

LIFE EXPERIENCES OF WOMEN WITH HIV

by

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A thesis submitted to the School of Nursing

In conformity with the requirements for

the degree of Master of Science

Queen's University

Kingston, Ontario, Canada

(August, 2010)

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Abstract

Rates of female Human Immunodeficiency Virus (HIV) infection continue to rise despite the existence of effective methods of prevention. What is the fundamental variable acting as a barrier to women's self-protection? Researchers have suggested that the oppression of women increases their vulnerability to HIV infection, and that the relationship between oppression and HIV infection must be examined to effectively address this public health issue.

The purpose of this research was to gain greater insight into the life experiences of women with HIV, in order to clarify whether or not women with HIV have, indeed, experienced oppression. Answering this question was necessary prior to the study of the relationships between oppression and subsequent female HIV infection.

Women, age 18 years of age or older, who live in Canada, are proficient at speaking English and HIV positive were recruited to this phenomenological study and each participant was asked to tell their "life story". The findings of this study provide support for the ongoing use of both the oppression framework and feminist perspective in future research. Future studies may include replication of this study in partnership with women with HIV and other academic/community organizations, as well as further analysis of the use of both the Theory of Gendered Power and Social Dominance Theory/Four Bases of Gendered Power in addressing female vulnerability to HIV.

Acknowledgements

A tremendous thank-you to Dr. Diane Buchanan for her sharing of knowledge and encouragement throughout this process and to my parents for the continual love and support they have given me over the years. Thank you to my husband, Andrew, for his unwavering love, support and encouragement in my achieving this degree, and, finally, to our little peanut who has been patiently awaiting its completion before he joins us. I could not have done this without all of you.

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Chapter 1

Introduction

Communicable diseases have challenged health care providers and societies throughout the ages, often presenting new challenges as old ones are addressed. Currently, rates of female Human Immunodeficiency Virus (HIV) infection continue to rise, even though effective methods for protection exist. What is the fundamental variable acting as a barrier to women's self-protection? Researchers have suggested that the oppression of women increases their vulnerability to HIV infection by limiting their ability to protect themselves, and that the relationship between oppression and HIV infection must be examined to effectively address this public health issue. What is oppression? How does it affect the health of women and at what levels does it act to do so? This research explored the experiences of women with HIV in order to further inform public health and grass roots, HIV prevention programming. In order to analyze the issues surrounding HIV vulnerability, it is necessary to begin with a sound understanding of HIV transmission, current diagnostics and epidemiology of HIV, both worldwide and here in Canada.

Background

Human Immunodeficiency Virus; transmission and testing

HIV is transmitted from person-to-person via sexual fluids, such as vaginal secretions and male ejaculate, and blood [Ontario Ministry of Health and Long-Term Care (OMHLTC), 2008, p. 11-12]. Transmission may occur via oral, vaginal or anal sexual intercourse, although oral sex is lower on the continuum of risk and usually requires an additional factor to be present,

such as poor oral hygiene of the receptive partner or concomitant Sexually Transmitted Infections (STI) of either receptive or insertive partner (OMHLTC, 2008, p. 11-12). HIV may also be transmitted via direct blood-to-blood contact, most commonly via sharing of drug paraphernalia, receipt of contaminated blood or organ products, or via mucous membrane exposure to blood (such as in the case of occupational needle-stick injury). The virus can also cross the placenta and is excreted in breast-milk, so vertical transmission may occur during pregnancy, during delivery through mucous membrane exposure to maternal blood, or later via consumption of breast-milk (OMHLTC, 2008, p.11-12).

In Canada, there are two options for HIV screening; the standard, venous blood draw sent to the provincial Public Health laboratory for testing, or the more recent option of the Point of Care capillary screen test. Both options use the EIA antibody screen test, with the same degree of sensitivity (99%) and specificity (99.5%) (Public Health Agency of Canada, 2000). This screen testing detects the antibodies created against the virus. While the average length of time to sero-conversion is twenty-two days, ninety-nine percent of the population will produce a reactive screen by twelve weeks. The remaining one percent of the population is delayed in sero-converting, either due to underlying immune impairment or having received post-exposure prophylaxis (PEP). Individuals with this history should be advised to repeat screening six months after exposure, at which time the result would be definitive (OMHLTC, 2008, p. 8). All reactive screens are confirmed by the Western Blot test (OMHLTC, 2008, p. 9).

If tested during the twelve-week window period, the CD4 white blood cells would be found to be very low, and the HIV viral load would be very high. For this reason, during the window period a person is likely to be unaware of having contracted the virus, yet is highly infectious to others. Also during this time, ninety percent of individuals who have contracted the virus will experience some degree of Anti-Retroviral Syndrome (ARS), characterized by fever,

myalgia, night sweats, nausea, diarrhea and rash. Because of the highly infectious nature of this stage of the disease, if an individual presents at least seven days since exposure, still within the window period, has a non-reactive screen and reports symptoms of ARS symptoms, a P24 antigen test should be performed for early detection and diagnosis (OMHLTC, 2008, p. 8).

HIV and Women

Worldwide, women account for half of the number of people living with HIV, a number that has remained relatively stable over the last few years. However, in many regions, such as Central Asia, South America, the Caribbean, sub-Saharan Africa and Eastern Europe, the percentage of women becoming infected [incidence] and living with [prevalence] HIV has continued to rise (UNAIDS, 2008). Globally, heterosexual contact continues to be the leading cause of HIV infection among women, and has been shown to be related to having sex with men with high risk behaviours, such as those who use injection drugs, have multiple female partners, pay for sex, and/or have sex with men (UNAIDS, 2008). Canada cannot be excluded from these regions, as rates of HIV infection of women have been steadily increasing over the last two decades. “The proportion of females has shown a steady rise over time, increasing from 11.3% of reports with known gender in the 1985-1996 period to 27.8% of adult positive HIV test reports in 2006.” [Public Health Agency of Canada (PHAC), 2007, p. 36]. The proportion of female HIV positive test reports is highest in the 15-29 age group, representing 35-45% of all tests among those with known age between 2001-2006 (PHAC, 2007, p. 36).

“Heterosexual contact and injecting drug use (IDU) are the two main risk factors for HIV infection in women” (PHAC, 2007, p. 35), however, a history of mental illness and/or sexual abuse has been documented to contribute significantly to HIV risk taking behaviours, such as lack of condom use, sex work, and IDU (PHAC, 2007; Poole, 2006). Aboriginal women and women from endemic countries are significantly represented in the positive HIV reports for women

(PHAC, 2007). In Canada, aboriginal women account for almost half of positive test reports with known ethnicity and between 1998 and 2006 “women represented 48.1% of all positive HIV tests reports among Aboriginal persons, versus 20.7% among non-Aboriginal persons” (PHAC, 2007, p. 36). “HIV/AIDS has a significant impact on women from countries where HIV is endemic. Women represented 54.2% of positive HIV test reports attributed to the HIV-endemic exposure category between 1998-2006” (PHAC, 2007, p. 97).

While both men and women are affected by HIV, “social inequalities lie at the heart of HIV risk for women and forces outside women’s control may reduce their ability to protect themselves against HIV infection (PHAC, 2007, p. 30). In order to assist in the reduction of risk for HIV among women in Canada, health care providers and researchers must thoroughly examine and confront these underlying social inequalities.

Chapter 2

Literature Review

These epidemiological data show that women are at the forefront of the global HIV epidemic. Condoms and sterile needles abound, yet women continue to become infected at greater rates. Why are more and more women getting HIV? What has been missed? What has not been addressed in prevention programming?

For the purposes of this research, a review of the literature was conducted in the CINAHL, Gender Studies and Social Science Abstracts databases. The initial search, using keywords women and HIV, identified significant global research on female populations at high risk for HIV infection. Included were young women (Lewis, Melton, Succop & Rosenthal, 2000; Ransom, 1998; Rickert, Sanghvi & Wiemann, 2002; Roberts & Kennedy, 2006; Sicard, 2003; Wayment & Aronson, 2002; Chambers & Rew, 2003; Gerteisen, 1998; Alroy, 1998), women who believed they were in monogamous relationships (Cabral, Posner, Macaluso, Artz, Johnson & Pulley, 2003; Cabral, Pulley, Artz, Brill & Macaluso, 1998), specific ethnic groups (Cappon, et al, 1996; DuBois, Brassar & Smeja 1996; Godin, et al, 1996), sex workers (Amadora-Nolasco, Alburo, Aguilar & Trevathan, 2001; Prybylski & Alto, 1999), substance users (Calsyn, Saxon, Freeman & Whittaker, 1992; Brown & Van Hook, 2006; Riehman, 1998; Worth, 1989), and women with a history of mental illness (Kelly, et al, 1992; Goodman & Fallot, 1998; Anonymous, 2000; Kloos, et al, 2005) and abuse (Goodman & Fallot, 1998; Wingood, et al, 2006). Further searching of articles with a focus on women, HIV and power were limited to those published since 2005, and the resulting articles were read through for significant references. A significant theme in the resulting literature was a recent shift in dialogue from that of female risk to female vulnerability.

According to the United Nations' 2008 Report on the Global AIDS Epidemic, "risk is defined as the probability or likelihood that a person may become infected with HIV" (UNAIDS, 2008, p. 65) due to engaging in certain behaviours, such as sharing needles or having unprotected sex. "Vulnerability results from a range of factors outside the control of the individual that reduce the ability of individuals and communities to avoid HIV risk" (UNAIDS, 2008, p. 65), such as access to services or socio-cultural norms. While addressing female risk for HIV is of great importance, it is a moot point if we do not also respond to women's increased vulnerability to the virus. If a woman knows that a condom will protect her from getting HIV, but is unable to access it due to economic or geographic reasons or if she is afraid that requesting its usage will result in violence from her partner, then this effective method of protection is of no consequence to her.

Cognitive-Behavioral Theoretical Models

Traditional models in HIV research, such as the Health Belief Model (Rosenstock, 1966), the Theory of Reasoned Action (Fishbein & Ajzen, 1975), the Trans-theoretical Model of Change (Prochaska & DiClemente, 1983), and Social Learning Theory (Bandura, 1977), focus on the cognitive-behavioural risks for HIV infection.

The Health Belief Model (Rosenstock, 1966) has been used to explain health related behaviour and claims behaviours are influenced by the individuals perception of threat related to engaging in a specific behaviour and the value placed on actions taken to reduce the threat (Polit & Beck, 2007). For instance, in the case of condom use, an individual must 1) perceive themselves as susceptible to a sexually transmitted infection 2) perceive this as severe, 3) perceive the use of condoms as beneficial, and 4) perceive the costs or barriers (such as decreased sensitivity) to condom use as worth overcoming. In the Theory of Reasoned Action, Fishbein and Ajzen, (1975) suggest that the personal attitudes about a specific behaviour influence the

individual's intention to engage in and execute the behaviour. For instance, an individual's attitude about and the social norms surrounding condom use will affect the individual's intention to use condoms and whether or not they will engage in their use (Albarracin, Johnson, Fishbein & Mullerleile, 2001).

In the Transtheoretical Model of Change, Prochaska and DiClemente (1983) suggest that health behavior change involves progress through six stages of change: precontemplation, contemplation, preparation, action, maintenance, and termination. Progress through the stages has many influences, such as perceived threat, self-efficacy, temptations, etc. In the case of sexual behaviour, a person has to perceive unprotected sex as a threat to their health, consider actions that can be taken to reduce that threat (such as condom use), have the knowledge of how to effectively use a condom and believe that they can do so successfully, and engage in the behaviour. This process is not linear, or uni-directional, as individual behaviour is easily influenced by such things as temptation, and apathy (Prochaska & Velicer, 1997)

Bandura's Social Learning Theory (1977) uses the concept of self-efficacy to explain behaviour. For example, an individual's appraisal of their ability to successfully use condoms, which is affected by past experiences, knowledge, and social norms, determines whether or not they will actually use condoms (Wulfert & Wan, 1993).

The use of these models in HIV prevention efforts implies that HIV infection results from a deficiency in knowledge, attitude and or behaviour, thereby placing responsibility and blame on the individual and neglecting the context in which a behaviour occurs (Amaro & Raj, 2000; Pulerwitz, Gortmaker & Dejong, 2000). A more recent meta-analysis (Albarracin, Kumkale, & Johnson, 2004), that evaluated global research which used Theory of Reasoned Action and Planned Behaviour to predict sexual risk behaviour, found that these theories were more

predictive amongst groups of lesser power, and concluded that power does play a role but were unable to explain why or how power influences behaviour.

The significant role power plays in female vulnerability to HIV has been well documented in the literature (Bunting, 1996; Cabral, et al, 1998; Ransom, 1998; Rhieman, 1998; Shannon, Kerr, Allinott, Chettiar, Shoveller, & Tyndall, 2008; Wayment & Aronson, 2002; Wingood, et al, 2006) and authors have argued that prevention programming must be aimed at the underlying social context in order to successfully address the phenomenon (Amaro, 1995; Amaro & Raj, 2000; Amaro, Raj & Reed, 2001; Bunting, 1997; Jones, 2006; Gutierrez, Oh & Gillmore, 2000; Rosenthal & Levy, 2010; Shannon, Kerr, Allinott, Chettiar, Shoveller & Tyndall, 2008; Wingood & Diclemente, 2000). The UNAIDS Global Report states that the “long-term success in responding to the HIV epidemic will require sustained progress in addressing human rights violations, gender inequality, stigma and discrimination...[and that] evidence-informed programmes to forge norms of gender equity should be brought to scale” (UNAIDS, 2008, p. 64).

Within the last decade, there has been increased discussion in the literature surrounding the relationship of gender and cultural role differences and resulting female vulnerability to HIV. Authors have acknowledged that women are often those within heterosexual relationships possessing lesser power than men (Amaro & Raj, 2000; Amaro, Raj & Reed, 2001; Riehm, 1998; Amaro, 1995; Wyatt & Riederle, 1994; Sewell, 2001; Phillips, 1998, Lako, 2004; Gimenez, 2005; Diaz, Bein, Henne & Marin 2001; Sharma, 2001; Fletcher, 2006). Over the last decade, academics have called for investigation into this issue and development of theoretical models that address the full context of female vulnerability and risk.

Power Related Theoretical Models

HIV researchers have begun to theorize and analyze the application of various power-related theoretical models to the study of women and HIV. These have included Bunting’s

(1997) analysis of the use feminist theory in nursing HIV research, Ruagjiratain and Kendall's (1998) discussion of applying critical hermeneutics to understanding HIV risk, Guitierrez, Oh and Gillmore's (2000) use of an empowerment framework, Wingood and DiClemente's (2000) use of Theory of Gendered Power, Jones' (2006) discussion on the use of sex script theory and theory of power of knowing participation in change, Shannon and colleagues (2008) use of the risk environment framework, and Rosenthal and Levy's (2010) articulation of social dominance theory and the four bases of gendered power.

Bunting (1997) analyzed nursing research reports on HIV and women through a feminist perspective by developing research questions based on the basic principles of feminism; "(a) a valuing of women and women's experiences, ideas, and needs; (b) recognition that there are structural, interpersonal, and ideological conditions that oppress women as women; and (c) commitment to bringing about change in the structures and conditions that support women's oppression (Bunting, 1997, p. 525). Bunting found that feminist principles were being used effectively and that feminism was an effective framework for studying vulnerable groups.

In their discussion, Ruagjiratain and Kendall (1998) argue that critical hermeneutics can be used to effectively identify the underlying socio-political variables attributing to risk of HIV infection in Thai women and to facilitate change in their oppressive reality.

Guitierrez, Oh and Gillmore's study (2000) on the use of an empowerment framework in predicting HIV risk among adolescent women found that the empowerment framework was more useful in predicting condom use in African American young women than those of European origin. As well, the age of first intercourse related significantly, but differently, in both groups to risk behaviour. They concluded that future research needed to take a more holistic approach, by addressing all aspects and levels of oppression, to gain greater understanding of how "each

dimension of power may operate independently and relate to different aspects of behavior” (Gutierrez, et al, p. 605).

Similarly, Jones (2006) combined sex script theory and theory of power as knowing participation in change as a framework to explain the sexual HIV risk behaviours of urban females. Again, the framework only attended to the gender-based issues related to sexual behaviour and neglected the multitude of other oppressive contexts, such as socio-economic level, violence, substance use, race and ethnicity, which also influence women’s sexual behaviours.

Shannon, et al (2008) used the risk environment framework to analyze the socio-structural and power influences on HIV risk behaviours for drug using sex workers in Vancouver, British Columbia. This framework described risks as operating on three levels; micro (interpersonal), meso (institutional/organizational) and macro (political). Although this framework was successful in shifting the prevention focus beyond the individual level to include those forces outside individual control, it does so almost to the extreme by neglecting the intra-personal aspects of risk.

As discussed earlier, a meta-analysis of existing research, which examined research using the Theory of Reasoned Action and Planned Behaviour, (Albarracin, et al, 2004), found that cognitive-behavioural interventions are, in fact, more effective among vulnerable groups (such as sex workers), and thus should not be overlooked when identifying the forces influencing individual behaviour. Additionally, although the economic aspects of risk are identified in the macro results, other pertinent power dynamics, such as gender and race, are absent from the discussion.

Wingood and DiClemente (2000) adapted and applied the Theory of Gender and Power to examine female risk factors for HIV and interventions. This theory appears to provide an effective tool for examining the issues of power and gender intersecting at both the societal and

institutional levels and how each influence individual behavior, increasing female vulnerability to HIV infection.

Finally, Rosenthal and Levy (2010) suggest that a combination of social dominance theory (SDT) and the four bases of gendered power (FBGP) could be used to effectively address the various, interconnected contexts of power that influence female risk for HIV. SDT asserts that groups and individuals are subjected to discrimination and marginalization based on the presence of various societal hierarchies, such as class, gender, religion and race. The FBGP deal with the power issues pertaining to gender, and suggest there are four aspects of such power that are interconnected and reinforcing. The first is force, which includes any “form of violence against women that undermines women’s power, even if it is indirectly the threat of violence that achieves this end (Rosenthal & Levy, 2010, p. 23). The second is resource control, which includes limited access to well-paying employment, education, health services and institutional influence. The third base of gendered power is social obligations. This base focuses on the inequalities that exist between men and women in relationships and the social obligations of caring. The final base of gendered power is that of consensual ideologies, including “gender roles, norms, stereotypes and any other beliefs or expectations that are generally agreed upon in a society or culture, putting women in weaker positions” (Rosenthal & Levy, 2010, p. 26).

Rosenthal and Levy (2010) argue that a discussion of risk is incomplete until all aspects of power are considered, which can be achieved through analyzing the multiple levels of gendered power (FBGP) while also acknowledging the influence of group membership (SDT), such as race and class.

The articulation of these two theories in the context of female vulnerability to HIV is an interesting one and is the most comprehensive of frameworks in the discussion thus far.

However, given that the issue at hand is one of oppression being perpetrated at a variety of levels,

it is important that academia does not add to the phenomenon by imposing a pre-conceived framework on women regarding their vulnerability to HIV, but, as the feminist perspective details, provide an opportunity for a framework to emerge from those who have lived the experience. Given that power is central to this phenomenon, the way in which power, or oppression, functions is worth exploring.

Chapter 3

Sensitizing Framework

As the concept of oppression had yet to be delineated, a conceptual analysis of oppression was executed in order to gain a greater understanding of its universal characteristics (Deiters & Buchanan, 2009). Franz Fanon (1968) was the original voice in the dialogue of oppression, whose ideas were further built on by Paulo Freire (Freire, 1970). Subsequent discourse has seen authors utilize the concepts and ideas of Fanon and Freire to describe oppressive contexts.

What the analysis showed was that in order for oppression to take place, three things must exist (antecedents). There must be at least two different people, at least one of these people must possess a desire to protect or gain something and there must be a power differential. Further, the three defining attributes of oppression are distrust, threat, and an exercise of power. The consequence of this exercise of power is the establishment of a dichotomy, (see Appendix A). The individual able to exert the most power becomes the oppressor, while the other becomes oppressed. Subsequent to the initial establishment of the dichotomy, actions taken by each side reinforce the new status quo and each group begins to manifest specific, positional traits (Deiters & Buchanan, 2009).

The characteristics of the system of oppression, the oppressors and the oppressed are universal and constant, while it is the people involved in the system that differ between contexts. Fear, dehumanization, prescription and unconsciousness are all characteristics that develop within the system of oppression, affecting all that exist within it. Two characteristics of the oppressor were repeatedly discussed in the literature: othering, exemplified in labels and blame, and control, identified by the domination of one group over another. Othering was frequently described as a

mechanism for the oppressor group to differentiate themselves from everyone else. Labels and blame function effectively to reinforce the “other” mentality, thereby justifying further oppression of the unacceptable group. The analysis highlighted the significance of control and domination for the maintenance of oppression (Deiters & Buchanan, 2009).

Two main characteristics are attributed to the oppressed group, internalization and assimilation. Internalization refers to the experiences of the oppressed group resulting from the labels, blame, dehumanization, and prescriptions involved in oppression, and can be identified by the occurrence of multiple phenomena within oppressed groups, such as silencing, shame, guilt, learned helplessness, horizontal violence and low self-esteem. Once internalization has occurred, assimilation of the oppressed group into the stronger, dominant culture inevitably follows. Assimilation can be identified in a population/person by the loss of individual cultural identities leading to a fairly homogenous society and the presence of marginalized individuals within the new norm. As discussed in the analysis, the system will develop traits of its own over time; fear, dehumanization, prescription and unconsciousness. The traits provide layers of protection for the system, reinforcing the separation and power differential between the two people(s) (Deiters & Buchanan, 2009).

Empirical referents found in the oppressor group include labeling, blaming and domination. These phenomena identify the presence of othering and control. Empirical referents also include the silencing, shame/guilt, horizontal violence, low self-esteem, learned helplessness, marginalization and loss of culture/identity found in the oppressed group which identify the internalization of and assimilation into the dominant culture (Deiters & Buchanan, 2009).

While this sensitizing framework was critical to this study, there was also a humanitarian component, a philosophical framework, which supported and guided this research.

Chapter 4

Philosophical Framework

The United Nations (UN) Declaration of Human Rights (1948), outlines the fundamental rights of all human beings, regardless of “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status” (p. 2). Of the thirty articles within the Declaration, the researchers of this study hypothesized that nine are violated when it comes to the rights of women in Canada to protection from HIV. These nine rights are:

Article 1

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood” (United Nations, 1948).

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty (United Nations, 1948).

Article 3

“Everyone has the right to life, liberty and security of person” (United Nations, 1948).

Article 5

“No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment” (United Nations, 1948).

Article 12

“No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the

protection of the law against such interference or attacks” (United Nations, 1948).

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality (United Nations, 1948).

Article 23

(1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

(2) Everyone, without any discrimination, has the right to equal pay for equal work (United Nations, 1948).

Article 25

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection (United Nations, 1948).

Article 26

(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace (United Nations, 1948).

These nine rights address the underlying issues of gender inequality that persists globally, where women and men do not share equal access to employment, education, safety, security,

freedoms, societal value and protection. An acknowledgment of this highlights the moral imperative of this research.

Chapter 5

Significance

Simple cognitive-behavioural interventions are insufficient in mitigating many of the underlying risks to female HIV acquisition. This study explored the dynamics of the under-addressed, yet pivotal role that certain aspects of oppression may play in the vulnerability of women in Canada to HIV, with the goal of identifying any overlooked factors in prevention efforts. As well, it was important to explore this as a human rights issue. Oppressive systems, groups and individuals violate the rights to which, in 1948, the United Nations deemed every human being was entitled. Though these rights were initially written in the masculine, they must apply to women of today.

Chapter 6

Methodology

Research Question

The research question for this study was: *What is the essential life experience of women in Canada with HIV?*

Design

A phenomenological approach was used to carry out a thematic analysis of the life experiences of women who have contracted HIV. Similar to Van Manen's (1990) method, "in which researchers try to grasp the essential meaning of the experience being studied" (Polit & Beck, 2007, p. 402), in depth interviews were conducted with a purposive sample of women with HIV who were willing to share their life experiences. This approach is appropriate in that there exists little understanding of the life experiences of women who have contracted HIV, and in using this method "...any phenomenological distinctions are only valid to the extent that they inform, confirm, value and validate one's own possible experiences from the perspective of the lifeworld of the subject" (Van Manen, 1998, p. 4). The researchers were able to use the selective approach to analyze data. This approach involved reviewing interview data and highlighting "key statements and phrases that seem essential to the experience under study" (Polit & Beck, 2007, p. 402), and then organizing these key statements into themes. Continued data collection from additional participants and follow-up interviews allowed for further reflection upon the themes, whereby the essential themes of the shared experience were discovered.

Sample

To study women who have avoided HIV infection would have posed significant sampling challenges to the study and the reliability and transferability of results would be highly limited.

Therefore, a purposeful sample of Canadian women with a diagnosis of HIV, who were eighteen years of age or older and who spoke English were the population of interest. The sample was recruited through an existing organization for individuals with HIV in Kingston, Ontario. A summary detailing the study was provided to the agency (see Appendix B). Posters (see Appendix C) describing the study were posted in the office, and a participant information sheet (see Appendix D) describing the study was given to staff who approached potential participants and provided details regarding the study. Informed, written consent was obtained from each participant (see Appendix E). Demographic information was collected from each participant (see Appendix F). In the end, there were four participants in this study who were between the ages of 37 and 54 at the time of interviewing, all four were Canadian born, although one spent time as a young child living in Europe and was then separated from her parents at age five or six and sent back to Canada to live.

Data Collection

The data collection process involved two one-on-one, face-to-face or phone interviews with each participant, depending on the participants' preference. Each participant was asked to select an alias which would be used in all transcriptions and documentation regarding what they shared. The chosen names were SQWRRL, Christine, Pam and Suzy. To initiate the first interview, participants were asked to tell their "life story" prior to acquiring HIV, and their thoughts on how those experiences influenced their risk for HIV infection. Two questions were used to engage clients in telling their story: 1) Tell me your life story prior to getting HIV and 2) Tell me the story of how you got HIV. The interviews were audio recorded on a digital recorder and immediately following each interview the primary researcher documented her initial impressions, reactions and feelings to the data collected. A second interview was held with three of the four participants, during which the researcher read aloud a composite story of a woman whose

experiences reflected the joint experiences of all participants (see Appendix G). Discussion was then held on the participants' reactions to the story, whether or not it reflected their own experiences, and further information and clarification was obtained.

Data Analysis

After each interview, the investigator transcribed the audio-recording into a Microsoft Word document, reviewed it for accuracy and made additional memos regarding key thoughts/interpretations. Both investigators analyzed the interviews independently, and applied codes to the raw data using key words and phrases. Discussion was then held between the investigators regarding individual interpretations, and codes were reviewed, clarified and revised as needed. Based on these discussions, broader concepts were identified and codes and concepts were organized into six themes.

Upon completion of the four initial interviews, a composite story was created which reflected the themes that emerged from the data. This story was then discussed, reviewed and revised to assure that it accurately reflect the codes from the analysis. Follow-up interviews were held with three of the four participants, during which the primary researcher read the story aloud and then received feedback. This data was then used to adjust the story and themes, as necessary, to reflect the true experience of the participants.

Trustworthiness

The trustworthiness of this study was heightened through the following strategies: Credibility was addressed via an interview guide that assisted the primary researcher in staying focused on relevant issues to the study. Triangulation was obtained through selection of female participants of various backgrounds and the active participation of two investigators who analyzed and interpreted the data independently. Post-interview journaling was completed by the primary researcher and discussions were held between the two investigators to allow for peer-

debriefing. The follow-up interviews, through the sharing of a composite story (Appendix G), provided an opportunity for member-checking. To address both dependability and confirmability, an audit trail, including reflexive journaling, notes, decision trail, analyses and interpretations, was used.

Ethics

This study was reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, and approval granted. Revisions were made to the original ethics application, to allow for interviews to occur by phone, in the City of Kingston and an extension on the time frame for the study. These changes were granted approval. Informed, written consent to participate (see Appendix E) was obtained from all participants. Had the process caused psychological distress to any of the participants to the extent that there was need for ongoing support, the participant would have been referred to a counselor at the agency with whom she already had a supportive relationship. This did not occur.

Chapter 7

Findings

The following six key themes emerged from the data collected from interviews with the four participants: childhood development; education; risk factors; survivor mentality; after diagnosis and what would have helped.

Childhood development -missing pieces

All four women spoke of aspects of their childhood, both in reference to their family structure and relationships with family members. Three out of the four women came from broken and/or step-families, and three were the eldest child in the family. For instance, Suzy, when asked about her family life stated,

I think, around fourteen, I left home, just not feeling part of a real family.

Having a step-part, and the rules not the same for the one then the other... So I

left home at fourteen, on my own. I hit the streets, as they call it. Started working on the market.

Similarly, Christine described her broken family life, stating

My dad, I didn't have a dad. He wasn't around. He'd come to see us once and a while, but not very often. My mom was our father and our mom together. When she had a boyfriend, she was never home. I was always babysitting.

The roles of mother and father were also frequently discussed. Three out of the four women described one or both of these roles as lacking in their childhood, and all described tensions between with their siblings, as well as having taken on the role of caretaker at an early age. Christine stated,

...he wasn't, in a way, he wasn't a good dad. And he wasn't because he should

been there for us, but he wasn't. I don't know, maybe that's why, you know, I let men do what they did to me. I didn't have a father figure.

SQWRRL described her father, saying

Oh, my father was just an asshole. He got me through divorce, at that time when the oldest one went with the father and the youngest one stayed with the mother. Well, I got shipped over from Belgium over to here with a step mother...she hated me...They put me in Children's Aid and my father made me a Crown ward. Instead of sending me back to my mother he made me a Crown ward, so I stayed here in Canada.

Suzy, who lived with her father and step-mother, spoke of her relationship with her birth mother.

My mother wasn't, we didn't, um I think I was sixteen when I got to, um...I was so bad, as my stepmother put it, asked me at sixteen what I wanted for my birthday and I said just to know my real mother and she gave me a phone number and...you know, it didn't go well...

When asked what it was like to grow up without a strong parental presence Suzy stated,

I think it gave me the green light to go ahead and do whatever I wanted.

Although Pam had an attached family growing up, one with involved parents who did not make her feel excessively responsible for herself or her siblings, she did describe tension created by birth order.

I was always the one left in charge if mom and dad were out and he didn't like that 'cause he's pretty close in age to me and I could pretty much tell him it's time for bed and I'm much bigger than him and, that relationship, it was kind of tense...

SQWRRL described her relationship with her younger, biological brother,

I taught my brother what a condom was by the time I was six. He use to find them on the floor and try and blow them up and I'd go, no, no, no....So , I had to pretty much grow up really fast and the experiences of growing up were not there...I had to act like a grown up and be a kid at the same time...so I guess I got a little confused along the way.

Pam echoed this caretaker feeling, pertaining to her social group rather than family.

That sense of responsibility would have been toward friends and people I know, more than my brothers. They were on their way up, they were doing fine....

Regardless of whether or not the families were together, or for whom the women described as feeling responsible, they were all able to provide descriptions of these missing pieces to their childhood.

Education –formal and informal

Only one of the participants, SQWRRL, finished high-school, although it was later in life. Both Suzy and Pam completed grade ten, and later Pam went back to school, upgraded her high-school grades and completed some college-level courses. Christine left school in grade eight. She stated,

I was in high school and then they shipped me to another special ed class...probably because I was stupid or something. I couldn't do the work in high school, in regular high school.

Pam reported,

I actually only got grade ten and then I was missing math so I did grade ten math at correspondence...

All four women spoke of the limitations within their formal schooling around sexual health, infectious diseases, and harm reduction/disease prevention practices, and their perceptions

of what formal education exists today. As Pam, who did not make it into high school, discussed,

It was back in the 50s, people learned their sex education in high school. That was it.

Pam shared what she felt was an ongoing, low level of awareness regarding HIV among young people these days.

I think Sasha [her daughter] would have told me about it if they had been talking about HIV. I know they know all about the reproductive system, and they've talked about drugs and everything...I was very surprised that kids didn't know. Like, you'd think a sixteen-year-old would at least have heard about it [HIV].

Suzy discussed both formal and informal education when she stated,

Compared to these days, kids in school, I think they are learning a lot earlier than when I did, and I think sex is being much more talked about in families as well, because of sexually transmitted diseases, not only AIDS...

This informal level of education was a reoccurring theme between the women, who spoke of learning about sexuality from siblings, peers and via poor modeling by watching how the adults behaved around them. SQWRRL described her experience in a juvenile detention centre, stating,

They send you to these reformatories to straighten you out and educate you and stuff. Oh, yeah, they educated you, on how to be a better street person. How to make better money when your selling drugs, how to put out better tricks, you know? Ya learn the worst part of life when you go to them places. They're not helping kids, they made me who I am.

Specifically regarding sexual health, SQWRRL continued,

Oh, I knew about STDs, 'cause I was in training school. I was in reformatory...being kids with infections, they have a tendency to talk a lot, so I got the gist of syphilis, crabs, gonorrhea, all the good stuff while I was there...through talking to the other girls.

Suzy discussed how she learned about the option of selling sex for money from her step-sister who was also a sex worker.

I heard the word 'tricks' from her. Didn't know what the market was or what they called where that was, but that's how I found out.

The participants related how they had learned about sexuality and relationships by watching the adults in their lives. Christine shared,

My dad walked out when my sister was eighteen months old and mom jumped, well she jumped from this man, that man, you know?...My dad was abusive to my mom...he beat her all the time, call her names, cheat on her...

Similarly, SQWRRL discussed the example that her mother led for her as a child.

She'd turn tricks to make her extra money, she brought home men. I experienced men in my bed, not sexually, but being taken from my bed and put into another bed so that some guy can sleep in my bed while she's got one in her bed and one in my brother's bed and one in my bed. Ya know, so, I learned all that stuff...

Rather than learning clear, accurate information in a formal setting, these women were forced to discover sexuality, health and relationships on their own.

Risk Factors

All four participants spoke of personal or partner risk factors for HIV, such as initiating sex at an age earlier than they would have liked, having multiple sex partners, not using condoms consistently, sharing drug paraphernalia, a history of abuse, living a somewhat transient lifestyle,

and issues in mental health. When asked how she felt about the age she was when she became sexually active, Christine stated,

I woulda liked to have finished school, get a job, waited 'til I was married to have inter-course, but that didn't happen.

Similarly, Suzy spoke of the age she was when she became sexually active.

Yeah, being the type of women that I was hanging around, working the market at fourteen, you know, wanting to uh, do a good job or make more money or whatever it was, do it right, you know? I think, yeah, I would have rather waited until I found, uh, love.

Again, Pam voiced this feeling,

I was, like, seventeen, which is way too young. I would hate it if Sasha started at that age, but I was always in with the wrong crowds.

She also discussed her feelings about the number of sexual partners she had and use of condoms when she was young.

It was too promiscuous on my part because, regardless of AIDS or not AIDS, I still should have been using protection for um, like birth control, but I never thought of AIDS. I mean, there are other STDs out there that I should have been more careful about all of them.

Similarly, Suzy voiced inconsistency with condom use between different types of partners.

At fifteen I had my own apartment and was turning tricks, didn't even know what the word HIV or AIDS was. Wore condoms, just because that's the way the other girls were telling me how it's done...never even crossed my mind to use a condom with a boyfriend.

When asked if she was aware of the possibility of disease transmission via needle-sharing, SQWRRL stated,

Oh yeah, yeah. She told me she had Hep C and cancer, so I didn't care. It didn't matter.

All four women described a history involving various forms of abuse. Christine was sexually abused by multiple men in her childhood, as she explained,

I was molested all my life practically. Yeah, her grandfather, her father, all the other...all the guys thought that they could just get me in the sac.

SQWRRL was physically abused by her stepmother and step-grandmother. Regarding these women she stated,

She hated me and it just kept escalating from there. And he [her father] got transferred to Viet Nam and I stayed with her mother who was an alcoholic and a very bad child abuser, very bad. Oh yeah. I once had bite marks on me for god sakes and I still wear the scar where I almost lost my life.

Pam was physically and emotionally abused by her husband, as she shared,

I could have, if I was thinking, foreseen that there were going to be troubles and it wasn't the greatest relationship but, you know, love is blind. Anyways, he was abusive...Actually, it got worse after we got married. He's, he's an alcoholic.

Although it may have been a degree condoned in society at the time, Suzy received corporal punishment from her stepmother that she identifies as abusive today. She revealed,

My stepmother got up and came over and slapped me in the face and I didn't like it...The strap and the belt and stuff like that. We all did. I think we thought it was normal. It went through all of our friends...I think that's how we learned to fight, the girls learnt to fight each other.

The issue of a transient life-style was something that came up frequently in the interviews. For instance, Pam spoke regarding a sexual partner she had,

There was one that I couldn't get a hold of and I kinda knew I wouldn't get a hold of 'cause he was a little bit of a transient type guy...I went to Florida one time with my brother and left him to look after my cat in my apartment and when I came back, oh, the apartment was just a mess. And he was there with some other girl and oh, it was just stressful, stressful. And in the process of cleaning up I found syringes and so he must have been a drug user...

SQWRRL also made mention of a transient life-style, but from her own experience.

I spent my first seven years between Germany, Belgium, France and...I like it, yeah. But then, I kinda got it in the blood, eh?

Christine described a similar frequency of moving around as a child when she stated,

I wish I'd never moved to Quebec...My mom moved me. Wherever she moved she said we had to move. Well, I could have found family down here and stayed with them but they say when, usually when parents say you're moving you're moving. That's it. I told her I didn't want to.

Another common theme between the women was the influence of a male partner, or the desire for motherhood, on their risk-taking or their willingness to persist in unhealthy relationships. For example, regarding how she started using injection drugs, SQWRRL stated,

I did it for spite once, and that was kind of the beginning of it all...I was spiting my boyfriend. He told me not to use drugs and I went and used them anyway...that was just to piss him off.

In addition to her lack of condom use with intimate partners discussed earlier, Suzy identified how she used injection drugs for the first time to try and gain the attention of a man.

I was more curious about what they [other girls] had that I didn't have, or the way I thought it was, you know? I was more curious why he was spending more time with them. What did they have that I didn't have? ...I paid him to give me that first hit...he didn't want to have sex with me...I always wondered why, another reason why I wanted to try the needle, maybe that would make him like me more or have sex with me instead of the other women...

Pam related,

He's an alcoholic. I coulda foreseen all this if I was thinking that way, but I was in my thirties and I thought, the only thing that I ever wanted to be, that I knew I wanted to be, was a mother, and so I was probably a bit blinded by that whole way of thinking.

Three out of the four women spoke about their struggles with mental health. SQWRRL reported,

I'm depressed about all kinds of things, but HIV is not one of them.

Pam revealed,

I'm sort of obsessive-compulsive. Actually, I've been diagnosed with it so I am obsessive- compulsive.

She later added,

I don't feel depressed in the way that I used to feel depressed, like crying and really heavy duty anxiety, but...I've been on Prozac probably since I've been in my teens. It's not working anymore. They've added Welbutrin to it.

Although she did not identify a clinical diagnosis, Christine also expressed feelings indicative of depression.

I would tell my mom, I wish I was never born and I still, from this day, I feel the same thing.

Whether it personal risk factors or those of their sexual partners, all four women discussed circumstances that may have created greater vulnerability to disease transmission.

Survivor mentality

A major theme running through the narratives was that of survival. Each woman described situations where she had accessed coping strategies that allowed her to successfully navigate her life, such as detachment, isolation and guarding against potential threat. SQWRRL clearly described this sentiment when she stated,

I was tough, and I just never cared. You know, you put me in a position like that, I'm going to learn, and I'm not gonna care. So I got every street smart that I needed before I was fifteen in a reform school...I'm no bullshit. Don't screw me up or over because you're gonna get it worse in the end...People are intimidated, they're intimidated by it...I just carry myself, like, don't even bother with me 'cause I'll break your neck. Get away from me...I got an eye for somebody trying to screw me over, like before they can even think about it...I trust nothing. I trust nothing, only half of what I see and nothing that I hear.

Suzy talked about how the stigma of having HIV affected her, and how she protected herself from it.

Got labeled, as you could say, labeled as having AIDS. So, um, I wasn't feeling very comfortable, so I had the guards switch me into a segregated cell for my own safety.

Similarly, Pam discussed how she protected herself, and her daughter, from potential discrimination.

We didn't tell anybody, because that's what I was afraid of. I thought, if their parents know, she [Sasha]'s going to be discriminated against...I only tell people that are either in the health field or have been in the health field or, like, super close friends. So, I don't tell very many people. People just don't get it. I always thought, if people did know and I had a drink at their house, they'd probably throw the glass out. They probably would feel they couldn't wash it well enough, get the germs off of it....I know that it's because of people's ignorance. I do know that, but there's still this bit of me that still knows that people will not accept me, or Sasha. Not because of me, it's because of them, but I do know those people are still around...

Regarding her relationship with her mother, Suzy shared,

I just remember crying and not feeling wanted. Just like, here we go again...and that's why I don't open up with my mother these days. I don't think she's mother material. That's the way I put it...Not rejected, pushed the other way or given the green light to do it, you know? I just, um, people say, do you feel love? And no, no I don't. I don't think I could have my mother in a loving way.

After a significant sexual abuse history, Christine discussed how she confronted the advances of her biological father.

He gave me his bed when I stayed, when I went to Ottawa and stayed there. He gave me his bed and he was taking the couch. Well, he climbs in bed with me and tried to touch me. I'm like, what the hell are you doing? I'm your daughter. So if you want your bed, you can have it.

Christine later went on to identify her emotional isolation. Regarding the interview, she stated,

I feel better now once I let my emotions out. My first time letting my emotions out like this.

Although each woman described unique ways in coping with the challenges they had encountered, the overall feeling is a sense of survivorship. Each of them accessed great personal strength in order to cope with their past experiences, or to protect themselves from additional harm.

After diagnosis –a time of change

Another significant theme through the women's stories was that their diagnosis acted as a catalyst for change in their lives. All spoke of developing greater knowledge and insight into aspects of HIV, as well as accessing supports available to them. Two expressed a desire for change in risk-taking behaviours, and all reported seeking greater stability in their lives. For instance, Suzy discussed how after diagnosis she connected with a local HIV organization.

It's an AIDS organization. Finally really learned to open up to the support workers there and learned what HIV/AIDS was all about and what I was doing to my body by not taking medications and suppressing and everything else. So they were a big part of my life...

Similarly, Pam discussed her experience when she was newly diagnosed.

It was a disease that you couldn't live with. It was a death sentence. So, then I got on with a really good doctor and he, it was a new generation of drugs that had just come out, and he said that if I'd, he said well, if you, if you'd been diagnosed a year ago I'd have to tell you - you probably only have about a year and a half to live. But, he said, this new medication is proving to be very effective and now I can say that if you're, you know, if you're good about taking your meds that you might live as long, like you might live a normal lifespan.

When questioned about the supports she has accessed, Christine reported,

She [mom] still loves me. She's there, supporting me. Yep. My sisters know, too. My sister, I told my sisters and my one sister, well they both cried. They've been there for me. It's hard.

Regarding more formal supports she stated,

[The HIV organization] is the only one, that's it....When I first met [counselor], I didn't know he was a support worker or anything. I met this other guy...and he's the same as me, he's HIV positive too, but he got it from needles.

SQWRRL discussed how her diagnosis influenced her activities on the street.

I hated being a street person. I really hated being a street person because you're condemned everywhere. You're thought of as nothing else but a piece of trash, you know? You don't deserve anything, you're not allowed to have anything...So I thought, if I'm going to be a street person I'm going to do something that helps other street people. I carried condoms around for the girls...I helped everybody that I could. And I went and volunteered in soup kitchens...

Pam, who had been living in an abusive relationship, discussed how her diagnosis and the birth of her child motivated her to make changes in her life.

I started the whole divorce stuff in '94, '93 maybe, mostly because I didn't want her to be raised in a house with drinking and abuse. I didn't want her growing up thinking that was okay...I left when the police had to come and everything because I knew it was going to be really frightening...I didn't really have a choice, for her life and for my own, well and for my own, ah, there was no, really there was no choice. It just had to be that way.

The diagnosis of HIV also influenced the way these women felt about themselves, their self-worth, either by validating their worth or further challenging it. For instance, Pam describes the effect of her blindness, secondary to having HIV, on her sense of self.

I'm very self-conscious. One of my eyes is now, the lid is almost closed because I don't use those muscles...Now I'm starting to look to other people that I'm blind...I know I'm depressed just because of all the symptoms I hear all the time on the T.V., and even the doctors agree that I'm depressed...I have no motivation, nothing excites me. I'm just flat. My emotions are kind of flat...people before would have said I'm the life of the party, sort of thing, but not anymore.

Similarly, Christine related,

I get treated like crap by men, I didn't, I don't like it...You see, when they told me I was diagnosed with HIV, why me? It's not fair. I don't do needles...

Conversely, SQWRRRL discussed how her diagnosis didn't really change the way she felt about herself.

It hasn't got me down, really. It's just another thing that I have to deal with...Try not to do too many drugs, and I don't put myself in a position where, you know, I could make myself sick or I could give it to somebody ...I just grinned and bared it, took it with a grain of salt and here I am, still laughing about it. You know? And if I can keep a good sense of humour about it and I can get through another day, I can make it on to next week, you know, it's my frame of mind.

However, she did discuss how she deals with the discrimination and ignorance she faces regularly regarding HIV.

If I walk into a conversation where they are being [discriminatory] about HIV, I don't get into it [her diagnosis]. But I do throw in comments, like, I'll throw negative comments at them, you know, and I will try to explain it to them...they're a little more knowledgeable and they're, the next time around, they're not quite so bad. But I still, I won't tell them, because of the fact. Hey, to me I'm still the same person I was five minutes ago when I told you, but you may think I'm different.

Whether it was a positive or negative effect, behavioural or psychological changes, each of the women described a transition in their lives that occurred after diagnosis. These four women also reflected on what would have helped prevent them from getting HIV, and the findings were quite similar.

What would have helped –looking back

Greater knowledge (both formal and informal education), healthy family relationships and a safe childhood were the main themes that emerged from the four interviews. Three of the four women identified that greater education and knowledge regarding sexuality would have made a difference in their vulnerability to HIV. Three spoke of the impact of healthy, supportive family relationships, as well as a safe and secure childhood. For example, SQWRRL offered advice for young people today,

If you have a home with parents that care about you, no matter how bad it is, it's not worse than the street. It's gotta be better than the street...Get your education first, you know? Stay at home, get your education, you've got all your life to do what you want to do after...these eighteen years are going to be school and the rest of it is your life. Do what you want to do then, but try and do what you have to do now. Be responsible for your future now...Always communicate with your

parents. I wish I had had parents. You know? Neither one of mine wanted anything to do with me...So I didn't get that normal parents, you know, within the realms of normality. So, if you can get some kind of stability early on, I think it leads to better decisions and better life choices.

Similarly, Christine talked about the importance of a secure relationship with parents. Regarding why she did not tell her mother about being sexually abused, she stated,

I didn't think that she'd believe me. I just think that she might have said, well, you're doing this to get him out of the house or get him out of my life...I guess safety before you can tell something....Keep your kids safe, talk to them, don't shut them out. Don't be shy, especially about sex. Right now, about HIV/AIDS.

Suzy also voiced similar feelings about education and family.

I think kids should be taught in public school, at an earlier age, because parents are ashamed. I didn't know what it is, to talk to their kids about sex and HIV and, prostitutes and all of the drugs and anything. I think that education played a big part in my life...[education] for children at an earlier age, and I don't know what age it is that they don't think it's funny, 'cause I remember, you know, in school, it's so funny and you're not getting it if you think something is funny. And there again, you know, I think the way we were raised, having a stepfamily and having to catch up to her [stepsister] and compete...I was always competing, not to get love, to get, I don't know what...

Pam came from a healthy family, with a normal childhood, so she felt these things did not contribute to her contracting HIV. Regarding this, she stated,

I think I had a pretty normal childhood, yeah, I'd say so...My parents were together and still are... I never drank and everyone was always drinking, but I

never, ever did. And I never smoked a cigarette in my life, so I think I was already pretty, my personality, I think I was already pretty strong...I was probably more of a leader.

Although all four women believed a knowledge deficit had contributed to their vulnerability, Pam wasn't sure if greater knowledge regarding HIV would have influenced her behaviour, that it may have been more of a primal desire for intimacy that motivated her behaviour. She explained,

I sort of don't think that would have had any influence on me anyways because I was rebellious and it wouldn't have mattered...it wouldn't have made any difference...it may have just been wanting the intimacy...I never felt left out of anything, really. It must have been just a personal, very personal need because, outwardly, everybody probably for sure thought, and maybe I did, have everything in place.

The findings of this study have provided significant insight into the life experiences of four women, presenting themes on how experiences may influence female vulnerability to HIV, how a diagnosis of HIV can influence women's lives and what may have decreased their vulnerability to HIV. It will be interesting to reflect on how this study's findings fit within the current dialogue on women and HIV in Canada.

Chapter 8

Discussion

Review of the findings in relation to the sensitizing framework, the study design, as well as the theoretical perspectives discussed in the literature, will provide direction for future study and practice. However, it is important to first acknowledge the challenges encountered throughout this study, and the way in which these challenges influenced the findings.

Many of this study's data support the use of the oppression framework when addressing female vulnerability to HIV. Each woman described many characteristics of multiple oppressive contexts. For example, Suzy described being sexually assaulted at gunpoint while working as a sex worker. The context of sex work meets the antecedent criteria of oppression by 1) there are at least two people involved, 2) one individual desires sexual satisfaction and/or a feeling of power of another, and 3) the woman is in need of something (money or drugs) which she will receive by submitting herself to sex with the other. In this specific situation, the defining attribute of exercise of power is evident in the use of violence, as well as simply the act of one person needing to provide sexual services to another in order to meet their own basic needs. The other two attributes, distrust and threat are not explicit in the data, but could be inferred by the use of a gun by the man. The consequence of this act is the establishment of a dichotomy, where Suzy was in an oppressed position. The characteristics of the system of oppression can be seen in the fear created by such a violent event, the dehumanization of each party, the prescriptions followed by each in the selling and solicitation of sex, and the degree of unconsciousness of Suzy and her father towards the appropriateness of sex work for a young woman. These feelings also demonstrate the characteristics of an oppressed individual, through internalization and assimilation of the acceptability of this form of trade, Suzy's low self-esteem in her intimate

relationship as a young woman, the violence that occurred between her and her sister, her eventual dependence on her male partner for housing, and the silencing and shame she described feeling while in prison. The very fact that Suzy became a sex worker in the first place demonstrates how easily, and at such a young age, she assimilated into the culture of female sexual exploitation. The characteristics of the oppressor, othering and control, can be inferred by the use of a weapon, the assault, and widespread social stigma, labels and blame attributed to sex work and sex workers.

Similar themes can be found running through the stories of the three other women, whose stories told of abusive relationships, limited education and economic opportunities, and the socialization of women into roles of caring and motherhood. This framework was successful in providing an explanation of how oppression functions and influences individual behaviour. There were instances, such as when discussing the care-taking role or the desire to be a mother or for intimacy, when the researcher suggested these instincts may have been a result of strong social norms and expectations. This was often met with resistance, with statements that these desires were not externally influenced. This conflict is interesting when viewed in the context of the oppression framework. It is possible that the participants were only internally motivated for these needs, that social norms had nothing to do with these drives. It is also possible that these findings may have been indicators of the presence of oppression still so strongly ingrained in the participants that they were totally unconscious to its existence, unaware of how they themselves had contributed to their own oppression. However, as the literature on oppression states, it is not for those outside to identify the oppression of others and to assist in their liberation, the consciousness must come from within the oppressed group membership (Friere, 1970). Interestingly, after diagnosis, all four women described greater access of resources, changes to their behaviours, seeking greater stability in their lives and using skills to protect themselves from

future harm. These descriptions of survivorship could indicate that the diagnosis of HIV actually somewhat challenged their level of unconsciousness to their own oppression. Unfortunately, due to the limited number of participants and that the study was led by someone outside the group in the one-on-one interview format, the data on this topic are very limited and there was little opportunity for verification of this, or for further consciousness to develop.

Although it was hoped that agencies within three Canadian cities (Kingston, Toronto and Vancouver) would agree to participate in this study to assist with diversity among participants, in the end only one agreed to be involved. It is believed that this relates to a variety of issues. For instance, people with HIV are a highly studied group and in order to protect members from exploitation, organizations have placed restrictions on who is able to conduct research on their membership. Further, many of the agencies were highly affiliated with the local academic institution(s) and therefore, related to the above, were reluctant to have research conducted in their agencies affiliated to another university. Additionally, given the sensitive nature of the study topic, as well as understanding that oppressed group behaviour often includes silencing of members from the oppressed group, once an organization did agree to assist with recruitment, there was some reluctance on the part of membership to participate in the study.

Due to time constraints related to completion of this thesis, recruitment discontinued prior to reaching data saturation, thereby limiting participant characteristics. All four participants were Canadian-born, Caucasian and between the ages of 37 and 54 years. This resulted in the study not capturing the experiences of foreign-born and Aboriginal women, who are strongly represented in the Canadian epidemiological data discussed earlier. Further, as suggested earlier, the study methods themselves may have contributed to the limitations of the findings. Had focus group interviews been used instead of one-on-one interviews, and had the facilitator been a member of the group, there may have been greater opportunity for consciousness development

and capturing of more macro-level data. For these reasons, the data are insufficient to be confident that the essential themes universally apply to women with HIV. However, it is possible to provide a reflection on the literature, as it relates to the findings of this study.

Reflections on the literature

The findings of this study reflect a number of aspects of what is found in the literature. The well-documented “risk factors” for women getting HIV were repeatedly described by participants, such as risk-taking in adolescence (multiple partners, limited condom use, drug use, etc), partners with risk behaviours, history of abuse, history of mental health issues, monogamy, and being of both low and middle socio-economic status. When the suggested theoretical models for analyzing female vulnerability to HIV are reviewed in light of this study’s findings, the significance and oversights of each approach become clearer.

Bunting’s feminist perspective (1997) provides a solid philosophical framework through which female vulnerability to HIV may be respectfully and supportively analyzed. It provides a positive valuation of the female experience while recognizing that women, and their behaviours, are influenced by multiple levels of oppression and identifying the primary goal of female liberation through challenging these systems of disempowerment. While conducting this research, it became strongly apparent that the use of any perspective that neglects to acknowledge women as experts, or the multiple layers of oppression that they encounter in their lives, would only serve to reinforce female vulnerability to HIV.

The use of critical hermeneutics, as suggested by Ruagjiratain and Kendall (1998), could be an effective approach to addressing the socio-political variables attributing to female vulnerability to HIV. The findings of this study reaffirmed the strong role socio-political variables play in female vulnerability. For instance, socio-economic status, limited access to education and employment, and the way in which women are socialized towards intimacy,

motherhood and caring for others were all identified by participants. However, the intra-personal aspects of vulnerability and risk such as mental health, knowledge of/attitude and self-efficacy towards condom use, and developmental level all could be easily overlooked by this framework alone.

This is not dissimilar from the use of the risk environment framework proposed by Shannon et al (2008). As discussed in the literature review, this framework effectively organizes risks into accessible levels, but neglects the intra-personal aspects that are so important. It would be erroneous to assume that female vulnerability to and risk factors for acquiring HIV are all outside her control, as much as it would be to neglect the influence of social norms or policies that reinforce female risk. Had Suzy or Pam perceived themselves as vulnerable to contracting HIV, recognized the protective factors of condom usage and felt they could effectively use them, their overall likelihood of getting HIV may have been mitigated.

Similarly, Jones' (2006) combined sex script theory and theory of power as knowing participation in change, only attends to the gender-based issues related to sexual behavior, neglecting the multitude of other oppressive contexts, such as socio-economic level, violence, substance use, race and ethnicity, which also influence women's sexual behaviours. Gender based issues were frequently identified in the data, such as caretaking, intimacy and motherhood, but these alone did not result in the risk behaviour of the four women.

The most promising theoretical frameworks in the literature are those proposed by Wingood and DiClemente (2000) and Rosenthal and Levy (2010). Both perspectives appear to address the entire breadth of female vulnerability to HIV in their own unique ways.

Wingood and DiClemente's (2000) Theory of Gender and Power can be applied to this study's findings. The first structure of gender and power, sexual division of labour, relates to the economic exposure of women, including socio-economic status, level of education, employment,

work environment, health care availability and housing. Two participants lived in poverty as children, with either parental receipt of social welfare or dependency on Children's Aid. The former has never held employment, and the latter became a drug dealer at an early age to support her life on the streets. Of the two participants who were raised in a middle class family, one left home at an early age and was forced to support herself by selling sex. All four women had limited education and were dependent on others for their housing at one point or another. The issue of access to health care was not significant to this group as all were Canadian citizens and, therefore, have access to universal health care services. It would be reasonable to expect this issue to come forth from a more diverse sample, one including women from rural parts of the country with limited health services and those born elsewhere, either living here illegally or having yet to receive their insurance coverage due to the minimum three month window period.

The second structure, sexual division of power, refers to physical exposure. This pertains to women who have experienced sexual or physical abuse, partner refusal to use condoms, a high risk regular partner, exposure to sexually explicit media, substance use, limited knowledge and self-efficacy and limited access to HIV prevention. These factors were all strongly evident in our findings. All four women reported an abuse history, three reported inconsistent condom use related to partner challenges, four reported having regular partners who were at high risk for acquiring HIV (even though two of the women were unaware of such risks at the time), all four reported limited knowledge regarding HIV and prevention methods, and two reported a personal substance use history. The issue of HIV knowledge may be partly explained by the age of the participants and the era in which their risk behaviours were taking place. Awareness of HIV and prevention methods were not as widespread as they are today. Participant age may also relate to social media exposure, as media have become much more sexually explicit since the participants'

youth. However, all four women discussed the drive for sexual intimacy at a young age, and three reported early exposure to sexuality through observation of parental or sibling behavior.

The third structure, cathexis: social norms and affective attachments, relates to social exposures and personal risk factors which were frequently identified in this study. This structure relates to having an older partner, the desire to conceive a child (both self and partner), conservative cultural (including religious) and gender norms, unsupportive family influences, low perceived risk, negative beliefs related to prevention methods, history of mental health issues and a mistrust of the medical system. In this study, all four women described having older steady partners, one described the desire to be a mother as influencing her behaviours, another described how a partner had poked holes in condoms in order to impregnate her, all reported a care-giving tendency, two learned about sex work from family members (one was specifically encouraged by a parent to pursue sex work as a way to make money), three did not see themselves as at risk for contracting HIV, and one had a clinically diagnosed mental illness. Though the issue of negative beliefs related to condom use did not come through in the findings, this may relate again to the participants' age and the prevalence of condom use at the time of risk taking behaviours, or just the overall lack of knowledge related to sexually transmitted infections and, therefore, limited overall use of condoms due to low perceived risk. A young woman today, who is aware of the potential threats of unprotected sex, may be more likely to report decision-making based on decreased sensation, etc. Similarly, a mistrust of the medical system was not a finding from this sample, but a more diverse sample including women from more marginalized areas/groups or from other countries may provide more diversity of findings.

The final structure, which was added by the authors, biological factors, is obviously significant to this study group. The biological factors attributing to female vulnerability include the female anatomy and the manifestation of other sexually transmitted infections. Women are

more vulnerable to all sexually transmitted infections, simply based on their anatomy and the fact that they are the receptive partner. Exposure for the insertive partner is limited to the duration of intercourse, whereas receptive exposure can be days if ejaculation by the partner occurs. This factor was identified by one of the participants when she spoke of the short duration of her relationship with the male she believed she contracted the virus from, compared to the long-term sexual relationship she had with her husband prior to knowing she was positive. Her husband did not contract HIV. Further, having sex while menstruating, being on hormonal contraceptives and the immature cervixes of young women (due to cellular composition) all put women at increased risk for contracting HIV. These vulnerable cervical cells are not unlike the cells under the foreskin of the male, however, as soon the area on a male dries, exposure ceases. In addition, sexually transmitted infections, such as Chlamydia, Gonorrhea and Trichomonas are more likely to be asymptomatic in women than men. Due to the degradation of mucosal immunity, the presence of one sexually transmitted infection places the individual at higher risk for contracting others, should he or she be exposed. Data on whether or not these women had ever been diagnosed with other sexually transmitted infections was not acquired in this study.

Overall, the Theory of Gender and Power may provide a thorough and effective lens through which programs for HIV prevention for women could be designed, and the findings of this study fit well within this framework. Where the theory lacks support from the findings may be reflective of the limited number participants and diversity of participant experience.

The final theoretical perspective proposed in the literature was Social Dominance Theory (SDT) and the Four Bases of Gendered Power (FBGP) (Rosenthal & Levy, 2010). The findings of this study support this perspective in the following ways.

The data support the theory that women exist in multiple social hierarchies, which reinforce their vulnerability to HIV. The most obvious of which is that all were of female gender.

Three of the four women experienced degrees of poverty in their lives and as a result, two were socialized towards the option of selling sex in exchange for drugs or money. One participant experienced discrimination or shame based on being labeled as “special needs” in school, one was a sex worker and two were drug users, one had a diagnosed mental illness, all of which are groups that have been shown in the literature to be marginalized in society. Had this study been more successful with recruiting a diverse sample, one could expect acquiring data from women who were from marginalized cultural (Aboriginal) and ethnic communities, as reports show women from these groups are highly represented in incidence/prevalence data.

The FBGP can be used to organize much of the data collected in this study. The first base, force, refers to varying forms of violence against women. This is reflected in the findings by the experiences of emotional, sexual and physical abuse, limited power or control regarding condom usage, and societal policies that result, indirectly, in violence against women, such as solicitation of sex workers. The second base, resource control, can be found in the data describing limited education and access to employment. These two prominent findings likely contributed significantly to these women living in poverty or being economically dependent on a male, leading to selling of sex/drug use and limited knowledge acquisition regarding risks, how to protect themselves, as well as the ability to challenge gender norms, or have any degree of institutional influence. The third base, social obligations, can be identified in the data describing an overall role of care-giver, the desire for children (both male and female), and the desire to maintain a relationship with a man despite risk to self. The final base, consensual ideologies, may be found in the social marginalization of sex work and drug use, the underlying perception that a girl/woman may be at least partly responsible for receiving abuse (demonstrated by Christine’s reluctance to tell anyone of her sexual abuse, or Suzy’s experience of being assaulted

at gun point while working as a sex worker), the widespread discriminations held against people with HIV, those with limited education and those of lower socio-economic status.

The frameworks proposed by Wingood & DiClemente (2000) and Resenthal & Levy (2010) appear to be significant perspectives for organizing analysis on women and HIV.

Chapter 9

Future Recommendations

Although the findings of this study are insufficient to make claims regarding the effectiveness of either approach, the data reinforce how promising the frameworks of Social Dominance Theory/The Four Bases of Gendered Power and the Theory of Gender and Power are to the study of HIV prevention among women. It is recommended that further research be undertaken in two ways. First, specifically analyze each theoretical approach. Either of these theoretical perspectives could be used at a variety of levels to lobby for the rights of women, thereby assisting in the effort to decrease female vulnerability to HIV. Second, implement this same study using different methods of data collection. The data gathered in this study was limited, largely related to the sample obtained and the methods of collection. Thematic analysis would still allow for a partnership to occur between participants and researchers, theoretically congruent the characteristics of an oppressed group. The usefulness of such a design would be heightened with the use of focus groups and a facilitator from the studied group, as both would allow for opportunity of consciousness development. Perhaps with the collaboration between multiple educational institutions and agencies across the country, a more diverse, representative sample could be obtained, and a partnership could be created whereby women with HIV are conducting their own study.

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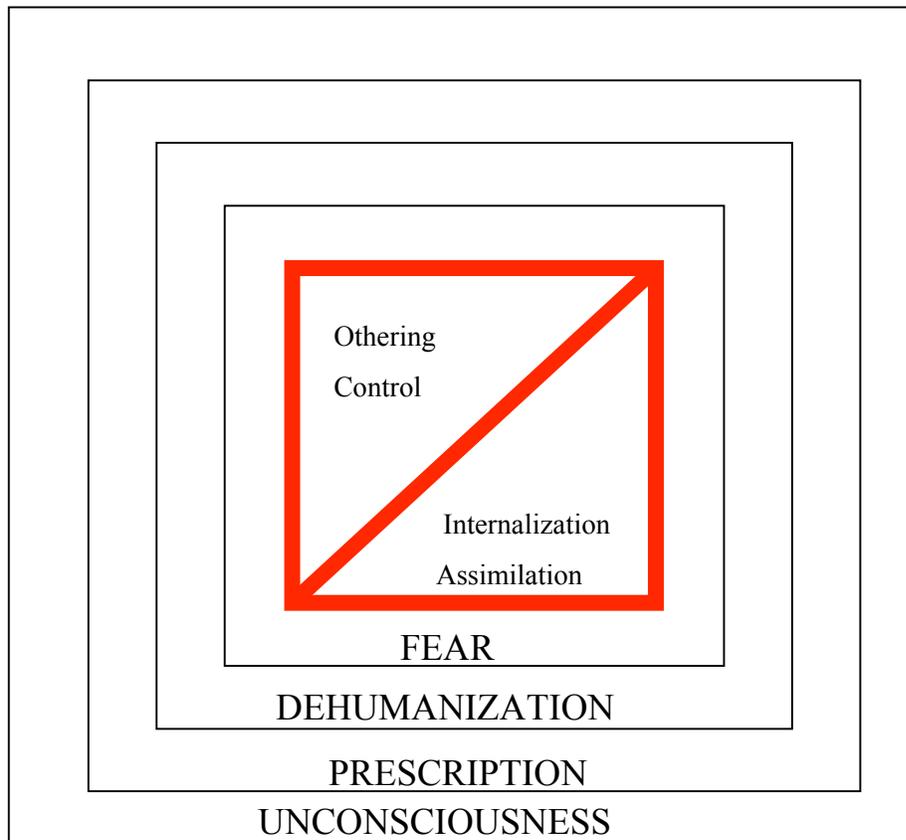
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Appendix A
Consequences of Oppression



Appendix B

Study Summary

Life Experiences of Women with HIV

Leia Deiters

Summary of Proposed Study

The Topic

Rates of female Human Immunodeficiency Virus (HIV) infection continue to rise even when effective methods for protection exist. What is the fundamental variable acting as a barrier to women's self-protection? Researchers have suggested that the oppression of women through socialization of gender roles increases their vulnerability to HIV infection, and that the relationship between oppression and HIV infection must be examined to effectively address this public health issue. Even the World Health Organization's Commission on Social Determinants of Health neglects to directly address this overarching variable. What is oppression? How does it affect the health of women? This proposal is for research a qualitative study to guide public health and grass roots programming aimed at understanding HIV infection among women.

The Method

A phenomenological approach will be used to explore the life experiences of women with HIV. The desired sample is women, 18 years of age or older who are proficient in speaking English and who are HIV positive. The agency will be asked to post a flyer for potential participants and informed consent will be obtained in writing from the participant prior to interviewing. At least two individual, face-to-face semi-structured interviews of approximately 45-60 minutes will be held between the researcher and each participant. To initiate the first interview, participants will be asked to tell their "life story" prior to acquiring HIV, and their thoughts on how those experiences influenced their risk for HIV infection. Participants will also be encouraged to share a visual representation (i.e. photograph, magazine clipping, etc) of the issues surrounding their exposure to HIV. This will provide an abstract way of discussing issues that could be difficult to

communicate.

The Researchers

Leia Deiters, a graduate student in the Master of Science program, School of Nursing at Queens University is the principal investigator. Dr. Diane Buchanan, School of Nursing at Queen's University, will be responsible for supervising the student's overall research.

Study Approvals

Approval has been obtained for this study from the Queen's University Ethics Board. In addition, approval will be sought from each participating agency, prior to the commencement of interviews. Confidentiality of the data will be maintained and no names of the participants will be used in any presentation or publication.

If any additional information is required, please do not hesitate to contact:

Leia Deiters, R.N., B.Sc.N., M.Sc. (c)

Queen's University

6lcf@queensu.ca

(416) 906-8831

or

Diane Buchanan, R.N., B.Sc.N., M.Sc.N., Ph.D.

(613) 533-6000, ext. 78907

Appendix C
Recruitment Poster

Women with HIV Requested!

What led to you
getting HIV?
How would you
describe your
experience?

Women 18 years of age
or older who are HIV
positive are needed

1- 2 hour private interviews.
Confidential.

Please contact Leia Deiters, R.N.,
B.Sc.N., M.Sc.N (c)
6lcf@ queensu.ca
(416) 906 – 8831
or
HIV/AIDS Regional Services
hars@kingston.net
(613) 545.3698 or 1.800.565.2209



Appendix D

Participant Information Sheet

Participant Information Sheet

Title of Project: Life Experiences Women with HIV

Background: You are being invited to participate in a research study directed by L.

Deiters and Dr. D. Buchanan to investigate life experiences of women with HIV. L. Deiters will read through this consent with you and describe procedures and answer any questions that you may have. This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Purpose: The purpose of this study is to gain understanding of the life experiences of women with HIV in Canada. This knowledge will be helpful for nurses, other health care providers and program planners to better understand how to help decrease the chances of other women getting HIV.

Description of interviews: You will be interviewed at least two times in a private room. The first interview will consist of the interviewer asking you to tell the story of your life and how you became HIV positive, for approximately one hour. The second session will consist of a follow-up session where I will be verifying the information that I have collected and ensuring that I have interpreted it as close to your ideas as possible. Both sessions will be audio-taped to ensure that I am able to capture all of the information.

Potential Risks: There could be the potential risk of having a strong emotional reaction to discussing your past experiences. If you require ongoing emotional support after the interviews, you will be referred to (insert agency upon approval) for ongoing support/counseling service.

Benefits: You may benefit from being able to candidly speak about your experiences within a comfortable and non-judgmental environment. However, should you not directly benefit, results from this study may improve the lives of Canadian women by decreasing the chance that they will contract HIV.

Confidentiality: All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all time. You will be identified by an alias of your choice and the only people who will be able to make the match to your name and the information will be the researcher and the supervisor. Data will be stored in a locked file cabinet, and will only be accessed by L. Deiters and Dr. D. Buchanan. You will not be identified in any publications or reports.

Freedom to Withdraw or Participate: Your participation in this study is voluntary. You may withdraw from this study at any time without any type of consequences. If at any time you have further questions, problems or adverse events, you can contact:

Leia Deiters, R.N., B.Sc.N., M.Sc. (c)
(416) 906-8831

or

Diane Buchanan, R.N., B.Sc.N., M.Sc.N., Ph.D.
(613) 533-6000, ext. 78907

If you have any questions regarding your rights as a research participant you can contact Dr. Albert Clark, Chair, Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081

Appendix E

Consent Form

Informed Consent Form

Title of Project: Life Experiences of Women with HIV

Background: You are being invited to participate in a research study directed by L.

Deiters and Dr. D. Buchanan to investigate life experiences of women with HIV. L. Deiters will read through this consent with you and describe procedures and answer any questions that you may have. This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Purpose: The purpose of this study is to gain understanding of the life experiences of women with HIV in Canada. This knowledge will be helpful for nurses, other health care providers and program planners to better understand how to help decrease the chances of other women getting HIV.

Description of interviews: You will be interviewed at least two times in a private room, or in the comfort of your own home. The first interview will consist of the interviewer asking open-ended questions for approximately one hour. The second session will consist of a follow-up session where I will be verifying the information that I have collected and ensuring that I have interpreted it as close to your ideas as possible. Both sessions will be audio-taped to ensure that I am able to capture all of the information.

Potential Risks: There could be the potential risk of having a strong emotional reaction to discussing your past experiences. If you require ongoing emotional support after the interviews, you will be referred to a counseling service.

Benefits: You may benefit from being able to candidly speak about your experiences

within a comfortable and non-judgmental environment. However, should you not directly benefit, results from this study may improve the lives of Canadian women by decreasing the chance that they will contract HIV.

Confidentiality: All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all time. You will be identified by an alias of your choice and the only people who will be able to make the match to your name and the information will be the researcher and the supervisor. Data will be stored in a locked file cabinet, and will only be accessed by L. Deiters and Dr. D. Buchanan. You will not be identified in any publications or reports.

Freedom to Withdraw or Participate: Your participation in this study is voluntary. You may withdraw from this study at any time without any type of consequences.

Statement and Signature Section: I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time I have further questions, problems or adverse events, I can contact:

Leia Deiters, R.N., B.Sc.N., MSc.N
(416) 906-8831

or

Diane Buchanan, R.N., B.Sc.N., M.Sc.N., Ph.D.
(613) 533-6000, ext. 78907

If I have any questions regarding my rights as a research participant I can contact Kathy Reed, Chair, Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6000 ext. 77000.

By signing this consent form, I am indicating that I agree to participate in this study.

Signature of Participant

Date

Signature of Witness

Date

Statement of Investigator:

I, or one of my colleagues, have carefully explained to the participant the nature of the above research study. I certify that, to the best of my knowledge, the participant understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

Leia Deiters, Principle Investigator

Date

Appendix F
Demographics Survey

Demographic Information

1. Date of Birth: _____

2. Country of Birth: _____

3. Years of Residence in Canada: _____

4. City of Residence: _____

5. Marital Status: Single___ Married___ Divorced___ Widowed___

6. Living Arrangements: Alone___ Family___ Others___

7. Number of Children: _____

8. Highest Educational Level: None___ Elementary school___ Some of high school___
All of high school___ College/University___

9. Employment: _____

10. Date of HIV diagnosis: _____

Appendix G

Composite Story

When looking back, it seems that Mary had to grow up quickly. She was always having to care for somebody, whether it was just taking care of herself or responsibility for others. She also didn't spend much time in school and now, looking back, she thinks this would have made a big difference in her life. One thing she was taught was that there were distinct roles for men and women, and there was an assumption that women have babies. Maybe it was normal back then, but there certainly wasn't much discussion about sex, and she was often left to learn by watching the adults in her life, through friends or her own experience. No one ever told her what a healthy sexual relationship was supposed to be like, or what risks were involved in having sex. She had absolutely no idea that *she* could get sick from having sex, or that there were ways to prevent getting sick from sex, like using condoms. Mary was younger than she would have liked to have been when she started having sex, and made decisions about sex that she now regrets.

There were definitely situations and experiences in her life that Mary would call abusive, when she wasn't treated well by others, and this really affected the way that she felt about herself. And whether it was herself, or those close to her, substance use played a big part in her life, limiting her ability to make decisions to protect herself. Often, Mary just did what she needed to do to survive and avoid conflict or situations that could be dangerous for her. She was a survivor. For her entire life, Mary has always wanted to feel a sense of safety, security and belonging or acceptance of who she is, and whether consciously or unconsciously, this desire has also really influenced how her life has evolved.

When she found out that she had contracted HIV, she was completely blind-sided. Mary didn't really even understand what HIV was, or that she had put herself at risk for getting it. After it finally sunk in that she had HIV, it really changed the way she thought about herself, in both

positive and negative ways. In some ways, it made her feel really lousy about herself, because people make a lot of judgments and hold stereotypes about people with HIV and she wasn't always treated with respect or dignity. But in other ways the diagnosis really motivated her to make positive changes in her life, whether it was to get connected with people and a supportive community, or to improve her living situation. And although Mary has occasionally felt guilt, shame or blame for having contracted HIV, she probably knows and loves herself more now than ever before. In some ways, this diagnosis has limited her ability to pursue her girlhood dreams, but in other ways it has given her a better understanding of who she is and what she wants in life.