PARTNER-SEEKING EXPERIENCES OF SINGLE HETEROSEXUAL PEOPLE LIVING WITH HIV IN A WESTERN CANADIAN CITY

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Abstract

This narrative research study aimed to answer the question: What is the experience of heterosexual people living with HIV in terms of partner-seeking in a Western Canadian city? Ten participants shared their experiences in semi-structured interviews. Relationship challenges were the major stressor of living with the illness. Feeling desperate about finding a partner and incorporating a new identity as a person living with HIV, some participants turned to celibacy. Other findings included lack of understanding of harm reduction strategies and favoring as partners people who also lived with HIV because of the shared knowledge, the absence of the need to disclose, and perceptions of greater self-stigma in a serodiscordant relationship. Recommendations for AIDS service organizations (e.g., discussions of healthy relationships, sexuality, self-esteem) and health care professionals (e.g., incorporating family planning and harm reduction strategies in discussions with patients) are suggested. Limitations and directions for future research are also discussed.

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Table of Contents

List of Tables

List of Abbreviations

AIDS – acquired immune deficiency syndrome
ALWH – adolescents living with HIV
ASO – AIDS service organization
CDC – Centers for Disease Control and Prevention
HAART – highly active antiretroviral therapy
HIV – human immunodeficiency virus
PID – person/people who inject(s) drugs
MLWH – men living with HIV
MSM – men who have sex with men
PHAC – Public Health Agency of Canada
PLWH – people living with HIV
PTSD – post-traumatic stress disorder
SDH – social determinants of health
SI – symbolic interactionism
WHO – World Health Organization
WLWH – women living with HIV

Chapter One: Introduction

Human Immunodeficiency Virus, or HIV, is one of the most challenging viruses that humanity has ever encountered. From a clinical standpoint, HIV prompts immunosuppression and therefore compromises the immune system of people living with HIV (PLWH), which results in extremely high susceptibility to a range of infectious pathogens and neoplasia (Antoni, 2011). It has been more than 30 years since the existence of HIV was recognized, but we remain without a cure that would eliminate the virus from the body or a vaccine that could prevent its further spread. From sociological and epidemiological standpoints, the HIV epidemic is a complex biosocial phenomenon, sustained by a number of multi-layered issues that need to be addressed in order to put an end to it. These issues exist at the intersection of politics, public health, and policy (Piot, Russell, & Larson, 2007). They create a complicated web of challenges that slows down and sometimes paralyzes initiatives—whether guided by holistic or atomistic approaches—of people who attempt to make a real difference (Farmer, 2002).

Experts in the field of HIV all over the world acknowledge that the current situation dictates the necessity to get deeper understanding of the concept of social determinants of health (SDH) as well as social inequalities, and legal and political aspects of the context of HIV. These issues will be the focus of this introductory chapter. However, I choose to begin with an exploration of global efforts to end the HIV epidemic and HIV statistics in order to provide the reader with a better understanding of the scope of the HIV epidemic in Canada and in particular, Western Canada where this research project took place.

Background

According to the optimistic prognosis of the World Health Organization ([WHO], 2015a), it is possible to end the HIV epidemic by 2030, if there is a considerable decline in the number of newly infected people and deaths from HIV-related causes. Positive changes to date that make the end of the epidemic possible include the following: (a) continued decline in the number of newly infected PLWH in most parts of the world; (b) dramatic decrease in the number of new cases of HIV infection among children; (c) increasing knowledge of HIV status in countries most affected by the HIV epidemic due to accessibility of HIV testing; (d) decrease in AIDS-related deaths by 35% since 2005; and (e) increased access to highly active antiretroviral therapy (HAART) (12.9 million now receive this therapy, thus testifying to an increase in health care access). The end of the HIV epidemic is close if we manage to reach the WHO's vision of zero new infections, zero HIV-related deaths, and zero HIV-related discrimination so that PLWH are able to live long and healthy lives (UNAIDS, 2014a; WHO, 2015a). To achieve this goal by 2030, it will be necessary to reach a "90% reduction in stigma and discrimination faced by PLWH, vulnerable populations and key populations" by 2020 (UNAIDS, 2014c, p. 296). New plans to battle the HIV epidemic also include achieving 90% of PLWH knowing their status, 90% of PLWH being virally suppressed, and 90% implementation of HAART by 2020 (UNAIDS, 2014b).

These plans are possible due to several successes in the HIV field that deserve acknowledgment. One of the major successes is without doubt the introduction of HAART, which is a combination therapy consisting of three or four antiretroviral medications taken together to discontinue HIV replication and prevent further

progression of HIV infection by increasing CD4+T-cell count, thus maintaining comparatively normal functioning of the immune system and preventing opportunistic infections (Hoffmann & Rockstroh, 2011). Within the first 10 years of the introduction of HAART, mortality from HIV illness decreased by 80% (Delaney, 2006). This success was a turning point in the reassessment of the HIV infection from a necessarily fatal and devastating condition to a manageable chronic disease (Delaney, 2006).

HAART has played a decisive role not only in saving the lives of PLWH, but also in the overall prevention of additional HIV infections in key populations (UNAIDS, 2014b). Strategies based on the availability of HAART, such as the Treatment as Prevention program and the introduction of pre- and post-exposure prophylaxis, also contribute to the general shift away from the perception of HIV as a lethal condition. As recent data show, the life expectancy of a 20-year-old individual living with HIV in the United States who receives treatment is approaching the life expectancy of any 20-year-old individual who is HIV-free (Samji et al., 2013). Although findings from another recent study in Canada show that life expectancy of PLWH is still slightly lower than that of people who do not live with HIV, the average longevity for men and women is still very high—59.7 and 63.9 years, respectively (Patterson et al., 2015).

Despite significant success in the HIV field, there are many issues deserving attention before one can say that the HIV epidemic is controlled. Indeed, according to UNAIDS (2014c), we could look to the multiple HIV epidemics affecting different countries, each of them having distinctive features and posing unique challenges. Each unique situation requires targeted interventions and the involvement of local experts who understand contextual complexities and the availability of resources to address specific

challenges faced by PLWH. While in the early years of the HIV epidemic most cases were concentrated in developing countries in key populations, this perspective no longer reflects reality: there are no borders nor ideologically imposed boundaries that HIV cannot cross. According to recent data, around 37 million people throughout the world continue to live with HIV (UNAIDS, 2015a), facing prejudice, isolation, and emotional struggles on a daily basis.

The HIV epidemic in Canada. In Canada, there were more than 80,000 PLWH at the end of 2014 (Public Health Agency of Canada [PHAC], 2015a). Alarmingly, around 21% of PLWH in Canada remain undiagnosed (PHAC, 2015b), thus they do not have access to health care professionals and successful disease management (Hoffmann & Rockstroh, 2011).

The prevalence of HIV in Western Canada has remained relatively stable and the majority of new HIV cases are concentrated in major cities across the provinces (e.g., Winnipeg, Edmonton, Calgary, Vancouver). According to a recent report by the Government of Manitoba (2015), the number of newly diagnosed PLWH declined by 31 cases in the period between 2013 and 2014, and the HIV rate in 2014 was 6.6 per 100,000, similar to Alberta's rate of 6.7 per 100,000 population (PHAC, 2015a). Alberta Health Surveillance and Assessment (2015) reported that the rate of newly diagnosed PLWH rose only slightly, by 0.6 cases per 100,000 in the period between 2000 and 2013. The HIV rate in British Columbia was 5.7 per 100,000 in 2014 (PHAC, 2015a), and the rates continue to decline as the result of various preventative programs and initiatives (Hogg et al., 2013). However, Saskatchewan remains a province with the highest HIV rates across Western Canada and Canada in general: all-age HIV diagnosis rate in 2014

was 10.8 cases per 100,000 (PHAC, 2015a), with growing concerns about increasing HIV

rates in Aboriginal communities in this province (Leo, 2015). However, the reader must

keep in mind that it is not the race that explains high incidence of HIV in Aboriginal

communities, but rather a variety of SDH that will be discussed throughout the thesis.

Sexual behaviour that poses risk in terms of acquiring HIV (precisely, condomless

sex between partners of different HIV status [WHO, 2011]) remains the leading cause of

new cases of HIV infection in Western Canada (PHAC, 2015b). PLWH unaware of their

status can unknowingly be a source of infection for their intimate partners. In a

systematic review, Marks, Crepaz, Senterfitt, and Janssen (2005) found that when PLWH

are aware of their HIV status, the risk of transmission can be reduced significantly. The

data from Alberta Health Surveillance and Assessment (2015) also point to the

importance of recognizing and addressing the needs of PLWH in terms of their sexuality

in the context of living with HIV illness, since the statistics show the increasing number

of PLWH who test positive for sexually transmitted infections other than HIV infection.

However, HIV statistics—the numbers we can easily find in the surveillance

reports—reflect only the tip of the iceberg. What is of greater importance is what is

hidden from view, the combination of factors operating at the societal level. As Paul

Farmer (1996, p. 12) justly noted, "large-scale social forces crystallize into the sharp,

hard surfaces of individual suffering," thus underlying the importance of the

"resocialization" of our understanding of the HIV epidemic as a biosocial phenomenon

(Farmer, Nizeye, Stulac, & Keshavjee, 2006). In light of this, I devote the following

subsection to the discussion of SDH in the context of HIV.

Structural violence and social determinants of health. Although there is a variety of determinants of health (e.g., genetics, physical environment), SDH are the most significant contributors to the HIV epidemic. As defined by the WHO (n.d., p. 1), SDH are "the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness." Mikkonen and Raphael (2010, p. 9) highlighted the following SDH for Canadians: Aboriginal ethnicity, disability, childhood experiences, education, employment, job security, working conditions, food security, health services, gender, housing, income, race, social exclusion, and social safety nets. These determinants are shaped by several forces, the main ones being politics and economics, which are intricately related to health outcomes (Mikkonen & Raphael, 2010). As Weber (2006) explained, the existence of these social determinants would not be possible without the existing power differential in social relationships with the dominant group having better access to material and social resources. Considering the complex interactions among various factors on different levels, it becomes evident that addressing merely human biology can hardly effect serious changes (Alsan, Westerhaus, Herce, Nakashima, & Farmer, 2011). In fact, only a biosocial lens allows us to see clearly the embodiment of structural violence, which has an incredible influence on the experience of living with a disease (Farmer et al., 2006).

Farmer et al. (2006, p. 1686) explained the origin of the term "structural violence" in the following way: *structural* refers to embeddedness in the political and economic organization of the world, while *violence* refers to the consequences of structural arrangements—people are put in harm's way. Structural violence, defined as "institutionalized biases and inequalities including racism, elitism, gender inequality,

militarism, and economic policy that fosters inequity" (Alsan et al., 2011, p. 615), boosts the spread of HIV by shaping the risk of acquiring the virus. Thus, using structural violence and SDH as a conceptual framework, one can better understand the HIV epidemic and reasons why it remains a public health threat across the globe.

Poverty, a very powerful SDH, greatly contributes to the spread of any infectious disease. In particular, it increases vulnerability to HIV and makes accessing medical care challenging once a person is living with HIV (Alsan et al., 2011). Increased vulnerability to HIV can be explained in several ways. First of all, poverty may lead to unstable housing (e.g., being homeless or without safe housing arrangements), which has been shown to be associated with practicing condomless sex and having multiple sex partners thus increasing risk of acquiring HIV (Banerjee, 2007; Centers for Disease Control and Prevention [CDC], 2014; Marshall et al., 2008; Sharpe et al., 2012). Secondly, many women in an attempt to escape profound poverty choose to engage in "consensual sex" with high risk of acquisition of HIV and later are blamed by society for the choices they have made. As Paul Farmer (1996) noted, the whole concept of "consensual sex" must be reconsidered. Foucault in *The History of Sexuality* (1986, p. 225) defined consensual sex as "making the object of pleasure into a subject who has control over his/her pleasures." When greatly influenced by other SDH, the decision to engage in sexual intercourse is not driven by pleasure and therefore application of the description "consensual" should cause hesitation. Moreover, women can experience gender inequality in relation to condomless sex. For example, women might have the belief that they do not have the right to ask men to use condoms or are afraid of violence from male sexual partners who do not want to practice protected sex (Zierler & Krieger, 1997). Gender inequality reveals

itself in the existence of gender norms that allow men to control women in transactional (or economically motivated) sexual encounters (Dunkle, Wingoog, Camp, & DiClemente, 2010) and intergenerational sex (where the age gap between sexual partners is 10 years and more [UNAIDS, 2015b]). As well, women experience difficulties in negotiating harm reduction strategies and have limited access to health care (Richardson et al., 2014). Women's lack of rights regarding property and inheritance, and limited access to education (Amin, 2015) are further consequences of gender inequality that all have been shown to fuel the HIV epidemic (Amin, 2015).

Racial oppression of particular groups of people also affects the risk of HIV illness. For example, racism leads to increased risk of HIV illness for African American and Latin American women (Davis & Tucker-Brown, 2013). Indeed, race is a socially constructed phenomenon rather than a biological attribute (Zierler & Krieger, 1997). It is not race or ethnicity themselves that increase vulnerability to HIV, but the social, political and economical consequences of belonging to a particular (marginalized) race or ethnicity. As the reader may have noticed from the HIV statistics in Canada, Aboriginal peoples continue to be over-represented (PHAC, 2010, 2015b), which can be explained by a variety of SDH, including childhood abuse and trauma, stigma of coming from a marginalized community, and unequal access to education and health care (PHAC, 2014). These SDH are intertwined with the long history of colonization of Aboriginal communities in Canada. Numerous impacts of colonization, such as disempowerment of Aboriginal peoples (particularly women), deprivation of their agency, and different forms of violence (McCall & Lauridsen-Hoegh, 2014), still require time to heal spiritually, culturally, and medically (Egan, 2014). The problem of HIV within the Aboriginal

8

community cannot be viewed outside of history, since "ideas, cultures and histories cannot seriously be understood or studied without their force, or more precisely their configurations of power, also being studied" (Said, 1979, p. 5). Residential Schools aimed to erase knowledge of Indigenous cultural and spiritual practices; the historical trauma that resulted from this cultural genocide has contributed to economic, racial, gender, and sexual inequity in Aboriginal communities. The history of residential schools continues to echo in poverty, limited access to education and fair employment, alcohol-related stigma (Egan, 2014), lack of access to health care and education, unsafe sexual behaviour, and use of contaminated injecting equipment (McCall & Lauridsen-Hoegh, 2014). Thus, social and economic conditions, which are significantly worse for Aboriginal individuals (Monette et al., 2011), shape the risk of acquiring HIV (Cain et al., 2013).

Despite recent attention paid to SDH (Caiola, Docherty, Relf, & Barroso, 2014; Lakew, Benedict, & Haile, 2015; Zeglin & Stein, 2015), there remain multiple barriers to the successful end of the HIV epidemic. One of them is the criminalization of HIV non-disclosure. Medical successes in the HIV field achieved so far could have already helped to reach punctuated equilibrium—"the adoption for a given policy area of new public policies that depart sharply from existing policy practices" (Francis & Francis, 2013, p. 521); however, once public policies around criminalization of HIV non-disclosure were established, there developed resistance to changes suggested by scientific findings. In the era of treatment as prevention, home testing kits (although not available in Canada, they can be easily ordered online or bought in US pharmacies [Broeckaert, 2014]) and post- and pre-exposure prophylaxis, PLWH are prosecuted and blamed for HIV transmission

and exposure. Despite an absence of evidence that criminalization of HIV non-disclosure reduces the incidence of HIV, PLWH live in fear (Weait, 2011). Criminalization of HIV non-disclosure is unique as no other infectious disease is surrounded by such severe legal consequences. Therefore, it "raises questions of whether people living with HIV are being held to an exceptional and unnecessarily strict standard of conduct" (Adam, Elliott, Corriveau, & English, 2014, p. 48).

North America is the region with the highest rates of convictions of PLWH for HIV exposure and transmission. As Weait (2011) discussed in his report regarding North America, PLWH are prosecuted for the intent to do harm; therefore the difference between sexual drive and actual intent to do harm is lost. In Canada, legal prosecution of HIV nondisclosure does not affect incidence rates, but rather increases vulnerability and uncertainty about the ways to balance legal aspects of living with HIV and confidentiality, which in turn affect psychological wellbeing (Adam et al., 2014) and access to, engagement in and retention within the cascade of HIV care (Patterson et al., 2015). Another disturbing point in the criminalization of HIV non-disclosure is the shift in responsibilities and choices that every individual makes in terms of her or his health. By criminalizing HIV exposure and transmission, society blames PLWH instead of promoting the ability to make choices regarding safe practices. According to criminal law, HIV is "a morally significant and harmful phenomenon affecting individuals" (Weait, 2011, p. 20). However, the punitive approach that was adopted by the legal system contradicts the public health perspective, which sees HIV as "biological, social and epidemiological phenomena affecting communities and populations" (Weait, 2011, p. 20).

In order to decrease the discrimination faced by PLWH, the François-Xavier

Bagnoud Center for Health and Human Rights and Open Society Foundations (2013, p.

2.33) listed human rights relevant to HIV and AIDS. They include the rights to: non-

discrimination and equality; health; liberty and security of the person; privacy; seek,

receive, and impart information; marry and found a family; work; and freedom of

movement, association, and expression. Despite these rights, there are numerous

examples of discrimination, including visa restrictions, difficulty in obtaining life

insurance, and the imprisonment of PLWH for transmitting the virus to other people

(Chalmers, 2008; Green, 2009), which are common in developing (Weait, 2011) and

developed countries (Adam et al., 2014; Dej & Kilty, 2012). Indeed, the violation of

human rights remains so profound that we can call the HIV epidemic a "human rights

tragedy" (Farmer, 2005, p. 11). While violation of human rights and social inequalities

lead to increased vulnerability to HIV, once a person acquires the virus, human rights are

violated even further. Therefore, only the human rights approach advocated by Farmer

(2005, p. 16) who emphasized that "health care is a right, not a commodity" together with

significant cooperation among agencies and stakeholders (UNAIDS, 2014a) is the way to

move forward if we want to reach the ambitious goals we continue to set (despite ever-

shifting deadlines).

Psychosocial Concerns of PLWH

Although ongoing medical research in the field of HIV gives hope for new

antiretroviral drugs with fewer side effects as well as new prevention strategies,

psychosocial concerns are very challenging to solve. They are paramount in the lives of

PLWH and are the focus of this research project.

11

PLWH experience stress from the moment they receive a positive result of the HIV test, and the stress increases with the appearance of common HIV-related symptoms and the necessity to initiate HAART (Antoni, 2011). Psychosocial concerns in some cases also include a substantial emotional burden due to the insufficiency of financial and other resources (Farber, Mirsalimi, Williams, & McDaniel, 2003). Women living with HIV (WLWH) in India identified the following major worries: decrease in parental functions and concerns about the future of their children, stating that life was worse since they were diagnosed; problems in sexual interactions with partners; social stigma, expressed in decreased social interactions, withdrawal from family events, and maintaining physical separation from others during conversation; predominantly negative emotions, such as fear of stigma, dying, being left alone in the terminal stages of the HIV infection; and voluntary and involuntary disclosure (Joseph & Bhatti, 2004). Despite the convenience sample and inclusion of women only, this study gave clear understanding of what PLWH experience daily. Other authors showed that mothers living with HIV were also concerned about discrimination against their children, which bothered them much more than discrimination against themselves (Pecheny, Manzelli, & Jones, 2007). Mothers living with HIV expressed concerns about balancing their feelings regarding non-breastfeeding in the midst of messages about the importance of breastfeeding and understanding of "good mothering" (Greene et al., 2015). As the reader can see, PLWH face a variety of HIV-related psychosocial concerns that add challenges to their lives. However, discussion of any psychosocial HIV-related issues is not complete without paying particular attention to stigma and its consequences.

While stigma has been present since the very beginning of the HIV epidemic, it quickly became the predominant narrative within which HIV was embedded, thus influencing every aspect of the lives of people who were infected. The issue of stigmatization is clearly recognized by all organizations dealing with HIV (UNAIDS, 2012; WHO, 2014a). According to UNAIDS (2011, p. 3), one of the main goals to accomplish in the HIV field by 2015 was to "eliminate stigma and discrimination against people living with HIV through promotion of laws and policies that ensure the full realization of all human rights and fundamental freedoms." However, the complexity of the HIV epidemic as a biosocial phenomenon did not allow the achievement of this goal, and the deadline was extended to 2020 (UNAIDS, 2014a).

Stigma is a negative social construct, "a mark of shame" (Green, 2009, p. 15), which identifies the stigmatized person as unable to fulfill social and/or cultural roles. Stigma against a particular disease or condition is a way of expressing prejudice while confirming and boosting the existing power relations within a society (Corrigan, 2014); thus, stigmatization is viewed as "an institutional and social control mechanism that contributes to the marginalization of persons living with HIV and AIDS" (Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010, p. 1478).

Stigma in all of its forms has an exceptionally significant impact on the well-being of PLWH by creating negative assessment of oneself, leading to social disconnection and distress (Sanjuan, Molero, Jose Fuster, & Nouvilas, 2013). Although stigma is the biggest stressor in the lives of PLWH, there are other factors that relate to any chronic conditions, such as the uncertainty of treatment outcomes and complexity of treatment, fears about health costs and insurance (Folkman, 2011). More specific to HIV

infection, potentially stressful aspects in addition to stigma include the following: (a) side-effects of antiretroviral medications; (b) the need to be adherent to HAART and the very thought that this is a life-long treatment (Moskowitz, Hult, Bussolari, & Acree, 2009; Moskowitz, Wrubel, Hult, Maurer, & Acree, 2013) ; (c) potential difficulties in interacting with complex health care systems; (d) the need to take on a new identity as a person with a serious infectious disease; and (e) the fear of disclosure (Folkman, 2011). Thus, living with HIV is exceptionally stressful due to both the chronicity of HIV illness and HIV-related stigma that pose unique psychosocial challenges to PLWH.

Unfortunately, despite the successful introduction of HAART and the resulting shift from HIV infection being an imminently fatal disease to a permanent, though manageable, chronic condition (Walker, Hart, & D'Silva, 2012), perception of HIV illness and the meaning of living with HIV have not changed as substantially as one may expect as it is still sounds like a death sentence for many people (Green, 2009; Moskowitz et al., 2013). PLWH are thus forced to use a variety of coping strategies to help them adapt. There are numerous strategies ranging from benefit-finding—defined as finding positive changes in life after the stressful event (Antoni, 2011; Friedman, 2011)— to denial (Kamen et al., 2012; Varni, Miller, McCuin, & Solomon, 2012) and complete avoidance (Moskowitz et al., 2009). Denial usually takes place during the first months of diagnosis, notwithstanding that a person behaves in a typical way. After receiving the positive result of the HIV test, PLWH may feel the need to repress this new reality (Moitra, Herbert, & Forman, 2011); thus, some manifestation of denial is almost inevitable (McIntosh & Rosselli, 2012). Later, denial may also include self-harming behaviour and deception about HIV status (McIntosh & Rosselli, 2012). Avoidant coping

is predominant among PLWH (Joseph & Bhatti, 2004), and while it might be useful to manage acute stress, several authors have shown that over time it leads to maladjustment (Kamen et al., 2012).

Social isolation and loneliness. During life's most stressful events, it is essential to seek emotional and informational support from our closest social support networks. Social support is one of the strongest predictors of successful coping, according to Vyavaharkar et al. (2007). However, social isolation is very common among PLWH. While in some cases it only occurs during the emotionally challenging period of the initial acceptance of the diagnosis, some PLWH completely lose their social circles (Holtz, Sowell, & Velasquez, 2012; Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011).

In a qualitative narrative study on experiential and emotional meanings of loneliness among PLWH, Cherry and Smith (1993) noted that social isolation greatly contributes to alienation and, as a result, to social exclusion, altered self-perception, and feelings of inferiority. Loss of one's social circle leads to great existential loneliness. Limited social supports for and the constant distress of living with the illness often lead to silent endurance and profound loneliness, as was shown in a qualitative study of 30 PLWH in the rural US South (Miles et al., 2011). In a quantitative study exploring the consequences of loneliness, Grov, Golub, Parsons, Brennan, and Karpiak (2010) found that loneliness and HIV-related stigma predict the occurrence of major depressive symptoms. The latter authors recommended a focus on reducing experiences of loneliness among PLWH as one of the major determinants of quality of life. Also, implementing

strategies to address loneliness was found to significantly decrease stress and anxiety in this population (Hill, 2012).

So, why do PLWH experience such loneliness? The most common reason is the absence of a partner (Miles et al., 2011), although one should keep in mind that emotionally unsatisfying relationships might not solve this issue. The relational challenges of PLWH are not well-explored or understood. Do PLWH seek partners? What influences the decision by PLWH to be or not to be involved in intimate relationship(s)? These questions remain unanswered. In this research project, I address this gap, which several authors previously recognized as a possible direction for future research (Courtenay-Quirk, Jun, & Wolitski, 2009; Psaros et al., 2012; Sastre, Sheehan, & Gonzalez, 2015).

Research Question

The question addressed in this research project was: What is the experience of heterosexual PLWH in terms of partner-seeking in a Western Canadian city? I intentionally left the question rather broad, as very little is known about the experiences of heterosexual PLWH in terms of relationship challenges.

Purpose of the Research Project

Community-situated research was conducted to: (a) gain knowledge about the emotional, social, and physical needs of single heterosexual PLWH living in a Western Canadian city; (b) increase advocacy around rights of PLWH for family planning; (c) increase knowledge about healthy relationships and ways to deal with relationship issues, as well as harm-reduction strategies in seroconcordant and serodiscordant relationship; and (d) meaningfully engage heterosexual PLWH in creating and mobilizing

16

new knowledge, thus fulfilling the UNAIDS (2007, p. 1) principle "The Greater Involvement of People Living with HIV."

The coinciding intellectual goals of this project included recognizing the factors that influence the decision to seek a partner, and identifying strategies and processes used in partner-seeking among heterosexual PLWH. Practical goals were oriented toward closing the "know-do" gap in the following ways: (a) by addressing a knowledge deficit about partner-seeking among heterosexual PLWH; (b) by promoting community-based scholarship, involving the research community, PLWH, and service providers; and (c) by enhancing advocacy initiatives around the importance of relationship for PLWH.

Significance of this Research Project

To my knowledge, this study is one of the few that has explored partner-seeking experiences among heterosexual PLWH. Although challenges that relationships pose to PLWH are well-recognized by some health care professionals, the lack of literature on this topic was quite evident. Furthermore, I have documented several authors who identified the need for further research on partner-seeking (Jarman, Walsh, & De Lacey, 2005; Sastre et al., 2015). As Courtenay-Quirk et al. (2009, p. 1126) mentioned in a research paper devoted to intentional sexual abstinence among homeless PLWH, the factors that influence sexual behaviour choices of heterosexual PLWH are understudied and require "[the application of] a more qualitative approach [which] might yield richer information on the ways in which factors such as housing-related problems affect sexual decision-making among heterosexual HIV-positive men." Psaros et al. (2012) also pointed to the lack of knowledge about factors that influence sexual health decision making for older WLWH. Knowledge of these sensitive issues is "important to inform

how programs serving PLWH address this issue in a targeted manner that supports the sexual health and risk reduction needs of PLWH" (Courtenay-Quirk et al., p. 1126).

Overview of the Thesis

Chapter One helps to deepen the reader's understanding of the social context of the HIV epidemic. I devoted this chapter to a discussion of the complexities that exist within the HIV field and then emphasized major issues that PLWH face on an everyday basis. This was followed by a review of the research question guiding my research, the purpose of the research project, and its significance for PLWH and service providers.

Over the next chapters, I describe the research process that went from setting the research question, "What is the experience of heterosexual PLWH in terms of partner-seeking in a Western Canadian city," to finding answers to this question. Chapter Two describes existing literature relevant to the research question. I begin by laying out the available literature on partner seeking as a phenomenon of interest and attitudes to relationships among different groups of PLWH. In Chapter Three, I discuss my philosophical stance, theoretical framework, and the research design. The findings of the project, as well as demographic information of the participants who shared their voices and experiences, are presented in Chapter Four. I discuss different aspects of living with HIV and relationship challenges of the participants. The final chapter contains a thorough review of the themes, explanation of the findings with the help of the available literature, recommendations for stakeholders involved in care for PLWH, limitations of the project, and directions for future research.

<center>**Chapter Two: Literature Review**</center>

In this chapter, I outline what is known about partner seeking among PLWH and discuss what is known about relational challenges among PLWH belonging to different social groups: MSM, youth, and heterosexual men and women. I also speak about both the criminalization of HIV non-disclosure and the struggle of disclosing HIV status as two main factors that influence relationships with existing and potential sexual partners.

Partner-Seeking

As a doctoral student from Simon Fraser University, Allison Carter, said,

> We've done a great job of using medicine and education to prevent HIV, and now we really have to teach people about how you can love someone with HIV. . . . HIV-positive Canadian women can and do enjoy meaningful intimate relationships and healthy sexuality after HIV. (as cited in Fletcher, 2016, para. 4)

Worth mentioning here is that after the introduction of HAART, relationship dynamics changed (Carter et al., 2013); it became much easier to engage in relationships knowing that the illness can be successfully managed (Vlahov et al., 2001). The rapid decrease in viral load after initiation of successful antiretroviral therapy significantly decreases the risk of HIV transmission (Attia, Egger, Müller, Zwahlen, & Low, 2009). However, keeping these facts in mind, the data show that the majority of PLWH do not have a partner.

According to Statistics Canada (2015), 52% of Canadians are either single, divorced, separated, or widowed, while more than 80% of PLWH live without partners (Farber et al., 2003; Kposowa, 2013; Psaros et al., 2012; Simoni, Martone, & Kerwin, 2002; Vyavaharkar et al., 2007). Recent data showed that only 22% of Canadian WLWH are engaged in relationships (Fletcher, 2016, para. 9). The percentage of single PLWH is

<center>19</center>

not surprising considering the scale of stigma and level of depression experienced by them (Herek et al., 2013; Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000; M. Lee, Nezu, & Nezu, 2014; Leserman, 2008). Although the data on marital status mentioned above comes mainly from research studies done in the US, the discrepancy in percentage is significant. These PLWH, deprived of emotional support that could be provided by their partners, may suffer the heavy burden that is brought by the HIV diagnosis. In a study by Medley, Kennedy, Luynolo, and Sweat (2009, p. 1749), for example, several WLWH emphasized how their lives could have changed in a positive way if they had a loving man who was living with the same illness. As one of the participants said, "It was five years ago that I met the person of my kind and here we are, happily married."

On the contrary, Psaros et al. (2012, p. 757) noted that some PLWH avoid seeking a partner, expressing doubts and hopelessness about finding one and perceiving themselves as "dirty." As a result, they used self-isolation as a way to deal with impaired body image, low self-esteem, disclosure dilemma, and the power differential existing between partners in serodiscordant relationships. Consequently, impaired psychological well-being may lead to decreased medication adherence (Dale et al., 2014; Vyavaharkar et al., 2007), therefore affecting the HIV treatment cascade and contributing to the identification of gaps in the systems connecting PLWH to specialized care (Wilton & Broeckaert, 2013).

Surprisingly, questions about whether PLWH are seeking partners, why they decide to seek, and many others are well-studied among gay men but not heterosexuals. The possible reason for this might be that men who have sex with men continue to be a

predominant category in developed countries. For example, 48.8% of PLWH in Canada contracted virus through MSM contacts (PHAC, 2015a). As Bauermeister (2012) reported, the majority of gay and bisexual men are engaged in partner-seeking. The phenomenon that received particular attention among researchers studying partner seeking in the MSM community is serosorting (Bradley-Springer & Cook, 2006; Cairns, 2006; Chen, Vallabhaneni, Raymond, & McFarland, 2012; Frost, Stirratt, & Ouellette, 2008; Golden, Dombrowski, Kerani, & Stekler, 2012). It is defined as the practice of seeking partners of the same HIV status (Peterson & Jones, 2009) or having condomless sex with a partner of the same (perceived) HIV status (Rowniak, 2009). Serosorting was initially described by Hoff, McKusick, Hilliard, and Coates (1992) when the epidemic was in its infancy. Their goal was to determine the degree to which HIV status of a potential partner mattered among intimate partners within the MSM community. It appeared that some (the minority) of the gay PLWH preferred a partner who also lived with HIV to share a common bond and not because of fear of potential transmission of the virus to a partner who does not live with HIV. In a more recent mixed methods study of 28 MSM living with HIV, participants named several reasons for seeking partners of the same HIV status, including concerns about transmission of HIV to an individual who does not live with HIV, and their shared experiences of the illness (Steward et al., 2009). However, partner-seeking behaviour, as well as reasons for seeking partners of the same HIV status, might have changed over time, considering the advancement in HIV treatment regimens and increasing use of online dating for PLWH (Mazanderani, 2012).

A great deal of research has been devoted to serosorting as a preventive measure among MSM who do not live with HIV. The effectiveness of serosorting in terms of

prevention in this population depends on disclosure rates and the perception of one's HIV status (Butler & Smith, 2007). Theoretically, serosorting, being an informal risk-reduction technique, could reduce HIV transmission only if all people disclosed their HIV status to their partners (Steward et al., 2009). However, stigma and the criminalization of HIV transmission and exposure prevent disclosure, therefore reducing effectiveness of serosorting as a prevention measure. It is interesting to note that research done among MSM focused mainly on sexual aspects of relationships. However, a healthy relationship has many aspects, and sex is only one of them. A healthy relationship is about support going both ways, sharing, respect, trust, feeling good and happy about having someone close (Military Family Resource Centres, n.d.), the ability to be yourself, encouraging and receiving encouragement (KFL&A Public Health, n.d.), and feeling safe (County of Los Angeles Public Health, n.d.). Better understanding of what constitutes a healthy relationship in the context of living with HIV illness would be helpful in developing strategies to facilitate meeting potential partners.

Attitudes to Relationships and Partner-Seeking among Heterosexual PLWH

The findings from studies about heterosexual people show that the reasons for seeking a partner are varied (Bauermeister, 2012). These reasons tend to differ among PLWH, based on age, gender, and cultural needs.

Adolescents. As Bauermeister, Elkington, Robbins, Kang, and Mellins (2012) noted, the beginning of sexual activity among adolescents living with HIV (ALWH) occurs at the same age as in the general population. However, the sexual domain is seriously affected by HIV and medications. The rate of sexual contacts and experience is reduced by the side effects of antiretroviral medications and the prospects of disclosure.

22

As Fair and Albright (2012) found in a qualitative study that explored perspectives of perinatally-infected ALWH (ages ranged from 15 to 30 years) on navigating their romantic relationships, only 20% were engaged in relationships. They reported having to keep their HIV status a secret, which prevented them from the obtaining the emotional support they needed (Leonard, Markham, Bui, Shegog, & Paul, 2010). Moreover, disclosure of one's status to an existing partner, despite hopes for deepening emotional connection, often led to rejection and separation. In contrast to these negative reactions, there were cases when partners became even more caring: they accompanied their partners who live with HIV to doctor's appointments, checked on their health, and wanted to learn more about HIV. Despite anxiety about future disclosure and the seemingly low percentage of those engaged in relationships, 71.4% of the participants reported being sexually active (Fair & Albright, 2012). Thus, existing tensions between disclosure and desire to have a partner accentuated difficulties in the sexual lives of ALWH.

Leonard et al. (2010) reported that nine of 14 participants (ages ranged between 13 and 24 years) commented that having a partner who does not live with HIV would complicate physical and emotional intimacy. Ten of 14 said that it would be much easier to date a partner living with the same condition and maintain seroconcordant relationships. As participants explained, seroconcordant relationships would provide commonalities with their partners, greater confidence in relationships, and better adherence to antiretroviral medications. Only half of the participants who perceived benefits of having a partner of the same HIV status were worried about wearing a

23

condom to prevent acquiring other strains of HIV, sexually transmitted infections, or getting pregnant.

Another concern that ALWH have to deal with is the perception that upon disclosure, HIV is going to be associated solely with sexually inappropriate behaviour, thus questioning the fidelity of ALWH (Greenhalgh, Evangeli, Frize, Foster, & Fidler, 2013). ALWH were also concerned with the best way to communicate with their partners, so that their relationships would not be prematurely terminated due to the anxiety associated with possible transmission. As the participants of this qualitative cross-sectional study indicated, they were afraid that potential partners would inadequately assess the risk, resulting in the end of their relationships. Due to these constraints, ALWH tended to utilize self-protective motivations to either settle for being single or chose partners who would accept their HIV status, often at the expense of the *quality* of the relationship (Greenhalgh, Evangeli, Frize, Foster, & Fidler, 2015). Several strategies that the participants utilized included: (a) testing possible reactions of partners towards HIV and PLWH, and the possibility of having a partner who also lived with HIV; (b) disclosure at early stages of relationships to avoid painful rejection later, when feelings for a partner are deeper; (c) using condoms to avoid or delay disclosure; and (d) making decisions about initiating or continuing relationships in light of the necessity to disclose.

In a qualitative study focusing on psychosocial issues among ALWH, many of the participants (ages ranged between 17 and 21 years) did not disclose (Hosek, Harper, & Domanico, 2000). All of those who decided to disclose had negative experiences with being shunned by their family members, preventing them from seeking intimate or more

casual relationships. Moreover, many of the participants perceived their medications as a reminder of their illness that they were trying to forget. Indeed, adherence to medication is of great concern among medical professionals with respect to this cohort of PLWH (Chandwani et al., 2012; Nichols et al., 2012).

Men. Heterosexual males stress the importance of integrating emotional and sexual domains by finding "the true meaning of love" (Missildine, Parsons, & Knight, 2006, p. 316). Through in-depth interviews with 18 heterosexual males living with HIV (mean age was 40.9 years), Missildine et al. (2006) found out that there was a split between these two important domains of sexuality. From one point of view, men tended to avoid intimacy because they associated it with partners for whom they had very deep emotional feelings. Therefore, to have sexual release, they tended to engage in sexual relationships with casual partners. Only one in 18 participants managed to integrate intimacy and sex—two domains greatly affected by HIV—after receiving the diagnosis.

Another research study devoted to partner selection among heterosexual and bisexual men showed that relationship-focused needs (i.e., the emotional needs of the self and the partner) are positively correlated with the likelihood of looking for a steady partner in life (Craft & Serovich, 2008). Although this study showed that individuals with high relationship-focused needs were eager to seek partners, it also showed that there was still significant fear of disclosure. Moreover, according to Sastre et al. (2015), heterosexual men tended to internalize HIV-related stigma and rejected potential relationships in which they would otherwise have engaged before testing HIV-positive. The same authors showed that although the majority of heterosexual men living with HIV (MLWH) were eager to date women living with the same illness, they noted that very few

women attended support groups and HIV programs, which made it very difficult to find anyone who would be interested in building a committed relationship. As Sastre et al. revealed, participants utilized a variety of strategies (mostly negative) to deal with relationship-related issues. For example, participants preferred to end current relationships or cease dating, while only a few continued their normal dating life or decided to seek partners using HIV status as a selection criterion.

Women. According to different sources, from 30% (Finger et al., 2012; Moses & Dhar, 2012) to 70% (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006) of young WLWH want to have children. Despite the fact that many women might appear healthy, feelings of loss of physical and sexual appeal, anxiety, and confusion about whether their post-diagnosis lives should include sex prevent them from moving ahead with this aspect of their lives (Hankins, Gendron, Tran, Lamping, & Lapointe, 1997).

The reasons older women sought partners was the fear of aging alone and the desire to share their time and lives with a prospective partner (Psaros et al., 2012). Semi-structured qualitative interviews with 19 women (mean age was 56.79 years old) showed that 84.2% of them were single, despite a strong desire to be engaged in a relationship with a man (Psaros et al., 2012). The main obstacle emphasized by the participants was HIV-related stigma. Perception of possible societal rejection led to the feeling of hopelessness about ever having a partner. Moreover, women were afraid of how they would be perceived after disclosing their status—such as stigma around having multiple sexual partners, working in the sex trade, or using needles. Feeling like a "second class citizen" (p. 757) made them feel as though they should be grateful to *anyone* who would consent to be in a relationship with them. These women's self-esteem created a potential

power differential, particularly when they were engaged in a relationship with a person who did not live with HIV. Women explained that they felt as though only men with questionable backgrounds would find them "datable" (p. 757), which was the reason why some of them preferred to "focus on themselves" (p. 757) instead of being open to the possibility of building a relationship. On the other hand, some women were grieving the loss of their intimate life and spoke about the loneliness they experienced as a result. Older women also have to face body changes. While some of them come with ageing (e.g., menopause and redistribution of body fat [Office on Women's Health U.S. Department of Health and Human Services, n.d.]), others, such as lipodystrophy (AIDSinfo, 2005), are attributed to HIV and might be just another reminder of their condition. These issues can significantly affect body image of WLWH and contribute to depression (Carr, 2014).

In a qualitative study aimed at uncovering a range of psychological and social issues, researchers discovered that WLWH have comparably low feelings of self-worth and value when compared to women who do not live with HIV (Hosek, Brothers, Lemos, & Adolescent Medicine Trials Network for HIV/AIDS Interventions, 2012). The social rejection that they encountered and the lack of support from loved ones impacted their daily lives, future goals, and possible relationships. Some of the participants preferred to stay in abusive relationships simply because they did not feel themselves worth someone else's attention. Others preferred to stay away from relationships altogether.

Being a single HIV-positive woman is difficult not only from a personal and emotional perspective, but also from cultural one. The authors of a study conducted with 20 heterosexual couples in Malawi identified stigma in the community around being

single or divorced (Gombachika, Chirwa, Sundby, Malata, & Maluwa, 2012). Therefore, it is not only one's emotional needs that are left unfulfilled; social and cultural pressures further complicate the lives of WLWH. Gombachika et al. (2012) also showed that some WLWH actively looked for seroconcordant relationships. During an in-depth interview, one woman in particular stressed that having a partner with the same HIV status was very important: "It was a good decision to marry someone who also had a similar problem because we would understand each other easily and follow the advice that we are given here at the hospital without any problems" (p. 4). This woman's feelings further underline the positive impact of seroconcordant relationships on medication adherence (Johnson et al., 2012).

The literature generally indicated a strong connection between partner seeking and sexuality. Gurevich, Mathieson, Bower, and Dhayanandhan (2007) highlighted that for WLWH, their positive diagnosis inhibited their sexuality in a variety of ways. Almost all of the 20 participants reported that their sexual life was very different from what they had before getting diagnosed, including diminished intimacy and spontaneity with limited power in making decisions about sex and feelings of sexual freedom during intercourse. The authors emphasized that women had a difficult time finding heterosexual men to date. In contrast, the MSM community expressed being less affected by HIV in terms of finding partners. In another study devoted to sexuality post-diagnosis among WLWH, Hankins et al. (1997) pointed to the significant drop in sexual activity immediately after being diagnosed. However, what is important to note is that those women who found new partners after their diagnosis (nothing is known about the partners' HIV status) had increased sexuality and feelings of sexual satisfaction.

Once a man or woman decides to seek a partner, the next step is to determine where to meet them. In a study of viral sociality, Mazanderani (2012) explored Internet-based partner-seeking strategies among PLWH. As the author defined it, viral sociality includes:

> practices of explicitly seeking out, forming and maintaining romantic and/or sexual relations between people living with HIV and others who also already have the virus; preventing the literal spread of the virus to uninfected others, while sharing it with each other in different ways—through, for example, mutual understanding, providing emotional support, helping with medical decisions. (p. 394)

In today's world, socialization is often Internet-based; indeed, there are many online dating websites specifically designed for PLWH. Mazanderani's research focused exclusively on the profiles and conversations of WLWH. According to the results, women's profiles tended to focus on prospective motherhood, intimacy, and romance—those aspects that constitute a "normalcy." Of particular interest in Mazanderani's work is that online dating for PLWH brought with it an opportunity to put disclosure (an extremely stressful aspect of living with HIV) at the beginning of relationships (or essentially remove it entirely from the relationship formation equation). Basically, HIV dating websites alleviated the burden of disclosure, because HIV is, or might be, precisely the reason why a potential partner is also registered at a given HIV dating website.

Factors Influencing Relationships with Sexual Partners

No one can argue that PLWH have all the rights of people who do not live with HIV, including the right for "happy, healthy and safer sex in their lives" (Welbourn, 2006, p. 125). However, this right is undoubtedly affected by the criminalization of HIV

non-disclosure with the majority of prosecution targeting heterosexual relationships (Dej & Kilty, 2012). While it is entirely up to PLWH to disclose or not to disclose their HIV status to their friends or family members, PLWH are obligated under criminal law to disclose their status to sexual partners (e.g., spouses, regular sexual partners, one-time sexual encounters, or other relationship involving sex) (Canadian HIV/AIDS Legal Network, 2015). Whether HIV transmission occurred or not, PLWH who know or suspect their diagnosis can be legally prosecuted if there was "a realistic possibility of transmission" (p. 1). Currently, the need to disclose under criminal law includes vaginal or anal sex without a condom regardless of viral load and with a condom if viral load is more than 1500 copies/ml. Thus, in the case of vaginal sex, the only time PLWH can choose not to disclose is when a condom was used and viral load was either very low (less than 1500 copes/ml) or undetectable (Canadian HIV/AIDS Legal Network, 2015).

Unfortunately, criminal law develops slowly, considering the ability of lawmakers to incorporate the findings of medical evidence in this area; there should be a specific case with specific circumstances addressed in court to obligate higher-level courts to develop certain principles of dealing with this case or to encourage development of new laws by the Parliament (Canadian HIV/AIDS Legal Network, 2014). For example, there is still uncertainty about obligations to disclose HIV status in cases of oral or anal sex (such as if a condom was used and the individual's viral load was low or undetectable). While experts agree that high profile cases should go to court, the use of criminal law to address HIV exposure and transmission is overly broad. Prosecution of PLWH when the risk of transmission is extremely low based on the current state of knowledge fuels stigma and discrimination (Canadian HIV/AIDS Legal Network, 2014) because

30

criminalization sends "a normative signal about certain populations . . . as potentially criminal or dangerous" (Ahmed, Kaplan, Symington, & Kismodi, 2011, p. S361)—despite what medical evidence may in fact demonstrate. Criminalization of HIV non-disclosure can also significantly decrease access to HIV testing due to fears of legal prosecution of non-disclosure (Patterson et al., 2015).

As Canadian HIV/AIDS Legal Network (2015, p. 2) stated, "criminal law is about disclosure," which is a multi-dimensional and iterative process (Gaskins et al., 2012). It seems that all PLWH have to do is disclose their HIV status before sex and make sure that sex is consensual, but is it that easy to disclose? The answer is, of course, no. According to the Disclosure Process Model, disclosure consists of several stages: antecedent goals, the disclosure event itself, mediating processes and outcomes, and a feedback loop (Chaudoir, Fisher, & Simone, 2011). Before going in depth into the issues of disclosure and its influence on partner-seeking experiences of PLWH, it is beneficial to consider the findings of a qualitative study with 122 PLWH (102 males, 19 females, and 1 transwoman) on how the legal climate regarding HIV exposure and transmission influences negotiation of potential romantic and sexual interactions in the everyday life of PLWH. According to the findings, criminalization of HIV non-disclosure further complicated pursuing intimate relationships, with some participants stating that they felt more anxious because of the legal complications around consensual sexual relationships and therefore chose to be celibate or to be in seroconcordant relationships (Adam et al., 2014).

Adam et al. (2014) also emphasised that the trend to put too much emphasis on disclosure does not go hand in hand with the message to the public to be responsible for

practicing safer sex. Similar thoughts resonate in the recent Foucauldian analysis of the experiences of nurses in HIV disclosure counselling (O'Byrne, Holmes, & Roy, 2015). According to the authors, the suggestion that promoting self-disclosure as one intervention to fight stigma and decrease the incidence of HIV can be misleading. If we think about disclosure carefully, new cases are mostly attributed to people who are not tested and are therefore unaware of their status. Therefore, O'Byrne, Holmes, and Roy (2015) argued that there should be a shift from active promotion of HIV disclosure, which is often viewed as "a gateway to HIV prevention" (Geary et al., 2014, p. 1419), to increasing access to and normalizing of HIV testing. The latter point is confirmed by the authors of a recent paper on late initiation of HAART in Canada (Cescon et al., 2015). As the authors stated, offering HIV testing during routine clinical visits to everyone, instead of exclusively to people that are perceived to belong to key populations, can help to "decrease the burden of undiagnosed HIV, reduce onward HIV transmission, and encourage earlier initiation of treatment and engagement in the HIV care cascade" (Cescon et al., 2015, Conclusions section, para. 1)

In addition to the possibility of legal prosecution, disclosure poses an enormous stress on PLWH due to fear of violence, abandonment, stigma, and relationship dissolution (Kennedy, Haberlen, Amin, Baggaley, & Narasimhan, 2015). The very thought of the necessity to disclose at some point brings the fear of being rejected, and perceived negative reactions from sexual partners discouraged many PLWH from disclosing their status (Tshweneagae, Oss, & Mgutshini, 2015). As Tshweneagae et al. (2015) found in their qualitative study that aimed to explore factors associated with disclosure, the majority of the partners of PLWH reacted negatively. These negative

reactions included fear, ignorance, secrecy (when a partner tested HIV-positive earlier but did not disclose his or her status before), rejection, and silence. However, many participants reported that later on, partners to whom they disclosed became very supportive and accepting, echoing the findings of a phenomenological study by Rouleau, Cote, and Cara (2012). Tshweneagae et al. (2015) also found that however fearful PLWH were of disclosure, they understood the necessity of disclosing their status for future negotiation of intimate relationships and preventing their partners from acquiring HIV.

A phenomenological study on the experiences of disclosure among WLWH showed that disclosure is a very difficult balancing of two paradoxical processes: revealing and concealing (Rouleau, Cote, & Cara, 2012). It requires freedom and control to choose to disclose or not in order to feel comfortable. Another question is to whom to disclose. It involved being afraid of losing a partner and being left alone, lying about the reasons for deteriorating state of health, encountering stigmatizing attitudes from friends and family members, and bearing the burden of keeping HIV status a secret (Rouleau et al., 2012). The decision to disclose requires time to learn about HIV and choosing a targeted recipient, commonly mothers or other close family members (Gaskins et al., 2012). As Gaskin et al. (2012) recommended, skill-building support services might help PLWH make disclosure decisions and prepare for the variety of possible reactions from the recipient. Interestingly, some authors also found that the first experience of disclosing significantly shaped further disclosure decisions. Thus, negative responses to initial disclosure resulted in reluctance to disclose to others, whereas positive experiences of disclosure encouraged further disclosure. Indeed, having a negative disclosure experience, experiences of involuntary disclosure, rejection following disclosure,

loneliness, and low self-esteem were all associated with having regrets following

disclosure (Henry et al., 2015).

Parsons, Vanora, Missildine, Purcell, and Gomez (2004) showed that PLWH also

were afraid of the prospects of losing income and drugs, and the fear for the violence.

Positive disclosure experiences included increased support and intimacy in existing

relationships, the opportunity to be more open emotionally, and the reaffirmation of one's

sense of self. The latter consequences show that while having the identity of a person

living with HIV might decrease self-worth, in some cases it can actually boost self-

esteem if a person accepts his or her HIV status as a part of the self. One of the ways to

deal with concerns about disclosure despite the possibility of negative consequences was

to avoid long-term intimate relationship and to seek other PLWH as potential intimate

partners (Parsons et al., 2004).

Emotional closeness to a partner and monogamous relationships were shown to

predict disclosure (Polansky, Teti, Chengappa, & Aaron, 2015). These authors suggested

relationship-based interventions to promote disclosure; the goal of PLWH in

monogamous relationships could strengthen relationships with an emphasis on intimacy,

monogamy, trust, and an easier ability to negotiate safe sex. The goal of PLWH who are

not sexually active, are not engaged in a committed relationship, or experience power

imbalance in existing relationships could be to develop skills for safe sex. Another

intervention suggested by Conserve, King, Devieux, Jean-Gilles, and Malow (2014) is

couple-based, with a focus on the disclosure process in serodiscordant couples and

among PLWH who have multiple partners. In a community-based cross-sectional study

of 300 PLWH, the authors found that high self-esteem and knowing other PLWH who

disclosed their HIV status publicly were associated with disclosure (Cissé et al., 2016). Disclosure was also associated with living with one's steady sexual partner, having a higher living-standard index, being a member of an AIDS service organization (ASO), discussing HIV with friends, and higher social exclusion scores (Loukid et al., 2014). In study by Xiao et al. (2015), fear of rejection and concern about privacy were shown to predict non-disclosure, while motivation to establish a close relationship was associated with status disclosure. Factors associated with non-disclosure included female gender, being a gay or bisexual man, having one-time sexual encounters, not taking medications, not always using condoms (Hirsch Allen et al., 2014), knowing that a partner had HIV-negative status, having a partner with unknown status, and having multiple partners in the last three months (Conserve et al., 2014).

Summary

Lives of PLWH remain complicated not only because of the chronic character of the HIV illness, but also because of the social consequences that come with the illness. The intimate lives of PLWH are unavoidably affected in a variety of ways. The literature shows that a large proportion of PLWH are single. The reasons for being single are varied, and include difficulties in finding a partner, feeling hopeless and desperate about the possibility of being engaged in relationships, and not knowing when and how to disclose. In this chapter I also explored the differences in partner-seeking experiences among youth, women, and MLWH.

Chapter Three: Research Design

A research design is "a flexible set of guidelines that connect theoretical paradigms, first, to strategies of inquiry and, second, to methods for collecting empirical material" (Denzin & Lincoln, 2013, p. 29). As Denzin and Lincoln (2013) noted, an appropriate design helps a researcher to find specific places, institutions, and participants that will contribute to answering the research question. Considering the importance of clear design for the quality of a research project, I will discuss every step of the design and rationale for choosing particular approaches in this chapter. However, before proceeding to the details of my qualitative design, I will explain my philosophical stance and position within this research project.

Personal Situatedness

Behind every theory, method, and analysis "stands the personal biography of the researcher [speaking] from a particular class, gendered, racial, cultural, and ethnic community perspective" (Denzin & Lincoln, 2005, p. 11). We cannot deny the fact that, whatever methodology a researcher is using, research is interpretive, meaning that it is guided by the researcher's beliefs about how the world works (Denzin & Lincoln, 2013). In addition, as Patton (2015) noted, qualitative inquiry is at the intersection of the personal and the professional; therefore, first, I will acknowledge my personal biases and assumptions.

I am a recently married, young woman, with a strong educational background. My experience as an epidemiologist in infectious diseases provided my first exposure to the field of HIV. I come from a country where HIV is, unfortunately, still considered a death sentence rather than a manageable chronic disease. In my home-country, Belarus,

practitioners face a great variety of ethical concerns related to HIV. In a setting with limited access to antiretroviral therapy, infectious disease specialists have to make uneasy choices of who will get treatment based on the number of CD4+T-cells, while the WHO (2015b) has recommended giving HAART to every PLWH regardless of CD4+T-cells count and viral load. I have spent the last five years studying clinical and epidemiological aspects of HIV; however, I was always interested in psychological aspects of living with a chronic disease. The research question for this project was dictated by my strong belief that every person's life can be changed for the better if an understanding and supportive partner is in it. In my opinion, a healthy relationship is a key to happiness.

Despite gathering the insights of both patients and health care professionals and despite my desire to be closer to the community I am studying, I still consider myself an "external-outsider" (Banks, 1998, p. 8):

> The external-outsider is socialized within a community different from the one in which he or she is doing research. The external-outsider has a partial understanding of and little appreciation for the values, perspectives, and knowledge of the community he or she is studying.

Although I agree that I was not socialized within the community of PLWH before starting this research project, I did my best to reduce my distance from the community by volunteering at a local ASO in a Western Canadian city. Despite the fact that I was raised when HIV was considered to be a concern for sex trade workers, men who have sex with men and PID, and billboards contained stigmatizing images of HIV and people from so-called risk groups, which were created to make people aware of the existence of the disease, I see HIV infection exclusively as a chronic condition, just the same as every other infectious disease with a tendency to become chronic. Medical education provided

me with up-to-date information on the subject and good understanding of the HIV field. However, I acknowledge that not all people are of the same opinion, even considering the latest achievements in treatment and prevention. High levels of stigmatization drive major issues in the field of HIV, and I had a chance to see the devastating effect of stigmatization on the treatment cascade in Eastern Europe. I believe the situation in the HIV field in Canada has its differences, which I attribute to a more favourable economic situation and greater investments in the health care sector. In order to get a better understanding of the context of HIV in Canada, I applied for scholarships to attend several conferences related to HIV infection and key populations. I have also entered the REACH Alberta Working Group, which consists of multiple stakeholders working with PLWH in Alberta (Musten, 2015).

Moreover, my understanding of the issues posed by HIV comes from my experience of communicating with PLWH and discussions with various stakeholders across Europe and Canada. When starting data collection, I expected to see some of the participants looking for a partner of the same HIV status in order to decrease the level of perceived stigma and to provide them with the necessary support. However, I also expected some people to be unwilling to look for any partner regardless of their HIV status, and I wondered if it might depend on the time since their diagnosis.

I also acknowledge the power imbalance that exists between participants and myself, which is commonly present in researcher-interviewee relationships. A power relationship arises from the fact that a researcher and a participant are both involved in the project. One of the tasks of a researcher is to care "for participants wholeheartedly, openly, and unconditionally" (Yang, Yang, & Chen, 2013, p. 238). Therefore, I did my

best to create a safe environment and maintain a listening stance to help participants tell their stories. However, through the research process, I kept in mind that power relations change, as a research project always has a trajectory, and each stage poses new challenges on how to balance power relationships (Karnieli-Miller, Strier, & Pessach, 2009). While I noticed that some participants could freely talk from the very beginning of the interview, in other cases, I had to reinforce that it was the participant who had the power to talk about anything he or she perceived important.

Philosophical Stance

Defining philosophical assumptions is a crucial step at the beginning of every qualitative work (Maxwell, 2012), because the philosophical stance of a researcher is an essential determinant of the quality of the research (Creswell & Miller, 2000). Qualitative research itself is grounded in symbolic interactionism (SI) (Cleary, Horsfall, & Hayter, 2014), the guiding paradigm in this research project. As Blumer (1969)—a founder of SI—stated, human life is unthinkable without social interaction. Individually and collectively, actors create a system of symbols and "[learn] through social experiences in significant relationships, small groups, formal organizations, and communities" (Forte, 2008, p. 173). This symbol system defines the meanings, which can be seen as social products (Klunklin, 2006) and which people assign to particular objects or actions (Forte, 2008). Therefore, the world, from a social interactionist perspective, "refers to a world of symbols"—verbal and non-verbal (Klunklin, 2006, p. 33).

SI, as a "distinctive approach to the study of human social life" (Schellenberg, 1990, p. 769), focuses on three main concepts: the self, the world, and social action (Klunklin, 2006). The following three propositions are core to SI: (a) the self is created

39

by interaction with society, although the contribution of biological features is important; (b) the self develops through the course of life "in response to social experience" (Schellenberg, 1990, p. 771); and (c) the self integrates and reflects society's and the individual's inner experiences. These core principles explain the main characteristic traits of SI: (a) its ability to construct complicated and essential interpretations of human life (Charmaz, 2008); (b) its incorporation of two processes—exploration (depiction) and inspection (analysis)—that help to study social phenomena (Blumer, 1969); (c) its intimate stance toward social acts, languages, and theories; (d) its analytical and policy approaches to sophisticated social concerns; and (e) its holistic orientation (Kotarba, 2014). These principles of SI match with my worldview; thus, I view my research project and emerging data from the SI lens.

Theoretical Framework

A theoretical framework guides researchers by identifying important issues and the population to be studied; as well, it helps researchers to reveal their position in the research (Creswell, 2014). Therefore, a focus on the theoretical framework is crucial, and its meaning cannot be undermined. In regard to the research question of this project, two theories were useful in understanding the phenomenon of partner seeking: identity theory by Stryker (1980) and Goffman's (1963) theory of spoiled identity. Stryker's identity theory appealed to me because of its conceptualization of the existence of various identities, defined by social roles, within the self. For this reason, Stryker's identity theory is extensively used in studies exploring changes to selfhood following the diagnosis of a chronic illness (Baumgartner & Niemi, 2013; Lee & Craft, 2002; Roberto & McCann, 2011; Snelgrove, 2015) and is one of the lenses through which to look at the

findings of this research project. In its turn, Goffman's theory is one of the benchmark social theories that underlines the importance of association between stigma and disease. It allows the reader to see how "socially constructed identification [of a person based on physical, behavioral and social traits] lays the groundwork for subsequent disqualification of membership from a group in which that person was originally included" (Castro & Farmer, 2005, p. 54). It also gives particular focus to the role of power located within different institutions in the construction and maintenance of narratives of people living with illness (Ezzy, 1998, p. 250).

In the following sections I further explore Stryker's identity theory and its application in this research project, and then move on to the concept of stigmatization using Goffman's theory of spoiled identity.

Society and the self. Individuals and society are inseparable. From an anthropological perspective, socialization was once the only possible way for primates to survive, which is the reason why social isolation is imagined as the most depressive event in the life of an individual (Folkman, 2011). Therefore, a sociological approach to interpreting the self and society (Stryker, 1980) is indispensable in terms of better comprehension of the partner-seeking experience. Reciprocal relationships between the self and society are well-established. We influence society by creating different organizations, networks, and institutions, and society influences individuals "through its shared language and meanings" (Stets & Burke, 2003, p. 1). In other words, people are embedded in the social structure they create. Structural SI, from which identity theory is derived, helps to explain how social structures affect self and how self affects social behaviour (Stryker & Burke, 2000). SI states that society has no real organization and

experiences constant changes. What gives hope, from the perspective of SI, is that this state of flux can be a background for positive changes in levels of stigmatization. Indeed, stigma is a good example of socially constructed avoidance of a particular group of people. Stigmatization from the standpoint of SI is linked to abuse of power and control in society, and stigma itself cannot exist without society. Relationships within society, which are to a great extent defined by power differentials, maintain existing inequalities (Bos, Pryor, Reeder, & Stutterheim, 2013). Structural factors discussed in earlier chapters create this power differential (Link & Phelan, 2001); therefore stigmatization cannot be viewed in isolation from the broader context of structural violence. Social structures emerge from the actions of individual selves. For example, if self-stigma, which results from internalization of HIV stigma, is revealed and identified by society, it reciprocally boosts stigmatization in the community, thus creating a vicious circle. However, I see that one of the possible solutions to breaking this circle is to empower PLWH and provide them with a safe environment for disclosure.

According to identity theory, making meaning out of what is happening and transferring it to society is made possible through language (Stets & Burke, 2003). Thus, it is extremely important to be very precise and accurate with the language used in the HIV field. For instance, even though from a medical standpoint people who test positive for the HIV antibody test can be called HIV-positive, or HIV-infected, the majority of affected people prefer to be called "people living with HIV" (UNAIDS, 2015a,b) to reflect that having HIV is one aspect of their lives, but it does not define their lives. In order to avoid perpetuation of stigma in this theses, two guidelines were used to choose the most appropriate terminology in terms of HIV: *UNESCO (2006) Guidelines on*

Language and Content in HIV- and AIDS-Related Materials and *UNAIDS (2015)*

Terminology Guidelines. Language is very powerful, therefore instead of using terms

such as "injecting drug users," "promiscuous," "high-risk population," "sharing," "risk of

contracting HIV," or "unprotected sex," I use "person/people who inject(s) drugs,"

"having multiple partners," "key populations," "use of contaminated injecting

equipment," "risk of acquiring HIV," and "condomless sex," respectively. I believe that

putting emphasis on a person instead of his or her status and acknowledging people's

choices have the power to change negative symbols attached to previously used

terminology. Indeed, probably no chronic illness is as full of symbols as HIV is. A person

living with HIV, HIV itself, the illness, and even HAART became symbols.

Embedding these symbols in the self creates a number of implications for the

social lives of PLWH; especially devastating is the experience of PLWH right after

diagnosis, when they face issues in the verification of self, thus causing additional stress.

As a consequence of the diagnosis, the desire to avoid labels is the main barrier to

seeking support and treatment (Green, 2009). According to Goffman's (1963) theory of

lost identity, the negative, stigmatizing symbols of HIV illness, in fact, replace an

infected person's identity.

Erwin Goffman (1963) defined stigma as the possession of some undesired

differentness from all other people. It has been recognized as a complex socially

constructed phenomenon that puts PLWH at the margins of society through varying

social, economic, and political processes (Mahajan et al., 2010; Scambler & Paoli, 2008).

Stigmatization is a process, and Green (2009) defined trajectories of stigmatization,

which consist of the following phases: (a) labelling of noticed differences; (b)

stereotyping (meaning the use of labels that have embedded negative associations or connotations); (c) othering (creating clear differentiation between *us,* those who are *normal*, and *them,* those who are *abnormal)*; (d) loss of status, leading to the devaluation of an individual by *society* and her- or himself; (e) discrimination, causing exclusion from social life; and (f) the creation of an "othered" power differential.

However, HIV stigma is unique due to its symbolic contamination, since people try to avoid PLWH even when the situation poses no danger for acquiring HIV (Green, 2009). HIV infection is an even more stigmatized condition when compared to other chronic infectious diseases, such as hepatitis C (HCV) infection (Pecheny et al., 2007). This attitude towards the HIV illness can be explained by the false perception of the possibility of acquiring the virus during habitual activities, such as hugging, kissing, shaking hands, formed in the early years of the HIV epidemic when little was understood from either clinical and epidemiological perspectives. It also relates to (a) the impact of some of the early, and not well-thought-through, mass media portrayals; (b) the still-persistent view of HIV infection as a lethal condition by people who have little, no, or poor education on the topic; and (c) the perception of *responsibility* for acquiring HIV.

Speaking of the latter point, during the initial phase of the HIV epidemic, popular culture divided all PLWH into two categories: (a) "innocent," consisting of children and those who contracted HIV through blood transfusions; and (b) "guilty," those who acquired HIV through sexual behaviour, gay and bisexual men, PID, and sex trade workers (Green, 2009). As stated by Green (2009), during interviews conducted in 1990, PLWH emphasized the devastating effects of stigmatization by saying that the stigma was much worse than the virus. Indeed, with the development of new antiretroviral drugs

and current changes in treatment guidelines, life as a person living with HIV in a country

that provides universal access to health care can be quite similar to that of a person who

does not live with HIV, with only one difference—the need to take antiretroviral drugs.

However, metaphorically speaking, there is no pill to "treat" the sociological

consequences of having a chronic disease with a 30-year history of stigmatization.

Therefore, people still see the association of HIV infection with norm-violating

behaviours, such as homosexuality, drug use and sex work (Bos, Schaalma, & Pryor,

2008; Lyimo et al., 2014; Pecheny et al., 2007).

   Types of stigma towards PLWH. Herek (2014, p. 123) identified several types of

stigma: structural, enacted, felt, and internalized or "self-stigma." Structural stigma is

found within laws, policies, and practices serving as barriers to PLWH functioning

effectively within an ideological system. Enacted stigma takes a variety of forms,

including avoidance, shunning of voluntary or involuntary disclosed PLWH, and physical

attacks (Herek, 2014, p. 124). It also includes service denial and isolation and exclusion

from social life, which affect the physical and mental health of PLWH (Lyimo et al.,

2014). Felt stigma relates to feeling shame and fearing manifestations of enacted stigma

(Green, 2009). Because of the fear of disclosure and discrimination, and the perception of

the likelihood of enacted stigma, PLWH are very selective in determining to whom they

disclose (Herek, Saha, & Burack, 2013). The interconnectedness of felt stigma and

adherence to antiretroviral medications is also important to note. According to Sankar,

Luborsky, Schuman, and Roberts (2002), felt stigma prompts selective medication

adherence. In an attempt to forget about their illness, and to distance themselves from

their HIV infection and from being objects of stigma and prejudice, women in this study self-reported missing doses.

Self-stigma is the result of the incorporation of negative perceptions of HIV in the self (Joffe, 1999) and leads to cessation of social contact, blaming, self-devaluation, and, accordingly, reinforcement of the societal stigma (Green, 2009). More than 50% of ALWH illness felt extremely uncomfortable around people who were discussing HIV in a negative way (Petersen et al., 2010); thus, these findings might serve as an approximate estimate of the scale of internalized stigma. Lyimo et al. (2014) showed that voluntary disclosure predicts self-stigma. Despite the cross-sectional design and suboptimal consistency of the scales used, knowledge about the relationship between openness in HIV status and self-stigma is important, as it shows the necessity of creating a safe environment in which newly diagnosed PLWH can disclose.

Lost identities of PLWH. The self is made up of different "interdependent and independent, mutually reinforcing and conflicting parts" (Stryker & Burke, 2000, p. 286), or identities. These multiple identities are ranked by the roles one plays (Stryker, 1980; Stryker & Burke, 2000). "With self thus specified . . . the higher the salience of an identity relative to other identities incorporated into the self, the greater the probability of behavioral choices in accord with the expectations attached to that identity" (Stryker & Burke, 2000, p. 286). In the manipulation of symbols, multiple identities create value and thus increase the likelihood that they will be activated in certain conditions (Stryker & Burke, 2000). Because the self can be realized only through social interactions, and most PLWH try to isolate themselves following diagnosis (Holtz et al., 2012), the process of losing different identities such as that of being a mother, father, friend, or partner

46

becomes difficult to stop. Psychological interventions should be directed at bringing back lost roles and identities as having multiple identities may play a positive role for the self (Stets & Burke, 2003). Moreover, consistent with the salience hierarchy, identities accompanied by negative feelings should be brought up less often than identities associated with positive feelings (Stryker, 1980).

Baumgartner (2007) has researched the impact of HIV on the self of PLWH. According to her extensive research, incorporation of the identity of a person living with HIV begins right after diagnosis and takes time. Incorporation of a new identity is a process that consists of four components: diagnosis, a post-diagnosis turning point, immersion into the HIV community, and integration (Baumgartner, 2012a). As the author stated, incorporation of the identity of living with HIV illness depends on the time since diagnosis; participants in her study fully adapted and integrated this new identity after 7-16 years of living with illness, and the saliency of this identity decreased over time. The incorporation process also depended on the state of health; feeling unwell made the identity of living with HIV more prominent. Although, as Baumgartner (2012b) noted, some researchers point to the influence of age of people suffering from a chronic condition on their acceptance of the disease, it does not seem to be the case either in the current research project, or in Baumgartner's (2012b). Baumgartner (2012a) also showed that race and class affected the experience of living with HIV and the incorporation of a new identity by limiting access to treatment and access to information regarding HIV.

This new identity of a person living with HIV "influences the development of how [PLWH] conduct themselves in terms of sex and relationships" (Baumgartner & Niemi, 2013, p. 14), thus explaining the shift in sexual practices and choice of partners.

47

As Baumgartner and Niemi (2013, p. 14) stated, "future actions concerning sexual encounters or relationships seem to be based upon this new identity, which is representative of the centering of the HIV/AIDS identity." Indeed, these authors see the identity of living with HIV as central, with other identities dependent upon it. This phenomenon of identity centrality is unique to HIV illness, as it is not described for any other chronic infectious illnesses (Baumgartner, 2007).

When discussing the symbolism of HIV infection, self-concept should also be mentioned, because it explains the reciprocal relationships between stigmatization and coping strategies that PLWH use. Self-concept "is based on our observations of ourselves, our inferences about who we are, based on how others act towards us, our wishes and desires, and our evaluations of ourselves" (Stets & Burke, 2003, p. 5). Thus, one's self-esteem is predominantly derived from others' views of us; the reflected appraisal process is focused on this interconnectedness (Gecas & Burke, 1995). In terms of identity theory and self-concept, it becomes explicit that the source of perceived stigma might be hiding in the fact that "our self-concepts are filtered through our perceptions and resemble how we think others see us" (Stets & Burke, 2003, p. 5).

The crucial importance of social support can also be explained with the help of SI (Stryker, 1980). Commitment to the identity of PLWH with self-stigma is dependent on the number and importance of stigmatizing people around PLWH. "The stronger or the deeper the ties to others based on a particular identity, the higher the commitment to this identity" (Stets & Burke, 2003, p. 13). This point underlines the importance of having supportive people, or partners, who would help to rebuild the self of PLWH by bringing back identities of a friend, a partner, a father/mother, and many others.

Qualitative Design

Qualitative methodology was chosen, because it is "a situated activity that locates the observer in the world" (Denzin & Lincoln, 2013, p. 6). The value of qualitative research lies in its ability to change the world by using a variety of data-collection methods, which can reveal perspectives and experiences of different people. This was one of the main reasons for me to employ qualitative methodology. I truly believe that relationship aspects of living with HIV are studied insufficiently, and many relevant and interesting research questions remain unanswered because of the sensitive matter of discussions. Also, as Denzin and Lincoln (2013) stated, qualitative methodology acknowledges the complex interconnectedness of the phenomenon under study; therefore, I saw it as the only one capable of unravelling the many aspects of living with HIV.

Qualitative methodology has been widely criticized by those researchers who support positivist and post-positivist approaches, but as Denzin and Lincoln (2013) justified, qualitative research is a separate field of inquiry, with its distinctive methods and approaches. This methodology is widely used by health researchers whose primary interest is the experiences of illness, the influence of chronicity on the quality of life, and the aspects of *living* with disease, as opposed to those researchers who focus on the disease itself, thereby "backstage[ing] the patient's experience'" (Morse, 2013, p. 379). Another aspect that I find fascinating is the ability of qualitative research to study a dramatic change on selfhood and being. As Morse (2013) pointed out, qualitative research is also about educating health care professionals, their families, and patients themselves about beneficial changes in the lives of the latter.

Good qualitative research requires adherence to principles identified by Patton (2015, pp. 46–47). These principles include emergent design flexibility, purposeful sampling, qualitative data, personal experience and engagement, empathic neutrality and mindfulness, dynamic system perspective, inductive analysis and creative synthesis, holistic perspective, context sensitivity, and reflexivity.

Narrative Approach

Narrative research is rooted in SI traditions, thus allowing researchers to approach "the problem of the analysis of lived experience, represented in words rather than numbers, for the benefit of social science understanding" (Wertz, Charmaz, & McMullen, 2011, p. 225). The stories drawn from participants reflect their meaning-making process with regard to the social context in which they are embedded; narratives allow for the exploration of how people integrate their experiences, select what should be told, and make links between different aspects of their experiences. Therefore, so-called narrative truth is relative and is a product of people's understanding of their experience, rather than a set of facts of what happened in reality (Wertz et al., 2011). Moreover, Hendry (2010, p. 73) called narrative research "an epistemology of doubt" and highlighted that one of the domains that it can address is the symbolic, along with the physical (i.e., science) and the metaphysical (i.e., sacred). Therefore, symbolic narratives focusing on the understanding of human experience require an understanding of symbol systems— "spaces in which humans have attempted to represent their understanding of lived experience and to make meaning" (Hendry, 2010, p. 76).

Although phenomenology, another possible methodology for the research question, also assumes that articulation of words and language is a tool for exploring the

lived experiences and emphasizes the interpretive power of people's stories, narrative

research has certain advantage, which made it more reasonable for this study. For

example, narrative research, in contrast to phenomenology, does not demand formalizing

a common method; it is freely compatible with different philosophical, literary, social,

and theoretical traditions (Wertz et al., 2011). Other advantages of narrative research

include the relative ease of inviting people to narrate their experiences, of gaining thick

description, of gaining in-depth understanding of participants' experiences, and the high

probability of obtaining truths when listening to the stories (Niekerk & Savin-Baden,

2007). It also offers exploration of internal psychological mechanisms and reveals

nuances of experience suitable for understanding related situations (Wertz et al., 2011).

Research Setting

Research projects cannot happen without sufficient collaboration between

students, who are starting their careers, and experts in the field. Besides providing her

knowledge and expertise, my research supervisor helped to initiate conversations with the

directors at several ASOs. Thus, prior to recruiting participants, in July 2015, I talked to

the Director of Programs and Services at a local ASO in one Western Canadian city, who

connected me with a Public Health Nurse and a Medical Officer of Health working with

PLWH at one of the sexual health clinics in the city. These people shared with me their

advanced understanding of the population of PLWH with whom they work. Also, I

discussed my research project with a professor at a local university, who has devoted her

research career to studying various aspects of living with HIV. These conversations

helped me to understand the setting in which PLWH, including the participants in this

project, are embedded.

The name of the city where the research took place, as well as the name of the agency where the recruitment was conducted, are concealed for the sake of protection of participants' identities. The population of the city approaches 1 million, and the city itself is considered to be one of the largest cities in Canada. It is a multicultural centre not only of the province, but of Canada as a whole. Only slightly more than 50% of all residents speak English, while others speak French, Cantonese, Tagalog, Spanish, Panjabi, and many other languages. Overall, there are more than 60 ethnic and cultural groups. However, as with any major urban centre, the city has to deal with issues that are related to an increase in the number of PLWH. As mass media and others emphasize, poverty in the city is on the rise, which adds a tremendous burden of food insecurity and homelessness. Understandably, poverty leads to poor health (Mikkonen & Raphael, 2010). Moreover, living on the streets is full of struggles, and one of them is drug addiction. The thing that provides optimism is an existing initiative to open supervised injection sites (Lunn, 2013) that would reduce overdoses by drug addicts and save lives ("Bill Adding New Safe-Injection Requirements," 2015; Eggertson, 2013).

Methods

  Recruitment. After obtaining Human Subject Research Committee (HSRC) approval (see Appendix A) from the University of Lethbridge in July 2015, purposive sampling was utilized as one of the strategies to recruit participants. In order to better situate myself within the setting and to get a chance to talk to and recruit prospective participants, I volunteered for a local ASO for five months between August and December 2015. This ASO is focused on enhancing lives of PLWH and those affected by HIV illness, developing HIV-focused resources for community, and supporting the

principles of harm reduction. It is involved in various projects that facilitate creating supervised injection sites and collaborating with other agencies in the city. Therefore, I benefited not only from the opportunity to communicate with the clients of the ASO, but also learned more about the most pressing social issues related to treatment and prevention of HIV. Volunteering at the ASO also gave me the opportunity to exchange opinions with educators and social workers on the struggles of implementing various programs targeting prevention of new HIV cases. This ASO provided enormous support for my project and served as the only recruitment location. My initial intention had been to recruit a heterogeneous group of participants, using several centres across the province. However, because of financial and time constraints, I chose to work through this one agency only. Also, a reader should keep in mind that participants in this research project comprised mainly people who attended the ASO to receive not only HIV-related or harm-reduction services, but also to get help with housing and free meals.

Two social and outreach workers at the ASO, to whom I explained the goals of the research project and inclusion criteria, introduced the research project to eligible participants and encouraged them to share their voices. Also, several participants learned about the research project from their friends who had already participated in the project. Other recruitment strategies, such as distributing flyers (see Appendix B) during a fundraising campaign, and posting announcements (see Appendix C) in the agency's monthly newspaper, website, and Twitter accounts, were performed in tandem with volunteering for the ASO, as the assumption was that those PLWH who had access to the Internet would represent another group of PLWH. However, none of them, to my knowledge, provided the project with participants. These unsuccessful recruitment

strategies emphasized the importance of involving local agencies and support workers in the recruitment of participants. Meeting times with prospective participants were arranged according to their availability and convenience.

Data collection. Data were collected through semi-structured interviews with 10 participants who were clients of the ASO. Written informed consent (see Appendix D) was obtained after a thorough explanation of the research process and before starting interviews. Interviews were audio-taped with the consent of all participants and lasted from 45 to 70 minutes. The participants received an incentive of $20 cash as compensation for their time and transportation expenses. Because the research question was: "What is the experience of heterosexual PLWH in terms of partner-seeking in a Western Canadian city," the interview guide consisted of questions regarding the experience of living with HIV, stigma manifestations, and relationships and probing questions to facilitate discussion (see Appendix E). The interview guide was developed based on an in-depth study of available literature. The guide was then reviewed by committee members with different areas of expertise, which included nursing, addictions counselling, and couple counselling. Following the interviews with each participant, the interview guide was reviewed for clarity in terms of language.

I felt that after the 8th interview no new themes or data emerged, and decided to conduct two other interviews to make sure the point of data saturation was reached. As Fusch and Ness (2015) suggested, in order to conclude that a researcher has reached the point of data saturation, data should be rich (i.e., detailed and multi-layered) and thick (i.e., large amount of data obtained in the process of data collection). It is necessary to add that the same questions (as only one additional question was added to the interview

guide) were asked of multiple participants. As Guest, Bunce, and Johnson (2006) noted, if a researcher is changing the interview guide significantly following each interview, the point of data saturation would become a moving target.

A demographic form (see Appendix F) was included with the interview guide and included questions about gender, age, employment, occupation, racial and ethnical background, and time since diagnosis. Field notes were also taken before and immediately after each interview. I found that keeping a research log was very helpful. Although it takes time to develop a habit of writing thoughts down instead of just thinking and acknowledging them, the journal played an important role when I had a chance to go back to it after some time to follow my flow of thinking and understanding.

One of the downfalls of qualitative research is the necessity to find a balance between flexibility and structure in the process of data collection. The ability to do so is greatly influenced by a researcher's experience and observation during data collection (Morse, 1990). Although, as mentioned above, I did not make any significant changes to the interview guide except to clarify the language for the benefit of participants' understanding, I was very flexible in the order of asking the questions that comprised the interview guide, since every participant was different in terms of the choice of what they wanted to discuss in depth and what they preferred to touch only slightly. In order to facilitate interviews, I also asked additional questions that described stories told by other participants, such as "Some people say that their lives have changed since the diagnosis. How does that fit for you?" Another technique that I used to balance flexibility and structure was to contact people with follow-up questions in order to clarify certain information or answer questions that emerged in the process of transcription and

preliminary analysis. This technique appeared to be very powerful in the process of co-

constructing narratives told earlier.

Analysis. I transcribed the audio-taped interviews verbatim using Express Scribe

software (http://www.nch.com.au/scribe/). Afterwards, transcripts were cleaned of

utterances and disfluencies. The data were then analyzed following traditions of narrative

research. According to Riessman (2008),

> Data [in narrative research] are interpreted in light of thematics developed by the
> investigator (influenced by prior and emergent theory, the concrete purpose of an
> investigation, the data themselves, political commitments, and other factors).
> There is minimal focus on how a narrative is spoken (or written), on structures of
> speech a narrator selects, audience (real and imagined), the local context that
> generated the narrative, or complexities of transcription. (p. 54)

Thus, "language is viewed as a resource, rather than a topic of inquiry" (Riessman, 2008,

p. 59). The theoretical framework for this research project, which included Goffman's

(1963) and Stryker's (1980) theories, was a prism through which I looked at the emerging

themes.

Squire (2003) explained the particular importance of narrative analysis in her

research devoted to the place of HIV in human relationships. According to the author,

> Narrative analysis allows attention to the personally and culturally significant
> story forms that people produce. It also gives access to discursive sequences of
> talk, as people move from one form of language to another, that a discourse
> analysis might pass over. In order to best display the results of this analysis, the
> article concentrates on particular interviews in which long or linked narrative
> sequences occur, rather than sampling elements from a broad set of interviewees'
> stories. (p. 76)

Riessman (2008) identified a study done by Williams (1984) as one of three

examples of working with narrative accounts in narrative research tradition. I strictly

followed the steps described by Williams in my analysis. Williams conducted fieldwork

based on semi-structured, tape-recorded interviews with 30 people suffering from a

chronic disease (rheumatoid arthritis) for at least five years. A variety of themes relevant to the experiences of living with the disease appeared during the interviews. Quotations were used extensively in order to present experiences from the narrator's perspective. I also found inclusion of extensive quotes from participants to be crucial. They are included throughout the findings section of this thesis, guided by rationale justified by Yang et al. (2013). Using quotations, according to Yang et al., is necessary to present the participant's individuality, reflect participants' voices in the most direct way, provide tangibility of results, and ensure research quality.

Williams (cited in Riessman, 2008, p. 57) defined narrative as "the biography as a whole, and specifically the story of the illness that unfolds over the course of a single interview" (p. 57). Moreover, Williams did not fracture biographical accounts into themes, but rather located relevant episodes in a chronological order for all the interviews. After this had been done, Williams identified and named assumptions. Later, every assumption was represented using a quote, and general patterns were compared using theoretical assumptions clarified before.

Although attention to local context in thematic narrative analysis is minimal, some context that shapes personal accounts can be included for the reader's better understanding of the narrative. While volunteering at the ASO, I had a chance to talk to almost all of the participants before and after the interview, getting to know their stories and asking questions that were missed during interviews. Volunteering also gave me an understanding about the clients at this ASO, generally. The sample of the participants by no means represents the broader population of PLWH in the city, and this assumption should be taken into account when interpreting the findings.

Ethical considerations. Ethical considerations have to be reviewed especially carefully for qualitative research, focusing on issues of consent, privacy, and confidentiality of participants (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada [Tri-Council], 2014) and safety protocol to ensure protection of me as a researcher (see Appendix G). In this section, I present the potential benefits and risks to participants, as well as the ways of addressing the core principles of the 2014 *Tri-Council Policy Statement*.

Benefits and risks. A direct benefit for the participants included receiving incentives, which consisted of 20 CAD in the form of gift cards. The importance of participants' voices was emphasized while informing them about the research, signing an informed consent form, and expressing appreciation for their participation at the end of the interviews.

Nevertheless, I acknowledged that there were potential, although minimal, psychological risks, arising from the sensitivity of the topics mentioned in interviews, and social risks, involving potential involuntary disclosure by coming to the ASO offices. One participant felt distressed. Every time I noticed that he was struggling with answering my questions or he started crying, I asked him whether he wanted to stop the interview. However, he clearly expressed the desire to continue it. After we decided to finish and the tape recorder was turned off, he told me that he felt much better after speaking up. Indeed, I found that for a person isolated to the extent that this participant was, an interview can have significant therapeutic meaning. For this participant, telling his story to a complete stranger (as he perceived me) was much easier than disclosing to

the support worker whom he saw on a regular basis. The risk of indirect disclosure was easy to address because the ASO building has several entrances, one of which is hidden. Therefore, clients can enter without being noticed by passers-by.

Respect for the person. All participants were provided with full, clearly stated, jargon-free information about the research. If they satisfied the inclusion criteria and expressed the willingness to participate in the study, they were offered the opportunity to familiarize themselves with the written informed consent form (see Appendix D). I thoroughly explained to the participants that informed consent is a dynamic, negotiated, and ongoing process. I also anticipated and prepared for the possibility that some participants might want to have a support person present during the interview; however, all of the participants felt comfortable to discuss the issues with me only.

Concern for welfare. All informed consent forms were put in sealed envelopes immediately after signing, to protect the anonymity of the participants, and were stored separately from the research data. At the beginning of the interview, participants were asked to pick a pseudonym to protect their identity. In addition, the following principles of data protection were applied: (a) contact information and names of the participants, in either paper or electronic formats, were stored separately from research data; (b) password protection of all electronic documents that might imply the possibility of a confidentiality breach was employed; (c) an encrypted tape-recorder was used; and (d) material was shared securely with my supervisor by granting her access to the password-protected electronic file. Only pseudonyms are used in the thesis and publications.

Principle of justice. This core principle states that all participants must be treated fairly and equitably. In order to diminish the imbalance of power between us, participants were provided with thorough explanations of the interview process and given the opportunity to ask any questions dealing with the research. They were invited to decline to answer questions and to withdraw from the study at any time without prejudice or penalty.

Trustworthiness. Lincoln and Guba (1985, p. 290) suggested the term *trustworthiness* to determine whether "the findings of an inquiry are worth paying attention to" (p. 290). Trustworthiness combines four major criteria, which have parallels with terminology used in quantitative research (Bryman, Bell, & Teevan, 2012): credibility, transferability, dependability, and confirmability. Strategies and the timeline for these four criteria applied in this research project are presented in Table 1.

Table 1. *Trustworthiness Criteria and Ways to Ensure Them*

Criterion	Processes to Ensure a Criterion	Definition of the Criterion	Specific Actions and Timeline
Credibility	Prolonged engagement	Allowing a researcher to check perspectives and participants to get used to the researcher (Pitney, 2004).	Volunteering for the ASO since August 2015. Participation in a variety of workshops, such as Dynamics HIV 101, Building the Circle, HIV in ABC communities, held by the ASO.
	Theory triangulation	Using different theoretical models to make sense of the same set of data (Denzin, 1970).	Two different theories—identity theory by Stryker (1980) and theory of spoiled identities by Goffman (1963)—were used to explain the phenomenon of interest.
	Member checking	A strategy "whereby data, analytic categories, interpretations, and conclusions are tested with members of those stakeholder groups from whom the data were originally collected" (Lincoln & Guba, 1985, p. 314).	At the end of each interview, I clarified for those participants who asked, that the way I would write about their experiences would depend on the general conclusions about the whole group (Clandinin, 2006). I offered to send participants a summary of their interview right after the interview was conducted and general findings from the study before writing up an article for publication. However, none of the participants were interested in receiving a copy of either of these documents.

61

Criterion	Processes to Ensure a Criterion	Definition of the Criterion	Specific Actions and Timeline
			Table 1 continued
Credibility (cont'd)	Reflexivity	Being reflexive is the key concept for researchers in qualitative studies, meaning that "the inquirers admit the value-laden nature of the study and actively report their values and biases as well as value-laden nature of information gathered from the field" (Creswell, 2007, p. 18).	I increased the validity of the study by taking detailed field notes before and after interviews with each participant. The field notes reflected my feelings about interviews, emerging thoughts, new concepts, and my understanding of how different concepts interact.
Transferability	Thick description	Thick, or dense, description is a strategy, focused on providing the reader with information about the setting and the lived experiences of participants.	I provide "dense background information about the informant and the research context and setting to allow others to assess how transferable the findings are" (Krefting, 1991, p. 220).
Dependability Confirmability	Audit trail	Attracting my supervisor "to follow through the natural history or progression of events in a project to try to understand how and why decisions were made" (Krefting, 1991, p. 221).	All records of the research phases are available to create a detailed audio trail (King & Horrocks, 2010), thus documenting the flow of my thinking.

Limitations

There are several limitations of narrative research relevant to this study. First of all, in order to do research of a high quality, a researcher should immerse him- or herself in the context of the participant's life (Creswell, 2007). Although I volunteered for quite a long time, if I had been given more responsibilities (e.g., providing support work for the clients) at the ASO, it would have been beneficial for the project. Secondly, the participant's experience will never be free from the researcher's interpretation (Bell, 2002), and the insufficiency of collected information cannot "give a true picture of the life stories of the participants" (Liamputtong, 2013, p. 136). Another issue is the crucial importance of the reflexivity of a researcher, since my assumptions and background inevitably affected the way I presented the participants' stories. However, inclusion of extensive quotes and keeping a research log helped to address reflexivity. Finally, this research project lasted only a few months, which made it impossible to know whether or not partner-seeking strategies change over time.

Summary

In this chapter, I demonstrated the rationale for choosing narrative research as the most approach suitable for answering the research question "What is the experience of heterosexual PLWH in terms of partner-seeking in a Western Canadian city?" I explained where I stood in the research process and why SI was the philosophical paradigm that played a crucial role in interpreting the findings. The guiding theoretical framework was also introduced, combining Goffman's (1963) theory of spoiled identity and Stryker's (1980) identity theory. Several limitations were outlined in this chapter and can be

addressed by researchers who choose to continue exploring sensitive issues that PLWH

encounter throughout their lives.

Chapter Four: Findings

In this chapter, I present the findings of this research project in which I explored the partner-seeking experiences of heterosexual PLWH. I begin by explaining demographic characteristics of the participants. I then move on to cover two main aspects of participants' lives: (a) the experience of receiving the diagnosis and subsequent life changes; and (b) heterosexual relationships within the context of living with HIV.

Demographic Information

In total, 10 participants agreed to share their experiences by participating in the research project. The age of the participants varied from 40 to 53 years old. The number of years since HIV diagnosis varied from 2 to 18 years. Five of the participants identified themselves as Aboriginal, three as White, and two as Black; this ethnicity breakdown was borrowed from the recent PHAC (2015a) surveillance report. Detailed information can be seen in Table 2. Participants represent the agency's client base, but do not necessarily represent the broader population of PLWH living in the city where the research took place.

The combined demographic report of the ASO gives a good understanding of the population characteristics of its clientele. Out of 358 registered clients, 60.6% are males, 39.1% females, and 0.3% transwomen. Almost 70% of registered clients are between 41 and 60 years old. Around 60% preferred not to answer the question about their marital status, while 31.3% indicated they are single, 6.1% live with a common law partner, 1.4% are married, 1.4% widowed, 1.1% separated, 0.8% divorced, and 0.3% have a domestic partner. It is hard to make any assumptions about real percentage of those people who are single, since the majority did not answer the question about marital status. The ethnicity

of ASO clients reflected 47.9% are Aboriginal, 19.5% Western European, 14.2% "other Canadian," 9.1% African, 3.4% Eastern European, 3.4% unknown, 1.4% Latin American, 0.8% South Asian, and 0.3% East Asian.

Table 2. *Participants' Demographic Information*

Pseudonym	Age	Gender	Employment status	Racial/ethnic background	Year of diagnosis
Abdul	53	Male	Full-time	Black	2000
Rick	48	Male	Unemployed	White	2009
Bill	48	Male	Unemployed	Aboriginal	2013
Steve	51	Male	Unemployed	White	2005
Sara	49	Female	Unemployed	Aboriginal	2008
Moe	49	Male	Unemployed	Aboriginal	2000
Carnie	51	Male	Part-time	White	1997
Mike	52	Male	Part-time	Black	2000
Archie	50	Male	Part-time	Aboriginal	2000
Liz	40	Female	Unemployed	Aboriginal	2006

In keeping with the noted heterogeneity of participants, the tone of participants' narratives varied quite significantly. There are diverse perceptions of HIV illness as well as differences in life priorities, and willingness to discuss sensitive topics. Participants who perceived HIV as an obstacle to "normalcy" gave different answers than those who thought of HIV illness as just another chronic condition that they should "keep in mind" and "move on." In narratives where HIV was central, participants talked in depth about stigma, while in the narratives of those for whom HIV illness was just another issue to

66

deal with, one could hear lengthy discussion of coping with drug addiction and looking

for a safe environment where they would feel accepted by others. Moreover, while some

participants felt comfortable going into depth to describe partner-seeking experiences and

experiences of past relationships, others chose to focus at greater length on the details of

what led to their behaviour that posed risk in terms of acquiring the virus.

Life after Receiving the Diagnosis

Relationship challenges can hardly be imagined without a broader context of

living with HIV illness. As one of the participants said, "I knew . . . I entered [a] different

world" (Mike). A discussion of relationships and the challenges they pose cannot be full

without acknowledging the perceived reality of this "different world." Moreover, a

discussion of the experiences of receiving the diagnosis of HIV infection and living with

this chronic condition has the potential to reveal the influence of structural factors and

helps to contextualize participants' experiences of seeking partners.

HIV diagnosis: "The light for me then turned dark." Receiving a chronic

illness diagnosis unavoidably changes one's attitude, health, and in some cases, lifestyle.

A diagnosis of a chronic infectious disease which is still highly stigmatized in society is a

heavy burden. It affects the individual's social life and emotional state, which can be seen

in the following quotes. For example, when answering whether he was in the same

depressed state of mind as he is now before receiving the diagnosis of HIV, Bill said

> Well, it wasn't [this way]. Most definitely not. I tried to be happy. I was always,
> you know, upbeat, always recognizing things around me, being formal and very
> nice to people, and now. Not just from having [HIV], but from being here [at the
> ASO] even and around these guys [ASO's clients]. It's just. It went peeeeew
> [showing a gesture with his hand]. Very down.

From his words, both having the virus and being associated with the community of

PLWH mean that life and he himself will never be the same again. Liz also noted rapid

changes in her emotional state:

> I was the funny person in my family and my circle of friends. After the diagnosis, I was very serious all the time. And just recently that part of me is coming back, when I make people laugh. Like I'm a very humorous person, and I lost that. I lost that humour, I lost that outgoingness that I had. It's coming back now, my voice. . . . I'm tired of using, and I'm tired of the anger, it's engulfing you. I don't want to end up in jail. I don't want to go black out and do something I regret.

Although she is slowly returning to that sense of normalcy and being herself, the time it

took for her to process all those changes shows just how profound they can be. Rick notes

a significant shift in his social life, from being very socially active with women to being

out of society. His inability to be completely open and honest because of HIV contributed

to his decision to stop seeking a relationship:

> When I was younger, my nickname was Stud. I would go out with my friends to bars and discos and everything, right? . . . I was less shy to go dance or to go and see girls, right? . . . I was very social. . . . [I: What about now?] Well, that's in a sense the disease. Like it's not the same because you don't feel safe, you know, right? You don't feel safe. [I: What do you mean by feeling safe?] I don't know, in French I'd say [speaking in French] put your things on the table, like, everything.

Thus, the reader can see a transition between being happy, outgoing, humorous, cheerful

people, and being profoundly lonely, with loneliness being "the hardest thing" in living

with HIV (Archie). The ASO was perceived as a safe place where one could avoid this

profound loneliness. Before immersing into the psychosocial issues that participants in

this project experienced, I would like to explore why participants decided to get tested,

and how they reacted to receiving the diagnosis, a turning point in their lives.

 The very decision to go and get tested is stressful, and receiving a positive HIV

diagnosis is such a dramatic event that some participants still remembered the exact date

and time of it. Some participants in this research project clearly identified that the

decision to get tested was made in recognition of the behaviour(s) that predisposed them

to acquiring HIV (e.g., condomless sex with multiple partners, injecting drugs using

contaminated equipment). Some participants seemed better prepared than others to

receive and accept the diagnosis. As Abdul noted, he had straightforward reasons to

suspect his HIV infection. A clear image of several former partners dying from AIDS

was so strong that it gave him a good understanding that he might have been infected

with the same virus.

> They asked me questions: "Why do you want test?" I told them, "They had died of HIV, and we had sex, so I want to know my status and get a chance of getting medications before it is too late." They said, "Okay." They drew the blood, took two for testing, and waited for like 15 minutes, then they brought the results. And they said, "Oh, yeah, it's true. You are HIV-positive." I said, "Yup. I knew it." I was strong.

One distinctive feature of Abdul's narrative is that his willingness to get tested can be

explained by a difficult economic situation in his home country in which he was tested

and started treatment prior to coming to Canada and which has still very limited access to

antiretroviral therapy. He was the only participant who was willing to start therapy as

soon as possible, while the rest needed time to prepare for HAART initiation:

> I have seen a lot with my eyes, hearing a lot what life is, so finding out that one is HIV-positive didn't scare me a lot. And it scared me a lot before there was ARVs [antiretrovirals], but since the ARVs, I got strong and said, "I've seen people live who is HIV."

From a SI perspective, HAART symbolized a chance for—and right to—life for Abdul,

and there were no doubts about whether to take it or not; he has seen people who died

before treatment became available and those who did not lose their lives because of

HAART. HAART also gave some participants the feeling of "normalcy" by making it

possible to meet potential partners and avoid legal prosecution by achieving an undetectable viral load: "You know you're undetectable, and you follow your health thing and you are healthy, use condom. There's no reason to be worried about" (Rick). In contrast, for other participants HAART was related to the feeling of being "invaded by [medications]" (Sara). Therefore, for some participants it took anywhere from several months to years to make a decision to start HAART, despite the fact that it is fully covered by provincial health care systems.

Carnie also critically assessed his risk of acquiring HIV, and as a result, the fact that he had HIV did not shock him:

> With the way I lived my life—yeah [I expected positive test]. … And I got tested, and nurse said to me, "Why are you getting HIV test?" "Because I've been promiscuous." "How many women have you slept with?" And I said, "Hundreds." And she just looked at me like I'm fucking lying to her, but it's true.

Nevertheless, although Carnie was aware of the risk his behaviour posed in terms of acquiring HIV, it did not make acceptance much easier. He was "going through mixed emotions—sad and angry," but, as did other men in this project, he took full responsibility for the illness he now is living with: "I lived an adventurous lifestyle, so I don't blame my HIV status." Another quote that reflects taking responsibility for acquiring HIV comes from Bill:

> There is nothing to be surprised or anything about it, because you know you have it, and you know what you've been dabbling in. There is no need to cry about it later when you know what the risks are.

However, female participants expressed clear feelings of anger towards the partner from whom they contracted HIV. Sara was certain that her partner knew about his HIV-positive status before they had condomless sex and injected drugs using the same

70

injecting equipment. She explained his non-disclosure by distinguishing traits of

relationships between two PID:

> He'd shown me that really fake trust I guess, where he'd inject me, and
> he'd pull the needle out, and he sees blood dripping my arm or something.
> He'd pick up my arm or my hand and suck it off, instead of wiping it off
> with Kleenex. So he got me more trust with blood and everything. . . .
> And, when you are in a relationship when you are in deep drug use, to
> keep that partner closer to yourself. By him, sharing [HIV] with me, it
> made him think that we were whole . . . and he gets something on me.

People draw meaning from everything that happens to them. For Sara, in the context of

relationship between two PID, trust took on a physical manifestation. Trust between two

people injecting drugs was shown to be the reason for accepting HIV-related risk. There

is a mutual agreement to share injecting equipment and have condomless sex (Lam,

2008). Moreover, seeing a man sucking Sara's blood after an injection, from her words,

was equal to saying, "I love you." Therefore, knowing that he passed the virus to her was

the worst betrayal she had ever experienced. Despite these feelings, when he came to

apologize, Sara reacted in a way she herself did not expect:

> I thought I'd hate him, but because I left him so much before it didn't matter. Like
> he came crying to me and saying that he was sorry and all this stuff, and you
> know, [what] I liked to do is put my arms around him.

Indeed, Sara's understanding and perception of intimate relationships has changed since

her relationship with that man. While using drugs, relationships centered around "keeping

[someone] close," while now, a relationship is about being "taken and loved by that

person whereas I do the same." It might also explain her unexpected reaction when her

"old man" showed up and disclosed to her. Being sober and feeling "clean" and "cured,"

she knew negative emotions toward him would not turn back time.

Although Liz still does not know whether her ex-partner was aware of his HIV-positive status before engaging in condomless sex, she lost her trust in him immediately after receiving the diagnosis. Despite the negative feelings that have been present in their relationship ever since, she stayed with him until he almost took her life. As Liz explained, his violent behaviour was related to the feelings of guilt that "[would come] up when he was drunk. . . . He would beat me up really bad one last time. . . . I had charged him. He got charged as an assault causing [bodily harm]." Although Liz always knew getting tested would be the right decision, it was her aunt who persuaded her to make this decision. Regardless of her suspicion that she might test positive for HIV, being with her 3-month old baby while receiving the diagnosis of what she perceived to be a devastating illness was an emotionally arduous experience. Her baby and the uncertainty of her baby's future, as well as the life-threatening nature of the illness, made her "cry and cry for hours," followed by several years of heavy drug and alcohol use as coping strategies.

Disclosure made her experience even more emotionally difficult, as the first thing that Liz experienced as a person living with HIV was being shamed by her mother, which appears to be "a huge trauma to this day." Mothers, indeed, tend to be the first recipients of the disclosure of HIV status (Gaskins et al., 2012), whatever the quality of the relationship may be, as Liz's experience shows. She decided to disclose to her mother despite the history of regular beatings and verbal abuse from the person who was supposed to care for her and provide emotional support. This shows the recurrence of childhood experience and the importance of parental relationships. While limiting information and choosing to whom to disclose are the forms of exercising control to ensure protection from negative consequences of disclosure (Rouleau, Cote, & Cara,

2012), Liz was deprived of this control when her mother betrayed her trust and disclosed

her status despite pleas to keep it a secret. This act of disrespect of Liz's autonomy has

influenced not only her relationship with her mother, but also future patterns of HIV

disclosure. Currently, Liz prefers to disclose to men only, since "they are not that

gossipy."

For Rick, getting diagnosed was not only a great shock, but also a very "illogical"

thing to happen. At first, he had no understanding of how he could have contracted HIV

because he was always careful with sexual partners and drug paraphernalia; therefore, for

him, the whole situation did not make any sense. Figuring out what led to acquisition of

HIV was part of his healing process, even though he clearly recognized that it changed

nothing. The resulting self-stigma was a trigger for self-isolation. As he said, "It was like

55 months I was out of society . . . the first six months, you are like very weird kinda

thing because you think you are a virus [chuckles]." The last part of this quote shows

how a new identity is built and begins to operate. Rick noticed that the healing process,

which included acceptance of the diagnosis, took time, but at the end, he could be "fine

with that," and "you start to see and feel you are OK after all." Nevertheless, "it's still a

shock, and it always is, in a way." In other words, although the perception of stress

associated with HIV is alleviated upon acceptance, some parts of it always remain in the

lives of PLWH and are reflected in their experiences of relationship, which I discuss in

the next section of this chapter.

While all participants spoke extensively about the ongoing social consequences of

living with HIV, none expressed any concerns about the side effects of HAART or

complained about the necessity of taking medications on a daily basis. For some

participants, availability of medication was the factor that facilitated acceptance of the diagnosis:

> It's just something I live with, and nothing overly worrisome, put it that way. If I had to pay for the meds myself, I imagine I'd be worried, but because it's paid here, in [province], it's not that much of an issue. (Moe)

However, the majority of participants had to go a long way before accepting the diagnosis. Sara was diagnosed while being in jail. Being physically confined and getting the diagnosis, about which she knew little and could hardly discuss with anyone, led her to feel "kind of freaked out [and became] isolated." As Steve also noted, receiving the diagnosis in jail prevents disclosure ("you don't tell other convicts in there that you're HIV"), since jail is a dangerous environment where disclosure poses great risks. Sara did not want to hear or talk about HIV with anyone, although guards and medical personnel tried to give her the necessary information to deal with the diagnosis successfully. Interestingly, after passing through this process of isolation, heavy drug use, loss of self-esteem, and getting to a point where her viral load is undetectable, Sara feels "even more cured than [she] was before." This state of "being cured" is reflected in her openness to opportunities she never considered before, such as going to school and becoming a social worker, looking for a healthy relationship, and getting to know herself. Gaining control over her life is her "cure" from addiction and social isolation.

Archie used to express suicidal thoughts because of the shame and fear of rejection, which is quite a common experience (Henry et al., 2015) when living with a stigmatizing condition and feeling like you are at the margins of society. After receiving his diagnosis in an unprofessional way, Archie isolated himself and "had this belief that I was gonna die. I had this disease, so I was just gonna go off somewhere and hopefully go

to sleep and die my way." These misunderstandings could have been different if someone

had simply taken the time to explain at least the following simple things to Archie: HIV

is manageable, treatment is easily available, and HIV has several modes of transmission;

therefore, a person should take care not to pass the virus to other people via these modes.

Without this knowledge, he felt "less than human being. No longer useful to the world

since I couldn't make a positive contribution." Archie used avoidance and denial to cope,

tried to stop thinking about HIV, and pretended it did not exist. While these coping

strategies may work to manage short-term issues, they are not suitable for long-term

issues (Folkman, 2011). Their use can significantly and negatively contribute to the

health of PLWH; the longer they try to forget about their condition, the more advanced

the disease may become before they see an infectious disease specialist.

> *Interviewer*: And after getting diagnosis? Did it change somehow?
> *Archie*: It got worse. My lifestyle, I didn't care. What I mean by that I didn't care about myself anymore. I believed that my life is over and I was dying. So I could cope myself is to self-medicate with drugs and alcohol. Up until that point, I used, but I just used, not abused. But after I got diagnosed, I used and abused drugs and alcohol to the extent where I overdosed twice. Not right away, but over a period of time.
> *I*: Does it mean that you tried to forget about the diagnoses?
> *A*: I tried to black it out of my life, yeah, deny it.

It took Archie about six years to accept the diagnosis and start changing his life. He took

"responsibility for the disease," and currently educates people to make the positive

changes in life for which he did not have strength before.

It took Liz almost 10 years to come to terms with her diagnosis. The HIV

diagnosis and stigma influenced her to the extent that it is only now that she is learning

"how to let go the shame of it. . . . [One of her friends who also live with HIV] says, 'I

don't think you really embraced your disease yet,' and I think now I am, because I can

come up and talk about it." Now that she has started to accept the illness, Liz feels power

and the right to talk about HIV out loud. Feeling that her voice is heard made Liz realize

that HIV should not take her rights away or prevent her from being herself. However,

following the initial diagnosis, drugs and alcohol were her main coping tools. Although

Liz admitted that addiction is still in her life and affects relationships with her children

and other people, she still perceived these coping tools in a positive rather than negative

way:

> Try to look at it in a good way. [One friend] told me 'Drugs and alcohol are
> resources that help you to survive as long as you did.' And he's right. Don't try to
> look at it in a bad or good way. You are here today, you got so far. It is just
> resource. Don't be hard on yourself about it. But that's how I coped till now.

Unlike Archie and Liz and despite the initial shock and long history of drug and

alcohol addiction, Mike did not "try to escape reality by using drugs or alcohol."

Avoidance coping in Mike's words is like "chasing the dragon:" the more you try to

escape HIV, the closer it gets to you. Mike accepted the idea that he "entered [a] different

world" and managed to hold himself together using his beliefs. Spirituality is a theme

present in almost every discussion of his life with HIV. While a spiritual identity has

emerged in some participants only after getting diagnosed ("I've never been spiritual in

my life, and [HIV] got me close to God and he helped me get through it" [Carnie]),

others experienced the increase in its salience:

> The only relationship I want and act as I have is with me and my God. . . . He's
> the only one who understands. He put me here. . . . He is the one I believe who
> loves me and understands me. (Archie)

Spiritual identity influenced disclosure of HIV status; as Abdul said, "God is

rewarding me [for disclosing to partners]." He also believes that "if God wants for me to

live 70-80 years, I will live these years even though I am HIV-positive," thus underlining

the importance of spirituality and its embeddedness in every aspect of living with HIV for some of the participants. Hope for a better future and positive changes in their lives was driven by spirituality: "It's always hope. When you go to dark-dark room, you don't concentrate in this whole dark, you concentrate on that hole that has a light that's coming in. And you wanna get there." (Mike)

Many participants spoke a great deal about their education as the way to "balance HIV in the head" (Carnie) and the education of those around them on the subject of HIV as a positive aspect of accommodating to changes initiated by the illness. For participants, learning about the disease itself can initiate the process of accepting the illness as part of their new identity of a person living with HIV. As Archie shared, "Once I've learnt about my HIV, more about it, it was easier to accept. Then from there I knew which steps to take to get where I wanted to be." From Archie's perspective, acceptance allowed him to see a clear path that should be followed in order to stay healthy.

PLWH who chose to educate people on the subject of HIV have incredibly powerful knowledge, which in fact is their first-hand experience of transformation. In addition, they are driven by the passion to prevent anyone from making the same mistakes they made. From Archie's perspective:

> The only way I can do is to educate and teach people not to follow the same road I took, you know. If I can prevent one person from following me, then I know that my life has not been a total waste.

For her part, Liz is willing to be a mentor for those adolescents who have just tested positive for HIV. While education at high schools focuses on the prevention of new HIV cases and giving knowledge about harm reduction strategies, mentorship involves providing support for a young mentee and helping him or her to manage the

illness and the resulting life changes. Liz points out how hard it might be for young

newly diagnosed people to accept their illness and learn strategies to successfully manage

their chronic condition. One barrier for mentorship is drug addiction, but Liz "feel[s] the

need to be better now . . . to be of help to the newly diagnosed people because [she

knows] what it feels like." However, as another participant noted, cleaning merely the

body of drugs is not enough: "By me being clean of the drugs, I wanted my whole being

[to be] clean." (Sara)

"No breaks for me." Although modes of transmission of any infectious disease

are important from an epidemiological point of view, HIV infection, as emphasized in the

first two chapters, is a biosocial phenomenon. Therefore, it is interesting to go back in

time and see why and how participants' lifestyles developed in the first place. To do this,

look closely at several participants' responses. In the first, Carnie talks about not

receiving love and affection from his mother:

> *Carnie*: Because I wasn't getting love and affection at home, I misinterpreted sex with love.
> *Interviewer*: Can you explain it more?
> *C*: My thought was that somebody [that] would have sex with me is loving me.
> *I*: What about now?
> *C*: Oh, I know the difference now, that sex isn't love.

This lack of affection made him seek other sources of love, which resulted in having

numerous partners "since I lost my virginity." Deprivation of love and affection can have

different reasons (including poverty and poor living conditions, illnesses of a caregiver

[Buston, 2010]), and the consequences are reflected in formation of the self and

psychological wellbeing. Parental love means valuing your child and seeking physical

and psychological proximity with him or her (Liao, 2011); in the interaction with a child,

the self of the latter emerges. Not receiving this essential type of love, Carnie was

substituting one type of love for another. Getting the diagnosis affected Carnie's former

relationship:

> The first thing my girlfriend said to me . . . she comes up to me, picked me up at
> the airport. 'Am I gonna die?' 'Yeah, eventually we are all [going to die]' . . .
> Needless to say, . . . we split up.

After that, Carnie was engaged in a relationship with another person living with HIV,

sine he believed that he could only be engaged in a seroconcordant relationship: "I was

with someone who was positive, and we kind of like, how do you say, fuck-buddies. We

were good friends. We were friends and slept together. And she was positive, but she

passed away few years back."

Following that interview with Carnie, one of the questions that was added later in

the interviews was: "What factors, in your opinion, influenced your lifestyle before

getting diagnosed with HIV?" Thinking a lot about how childhood traumas influence

participants' lives and their choices about the environments and people with whom they

surrounded themselves, I decided to find out whether all of my participants connected

their lifestyle to childhood experiences. I formulated the question in such a way that it did

not include any mention of childhood and thus was not leading. Carnie's experience of

misinterpreting sex for love because of his family history resonated with a story told by

Liz. Having no "mother and child bond," witnessing all the violence between her parents

(including threats to kill each other, divorce, and regular beatings), and being sexually

abused as a child, contributed enormously to the trauma she still carries with her today.

> I think my trauma is deep. I think my [trauma] started way back from birth,
> because my dad had beaten up my mom really bad, and she went into labor with
> me, she almost hemorrhaged to death. She didn't hold me right away. For three

79

> days she was unconscious. There was never that connection, that bond with my mother. . . . I believe it's so true that connection with your mother is so very very important, while you carry, at labor, the first, you know, put your baby on you. I never had that with my mother, even now, because no affection.

Discussion of this quote requires understanding of the historical trauma affecting Aboriginal peoples across Canada, which has its impacts at the individual, family, and community levels. This trauma is the direct result of the colonization of Canada. As Kwan (2015) explained, family violence prior to colonization was extremely rare. However, colonization resulted in structural oppression, characterized by a devaluation of women's roles within the community and family, their sexuality, and parenting skills; depreciation of men's ability to protect their families and prevent the impact of colonization; and the creation of residential schools, where Aboriginal children experienced physical and sexual abuse and were deprived of love and an understanding of healthy relationships. These outcomes of colonization cause intergenerational trauma, as evidenced by the statistics showing that Aboriginal women and children are more likely to experience family violence (Kwan, 2015). This influences future relationship and attachment patterns (Cascardi, 2016; Lohman, Neppl, Senia, & Schofield, 2013). As Liz added later, "The only way I got attached—through physical abuse or sexual abuse. My auntie gave me a lot of love, my grandparents, I think. Without their love I wouldn't get through what I got through." Later she told about her "on and off relationship" that has lasted for the past five years:

> I left him when I was pregnant from him. I'm currently fighting for her [her youngest daughter from this man]. And he is still very much the same, very emotionally- and mentally abusive. He withholds affection and sex. He knows I like it. I feel he sexually exploited me. I was just another one of his prostitutes. He is more like a sugar daddy. . . . And even during months we were apart, I just couldn't be with anybody [else].

This quote revealed a pattern of attachment through violence, which is perpetuated in

Liz's other relationships. While she witnessed and understands the horror of violent

relationships, she cannot help herself and admits that she still loves this man:

> He would beat me up really bad one last time. . . . I had charged him. He got
> charged as an assault causing [bodily harm]. It's still the same with him, he hasn't
> changed the whole lot. I think he is still out there sleeping around. I love him. He
> is the father of my 3 younger children, but even now our relationships are pretty,
> we try to keep in contact with each other, but when he wants to get [together] I
> don't [want to]. And then he gets angry and leave for another year or two.

Moe also contributed a narrative about the influence of childhood experiences on

his lifestyle. Moe was raised by foster parents:

> *Interviewer*: Why do you think it [getting into addiction] happened?
> *Moe*: I'm not sure. I really don't know. Because I came from the foster home I
> never grew up with my own family, never had the support. I don't know. That's
> not an excuse! . . . I was more susceptible to that lifestyle than other people,
> where they have family support and the whole works. . . . If anybody that has a
> family of their own, they have some buffer of some people they can talk to, right?
> You know, somebody that says, "Don't do that, don't do this," you know, and
> there is no breaks for me.
> *I*: What about the relationship with your foster home?
> *M:* Well, they helped me until I turned 18 and then after I turned 18, that was it.
> That was over. That was like 'See you!' And it was, happened that fast. That had
> a lot to do with why I have such a care-free way.

Moe thought he was "more susceptible" to the lifestyle that led to contraction of HIV.

Family gives not only support, it constructs a person and gives skills to build life, and

Moe was deprived of such support. Although he was formally living in a family, as soon

as he turned 18 he was told to leave. Being alone on the streets is what "screw[ed]

everything up" for him.

Archie was also raised in a foster family. While his relationship with his foster

parents is very good, he found himself in a similar situation to Moe's. However, in

contrast to Moe's suggestion about the influence of an upbringing in a foster home,

Archie explained his lifestyle through his Aboriginal roots:

> *Archie*: Because of my heritage, I believe. I started to drink. Because of my Native heritage.
> *Interviewer*: Do you think Native people are more susceptible to these issues?
> *A*: Alcohol, yeah. Because once I started drinking [inaudible] alcohol, I loved it. I wanted it more, I love what it did for me.
> *I:* What did it do for you?
> *A*: It made me feel comfortable, more relaxed, more accepted, socially accepted. . . .
> *I:* What about drugs? . . .
> *A:* I always did drugs. It made me feel good. I smoked pot and I started, as it [the effect of marijuana] got low, I just tried [crack].

Behind these words is hiding a very shy and sensitive personality with an exceptionally

difficult identity crisis. As he said after, being brought up in a non-Aboriginal

environment and feeling so different immensely influenced his personality:

> *Archie:* Not knowing who I was. Not knowing my strengths, my history, where I come from. That was what I believe. I had no sense of pride, no sense of belonging. I was outside looking in.
> *Interviewer:* You're saying a lot about this feeling of not belonging to this place. What is the reason for this feeling? Did you think about this?
> *A:* Well, everything. Right from the day first since birth. I believe I don't deserve this life. I don't deserve. . . . Every time I reach for these things they would be taken from me by God. [He] took my wife, [he] took my unborn son, took my Dad, my brothers, my life, my health, my freedom.

Thus, the trauma of being removed from his family and community at a very young age

has shaped his perceptions and expectations of the meaning and value of relationships. As

he says, "I didn't grow up with my natural father and mother. No, I didn't. So that I

believe is vital. That upbringing. . . . I probably would have listened more, would have

been more careful I guess." Another piece of narrative that provides more understanding

of the depth of his trauma and identity crisis is that even when Archie found and got to

know his biological parents and siblings, it did not help him much. He said, "It wasn't

really deep relationship or anything," and to some extent, his lifestyle got even worse after this. He perceived that he did not belong within his non-Aboriginal foster family, nor, later, to his Aboriginal community. He, just like Liz, mentioned that the "mother-child bond was broken." He never had the "sense of community, your family, belonging. Being loved and needed, wanted. I just don't feel that. Never did. It's probably why I preferred to live out in the bush, go out and fishing and prefer that life of solitude."

The trauma that Archie has carried throughout his life profoundly influenced his relationships with women, as he says: "[Having a relationship] wasn't for me. That was for somebody else. My lot in life was to suffer, alone, inside. That's what I believe. That's what I'm doing." Archie's lifestyle before his diagnosis was characterized by high-risk behaviour; he was using drugs and alcohol to escape reality, loneliness, and pain. At the same time, he was engaged sexually with a woman living with HIV, who disclosed to him before the relationship started, without using any protection. However, this relationship changed after he got diagnosed: "She was a common law wife. The only thing we had in common is that we liked to drink and party and have a good time. And it changed when I was diagnosed. I couldn't continue doing this [high-risk] lifestyle."

Also, Archie surrounded himself with people who were "old-school alcoholics living on the streets. Homeless, jobless. Just trying to get by day to day, and they drank like I did. So that's people I hang around with. Because to me that was normal." This sense of normalcy can be explained using Stryker's (1980) identity theory. The people one surrounds oneself with have immense influence over who one is. They confirm one's identity and give feedback; if there is a sense of normalcy when communicating with these people, a person does not perceive the need to make any changes. Interestingly,

Archie was the only participant who admitted that his lifestyle would have been even worse if he was not diagnosed with HIV. Living with HIV made him think of sobering-up in order to take better care of himself and be adherent to medications. As he said,

> *Archie*: I wouldn't be living the way I'm living now.
> *Interviewer*: How would you be living?
> *A*: I'd probably be dead.
> *I*: Why?
> *A*: Because that's what I wanted to be.

Facing stigma. The stigma associated with HIV (i.e., HIV-related stigma or HIV stigma) has a profound impact on the lives of PLWH. While a great deal of research has been done, support workers do not really have any tools focused on stigma management to provide to their clients. PLWH might encounter HIV-related stigma right at the moment of getting the diagnosis. Despite the knowledge we would assume healthcare practitioners receive during their training, some showed ignorance about HIV and how the diagnosis should be delivered:

> I found out by a doctor who just called me in his office from my unit, and he just basically told me, "By law, I have to tell you in your face your HIV status. There, I've done it. Now you can go back to your unit," and that was it. He didn't ask me if I had any questions or gave me any information, follow-up information, or how to even go about treating it or whether it was even treatable. So, I would have to say it was very unprofessional [chuckles], and I just, [it] made me fell less than when I was told. (Archie)

Abdul encountered enacted stigma that prevented him from finding a job, and he was left without any income for eight months, while some participants had to face the "double" stigma that resulted from cultural prejudices towards homosexual men. Mike's family members assumed that if he contracted HIV, he might had been involved in sexual relationships with men:

84

If there is homosexuality . . . it is very very hidden. They are too conservative about that. They figured if you are HIV, you must be homosexual. They start to question. (Mike)

Other participant struggled with stigma because of their past lifestyles. Indeed, stigma faced by PLWH is extremely diverse, and sometimes other life circumstances may be even harder to admit to than HIV. For example, for Sara, this included receiving welfare:

I'm scared to tell [men] that I'm on welfare. I don't wanna be looked down. That's the way I feel like, and, you know, I'd be right out of telling them that I'm HIV. . . . Them knowing that I'm on welfare was like me even lower.

Liz has encountered stigma while living on a reserve. She is not the only participant who emphasized the stigmatizing potential of closed communities. Moe said that while he and his ex-partner were living in a small community, "[they] didn't want everyone to know that we were HIV-positive. Otherwise, the chances are they wouldn't understand." Liz was forced to get away from her community and province and find another place to live. Unfortunately, whenever she discloses her status, she faces the same stigma from which she was running.

I'm a member of the Native American Church. We had a shared bowl and spoon ceremony, and we all had to share one bowl and spoon. And this one fellow he's so scared of it from me, from sharing that. And then I had [some kind of a] ceremony for myself and my HIV, and he'd asked if I could bring my own spoon and bowl. And he asked the old man who was running the ceremony to ask me. And I said 'No. We are all going to use the same bowl and spoon. If somebody else is uncomfortable with me, they can bring their own bowl and spoon.' And even the older people from that church was just blown away by that. Because when it's done in prayer, Creator is not going to make everybody sick with my sickness.

Spirituality is threaded through this narrative. It clearly shows how salient being involved in her cultural and spiritual practices is for Liz. Stigma is a very powerful social phenomenon, which influences not only the lives of PLWH, but also those close to them.

85

Liz's children faced HIV-related stigma at school, and that was what hurt her the most.

As she described, her children were refused daycare and later were bullied at school.

Stigma also influenced Liz's relationship. Her quote shows that although some men

wanted to have sex with her after she disclosed to them, they tended to disappear from

her life and did not want anyone else to know that they had sex with her:

> He wanted to be with me, but only in a sexual way. And then I told him I was HIV, and he was blown away. It changed him. I could feel it. You can feel it when you tell somebody. You feel how they feel. He still wants to have sex with me. But he doesn't want to tell anybody he was with me. . . . I hate going through the rejection part. When you tell somebody you have HIV, and you get rejected. I mean yeah, you have a few drinks, wear a condom, have sex, and the next morning he is gone.

> Another example of how stigma shapes relationship dynamics is the following

quote:

> *Interviewer:* Do you think stigma plays any role in . . . how you are looking for a partner?
> *Rick:* Well, that would be pretty easy to find out, right [chuckles]? I know if you go to the bar or a place and then you say 'Hey, I'm HIV-positive,' and see what happen, right? So you'd find people who would stay around you. You'll find people who [wouldn't]. I heard some stories. . . . Scares for us. Like, for sexual. Because gay people don't seem to have this problem, right? They're laughing about it and they get so many together and everyone, right? In the bathhouse and stuff like this. I don't know they are more, you won't see heterosexual like this, right? They are more serious about that. (Rick)

This quote shows the influence of stigma is multi-layered and profound, and can be

revealed quite easily. Rick noted that one statement is enough to quickly divide a group

of people into those who would accept a person living with HIV and those who try to

keep their distance. Another interesting finding is the perception that HIV does not affect

relationships in the MSM community to the extent that it affects relationships in the

heterosexual community. In a sense, Rick finds that HIV is normalized in the former

community, while still highly stigmatized in the latter. However, the literature shows the

opposite: HIV stigma is quite prevalent in the MSM community. It results in social

isolation and relationship avoidance (Courtenay-Quirk, Wolitski, Parsons, & Gomez,

2006), discrimination based on physical appearance or health status, and violence (Smit

et al., 2012).

In this research project, family members were a source of stigma rather than

support:

> It's just with my family out here. They make me feel like 'Oh, I can't do anything because I got HIV.' I can't go get my nails done, because I have HIV. I can't go get a tattoo because I got HIV. I can't . . . double dip with my fork to take seconds because I got HIV. (Sara)

As Sara explained, all her attempts to educate her family members about HIV failed, and

after trying to explain the state of her health in terms of HIV, she gave up. Their

arrogance, she said, was no longer her problem. Liz also experienced stigma in relation to

motherhood as a woman living with HIV:

> My brother in law told me to have an abortion. "Why do you guys bring these kids into this world, to make them sick." And we explained to him: 'If she takes medications, she can have a healthy baby,' and a lot of people find this hard. Especially in my community, like, our community, his too. "Oh, look at her, she is pregnant, she is going to make her baby sick." I try to educate people that I can still have kids. I have two babies since I've been positive.

Archie noted that the fact that he identifies himself as a person living with HIV is

stressful enough, and stigma on top of it only makes his life harder:

> Mostly the concern is that no acceptance. I wish they let me live with it [HIV], quit reminding me or quit treating me differently. You know, I'm not made of sugar. I'm still the same person. . . . It's just the way I identify myself – the person living with HIV. That's it. As simple as that. It's already complicated enough to live with this disease, I don't need your stigma, your whatever else on top of that.

Indeed, for Archie, the very concept of family was no longer about shared genes, but about people who accept: "The [ASO] is the closest thing I have to the family. My friends who are here [at the ASO] are all living with HIV. It's where society put me. It's the best as it can get." Archie, who never felt as though he belonged within either his foster home or his biological home, was looking for people who would accept him the way he was: "They [staff and clients at the ASO] accept who I am. They know about my status. They don't ask questions, they just accept me for who I am and just allow me to live the way I wanna live." However, while one of the reasons he made friends at the local ASO was shared experience, another was the perception of his place as defined by society.

    Desired changes. Although participants identified a number of desired changes in their lives, only Rick talked about those that were directly related to HIV: "What would I change? Find that undetectable little thing in me. . . . Because it affects everything in my life, in a way it's all connected." However, far more participants would prefer to see changes in areas of their lives completely unrelated to the medical condition they have. While desired changes for some were related to living a peaceful life, having enough money to provide for themselves and their dependents, or even gaining computer literacy, Liz planned to stop using drugs and reconnect with her family, especially with her children, in order to transfer her experience and knowledge to them. For Sara the biggest change would be to get rid of her criminal record that posed barriers to bringing her life to "normal" and to seek an education.

    For Bill, the greatest desire was to "live again," which was equivalent to "get[ting] rid of depression and negative feelings." Mental illness is what makes PLWH's

lives a hundred times more difficult (Delaney & O'Brien, 2012). Bill's condition created

a vicious circle for him, whereas HIV illness was just another variable. Although he

understands that he has a mental illness, he does not allow any specialists—whether it is a

psychiatrist or an infectious disease specialist—to help him take care of himself. Mike

also mentioned that the reason why he did not let depression take over was that

"depression does not lead to acceptance. Depression leads to destruction." "Destruction"

is precisely what was happening with Bill. He was left to fight his "demons" ("one wants

to live and one that doesn't want me to") all alone, even though he understands that

meeting with a specialist would have helped to address many of his problems. Answering

the question about the ways HIV affected his life, Bill said that he hardly sees any

consequences of having HIV illness, which might be explained by existence of saliency,

or hierarchy, of issues in life. For example, drug abuse might be perceived as a more

salient issue compared to HIV. Or possibly, HIV might not be as worrisome as having to

deal with the mental illness that defined Bill's lifestyle and attitude:

> I'm a little suicide. . . . [I] went purposely jabbed myself with lots of needles. I
> guess you would say it's a slow suicide as opposed to just a suicide, because I
> can't move ahead up here and it totally screw me up and finding that I had this, it
> was no surprise.

Another participant mentioned his own experience of the devastation of mental illness;

his sister is also living with the virus while managing mental illness. In Moe's words,

"you throw to somebody that has HIV with mental health disorders, and they tend to fall

off, be compulsive what they think is right."

One of the most interesting desired changes was that of having a family. There are

comparatively few studies about parenthood desires among heterosexual MLWH, a group

that is often overlooked. Mike's desire to have a family of his own is influenced greatly

by his cultural and spiritual background, as you can see from the following quote:

> My hope is to, please, I'd like to have wife and kid, carry my name. . . . It is important from my background. It's good to have somebody take after you. . . . Let's say, if you read Bible, it says 'Solomon is the son of David, and David was the son of so and so'. To us, in our culture, it means the son or daughter—I've left something behind.

Archie also said that his greatest desire is to attain a normal life, and the most

important component is having a partner:

> Well, I'd love to have a normal life, I'd love to have somebody, partner that loves me unconditionally, willing to have sex with me so that I can have just a normalized life. That I never had. Like, family.

This desire of intimacy and association of having a partner with being normal is the focus

of the next section, which describes the relational challenges PLWH face.

Relationships: "Intimacy and Sex are No Longer in My Life"

Having sensitive conversations is always emotionally intense, whether stories are

sad or happy. One of the research-related concerns included having participants discuss

relationships with a person (me), whom some of them (though not all) were seeing for the

first time. However, to my surprise, all of them shared their stories freely. One of the

possible reasons for it was the structure of the interview guide; many questions about

their lives and experiences of having HIV preceded more sensitive questions related to

relationships.

This section begins with participants' definitions of relationship and is followed

by discussions of the major relationship challenges they faced. Particular attention is

given to disclosure as the main obstacle towards being engaged in a relationship. I then

move on to address the importance of the HIV status of potential partners—the question

90

that has been highlighted by several authors as one deserving further attention and research (Jarman et al., 2005; Sastre et al., 2015). At the end of this section, I discuss partner-seeking strategies used by participants.

Celibacy following the HIV diagnosis. Every person defined a relationship in his or her own way. For Liz, a relationship is about being "intimate, but not only through sex. Just hold each other, share the same values and beliefs." The ideal partner for her would be the one who:

> would walk down the red road with [her], and that is [a] spiritual road. Somebody who's traditional. Share the same other values and beliefs from our culture that I do. . . . To me relationship is walking down with somebody down the road with me, who respects me, who loves me and accepts me no matter what.

Liz was one of the participants who was strongly guided by her cultural background, and she associated relationships with her cultural traditions.

For Mike, "it's more spiritual—engagement. Having [points] of intersection that we share with each other and juice of life. Respect each [other's] opinion, go the extra mile to serve, to please." For him, a relationship requires two equal parties, where both sides give and receive. Moe defined a relationship as "something that you can talk openly and that you care for each other, . . . that you want to spend the rest of your life together." Another participant, Rick, gave a very emotional definition of a relationship: "It's the two of us doing things, enjoy each other, live, love, cry." Love is a central part of Rick's life. He does not have the illusion that a relationship equals happiness. Sometimes relationship can hurt, but emotions "give colors" to one's life and make it complete.

Surprisingly, the majority of participants did not recognize any major changes in their lives after being diagnosed, even despite the fact that they talked in depth about

91

stigma and discrimination after testing positive for HIV. However, when asked what was the most stressful part of living with HIV, the first thing that each of the ten participants mentioned was their relationships or, to be more precise, the absence of any relationship with a person of the opposite sex. The most vivid example is Carnie's story, which deserves particular attention. He told about his life before the diagnosis:

> I never had a problem getting laid. I was cute, good-looking and I never had to make move on a woman once in my life. . . . Ever since I lost my virginity I didn't stop [sleeping around]. My mother used to say to me, "You know what you'd be called if you were a girl?" And I said, "Yeah, whatever."

He was always the focus of women's attention; having charm and being handsome, he did not have to do anything to attract women, which later became, and remains, very problematic. However, there was a huge shift in Carnie's relationships after being diagnosed:

> The only thing that is stressful and it pisses me off is that I haven't had intimate relationships basically since I've had this. And that's the only stress that I have. . . . Because I do miss it, and it's not just sex; it's the companionship. You know, cuddling up, watching TV movie on TV and shit. Just having companionship. Someone you come home to.

Therefore, a man who perceived himself as one with a very active sexual life, turned to celibacy immediately after being diagnosed. As he said "I was always in the relationship, my whole life, and then pulling from that to being single. . . . I never been single for more than two weeks in my whole life." Thus, he lost a part of his life that was salient, and now was forced to put this part—this identity—aside. Even when women imply interest in intimacy or want to get to know Carnie better, he himself stops any flirting, something he would never had done before the diagnosis. Moreover, at the time of the interview, Carnie had not been engaged in any relationship for almost two decades. As he said, he has had enough time to think about what a relationship is and what partners should do to

92

preserve their connection. He reassessed his life and his identity as a partner by looking at

himself as someone's partner from different angles:

> I think that I would make a really good boyfriend because I know so much more
> now. I could learn to respect women. I know how to make a relationship work. . .
> . I've been down that road, I know what not to do. . . . I'm like a relationship
> expert, but I don't have nobody to practice anymore.

It shows a profound reassessment of his identity as a partner, going from a position of

"having plenty of women" in his life to one of having no one to care for or about.

Carnie's narrative is similar to Liz's; she was sexually very active throughout her

adolescence. She had multiple partners, but right after her diagnosis she limited her

sexual encounters. The reason for this was the absence of sexual drive, commonly

reported as the result of HIV and which affects enjoyment of sex or makes sexual

encounters seem impossible (Lambert, Keegan, & Petrak, 2005). Currently Liz is

reassessing her sexuality and trying to manage her childhood trauma:

> Sex is important to me now, because recently I've embraced that part of me and
> truly accepted. I'm a beautiful sexual woman, and all my life I was meant to feel
> dirty about it. And it's more important to me now, more than ever.

Several other participants talked about the significance of not having a partner in

life. For example, Mike said that for him stressful part of living with HIV is:

> When you want a presence of a partner, but you don't want to tell them [about
> HIV] and you know you should tell them. . . . and it happened quite few times.
> One, I avoid. At lots of times, I have women who make indirectly the invitation, I
> would treat the body language and ignore. It is this part that stresses me out.

Mike's story is similar to Carnie's; his life will never get to the point of normalcy,

because he cannot fulfill the identity of a man who needs love and intimacy. Furthermore,

Mike is experiencing the pressure of his cultural background, which dictates that he

should have "a wife and a kid" at his age. Mike told a story when he met a woman and

had to overcome his fear of disclosure. Right before having sex he disclosed to her, and was relieved when it appeared that she was also living with HIV. He tried to continue this relationship: "I thought we could talk. I tried to, but I see how she likes to smoke crack and to do stuff I don't want to do anymore." For him, the lifestyle she lived is what he would have been living before, but now he considered it to be a "not totally complete lifestyle."

Some participants had experienced dating while living without, and then later with the virus. These participants had a chance to compare their relationships both before and after being diagnosed. Archie's story is one that helps demonstrate how relationship patterns changed or stayed the same. It is related to the experience of dating women, and is full of violence on the part of his partners. Indeed, spousal violence against men is a dark area with little research done, although the latest report from Statistics Canada (2014) showed that equal proportions of men and women experienced spousal violence in 2014. Commonly explained reasons for women's aggressive behaviour include women's reactions as victims fighting back or traits of women's psychopathology (e.g., negative emotionality, impulsivity) (Graham-Kevan, 2009). However, as Archie explained, one of the reasons for the violence in his relationships was his extremely low self-esteem, which he mentioned several times by saying that he never got the sense of belonging to any place on this Earth, and having always felt like "less than a man." Indeed, his story of living with HIV started in a violent relationship. He contracted HIV from his last partner, whom he described as a common-law wife and the one who "used to beat me up. Believe that. And she was smaller than me." He knew about her HIV diagnosis before they had condomless sex. This is how Archie explains how he reacted to her disclosure:

It didn't take me even five seconds to make a decision on where I stood on with her having HIV. Didn't bother me one a bit. Because as I put myself in her shoes, I didn't want her to feel that because of her disease that I wanted her to feel less than or that she was a disease. I didn't want her to feel [avoided]. Especially by me.

Archie himself did not have any negative HIV-related attitude towards his common-law wife. He did not want to offend her or make her feel isolated. First, he thought about her feelings, and about how being rejected by him would hurt her. Even having no experience of living with HIV himself, he clearly recognized the stigma surrounding HIV. Archie was afforded a unique perspective, having been *outside* of the HIV-world but with a partner living with HIV, and later becoming an *insider* himself. We can see his transition between no stigma as an *outsider* to the devastating effects of experienced self-stigma as an *insider*. This transition had a lot to do with low self-esteem. Indeed, Mike emphasized the importance of self-esteem in his experience of living with HIV by answering the following interview question:

> *Interviewer*: Some HIV-positive people told me that other people treat them badly when they get to know about [HIV status].
> *Mike*: No. That's a low self-esteem in them. They take everything because it does put you in that defensive [position]. If somebody doesn't say Hi to you and you [think] 'Oh, maybe they found out that I'm HIV'. No!

According to Rick, low self-esteem is what makes people perceive their problems incorrectly: "Somebody at meetings will bring out a personal problem and make it an HIV problem. And . . . I'm listening and it's like, it's not an HIV problem. It's more like a personal problem." Indeed, according to Sara, boosting self-esteem is what different agencies, especially Drug Treatment Court and the counsellors there, helped her to achieve, thus changing her life for the better. Drug Treatment Court programs exist in different provinces across Canada; these programs help to decrease crimes committed

95

because of drug dependency by judicial supervision of those who committed crimes, substance abuse treatment and drug testing, social services support, and other activities (Government of Canada, 2015). Low self-esteem is what stops people from taking the first step, meeting other people, and giving relationships a chance to develop.

Another important point is the altered body image of participants after having been diagnosed with HIV. As Archie said, "I just don't feel sexy or desirable anymore." Carnie shares a similar sentiment: "Because I'm in my 50s now [chuckles]. I'm not good-looking anymore [chuckles]. . . . I'm skinny too. I'm not attractive anymore. I get grey hair. I got no top teeth." While Carnie points to the thinness of his body, Sara is concerned about gaining weight:

> I'm still really self-conscious about my weight and how people see me. Like, you know. Because how big I am. When I was using I was so small, you know, and I gained this weight, I got this big in 2 months while I was in jail, so. You know, you don't give a shit when you were in jail on how much weight you gained. Because you knew as soon as you step out of the gate, you are going to get high, and you'll lose it in a week.

Body image is a complex concept that reflects the "individual's perception of their [sic] existential self, physical self and social interpretation of their [sic] body by others" (Palmer et al., 2011, p. 1456). Feeling of loss of control over body changes related to HIV, especially if they include lipodystrophy (which is one of the side effects of particular classes of antiretrovirals [AIDSinfo, 2005]), is especially stressful for PLWH as these changes are visible marker of the illness (Alexias, Savvakis, & Stratopoulou, 2016; Kelly, Langdon, & Serpell, 2009). The changes are hard to control, and often result in PLWH being celibate (Siegel & Schrimshaw, 2003).

Harm reduction in intimate relationships. An interesting note relates to the lack of knowledge about harm reduction in relationships. As Mike said, "We had safe sex both, and she had woman condom, and I had my condom. So it was really safe. I was undetectable, so it's all good."

Liz leaves the decision concerning harm reduction to her partner regardless of his HIV status. She takes responsibility by disclosing her HIV status at the beginning of any relationship, but then she "steps back" and lets her partner decide what harm reduction strategy he will use. Some partners choose not to use condoms. Although it sounds like they are taking unnecessary risks of HIV transmission, most of Liz's partners have already exposed themselves to HIV by other modes of transmission (e.g., injecting drugs with used needles). As she noted about one of her former partners:

> He is an IV drug user. We never had protected sex and he accepted that part of me. I guess there were couple of times, where I did get into relationship, and he didn't want me to use condom. He knew about my status. He ended up getting it. But he didn't care. He said 'Maybe I had it too,' because he lived high risk.

Liz's story is very similar to Abdul's, whose wife decided not to use a condom after learning that he was living with HIV. At first, Abdul insisted on using condoms and was consistent for one year. However, it gave his wife a sense that if she had not contracted the virus yet, she was not susceptible to it. She felt invincible. Abdul noted a clear difference in attitudes toward condoms between men and women:

> I have discovered we, men, condoms work for us very very well. We don't have a problem with condoms, but I discovered women don't like condoms. They are allergic. Most of them are allergic. They don't like it. So if you try first or second time later they may say, "Oh, leave it."

There are at least two ways to interpret the word "allergic" that Abdul used. Some people, indeed, have allergic reactions to latex, and they have to opt out for using non-

latex condoms. However, Abdul is using this word rather to describe unpleasant feelings that might occur while having protected sex. Surprisingly, despite seeing how devastating the HIV epidemic is in his country of origin with limited access to antiretroviral drugs and knowing people who have died from AIDS-related causes, Abdul did not fully understand the importance of harm reduction.

   HIV status of a potential partner. A questions addressed in this research study was whether or not the HIV status of a potential partner plays a role in partner selection. Of course, HIV status is not the only criterion for selecting a partner, and all participants were clear about that. However, status did matter, albeit to a different extent for each participant. Only two participants indicated that they did not consider HIV status as a partner selection criterion. As Sara said, with treatment easily available, HIV is not "that big of a deal nowadays." Therefore, it would not influence her choice. Moe said that he treats all people the same regardless of their HIV status, therefore the only criteria that he uses when considering whether or not to start a relationship is that a partner is "smart, intelligent, good looking. . . . One that probably [is] not naïve to the way the world works, when you are from the street level up. Somebody that has a little bit of insight to, let's say, poverty." As the reader can see, to Moe, who has struggled with poverty, homelessness, and drug addiction for a long time, having a partner who shared—or at least who would understand—his background is much more important than HIV status.

   Three participants indicated that they preferred a partner who does not live with HIV, and the rationale for this choice warrants further exploration. Rick, for example, expressed hope that there will someday be a cure or vaccine: "I would definitely date somebody that's not [living with HIV] . . . because eventually there will be cure, ok?" As

98

Bill also said, "You can't have two sick people trying to make go over it, because it won't work." He, as well as several other participants, demonstrated a limited understanding of harm reduction in seroconcordant relationships by saying "everything will be fine [with a partner living with HIV]; you don't have to do any sort of extra protection [e.g., condoms] and not having a hard time maintaining myself and understanding myself and my attitude in a way I've been." In contrast to this, Archie's words showed that knowing a little more about the risk of transmitting and acquiring resistant strains of the virus diminishes positive sides of having a seroconcordant partner: "I understand about different strains. So why would I wanna come down my life with that, with another sick person? No, I don't think so. No." The reader should note that Archie has drastically changed his attitude towards health and lifestyle, which might explain his views on seroconcordant relationship. His health now is a measure of the stability and meaningfulness of his life; therefore, he tries to eliminate any potential threats to his hard work.

Nevertheless, five of 10 participants indicated that they preferred having a partner living with the same illness. Liz explained her feelings that a potential partner would "understand more about me, the disease, the experience of disease. [Other] people will never know what it feels like." However, although HIV status plays a role, it does not define whether she wants to be in a relationship with this person or not. She just does not want to be lonely anymore. As she said, "I pray, Creator, just find me somebody to love who would just love me."

Spiritual identity was also tightly connected with disclosure in intimate relationships. Abdul, who believes he passed the virus to his wife (although not formally

divorced, he ceased relationship with her), said that after witnessing his wife's shock and her struggles with accepting the diagnosis, he made the decision to date exclusively WLWH. Drawing on his experience of dating a woman living with HIV, he said that one of the benefits is that "we have the same thing . . . You talk about how to eat healthy, and sometimes she tells you, 'No, this thing is not good for us. We got to know this in the workshop, this stuff is not good for us.'" Interestingly, Abdul did not perceive that he is in a relationship, because it is a long-distance relationship. When asked to confirm eligibility for participation in the project, he identified himself as a single man several times, although a woman living in Toronto comes to see him several times a year.

Carnie, when asked about the HIV status of his potential partner, said that having a partner living with HIV was the first thought he had when he got diagnosed. However, his doctor educated him about the risk of transmitting resistant strains, and Carnie keeps it in mind. He is probably the only one from the group of participants who possessed this information. Other participants assumed that having a partner who also live with HIV makes condoms obsolete, which poses a risk for their health and health of potential partners. Although Carnie's decision at first was guided by his poor knowledge of the risk of getting a resistant strain, now his decision is shaped by stigma:

> *Carnie*: Well, I don't think a negative person would ever go out with me. See, it's something that I found out for 18 years too. If I was negative, would I go with a positive woman? I don't think I would.
> *Interviewer*: Why?
> *C*: Just because I wouldn't. You kind of on that side of the fence. And I know I had met couples who were one positive, one negative. I've yet to meet somebody like that. Now, the person that is like obviously negative would have to be pretty educated about HIV, because I wouldn't wanna be in a bedroom, be intimate and her having that at the back of her head, being worried. It's kind of shies me away from relationships, I guess. I don't know. Psychologically. . . . If I was negative

[with] someone who is positive, being at the back of my head, "Ugh. Am I gonna catch it?" That's all.

So, as can be seen, Carnie perceived himself "on that side of the fence." Self-stigma was also revealed in Mike's narrative. He sees himself as a person confined by the virus, and being in that category with someone who has the same issue would alleviate his psychological concerns:

> *Interviewer*: Does HIV status of your potential partner . . . matter to you? Does it play any role at all?
> *Mike*: If that happens, that would be awesome. If I find an HIV-positive woman . . . then we are the same.
> *I*: In what ways?
> *M*: We are suffering the same. Not I would say something, but we are living in that category. We're living in two brackets, HIV and two brackets. We both have it. So that makes us one.

Some participants had experienced seroconcordant relationships, and one of the main positive aspects was the absence of pressure to disclose or hide the diagnosis. Moe had had a relationship with a woman living with HIV and commented, "We didn't have to hide. No big secret. Like hide the fact that we were HIV-positive from each other . . . which was a little bit of a help."

Disclosure. For the majority of the participants disclosure was associated with negative feelings. However for one participant, it was used as a way to separate from his ex-wife:

> When I got out of a jail, I stayed with my ex-wife for a bit, and she wanted. I thought she wanted to get into relationship. I didn't want to get into relationship with her, so I told her right away that I'm HIV. (Steve)

Although Steve knows that his daughters would very much like if he went back to his ex-wife and lived together again, he does not want to be engaged with her. However, he acknowledges that he would like to find a partner some day and it would be easier if he

101

was not living with HIV: "If I wasn't HIV I'd probably be looking [for a partner] right now . . . because there's time I don't like to be alone, it's just too quiet, right?"

Archie's thoughts framed the idea of disclosure quite well: "Disclose your HIV status to people. Let them know that you're hurting, that you're scared." People were afraid of being perceived by others as weak, and therefore hid their inner pain. However, the pain of keeping a stigmatized condition a secret proved too difficult to tolerate. HIV is a tremendously heavy burden, and despite the fear of being rejected, disclosure might help society understand the challenges faced by PLWH. Therefore, one of the strategies Archie used was to disclose his status at the beginning of any relationship. In his case, disclosure was a tool to shift responsibility for any further steps in a relationship from himself as a person living with HIV to his potential partner, as the major obstacle for a relationship was his fear of transmitting the virus, which "keeps [him] at arm-length with anybody":

> I wanted them to know. I wanted to know where they stood. I tell you my status because I want you to [know]. Now I put it in your ball park. You deal with it. Your way, and it's as far as I'm gonna go with it. Just tell you about my HIV status. If you have questions I'm open to answer them.

The same concern of infecting other individual was expressed by Rick:

> Even that bylaw [meaning legal obligation to disclose to sexual partners] and all this. You know you're undetectable, you follow your health thing, and you are healthy, use condom. There's no reason to be worried about, but not here [touching his forehead], in my head. . . . That little thing, that zero point zero one that you might get it, right? . . . That's the reason that relationship don't work right.

> Regarding disclosure to potential partners, Liz takes the same approach as Archie.

She confronts disclosure right after meeting a new partner and before having sex. Thus,

the power of making decision about a relationship's possible future is in the hands of the

potential partner.

A huge part of a relationship is feeling safe, being able to freely say what is on

your mind (Rick). Therefore, the pressure of disclosing at some point in the future is a

major obstacle. The reason is the existing stigma in society and the feeling that HIV

status will destroy trust and feelings:

> I hear some people talking about 'When should you tell somebody you are positive? Before it gets intimate? Right off the get-go?' And I've been thinking about that. [Saying before is a] no-no, because it doesn't make this person realize who you are as a person, so I think it's wrong. . . . So, what do I have to do? I have to get a relationship and someone love me before I diagnosed? See, that can cause friction too. Some might accept it, some might smack in face! That 'Why didn't you let me know sooner blah-blah-blah before I felt for you?' . . . Some might say 'I don't give a shit, I love you', right? Those are the only two ways that you can go with that. (Carnie)

This uncertainty about the appropriate time for disclosure leads to deception and

finding other reasons to use a condom:

> I myself right now I would tell them afterwards, and I guess I'd have smack in the face because we would have sex already. But I would always wear protection. And I might even use an excuse that I don't want to get somebody pregnant, that's why I'm using a condom. (Carnie)

> I don't know when to allow myself to tell them. . . . I know it'd be beautiful sex or whatever, but when exactly is the best time to tell somebody that you do have HIV? (Sara)

Nevertheless, those who were using drugs had different attitudes toward disclosure. It

usually included disclosure to potential needle-sharers and further strategies to prevent

transmission of the virus to people who do not live with HIV.

> As soon as I was HIV-positive, I was pretty open, like, as if you wanna call it the street, I'll let everybody know that I was HIV-positive because, hey, I was into more intravenous drug use then. I didn't want anyone else to catch it, so I just was open with it. (Moe)

103

I started my needle use again in about 2005. So about from there up until like when I found out that, I was using, I tried to be more safe and not let other people use my needles. Like if I were really desperate. Because I knew I had it, I didn't care if I used a dirty needle. . . . There is a needle exchange, so we always went there, always made sure we got enough to [use]. (Sara)

Disclosure was also connected to spirituality for one of the participants:

Up to now, I think this is what has caused me to live a bit longer. God is rewarding me. I am open. I don't have that heart of saying, "I'm HIV-positive, so I'm going to give it someone."' No, I can't do it, and I always say to people who are HIV-positive: "Please, please, always open to people before you have sex. Tell them you are HIV-positive. Use condoms. Or look for people who are the same like you." (Abdul)

In some cases, the disclosure of a participant's status happened without consent.

As Mike commented, he disclosed to his brother whom he trusted, but who was also under the influence of substances, and the brother spread this information to all other family members. This situation led to the entire family turning away from Mike, and even today, he does not get any help or support from them. It could have been very different if Mike had had more control over his disclosure. As Moe mentioned, having control in disclosing status is what gives some sort of freedom, so he "keep[s] it at the back of [his] mind and continue[s] on." Steve was in the same situation as Mike. He had disclosed his status to his ex-wife more as a reason to stop their relationship, rather than to share his troubles with her. Later, she disclosed his status to the whole family, which then broke off communication.

Search strategies. None of the participants were intentionally looking for a partner during the time of the research study, although half of them desperately wanted to be in a relationship. As Archie says:

"As far as pursuing any kind of physical relationship? That's the last thing on my mind. [I: Why?] I don't believe I'm entitled to that anymore. [I: Why so?] It's just, I don't feel like a man anymore. I feel less than a man. . . . I can continue to

104

be the person I am until maybe the one human being out of 7 billion is out there, I still don't believe it. I don't think it exists, this person. So there is no point for me to try to pursue relationship with another girl. The last three girls that I had all died, so to me that's just says 'Oh, [Archie], maybe you shouldn't be in a relationship!' So I don't pursue any."

Another participant, Bill, also noted: "I'm not just interested in anything, like, not even with partners. Nothing. It's like the plug is pulled. Yeah. And it just don't come on any more."

When asked about suitable venues, several said that bars and pubs are not a "good place to find an ideal partner." Moreover, these social places often posed many potential social risks (e.g., getting involved in a fight). Therefore, the majority of participants took the attitude that "if it comes it comes:" For example, Mike chose not to focus on looking for a partner, but rather wanted to become more social and meet people: "I don't go to places to meet women [with emphasis]. To meet people in general—yes. [I: Where do you go to meet people?] People? Weddings, funerals, occasions, banquets. Somebody invites you for a Christmas party!" For Mike, social places and meeting people face-to-face is important. He would prefer to have social events at a local ASO where he could be introduced to new people (and potentially partners): "Let's say . . . 'Mike, I wanna introduce you to Kate.' 'Sure!' It doesn't mean I'm going to marry Kate, but I'll get to know Kate." Having more social events at a local ASO would allow opportunities to meet potential partners, but more importantly, to develop communication skills and strategies in a stigma-free environment.

Sara decided to be more pro-active in searching for partners on dating websites. However, she had had a previous negative experience of dating online: "I just met a few people, but right away they are just out there for sex . . . and it turns me off. . . . I quit

that." Moreover, as she noted, she was dealing with drug and alcohol addiction for so long that she simply did not know herself. She did not know how to behave with men, and she did not know her feelings about many things in life. Therefore, she perceived that getting to know her true self is the first step.

Carnie simply did not know how to approach women as he had never had to make:

> a move on a woman, the first move on a woman. I mean I flirt. I know how to flirt and stuff, but… I've never made the first move on a woman. . . . And I guess I should learn.

Abdul looked for groups of African WLWH, as this search strategy corresponded to his cultural and religious background. Since he tested positive, these groups are the only ones where he can find a partner also living with HIV. As became evident, none of the participants used websites designed to help PLWH find each other. Only Sara had any experience with online-dating, although she did not try websites for PLWH. The reason is computer illiteracy, which was emphasized by both Mike and Moe: "No. I'm unfamiliar with computers. I don't know how to put my name there. And that is why I avoid [using computers]" (Mike); "I'd like to learn a little bit more about computers, that's about it. . . . That's because it's just part of the normal future" (Moe). There are plenty of dating web-sites for PLWH (such as Pozmatch, Positive Singles, HIV Match), from which participants could benefit and therefore alleviate the most stressful part of their lives.

Summary

The goal of this chapter was to report the findings of the research project. Relationships represent the most stressful part of living with HIV illness, and the majority of participants decided to abstain from them simply because of a lack of knowledge about

how and when to disclose. Thus, although desperately wanting to be in relationship,

participants could not let themselves take on a partner. None of the participants was

looking for partners using on-line dating websites or other strategies. The findings also

revealed poor knowledge of harm reduction in seroconcordant and serodiscordant

relationships.

Chapter Five: Discussion

In this chapter, I discuss the findings of this research study as well as the relevant literature. In order to answer the initial research question, "What is the experience of heterosexual PLWH in terms of partner-seeking in a Western Canadian city," qualitative methodology and narrative approach were utilized. Following the principles of good qualitative research identified by Patton (2015), this study illuminates the meaning of partner seeking, as captured through stories of PLWH, and reveals the importance of social context. Narrative research allowed me together with the participants to co-construct accounts of their lives after being diagnosed with HIV and, through that process, to better understand their experience of being single heterosexual people living with a chronic illness. One of the distinctive feature of narrative research and the reason why it was chosen for this research project, was its relevance "to examining the ways in which an individual's self-identity is challenged and changed through the impact of traumatic life events" (Thomas et al., 2009, p. 789).

Semi-structured interviews were used as the main data collection technique, and the point of data saturation was reached by the eighth interview; however, I decided to conduct two additional interviews to make sure no new data or themes emerged. The interview guide was developed considering the sensitive matter of the discussion and included questions related to the experience of being diagnosed with HIV illness and relationship challenges. The first set of questions helped to illuminate the context in which each participant lived, which, in turn, was related to their relationships patterns and challenges.

This discussion chapter begins with a thorough review of the themes that emerged during research: receiving the diagnosis, coping with HIV illness, stigma, and education. The focus then moves on to a discussion of relationships of PLWH, focusing on celibacy, the need for disclosure as the main obstacle for relationships, HIV status as one of the partner selection criteria, search strategies, and decreased sex drive. I also determined it was necessary to include a separate section about the factors that influenced partner-seeking experiences among participants. Many of these factors are related to the context of living with HIV, which is discussed in the first section of this chapter. Thus, the reader will be able to see clearly how invaluable the context is and how many aspects of living with HIV are intertwined. This is followed by recommendations, limitations, and directions for future research.

Life after Receiving the Diagnosis

Although in most cases participants began their stories with the moment they received their HIV-positive test result, I begin with the factors that, according to the participants, pre-determined behaviours that posed a risk of acquiring HIV.

Contribution of childhood traumas. According to many participants, the lifestyle that eventually resulted in the HIV diagnosis was established in their early years. In some cases, participants' childhoods included sexual assault, not having a close or loving relationship with their parents, and being raised in a foster home. The findings of this study are confirmed by Seedat (2012), who stated that indeed a history of trauma greatly contributes to acquisition of HIV. The combination of HIV infection and childhood trauma prevalence is so high that some authors have called it "the syndemic illness of HIV and trauma" (Brezing, Ferrara, & Freudenreich, 2015, p. 108). In turn,

trauma is associated with poor adherence to medications, poor HIV-related health

outcomes (Brezing et al., 2015), and poor quality of life for PLWH (Troeman et al.,

2011). The prevalence of moderate or severe childhood sexual abuse among PLWH was

shown to be around 30% in several studies (Lee et al., 2015; Whetten et al., 2006), with

Aboriginal communities being affected by childhood sexual abuse most of all (PHAC,

2008). Childhood sexual abuse among Aboriginal peoples is to great extent a legacy of

the residential school system and is well known to have contributed to various forms of

addictions (e.g., drug use, gambling) and utilization of maladaptive coping, thus affecting

the entire lives of individuals (Dion, Collin-Vézina, De La Sablonnière, Philippe-Labbé,

& Giffard, 2010). Whetten et al. (2012) also found that heterosexual males living with

HIV who experienced childhood sexual abuse were more likely to lose trust in health care

providers, and have higher rates of post-traumatic stress disorder (PTSD) and depression.

The latter may explain the suicide attempts in several participants, which they explained

as the result of shame and fear of rejection because of their stigmatized conditions. As

McCall and Lauridsen-Hoegh (2014) noted, while colonization and experiences of

interpersonal violence lead to hopelessness and depression, childhood sexual abuse

increases risk of acquiring HIV by creating threats to bodily integrity. Moreover, one

participant in this project, who told of being sexually abused in her early childhood,

showed signs of revictimization by overidealizing her sexual partners despite the

continuing harm they inflict upon her.

Another consequence of childhood trauma was a higher number of sexual partners

(Klein, 2014; Whetten et al.,2012). Emotional maltreatment in childhood has profound

and long-term consequences. It predisposes health-compromising behaviour in adulthood

and engagement in relationships lacking commitment and stability (Wilson & Widom, 2011). As Preston, D'augelli, Kassab, and Starks (2007) explained, emotional maltreatment results in lower self-esteem, which is associated with the lack of power to make choices about what is best for one's health (Klein, 2014). According to the participants in this project, experiencing violence from parents and not having a loving relationship with them, created an urge to seek love from someone else; for some participants, this resulted in misinterpreting sex for love and thus taking multiple sexual partners. Indeed, some authors showed that healthy relationships with parents contribute to future healthy romantic relationship patterns (Del Toro, 2012). Dinero, Conger, Shaver, Widaman, and Larsen-Rife (2008) found that parent-child interactions in adolescents predicted attachment styles in romantic relationships in early adulthood, thus emphasizing the great influence parents have on children.

Another childhood trauma mentioned by Aboriginal participants was related to being raised in foster homes, especially if foster parents were not themselves Aboriginal. From participants' perspectives, it created disruption in their cultural identity and brought about feelings of not being loved and of not belonging in the world in which they were brought to live. The importance of culture is pivotal in construction of the self. According to Usborne and Sablonnière (2014, p. 436), "having a clear and confident understanding of one's cultural identity is important for psychological well-being, as it clarifies one's understanding of personal identity." Needless to say, through the history of colonization and residential schools the cultural identity of Aboriginal peoples was taken away, together with the understanding of the world, their place in the world, ideas about what a person should aim for in life, and ways to interact with other people (Oyserman,

Kemmelmeier, & Coon, 2002). In accordance with the explanation given by Usborne and Sablonnière (2014), many Aboriginal peoples, although they may associate themselves with an Aboriginal community, do not have a clear understanding of its norms, values, and behaviours. Without a clear understanding of their cultural identity, personal identity can hardly be clearly established, and as a result, psychological wellbeing is greatly affected (Usborne and Sablonnière). The results of this project confirms this point; according to participants, after leaving foster care they did not have any idea of what they might do with their lives and what kind of lifestyle they wanted to lead. Because of this disruption in their cultural identity, some participants became homeless PID shortly after leaving foster care. Along with homelessness and drug use, foster care for young Aboriginal peoples was shown to be associated with involvement in sex work (Larkin et al., 2007).

Another reason for living a lifestyle with a high risk of acquiring HIV was limited aspirations for the future or future orientation. Positive future orientation (e.g., having goals to pursue, and education or career aspirations) of young adults is associated with safer HIV-related attitudes, better knowledge of HIV, and less likelihood of being engaged in behaviours that predispose to acquiring HIV, including unsafe sex with multiple partners (Cabrera, Auslander, & Polgar, 2009). The results of this research study are also congruent with Cabrera and colleagues' (2009) suggestion that there is a great need to modify future orientation in young people who are coming out of foster care in order to give them a sense of purpose and build life skills, thus reducing their engagement in behaviours that predispose youth to acquiring HIV.

A common thread in this subsection is, of course, historical trauma that penetrates the lives of participants. In light of this, a suggestion made by Lee et al. (2015) is extremely relevant; better patient care begins with addressing existing historical trauma. As one of the participants in this research study emphasized, childhood traumas are still "haunting" her, leading to several attempted suicides, and have prevented her from successfully managing her drug addiction. This finding was also present among people who use substances in the research done by Brezing et al. (2015). As the authors suggested, successful management of HIV in those who have experienced trauma should incorporate a trauma-informed approach. This approach follows several principles: (a) creating a trauma-specific practice environment; (b) recognizing trauma; (c) providing education to patients in order to enhance understanding of the relationships between their trauma and health outcomes; and (d) making referrals to specialists capable of addressing childhood traumas.

Receiving the diagnosis of the HIV illness. The first challenge for people who suspect their diagnosis is the decision "whether or not to be tested, and if tested, whether or not to learn the test result" (Folkman & Chesney, 1995, p. 116). Some people, from one participant's perspective, prefer to not know about their HIV status at all. It can be explained by the fact that the diagnosis of HIV infection brings challenging life experiences that make even the most well-adjusted individuals feel overwhelmed and devastated (Joseph & Bhatti, 2004), as well as the need to reorganize daily life and redefine identity and relationships with the most important and intimate people in their lives (Pecheny et al., 2007).

The major reasons for getting tested cited by participants in this project were the following: (a) engaging in behaviours that pose risk of acquiring HIV (either having many partners or using contaminated injecting equipment); (b) seeing former partners dying from AIDS-related causes; and (c) perceived benefits of earlier testing, such as initiation of HAART. In a qualitative research study on the reasons for seeking HIV testing among 59 adolescents, a clear gender difference was observed (Siegel, Lekas, Olson, & VanDevanter, 2010). Female participants made the decision to get tested mainly because of the perception of their partners' high-risk behaviour and infidelity, while male participants accessed health care because of existing HIV-related symptoms. Similarly, one female participant in the current project also indicated that the primary reason for being tested was a rumor about her partner's infidelity.

In addition, my findings showed that the majority of tests occurred while consulting a health care professional because of HIV-unrelated reasons (e.g., HCV infection, drug use), which has also been noted by Sivaram, Saluja, Das, Reddy, and Yeldandi (2008) and Young and Zhu (2012). In the current project, participants who had HCV infection and agreed to get tested for HIV did not have a perception of being at risk in terms of HIV. In contrast, according to Young and Zhu, the majority of patients *suspecting* their HIV diagnosis chose to come to the health care setting requesting additional testing, unrelated to HIV, in order to cover the real reason of their visit to a doctor. Therefore, negativity and stigma attached to HIV influences behaviours related to testing, and by choosing a different reason to visit a doctor, people attempt to avoid that stigma within the health care system. In other words, HIV-related stigma affects people

even before they know their diagnosis, which shows the power of attitudes existing in society.

Speaking of the perceived benefits of HAART initiation, only one participant in the current project indicated his willingness to start HAART as soon as possible. From a SI perspective, his willingness can be explained by the positive meaning attached to HAART as a symbol. Considering the difficult economic situation in the country from which this participant came, HAART symbolized a chance for and right to life and relationships. However, for other participants, HAART was instead a symbol of a stigmatizing condition they had acquired, with one participant expressing her unwillingness to be "invaded" by medications. Although many people associate their high-risk behaviour with the likelihood of testing HIV-positive (Johnston et al., 2010), the findings of this research study showed that suspicion of having HIV did not make acceptance of the diagnosis any easier.

For some participants, the day of the diagnosis was the dividing point between their life "before" and "after." They remembered the exact date and time of receiving their positive result. Participants also remembered the way health care professionals delivered the diagnosis. A critical point that some health care professionals might miss due to the time constraints of clinical work is the following: It is not only *what* the diagnosis is, but *how* the news is delivered. Importantly, the latter influenced acceptance of the illness among the participants. The lack of explanation of HIV (e.g., that HIV infection is manageable, treatment is easily available, and there are several modes of transmission), the lack of careful considerations of ethics, and perceived stigma from health care providers resulted in depression and difficulty accepting the diagnosis.

115

Stigma, conferred in any way by a health care professional, is very hard to deal with, considering the status held by people in white coats and the common assumption that their knowledge is free from bias or prejudice. Therefore, it is of the utmost importance to promote education that teaches health professions students about respectful communication with patients, regardless of the illness they are suffering.

Indeed, education is one of the ways to normalize HIV, particularly when PLWH are involved in educational activities provided for health profession students (Maim, Sutankayo, Chorney, & Caine, 2014). As Paxton (2002) discovered, educational activities with an educator living with HIV decreased fear and stigma, emphasized the preventable nature of HIV, and reinforced harm reduction strategies. Participants in this project emphasized a variety of ways in which HIV education can happen; in schools during sex-education classes, on the streets, and in one-on-one conversations. There is great dignity in being a person living with HIV and providing education on the subject of living with HIV; societal prejudices can be confronted head-on. These educators show that they are no different from others, thereby resisting the process of "othering" as described by Goffman (1963). They have their stories, life circumstances, struggles, and, sometimes, poor choices like everyone else.

In the narratives of many participants, education was a very salient theme. Self-education on the matter of HIV was the first step towards the acceptance of HIV illness and incorporation of a new identity as a person living with HIV, resonating with the conclusions made by Baumgartner (2007). Some participants chose to be HIV educators, a decision that cannot come without the complete acceptance of HIV illness. As a person living with HIV and an educator on the subject of HIV, open and willing to answer all

116

relevant questions, participants realized the power of their knowledge that came from their first-hand experience.

Coping with HIV illness. Across the narratives, there was a variety of grief scenarios, in which participants took several months to several years to come to terms with their chronic condition or to cope with their illness. There are several coping styles that PLWH use, ranging from benefit-finding, that is finding positive changes in life after a stressful event (Antoni, 2011; Friedman, 2011), to complete avoidance (Moskowitz et al., 2009) and denial (Kamen et al., 2012).

At the beginning, almost all of the participants in this research study used denial or avoidance coping, as did many of the PLWH in a study by Joseph and Bhatti (2004); and for those participants who received their diagnosis while being in jail, acceptance took even longer. The challenge of accepting the diagnosis hides in fact that PLWH feel the need to repress their new reality (Moitra et al., 2011), thus denial as a coping strategy is commonly utilized. Only a small number of participants preferred to use active coping strategies, such as educating themselves on the subject of the HIV illness or quitting drugs and alcohol use to maintain better adherence to antiretroviral therapy. One of these participants emphasized that knowing the mode of transmission was critical for disease acceptance, defined as "a person's willingness to experience thoughts, feelings, and physical symptoms without engaging in efforts to avoid or control them" (Delaney & O'Brien, 2012, p. 255).

Notably, there were signs of post-traumatic growth in some of my participants, who clearly identified their life being better after careful reassessment of the importance of their health and well-being. One of them felt even more "cured" than before and was

117

considering other directions for her life in terms of career and education. To clarify, post-traumatic growth does not imply return to a baseline level of functioning, but instead implies significant improvement with a potential to increase appreciation of life and ability to forge intimate relationships (Kamen et al., 2015), which is precisely what this participant described. Although most of the participants accepted the disease and learnt to live with it, HIV illness remained a significant stressor due to its social consequences. In fact, none of the participants talked about side effects of lifelong HAART. As the participants in this study noted, the only reason why they would be stressed about managing HAART was if they had to pay for HIV medications themselves. Instead of mentioning the stress of managing their therapeutic regimen, participants focused on social consequences of living with HIV, which have remained the most challenging aspect for them.

Moskowitz et al. (2013) highlighted that the way people manage the illness reflects the dynamic relationship between the individual and the surrounding environment, meaning that absence of this relationship—or social isolation—has a variety of negative consequences. During life's most stressful events, emotional support from one's closest friends and family becomes essential. Indeed, social support was shown to be one of the strongest predictors of positive adaptive coping and medication adherence in PLWH (Vyavaharkar et al., 2007), which in turn are crucial predictors of successful management of HIV illness. However, many participants in this research study did report social isolation. Social support workers engaged in the work of the ASO also emphasized the profound loneliness that exists in their clients. Social isolation drives

alienation, altered self-perception, and feelings of being less than the other (Cherry &

Smith, 1993), which was articulated by participants in this project.

Social support from family is one of the major factors determining resilience

among PLWH (De Santis, Florom-Smith, Vermeesch, Barroso, & DeLeon, 2013)—a

process that occurs during confrontation with adversity (Dyer & McGuinness, 1996).

Unfortunately, in the case of several participants in this project, family members were

mainly a source of stigmatizing attitudes (e.g., shunning family members who live with

HIV, forbidding them to receive services such as manicure/pedicure at salons, making

PLWH drink and eat from different plates, terminating communications). While being

denied the comfort of family support, many participants started attending the local ASO,

and for some of them, their entire concept of "family" changed; family was no longer

about shared genes, but shared values and acceptance. These findings resonate with those

of De Santis et al. (2013), who found that in the case of loss of relationships with family,

PLWH discover support groups and local ASOs as tremendously helpful sources of

emotional support. Participants in this research project felt so comfortable at a local ASO

that one of the suggestion expressed by a male participant was to have more social events

there to allow him to meet new people and broaden his social circle.

Some of the participants in this study highlighted other challenges they face that

are indirectly related to HIV, such as housing and the environment in which they live,

money, and drugs. For some participants, the idea of having a safe environment is crucial,

as an unsafe environment leads to a limited social circle consisting mainly of those who

use drugs. Therefore, a safe environment was perceived to be the main condition that

would help them successfully withdraw from drug use. These findings are similar to

findings on the life priorities among PID. According to the cross-sectional data from a sample of 161 PLWH who injected drugs, 63% did not rank HIV illness as their main priority in life (Mizuno, Purcell, Borkowski, Knight, & Team, 2003), mentioning the same salient issues as the participants in this project. Among those participants who did not rank HIV as the most important issue, 27% ranked housing, 18% money, and 8% safety from violence as taking priority. These findings reaffirmed the experiences of the participants in this research project.

Another interesting finding of this research study concerns the feelings held by participants towards the person from whom they contracted HIV. Women (although there were only two females among the participants) expressed negative feelings, while men felt more responsibility for the lifestyle that predisposed them to acquisition of HIV. This finding supports the results of a study conducted by Siegel and Schrimshaw (2003). In a qualitative study focused on celibacy among PLWH, both heterosexual and homosexual, older than 50 years, the authors found gender difference in attitudes toward the person from whom PLWH contracted the virus, either through condomless sexual intercourse or intravenous drug use. Women felt betrayed and angry, and sometimes these feelings grew into rage and a desire to kill the one who infected them. This led to a feeling of general distrust of all men, influencing women's decision to stay away from any kind of relationships. Trust is an essential component of a healthy relationship, as distrust leads to partner abuse, feelings of being jealous, and anxious attachment (Rodriguez, DiBello, Øverup, & Neighbors, 2015). However, victimization, blaming, and anger were almost absent among men (Siegel & Schrimshaw, 2003), which resonated with the findings in the current research project. According to the men who participated in this study, they felt

responsible for acquiring HIV and did not blame the person from whom they contracted the virus.

Encountering stigma. According to the narrators in this project, it is not HIV (the virus itself) that worries them, but rather the processes of acquiring a new identity as a person living with a stigmatized illness. Explained with the help of SI, identity, and Goffman's (1963) theories, from the moment of receiving the diagnosis, HIV becomes embedded in every aspect of a person's life. HIV—or to be precise, the symbolism that HIV carries—profoundly influences the personality of the newly diagnosed. At the center of HIV symbolism lies stigma, which is a recognized obstacle towards the successful management of the HIV epidemic (UNAIDS, 2014b, 2015), and it was a salient theme across all narratives.

The majority of the participants in this research study experienced stigma from different sources, manifesting in different ways. No matter what form HIV stigma takes, it has an exceptionally significant impact on the well-being of PLWH by creating negative assessments of the self, leading to social disconnection and distress (Sanjuan et al., 2013). The main source of stigma in this project was family members, which has also been shown in the literature. For example, in a study by Hosek et al. (2000), ALWH had to hide their diagnosis from family members. Many participants in the current project have experienced shunning and isolation following disclosure of their HIV status to family members. As Henry et al. (2015) discovered, around 30% of PLWH who disclosed considered it a mistake that they deeply regretted. Only one participant in this research project expressed regrets about disclosing to her family members immediately upon receiving the diagnosis. The rest of the participants did not talk about having any

121

regrets about their decision, and by disclosing, many participants wanted to educate their relatives on the matter of HIV and update them on their HIV-related health status.

Some participants encountered enacted stigma which delayed employment. HIV-related employment discrimination can manifest in denial of employment despite qualifying for a job, limited career development opportunities, stigmatizing attitude at the workplace (Lepore, 2011; National Center for AIDS/STD Control and Prevention, n.d.; Scaccia, 2014), and being refused access to educational opportunities and promotions (Global Network of People Living with HIV, 2012). One participant could not obtain the medical clearance required to attempt a driving test, and therefore could not find a job as a driver. Thus, after coming to Canada as an asylum seeker, he was left to survive without any income. Every case of stigma and discrimination in the workplace hides someone's personal story of frustration and devastation of being rejected by society and deprived of an opportunity to provide for themselves and their family.

Children of one of the participants experienced courtesy stigma, or "stigma-by-association" (Mason, Sultzman, & Berger, 2014, p. 323), which "refers to a person who perceives or experiences stigmatization due to their association with a person who bears the chastised attribute" (Liu, Xu, Sun, & Dumenci, 2014, p. 1). Courtesy stigma profoundly influenced both the children and their mother living with HIV. For children whose parents are living with HIV, the necessity to choose the position to stand for in regard to their parents' HIV status is exceptionally stressful (Mason et al., 2014). As Mason et al. (2014) showed, keeping one's mother's HIV status secret limited teenagers' interactions with peers but in some cases led to reinforcement of the mother-teen connection. Interestingly, in this research project, one participant was motivated to fight

drug and alcohol addiction to stay connected with her children and transfer to them her knowledge. This finding is similar to that of Baumgartner and Niemi (2013), who, from the standpoint of the identity theory, explained that the new identity of living with HIV forces some PLWH to bring back their identity of being parents, "stolen" by drug and alcohol addiction.

"Double," or layered (Grossman, 1991), stigma, is "HIV-related stigma combined with stigma towards marginalized groups—a scenario MSM and SW [sex workers] frequently experience as they are often assumed to be core transmitters of HIV infection" (Brown, Bailey, Palmer, & Tureski, 2012, p. 1). Concerns about the association of an HIV diagnosis with behaviours perceived by society to be undesirable were expressed by the participants in this research project. For example, one participant was more stressed about his family members' concerns regarding his sexual orientation than about concerns related to the illness itself. This unease was rooted in the participant's cultural background, as he came from a country with comparatively conservative views on homosexuality. Indeed, different people have different attitudes and laws that impact MSM (Pew Research Center, 2013), from being pro-active in fighting for LGBTQ rights (e.g., Canada, Brazil) to imprisonment and even the death penalty (e.g., Yemen, Nigeria, Somalia, Saudi Arabia) (Rupar, 2014).

Stigma layering also exists when a person is co-infected with HIV and HCV infection. Surprisingly, despite similarities between HCV infection and HIV infection (such as identical routes of transmission although with slightly different probabilities of contraction), the two illnesses are very different clinically, psychologically, sociologically, and epidemiologically. As this research study showed, one co-infected

participant perceived HCV and HIV-related stigma differently. HIV-related stigma was more salient and gave the participant more reasons to be worried, which is congruent with the findings of a qualitative study that explored stigma layering among 132 HIV/HCV co-infected patients (Lekas, Siegel, & Leider, 2011). According to these authors, the majority of patients had a "hierarchy" of stigmas they had to deal with. HIV-related stigma was identified as the most important, while only a small number of participants mentioned that these two stigmas were perceived as equally worrisome.

Self-stigma, which is the result of the internalization of HIV stigma by PLWH (Joffe, 1999), was also noticed among the participants in this project. It is well known that self-stigma leads to cessation of any social contacts, blaming, self-devaluation, and, accordingly, the domination of stigma in the internal world of PLWH (Green, 2009). Thus, self-stigma influenced every aspect of participants' lives and, in particular, their relationships. Some participants felt as though they were "less human than before" or worse than other people; self-stigma appeared to be one of the factors that influenced the decision to stop seeking a partner, which might be explained by its effect on self-esteem (Arrey, Bilsen, Lacor, & Deschepper, 2015). These findings mirrored those of France et al. (2015) who noted that self-stigma greatly affected the self-perceptions of PLWH, resulting in hopelessness, self-pity, and restricted agency in terms of opportunities and actions. For some people, this restricted agency included perception of not being able to find a life partner, the necessity of choosing friends from a particular circle, and an inability to work at a desired workplace.

Moreover, several Aboriginal participants mentioned HIV-related stigma in small communities. One male participant was concerned about the consequences of disclosure,

such as the lack of understanding and cessation of communication, while another female participant had to move to a different province in order to avoid further discrimination and violence on the part of the members of her community. These results might be explained by the difficulties in maintaining privacy and anonymity as well as conservative views that are quite common in small communities (Tiemann, 2006). Indeed, Gonzalez, Miller, Solomon, Bunn, and Cassidy (2009) showed, community size has an impact on HIV stigma. However, in contrast to the findings of Gonzales et al. (2009), the hypothesis that PLWH living in rural or micropolitan areas would report higher levels of HIV stigma compared to PLWH living in metropolitan area was not confirmed. Gonzales and colleagues explained this outcome by citing the limitations in their study, including a small number of rural women involved in the project and failure to include a variety of important variables that might contribute to better understanding of the impact of community size has on HIV-related stigma. However, the authors found that overall, rural WLWH reported higher stigma levels compared to males living with HIV. In addition, rural women reported more disclosure concerns than rural men and metropolitan women (Gonzalez et al., 2009).

Relationships of PLWH

When asked about the most stressful part of living with HIV, almost all participants noticed how profoundly the HIV diagnosis has influenced their relationships and intimate life. Indeed, having a relationship was considered a part of a "normal life," the one that the participants did not feel they had and, at the same time, desired so desperately. As Sastre et al. (2015, p. 146) noted, "Quality of life is related to a satisfied

personal life including a healthy sexual and dating life as well as, for some, the expectation of marriage and family."

A steady partner was shown to have beneficial effects for PLWH in terms of being more sexually satisfied (Hankins et al., 1997), experiencing significantly less intimate partner violence (Antle, Karam, Christensen, Barbee, & Sar, 2011; Cleary Bradley & Gottman, 2012), and following sexual behaviours that posed less risk in terms of acquiring HIV (Heitgerd et al., 2011). Unfortunately, despite a good understanding of the importance of a healthy relationship in their lives and extensive discussion of dreams about having someone close to themselves, most of the participants in this project did not anticipate having any relationships in future.

A regular partner was also associated with the desire to have children (Ogilvie et al., 2007) and better quality of parenting (Fagan & Lee, 2014; Tartakovsky & Hamama, 2011). As the current research study showed, even those participants with a pessimistic vision of their romantic life, viewed children as one of the normal desires that relationships promise. Pregnancy desires and intentions were well-described in the HIV-related literature, and data show an increase over time in the number of PLWH willing to have children or planning pregnancy (Berhan & Berhan, 2013). For example, Carter et al. (2013) provided a review of 32 articles published between 2001 and 2012. They found that many young PLWH were sexually active and desired pregnancy at some point in their future. .

Turn to celibacy. HIV diagnosis triggers profound identity changes, as was quite evident from analysis of the relationship challenges of the participants. The appearance of a new identity as a person living with HIV resulted in identity crisis and brought about

126

feelings of despair and unhappiness. Those who used to have very active intimate lives

suffered because of a tremendous contrast between their levels of intimacy before and

after being diagnosed. In some cases, participants significantly decreased interactions

with the opposite sex. In others, PLWH turned to celibacy right after receiving the life-

changing news—the most striking finding of this research project.

Periods of celibacy varied among participants and lasted from several months to

two decades. For some, celibacy was time spent reassessing their identity in relation to a

potential partner. Participants spoke about knowing and understanding more about how a

relationship works and how they would behave toward a potential partner; nevertheless,

this reassessment did not lead to active partner-seeking. The same results were noted by

Baumgartner (2007). According to her, after incorporating the identity of a person living

with HIV, PLWH tend to reassess their former relationships and their roles in those

relationships.

While in some cases the turn to celibacy was caused by the process of taking on a

new identity of a person living with HIV, another possible reason, articulated by female

participants, was the blame and anger felt towards the person from whom they contracted

the virus. The same results were shown by Siegel and Schrimshaw (2003) in their study

of issues of intimacy among PLWH. According to their findings, being diagnosed with

HIV for women usually led to the negative feelings toward the partner who did not

disclose his HIV status. Meanwhile, for men, feelings of victimization or anger towards

the person from whom they contracted the virus were almost absent. Another interesting

finding in the research by Siegel and Schrimshaw was that women's decisions to abstain

from relationships were predominantly emotionally driven; the reasons for celibacy

included pursuing their own needs, concerns about reinfection and risk of infecting their

partners, and trauma of being abandoned because of the diagnosis. However, as Siegel

and Schrimshaw (p. 198) stated, "with the men, one had the clear impression that their

choice to be celibate was usually the outcome of a reasoned decision-making process."

The reasons for celibacy among men included perception of guilt following sexual

intercourse due to the risk of transmitting the virus, performance problems, and stress of

caring for partners who had died from AIDS-related causes. However, men perceived that

prevention measures might diminish these concerns, and several men were eager to

regain their sexual activity, while women were very strict about their celibacy, and some

experienced aversion to sex (Siegel & Schrimshaw).

In another study by Bogart et al. (2006), 415 of 1,339 heterosexual men and

women and bisexual men/MSM were deliberately abstinent. Sexual abstinence was more

common among heterosexual participants compared to bisexual men and MSM; the

decision to abstain from intimate relationships was associated with older age and a

stronger sense of responsibility. In another study among heterosexual PLWH with

unstable housing, Courtenay-Quirk et al. (2009) described 20% of their sample as being

abstinent by choice. The reasons for sexual abstinence included the following: having no

interest in sex, being afraid of transmitting the virus, having no primary partner, being

afraid of the risk of reinfection, and higher education among heterosexual males. In

addition, experiences of social exclusion and shunning by family members incited fear of

any relationships, including intimate, among ALWH (Hosek et al., 2000). Sastre et al.

(2015), in a study of dating and marriage approaches among heterosexual MLWH, found

that rejection following disclosure, internalization of stigma, and accepting the thought

128

that they could never have the same quality of relationships as when they were not living with HIV, all confirmed the decision to stop engaging in relationships.

Resonating with the findings of the previously mentioned projects, participants in this research project named the following additional reasons for celibacy: (a) decreased self-esteem and self-isolation following the diagnosis; (b) perceived stress of disclosure; (c) fear of transmitting the virus to an individual who does not live with HIV; and (d) fear of acquiring resistant strains of HIV.

The findings of this research project also suggest that stigma is a complex social construct that has the ability to form and be internalized very quickly: While one of the participants, prior to his own diagnosis, dated a woman who was living with HIV, he did not express or feel any stigma toward her. In fact, he was very protective of her. However, after becoming a person living with HIV himself, self-stigma began to dominate. These findings parallel those of another qualitative study that focused on psychological and social issues faced by WLWH (Hosek et al., 2012), in which the perceived self-worth of WLWH was considerably less than the self-worth of women who did not live with HIV. WLWH also reported emotional abuse and a perceived necessity to stay with a partner who express violence or who infected them because of the fear of being rejected by other men. According to Sastre et al. (2015), similar compromises were made by heterosexual MLWH who chose to date transsexual people of the same status, although they would never have engaged in a relationship with transsexual people while being HIV-negative themselves.

Among participants, childhood trauma profoundly influenced relationships dynamics. One noted that physical and sexual abuse as a child led to the formation of

129

relationships characterized by intimate partner violence. Actually, intimate partner violence has become a reality of our post-colonial time, where Aboriginal women are disempowered, and various forms of oppression are internalized (Stark, 2013). Devaluation of Aboriginal women's rights has significantly increased the social acceptability of the coercive control that male partners have in relationships, thus underlining the influence of gender inequality (Pedersen, Malcoe, & Pulkingham, 2013). Driven by gender inequality, intimate partner violence is aggravated by other SDH (e.g., poverty) that come into play and which altogether significantly affect mental health (Alani, 2013). As one female participant described it, all these factors created a vicious circle of sexual abuse, drug use, and loneliness.

For some of the participants, relationships were tightly connected with the cultural background; shared tradition and world view played a major role in the partner selection process. Indeed, spirituality was interwoven in definitions of relationships, highlighting respect for each other and the importance of having equality in giving and receiving emotional support. Baumgartner and Niemi (2013) similarly found that after receiving the diagnosis, the saliency of spiritual identity increased in participants, as many of them stated that they started praying more than before and were more engaged in religious activities.

Other participants in this research project, who already had experience in relationships both before and after diagnosis, emphasized that there is no relationship without openness and acceptance, thus leading to the main obstacle encountered by those willing to be engaged in relationships—the necessity to disclose at some point in future.

Disclosure. Disclosure is a heavy burden for all PLWH, and the participants in this research study expressed concerns and confusion about not knowing the best time and strategies to disclose. Only two participants in this project expressed a clear idea of the disclosure strategy they preferred to use. According to them, disclosing as soon as possible was perceived as the best strategy because it allowed the other person some time to decide whether a relationship could continue. In this way, the participants gave the power to decide on the future of their relationships to potential partners.

Kimberly, Serovich, and Greene (1995) described six stages of disclosure: (a) adjusting to the diagnosis and dealing with the shock of testing positive for HIV; (b) evaluating personal skills required for disclosure; (c) assessing whether a particular person should be told; (d) evaluating circumstances appropriate for disclosure; (e) attempting to foresee the recipient's reaction; and (f) identifying motivation for disclosure. Knowledge of the stages of the disclosure process is crucial for all practitioners working with PLWH, because it might help to provide PLWH with psychological help specific for each stage, thus making disclosure as safe as possible (Medley et al., 2009). Pecheny et al. (2007) underscored the most significant factors affecting disclosure, which include the type and length of relationship with a person to whom PLWH want to disclose, the anticipated reaction, and the serologic status of the other. Keeping these factors in mind when making the decision about telling somebody of the HIV diagnosis might help to decrease the rates of non-disclosure, which predisposes one to self-isolation and, therefore, the absence of any social support (Green, 2009). However, support is vital for intimate relationships as well; as Baumgartner and Niemi

(2013) noted, support from one's social circle together with education on the subject of HIV can help to restart one's intimate relationships.

As different authors have shown, the key motives for non-disclosure are various and include fear of blame, unwillingness to upset family members, not being emotionally prepared to disclose (Medley et al., 2009), fear of discrimination at work, and the attempt to avoid pity and maintain daily routines (Pecheny et al., 2007). However, some PLWH have recounted that the people to whom they disclose became even more caring (Medley et al., 2009), especially nuclear family members like parents and siblings (Pecheny et al., 2007). Therefore, these findings support the idea that expectations of the outcomes of disclosure are exaggerated, and the possible reasons for this are self-stigma, defined as an individual's acceptance of stigma as part of his or her conceptualization of the self (Herek, Gillis, & Cogan, 2009), and stigma existing in society (Delaney & O'Brien, 2012). Disclosure and stigma comprise a vicious cycle. Disclosure leads to stigmatization, especially if done through gossip and rumor (Petersen et al., 2010), and stigmatization in society substantially affects disclosure rates (Lyimo et al., 2014).

HIV status of a potential partner. The current findings clearly show that HIV status, along with personal preferences such as beauty, intelligence, understanding nature, and similar cultural and spiritual backgrounds, play a meaningful role in partner seeking. Only two participants stated they would not consider HIV status as a criterion, while HIV status mattered to a greater or lesser extent for the rest of the participants.

Three participants indicated their desire to have a partner who does not live with HIV due to the fear of acquiring resistant strains, or the perceived absence of the rationale in having "two sick people together," or the hope of discovering a cure for HIV infection.

132

The rationale behind the preference of having a partner who also live with HIV included shared understanding of the problems related to living with HIV, taking better care of their health, self-stigma that prevents from seeking a partner who does not live with HIV, and greater ease in or absence of the need to disclose. Some WLWH in a research study by Keegan, Lambert, and Petrak (2005) mentioned that having a partner of the same status would allow them to be more open, while others stated that having a partner who does not live with HIV would help to maintain a sense of "normalcy" and be a part of "normal" society (p. 651). However, both choices posed issues—the possibility of transmitting drug resistant strains and having to deal with disclosure. Some women also said that because they were feeling like "damaged goods," they made compromises and dated men whom they would never have dated before for many reasons (Keegan et al., 2005, p. 651).

Squire (2003) explored how HIV changes partner selection criteria. According to her findings, HIV creates an additional criterion for choosing a partner, in addition to social and personal compatibility. To PLWH, finding a person who also live with HIV or at least one who would understand HIV is an additional criterion. According to those engaged in a relationship with another person living with HIV, women no longer felt lonely and left alone to deal with HIV, taking medications, deciding on a HAART regimen, and visiting specialists. However, not all seroconcordant relationships allowed for less HIV-centred attitudes, where partners could forget about HIV. In some cases, women perceived that their seroconcordant partners chose them because of HIV and not because of their personalities, which created a conflict. Indeed, as Squire (p. 87) mentioned, stories of romance between two PLWH are quite messy and lead to questions

133

about "whose illness, whose guilt, and whose death [drives] the story." Squire also

showed that in seroconcordant relationships, WLWH usually act as representatives of

their partners who are also living with HIV by contacting HIV service providers. In many

cases, women act as a link between a man and a service provider, while in the current

study, single WLWH rarely attended the ASO, and the majority of clients were men. One

possible explanation might be that the ASO holds cooking classes, which are usually

attended by 5–10 men. As one of the participants noted, he comes to these cooking

classes because he wants to know more about healthy eating and learn to cook food for

himself. Women in this project did not mention it as the reason to come to the ASO; their

rationale for coming to the ASO was usually an appointment with a social worker.

As Jarman et al. (2005, p. 542) recounted in their qualitative study on post-

HAART era relationship experiences, having a partner to whom women could disclose

and who understood the HIV context provided women with a psychological shield from

experiencing "otherness." This allowed women to relax and have some rest from the

sense of social isolation associated with hiding their identity as a person living with HIV

from other people (e.g., co-workers, friends). In contrast, the inability to disclose to a

partner made women hold tight boundaries around their new identities, therefore creating

inner conflict because of the necessity to manage duplicitous identities. This conflict had

a significant emotional cost. Indeed, some women realized the importance of the

protective function of relationships only when they terminated a relationship and no

longer had that protection. As Jarman et al. suggested, relationships may influence how

the identity of a woman living with HIV relates to other identities within the self, thus

emphasizing the importance of talking about relationships in the context of HIV as one component of integrated HIV care.

Search strategies. All of the participants in this research project expressed difficulties in finding a partner. Men stated that it was difficult to find any potential partners at the ASO, because there were very few women. The same concern was expressed by both heterosexual women (Gurevich et al., 2007) and heterosexual men (Sastre et al., 2015) in other studies.

Despite the availability of many search strategies, such as meeting potential partners at support groups, through personal columns of HIV-related magazines, or other social contacts (Squire, 2003), participants in this study did not use any of them, and the majority took the approach "if it comes, it comes." However, there is an interesting search strategy that is getting more attention in this virtually-connected era—HIV dating websites. Mazanderani (2012) explored the phenomenon of viral sociality among WLWH. As she stated, the practice of online dating is important for PLWH, because it allows them to put disclosure upfront instead of wondering whether this potential partner would accept their HIV-positive status later in the relationship. Women explained that they could better manage disclosure, as it was up to them whether or not they wanted to share their photograph. Also, they could carefully select the information to be made available on their profiles. Most of the women in Mazanderani's research were looking specifically for partners living with the same illness, because they perceived seroconcordant relationships to be mutually supportive both emotionally and practically.

However, viral sociality was not present in the current project as none of the participants used HIV-dating websites. One chose to register on a regular online dating

website. She was soon disappointed, as she perceived that men solely desired sex, and their intentions were too different from hers. However, there is a possibility that people on HIV dating websites are quite different in terms of desires and aspirations. As this research showed, one of the changes most desired of future relationships was the opportunity to have children and a family. However, while having intimate relationships mattered for the participants, it was not their first priority.

Decreased sex drive after diagnosis. According to one of the female participants, after receiving the diagnosis, she lost interest in sex. It is necessary to note that the sexuality of this participant was greatly affected by historical trauma and sexual abuse that many Aboriginal people bear. Loss of interest in sex is a common phenomenon, as receiving the diagnosis of HIV illness is a life-changing event. In a qualitative research study by Keegan et al. (2005), many women experienced the same decrease in sex drive. The reasons for this included constant thoughts about HIV and the fear of transmitting the virus to an intimate partner, which influenced enjoyment and ability to achieve orgasm and which points to the existence of a variety of challenges in navigating healthy and satisfying sexual lives among WLWH (Kaida et al., 2015). One's sexuality can be significantly affected by the diagnosis of HIV infection. . Changes in sexuality can be related to the feelings as a transformed sexual subject or object (Gurevich et al., 2007). In the majority of cases, WLWH need time to adjust sexually, a period that can vary in length after receiving the HIV diagnosis (Hankins et al., 1997). As Hankins et al. (1997) noted, right after the diagnosis, sexual satisfaction levels drop, but then can rise even higher than before the diagnosis. Many women reassessed their

sexuality, which they took for granted prior to their diagnoses—this is precisely the experience of one of the female participants in this research project.

Heterosexual MLWH can also experience changes in sexuality. Missildine et al. (2006, p. 313) noted that the feeling of being "contaminated" with the virus affected masculinity and sexuality in a variety of ways. For example, of 18 heterosexual men in Missildine et al.'s study, many indicated that losing their sense of self and the fear of transmitting the virus were factors that prevented them from initiating or continuing relationships with a steady partner. Participants perceived themselves as a threat to the ones they cared about; therefore, they experienced the so-called "split" between partners they cared about (and with whom they therefore avoided intimacy) and partners with whom they engaged in for casual sex. Thus, MLWH avoided significant emotional intimacy and expressed their sexuality through casual partners, who in many cases were sex workers. Missildine et al. suggested the existence of a split of the sexual-emotional domain, as only 1 in 18 participants effectively integrated emotional intimacy and sexuality after receiving the HIV diagnosis. Most of the men desired emotional intimacy, and sexuality was seen as the way to express it. Therefore, having a steady partner who would provide emotional intimacy and at the same time would understand changes in sexuality was an important factor in maintaining resilience (Missildine et al.).

In order to understand why sexual function drops, it is important to look at sexuality from a SI perspective. As Longmore (1998) emphasized, sexual behaviour is symbolic, as the meanings attached to every aspect of sexuality change the way people think about themselves and other people's attitudes toward them, and is a deeply social phenomenon.

137

Socialization is a "process of social interaction by which individuals selectively acquire the skills, knowledge, attitudes, values, motives, norms, beliefs, and language of the group of which they are or will become members" (Longmore, p. 53). However, what if there is no socialization? What about those cases, when the presence of a *spoiled identity* interferes with the process of socialization and puts an individual outside of society? By not having this opportunity, an individual's self cannot be created and shaped. If an individual is isolated and experiences no sexual socialization, there can be no formation of new or development of existing identities, as well as no self-evaluation that would help to position an individual within the context of intimate and reciprocal interaction (Longmore).

Lack of knowledge of harm reduction. Another important finding of this research project is that the primary rationale for seeking a partner living with the same illness was the perceived obsoleteness of condoms. However, this lack of understanding of effective transmission prevention might pose a public health threat, because HIV superinfection—acquisition of a different strain of HIV from another person living with HIV—is quite common (Campbell et al., 2009; Poudel, Poudel-Tandukar, Yasuoka, & Jimba, 2007; Redd, Quinn, & Tobian, 2013; Smith, Richman, & Little, 2005). The same finding was observed in a study by Rhodes and Cusick (2000). As these authors emphasized in their study of intimacy among 73 heterosexual, homosexual, and bisexual PLWH, searching for a partner who was also living with HIV was the result of emotional and pragmatic risk decision-making, which can be considered from within both a social (i.e., public health risk management) and individual (i.e., relationship risk management) lens. The results of this study by Rhodes and Cusick, as well as findings in the current

138

project emphasize the need to provide all newly diagnosed PLWH with information that would help them to make informed decisions about risks and benefits of being engaged in both seroconcordant and serodiscordant relationships.

Factors Influencing Partner-Seeking Experiences

The voices of the participants revealed several factors that influence partner-seeking experiences, whether an individual decided to stop seeking relationships or, in contrast, was interested in finding a person with whom he or she shared a strong emotional and physical connection. These factors, working in synergy and influencing one another, contributed to making a decision regarding partner-seeking.

Poor body image, which in some cases resulted from experiences during childhood, was a factor that might contribute to the decision to stop seeking a partner. As some participants noted, they felt less attractive and desirable to the opposite sex. These feelings affected participants' sexuality and resulted in decreased sex drive and loss of interest in looking for a partner. However, one participant clearly stated that she has reassessed her sexuality and was interested in seeking a partner. Moreover, through reassessment of their experiences—mistakes made in former relationships, and components of healthy relationships—some felt ready to be engaged in a new relationship as a caring and supportive partner. However, the perception of the possibility of transmitting the virus to a potential partner, even when the risk was close to zero, stopped participants from engaging in a relationship. In contrast, salient spiritual identity gave hope to find a partner. Another factor, HAART, was also taken into account when considering an opportunity to be in a relationship. Successful HAART, which helped to achieve undetectable viral load, was perceived as one of the factors that made

139

relationships possible for PLWH. However, and despite this, some participants used the HIV status of a potential partner as an additional selection criterion. Half of the participants perceived seroconcordant relationship as desirable because of shared understanding, the absence of the need to disclose, the ability to take better care of health due to joint efforts of both partners living with HIV, and a perception of lower self-stigma. Others believed that HIV status does not play any role considering the advancement in treatment, or that serodiscordant relationship is preferable since it does not pose risk in terms of acquiring resistant HIV strains. Moreover, participants had a hope for a cure and thought that seroconcordant relationship is more challenging than serodiscordant.

Recommendations

Findings of this project revealed how childhood experiences (e.g., being sexually abused and brought up in foster care) affect lives and relationships of PLWH. These findings, along with available literature, highlight a great need to address historical trauma among Aboriginal peoples who are at risk or living with HIV. The Truth and Reconciliation Commission ([TRC], 2015) clearly stated the importance of bringing back the cultural identity of Aboriginal peoples, which is crucial in managing the horrific consequences of historical trauma to social and intimate aspects of people's lives. Respectful relationships may be achieved by creating equal educational opportunities, revitalizing Aboriginal cultures and traditions (with particular attention paid to Aboriginal languages and spiritual ceremonies), and providing Aboriginal peoples with the opportunities to speak up about their experiences in the residential schools system and trauma they continue to experience today (TRC, 2015). In light of this, utilizing a trauma-

informed approach in caring for people who experienced any kind of abuse, with particular attention to childhood sexual abuse, is critical. Moreover, a trauma-informed approach should include not only victims, but also family members and partners. In this case, faster and more sustained recovery can be achieved in the therapeutic process (Mcllwaine & O'Sullivan, 2015). A trauma-informed approach should also be incorporated in the criminal justice system, as understanding of the complexities of victim responses is crucial to the service of justice. Moreover, by using a trauma-informed approach, service providers might be better equipped to screen for abuse and domestic violence (Randall & Haskell, 2013).

Taking in account the legal context of HIV, there is a great need for organizing a strong working group consisting of various stakeholders (e.g., HIV researchers, health care professionals, policy-makers, service providers, PLWH) to contribute to the development of criminal law concerning HIV. Currently, criminal law has a number of gaps regarding when non-disclosure should and should not be prosecuted. Some of these uncertainties could be resolved if medical and scientific evidence was enacted by healthcare professionals, researchers, and knowledge brokers.

Looking at the bigger picture, health issues should be framed within the discourse of SDH, which define vulnerability to infectious diseases in general and HIV in particular. For example, without addressing gender social injustice and gender inequality, women remain at risk of HIV. Although these issues "are rooted in a long history of tradition [and] colonisation" (Anderson, 2015, p. 156) and cannot be fixed easily, bringing to the table local perspectives of the context and empowering women would help immensely.

Some recommendations can be fulfilled at the level of ASOs. The ASO setting is ideal, since PLWH already acknowledge ASOs as safe environments; therefore, organizing more social events at the level of ASOs could have the potential to make PLWH more comfortable with meeting new people and help to build social skills. During the first visit of a new client, support workers should include in their conversations discussion of alternatives to abstinence (Bogart et al., 2006), including sex-positive messages (Hankins et al., 1997) and self-determination opportunities (Carter et al., 2013). This would allow increased understanding of sexuality by PLWH and would help them to live full, meaningful lives. Counselling of newly diagnosed people should also include discussions of the components of healthy relationships, both generally and in the context of living with illness. This counseling should also touch on effective communication, conflict resolution, and family planning (Fair & Albright, 2012; Sastre et al., 2015). Because the greatest fear of PLWH who chose celibacy was the need to disclose, another strong recommendation for support workers at ASOs is to promote knowledge about how to disclose safely (Greenhalgh et al., 2013) including the legal context of HIV in Canada. However, before doing so, the psychosocial issues associated with disclosure should be fully understood by support workers and those at local ASOs; therefore, the importance of involving a counsellor with expertise in HIV and organizing gender-, culture- and HIV-sensitive training for support workers cannot be undervalued (Carter et al., 2013). Such a strategy would allow enhanced support to be provided to PLWH, including timely referral to specialists (Keegan et al., 2005) and would also help support workers to feel more comfortable about initiating or maintaining conversations with their clients on sensitive topics. Although discussion of HIV-related topics is crucial, it is necessary to

142

address ways to improve self-esteem, self-confidence, and self-worth, as well as coping mechanisms (Hosek et al., 2012) and body image (Palmer et al., 2011). According to Hosek et al. (2012), learning something positive about themselves helps empower PLWH. Empowerment, defined as "action taken to overcome the obstacles of structural inequality that have placed people . . . in a disadvantaged position" (UNAIDS, 2015b, p. 18), is one of the most effective ways to respond to discrimination and marginalization. Also, involvement of Aboriginal peoples in prevention programs is essential, considering the mistrust in health and social services which results from a long history of colonization and discrimination (Negin, Aspin, Gadsden, & Reading, 2015). Considering the power of knowledge that comes from educators who live with HIV, support workers at ASOs might be able to distinguish those who are interested in sharing their experience and engage these PLWH in education of their newly diagnosed peers and students at educational institutions and practicing healthcare professionals.

Health care providers who meet newly diagnosed PLWH of childbearing age should make family planning an integral part of HIV care. Health care providers should give their patients information about the available methods for prevention of vertical transmission and conception methods with the least risk for an partner who does not live with HIV, in the case of a serodiscordant relationship (Berhan & Berhan, 2013), in order to facilitate safe pregnancies (Finocchario-Kessler et al., 2010). Another important recommendation for health care practitioners is that all newly diagnosed people bring a family member or significant other to their first visit with a specialist (Hosek et al., 2000). Because stigma emerges partly out of a lack of knowledge, acquiring appropriate

information from a health care professional has the potential to eliminate unnecessary stress and stigma originating from family members.

Considering the lack of knowledge among the participants about risk-reduction strategies in seroconcordant and serodiscordant relationships, both ASOs and health care providers who are involved in HIV care should pay particular attention to providing education about the risk of condomless sex with other PLWH (Hosek et al., 2000). Participants in this research project spoke about harm reduction in their past and future relationships. In many cases, PLWH gave the power to decide on harm reduction to their partners who do not live with HIV. Many participants did not have the appropriate knowledge about which harm-reduction strategies should be used in intimate relationships. Sensitivity of the topic might explain why few health care professionals or support workers are willing to discuss this aspect of living with HIV with their clients. However, this lack of knowledge about harm reduction poses the risk of transmitting HIV to partners. Some PLWH might feel that it is "safer" in terms of possible transmission of the virus to have sex with two condoms, such as two male condoms or using both male and female condoms. While there is no evidence that shows whether or not the practice has an impact on the risk of transmission (Morineau, Prybylski, Song, Natpratan, & Neilsen, 2007; The Free Library, 2008), there is speculation of an increased frequency of condom failure because of added friction (AIDS Vancouver, 2012).

Another interesting finding concerning condoms is that, as one of the participants noted, women tend to be resistant to using condoms. During the first sexual encounters, women might agree to their use, but the longer they know a person, the weaker this sense of potential risk becomes. Therefore, if a health care practitioner or a support worker

144

works with serodiscordant couples or those PLWH who engage in intimate relationships, presumably with people who do not live with HIV, the focus should be not only on condom use, but also on *consistent use* as an important way to prevent all sexually-transmitted infections. Moreover, PLWH, as was shown in this research study, might withdraw from sexual decision-making in order to give power to their partners to decide which harm reduction strategies will be used. Thus, empowering PLWH to be pro-active in sexual decision-making, guided by the information they receive from a health care provider, might also play a critical role.

In light of this lack of knowledge about available harm reduction strategies, promoting knowledge about and use of Treatment as Prevention strategies and pre-exposure prophylaxis is crucial for attaining a higher quality of life and intimate relationships among PLWH. Treatment as Prevention focuses on initiating HAART at any CD4+T-cell count and maintaining virologic suppression, offering partners who do not live with HIV a lower risk of acquiring the virus (Anglemver et al., 2013; Cohen et al., 2011; Hull & Montaner, 2013). Similarly, pre-exposure prophylaxis is based on the use of antiretrovirals by a person who does not live with HIV engaged in a relationship with an individual who is living with the virus. Continuous use has been shown to reduce significantly the risk of HIV transmission (Jiang et al., 2014). Thus, both Treatment as Prevention and pre-exposure prophylaxis are changing the risk of acquiring the virus in serodiscordant relationships from very high to extremely low. This is a critical step that results in a great shift in understanding of intimacy—and its very possibility—among PLWH, from that of being almost unimaginable to being a normal part of life for PLWH. Having knowledge and understanding of a variety of ways that help to normalize life

have the potential to bring back lost identities of PLWH, such as those of being a partner, or a father or a mother.

Limitations of this Research Study and Directions for Future Research

In this research project, no conclusions about gender differences can be drawn, considering the analysis included only two interviews with female participants. However, deeper understanding of the different gender perspectives on living with HIV, romance within the HIV context, and partner seeking might help to create more targeted recommendations for heterosexual men and women. A possible research question might be: "What are the differences and similarities between heterosexual men and women living with HIV in terms of partner-seeking?" Also, the majority of the participants in this research project had a history of drug and alcohol use. It would be very interesting to recruit people with different backgrounds. This would allow to see the impact of SDH on the relationship challenges.

The second limitation is that this research project did not allow participants to answer the question: "Do partner-seeking behaviours in heterosexual PLWH change over time post-diagnosis? If so, what are the factors contributing to these changes?" Exploring the changes in sexuality of heterosexual PLWH might result in developing strategies to address these changes. This direction for future research would greatly benefit from a research approach (such as narrative inquiry) that would allow to conduct at least several interviews with each of the participants. Attention should be also paid to developing programs that prevent the loss of one's identity as a potential partner and acquisition and dominance of the identity of a person living with HIV.

Conclusion

This project, devoted to partner-seeking experiences of PLWH, is another piece that helps to complete the puzzle of our knowledge and understanding of the HIV epidemic. It shows how profoundly HIV illness affects not only social lives of PLWH, but also the very concept of the self, thus highlighting the importance of seeing HIV illness not as a clinical condition isolated from the influence of various social factors.

In the process of data collection and analysis, I revealed the importance of childhood traumas, which greatly contributed to the vulnerability of participants. The experiences of receiving the HIV diagnosis, various coping styles, and stigma manifestations were also described. I showed how various aspects of living with HIV influenced the decision to transition from partner seeking to celibacy. The need to disclose to a potential partner combined with a lack of knowledge about disclosure was the main reason for terminating or avoiding partner seeking. Although HIV status was not the only partner selection criteria, when speaking about potential partners, many PLWH wanted to date PLWH due to the shared experience of living with the disease, perceived higher self-stigma in serodiscordant relationships, and the absence of the need to disclose.

A set of recommendations was outlined that can be utilized by AIDS service organizations and health care professionals involved in the HIV care. I also provided the project's limitations, directions for future research and potential research questions. I expect to see greater involvement of the research community in exploring a complicated web of political and psychosocial factors, including sexuality and intimate relationship challenges experienced by people living with chronic conditions. Researchers interested in these factors should be very flexible in utilizing different approaches when studying

HIV, looking at the bigger picture of the social context and then revealing consequences on the individual level. Although research on relationship challenges is hardly able to end the HIV epidemic, it can help to improve the lives of millions of people who live with the virus. And these lives matter.

References

Adam, B. D., Elliott, R., Corriveau, P., & English, K. (2014). Impacts of criminalization on the everyday lives of people living with HIV in Canada. *Sexuality Research and Social Policy, 11*(1), 39–49. doi:10.1007/s13178-013-0131-8

Ahmed, A., Kaplan, M., Symington, A., & Kismodi, E. (2011). Criminalising consensual sexual behavior in the context of HIV: Consequences, evidence, and leadership. *Global Public Health, 6*(Suppl. 3), S357–S369.

Anderson, E. L. (2015). Conclusion. In E. L. Anderson, *Gender, HIV and Risk*. (pp. 147–157). Retrieved from http://www.palgraveconnect.com/pc/doifinder/10.1057/9781137316127.0010

AIDS Vancouver. (2012, May 3). Double bagging. *AIDS Vancouver. The HIV Helpline.* Retrieved from http://helpline.aidsvancouver.org/what-we-do/helpline/online/double-bagging

AIDSinfo. (2005). *Side effects of anti-HIV medications.* Retrieved from https://aidsinfo.nih.gov/ContentFiles/SideEffectAnitHIVMeds_cbrochure_en.pdf

Alani, T. (2013). The bigger picture: The effects of intimate partner violence on Aboriginal women's mental health. *Pimatisiwin, 2*, 231–240.

Alberta Health Surveillance and Assessment. (2015). *Notifiable sexually transmitted infections and human immunodeficiency virus: 2013 annual report*. Retrieved from http://www.health.alberta.ca/documents/STI-ND-Annual-Report-2013.pdf

Alexias, G., Savvakis, M., & Stratopoulou, I. (2016). Embodiment and biographical disruption in people living with HIV/AIDS (PLWHA). *AIDS Care, 28*(5), 585–590. doi:10.1080/09540121.2015.1119782

Alsan, M. M., Westerhaus, M., Herce, M., Nakashima, K., & Farmer, P. E. (2011). Poverty, global health, and infectious disease: Lessons from Haiti and Rwanda. *Infectious Disease Clinics of North America, 25*(3), 611–622.

Amin, A. (2015). Addressing gender inequalities to improve the sexual and reproductive health and wellbeing of women living with HIV. *Journal of the International AIDS Society, 18*(Suppl. 5), 4–6.

Anglemyer, A., Rutherford, G. W., Horvath, T., Baggaley, R. C., Egger, M., Siegfried, N. (2013). Antiretroviral therapy for prevention of HIV transmission in HIV-discordant couples. *Cochrane Database of Systematic Reviews, 4*, CD009153. doi.org/10.1002/14651858.CD009153.pub3

Antle, B. F., Karam, E., Christensen, D. N., Barbee, A. P., & Sar, B. K. (2011). An evaluation of healthy relationship education to reduce intimate partner violence. *Journal of Family Social Work, 14*(5), 387−406. doi:10.1080/10522158.2011.616482

Antoni, M. H. (2011). Stress, coping, and health in HIV/AIDS. In H. S. Friedman (Ed.), *The Oxford handbook of stress, health, and coping* (pp. 428−449). New York, NY: Oxford University Press.

Arrey, A. E., Bilsen, J., Lacor, P., & Deschepper, R. (2015). "People don't know that I'm HIV positive": Self-stigma in the lives of sub-Saharan African migrant women in Belgium. *Global Advanced Research Journal of Medicine and Medical Sciences, 4*(3), 121−131.

Attia, S., Egger, M., Müller, M., Zwahlen, M., & Low, N. (2009). Sexual transmission of HIV according to viral load and antiretroviral therapy: Systematic review and meta-analysis. *AIDS, 23*, 1397−1404.

Banerjee, S. (2007). *Gender, sexuality, rights and HIV*. Retrieved from http://www.icaso.org/publications/genderreport_web_080331.pdf

Banks, J. A. (1998). The lives and values of researchers: Implications for educating citizens in a multicultural society. *Educational Researcher, 27*(7), 4−17. doi:10.2307/1176055

Bauermeister, J. A. (2012). Romantic ideation, partner-seeking, and HIV risk among young gay and bisexual men. *Archives of Sexual Behavior, 41*(2), 431−440. doi:10.1007/s10508-011-9747-z

Bauermeister, J. A., Elkington, K. S., Robbins, R. N., Kang, E., & Mellins, C. A. (2012). A prospective study of the onset of sexual behavior and sexual risk in youth perinatally infected with HIV. *Journal of Sex Research, 49*(5), 413−422. doi:10.1080/00224499.2011.598248

Baumgartner, L. M. (2007). The incorporation of the HIV/AIDS identity in the self over time. *Qualitative Health Research, 17*(7), 919–931.

Baumgartner, L. M. (2012a). The perceived effect of the sociocultural context on HIV/AIDS identity incorporation. *The Qualitative Report, 17*(45), 1–21.

Baumgartner, L. M. (2012b). The perceived effect of time on HIV/AIDS identity incorporation. *The Qualitative Report, 17*(46), 1–22.

Baumgartner, L. M., & Niemi, E. (2013). The perceived effect of HIV/AIDS on other identities. *The Qualitative Report, 18*(8), 1–23.

Bell, J. S. (2002). Narrative inquiry: More than just telling stories. *Tesol Quarterly, 36*(2), 207–213. doi:10.2307/3588331

Berhan, Y., & Berhan, A. (2013). Meta-analyses of fertility desires of people living with HIV. *BMC Public Health, 13*(1), 409–409. doi:10.1186/1471-2458-13-409

Bill adding new safe-injection requirements receives royal assent. (2015, June 22). *CTVNews*. Retrieved from http://www.ctvnews.ca/politics/bill-adding-new-safe-injection-requirements-receives-royal-assent-1.2434656

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.

Bogart, L. M., Collins, R. L., Kanouse, D. E., Cunningham, W., Beckman, R., Golinelli, D., & Bird, C. E. (2006). Patterns and correlates of deliberate abstinence among men and women with HIV/AIDS. *American Journal of Public Health, 96*(6), 1078–1084. doi:10.2105/AJPH.2005.070771

Bos, A. E., Schaalma, H. P., & Pryor, J. B. (2008). Reducing AIDS-related stigma in developing countries: The importance of theory- and evidence-based interventions. *Psychology, Health & Medicine, 13*(4), 450–460.

Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology, 35*(1), 1–9.

Bradley-Springer, L. A., & Cook, P. F. (2006). Prevention with HIV-infected men: Recommendations for practice and research. *Journal of the Association of Nurses in AIDS Care, 17*(6), 14–27.

Brezing, C., Ferrara, M., & Freudenreich, O. (2015). The syndemic illness of HIV and trauma: Implications for a trauma-informed model of care. *Psychosomatics, 56*(2), 107–118. doi:10.1016/j.psym.2014.10.006

Broeckaert, L. (2014). *HIV home-based testing: Potential benefits and ongoing concerns*. Retrieved from http://www.catie.ca/en/pif/spring-2014/hiv-home-based-testing-potential-benefits-and-ongoing-concerns

Brown, A., Bailey, A., Palmer, Q., & Tureski, K. (2012). *Layered stigma among health facility and social services staff toward most-at-risk populations in Jamaica*. Retrieved from https://c-changeprogram.org/sites/default/files/Layered-Stigma-Jamaica.pdf

Bryman, A., Bell, E., & Teevan, J. J. (2012). *Social research methods* (3rd ed.). Don Mills, ON: Oxford University Press.

Buston, K. M. (2010). Experiences of, and attitudes towards, pregnancy and fatherhood amongst incarcerated young male offenders: Findings from a qualitative study. *Social Science & Medicine*, *71*(12), 2212–2218.

Butler, D. M., & Smith, D. M. (2007). Serosorting can potentially increase HIV transmissions. *AIDS, 21*, 1218–1220.

Cabrera, P., Auslander, W., & Polgar, M. (2009). Future orientation of adolescents in foster care: Relationship to trauma, mental health, and HIV risk behaviors. *Journal of Child & Adolescent Trauma, 2*(4), 271–286. doi:10.1080/19361520903317311

Cain, R., Jackson, R., Prentice, T., Collins, E., Mill, J., & Barlow, K. (2013). The experience of HIV diagnosis among Aboriginal people living with HIV/AIDS and depression. *Qualitative Health Research*, *23*(6), 815–824.

Caiola, C., Docherty, S. L., Relf, M., & Barroso, J. (2014). Using an intersectional approach to study the impact of social determinants of health for African American mothers living with HIV. *Advances in Nursing Science, 37*(4), 287–298.

Cairns, G. (2006, February). New directions in HIV prevention: Serosorting and universal testing. *IAPAC monthly.* Retrieved from http://www.aidsmap.com/New-directions-in-HIV-prevention-serosorting-and-universal-testing/page/1423247/

Campbell, M. S., Gottlieb, G. S., Hawes, S. E., Nickle, D. C., Wong, K. G., Deng, W., . . . Mullins, J. I. (2009). HIV-1 superinfection in the antiretroviral therapy era: Are seroconcordant sexual partners at risk? *PloS One, 4*(5), e5690.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada [Tri-Council]. (2014). *Tri-council policy statement: Ethical conduct for research involving humans*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf

Canadian HIV/AIDS Legal Network. (2014). *Criminal law and HIV non-disclosure in Canada.* Retrieved from http://www.aidslaw.ca/site/wp-content/uploads/2014/09/CriminalInfo2014_ENG.pdf

Canadian HIV/AIDS Legal Network. (2015). *HIV disclosure to sexual partners: Questions and answers for newcomers.* Retrieved from http://www.aidslaw.ca/site/hiv-disclosure-to-sexual-partners-qa-for-newcomers/

Carr, J. N. (2014). *Lipodystrophy, body image and depression in HIV positive Black women.* (Master's thesis, University of North Texas). Retrieved from UNT Digital Library.

Carter, M. W., Kraft, J. M., Hatfield-Timajchy, K., Snead, M. C., Ozeryansky, L., Fasula, A. M., . . . Kourtis, A. P. (2013). The reproductive health behaviors of HIV-infected young women in the United States: A literature review. *AIDS Patient Care and STDs, 27*, 669–680. doi:10.1089/apc.2013.0208

Carter, A. J., Bourgeois, S., O'Brien, N., Abelsohn, K., Tharao, W., & Greene, S. (2013). Women-specific HIV/AIDS services: Identifying and defining the components of holistic service delivery for women living with HIV/AIDS. *Journal of the International AIDS Society, 16*(1), 1–13. doi.org/10.7448/IAS.16.1.17433

Cascardi, M. (2016). From violence in the home to physical dating violence victimization: The mediating role of psychological distress in a prospective study of female adolescents. *Journal of Youth and Adolescence, 45*(4), 777–792. doi:10.1007/s10964-016-0434-1

Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health, 95*(1), 53–59.

Centers for Disease Control and Prevention. (2014). *Today's HIV/AIDS Epidemic.* Retrieved from http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf

Cescon, A., Patterson, S., Davey, C., Ding, E., Raboud, J. M., & Chan, K. (2015). Late initiation of combination antiretroviral therapy in Canada: A call for a national public health strategy to improve engagement in HIV care. *Journal of the International AIDS Society, 18*(1).

Chalmers, J. (2008). Intimacy and responsibility: The criminalisation of HIV transmission. *Modern Law Review, 71*, 1035–1038. doi:10.1111/j.1468-2230.2008.00728_1.x

Chandwani, S., Koenig, L. J., Sill, A. M., Abramowitz, S., Conner, L. C., & D'Angelo, L. (2012). Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. *The Journal of Adolescent Health, 51*, 242–251. doi:10.1016/j.jadohealth.2011.12.013

Charmaz, K. (2008). A future for symbolic interactionism. *Studies in Symbolic Interaction, 32*, 51–59. doi:10.1016/s0163-2396(08)32005-5

Chaudoir, S. R., Fisher, J. D., & Simone, J. M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model. *Social Science & Medicine, 72*(10), 1618–1629.

Chen, Y. H., Vallabhaneni, S., Raymond, H. F., & McFarland, W. (2012). Predictors of serosorting and intention to serosort among men who have sex with men, San Francisco. *AIDS Education and Prevention, 24*(6), 564–573. doi:10.1521/aeap.2012.24.6.564

Cherry, K., & Smith, D. H. (1993). Sometimes I cry: The experience of loneliness for men with AIDS. *Health Communication, 5*(3), 181–208. doi:10.1207/s15327027hc0503_3

Cissé, M., Diop, S., Abadie, A., Henry, E., Bernier, A., . . . & Preau, M. (2016). Factors associated with HIV voluntary disclosure to one's steady sexual partner in Mali: Results from a community-based study. *Journal of Biosocial Science*, *48*(1), 51–65.

Clandinin, D. J. (2006). *Handbook of narrative inquiry: Mapping a methodology*. Los Angeles, CA: Sage.

Cleary Bradley, R. P., & Gottman, J. M. (2012). Reducing situational violence in low-income couples by fostering healthy relationships. *Journal of Marital and Family Therapy, 38*(Suppl. 1), 187–198. doi:10.1111/j.1752-0606.2012.00288.x

Cleary, M., Horsfall, J., & Hayter, M. (2014). Data collection and sampling in qualitative research: Does size matter? *Journal of Advanced Nursing, 70*, 473–475.

Cohen, M. S., Chen, Y. Q., McCauley, M., Gamble, T., Hosseinipour, M. C., Kumarasamy, N., . . . Fleming, T. R. (2011). Prevention of HIV-1 infection with early antiretroviral therapy. *New England Journal of Medicine, 365*(6), 493–505.

Conserve, D. F., King, G., Devieux, J. G., Jean-Gilles, M., & Malow, R. (2014). Determinants of HIV serostatus disclosure to sexual partner among HIV-positive alcohol users in Haiti. *AIDS and Behavior, 18*(6), 1037–1045.

Corrigan, P. W. (2014). *The stigma of disease and disability: Understanding causes and overcoming injustices* (1st ed.). Washington, DC: American Psychological Association.

County of Los Angeles Public Health (n.d.). *Healthy relationships.* Retrieved from http://publichealth.lacounty.gov/mch/ReproductiveHealth/PreconceptionHealth/PCHFiles/Healthy%20Relationships%20Every%20Woman%20California.pdf

Courtenay-Quirk, C., Wolitski, R. J., Parsons, J. T., & Gomez, C. A. (2006). Is HIV/AIDS stigma dividing the gay community? Perceptions of HIV-positive men who have sex with men. *AIDS Education and Prevention*, *18*(1), 56–67.

Courtenay-Quirk, C., Jun, Z., & Wolitski, R. J. (2009). Intentional abstinence among homeless and unstably housed persons living with HIV/AIDS. *AIDS & Behavior, 13*(6), 1119–1128. doi:10.1007/s10461-008-9461-6

Craft, S. M., & Serovich, J. M. (2008). Sexual need fulfillment in the relationships of straight and bisexual men with HIV. *AIDS Education & Prevention, 20*(3), 239–248.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124–130.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles, CA: Sage.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods*. Los Angeles, CA: Sage.

Dale, S., Cohen, M., Weber, K., Cruise, R., Kelso, G., & Brody, L. (2014). Abuse and resilience in relation to HAART medication adherence and HIV viral load among women with HIV in the United States. *AIDS Patient Care and STDs, 28*, 136–143. doi:10.1089/apc.2013.0329

Davis, S. K., & Tucker-Brown, A. (2013). The effects of social determinants on Black women's HIV risk: HIV is bigger than biology. *Journal of Black Studies, 44*(3), 273–289. doi:10.1177/0021934713481805

Dej, E., & Kilty, J. M. (2012). "Criminalization creep": A brief discussion of the criminalization of HIV/AIDS non-disclosure in Canada. *Canadian Journal of Law and Society, 27*(1), 55–66. doi:10.3138/cjls.27.1.055

Del Toro, M. (2012). The influence of parent-child attachment on romantic relationships. *McNair Scholars Research Journal, 8*(1), 1–5. Retrieved from http://scholarworks.boisestate.edu/cgi/viewcontent.cgi?article=1105&context=mcnair_journal

Delaney, E., & O'Brien, W. H. (2012). The association between acceptance and mental health while living with HIV. *Social Work in Mental Health, 10*(3), 253–266. doi:10.1080/15332985.2011.649107

Delaney, M. (2006). History of HAART - the true story of how effective multi-drug therapy was developed for treatment of HIV disease. *Retrovirology, 3*(Suppl. 1):S6. doi:10.1186/1742-4690-3-S1-S6

Denzin, N. K. (1970). *The research act: A theoretical introduction to sociological methods*. New York, NY: McGraw Hill.

Denzin, N. K., & Lincoln, Y. S. (2005). *The Sage handbook of qualitative research*. Los Angeles, CA: Sage.

Denzin, N. K., & Lincoln, Y. S. (2013). *The landscape of qualitative research*. Los Angeles, CA: Sage.

De Santis, J. P., Florom-Smith, A., Vermeesch, A., Barroso, S., & DeLeon, D. A. (2013). Motivation, management, and mastery: A theory of resilience in the context of HIV infection. *Journal of the American Psychiatric Nurses Association, 19*(1), 36−46. doi:10.1177/1078390312474096

Dinero, R. E., Conger, R. D., Shaver, P. R., Widaman, K. F., & Larsen-Rife, D. (2008). Influence of family of origin and adult romantic partners on romantic attachment security. *Journal of Family Psychology, 22*(4), 622−632. doi:10.1037/a0012506

Dion, J., Collin-Vézina, D., De La Sablonnière, M., Philippe-Labbé, M. P., & Giffard, T. (2010). An exploration of the connection between child sexual abuse and gambling in Aboriginal communities. *International Journal of Mental Health and Addiction*, *8*(2), 174–189.

Dunkle, K. L., Wingood, G. M., Camp, C. M., & DiClemente, R. J. (2010). Economically motivated relationships and transactional sex among unmarried African American and white women: Results from a U.S. National Telephone Survey. *Public Health Reports, 125*(Suppl. 4), 90–100.

Dyer, J. G., & McGuinness, T. M. (1996). Resilience: Analysis of the concept. *Archives of Psychiatric Nursing, 10*(5), 276−282. Retrieved from http://www.psychiatricnursing.org/article/S0883-9417(96)80036-7/abstract

Egan, J. P. (2014). Injection drug users, Aboriginality, and HIV: A postcolonial glance from a strong ally. In Collins, J. C., Tonette, S. R., & Lawrence, O. B. (Eds), *Health and wellness concerns for racial, ethnic, and sexual minorities: New directions for adult and continuing education* (pp. 37–47). San Francisco: Jossey-Bass. doi:10.1002/ace.20093

Eggertson, L. (2013). Legislation ignores benefits of safe injection sites, say doctors. *Canadian Medical Association Journal, 185*(12), E555. doi:10.1503/cmaj.109-4536

Ezeanolue, E. E., Wodi, A. P., Patel, R., Dieudonne, A., & Oleske, J. M. (2006). Sexual behaviors and procreational intentions of adolescents and young adults with perinatally acquired human immunodeficiency virus infection: Experience of an urban tertiary center. *Journal of Adolescent Health, 38*, 719–725. doi:10.1016/j.jadohealth.2005.06.015

Ezzy, D. (1998). Theorizing narrative identity: Symbolic interactionism and hermeneutics. *Sociological Quarterly, 39*(2), 239–252. doi:10.1111/j.1533-8525.1998.tb00502.x

Fagan, J., & Lee, Y. (2014). Longitudinal associations among fathers' perception of coparenting, partner relationship quality, and paternal stress during early childhood. *Family Process, 53*(1), 80–96. doi:10.1111/famp.12055

Fair, C., & Albright, J. (2012). "Don't tell him you have HIV unless he's 'the one'": Romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS Patient Care and STDs, 26*, 746–754. doi:10.1089/apc.2012.0290

Farber, E. W., Mirsalimi, H., Williams, K. A., & McDaniel, J. S. (2003). Meaning of illness and psychological adjustment to HIV/AIDS. *Psychosomatics, 44*(6), 485–491. doi:10.1176/appi.psy.44.6.485

Farmer, P. E. (1996). On suffering and structural violence: A view from below. *Daedalus, 125*(1), 261–283.

Farmer, P. E. (2002). Rethinking health and human rights: Time for a paradigm shift. *The Journal of Law, Medicine and Ethics, 30*(4), 655–666.

Farmer, P. E. (2005). Global AIDS: New challenges for health and human rights. *Perspectives in Biology and Medicine, 48*(1), 10–16.

Farmer, P. E., Nizeye, B., Stulac, S., Keshavjee, S. (2006). Structural violence and clinical medicine. *PLoS Medicine, 3*(10), e449.

Finger, J. L., Clum, G. A., Trent, M. E., Ellen, J. M., & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2012). Desire for pregnancy and risk behavior in young HIV-positive women. *AIDS Patient Care and STDs, 26*, 173–180. doi:10.1089/apc.2011.0225

Finocchario-Kessler, S., Sweat, M. D., Dariotis, J. K., Trent, M. E., Kerrigan, D. L., Keller, J. M., & Anderson, J. R. (2010). Understanding high fertility desires and intentions among a sample of urban women living with HIV in the United States. *AIDS Behavior, 14*, 1106–1114. doi:10.1007/s10461-009-9637-8

Fletcher, T. (2016, February 10). Nearly half of women with HIV in Canada not dating: SFU study. *Metro*. Retrieved from http://www.metronews.ca/news/vancouver/2016/02/10/sfu-study-finds-half-of-women-living-with-hiv-not-dating.html

Folkman, S. (2011). *The Oxford handbook of stress, health, and coping*. New York, NY: Oxford University Press.

Folkman, S., & Chesney, M. (1995). Coping with HIV infection. In M. Stein and A. Baum (Eds.), *Chronic diseases. Perspectives in behavioral medicine* (pp. 115–133). Hillsdale, NJ: Lawrence Erlbaum Associates.

Forte, J. A. (2008). Symbolic interactionism: Artful inquiry. *Patient Education and Counseling, 73*(2), 173–174. doi:10.1016/j.pec.2008.09.003

Foucault, M. (1986). *The history of sexuality. Volume 2: The use of pleasure.* New York: Random House.

France, N. F., McDonald, S. H., Conroy, R. R., Byrne, E., Mallouris, C., Hodgson, I., & Larkan, F. N. (2015). "An unspoken world of unspoken things": A study identifying and exploring core beliefs underlying self-stigma among people living with HIV and AIDS in Ireland. *Swiss Medical Weekly, 145*, w14113.

Francis, J. G., & Francis, L. P. (2013). HIV treatment and prevention: Not an argument for continuing criminalisation of HIV transmission. *International Journal of Law in Context, 9*(4), 520–534.

François-Xavier Bagnoud Center for Health and Human Rights and Open Society Foundations. (2013). *Health and human rights resource guide.* Retrieved from http://www.hhrguide.org/2014/03/05/471/

Friedman, H. S. (2011). *The Oxford handbook of health psychology*. New York, NY: Oxford University Press.

Frost, D. M., Stirratt, M. J., & Ouellette, S. C. (2008). Understanding why gay men seek HIV-seroconcordant partners: Intimacy and risk reduction motivations. *Culture Health & Sexuality, 10*(5), 513–527. doi:10.1080/13691050801905631

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report, 20*(9), 1408–1416.

Gaskins, S. W., Payne Foster, P., Sowell, R. L., Lewis, T. L., Gardner, A., & Parton, J. M. (2012). Making decisions: The process of HIV disclosure for rural African American men. *American Journal of Men's Health, 6*(6), 442–452.

Geary, C., Parker, W., Rogers, S., Haney, E., Njihia, C., . . . & Walakira, E. (2014). Gender differences in HIV disclosure, stigma, and perceptions of health. *AIDS Care, 26*(11), 1419–1425.

Gecas, V., & Burke, P. J. (1995). Self and identity. In K. S. Cook, G. A. Fine, & J. S. House (Eds.), *Sociological perspectives on social psychology* (pp. 41–67). Boston, MA: Allyn and Bacon.

Global Network of People Living with HIV. (2012). *Evidence brief: Stigma and discrimination at work. Findings from the PLHIV Stigma Index*. Retrieved from http://www.ilo.org/wcmsp5/groups/public/@ed_protect/@protrav/@ilo_aids/documents/publication/wcms_185808.pdf

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Golden, M. R., Dombrowski, J. C., Kerani, R. P., & Stekler, J. D. (2012). Failure of serosorting to protect African American men who have sex with men from HIV infection. *Sexually Transmitted Diseases, 39*, 659−664. doi:10.1097/OLQ.0b013e31825727cb

Gombachika, B., Chirwa, E., Sundby, J., Malata, A., & Maluwa, A. (2012). Marriage partner selection by heterosexual couples living with HIV from rural southern Malawi. *Journal of AIDS and Clinical Research,* (Supp. 1), 016. doi:10.4172/2155-6113.S1-016

Gonzalez, A., Miller, C. T., Solomon, S. E., Bunn, J. Y., & Cassidy, D. G. (2009). Size matters: Community size, HIV stigma, and gender differences. *AIDS and Behavior, 13*, 1205−1212. doi:10.1007/s10461-008-9465-2

Government of Canada. (2015). *Drug treatment court funding program.* Retrieved from http://www.justice.gc.ca/eng/fund-fina/gov-gouv/dtc-ttt.html

Government of Manitoba, Manitoba Health, Healthy Living and Seniors, Public Health and Primary Health Care Division, Public Health Branch, Epidemiology and Surveillance. (2015). *Annual Statistical Update: HIV and AIDS 2014*. Retrieved from http://www.gov.mb.ca/health/publichealth/surveillance/hivaids/docs/dec2014.pdf

Graham-Kevan, N. (2009). The psychopathology of women's partner violence: Characteristics and cautions. *Journal of Aggression, Maltreatment & Trauma, 18*(6), 587–603.

Green, G. (2009). *The end of stigma? Changes in the social experience of long-term illness*. New York, NY: Routledge.

Greene, S., Ion, A., Elston, D., Kwaramba, G., Smith, S., . . . & Loutfy, M. (2015). "Why aren't you breastfeeding?" How mothers living with HIV talk about infant feeding in a "breast is best" world. *Health Care for Women International, 36*(8), 883–991. doi:10.1080/07399332.2014.888720

Greenhalgh, C., Evangeli, M., Frize, G., Foster, C., & Fidler, S. (2013). Intimate relationships in young adults with perinatally acquired HIV: Partner considerations. *AIDS Care, 25*, 447–450. doi:10.1080/09540121.2012.712671

Greenhalgh, C., Evangeli, M., Frize, G., Foster, C., & Fidler, S. (2015). Intimate relationships in young adults with perinatally acquired HIV: A qualitative study of strategies used to manage HIV disclosure. *AIDS Care*, *28*, 283–288.

Grossman, A. H. (1991). Gay men and HIV/AIDS: Understanding the double stigma. *The Journal of the Association of Nurses in AIDS Care, 2*(4), 28–32.

Grov, C., Golub, S. A., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS Care, 22*, 630–639. doi:10.1080/09540120903280901

Guest, M., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59–82. doi:10.1177/1525822X05279903 Gurevich, M., Mathieson, C. M., Bower, J., & Dhayanandhan, B. (2007). Disciplining bodies, desires and subjectivities: Sexuality and HIV-positive women. *Feminism & Psychology, 17*(1), 9–38. doi:10.1177/0959353507072910

Hankins, C., Gendron, S., Tran, T., Lamping, D., & Lapointe, N. (1997). Sexuality in Montreal women living with HIV. *AIDS Care, 9*, 261–271.

Heitgerd, J. L., Kalayil, E. J., Patel-Larson, A., Uhl, G., Williams, W. O., Griffin, T., & Smith, B. D. (2011). Reduced sexual risk behaviors among people living with HIV: Results from the healthy relationships outcome monitoring project. *AIDS and Behavior, 15*, 1677–1690. doi:10.1007/s10461-011-9913-2

Hendry, P. M. (2010). Narrative as inquiry. *The Journal of Educational Research, 103*(2), 72–80.

Henry, E., Bernier, A., Lazar, F., Matamba, G., Loukid, M., Bonifaz, C., . . . The Partages study group. (2015). "Was it a mistake to tell others that you are infected with HIV?": Factors associated with regret following HIV disclosure among people living with HIV in five countries (Mali, Morocco, Democratic Republic of the Congo, Ecuador and Romania). *AIDS and Behavior, 19*(2), 311–321. doi:10.1007/s10461-014-0976-8

Herek, G. M. (2014). HIV-related stigma. In Corrigan, P. W. (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (1st ed.). Washington, DC: American Psychological Association.

Herek, G. M., Gillis, J. R., & Cogan, J. C. (2009). Internalized stigma among sexual minority adults: Insights from a social psychological perspective. *Journal of Counseling Psychology, 56*(1), 32–43. doi:10.1037/a0014672

Herek, G. M., Saha, S., & Burack, J. (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology, 35*(1), 41-54. doi:10.1080/01973533.2012.746606

Hill, J. (2012). *Forgiveness and loneliness: Stress and anxiety's correlates in a student and clinical HIV-positive population* (Master's thesis). Available from ProQuest Dissertation and Theses database. (UMI No. 1521480)

Hirsch Allen, A. J., Forrest, J. I., Kanters, S., O'Brien, N., Salters, K. A., . . . & Hogg, R. S. (2014). Factors associated with disclosure of HIV status among a cohort of individuals on antiretroviral therapy in British Columbia, Canada. *AIDS and Behavior, 18*(6), 1014–1026.

Hoff, C. C., McKusick, L., Hilliard, B., & Coates, T. J. (1992). The impact of HIV antibody status on gay mens' partner preferences - a community perspective. *AIDS Education and Prevention, 4*(3), 197–204.

Hoffmann, C., & Rockstroh, J. K. (2011). *HIV 2011*. Hamburg, Germany: Medizin Fokus Verlag.

Hogg, R. S., Nosyk, B., Harrigan, P. R., Lima, V. D., Chan, K., Heath, K., . . . Montaner, J. S. G. (2013). Rates of new infections in British Columbia continue to decline at a faster rate than in other Canadian regions. *HIV Medicine*, 14, 581–582. Doi:10.1111/hiv.12079

Holtz, C. S., Sowell, R., & Velasquez, G. (2012). Oaxacan women with HIV/AIDS: Resiliency in the face of poverty, stigma, and social isolation. *Women & Health, 52*(6), 517–535. doi:10.1080/03630242.2012.690839

Hosek, S., Brothers, J., Lemos, D., & Adolescent Med Trials Network for HIV/AIDS Interventions. (2012). What HIV-positive young women want from behavioral interventions: A qualitative approach. *AIDS Patient Care and STDs, 26*, 291–297. doi:10.1089/apc.2011.0035

Hosek, S., Harper, G. W., & Domanico, R. (2000). Psychological and social difficulties of adolescents living with HIV: A qualitative analysis. *Journal of Sex Education & Therapy, 25*(4), 269–276.

Hull, M. W., Montaner, J. S. G. (2013). HIV treatment as prevention: The key to an AIDS-free generation. *Journal of Food and Drug Analysis, 21*(4), S95–S101. doi:10.1016/j.jfda.2013.09.043

Jarman, M., Walsh, S., & De Lacey, G. (2005). Keeping safe, keeping connected: A qualitative study of HIV-positive women's experiences of partner relationships. *Psychology & Health, 20*(4), 533–551.

Jiang, J., Yang, X., Ye, L., Zhou, B., Ning, C., Huang, J., . . . Liang, H. (2014). Pre-exposure prophylaxis for the prevention of HIV infection in high risk populations: A meta-analysis of randomized controlled trials. *PloS One, 9*(2), e87674. doi:10.1371/journal.pone.0087674

Joffe, H. (1999). *Risk and 'the other'*. New York, NY: Cambridge University Press.

Johnson, M. O., Dilworth, S. E., Taylor, J. M., Darbes, L. A., Comfort, M. L., & Neilands, T. B. (2012). Primary relationships, HIV treatment adherence, and virologic control. *AIDS and Behavior, 16*, 1511−1521. doi:10.1007/s10461-011-0021-0

Johnston, L., O'Bra, H., Chopra, M., Mathews, C., Townsend, L., Sabin, K., . . . Kendall, C. (2010). The associations of voluntary counseling and testing acceptance and the perceived likelihood of being HIV-infected among men with multiple sex partners in a South African township. *AIDS and Behavior, 14*(4), 922−931.

Joseph, E. B., & Bhatti, R. S. (2004). Psychosocial problems and coping patterns of HIV seropositive wives of men with HIV/AIDS. *Social Work in Health Care, 39*(1-2), 29−47. doi:10.1300/J010v39n01_04

Kaida, A., Carter, A., de Pokomandy, A., Patterson, S., Proulx-Boucher, K., Nohpal, A., . . . & Beaver, K. (2015). Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. *Journal of the International AIDS Society*, *18*(6Suppl. 5).

Kalichman, S. C., Heckman, T., Kochman, A., Sikkema, K., & Bergholte, J. (2000). Depression and thoughts of suicide among middle-aged and older persons living with HIV-AIDS. *Psychiatric Services, 51*(7), 903−907. doi:10.1176/appi.ps.51.7.903

Kamen, C., Taniguchi, S., Student, A., Kienitz, E., Giles, K., Khan, C., . . . Koopman, C. (2012). The impact of denial on health-related quality of life in patients with HIV. *Quality of Life Research, 21*(8), 1327−1336. doi:10.1007/s11136-011-0045-y

Kamen, C., Vorasarun, C., Canning, T., Kienitz, E., Weiss, C., Flores, S., . . . & Gore-Felton, C. (2015). The impact of stigma and social support on development of post-traumatic growth among persons living with HIV. *Journal of Clinical Psychology in Medical Settings*, 1−9.

Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research, 19*, 279−289. doi:10.1177/1049732308329306

Keegan, A., Lambert, S., & Petrak, J. (2005). Sex and relationships for HIV-positive women since HAART: A qualitative study. *AIDS Patient Care and STDs, 19*, 645–654. doi:10.1089/apc.2005.19.645

Kelly, J. S., Langdon, D., & Serpell, L. (2009). The phenomenology of body image in men living with HIV. *AIDS Care, 21*(12), 1560–1567. doi:10.1080/09540120902923014

Kennedy, C. E., Haberlen, S., Amin, A., Baggaley, R., & Narasimhan, M. (2015). Safer disclosure of HIV serostatus for women living with HIV who experience or fear violence: A systematic review. *Journal of the International AIDS Society, 18*(Suppl. 5), 74–79.

KFL&A Public Health. (n.d.). *Healthy relationship.* Retrieved from http://www.kflapublichealth.ca/Files/Resources/Healthy_Relationship.pdf

Kimberly, J. A., Serovich, J. M., & Greene, K. (1995). Disclosure of HIV-positive status: five women's stories. *Family Relations, 44*(3), 316–322. doi:10.2307/585531

King, N., & Horrocks, C. (2010). *Interviews in qualitative research*. Los Angeles, CA: Sage.

Klein, H. (2014). Early life emotional neglect and HIV risk taking among men using the Internet to find other men for unprotected sex. *Child Abuse & Neglect*, *38*(3), 434–444.

Klunklin, A. (2006). Symbolic interactionism in grounded theory studies: Women surviving with HIV/AIDS in rural northern Thailand. *Journal of the Association of Nurses in AIDS Care, 17*(5), 32–41. doi:10.1016/j.jana.2006.07.005

Kotarba, J. A. (2014). Symbolic interaction and applied social research: A focus on translational science. *Symbolic Interaction, 37*(3), 412–425. doi:10.1002/symb.111

Kposowa, A. J. (2013). Marital status and HIV/AIDS mortality: Evidence from the US national longitudinal mortality study. *International Journal of Infectious Diseases, 17*(10), E868–E874. doi:10.1016/j.ijid.2013.02.018

Krefting, L. (1991). Rigor in qualitative research—the assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214–222.

Kwan, J. (2015). From taboo to epidemic: Family violence within Aboriginal communities. *Global Social Welfare, 2*(1), 1–8.

Lakew, Y., Benedict, S., & Haile, D. (2015). Social determinants of HIV infection, hotspot areas and subpopulation groups in Ethiopia: Evidence from the National Demographic and Health Survey in 2011. *BMJ Open, 5*(11), e008669. doi:10.1136/bmjopen-2015-008669

Lam, N. T. (2008). Drugs, sex and AIDS: Sexual relationships among injecting drug users and their sexual partners in Vietnam. *Culture, Health & Sexuality, 10* (Suppl. 1), S123–S137. doi:10.1080/13691050701832315

Lambert, S., Keegan, A., & Petrak, J. (2005). Sex and relationships for HIV positive women since HAART: A quantitative study. *Sexually Transmitted Infections*, *81*(4), 333–337.

Larkin, J., Flicker, S., Koleszar-Green, R., Mintz, S., Dagnino, M., & Mitchell, C. (2007). HIV risk, systemic inequities, and Aboriginal youth: Widening the circle for HIV prevention programming. *Canadian Journal of Public Health*, *98*(3), 179–182.

Lee, J. D., & Craft, E. A. (2002). Protecting one's self from a stigmatized disease once one has it. *Deviant Behavior, 23*(3), 267–299. doi:10.1080/016396202753561248

Lee, M., Nezu, A. M., & Nezu, C. M. (2014). Positive and negative religious coping, depressive symptoms, and quality of life in people with HIV. *Journal of Behavioral Medicine, 37*(5), 921–930. doi:10.1007/s10865-014-9552-y

Lee, W., Ti, L., Marshall, B. D. L., Dong, H., Wood, E., & Kerr, T. (2015). Childhood sexual abuse and syringe sharing among people who inject drugs. *AIDS and Behavior, 19*, 1415–1422. doi:10.1007/s10461-014-0930-9

Lekas, H.-M., Siegel, K., & Leider, J. (2011). Felt and enacted stigma among HIV/HCV-coinfected adults: The impact of stigma layering. *Qualitative Health Research, 21*, 1205-1219. doi:10.1177/1049732311405684

Leo, G. (2015, June 3). HIV rates on Saskatchewan reserves higher than some African nations. *CBC News.* Retrieved from http://www.cbc.ca/news/canada/saskatchewan/hiv-rates-on-sask-reserves-higher-than-some-african-nations-1.3097231

Leonard, A. D., Markham, C. M., Bui, T., Shegog, R., & Paul, M. E. (2010). Lowering the risk of secondary HIV transmission: Insights from HIV-positive youth and health care providers. *Perspectives on Sexual and Reproductive Health, 42*(2), 110–116. doi:10.1363/4211010

Lepore, M. (2011). *The stigma of AIDS in the workplace is a global issue.* Retrieved from http://www.one.org/us/2011/11/29/the-stigma-of-aids-in-the-workplace-is-a-global-issue/

164

Leserman, J. (2008). Role of depression, stress, and trauma in HIV disease progression. *Psychosomatic Medicine, 70*, 539–545. doi:10.1097/PSY.0b013e3181777a5f

Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). South Melbourne, Australia: Oxford University Press.

Liao, S. (2011). Parental love pills: Some ethical considerations. *Bioethics*, *25*(9), 489–494.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363–385.

Liu, H., Xu, Y., Sun, Y., & Dumenci, L. (2014). Measuring HIV stigma at the family level: Psychometric assessment of the Chinese Courtesy Stigma Scales (CCSS). *PloS One, 9*(3), e92855.

Lohman, B. J., Neppl, T. K., Senia, J. M., & Schofield, T. J. (2013). Understanding adolescent and family influences on intimate partner psychological violence during emerging adulthood and adulthood. *Journal of Youth and Adolescence, 42*(4), 500–517. doi:10.1007/s10964-013-9923-7

Longmore, M. A. (1998). Symbolic interactionism and the study of sexuality. *Journal of Sex Research, 35*(1), 44–57. doi:10.1080/00224499809551916

Loukid, M., Abadie, A., Henry, E., Hilali, M. K., Fugon, L., . . . & Preau, M. (2014). Factors associated with HIV status disclosure to one's steady sexual partner in PLHIV in Morocco. *Journal of Community Health, 39*(1), 50–59.

Lunn, S. (2013, June 5). Supervised drug injection site rules coming tomorrow. *CBC News*. Retrieved from http://www.cbc.ca/news/politics/supervised-drug-injection-site-rules-coming-tomorrow-1.1390364

Lyimo, R. A., Stutterheim, S. E., Hospers, H. J., de Glee, T., van der Ven, A., & de Bruin, M. (2014). Stigma, disclosure, coping, and medication adherence among people living with HIV/AIDS in Northern Tanzania. *AIDS Patient Care and STDs, 28*, 98–105. doi:10.1089/apc.2013.0306

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, . . . & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, *22*(Suppl. 2), S67–S79. doi: 10.1097/01.aids.0000327438.13291.62

Maim, G., Sutankayo, L., Chorney, R., & Caine, V. (2014). Living with and teaching about HIV: Engaging nursing students through body mapping. *Nurse Education Today, 34*(4), 643–647. doi:10.1016/j.nedt.2013.05.004

Marks, G., Crepaz, N., Senterfitt, J. W., & Janssen, R. S. (2005). Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: Implications for HIV prevention programs. *Journal of Acquired Immune Deficiency Syndromes, 39*(4), 446–453.

Marshall, B. D. L., Kerr, T., Shoveller, J. A., Patterson, T. L., Buxton, J. A., & Wood, E. (2008). Homelessness and unstable housing associated with an increased risk of HIV and STI transmission among street-involved youth. *Health and Place, 15*(3), 783–790. doi:10.1016/j.healthplace.2008.12.005

Mason, S., Sultzman, V., & Berger, B. (2014). "Like being in a cage": Stigma as experienced by adolescents whose mothers are living with HIV. *Vulnerable Children and Youth Studies, 9*(4), 323–331. doi:10.1080/17450128.2014.933941

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (Vol. 41). Thousand Oaks, CA: Sage.

Mazanderani, F. (2012). An ethics of intimacy: Online dating, viral-sociality and living with HIV. *BioSocieties, 7*(4), 393–409. doi:10.1057/biosoc.2012.24

McCall, J., & Lauridsen-Hoegh, P. (2014). Trauma and cultural safety: Providing quality care to HIV-infected women of aboriginal descent. *The Journal of the Association of Nurses in AIDS Care, 25*(Suppl. 1), S70–S78. doi:10.1016/j.jana.2013.05.005

McIntosh, R. C., & Rosselli, M. (2012). Stress and coping in women living with HIV: A meta-analytic review. *AIDS and Behavior*, *16*(8), 2144–2159.

Medley, A. M., Kennedy, C. E., Lunyolo, S., & Sweat, M. D. (2009). Disclosure outcomes, coping strategies, and life changes among women living with HIV in Uganda. *Qualitative Health Research, 19*, 1744–1754. doi:10.1177/1049732309353417

Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. Retrieved from http://www.thecanadianfacts.org/the_canadian_facts.pdf

Miles, M. S., Isler, M. R., Banks, B. B., Sengupta, S., & Corbie-Smith, G. (2011). Silent endurance and profound loneliness: Socioemotional suffering in African Americans living with HIV in the rural south. *Qualitative Health Research, 21*, 489–501. doi:10.1177/1049732310387935

Military Family Resource Centres. (n.d.). *What is a healthy relationship?* Retrieved from http://www.familyforce.ca/sites/Trenton/EN/Documents/Relationships.pdf

Mill, J. E., Edwards, N., Jackson, R. C., MacLean, L., & Chaw-Kant, J. (2010). Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qualitative Health Research, 20*, 1469−1483. doi:10.1177/1049732310375436

Missildine, W., Parsons, J. T., & Knight, K. (2006). Split ends - masculinity, sexuality and emotional intimacy among HIV-positive heterosexual men. *Men and Masculinities, 8*(3), 309−320. doi:10.1177/1097184x05282079

Mizuno, Y., Purcell, D., Borkowski, T. M., Knight, K., & Team, S. (2003). The life priorities of HIV-seropositive injection drug users: Findings from a community-based sample. *AIDS and Behavior, 7*(4), 395−403. doi:10.1023/b:aibe.0000004731.94734.77

Moitra, E., Herbert, J. D., & Forman, E. M. (2011). Acceptance-based behavior therapy to promote HIV medication adherence. *AIDS Care, 23*, 1660−1667. doi:10.1080/09540121.2011.579945

Monette, L. E., Rourke, S. B., Gibson, K., Bekele, T. M., Tucker, R., & Greene, S. (2011). Inequalities in determinants of health among Aboriginal and Caucasian persons living with HIV/AIDS in Ontario: Results from the Positive Spaces, Healthy Places Study. *Canadian Journal of Public Health, 102*(3), 215−219.

Morineau, G., Prybylski, D., Song, N., Natpratan, C., & Neilsen, G. (2007). Simultaneous use of multiple condoms among male Cambodian military personnel visiting female sex workers. *Sexually Transmitted Diseases, 34*, 808−812.

Morse, J. M. (1990). *Qualitative nursing research: A contemporary dialogue*. US: Sage.

Morse, J. M. (2013). What is qualitative health research? In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (4th ed., pp. 401−414). US: Sage.

Moses, S. H., & Dhar, J. (2012). A survey of the sexual and reproductive health of HIV-positive women in Leicester. *International Journal of STD & AIDS, 23*(4), 282−284. doi:10.1258/ijsa.2009.009094

Moskowitz, J. T., Hult, J. R., Bussolari, C., & Acree, M. (2009). What works in coping with HIV? A meta-analysis with implications for coping with serious illness. *Psychological Bulletin, 135*(1), 121−141.

Moskowitz, J. T., Wrubel, J., Hult, J. R., Maurer, S., & Acree, M. (2013). Illness appraisals and depression in the first year after HIV diagnosis. *PloS One, 8*(10), e78904. doi:10.1371/journal.pone.0078904

Musten, A. (2015). *REACH Alberta Working Group meets, maps and identifies.* Retrieved from http://www.reachprogramscience.ca/reach-alberta-working-group-meets-maps-and-identifies/

National Center for AIDS/STD Control and Prevention. (n.d.). *HIV and AIDS related employment discrimination in China*. Retrieved from http://www.ilo.org/wcmsp5/groups/public/---asia/---ro-bangkok/---sro-bangkok/documents/publication/wcms_150386.pdf

Negin, J., Aspin, C., Gadsden, T., & Reading, C. (2015). HIV among Indigenous peoples: A review of the literature on HIV-related behaviour since the beginning of the epidemic. *AIDS and Behavior*, *19*(9), 1720–1734.

Nichols, S. L., Montepiedra, G., Farley, J. J., Sirois, P. A., Malee, K., Kammerer, B., . . . Team, P. P. (2012). Cognitive, academic, and behavioral correlates of medication adherence in children and adolescents with perinatally acquired HIV infection. *Journal of Developmental and Behavioral Pediatrics, 33*(4), 298–308.

Niekerk, L. V., & Savin-Baden, M. (2007). Narrative inquiry: Theory and practice. *Journal of Geography in Higher Education, 31*(3), 459–472. doi:10.1080/03098260601071324

O'Byrne, P., Holmes, D., Roy, M. (2015). Counselling about HIV serological status disclosure: Nursing practice or law enforcement? A Foucauldian reflection. *Nursing Inquiry, 22*(2), 134–146.

Office on Women's Health U.S. Department of Health and Human Services. (n.d.). Healthy aging. Retrieved from http://womenshealth.gov/publications/our-publications/the-healthy-woman/healthy_aging.pdf

Ogilvie, G. S., Palepu, A., Remple, V. P., Maan, E., Heath, K., MacDonald, G., . . . Burdge, D. R. (2007). Fertility intentions of women of reproductive age living with HIV in British Columbia, Canada. *AIDS, 21*(Supp. 1), 83–88. doi:10.1097/01.aids.0000255090.51921.60

Oyserman, D., Kemmelmeier, M., & Coon, H. M. (2002). Cultural psychology, a new look: Reply to Bond (2002), Fiske (2002), Kitayama (2002), and Miller (2002). *Psychological Bulletin, 128*, 110–117.

Palmer, A. K., Duncan, K. C., Ayalew, B., Zhang, W., Tzemis, D., Lima, V., . . . Hogg, R. S. (2011). "The way I see it": The effect of stigma and depression on self-perceived body image among HIV-positive individuals on treatment in British Columbia, Canada. *AIDS Care, 23*(11), 1456–1466. doi:10.1080/09540121.2011.565021

Parsons, J. T., Vanora, J., Missildine, W., Purcell, D. W., Gomez, C. A. (2004). Positive and negative consequences of HIV disclosure among seropositive injection drug users. *AIDS Education and Prevention, 16*(5), 495–475.

Patterson, S., Cescon, A., Samji, H., Chan, K., Zhang, W., Raboud, J., . . . Hogg, R.S. (2015). Life expectancy of HIV-positive individuals on combination antiretroviral therapy in Canada. *BMC Infectious Diseases, 15*, 274. doi:10.1186/s12879-015-0969-x

Patterson, S. E., Milloy, M.-J., Ogilvie, G., Greene, S., Nicholson, V., & Vonn, M. (2015). The impact of criminalization of HIV non-disclosure on the healthcare engagement of women living with HIV in Canada: A comprehensive review of the evidence. *Journal of the International AIDS Society, 18*(4). doi.org/10.7448/IAS.18.1.20572

Patton, M. Q. (2015). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.

Paxton, S. (2002). The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Education and Prevention, 14*(4), 282–294. doi:10.1521/aeap.14.5.282.23874

Pecheny, M., Manzelli, M. H., & Jones, D. E. (2007). The experience of stigma: People living with HIV/AIDS and Hepatitis C in Argentina. *Interamerican Journal of Psychology, 41*(1), 17–30.

Pedersen J. S., Malcoe, L. H., & Pulkingham, J. (2013). Explaining Aboriginal/non-Aboriginal inequalities in postseparation violence against Canadian women: Application of a structural violence approach. *Violence Against Women, 19*(8), 1034–1058.

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., . . . Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV-positive adolescents in South Africa: A qualitative investigation. *AIDS Care, 22*, 970–978. doi:10.1080/09540121003623693

Peterson, J. L., & Jones, K. T. (2009). HIV prevention for black men who have sex with men in the United States. *American Journal of Public Health, 99*, 976–980.

Pew Research Center. (2013). *The global divide on homosexuality.* Retrieved from http://www.pewglobal.org/2013/06/04/the-global-divide-on-homosexuality/

Piot, P., Russell, S., & Larson, H. (2007). Good politics, bad politics: The experience of AIDS. *American Journal of Public Health, 97*, 1934–1936. doi:10.2105/ajph.2007.121418

Pitney, W. A. (2004). Research digest - strategies for establishing trustworthiness in qualitative research. *Athletic Therapy Today, 9*(1), 26–28.

Polansky, M., Teti, M., Chengappa, R., & Aaron, E. (2015). Risk and protective factors for HIV self-disclosure among poor African-American women living with HIV/AIDS. *Issues in Mental Health Nursing, 36*(3), 171–181.

Poudel, K. C., Poudel-Tandukar, K., Yasuoka, J., & Jimba, M. (2007). HIV superinfection: Another reason to avoid serosorting practice. *Lancet, 370*(9581), 23. doi:10.1016/s0140-6736(07)61033-2

Preston, D. B., D'augelli, A. R., Kassab, C. D., & Starks, M. T. (2007). The relationship of stigma to the sexual risk behavior of rural men who have sex with men. *AIDS Education & Prevention*, *19*(3), 218–230.

Psaros, C., Barinas, J., Robbins, G. K., Bedoya, C. A., Safren, S. A., & Park, E. R. (2012). Intimacy and sexual decision making: Exploring the perspective of HIV-positive women over 50. *AIDS Patient Care and STDs, 26*, 755–760. doi:10.1089/apc.2012.0256

Public Health Agency of Canada. (2008). *Canadian incidence study of reported child abuse and neglect*. Retrieved from http://cwrp.ca/sites/default/files/publications/en/CIS-2008-rprt-eng.pdf

Public Health Agency of Canada. (2010). *Population-specific HIV/AIDS status report: Aboriginal peoples*. Retrieved from http://www.catie.ca/sites/default/files/26344.pdf

Public Health Agency of Canada. (2014). *HIV/AIDS among Aboriginal people in Canada*. Retrieved from http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/pdf/ch8-eng.pdf

Public Health Agency of Canada. (2015a). *HIV and AIDS in Canada: Surveillance report to December 31, 2014*. Retrieved from http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/hiv-aids-surveillance-2014-vih-sida/index-eng.php?page=8

Public Health Agency of Canada. (2015b). *Summary: Estimates of HIV incidence, prevalence and proportion undiagnosed in Canada, 2014*. Retrieved from http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/hiv-aids-estimates-2014-vih-sida-estimations/alt/hiv-aids-estimates-2014-vih-sida-estimations-eng.pdf

Randall, M., & Haskell, L. (2013). Trauma-informed approaches to law: Why restorative justice must understand trauma and psychological coping. *Dalhousie Law Journal*, *36*(2), 501–533.

Redd, A. D., Quinn, T. C., & Tobian, A. A. R. (2013). Frequency and implications of HIV superinfection. *The Lancet. Infectious Diseases, 13*, 622−628. doi:10.1016/S1473-3099(13)70066-5

Rhodes, T., & Cusick, L. (2000). Love and intimacy in relationship risk management: HIV positive people and their sexual partners. *Sociology of Health & Illness, 22*(1), 1−26. doi:10.1111/1467-9566.00189

Richardson, E. T., Collins, S. E., Kung, T., Jones, J. H., Tram, K. H., Boggiano, V. L., . . . & Zolopa, A. R. (2014). Gender inequality and HIV transmission: A global analysis. *Journal of the International AIDS Society, 17*(1), 1−5.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles, CA: Sage.

Roberto, K. A., & McCann, B. R. (2011). Everyday health and identity management among older women with chronic health conditions. *Journal of Aging Studies, 25*(2), 94–100.

Rodriguez, L. M., DiBello, A. M., Øverup, C. S., & Neighbors, C. (2015). The price of distrust: Trust, anxious attachment, jealousy, and partner abuse. *Partner Abuse, 6*(3), 298−319.

Rogers, S. J., Tureski, K., Cushnie, A., Brown, A., Bailey, A., & Palmer, Q. (2014). Layered stigma among health-care and social service providers toward key affected populations in Jamaica and The Bahamas. *AIDS Care, 26*, 538−546. doi:10.1080/09540121.2013.844762

Rouleau, G., Cote, J., Cara, C. (2012). Disclosure experience in a convenience sample of Quebec-born women living with HIV: A phenomenological study. *BMC Women's Health, 12*(1), 37–37. doi:10.1186/1472-6874-12-37

Rowniak, S. (2009). Safe sex fatigue, treatment optimism, and serosorting: New challenges to HIV prevention among men who have sex with men. *Journal of the Association of Nurses in AIDS Care, 20*(1), 31−38.

Rupar, T. (2014, February 24). Here are the 10 countries where homosexuality may be punished by death. *The Washington Post.* Retrieved from https://www.washingtonpost.com/news/worldviews/wp/2014/02/24/here-are-the-10-countries-where-homosexuality-may-be-punished-by-death/

Said, E. W. (1979). *Orientalism*. New York: Vintage Books.

Samji, H., Cescon, A., Hogg, R. S., Modur, S. P., Althoff, K. N., Buchacz, K., . . . Gange, S. J. (2013). Closing the gap: Increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *PloS One, 8*(12), e81355.

Sanjuan, P., Molero, F., Jose Fuster, M., & Nouvilas, E. (2013). Coping with HIV-related stigma and well-being. *Journal of Happiness Studies, 14*, 709–722. doi:10.1007/s10902-012-9350-6

Sankar, A., Luborsky, M., Schuman, P., & Roberts, G. (2002). Adherence discourse among African-American women taking HAART. *AIDS Care, 14*, 203–218. doi:10.1080/09540120220104712

Sastre, F., Sheehan, D. M., & Gonzalez, A. (2015). Dating, marriage, and parenthood for HIV-positive heterosexual Puerto Rican men: Normalizing perspectives on everyday life with HIV. *American Journal of Men's Health, 9*(2), 139–149.

Scaccia, A. (2014). Stigma drives workplace discrimination against workers living with HIV. *RH Reality Check.* Retrieved from http://rhrealitycheck.org/article/2014/05/07/stigma-drives-workplace-discrimination-hiv-positive-workers/

Scambler, G., & Paoli, F. (2008). Health work, female sex workers and HIV/AIDS: Global and local dimensions of stigma and deviance as barriers to effective interventions. *Social Science and Medicine, 66*, 1848–1862.

Schellenberg, J. A. (1990). James, William and symbolic interactionism. *Personality and Social Psychology Bulletin, 16*, 769–773. doi:10.1177/0146167290164016

Seedat, S. (2012). Interventions to improve psychological functioning and health outcomes of HIV-infected individuals with a history of trauma or PTSD. *Current HIV/AIDS Reports, 9*(4), 344–350.

Sharpe, T. T., Voûte, C., Rose, M. A., Cleveland, J., Dean, H. D., & Fenton, K. (2012). Social determinants of HIV/AIDS and sexually transmitted diseases among black women: Implications for health equity. *Journal of Women's Health, 21*(3), 249–254. doi:10.1089/jwh.2011.3350

Siegel, K., Lekas, H.-M., Olson, K., & VanDevanter, N. (2010). Gender, sexual orientation, and adolescent HIV testing: A qualitative analysis. *Journal of the Association of Nurses in AIDS Care, 21*(4), 314–326. doi:10.1016/j.jana.2009.12.008

Siegel, K., & Schrimshaw, E. W. (2003). Reasons for the adoption of celibacy among older men and women living with HIV/AIDS. *Journal of Sex Research, 40*(2), 189–200.

Simoni, J. M., Martone, M. G., & Kerwin, J. F. (2002). Spirituality and psychological adaptation among women with HIV/AIDS: Implications for counseling. *Journal of Counseling Psychology, 49*(2), 139–147. doi:10.1037/0022-0167.49.2.139

Sivaram, S., Saluja, G. S., Das, M., Reddy, P. S., & Yeldandi, V. (2008). Reasons for seeking HIV-test: Evidence from a private hospital in Rural Andhra Pradesh, India. *Journal of Health, Population and Nutrition, 26*(4), 431–441.

Smit, P. J., Brady, M., Carter, M., Fernandes, R., Lamore, L., Meulbroek, M., . . . & Thompson, M. (2012). HIV-related stigma within communities of gay men: A literature review. *AIDS Care*, *24*(4), 405–412. doi.org/10.1080/09540121.2011.613910

Smith, D. M., Richman, D. D., & Little, S. J. (2005). HIV superinfection. *The Journal of Infectious Diseases, 192*, 438–444. doi:10.1086/431682

Snelgrove, R. (2015). Youth with chronic illness forming identities through leisure. *Journal of Leisure Research, 47*(1), 154–173.

Squire, C. (2003). Can an HIV-positive woman find true love? Romance in the stories of women living with HIV. *Feminism & Psychology, 13*(1), 73–100. doi:10.1177/0959353503013001009

Stark, J. (2013). Unequal communities: Exploring the relationship between colonialism, patriarchy and the marginalization of Aboriginal women. *Footnotes, 6.* Retrieved from https://journal.lib.uoguelph.ca/index.php/footnotes/article/view/2383/2832

Statistics Canada. (2014). *Trends in self-reported spousal violence in Canada, 2014.* Retrieved from http://www.statcan.gc.ca/pub/85-002-x/2016001/article/14303/01-eng.htm

Statistics Canada. (2015). *Population by marital status and sex*. Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/famil01-eng.htm

Stets, J. E., & Burke, P. J. (2003). A sociological approach to self and identity. In M. R. Leary & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 128–152). New York, NY: Guilford Press.

Steward, W. T., Remien, R. H., Higgins, J. A., Dubrow, R., Pinkerton, S. D., Sikkema, K. J., . . . Morin, S. F. (2009). Behavior change following diagnosis with acute/early HIV infection-a move to serosorting with other HIV-infected individuals. The NIMH multisite acute HIV infection study. *AIDS and Behavior, 13*, 1054–1060. doi:10.1007/s10461-009-9582-6

Straits-Troster, K. A. (1993). *Health consequences of loneliness, social support and life adversity among HIV-infected men* (Doctoral dissertation, University of California at San Diego). Available from http://phdtree.org//pdf/24884870-health-consequences-of-loneliness-social-support-and-life-adversity-among-hiv-infected-men/

Stryker, S. (1980). *Symbolic interactionism: A social structural vision*. Menlo Park, CA: Benjamin/Cummings.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social Psychology Quarterly, 63*(4), 284–297. doi:10.2307/2695840

Tartakovsky, E., & Hamama, L. (2011). Mothers' acceptance-rejection of their children infected with HIV: The role of the mothers' social axioms, psychological distress, and relationships with the partner. *Journal of Pediatric Psychology, 36*, 1030–1042. doi:10.1093/jpepsy/jsr032

The Free Library. (2008). *Simultaneous use of multiple condoms in Cambodia.* Retrieved from http://www.thefreelibrary.com/Simultaneous+use+of+multiple+condoms+in+Cambodia.-a0181813663

Thomas, C., Reeve, J., Bingley, A., Brown, J., Payne, S., & Lynch, T. (2009). Narrative research methods in palliative care contexts: Two case studies. *Journal of Pain and Symptom Management, 37*(5), 788–796. doi:10.1016/j.jpainsymman.2008.05.006

Tiemann, K. A. (2006). Why is their picture on the wedding page? A rural community responds to a union announcement. *Journal of Homosexuality, 51*(4), 119–135. doi:10.1300/J082v51n04_06

Troeman, Z. C. E., Spies, G., Cherner, M., Archibald, S. L., Fennema-Notestine, C., Theilmann, R. J., . . . Seedat, S. (2011). Impact of childhood trauma on functionality and quality of life in HIV-infected women. *Health and Quality of Life Outcomes, 9*(1), 84. doi:10.1186/1477-7525-9-84

Truth and Reconciliation Commission. (2015). *Honouring the Truth, Reconciling for the Future: Summary of the final report of the Truth and Reconciliation Commission of Canada.* Retrieved from http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Exec_Summary_2015_05_31_web_o.pdf

Tshweneagae, G. T., Oss, V. M., Mgutshini, T. (2015). Disclosure of HIV status to sexual partners by people living with HIV. *Curationis, 38*(1), 1–6.

UNAIDS. (2007). *The greater involvement of people living with HIV (GIPA).* Retrieved from http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

UNAIDS. (2011). *Targets and elimination commitments*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2262_UNAIDS-ten-targets_en.pdf

UNAIDS. (2012). *Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/Key_Human_Rights_Progra mmes_en_May2012_0.pdf

UNAIDS. (2014b). 90-90-90 *An ambitious treatment target to help end the AIDS epidemic*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf

UNAIDS. (2014a). *Fast track: Ending the AIDS epidemic by 2030*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublicatio n/2014/20140925_Fast_Track_Brochure.pdf

UNAIDS. (2014c). *Gap report*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublicatio n/2014/UNAIDS_Gap_report_en.pdf

UNAIDS. (2015a). *Fact sheet 2015*. Retrieved from http://www.unaids.org/en/resources/campaigns/HowAIDSchangedeverything/fact sheet

UNAIDS. (2015b). *UNAIDS terminology guidelines 2015*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelin es_en.pdf

UNESCO. (2006). *UNESCO guidelines on language and content in HIV- and AIDS-related materials.* Retrieved from http://unesdoc.unesco.org/images/0014/001447/144725e.pdf

Usborne, E., & Sablonnière, R. (2014). Understanding my culture means understanding myself: The function of cultural identity clarity for personal identity clarity and personal psychological well-being. *Journal for the Theory of Social Behaviour*, *44*(4), 436–458.

Varni, S. E., Miller, C. T., McCuin, T., & Solomon, S. E. (2012). Disengagement and engagement coping with HIV/AIDS stigma and psychological well-being of people with HIV/AIDS. *Journal of Social and Clinical Psychology*, *31*(2), 123–150.

Vlahov, D., Safaien, M., Lai, S., Strathdee, S. A., Johnson, L., Sterling, T., & Celentano, D. D. (2001). Sexual and drug risk-related behaviours after initiating highly active antiretroviral therapy among injection drug users. *AIDS, 15*, 2311–2316.

Vyavaharkar, M., Moneyham, L., Tavakoli, A., Phillips, K. D., Murdaugh, C., Jackson, K., & Meding, G. (2007). Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the southeastern United States. *AIDS Patient Care and STDs, 21*, 667−680. doi:10.1089/apc.2006.0131

Walker, K. L., Hart, J. L., & D'Silva, M. U. (2012). *Communicating about HIV/AIDS: Taboo topics and difficult conversations*. New York, NY: Hampton Press.

Weait, M. (2011). *Criminalization of HIV exposure and transmission: A global review*. Retrieved from http://www.hivlawcommission.org/index.php/working-papers?task=document.viewdoc&id=90

Weber, L. (2006). Reconstructing the landscape of health disparities research: Promoting dialogue and collaboration between feminist intersectional and biomedical paradigms. In Shultz, A. J., & Mullings, L. (Eds.), *Gender, race, class & health.* (pp. 2–59). San Francisco: John Wiley & Sons.

Welbourn, A. (2006). 'Man hunt intimacy: Man clean bathroom': Women, sexual pleasure, gender violence and HIV. *Institute of Development Studies, 37*(5), 123−126.

Wertz, F. J., Charmaz, K., & McMullen, L. M. (2011). *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry*. New York, NY: Guilford Press.

Whetten, K., Leserman, J., Lowe, K., Stangl, D., Thielman, N., Swartz, M., . . . Van Scoyoc, L. (2006). Prevalence of childhood sexual abuse and physical trauma in an HIV-positive sample from the deep south. *American Journal of Public Health, 96*, 1028−1030. doi:10.2105/AJPH.2005.063263

Whetten, K., Reif, S., Toth, M., Jain, E., Leserman, J., & Pence, B. W. (2012). Relationship between trauma and high-risk behavior among HIV-positive men who do not have sex with men (MDSM). *AIDS Care, 24*, 1453−1460. doi:10.1080/09540121.2012.712665

World Health Organization. (2011). *A new health sector agenda for HIV/AIDS*. Retrieved from http://whqlibdoc.who.int/hq/2011/WHO_HIV_11.03_eng.pdf?ua=1

World Health Organization. (2014a). *Global summary of the AIDS epidemic 2013*. Retrieved from http://www.who.int/hiv/data/epi_core_dec2014.png

World Health Organization. (2014b). *HIV/AIDS fact sheet*. Retrieved from http://www.who.int/mediacentre/factsheets/fs360/en/
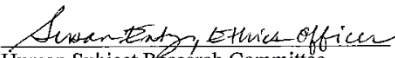
World Health Organization. (2015a). *Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV*. Retrieved from http://apps.who.int/iris/bitstream/10665/186275/1/9789241509565_eng.pdf?ua=1

World Health Organization. (2015b). *Progress report: Global health sector response to HIV, 2000-2015*. Retrieved from http://apps.who.int/iris/bitstream/10665/198065/1/9789241509824_eng.pdf?ua=1

World Health Organization. (n.d.). *Social determinants of health: Key concepts*. Retrieved from http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/

Williams, G. (1984). The genesis of chronic illness: Narrative reconstruction. *Sociology of Health and Illness, 6*(2), 175–200.

Wilson, H. W., & Widom, C. S. (2011). Pathways from childhood abuse and neglect to HIV-risk sexual behavior in middle adulthood. *Journal of Consulting and Clinical Psychology*, *79*(2), 236–246.

Wilton, J., & Broeckaert, L. (2013). *The HIV treatment cascade: Patching the leaks to improve HIV prevention.* Retrieved from http://www.catie.ca/en/pif/spring-2013/hiv-treatment-cascade-patching-leaks-improve-hiv-prevention

Xiao, Z., Li, X., Qiao, S., Zhou, Y., Shen, Z., Tang, Z. (2015). Using communication privacy management theory to examine HIV disclosure to sexual partners/spouses among PLHIV in Guangxi. *AIDS Care, 27*(Suppl. 1), 73–82.

Yang, W.-P., Yang, P.-H., & Chen, Y.-J. (2013). Can one get fish and bear's paws at the same time? In *International Conference on the Modern Development of Humanities and Social Science* (pp. 239–246). Retrieved from www.atlantis-press.com/php/download_paper.php?id=10048

Young, S. D., & Zhu, Y. (2012). Behavioral evidence of HIV testing stigma. *AIDS and Behavior, 16*, 736–740. doi:10.1007/s10461-011-0018-8

Zeglin, R. J., & Stein, J. P. (2015). Social determinants of health predict state incidence of HIV and AIDS: A short report. *AIDS Care, 27*(2), 255–259. doi:10.1080/09540121.2014.954983

Zierler, S., & Krieger, N. (1997). Reframing women's risk: Social inequalities and HIV infection. *Annual Review of Public Health, 18*(1), 401–436. doi:10.1146/annurev.publhealth.18.1.401
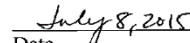
Appendix A: Human Subject Research Committee (HSRC) Approval

CERTIFICATE OF HUMAN PARTICIPANT RESEARCH
University of Lethbridge
Human Subject Research Committee

PRINCIPAL INVESTIGATOR: Julia Dabravolskaj

CO-INVESTIGATOR: Jean Harrowing

ADDRESS: Faculty of Health Sciences
University of Lethbridge
4401 University Drive
Lethbridge, AB   T1K 3M4

PROJECT TITLE: Partner-seeking Experiences of Heterosexual People
Living with HIV/AIDS in   Canada

INTERNAL FILE: 2015-051

INFORMED CONSENT: Yes

LENGTH OF APPROVAL: July 8, 2015 – June 30, 2016
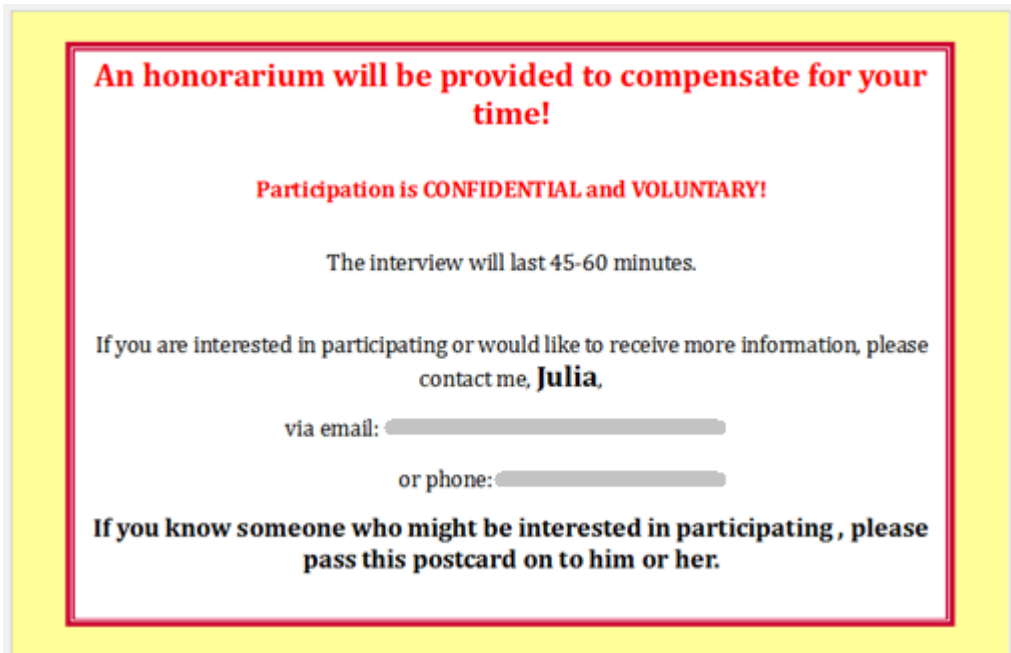
The Human Subject Research Committee, having reviewed the above-named proposal on matters relating to the ethics of human research, approves the procedures proposed and certifies that the treatment of human participants will be in accordance with the Tri-Council Policy Statement and University policy.

Susan Entz, Ethics Officer   _July 8, 2015_
Human Subject Research Committee   Date

Appendix B: Post Cards

Post cards (double-sided) for distribution to potential participants and service providers

LOOKING FOR STUDY PARTICIPANTS

If you are a *SINGLE HETEROSEXUAL HIV-positive* adult, you are invited to participate in the research project!!!

The goal is to understand the experiences of living with HIV in terms of seeking partners.

University of Lethbridge

An honorarium will be provided to compensate for your time!

Participation is CONFIDENTIAL and VOLUNTARY!

The interview will last 45-60 minutes.

If you are interested in participating or would like to receive more information, please contact me, **Julia**,

via email:

or phone:

If you know someone who might be interested in participating, please pass this postcard on to him or her.

Appendix C: Research Announcement

University of Lethbridge

FIAT LUX

RESEARCH PROJECT

Single Heterosexual HIV-positive People Older than 18 Years are Invited to Participate in a Research Study

The **interview lasting 45-60 minutes** will be conducted at a place convenient for you and will include exploring the experiences of seeking partners. **Participation is confidential.**

If you are interested in participating or would like to receive more information, please do not hesitate to contact me, **Julia,**

via email: _____

or phone : _____

Appendix D: Informed Consent Form
Partner-Seeking Experiences of Single Heterosexual People Living with HIV in a Western Canadian City

Dear Participant,

My name is Julia Dabravolskaj, and I am a master's degree student at the University of Lethbridge. My master's research project is about the experiences of heterosexual, single, HIV-positive people in terms of seeking a partner. The goals of this project include learning about your experience of seeking a partner and providing an opportunity for your voice to be heard by other members of society in order to increase knowledge about what it is like to live with or care for people with HIV illness.

This interview will take about 45-60 minutes. I will begin by asking if you are compliant with the current laws regarding disclosure of HIV status to a sexual partner. I will ask you to fill in a form about your gender, age, occupation, to give me general information about you. After that, I will ask you to pick a fake name. This name will be used during the interview. We will then talk about your decisions and experiences of seeking or not seeking a partner. The interview will be conducted in a private room or area that we agree on, at a convenient time for you. I will audio-record the interview. If you do not want to be recorded, I will ask your permission to take notes during the interview. After we finish, you will get 20 dollars in cash.

What are the benefits and risks for you as a participant?

You will not benefit directly from participating in this research study. However, you will get a wonderful opportunity to share your thoughts about everything you feel you want to tell me. Your experience may also help other HIV-positive people to learn to live a good life with the illness. It will also help me better understand issues that should be addressed for the benefit of all people living with HIV and AIDS.

You might feel distress when discussing living with HIV and AIDS. In this case I will refer you to a free counsellor.

What about confidentiality issues?

Before the interview, you will pick a fake name to be used during the interview. I will type up the interview myself or use a trusted professional transcriber so that no one else will hear the recording. There are several ways I will make sure your identity is safe: your contact information and names, in either paper or electronic formats, will be stored separately from research data; I will ensure that all electronic documents are password-protected and encrypted; I will remove your name and identifying information from the written copy of the interview; and original materials will be securely shared only with my supervisor. The transcriber will sign a confidentiality form and promise not to share any information from the interview.

How and when can I withdraw from the research?

Participation in this research project is voluntary, and you can withdraw any time during the interview. Withdrawal does not have any consequences for you: you will get

the honorarium, my attitude to you will be respectful and non-judgmental, and withdrawal will not affect the services that you get, in any way. However, when I am analyzing the interviews (anticipated for February 2016) or when the research findings are published (anticipated for December 2016) you will not be able to withdraw. Therefore, please let me know within a month of the interview if you want me to delete your interview from the analysis.

How will I use the data?
- I will destroy the recorded interviews right after I finish typing them. I will anonymize the transcripts (i.e., delete any identifying information or your name from the transcript). I might use some of the anonymized quotes for publications, teaching, and conferences, but I will **never** reveal your identity in any way.
- I will compile the demographic data of all the participants into a table and will report it in any publications or presentations arising from the research. The demographic data will include the average age of participants, gender, employment (full- or part-time), racial/ethnic background, and average age since diagnosis. No identifying information (direct or indirect) will be included.
- If you sign the informed consent form, you agree to let me use the information you provide.
- If you are interested in reading the summary of the findings, you can provide contact information, and I will send it to you. I will also create the final report for service organizations and my committee, but it will not contain any identifying information. My thesis will contain my interpretation of the interviews with all of the participants, rather than any direct information from the participants.

If you have any questions about this research project please contact:

Julia Dabravolskaj, MD, M.Sc. (candidate) via email: [email address] or phone: [phone #].

Dr. Jean Harrowing (supervisor), Faculty of Health Sciences, University of Lethbridge, via email: [email address] or phone: [phone #].

Questions regarding your rights as a participant in this research may be addressed to the Office of Research Ethics, University of Lethbridge, via phone [phone #] or email at [email address].

If you have read (or have been read) the above information regarding this research study on the experience of partner-seeking among heterosexual people living with HIV/AIDS, and consent to participate in this study, please sign below:

_____ (Printed Name)
_____ (Signature)
_____ (Date)

_____ (Researcher's name)
_____ (Signature)
_____(Date)

Please let me know if I can contact you via phone or meet in person if there are any questions that need clarification or if you would be willing to go over the transcript of our interview with me to help me be sure that my interpretation of what you said is correct:

_____

If you want to receive the final report of the research, please provide your contact information below (e.g., email, phone, etc.):

_____

A signed copy of this form has been given to you for your records.

Appendix E: Interview Guide

1. Could you please tell me about your experience of living with HIV infection?
   a. When you think about your diagnosis, how do you describe this experience in relation to your life as a whole?
   b. What is most stressful about living with the illness?
   c. What changes would you like to see in your life?
   d. Can you tell me more about support that you have? What, if anything, would you like to add to the support you have?
2. Could you please tell me how other people treat you?
   a. Do you feel yourself being different in any way from other people?
   b. How has your perception of yourself changed after being diagnosed?
   c. How would you describe yourself when it comes to your social life? What changes have you noticed if there were any?
3. Could you please tell me what is 'relationship' for you? What does it mean?
   a. In what ways does a relationship, or absence of one, influence your life?
   b. Are you engaged in partner-seeking at the moment?
4. What factors did you take into account while making the decision to seek/not to seek (depends on the answer to the 3c question) a partner?
   a. Did you feel any societal or family influence on this decision? If yes, in what ways?
   b. How did your life change after this decision?
   c. If a participant is engaged in partner-seeking, ask the following questions:
      i. How would you picture your ideal partner? Can you mention criteria you have in mind when looking for a partner?
      ii. Does the HIV status of your potential partner play any role in this process of looking for a partner?
      iii. In your opinion, what are pros and cons of being in a relationship with an HIV-positive person? What about a relationship with an HIV-negative person?
      iv. Could you tell me how are you seeking a potential partner (e.g., using the Internet, personal connections, etc.)? What strategies work best for you (easier, feel more comfortable, etc.)?
   d. If a participant is NOT engaged in partner-seeking:
      i. What is it like to be a single person living with the virus?
      ii. When did you stop seeking a partner? How did it happen?
      iii. How did you seek partners before this decision (e.g., the Internet)?
      iv. Do you think you might start seeking a partner in the future? If yes, what might influence this decision?
5. What advice would you give to other single people living with HIV?
   a. What are your hopes and plans for the future?
   b. What would you like to change now in your life?

I think that is basically everything I wanted to ask you to talk about. Do you have anything else you would like to say or final thoughts you'd like to follow up that I haven't asked you?

Appendix F: The Demographic Form

**Partner-Seeking Experiences of Single Heterosexual People Living with HIV
in a Western Canadian City**

Since it is important to learn more about the participants of this research project, I would be very grateful if you could answer several questions. All information is anonymous and will be stored on a password-protected computer in a locked room, thus excluding the chance of a breach of confidentiality.
Please either check the boxes or write your answer in the space provided.

1. How old are you? ……………….. years
2. Your gender: ………………………………………………
3. Your employment (check which applies to you):
   - ☐full-time employment
   - ☐part-time employment
   - ☐full-time student
   - ☐part-time student
   - ☐other (please specify) …………………………

4. Your occupation (if you are employed): ……………………………..
5. Your racial/ethnical background: ………………………………
6. Time since diagnosis of HIV infection (weeks, months, or years):……………....

Appendix G: Safety Protocol

1. I will share an interview schedule with my supervisor. This interview schedule will contain the date, time, address of each interview, and anticipated completion time. If any changes occur, I will let my supervisor know immediately via email.
2. I will contact my supervisor right after the completion of each interview, no later than 1.5 hrs after the scheduled time for the interview.
3. If my supervisor is unavailable during the date or time of the scheduled interview, one of the committee members will be asked to fill this role.
4. I will have two charged mobile phones (one will be my personal, the other one will be used exclusively for communication with the participants).
5. I will carry two pieces of ID (my student ID and driver's license) to prove my identity in case I am asked.
6. If I feel unsafe for any reason, I will leave my location immediately.