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Life in the Shadows: Examining the Role that HIV Status Plays in the Decision Making Processes of HIV Positive Aboriginal Women in Terms of Their Reproductive Health and Their Decisions to Have a Child or Not

Nash, Tina Marie Lynn

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Life in the Shadows: Examining the Role that HIV Status Plays in the Decision Making
Processes of HIV Positive Aboriginal Women in Terms of Their Reproductive Health and Their
Decisions to Have a Child or Not

by

Tina Marie Lynn Nash

A THESIS

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Abstract

This thesis represents a qualitative research study involving three urban dwelling HIV positive Aboriginal women. It highlights the factors that participants describe as being influential in their decision to have a child or not, given positive HIV status. In depth semi-structured interviews were conducted with participants and descriptive construction of emerging themes and categories were developed to explain the results. Key factors that were found to influence participant's decisions to have a child or not were: intention; fertility options; stigma; fear; social support; personal health status; spirituality; and cultural safety. This study also found that an analysis of the role HIV status plays in the decision making processes of HIV positive Aboriginal women with regards to whether or not to have a child must take into account how colonization, systemic discrimination, racism, early childhood and adolescent experiences, poverty, addictions, homelessness, co-morbidity of illness, and culture intersect to influence their decisions.

Keywords: Aboriginal, HIV, pregnancy, reproductive, child bearing, decision

Preface

Canadian Aboriginal women suffer from a range of health problems at higher rates than occur in the general Canadian population and the rate of new HIV infections for Aboriginal women of child bearing age, 15-52 years of age, has been steadily increasing since 1999 with the greatest increases found in the 15-44 age group (Public Health Agency of Canada, 2010; 2014). In 2014 alone, Aboriginal individuals accounted for twenty percent of the number of cases of HIV in the province of Alberta despite only representing 5.3% of the population of Alberta (Alberta Health Surveillance and Assessment Branch, 2015).

Research to date has been inadequate in describing the factors that influence HIV positive Aboriginal women's decisions to have a child or not and have focused on vertical transmission, pregnancy planning, unintended pregnancy, and fertility intentions and desires (Forbes et al., 2012; Hughes et al., 2009; Loutfy et al., 2009; Loutfy et al., 2012; Loutfy et al., 2014; Ogilvie, Monday & Forbes, 2002; Ogilvie et al., 2007; Money, M. 1998; Nattabi et al., 2009). There are no studies that specifically examine the role that HIV status plays in the decision making processes of HIV positive Aboriginal women in terms of their reproductive health and their decisions to have a child or not. Thus, this study will aid in understanding the factors that influence HIV positive Aboriginal women's decisions to have a child or not.

The goal of this study is to produce a rich, detailed, descriptive narrative of the lived experience of HIV positive Aboriginal women regarding the factors that influence their decision to have a child or not. This study will also serve to fill some of the gaps in knowledge and develop the literature regarding the role that HIV status plays for HIV positive Aboriginal women with regards to their reproductive and pregnancy health and outcomes.

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List of Symbols, Abbreviations and Nomenclature

Symbol	Definition
AAMHP	Adult Aboriginal Mental Health Program
ACAA	AIDS Calgary Awareness Association
AIDS	Acquired Immune Deficiency Syndrome
AISH	Alberta Income for the Severely Handicapped
AHRB	Assessment of HIV Risk Behavior
AHS	Alberta Health Services
ART	Antiretroviral Therapy
AZT	Azido thymidine
CCC	Canadian Contraceptive Study
CD4	Cluster of Differentiation 4
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CPHSP	Canadian Perinatal HIV Surveillance Program
CSC	Calgary STI Clinic
C-Section	Cesarean Section
CSHC	Calgary Sexual Health Clinic
CUAI	Calgary Urban Aboriginal Initiative
CUPS	Calgary Urban Project Society
ERHL	Elbow River Healing Lodge
DHSS	Department of Human Service
HAART	Highly Active Anti-Retroviral Therapy
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug Use
LCDC	Laboratory Centre of Disease Control
MEDLINE	Medical Literature Analysis and Retrieval System Online
MRSA	Methicillin Resistant Staphylococcus Aureus
OB-GYN	Obstetrician-Gynecologist
OCAP	Ownership, Control Access and Possession
PHAC	Public Health Agency of Canada
PsycINFO	Psychological Information Database
NUD*IST	Non-numerical Unstructured Data Indexing, Searching and Theorizing
RCAP	Royal Commission on Aboriginal Peoples
RTI	Reverse Transcriptase Inhibitor
SAC	Southern Alberta Clinic
SES	Socio-Economic Status
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Illnesses
USB	Universal Serial Bus

Chapter 1 Background

1.1 Personal Experience with Pregnancy and HIV

My perceptions of HIV, Aboriginal people, Aboriginal culture and reproductive health have been shaped by my experiences in each one of these areas. I am an Aboriginal female of the Tahltan First Nation, mother of eleven children and a member of the urban Aboriginal community for 40 years. Subsequently, my reproductive experience as an Aboriginal woman within an urban context of health service delivery is extensive. Furthermore, I am familiar with Aboriginal ways of life, culture, attitudes, beliefs and mechanisms of societal marginalization by virtue of my ethnicity and involvement in Aboriginal culture and traditional ways of life. I also have both personal and professional experience with individuals who are HIV positive, as I have witnessed family members living with HIV and I have served in the capacity of nursing assistant, laboratory technician, and unit clerk for an isolation unit for HIV infected patients.

Fifteen years ago, my partner at the time, was diagnosed with HIV and as an Aboriginal woman in the prime of my reproductive period in life, his diagnosis was very difficult for me psychologically, socially, and emotionally and it often was at the forefront of my decisions of whether or not to have another child and the fears that surrounded my reproductive health. Although I myself never tested HIV positive, there were very few opportunities where I could openly express my concerns as well as my desire to still have children without facing judgment and stigma from friends, family, and even the health care profession. Luckily, I did have a very compassionate and understanding obstetrician-gynecologist (OB-GYN) who validated my desires for more children and never once tried to discourage me from having children, despite my partner being HIV positive, but rather provided me with the most up to date educational information available and routine HIV testing so that I could make informed decisions regarding

my reproductive health that guided my decisions of whether or not to have another child and how to proceed with my reproductive health care. Although I never did go on to have more children with my HIV positive partner, I did come to understand the physical strains, stigma, relationship difficulties, emotional turmoil, social isolation, and decreases in self-worth that accompany having HIV or being in a relationship with someone who does. Thus, my personal understanding of context, participants, and subject matter enhanced my awareness, knowledge and sensitivity to many of the challenges, decisions, and issues encountered by HIV positive Aboriginal women seeking perinatal health care services in an urban setting. I brought to this research project both knowledge of Aboriginal culture and perinatal healthcare as well as knowledge of HIV disease and treatment. Thus, due to my previous experience and knowledge, I also had certain biases with regards to this study, and although every effort was made to ensure respect of participant stories, these biases shaped the way I viewed and understood the collected data and the way I interpreted the experience under investigation.

I commenced this study with the perspective that, in the urban setting, HIV positive Aboriginal women experience reproductive healthcare with difficulty due to broader social issues related to addictions, poverty, service accessibility, societal marginalization, HIV positive status stigmatization, and cultural insensitivity, and that these factors impact upon their decisions about whether or not to have children. Furthermore, I believe that the reproductive decision making processes of this population of women are influenced by their reproductive health experience and experience with health care professionals.

1.2 Situation of HIV in the Aboriginal Population in Canada

Worldwide the HIV epidemic has reached gender parity, with 50% of the 3.3 million people living with HIV globally being women (UNAIDS, 2010). In Canada in 2006, Aboriginal

women represented close to half (45.3%) of all positive test results among Aboriginal people compared to 19.2% among non-Aboriginal women (McKay-McNabb, 2006) with Aboriginal also women having died sooner of AIDS and having a lower utilization of antiretroviral therapy (ART) programs (McCall, Browne & Reimer-Kirkham, 2009). Canadian demographics have shifted towards increased rates of Aboriginal women of child bearing age being infected (McKay-McNabb, 2006; Public Health Agency of Canada, 2014). While Aboriginal people constitute 4.3% of the total Canadian population (Statistics Canada, 2011), male and female combined, 15.9% of reported HIV cases in 2013 were Aboriginal and of these, 50.1% contracted their HIV through IDU exposure. In 2009, 26% of newly diagnosed HIV infections were among females aged 15 years or older which is more than double the proportion (12%) observed in 1999 (Public Health Agency of Canada, 2010). This is an important statistic given that the diagnosis of HIV occurs at the onset of these women's reproductive life span. Of all 2013 new cases of HIV infection, Aboriginal females accounted for about one-third (32.0%) of female HIV cases while Aboriginal males accounted for 11% of the total male population infected and Aboriginal females contracted HIV 66.2% of the time through heterosexual contact (Public Health Agency of Canada, 2014). In Alberta the picture is similar with 19.2% cases reported in 2014 being Aboriginal despite Aboriginal people only constituting 5.3% of the total Alberta population and the majority (over 80%) of HIV exposure occurring during reproductive age (15-50 years) (Alberta Health Surveillance & Assessment, 2015).

Thus, it is clear that the Canadian Aboriginal female population has high rates of HIV infection (32.0%) that are greater than those of the Aboriginal male population (11.5%) and as the Public Health Agency of Canada (2014) reports, females are being diagnosed at a younger age with 97.5% of all HIV infections being diagnosed during reproductive age.

1.3 Introduction

Worldwide, women face the greatest risk of acquiring HIV. Women face structural barriers, social and economic inequality, gender violence, and they occupy lower social positions which combined with biological vulnerability, make them at considerable risk of HIV. Women are biologically more vulnerable to HIV infection, with male to female transmission estimated to be eight times more likely than female to male transmission, due to the thin layer of cells and greater surface area within the female genital tract that results in substantial mucosal exposure to seminal fluids. Additionally, women have a higher prevalence of non-consensual sex and sex without condom use and have higher rates of sexually transmitted illnesses (STI) which when active, can facilitate the transmission of HIV (University of California, San Francisco (UCSF) Center for AIDS Prevention Studies, 2011). This data presents a very problematic picture of how HIV is spreading in the female population and the Aboriginal population specifically.

The increase of HIV positive Aboriginal women of childbearing age is not only alarming in terms of individual and societal health impacts, but it is also not clearly understood in terms of the complex factors of a contextual legacy of abuse, Aboriginal specific risk factors, societal marginalization, and colonization. The *Royal Commission on Aboriginal Peoples* (RCAP) (1996) found that because of a history of unequal access to resources, residential schooling and racism, Aboriginal people in general are over-represented among Canadians who are unemployed, abuse alcohol and drugs and commit suicide (Canada, Erasmus & Dussault, 1996). Over the 100+ years of residential school operation in Canada, sexual, physical, mental and spiritual abuse was rampant and several generations were taught to internalize shame for being Aboriginal. As a result of this contextual legacy, a system of abuse and shame was set in motion

for Aboriginal people that is now reflected in the increased risk behaviors of Aboriginal women and is becoming manifest in the epidemic of HIV infections occurring in Aboriginal women.

The historical and present day reality of colonization for the Aboriginal peoples of Canada has a direct impact on the everyday challenges that Aboriginal women face. Cumulative effects of colonization include; poverty, discrimination, displacement, intergenerational trauma, violence, and addiction (Adelson, 2005; Walters & Simoni, 2002). Studies indicate that 44% of Aboriginal women who were abused during childhood were younger when they first had sexual intercourse, they were 6 times more likely to have more than 20 sexual partners, a history of sexually transmitted illnesses (STI) and more likely to use injection drugs (Prentice, 2004; Mill, 1997; Young & Kantz, 1998), all of which are risk factors that increase the likelihood of becoming infected with HIV. Also, being a victim in an abusive relationship may lead to powerlessness in sexual relationships and an inability to negotiate safer sex practices. This then means that Aboriginal women become vulnerable to coerced sex, including rape, sexual assault and forced sex work where men are unlikely to wear condoms and Aboriginal women are unable to protect themselves (Prentice, 2004; Ship & Norton, 2000). Thus, a contextual legacy of abuse, such as that historically experienced by Aboriginal people, is associated with increased health risk behaviors that go beyond specific physical and psychosocial issues.

In addition, economic and social power imbalances between Aboriginal and non-Aboriginal people have contributed to a host of social problems that increase the risk of Aboriginal women becoming infected with HIV. Aboriginal women experience higher levels of poverty, violence, mobility, substance abuse, dislocation, lack of access to adequate healthcare, and a tendency to make self-care a lower priority than the care of children and family (McCall et al., 2009; McKay-McNabb, 2006; Mwakisha, 1996). To deal with these issues, intravenous drug

use (IDU) becomes a method of coping whereby illegal activities become part of the lives of Aboriginal women to sustain their drug use. Aboriginal female intravenous drug users are at great risk of HIV infection due to poverty, unstable housing, frequent incarceration, insufficient use of condoms, violence, racism (Browne, 2007; Varcoe & Dick, 2008), high rates of STI and frequent sharing of needles (Prentice, 2004). These intersecting factors have been shown to contribute to the risk of HIV seroconversion and adversely affect the health status of those who are living with HIV/AIDS (Mehrabadi, et al., 2008; Pearce et al., 2008; Spittal, et al., 2007). Given that the lifestyle of female Aboriginal IDU's is characterized by movement to and from the street, prisons and reserves, the spread of HIV into other segments of the Aboriginal community is inevitable (Prentice, 2004; Mill, 1997). Furthermore, women who abuse drugs are more likely to turn to sex trade related work to feed their habit and are more likely to have impaired judgment when it comes to negotiating safer methods of using or having sex. Thus, the potential for HIV positive Aboriginal women to become pregnant and have children increases with risky sexual practices, STI and IDU (Prentice, 2004).

Women in general have experienced marginalization within society. Aboriginal women experience this same marginalization but to a greater extent and HIV positive Aboriginal women experience it even greater still. Aboriginal women who are HIV positive and of child bearing age in Canada experience a triple jeopardy in the sense that, they are discriminated against because they are racial minorities by virtue of being Aboriginal, they are women and they are HIV positive (Aboriginal Nurses' Association, 1996). Additionally, there are numerous structural and institutional barriers that these women face along with internalized shame and stigmatization. In many areas, culturally sensitive health services do not exist, and where they do, treatment compliance and illicit drug abstinence are prerequisites for entrance into a

program. Furthermore, racial stereotypes, layers of discrimination related to sex, ethnicity, IDU status, being poor, unemployed, homeless and having a criminal record further marginalizes Aboriginal HIV positive women from society and social services (Binder, 2004). Internalized shame and the negative attitudes of health providers are also barriers that HIV positive women must overcome when accessing appropriate reproductive health services and care (Buchariski, Reutter & Ogilvie, 2006; Cain et al., 2013; Loutfy et al., 2012; Ship & Norton, 2000).

A high birth rate coupled with an increasing rate of HIV infection within the female Aboriginal population is predictive of high rates of vertical transmission of HIV which means that HIV has the potential to impact many families and communities (Forbes et al., 2012). A study of all pediatric centers in Canada found that between 1995-1997, 19% of women known to be infected with HIV at the time of the birth of their child were Aboriginal (Money, 1998). In 2.4% of HIV cases in Aboriginal females and 1.4% in Aboriginal males, vertical transmission – passing on of the HIV virus through breast milk, during pregnancy or during delivery via exchange of blood between mother and fetus and/or child - was the mode of acquiring HIV (Prentice, 2004). Available evidence suggests that 19.3% of all perinatally HIV exposed infants confirmed to be HIV positive through vertical transmission in Canada are born to Aboriginal women (Public Health Agency of Canada, 2010).

Although it appears that pregnancy does not change the course of HIV disease (Landesman & Minkoff, 1998), it can be devastating to HIV positive pregnant women when complications from chronic immunosuppression and subsequent opportunistic infections develop during the course of pregnancy. In addition, HIV and pregnancy both place major nutritional burdens on a woman's body. Studies also indicate that the health of children born to HIV positive mothers may be compromised in a number of ways including increased risk of lower

birth weight, cardiac abnormalities, bacterial infections, gastrointestinal, pulmonary, and renal complications, increased risk of encephalopathy, and AIDS associated malignancies despite advancements in anti-viral therapy (Blanche, Tardiwu, Duliege & Rouzioux, 1990; Barasch, Safford, Catalanotto & Fine, 2000; Croft, Jacob & Goodman, 1993; Goedert, 2000; Johnson, Hendson & Crewe-Brown, 2000; Lipshultz & Eastly, 1998; Lobato, Caldwell, Ng & Oxtoby, 1995; Luginbuhl, Orav & McIntosh, 1993; Ray, Rakusan, Loechelt & Selby, 1998; Staarc, Lipshultz & Kaplan, 1999). However, many of these complications can be reduced or eliminated when anti-viral therapy is administered during pregnancy. Prospective studies indicate that vertical transmission is reduced from 15-25% to less than 8% (and in some cases 3%) when such chemo-prophylactic treatment is administered (Hughes et al., 2009; Public Health Agency of Canada, 2010).

Despite improvements in HIV treatment and prevention, HIV still has devastating effects for Aboriginal women. A critical aspect of HIV among women of reproductive age and their children is the reality that children become orphaned. Even if children are lucky enough to escape infection from HIV positive mothers, they are still likely to join the growing number of children orphaned by parents who have died of AIDS (Rutenberg, Biddlecon & Karna, 2000). In addition, even if children are not infected, they still will have an HIV positive parent(s) that must deal with the disease on a daily basis (Prentice, 2004) and in an Aboriginal culture where family is central, HIV has a devastating intergenerational impact.

1.4 Need for Research

Few studies to date have examined HIV positive Aboriginal women of reproductive age (Forbes et al., 1997; McCall et al., 2009; McKay-McNabb, 2006; Ogilvie, Monday & Forbes, 2002; Ogilvie, et al., 2007; Ship & Norton, 2000) and so there has been limited impact in fields

of research, policy and services (Ship & Norton, 2000) contributing to the growing health disparity of Aboriginal women (Benoit, Carroll & Chaudry, 2003). Where data does exist, epidemiological information that documents prevalence/incidence estimates of HIV disease and qualitative studies that explain the impact that HIV positive status has for Aboriginal women have been the only sources of information generated for this population. The HIV epidemic among Aboriginal women is still poorly understood and there are only a handful of studies (Loutfy et al., 2009; Nattabi, Li, Thompson, Orach & Earnest, 2009; Ogilvie et al., 2007) that have explored reproductive decision making experiences of HIV positive women, not even Aboriginal specific women, to provide meaning to the current statistical data and help illuminate and understand social phenomenon in the natural setting (Browne, 2007). Thus, qualitative research methods are needed to explore this gap in existing research literature concerning HIV positive Aboriginal women's reproductive health that describes the perinatal experience of urban Aboriginal women living with HIV.

Although there are a few studies that discuss the reality and experiences of Canadian Aboriginal women living with HIV (Carter et al., 2013; Loutfy et al., 2012; McCall & Pauly, 2012; McCall et al., 2009; Wagner et al., 2010) only two do so within the context of reproductive care and fertility desires and/or intentions (Loutfy et al., 2009; Ogilvie et al., 2007). Even then, these two studies do not discuss the role that HIV status plays in the decision making processes of HIV positive Aboriginal women with regards to their decisions of whether or not to have a child. Instead, these studies discuss the characteristics of women of reproductive age with HIV who intend to have children as well as predictors of intention to have children such as ethnicity, age, and relationship status. Thus, the need for this particular study which was designed to examine the role the HIV plays in the decision making processes of HIV positive

Aboriginal women in terms of their reproductive health and decisions to have a child or not is required to fill a gap in existing research literature.

This study highlights and make visible some of the issues that HIV positive Aboriginal women experience when making reproductive decisions in the context of their daily lives, and it also provides healthcare providers with information related to the reproductive decision making processes and attitudes of these women. Future benefits also include recommendations for the development of effective and culturally appropriate care and programming to meet the reproductive health needs of Aboriginal women with HIV (Barlow et al., 2008). Moreover, this study gives a voice to a segment of the population who too often have been marginalized into a societal position of silence and forced to live neglected in the shadows of HIV.

1.5 Objectives of Study

The primary objective of this study was to generate a rich, detailed, descriptive narrative of the lives of HIV positive Aboriginal women with regards to what influenced their decisions to have children or not within an urban environment.

The secondary objective of this study was to examine the implications for primary health care providers of HIV positive Aboriginal women's reproductive decisions about having a child or not.

1.6 Conceptual Framework of Study

The conceptual framework of this study, the Medicine Wheel (Figure 1), is a traditional model of health and healing for Aboriginal people in which four equal quadrants represent aspects of being, stages of development, elements of life, harmony of the seasons, races of humanity and aspects of interconnectivity in relationships. It is presented in a circular format to illustrate the interconnectivity of everything and the interplay of these quadrants, present life

teachings, and lessons for living in balance and harmony. It is a spiritual, emotional, psychological, and physical model that illustrates how mind, body, emotions, and spirit are connected and present in every part of life to varying degrees and it can be used to evaluate ones balance and harmony in life. It provides a meaningful framework based on an Aboriginal worldview of wholistic health and healing pathways and the term “medicine” as it is used in the term “Medicine Wheel” refers to a healing, a teaching, and an enlightening spiritual energy. It is described as a mirror within which everything is reflected. The path of the Medicine Wheel is analogous to the journey that each woman takes in her life and it helps to integrate personal experience into a holistic sense of identity (McKay-McNabb, 2006) whereby an understanding of an individual’s journey develops.

Since the Medicine Wheel is a circle, it symbolizes interconnectivity, strength, and continual seeking and development of self. It provides the gift of understanding within its domains and constructs to assist in understanding one’s self within the context of connective relationships that naturally exist across family, community, and nations. It is a tool to reflect upon where an individual has been, where they are currently and where they are on a journey towards and it has no true beginning and no true end. Thus, one must only chose a starting point and continue in a sunrise direction until one returns to where they began. Once travel along the Medicine Wheel has been completed, the individual is ready to begin again with new understanding. This approach to health and well-being then becomes a life-long quest.

The teachings of the medicine wheel that were used for this study are based on the teachings of the First Nations people of the Alberta Plains and adapted from the “Strong Voices: Stories of Struggle and Strength – Living with HIV” project and publication (Wolfleg, 2013).

The East is the morning direction and represents new day, new birth, thought, resolve and childhood. It is where one's growth and development are characterized by the physical aspect of self. The South represents connectivity through relationships and introspective thought where emotional health is developed and nurtured through self-honesty which is fundamental to our development in the youth stage of life. The West represents our ability as adults to intellectualize, think, plan, organize and gain knowledge that will help us develop wisdom in the mental aspect of being. The North is the stage where collective experience and knowledge gained as a senior or Elder, are used to make decisions based on spiritual understandings of the universe and how to live in harmony with it and all of creation. Thus, utilizing the Medicine Wheel as the conceptual framework to describe the reproductive health experience of HIV positive Aboriginal women and how they make decisions about whether or not to have a child, allows for a rich holistic description and approach to understanding reproductive health. It also provides a framework that is meaningful for this segment of the population which is not only culturally sensitive but also relevant for understanding and appropriate for the purposes of this study.

Chapter 2 Literature Review

2.1 Colonization Effects

Colonization of Canada's Aboriginal people began with the first European contact wherein Aboriginal peoples were rendered powerless to illnesses and diseases for which, they had no immunity. Then European patriarchy was imposed with economic domination via the fur trade and it gained momentum with oppressive government policies and religious orders. The colonization of Aboriginal people was built upon European notions of conquest that favoured competition over cooperation, and European philosophies that dictated power over Aboriginal people to control their resources, land, skills, knowledge, labour, military, economic development, political and social structure, ideology and reproductive ability (Bishop, 2006). "As a result of the white intrusion, the matriarchal character of Aboriginal spiritual, economic, kinship and political institutions was drastically altered" (La Rocque, 1994:3).

Although colonization affects all Aboriginal Canadians, it "has taken perhaps its greatest toll on Aboriginal women (because) prior to colonization, Aboriginal women enjoyed comparative honour, equality and even political power in a way European women did not at the same time in history" (La Rocque, 1994:1) but with the onset of colonization, all of that changed for Aboriginal women. Colonization and its accompanying paternalism has been the source of diminutive status for Aboriginal women (Romanow, 2003). As the Royal Commission on Aboriginal Peoples (RCAP) (1996 IV: 9) states, "the colonial and post-Confederation legislation applied to Aboriginal people finds its conceptual origins in Victorian ideas of race and patriarchy. Its effects have been increasingly to marginalize women in Aboriginal society and to diminish their social and political roles in community life." Subsequently, Aboriginal women have been relegated to subservience and denigration through colonialist attitudes and political

policies that, have created inaccurate stereotypes of Aboriginal women. These continue to be expressed within society and through policies that consistently undermine the strength of Aboriginal women.

Colonization, racism and sexism coexist together in that, racism and sexism provide justification for the subjugation of Aboriginal women and create levels of systematic oppression that differentially affect specific Aboriginal groups such as HIV positive Aboriginal women of childbearing age (Bourassa, McKay-McNabb & Hampton, 2004). With colonization, Aboriginal women were considered to be inferior to other races of women and even more inferior when compared to men. As Razack, (2002:65) contends, “within the colonizer’s cultural context, images like the romantic Indian princess, the easy squaw, and the helpless, suffering victim, are constructed to distort the reality of Indigenous women and justify social, political, economic and spiritual oppression.” With this type of denigration of the Aboriginal woman, racist and sexist stereotypes are born that foster current cultural attitudes that encourage sexual, physical, verbal and/or psychological violence against Aboriginal women and reinforce violence and stigmatizing attitudes against HIV positive Aboriginal women specifically. Thus, violence expressed directly or indirectly through legislative means, has become a legacy of colonialism that puts Aboriginal women at risk of contracting HIV and also keeps them from being able to rise above their HIV diagnosis or give voice where reproductive and fertility health are concerned.

Colonialist policies such as the Indian Act and mandatory residential schooling are designed to keep Aboriginal women in subservient positions within society, have made them at greater risk of contracting HIV and have also rendered them virtually voiceless when it comes to speaking to matters that, impact upon their daily living with HIV. As RCAP (1996 IV:9) reports, “Many Aboriginal people told the Commission that government policies and legislation designed

to undermine their collective sense of identity have chipped away at the right to be self-governing, self-determining peoples.” Through the Indian Act (1876), “Indian women were denied the rights to vote in band elections or to participate in reserve land-surrender decisions and where their husbands died without leaving a will, they were required to be of ‘good moral character’ in order to receive any of their husband’s property” (Canada, Erasmus, Dussault, 1996 IV:9). Additionally, if they married an Indian man from another band, they lost membership in their home communities, or if they wed a non-Indian man, they lost their Indian status, membership in their home community and the right to transmit Indian status to the children of that marriage. If they married an enfranchised Indian man, they lost status, membership, treaty payment and related rights as well as the right to inherit the enfranchised husband’s lands when he died (Canada et al., 1996:11). The legislation of the Indian Act legalized the discrimination of Aboriginal women and set them apart to be displaced, stigmatized, marginalized and subsequently vulnerable in multiple ways, including being at risk of contracting HIV.

The assimilative policies that followed the Indian Act such as mandatory residential schooling for all First Nation children was a tool that caused irrevocable damage to Aboriginal culture and has had serious consequences for Aboriginal women in terms of loss of cultural traditions, parenting, language, continued racism and social disconnection (Cain et al., 2013). “Children that were taken from their families and communities and held captive within these schools are still suffering the consequences of those actions. Parental care and guidance were lost and replaced by institutionalized childcare characterized by authoritarianism, often to the point of physical, psychological and sexual abuse” (Chrisjohn, 1991:173). This damage has continued for generations and manifest as intergenerational trauma for many Aboriginal women as the erosion of traditional norms and respect became the fallout of the residential school experience.

For Aboriginal women, it translates into a loss of understanding of healthy sexuality, ways of being within the world, ways of relating to others and self and has resulted in acceptance of self harm, risky behavior and denigration. As such, it has set the stage for Aboriginal women to be powerless in situations that, put them at increased risk for contracting HIV such as being in unsafe partnerships, violent relationships, substance abuse situations and sex trade work, which then has had a ripple effect upon reproductive and fertility behavior and accessing care. As Romanow (2003:34) suggests the, “inception of colonialism, disease, paternalism, segregation, assimilation, Christianization and discriminatory legislation have transcended into who Aboriginal women are today.” Subsequently, HIV positive Aboriginal women of child bearing age, have come to “subconsciously judge themselves against the standards of white society, often adopting...the White Ideal...internalizing or believing the standards, judgments, expectations and portrayals of the dominant white world...the result was/is often shame and rejection not only of the self, but also of the similar other, i.e., other Aboriginal people” (La Rocque, 1994:3). Thus, the effects of colonization for the HIV positive Aboriginal woman of childbearing age, begins first with European attitudes that, define Aboriginal women within a context of negative stereotypes. Canadian legislation then further defines Aboriginal identity from a discriminatory position where sexism inherent in legislation such as the Indian Act is more severe for women than men. Finally colonization exerts it’s effects through the injustices that continue to occur for HIV positive Aboriginal women through the implications that these colonizing attitudes and policies have over their everyday lives and the choices they have available to them (McKay-McNabb, 2006).

There is other research literature that echo the effects of colonization in the lives of HIV positive Aboriginal women of child bearing age (Buharski et al., 2006; Cain et al., 2013;

McCall & Pauly, 2012; McKay-McNabb, 2006; Romanow, 2003; Ship & Norton, 2000) and where “intergenerational effects of historical injustices and the ongoing impact of colonialism were omnipresent in the women’s stories” (McCall et al., 2009:1778). Bucharski et al. (2006) found that, colonization created a lack of trust with the allowance of institutionalized and legalized discrimination within the system. This left Aboriginal women feeling helpless within not only the health care system but also other systems such as Child Welfare. The mistrust that colonization bred within Aboriginal women created a reluctance to engage with any system of care, including routine pre-natal HIV testing because of the fear that, other systems, like Child Welfare would act in discriminatory ways and apprehend the child at birth. This fear and mistrust did not come about with the onset of HIV, but it has been 500 years in the making and a direct effect of the colonization experience.

Duran and Duran (1995) suggest that unresolved grief and trauma reactions in response to colonizing effects as experienced in the loss and destruction of lands, community and loved ones, as well as social and spiritual dislocation, contribute to long-term hardships and disadvantages that manifest as increased risk for HIV and social suffering. The invisibility of social suffering that HIV positive Aboriginal women of childbearing age experience “leads in turn to a marked invisibility of the root causes of the health and social inequalities affecting them” (McCall et al., 2009: 1773) and ignores the powerful social, cultural and legislative inequities that shape it. Thus HIV positive Aboriginal women of childbearing age are rendered virtually powerless once again as they continue to experience economic marginalization, systemic and social discrimination, and often are dismissed in health care contexts making it impossible to rise above the HIV shadow they live in and take control of their fertility and reproductive health care (Fiske & Browne, 2006).

There is no denying that Aboriginal women have borne the effects of colonization disproportionately and that, the racism and sexism embedded in colonialism have dramatically undermined the place and value of Aboriginal women, leaving them vulnerable to poverty, ill health, HIV, violence and lack of control over their own bodies and health (La Rocque, 1996; McCall & Pauly, 2012; McCall et al., 2009). Consequently, Aboriginal women are at greater risk of contracting HIV, less likely to seek testing and treatment for HIV, and more likely to be reluctant to discuss reproductive care and fertility intentions with health care providers. The effects of colonialism for the HIV positive Aboriginal woman of childbearing age extend beyond Canadian law, policy and program delivery (Loppie Reading & Wien, 2009), and continues to multiply and encircle HIV positive Aboriginal women “in ever-tighter grips of landlessness and marginalization, hence, of anger, anomie and violence, in which women are the most obvious victims” (La Rocque, 1996:12). Thus, a direct link can be drawn between the historical impacts of colonization and the challenges and realities that HIV positive Aboriginal women of childbearing age face with regards to legacies of subordination, stereotyping, legalized discrimination, stigma, and powerlessness and internalized shame. These legacies and effects are not just historical, but present day realities for these women (Furniss, 1999) as they continue to have cumulative effects through intergenerational traumas, poverty, substance abuse, discrimination, racism, sexism, and displacement (McCall et al., 2009).

2.2 Fertility Desires and Intentions of HIV Positive Aboriginal Women

There are direct health implications and a cause for concern with regards to fertility intentions and the desire of HIV positive Aboriginal women to have children because a greater proportion of the female HIV population are Aboriginal and they are being diagnosed at younger ages and during reproductive years (PHAC, 2014). Most women who are HIV positive, are of

childbearing age and the desire for pregnancy will become an increasingly important component of HIV medicine.

Historically, policies and health practices in many countries including Canada have discouraged HIV infected individuals from having children in order to reduce the population health burden of HIV; however, with a more flexible approach towards reproductive choice and rights, the desire to have children and fertility intentions of HIV positive women of child bearing age have resulted in an increased number of pregnancies and children being born to HIV infected mothers (Nattabi et al., 2009). There are two studies that suggest that approximately 30%-37.5% of Canadian women who are HIV positive and of child-bearing age intend to have children (Ogilvie et al., 2007; Payne, 2003). This is similar to studies conducted in the United States that suggest that approximately one-third of HIV positive women intend to have a child (Craft, Delaney, Bautista & Serovich, 2007; Sowell, Murdaugh, Addy, Moneyham & Tavokoli, 2002) after being diagnosed with HIV regardless of the possible risks associated with HIV transmission to sexual partners and offspring. In a study conducted by Loutfy et al. (2009), 69% of the Canadian HIV positive women who participated in the study stated positively that they would like to give birth in the future and approximately half of those desiring and intending to become pregnant in the future had already taken action to become pregnant. Conversely, a Canadian study (Ogilvie et al., 2007) that, took into account ethnicity as a determinant of fertility desire and intention found that Aboriginal women who participated were less likely to intend to have children because they had already achieved their fertility goals having had a greater number of pregnancies at a younger age, suggesting that Aboriginal women have more children and at younger ages regardless of their HIV status.

Across the multitude of studies (Bedimo-Rung, Clark, Dumestre, Rice & Kissinger,

2005; Craft et al., 2007; Kannipan, 2008; Nattabi et al., 2009; Nobrega, Oliverira, Galvao, Mota, Barbosa, 2007; Ogilvie et al., 2007; Oosterhoff et al., 2008; Sowell, Phillips & Misener, 1999; Stanwood, Cohn, Heiser & Pugliese, 2007) that examined the fertility intentions and desires of HIV positive women of child bearing age, HIV clinical status has not been found to be a significant predictor of fertility intention or desire to have a child. Instead, factors such as marital status, education level, age, drug use (addictions), co-occurring illnesses/diseases, fertility history and ethnic background were better predictors of fertility intention and desire than HIV status. These studies suggest that HIV positive women of child bearing age are making fertility decisions based on social factors rather than clinical HIV status and as such, issues of family planning, contraception, and healthy birthing experiences are a greater priority for these women.

Aboriginal women are disproportionately affected by HIV at younger ages, have higher birth rates than the non-Aboriginal population, and have similar aspirations regarding future pregnancy and fertility as other women living with HIV, provided they have not already fulfilled their fertility intentions. Research indicates that, “the potential for motherhood has been shown to be more influential for reproductive decision making than health risks to mother and child” (Nattabi et al., 2009) and so it stands to reason that it is important to understand the fertility desires and intentions of HIV positive Aboriginal women, apart from their clinical HIV status alone, in order to develop programs to support them in having safer pregnancies and stronger social supports. Additionally, it has also been suggested by the Department of Human Service (DHSS)’s Perinatal Guidelines (2012) that reproductive decisions should be discussed with all women of reproductive age on an ongoing basis throughout the course of their reproductive lifespan and care (Loutfy et al., 2014). Research also suggests that the

Contraceptive Decisions of HIV-positive Women survey instrument be used during routine examinations to assess knowledge, attitudes, and behavior of HIV positive women with respect to contraception and reproductive health issues (Ogilvie et al., 2007). The Assessment of HIV Risk Behavior (AHRB) (Fisher et al., 2004; Fisher et al., 2006) instrument for sexual and injection drug risk behaviors provides information for “additional constructs that assess menstrual cycle, fertility intention and quality of life changes in menstruation and contraception since HIV diagnosis” (Ogilvie et al., 2007:S84). These assessment instruments, while not diagnostic, could be incorporated into routine health exams to obtain valuable information and initiate the conversation regarding fertility intentions and desires of HIV positive Aboriginal women.

2.3 Fertility and Reproductive Options for HIV Positive Women

Current fertility and reproductive options for HIV positive Aboriginal women are rooted in oppression and colonizing ideologies that separate sexual and reproductive behaviour from the wider social and cultural influences that inform human behavior (Romanow, 2003). They are based on HIV being a medical issue rather than viewing HIV, as it pertains to fertility and reproduction, as an issue of inequality, violence, racism, and internalized shame (Conrad, 1989; Foucault, 1984; La Rocque, 1994; Razack, 2002; Showalter, 1990; Squire, 1993). By taking a broader lens approach, the medicalization of HIV that reinforces social iatrogenesis (obscuring political conditions which render society unhealthy) and cultural iatrogenesis (mystifying and expropriating the power of the individual to heal himself and to shape his or her environment) is not only exposed, but it also open to now being addressed (Segall & Fries, 2011). Historically, application of a lens that only medicalizes HIV and ignores broader social and cultural issues, has resulted in the majority of HIV positive Aboriginal women being discouraged from

becoming pregnant. Many are counselled by medical and health care professionals to avoid pregnancy all together, delay or abort pregnancy to combat the risk of vertical transmission, horizontal transmission, and the side effects of teratogenic drugs used during pregnancy and/or to have a tubal ligation to prevent future pregnancy (Loutfy et al., 2011; Loutfy et al, 2014; Ship & Norton, 2000). A significant number of HIV positive Aboriginal women report feeling pressured into having a tubal ligation to prevent future pregnancy or unintended pregnancy by medical professionals; however, despite prior tubal ligation, almost half of all HIV positive women still desire to become pregnant while a quarter still intend to give birth in the future by having the tubal ligation reversed (Loutfy et al., 2014). Thus, the desire and intention to become pregnant even when it is medically impossible, can and is still present for many HIV positive women of child bearing age. Subsequently, this approach of discouraging pregnancy for the HIV positive Aboriginal woman, ignores the importance of self-determination and empowerment of women, need for services that address pre-conception health and healthy sexuality, the intersectionality of women's reproductive health and social factors, the reality of unplanned pregnancy and the underlying social and structural factors that undermine women's health as well as underlying issues of sexism and racism that pervade women's health. Thus, research suggests that, there is a need for fertility and reproductive options to be advocated for, offered to HIV positive women and pregnancy planning guidelines developed to support fertility options and safer planned reproduction for HIV positive women (Loutfy et al., 2014). There is no doubt that European colonization, attitudes of forced assimilation, imposition of European notions of women's social position, the introduction of cultural disruption, residential schooling and unequal application of the law initiated the disposal of Aboriginal women's rights and the devaluation of their social roles. These experiences have resulted in reinforced stereotypes of

Aboriginal men and women and the subordination of Aboriginal women in Canadian society (Shawanda, 1995). These imposed stereotypes, rooted in subordination, dominate and perpetuate sexist and racist attitudes towards Aboriginal women, especially HIV positive Aboriginal women. With colonization came the introduction of an unequal power dynamic that influenced the devaluing of Aboriginal women and their roles, a double standard for male and female sexuality, increased violence, sexism and racism against Aboriginal women, increased objectification and degradation of Aboriginal women and a lack of attention to Aboriginal women's health, specifically their fertility and reproductive needs (Acoose, 1995; Easton, 1992; Kane, 1996; La Rocque, 1994; Razack, 2002; Romanow, 2000; Squire, 1993). It has been suggested that our society perpetuates racism and sexist stereotypes of Aboriginal women because it upholds "racist/sexist views of the 'Indian' male as a violent 'savage' and the Aboriginal female as a debased, sexually loose 'squaw'...(that results) in the dehumanizing portrayal of Aboriginal women as 'squaws', which renders all Aboriginal female persons vulnerable to physical, verbal and sexual violence" (La Rocque, 1994:3) which, can then lead to increased risk of HIV infection (Ship & Norton, 2000). Thus, racism provides justification for the subjugation of HIV positive Aboriginal women and sexism breeds hatred for HIV positive Aboriginal women which, results in a society that is accepting of sexual violence against Aboriginal women leading to increased risk of acquiring HIV and a stance of ignorance in relation to HIV positive Aboriginal women's reproductive and fertility health needs. A consequence of oppression, as found in sexism and racism is that social rejection and stereotypes become internalized by the colonized group (Bishop, 2002; La Rocque, 1994). In this case, the colonized group is Aboriginal women in generally but more so, HIV positive Aboriginal women

because they carry not only internalized shame for being an Aboriginal woman but also internalized shame for having HIV. Additionally, it has been argued that,

In much of Anglophone Canadian fiction, Indigenous women are misrepresented in images that perpetuate racist and sexist stereotypes. Stereotypic images of Indian princess, squaw drudges, suffering helpless victim, tawny temptresses or loose squaws falsify realities and suggest in a subliminal way that those stereotypic images are us. As a consequences, those images foster cultural attitudes that encourage sexual, physical, verbal or psychological violence against Indigenous women (and)...function as sentinels that guard and protect the White Euro-Canadian Christian patriarchy against any threatening disturbances that might upset the status quo (Razack, 2002:55).

In turn, Western culture tends to objectify and denigrate women presenting them as “sexual play things that must conform to male needs” (La Rocque, 1994:7). This creates a direct power over mentality that further influences Aboriginal women’s subordination to men, placing them as a marginalized social group at greater risk of HIV (Ship & Norton, 2000). These societal attitudes against Aboriginal HIV positive women result in the internalization of a “less than” core message of self for these women and it is “this internalization process (that) is one of the most problematic legacies of long-term colonization” (La Rocque, 1994:3). Often is the reason that Aboriginal women in general, but more specifically, HIV positive Aboriginal women are reluctant to seek out reproductive services or discuss healthy sexuality and fertility options with health care providers.

Global attitudes towards HIV positive women in general have reinforced a paradox for women living with HIV; HIV positive women are expected “to assume responsibility for the prevention of both pregnancy and sexually transmitted diseases, in a context in which they have limited control over, with whom and how they engage in sexual activity” (Romanow, 2003:29) and yet women’s reproductive health and discussions of sexuality have not changed dramatically

since the eighteenth and nineteenth centuries except as it pertains to contraception where the objective is “disciplining the body and that of regulation populations” (Foucault, 1984:208). Subsequently, sex, sexuality, fertility and reproductive health for all women, regardless of HIV status, have political, economic and social issues that, are grounded in power relations as “expressed through the scrutiny, domination, control and exertion of authority over the body, especially women’s bodies” (Squire, 1993:152). As such, HIV models for reproductive health, fertility and safer sex “have of often not been useful to women, because they reflect male expressions of sexuality and power” (Easton, 1992:15) that, reinforce gender bias and “women” as a social category of analysis (Ship & Norton, 2000:75) and do not provide options for healthy sexuality or reproductive pursuits.

Thus, women have generally been marginalized in HIV/AIDS research, policy and service agendas and HIV positive Aboriginal women remain particularly invisible (Ship & Norton, 1999) especially in areas that relate to reproductive and fertility care. “As a consequence, there is little, if any, systematic research as to how poverty, racism, sexual orientation and age, in addition to gender discrimination, affect women’s health, HIV risk potential, capacity to cope with HIV or AIDS and access to services. Moreover, little if any, research has looked at the links between multigenerational abuse and HIV/AIDS among First Nations women” (Ship & Norton, 2000:76).

The fact that Canadian society continues to uphold reproductive and fertility care along divided lines of race, gender and class without the research base to support best practices as they pertain to HIV positive Aboriginal women, suggests that HIV positive Aboriginal women will continue to bear the burden of a lack of reproductive and fertility options afforded to them; relying heavily on options of delay, abort or avoid pregnancy all together and modify sexual

behavior, controlling for intravenous drug use, when it comes to consideration of fertility intentions. Options such as these only address a fraction of what constitutes HIV positive Aboriginal women's reproductive health and fertility intentions. Thus, there needs to be more options afforded to HIV positive Aboriginal women for pre-pregnancy health, and for those who are of child bearing age, considering having children or who find themselves in situations of unintended pregnancy or late diagnosis of HIV infection during pregnancy.

Literature suggests that options for the reproductive and fertility health of HIV positive women begins long before contraception, family planning, pregnancy and the use of antiretroviral drugs to prevent vertical transmission occurs (Ogilvie et al., 2007; Carter et al., 2013; Loutfy et al., 2007). Options begin by creating an atmosphere of safety, respect and acceptance (Vancouver/Richmond Health Board, 2001; Judd, Armstrong, & Kulkarni, 2009) where the unique health and social needs of HIV positive Aboriginal women are recognized and interventions and programs are tailored to addressing underlying social and structural intersections that further marginalize an already marginalized population group. Access to services, population specific services and best practice research all need to be incorporated into providing options for the reproductive and fertility health of HIV positive Aboriginal women (Loutfy et al., 2011; Ogilvie et al., 2007; Carter et al, 2013; Ship & Norton, 2000). As such, reproductive and fertility options for HIV positive Aboriginal women need to go beyond tubal ligation, abortion and anti-retroviral treatment and explore "additional constructs such as menstrual cycle, fertility intention, quality of life and changes in menstruation and contraception since HIV diagnosis" (Ogilvie et al., 2007:84).

Options should acknowledge the desire of HIV positive Aboriginal women to have children, meeting women where they are at and supporting their intentions by addressing

reproductive health and social concerns. Additionally, exploring fertility intentions using dialogue and incorporating validated instruments such as the Canadian Contraceptive Study (CCS) instrument, the Contraceptive Decisions of HIV positive Women instrument, and the Assessment of HIV Risk Behavior (AHRB) instrument (Ogilvie et al., 2007), providing education and options for family planning, and providing “approaches to care that are substantially different than the traditional care provided in mixed-gender settings” (Carter et al., 2013) need to be incorporated into routine reproductive care. Ultimately, the literature suggests that there needs to be national guidelines on pregnancy planning as well as provincial and national HIV Fertility Programs (Loutfy et al., 2009; Yudin & Loutfy, 2011; Yudin, Shapiro & Loutfy, 2010) for all women of child bearing age, but especially for HIV positive women of child bearing age. National guidelines and specialized provincial and national HIV programs for HIV positive women would create “stronger linkages between sexual and reproductive health and HIV policies, programs and services” (Loutfy et al., 2011:114). Potentially, they could also afford options to HIV positive Aboriginal women with regards to their reproductive health and support for their fertility intentions that, not only addresses Aboriginal specific women’s health needs but also the oppression that they experience at a systemic level.

2.4 Vertical Transmission

Vertical transmission is the passing on of HIV infection from mother to child via pregnancy, childbirth experience or breastfeeding whereby the fetus and/or infant becomes infected with HIV through the maternal transfer of bodily fluids (blood and/or breastmilk). Over the past 25 years significant breakthroughs have occurred in the area of HIV and pregnancy, largely centered on the prevention of vertical transmission (Loutfy et al., 2012) as almost all pediatric HIV infections are the result of the vertical transmission (Forbes et al., 2012). Prior to

the introduction of ART and azido-thymidine (AZT) monotherapy in 1994, approximately 25% of infants born to HIV infected mothers also become HIV infected via vertical transmission; however with the introduction of ART, AZT monotherapy and highly active antiretroviral therapy (HAART), the number of confirmed HIV infections attributable to vertical transmission has decreased to less than 1% with only 2 transmissions confirmed in the 201 perinatally exposed infants born in 2013 in Canada (PHAC, 2014; Hughes et al., 2009). In the absence of ART or any other intervention, the overall risk of vertical transmission ranges from 15 to 45% (Forbes et al., 2012). Although the number of Canadian infants exposed perinatally to HIV as reported by the Canadian Perinatal HIV Surveillance Program (CPHSP) (2014), increased between 1984-2013, with a total of 4,025 infants being susceptible to vertical transmission during this period, so also has the proportion of HIV positive mothers receiving ART (95.5% in 2013). During the period of 1984-2013, almost one-fifth of all HIV vertical transmission cases were in the Aboriginal population (17%) and the majority (74.1%) were born to mothers who acquired HIV through heterosexual contact (PHAC, 2014). In order to reduce vertical transmission of HIV and increase maternal health, combination ART or HAART is recommended during pregnancy (Hughes et al., 2009).

In a study conducted by Hughes et al. (2009) that examined ART for 98 Northern Alberta HIV positive pregnant women who gave birth to 113 infants over a 7 year period of study, 43% of them were first diagnosed with HIV during prenatal screening. The majority of women who gave birth were Aboriginal (62.2%) and more than half (55%) of the women acquired HIV through heterosexual activity while 38% acquired it through injection drug use. In 18 of the 113 births (16%), there was no ART given and at the end of the study, 1 infant was diagnosed with HIV while 9 had indeterminate status. This rate, although a decrease from a previous study that

found 21% vertical transmission in pregnant women diagnosed prior to delivery and 39% vertical transmission in women diagnosed post pregnancy (Robinson & Lee, 2000) still suggests that vertical transmission, especially in the female Aboriginal HIV positive population that represents 30-86% of mothers in Western Canada and one in every five HIV infected pregnant women (Forbes et al., 2012), is an issue of fertility and reproductive concern. As such, special attention and resources need to be considered for reducing vertical transmission amongst Aboriginal HIV positive women of child bearing age and when examining the fertility intentions and decisions about whether or not to have a child that HIV positive Aboriginal women make.

Since 1997, HAART has become the standard of care for HIV positive pregnant women in Canada. It consists of decreasing the rate of vertical transmission to less than 1% (0.4%) for mothers who received HAART more than 4 weeks before delivery; however, for women who received less than 4 weeks of HAART prior to delivery, the transmission rate increased to 9% (Forbes et al., 2012). For women who receive HAART four weeks prior to delivery, it does not matter if they deliver vaginally or by caesarean section, their transmission rates remain in the 1% range but for women who have received sub-optimal or no medication treatment, caesarean section affords a lower transmission rate. The HAART treatment consists of the administration of three drugs including two nucleoside reverse transcriptase inhibitors (RTIs) whereas ART treatments have only one or two RTI's and as such, are less effective at reducing vertical transmission of HIV (1.6%) from mother to infant (Forbes et al., 2012). The use of antiretroviral therapy has also been found to be associated with increased sexual activity in women living with HIV, increasing the likelihood of pregnancies (Ogilvie et al., 2007; Wilson et al., 2004). Thus, while findings indicate that sexuality activity increases with ART and HAART treatments, increasing the possibility of pregnancy, rates of vertical transmission of HIV in Canada are low

for women who receive HAART and ART treatments during pregnancy. Subsequently, these antiretroviral treatments afford HIV positive women new opportunities for parenthood, healthy offspring and increased life expectancy; however, vertical transmission still does occur and remains a concern for HIV positive Aboriginal women of child bearing age as they represent one out of every five HIV positive pregnancies in Canada and more than half of HIV-infected pregnant women in northern Alberta (Hughes et al., 2009).

The use of ART, AZT and HAART, combined with a desire to want to have children, has led many HIV positive women to consider pregnancy and provided hope for reproductive potential; however, despite universal access to health care services, an estimated 5% of pregnant women in Alberta do not receive routine prenatal or antenatal care for social or geographic reasons, with the majority of these being Aboriginal women (Hughes et al., 2009). The fact that only 5.8% of Alberta population is Aboriginal yet Aboriginal women represent more than half of the HIV infected women in Northern Alberta alone makes the issue of vertical transmission a priority for health care policy and providers to consider and respond to. Subsequently, research suggests that, pre-pregnancy HIV testing of Aboriginal women of child bearing potential, prenatal screening, family planning counselling for HIV positive women of child bearing age, repeat HIV testing of high risk women (injection drug users, multiple partners, prostitution etc.) either at the end of pregnancy or with rapid HIV testing during labor as well as having multidisciplinary teams to encourage clinic attendance, medication adherence, arrange for medication supply at the planned site of delivery, provide funded infant formula to avoid breastfeeding and provide ongoing support for complex social issues or substance use issues are all strategies that can reduce the risk of vertical transmission of HIV from the Aboriginal HIV

positive mother to her child (Forbes et al., 2012; Hughes et al., 2009; Loutfy et al., 2014; Wagner et al., 2010).

2.5 Stigma and Fear

All individuals who are diagnosed with HIV experience stigma to one degree or another. Stigma, for the purposes of this study, is defined in accordance with another Canadian study that examined stigma and HIV (Loutfy et al., 2012) as, a mark of disgrace associated with a particular circumstance, quality or person. For those individuals who are HIV positive, stigma is experienced in a compounded fashion both internally and externally and at individual and social levels. HIV positive individuals first experience stigma upon diagnosis. This stigma is associated with having a lifetime medical label of HIV positive serostatus which represents being a member of society that carries and can transmit an incurable disease. Stigma is also experienced as a result of how HIV was contracted, whether that be through homosexuality, injection drug use, involvement in the sex trade etc., which are all activities that society tends to frown upon and hold prejudice attitudes towards those who are involved in them. HIV positive individuals also experience stigma associated with putting others at risk of infection such as partners and children which subsequently makes the HIV positive individual more susceptible to moral and social judgment. Stigma can also manifest as a shame core in the HIV positive individual that develops in response to the diagnosis itself. This shame core, reinforces an internal message to the self whereby the HIV positive individual sees themselves as being “less than” simply by virtue of their HIV diagnosis.

Stigma at a societal level can only be fought by first changing negative personal, societal and cultural attitudes towards individuals who are HIV positive. By shifting attitudes rooted in fear, prejudice and judgment to attitudes that have their foundations in compassion,

understanding of broader cultural, social and historical contexts, and accurate, evidence based information, the societal stigma that HIV positive individuals experience can be alleviated to some degree. While not all individual and social attitudes may change just because there is an attitude shift in the population, changing the attitudes of a few across generations to come means that those who are diagnosed in the future may experience less stigma than those who are diagnosed today. With social attitude changes come policy and practice changes and while these changes do not happen overnight, they do promote progress in terms of their potential to advance human rights and increase social acceptance of HIV positive individuals while decreasing the discrimination, racism and judgment that HIV positive individuals currently face.

At an individual level, the internalized stigma that HIV positive individuals experience can be fought on a front that involves strategies and techniques to address and change negative self talk and promote self-esteem and confidence. By providing the HIV positive individual with grounding techniques to calm themselves in the midst of anxiety, activities and strategies to build self-esteem and reinforce strength qualities, and cognitive behavioral strategies to address negative self talk and core beliefs, HIV positive individuals can begin to address and fight their own internalized stigma that develops in response to an HIV diagnosis. As the HIV positive individual becomes better equipped with tools that promote individual development of self-esteem, self-reflection, self-efficacy, self-compassion, and self-discovery, they are better able to not only recognize when they are living in their own internalized stigma and shame and get out of doing so, but also able to recognize and deal with the current external stigma within society and brought against them by others.

2.5.1 types of stigma.

HIV related stigma is experienced at many levels as perceived, internalized, enacted, layered/compounded and/or symbolic (Loutfy et al., 2012) stigma. Literature suggests that, *perceived stigma* involves an awareness of negative social attitudes, the fear of discrimination and feelings of shame (Berger, Ferrans, & Lashley, 2001; Herek, Capitanio & Widaman, 2002; Meyer, 2003). In many studies, HIV positive Aboriginal women have commented on the guilt and shame they feel as the result of being aware that society views them as inferior and then translating this into a feeling of inadequacy as a person when diagnosed with HIV (McKay-McNabb, 2006; Sandelowski, Lambe & Barosso, 2004). Wagner et al. (2010) describes how negative experiences with physicians around reproductive health care is associated with higher perceived stigma and that, “the importance of health care provider support and acceptance regarding HIV positive women’s fertility decisions is reflected in their overall perceived HIV stigma” (Carvalho, 2010:182). The shame an HIV positive individual experiences is the direct result of their internal acceptance of negative beliefs, views and feelings that are perpetrated upon them by society and then reinforced through an individual process of negative feelings and self-talk towards oneself which, builds upon negative core beliefs and a develops a shame core that, manifests as *internalized stigma* (Kalichman, Simbayi, Cloete, Mthembu & Mkhonta, 2009; Nattabi et al., 2009). Overt acts of discrimination, such as violence, exclusion, and disrespect for confidentiality are what constitute *enacted stigma* (Herek et al., 2002; Nyblade, 2006). Holding more than one stigmatized identity such as being a sex trade worker, being Aboriginal, being homeless, being labelled an addict and being HIV positive creates *layered or compound stigma* for the HIV positive Aboriginal woman whereby the interaction of different stigmatizing identities increases the degree of stigma experienced overall (Loutfy et al., 2012; McCall et al.,

2009; McKay- McNabb, 2006). Additionally, gender norms that are accepted as positive attributes for a woman to have, coupled with a stigmatizing identity can create layered or compound stigma for the HIV positive Aboriginal woman of child bearing age. Women in general in society are constructed within a gender norm that, sees them as caregivers, mothers and nurturers just by virtue of their gender but then when these same women are given an HIV positive identity, they are then viewed as ill and diseased and therefore unable to fulfill personal or social roles, which creates layered or compounded stigma (Loutfy et al., 2012). The fact that Aboriginal HIV positive women also have demographic overrepresentation within socially marginalized groups such people with lower income or lower education level also means that they are more likely to experience layered and compound stigma (Wagner et al., 2010).

Symbolic stigma refers to the social blaming and judging of already stigmatized groups for causing, spreading and/or perpetuating HIV in the mainstream, dominant population (Deacon, 2006; Herek & Capitanio, 1999; Herek et al., 2003). Thus, it has been suggested that, “HIV-related stigma remains one of the greatest barriers to the health and well-being of people living with HIV” (Loutfy, et al., 2012:1).

HIV related stigma is a socially constructed experience, wherein an individual is subjected to structural, social and systemic oppression within the society to the point that they do not feel wholly integrated or accepted into the dominant society or affiliated cultures (Goffman, 1963) and it “includes both the perception of societal attitudes toward HIV and the personal experience of HIV stigma” (Wagner et al., 2010:208). Stigma marks the boundaries a society creates between “normal” and “outsiders” and contributes to the vulnerability of HIV positive Aboriginal women and their children (Romanow, 2003:33). HIV related stigma is rooted in the devaluing of HIV positive individuals and results in the prejudice, discounting, discrediting and

discrimination of those individuals who do have or are perceived to have HIV as well as loved ones, associates, groups, and communities to which these actual or perceived HIV positive individuals are affiliated (Loutfy et al., 2012; Herek & Capitanio, 1999). In turn, HIV related stigma, whether perceived or actual, can exacerbate other inequities that an HIV positive individual experiences in relation to their race, class, gender and/or sexual orientation (Parker & Aggleton, 2003; Sumartojo, 2000).

Studies indicate that, HIV related stigma produces detrimental mental, psychological, physical, spiritual, sexual and emotional health outcomes that, manifest as: increased perceived stress (Remien, et al, 2006; Riggs, Vosvick & Stallings, 2007; Wingood et al., 2007); higher risk of depression (Carvalho, 2010; Catz et al, 2002; St. Lawrence, Snodgrass, Robertson & BairdThomas, 2008); decreased self-esteem, lack of self efficacy, hopelessness, and increased psychological distress (Emlet, 2006; Lee, Kochman & Sikkema, 2002; Rao, Pryor, Gaddist & Mayer, 2008); poor coping mechanisms, disease progression and negative quality of life outcomes (Catz, Gore-Felton & McClure, 2002; Prachakul, Grant & Keltner, 2007; Wagner et al., 2010); which, can compromise health opportunities received and sought, lead to substandard levels of treatment, reduce continuity of care and present a barrier for accessing and retaining healthcare services for individuals who are HIV positive (Carvalho, 2010; Kinsler, Wong, Syles, Davis & Cunningham, 2007; Loutfy et al., 2012; Wagner et al., 2010). Studies also suggest that, the mere perception of HIV stigma is more strongly related to negative outcomes than whether or not the individual has objectively experienced HIV related stigma (Kinsler et al., 2007; Wagner et al., 2010) because it can radically change how the HIV positive Aboriginal woman views herself as well as how she is viewed by others (Romanow, 2003:33). Thus, stigma reaches its oppressive hand from within society to impact the HIV positive Aboriginal woman of

child bearing age at the very core of who she is as a human being and in doing so, further oppresses her in her already marginalized state of being.

2.5.2 fear of rejection, judgement and discrimination.

HIV related stigma, as felt at the personal level by HIV positive Aboriginal women is driven by fear – fear of rejection, fear of judgement, fear of discrimination and fear of confidentiality being undermined in response to their disclosure of HIV positive status (Bucharski et al., 2006; Cain et al., 2013; McCall & Pauly, 2012; McCall et al., 2009; McKay-McNabb, 2006; Ship and Norton, 2000). Studies have found that “disclosure of one’s HIV positive serostatus to friends, family, social support networks and health care providers has been associated with marginalization, isolation and social exclusion” (Loutfy et al., 2012:1) and that, HIV positive women experience guilt, shame and humiliation when they disclose their HIV status to friends, family and when obtaining health care (Blake, Jones, Taylor, Reid & Kosowski, 2007; McCall et al., 2009). Many HIV positive Aboriginal women must also disclose their HIV status to their children with little or no emotional support making disclosure a difficult, complex and stressful task (Ship & Norton, 2000:81). Additionally, the “biggest barrier that women face in disclosing their HIV status to their partners is fear of violence” (Carvalho, 2010). A study by Cain et al., (2013) discovered that, for Aboriginal people, the shame associated with how HIV was contracted (sex or IV drug use) kept individuals from telling others of their diagnosis. HIV positive Aboriginal women learn from experience that, “when their status is known, whether by health care workers or significant others, they experience stigmatizing comments and behavior, and rejection” (McCall et al., 2009). Subsequently, they become very selective about whom they disclose to, under what circumstances they disclose and essentially, they learn to live their lives with selective concealment of their infection (Nattabi et al., 2009; Sandelowski et al.,

2004). This results in having to live a life of secrecy that mirrors living in the shadows where HIV positive Aboriginal women often do not realize that they are not alone in their struggle with HIV infection (Carr & Gramling, 2005). Thus, disclosure and secrecy go hand in hand because while the HIV positive Aboriginal woman must disclose her HIV status in order to seek out care and be privy to opportunities that support improved health and quality of life, she must also balance this disclosure with secrecy to protect not only herself from discrimination and rejection, but also her children, family, and community and her right to pregnancy and fertility options (McKay-McNabb, 2006; Ship & Norton, 2000).

Since there is so much stigma associated with HIV, disclosure carries with it such a high risk of rejection. As a result, many HIV positive Aboriginal women choose to conceal their HIV status and live in self-imposed isolation rather than reveal their HIV status to family and friends which, then compounds the losses that, HIV positive Aboriginal women experience, making it difficult for them to move forward with their healing journey (Cain et al., 2013; McKay-McNabb, 2006). These women make voluntary choices to cut ties with their family, friends and home communities because they anticipate that, they will be rejected just by virtue of their HIV status alone and for some, they are advised to stay away by friends, family members and the community for fear of spreading the HIV infection or bringing shame upon the family name or community. Others, on the hand, seek out isolation to protect family and friends from community gossip, sacrificing their own personal need for support and acceptance, in the interests of the greater good of the family or community. Additionally, it has also been suggested that “ongoing racism and discrimination also contribute to isolation and self-blame” (Cain et al., 2013:822).

The fear of rejection is almost universal amongst people living with HIV/AIDS (McKay-McNabb, 2006; Paxton, 2002); however, for HIV positive Aboriginal women, that fear is complicated by intersecting factors such as poverty, abuse, substance use, social positioning, racism and societal stereotyping. These vulnerabilities put HIV positive Aboriginal women at high risk of rejection and the marginalization and exclusion that is normally experienced by Aboriginal women, is further heightened when the Aboriginal woman is also HIV infected and pregnant or considering pregnancy. The fear of judgement is intimately tied to the fear of rejection that HIV positive Aboriginal women experience. Rejection is first felt at the societal level through discrimination, marginalization and stigmatization and in the health care system itself, it is expressed through a lack of confidentiality and perceived judgement. Canadian studies of Aboriginal women living with HIV/AIDS report a significant fear of being rejected by health care providers and a persistent sense of feeling judgment which leads to isolation and hesitancy in accessing services (McCall et al., 2009; Bucharski et al., 2006). “Women spoke of both a reluctance and an inability to access health care due to fear of rejection or poor treatment and... women were reluctant to disclose their HIV status to health care workers because they feared that confidentiality would not be respected and that they would be judged and censured” (McCall & Pauly, 2012;138). If rejection is not felt outright by HIV positive Aboriginal women of child bearing age post HIV diagnosis, it is definitely felt through the judgment that is passed along when health care professionals discourage discussion about fertility issues and do not provide adequate information for an informed reproductive decision to be made, opting instead to provide biased information in order to discourage the HIV positive Aboriginal woman from having more children (Nattabi et al., 2009). The refusal of health care personnel to discuss reproductive options in a non-biased way discourages and antagonizes HIV positive Aboriginal

women and it can negatively impact on their health seeking behavior as it pertains to fertility and reproductive care. Thus, the “fear of rejection by health-care providers is clearly linked to feelings of being unsafe as a result of the marginalizing social processes of stigma and discrimination...and that, fears related to rejection or poor treatment are significant barriers to accessing health services” (McCall & Pauly, 2012:137) for HIV positive Aboriginal women of child bearing age.

This fear of judgment is compounded by substance use and lack of access to biological children. Many HIV positive Aboriginal women fear being dismissed from services due to their substance use or being judged for not having access to their children and despite the effort to provide culturally sensitive services, HIV positive Aboriginal women still experience inequities because the health care system itself can be alienating and approaches to service delivery perceived as discriminatory and judgmental (McCall et al., 2009). Many HIV positive Aboriginal women are concerned about having children because of the perceived shame and judgment that will ensue for both them and their potential children. “Negative experiences with physicians around reproductive health care, in particular, perceived judgement by health care provider for trying to become pregnant, is associated with higher perceived stigma” (Wagner et al., 2010:212). Subsequently, HIV positive Aboriginal women of child bearing age are less likely to become pregnant or desire more children, once diagnosis is known, in an effort to avoid societal criticism and the judgment that accompanies having a child when infected with HIV and knowing the risks of transmission (Craft et al., 2007; Nattabi et al., 2009; Wagner et al, 2010).

For the majority of HIV positive Aboriginal women of child bearing age, being judged unfairly, is due in part to the lack of understanding of the context of Aboriginal women’s past

and present lives. Subsequently, the insensitivity of health care providers to take into account the full life and intergenerational experiences of HIV positive Aboriginal women can lead to “preaching” or “pressuring” women to reduce their HIV risk behaviors and desires to have children without exploring or understanding the multiple reasons for engaging in these behaviors (Bucharski et al., 2006). Thus, it is this type of judgement that leads to a fear of rejection for HIV positive Aboriginal women of child-bearing age and adds to the stigma that these women encounter.

Additionally, HIV positive Aboriginal women fear judgment from the medical profession when they are non-compliant with medical care and medication regimes. Many internalize their non-adherence to taking medication as a failure of self (Leserman, Ironson, O’Cleirigh, Fordiani & Balbin, 2008) despite the fact that non-adherence is “the result of multiple stressful life events and not a person’s inability to take responsibility for their health” (Greene et al., 2010:226). HIV positive women are forced to make trade-offs concerning how they will spend their money between paying bills, buying food or attending to medications or other health related finances which, can impact on overall personal health and mental health and the health of their children (Greene et al., 2010).

2.5.3 exposure to violence and abuse.

Stressful life events for HIV positive Aboriginal women are often exacerbated by exposure to violence and abuse. There are many studies that suggest that HIV positive Aboriginal women suffer violence, abuse and trauma, both past and present at high rates, that contribute to the multiple stressful life events they must contend with in addition to medication and health care adherence (Bucharski et al, 2006; Greene et al., 2010; McCall et al., 2009; Neron & Roffey, 2006; Ship & Norton, 2000). In a study by Bucharski et al., (2006;729), HIV positive

Aboriginal women reported that, “their relationships were typified by tolerance of negative behaviors from their partners, including alcohol and drug abuse, unprotected sexual intercourse outside of primary relationships, and various forms of abuse” and that, when their abusive relationships ended, they were more likely to engage in multiple sexual experiences to increase self-worth, feelings of control or as payment for drugs or other favors making addressing medical issues and adhering to medical interventions difficult to manage and achieve.

Additionally, violence and abuse can occur when an HIV positive Aboriginal woman asks a man to use condoms or upon informing a sexual partner of her HIV positive status (Ship & Norton, 2000). This violence can translate into the partner then interfering with the HIV positive Aboriginal women being able to attend to medical issues or medication adherence as dealing with interpersonal difficulties outweighs the need to address personal health issues and treatment regimes. Mannheimer and Beirn (2005) found that, women living with HIV who are or have a history of being subjected to violence and abuse are less likely to access treatment and more likely to develop AIDS related illnesses. Thus, for HIV positive Aboriginal women there is a fear that medical professionals will judge their non-adherence to medical care and interventions without consideration of the stressful life events and interpersonal difficulties that they face daily and in doing so, add to the stigmatization and marginalization they experience, especially when it involves reproductive and fertility decisions.

2.6 Impact of Social Resource Disparities

Social support has been reported in the literature to be a defining and significant variable in enabling HIV positive Aboriginal women in achieving and maintaining health (Cain et al., 2013; McCall et al., 2009; McKay-McNabb, 2006; Ship & Norton, 2000). When problems such as substance use, addictions, violence, stigma, sex trade work and intergenerational trauma

intersect with unstable housing and poverty, HIV positive Aboriginal women often become neglected and limited by the appropriateness of health and social service programs which, then has an adverse impact on the ongoing health status and reproductive care for this specified population (McCall et al., 2009; Mehrabadi, et al., 2008; Pearce et al., 2008; Spittal et al, 2007).

2.6.1 poverty.

In a 1998 study conducted for the Canadian AIDS Society, 6 out of every 10 individuals living with HIV have incomes of less than \$20,000 (De Bruyn, 1998). For most HIV positive Aboriginal women of child bearing age, life is a daily struggle because of the difficulty of providing for basic needs such as food, clothing, shelter and transportation for themselves and their children (McCall et al., 2009; Ship & Norton, 2000). Many cannot afford the transportation needed to get to their medical appointments or afford medications or the healthy foods that need to be taken with medication to optimize its effectiveness and as such, a definitive link between poverty and failure to access and adhere to treatment and services exists (Vernon, 2000; Wood, Montaner, Tyndall, Schecter & O'Shaughnessy, 2003). As a result of poverty, many HIV positive Aboriginal women are forced to eat unhealthy alternatives such as processed foods with no fresh vegetable/fruit content or adequate proteins and mineral/vitamin content to support optimal reproductive health, if they are lucky enough to have anything at all to eat. The situation is even bleaker for those living on reserve, where the social conditions mirror third world conditions for some and where high levels of unemployment and poverty, lack of adequate housing, low levels of education and high levels of mobility characterize almost all reserve community conditions for HIV positive Aboriginal women (Cain et al., 2013). While the issue of poverty in the lives of HIV positive Aboriginal women, will not be resolved anytime soon, it is important to mention, raise concern about, and take action against, as poverty accounts for

higher all-cause morbidity and mortality among people at the lowest socioeconomic levels (Amaro et al., 1995) and HIV positive Aboriginal women of child bearing age occupy the lowest socioeconomic level in Canada. As DeBruyn (1998:19) suggests, “any analysis of what makes people vulnerable to HIV infection or what makes people with HIV vulnerable to sickness and death, must now take into account the role of poverty, independent of any risk factors, in leading to HIV infection and to sickness and death and how the structures of our economy and our society benefit (discriminate in favor of) people with higher incomes or more wealth.” Thus, poverty directly affects an HIV positive Aboriginal woman’s ability to manage and live with HIV (Carvalho, 2010).

For HIV positive Aboriginal women in a number of studies, poverty was the driving force behind inadequate housing and homelessness (Cain et al., 2013; Greene et al., 2010; McCall et al., 2009; McKay & McNabb, 2006; Ship & Norton, 2000). All of the HIV positive Aboriginal women in these studies expressed concerns with accessing safe, secure and affordable housing which, often superseded considerations about ongoing health and reproductive issues. The majority of HIV positive Aboriginal women either live homeless or live in substandard housing which, has been linked to poorer health outcomes (Kilbourne, Herdon, Andersen, Wenzel & Gelberg, 2002; Spittal & Schechter, 2001; Zierler & Krieger, 1997) and is a very realistic life threat for those living with HIV (Pearce et al., 2008). As the Ontario and pan-Canadian HIV/AIDS Strategy (CSHA) highlights, “housing is the most urgent unmet need for people living with HIV” (Greene et al, 2010:223).

2.6.2 homelessness.

Studies further indicate that, HIV positive women are most at risk of homelessness

(Gielen, McDonnell, Burke & O'Campo, 2000) and HIV positive Aboriginal women even more so (Duran et al., 2000). Additionally, HIV has been found to be the leading cause of death of homeless women in the prime of their reproductive life, between the ages of 18-44 (Cheung & Hwang, 2004) because housing instability, homelessness and transience compromise access to adequate health and reproductive care (Parish, Burry & Pabst, 2003) and create barriers to accessing appropriate and effective social supports (Fisher, Hovell, Hofstetter & Hough, 1995). Housing has also been found to be a “critical determinant of mental health that plays an important role in prevention, resilience and recovery from mental illness and addictions” (Greene et al., 2010:224) and since the majority of HIV positive Aboriginal women are dealing with mental health issues (trauma, depression, addictions etc.) in conjunction with their HIV status, housing becomes an important bridge in addressing reproductive and fertility with this population.

Housing instability has unique consequences for HIV positive Aboriginal women during pregnancy. Changes to medications due to missed doses, making choices of living in abuse which often is heightened when a women is pregnant or taking off to the streets to stay alive, living in fear of children being mandated into custody because housing conditions are inadequate or having the threat of homelessness maintain HIV positive Aboriginal women living in unsafe or unhealthy living situations and/or housing arrangements (Greene et al., 2010; McKeown, Reid, Turner & Orr, 2002;). These unique consequences highlight the impact that housing instability and homelessness have on the HIV positive Aboriginal mother and her ability to prioritize pregnancy, reproductive health, medication compliance and fending off drug resistance. Thus, addressing the social disparity that HIV positive Aboriginal women experience is required to maximize the reproductive health of these women. This begins with alleviating the

threat of poverty and homelessness in their lives through adequate and responsive social supports that, take into account the layered impacts of colonization, stigma, racism, mental health issues, addictions, child custody, violence, sex trade work and intergenerational trauma that, operate daily in the lives of HIV positive Aboriginal women.

2.7 Health Factors and Conditions

Studies suggest that HIV positive women who feel healthier, are more positive about having children (Chen, Phillips, Kanouse, Collins & Miu, 2001; Nattabi et al., 2009). HIV serostatus and CD4 count levels do not influence fertility desires or intentions (Loutfy, 2009; Ogilvie et al., 2007) as they do not reflect “health” but rather are the factor by which, treatment is determined. Thus, as research indicates, for HIV positive Aboriginal women absence of mental health issues such as depression and substance use, as well as the ability to adhere to medication regimes and seek out medical attention are more important factors for health than HIV viral load and CD4 counts.

2.7.1 depression.

In addition to increased risk of HIV infection, Aboriginal people in Canada suffer from depression at a greater frequency than non-Aboriginal people (Kirmayer, Brass & Tait, 2000) and depression is a common co-morbidity in Aboriginal women with HIV infection due to the compounding factors of medical illness and social marginalization (Catz et al, 2002; McKay-McNabb, 2006). It is estimated that depression prevalence rates in those infected with HIV range from 30%-60% in community samples (Bing et al, 2001). Radcliffe et al. (2010) found that being diagnosed with HIV was the most traumatic experience that, individuals who had been diagnosed, had experienced in their life to date and in response, immediate reactions included devastation, shock and indignation while long term reactions included depression, an escalation

of drug and alcohol use, feelings of shame and increased suicidality. These reactions were often tied to concerns that HIV positive women had with regards to infecting their partners and future children or effects of future pregnancies on their own health (Cooper, Harries, Myer, Orner & Bracken, 2007; Craft, Delaney, Bautista & Serovich, 2007; Kanniappan, Jeyapaul & Kalyanwala, 2008) as well as feelings of guilt for giving birth to an infected child (Aka-DagoAkribi, Du Lou, Msellati, Dossou & Welffen-Ekra, 1999). These reactions are similar to the relationship between HIV diagnosis and depression that has been described elsewhere wherein, HIV positive individuals lose hope and begin to isolate themselves in an effort to minimize the rejection of others which, leads to increased risk for depression (Anderson et al., 2009; Stevens & Doerr, 1997; Stevens & Hildebrandt, 2006; Wagner et al., 2010).

In contrast, a study by Cain et al. (2013) found that depression leads to behaviors that, put the individual at risk of contracting HIV rather than depression following the diagnosis. This is important to consider as it provides a causal link between depression and HIV diagnosis that suggests that there is a pre-existing condition of depression brought on by family of origin issues, exposure to violence, parental abuse and neglect and/or substance use that is only made worse by an HIV diagnosis. For the Aboriginal participants in the Cain et al. (2013) study, 1 in 3 had a history of childhood abuse, 1 in 10 had been sexually abused and many spoke of how their parent's drinking led to physical or sexual abuse or neglect and violence and how these early experiences of abuse, neglect and violence were central in their own substance use and feelings of depression that existed prior to their HIV diagnosis. The presence of psychological stress plays an important role in the development of depressive symptoms that, then can lead to behaviors that put the Aboriginal individual at increased risk of contracting HIV. Regardless of whether depression precedes or follows HIV diagnosis, the fact that depression is, "associated

with poor health, greater health service utilization, and adverse effects on quality of life, social support and poor adherence to HIV medication” (Carvalho, 2010) makes fertility considerations and reproductive care more difficult to manage for HIV positive Aboriginal women.

2.7.2 substance abuse.

A disproportionate number of Aboriginal people struggle with substance abuse issues (Kirmayer et al., 2000) and Aboriginal women because of their disproportionate use of injection drugs are at a higher risk of acquiring HIV infections than other populations (PHAC, 2014) and they are also more likely to use substances prior to contracting HIV infection (Cain et al., 2013; McCall et al., 2009). The intersection of poverty, discrimination, marginalization, violence, abuse and early childhood events puts Aboriginal women at increased risk of substance use and HIV infection (McCall et al., 2006). For Aboriginal women, “early experiences with substance use at home often results in ongoing struggles with drugs and alcohol, which in turn contribute to HIV risk behavior” (Cain et al., 2013:821) and unintended pregnancies (Loutfy et al., 2011).

Additionally, Aboriginal women, “often use alcohol and drugs as coping strategies to ‘forget’ their childhood experiences, which leads to addictions at an early age, and ‘promiscuous’ and self-destructive behaviors” (Bucharski et al., 2006) increasing the risk of contracting HIV. Alcohol and drug use has also been shown to be related to increased frequency of depression and other mental health concerns (Hirschfeld, Kosier, Keller, Lavori & Endicott, 1989). In a study by Forbes et al. (2012), 63% of the Aboriginal women who were pregnant, had contracted HIV through intravenous drug use and in a study by Cain et al. (2013) almost all of the participants discussed substance use, either current or in the past as a key health problem with many starting to drink at a young age, drinking heavily and using drugs as adults and also in response to their HIV diagnosis. For many, their substance use resulted in then

ending up living on the streets and being homeless, or engaged in the sex trade or in criminal activity to support their substance use. Additionally, HIV positive women report that they are unable to focus on their HIV diagnosis and treatment until they have dealt with their substance use issues (Cain et al., 2013; McCall et al., 2006; Ship & Norton, 2000). Thus, for HIV positive Aboriginal women substance use is a health issue that complicates dealing with HIV infection, impacts on health status in many ways and has can have dramatic implications for fertility and reproductive health.

2.7.3 medication adherence.

HIV positive women are more likely to experience adverse drug reactions when being medication compliant, but they are also more likely to experience treatment interruptions and become non-adherent as a result (Nicastri et al., 2007; Prins, Myers, & Hessel, 2005). Literature suggests that, there are a number of factors that affect medication adherence which, go beyond the racism, sexism and discrimination embedded at the systems and societal level that, HIV positive women experience (Carr & Gramling, 2004; Rintamaki, Davis, Skripkauskas, Bennett & Wolf., 2006). In addition to an HIV diagnosis, HIV positive Aboriginal women also contend with violence, mental health and addiction issues, lack of financial resources and social support, feelings of isolation, inflexibility of clinic hours, negative experiences with health care providers, lack of women specific and/or culturally appropriate services, transportation issues, and competing responsibilities as mothers, partners, friends, homemakers, paid-workers, and caregivers where needs of others are prioritized over needs for self (Cain et al., 2013; Carter et al., 2013; Csete, 2005; Cunningham et al., 1995; Gahagan & Loppie, 2001; Lichenstein, 2006; McKay-McNabb, 2006; McCall et al., 2009; McCall & Pauly, 2000; Neron & Roffey, 2006;

Quinn, 2012; Seals et al., 1995; Ship & Norton, 2010; Sowell et al., 1996; Stein et al., 2000).

Medication adherence is an important measure of health both from a professional standpoint and for the individual affected with HIV as it suggests a willingness to maintain and improve health at the professional level and a desire to not become drug resistant at an individual level; however, as illustrated, medication adherence is also influenced by a number of factors, and for the HIV positive Aboriginal woman of child bearing age, it is not that they do not want to be compliant with medication regimes, it is that, they often at times cannot adhere due to unforeseen, unavoidable and uncertain circumstances. Thus, while medication adherence does influence the health status of HIV positive Aboriginal women, it must not be evaluated in isolation from other contending factors, as the other competing factors are just as much about health status as adherence to HIV medication regimes are.

2.8 Spiritual and/or Traditional Practice

While not all HIV positive Aboriginal women align, endorse or engage in traditional practices or Native spirituality, the role of Elders and spiritual leaders in providing spiritual care and counselling in the health care setting for Aboriginal people is well supported (BucharSKI et al., 2006; Clark et al., 1998; McCall et al., 2009; McCormick, 2000). In a few studies where spirituality and traditional cultural ways were discussed by HIV positive Aboriginal women of child bearing age, the opportunity to engage in traditional Aboriginal practices and spirituality such as healing and sharing circles, engaging with someone who was knowledgeable about Aboriginal culture and being able to smudge were important for overall health and deemed to be significant factors in maintaining resiliency and experiencing healing (BucharSKI et al., 2006; Cain et al., 2013; McCall et al., 2009).

Since the majority of services that HIV positive Aboriginal women access focus on physical health and the physical aspects of living with HIV, “relying on inner resources, including strategies to incorporate their spiritual values, was an approach that most of the women turned to in order to address the shortfalls of existing health care and support programs” (McCall et al., 2009:1775). For some HIV positive Aboriginal women, having access to Elders and spiritual practice traditions allows for individualized support, relevant to personal situations and fills a void in care, addressing medicine for the spirit and the soul rather than just the body. “Almost half of all Aboriginal people in Canada live in urban area...culture is not something Aboriginal people discard at the city limits. The cultures in which people are raised and given their identity reside deep inside them and shape every aspect of their being – wherever they happen to be living” (Canada, Erasmus, & Dussault, 1996 IV:12). Thus, incorporating traditional teachings, practices, and Aboriginal spirituality into the environments that HIV positive Aboriginal women of child bearing age access, including reproductive health, counselling and social environments, increases the sensitivity and knowledge of the issues that Aboriginal women experience with regards to their fertility and reproductive health and provides services that address the inner spirit fostering resiliency and inner peace.

2.9 Cultural Safety

Culture, as identified by the College of Nurses of Ontario practice guidelines (2005:3) refers to “the learned values, beliefs, norms and way of life that influence an individual’s thinking, decisions and actions in certain ways.” To create cultural safety within a health care system that provides service to HIV positive Aboriginal women, cultural awareness and sensitivity, need to be present first. Cultural safety is part of the continuum that supports the development of cultural competency in practice. This continuum begins with developing

cultural awareness and sensitivity in the provider through awareness training. Cultural sensitivity then develops in response to what is learned about a given culture through awareness training. When there is cultural awareness and sensitivity present, then cultural competency within the profession itself and for the professional can begin to develop with the introduction of culturally appropriate ways of practicing that respect and honor the culture of an individual and the cultural ways of knowing and being of a particular cultural group. Developing personal competency requires the professional to intentionally and continually seek out additional learnings about the culture of interest and to challenge and reflect on their own personal biases, stereotypes, and attitudes as they do so, thus revealing their own culture. Cultural safety is what is created when cultural awareness, cultural sensitivity, and cultural competency intersect to produce an environment and practice setting in which professionals have the required understanding, sensitivity, and skill set to work with the diversity of a cultural group, and are supported through an organizational practice policy that strives to honor and respect each client's cultural ways of knowing, being, and doing.

Developing cultural safety relies on acknowledging that everyone and every system has a culture that is influenced by many factors, such as, religion, SES, race, gender, life experience, and system values. In turn, culture is also individual and dynamic and as such, changes over time and often is subconscious and influenced by the dynamic of the client-health professional relationship. Personal and professional values also influence the manner in which culture is expressed and upheld.

Providing cultural safety within the health care environment begins with acquiring cultural knowledge that recognizes that behaviors and responses that occur in one culture may be viewed in another way, or have a different meaning in another cultural context. As such, having cultural

knowledge is not enough to provide culturally safe care for HIV positive Aboriginal women. Health professionals must go beyond just learning about cultural differences and similarities, and reflect on their own personal and professional values and beliefs that could potentially influence the client-health care professional relationship. This requires the health care professional to “explore the client’s view and attempt to understand the meaning behind their particular request, as well as the overall goals for treatment” (College of Nurses of Ontario, 2005: 6).

Cultural safety within the healthcare system has long been acknowledged as an important consideration for the planning and delivery of services; however, it has often been synonymous with ethnicity which, highlights differences in groups or whole societies and leads to generalizations, places an emphasis of the differentness of those who have less power and fewer resources, and it can obscure or miss the importance of culture in social structures such as health care (McCall & Pauly, 2012). To expand the view of cultural safety as it applies to HIV positive Aboriginal women of child bearing age requires understanding of *culture as a relational process* with power differentials, shifting sets of meanings that pertain to historical, social, economic and political processes and how organizational and systemic processes produce structural inequities that oppress the reproductive health of HIV positive Aboriginal women and their ability to access care. Creating a culturally safe environment and service delivery model involves taking into account, “an analysis of power imbalances, institutionalized discrimination, and the nature of relationships between colonizers and the colonized, as they apply to health care interactions at the macro and micro levels” (Browne, Fiske, & Thomas, 2000:9). Thus, cultural safety is about recognizing one’s own privilege and the positioning of certain groups within a society (Anderson et al., 2003; Browne, Varcoe, Smye, Reimer-Kirkham, Lynam & Wong, 2009) as well as the power differentials in health service delivery so that, those tendencies that create cultural risk

and/or cause HIV positive Aboriginal women to feel unsafe and result in them delaying or avoiding reproductive care and fertility treatment, can be minimized.

Essentially, providing culturally sensitive care and creating cultural safety for the HIV positive Aboriginal woman of child bearing age demands of the health care professional that:

To care for someone, I must know who I am.

To care for someone, I must know who the other is.

To care for someone, I must be able to bridge the

Gap between myself and the other.
(College of Nurses of Ontario, 2005:3)

2.9.1 providers as bearers of culture.

Cultural safety for HIV positive Aboriginal women of child bearing age, first requires providers of care to acknowledge that, they too, are bearers of culture and to examine their own personal beliefs, values and assumptions and position them against the impact that they may have on the therapeutic relationship they have with HIV positive Aboriginal women seeking fertility and reproductive care (McCall et al., 2009:1779). Cultural safety in this regard differs from cultural competency in that, instead of learning about cultural characteristics of particular groups, “the provider must form a relationship with the user such that, the user is able to make a judgment about whether the therapeutic relationship is safe and appropriate...and the user is given the power to say when he or she feels that an encounter is safe or unsafe” (McCall & Pauly, 2012:134). In many studies, the relationship between the provider and the HIV positive Aboriginal women seeking reproductive or fertility care was instrumental in terms of alleviating the stigma and discrimination that these women felt or conversely, it reinforced the stigma and discrimination that these women experienced just by virtue of the relationship that was formed (Carter et al., 2013; Cain et al., 2013; McKay-McNabb, 2006; McCall & Pauly, 2012; McCall et

al, 2009; Ship & Norton, 2000). In this sense, providers of care are prompted to reflect on the broad structural factors that shape interactions, examine their cultural self as a particular provider (doctor, nurse, counsellor etc.) within the context of their own personal culture and assess how their ‘self’ and the meanings they bring to the therapeutic relationship impacts upon the HIV positive Aboriginal woman with whom they are involved with, keeping in mind that, the power relationship is always skewed in favor of the health professional.

2.9.2 enacting cultural safety.

Additionally, cultural sensitivity with regards to acceptance of being an HIV positive Aboriginal woman, sexuality, reproductive choice, and the impact that sexual and physical violence have on reproductive and fertility decisions were requests that, HIV positive Aboriginal women had for the health care system to make it more culturally safe for them to use and benefit from (Ship & Norton, 2000). Enacting cultural safety for HIV positive Aboriginal women of child bearing age requires taking into account differences that each women has so that each plan of care is tailored to these individual differences and reproductive and fertility care is regardful, rather than regardless, of difference (McCall & Pauly, 2012). A therapeutic relationship that is based on trust and respect where HIV positive Aboriginal women are partners in their reproductive and fertility care, are given an opportunity to contribute to the decisions regarding their treatment and are provided a safe space to confidently communicate their needs and preferences is how cultural safety can be enacted under conditions of “positive expressive caring, understanding of cultural practice and patient background and purposeful relationship building”(McCall & Pauly, 2012:141). Thus, the creation of positive and healing environments where discrimination and judgement are non-existent and complex social and economic challenges are taken into account is crucial to ensuring cultural safety for HIV positive

Aboriginal women of childbearing age.

Chapter 3 Methodology

3.1 Design

A qualitative design was chosen as this would best meet the objectives of the study and the conceptual framework. Qualitative approaches encourage discussion, interpersonal interaction, allow for fuller responses related to attitudes, beliefs, and levels of satisfaction (Barlow et al., 2008) than more structured data collection methods, and qualitative methods can accommodate the emergence of unanticipated issues. Furthermore, the intent of qualitative research is to understand a particular social situation, event, role, group, or interaction (Creswell, 1994; Creswell, 2007) and since subjectivity was of desirable value in this study, using a qualitative approach was considered to be just as capable and, in some ways, more beneficial than a quantitative approach, in obtaining valid information regarding the role that HIV status plays in the decision making processes of Aboriginal women as it pertains to the reproductive health and decisions to have a child or not. The study design was also well suited for research with this particular group because oral storytelling is part of the traditions and historical knowledge translation processes of Aboriginal peoples and communities, and it is a qualitative method that has been shown to be useful for exploring areas about which little is known (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2007).

3.2 Methods

This study adapted an ethnographic approach (Morse & Richards, 2002). Ethnography explores the everyday lived experience of people within a cultural context and conceptual framework to foster understanding and contextualize the findings (Morse & Richards, 2002). Examples from participants, in the form of vignettes, then illustrate the central concepts. Qualitative analysis requires the researcher to state his/her assumptions regarding the

phenomenon under investigation and then bracket or suspend these preconceptions in order to fully understand the experience of the participants and not impose a priori hypotheses on the experience (Creswell, 2007). Atkinson et al. (2002) suggest that ethnography seeks to establish the social nature of self, thought, and community as a product of human meaning and interaction. Through the use of face to face interactions that explore life history in specific locations, social worlds are captured through descriptive narratives. An ethnographic lens provides for the ability to create a vital picture of urban life grounded in local studies while using an objective, sympathetic eye to view, understand, and share aspects of human behavior. Thus, the use of ethnographic qualitative methods was the most suitable method for the research objectives as they are inductive and primarily concerned with process and meaning wherein the researcher is the primary instrument for data collection and analysis.

This study utilized multiple methods to collect data. A cultural component was included in the interview process. Fieldwork contributed to a rich, descriptive narrative of the experience under investigation.

3.2.1 participant sampling and recruitment.

Purposeful, criterion, homogenous convenience sampling was employed for this study. In a narrowly focused study such as this, it is essential that all participants experience the phenomenon being studied (Creswell, 2007). Criterion sampling ensures that all cases meet the study criteria and therefore it is useful for quality assurance. Homogenous sampling further focuses, reduces, simplifies, and facilitates interviewing (Creswell, 2007). Thus, only participants who met the following self-identified inclusion criteria were eligible for participation in this study: 1) HIV positive status; 2) biologically female; 3) of Aboriginal descent and/or ethnicity (First Nations, Metis and/or Inuit); 4) of reproductive age (between the

ages of 18-54); 5) residing within Calgary (a Western Canadian urban center); and 6) enrolled in the health program offered through one of the recruitment sites. The upper age limit was chosen to reflect the cut-off for fertility clinic consultation in Canada as reported in a study by Loutfy et al., (2009).

Recruitment sites were suggested by the advisory committee for this study and selected based on the services that they offered to HIV positive Aboriginal women specific to the area of reproductive health. The Southern Alberta Clinic (SAC), Calgary HIV Connect formerly known as AIDS Calgary Awareness Association (ACAA), Elbow River Healing Lodge (ERHL), Adult Aboriginal Mental Health Program (AAMHP), Calgary STI Clinic (CSC), and the Calgary Sexual Health Clinic (CSHC) were initially contacted by the researcher to explain the study. A written agreement was obtained from the managers of each recruitment site once the agency had committed support for recruitment to be conducted through the agency.

Recruitment and study qualification determination was carried out by the researcher in conjunction with recruitment site personnel. Participants who accessed any of the above listed services or agencies between April 2014 and April 2015 were offered the opportunity to contact the researcher regarding participation in the study by staff at the agency sites. Notices of the study were posted in recruitment site offices and recruitment posters (Appendix B) and a study summary (Appendix C) were made available at participating recruitment sites through front-line staff whereby participants could voluntarily contact the researcher with regards to interest in participating at their own convenience. Participants initiated contact with the researcher regarding interest to participate in the study via phone and then consented to further engagement.

The Southern Alberta Clinic (SAC) is a facility that provides HIV treatment, counselling, support and referral services to people diagnosed with HIV/AIDS. It is located in Calgary and is

the service delivery agent for the Alberta Health Services (AHS), Calgary Health Zone health program for HIV positive women. ERHL is a primary health care center operated through AHS for Aboriginal individuals and families seeking primary medical care. The CSC and CSHC are both operated by AHS and provide sexual and reproductive counseling for individuals, including those with HIV/AIDS. The AAMH Program is operated through AHS and provides clinical mental health services for Aboriginal individuals and families, including those affected by HIV/AIDS. Calgary HIV Connect is a not-for-profit HIV/AIDS social service agency that provides basic needs and Aboriginal specific services for individuals living with HIV/AIDS. At each of these locations, office space was provided in order to conduct interviews with participants if they so desired.

All six recruitment partners provided a letter of agreement to participate as recruitment sites for this study. Entry to the locations specified above were granted by the Manager for each of the participating AHS programs (SAC, ERHL, AAMH, CSHC, CSC) in accordance with AHS policies for research and access. For the service that operates as not-for-profit, Calgary HIV Connect, entry was granted by the Executive Director of the program. These contacts were essential for establishing rapport with clinic administration personnel and Aboriginal participants recruited for this study.

The three women who participated in this study were currently living in Calgary at the time of the study and had given birth to at least one child. Only one participant had been born in a Western Canadian urban center and the other two in rural communities in Western Canada. They were all over the age of 18, English speaking, and of First Nation ancestry. The interviews were conducted in the same setting, in a meeting room located in a medical facility in Calgary that also housed five of the six recruitment agencies.

3.2.2 sample size.

There is no definitive criteria for establishing sample size when working within an ethnographic qualitative design. The sample size is dependent upon the research question and the study design (Creswell, 2007). In other studies of women's health data saturation has been reached with 8-10 participants (McCall et al., 2009; Ship & Norton, 2000; Thurston & Meadows, 2004; Meadows, Thurston & Lagendyk, 2003). As McCall et al., (2009, p. 1771) suggest, "smaller samples can be particularly relevant when sensitive issues (such as HIV status and reproductive issues) are discussed and when rich or detailed data is elicited from participants, and when there are challenges recruiting participants given their social context and overall state of health", all of which were factors in this study.

3.2.3 data collection and analysis.

The researcher assisted the interview process by introducing a number of traditional and cultural aspects that, the participants could choose to be involved with or not depending upon their level of acculturation and comfort. Participants were offered the option of smudging before, after or during the interview process with their own sweet grass, sage, cedar or tobacco or that, which the researcher had on hand. Smudging is often a ceremony that is used before or after an individual has shared a story that may be traumatic to recall and so smudging allows the participant to "cleanse" away any bad spirits that may be present or come forth in the course of telling their story. It is a way of making "clean" the spirit of the individual. The researcher also had an eagle feather available for participants to hold while sharing their story and participants were given the opportunity to choose a stone or two to hold for support though the interview process.

The holding of symbolic elements such as an eagle feather or stone represents the Aboriginal understanding of interconnectedness to all life and Mother Earth. The eagle feather represents the ability of the feather to carry our prayers and thoughts to the Creator and it is considered sacred so that when one holds it, they can only speak truth. The stone represents the earth and the connection that Aboriginal people share with Mother Earth. After the interview was concluded the participants were given the option to choose to keep the sweet grass braid that was offered or not as well as a stone to keep or give back to the researcher once the interview was concluded. The researcher offered to take the stone(s) to a ceremonial sweat at the conclusion of the research, where the stones would be cleansed in a sweat ceremony and the women's stories released back to the Creator (McKay-McNabb, 2005).

These processes were important to the research methodology of this study as they represent a decolonizing approach to the standard research process. First choosing a topic that focuses on an extremely marginalized population group, HIV positive Aboriginal women of child bearing age, begins to shift the research focus from ignorance to acknowledgment. The acknowledgement of this marginalized population group through this subject of research sends a clear message to the research community that this type of research is important as a means of reconciliation for past research that has largely ignored the existence, stories, and needs of HIV positive Aboriginal women. The prior vetting of this research through members of the urban Aboriginal community allowed for a decolonizing process in research to occur as community approval and support were gained. In the predominant mainstream research, this vetting process is often not considered; however, with Aboriginal research it would be considered disrespectful to the broader Aboriginal community to not do so. Thus, by vetting this study through the urban Aboriginal community before the research commenced the colonization and paternalism that

mainstream research supports was addressed. The incorporation of Aboriginal cultural ways of interacting in a good way through the use of ceremony, holding an eagle feather and/or rock, the use of smudging and prayer with participants, if they so desired, were also ways to decolonize the research process and move away from the Western roles of researcher and participant to more Aboriginal ways of reciprocity in sharing where researcher and participant are more like fellow travelers on a shared journey to knowledge. The use of the Medicine Wheel as a way to explain results is also a decolonizing approach in that it takes a framework of understanding that is used in the Aboriginal culture to explain the interconnection of mind, body, spirit, and emotions and replaces the Western ways of interpreting data in silo categories. Finally, an Aboriginal cultural approach to story sharing and honoring the connection and traditional aspects of Aboriginal culture that are shared through a connection to Mother Earth, the sharing of oneself with another, and the connections that are shared within the spiritual realm of being are other ways of decolonizing the Western research process. Using the stories of the women as the evidence embraces the importance of story-telling in the Aboriginal culture and respects Aboriginal principles of honouring one another's journey. Thus, through the methodology that was utilized in this study, an approach that decolonized the research process for the participants of this study and brought truth and reconciliation to the forefront of Aboriginal research was realized.

Data was then obtained through semi-structured, in-depth interviews. Face to face interviews, lasting approximately 35-90 minutes in duration, used open ended questions and a semi-structured interview guide (Appendix D) based on the research questions. Interviews were conducted during the months of July 2014 and August 2014. The advisory committee reviewed the interview guide for relevancy, clarity, sensitivity, and completeness and did suggest several

changes prior to its use in this study. Interview questions were broad based and intended to stimulate conversation and generate more in-depth exploration of a particular subject matter. This type of data collection strategy is considered a useful tool for discovering information about under-researched issues (Rubin & Rubin, 1995) because the interview questions are designed to allow the participants the freedom to share their story and unique experience of being HIV positive, having Aboriginal identity, and having to make decisions about whether or not to have a child given their HIV positive status. The use of open ended questions encourages participants to describe their unique experience and the questions can be adapted to accommodate differences in the participant's stories.

A self-report questionnaire included demographic characteristics for measures of participant age, gender, race/ethnicity, birthplace, educational and income level, marital status, number of pregnancies and children, employment status, and occupation. In addition, women were asked to report the presence of other sexually transmitted illnesses (STI) and/or health conditions as well as their use of reproductive health care services and family planning counselling services. Participants were also encouraged to voice their recommendations for health care professionals with regards to what they should be mindful of when working with HIV positive Aboriginal women of child bearing age in a reproductive care setting.

Participant observation, researcher field notes capturing conditions around each interview, as well as in participant observation and personal journal chronicles were also included as methods of data collection. The journal chronicled personal thoughts, feelings, perceptions, attitudes and experiences that developed during the course of the study and was maintained for reflection purposes before and after data collection. To assist in the data

collection phase, a field log was used by the researcher to provide a detailed account of time management throughout the course of the study.

Interviews were audio-recorded with the participant's permission and the interview guide amended where appropriate to reflect the Aboriginal context of the study and accommodate participant differences. Taped interviews were transcribed verbatim and transferred into qualitative data analysis computer program QSR NUD*IST N-Vivo for coding where emerging themes and categories were identified. The transcripts were repeatedly reviewed by the researcher to identify recurring, converging and contradictory patterns so that key concepts and emerging themes could be ascertained. Using N-Vivo, the researcher entered field data, observations, researcher's memos and illustrations and was able to tag or code all or part of the source data so that chunks of data could be pulled out and then reassembled in a new and illuminating configuration to compare segments of participant stories during coding. Data analysis using N-Vivo also allowed for the storing and organization of the data, crossing themes and allowed for the creation of templates to aid in analysis. Field notes were reviewed regularly and unexpected findings were probed for meaning and the qualitative data was supplemented with statistics from the a) 2014 HIV/AIDS Epi Updates from the Laboratory Centre of Disease Control (LCDC) at Health Canada that, reported on HIV statistics for the period of 2008-2011, b) the 2014 HIV and HCV Epidemiological Update from the Alberta Health Surveillance & Assessment Branch which, reported HIV statistics for the period of 2005-2014 and c) the HIV and AIDS in Canada Surveillance Report to December 31, 2013 as reported by the Public Health Agency of Canada.

Data analysis was conducted as an activity simultaneously with data collection, data interpretation, and narrative report writing (Creswell, 2004; Creswell, 2007) in Figure 2. This

process of analysis was based on reducing information to patterns, categories and themes. The data was analyzed categorically, and chronologically, reviewed repeatedly and continually coded with unique ideas chronicled as they surfaced. Interpretation of emerging themes were also considered within the contextual framework of the Medicine Wheel followed. Coding of the data used one or more of the following types of coding simultaneously and was continually refined and clarified as data was analyzed. Descriptive coding was used to identify information according to topic (Creswell, 2004) and analytic coding was utilized to facilitate interpretations through discovery and development of categories, linking them to field notes and utilizing the QSR NUD*IST N-Vivo program to support the discovery and explanation of themes.

As this is considered to be a naturalistic study with a small and limited sample of participants, results were presented in a thick, rich descriptive narrative form with vignettes that communicated the holistic experience of the participants. Furthermore, scholarly literature was critically reviewed following a comprehensive literature search using online databases including PsycINFO, MEDLINE, PubMed, OvidSP, and CINAHL. The literature obtained was used in the interpretation of findings for comparison within and between studies. Thus, this final thesis write up constitutes the construction of participant's experiences and the meaning that they attach to them. Readers are therefore able to vicariously experience the struggles, challenges, triumphs, and decision-making processes that impact on whether or not to have a child and that encompass the everyday lives of HIV positive Aboriginal women who seek care and service in an urban environment.

Chapter 4 Ethical Considerations

4.1 Guiding Principles and Policies

Ethical considerations for this study were guided by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2010) (Canadian Institutes of Health Research, 2010), the Ownership, Control, Access and Possession (OCAP) Principles (2005) published by the First Nations Centre (National Aboriginal Health Organization, 2005) and the Helsinki Declaration (2013). These documents provide guidelines for conducting research with human subjects and more specifically, vulnerable populations such as Aboriginal peoples and they emphasize the importance of participatory and respectful interactions with Aboriginal individuals and communities where the dissemination of results and knowledge translation of learning brings benefit to the Aboriginal community participating in the research. The principles of OCAP were respected throughout this study through partnerships with the urban Aboriginal community and Aboriginal serving agencies via consultation and involvement with the Calgary Urban Aboriginal Initiative (CUAI). An advisory committee, composed of members of the Cumming School of Medicine, Community Health Sciences Department, University of Calgary, was developed to ensure relevancy and sensitivity of this study. The committee was composed of two males, an Aboriginal physician and a PhD level professor specializing in mental health research, as well as a female PhD level professor specializing in Aboriginal research.

As five of the six recruitment sites were affiliated with Alberta Health Services (AHS) and the researcher was also an employee of AHS at the time of this study, a Conflict of Interest Declaration was completed and approved by the AHS Ethics and Compliance Department. This declaration was also submitted to the University of Calgary Conjoint Ethics Review Department

as part of seeking ethical approval for this study. Ethical approval for this study was obtained from the Conjoint Research Ethics Board at the University of Calgary.

4.2 Participant Consent

Participation in this study was voluntary and written informed consent was obtained from all the women who participated prior to interviews being conducted. Participants were provided a copy of the study information sheet which provided a general outline of the nature, purpose of study and researcher and Supervisor contact information. A consent form that adheres to University of Calgary requirements will be used for participants (Appendix E). Two copies of the consent form requiring the participant's signature was obtained prior to participation in the study, with one belonging to the participant and the other to the researcher. As part of the consent process, participants were informed of their right to ask questions, make comments, and refuse to participate on particular questions, or withdraw completely from the study at any point during the study up to data analysis without penalty. If signing a consent form was viewed as threatening or unacceptable by a woman, verbal consent as recorded on the audio recording of the interview was an option offer to the participants; however, all participants provided written consent and this option was not exercised. Participants were informed that they may use a pseudonym to further protect their confidentiality, if they wished; however, all declined this option as well. Participants were further informed that if they withdrew or terminated their interview, the services they received from the recruitment sites through which they were recruited would be affected in any way, nor would their withdrawing affect the offer of the honorarium for participation. Services were not informed by the researcher with regards to who agreed to participate and who did not, but women are free to disclose this if they wanted to on their own time.

Since there is a legal obligation to report to Alberta Child and Family Services, acts of child abuse, child neglect, or situations of family violence in homes where children are present, as well as threats of self harm or harm to others to Calgary City Police, participants were informed of these limitations to their confidentiality in each consent letter and verbally, prior to the start of each interview.

4.3 Participant Confidentiality and Anonymity

Strategies used to protect the participant's identities included the use of a unique alphanumeric code for each participant on all data sheets, non-identification of participants in transcripts and/or field notes and the use of fictitious names in the final report. To protect participant confidentiality and anonymity during and after the study, HIV positive Aboriginal women who participated in the study were given at the onset of their participation, an alphanumeric code for interview paperwork and audio recordings to protect their identity and ensure confidentiality. The original list of names and corresponding codes was stored separately from the transcribed data in a locked fireproof box and participant identifiers were stripped from the data after transcription.

Each participant was compensated with an honorarium for their involvement in the study, which was determined at the onset of the study to be offered regardless of whether or not the participant completed the study or not; however, all participants completed the study and were compensated accordingly with a \$50 Canadian funds honorarium and a braid of sweet-grass. Aspects of participating in a cultural manner were offered to each participant through the use of smudge, sweet grass, and an eagle feather and spirit stones.

4.4 Participant Privacy

To ensure that the privacy of participants was maintained throughout the course of the study from recruitment to reporting of findings, participation in the study was voluntary and initiated by the participant themselves, data coded, password protected, and stored in a locked fire-proof box at a secure location and findings were presented in aggregate form. Participants were invited via poster information to contact to the researcher initially if they were interested in participating in the study. The research was able to receive immediately the phone call from the participants and set up a time and meeting place with the participants that was private and located in a facility that housed many health programs so that the participant could not, in any way, be identified as a client of any of the recruitment programs. The participants were also informed that if the researcher happened to see the participant in a public place or unintentionally meet the participant following their participation in the study, that the researcher would not make any attempt to acknowledge the participant unless the participant initiated that contact first. In this way, the research was able to maintain participant privacy outside of the study itself as well.

Since much of the data was transcribed and entered into a computer program for analysis, transcription tapes, USBs, and field notes were kept in a locked, fire-proof, secure location when not in use and all computer files were pass-word protected. Only the researcher and the study Supervisor had access to the data and to the master code-lists that matched the true names to coded data.

Dissemination of results was conducted in such a manner as to not stigmatize the Aboriginal community and its members or further marginalize this vulnerable segment of the population. Thus, all data was reported in aggregate form despite having information that may specify tribal affiliation and geographic location of participants. Knowledge translation of the

findings was conducted through formal presentations to the CUIAI Health Domain and any of the requesting recruitment agencies. Dissemination of findings was also considered for presentation through academic research conference opportunities to formally present findings or have a poster presentation for viewing. Finally, to contribute to the broader research community learning and knowledge translation, this study will be written up for journal submission and publication.

4.5 Community Engagement and Support

Community engagement of urban Aboriginal community members was conducted through CUIAI involvement and the CUIAI health domain to provide advice, oversight, community support and a venue for knowledge translation activities for this research study. Other CUIAI domains – employment, housing, education, human rights, services, and justice – were consulted and members of these domain groups were informed and updated through the domain with regards to study progress and findings so that the urban Aboriginal community was able to give consent and approval of this study involving urban Aboriginal participants.

4.6 Other Ethical Considerations

The subject matter of this study has the potential to illicit distress for participants because of its sensitive subject matter and associated memories or experiences that may be shared, and so there was an ethical obligation to support participants when issues such as these arose. The researcher for this study was employed in the field of mental health and trained through the Centre for Suicide Prevention to recognize signs of distress, potential for self-harm and trauma in individuals. If participants demonstrated any distress, potential for self-harm or trauma at any time during the interview process, the interview would have been terminated immediately and resources would have been offered and made available to the participant; however, this did not occur in any of the interviews or with any of the participants. A pamphlet of community

resources that specialize in mental health counseling and distress services (Appendix F) was made available to each participant at the beginning of the study as a proactive measure to provide participants with resources to address any post study interview distress that participants may experience. All ten recruitment partners offer counseling and support services as part of their service delivery models and they agreed to facilitate support for participants who, indicated through their comments, responses or behavior the presence of distress, risk of self harm or harm to others and/or exposure to violence. Once again, none of the participants required that such contact to recruitment sites be initiated by the researcher. Recruitment partners also agreed to be the point of contact for reporting of issues that carry a legal obligation to report to Alberta Child and Family Services or Calgary Police Services as outlined previously; however, this also was not required at any time during the study with regards to any of the participants.

Chapter 5 Results

5.1 Introduction

Initially a target sample size of fifteen participants was proposed for this study to coincide with budget concerns; however, only three participants responded to the recruitment initiatives of the researcher as it was difficult to obtain participants due to the stigma associated with HIV and the reluctance of women to want to come forward to share their story and feeling that they were “not good at this sort of thing.” There were no difficulties that arose in getting those women who initiated contact with the researcher to follow through with interviews once they had been debriefed on the study purpose and had committed themselves to the interview. All the women showed up on time at the specified location for their respective interviews and none needed to cancel or reschedule an interview. Thus, despite the offer of an honorarium for participation and having many avenues made available through Western Canadian urban recruitment sites to gain access to HIV positive Aboriginal women of child bearing age who could be potential participants in this study, only a few women initiated contact with the researcher for participation in this study.

All three of the Aboriginal women in this study chose to keep the sweet grass braid that was offered to them at the conclusion of the interview; however one woman declined the offer to select a stone or smudge, citing that she did not grow up with Aboriginal traditional ways. The other two women choose stones to hold during the interview and one woman requested a second stone as the first reminded her of a circle and that, life goes on and the second stone reminded her of a sacred area of land in her home community. Two women who chose stones during the interview process also accepted the offer of sage and tobacco that the researcher had on hand for smudging purposes, with one woman citing that she would use it to smudge with her sister later

on. While none of the women who participated chose to smudge before, during or after the interview process, they all expressed gratitude for the sacred medicine gifts offered at that conclusion of the interview regardless of whether or not they followed traditional Aboriginal ways.

5.2 Presentation and Analysis of Study Data

This chapter will present and analyze the data accumulated from the personal histories of three HIV positive Aboriginal women of child bearing age, living Calgary, who participated in this study. Using excerpts from their own story, and written in the context of their own experience, the researcher thought it necessary to use the precise words of the participants in keeping with the oral story telling tradition of Aboriginal people as well as providing a voice for the women involved in this study as per the qualitative design of this study. It is intentional on behalf of the researcher that the words of the women in this study be presented as much as possible to extend an avenue for them to be able to step out of the shadows of living with HIV and comment on what influences their decisions of whether or not to have a child given their HIV positive status.

5.3 Location of Interviews

All of the interviews for this study were conducted in the same private meeting room at a large multiservice medical facility located in Calgary. The women who participated were met by the researcher upon arrival to the meeting location and given bus tickets, if needed for transportation purposes following the interview as well as an honorarium following the interview. All of the women agreed to being contacted if there were follow up questions and only two expressed interest in receiving a copy of their interview or a copy of the final report of this study.

5.4 Responses to Semi-Structured and Open-Ended Questions

The women who participated in this study were asked to respond to semi-structured and open-ended questions during the interview that were designed to explore their lived experience, reproductive experiences, influence of HIV diagnosis on their decision of whether or not to have a child, and resources and services used during pregnancy or for reproductive care. These semi-structured and open ended questions resulted in data that generated demographic information of participants as well as a number of themes across the stories of the participants in relation to the factors that influence their decision of whether or not have a child given their HIV positive status. The themes that were generated from the data of the women's stories included: intention to having children; personal stigma and fear associated with having children and being HIV positive; personal health status; reproductive options available; spiritual and/or traditional connectedness; the need for additional social supports when pregnant or for reproductive care; and cultural safety when accessing reproductive and pregnancy care services. Demographic data is summarized first.

5.5 Demographic Information

Table 1 provides an overview of the demographic information of participants. The three self-identified HIV positive Aboriginal women of child bearing age as defined by presence of menstrual cycles that would support a pregnancy, who were participants in this study were 33, 35 and 54 years of age. The 54 year old participant despite probably not being fertile and able to carry a pregnancy at her age considered herself to be of child-bearing capability as she still experienced menstruation and as an HIV positive Aboriginal woman, shared her opinions on HIV and pregnancy as such. All participants as indicated in Table 1 were born in Western

Canada with one born within a Western urban center and the other two in small towns close to reserve communities. All of the participants at the time of the study were living in Calgary but they also reported returning back to their places of birth at various times throughout their life and at times being transient between different provinces, towns, cities and reserve communities.

5.5.1 respondent's marital status.

Two of the participants shared that they were currently single, despite reporting having boyfriends:

I'd say single. I have a boyfriend. It's nothing. Its, its, he's never left me, even when he found out, he didn't leave me. I had to tell him. He's still, he's still in my life.

One participant considered her partner relationship to be common law and shared the most recent experience she had with boyfriend relationships providing insight into her interpersonal relationship challenges:

The other guy was not gonna last, we just weren't right. He was too drunk all the time. I had to carry him home all the time or carry him to the shelter. I'm not like the carrying kind (giggles). And the other guy was into drugs and now I have a guy who barely drinks, he just smokes weed... I'm common law. He wants to marry me, but I don't know (giggles.)

None of the women reported longevity of any kind within their intimate interpersonal relationships and each reported that HIV status was an issue within the relationship in terms of concern for partner safety and not infecting them with HIV.

5.5.2 respondent's level of education.

None of the participants completed high school or had any additional trade skills training. Two reported obtaining a grade eleven level of education while the other obtained a grade 10 level of education. One participant reported attending a private Christian school and having FAS. Despite her reported FAS condition, this participant was able to comprehend and understand the questions asked of her and she did not interview any differently than the other participants. This is the recounting she provided of her education:

I had to go to a Christian school and I was the only native person there. It was totally fucked. Um...because I had FAS, I was slower at a Christian school, they're really hard with the academics. So I got sent to one of those schools that teach you, what, those trades too. That's when I rebelled, oh pretty much that's where I lost it. I started doing drugs and drinking.

Another reported attending residential boarding school and being separated from her family as a result and another reported that she attended school through the public education system. The lower educational level of the participants in this study is reflective of what is also found in the literature in terms of Aboriginal women who are HIV positive having a higher number of lifetime and unintended pregnancies if they do not finish high school (Loutfy et al., 2012)

5.5.3 respondent's upbringing and family life.

All of the respondents reported not being raised by their biological parents. One participant reported being raised by her grandmother despite being in the care of her parents

prior to going to boarding school. When asked how her upbringing influenced her reproductive choices, this participant explained:

I was in a boarding school. We weren't taught that. I wasn't even taught by my mother and my dad was so strict that a boy won't come near us. I didn't have a chance, I didn't know how to befriend a male because we were so uh...to meet boys, that was a stupid idea because I didn't know what making love was all about.

Another woman reported that, despite being adopted out, she felt that she had a good family although some aspects of her early upbringing held challenges.

I had a good family. They were a bit too controlling. I was adopted too. My birth mom, who birthed us, was alcoholic so I was adopted. My dad was Scottish and mom was French. But they were good, really Christian you know. I wasn't allowed to do things that other kids did.

Another participant reported being raised in numerous foster care homes and expressed fear in repeating the patterns of her upbringing experience; however, she also expressed the importance having traditional ways as a part of her up-bringing:

I was raised in the system. The child welfare system. I was kind of scared to be a parent. Like thinking oh well, would I make the same mistakes that my foster parents did. I had a good Elder, like she would always come and see me and I still talk to her to this day, since I was thirteen. I would stay at her house for the weekend

when my foster parents wanted to go on vacation...she gave me my first pow-wow dress and taught me how to smudge. Gave me the love that I never really had I guess.

5.5.4 respondent's number of pregnancies and children.

All of the participants reported having experience with being pregnant and having unintended pregnancies during their late adolescence and early adulthood, between the ages of 16 and 25 as illustrated in Table 1. This is consistent with the literature regarding Aboriginal women being younger at time of pregnancy than the general population and having a high prevalence of unintended pregnancy during reproductive age given HIV positive status (Hughes et al, 2009; Loutfy et al., 2012; Ogilvie et al., 2007). Two of the women reported being pregnant, knowing their HIV positive status at the time of pregnancy and having anti-retroviral treatment during pregnancy. As two of the women explained:

It isn't really bad, if you're HIV positive you just gotta take a bunch of medication for the kids and the kids gotta be on medication for a year, six months.

I knew that like, if I took my medications, and I uh, I kept my medication schedule for my kids that they would be ok.

Like I knew that I wouldn't be able to pass it on if I took care of myself.

Two women also reported having suffered miscarriages during pregnancy and one reported having had an abortion in her adolescence. All of the women did report giving birth to children who were still alive at the time of the study and who were living without HIV infection.

For one participant, her children were grown and on their own and she also had grandchildren.

She commented on her experience of pregnancy:

I just didn't know anything about having a baby. I just, there was nobody to there to tell me cause I came out of boarding school and then I went right into, into work. I don't know, I never knew anything about guys or sex or how to befriend guys, you know. I, just, I just met a guy and fell in love. I was too young to know that I just got pregnant and that's how everything changed.

All of the participants commented on their children either being adopted out, under a guardianship order or in the care of child and family services following pregnancy. Despite their children being taken from them and in the care of others, these women expressed a desire to increase their contact with their children. As one woman shared:

I wanna be able to go see my son more often and stuff.

All of the women who participated in the study believed they were of child bearing age because they all were still experiencing monthly menstruation; however, none of them were able to become pregnant due to one of them feeling as though she were too old to have any more children and two other participants spoke of having had tubal ligations at the recommendation of health care professionals following their most recent child birth. As both women who had tubal ligations commented:

Well, I can't have any kids now...because if I have a third kid, like because I've had all my kids though caesarean sections like they said it's probably not good to have another kid, so

I had to get my tubes tied.

They (medical professionals) really pressured me to tie my tubes when I was done and I did too because I didn't really know, uh, so now I can't have any more kids even if I wanted one.

One of the participants considered herself to be too old to have children and stated:

Like I said, I'm too old. They (health professionals) tried to tell me like of course how to have safe sex and to have protected sex since my partner doesn't have this.

But for this participant, the opinions she held about pregnancy and being HIV positive went beyond just being too old. She also reported that she felt that it was selfish for her to consider having a child when she is HIV positive. She explained her views on pregnancy in this manner:

I think that it'd be selfish with what I'm going through, like emotional rollercoasters and fears of pain around people that could jeopardize my health...and it's just your body... it's just not normal. So I don't think it would be right to bring a child into the world when you have to take care of yourself and nurture a child. I find it selfish to bring a child into that home.

For the participants in this study, one participant had three pregnancies with the first pregnancy being prior to HIV diagnosis but ending in a therapeutic abortion because she was only 16 years old at the time of her first pregnancy. This participant later went on to give birth to two children by the age 31 with both pregnancies occurring after she was diagnosed with HIV.

Another participant had five pregnancies and gave birth to five children by the time she was 30 years old with all of her pregnancies occurring prior to HIV diagnosis. The other participant had four pregnancies with two ending in miscarriage and gave birth to two children by the time she was 29 years old, having had one child prior to HIV diagnosis and the other following HIV diagnosis. The participant pregnancy data of this study, is reflective of what is known in the current literature in that, HIV positive Aboriginal women tend to have more children and at younger ages than the general population (Hughes et al., 2009; Loutfy et al., 2012; Nattabi et al., 2009;) and that HIV positive women do desire and pursue having children following an HIV diagnosis (Loutfy et al, 2009; Loutfy et al., 2011; Ogilvie et al, 2007).

5.5.5 respondent's employment and income level.

One of the women in this study reported being unemployed but relied on bottle picking, landscaping and the sex trade to earn income. Another participant was receiving disability income support (Alberta Income for the Severely Handicapped - AISH) at the time of the study but also reported having worked in occupations in the field of labourer and construction, daycare and caregiver capacities, and the food supply industry prior to being on disability. Another participant reported that she was currently employed part time in construction or cashier capacities. All of the participants reported living in poverty, two of them reported making between \$10,000 - \$25,000 per year and the other reported making less than \$10,000 per year. All of the participants were living homeless meaning they were living rough on the streets and accessing shelter services at the time of the study.

5.5.6 respondent's health concerns.

Two of the participants reported being diagnosed with HIV at 21 and 22 years of age respectively while the other was not diagnosed until she was 50 years of age. All of the women reported being diagnosed

with either hepatitis or chlamydia as well. Each woman discussed their struggle in dealing with other health conditions such as osteoarthritis, cirrhosis, pneumonia, and methicillin resistant staphylococcus aureus (MRSA), body aches and pains and depression in addition to their HIV. Additionally, every participant reported struggling with addiction to drugs or alcohol from early adolescence throughout their life and that, their struggle with addictions was still a daily issue.

5.6 Agency Involvement of Participants

All of the women reported being involved with agencies that provided health and reproductive care as well as social services agencies that support housing, transportation, social opportunities, counselling and nutritional service linkages. For all of the participants, HIV medical attention and reproductive family planning care were delivered through a centralized HIV clinic, The Southern Alberta Clinic (SAC), while medical attention for other health issues related to pregnancy and overall wellbeing was sought through agency services such as Best Beginnings, Alberta Health Services Sexual Health Clinic (CSHC), Calgary Urban Project Society (CUPS), Elbow River Healing Lodge (ERHL), HIV Connect (formerly AIDS Calgary), Alpha House, Calgary Drop in Centre, and Beswick.

Table 1 Demographics of Study Participants

<i>Participant 3</i>	<i>Demographics</i>	<i>Participant 1</i>	<i>Participant 2</i>
<i>Age</i>	35	54	33
<i>Place of birth</i>	Small town	Small town	Urban Center
<i>Marital status</i>	Common Law	Single	Single
<i>Total Pregnancies</i>	4	5	3
<i>Live Births</i>	2	5	2
<i>Number of children born after HIV diagnosis</i>	1	0	2
<i>Age at which HIV was diagnosed</i>	21	51	22
<i>Years known to be infected with HIV</i>	14	3	11
<i>Desire to have children following HIV diagnosis</i>	Yes	No	Yes
<i>Ability to become pregnant at time of study</i>	No	No	No
<i>Other health issues present</i>	Hepatitis Chlamydia MRSA+ Chronic pneumonia Fatigue Infections	Chlamydia Cirrhosis Osteoarthritis Blurry vision Dementia Painful intercourse	Hepatitis Depression Weaken immune system
<i>Types of addictions And age of first use</i>	Drugs and Alcohol. First used marijuana & alcohol at age 17	Alcohol. First used alcohol at age 20	Drugs and Alcohol. First used drugs& alcohol at age 14
<i>Level and type of education completed</i>	Grade 11 Attended private Christian School	Grade 11 Attended residential boarding school	Grade 10 Attended public school

<i>Demographics</i>	<i>Participant 1</i>	<i>Participant 2</i>	<i>Participant 3</i>
<i>Employment status</i>	Unemployed	Disability (AISH)	Employed part-time
<i>Usual Employment</i>	Bottle picking Landscaping Sex Trade	Labourer Construction Daycare/Caregiver Food Industry	Cashier Construction
<i>Yearly Income</i>	Up to \$10,000	\$10,000-\$25,000	\$10,000-\$25,000
<i>Housing Status</i>	Homeless – using shelter services	Homeless – using shelter services	Homeless – using shelter services
<i>Family Upbringing</i>	Adopted into non-Native Family	Relationship with parents but raised by grandmother	Involved in child welfare system - foster homes
<i>Agencies accessed and used for reproductive and pregnancy care</i>	<ul style="list-style-type: none"> • Southern Alberta Clinic (SAC) • Calgary Sexual Health Center (CSHC) • Elbow River Healing Lodge (ERHL) • HIV Connect (formerly AIDS Calgary) 	<ul style="list-style-type: none"> • Southern Alberta Clinic (SAC) • Beswick • HIV Connect (formerly AIDS Calgary) 	<ul style="list-style-type: none"> • Southern Alberta Clinic (SAC) • Elbow River Healing Lodge (ERHL) • Calgary Urban Project Society (CUPS) • Best Beginnings

5.7 Intention and Desire to Have a Child

There are a number of studies that suggest most HIV positive Aboriginal women desire and want to have children leading them to consider pregnancy (Carter et al., 2013; Loutfy et al., 2009; Loutfy et al., 2014; Nattabi et al., 2009; Ogilvie et al., 2007); however, these studies have found that, rarely are the pregnancies planned either prior to HIV diagnosis or following HIV diagnosis and most of the pregnancies occur during adolescence or young adulthood, regardless

of HIV diagnosis (Loutfy et al., 2011). There is consistency in this study with previously published data in that, despite the participants each having multiple pregnancies, none of their pregnancies were planned:

I never really planned on having kids at all, and then I have a son and a daughter...uh well, my boyfriend at the time, my son's daddy, he was kind of wanting to, it was kind of an accident...I never planned on having kids, like it wasn't a planned thing, like "I'm gonna go get pregnant today.

I got pregnant once like when I was sixteen but that was before I was HIV...but then when I actually had my kids actually...well uh, my first kid, I well, both my kids, I didn't really make a decision eh. They just came along I guess...

I was HIV since I was twenty-two so I had my kids when I was like thirty-one and twenty-five.

It started at a young age...I was twenty years old when I had my first. All my decision making was flawed, right from day one all of my decision making was the opposite of what I should have done.

Despite the fact that the children born to the women in this study were unplanned two of the women alluded to the fact that “desire” was a factor that influenced their decision to become pregnant and have children.

Oh when I had that abortion when I was sixteen, I didn't really want to have any kids, but then when I grew older you know, yeah, I wanted to experience having kids. I wanted kids. I was doing good at the time...I wanted to be a mother (giggles). I wanted to experience having kids and you know, I wanted to leave my legacy too.

Yeah, I wanted to have kids. I just never planned them when they came. Sometimes that's how it happens.

The other participant cited a lack of reproductive knowledge being the catalyst for her first pregnancy.

*I just didn't even know anything about having a baby...
I just got pregnant and that's how everything changed.*

Thus, the participants of this study reflect the reported experiences of other HIV positive Aboriginal women of child bearing age in the research literature with regards to having a desire to become pregnant, regardless of HIV status, and also having unintended pregnancies. The women in this study also demonstrated consistency with previously published data in that, they were pregnant at a younger age than the national average and did not plan their pregnancies, even following HIV diagnosis.

5.8 Stigma and Fear Associated with Being HIV Positive and Having a Child

All of the women in this study relayed how stigma and fear influence their decisions of whether or not to have children. The different types of stigma that HIV positive individuals experience as described by Loutfy et al. (2012) were all present in the stories of the women of this study. Perceived, internalized, and layered stigma had the strongest representation in the stories of the participants, while symbolic and enacted stigma seemed to be less of an issue for them. For all of the participants, the fear of stigma heavily influenced their decisions of whether or not to have children following an HIV diagnosis.

Perceived stigma as the result of negative social attitudes, feelings of shame and the fear of rejection and/or discrimination were major factors for the HIV positive Aboriginal women of this study in terms of not wanting to come forward and be known as HIV positive either in this study or outside of it. Perceived stigma for women in this study was found to be tied to fear of rejection in close relationships, fear of rejection of their children, and discrimination within the healthcare system itself towards HIV positive Aboriginal women. As one woman commented, being HIV positive, limited her ability to be open and honest with others, especially when it came to protecting her children from perceived and symbolic stigma:

*Some people I don't tell that I'm HIV, like I gotta hide
that and you know like, people are always wondering
like, why you giving your daughter medicine all the time.
I kinda had to lie and say that its heart medicine or something
right. Because you know it's different, its people, you know
its HIV, people don't want nothing to do with you no more.
They think they're gonna catch it like a common cold.*

For another participant, perceived stigma created out of the fear of others finding out about her HIV positive status rendered her unable to share with those who were close to her, reinforcing both perceived and internalized stigma.

*I didn't want to tell anybody until I told the social worker...
I told her I had HIV. I think it's just my fears, my fears that
cling...I try to keep my space...and when I go away for my
appointments and everything, I have to tell my friends you
know, I have to go and I can't give them a reason why I'm
leaving...and I can't bring them there. The fear of us you
know, shouldn't be there.*

There was also the presence of layered or compound stigma present in the stories of these women. It is one thing to experience the stigma of being HIV positive, but when that is layer upon also being a woman and then layered once again upon being an Aboriginal woman who also is a grandmother, then the stigma experienced by one who is an HIV positive Aboriginal woman and grandmother is a layered or compounding of the stigmas experienced within each level of identity. One woman, through her tears, commented on how her fear and her HIV positive status impacted on her ability to be a grandmother or experience joy which also reinforced internalized stigma for her:

*I have a granddaughter, that's just recent, she'll be a year old
and I fear being around her. You know, I am scared. I feel like
I am not playing my part as a grandmother because of the fact
that I am HIV positive...I talk with family and I see them going*

on with their life, you know, and going through their day and they're happy and I'm just beating up myself all the time.

Another woman went so far as to call into question her ability to be a parent simply because of her HIV status stating, *"I thought I was, wasn't a good enough parent...cause I was HIV."*

The perception of rejection and discrimination from others when one is an HIV positive Aboriginal woman of child bearing age has been documented by other researchers to be related to feelings of fear, negative outcomes, increased perceived stress, and lack of self-esteem (Loutfy et al., 2012; Ship and Norton, 2000; Wagner et al., 2010;) and for the women in this study, fear, lack of self-esteem and negative core beliefs were revealed through the telling of their stories and body language. All of the women in this study told their stories with quiet shyness and timidity, often looking away or at the floor, sometimes crying or tearing up when discussing their children, recalling when they first tested HIV positive or commenting on their inability to have any other children due to age or tubal ligation. All of the women also made comments during the interview that, *"they were not good at this kind of thing"*, implying that sharing their story was difficult. This type of comment reflected to the researcher that these women held a core belief of, "not being good enough" because after all, who is best suited and able to share about ones' story than the individual whose story it is? Yet, these women, who are the experts of their own experience, would repeatedly comment during the interview that they were not good at talking about their story or experience. Evidence to the researcher that the magnitude of importance that these women placed on their stories and experiences, were based on self beliefs and tied to performance measures they held themselves to.

At the end of the interview each participant commented on how they had taken contact information for the researcher from a poster, but had held on to it for a period of time prior to

contacting the researcher because they were unsure about their ability to share their story or how relevant it would be for the research. Once again, these types of comments reinforced the negative core beliefs that these women held and the degree to which they doubted their own personal value and self-worth. Thus, the perceived, internalized and layered stigma of the participants in this study mirrored that found in current research literature and was found to be a determining factor for making a decision of whether or not to have a child given HIV positive status.

5.9 Personal Health Experience

When participants in this study were questioned about how their personal health experiences influenced their decision to have a child or not, health was considered across domains of physical, mental, emotional and spiritual aspects of being using the Medicine Wheel as a framework for discussion. It is these domains that contribute to the quality of life of an individual and while some studies suggest that physical health (Nattabi et al., 2009; Wagner et al., 2010) and/or mental health, as measured by the absence or presence of depression (Cain et al., 2013; Carvalhal, 2010), are good indicators for whether or not an HIV positive woman will chose to have a child or not, they alone, do not fully explain how personal health from a holistic perspective impacts on the decision to have a child or not when a women is HIV positive and of child bearing age. What follows is what the women of this study consider to be physical, mental, emotion and spiritual aspects of what contributes to their health or lack of health as it pertains to pregnancy and making a decision to have a child or not.

5.9.1 physical health.

For the HIV positive Aboriginal women in this study, their physical health was a reflection of CD4 counts, immune system functioning, body changes, ability to adhere to medication

regimes and the presence of addictions. While some of these self-reported indicators of physical health may be classified by health professionals as issues of behavior and attitude or better categorized under mental health, it is important to acknowledge that these are the indicators that the women of this study reported as being the most important and having the most influence in determining whether or not their health is “good” enough to support a pregnancy and result in a healthy child. As one woman commented:

Whether or not my C4 status is up. How my health is, is like, if my status is in the eights, then I can't have a kid, or I'd have to be looking after myself really good...It doesn't matter what you have you know, you can still be a good parent. You know, I guess it just depends how your C4 is - your count.

Additionally, immune system functioning seemed to be another physical health factor that women in this study considered to be important for making a decision about whether or not to have a child and that seemed to impact strongly on perceived physical health status. All of the participants reported how their physical health was impacted by HIV and tied to their immune system function.

I've slowed down. Pretty much, I've got the immune system of a 60 year old. I've slowed down, like I feel it more physically. If I get sick, you know, like sometimes my immune system can't handle it.

The HIV...its affecting my whole body and my scars won't heal, my bruises won't heal. Um, my skin's getting really bad...and I'm tired all the time. I get chronic pneumonia. Hum...I get super tired a lot, and like when I eat a lot of food, I can't gain any weight. I'm going downhill.

Every time I am hospitalized, I go into isolation...it's very delicate. You're just like a piece of glass, like you could break easily like, just the common cold and that cuts on you and it's hard to heal. And it's your body, it's just not normal...Your body doesn't feel the same. It's like the pain is like all over...and it hurts having sex. And your eyes, they just kind of, just hurts too. They get blurry...I don't know how to explain it, but your body's not the same – it isn't right...I don't think it's possible to have a baby because physically you're not the same. You're not the same.

One woman in this study considered herself to be too old to be having children and described that a decision to have a child would be, “*selfish with what I'm going through (alluding to her current health struggles).*” The two other participants however, did make the decision to have children post HIV diagnosis and shared that medication adherence was a key factor in their decision to continue with their pregnancy in the hopes of having a healthy child. Both of these women also shared that their HIV positive status did not necessarily affect their decisions to have a child or not because they knew that, if they were connected to health care resources and taking HIV suppression medication, had C-Sections, and were provided with

formula post-partum that they then could prevent vertical transmission of HIV to their unborn child. Thus, diminishing the risk of vertical transmission was considered, by the women of this study, to be an important factor in influencing their decisions for pregnancy. As one participant shared when asked if her HIV status affected her decision of whether or not to have a child:

Well it didn't really affect my decision making because I knew that like, if I took my medications, and I uh, I kept my medication schedule for my kids that they would be ok. Like I knew that I wouldn't be able to pass it on if I took care of myself.

Another participant spoke about her experience with medication while being pregnant with both her son and her daughter in this manner:

Everything was fine through their pregnancies. Through the Southern Alberta Clinic, they give you medications and help you with everything you need...I had really good medication and care for, and so my kids came out fine...I was getting lots of headaches and muscle aches (referring to being on medication during pregnancy), but it didn't really affect it as long as I kept my son safe was all that mattered...you can't breast feed, they give you, uh, free formula.

When asked about the delivery of her two children following adherence to a medication regime to prevent vertical transmission, this same participant shared that, “*Um, the C-Section sucked.*” She then elaborated on why a C-Section was required citing, “*because there would be too much blood transfer and the medication makes you a bit sick, but my son came out perfectly.*” Thus, for two of the women in this study, a medication regime, free formula, and C-

Section birthing were factors that influenced their decision to continue on with their pregnancies and have children despite their own HIV positive diagnosis.

The women in this study, shared that substance addiction seems to be one of the most important indicators of physical health in relation to whether or not the women in this study considered having a child or not. While all of the women in this study reported substance related issues beginning in their teenage years and being related to their contraction of HIV, which is consistent with the current research literature, all of the women at the time of this study, were also still struggling with substance addiction issues years after having had their children. What is important to note though, is that, despite having substance addiction issues, the women in this study, when they found out they were pregnant, reportedly ceased their substance use indicating a deep respect for the life they carried inside of them. For all of the women in this study, substance use began at an early age. One of the participants shared how her substance use began at age 17 and how she dealt with her addictions when she found out she was pregnant:

Sometimes people's addictions get away with their health and do things they don't know. I started doing drugs and drinking and it started with pot and I just kept on going to mushrooms, acid and eventually I ended up with coke. Um, it was first smoking and snorting it and then I started injecting it. When I had no needles left, then I used somebody else's and that's when I got it – HIV... I was so messed up that I didn't really care at the time.

When asked how addictions impacted on her during her pregnancy, this same participant shared:

I had one beer through my whole pregnancy, which was amazing. I was also on the methadone treatment. When I went to Vancouver,

I got on the heroin so I was addicted to that and when I found out I was pregnant I got onto the methadone program...I went down to nothing (giggles). It sucked but my son, he came out perfectly healthy. There's no withdraws or anything. That's all that mattered. I didn't want to see my kid go through that... I still struggle with my alcohol, but not as bad as I used to...I do drink to forget a lot.

Another participant, when asked about what influenced her reproductive choices growing up, bluntly stated, “*addictions.*” She then went on to explain that her substance use began at, “*about fourteen, pot then alcohol and harder stuff*” and when asked if she still struggled with these substances today, she replied, “*a little bit with the alcohol, yeah.*”

For yet another participant, substance use began at the age of 20 but it did not escalate until after she had had three children and was 26 years of age. The price of this participant's addictions was the loss of her children and yet when her children were taken away, she sought comfort in the very thing that caused her children to be removed from her care – alcohol. This woman discussed her struggle with alcohol saying:

I tested it often until I was 26...off and on, like I hate it. When I started drinking, I was 26 cause I had my children and I had work. I never had help from anybody...I just, I don't know what got into me. I met up with some other people and when I was 26, I started drinking all the time because my kids got taken away and so I had nothing and I turned to the bottle and just kept going ever since and my life stopped. Well, I stopped and had another two kids-

stopped drinking - and then they got taken away because of my track record and I, they won them in court and I felt I got badgered and then it made it worse. Drinking was the solution, I had nothing, no responsibilities.

When asked if alcohol use is still an issue for this participant, she replied:

I want sometimes to drink, but I know that because I know the the pills won't work if I drink. And if I drink, that's making my HIV worse. My immune system will go down.

Thus, for all of the participants in this study, substance use and addiction was something that preceded their HIV diagnosis, sometimes possibly leading to contraction of HIV, and addictions were still an issue for the participants at the time of this study, indicating a life long struggle with substance use for the women of this study. The participant's stories of addiction support what is found in current epidemiological research that reports more than 50% of HIV cases being attributed to intravenous drug use exposure in the Aboriginal population (Public Health Agency of Canada, 2013). Additionally, the struggle with addictions that the women in this study shared— escalation of substance use, loss of children, consistent struggle for sobriety - also mirrors the stories of other HIV positive Aboriginal women and their struggle with addictions from an early age (Buharski et al., 2006; McCall et al., 2009; Romanow, 2003). What is important to note though, is that when faced with pregnancy and having children, the women of this study were willing to address their addiction issues for the sake and health of their children during their pregnancies.

5.9.2 mental health.

When asked how HIV status has impacted on the study participant's mental health, one participant reported findings similar to current research literature, citing post-partum

depression and a lack of mental health resources to deal with the depression, as issues associated with pregnancy that affect mental health; however, depression itself did not seem to influence any of the participant's decisions of whether or not to have a child. As one participant noted:

I think they need to deal with a little more, a little more post traumatic for depression after the kids are born so that wouldn't happen...I didn't find too many services then to help me out. I kinda had to deal with it on my own.

Ironically, most mental health effects for the women in this study were related to stigma, worry, and the lack acceptance by others in the presence of HIV disclosure. As two of the participants shared:

It's kinda, it's hard cause you, you know, you can't really tell anybody you're HIV cause when you do, you know they just wanna run away from you. Like they think they're easily gonna get it, like if I breathe or cough on them that they're gonna get it and then, you know, you are just kinda lowered down in their eyes, you know, they look down on you.

It (being HIV positive and a mother) doesn't really bug me unless it comes to relationships. Uh, trying to find a great person to be with that accepts it all and then when you find someone you like and then the whole thing that comes up, into play, is telling them.

Only one of the participants commented on how HIV affects her mental health in terms of cognitive deficits and the forgetfulness she experiences.

I get a touch of dementia at times and I just forget and now this could happen to a mother, it could be like that, and I don't know if it happens to all, but dementia...it's so, I don't know, like living and trying to stay sane, going through my head.

Another participant began to tear up as she expressed an existentialist worry that other HIV positive Aboriginal women (Ship & Norton, 2000) have expressed with regards to their own children's health, well-being, security and future, "*I don't know, I think I am gonna pass away or something on my kids.*"

5.9.3 emotional health.

For all of the women in this study, emotional health was closely tied to feelings of isolation and the ability to have social interactions. As two participants shared:

I'm a loner. I have my few friends that I have known for years that I talk to. Or I'll feel, just like I need to get away I'll go to another city for a year or two and I'll come back.

It's like alone time.

Um, just the fact that I don't tell anybody and they don't know. So you'd like to tell them, but you don't know what they're gonna think.

One woman indicated that emotional health was also represented by the extent to which life could be interpreted as being good or bad on any given day. She summed up her emotional health by saying, “...*what I’m going through, like emotional rollercoasters and fears of pain...like you’re just always wondering if it’s gonna be good or bad.*” Another participant didn’t find that her emotional health was necessarily affected because she, “*didn’t really care about it, you know.*”

5.9.4 spiritual health.

When asked about how spiritual health was impacted by HIV status and whether or not spiritual health played a role in their decision to have a child or not given an HIV positive status, the women in this study all commented that spirituality did have a role in their lives and decisions. One woman, who reported that she grew up in a Christian home, took a paradoxical approach saying, “*I’ve never been really spiritual. Uh, God really always taught me consequences.*” Spirituality, as another participant indicated, hadn’t been influenced by her HIV diagnosis and the role it played in her decisions to have a child or not. She commented that, “*I still pray and whatnot. I put that situation in Creator’s hands and I know that he’ll look after me.*” Another participant, when asked about her spirituality reported that, “*I feel like it is gone*”; however, this participant then went on to talk about how she engages in gratitude and prayer for strength.

I pray a lot. To keep me strong, to keep me going...each and every day and thanking him (referring to Creator) for a new day.

And when asked if the spiritual aspect of her health had changed since her HIV diagnosis, this participant began to cry and shared:

I've gone very, very into it and I've started to see people and things different. You know, I used to be resentful and I was angry – it might have come from alcohol. But I've kinda changed where I try to understand people more, cause I don't know what tomorrow is going to be you know. I just pray that you know, kids be safe, and I thank that people made a path for me and I pray for them so...I can't close off my prayers. In the morning and at night...he (referring to Creator) brought me through it, you know.

The importance of spirituality in the lives of the women in this study as it pertains to their health and well-being was not only evident in the words of their story, but also in the gratitude they expressed when presented with a sweet-grass braid, ceremonial stone, or sacred tobacco during or following the interview. At the end of one of the interviews the participant wrapped the sweet grass braid around her hand, forming a circle with it and held it up to her heart expressing gratitude for it. Yet another participant, although she expressed not growing up with traditional ways, accepted the sweet-grass braid as well with gratitude. Thus, it was apparent to the researcher, that spirituality for the HIV positive Aboriginal women of this study was a very important aspect of health for them and although they expressed their spiritual connection in different ways, they still held spirituality in high regard as it pertained to overall health and wellbeing. At times, spirituality for the participants seems to provide a means to connect to something greater through the practice of prayer, praying for “*kids be safe*” and putting reproductive and pregnancy concerns into “*Creator's hands.*” In these ways, spirituality does appear to have an impact on the lives of HIV positive women; however, it does not appear to

influence their decisions to have a child or not prior to pregnancy as none of their pregnancies were planned, but it does have an influence during and following pregnancy for them.

5.10 Availability of Reproductive Options

For the women in this study, reproductive options were made available to them through sexual and reproductive health services and HIV agencies, such as, the Southern Alberta Clinic (SAC), Elbow River Healing Lodge (ERHL), Calgary Urban Project Society (CUPS), Sexually Transmitted Illnesses (STI) Clinic, HIV Connection Calgary (formerly AIDS Calgary), Best Beginnings, and Beswick. For the women in this study, contraception came in the form of family planning consultation and counselling, condom distribution, and Depro-Provera and birth control pill prescriptions through the afore mentioned agencies and clinics. Some of the clinics also referred some of the women in this study for tubal ligation following their most recent delivery. Additionally, participants received prenatal care, obstetrical care, and support through these services as well. One participant commented on how the care she received through these services was different then receiving care through other avenues because:

These guys they understand, they have like Elbow River is like for Aboriginal people. CUPS is more like downtown, like so they kinda understand more than the regular doctor on like the outskirts of the suburbs or whatever...they know what it's like to be downtown of they know, you know, like they deal with us more, they know more than people in the suburbs cause they, they are less houdy-toudy... less judgmental maybe.

For one of the women in this study, CUPS provided necessary reproductive and pregnancy services.

The reason that I had to go to CUPS is because Elbow River didn't have an obstetrician there. So I had to go to CUPS to get an obstetrician, just cause I needed it. I went there for like my appointments – my family doctor's at Elbow River. I just went once a week to CUPS to check on my baby.

Despite all of the women in this study expressing gratitude for being able to access specialized HIV reproductive and health services, two of the women commented that although the services they received benefited them, they also reinforced some of the stigma they experienced as HIV positive Aboriginal women of child bearing age. One of the participants commented that, when it came to her reproductive care and being afforded options:

“The only thing that I didn't like is that the doctors pressure you to tie your tubes when you are done – they feel that you shouldn't have any more kids.

When I asked this particular participant how that made her feel, she commented:

Um, sometimes sad, but sometimes I'm ok with that. I don't really think that I am ready to have another child anyways.

Upon further inquiry into whether or not this participant's HIV status played a role in her consideration of having her tubal ligation reversed in the future she responded:

Um, a little bit I guess. The doctor would probably try and talk me not to do it. But it's like, there's medications out there, and they shouldn't be like that, they should just mention it and keep on talking to me.

Thus, while HIV reproductive and pregnancy services do benefit HIV positive Aboriginal women they also do not seem to, according to the women in this study, encourage the idea of having children. The HIV positive Aboriginal women in this study felt as though HIV, reproductive care services and health professionals discouraged pregnancy by providing contraception and sterility consultation despite the fact that, the women in this study desired children and were aware of safe means by which, they could experience pregnancy and effectively reduce the risk of vertical transmission of HIV to their offspring. Although not deeply explored in this study, it is an interesting point to raise, in that the HIV positive Aboriginal women had perceptions of current services being concerned with limiting pregnancy rather than engaging in dialogue about safe pregnancy options. If the perceptions of the women in this study are true with regards to the perceived coercion that exists within the current system of pregnancy care for HIV positive Aboriginal women, then the goal should be to provide ethical care and offer informed consent rather than coercion so that the rights of the individual are balanced against protecting and ensuring the health of the child. As one participant stated,

I think they (referring to health care professionals) should support it (referring to the pregnancy of HIV positive Aboriginal women). Just get them on the right medications. My son came out perfect and there's nothing wrong at all.

It is unclear why the HIV reproductive and pregnancy services that the women in this study accessed tended to lean towards preventing pregnancy rather than providing informed options for reproductive and pregnancy health. The women in this study presented with complex and intersecting issues; experiencing homelessness, addictions, poverty and involvement with child and family services. Thus, perhaps the suggestions by medical professionals towards

contraception and sterility is more about the presence of confounding social issues and possible racism than it is about HIV status alone. What is important to note though, is that the HIV positive Aboriginal women in this study felt that it was more about their HIV status than the other social issues they were confronting that influenced, in their mind, the suggestions made by medical professionals for contraception and sterility procedures over options for pregnancy and child bearing.

5.11 Need for Additional Social Supports

All of the women in this study were homeless, living rough on the streets and accessing shelter services at the time of their study interview. Each expressed having a need for additional supports, such as housing, nutrition, counselling and transportation to and from medical appointments while being pregnant or raising their children. The need for additional supports, as reported by the women in this study is consistent with current research literature that also suggests that HIV positive Aboriginal women of child bearing age suffer higher rates of poverty, homelessness, and lack of access to services than the general population (Carvalho, 2010; Greene et al., 2010; McCall et al., 2009; Ship & Norton, 2000).

All of the women in this study accessed support services through the same services that provided reproductive and pregnancy care for them. This indicates that reproductive and pregnancy services for HIV positive Aboriginal women of child bearing age need to be responsive to needs that go beyond just reproduction and pregnancy care and which address broader social needs as they arise. All of the women in this study spoke about how reproductive and pregnancy services helped them in meeting their additional needs. One participant commented on the additional services she received through CUPS.

They met my needs pretty good. You know, they helped me out with getting around town, and you know, food bank services and housing as much as they could...those nurses that come out (referring to Best Beginnings program)...they come check on the baby after.

Another participant commented on the services she received through HIV Connect Calgary.

They have a lot of services. They have counselling and they give out bus tickets and vitamins and they have clothes and they can help you do your taxes and there's always healthy food there. They have a fund...you can access it every three years if you are short on your rent or electricity. You can access their services and they'll pay your bill off. They're really good.

Another participant commented on the additional services she received when she accessed the Southern Alberta Clinic (SAC).

The SAC clinic, the Southern Alberta Clinic, they'll help you out and they'll give you bus tickets if you need to get to doctor's appointments somewhere else or they'll refer you to and give you gift cards if you need food or something.

One of the participants stressed the importance of having additional supports when being an HIV positive Aboriginal woman and having children in this manner.

If I had to raise a kid alone I would. Uh, I'd definitely want a good support network, like if I didn't have that, I probably wouldn't have the kid.

Thus, as the HIV positive Aboriginal women who participated in this study shared, the need to provide additional supports during pregnancy and following pregnancy is definitely important for reproductive and pregnancy health. Despite having additional supports, in the form of transportation, food, counselling, vitamins, and bill payments, the HIV positive Aboriginal women who participated in this study, all shared that housing supports were lacking. All of the women in this study commented on the difficulty they experienced in terms of securing housing and the impact that this had on their ability to care for their children or maintain good health that would support pregnancy and motherhood.

I was living in a rooming house and, and they didn't want no kids there and Calgary Housing took forever to get in to. Uh, I got sick and I had to go into the hospital so I had to put my children with my aunt for now...I'm still waiting for Metis Housing or like one of those low income housing or to give me a place. There's a pretty long wait, it's like two years almost.

While one women in this study was able to secure housing through Beswick, a housing initiative for HIV positive individuals, she later found herself homeless because as she explained,

The home I was in, that gave me a lot of insights you know because they've been there, they've seen HIV for years. It's all HIV victims...I just left, you know, when people live there

they live with death and I didn't want my situation to be the same way. I wanted to, I just wanted to be with my people. I wasn't feeling needed in there...it wasn't no different cause everybody is HIV because they're all suffering from the same thing and nobody was different. I went to be with my niece. My family, my daughter and my younger sister...like right now I'm homeless. After a whole year, more than a year, it's been like 15 months now I've been bouncing around...being out there, I kept ending up in hospital...cause the street life isn't a place for somebody that's scared.

Thus, as the women's stories of this study suggest HIV reproductive and pregnancy services need to be tailored and responsive to the diverse and additional needs of HIV positive Aboriginal women, they also can be detrimental if they further marginalize HIV positive Aboriginal women and segregate them from the rest of society, reinforcing the perceived and internalized stigma they feel as well as the isolation they experience.

5.12 Spiritual and/or Traditional Connectedness

Spirituality is a personal dimension that varies from individual to individual. It can only be truly defined by the individual themselves; however, others can relate to the spiritual ways of another individual when something that is common to one person's spiritual walk is witnessed in another individual. The common thread in all spiritual ways of knowing and doing is the concept of connection – connection to self, others, and/or something that is greater. The importance of spiritual and/or connection to traditional Aboriginal cultural ways and cultural ways of knowing was thus apparent to the researcher in the stories of all of the participants. Spirituality and

traditional connections to culture was left open to the interpretation of the participants as to what these concepts meant to them. Participants spoke about spirituality in terms of having a connection to either something greater than themselves – a God, a Creator – that could be accessed through prayer or ceremony or through a connection that they shared with other individuals and in understanding self and their place of self in the world. Spirituality was also represented in the stories of these women when they described the connection they shared with Aboriginal Elders or traditional Aboriginal cultural ways or in relationships between others and self.

One participant, who reported having been raised in a Christian home reported no connection to spirituality in terms of daily spiritual practice but rather she expressed her spirituality as understanding that there are consequences as taught by God, which she was taught through her early childhood upbringing experiences. Interestingly though, this participant demonstrated that her spirituality ran much deeper than maybe she was even aware of in terms of concern for others and understanding how her actions can affect the welfare of others. This participant demonstrated deep empathy for others even in the midst of situations of self-preservation. This is indicative of spiritual connectivity that runs at a deeper level and considers how the actions of one can affect another, placing emphasis on the ‘other’ for the wellbeing of all. She was recounting her experience as a sex trade worker when she shared:

It's like you're giving everything away, your body, and eventually your soul and you have to worry about if anything happens. Like, lots of the guys are family men and if I made one of them sick, that would have sucked and it's like worry for the dads.

The other two participants who did have some understanding and experience of traditional Native ways and spirituality, expressed how their experience shaped their spiritual connectedness. One woman spoke of how, although she lived in foster care growing up, she was connected to traditional ways through an Elder. She spoke of how the relationship she had with this Elder brought meaning and love into her life and influenced the relationship she has with her daughter. She explained the importance of spirituality and traditional ways in her life through this account:

I had this good Elder, like she would always come to see me and I still talk to her to this day, but since I was thirteen. I would stay at her house for the weekend when my foster parents wanted to go on vacation. They sent me to this Elder's house and she's still my friend to this day. She gave me my first pow-wow dress and um, taught me how to smudge. Gave me the love that I never really had I guess...I gave my two year old this pow-wow dress. Yeah, it's still engraved in my head (referring to traditional ways). I think it helps. You know, like a bit of hope and it keeps my levels of positive thinking. It's like going to church I guess.

The only participant in this study who also is a residential school survivor indicated that her Native grandmother taught her traditional ways and expressed her deep connection to spirituality through learning those traditional ways, prayer and having an attitude to move forward in life. Thus, tangible ways of connecting spiritually as well as existentialistic beliefs about life, as demonstrated in one participant's comments, help to nurture spiritual health and feelings of connectedness.

*My grandmother was the one that raised me. How to cook the
and how to prepare that, but the language, I didn't catch
on...it's always about the roots...I just pray you know...I can't
close off my prayers...you can always go on with life instead
of wanting to give up.*

Regardless of whether spirituality was expressed in traditional ways through ceremony or prayer or understood in the context of religion and consequences, all of the women in this study alluded to having a spiritual connection that guided them in some manner in their daily lives. This speaks to the possible importance that spirituality can have in the lives of the HIV positive Aboriginal women of child bearing age.

5.13 Cultural Safety

Cultural safety, understood as a relational, systemic, organizational, self-reflective or 'ritual of encounter' process (Bucharski et al., 2006; McCall & Pauly, 2012; McCall et al., 2009; Ship & Norton, 2000;) was for the participants of this study lacking when it came to reproductive and pregnancy issues. Although all of the women in this study spoke highly of the services they received in dealing with their HIV status, pregnancy and/or reproductive services as being useful for them, they also all spoke of moments where there was a lack of cultural safety for them while using these services. The lack of cultural safety for the women of this study manifest in the form of insensitivity to situation and/or confounding factors, personal judgment from professionals, and the perceived stigma from professionals that the participants felt was present when options were not afforded to them in the context of the professional relationship.

Two of the women in this study spoke about how health care professionals created situations that were culturally unsafe because they pushed their own health agenda or opinion and/or made negative comments towards the HIV positive women during their pregnancy or following the birth of their child. One woman shared some of the judgmental comments that were made to her in relation to her pregnancy by health care professionals that created an atmosphere of insensitivity and unsafety for her:

Well, it's, it's like, just like, they were, you wanna have a kid?

Yeah, what are you doing having kids? Like when you die, you're gonna die and what's gonna happen with your kids?...

I seen some nurses and they'd be 'eeehhh' you've got HIV and you could tell they want to run out of the room.

When I asked this participant what she thought health care providers should know about HIV positive women who are of child bearing age, her reply echoed the need for cultural safety.

Don't be judgmental I guess. Uh, you know we're people too you know like. Keep judgment to themselves or go see someone else, someone better.

For another study participant, she felt that cultural safety was absent when it came to having reproductive options explained to her. She summed up the lack of cultural safety as it applied to her reproductive care in this manner:

The doctors pressure you to tie your tubes when you are done – they feel that you shouldn't have any more kids.

They really pressured me to tie my tubes when I was done

*and I did too at the time because I didn't really know, uh,
so now I can't have any more kids even if I wanted one.*

Thus, for the women in this study, they believed that there was a lack of cultural safety with in the current system of reproductive and pregnancy care. They discussed how the lack of cultural safety was manifest through the comments made by health care professionals that reinforced stigma and fear and included bias and insensitivity. The participants also felt there was a lack of cultural safety when suggestions made by health care professionals in the context of their own professional cultural, limited the reproductive options available to the HIV positive women in this study. Thus, the women in this study perceived that, the lack of options discussed with them created an unsafe environment within the professional culture of care itself.

Chapter 6 Discussion

6.1 Introduction

HIV is not a disease that discriminates and as such it is not someone else's problem but rather a public health crisis for all. Research has shown that anyone can become infected with HIV regardless of age, race, sex, religion, socio-economic status (SES), sexual preference, level of education, or rural versus urban living environment; however, Aboriginal women of child bearing age are more vulnerable and at greater risk of contracting HIV because of the cumulative effects they experience.

As De Bruyn (1998:11) suggests, "The cumulative effect of HIV/AIDS-related stigma and discrimination is to objectify, marginalize and exclude people with HIV/AIDS. Those who were already objectified, marginalized and excluded are pushed even further from a recognition of shared humanity and from the support of human society." Aboriginal women of child bearing age experience cumulative effects that increase their risk of contracting HIV during child bearing age, because they experience high rates of sexually transmitted infections, intravenous drug use, sex trade work exposure, addictions, abuse and traumatic childhood experiences, intergenerational trauma, pregnancy in adolescence and young adulthood, domestic and family violence, over-representation in correction facilities, homelessness, the collective transient movement between urban, rural and reserve communities as well as other health and social issues. There is also an overwhelming lack of self-esteem and self-worth evident in the lives of Aboriginal women of child-bearing age that is embedded in racism, discrimination, stigma, abuse, poverty and intergenerational trauma. This translates into an inability or unwillingness to affirm "the self" in any type of relationship be it interpersonal or professional which, further restricts HIV positive Aboriginal women from speaking up about their reproductive care and

fertility desires.

Thus, these factors compound the risk that Aboriginal women of child bearing age face when it comes to contracting HIV and have resulted in Aboriginal women having the poorest overall health and SES of any identifiable group in Canada. Subsequently, the response to the needs of HIV positive Aboriginal women of child bearing age when it comes to their reproductive health and desire to have children or not, is not merely one of medical context. The response, as also suggested by RCAP (1996, IV: 4), requires addressing simultaneously, economic, social, cultural, political, medical and spiritual issues. This chapter looks at the implications, strengths and limitations of the data produced from this study and offers some practical recommendations for addressing HIV positive Aboriginal women's reproductive health and pregnancy issues.

6.2 Significance of this Study

The information obtained through this study contributed to the development of a comprehensive understanding of what constitutes HIV positive Aboriginal women's reproductive health experiences in an urban environment and how such an experience influences and impacts HIV positive Aboriginal women's reproductive choices, behaviors and general health and well-being. The data provided an understanding of personal reproductive experiences and contributed to recommendations that, originate at a grass roots level and can be used to inform professional policy and practice for those health care professionals providing reproductive and fertility care for HIV positive Aboriginal women of child bearing age. The significance of this study is that, it expands on the findings of previous literature that examined Aboriginal women's experiences of living with HIV by investigating how they experience a) reproductive health and the role that HIV status plays in influencing their decisions of whether or

not to have a child; and b) formal health care support services as they pertain to reproductive health. This study also resulted in recommendations for health care providers in the field of reproductive and perinatal health that, specifically address the needs of Western Canadian urban Aboriginal women living with HIV who are of child bearing age.

6.3 Limitations

There are several limitations that need to be considered when examining the findings of this study and which suggest the need for further research in this domain of interest. Some limitations of this study include, but are not limited to, the nature and size of the study sample, the study design itself, self-reporting of participants, and the lack of studies in current research that use a framework for understanding the impact that culture has on the fertility desires of Aboriginal HIV positive women.

6.3.1 study sample size.

The major limitation of this study relates to the nature and size of the study sample. While efforts were made to recruit Aboriginal women who self-identify as HIV positive, of child bearing age and living within a Western urban center of Canada, via voluntary participation through six different HIV population serving agencies over a period of one year, only a small sample of three Aboriginal women responded to the recruitment poster and contacted the researcher. Of these three women, all self-reported being HIV positive and only two were within the mid-range of child bearing age. One of the women who responded to participate was on the later life cusp of child bearing age and so her data was included but it is questionable whether or not she fully met study eligibility criteria. None of the participants were confirmed to be HIV positive through medical documentation or testing, only verbal self-reports of HIV status were obtained from participants. Thus, this small sample limits the generalizability of the findings to

the broader population group of Aboriginal women who are HIV positive, of child bearing age and living within a Western urban center of Canada. Despite this limitation of generalizability, the sample size does hold transferability and relatability of findings to not only HIV positive Aboriginal women of child bearing age, but to other female Aboriginal population groups, such as, Aboriginal women who experience incarceration, homelessness, addictions, involvement with Child and Family Services, and family violence. The findings of this study with relation to issues of racism, discrimination, lack of cultural safety, stigma, and fear are also issues experienced by those Aboriginal women

6.3.2 selection bias.

Since this study relied on voluntary non-random sampling of participants, there is the potential for selection bias. The participants who responded to the recruitment poster may differ from the general population of HIV positive Aboriginal women of child bearing age, who live in a Western urban center of Canada. There is the possibility that the women who participated in this study experienced more or less events or had greater or fewer concerns regarding HIV status and pregnancy in their lives than the general study population. The voluntary, non-random selection of participants introduces a bias towards participants who were able to access services at the recruitment agencies making it possibly less representative of the target population.

6.3.3 social desirability bias.

This study relied on participant self-reported behaviors throughout, including fertility intentions and attitudes and beliefs that influence decisions of whether or not to have a child. This creates the potential for inaccurate reporting of events and a social desirability bias. Women reported on what influences their decisions to have children or not given their HIV status but it did not use a decision making theoretical framework such as the Health Belief

Model (Hochbaum, 1958; Rosenstock, 1966) or the Theory of Planned Behavior (Ajzen & Fishbein, 1986) to explain how women arrived at their decisions of whether or not to have a child given their HIV positive status. Thus, determining how HIV positive Aboriginal women of child bearing age arrive at their decision of whether or not to have a child via reputable theory of decision making was not explored in this study.

6.3.4 lack of comparable research.

There continues to be a lack of comparable research regarding this topic of interest and specified population group. A limitation in the majority of studies that examined this specific population group and topic of interest was the general lack of consideration for an understanding of cultural influences on the decisions made by Aboriginal HIV positive women of child bearing age living in a Western urban center of Canada regarding whether or not to have a child given HIV positive status. While there are a few ethnographic studies that examine cultural influences on fertility desire and decisions of HIV positive women to have a child a not given HIV status, (Ko & Muecke, 2005; Oosterhoff et al., 2008; Smith & Mbakwem, 2007) these studies do not provide findings with relation to HIV positive Aboriginal women. Of the Canadian studies that focused on fertility intentions and desires (Loutfy, 2009; Ogilvie et al., 2007), unintended pregnancies (Loutfy, 2011), reproductive counselling (Buharski et al., 2006), perinatal and vertical transmission of HIV in pregnancy (Forbes et al., 2012; Hughes et al., 2009), only two contained findings specific to Aboriginal HIV positive women with regards to vertical transmission statistics for Northern Alberta, general population Aboriginal HIV statistics and reproductive counselling experiences of HIV positive Aboriginal women. Thus, comparison research literature is sparse with regards to the role that HIV status plays in the decision making

processes of HIV positive Canadian Aboriginal women of child bearing age in terms of their reproductive health and decisions to have a child or not.

6.4 Strengths

Despite some limitations, this study has many strengths and provides valuable insight into the reproductive experiences of HIV positive Aboriginal women of child bearing age with regards to the role that HIV status plays in their decision making processes of whether or not to have a child. It highlights the struggles and challenges that HIV positive Aboriginal women who are of child bearing age and who live in Calgary face with regards to making reproductive decisions and it provides recommendations for health care providers with regards to professionalism, cultural safety and future research.

6.4.1 the power of personal stories and history.

As Romanow (2013) suggests, personal histories can draw the lives of Aboriginal women out of obscurity, repair historical records and provide an opportunity for other women to identify with them. The process of gathering information through personal stories and histories is reflective of Aboriginal ways of knowing that stress the importance of personal narratives and story-telling as a means to achieving knowledge through the wisdom gained in experience. Narratives are a part of Aboriginal culture and are passed down from generation to generation. Written knowledge comes from the perspective of the writer, whereas personal histories are the integration of generations of lenses through which the world is viewed. Thus, personal histories can contain valuable knowledge when examined qualitatively that other accounts may not contain. Personal stories can also help explain and supplement what quantitative studies may suggest.

The HIV positive Aboriginal women in this study had never had the opportunity to talk about their reproductive health and the influences that impact on their decisions to have a child or not prior to this study and in essence to share their reproductive health story with anyone. This study provided the opportunity for HIV positive Aboriginal women of child bearing age to rise out of the shadows of living with HIV and describe through narrative, their personal lived experience and history for others to bear witness to, learn from and validate as significant. As the Vancouver/Richmond Health Board (2001) affirms, “women’s voices are an important part of evidence.”

The power of personal histories lies in their ability to facilitate understanding between social classes, bridge knowledge gaps in education, promote knowledge translation across domains of learning, contribute to social justice and connect ethnic and cultural groups through shared learning and understanding. Ellen Clark (1999:2) has written that, “Oral history has been hailed as a means of redressing the class, race, and gender biases of traditional history based on written records. It can be an important tool in recording social change, especially from the viewpoint of disadvantaged or subordinate groups.” By exploring the meaning of events, the experiences and the silence that accompanied the sharing of each participant’s story and personal history, the reader is given a glimpse into the challenges, struggles and triumphs that abound in the lived experience of the HIV positive Aboriginal women of child bearing age who participated in this study. Readers are also afforded understanding of the role that HIV plays in the decision making processes of these women as it pertains to their reproductive health and decisions to have a child or not through their personal stories and histories, something that cannot be captured with quantitative methods but which does illuminate the current epidemiological findings. Thus, a prominent strength of this study is found in the rich

descriptions of the personal stories and histories of the participants that allow the reader to make their own decision regarding the degree and transferability of knowledge with regards to its trustworthiness and utility (Morse, Barrett, Mayan, Olson, & Spiers (2002) .

6.4.2 personal background and relatability.

As a First Nations woman who has had many pregnancies and children I can relate to the perinatal and reproductive experiences of the women in this study. I not only relate to becoming pregnant and having children at a young age, but also to what it feels like to be faced with the possibility of being HIV positive, being of child bearing age and still having a desire to want to have children. While my story is different in that I was exposed to HIV in my early twenties and at the prime of my own child bearing age, but did not contract HIV; however, I can still relate to the fear, shame, embarrassment, and lack of self-worth that the women in this study presented with and spoke about, because for a year while I underwent HIV testing, I had to contend with the possibility that I may be one of many Aboriginal HIV statistics. As a mother, I feared for the safety of my children and yet simultaneously struggled with thoughts of still wanting children and being a good mother, some of the same internal struggles the women in this study alluded to and spoke candidly about.

HIV steals one's voice. It forces one to live their life in the shadows. It is not something that generally, an individual openly discusses and I can relate with the feeling of living with a secret because my personal exposure to HIV caused me lose my voice, become silent, feel like I was living in the shadow of a disease that society was not accepting of which, translated to me as a society that was not accepting of me. When the women in this study spoke of how difficult it was for them to come forward to contact me as a researcher to discuss their reproductive decisions and the factors they considered when deciding whether or not to have a child given

their HIV status, I understood their apprehension in contacting me. I too, when I found out I had been exposed to HIV, was also very apprehensive to share with anyone my experience because of the stigma that is afforded to those who have HIV and I carried my own shame in having allowed myself to be in a situation where HIV was a risk factor. The women in this study shared the same feelings I had experienced but for them, HIV was, and continues to be, an everyday reality. Thus, as a researcher with similar experiences - being Aboriginal, having been pregnant and had children and being exposed to HIV myself during the height of my child bearing period in life - I was able to connect with the women in this study in a manner that allowed me ask probing questions but that also informed me on a very conscious level of those unspoken boundaries that I should not tread upon but rather respect and avoid. Had this study been designed to be more longitudinal in nature where there were multiple opportunities to develop a deeper and more intimate relationship with the women of this study, those unspoken territories of experience may have been able to be explored in more depth; however, this study design did not allow for that. Since I could relate to the experiences of the women in this study, this study was strengthened by my own personal experience and relatability because I was able to respect the boundaries of participants and capture valuable data through the research process while simultaneously being able to afford compassion and respect the human dignity of the women in this study because I understood their experience from a personal perspective and place of relatability.

6.5 Implications

Since the sample size for this study was considerably less than what was expected for data saturation, this study does not allow for generalizations; however, it is helpful in highlighting a) the reproductive experiences of HIV positive Aboriginal women of child bearing age b)

initiating a conversation with regards to what is needed for reproductive health care services to be responsive to the reproductive needs of HIV positive Aboriginal women of child bearing age and it c) provides suggestions for future research directions. Thus, the results and analysis of this study have both implications for the current health care system and for future research.

6.5.1 implications for the current health care system.

The reality of an increasing number of young Aboriginal women having unintended pregnancies and being at high risk of contracting HIV requires a more effective development of education, understanding of fertility intention along the prevention to post-vention continuum of care and creation of an atmosphere of safety, respect and acceptance. Effective reproductive, pregnancy and HIV strategies must no longer be about just preventing pregnancy and managing HIV during pregnancy, they must also be about improving and enhancing the quality of life of HIV positive Aboriginal women and their families throughout their journey.

While all women who live with HIV often experience stigma and prejudice, HIV positive Aboriginal women of child bearing age have a unique experience in that the existing social, economic, political, education, health and cultural inequities they experience are reinforced through racism, animosity, and colonialist attitudes that prevail in society in general, and more specifically, within the health care system, towards them. Subsequently, broader social, economic, political and cultural issues faced by the Aboriginal community as a whole within the health care system needs to be addressed while simultaneously acting upon the immediate needs of HIV positive Aboriginal women of child bearing age. If health care professionals initiate a respectful dialogue about fertility intention this then sets the foundation for an atmosphere of safety, respect and acceptance. By providing comprehensive psychoeducation and options for HIV positive Aboriginal women of child bearing age, the current health care system could be

more responsive to the needs of this specified population thereby enhancing the quality care HIV positive women receive and the service that professionals deliver.

6.5.1.1 assess intention.

In a study conducted by Loufty et al., (2014) more than 95% of HIV positive women of child bearing age reported having a family physician (92%), an HIV specialist (96%) or had seen an obstetrician-gynecologist (45%); however, of those who had care from a family physician, HIV specialist or obstetrician-gynecologist, only 34%, 41% and 37% respectively, reported that these professionals counselled them on pregnancy planning. Additionally, only 221 of the 431 HIV positive study participants (51%) reported having any medical health care professional discuss pregnancy planning with them. Additionally, research has found that “women of reproductive age living with HIV describe an intention to have children at levels approaching those found among the general population and regardless of their clinical HIV status” (Ogilvie et al, 2007). This research combined suggests that there are high desires for women who are HIV positive to have children yet low rates of communication happening between professionals and HIV positive women of child bearing age with regards to pregnancy planning and/or fertility intention and desire.

Conversations regarding reproductive care and pregnancy generally arise out of need, but they can also be stimulated in the absence of conscious health seeking behavior through routine assessment. Just as an individual has routine blood lab work conducted during a visit to a health care professional, so also could fertility desire and intention of HIV positive women of child bearing age be assessed during a visit with a health professional. Using an assessment tool to stimulate conversation, involves HIV positive Aboriginal women in the process of discussion, which can lead to them being involved in the planning and delivery of reproductive and

pregnancy related services. Dialogue and conversation regarding fertility intention and desire for children can also create an atmosphere of safety, respect and acceptance because it creates a forum where HIV positive Aboriginal women of child bearing age can bring forward their voice for fertility intention and desire for children in a manner that does not stigmatize them. Loutfy et al., (2009) developed a fertility desire and intention assessment instrument specifically designed to be used with HIV positive women of child bearing age. Using a fertility and/or intention assessment instrument could be a first step to developing an individualized program for fertility and pregnancy planning for HIV positive Aboriginal women and at the very least it is a tool that can help initiate reproductive, fertility and intention conversations between the health care provider and the HIV positive Aboriginal women of child bearing age.

The women in this study were consistent with current research when they alluded to the importance of health care professionals in recognizing that HIV positive Aboriginal women value their fertility and do desire and intend to have children despite their HIV status. Thus, to maximize the health of these women, health care providers need to discuss fertility intentions, the desire for children, pregnancy plans, healthy pre-conception lifestyle and family planning with all HIV positive Aboriginal women of child bearing age that they serve prior to conception (Loutfy et al. 2009; Loutfy et al, 2012; Loutfy et al., 2014). Using an assessment tool that supports these conversations is but one way to open the door to them. Having open and respectful conversations as a part of any routine HIV health care visit should be mandatory in the development of any national guidelines on pregnancy planning and/or national HIV fertility program initiatives. These conversations provide great benefit for both the health care provider and the patient and may have the effect of promoting happier reproductive, fertility and pregnancy experiences which may lead to better maternal and fetal outcomes.

6.5.1.2 provide psychoeducation.

Providing psychoeducation refers to offering individuals education to help empower them to deal with a particular condition in a way that allows them to optimize resources and improve their quality of life by developing their awareness, sensitivity, and understanding of a particular condition, situation or belief system. The use of psychoeducation tools such as pamphlets, videos, workshops, seminars, lunch and learn gatherings etc. to inform HIV Aboriginal women of child bearing age about how they can have children while managing their HIV could empower women to make informed choices. The use of psychoeducational tools could also help women to understand the complications of HIV and HIV medication treatment on fertility or reproductive health. Intersecting issues such as unresolved addictions, homelessness, family violence, involvement with child and family services and intergenerational trauma could also be addressed within the context of the impact they have on child bearing and rearing processes to help women empower themselves as they encounter these issues. I have heard Don Coyhis, a Mohawk Elder say, “You don’t know what you don’t know, but when you find out what you don’t know, it will change you.” There is such profound truth to this statement that supports the need for continued psychoeducation for HIV positive Aboriginal women of child bearing age to empower them with knowledge.

Psychoeducation initiatives need to go beyond just health related information about reproduction, fertility and HIV. They need to encapsulate the effects of living a colonized experience and teach how patterns of attachment, shame and resilience are passed down from generation to generation. They need to incorporate how racism, discrimination and oppression have silenced the voices of HIV positive Aboriginal women and they need to provide tools for these women to begin to reclaim back their life and story, walk with pride and self-worth, and

empower them to be advocates for themselves and others. Additionally, psychoeducational resources need to be culturally and linguistically appropriate (Quinn & Overbaugh, 2005) and provide accurate, non-judgmental information (Ogilvie et al, 2007) for this population group in order for them to access and apply this information. Thus, professionals need to advocate and develop psychoeducational tools that go beyond just health related educational empowerment and develop educational tools that empower HIV Aboriginal women in areas of social justice, political, economic and cultural realms so that psychoeducational initiatives not only encompass the micro-level realities of these women's lives, but also the macro-level features of their social, political and cultural contexts.

In terms of psychoeducational implications for professionals, participants of this study echoed what current research (Carter et al., 2013; McCall & Pauly, 2012) has suggested in that, health care professionals “should take stock of their own assumptions and incorporate into practice only those values that support women-centered health” (Vancouver/Richmond Health Board, 2001). Women in this study spoke candidly about the judgment, racism, discrimination and negative comments they experienced with health care professionals with regards to their pregnancies, desire for children or reproductive situation. Overcoming these types of oppression and changing those negative aspects of health care culture begins with providing awareness and sensitivity training for health care professionals that involve HIV positive Aboriginal women of child bearing age in the development and delivery of such training programs. Including HIV positive Aboriginal women in the process and delivery of said programs provides self-determination opportunities for these women while gifting professionals with valuable insight into the lived experience of these women. By engaging in sensitivity and awareness training, health care professionals are encouraged to take stock of their language, training, performance

and behavior in order to minimize the possibility that they could traumatize the HIV positive Aboriginal women of child bearing age who is seeking reproductive, pregnancy and/or fertility care. Thus, by engaging in sensitivity and awareness training, a foundation can be laid for creating an atmosphere and professional culture of safety, acceptance and respect for HIV positive Aboriginal women of child bearing age.

6.5.1.3 openness to options.

While research has shown that HIV positive women desire to have children at a rate similar to the general population (Ogilvie et al., 2007), it also indicates that approximately half of all pregnancies in HIV positive women are unintended (Gogna, Pecheny, Ibarlucia, Manzelli & Lopez, 2009; Hubacher, Mavranezouli, & McGinn, 2008; Loutfy et al., 2012). Subsequently, HIV positive women are increasingly becoming pregnant and giving birth (Carvalho, 2010) with rates expected to increase over time as a result of the success of antiretroviral therapy and normalization of pregnancy for HIV positive women (Shannon et al., 2008). While all of the participants in this study desired children, none of them reported that their pregnancies were planned which is consistent with the research findings. HIV positive Aboriginal women of child bearing age have the highest risk of unintended pregnancy as they have a greater amount of significant correlates of unintended pregnancy present in their everyday lives – being of younger age, unmarried, lower income and less education which translates into poor maternal and fetal outcomes (Loutfy et al., 2012). Thus, it is important for health care professionals to target HIV positive Aboriginal women at higher risk of unintended pregnancy and provide options that meet these women where they are at because unintended pregnancy does not necessarily equate to unwanted pregnancy.

Options, encouraged by health care professionals, that support healthy reproductive lifestyles, fertility desires and intentions and pregnancy for HIV positive Aboriginal women of child bearing age are themes that emerged out of this study and that have been echoed by women and researchers of other studies (Carter et al., 2013; Loutfy et al., 2012; Ogilvie et al., 2007; Ship & Norton, 2000). Options need to include: a) providing contraceptive care to prevent unintended pregnancies that takes into account the interaction of HIV medication and types of contraception paying attention to changes in women's bodies as they age; b) providing flexible, adjusting care for the different needs and stages of the HIV positive Aboriginal woman's life which includes meeting women where they are at and working with multiple overlapping needs simultaneously as they arise in their experience with living with HIV; c) providing financially accessible alternative and complementary services such as personal counselling, family planning and counselling, routine consultation with nutritionists, ability to access Elders, child care and travel and transportation support d) develop HIV positive Aboriginal specific programming and services that includes fertility, reproductive, pregnancy and family planning conversations built into routine visits with both HIV positive Aboriginal women and men; e) providing education and supports the use of antiretroviral medications prior to pregnancy and throughout pregnancy to increase positive maternal and fetal outcomes and reduce vertical transmission rates f) support and encourage HIV positive Aboriginal women to pursue their fertility desires while helping them to create a healthy and sustainable environment in which to raise their desired offspring g) support HIV positive Aboriginal women in maintaining the wholeness of their bodies where the suggestion for tubal ligation is a part of the options presented but is not the option that is pushed as the only way to avoid future unintended pregnancy.

Providing options for HIV positive Aboriginal women that allows them to choose the type of care and provider, based on the presentation of accurate, non-judgmental information by well informed and culturally sensitive and aware professionals, that best suits their reproductive and fertility needs and desires creates an atmosphere of safety, respect and acceptance while developing self-determination opportunities through tailored programming for this specified population. A professional culture where options that support the pregnancy, fertility intentions and desires of HIV positive Aboriginal women, needs to become the norm rather than the default. Professionals need to take into account when discussing options with HIV positive Aboriginal women of child bearing age, historical trauma and effects of colonization and respect individual choice and Aboriginal cultural practice (Cain et al., 2013) and beliefs regarding the role of children and fertility in the lives of Aboriginal women.

6.5.1.4 provide multidisciplinary integration and coordination of services.

All of the HIV positive Aboriginal women in this study presented with and described how intersecting and complex issues such as racism, discrimination, stigma, isolation, depression and anxiety, homelessness, transient lifestyle, street life involvement, family violence, involvement with child and family services, comorbidity of illness, alcohol and drug use, and a lack of education and employment contributed to their situation and also influenced their decision of whether or not to have a child given their HIV positive status. The intersecting and complex issues that the women of this study described are also the experiences of many of other HIV positive Aboriginal women in current research literature (Bucharski et al., 2006; Cain et al., 2013; Carter et al., 2013; McCall & Pauly, 2012; McCall et al., 2009; McKay & McNabb, 2006; Mill, 1997; Neron & Roffey, 2000; Ship & Norton, 2000). Thus, complex and intersecting issues that complicate and challenge the lives of HIV positive Aboriginal women of child

bearing age were not only issues for the women of this study, but also appear to be issues, to one degree or another, for all HIV positive Aboriginal women who have participated in peer reviewed and published research studies. As such, health care professionals need to address these intersecting and complex issues with multidisciplinary integration and coordination of services when delivering care and treatment to HIV positive Aboriginal women of child bearing age as it pertains to reproductive, fertility and pregnancy care.

To manage the complex and intersecting issues that arise in the lives of HIV positive Aboriginal women of child bearing age requires “the multidisciplinary integration and coordination of an array of services such as primary care, psychiatry, HIV specialists, STI specialists, social workers, outreach workers, pharmacists, ophthalmologists, gynecologists, fertility specialists, pediatricians and many others. Acquiring stable housing, employment, nutritious food, reliable transportation, disability benefits, financial security, child care and other supportive services may also be critical” (Carter et al., 2013) to promoting and maintaining the reproductive, fertility and pregnancy health of HIV positive Aboriginal women. Addressing cultural and spiritual needs is also a unique addition to providing collaborative care for these women and addressing their spiritual and cultural needs.

Without addressing the intersectionality present in the lives of HIV positive Aboriginal women of child bearing age, these women face multiple challenges; doing so without support which translates into needs being unmet. Thus, by delivering multiple services at one particular site or through integrated case management via a network of services working in partnership, the intersecting and complex issues that are a part of the lives of HIV positive women can be addressed and the fragmentation of services and care they currently experience can be reduced and/or eliminated.

6.5.2 implications for future research.

HIV positive Aboriginal women have been inadequately represented in HIV/AIDS research and there is a critical need to address the intersecting issues of culture, ethnicity and gender in future research to effectively respond to HIV positive Aboriginal women in practice. Future research implications arising out of this study that need to be considered in order to advance the current knowledge of the role that HIV status plays in the decision making processes of HIV positive Aboriginal women in terms of their reproductive health and their decisions to have a child or not include, but are not limited to: barriers to study recruitment; a more in depth exploration of complex and intersecting issues such as comorbidity of illnesses, substance use, addictions and homelessness, poverty, stigma and discrimination, intergenerational trauma impacts, involvement of child and family services and interpersonal relationships and intimacy patterns of HIV positive Aboriginal women of child bearing age; longitudinal study project considerations; and incorporation of current theories and frameworks to explain findings. Additionally, quantitative data measurements regarding health status of participants (i.e. viral load at time of pregnancy and child birth, use of medications during pregnancy to prevent vertical transmission and/or progression of HIV, confirmed STIs and their interplay with health status and/or treatment, and/or other health related measures), results from assessment tools such as the HIV Pregnancy Planning Questionnaire (Loutfy et al., 2009) that measures pregnancy intention, desire and actions take to become pregnant and the “concern with public attitudes about people with HIV” subscale of the Berger HIV Stigma Scale (Berger, Ferrans & Lashley, 2001) are all quantitative data avenues that can be used to support and enhance qualitative findings of future research in this domain.

6.5.2.1 study recruitment.

Recruitment of study participants for future research endeavors needs to consider the safety of participants in terms of recruitment strategies that could leave potential participants feeling vulnerable to stigmatization and psychological harm. All of the participants in this study were recruited through posters placed in participating agencies where HIV positive Aboriginal women of child bearing age were most likely to present for sexual/reproductive and/or HIV health care needs or broader social (housing, food, counselling etc.) needs. Having a poster accessible in the waiting rooms of these agencies served as a deterrent for potential participants because it created vulnerability to public stigmatization as participants were required to remove a strip of paper from the poster that had the researcher's contact information on it while in view of others. Having noticed that this was a barrier to recruitment, albeit late in the recruitment phase of this study, posters were created that could be placed in more private rooms (exam, counselling and private office spaces) where potential participants could remove the contact information strip with more privacy, avoiding potential perceived stigmatization by others. Placing posters in more private spaces did increase the recruitment of participants by 50% and so it is recommended that future research endeavors that have an HIV focus consider the balance between publicity of a study for recruitment purposes and the perceived stigmatization by potential participants that posters displayed in public areas may afford which could result in decreased participant recruitment.

6.5.2.2 exploration of complex and intersecting issues.

For HIV positive Aboriginal women of child bearing age, complex and intersecting issues such as poverty, homelessness and/or lack of affordable housing, poor nutrition, substance abuse and addictions, family violence, isolation, incarceration, involvement

with child and family services, child stressors, psychological distress, racism and discrimination (Cain et al, 2013; Carter et al., 2013; Carvalhal, 2010; Greene et al., 2010; McCall & Pauly, 2012; McCall et al., 2009 ; McKay & McNabb, 2006; Mill, 1997; Neron & Roffey, 2000; Ship & Norton, 2000; Wagner et al., 2010) are all factors that impact on decisions of whether or not to have a child given an HIV positive status. Future research needs to examine how each of these intersecting factors influence HIV status and health and the decision to have a child or not and provide recommendations for professionals in areas of social services, justice, mental health, economics and policy with regards to how to support this specified population group with overcoming obstacles and barriers imbedded within these intersecting and complex issues. This study as well as others only touch upon the fact that these intersecting and complex issues exist for HIV positive Aboriginal women of child bearing age, but there are no studies that go beyond acknowledging their existence to really understand the impact that these complex issues have on the fertility intentions, desires or reproductive care for these women. Thus, future research should expand upon how complex and intersecting issues inform fertility and reproductive decision making processes of HIV positive Aboriginal women of child bearing age to illuminate and the develop further the results of the data obtained in this study.

6.5.2.3 longitudinal study project.

This study only grazed the surface of understanding what contributes to the decision making experience of HIV Aboriginal women of child bearing age when it comes to them making a decision of whether or not to have a child given their HIV positive status. To gain more in depth and personal accounts of experience, a longitudinal study project should be undertaken where HIV positive Aboriginal women are given multiple opportunities to discuss their experience and the researcher is afforded multiple moments to develop a deeper connection

and relationship with the participants. Affording multiple opportunities for sharing allows for the participants to reflect on their experience in between interviews and bring what they might have felt they missed in a previous interview to a later interview. This alone would increase the depth of data. With longitudinal projects, there is also the ability to focus on a particular aspect of the interview contributing to greater depth of sharing of experience rather than covering a multitude of experiences within one sitting. Thus, with a longitudinal project, the researcher is better able to establish a trusted relationship with the participant to where the participant can begin to feel more comfortable discussing issues of vulnerability and the researcher feels more comfortable probing those issues that require increased vulnerability and exposure of the participant's life and experience leading to greater depth of data obtained and safety for participant.

A longitudinal study project would also allow for more of the complex and intersecting issues that HIV positive Aboriginal women of child bearing age experience to be explored, contributing to a more comprehensive understanding of how these women arrive at their decisions to have a child or not given their HIV status. It would also allow participants the ability to have their voice heard on a number of issues that influence the topic of interest. Additionally, a longitudinal study project could have more of a healing effect for participants rather than just an exposure of their personal experience for research purposes. Since this was the first time any of the participants in this study spoke about their reproductive, fertility and/or pregnancy experience with anyone in a candid and personal way ever, it ended up being a forum where for the first time these women came face to face and verbalized those factors that influenced their decision to have a child or not given their HIV positive status. For all of these women, it was also the first time they had shared with a complete stranger how intersecting

issues such as family violence, alcohol and drug addiction, homelessness, having children in care, feeling stigma, discrimination and shame contributed to their decision of whether or not to have a child. When participants open up about some of the darkest times of their lives coupled with some of the most joyous times, it leaves the researcher in a place of privileged voyeurism. With a longitudinal project, privileged voyeurism is reduced and in its place, sharing that results in participant healing as a potential outcome of the research.

6.5.2.4 use of theory and framework.

In order to expand understanding of the mechanisms underlying “*how*” HIV positive Aboriginal women of child bearing age make decisions about whether or not to have a child given their HIV status, decision making theories need to be incorporated into future research initiatives. Theories such as the Theory of Planned Behavior (Ajzen & Madden, 1986; Fishbein & Ajzen, 1975), implementation intentions (Gollwitzer, 1993; Gollwitzer 1999), the Health Belief Model (Hochbaum, 1958; Rosenstock, 1966), and the Prospect Model (Kahneman & Tversky, 1979) are all theoretical frameworks that could be applied to develop a greater understanding of the “*how*” of decision making that occurs with this population group. To date, no such research has been conducted with regards to “*how*” HIV positive Aboriginal women of child bearing age make decisions about whether or not to have a child based on current decision making theory knowledge. Thus, using a theory to explain the mechanisms of their decision making would contribute to the understandings and expand on the knowledge gained in this study.

Finally, conducting future research using conceptual frameworks that examine the impact of services for women living with HIV, such as the one developed by the Vancouver/Richmond Health Board (2001) that places the context of the lives of HIV positive women within

dimensions of health, determinants of health and pillars of services, can help to establish standards for services and facilitate evaluation of services that are designed to meet the needs of HIV Aboriginal women of child bearing age. Use of frameworks can also assist in contributing to the development of a more comprehensive and appropriate means for recommending care of HIV positive Aboriginal women of child bearing age and they can provide a basis for consistency and continuity of care for this specified population group regardless of whether services are delivered in an urban, rural or reserve setting. Thus, by incorporating frameworks that examine the impact of services for HIV positive Aboriginal women of child bearing age, services currently being used can be assessed for appropriateness, sensitivity and effectiveness which, would also supplement the finding of this study.

6.6 Recommendations

While advances in medical drug treatment and behavioral practices regarding breast feeding have reduced vertical transmission of HIV from mother to child, there still remains concern regarding the reproductive, fertility and pregnancy journey that HIV positive Aboriginal women of child bearing age are afforded under the current system of care. HIV positive Aboriginal women of child bearing age face a wide range of barriers in maximizing their reproductive health and realizing their fertility intentions and desires. Sadly, many of these barriers are embedded in the very structures to which these women turn for assistance. Racism, discrimination, colonialism, stigma, and inappropriate care work to impede the gains made through medical technology advancements and research. Thus, wider attention to understanding the lived experience of HIV positive Aboriginal women of child bearing age, the limitations of the current system and the pursuit of continued research needs to be a priority for future

endeavors if the health and wellbeing of HIV positive Aboriginal women of child bearing age is to be improved.

In order to better understand the experience of HIV positive Aboriginal women of child bearing age who are considering having a child or not and the factors that influence those decisions, additional research is required. A wide ranging research agenda, qualitative and quantitative addressing the following gaps in current knowledge should be undertaken: application of theory to determine the decision making processes used by HIV positive Aboriginal women of child bearing age; the impact of intersecting and complex issues; service utilization rates; service satisfaction and evaluation by both professionals and clients; influence of generational relationships; peer influences and self-esteem. Priority research must be given to Aboriginal female youth and women in order to identify exact barriers to safer sexual activity, family planning, early age pregnancy, fertility intentions and desires and HIV risk factors. Issues of perinatal transmission must continue to be addressed with attention paid to understanding those behaviors and attitudes that would reduce HIV transmission rates to the fetus and avoid unintended pregnancies. Additionally, future research must focus on addressing the social determinants and risk factors associated with Aboriginal women contracting HIV and becoming pregnant. Inequalities and inequities in current care and services afforded HIV positive Aboriginal women of child bearing age require highlighting and recommendations to address them. There is no published research literature that is specific to Aboriginal women living in Aboriginal communities or on reserve. Where literature exists that explores reproductive, fertility intentions/desires and pregnancy experiences of HIV positive Aboriginal women it does not examine how decisions to have a child or not given HIV status, or the reproductive and pregnancy experience changes with age and across the life span. Thus, there are numerous

avenues that future research could take in order to provide a more comprehensive understanding of the experience of HIV positive Aboriginal women of child bearing age with regards to how they make decisions about having a child or not given their HIV status.

Better coordination of current services, sharing of resources and information and cooperation between all levels of government and service delivery agents must become a priority to address the intersecting and complex issues of HIV positive Aboriginal women as well as the ongoing structural abuses and oppression that HIV positive Aboriginal women face when making decision about whether or not to have a child. Better overall information sharing, coordination of programs and services, collaboration between services, and integrating HIV positive Aboriginal women of child bearing age in the planning, delivery and evaluation of programs and services via representation on boards or steering committees or through key informant surveys and/or exit interviews must be implemented if current and future services are to be effective and utilized. In this manner, expert knowledge from diverse, multidisciplinary professionals coupled with input from HIV positive Aboriginal women who utilize services and have lived the experience can bring about real change and improve the quality of life for HIV positive Aboriginal women of child bearing age.

Factors that influence the creation of an atmosphere of safety, respect and acceptance must be strengthened. This involves creating inclusive, welcoming and non-competitive spaces where HIV positive Aboriginal women feel comfortable sharing potentially sensitive and painful issues or experiences and where routine non-judgmental discussions regarding fertility intentions and desires can be realized. The prolonged history of discriminatory practices and attitudes and acceptance of racism within the professional structures and culture of professionals must be dealt with if quality reproductive and fertility care for HIV positive Aboriginal women is to be

realized. Cultural sensitivity, awareness and safety through psychoeducation and direct experiential learning initiatives with HIV positive Aboriginal women must be created not only within the boundaries of professional culture and practice but also within the everyday lives of individuals. In creating an atmosphere of safety, respect and acceptance, providers are encouraged to support HIV positive Aboriginal women's choices and provide options that help them to realize their reproductive, fertility and pregnancy intentions and desires, based on their own unique circumstances, while also acknowledging their personal struggles and validating their concerns.

Chapter 7 Conclusions

HIV positive Aboriginal women of child bearing age present with unique experiences and circumstances that are not present for members of mainstream society. They experience stigma and discrimination that other HIV positive individuals do, but is made more intense by the racism, oppression and colonization that Aboriginal people as a whole have had to endure over the generations. This study is but one of a few efforts to understand the influences that exist for HIV positive Aboriginal women of child bearing age, with respect to making decisions about whether or not to have a child given their HIV status.

As Health Canada (1998:58) states:

What differentiates discrimination against Aboriginal people living with or affected by HIV/AIDS is the *history of oppression and social disintegration* that has been meted out to Aboriginal, Metis and Inuit in Canada. This history has resulted in a maze of interconnected spiritual, communal, social, economic, and political problems that strain the resources, the will, and the spirit of Aboriginal communities. Therefore, improving the health and wellbeing of Aboriginal people means addressing the causes of cultural dislocation, ruptures within families, violence within families substance use, chronic poverty, unemployment, poor housing and utilities, environmental destruction, lack of information and services, and lack of control over resources and programming.

The HIV positive Aboriginal women that were profiled in this study are primary examples of how a history of oppression and social disintegration can impact on the here and now lives and the reproductive health of HIV positive Aboriginal women. Women who participated in this study experienced all of the situations that Health Canada suggest need to be addressed in order for the health and wellbeing of HIV positive Aboriginal women to improve. To date, little has been done to address the causes that manifest in complex and intersecting realities for HIV positive Aboriginal women of child bearing age; however, illuminating the experience of these women through qualitative studies such as this one,

provides validation for these women's experiences, ensures a forum for their voice and creates a window of opportunity for them to be able to step out of the shadows of living with HIV and share with a broader audience their lived experience and the importance of *evidencing* that experience.

Neither HIV nor the birth rate for Aboriginal women has decreased since the Royal Commission on Aboriginal Peoples Report (RCAP) was released in 1996 and if anything, birth rates have risen alongside risk for contracting HIV intensifying. Now is the time where it is fundamental that HIV positive Aboriginal women of child bearing age engage in determining the developing relationship they will have with urban centers of care, especially as it pertains to their reproductive, fertility and pregnancy journey. This study is a step towards helping HIV positive Aboriginal women explore and contribute to the development of that relationship. With continued research initiatives and implications from this study considered by professionals for implementation and action, the relationship that HIV positive Aboriginal women of child bearing age have with themselves and the health care professionals they encounter can be strengthened and enhanced. In doing so, reproductive, fertility and pregnancy care for HIV positive Aboriginal women can become more effective through the increased utilization of appropriate services and the quality of life, health and wellbeing of HIV positive Aboriginal women, their children, families and communities can be maximized.

References

- Aboriginal Nurses Association of Canada. (1996). *HIV/AIDS and its impact on aboriginal women in Canada*. Ottawa, ON: Health Canada.
- Acoose, Janice. (1995). *ISKWEWAK- Kah' Ki Yaw Ni Wahkomakanak*. Women's Press, Toronto.
- Adelson, N. (2005). The embodiment of inequity: Health disparities in aboriginal Canada. *Canadian Journal of Public Health, 96*(S2), S45-S61. Retrieved from <http://journal.cpha.ca/index.php/cjph/article/view/1490/1679>
- Ajzen, I., & Madden, T.J. (1986). Prediction of goal-directed behavior: Attitudes, intentions and perceived behavioral control. *Journal of Experimental Social Psychology, 22*(5), 453-474. doi:10.1016/0022-1031(86)90045-4
- Aka-Dago-Akribi H., Du Lou, A.D., Msellati, P., Dossou, R., & Welffens-Ekra., C. (1999). Issues surrounding reproductive choice for women living with HIV in Abidjan, Cote d'ivoire. *Reproductive Health Matters, 7*(13), 20-29. doi:10.1016/S0968-8080(99)90108-9
- Alberta Health, Surveillance and Assessment. (2015). *Notifiable sexually transmitted infections and HIV – 2013 annual report*. Edmonton, AB: Government of Alberta. Retrieved from <http://www.health.alberta.ca/documents/STI-ND-Annual-Report-2013.pdf>
- Anderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K., & Easterbrook, P. (2009). Coping with HIV: Caribbean people in the United Kingdom. *Qualitative Health Research, 19*, 1060-1075. doi:10.1177/1049732309341191
- Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L. (2002). *Handbook of ethnography*. Thousand Oaks, CA: Sage Publications Inc.

- Barash, A., Safford, M.M., Catalanotto, F.A., Fine D.H., & Katz, R.V. (2000). Oral soft tissue manifestations in HIV-positive vs. HIV negative children from an inner city population: A two-year observational study. *Pediatric Dentist*, 22(3), 215-220. Retrieved from https://www.researchgate.net/profile/Frank_Catalanotto2/publication/12471124_Oral_soft_tissue_manifestations_in_HIV-positive_vs._HIVnegative_children_from_an_inner_city_population_A_twoyear_observational_study/links/0046353c6b904f39a6000000.pdf
- Barlow, K., Loppie, C., Jackson, R., Akan, M., MacLean, L., & Reimer, G. (2008). Culturally competent service provision issues experienced by aboriginal people living with HIV/AIDS. *Pimatisiwin*, 6(2), 155-180. Retrieved from <http://pubmedcentralcanada.ca/pmcc/articles/PMC2936585/pdf/nihms1069.pdf>
- Bedimo-Rung, A.L., Clark, R.A., Dumestre, J., Rice, J., & Kissinger, P. (2005). Reproductive decision making among HIV infected women. *Journal of the National Medical Association*, 97(10), 1403-1410. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594717/pdf/jnma00299-0093.pdf>
- Benoit, C., Carroll, D., & Chaudry, M. (2003). In search of a healing place: Aboriginal women in Vancouver's downtown eastside. *Social Science and Medicine*, 56(4), 821-833. Retrieved from <http://docplayer.net/359689-In-search-of-a-healing-place-aboriginal-women-invancouver-s-downtown-eastside.html>
- Berger, B.E., Ferrans, C.E., & Lashley, F.R. (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in Nursing Health*, 24(6), 518-529. doi:10.1002/nur.10011

- Bing, E., Burnham, M., Longshore, D., Fleishman, J.A., Sherbourne, C.D., Turner, L.A.S.,...& Shapiro, M. (2001). Psychiatric disorders and drug use among human immunodeficiency virus-infected adults in the United States. *Archives of General Psychiatry*, *58*(8), 721-728. doi:10.1001/archpsyc.58.8.721
- Bishop, B. J., Colquhoun S. D., & Johnson J. (2006). Psychological sense of community: An Australian Aboriginal experience. *Journal of Community Psychology*, *34*, 1-7. doi:10.1002/jcop.20079
- Bishop, B.J., Vicary, D.A, Mitchel, J.R., & Pearson, G. (2012). Aboriginal concepts of place and community and their meaning in mental health. *The Australian Community Psychologist*, *24*(2), 26-42. Retrieved from <https://groups.psychology.org.au/Assets/Files/ACP-24-2-Bishop.pdf>
- Blake, B.J., Jones Taylor, G.A., Reid, P., & Kosowski, M. (2007). Experiences of women in obtaining human immunodeficiency virus testing and healthcare services. *Journal of American Academy of Nurse Practitioners*, *20*, 40-46. Retrieved from http://www.academia.edu/21638096/Experiences_of_women_in_obtaining_human_immunodeficiency_virus_testing_and_healthcare_services
- Blanche, S., Tardiwu, M., Duliege, A., & Rouzious, C., Le Deist, F., Fukunaga, K.,...Griscelli, C. (1990). Longitudinal study of 94 symptomatic infants with perinatally acquired HIV-1 infection. Evidence for a bimodal expression of clinical and biological symptoms. *American Journal of Disease in Childhood*, *144*(11), 1210-1215. doi:10.1001/archpedi.1990.02150350042021
- Binder, I. (2004). Living with HIV. *Canadian Women Studies*, *24*(1), 55-58. Retrieved from <http://cws.journals.yorku.ca/index.php/cws/article/view/6178/5366>

- Bourassa, C., McKay-McNabb, K., & Hampton, M. (2004). Racism, sexism and colonialism: The impact on the health of aboriginal women in Canada. *Canadian Woman Studies*, 24(1), 23-29. Retrieved from <http://cws.journals.yorku.ca/index.php/cws/article/view/6172/5360>
- Browne, A. (2007). Clinical encounters between nurses and First Nations women in a western Canadian hospital. *Social Science and Medicine*, 64(10), 2165-2176. doi:10.1016/j.socscimed.2007.02.006
- Browne, A., Fiske, J., & Thomas, G. (2000). *First Nations women's encounters with mainstream health care services and systems*. Vancouver, BC: British Columbia Center of Excellence for Women's Health. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.530.772&rep=rep1&type=pdf>
- Browne, A.J., Varcoe, C., Smye, V., Reimer-Kirkham, S., Lynam, M.J., & Wong, S. (2009), Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nursing Philosophy*, 10, 167-179. doi:10.1111/j.1466-769X.2009.00406.x
- Bucharski, D., Reutter, L.I., & Ogilvie, L.D. (2006). "You need to know where we're coming from": Canadian aboriginal women's perspectives on culturally appropriate HIV counselling and testing. *Health Care for Women International*, 27(8), 723-747. doi:10.1080/07399330600817808
- 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. doi:10.1177/1049732313482525
- Canada., Erasmus, G., & Dussault, R. (1996). *Report of the Royal Commission on Aboriginal Peoples*. Ottawa, ON: The Commission. Retrieved from <https://qspace.library.queensu.ca/handle/1974/6874>

- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. December 2010. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Carr, R.L., & Gramling, L.F. (2005). Stigma: A health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care, 15*(5), 30-39. doi:10.1177/1055329003261981
- Carter, A.J., Bourgeois, S., O'Brien, N., Abelsohn, K., Tharao, W., Greene, S., ...Loutfy, M.R. (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), 17433. doi:10.7448/IAS.16.1.17433
- Carvalho, A. (2010). Are women a different group of HIV-infected individuals? *Archives Women's Mental Health, 13*, 181-183. doi:10.1007/s00737-010-0167-1
- Catz, S.L., Gore-Felton, C., & McClure, J.B. (2002). Psychological distress among minority and low-income women living with HIV. *Journal of Behavioral Medicine, 28*, 53-60. doi:10.1080/08964280209596398
- Chen, J.L., Phillips, K.A., Kanouse, D.E., Collins, R.L., & Mie, A. (2001). Fertility desires and intentions of HIV-positive men and women. *Family Planning Perspectives, 33*(4), 144-152. doi:10.2307/2673717
- Cheung, A.M., Hwang, S.W. (2004). Risk of death among homeless women: a cohort study and review of the literature. *Canadian Medical Association Journal, 170*(8), 1243-1247. doi:10.1503/cmaj.1031167

- Chrisjohn, R. (1991). Faith misplaced: Lasting effects of abuse in a First Nations community. *Canadian Journal of Native Education*, 18(2), 161-197. Retrieved from <http://eric.ed.gov/?id=EJ441973>
- Clark, E. (1999). The pursuit of truth in oral history. *The Journal of the Australian Association for Social Research*. In Romanow, C. (2003). *HIV/AIDS and aboriginal women in Saskatchewan: Colonization, marginalization and recovery*. (Master's thesis). Retrieved from <http://www.collectionscanada.gc.ca/obj/s4/f2/dsk3/SSU/TC-SSU-12242003223027.pdf>
- Clarke, H., Joseph, R., Deschamps, M., Hislop, G., Band, P., & Atleo, R. (1998). Reducing cervical cancer among First Nations women. *The Canadian Nurse*, 94(3), 36-41. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/9633320>
- College of Nurses of Ontario. (2005). *Practice guideline: Culturally sensitive care* (Publication No. 41040). Retrieved from http://www.cno.org/globalassets/docs/prac/41040_culturallysens.pdf
- Conrad, Peter. (1989). *The social meaning of AIDS. Perspectives in medical sociology*. Chicago, IL: Waveland Press Inc.
- Cooper, D., Harries, J., Meyer, L., Orner, P., & Bracken, H. (2007). "Life is still going on": Reproductive intentions among HIV-positive women and men in South Africa. *Social Science and Medicine*, 65(2), 274-283. doi:10.1016/j.socscimed.2007.03.019
- Craft, S.M., Delaney, R.O., Bautista, D.T., & Serovich, J.M. (2007). Pregnancy decisions among women with HIV. *AIDS and Behavior*, 11(6), 927-935. doi:10.1007/s10461-007-9219-6
- Creswell, J.W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications Inc.

- Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage Publications Inc.
- Creswell, J.W. (2012). *Educational research: Planning, conducting and evaluating quantitative and qualitative research*. (4th ed.). Boston, MA: Pearson Education Inc.
- Croft, N.M., Jacob, A.J., & Godman, M.J., Boon, N.A., & Mok, J.Y.Q. (1993). Cardiac dysfunction in pediatric HIV infection. *Journal of Infectious Disease*, 26(2), 191-194.
doi:10.1016/0163-4453(93)92950-2
- Csete, J. (2005). *Vectors, vessels and victims: HIV/AIDS and women's human rights in Canada*. Toronto, ON: Canadian HIV/AIDS Legal Network. Retrieved from
<http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Women+and+HIV+-+Rpt+-+Womens+Rights+-+ENG.pdf>
- Cunningham, W.E., Hays, R.D., Williams, K.W., Beck, K.C., Dixon, W.J., & Shapiro, M.F. (1995). Access to medical care and health-related quality of life for low-income persons with symptomatic human immunodeficiency virus. *Medical Care*, 33(7), 739-754.
Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/7596212>
- Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. *Journal of Community Applied Social Psychology*, 16, 418-425.
doi:10.1002/casp.900
- Duran, B., Butlerys, M., Iralu, J., Graham, C., Edwards, A., & Harrison, M. (2000). American Indians with HIV/AIDS: Health and social service needs, barriers to care, and satisfaction with services among a Western tribe. *American Indian Alaskan Native Mental Health Research* 9(2), 22-36. Retrieved from
https://www.researchgate.net/publication/12053077_American_Indians_with_HIVAIDS

Health_and_social_service_needs_barriers_to_care_and_satisfaction_with_services_among_a_western_tribe

Duran, E., & Duran, B. (1995). *Native American post-colonial psychology*. Albany, NY: State University of New York Press.

Easton, Beth. (1992). Women & AIDS. *Healthsharing*, 12-19.

Emler, C.A. (2006). An examination of the social networks and social isolation in older and younger adults living with HIV/AIDS. *Health and Social Work*, 31(4), 299-308.
doi:10.1093/hsw/31.4.299

Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.

Fisher, B., Hovell, M., Hofstetter, C.R., & Hough, R. (1995). Risks associated with long-term homelessness among women: battery, rape and HIV infection. *International Journal of Health Services*, 25, 351-369. Retrieved from
<https://www.ncbi.nlm.nih.gov/pubmed/7622323>

Fisher, J.D., Cornman, D.H., Osborn, C.Y., Amico, K.R., Fisher, W.A., & Friedland, G.H. (2004). Clinician-initiated HIV risk reduction intervention for HIV-positive persons: Formative research, acceptability, and fidelity of the options project. *Journal of Acquired Immune Deficiency Syndrome*, 37(S2), S78-S87. Retrieved from
<https://www.ncbi.nlm.nih.gov/pubmed/15385903>

Fisher, J.D., Fisher, W.A., Cornman, D.H., Amico, R.K., Bryan, A., & Friedland, G.H. (2006). Clinician-delivered intervention during routine clinical care reduces unprotected sexual behavior among HIV infected patients. *Journal of Acquired Immune Deficiency Syndrome*, 41, 44-52. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/16340472>

- Fiske, J., & Browne, A. (2006). Aboriginal citizen, discredited medical subject: Paradoxical construction of subjectivity in Canadian health care policies. *Policy Sciences*, 39(1), 91-111. doi:10.1007/s11077-006-9013-8
- Forbes, J.C., Alimenti, A.M., Singer, J., Brophy, J.C., Bitnun, A., Samson, L.M., ...Read, S.E. (2012). A national review of vertical HIV transmission. *AIDS*, 26, 757-763. doi:10.1097/QAD.0b013e328350995c
- Foucault, Michel. (1984). *The Foucault reader*. New York, NY: Pantheon Books
- Furniss, E. (1999). *The burden of history: Colonialism and the frontier myth in a rural Canadian community*. Vancouver, BC: University of British Columbia Press.
- Gahagan, J., & Loppie, C. (2001). Counting pills or counting on pills? What HIV+ women have to say about antiretroviral therapy. *Canadian Woman Studies*, 21(2), 118-123. Retrieved from cws.journals.yorku.ca/index.php/cws/article/download/12610/11693
- Gielen, A.C., McDonnell, K.A., Burke, J.G., & O'Campo. (2000). Women's lives after HIV positive diagnosis: Disclosure and violence. *Maternal Child Health Journal*, 4(2), 111-120. doi:10.1023/A:1009522321240
- Goedert, J., (2000). The epidemiology of acquired immunodeficiency syndrome malignancies. *Seminars in Oncology*, 27(4), 390-401. Retrieved from https://www.researchgate.net/publication/12371237_The_epidemiology_of_acquired_immunodeficiency_syndrome_malignancies
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall

- Gogna, M.L. Pecheny, M.M. Ibarlucia I., Manzelli, H., & Lopez, S.B. (2009). The reproductive needs and rights of people living with HIV in Argentina: health service users' and providers' perspectives. *Social Science and Medicine*, *69*, 813-820.
doi:10.1016/j.socscimed.2009.06.002
- Gollwitzer, P.M. (1993). Goal achievement: The role of intentions. In W. Stroebe & M. Hewstone (Eds). *European Review of Social Psychology* (Vol. 4, 141-185). Chinchester, England: Wiley.
- Gollwitzer, P.M. (1999). Implementation intentions: Strong effects of simple plans. *American Psychologist*, *54*, 493-503. doi:10.1037/0003-066X.54.7.493
- Greene, S., Tucker, R., Rourke, S.B., Monette, L., Koornstra, J., Sobata, M.,...Watson, J. (2010). "Under my umbrella": The housing experiences of HIV positive parents who live with and care for their children in Ontario. *Archives Women's Mental Health*, *13*, 223-232.
doi:10.1007/s00737-009-0090-5
- Health Canada. (1998). Situational Analysis: A background paper on HIV/AIDS and aboriginal people. Ottawa, ON: Canadian HIV/AIDS Clearinghouse Canadian Public Health Association
- Herek, G.M., & Capitano, J.P. (1999). AIDS stigma and sexual prejudice. *American Behavioral Scientist*, *42*, 1130-1147. Retrieved from
http://psc.dss.ucdavis.edu/faculty_sites/rainbow/html/abs99_sp.pdf
- Herek, G.M., Capitano, J.P., & Widaman, K.F. (2002). HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health*, *92*, 371-377. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447082>
- Herek, G.M., Capitano, J.P., & Widaman, K.F. (2003). Stigma, social risk and health policy:

- Public attitudes towards HIV surveillance polices and the social construction of illness. *Health Psychology*, 22, 533-540. doi:10.1037/0278-6133.22.5.533
- Hirschfeld, R.M.A., Kosier, T., Keller, M.B., Lavori, P.W., & Endicott, J. (1989). The influence of alcoholism on course of depression. *Journal of Affective Disorders*, 16(2), 151-158. doi:10.1016/0165-0327(89)90069-4
- Hochbaum, G. (1958). *Public participation in medical screening programs*. (DHEW Publication No. 572, Public Health Service. Washington, DC: U.S. Government Printing Office. Retrieved from <http://www.worldcat.org/title/public-participation-in-medical-screeningprograms-a-socio-psychological-study/oclc/9471787>
- Hubacher, D., Mavranouzouli, I., & McGinn, E. (2008). Unintended pregnancy in sub-Saharan Africa: magnitude of the problem and potential role of contraceptive implants to alleviate it. *Contraception*, 78(1), 73-78. doi: 10.1016/j.contraception.2008.03.002
- Hughes, C.A., Zuk, D., Foisy, M., Robinson, J., Singh, A.E., & Houston, S. (2009). Prenatal screening and perinatal HIV transmission in northern Alberta, 1996-2006. *American Journal of Public Health*, 99(S2), S412-S416. doi:10.2105/AJPH.2007.133306
- Johnson S., Hendson, W., Crewe-Brown, H., Dini, L., Frean, J., Perovic, O., Vardas, E. (2000). Effect of human immunodeficiency virus infection on episodes of diarrhea among children in South Africa. *Journal of Pediatric Infectious Disease*, 19(10), 272-979. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/11055599>
- Judd, F., Armstrong, S., & Kulkarni, J. (2009). Gender-sensitive mental health care. *Australian Psychiatry*, 17(2), 105-111. Retrieved from <http://www.tandfonline.com/doi/abs/10.1080/10398560802596>

- Kahneman, D., & Tversky, A. (1979). Prospect theory: An analysis of decision under risk. *Econometrica*, *14*(2), 263-292. Retrieved from https://www.princeton.edu/~kahneman/docs/Publications/prospect_theory.pdf
- Kalichman, S.C., Simbayi, L.C., Cloete, A., Mthembu, P.P., Mkhonta, R.N., & Ginindiza, T. (2009). Measuring SIDS stigmas in people living with HIV/AIDS: The international AIDS-related Stigma Scale. *AIDS Care*, *21*, 87-93. doi:10.1080/09540120802032627
- Kane, M. (1996). In Royal Commission on Aboriginal Peoples. Vol. 4. *Aboriginal Women in Urban Areas*. Ottawa, ON: Canadian Group-Publishing.
- Kanniappan, S., Jeyapaul, M.J., & Kalyanwala, S. (2008). Desir for motherhood: Exploring HIVpositive women's desires, intentions and decision making in attaining motherhood. *AIDS Care*, *20*(6), 625-630. doi:10.1080/09540120701660961
- Kilbourne A., Herndon, B., Anderson, R.M., Wenzel, S.L., & Gelberg, L. (2002). Psychiatric symptoms, health services, and HIV risk factors among homeless women. *Journal of Health Care for the Poor and Underserved*, *13*(1), 49-65. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/11836913>
- Kinsler, J.J., Wong, M.D., Sayles, N.J., Davis, C., & Cunningham, W.E. (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIVpositive population. *AIDS Patient Care and STD's*, *21*(8), 584-592. doi:10.1089/apc.2006.0202
- Kirmayer, L., Brass, G.M., & Tait, C.L. (2000). The mental health of aboriginal peoples: Transformations of identity and community. *Canadian Journal of Psychiatry*, *45*(7), 607-614. doi:10.1177/070674370004500702

- Ko, N.Y., & Muecke, M. (2005). To reproduce or not: HIV concordant couples make a critical decision during pregnancy. *Journal of Midwifery & Women's Health*, 50(1), 23-30.
doi:10.1016/j.jmwh.2004.08.003
- Landesman, S., & Minkoff, H. (1998). The influence of pregnancy on HIV type I infection: Antepartum and postpartum changes in HIV type I viral load. *American Journal of Obstetrics and Gynecology*, 178, 355-359. doi:10.1016/S0002-9378(98)80025-2
- La Rocque, Emma D. (1994). *Violence in aboriginal communities*. Ottawa, ON: Health and Welfare Canada.
- Lee, R.S., Kochman, A., & Sikkema, K.J. (2002) Internalized stigma among people living with HIV/AIDS. *AIDS Behavior*, 6(4), 309-319. doi:10.1023/A:1021144511957
- Leserman, J., Ironson, G., O'Cleirigh, C., Fordiani, J.M., & Balbin, B. (2008). Stressful life events and adherence in HIV. *AIDS Patient Care and STDs*, 22(5), 403-411. doi: 10.1089/apc.2007.0175
- Lichtenstein, B. (2006). Domestic violence in barriers to health care for HIV-positive women. *AIDS Patient Care and STDs*, 20(2), 122-132. Retrieved from https://www.researchgate.net/profile/Bronwen_Lichtenstein/publication/7300876_Domestic_violence_in_barriers_to_health_care_for_HIVpositive_women/links/54e3ca440cf2dbf606945e9c.pdf
- Lipshultz, S.E, Eastley, K.A, Orav, E.J., Kaplan, S., Starc, T.J., Bricker, J.T., ... Colan, S.D. (1998). Left ventricular structure and function in children infected with HIV: the prospective P2C2 HIV multicenter study. *Pediatric pulmonary and cardiac complications of vertically transmitted HIV infection. Circulation*, 97(13), 1246-1256.
doi:10.1161/01.CIR.97.13.1246

- Lobato, M., Caldwell, M., Ng, P., & Oxtoby, M., (1995). Encephalopathy in children with perinatally acquired HIV infection. *Journal of Pediatrics*, 126(5), 710-715.
doi:[http://dx.doi.org/10.1016/S0022-3476\(95\)70397-7](http://dx.doi.org/10.1016/S0022-3476(95)70397-7)
- Loppie Reading, C., & Wien, F. (2009). *Health inequalities and social determinants of Aboriginal peoples' health*. Prince George, BC: National Collaborating Centre for Aboriginal Health. Retrieved from
http://www.nccahccnsa.ca/docs/social%20determinates/NCCAH-loppie-Wien_report.pdf
- Loutfy, M.R., Hart, T.A., Mohammed, S.S., Su, D., Ralph, E.D., Walmsley, S.L.,...Yukin, M.H. (2009). Fertility desires and intentions of HIV-positive women of reproductive age in Ontario, Canada: A cross-sectional study. *PLoS ONE*, 4(12): e7925.
doi:10.1371/journal.pone.0007925
- Loutfy, M.R., Logie, C.H., Zhang, Y., Blitz, S.L., Margolese, S.L., Tharao, W.E.,...Raboud, J.M. (2012). Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS ONE*, 7(12): e48168, 1-9.
doi:10.1371/journal.pone.0048168
- Loutfy, M.R., Raboud, J.M., Yudin, M.H., Diong, C., Blitz, S.L., Margolese, S.L.,...Walmsley, S.L. (2012). High prevalence of unintended pregnancies in HIV-positive women of retrospective age in Ontario, Canada: A retrospective study. *HIV Medicine*, 13, 107-117.
doi: 10-1111/j.1468-1293.2011.00946.x
- Loutfy, M.R., Blitz, S., Zhang, Y., Hart, T.A., Walmsley, S.L. Smaill, F.M.,...Raboud, J.M. (2014). Self-reported preconception care of HIV-positive women of reproductive potential: A retrospective study. *Journal of the International Association of Providers of AIDS Care* 13(5), 424-433. doi:10.1177/232595741349238

- Luginbuhl, L.M., Orav E.J., McIntosh, K., & Lipshultz, S.E. (1993). Cardiac mobility and related mortality in children with HIV infection. *Journal of American Medical Association, 269*(22), 2869-2875. doi:10.1001/jama.1993.03500220055026.
- Mannheimer, S.B., Matts, J., Telzak, E., Chesney, M., Child, C., Wu, A.W., Friedland, G., & Beirn, T. (2005). Quality of life in HIV-infected individuals receiving antiretroviral therapy is related to adherence. *AIDS Care, 17*(1), 10-22. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/15832830>
- McCall, J., & Pauly, B. (2012). Providing a safe place: Adopting a cultural safety perspective in the care of aboriginal women living with HIV/AIDS. *CJNR, 44*(2), 131-145. Retrieved from <http://cjnr.archive.mcgill.ca/article/viewFile/2354/2348>
- McCall, J., Browne, A.J., & Reimer-Kirkham, S. (2009). Struggling to survive: The difficult reality of aboriginal women living with HIV/AIDS. *Qualitative Health Research, 19*(2), 1769-1782. doi:10.1177/1049732309353907
- McCormick, R. (2000). Aboriginal traditions in the treatment of substance abuse. *Canadian Journal of Counselling, 34*(1), 25-32. Retrieved from <http://cjcrcc.ucalgary.ca/cjc/index.php/rcc/article/view/152/367>
- McKay-McNabb, K. (2006). Life experiences of aboriginal women living with HIV/AIDS. *Canadian Journal of Aboriginal Community Based HIV/AIDS Research, 1*(1), 5-16. Retrieved from <http://www.cahr.uvic.ca/nearbc/documents/CJACBR.pdf#page=13>
- McKeown, I., Reid, S., Turner, S., & Orr, P. (2002). Sexual violence and dislocation as social risk factors involved in the acquisition of HIV among women in Manitoba. The Prairie Women's Health Center of Excellence, Project #25. Retrieved from <http://www.pwhce.ca/sexualViolence.htm>

- Meadows, L.M., Thurston, W.E., & Lagendyk, L.E. (2005). Aboriginal women at midlife: Grandmothers as agents of change. *Canadian Woman Studies*, 24(1), 159-165. Retrieved from <http://cws.journals.yorku.ca/index.php/cws/article/view/6195/5383>
- Mehrabadi, A., Craib, K.J.P., Patterson, K., Adam, W., Moniruzzaman, A., Ward-Burkitt, B.,...Spittal, P.M. (2008). The Cedar Project: A comparison of HIV-related vulnerabilities amongst young aboriginal women surviving drug use and sex work in two Canadian cities. *International Journal of Drug Policy*, 19(2), 159-168. Retrieved from https://www.researchgate.net/publication/5971202_The_Cedar_Project_A_comparison_of_HIVrelated_vulnerabilities_amongst_young_Aboriginal_women_surviving_drug_use_and_sex_work_in_two_Canadian_cities
- Meyer, I.H. (2003). Prejudice, social stress, and mental health in lesbian, gay and bisexual populations: Conceptual issues and research evidence. *Psychology Bulletin*, 129, 674-697. doi:10.1037/0033-2909.129.5.674
- Mill, J. (1997). HIV risk behaviors become survival techniques for aboriginal women. *Western Journal of Nursing Research*, 19(4), 466-490. doi:10.1177/019394599701900404
- Money, D. (1997). Antiretroviral therapy in HIV-infected pregnant women. *Journal SOGC*, 21(4), 251-261. Retrieved from [http://www.jogc.com/article/S0849-5831\(16\)30071-4/pdf](http://www.jogc.com/article/S0849-5831(16)30071-4/pdf)
- Morse, J., & Richards, L. (2002). *Read me first for a user's guide to qualitative research*. Thousand Oaks, CA: Sage Publications Inc.
- Morse, J.M., Barrett, M., Mayan, M., Olson, K., & Spires, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), Article 2. Retrieved from https://sites.ualberta.ca/iiqm/backissues.1_2final/html/morse.html

- Mwakisha, J. (1996) Women's forum female condom study explores role of peer support in sustaining use. *AidsCaptions*, 3(12), 46-48. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/12347595?dopt=Abstract>
- National Aboriginal Health Organization (NAHO). *Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities*. (October 2005). First Nations Centre. Retrieved from http://www.naho.ca/documents/fnc/english/FNC_OCAPCriticalAnalysis.pdf
- Nattabi, B., Jianghong, L., Thompson, S.C., Orach, C.G., & Earnest, J. (2009). A systematic review of factors influencing fertility desires and intentions among people living with HIV/AIDS: Implications for policy and service delivery. *AIDS Behavior*, 13, 949-968. doi:10.1007/s10461-009-9537-y
- Neron, C., & Roffey, R. (2000). HIV, sexual violence and aboriginal women. *Native Social Work Journal*, 3(1), 57-72. Retrieved from <https://zone.biblio.laurentian.ca/bitstream/10219/443/1/NSWJ-V3-art4-p57-72.pdf>
- Nicastri, E., Leone, S., Angeletti, C., Palmisano, L., & Sarmati L. (2007). Sex issues in HIV-1 infected persons during highly active antiretroviral therapy: A systematic review. *Journal of Antimicrobial Chemotherapy* 60(4), 724-732. doi:10.1093/jac/dkm302
- Norbrega, A.A., Oliveira, F.A.S., Galvao, M.T.G., Mota, R.S., Barbosa, R.M., & Dourado, I. (2007). Desire for a child among Monday living with HIV/AIDS in northeast Brazil. *AIDS Patient Care and STDs*, 21(4), 261-267. doi:10.1089/apc.2006.0116
- Nyblade, L.C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health and Medicine*, 11(3), 335-345. doi:10.1080/13548500600595178

Ogilvie G, Money D.M., Forbes J.C., Remple V.P., Alimenti, A., Burdge, D.P. (2002). Perinatal HIV infection in Aboriginal maternal infant pairs (MIP) in British Columbia. *Canadian Journal of Infectious Disease*, 13(SA), 50A-Abstract 321}.

Ogilvie, G.S., Palepu, A., Remple, V.P., Mann, 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(S1), S83-S88. doi:10.1097/01.aids.0000255090.51921.60

Oosterhoff, P., Anh, N.T., Hanh, N.T., Yen, P.N., Wright, P. & Hardon, A. (2008). Holding the line: Family responses to pregnancy and the desire for a child in the context of HIV in Vietnam. *Culture Health and Sex*, 10(4), 403-416. doi: 10.1080/13691050801915192.

Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission. *Recommendations for use of antiretroviral drugs in pregnant HIV-1-infected women for maternal health and interventions to reduce perinatal HIV transmission in the United States*. Retrieved from <https://aidsinfo.nih.gov/contentfiles/lvguidelines/PerinatalGL.pdf>

Panel on Antiretroviral Guidelines for Adults and Adolescents. *Guidelines for the use of antiretroviral agents in HIV-1-Infected adults and adolescents*. Department of Health and Human Services. (January 2011). Retrieved from <https://aidsinfo.nih.gov/contentfiles/lvguidelines/AdultandAdolescentGL.pdf>

Parish, M., Burry, C., & Pabst, M.S. (2003). Providing comprehensive case management to urban women with HIV/AIDS and their families. *Affilia*, 18(3), 302-315.

Parker, R., & Aggleton, P. (2003). HIV and AIDS related stigma and discrimination: A conceptual framework and implication for action. *Social, Science and Medicine*, 57, 1324. Retrieved from <http://canadianharmreduction.com/sites/default/files/2003%20Parker->

HIV%20and%20AIDSrelated%20stigma%20and%20discrimination%20a%20conceptual
%20framework%20and%20implications%20for%20action.pdf

- Payne, J. (2006). *Impact of a reduced fertility rate on women's health*. In Women's Health Surveillance Report, 2003. Ottawa, ON: Public Health Agency of Canada. Retrieved from https://secure.cihi.ca/free_products/CPHI_WomensHealth_e.pdf
- Paxton, S. (2002). The paradox of public HIV disclosure. *AIDS Care, 14*(4), 559-567.
doi:10.1080/09540120208629674
- Pearce, M.E., Christian, W.M., Patterson, K., Norris, K., Montruzzaman, A., Craib, J.P.,...Spittal, P.M. (2008). The Cedar Project: Historical trauma, sexual abuse and HIV risk among young aboriginal people who use injection and non-injection drugs in two Canadian cities. *Social Science and Medicine, 66*(11), 2185-2194. Retrieved from <http://caid.ca/SocSciMed662008.pdf>
- Prachakul, W., Grant, J.S., Keltner, N.L. (2007). Relationships among functional social support HIV related stigma, social problem solving, and depressive symptoms in people living with HIV: a pilot study. *Journal of the Association of Nurses AIDS Care, 18*(6), 67-76. Retrieved from [http://www.nursesinaidscarejournal.org/article/S1055-3290\(07\)00216-6/abstract](http://www.nursesinaidscarejournal.org/article/S1055-3290(07)00216-6/abstract)
- Prins, M., Meyer, L., Hessel, N.A. (2005). Sex and the course of HIV infection in the pre-and highly active antiretroviral therapy eras. *AIDS, 19*(4), 357-370. Retrieved from <http://www.medscape.com/viewarticle/501682>
- Prentice, T. (2004). HIV/AIDS and aboriginal women, children and families. (A position paper). Retrieved from http://caan.ca/wp-content/uploads/2010/03/Women_and_HIV.pdf
- Public Health Agency of Canada (PHAC). (2010). *HIV/AIDS epi updates, July 2010*. Ottawa,

- ON: Surveillance and Risk Assessment Division, Centre for Communicable Diseases and Infection Control, Public Health Agency of Canada. Retrieved from http://www.phac.aspc.gc.ca/aids-sida/publication/epi/2010/pdf/EN_Intro_Web.pdf
- Public Health Agency of Canada (PHAC). (2014). *HIV/AIDS epi updates: National HIV prevalence and incidence estimates for 2011, October 2014*. Ottawa, ON: Surveillance and Risk Assessment Division, Centre for Communicable Disease and Infection Control, Public Health Agency of Canada. Retrieved from <http://www.phac.aspc.gc.ca/aidssida/publication/epi/2010/1-eng.php>
- Public Health Agency of Canada (PHAC). (2014). *HIV and AIDS in Canada: Surveillance report to December 31, 2013*. Ottawa, ON: Minister of Public Works and Government Services Canada. Retrieved from <http://www.phac.aspc.gc.ca/aidssida/publication/survreport/2013/dec/assets/pdf/hiv-aids-surveillance-eng.pdf>
- Quinn, E. (2010). *Leadership, engagement, action and dialogue project: Final report*. Vancouver, BC: Positive Women's Network.
- Quinn, T.C., & Overbaugh, J. (2005). HIV/AIDS in women: an expanding epidemic. *Science*, 308(5728), 1582-1583. doi:10.1126/science.1112489
- Rao, D., Pryor, J.B., Gaddist, B.W., & Meyer, R. (2008). Stigma, secrecy, and discrimination: ethnic/racial differences in the concerns of people living with HIV/AIDS. *AIDS Behavior*, 12, 265-271. doi: 10.1007/s10461-007-9268-x
- Radcliffe, J., Doty, N., Hawkins, L.A., Gaskins, C.S., Beidas, R., & Rudy, B.J. (2010). Stigma and sexual health risk in HIV-positive African American young men who have sex with men. *AIDS Patient Care and STDs*, 24(8), 293-499. doi:10.1059/apc.2010.0020

- Ray, P.E, Rakusan, T., Loechelt B.J., & Selby, D.M., Liu, X.H., & Chandra, R.S. (1998). HIV associated neuropathy in children from the Washington DC area: 12 years' experience. *Seminars in Nephrology*, 18(4), 396-405.
- Razack, S. H. (2002). *Race, space, and the law: Unmapping a white settler society*. Toronto, ON: Between the Lines.
- Reimer, R.H., Exner, T., Kertzner, R.M., Ehrhardt, A.A., Rotheram-Rorus, M.J., Johnson, M.O.,...Kelly, J.A. (2006). Depressive symptomatology among HIV-positive women in the era of HAART: a stress and coping model. *American Journal of Community Psychology*, 38, 275-285. doi: 10.1007/s10464-006-9083-y
- Riggs, S.A., Vosvick, M., & Stallings, S. (2007). Attachment style, stigma and psychological distress among HIV+ adults. *Journal of Health Psychology*, 12, 922-936. doi: 10.1007/s10464-006-9083-y
- Rintamaki, L.S., Davis, T.C., Skripkauskas, S., Bennett., C.L., & Wolf, M.S. (2006). Social stigma concerns and HIV medication adherence. *AIDS Patient Care and STDs*, 20(5), 359-368. doi:10.1089/apc.2006.20.359
- Robinson, J.L., & Lee, B.E. Prevention of perinatal transmission of HIV infection. *Canadian Medical Association Journal*, 163(7), 831-832. Retrieved from <http://www.cmaj.ca/content/163/7/831.short>
- Romanow, C. (2003). *HIV/AIDS and aboriginal women in Saskatchewan: Colonization, marginalization and recovery*. (Master's thesis). Retrieved from <http://www.collectionscanada.gc.ca/obj/s4/f2/dsk3/SSU/TC-SSU-12242003223027.pdf>
- Rosenstock, I.M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly*,

44, 1-32. Retrieved from

<http://www.milbank.org/uploads/documents/QuarterlyCentennialEdition/Why%20ppl.%20Use%20Health%20Srvcs.pdf>

Royal Commission on Aboriginal Peoples (RCAP). (1996). *Looking forward, looking back*.

Ottawa, ON: Canadian Group-Publishing. Retrieved from

<http://caid.ca/RepRoyCommAborigPple.html>

Royal Commission on Aboriginal Peoples (RCAP). (1996). *Gathering strength*. Ottawa, ON:

Canadian Group Publishing. Retrieved from

https://qspace.library.queensu.ca/bitstream/1974/6874/3/RRCAP3_combined.pdf

Rubin, H., & Rubin, I. (1995). *The art of hearing data*. Thousand Oaks, CA: Sage Publications

Inc.

Rutenberg, N., Biddlecon, A., & Karna, F. (2000). Reproductive decision making in the context

of HIV and AIDS: A qualitative study in Ndola, Zambia. *International Family Planning Perspectives*, 26(3), 124-130. Retrieved from

<https://www.guttmacher.org/about/journals/ipsrh/2000/09/reproductive-decision-makingcontext-hiv-and-aids-qualitative-study>

Sergeant, S., & Jones, E. (2008). *Barriers to access to primary health care for young HIV+*

women: a qualitative research study. Vancouver, BC: YouthCO AIDS Society and Positive Women's Network.

Sandelowski, M., Lambe, C., & Barosso, J. (2004). Stigma in HIV positive women. *Journal of*

Nursing Scholarship, 36(2), 122-128. doi:10.1111/j.1547-5069.2004.04024.x

Seals, B.F., Sowell, R.L., Demi, A.S., Moneyham, L. Cohen, L. & Guillory, J. (1995). Falling

through the cracks: Social service concerns of women infected with HIV. *Qualitative*

Health Research, 5(4), 496-515. doi:10.1177/104973239500500410

Segall, A. & Fries, C.T. (2011). *Pursing health and wellness: Healthy societies, healthy people*.

Don Mills, ON: Oxford University Press.

Shannon, K., Kerr, T., Allinott, S., Chettiar, J., Shoveller, J., & Tyndall, M.W. (2008). Social and structural violence and power relations in mitigating HIV risk of drug-using women in survival sex work. *Social Science and Medicine*, 66(4), 911-921. Retrieved from <http://wish-vancouver.net/wpcontent/uploads/2012/08/SocialandStructuralViolenceSCMKFeb20081.pdf>

Shawanda, B. (1995). *Healing journey of native women*. In Atlantic First Nations AIDS Task Force, *Healing Our Nations Resource Manual*. Halifax, NS:

Ship, S.J., & Norton, L. (2000). "It's hard to be a woman!" First Nations women living with HIV/AIDS. *Native Social Work Journal* 3(1), 73-89. Retrieved from <https://zone.biblio.laurentian.ca/bitstream/10219/444/1/NSWJ-V3-art5-p73-89.pdf>

Showalter, Elaine. (1990). *The way we write now: Syphilis and AIDS. Sexual anarchy: Gender and culture at the Fin De Siecle*. New York, NY: Penguin Books.

Smith, D.J., & Mbakwem, B.C. (2007). Life projects and therapeutic itineraries: marriage, fertility, and antiretroviral therapy in Nigeria. *AIDS*, 21(S5), S37-S41. doi:10.1097/01.aids.0000298101.56614.af

Sowell, R., Seals, B., Moneyham, L., Guillory, J., Demi, A., & Cohen, L. (1996). Barriers to health-seeking behaviors for women infected with HIV. *Nursingconnections*, 9(3), 5-17. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/9110785>

- Sowell, R.L., Phillips, K.D., & Misener, T.R. (1999). HIV-infected women and motivation to add children to their families. *Journal of Family Nursing* 5(3), 316-331.
doi:10.1177/107484079900500305
- Sowell, R.L., Murdaugh, C.L., Addy, C.L., Moneyham, L., & Tavokoli, A., (2002). Factors influencing intent to get pregnant in HIV-infected women living in southern USA. *AIDS Care*, 14(2), 181-191. doi: 10.1080/09540120220104695
- Spittal, P., & Schechter, M.T. (2001). Injection drug use and despair through the lens of gender. *Canadian Medical Association Journal*, 164(6), 802-803. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC80877/>
- Spittal, P.M., Craib, K.J.P., Teegee, M., Baylis, C., Christian, W.M., Moniruzzaman, A.K.M., Schechter, T.M. (2007). The Cedar Project: Prevalence and correlates of HIV infection among young aboriginal people who use drugs in two Canadian cities. *International Journal of Circumpolar Health*, 66(3), 226-240. Retrieved from <http://www.circumpolarhealthjournal.net/index.php/ijch/article/view/18259>
- Squire, C. (1993). *Women and AIDS: Psychological perspectives*. London, ON: Sage Publications.
- Stein, M., Crystal, S., Cunningham, W., Ananthanarayanan, A., Andersen, R., Turner, B.J., ...& Schuster, M.A. (2000). Delays in seeking HIV care due to competing caregiver responsibilities. *American Journal of Public Health* 90(7), 1138–1140. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446306/>
- Stanwood, N.L., Cohn, S.E., Heiser, J.R., & Pugliese, M. (2007). Contraception and fertility plans in a cohort of HIV-positive women in care. *Contraception*, 75(4), 294-298.
doi:10.1016/j.contraception.2006.12.012
- Starc, T., Lipshultz, S., Kaplan, Eastly, T.A., Bicker, J.T, Colan, S.D.,...Schluchter, M.D.

- (1999). Cardiac complications in children with human immunodeficiency virus infection. *Pediatric Pulmonary and Cardiac Complications of Vertically Transmitted HIV Infection (P2C2 HIV) Study Group, National Heart, Lung, and Blood Institute. Pediatrics, 104(2)*, e14. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4358844/>
- Statistics Canada. (2011). *Aboriginal Peoples in Canada, First Nations Peoples, Metis and Inuit. National Household Survey. (SC Catalogue No. 99-011-X2011001)*. Retrieved from <http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.pdf>
- Stevens, P., & Hildebrandt, E. (2006). Life changing words: Women's responses to being diagnosed with HIV infection. *Advances in Nursing Science, 29(3)*, 207-221. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/17139203>
- Stevens, P., & Tighe Doerr, B. (1997). Trauma of discovery: Women's narratives of being informed they are HIV-infected. *AIDS Care, 9(5)*, 523-538. doi:10.1080/713613201
- St. Lawrence, J.S., Snodgrass C.E., Robertson, A., & Baird-Thomas, C. (2008). Minimizing the risk of pregnancy, sexually transmitted diseases, and HIV among incarcerated adolescent girls: identifying potential points of intervention. *Criminal Justice and Behavior, 35(12)*, 1500-1514. doi:10.1177/0093854808324669
- Sumartojo, E. (2000). Structural factors in HIV prevention: Concepts, examples, and implications for research. *AIDS, 14(S)*, 3-10. Retrieved from journals.lww.com/aidsonline/Abstract/2000/06001/Structural_factors_in_HIV_prevention___concepts,.2.aspx
- Thurston, W.E., & Meadows, L.M. (2004). Embodied minds, restless spirits: Mid-life rural women speak of their health. *Women and Health, 39(3)*, 97-112. doi:10.1030/J013v39n03_07

- UNAIDS (2010). *UNAIDS report on the global AIDS epidemic*. Retrieved from http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf
- University of California, San Francisco (UCSF) Center for AIDS Prevention Studies Prevention Research Centre (2011). *What are young women's HIV prevention needs?* (Factsheet). Retrieved from <http://caps.ucsf.edu/archives/factsheets/young-women-2>
- Vancouver/Richmond Health Board. *A framework for women centered health*. Vancouver: Vancouver/Richmond Health Board; 2001. Retrieved from <http://www.atira.bc.ca/AdvancingHealthCareWorkshop/womenframework.pdf>
- Varcoe, C., & Dick, S. (2008). The intersecting risks of violence and HIV for rural aboriginal women in a neo-colonial Canadian context. *Journal of Aboriginal Health, 4*(1), 42-52. Retrieved from http://naho.ca/documents/journal/jah04_01/07ViolenceHIV_42-52.pdf
- Vernon, I.S. (2000). Facts and myths of AIDS and Native American women. *American Indian Culture and Research Journal, 24*(3), 93-110. doi:10.17953/aicr.24.3.a08g7n6h1804mp5p
- Wagner, A.C., Hart, T.A., Mohammed, S., Ivanova, E., Wong, J., & Loutfy, M.R. (2010). Correlates of HIV stigma in HIV-positive women. *Archives Women's Mental Health, 13*, 207-214. doi:10.1007/s00737-010-0158-2
- Walters, K.L., & Simoni, J.M. (1999). Trauma, substance abuse and HIV risk among urban American Indian women. *Cultural Diversity and Ethnic Minority Psychology, 5*(3), 236-248. doi:10.1037/1099-9809.5.3.236
- Wilson, T.E., Gore, M.E., Greenblatt, R., Cohen, M., Minkoff, H., & Silver, S. (2004). Changes in sexual behavior among HIV-infected women after initiation of HAART. *American Journal of Public Health, 94*(7), 1141-1146. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/15226134>

- Wingood, G.M., DiClemente, R.J., McCree, D.H., Davis, S.L., Hardin, J.W., Peterson, S.H. (2007). HIV discrimination and the health of women living with HIV. *Women's Health*, 46(2), 99-112. 10.1300/J013v46n02_07
- Wolfleg, A., (2013). *Strong voices: Stories of struggle and strength, living with HIV*. Calgary, AB: AIDS Calgary Awareness Association.
- Wood, E., Montaner, J.S., Tyndall, M.W., Schechter, M.T., O'Shaughnessy, M.V., & Hogg, R.S. (2003). Prevalence and correlates of untreated human immunodeficiency virus type I infection among persons who have died in the era of modern antiretroviral therapy. *Journal of Infectious Diseases*, 188(8), 1164-1170. doi:10.1086/378703
- World Medical Association. *MA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects*. (October 2013). World Medical Association. Retrieved from <http://www.wma.net/en/30publications/10policies/b3/>
- Young, T.K., & Kantz, A. (1998). Survivors of sexual abuse: Clinical lifestyle and report consequences. *Canadian Medical Association Journal*, 159(4), 329-334. Retrieved from <http://www.cmaj.ca/content/159/4/329.full.pdf+html>
- Yudin, M.H., & Loutfy, M. (2011). Advocating for assistance with pregnancy planning in HIVpositive individuals and couples: an idea whose time has come. *Journal of Obstetrics and Gynecology Canada*, 33(3), 269-271. Retrieved from [http://www.jogc.com/article/S1701-2163\(16\)34829-0/pdf](http://www.jogc.com/article/S1701-2163(16)34829-0/pdf)
- Yudin, M.H., Shapire, H.M., & Loutfy, M.R. (2010). Access to infertility services in Canada for HIV-positive individuals and couples: a cross-sectional study. *Reproductive Health*, 7(1), 7. doi:10.1186/1742-4755-7-7.

Zierler, S., & Krieger, N. (1997). Reframing women's risk: Social inequalities and HIV infection. *Annual Review of Public Health, 18*, 401-436.

doi:10.1146/annurev.publhealth.18.1.401

Figure 1 Medicine Wheel Framework

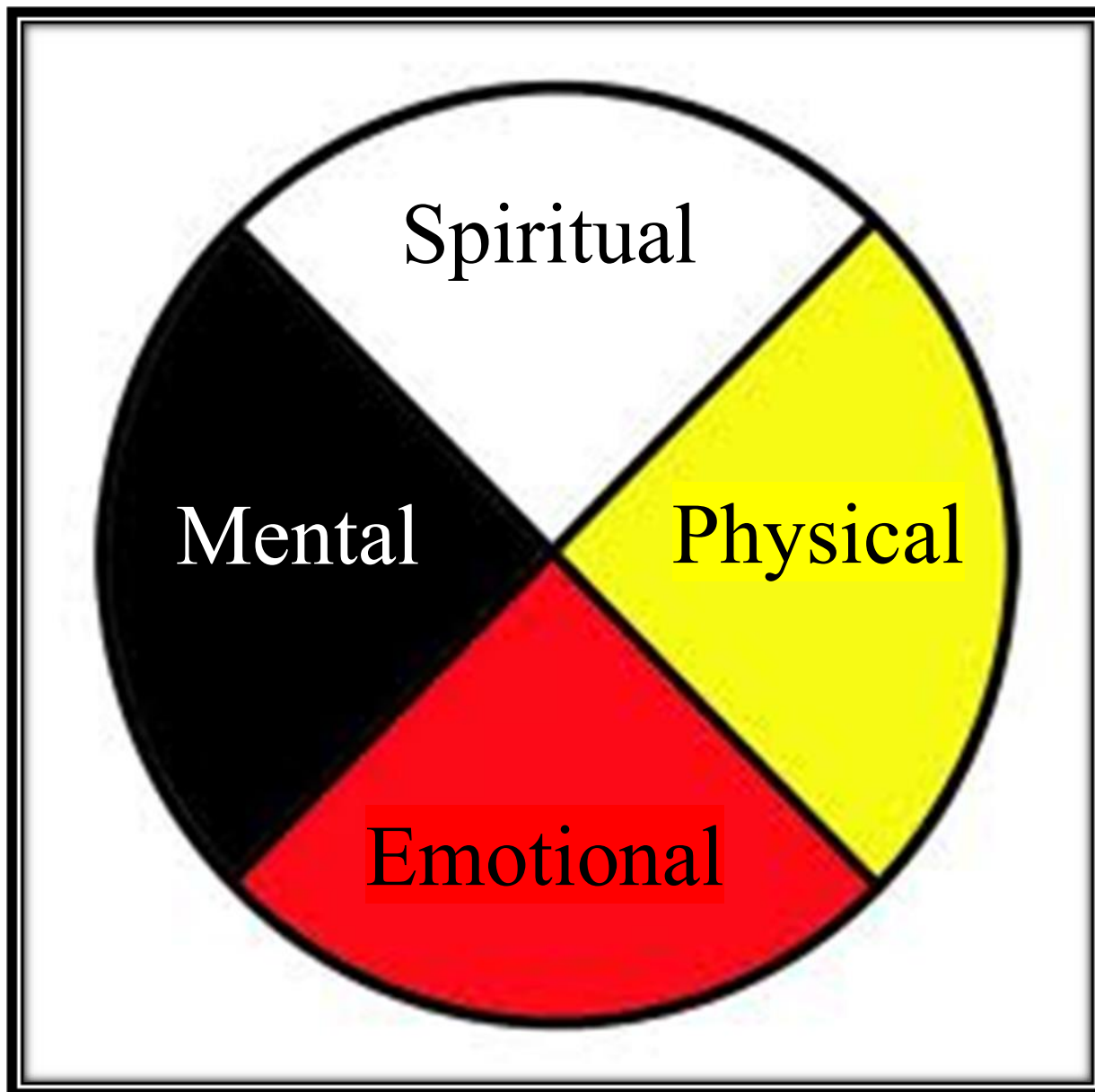
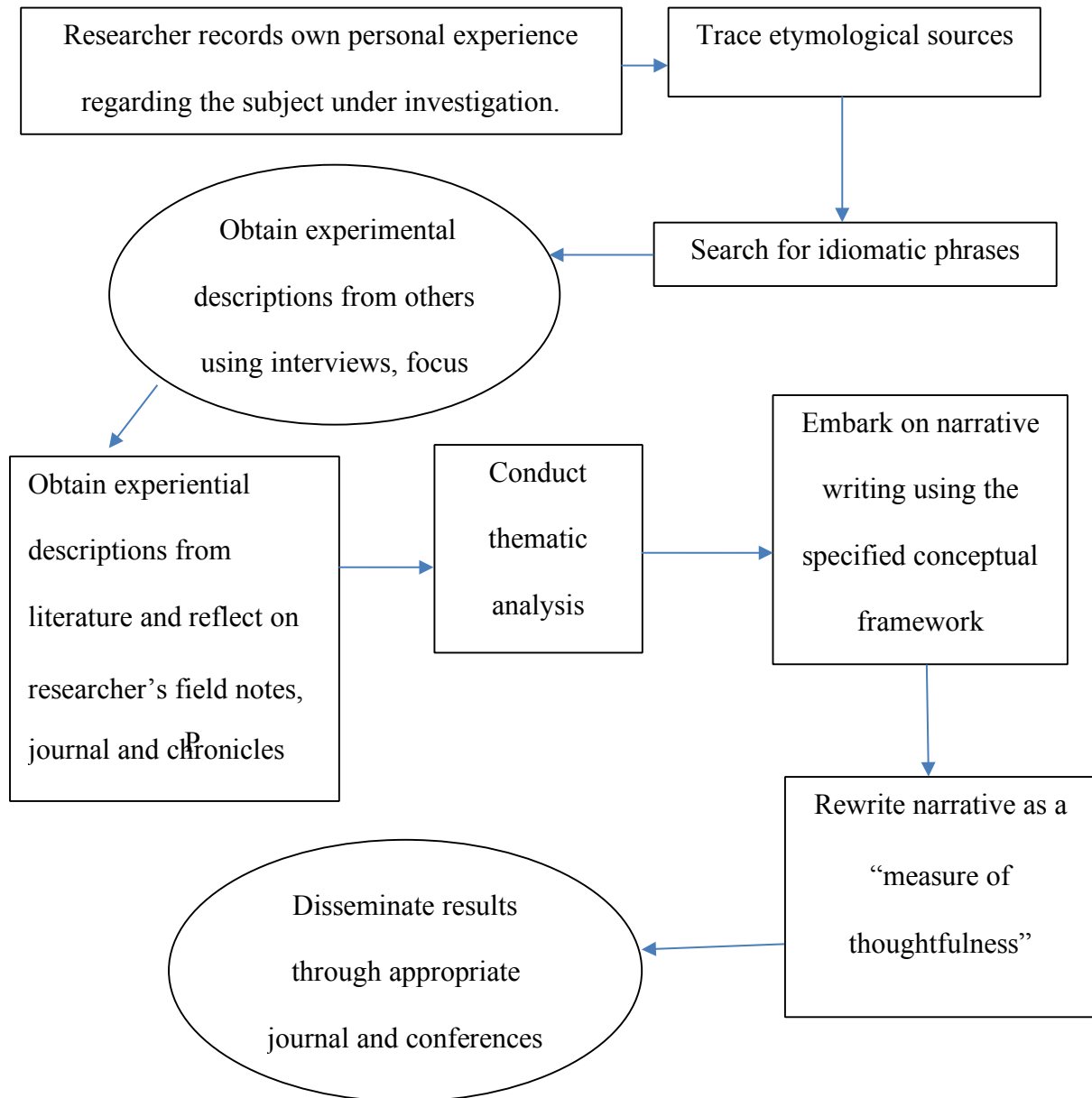


Figure 2 Data Analysis Flowchart

Appendix B

Recruitment Poster



Life in the Shadows

A University of Calgary study honoring the stories of HIV⁺ Aboriginal women









If you are an Aboriginal woman living with HIV, you are invited to share your story about how you make decisions about having a child or not. I would be honored to listen to your story and as a thank you for sharing your story you will receive a sweet grass braid and a \$50 honorarium.

This study is conducted in partnership with Elbow River Healing Lodge, Adult Aboriginal Mental Health, Southern Alberta Clinic, Calgary STI Clinic, Calgary Sexual Health Clinic, and HIV Community Link. The goal of this study is to understand what influences HIV⁺ Aboriginal women in their decision to have a child or not.

This study has been approved by the:
University of Calgary Conjoint Health Research Ethics Board - Ethics ID: REB13-0819

FOR MORE INFORMATION PLEASE CONTACT:

587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher 	587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher 	587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher 	587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher 	587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher 	587-894-9372	 <ul style="list-style-type: none"> • Tina Nash • Researcher
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Appendix C

Summary Description of Study

Life in the Shadows: Examining the Role that HIV Status Plays in the Decision Making Processes of HIV Positive Aboriginal Women in Terms of Their Reproductive Health and Their Decisions To Have a Child or Not – Research Study Abstract

Tina Nash - MSc Student – Department of Community Health Science (Faculty of Medicine, University of Calgary) - Researcher

Dr. Wilfreda Thurston – Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) - Supervisor

Dr. Scott Patten – Professor – Department of Community Health Sciences and Department of Psychiatry (Faculty of Medicine, University of Calgary)

Dr. Lindsay Crowshoe, Assistant Professor, Department of Family Medicine (Faculty of Medicine, University of Calgary)

Significance: Canadian Aboriginal women suffer from a range of health problems at higher rates than occur in the general Canadian population and the rate of new HIV infections for Aboriginal women between 15-29 years of age has been steadily increasing to epidemic proportions over the last two decades. Birth rates that are twice that of the National average, coupled with increased intravenous drug use (IDU), increased prevalence of sexually transmitted diseases, and greater mobility, indicate that Aboriginal women are more likely to be exposed and infected with HIV as well as more likely to be the vector of vertical transmission of HIV to their children at a rate that is 7 times higher than among non-Aboriginal women of child bearing age.

Furthermore, what is known about HIV and Aboriginal women is limited to quantitative studies that primarily report incidence and prevalence measurements. There are very few studies that examine fertility intentions and reproductive health issues of women living with HIV and no studies which, examine HIV+ Aboriginal women's reproductive health experience or explore their reproductive decisions making processes. Such information is crucial to understanding the statistical reality of Aboriginal women and HIV that is presently unfolding in Canadian society today.

Purpose: This study will use qualitative methodology to explore the influences that impact on the reproductive decision making processes of HIV+ Aboriginal women and what the implications of those decisions are for primary health care providers. The objective of this study is to produce a rich, detailed, descriptive narrative of the lived experience of HIV+ Aboriginal women regarding what influences their decisions to have children or not within an urban environment. This study will help to develop the sparse literature about Aboriginal women who are living with HIV/AIDS and the influences that impact on their reproductive health and their decisions about having a child or not given their HIV+ health status. A secondary objective of this study is to examine the implications that HIV+ Aboriginal women's decisions on whether or not to have children has for primary health care providers.

Methods: This research study will recruit participants from and be conducted at locations within

Calgary - the Southern Alberta Clinic - AHS, AIDS Calgary Awareness Association, Elbow River Healing Lodge - AHS, Adult Aboriginal Mental Health Program – AHS, Calgary Sexual Health Centre– AHS, and the Calgary STI Clinic – AHS,. These organizations currently serve Aboriginal women of reproductive age and provide health, housing and/or supportive programs for Aboriginal women who are HIV+. Data for this study will be collected through multiple

methods including face to face semi-structured interviews, participant observation, informal conversations, researcher journal, field notes and chronicles as well as a scholarly literature review and researcher reflection. Aboriginal women will be asked to reflect upon and describe how their HIV+ status has impacted on their reproductive decision-making processes to have a child or not, to describe reproductive health services that they have accessed or are in need of, and to reflect on connections between their daily life activities and circumstances as it relates to their reproductive health and general well-being. Many sensitive issues will be investigated such as sexual behavior, urban integration, the role of abuse, IDU, mobility and the impact that being HIV+ has had on the lives of these women. Therefore, data will be descriptive and presented in a narrative form to capture and interpret meanings associated with the sensitive nature of this topic. To assist in the data collection phase, a field log will be utilized by the researcher to provide a detailed account of time management throughout the course of the study. In addition, a field notebook to record observation details and a journal to chronicle personal thoughts, feelings, perceptions, attitudes and experiences that develop during the course of this study will be maintained for reflective purposes. Data collection and analysis will follow an ethnographic qualitative approach that incorporates cultural activities and utilizes the Medicine Wheel as the conceptual framework for understanding and explaining the journey of each woman so as to integrate their personal experiences into a wholistic sense of understanding across physical, mental, emotional and spiritual aspects of being. Participants will be provided with an honorarium for their participation. Recruitment and analysis will occur simultaneously so as to ensure saturation of the data and will continue until the data begins to repeat itself or result in common themes. Data will be transcribed from recorded interviews and analyzed using QRS NUD*IST N-Vivo analytical software. This research is estimated to cost \$6340.00 and is self

funded by the researcher. This study is proposed to be completed, including written submissions, within eight months following ethical approval. Ethical considerations for this study are guided by The Tri-Council Policy Statement and Ownership, Control, Access and Possession (OCAP) recommendations and ethical approval is through the University of Calgary Conjoint Health Research Ethics Board (REB 13-0819).

Outcomes: This study will culminate in a written submission to journals for peer review and publication, and thesis submission. Results from this study will also be submitted for presentation at conferences and community education forums to contribute to academic knowledge translation and cultural sharing of research findings with the broader health and Aboriginal community. Following the completion of this study, a ceremonial sweat will be undertaken so that the stories of those women who have participated can be released back to Creator for continued healing and safe keeping.

If you have any further questions or concerns related to this study, please contact:

Dr. Wilfreda (Billie) Thurston: (phone) 403-220-6940 or (email) thurston@ucalgary.ca

or

Tina Nash: (phone) 587-894-9372 or (email) tina.nash@albertahealthservices.ca

Appendix D

Study Interview Guide

Life in the Shadows: Examining the Role that HIV

Status Plays in the Decision Making Processes of HIV Positive Aboriginal Women in Terms of Their Reproductive Health and Their Decisions To Have a Child or Not

Time of Interview:

Date:

Place:

Interviewer:

Interviewee Code Number:

Thank you for agreeing to participate in this research regarding HIV positive Aboriginal women's reproductive health experiences and decision making processes about whether or not to have a child. This study is part of a Master's thesis that is focused on Aboriginal population health and self-funded by the researcher, Tina Nash, through scholarships received from New Relationship Trust, Indspire and the Foundation for the Advancement of Aboriginal Youth. Although I am interested in getting information about the following questions, please feel free to tell me about other things in your life that, have had an effect upon your reproductive health and decision making processes about whether or not to have a child. You are free to end the interview at any time and you do not have to answer any question that you are not comfortable with answering. Thank you in advance for your time and generosity in participating in this research study and for sharing your experiences and story.

Questions:

1. Please describe your reproductive experience and decision to have a child or not?

Probes:

1. When did you first seek reproductive care? Why or why not?
2. How has your HIV+ status affected your reproductive decision making processes and subsequent care-seeking behavior?
3. Did you know your HIV status at the time of pregnancy? If yes, how did this affect your decision to become pregnant and/or have a child? If no, how did you find out? And how has this discovery affected your pregnancy, reproductive health and decision to have a child or not?

2. What resources do you use for your reproductive health?Probes:

1. How often do you use these resources?
2. Are you satisfied with the care/services that you receive? Why or why not?
3. What care/services do you believe that you need that are currently not offer to you?
4. How reflective are the services for your needs?

3. How would you describe your reproductive health?Probes:

1. What does reproductive health consist of for you?
2. What influences your reproductive health?
3. What resources do you use for your reproductive health?
4. What resources do you use for family planning?

4. How does your HIV status affect your decisions regarding reproductive health and pregnancy?Probes:

1. How do you make decisions regarding pregnancy? (i.e. / Family or partner involvement? Self only decision? Counseling?)
2. How has your reproductive health been affected by HIV infection?
3. How has your reproductive health been affected by pregnancy?
4. What factors influence your decision to become pregnant and/or have children?

5. How has your upbringing influenced the reproductive choices you make today?

Probes:

1. What level of education have you completed?
2. Describe the family unit and situation that you grew up in?
3. Were there adverse events in your childhood that now influence your reproductive choices and health?
4. Were there other events in your life that impacted on your reproductive choices and decisions to have or not have children?
5. Was your upbringing traditional or non-traditional? And how did this influence your reproductive choices and experiences?

6. Explain your understanding of the Medicine Wheel as it relates to your reproductive health experience and your decision to have or not have a child?

Probes:

1. How has your physical health been influenced by your HIV+ status as it relates to your reproductive health experiences and whether or not to have a child?
2. How has your mental health been influenced by your HIV+ status as it relates to your reproductive health experiences and whether or not to have a child?
3. How has your emotional/social health been influenced by your HIV+ status as it relates to your reproductive health experiences and whether or not to have a child?
4. How has your spiritual health been influenced by your HIV+ status as it relates to your reproductive health experiences and whether or not to have a child?

In order to generally describe women, who have participated in this study, would you please share the following information:

Year of Birth:

Place of Birth:

Marital Status:

Number of Pregnancies:

Number of Children:

Highest Year of Education:

Current Employment Status:

Usual Occupation:

Annual Personal Income: up to \$10,000 \$10,000-\$25,000

\$25,000-\$35,000 \$35,000-\$45,000 \$45,000-\$55,000 over \$55,000

Do you currently have (or have you had) reproductive health care services?

Will you or have you had family planning counseling or discussions with a health care provider?

Have you had (or will you participate in) family planning?

Do you currently have or have you ever had any of the following?

HIV? STI's Hepatitis? Other conditions?

(If yes, how long?) (specify which type) (specify type and duration)

May we contact you again if there are any follow up questions that result from this interview? If so, please provide contact information below.

Name:

Address:

Phone Number:

Would you like a copy of this interview or the final report of this project? If so, please provide contact information below.

Name:

Address:

Phone Number:

Appendix E

Participant Consent Form



UNIVERSITY OF
CALGARY

TITLE: Life in the Shadows: Examining the Role that HIV Status Plays in the Decision Making Processes of HIV Positive Aboriginal Women in Terms of Their Reproductive Health and Their Decisions to Have a Child or Not

SPONSOR: Thesis project self-funded by student Tina Nash through scholarships obtained from New Relationship Trust, Indspire, and the Foundation for the Advancement of Aboriginal Youth

INVESTIGATORS:

Principal Investigator: Dr. Wilfreda Thurston, Professor, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) and Department of Ecosystem and Public Health (Faculty of Veterinary Medicine, University of Calgary) –Supervisor for this research study

- Telephone: 403-220-6940
- Email: thuston@ulcalgary.ca

Student Researcher: Tina Marie Nash, Masters Student, Department of Community Health Sciences (Faculty of Medicine, University of Calgary) – Principle Researcher for this study

- Telephone: 587-894-9372
- Email: tina.nash@albertahealthservices.ca

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like

more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Canadian Aboriginal women suffer from a range of health problems at higher rates than occur in the general Canadian population. The rate of new HIV infections for Aboriginal women between 15-29 years of age has been steadily increasing over the last two decades. Aboriginal women have birth rates that are twice that of the National average. Aboriginal women are also more likely to be involved with intravenous drug use (IDU), as well as to be affected by sexually transmitted diseases. These factors suggest that Aboriginal women are more likely to be exposed and infected with HIV as well as more likely to transmit HIV to their children at a rate that is 7 times higher than among non-Aboriginal women of child bearing age. What is currently known about HIV and Aboriginal women is limited to statistics and does not provide a story to explain the numbers. There are very few studies that examine fertility intentions and reproductive health issues of women living with HIV. There are only a few studies which, examine HIV+

Aboriginal women's reproductive health experience or explore their reproductive decisions making processes.

This research study will recruit adult participants from and be conducted at locations within

Calgary - the Southern Alberta Clinic - AHS, AIDS Calgary Awareness Association, Elbow River Healing Lodge - AHS, Adult Aboriginal Mental Health Program – AHS, Calgary Sexual

Health Centre– AHS, and the Calgary STI Clinic – AHS,. These organizations currently serve Aboriginal women of reproductive age and provide health, housing and/or supportive programs for Aboriginal women who are HIV+.

Aboriginal women, over the age of 18, will be asked to describe how their HIV+ status has impacted on their reproductive decision-making processes to have a child or not. They will also be asked to describe reproductive health services that they have accessed or are in need of, and to reflect on connections between their daily life activities and circumstances as it relates to their reproductive health and general well-being.

Many sensitive issues will be investigated such as sexual behavior, urban integration, the role of abuse, IDU, mobility and the impact that being HIV+ has had on the lives of these women. Data for this study will describe Aboriginal women experiences who are HIV+. Data will be collected from participants through a one-on-one interview process, informal conversations and participant observation.

Data collection and analysis will use cultural activities, such as smudging and the Medicine Wheel will be used as the conceptual framework for understanding and explaining the journey of each woman across physical, mental, emotional and spiritual aspects of being. Data will be transcribed from recorded interviews and analyzed using computer software. Participants will be provided with an honorarium for their participation.

This research is estimated to cost \$6340.00 and is self-funded by the student researcher Tina Nash, through scholarships obtained from New Relationship Trust, Indspire and the Foundation

for the Advancement of Aboriginal Youth. This study is proposed to be completed, including written submissions, within eight months following ethical approval. Ethical considerations for this study are guided by The Tri-Council Policy Statement and Ownership, Control, Access and Possession (OCAP) recommendations and ethical approval is through the University of Calgary Conjoint Health Research Ethics Board.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to understand adult HIV positive Aboriginal women's reproductive health experiences and their decision making processes that influence whether or not to have a child.

The objective of this study is to produce a rich, detailed, descriptive narrative of the lived experience of HIV+ Aboriginal women regarding what influences their decisions to have children or not within an urban environment. This study will help to develop understanding about Aboriginal women who are living with HIV/AIDS and the influences that impact on their reproductive health and their decisions about having a child or not. A secondary objective of this study is to examine the effects that HIV+ Aboriginal women's decisions on whether or not to have children has for primary health care providers.

Through your participation in this study, it is hoped that we will gain a better understanding of how Aboriginal women who are HIV+ make decisions about having a child or not and what factors influence their decision. This information will help to inform the limited research currently

available on this subject matter and help to design effective programs and services that focus on family planning and reproductive care for HIV+ Aboriginal women. This study is part of a Master's thesis that is focused on Aboriginal health services and population health that is being conducted by an Aboriginal Masters Student, Tina Nash, through the Department of Community Health Sciences, University of Calgary.

WHAT WOULD I HAVE TO DO?

As a participant in this study, you will be asked to describe your experience as an Aboriginal woman who is HIV+ and the impact that your HIV status has on your decisions to have a child or not. Through your participation in this study, it is hoped that we will gain a better understanding of how Aboriginal women who are HIV+ make decisions about having a child or not and what factors such as health, upbringing, education, etc., influence their decision.

After you have provided consent for participation in this study, you will be asked to participate in a face to face interview with the student researcher for this project, Tina Nash that will last approximately 1 hour in duration. The interview will be audio-recorded, if you so consent to, and transcribed verbatim for later data analysis that will examine the themes and the content of your experience that you share with the researcher. Some of your story may be used and quoted verbatim in the final write up of this research; however, your anonymity and confidentiality will be protected and your name and/or identity will never be revealed through the use of quotations of your story and experience. You also have the option of not having any of your experience

quoted verbatim in the final write up. Notes will also be taken during the interview and you may be contacted for a follow up interview, if you so agree.

If you are interested in smudging before, during or after the interview, the researcher will have smudge available for you to use. The researcher will also have other cultural symbols, such as an eagle feather and rocks available if you should decide that you would like to hold them during the telling of your story. The rocks are yours to keep at the end of the interview or you also have the opportunity to return them to the researcher where they will be used in a sweat ceremony following the completion of this study, to return your story to the Creator for safe keeping.

WHAT ARE THE RISKS?

There are no direct risks to you as a participant in this study; however, there may be some indirect risks associated with your participation in this study that are related to your recall of possible traumatizing events that have impacted upon your HIV status and experience as an Aboriginal HIV+ woman. Discussion of your experiences as they relate to children and/or child bearing may also cause distress as you recall your experiences. A listing of resources to address these risks will be provided to you by the researcher at the onset of your interview and you are free to end the interview at any time regardless of the reason.

ARE THERE ANY REPRODUCTIVE RISKS?

There are no reproductive risks associated with this study.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a direct benefit to you. If you are participating in this study and have self-identified as being HIV+ your condition will not be improved during this study and there is no guarantee that this research will help you. The information we obtain from this study may help us in the future to provide better treatments and increase professional understanding of the factors that affect the experience of HIV+ Aboriginal women who contemplate having a child or not.

For your participation in this study, you will receive a \$50 honorarium and a sweet grass braid as a gesture of gratitude for the sharing of your time and story with the researcher of this study.

DO I HAVE TO PARTICIPATE?

You may refuse to answer any questions and/or you may stop the interview, observation, or conversation at any time. As a participant you have the right to withdraw from this study at any time without penalty or impact upon your current health care or association with any of the services from which you may have been recruited from, simply by verbally requesting to do so. The information that you share during your interview should you chose to withdraw from the study, will be destroyed and not used in the final analysis of this study.

You also have the right to have your interview audio-recorded or not. If you do not want to have your interview audio-recorded please verbally advise the researcher during the review of your consent for your participation and prior to the interview commencing. You have the right to also

have the audio-recording turned off at any point during the interview and request that the audio-recording be erased immediately if you do not want it used as part of your participation.

You also have the right to have aspects of your experience shared in quotations or not in the final write up of this research. If you do not want to have any part of your story shared in quotations in the final write up of this study, please verbally advise the researcher and this will be noted on your consent form so that the information you share will only be used in aggregate form for analysis and not specifically quoted in the text of the final write up.

You may be contacted for a follow up interview at a later date. You have the right to refuse participation in this follow up interview. If you decide that you do not wish to be contacted again following your participation, please verbally advise the student researcher, Tina Nash, and this will be noted on your consent form.

The student researcher, Tina Nash, can also withdraw you from the study if she feels that your experience in recalling events is causing you distress at any point during the interview or study. This type of withdraw from the study will not in any way affect the services and health care you currently receive. If the researcher decides that it is in your best interest to be withdrawn from the study, you will still receive a \$50 honorarium and a sweat grass braid in appreciation for your time and sharing.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Alberta law requires researchers to report any suspected or threatened abuse of a child under the age of 18 years. If you disclose abuse of a child under the age of 18 or the student researcher suspects that a child under the age of 18, under your care is being abused or threatened, the student researcher will report this information to the agency from which you were recruited. Each participating recruitment agency has agreed to handle any such reporting.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

As a participant in this study, you will not incur any personal costs. You will receive a \$50 honorarium and a sweet grass braid as a gesture of gratitude for the sharing of your time and story with the researcher of this study. Regardless of whether or not you complete the interview with the researcher and/or decide to withdraw your participation, you will still receive a \$50 honorarium and a sweat grass braid as a token of appreciation.

WILL MY RECORDS BE KEPT PRIVATE?

Some of the information that you share during your interview may be directly quoted in the text of the final report of this study, and any subsequent publications, but your name and identity will be concealed so as to protect your anonymity and confidentiality. Your interview answers will also be combined with interview answers from other participants and analyzed in aggregate form. Any identifying information (name, contact information, tribal affiliation) will be separated from your interview answers, and will never be released.

Your personal information and interviews will be encoded to protect your identity and kept in a locked storage cabinet in the Department of Community Health Sciences at the University of Calgary. Electronic files will be pass-word protected and information destroyed when this study is completed according to the research policies of the University of Calgary. Except as required by law, access to personal information will be limited to only the lead investigators and the University of Calgary Conjoint Health Research Ethics Board will have access to the records.

SIGNATURES:

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Principal Investigator: Dr. Wilfreda Thurston (403) 220 – 6940

Or

Student researcher: Tina Nash (587) 894 -9372

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Appendix F

Resource List



Life in the Shadows Research Project - Resource Guide

Crisis Services

Emergency	911
Distress Center	
• 24 hour crisis	266-4357
Mobile Response Team (MRT)	
• 9:30am-9:30pm	266-4357
Community Resource Team (CRT)	
• Child and Adolescent Crisis	299-9699
LGBTQ Crisis Line	1-800-688-4765
Native Youth Crisis Line	1-877-209-1266
Protection for Persons in Care	1-888-357-
9339 Suicide Prevention Help Line	1-800-784-
2433	
Support Network Help Line	1-800-232-7288
Bullying Helpline	1-888-
456-2323 Child Abuse Hotline	1-800-387-5437
Police (non-emergency)	266-1234
Ambulance (non-emergency)	261-4000
Health Link	943-5465
Poison Information	944-1414
Red Cross	541-6100
Child and Family Services	
• 24 hour crisis	297-2995

Counselling and Mental Health Services

Calgary Resource Helpline	211
Mental Health Help Line (24 hours)	1-877-303-2642
Access Mental Health	
All mental health and addiction services	943-1500
Aboriginal Mental Health Program	955-6645
Aboriginal Spiritual Care	944-4110
Calgary Urban Project Society (CUPS)	221-8797
Calgary Counselling Centre	265-4980
Calgary Family Services	269-9888
Catholic Family Services	233-2360
CCASA (sexual abuse)	237-5888
Credit Counseling Services	265-2201
Distress Centre Counseling	266-4357
Eastside Family Centre (Mon-Sat)	299-9696
Calgary Family Therapy Centre	802-1680
Grief Support Program	955-8011
Jewish Family Services	287-3510
Native Counseling Services	237-7850
Urgent Therapy (Doctor referral required)	943-3230
Psychologist Association of Alberta	246-8255
Emotions Anonymous	247-5381
Street Outreach and Stabilization Team	297-1700
Suicide Services	297-1744
Calgary Association of Self Help	266-8711

Alberta Works	297-2094
• After hours	1-866-644-5135
SPCA (safe keeping program)	723-6024
Connect (family and sexual abuse)	237-5888

Hospitals and Medical Clinics Alberta

Children's Hospital	955-7070
• Inpatient Services	955-7289
Foothills Hospital	944-1110
• Psychiatric Emergency	943-4555
Adult Outpatient Progressive Treatment	944-944-1275/1280
Peter Lougheed Centre	943-4555
• Psychiatric Emergency	943-4904
• Carnet Centre (day hospital)	943-5719
Rockyview General Hospital	943-3000
• Psychiatric Emergency	541-3537
Sheldon Chumir Health Centre	Assessment Team 955-6200 943-3537
South Calgary Health Centre	943-9300
Alex Community Health Centre	266-2622
CUPS	221-8780
STI Clinic	955-6700
Elbow River Healing Lodge	955-6600

Calgary Addiction Resources

AHS Addictions Help Line
 AADAC
 Addictions Centre
 AI-Anon/AI-Ateen
 Alcoholics Anonymous
 Alpha House
 Aventa Treatment Centre for Women
 Cocaine Anonymous
 DOAP Team
 Gambling Help Line
 Narcotics Anonymous
 Opiate Dependence Program
 Oxford House Intake
 Renfrew Recovery and Detox Centre
 Safeworks (harm reduction)
 Salvation Army Addictions Team
 Servants Anonymous Society for Women
 Smart Recovery Centre
 Sunrise Native Addictions Service Society
 Victory Outreach Foundation for Women
 Women for Sobriety
 Youville Women's Treatment Centre