking HIV-related psychosocial support in western Kenya. *AIDS Care*, 19(10), 1194-1200.
- Remien, R.H., Exner, T., Kertzner, R.M., Ehrhardt, A.A., Rotheran-Borus, M.J., Johnson, M.O., et al. (2006). Depressive symptomatology among HIV-positive women in the era of HAART: A stress and coping model. *American Journal of Community Psychology*, 38, 275-285.
- Remis, R.S. (2008). *Tables of Prenatal Testing in Ontario: Prenatal HIV testing in Ontario, January 1999 to December 2008 HIV testing rates by quarter and 'current' versus 'prior'*. Toronto, ON: University of Toronto. Available online: <http://www.phs.utoronto.ca/ohemu/tech%20reports.html>.
- Remis, R.S., Swantee, C., Schiedel, L., & Liu, J (2008). *Report on HIV/AIDS in Ontario, 2006*. Toronto, ON: University of Toronto.

- Remis, R.S., Swantee, C., Schiedel, L., Merid, M.F., & Liu, J. (2006). *Report on HIV/AIDS in Ontario, 2004*. Toronto, ON: University of Toronto.
- Richter, D.L., Sowell, R.L., & Pluto, D.M. (2002). Factors affecting reproductive decisions of African American women living with HIV. *Women & Health, 36*(1), 81-96.
- Riggs, S.A., Vosvick, M., & Stallings, S. (2007). Attachment style, stigma and psychological distress among HIV+ adults. *Journal of Health Psychology, 12*, 922-936.
- Rusch, N., Angermeyer, M., & Corrigan, P. (1995). Mental illness stigma: Concepts, consequences, and initiative to reduce stigma. *European Psychiatry, 20*(8), 529-539.
- Sawyer, S.M., Phelan, P.D., & Bowes, G. (1995). Reproductive health in young women with cystic fibrosis: knowledge, behavior and attitudes. *Journal of Adolescent Health, 17*, 46-50.
- Shepherd, S.L., Hovell, M.F., Harwood, I.R., Granger, L.E., Hofstetter, R.H., Molgaard, C., & Kaplan, R.M. (1990). A comparative study of the psychosocial assets of adults with cystic fibrosis and their healthy peers. *Chest, 97*(6), 1310-1317.
- Smits, A.K., Goergen, C.A., Delaney, J.A., Williamson, C., Mundy, L.M., & Fraser, V.J. (1999). Contraceptive use and pregnancy decision making among women with HIV. *AIDS Patient Care and STDs, 13*(12), 739-746.
- Sowell, R.L., Phillips, K.D., Seals, B.F., Misener, T.R., & Rush, C. (2001). HIV-infected women's experiences and beliefs related to AZT therapy during pregnancy. *AIDS Patient Care and STDs, 15*(4), 201-209.
- Sowell, R.L., Murdaugh, C.L., Addy, C.L., Moneyham, L., & Tavokoli, A. (2002). Factors influencing intent to get pregnant in HIV-infected women living in the southern USA. *AIDS Care, 14*(2), 181-191.

- Stebbing, J., Portsmouth, S., & Gazzard, B. (2003). How does HAART lead to the resolution of Kaposi's sarcoma? *Journal of Antimicrobial Chemotherapy*, 51, 1095-1098.
- Taylor, S.I., & Arioglu, E. (1999). Genetically defined forms of diabetes in children. *The Journal of Clinical Endocrinology and Metabolism*, 84(12), 4390-4396.
- UNAIDS. (2006). *AIDS Epidemic Update: Global Summary*. Available online:
<http://www.unaids.org>
- UNAIDS. (2008). *Estimated number of people living with HIV by country, 1990-2007. 2008 Report on the global AIDS epidemic*. Available online:
<http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/latestEpiData.asp>.
- Vahratian, A., Barber, J.S., Lawrence, J.M., & Kim, C. (2009). Family-planning practices among women with diabetes and overweight and obese women in the 2002 National Survey for Family Growth. *Diabetes Care*, 32(6), 1026-1031.
- VanDevanter, N., Thacker, A.S., Bass, G., & Arnold, M. (1999). Heterosexual couples confronting the challenges of HIV infection. *AIDS Care*, 11(2), 181-193.
- Vosvick, M., Martin, L.A., Smith, N.G., & Jenkins, S.R. (2008). Gender differences in HIV-related coping and depression. *AIDS and Behavior*, [Epub ahead of print].
- Wesley, Y. (2003). Desire for children among black women with and without HIV infection. *Journal of Nursing Scholarship*, 35(1), 37-43.
- Wesley, Y., Smeltzer, S.C., Redeker, N.S., Walker, S., Palumbo, P., & Whipple, B. (2000). Reproductive decision making in mothers with HIV-1. *Health Care for Women International*, 21, 291-304.

- White, R.T., Pope, C., & Malow, R. (2008). HIV, Public Health, and Social Justice: Reflections on the ethics and politics of health care. In C. Pope, R.T. White, & R. Malow (Eds.), *HIV/AIDS: Global frontiers in prevention/intervention* (pp. 269-277). New York: Routledge.
- Wood, S.A., & Tobias, C. (2005). Barriers to care and unmet needs for HIV-positive women caring for children. *Journal of HIV/AIDS & Social Sciences*, 3(2), 47-65.
- Yudin, M.H., Shapiro, H.M., & Loutfy, M.R. (2008). Access to fertility services for HIV-positive individuals is regionally dependent in Canada. *The Canadian Journal of Infectious Diseases and Medical Microbiology*, 19 (Supplement A). Poster Presented at the 17th Annual Canadian Conference on HIV/AIDS Research.
- Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

④ BW-60-257